School of Allied Health

Are families hard to reach or services difficult to access? Parent experiences when a child is developmentally delayed.

Belinda Michelle Cuomo
0000-0003-2841-7484

This thesis is presented for the Degree of
Doctor of Philosophy
0f
Curtin University

February 2021

Author's Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.
This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Human Ethics

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The research studies received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval numbers HRE2017-0701 and HRE2018-0712, and from the Child and Adolescent Health Services Human Research Ethics Committee (RGS0000000198).

Belinda Cuomo
Date: 11 February 2021

Abstract

More than one in five children in Western Australia (WA) are considered developmentally vulnerable at school-entry, and it is well-established that intervening early is essential to supporting lifelong developmental trajectories. However, research globally has identified significant delays across the stages of noticing, sharing concerns, and accessing services for children with developmental delays compared to children with disabilities. Additionally, there is a consistent mismatch between levels of need for early intervention (EI) and actual numbers of those who access EI – with many families being labelled as 'hard-to-reach'. It is currently unclear how and why such pathways may be different for developmental delays. In my PhD, I aimed to understand family experiences of noticing and help-seeking for suspected child developmental delays and identify factors that impact pathways to service access – with a focus on experiences here in metropolitan WA. My program of research combined locally-focused exploration of WA experiences with a deep dive into existing knowledge. A series of three scoping reviews were conducted to understand: 1) how developmental delays are 'noticed' and by whom; 2) how parent beliefs influence their decision-making to act on developmental concerns (underpinned by the Health Belief Model); and 3) how family and service barriers impact caregiver sharing of concerns and service access. The reviews are bookended by a cross-sectional database analysis of referrals to the Child Development Service located in metropolitan Perth to establish profiles of children and families referred for EI - who they are, what they are referred for, and by whom; as well as modelling significant factors associated with service non-access – who are the 'hard-to-reach' families? This narrative was then flipped to consider caregiver perspectives of factors that make services difficult to access. Qualitative interviews were conducted with 13 caregivers of children with suspected delays to explore their experiences of noticing, sharing concerns, and accessing services. Findings across these explorations were then woven into a conceptual framework that outlines key elements of journeys for developmental delays – including barriers or breakdowns, ingredients for success, and stakeholders and supporters.

Acknowledgements

A PhD journey is never undertaken alone.

To my supervisors, who helped steer me through. Drs Sharmila Vaz, Annette Joosten, Donna Cross and Angus Buchanan – thank you for your guidance, feedback and nudges along the way.

Sharmila – you helped to spark my love of research (especially data!) during long summer days spent working on our survey. I am forever grateful for what you saw and nurtured in me and for the working relationship (and friendship) we now have.

Annette – for inspiring me from my undergraduate days to always operate with integrity, evidence and kindness. Thank you for pushing me to produce ‘good stuff’.

Donna – your connections set this whole project in motion. Thank you for your strategic advice, for always knowing the right person to steer me to, and for supporting this work through CoLab.

Angus – for guiding me through my introduction to the world of qualitative research and making sure I don’t ‘slip through the cracks’!

To my family, who always encouraged my education – but probably never thought it would result in this. You made this journey seem possible and were always unwaveringly proud. We ‘finally’ made it! To my mum especially – my ultimate role model. You show me how to be strength and softness, an advocate and a friend for families who need it.

To my partner Matt, who often had more faith in me than I did. Thank you for the dinners cooked, the edits read, the constant love. I cannot wait to be your wife.

To my colleagues and friends, who knew when to ask about the dreaded ‘P’ word and when to just cheer me on. Bec Waters, Alison Blaine, Jess Pretty, Jaya Saraswati to name but a few.

Thank you to the Child Development Service staff who facilitated the analysis of their database. Thank you to Dr Richard Parsons and Dr Therese Shaw for data analysis support.

Thank you CoLab (Telethon Kids Institute) on behalf of the Minderoo Foundation and the Australian Government Research Training Program for the provision of scholarship support.

Most of all, to the families who shared so much of themselves and their journeys with me – I hope this work does justice to your experiences.

Dedication

To my brother, Darren. This whole journey began because of you and the impact that the healthcare system had on our family.

List of Publications

Chapter 3 of this thesis is published as Cuomo, B., Joosten, A., & Vaz, S. (2019). Scoping review on noticing concerns in child development: A missing piece in the early intervention puzzle. *Disability and Rehabilitation*. doi:10.1080/09638288.2019.1707296

	Conception and Design	**Acquisition of Data and Method**	**Data Conditioning and Manipulation**	**Analysis**	**Interpretation and Discussion**	**Final Approval**
Co-author 1 (Belinda Cuomo)	70	70	80	80	80	70
Co-author 1 acknowledgement: I acknowledge that these represent my contribution to the above research output Signed:						
Co-author 2 (Annette Joosten)	15	15	10	10	10	15
Co-author 2 acknowledgement: I acknowledge that these represent my contribution to the above research output Signed:						
Co-author 3 (Sharmila Vaz)	15	15	10	10	10	15
Co-author 3 acknowledgement: I acknowledge that these represent my contribution to the above research output Signed:						
Total %	100	100	100	100	100	100

I provide assurance that I have obtained, where necessary, permission from the copyright owners to use any third-party copyright material reproduced in the thesis (e.g. artwork), or to use any of my own published work in which the copyright is held by another party.

Statement of Contributors

Supervisors:

- Dr Sharmila Vaz
- Associate Professor Annette Joosten
- Professor Donna Cross
- Professor Angus Buchanan

Statisticians:

- Dr Richard Parsons
- Dr Therese Shaw

Funding:

Research Training Program stipend from the Curtin University Faculty of Health Sciences and the School of Occupational Therapy, Social Work and Speech Pathology was received commencing 1 March 2016.

Top-up scholarship received from CoLab, Telethon Kids Institute (funded by the Minderoo Foundation) commencing September 2017

Soroptimist Riverside Bursary was received in 2017.

Table of Contents

List of Figures

List of Tables

List of Abbreviations

ADHD	Attention deficit hyperactivity disorder
AEDC	Australian Early Development Census
ASD	Autism spectrum disorder
CAHS	Child and Adolescent Health Service
CAHS-CH	Child and Adolescent Health Service - Community Health
CALD	Culturally and linguistically diverse
CAMHS	Child and Adolescent Mental Health Service
CDS	Child Development Service
CHN	Child Health Nurse
DHD	Developmental hip dysplasia
ECEI	Early Childhood Early Intervention
EI	Early intervention
GP	General practitioner
ICCF	Innovative Care for Chronic Conditions framework
NDIS	National Disability Insurance Scheme
U.K.	United Kingdom
U.S.	United States of America
WA	Western Australia
WACHS	Western Australian Country Health Service
WHO	World Health Organization

Preface

My PhD journey focused on answering one question: why are children with developmental delays slipping through the cracks of early intervention (EI) services?

When I embarked on this PhD journey, I was working as a school-based occupational therapist in a community identified as having one of the highest rates of early childhood developmental vulnerability in metropolitan Perth. Services were attempting to respond to this in a myriad of ways – including employing allied health professionals to provide direct school support. My role was to assess and provide strategies and advice for children 'red-flagged' by their classroom teachers – children who were experiencing difficulties with their motor development, social-emotional skills, behavioural concerns, or all-round learning; but did not have a diagnosed disability.

I discovered that in every classroom, there were many vulnerable students. Occupational therapy referrals were triaged to identify children with the highest needs as there was not the capacity to provide individual support to all students. I encountered children with significant developmental delays, many of whom had never received individualised support. I often also saw stark contrasts between the children with delays and their peers with diagnosed developmental disabilities - who often (though not always) already had services and supports in place. The children most in need of occupational therapy were the ones without formal diagnoses.

I wondered how and why these children were not getting the supports they needed – had no one noticed them before? What were the parents doing about it? Some school staff reported that they had spoken to the parents, but some families were not concerned; they had referred children on to services, but parents had not always acted on the advice. Such comments seemed to indicate that some teachers felt it all came down to the families – the services were available, families just needed to attend them.

At the same time, I began having conversations with the Child Development Service (CDS) – the government-funded provider of EI for children with developmental delays in Perth. The narrative from CDS management appeared to fit with my experiences; of the referrals they received, a large number of families did not act on the referral and so did not access their services. The service labelled the non-responding families as 'hard-to-reach'. The CDS wanted to understand who these hard-to-reach families were, and to design a targeted intervention they could roll out to reduce their rates of non-attendance. Thus, the initial focus of my PhD was born.

As I began this PhD journey and continued in my clinical role, I quickly found that my narrative, and the narrative of both CDS and some teachers, did not fit with reality. I came to know the parents of the children I supported and learned about the complexity of their lives – the many 'balls' they were juggling, only one of which was their child's development. I began hearing stories about referral paperwork being lost, of being sick on appointment day and waiting months for a new appointment, and of being on waitlists to access professionals for years.

I started looking more deeply into the literature and began to appreciate the deep complexity of this issue. I also identified glaring holes from a research perspective in our understanding of the journeys experienced by the families of children with suspected delays. Family journeys do not begin at the doors of services – they begin with the first initial inklings of concern that trigger everything that follows. What happens from that starting point influences when, how, and even if the service doors are ever walked through – yet to date this had not been clearly acknowledged or fully explored in the context of developmental delays. My PhD therefore shifted away from getting ready to act, to taking a step back to understand what was happening. The resulting direction and narrative of this thesis speak greatly to this perceptual shift – from seeing families as hard-to-reach, to turning the gaze onto services as well as families, and to the myriad of factors that can make these services difficult to access.

So why are children with developmental delays slipping through the cracks of EI services? I hope this research goes some way to answering this question and to offering some initial recommendations that will contribute to systemic change.

Chapter 1 Introduction

1.1 Child development and developmental delays

Every child's unique developmental trajectory is determined by complex interactions between aspects of the child, their environment, and the tasks they perform, with a dynamic cascade of risk and protective factors that continuously shape one another (Shonkoff, 2010; Thelen & Smith, 2007). These interactions shape both short- and long-term growth, health, development, and learning (Shonkoff, 2010; Thelen & Smith, 2007). As stated by Shonkoff, "…reciprocal interactions among genetic predispositions and early experiences affect the extent to which the foundations of learning, behaviour, and both physical and mental health will be strong or weak" (Shonkoff, 2010, p. 357). When the development of these foundations is negatively impacted, a child may be at risk of developmental delays (Maggi et al., 2010; Walker et al., 2011)

Developmental delays, subtle developmental problems, or developmental concerns relate to the development of the child's cognition, motor skills, speech and language, social-emotional development, and/or behaviour (Oberklaid & Efron, 2005; Williams & Holmes, 2004). A delay may be considered to be present when a child was 'delayed' in the attainment of age-expected developmental milestones or when their development was considered to be 'atypical'; and the delays were beyond reasonable expectations of developmental variation (Choo et al., 2019; Oberklaid & Efron, 2005). Based on the breadth of this definition, there is significant variability in the presentation of children with developmental delays. Children may have established delays in one or more areas, they may have diagnosed physical or mental conditions that result in delay, or they may be considered at-risk of experiencing delays (Hebbeler et al., 2007). Global estimates suggest that between 13% to 32% of children experience delays in their development (Curtin et al., 2013; Human Early Learning Partnership, 2016; Offord Centre for Child Studies; Rosenberg et al., 2008).

1.2 Early intervention

The United Nations Convention on the Rights of the Child (ratified by Australia in December 1990) states that “every child has the inherent right to life”, and that “parties shall ensure to the maximum extent possible the survival and development of the child” (United Nations, 1990, p. 3). The Convention also recognises “the right of the disabled child to special care” including early intervention (EI), education, health, and rehabilitation services to support the achievement of their fullest individual development (United Nations, 1990, p. 7).

Evidence-based EI has developed through longitudinal intervention studies, with notable examples including the 1960s Perry Preschool Program and 1970s Abecedarian Project (Campbell et al., 2014; Heckman et al., 2006; Schweinhart et al., 2005). The Perry Preschool program was a 2-year experimental intervention for preschool-aged children in disadvantaged African American communities (Schweinhart et al., 2005). Over the course of 30 years of follow-up, program participants demonstrated ongoing positive outcomes compared to controls – with higher rates of high school completion, home ownership, and higher wages; lower rates of social support and justice system contact (Schweinhart et al., 2005); and a benefits-to-costs ratio of 8.74 (Heckman, 2006). The Carolina Abecedarian Project tested the provision of a stimulating early childhood environment for children with mild cognitive delays in communities of disadvantage. The project generated a 4:1 system return on investment, with participants demonstrating significant benefits in health outcomes well into adulthood (Campbell et al., 2014; Masse & Barnett, 2002).

The lasting effects of the two programs demonstrated that supports provided during early childhood have long-term impacts on a range of outcomes into adulthood (Campbell et al., 2014; Conti et al., 2016; Masse & Barnett, 2002; Schweinhart et al., 2005). The importance of providing effective EI supports in the early years was identified by Nobel-Prize winning economist John Heckman who found that experiences in middle childhood and beyond had a limited ability to reduce developmental ‘gaps’ in children that were present during the early years (Cunha et al., 2006) and that “a child who falls behind may never catch up” (Heckman, 2006, p. 1900; Heckman & Krueger, 2003). From a government policy perspective, Heckman also identified that the rates of return on investment were highest when concentrated during preschool years (see Figure 1-1) – demonstrating both individual and systemic benefits to acting early (Heckman, 2006).

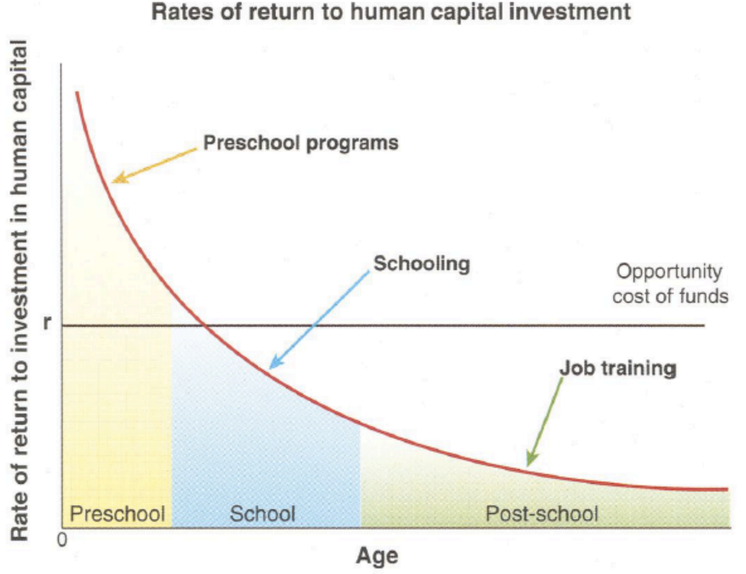


Fig. 2. Rates of return to human capital investment in disadvantaged children. The declining figure plots the payout per year per dollar invested in human capital programs at different stages of the life cycle for the marginal participant at current levels of spending. The opportunity cost of funds (*r*) is the payout per year if the dollar is invested in financial assets (e.g., passbook savings) instead. An optimal investment program from the point of view of economic efficiency equates returns across all stages of the life cycle to the opportunity cost. The figure shows that, at current levels of funding, we overinvest in most schooling and post-schooling programs and underinvest in preschool programs for disadvantaged persons.

Figure 1-1 Rates of return to human capital investment from Heckman, 2006[1]

1.3 Importance of families

Family environments have a strong and lasting influence on early child development (Francesconi & Heckman, 2016; Warren & Edwards, 2017). Families hold central responsibility for providing children with foundational experiences essential for shaping early learning and development (Francesconi & Heckman, 2016; Shonkoff, 2010). Families also enable children to access services and supports when it is required; as Staudt (2007) states, children do not seek out services – families do. In line with this is the recognition of the role of families in EI service participation. The family-centred approach has been a core part of EI service delivery since the 1990s and may be defined as an approach to care that recognises and respects the central role of the family as equal to professionals, whereby families are supported in caregiving and decision-making (Espe-Sherwindt, 2008). This includes a strengths-based emphasis (as opposed to deficit-focused), the promotion of family choice and control, and the development of collaborative relationships between families and therapists (Dunst et al., 1994). Understanding EI access therefore requires a focus on the family unit as a whole.

1.4 Service access - disparities and delays

Developmental delays can be difficult to detect for several reasons, including presenting in a myriad of ways, the often lack of obvious physical or neurological signs, manifesting slowly over time, as well as not necessarily fitting “into nice, neat diagnostic categories” (Hebbeler et al., 2007; Johnson, 2011; Shannon, 2000, p. 172; Williams & Holmes, 2004). Confirming the presence or ‘realness’ of delays is complicated by the nature of

---

[1] Reuse permitted under JSTOR terms and conditions for institutions

developmental milestones as unfixed - creating confusion as to whether the child is delayed or simply at the tail-end of an expected milestone acquisition; as well as perceptions regarding their transience and ability to correct given time (Williams & Holmes, 2004).

This fluid boundary may partly account for why families of children with developmental delays have very different experiences compared to families of children with noted disabilities on the road to validation of their concerns (Shannon, 2000). Children with delays are frequently identified at a later age than children with diagnosed disabilities (Hebbeler et al., 2007). A United States (U.S.) longitudinal study of EI access found that families of a child with a disability had concerns about their child's development by two months of age, while children with delays were not 'noticed' by parents until 11 months of age (Hebbeler et al., 2007). This initial delay in noticing impacts subsequent EI processes, with diagnosed children receiving services by nine months of age compared to 20 months for children with delays (Hebbeler et al., 2007). Significant disparities exist between rates of parental concerns about child development and the seeking out of services and supports, with a mismatch between numbers of children identified, referred for, and receiving support for developmental delays (Hebbeler et al., 2007; McManus et al., 2009; McManus et al., 2020; Rosenberg et al., 2013). For example, population-based data from the U.S. suggest that despite 39% of parents reporting their child aged 0-5 years experienced one or more developmental concerns, less than 5% of the sample engaged with developmental services (Marshall, Kirby, et al., 2016). Recent analysis in the U.S. identified that in a retrospective cohort of over 14,000 children with developmental disability or delay, less than 19% received a referral and only 26% of those were enrolled in services; with an overall net enrolment of 5% of EI-eligible children (McManus et al., 2020).

1.5 Developmental delays in Australia

The Australian Early Development Census (AEDC) indicates that over 20% of Australian children in their first year of full-time school are considered to be 'developmentally vulnerable' or falling below the 10th percentile across one or more domains of physical health and wellbeing, social competence, emotional maturity, language and cognitive skills, and communication skills and general knowledge (Department of Education and Training, 2019). Children living in areas of socioeconomic disadvantage, Aboriginal and Torres Strait Islander children, and children with a language background other than English are at higher risk of vulnerability (Department of Education and Training, 2019). In terms of EI access, findings from a 2012 Australian study utilising AEDC data reported that 18% of school-age children were considered to be 'of concern' – yet only 15% of the 18% had attended EI services (Goldfeld et al., 2012) - constituting significant levels of unmet needs.

Despite this, relatively limited research has been undertaken in Australia regarding developmental delays and the experiences of families accessing EI services (Ahern, 2000; Alexander et al., 2015; Eapen et al., 2017; Green et al., 2016; McAllister et al., 2011; Williams, 2007; Williams & Holmes, 2004; Woolfenden et al., 2015). The majority of this work qualitatively explores family experiences, often specific to certain populations such as culturally and linguistically diverse (CALD) families (Woolfenden et al., 2015) or children with language delays (McAllister et al., 2011). The bulk of previous research on the experience of developmental delays comes from the U.S. and the United Kingdom (U.K.) (Giordano, 2008; Harris, 2009; Hendrickson et al., 2000; Magnusson et al., 2017; Marshall et al., 2017; McAllister et al., 2011; Morton, 2012; Mulcahy & Savage, 2016; Persoff, 1998; Ramirez, 2004; Rannard et al., 2004; Shannon, 2000; Silbersack, 2014; Smith et al., 2015; Smith et al., 2010).

While Australia shares similarities with these nations, there are key differences in each country's health care system – such as levels of public system financing, the role of private insurance, and the model of primary care delivery (Mossialos et al., 2017). Therefore, each of these elements will impact on the context-specific experiences of families in seeking EI supports; for example, different age-related eligibility cut-offs for EI services (Giordano, 2008). This consequently means that drawing from research in these nations will not necessarily reflect the needs of Australian communities (Williams & Holmes, 2004). Thus, further research is needed to understand the experiences of Australian families of children with developmental delays and begin developing a context-specific understanding of what families need to support their journeys. Additionally, there is significant variation in developmental vulnerability between different Australian states and territories (Collier et al., 2020), requiring exploration of family experiences within and across jurisdictions.

1.6 'Hard to reach' families or difficult to access services?

Historically, families who do not take up opportunities to access services have been labelled as 'hard-to-reach' (Boag-Munroe & Evangelou, 2012). The term 'hard-to-reach' is context-dependent, but broadly refers to groups of people who may be eligible for services but who are considered difficult to engage (Cortis et al., 2009; Mumby-Croft, 2014). Several typologies of who is considered hard-to-reach have been proposed. Work from the U.K. considers hard-to-reach families to include: 1) the underrepresented – groups who are marginalised, excluded, or disadvantaged on the basis of social, economic, or cultural circumstances; 2) the invisible or overlooked, who are underserved by services and 'slip through the net'; and 3) the service-resistant, who may be unwilling to seek help or wary of doing so based on prior experiences (Doherty et al., 2003).

Research in EI has traditionally sought to understand who these so-called ‘hard-to-reach’ families are, through identifying child, family, and/or community risk factors that impact their access (Chin & Teti, 2013; Clements et al., 2008; Giannoni & Kass, 2010; Pritchard et al., 2013; Shapiro & Derrington, 2004). Factors such as low socioeconomic status (Chin & Teti, 2013; Marshall, Coulter, et al., 2016; McManus et al., 2009; Peterson et al., 2004; Twardzik et al., 2017); racial, cultural, and linguistic diversity (Clements et al., 2008; Giannoni & Kass, 2010; Marshall, Coulter, et al., 2016; McManus et al., 2020; Peterson et al., 2004; Rosenberg et al., 2008; Swanson, 2013); mother’s education level (Giannoni & Kass, 2010; Peterson et al., 2004); and lower severity of child delay (McManus et al., 2009; McManus et al., 2020; Swanson, 2013) have been consistently linked to lower odds of EI service access - despite many of these groups being historically overrepresented in EI populations (Hebbeler et al., 2007; McManus et al., 2009; Rosenberg et al., 2008; Shapiro & Derrington, 2004). Use of the term ‘hard-to-reach’ has been criticised in recent years, for several reasons. Firstly, it is not a term that service users identify with, but is instead used almost exclusively by service providers (Cortis et al., 2009). Additionally, the term places emphasis on the individual and frames access of services as the individual’s responsibility – and thus places the onus of access on the individual (Cortis et al., 2009). Such an approach links to the ‘risk versus protective factor’ view of child development; whereby ‘high-risk’ families have increased risk of negative outcomes based on biological, behavioural, or environmental factors (Guralnick, 2001; Phoenix & Rosenbaum, 2019). Phoenix and Rosenbaum’s Model of Risk, Disability and Hard-to-Reach Families sought to differentiate high-risk families from hard-to-reach families, while also acknowledging that these groups may overlap (Phoenix & Rosenbaum, 2019). High-risk families were defined as families who have high levels of personal, family, or community-level demands that may increase their risk of experiencing crisis. In contrast, hard-to-reach families experience barriers to accessing services, due to their ‘high-risk’ experiences; other individual or family reasons such as illness or poor organisation; and/or service-based attitudinal, physical, or pragmatic barriers including transport or lack of staff experience (Phoenix & Rosenbaum, 2019). A traditional family-based risk focus, therefore, fails to consider the role and responsibility of services themselves in this interaction, and the barriers within service delivery that may preclude or undermine a family’s ability to access them (Cortis et al., 2009; Doherty et al., 2003). There is an increasingly strong narrative from the research community calling for a need for services to understand better what makes families ‘hard-to-reach’ in the first place (Phoenix & Rosenbaum, 2019) and placing the onus back on services themselves to consider how they may better provide services in an accessible way (Boag-Munroe & Evangelou, 2012; Mumby-Croft, 2014).

1.7 Framing pathways to service access

Much of the work on service pathways for children with developmental delays has focused on just some aspects or perspectives of their journey. Studies have commonly focused on analysing characteristics or risk factors associated with rates of parental concern (Marshall, Kirby, et al., 2016), presence of delays (Rosenberg et al., 2013; Rosenberg et al., 2008), referral to EI (Barfield et al., 2008; Clements et al., 2008; Johnson, 2011; Shapiro & Derrington, 2004), EI enrolment (Clements et al., 2008; Shapiro & Derrington, 2004), and service access and attrition (Chin & Teti, 2013; Giannoni & Kass, 2010; Glaun et al., 1998; Hebbeler et al., 2007; Marshall, Kirby, et al., 2016; McManus et al., 2009; McManus et al., 2014; Rosenberg et al., 2008; Swanson, 2013). There is also a body of work, predominantly qualitative, that has sought to privilege the family voice in unpacking family experiences of developmental delay (Eapen et al., 2017; Giordano, 2008; Harris, 2009; Hendrickson et al., 2000; Magnusson et al., 2017; Marshall et al., 2017; McAllister et al., 2011; Morton, 2012;

Mulcahy & Savage, 2016; Persoff, 1998; Ramirez, 2004; Rannard et al., 2004; Shannon, 2000; Silbersack, 2014; Smith et al., 2015; Smith et al., 2010; Williams, 2007; Woolfenden et al., 2015).

To date, the processes or pathways for developmental delay identification and service access have not been understood or formalised in the same way that has occurred in similar fields such as broader community early intervention, paediatric mental health, and public health. We can, however, draw from these related fields to understand how they conceptualise service pathways. The following section will explore the guiding principles, benefits, and drawbacks to key models and frameworks across: broader community-based early intervention (Developmental Systems Model for EI (Guralnick, 2001)); child mental health (Barriers to Treatment Participation (Kazdin, Holland, Crowley, et al., 1997), Conceptual framework of the engagement process (Staudt, 2007), and the Connect, Attend, Participate, Enact (CAPE) Model of Parental Engagement (Piotrowska et al., 2017)); and chronic conditions (Innovative Care for Chronic Conditions Framework (ICCCF) (World Health Organization Health Care for Chronic Conditions Team, 2002)).

1.7.1 Community-based EI

Frameworks in EI have traditionally had a focus on systems. The Developmental Systems Model for Early Intervention (Guralnick, 2001) presents core principles of community-based EI services. The model firstly outlines child developmental outcomes as governed by three patterns of family interaction: the quality of parent-child transactions, family-orchestrated child experiences, and providing for the child’s health and safety – which impact and are impacted by stressors related to both child and family characteristics (Guralnick, 2001). These include information needs, interpersonal and family distress, resource needs (including financial), confidence threats, personal characteristics of both the child and parents, and social supports (Guralnick, 2001). The emphasis of the model is one of ‘risk’ – that child and parent stressors, or biological and environmental risks, place the child at risk of poorer outcomes – and thus developmental systems are in place to mitigate and/or manage these risks for vulnerable children and their families (Guralnick, 2001).

The model begins at the initial interaction with developmental systems at the point of screening or referral (see Figure 1-2). From this starting point, the model outlines a decision-making tree of subsequent actions based on presence of developmental concern or risk; determining whether there is an identified delay or established disability, as well as undertaking steps to assess and implement strategies to address identified stressors (Guralnick, 2001). The model presents a clear service pathway for general practitioners (GPs) or others responsible for screening and referral as well as tiered or targeted pathways including preventive, monitoring, and intervention programs (Guralnick, 2001).

While the Developmental Systems Model provides a comprehensive series of pathways and required actions, it does so from a purely systems-perspective. The Model recognises the importance of family factors; but does not account for how families may experience or respond to different aspects of the pathway, nor how families come to arrive at services in the first instance. For example, the model does not take into account service-based factors that may impact family arrival at services, such as extensive waitlists, as well as family perspectives of service quality. Given the statistics on disparities between parent concerns and taking action for developmental delays, there is a need for more in-depth consideration of the family narrative such as service waitlists and the quality of available services, that may influence service access pathways and whether this model represents key journey points specific to developmental delays.

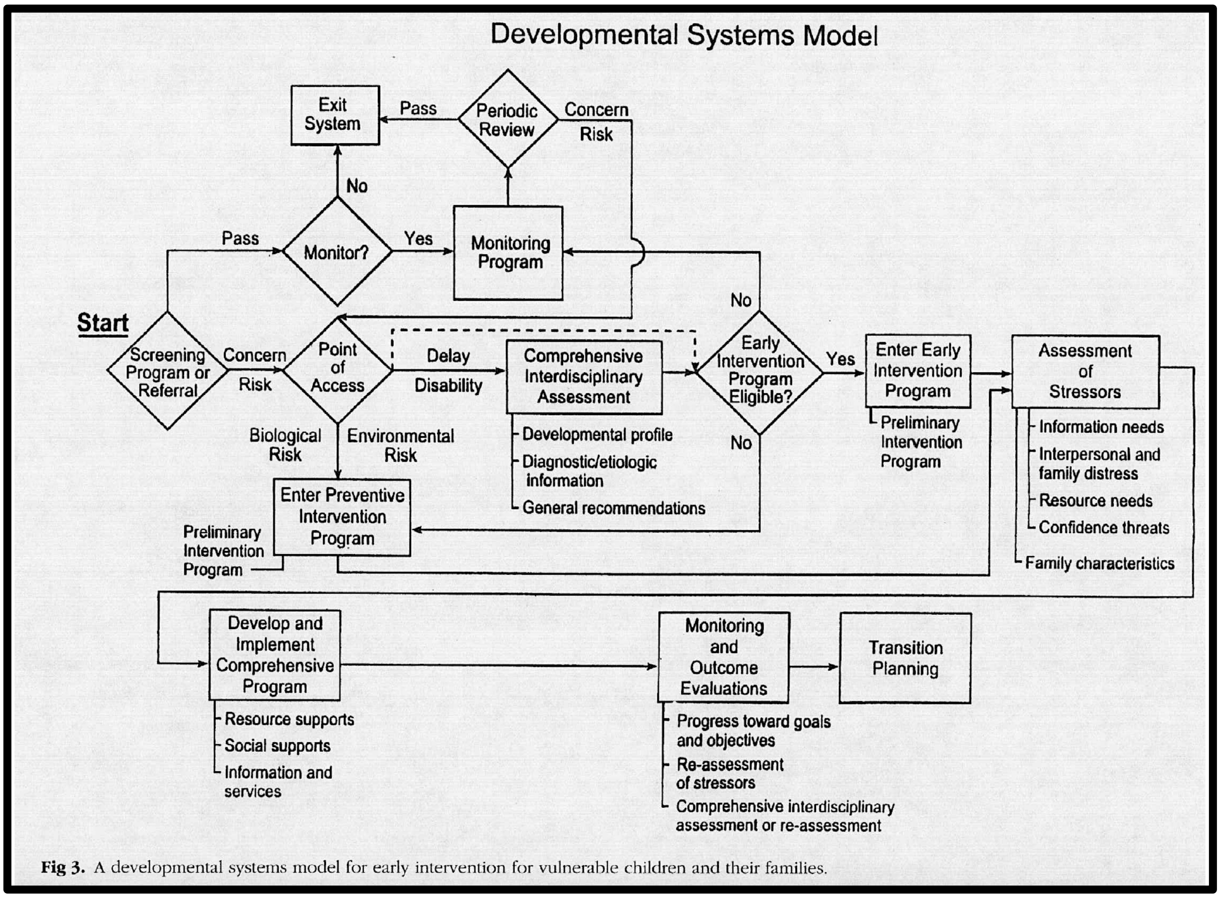


Fig 3. A developmental systems model for early intervention for vulnerable children and their families.

Figure 1-2. Developmental Systems Model of Early Intervention, Guralnick 2001[2]

1.7.2 Child mental health

The literature on access to child mental health services has focused on family experiences and barriers families encounter when accessing services. Two notable examples are the Barriers to Treatment Participation (BTP) scale (Kazdin, Holland, & Crowley, 1997; Kazdin, Holland, Crowley, et al., 1997) and the Conceptual Framework of the Engagement Process (Staudt, 2007). The BTP scale addresses the following five barriers:

1. Stressors and obstacles that compete with treatment – e.g. transportation availability, appointment scheduling conflict, child or family sickness, needs of other children.
2. Treatment demands and issues – e.g. treatment cost, confusing information.
3. Perceived relevance of treatment e.g. treatment not what they expected, treatment did not seem necessary.
4. Relationship with the therapist – e.g. not liking the therapist, not feeling support by them.
5. Critical events – e.g. moved to a new house, parent lost their job, illness/death in the family.

Use of the BTP scale to examine family drop-out from outpatient child mental health services identified a cumulative effect of barriers – the greater the number of perceived barriers, the greater the risk of family drop-out from services (Kazdin, Holland, Crowley, et al., 1997). Interestingly, the type of barrier with the largest effect size in predicting drop-out was perception of the relevance of treatment – a factor that would not be addressed via traditional ‘risk’ factor identification. This work acknowledged the presence and impact of family circumstances as placing families ‘at-risk’ of experiencing difficulties with access.

---

[2] Reuse permission obtained from publisher Wolters Kluwer Health, Inc; see Appendix A.1

As the authors stated, this “does not address factors related to the experience of treatment and facets of that experience that might lead to dropping out” (Kazdin, Holland, Crowley, et al., 1997, p. 461).

The Conceptual Framework of the Engagement Process was developed from Kazdin’s work (see Figure 1-3) (Staudt, 2007). This framework proposed a similar set of perceived barriers to treatment as identified by parents of young children using the BTP scale: treatment relevance/acceptability, daily stresses, therapeutic alliance, external barriers to treatment, and cognitions and beliefs about treatment (Staudt, 2007). Like the BTP work, the barriers related to family experiences outside of the service that would nonetheless impact their ability to access the service, such as family cognitions, beliefs, and/or perceptions related to the service; as well as experiences of the service itself including interactions with service providers (Kazdin, Holland, Crowley, et al., 1997; Staudt, 2007). The framework proposed that if services wanted to create behaviour change – such as increased attendance at therapeutic appointments – then they needed to consider a family’s attitudinal engagement. This included their “emotional investment in and commitment to treatment” and perceptions as to whether services were “worth their time and energy” (Staudt, 2007, p. 185). The author reasoned that families who did not see that access was worthwhile – or who perceived that the ‘costs’ of access outweighed the potential benefits – would be less likely to access services (Staudt, 2007). The framework also considered that this emotional investment was equally (if not more) important to outcomes as the behaviour component of simply ‘showing up’ to services (Staudt, 2007).

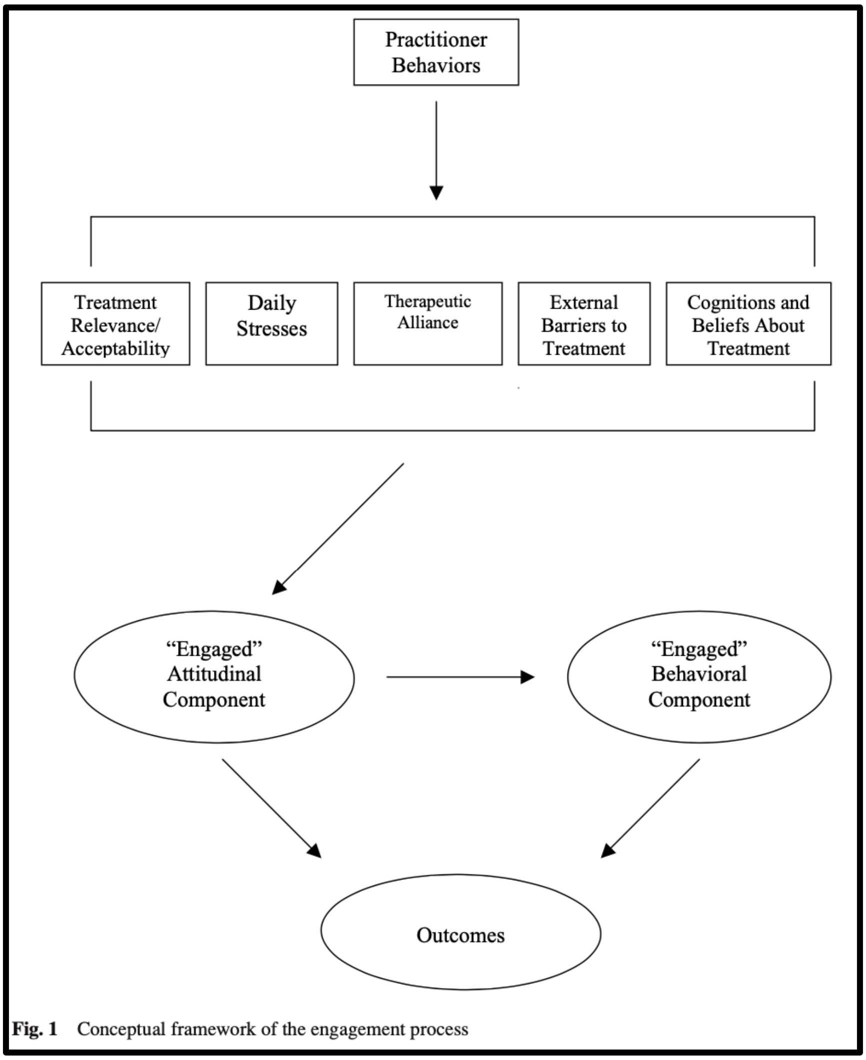


Fig. 1 Conceptual framework of the engagement process

Figure 1-3. Staudt's 2007 conceptual framework of the engagement process[3]

Both BTP and the Engagement Process Framework strongly consider the family narrative and barriers and enablers that underpin actual engagement in services – beyond notions of simple attendance. With both frameworks coming from child mental health services, whether similar concepts exist in family experiences for developmental delays warrants investigation.

Alongside the BTP and Engagement Process Framework research sits the CAPE Model of Parental Engagement (Piotrowska et al., 2017) (see Figure 1-4). This conceptual model

---

[3] Reuse permission obtained from publisher Springer Nature; see Appendix A.2

focuses on access specific to parenting programs for child mental health and focuses on considering the interdependent stages associated with program participation and ongoing attendance (what the authors term “engagement”) (Piotrowska et al., 2017). The CAPE defines parental engagement as a process that consists of participation (i.e., recruitment and involvement of families in services) (Ingoldsby, 2010); plus ongoing service attendance (Piotrowska et al., 2017). The model outlines the following four stages:

1. Connect – families learn about and 'connect' to or enrol in available services.
2. Attendance – the act of physically attending the service/program on an ongoing basis.
3. Participation – active involvement in service provision (e.g. collaborating in the therapy or in discussions with the provider).
4. Enactment – the application of learned strategies with the child across time and situations (i.e., knowledge transfer).

The CAPE model has an ecological underpinning; with the dynamic interplay of enablers and barriers within child, family, and contextual factors that can potentially impact successful ‘negotiation’ of services (Piotrowska et al., 2017). Therefore, it posits that any family faces a series of unique barriers and enablers that can impact their pathway both within and between the stages (Piotrowska et al., 2017), and it offers an extension to the notion of how family service access can be defined. What the model does not include is what initiates or prompts parents to ‘connect’ with services, such as initial stages of ‘noticing’ differences or delays in a child’s development (Restall & Borton, 2010).

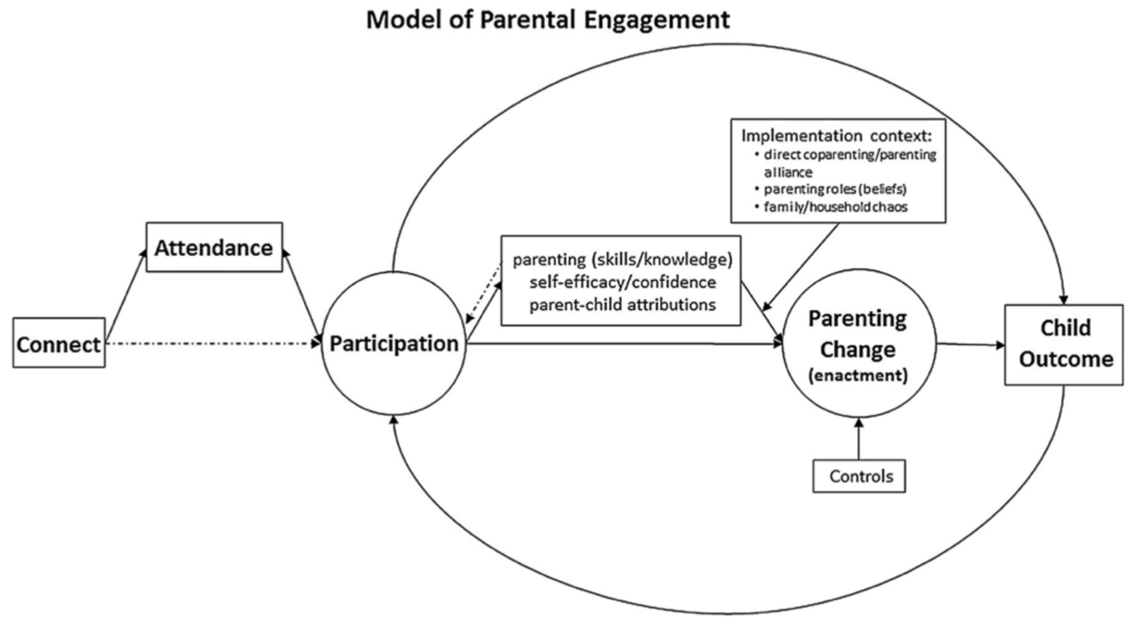


Fig. 1 Model of parental engagement

Figure 1-4 CAPE model of parental engagement[4]

1.7.3 Chronic conditions

The World Health Organization (WHO) Innovative Care for Chronic Conditions Framework (ICCCF, see Figure 1-5) provides guidance in both the prevention and management of chronic health conditions at micro-, meso- and macro-levels (WHO Health Care for Chronic Conditions Team, 2002). The ICCCF states three fundamental needs of people with chronic conditions and their families that need to be met for them to experience better outcomes: to be informed, to be motivated to change, and to be prepared through skills to manage their conditions (WHO Health Care for Chronic Conditions Team, 2002). These outcomes are produced via partnership between patients and their families, the community, and health care organisations; all of which needs to occur within a broader positive policy environment (WHO Health Care for Chronic Conditions Team, 2002).

---

[4] Reuse permitted under Creative Commons Attribution 4.0 International License (http://creativecommons.org/licenses/by/4.0/)

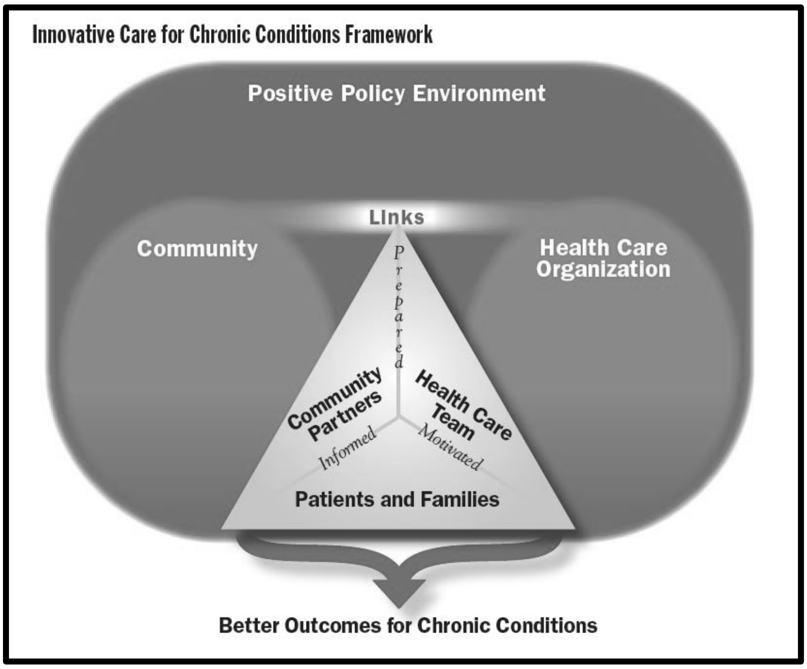


Figure 1-5 World Health Organization Innovative Care for Chronic Conditions Framework[5]

The ICCCF provides a more macro-level view of care pathways than the other discussed models, enabling consideration of the broader policy environment for healthcare systems and families. It could be argued that the WHO definition of chronic conditions should include developmental delays as like chronic conditions they may be persistent, and require ongoing management over a period of time (WHO Health Care for Chronic Conditions Team, 2002). As with other chronic conditions, developmental delays impact individuals, their families, communities, and the broader health system; and as a result, require an approach that considers each of these levels. Thus, the ICCCF has potential explanatory power for developmental delay experiences, however in its current form it is more reflective of traditional chronic conditions such as diabetes or cardiovascular disease (WHO Health Care for Chronic Conditions Team, 2002). The development of more inclusive and/or specific language and concepts relating to developmental delays would be required to enable this framework to be applicable in this population. Additionally, similar to the

---

[5] Reuse permission obtained from WHO; see Appendix A.3

Developmental Systems Model (Guralnick, 2001) the ICCCF begins the model at the point of systems contact and thus makes a level of assumptions about the connection of families to health care services. Models for developmental delays need to include the stages leading up to the connection to services, as data describing service access delays and non-attendance suggest this is where many of the breakdowns in ultimate service access occur (Hebbeler et al., 2007; McManus et al., 2020).

1.8 Framework for developmental delays

Each of the discussed frameworks from community-based EI, child mental health, and chronic conditions contain elements that may have explanatory power specific to the experiences of families with children with developmental delays. However, no single model adequately generates an understanding of what pathways to services for children with developmental delays specifically look like and the barriers and enablers that underpin the navigation of such pathways for families. Therefore, this thesis will culminate in the conceptualisation of a proposed framework specific to developmental delays.

1.9 Overall aim

This program of research took a step back from the endpoint of service access for developmental delays and looked instead at the journey leading up to it – acknowledging that experiences during the steps of noticing delays, sharing them with others, and seeking out initial supports were vital, and deeply influential, to how and if parents engage with EI services. The overarching aim of this thesis was to understand family experiences of noticing and help-seeking for suspected child developmental delays and identify factors that impact pathways to service access.

1.10 Thesis structure

This research was multi-phased, comprised of six studies using different designs to answer the research aim collectively. Qualitative, quantitative, and scoping review methodologies were undertaken to examine both previous research findings as well as local-based knowledge. Figure 1-6 provides an overview of the thesis structure and the chapters therein.

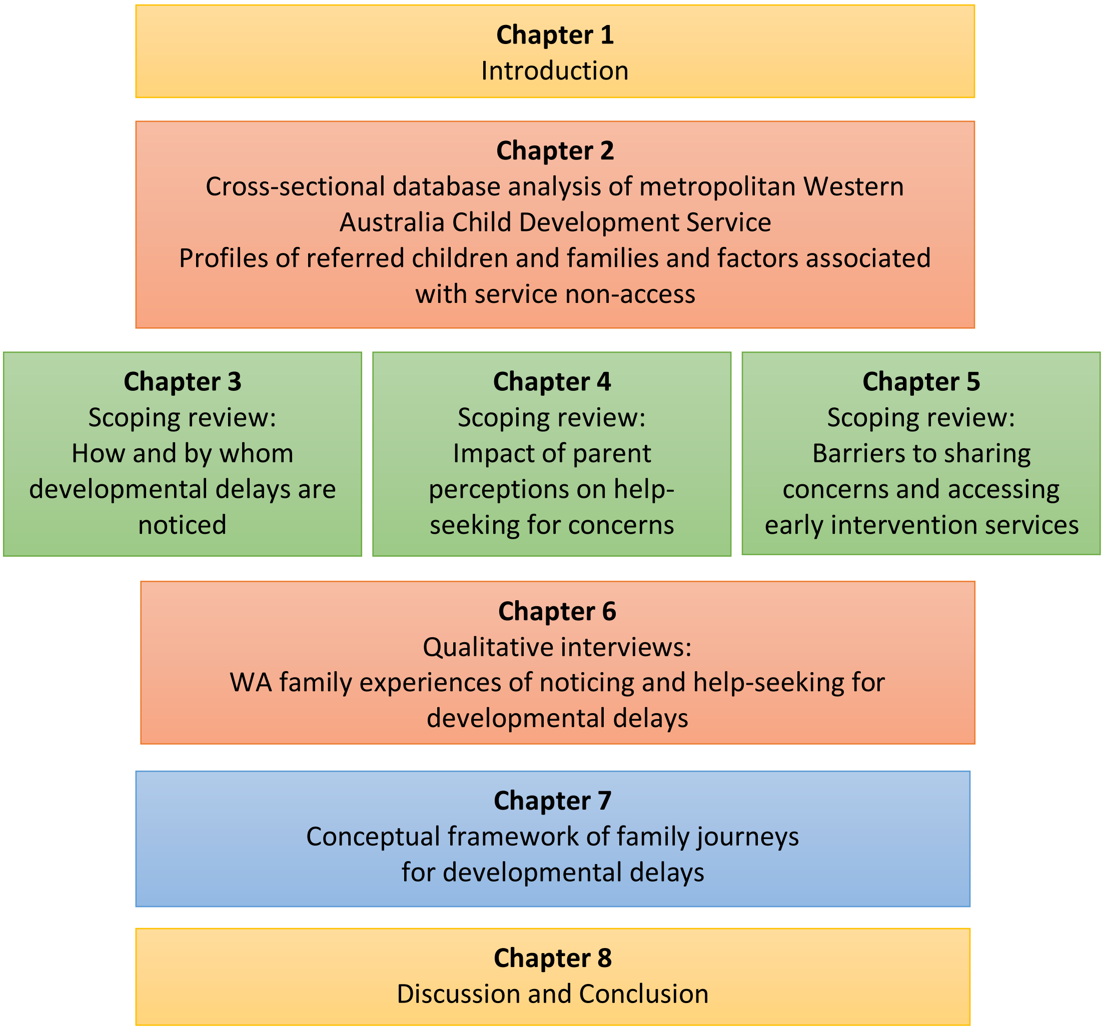


Figure 1-6 Overview of thesis structure

Chapter 1 provides an introduction to the focus of the research. Chapter 2 begins with an orientation to the Western Australian health system and is followed by a cross-sectional database analysis of referrals and factors associated with the non-access of the Child Development Service. Chapters 3, 4, and 5 are a series of three scoping reviews that provide an understanding of existing research on the developmental delay pathway. Chapter 3 is a published scoping review that synthesises findings on how and by whom developmental delays are initially noticed. Chapter 4 builds on the concept of noticing utilising the Health Belief Model to frame how parent perceptions of developmental delays impact help-seeking of services. Chapter 5 is the final in the scoping review series and reports findings on barriers that may inhibit parent sharing of developmental concerns and EI service access. Chapter 6 is a qualitative phenomenological study of interviews with 13 caregivers of children with suspected developmental delays in metropolitan WA. Chapter 7 brings together the understanding, knowledge, and interpretation of Chapters 2 to 6 by creating a conceptual framework of the core elements of family journeys for developmental delays. Chapter 8 synthesises the research findings and discusses the significance of the findings for families, EI services, and the broader community. Strengths and limitations of the research are discussed, with recommendations made for future research.

1.11 References

Ahern, K. (2000). "Something is wrong with my child": A phenomenological account of a search for a diagnosis. *Early Education and Development, 11*(2), 187-201. https://doi.org/10.1207/s15566935eed1102_4

Alexander, K., Brijnath, B., & Mazza, D. (2015). Parents' decision making and access to preventive healthcare for young children: Applying Andersen's Model. *Health Expectations, 18*, 1256-1269. https://doi.org/10.1111/hex.12100

Barfield, W. D., Clements, K. M., Lee, K. G., Kotelchuck, M., Wilber, N., & Wise, P. H. (2008). Using linked data to assess patterns of Early Intervention (EI) referral among very low birth weight infants. *Maternal and Child Health Journal, 12*(1), 24-33. https://doi.org/10.1007/s10995-007-0227-y

Boag-Munroe, G., & Evangelou, M. (2012). From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Research Papers in Education, 27*(2), 209-239. https://doi.org/10.1080/02671522.2010.509515

Campbell, F., Conti, G., Heckman, J. J., Moon, S. H., Pinto, R., Pungello, E., & Pan, Y. (2014). Early childhood investments substantially boost adult health. *Science, 343*. https://doi.org/10.1126/science.1248429

Chin, F., & Teti, D. M. (2013). Infants at double jeopardy: Socioeconomic, medical, and attachment-based predictors of maternal engagement with an early intervention program. *Infant Mental Health Journal, 34*(5), 420-434. https://doi.org/10.1002/imhj.21398

Choo, Y. Y., Agarwal, P., How, C. H., & Yeleswarapu, S. P. (2019). Developmental delay: Identification and management at primary care level. *Singapore Medical Journal, 60*(3), 119-123. https://doi.org/10.11622/smedj.2019025

Clements, K. M., Barfield, W. D., Kotelchuck, M., & et al. (2008). Maternal socio-economic and race/ethnic characteristics associated with early intervention participation. *Maternal and Child Health Journal, 12*(6), 708-717. https://doi.org/10.1007/s10995-007-0291-3

Collier, L. R., Gregory, T., Harman-Smith, Y., Gialamas, A., & Brinkman, S. A. (2020). Inequalities in child developmental at school entry: A repeated cross-sectional analysis of the Australian Early Development Census 2009-2018. *The Lancet Regional Health - Western Pacific, 4*. https://doi.org/10.1016/j.lanwpc.2020.200057

Conti, G., Heckman, J. J., & Pinto, R. (2016). The effects of two influential early childhood interventions on health and healthy behaviour. *The Economic Journal, 126*, 28-65. https://doi.org/10.1111/ecoj.12420

Cortis, N., Katz, I., & Patulny, R. (2009). *Engaging hard-to-reach families and children* (FaHCSIA Occasional paper no. 26). http://dx.doi.org/10.2139/ssrn.1728576

Cunha, F., Heckman, J. J., Lochner, L., & Masterov, D. V. (2006). Interpreting the evidence on life cycle skill formation. In E. A. Hanushek & F. Welch (Eds.), *Handbook of the economics of education* (Vol. 1, pp. 697-812). North Holland. https://doi.org/10.1016/S1574-0692(06)01012-9

Curtin, M., Madden, J., Staines, A., & Perry, I. J. (2013). Determinants of vulnerability in early childhood development in Ireland: A cross-sectional study. *BMJ Open, 3*, e002387. https://doi.org/10.1136/bmjopen-2012-002387

Department of Education and Training. (2019). *Australian early development census national report 2018*. https://www.aedc.gov.au/resources/detail/2018-aedc-national-report

Doherty, P., Hall, M., & Kinder, K. (2003). *On track thematic report: Assessment, referral and hard-to-reach groups*. https://webarchive.nationalarchives.gov.uk/20110506162108/https://www.education.gov.uk/publications/eOrderingDownload/RR475.pdf

Dunst, C. J., Trivette, C. M., & Deal, A. (1994). *Supporting and strengthening families: Methods, strategies and practice* (Vol. 1). Brookline Books.

Eapen, V., Walter, A., Guan, J., Descallar, J., Axelsson, E., Einfeld, S., Eastwood, J., Murphy, E., Beasley, D., Silove, N., Dissanayake, C., Woolfenden, S., Williams, K., Jalaludin, B., & The 'Watch Me Grow' Study, G. (2017). Maternal help-seeking for child developmental concerns: Associations with socio-demographic factors. *Journal of Paediatrics and Child Health*. https://doi.org/10.1111/jpc.13607

Espe-Sherwindt, M. (2008). Family-centred practice: Collaboration, competency and evidence. *Support for Learning, 23*(3), 136-143. https://doi.org/10.1111/j.1467-9604.2008.00384.x

Francesconi, M., & Heckman, J. J. (2016). Child development and parental investment: Introduction. *The Economic Journal, 126*(October), 1-27. https://doi.org/10.1111/ecoj.12388

Giannoni, P. P., & Kass, P. H. (2010). Risk factors associated with children lost to care in a state early childhood intervention program. *Research in Developmental Disabilities, 31*(4), 914-923. https://doi.org/10.1016/j.ridd.2010.02.013

Giordano, K. (2008). *Barriers to early intervention services in New Jersey* [Doctoral dissertation, Fairleigh Dickinson University]. ProQuest Dissertations & Theses.

http://dbgw.lis.curtin.edu.au:2048/login?url=https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/304403224?accountid=10382

Glaun, D. E., Cole, K. E., & Reddihough, D. S. (1998). Six month follow-up: the crucial test of multidisciplinary developmental assessment. *Child: Care, Health and Development, 24*(6), 457-472. https://doi.org/10.1046/j.1365-2214.1998.00082.x

Goldfeld, S., O'Connor, M., Sayers, M., Moore, T., & Oberklaid, F. (2012). Prevalence and correlates of special health care needs in a population cohort of Australian children at school entry. *Journal of Developmental & Behavioral Pediatrics, 33*, 319-327. https://doi.org/10.1097/DBP.0b013e31824a7b8e

Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P. M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services. *BMC Health Services Research, 16*(1), 680. https://doi.org/10.1186/s12913-016-1926-0

Guralnick, M. J. (2001). A developmental systems model for early intervention. *Infants and Young Children, 14*(2), 1-18. http://depts.washington.edu/chdd/guralnick/pdfs/dev_sys_model_EI_IYC_10_01.pdf

Harris, S. R. (2009). Listening to parents' concerns: three case examples of infants with developmental motor delays. *Pediatric Physical Therapy, 21*(3), 269-274. https://doi.org/10.1097/PEP.0b013e3181b12fbc

Hebbeler, K., Spiker, D., Bailey, D. B., Scarborough, A., Mallik, S., Simeonsson, R. J., Singer, M., & Nelson, L. (2007). *Early intervention for infants and toddlers with disabilities and their families: Participants, services, and outcomes*. SRI International. https://www.sri.com/wp-content/uploads/pdf/neils_finalreport_200702.pdf

Heckman, J. J. (2006). Skill formation and the economics of investing in disadvantaged children. *Science, 312*(5782), 1900-1902. https://www.jstor.org/stable/3846426

Heckman, J. J., & Krueger, A. B. (2003). *Inequality in America: What role for human capital policies?* MIT Press.

Heckman, J. J., Stixrud, J., & Urzua, S. (2006). The effects of cognitive and noncognitive abilities on labor market outcomes and social behavior. *Journal of Labor Economics, 24*(3), 411-482. https://doi.org/10.1086/504455

Hendrickson, S., Baldwin, J. H., & Allred, K. W. (2000). Factors perceived by mothers as preventing families from obtaining early intervention services for their children with special needs. *Children's Health Care, 29*(1), 1-17. https://doi.org/10.1207/S15326888CHC2901_1

Human Early Learning Partnership. (2016). *EDI [Early Years Development Instrument] British Colombia: 2016 Provincial Report*. University of British Colombia School of Population and Public Health. http://earlylearning.ubc.ca/media/edibc2016provincialreport.pdf

Ingoldsby, E. (2010). Review of interventions to improve family engagement and retention in parent and child mental health programs. *Journal of Child and Family Studies, 19*(5), 629-645. https://doi.org/10.1007/s10826-009-9350-2

Johnson, J. F. (2011). *An evaluation of the Early Steps Program referral process in Hillsborough County to detect delays in access to early intervention services* (Publication Number 2012-99080-337) [Doctoral dissertation, University of South Florida]. Scholar Commons. http://scholarcommons.usf.edu/etd/3171

Kazdin, A. E., Holland, L., & Crowley, M. (1997). Family experiences of barriers to treatment and premature termination from child therapy. *Journal of Consulting and Clinical Psychology, 65*, 453-463. https://doi.org/10.1037/0022-006X.65.3.453

Kazdin, A. E., Holland, L., Crowley, M., & Breton, S. (1997). Barriers to treatment participation scale: Evaluation and validation in the context of child outpatient treatment. *Journal of Child Psychology and Psychiatry, 38*(8), 1051-1062. https://doi.org/10.1111/j.1469-7610.1997.tb01621.x

Maggi, S., Irwin, L. J., Siddiqi, A., & Hertzman, C. (2010). The social determinants of early child development: An overview. *Journal of Pediatrics and Child Health, 46*, 627-635. https://doi.org/10.1111/j.1440-1754.2010.01817.x.

Magnusson, D. M., Minkovitz, C. S., Kuhlthau, K. A., Caballero, T. M., & Mistry, K. B. (2017). Beliefs regarding development and early intervention among low-income African American and Hispanic mothers. *Pediatrics, 140*(5). https://doi.org/http://dx.doi.org/10.1542/peds.2017-2059

Marshall, J., Adelman, A., Kesten, S. M., Natale, R. A., & Elbaum, B. (2017). Parents’ experiences navigating intervention systems for young children with mild language delays. *Journal of Early Intervention, 39*(3), 180-198. https://doi.org/10.1177/1053815117704958

Marshall, J., Coulter, M. L., & Gorski, P. A. (2016). Parent recognition and responses to developmental concerns in young children. *Infants and Young Children, 29*(2), 102-115. https://doi.org/10.1097/IYC.0000000000000056

Marshall, J., Kirby, R. S., & Gorski, P. A. (2016). Parent concern and enrollment in intervention services for young children with developmental delays: 2007 National survey of children's health. *Exceptional Children, 82*(2), 251-268. https://doi.org/10.1177/0014402915585563

Masse, L. N., & Barnett, W. S. (2002). *A benefit cost analysis of the Abecedarian early childhood intervention*. National Institute for Early Education Research. https://files.eric.ed.gov/fulltext/ED479989.pdf

McAllister, L., McCormack, J., McLeod, S., & Harrison, L. J. (2011). Expectations and experiences of accessing and participating in services for childhood speech impairment. *International Journal of Speech-Language Pathology, 13*(3), 251-267. https://doi.org/10.3109/17549507.2011.535565

McManus, B., McCormick, M. C., Acevedo-Garcia, D., Ganz, M., & Hauser-Cram, P. (2009). The effect of state early intervention eligibility policy on participation among a cohort of young CSHCN. *Pediatrics, 124*, S368-S374. https://doi.org/10.1542/peds.2009-155G

McManus, B., Richardson, Z., Schenkman, M., Murphy, N. J., Everhart, R. M., Hambidge, S., & Morrato, E. (2020). Child characteristics and early intervention referral and receipt of services: A retrospective cohort study. *BMC pediatrics, 20*(8). https://doi.org/10.1186/s12887-020-1965-x

McManus, B. M., Carle, A. C., & Rapport, M. J. (2014). Classifying infants and toddlers with developmental vulnerability: who is most likely to receive early intervention? *Child: Care, Health and Development, 40*(2), 205-214. https://doi.org/10.1111/cch.12013

Morton, D. S. (2012). *Parental descriptions of awareness and associated reactions to developmental delay in children* (Publication Number AAI3545470) [Doctoral dissertation, Capella University]. ProQuest Dissertations & Theses Global. https://www-proquest-com.dbgw.lis.curtin.edu.au/docview/1520325243/B7F1BC2997EB4B37PQ/1?accountid=10382

Mossialos, E., Djordjevic, A., Osborn, R., & Sarnak, D. (2017). *International profiles of health care systems*. Commonwealth Fund. https://www.commonwealthfund.org/sites/default/files/documents/___media_files_publications_fund_report_2017_may_mossialos_intl_profiles_v5.pdf

Mulcahy, H., & Savage, E. (2016). Uncertainty: A little bit not sure. Parental concern about child growth or development. *Journal of Child Health Care, 20*(3), 333-343. https://doi.org/10.1177/1367493515587059

Mumby-Croft, K. J. (2014). *Defining 'hard to reach': The work for health visitors with vulnerable families* [Doctoral dissertation, University of Hertfordshire]. https://pdfs.semanticscholar.org/c3fd/8ad087b3b8478e96a77027a1da309074d072.pdf

Oberklaid, F., & Efron, D. (2005). Developmental delay - identification and management. *Australian family physician, 34*(9), 739-742.

Offord Centre for Child Studies. *Early Development Instrument in Ontario over time*. McMaster University. https://edi.offordcentre.com/partners/canada/edi-in-ontario/

Persoff, J. R. (1998). *Poverty and early childhood developmental delay: Perspectives from Hispanic mothers* [Doctoral dissertation, University of Denver]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/304432454?accountid=10382

Peterson, C. A., Wall, S. M., Raikes, H. A., Kisker, E. E., Swanson, M. E., Jerald, J., Atwater, J. B., & Qiao, W. (2004). Early head start: Identifying and serving children with disabilities. *Topics in Early Childhood Special Education, 24*(2), 76-88. https://digitalcommons.unl.edu/cgi/viewcontent.cgi?referer=https://www.google.com/&httpsredir=1&article=1041&context=famconfacpub

Phoenix, M., & Rosenbaum, P. (2019). Presenting the model of risk, disability and hard-to-reach families to inform early intervention services. *Disability and Rehabilitation, 41*(2), 244-249. https://doi.org/10.1080/09638288.2017.1385650

Piotrowska, P. J., Tully, L. A., Lenroot, R., Kimonis, E., Hawes, D., Moul, C., Frick, P. J., Anderson, V., & Dadds, M. R. (2017). Mothers, fathers, and parental systems: A conceptual model of parental engagement in programs for child mental health - connect, attend, participate, enact (CAPE). *Clinical Child and Family Psychology Review, 20*, 146-161. https://doi.org/http://dx.doi.org/10.1007/s10567-016-0219-9

Pritchard, M. A., Colditz, P. B., Cartwright, D., Gray, P. H., Tudehope, D., & Beller, E. (2013). Risk determinants in early intervention use during the first postnatal year in children born very preterm. *BMC pediatrics, 13*, 201-201. https://doi.org/10.1186/1471-2431-13-201

Ramirez, M. C. (2004). *Latino parents with developmentally delayed children: Perceptions of early intervention services* [Master’s thesis, California State University]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/305036959?pq-origsite=gscholar

Rannard, A., Lyons, C., & Glenn, S. (2004). Children with specific language impairment: Parental accounts of the early years. *Journal of Child Health Care, 8*(2), 165-176. https://doi.org/10.1177/1367493504041875

Restall, G., & Borton, B. (2010). Parents' concerns about their children's development at school entry. *Child: Care, Health and Development 36*(2), 208-215. https://doi.org/10.1111/j.1365-2214.2009.01019.x

Rosenberg, S. A., Robinson, C. C., Shaw, E. F., & Ellison, M. S. (2013). Part C early intervention for infants and toddlers: Percentage eligible versus served. *Pediatrics, 131*, 38-46. https://doi.org/10.1542/peds.2012-1662

Rosenberg, S. A., Zhang, D., & Robinson, C. C. (2008). Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics, 121*(6), e1503-1509. https://doi.org/10.1542/peds.2007-1680

Schweinhart, L. J., Montie, J., Xiang, Z., Barnett, W. S., Belfield, C. R., & Nores, M. (2005). *Lifetime effects: The high/scope Perry Preschool study through age 40*. H. S. Press.

Shannon, P. (2000). *Family-centered practice in early intervention services for infants and toddlers: The experience of families and professionals in one Local Interagency Coordinating Council* [Doctoral dissertation, Virginia Commonwealth University]. ProQuest Dissertations & Theses Global. https://scholarscompass.vcu.edu/etd/5304/

Shapiro, B. J., & Derrington, T. M. (2004). Equity and disparity in access to services: An outcomes-based evaluation of early intevention Child Find in Hawai'i. *Topics in Early Childhood Special Education, 24*(4), 199-212. https://doi.org/10.1177/02711214040240040201

Shonkoff, J. P. (2010). Building a new biodevelopmental framework to guide the future of early childhood policy. *Child Development, 81*(1), 357-367. https://doi.org/10.1111/j.1467-8624.2009.01399.x

Silbersack, E. W. (2014). *Mothers' initial discovery of childhood disability: Exploring maternal identification of developmental issues in young children* [Doctoral dissertation, Adelphi University]. ProQuest Dissertations & Theses Global. https://eric.ed.gov/?id=ED557029

Smith, E., Koerting, J., Latter, S., Knowles, M. M., McCann, D. C., Thompson, M., & Sonuga-Barke, E. J. (2015). Overcoming barriers to effective early parenting interventions for attention-deficit hyperactivity disorder (ADHD): Parent and practitioner views. *Child: Care, Health and Development, 41*(1), 93-102. https://doi.org/10.1111/cch.12146

Smith, L. E., Akai, C. E., Klerman, L. V., Keltner, B. R., & The Centers for the Prevention of Child, N. (2010). What mothers don't know and doctors don't say: Detecting early developmental delays. *Infant Mental Health Journal, 31*(4), 455-466. https://doi.org/10.1002/imhj.20266

Staudt, M. (2007). Treatment engagement in caregivers of at-risk children: Gaps in research and conceptualization. *Journal of Child and Family Studies, 16*, 183-196. https://doi.org/10.1007/s10826-006-9077-2

Swanson, C. (2013). *Attrition from early intervention: Associations with several child characteristics* [Master’s thesis, University of Rhode Island]. ProQuest Dissertations & Theses Global. Ann Arbor. https://search.proquest.com/docview/1476204055?accountid=10382

Thelen, E., & Smith, L. B. (2007). Dynamic systems theories. In R. M. Lerner (Ed.), *Handbook of Child Psychology: Theoretical Models of Human Development* (Vol. 1, pp. 258-312). John Wiley and Sons.

Twardzik, E., Cotto-Negrón, C., & Macdonald, M. (2017). Factors related to early intervention Part C enrollment: A systematic review. *Disability and Health Journal, 10*(4), 467-474. https://doi.org/10.1016/j.dhjo.2017.01.009

United Nations. (1990). *Convention on the rights of the child*. United Nations. https://www.unicef.org/child-rights-convention/convention-text#

Walker, S. P., Wachs, T. D., Grantham-Mcgregor, S., Black, M. M., Nelson, C. A., Huffman, S. L., Baker-Henningham, H., Chang, S. M., Hamadani, J. D., Lozoff, B., Gardner, J. M. M., Powell, C. A., Rahman, A., & Richter, L. (2011). Inequality in early childhood: Risk and protective factors for early child development. *The Lancet, 378*(9799), 1325-1338. https://doi.org/10.1016/S0140-6736(11)60555-2

Warren, D., & Edwards, B. (2017). *Contexts of disadvantage* (Occasional paper no. 53). Australian Institute of Family Studies. https://www.dss.gov.au/sites/default/files/documents/11_2017/occpaper53_contexts_disadvantage_web.pdf

Williams, J. (2007). Learning from mothers: how myths, policies and practices affect the detection of subtle developmental problems in children. *Child: Care, Health and Development, 33*(3), 282-290. https://doi.org/10.1111/j.1365-2214.2006.00690.x

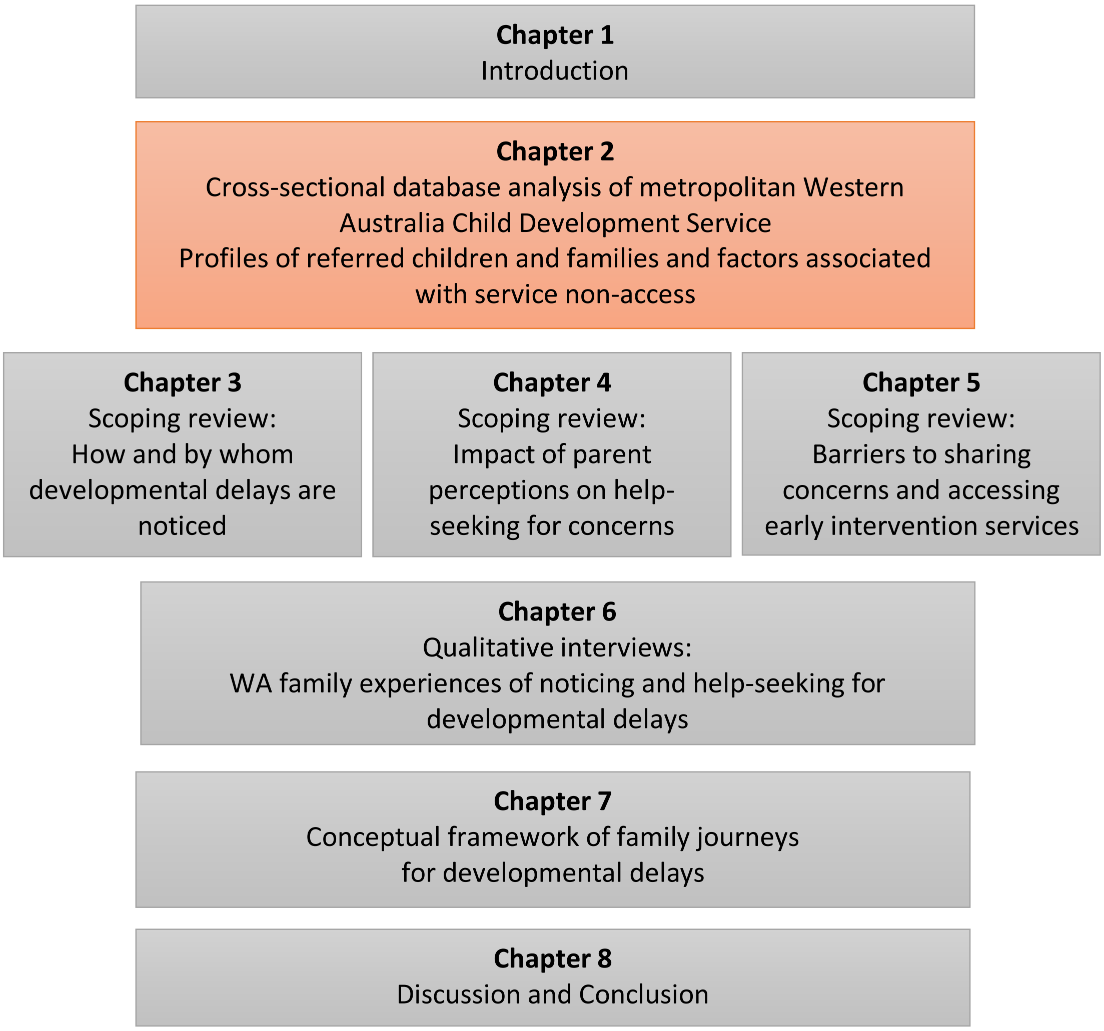
Williams, J., & Holmes, C. A. (2004). Improving the early detection of children with subtle developmental problems. *Journal of Child Health Care, 8*(1), 34-46. https://doi.org/10.1177/13674950401852

Woolfenden, S., Posada, N., Krchnakova, R., Crawford, J., Gilbert, J., Jursik, B., Sarkozy, V., Perkins, D., & Kemp, L. (2015). Equitable access to developmental surveillance and early intervention - understanding the barriers for children from culturally and linguistically diverse (CALD) backgrounds. *Health Expectations, 18*(6), 3286-3301. https://doi.org/10.1111/hex.12318

World Health Organization Health Care for Chronic Conditions Team. (2002). *Innovative care for chronic conditions: Building blocks for action: Global report*. World Health Organization. https://www.who.int/chp/knowledge/publications/icccglobalreport.pdf?ua=1

Chapter 2 Database analysis

The preface to this chapter provides an overview of the overall Australian health care system; an introduction to the state of Western Australia; and how child developmental services and associated supports operate in the WA health system. Findings of a cross-sectional database analysis of referrals to the Child Development Service (CDS), the key government-provider of developmental services in metropolitan WA, are presented.



Chapter 1
Introduction

Chapter 2
Cross-sectional database analysis of metropolitan Western Australia Child Development Service
Profiles of referred children and families and factors associated with service non-access

Chapter 3
Scoping review:
How and by whom developmental delays are noticed

Chapter 4
Scoping review:
Impact of parent perceptions on help-seeking for concerns

Chapter 5
Scoping review:
Barriers to sharing concerns and accessing early intervention services

Chapter 6
Qualitative interviews:
WA family experiences of noticing and help-seeking for developmental delays

Chapter 7
Conceptual framework of family journeys for developmental delays

Chapter 8
Discussion and Conclusion

2.1 The Australian health care system

The Australian health care system is a hybrid model, whereby citizens have access to publicly-funded health services (via universal public insurance known as Medicare) as well as having the ability to purchase additional private insurance (Dixit & Sambasivan, 2018). The Medicare insurance scheme provides coverage to Australian and New Zealand citizens, permanent residents, special visa holders (e.g. humanitarian visas), and for citizens of countries with a reciprocal health agreement (Australian Institute of Health and Welfare, 2020a). The scheme enables fee-free public hospital services, and pays rebates for medical services provided by private practitioners such as general practitioners (GPs). Primary health care is the 'front line' of Australia's health care system, and includes dental, pharmaceutical, allied health, community and public health, and GP services (Australian Institute of Health and Welfare, 2020b). General practitioners in particular are frequently the first point of contact for people with the health system, often due to their nature as gatekeepers of referrals to specialist services (Australian Institute of Health and Welfare, 2020b). In 2018-19 there were 158 million GP attendances nationally, averaging 6.3 visits per person (Australian Bureau of Statistics, 2019a).

Responsibility for funding, operating, and managing public health services is predominantly shared between the national (or Commonwealth) government and individual state and territory governments (Australian Institute of Health and Welfare, 2020a). The Commonwealth government is responsible for the development of national health policy; funding of medical services via Medicare and medicines via the Pharmaceutical Benefits Scheme; providing funding to state and territory governments for the provision of public hospital services; and providing population-specific services (e.g. for Aboriginal and Torres Strait Islander-specific primary health care) (Australian Institute of Health and Welfare, 2020a). The state and territory governments provide additional funding to public hospitals and are responsible for their operation; regulate the operation of private hospitals and other associated private services; and deliver community-based and preventive services (e.g. immunisation programs and maternal and child health services) (Australian Institute of Health and Welfare, 2020a).

This split between national and individual state and territory responsibilities means that while broader health care decisions are implemented at a national level, and thus there are overall similarities across Australia, much of the day-to-day delivery of services is regulated at the state or territory level. This therefore requires that exploration of family experiences of health care pathways takes a state-based focused that is reflective of the unique structure of that region's health system. The following section provides an introduction to Western Australia and an overview of how developmental services are administered in this state.

2.1.1 Introduction to Western Australia

Western Australia (WA) is one of the eight states and territories of Australia. As of 2020, over 2.6 million people reside in WA, of which approximately 2.1 million live in the capital city of Perth (Australian Bureau of Statistics, 2021). While the population of WA only comprises approximately 10% of the total population, the state geographically constitutes one-third of the total land area of the nation – comprising an area of over 2.5 million square kilometres (Geoscience Australia, n.d.).

2.1.2 Developmental services in Western Australia

Health services in WA include public and private services delivered in metropolitan, regional, rural, and remote areas. Public health services are administered at the State level by the WA Department of Health, which includes the WA Country Health Service (WACHS) for non-metropolitan areas (Department of Health Western Australia, n.d.). The WA Child and Adolescent Health Service (CAHS) is the publicly-funded metropolitan provider of child and adolescent services – consisting of neonatology, child and adolescent mental health services (CAMHS), specialist paediatric hospital and trauma (Perth Children's Hospital), and child and adolescent health services - community health (CAHS-CH) (Child and Adolescent Health Service, 2019).

Free universal care to children and families from birth to 18 years provided by CAHS-CH consists of child health nursing (CHN), school health, immunisation, and targeted Aboriginal and refugee health services (Child and Adolescent Health Service, 2020). Child health nursing offers a schedule of universal developmental surveillance checks to assess child health and development and provide parenting support to families. The nature and age of the child when the checks occur have undergone changes following a 2015 review. As of July 2017, the five scheduled developmental checks occur at ages 0-14 days, 8-weeks, 4-months, 12-months and 2-years (replacing the 18-month check) – followed by school-age checks by school health nursing (Child and Adolescent Health Service, 2018).

Fee-for-service private practices operate across WA as an alternative service for families. Service costs may be covered in part by private health insurance coverage, or by the publicly-funded Medicare Benefits Schedule rebates provided for a set number of sessions if the child meets specific eligibility criteria – such as via the Better Start for Children with Disability initiative (soon to be phased out) (Department of Social Services, 2020). There is no centrally managed list or register of private health providers in WA, however many health professional association websites contain discipline-specific lists (e.g. WA Occupational Therapy Association).

Given the overlap and 'greyness' between developmental delay and disability, it is important to understand the Australian disability sector's changing landscape. Since 2013, with the introduction of the National Disability Insurance Scheme (NDIS), Australia has been transitioning to a nationally consistent approach for the provision of disability services (National Disability Insurance Agency, 2014). Previously, disability services had been under the remit of state governments, such as the WA Disability Services Commission (now Department of Communities). A subset of the NDIS is the Early Childhood Early Intervention (ECEI) model which provides developmental support and brief intervention to children under 7-years of age with a developmental delay or disability (National Disability Insurance Agency, 2019). The introduction of this model was flagged in the 2017-18 CAHS annual report as at 'risk' of creating replication, due to the overlap between services currently provided by the state government Child Development Service (see further below) and what would be undertaken by ECEI (Child and Adolescent Health Service, 2018). Other services that provide universal or targeted support for WA children with developmental needs include the Child and Parent Centres and Ngala. Child and Parent Centres operate in partnership with the WA Department of Education and non-government organisations to support families of children aged 0-8 years (Government of Western Australia, n.d.). Specific services are unique to the 21 communities they are located in, but may include hosting maternal and child health services, facilitating playgroups, and providing parenting and counselling services (Government of Western Australia, n.d.). Ngala is a longstanding service in the parenting sector which has been operating in WA for 130 years. Ngala provides parenting and child development support across the WA community via a range of services, including its free Parenting hotline and fee-for-service programs such as admissions at the Ngala Private Hospital (Ngala, n.d.).

2.1.3 The Child Development Service

The major publicly funded metropolitan provider of developmental EI services in WA is the Child Development Service (CDS), which sits within CAHS-CH (Department of Health Western Australia, 2020a). The CDS provides assessment, intervention, and treatment across eleven main sites in the Perth metropolitan area, through a direct individual or group-based therapy model – including speech pathology, occupational therapy, physiotherapy, social work, clinical psychology, audiology, nursing, and paediatrics (Department of Health Western Australia, 2020a). Children are eligible to access CDS services if they live in the greater Perth region, are aged 0-16 years, have an eligible Medicare card, and present with developmental delay or difficulty that affects their function, participation, or parent-child relationship (Department of Health Western Australia, 2020a). Referrals to the CDS can be made by either parents or professionals via an intake referral form (Department of Health Western Australia, 2016 33). According to the 2018-19 CAHS annual report, referrals to CDS have been increasing – from 24,434 discipline referrals in 2015-16 through to 27,083 in 2018-19, an increase of 11 per cent (Child and Adolescent Health Service, 2019). Of note, discipline referrals refer to internal referrals made to and between health professionals within the service, such as to a paediatrician or physiotherapist following the referral of a child; thus one child referral can result in multiple discipline referrals based on child needs. The report states that 26,402 children accessed services from CDS during 2018-19, which according to CAHS-CH constitutes approximately five per cent of the metropolitan Perth zero to 18-year-old population (Child and Adolescent Health Service, 2019).

For the past two decades, it has been well-established that CDS capacity has not kept pace with demand, due in part to growing WA birth rates and migration particularly during the early 2000s (Education and Health Standing Committee, 2009). A State Parliamentary committee report in 2009-10 highlighted “lengthy waitlists” and wait times that “vary from two - 18 months with some children not obtaining any services” (Education and Health Standing Committee, 2009, p. 12). The Department of Health responses identified that while average wait times for children deemed as priority one were between 2.5 - 6.6 months, priority two and three children had average wait times of 5.5 - 12.6 months, and up to 19 months ‘maximum’ wait time for a priority three child to see a paediatrician (Education and Health Standing Committee, 2011). The 2010 committee report called for greater accountability and transparency from the service through providing annual ‘report cards’ of current wait times for each discipline (Education and Health Standing Committee, 2010). This recommendation was supported by the Department of Health but deemed technically difficult at the time – although the service undertook to test new systems to enable this in 2011 (Minister for Health, 2011). At the time of writing this thesis, this waitlist information remains unavailable. This same report identified that families who were most vulnerable to ‘falling through the gaps’ due to resource constraints that create such prohibitive waitlists are “those from poorer, culturally and linguistically diverse (CALD), refugee or Indigenous families” (Education and Health Standing Committee, 2009, p. 44).

In late 2016, CDS incorporated a service planning appointment model to triage the priority supports required by referred families and to provide families with information about alternative modes of support such as private providers in the community (Child and Adolescent Health Service, 2018). CDS operations dictate that within eight weeks of receipt of a referral, families are to be mailed an invitation to attend a scheduled service planning appointment with a CDS clinician via phone call (Child and Adolescent Health Service, 2018). Based on referral information and discussion with the parent, a service plan is collaboratively created. This service plan may consist of discipline specific assessment services, team assessment services, parent information workshops workshops, and/or suggested community-based services. Following plan creation, families are booked into identified parent workshops, placed on waitlists for the identified discipline (e.g. a paediatrician), and then provided with an allocated appointment date once available. According to a 2017-2018 CAHS report, over 90% of families receive a service planning appointment within the targeted eight-week timeframe (Child and Adolescent Health Service, 2018).

Children referred to the metropolitan Perth Child Development Service: Cross-sectional analysis of referral characteristics and factors associated with service non-access

2.2 Abstract

More than one in five children in Australia at school entry are considered to be developmentally vulnerable in one or more areas. Previous research has, however, consistently identified a mismatch between the number of children identified, and the number referred for and receiving support for developmental delays. The Child Development Service (CDS) is the key provider of publicly funded EI services in metropolitan Perth, Western Australia and report anecdotally to experience similar mismatches between numbers of children referred and those who ultimately access

services. The current study sought to describe the characteristics of children and families referred to CDS; describe the nature of and sources of these referrals; and identify factors (child, family and community) associated with service non-access. Cross-sectional analysis of referrals received by CDS over a six-month timeframe from January 1 to June 30, 2017 was performed. Descriptive analyses of sample characteristics were conducted, and inferential chi-square tests were performed to determine between-group differences. Binary logistic generalised estimating equations were conducted to determine the likelihood of referral and odds of non-attendance based on child, family, and referrer factors. Over the six-month period, 6430 children were referred to CDS. Of these, 5568 or 86.6% accessed the service and 862 or 13.4% of children did not. Multivariate modelling identified that those who did not access services were significantly more likely to be female children, identify as Aboriginal, live in areas of greater socioeconomic disadvantage, be referred for hearing concerns, or be referred for one or no specific reason. Non-accessors were less likely to be referred for sensory concerns or by Child and Adolescent Health Service - Community Health services or parents/guardians themselves. Findings identified significant factors associated with service non-access, however why these factors are significant and how CDS needs to respond remains unclear.

2.3 Introduction

Developmental delays relate to delays in the development of a child’s cognition, motor skills, speech and language, social-emotional skills, and/or behaviour (Oberklaid & Efron, 2005; Williams & Holmes, 2004). A delay may be considered to be present when a child is ‘delayed’ in their attainment of age-expected developmental milestones; or when their development is considered to be ‘atypical’ and is beyond reasonable expectations of developmental variation (Choo et al., 2019; Oberklaid & Efron, 2005). Children may have delays in one or more areas; they may have diagnosed physical or mental conditions that result in delay; or they may be considered at-risk or vulnerable to experiencing delays (Hebbeler et al., 2007).

Global estimates suggest that between 13 - 32% of children in developed countries are at risk of experiencing developmental delays (Curtin et al., 2013; Department of Education and Training, 2019; Human Early Learning Partnership, 2016; Offord Centre for Child Studies; Rosenberg et al., 2008). In Australia, the introduction of the Early Development Census (AEDC) has enabled a nation-wide evaluation of the levels of child developmental vulnerability across communities and subsequently recognised high levels of unmet need (Department of Education and Training, 2019; Goldfeld et al., 2012). Data from the 2018 AEDC identified that more than one in five kindergarten-age children in Australia were considered to be developmentally vulnerable in one or more areas, with increased vulnerability in children living in areas of greater socioeconomic disadvantage, Aboriginal and Torres Strait Islander children, and children with a language background other than English (Department of Education and Training, 2019).

As early childhood lays the foundation for school and post-school outcomes, early intervention (EI) to address delays is considered vital (as well as most cost-effective)

(Knudsen et al., 2006). Previous research has however consistently identified a mismatch between the number of children identified, and the number of children referred for and receiving support for developmental delays (Hebbeler et al., 2007; McManus et al., 2009; Rosenberg et al., 2013). For example, a nation-wide analysis in the U.S. identified that while between 2 - 78% of young children across the country may have been eligible for EI services, only between 1.48 - 6.96% were enrolled (Rosenberg et al., 2013). To our knowledge, there has been limited exploration of this relationship in Australia. A 2012 study utilising AEDC data identified that 18% of children were considered to be 'of concern' – yet only 15% of this subgroup had attended EI services (Goldfeld et al., 2012) - constituting significant levels of unmet needs

Historically, families who do not take up opportunities to access EI services have been labelled as 'hard-to-reach' (Boag-Munroe & Evangelou, 2012). Previous research in nations similar to Australia such as the U.S. and the U. K. has sought to understand who these 'hard-to-reach' families are through identifying child, family, and/or community risk factors that impact their access to EI (Chin & Teti, 2013; Clements et al., 2008; Giannoni & Kass, 2010; Pritchard et al., 2013; Shapiro & Derrington, 2004). Factors such as low socioeconomic status (Chin & Teti, 2013; Marshall, Kirby, et al., 2016; McManus et al., 2009; Twardzik et al., 2017), racial, cultural, and linguistic diversity (Clements et al., 2008; Giannoni & Kass, 2010; Marshall, Kirby, et al., 2016; Rosenberg et al., 2008; Swanson, 2013), mother's education level (Giannoni & Kass, 2010), and level of severity of child delay (McManus et al., 2009; Swanson, 2013) have been consistently linked to higher risk of service non-access (Hebbeler et al., 2007; McManus et al., 2009; Rosenberg et al., 2008; Shapiro & Derrington, 2004). Understanding barriers undermining a family's ability to access EI services is vital if the barriers are to be addressed (Giannoni & Kass, 2010; Phoenix & Rosenbaum, 2019) through measures such as reviewing service delivery models and the provision of targeted strategies (Boag-Munroe & Evangelou, 2012; Phoenix & Rosenbaum, 2015).

In Western Australia (WA), public and private developmental services are provided in metropolitan and country areas. The Child Development Service (CDS) is the key provider of publicly funded EI services in metropolitan Perth (Department of Health Western Australia, 2020a). Anecdotally, CDS reported mismatches between the numbers of children referred to them and those who ultimately access their service. The CDS has identified a need to better understand the characteristics of families who do not access their services following a referral, in order to identify avenues for intervention. The current study was initiated to address a two-fold aim: to firstly describe the characteristics of referrals received by CDS; and to secondly identify factors associated with families who do not access CDS services following referral.

Four related objectives were identified to meet the aim:

- describe the characteristics of children and families referred to CDS;
- describe the indicated reasons for referral;
- describe the sources of these referrals; and
- describe the characteristics of children and families who did and did not access CDS services, and identify bioecological factors (child, family and community) associated with non-access.

2.4 Methods

2.4.1 Study design

A cross-sectional snapshot of the Child Development Information Service (CDIS) database was undertaken. This database houses the initial referral and subsequent service records, including all contact and/or activity, of all children referred to CDS. Extracted data were restricted to referrals received from January 1 to June 30, 2017. This timeframe was selected to reflect the change to the CDS service planning appointment model in late 2016 (Child and Adolescent Health Service, 2018). This delay also allowed sufficient time following referral for initial intake and service appointments to be offered and/or accessed prior to data extraction in May 2019 - at which point all referred families had been invited to engage with the service.

2.4.2 Data collection

Factors were selected for analysis in accordance with the child, family, and community risk factor approach undertaken in similar research (Clements et al., 2008; Giannoni & Kass, 2010; McManus et al., 2009; Rosenberg et al., 2008). While not explicitly stated in previous studies, this approach appears to be based on bioecological theories of child development, such as proposed by Bronfenbrenner and Ceci (1994), Thelen and Smith (2007), and Shonkoff (2010). These noted theories posit that developmental outcomes are the dynamic product of both inherent biological factors and social or environmental experiences or factors surrounding the child, particularly the influence of family characteristics. Factors that increase the risk of negative outcomes and/or act as 'stressors' are considered important to assess, particularly at the point of service access, to enable implementation of associated interventions (Guralnick, 2001).

As previous studies have encountered, selection of child, family, and community factors for analysis largely depends on the nature of the data collected by the service of interest (Clements et al., 2008; Giannoni & Kass, 2010). For this analysis of CDS referrals, information was predominantly provided via the CDS referral intake form (see Appendix B), plus intake and engagement status. Some of these data (e.g. from the 'relevant health history' section) were free-text and not approved for extraction by CDS. At the time of data collection, data linkage of CDS data to other databases such as state government departments (e.g. social services) were not available.

2.4.2.1 Child and family factors

Child and family factors examined were child age (at time of referral), child gender, child being of Aboriginal descent, child being in the care of the Department for Child Protection and Family Support (DCPFS, now Department of Communities), and family requiring an interpreter (proxy for CALD groups). ‘Child being of Aboriginal descent’ is the terminology used in the CDS referral form, and thus carried forward throughout this analysis. Socio-Economic Index for Areas (SEIFA) based on family suburb was used as a proxy for socioeconomic status (SES), using decile figures from the 2016 Index of Relative Disadvantage (Australian Bureau of Statistics, 2018). For modelling purposed, SEIFA deciles were collapsed into quintiles each representing 20% of the distribution (i.e. deciles 1+2=quintile 1, 3+4=quintile 2, etc.) using visual binning to determine the most appropriate groupings (IBM Corp, n.d.).

2.4.2.2 Referral factors

On the CDS referral intake form the referrer selects one or more of the 15 available reasons for referral: attention/concentration; behaviour/emotion; family/relational; feet/lower limbs/gait; fine motor; functional skills (feeding, toileting, sleeping); general development; gross motor; head shape/position; hearing; learning; ‘other’; play skills; sensory; and/or speech/language (Department of Health Western Australia, 2016). For the purposes of analysis, the reason(s) for referral and information on who completed the referral were extracted. Importantly, free-text entry regarding reasons for referral was unable to be analysed, which contained further information at times beyond the selected options. The source of referral was categorised by the nature of the referrer organisation (e.g. education setting), with some groups collapsed to ensure there was sufficient power for analysis (e.g. school + childcare = education settings).

2.4.2.3 Service access

Service access in this study was determined by whether the child's family had (at a minimum) attended the service planning appointment phone call with a clinician and/or accessed further services offered by CDS. During the study period, children could have been referred to CDS multiple times. For children with one referral, the access outcome was determined by whether they accessed services offered from that referral. If a client had multiple referrals and was inactive for services (i.e., if the client had been discharged between referrals), then the access outcome for the initial referral and the subsequent referral were both counted separately. If a subsequent referral was received while the client was active for CDS services (not discharged), then the access outcome was counted against the initial referral (accessed or not) and the subsequent referral was excluded.

2.4.3 Data management and analysis

Data were analysed using SPSS Statistics software (IBM Corp, 2020). As stated, children could have been referred multiple times over the study period. The sample was limited to unique children for the majority of analyses; however, all referrals were retained for source of referral modelling via the use of system-generated unique Client ID numbers. The dataset was intact aside from two postcodes without associated SEIFA scores (undesignated new suburbs). As these two participants only constituted <0.1% of all referrals and all other data for the participants were intact, missingness was managed via pairwise deletion (Kang, 2013).

Descriptive analyses were conducted to describe sample characteristics, and inferential chi-square tests of independence were performed to identify group differences for categorical variables. Binary logistic generalised estimating equations were used to calculate odds ratios (*OR*) for likelihood of referral for specific reasons, from specific referrers, or based on specific child and family factors compared to the rest of the sample; as well as for determining odds of service non-access based on child, family, and referrer factors (Pekar & Brabec, 2018). Dummy variables were created in preparation for modelling to denote a reference group (e.g. family require an interpreter, no = 0, yes = 1 with 0 as the reference group) (SAS Institute Inc, 2015). The individual contribution of factors was firstly tested at univariate level, with significance set at $p = .05$. Factors identified to be significant at univariate level were used to build the multivariate model, with the backwards elimination process utilised until statistical significance was reached across all included factors (Heinze et al., 2017). The presence of interactions was tested for between factors - interactions that reached significance when entered in the multivariate model were retained. Odds ratios were used to denote the odds of outcomes, such as being referred for speech/language compared to other reasons for referral (SAS Institute Inc, 2015).

2.4.4 Ethics

Ethics and governance approvals were received from the Department of Health (Child and Adolescent Health Service) Human Research Ethics Committee (RGS0000000198) with reciprocal approval from the Curtin University Human Research Ethics Committee (HRE2017-0701). See Appendices C and D.

2.5 Results

From 1 January to 30 June 2017, 6524 referrals were received for 6430 unique children (see Figure 2-1). From the original data extract of 6784 referrals, 260 referrals were excluded. Fifty-two referrals were ineligible for CDS due to being outside the CDS catchment area, 186 were system errors, with a further 22 not invited to receive services directly from CDS (transferred to another provider or participant in neonatal follow-up program), and thus excluded from subsequent analyses. The majority of children (98.5%) received a single referral during the six-month duration, with 94 children or 1.5% of the sample receiving two separate referrals.

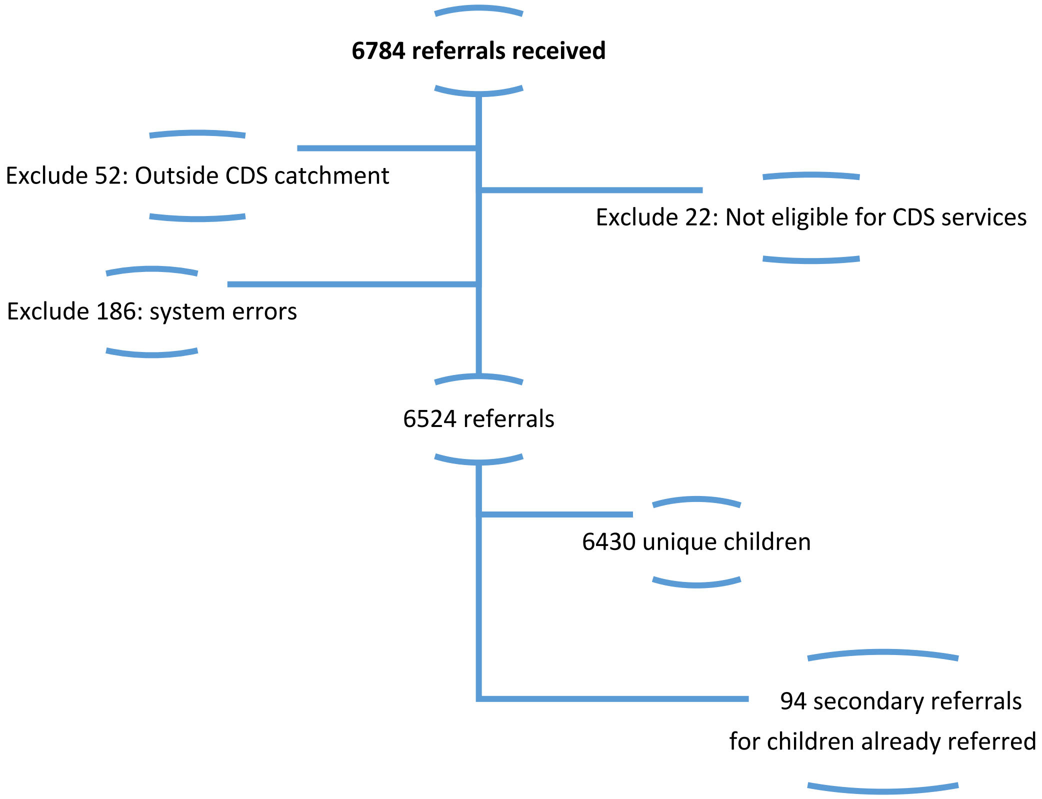


Figure 2-1 CDS Referral inclusion/exclusion

2.5.1 Sample overview

Referred children were predominantly male, with a mean age of 3.5 years at time of referral (see Table 2.1). Over 6% of children (*n* = 406) identified as Aboriginal, while 2.3% (*n* = 145) were in the care of Department for Child Protection and Family Support (DCPFS). Three percent of the sample (*n* = 193) indicated the need for an interpreter, with major languages spoken being Arabic (15%), Vietnamese (14%) and Mandarin (14%).

Sample data were compared to population-based estimates to determine representativeness of the wider metropolitan population. Compared to Census data on 0-16-year-old children in Perth, WA, the referred sample consisted of a higher percentage of male children as well as predominantly representing the early childhood years, with over 90% of the sample aged <7 years of age (Australian Bureau of Statistics, 2016). There was a relative overrepresentation of children who identified as Aboriginal or in the care of DCPFS, and an underrepresentation of families with limited English language skills (Australian Bureau of Statistics, 2016; Department for Child Protection and Family Support, 2017). There was no linear trend in spread of referral across the sample by SEIFA decile (see Table 2.2).

Table 2.1. Sample demographics

Demographics		**Children referred to CDS (*N* = 6428) Count, %**	**Total metropolitan Perth (ABS 2016 census) Count, %**
Gender*:	Male	4113, 64.0%	214620, 51%
	Female	2315, 36.0%	203723, 49%
Age (years)*:	0-3	2936, 45.7%	101614, 24%
	4-6	2866, 44.6%	76654, 18%
	7-12	578, 9.0%	147315, 35%
	13-16	48, 0.7%	92830, 22%
Is the child of Aboriginal descent (specific referral form wording) #	Yes	406, 6.3%	10706 (of 353463), 3.0%
	No	6022, 93.7%	
Is the child in the care of the Department for Child Protection and Family Support (DCPFS)~	Yes	145, 2.3%	4795 (of 1043852), 0.5%
	No/blank	6283, 97.7%	
Is an interpreter required ^	Yes	193, 3.0%	12343 (of 269224), 4.6%
	No/blank	6235, 97.0%	

Note. *Data source for population comparison: 2016 ABS Census - Basic Community Profile by LGA (children 0-16 years) (Australian Bureau of Statistics, 2016)
#Data source: 2016 ABS Census - Basic Community Profile by LGA, Indigenous status (children 0-14 years) (Australian Bureau of Statistics, 2016)
~Data source: 2016-17 annual report, Department for Child Protection and Family Support, children in out of home care Western Australia (children 0-17 years) (Department for Child Protection and Family Support, 2017)
^Data source: 2016 ABS Census – General Community Profile by LGA, Proficiency in Spoken English/Language of Parents by Age of Dependent Children (children 0-14 years, one or both parents do not speak English well or not at all) (Australian Bureau of Statistics, 2016)

Table 2.2. Sample SEIFA Disadvantage Deciles

SEIFA Decile	Children referred to CDS (N = 6428) Count, % of sample	Total metropolitan Perth (ABS 2016 census)@ Count
1 (most disadvantaged)	471, 7.3%	14544
2	653, 10.1%	19630
3	406, 6.3%	27056
4	513, 8.0%	36152
5	1228, 19.1%	38110
6	279, 4.3%	52929
7	566, 8.8%	53336
8	597, 9.3%	57734
9	997, 15.5%	73095
10 (least disadvantaged)	712, 11.1%	43331

Note. @Data source: 0-16yr population residing in ABS SA2 Perth metropolitan area by SEIFA disadvantage deciles (Australian Bureau of Statistics, 2018)

2.5.2 Reasons for referral

On average, children were referred to CDS based on two or more developmental reasons. Almost 50% of referrals were referred for one reason, 19% for two reasons, 11% for three, 6% for four, and 10% for five or more. The reason for referral was left blank for 4% of the sample. Table 2.3 provides an overview of the indicated reasons for referral. Concerns with speech/language (~58%) was the most common reason; 30% of referrals were for speech/language alone. Over half of referrals for behaviour/emotion were also for attention/concentration and vice versa. Referrals for one specific reason were common –

82% of referrals for head shape/position were for that reason alone; similarly, for speech (52%), hearing (38%) and feet/lower limbs/gait (38%).

Table 2.3. Reasons for Referral

Reason for referral	**Count, %**
Attention/concentration	1202, 18.4%
Behaviour/emotion	1373, 21.0%
Family/relational	195, 3.0%
Feet/lower limbs/gait	311, 4.8%
Fine motor	1276, 19.6%
Functional skills (feeding, toileting, sleeping)	366, 5.6%
General development	549, 8.4%
Gross motor	930, 14.3%
Head shape/position	551, 8.4%
Hearing	766, 11.7%
Learning	736, 11.3%
Other	404, 6.2%
Play skills	419, 6.4%
Sensory	402, 6.2%
Speech/language	3779, 57.9%

Note. As children could be referred for more than one reason, the total percentage will not be 100%

2.5.3 Factors associated with reason for referral

Table 2.4 presents significant factors from multivariate modelling for odds of referral for each reason referral.

Table 2.4. Referral reason by child and family characteristics

Referral reason	**Factor**	***OR***	**95% CI**	***p* value**
Attention/ concentration	Child male	1.8	1.6-2.1	<.001
	Child aged 7+ years	4.6	3.9-5.5	<.001
	Living in least disadvantaged SEIFA quintile	0.8	0.7-0.9	.009
Behaviour/ emotion	Child male	1.7	1.5-1.9	<.001
	Child aged 4-6 years	1.5	1.3-1.7	<.001
	Child aged 7+ years	5.9	4.9-7.2	<.001
	Living in least disadvantaged SEIFA quintile	0.8	0.7-0.9	<.001
Family/ relational	Child aged 7+	3.8	2.7-5.2	<.001
	Child identified as of Aboriginal descent	1.9	1.2-2.9	.006
Feet/lower limbs/gait	Child female	1.7	1.3-2.1	<.001
	Child aged 0-3 years	3.0	2.3-.8	<.001
	Living in least disadvantaged SEIFA quintile	0.7	0.6-0.9	.018
	Child identified as of Aboriginal descent	0.4	0.2-0.8	.013
Fine motor	Child male	2.3	2.0-2.6	<.001
	Child aged 4-6 years	3.2	2.8-3.7	<.001
	Child aged 7+ years	1.4	1.1-1.8	.006
Functional skills	Child aged 0-3 years	2.0	1.6-2.5	<.001
General development	Child male	1.4	1.1-1.7	.001
	Child age 0-3 years	1.2	1.0-1.5	.046
	Child aged 7+ years	2.5	1.9-3.3	<.001
	Child in the care of DCPFS	2.5	1.6-3.8	<.001
	Family requires interpreter	1.8	1.2-2.8	.009
	Child identified as of Aboriginal descent	1.4	1.0-2.0	.038
Gross motor	Child male	1.2	1.0-1.4	.038
	Child aged 0-3 years	1.2	1.2-1.6	<.001
	Living in least disadvantaged SEIFA quintile	1.2	1.1-1.5	.004
	Child identified as of Aboriginal descent	0.7	0.5-0.9	.037
Head shape/ position	Child aged 0-3 years	86.4	44.7-167.3	<.001
	Living in least disadvantaged SEIFA quintile	1.3	1.0-1.6	.016

Hearing	Living in most disadvantaged SEIFA quintile	1.2	1.1-1.5	.020
	Child in the care of DCPFS	1.7	1.1-2.6	.012
	Family requires interpreter	1.8	1.2-2.6	.003
	Child identified as of Aboriginal descent	1.9	1.5-2.5	<.001
Learning	Child male	1.2	1.0-1.5	.014
	Child aged 4-6 years	3.6	3.0-4.5	<.001
	Child aged 7+ years	9.3	7.3-11.9	<.001
	Family requires interpreter	1.7	1.1-2.5	.015
	Child identified as of Aboriginal descent	1.6	1.2-2.1	.002
Other	Child aged 0-3 years	1.5	1.1-1.9	.003
	Child aged 7+ years	7.4	5.7-9.7	<.001
Play skills	Child male	1.8	1.4-2.3	<.001
	Family requires interpreter	2.3	1.5-3.5	<.001
	Living in most disadvantaged SEIFA quintile	1.4	1.1-1.8	.011
	Living in middle disadvantaged SEIFA quintile	1.3	1.0-1.6	.033
Sensory	Child male	2.2	1.7-2.9	<.001
	Child age 4-6 years	2.1	1.7-2.7	<.001
	Child aged 7+ years	2.8	2.0-3.8	<.001
Speech/ language	Child male	1.2	1.0-1.3	.005
	Child aged 0-3 years	2.6	2.1-3.1	<.001
	Child aged 4-6 years	6.2	5.1-7.5	<.001
	Family requires interpreter	1.6	1.1-2.2	.009
	Child identified as of Aboriginal descent	1.4	1.1-1.8	.002
	Living in lowest SEIFA quintile	1.2	1.1-1.4	.004
	Child in the care of DCPFS	0.6	0.4-0.9	.009

2.5.3.1 Child factors

Compared to other age groups, 0-3-year-olds were significantly more likely to be referred for feet/lower limbs/gait (70% of all referrals for this reason); functional skills (60% of all referrals); gross motor; and particularly head shape/position concerns - making up 98% of all referrals for this reason. Four to six-year-olds were significantly more likely to be referred for fine motor (66% of all referrals for this reason), speech/language, learning, and sensory. Older children (7+) were significantly more likely to be referred for ‘other’, attention/concentration, learning, behaviour/emotion, general development, sensory, fine motor, and family/relational. Boys were slightly more likely to be referred for almost all referral reasons; however, girls were more likely to be referred for feet/lower limbs/gait (6.3% of all females compared to 3.9% of males).

2.5.3.2 Family factors

Children identified as being of Aboriginal descent, who had families who required an interpreter, or who were under the care of DCPFS were all more likely to be referred for hearing and general development. Children who identified as Aboriginal or who required an interpreter were also more likely to be referred for learning and speech/language, while children in the care of DCPFS were found to be less likely to be referred for speech/language. Children who as identified as Aboriginal were more likely to be referred for family/relational reasons, and less likely for feet/lower limb/gait or gross motor; while children of families requiring interpreters were more likely to be referred for play skills (14%, compared to 6% of the rest of the sample). In terms of socioeconomic status, children living in the highest SEIFA quintile (i.e., areas of lowest socioeconomic disadvantage) were less likely to be referred for attention/concentration, behaviour/emotion, and feet/lower limbs/gait compared to children in other areas. They were significantly more likely to be referred for head shape/position concerns or gross motor skills. Conversely, children in the lowest SEIFA quintile (i.e., areas of highest socioeconomic disadvantage) were significantly more likely to be referred for hearing or speech/language, with children from both the lowest and middle SEIFA quintiles were more likely to be referred for concerns with play skills.

2.6 Source of referrals

Referrals were received primarily from CAHS-CH (predominantly by child health nurses, CHNs) (*n* = 2584, 40%) and education settings (such as early learning centres and schools) (*n* = 2300, 35%). Other referrers included general practitioners (GPs) (*n* = 881, 14%); other health services including hospitals (*n* = 426, 7%); parents/guardians (*n* = 306, 5%); and 'other' (*n* = 27, <1%), consisting primarily of child welfare service professionals.

2.6.1.1 CAHS-CH

CAHS-CH referrals were predominantly for speech/language (44%), followed by head shape/position concerns (19%), hearing (17%), behaviour/emotion (14%), and gross motor (14%). Compared to other referrers, CAHS-CH were more likely to refer for head shape/position concerns (*OR* = 19.3, 90% of all referrals for this reason), hearing (*OR* = 2.2), feet/lower limbs/gait (*OR* = 2.0), and functional skills (*OR* = 1.6) – while each of the latter two only made up 7% of CAHS-CH referrals, they represented approximately half of all referrals for these reasons.

2.6.1.2 Education-based settings

The top five reasons for a referral from education-based settings were speech/language (81% of all education referrals), fine motor (35%), attention (27%), behaviour (20%), and learning (18%). Compared to others, education-based settings were significantly more likely to refer for speech/language (*OR* = 5.1), fine motor (*OR* = 4.5), learning (*OR* = 2.5), attention/concentration (*OR* = 2.3), sensory (*OR* = 2.6, 57% of all sensory referrals), or play (*OR* = 2.0, 51% of play referrals).

2.6.1.3 General practitioners

General practitioners (GPs) primarily referred for speech/language (43%), behaviour/emotion (43%), attention/concentration (27%), 'other' (24%), and learning

(13%). They were significantly more likely to be the referrer for behaviour/emotion (*OR* = 3.4), general development (*OR* = 1.4), or learning (*OR* = 1.3). Of interest, GPs were over eight times more likely to refer for ‘other’ reasons, comprising 52% of all referrals for this reason (*OR* = 8.6). As free text data were not available, the nature of concerns that comprised ‘other’ was unavailable for analysis.

2.6.1.4 Other health services

Referrals from other health services were predominantly for speech/language (45%), gross motor (24%), behaviour/emotion (20%), ‘other’ (18%), and hearing (17%). These settings were more likely to refer for play (*OR* = 8.7), attention/concentration (*OR* = 6.2), sensory (*OR* = 4.0), behaviour/emotion (*OR* = 3.8), or functional skills (*OR* = 1.1). Five percent of health services referrals were for family/relational compared to 2 - 4% from other settings (*OR* = 13.6).

2.6.1.5 Parent/guardian

The top five reasons for referrals from parents/guardians were for speech/language (64%), attention/concentration (27%), behaviour/emotion (26%), fine motor (18%), and learning (16%); the same as schools, albeit in a different order. Parents were 1.3 - 1.6 times significantly more likely to refer for speech/language, behaviour/emotion, attention/concentration, or learning, and twice as likely to refer for sensory concerns, compared to other referrers.

2.6.1.6 Other

Referrals from ‘other’ were largely for speech/language (52%), general development (41%), behaviour/emotion (26%), hearing (19%), and ‘other’ (19%). Due to the small sample size, odds ratios were unable to be accurately calculated.

2.6.2 Factors associated with the source of referral

Table 2.5 presents significant child and family factors associated with the source of referral.

Table 2.5. Source of referral by child and family factors

Source of referral	**Factor**	***OR***	**95% CI**	***p* value**
CAHS-CH	Child female	1.2	1.0-1.3	.012
	Child aged 0-3 years	12.2	9.6-15.5	<.001
	Child aged 4-6 years	1.7	1.3-2.1	<.001
	Child identified as of Aboriginal descent	1.4	1.1-1.8	.003
	Interpreter required	1.6	1.1-2.3	.007
	Child in the care of DCP	1.6	1.0-2.6	.047
Education	Child male	1.2	1.0-1.3	.044
	Child aged 4-6 years	15.0	13.0-17.3	<.001
	Child aged 7+ years	2.6	2.1-3.2	<.001
	Child in the care of DCP	0.2	0.1-0.4	<.001
	Living in least disadvantaged SEIFA quintile	0.8	0.7-0.9	<.001
GP	Child male	1.2	1.0-1.4	.036
	Child aged 7+	8.2	6.8-9.8	<.001
	Child identified as of Aboriginal descent	0.6	0.4-0.8	.004
Other health services	Child aged 0-3 years	3.0	2.4-3.8	<.001
	Child aged 7+ years	2.6	1.8-3.6	<.001
	Interpreter required	0.4	0.1-0.9	.026
	Child in the care of DCP	2.3	1.4-3.7	.001
Parent/guardian	Child aged 7+ years	1.8	1.3-2.5	<.001
	Child identified as of Aboriginal descent	0.4	0.2-0.9	.021
	Living in middle disadvantaged SEIFA quintile	1.6	1.1-2.2	.014
	Living in second-least disadvantaged SEIFA quintile	1.8	1.2-2.6	.002
	Living in least disadvantaged SEIFA quintile	2.4	1.8-3.4	<.001

2.6.2.1 Child factors

Compared to other age groups, CAHS-CH were more likely to refer 0-3-year-olds, accounting for 63% of all referrals. Education referrers were more likely to refer 4-6-year-olds (63% of all 4-6-year-old referrals) and 7+ year-olds compared to other age groups. General practitioners and hospitals were more likely to refer either the younger or older age groups, with GPs more likely to refer older children (47% of all 7+ year old referrals). Parent/guardians were more likely to refer older children compared to other age groups, though this group only constituted 15% of all parent referrals. Referrals from CAHS-CH were slightly but significantly more likely to be for females while GPs were more likely to refer males.

2.6.2.2 Family factors

Staff from CAHS-CH were more likely to refer children identified as being of Aboriginal descent, while parent/guardians were significantly less likely (3% of parent referrals compare to 5-18% of referrals from the other sources). While too small a sample to analyse, it is of note that almost one-fifth of ‘other’ referrals were for children of Aboriginal descent. Compared to other referrers, CAHS-CH were significantly more likely to refer children of families indicating an interpreter was required (4% of all CAHS-CH referrals), while hospitals were least likely (1% of referrals). Both CAHS-CH and health services were significantly more likely to refer children in care than other sources (3% of CAHS-CH and 5% of all hospital referrals), while schools were less likely (<1%) compared to other referrers. While too small a sample to conduct an odds analysis, two-thirds of referrals from ‘other’ sources were for children described as being in care; as the majority of these referrers were from DCPFS. Parent/guardians who self-referred were significantly more likely to live in middle to high SEIFA quintile areas (i.e., areas of lowest to middle socioeconomic disadvantage), with increasing odds as disadvantage decreased (38% of all parent referrals lived in the highest SEIFA decile). Education referrals were less likely to be for families from the highest SEIFA quintile areas (i.e., areas of lowest disadvantage) (23%). General practitioner and health service referrals did not significantly differ across areas of socioeconomic disadvantage.

2.7 Service access

Of the 6430 children referred to CDS, 5568 (or 86.6%) accessed the service to some extent (see Figure 2-2). As stated, service access in this study was determined by whether the child's family had (at a minimum) attended the service planning appointment phone call with a clinician and/or accessed further services offered by CDS. Of the 5568 children and their families who accessed services, 4022 attended the initial intake appointment, while 1546 attended either internal services provided by CDS clinicians (*n* = 1342) or services through an external provider (*n* = 204). Conversely, 862 children (or 13.4%) did not access the service – evident by not responding to service or appointment offers (*n* = 676), not attending booked appointments (*n* = 83), or following discharge by parent request (*n* = 103). Table 2.6 provides an overview and chi-square comparison of those who did and did not access CDS.

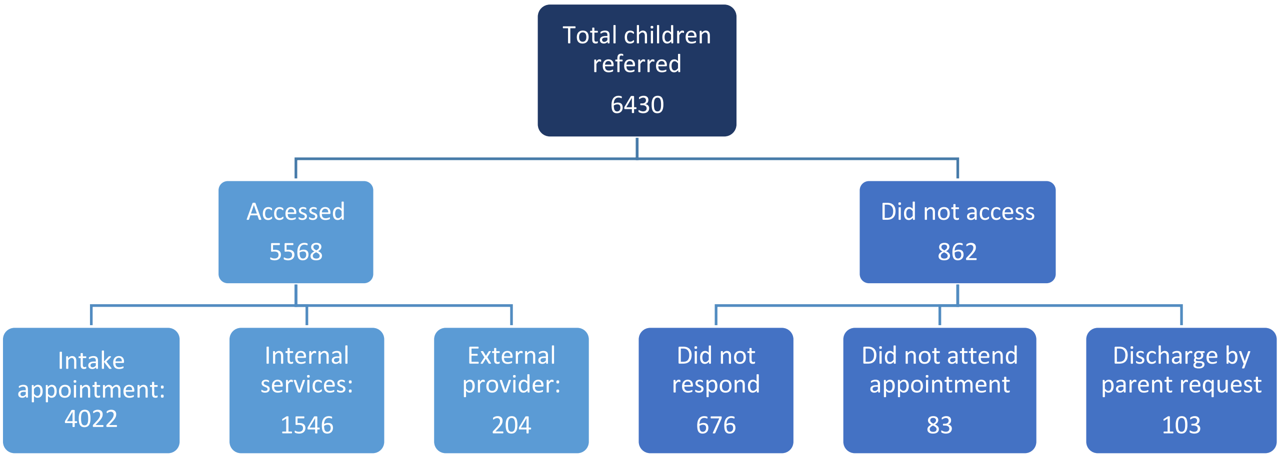


Figure 2-2 Service access pathways

Table 2.6. Demographics of families who did and did not access services following referral

Referrals to CDS		**Accessed**		**Did not access**		**% of total who did not access**	***p* value**
		n	**%**	***n***	**%**		
Gender	Male	3622	61.5%	492	57.1%	11.9%	<.001
	Female	1946	34.9%	370	42.9%	16.0%	
Age	0-3	2589	46.5%	349	40.5%	11.8%	.004
	4-6	2449	44.0%	417	48.4%	14.5%	
	7+	530	9.5%	96	11.1%	15.3%	
Aboriginal descent	Y	325	5.8%	81	9.4%	20.0%	<.001
	N	5243	94.2%	781	90.6%	13.0%	
Interpreter	Y	168	3.0%	25	2.9%	13.0%	NS
	N	5400	97.0%	837	97.1%	13.4%	
DCPFS	Y	130	2.3%	16	1.7%	11.0%	NS
	N	5438	97.7%	846	98.3%	13.5%	
SEIFA quintiles	1 (most disadvantaged)	946	17.0%	178	20.7%	15.8%	.001
	2	776	13.9%	144	16.6%	15.7%	
	3	1296	23.3%	211	24.5%	14.0%	
	4	1035	18.6%	128	14.9%	11.0%	
	5 (least disadvantaged)	1513	27.2%	201	23.3%	11.7%	
Reason for referral	Attention/ concentration	1052	18.9%	136	15.7%	11.4%	.028
	Behaviour/ emotion	1189	21.4%	167	19.3%	12.2%	NS
	Family/ relational	163	2.9%	28	3.3%	14.7%	NS
	Feet/lower limbs/gait	275	4.9%	33	3.8%	10.7%	NS
	Fine motor	1104	19.8%	160	18.4%	12.7%	NS
	Functional	320	5.7%	41	4.8%	11.4%	NS

	General development	480	8.6%	60	6.7%	11.1%	NS
	Gross motor	803	14.4%	117	13.4%	12.7%	NS
	Head shape/ position	496	8.9%	54	6.0%	9.8%	.012
	Hearing	608	10.9%	115	13.4%	15.9%	.036
	Learning	633	11.4%	98	11.4%	13.4%	NS
	Other	337	6.1%	57	6.5%	14.5%	NS
	Play skills	376	6.8%	40	4.7%	9.6%	.021
	Sensory	369	6.6%	25	2.9%	6.3%	<.001
	Speech/language	3246	58.3%	501	58.0%	13.4%	NS
Indicated reasons for referral	0 or 1	3033	54.5%	517	60.1%	14.6%	.001
	2+	2535	45.5%	345	39.9%	11.9%	
Source of referral	CAHS-CH	2244	40.3%	297	34.5%	11.7%	.001
	Education	1927	34.6%	350	40.7%	15.4%	.001
	GP	745	13.4%	123	14.3%	14.2%	NS
	Health service	348	6.3%	64	7.4%	15.5%	NS
	Parent/guardian	277	5.0%	26	3.0%	8.6%	.012
	Other	27	0.5%	0	0%	0.0%	-
Number of referrals	1	5476	98.3%	860	99.8%	13.5%	.006
	2	92	1.7%	2	0.2%	2.1%	

2.7.1 Service access multivariate modelling

The final multivariate logistic model found that children who did not access services were significantly more likely to be female, identify as of Aboriginal descent, live in the two lowest SEIFA quintiles (i.e., areas of higher socioeconomic disadvantage), and to be referred for hearing concerns (see Table 2.7). They were significantly more likely to be referred for only one concern or have no specific concerns indicated. These children were significantly less likely to have been referred for sensory concerns, or to have been referred by either CAHS-CH or parent/guardians themselves – meaning that on the reverse, children referred for sensory concerns or by these two sources were more likely to access CDS. Despite being significantly different at univariate level, there was no difference based on child age, referral for attention/concentration, head shape/position concerns or play skills, or referral from education settings.

Table 2.7. Multivariate factors associated with non-access of CDS

Factors		**OR**	**95% CI**	***p value***
Child and family factors	Child female	1.4	1.2-1.6	<.001
	Child identified as of Aboriginal descent	1.6	1.2-2.1	<.001
	Family lives in second-most disadvantaged socioeconomic area	1.3	1.1-1.6	.014
	Family lives in most disadvantaged socioeconomic area	1.3	1.1-1.7	.002
Nature of referral	Referred for hearing	1.4	1.1-1.8	.002
	Referred for hearing AND lives in most disadvantaged socioeconomic area (interaction)	0.5	0.3-0.9	.016
	Referred for sensory	0.5	0.3-0.7	.001
	Referred for 0 or only 1 reason	1.3	1.1-1.5	.003
Source of referral	*Referred by Child and Adolescent Health Service*	0.7	0.6-0.8	<.001
	Referred by a parent/guardian	0.5	0.4-0.8	.004

Interactions between all factors were tested. When added to the final model, there was significantly lower odds of not accessing (i.e. higher likelihood of accessing CDS) when a child was both referred for hearing concerns and lived in the lowest SEIFA quintile. It should additionally be noted, that while the number of referrals was unable to be included as a variable in the multivariate model due to small numbers, only 2% of children (*n* = 2) who received additional referrals during the period did not access services (compared to 13% of those with a single referral) – indicating that this may be an important variable.

2.8 Discussion

Study findings provide a snapshot of the profiles of WA children and families referred to CDS, the major metropolitan developmental EI service provider in Perth, WA. Over the 6-month duration, children were referred to CDS for a range of concerns - most common of which were related to speech and language concerns, followed by behavioural and motor-based concerns. Interestingly, WA data from the 2018 AEDC found that the speech and language domains (language and cognitive skills, communication and general knowledge) had the lowest rates of developmentally vulnerable children of the five domains, consisting of 6.6% and 7.0% respectfully; compared to physical health and wellbeing (8.9%), emotional maturity (7.7%) and social competence (7.4%) (Department of Education and Training, 2019). These statistics generate questions as to why speech and language concerns are overrepresented in referrals. Findings are similar to those identified in other research studies into service referral in the U.S. and the U.K. (Glaun et al., 1998; Glogowska & Campbell, 2004; Hebbeler et al., 2007; Jimenez et al., 2012; Johnson, 2011; Marshall, Kirby, et al., 2016; McAllister et al., 2011; Nelson et al., 2011; Peterson et al., 2004; Porter & Ispa, 2013; Raspa et al., 2015; Tervo, 2005), where child speech was frequently of the greatest concern to parents compared to other developmental issues (Cuomo et al., 2019), as well as being an issue parents were more aware of (Peterson et al., 2004). One hypothesis is the overflow influence of speech and language on other domains of development, such as building social skills, emotion regulation, play with peers, and literacy skills (Cohen & Mendez, 2009; Fujiki et al., 2002; Nathan et al., 2004), that therefore elevates the necessity for intervention. Additionally, high referrals levels may be explained by both AEDC and the study findings that speech and language issues are more predominant in some vulnerable populations, such as children living in areas of higher socioeconomic disadvantage, children who are Aboriginal or Torres Strait Islander, and children of families with a language background other than English (Department of Education and Training, 2019); all of whom were strongly represented in the sample. These combined findings are important in relation to how developmental concerns are approached and prioritised – while national data may suggest a universal approach to addressing all domains of development, CDS referrals potentially infer the need to prioritise services and supports for speech and language delays. Western Australian parent perceptions of developmental concerns and the role of speech and language specifically thus warrants further investigation.

Certain child and family factors were found to be significantly associated with specific referral reasons. For example, referrals for attention/concentration were for older male children from areas of higher socioeconomic disadvantage, while the majority for head shape/position concerns were for pre-school age children from less disadvantaged socioeconomic areas. These findings help to build patterns of developmental need in the WA community and provide insights into populations whose needs may require further exploration and intervention. For example, children of families who required an interpreter were more likely to be referred for general development, hearing, learning, play skills, and/or speech and language. These findings raise questions regarding the needs of CALD communities, and how the specific developmental needs of these children and families are being supported. Previous research on Australian CALD families report that factors such as social isolation, professional misunderstanding of bilingualism, and lack of or poor interpretation within services all have important impacts on family experiences in accessing developmental supports (Woolfenden et al., 2015). Given that approximately one in 34 referrals were for a family who required an interpreter, these barriers are vital for services like CDS to both understand and accommodate within their service delivery model to support access efforts of different communities.

There has been limited published information to date on the source of referrals to EI services in metropolitan WA. Study findings indicated that CAHS-CH (consistently predominantly of CHNs) and education settings were the major sources of referral, followed by GPs and other health services. This information is important to building an understanding of the professionals whom families are sharing their developmental concerns with; and thus generating a ‘piece of the puzzle’ of what pathways to EI services look like for families in WA. Previous research has explored the roles of GPs and CHNs in developmental screening and referral; however, discussion of education settings has been more limited – likely due to studies mostly focusing on pre-school age children (Alexander et al., 2015; Eapen et al., 2017; Woolfenden et al., 2015). Given that over one-third of referrals were from education settings, there is a need for further exploration of both the role of such settings in developmental monitoring and referral, as well as the experiences of school-aged children more broadly.

Current study findings additionally suggest that deeper investigation of family experiences with GPs and CHNs is required, particularly in light of previous research. Being referred by CAHS-CH (i.e. CHNs) was associated with being significantly more likely to access CDS. This finding may be indicative of the interrelationship between the two services, thus constituting to some extent a ‘softer’ referral than via other service providers. However, negative experiences with CHN services have been reported by Australian families, as well as significant drop-offs in CHN attendance for developmental checks documented both as a child gets older and with subsequent children (Alexander et al., 2015; Commissioner for Children and Young People, 2019; Eapen et al., 2017; Rossiter et al., 2019; Woolfenden et al., 2015). Some similar experiences with GPs have been identified, such as child developmental concerns being missed and family uncertainty regarding how to raise such concerns with a medical professional (Alexander et al., 2015; Woolfenden et al., 2015). Both CHNs and GPs provide an essential role to the broader pathway of developmental screening, monitoring, and referral to EI services; however, given the previously reported experiences there are questions regarding the effectiveness of these providers in supporting a broad range of families. Additionally, drop-offs in CHN developmental checks raises concerns as to whether large numbers of children with delays are potentially not being identified, and thus missing opportunities for intervention and support. Qualitative exploration of both family and provider experiences in WA may provide insights into this broader picture of developmental services.

The current study identified that over 13% of children referred to CDS over a 6-month timeframe did not access the service. Given the nature of the access variable utilised for analysis, this number is believed to be conservative; access in this instance was defined as having attended any service event, including the initial service planning appointment. This suggests that the number of children who went on to access actual therapeutic appointments through CDS, either for assessment or intervention, is unknown. AEDC findings suggest that children who are Aboriginal or Torres Strait Islander, or who live in the most socioeconomically disadvantaged communities have increased odds of developmental vulnerability (Department of Education and Training, 2019). While the current study identified a higher rate of referral of vulnerable families to CDS compared to population norms, the finding that children who identify as Aboriginal or who live in areas of higher socioeconomic disadvantage are less likely to go on to access the CDS is of particular concern - and unfortunately is congruent with a myriad of past studies on service access for vulnerable populations (Chin & Teti, 2013; Clements et al., 2008; Giannoni & Kass, 2010; Marshall, Kirby, et al., 2016; McManus et al., 2009; Rosenberg et al., 2008; Swanson, 2013; Twardzik et al., 2017). Findings also align with the State Parliamentary committee report in 2009-10 that identified that the WA families who were most vulnerable to “falling through the gaps” in accessing EI services were “those from poorer, CALD, refugee or Indigenous families” (Education and Health Standing Committee, 2009, p. 44). Despite this report being compiled over 10 years ago, findings from the current study indicate that the same issues of service access within CDS remain – indicate a significant need for change.

What the above finding does not explain is why vulnerable families are less likely to access services, and what may be making service access difficult for these families. This is the information that CDS requires to make the requisite changes and move towards targets of greater accessibility for all families. Traditionally, vulnerable families have been viewed as ‘hard-to-reach’, however, modern research takes the stance that it may be services that are difficult to access (Boag-Munroe & Evangelou, 2012); with frustrations with the process of accessing services found to be a major barrier influencing family EI access (Giordano, 2008). Cognitions and beliefs about treatment, such as previous negative experiences of services; perceptions of treatment relevance; experience of daily stresses such as physical or mental health concerns (both child or parent) or balancing the needs of other children; external barriers including transportation difficulties and work commitments; and the strength of the therapeutic alliance all influence parents’ decisions to access services for their child (Gerlach et al., 2017; Green et al., 2016; Hebbeler et al., 2007; Hendrickson et al., 2000; Kummerer & Lopez-Reyna, 2009; Leiter, 2001; Marshall, 2013; Marshall et al., 2017; Persoff, 1998; Ramirez, 2004; Shannon, 2000; Smith et al., 2015; Staudt, 2007; Wall et al., 2005; Woolfenden et al., 2015). Thus, identifying 'risk factors' for non-access provides a superficial understanding of why some families do not access services. There is a need for deeper exploration of the experiences of these families to begin to understand how services like CDS may better accommodate the needs of a broader spectrum of families. For example, more information is required to understand needs and barriers to access specific to WA families, such as the impact of transportation issues, parent health concerns, or other adversity that was unable to captured in this analysis. Another key piece of data missing from this analysis is information on waitlists. Previous reports on CDS waitlists called for the provision of annual 'report cards' of current wait times for each health professional discipline, following findings of extensive waitlists that result in some children ultimately not obtaining services (Education and Health Standing Committee, 2010). Waitlists for service access are consistently identified as a key roadblock and source of frustration for families (Giordano, 2008; Green et al., 2016; Marshall, 2013; McAllister et al., 2011; Woolfenden et al., 2015), that may result in them seeking out alternative avenues for support (Glaun et al., 1998; Marshall, 2013). Deeper understanding of how waitlist lengths and uncertainty influence family decisions regarding service access in the WA context, in addition to other barriers, is needed.

Child being female as a risk factor for non-access is a finding worth attention. Children who were referred were predominantly male, which aligns with previous findings on gender-distribution in EI referrals (Goldfeld et al., 2012). Research on gender largely suggests that parents are more likely to access developmental EI services for male children (Hebbeler et al., 2007; Johnson, 2011; Marshall, Kirby, et al., 2016), with male children having consistently higher rates of both developmental vulnerability (Department of Education and Training, 2019) and diagnosed disabilities (Australian Bureau of Statistics, 2019b).

Qualitative work on parental perceptions of child development suggests that girls are perceived to develop earlier and faster than boys, with boys being perceived as 'slower' to develop particularly in expressive language (Marshall et al., 2007; Rannard et al., 2004; Wall et al., 2005). These findings lead to questions as to whether perceptions of gender-based difference in development are influencing a lower level of concern in girls. Community perceptions of the impact of child gender on development may warrant further exploration to attempt to understand this finding.

The finding of specific referral reasons increasing or decreasing the likelihood of services non-access was a finding of interest, such as for sensory concerns. It should be noted that the CDS referral form does not define what is meant by 'sensory', however it is likely that this refers to sensory processing. There are a number of possible explanations for why children with sensory concerns may be more likely to access CDS services. Children referred for sensory concerns were more likely to be male, who were significantly more likely to access services than female children. Sensory processing concerns are also commonly associated with autism spectrum disorder (ASD), which can raise the concern level of parents (Jimenez et al., 2012). Diagnosis for ASD in WA requires input from a multidisciplinary team consisting of medical practitioners, psychologists, and/or allied health professionals (Whitehouse et al., 2018), and as such can be both a lengthy and expensive process. Diagnostic assessment through the public system such as by CDS is provided at no cost which might mean that it is an important option for families who do not have the financial capacity to pay out-of-pocket costs for private assessment. Comparatively, children referred for hearing issues were significantly less likely to access CDS. One possible explanation for this finding is the availability of alternative hearing services. It may be that families agree to CDS referral for hearing but then opt to access private audiology services such as Telethon Speech and Hearing – a specialised paediatric hearing, speech, and language not-for-profit organisation (Telethon Speech and Hearing, n.d.). The ‘exception to the rule’ of hearing referrals as a risk factor for service non-access is, according to interaction testing, when families lived in areas of higher socioeconomic disadvantage. Findings identified that when children were referred for hearing and lived in the lowest SEIFA decile areas, they were significantly more likely to access CDS. In further discussion with CDS management, the service identified that it is likely that some of these families were accessing services via a targeted hearing program for Aboriginal and Torres Strait Islander children; attendance of which was inconsistently captured in the CDIS database from which data were extracted. Skewing of the data is therefore likely to have occurred.

Discussions such as the above highlighted the flaws inherent in using a clinical dataset that has not been designed for research purposes. It also asks questions of the services’ ability to genuinely understand the children and families that they are providing services to – and most importantly, to understand the families who are not accessing their service. If large aspects of the database are unable to be systematically analysed due to their free-text nature; if aspects of service delivery are not accurately documented; and if only a limited set of information relating to the child and their family are available for analysis; then such conditions do not necessarily lend themselves to full transparency of CDS operations and outcome measurement. As previously discussed, a State Parliamentary committee report made recommendations relating to greater transparency of CDS operations, particularly in relation to waitlist information, but this was deemed by the service to be outside of the current ability of their database at the time (Education and Health Standing Committee, 2010). It is vital that services like CDS, a government-provided, taxpayer-funded service, review how data are collected, stored, and utilised for the purposes of research and quality improvement.

As discussed in the methods section of this chapter, the dataset utilised for analysis contains a number of limitations. Firstly, data were restricted to information derived from the intake referral form (with further constraints on free-text fields), which limited the selection of bioecological factors available for analysis. This also creates the need for caution in interpreting findings – for example, CDS staff noted a history of discrepancies between ticked reasons for referral and reasons discussed via free-text entry – meaning reliance on ticked-boxes alone may have failed to account for or skewed the prevalence of some reasons over others. Further, by the nature of CDS as a public, metropolitan service, this study did not capture the experiences children accessing private services or living in regional, rural or remote WA. This limits the generalisability of the study's findings to these wider populations. Additionally, the analysis undertaken was representative of a specific 'snapshot' in time of CDS referrals and service access and thus may not be representative of broader trends in the service. More research is needed to understand why certain factors impact service access, particularly for vulnerable families, and how services like CDS may better enable the successful participation of higher-need families. There is also a need for an in-depth examination of the pathways of children from referral to services, included referrers such as GPs and CHNs, and whether families ultimately access the services and support they require. Qualitative exploration of the experiences of families in Perth, WA who are seeking EI services like CDS is warranted to begin to address these gaps in understanding.

2.9 Conclusion

In conclusion, the current snapshot provides initial insights into the nature of children and their families referred to CDS in metropolitan Perth, WA. Understanding what children are referred for and by whom enables the identification of both specific families in the community who may require support, as well as knowing who are the main referral stakeholders. Additionally, this snapshot provides tentative insights into reasons behind service non-access and provides some direction for possible future action and investigation. However, identification of ‘risk’ factors does not provide sufficient understanding of why families may experience difficulties in accessing services. Further in-depth investigation is needed to unpack family perceptions of barriers to service access in metropolitan WA.

2.10 References

Alexander, K., Brijnath, B., & Mazza, D. (2015). Parents' decision making and access to preventive healthcare for young children: Applying Andersen's Model. *Health Expectations, 18*, 1256-1269. https://doi.org/10.1111/hex.12100

Australian Bureau of Statistics. (2016). *Census of Population and Housing: General community profile tables* (2001.0). https://www.abs.gov.au/ausstats/abs@.nsf/mf/2001.0

Australian Bureau of Statistics. (2018). *Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia, 2016* (2033.0.55.001). https://www.abs.gov.au/ausstats/abs@.nsf/mf/2033.0.55.001

Australian Bureau of Statistics. (2019a). *Australian demographic statistics* (ABS cat. no. 3101.0).

Australian Bureau of Statistics. (2019b). *Disability, ageing and carers, Australia: Summary of findings*. https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release

Australian Bureau of Statistics. (2021). National, state and territory population. https://www.abs.gov.au/statistics/people/population/national-state-and-territory-population/latest-release

Australian Institute of Health and Welfare. (2020a). *Health system overview*. Retrieved 13 May 2021 from https://www.aihw.gov.au/reports/australias-health/health-system-overview

Australian Institute of Health and Welfare. (2020b). Primary health care. https://www.aihw.gov.au/reports/australias-health/primary-health-care

Boag-Munroe, G., & Evangelou, M. (2012). From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Research Papers in Education, 27*(2), 209-239. https://doi.org/10.1080/02671522.2010.509515

Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualised: A bio-ecological model. *Psychological Review, 10*(4), 568-586.

Child and Adolescent Health Service. (2018). *2017-18 Annual report*. https://www.cahs.health.wa.gov.au/-/media/HSPs/CAHS/Documents/About-us/Annual-Reports/2017-18AnnualReport.pdf

Child and Adolescent Health Service. (2019). *2018-19 Annual report*. https://www.cahs.health.wa.gov.au/-/media/HSPs/CAHS/Documents/About-us/Annual-Reports/2018-19AnnualReport.pdf

Child and Adolescent Health Service. (2020). Community Health. https://cahs.health.wa.gov.au/Our-services/Community-Health

Chin, F., & Teti, D. M. (2013). Infants at double jeopardy: Socioeconomic, medical, and attachment-based predictors of maternal engagement with an early intervention program. *Infant Mental Health Journal, 34*(5), 420-434. https://doi.org/10.1002/imhj.21398

Choo, Y. Y., Agarwal, P., How, C. H., & Yeleswarapu, S. P. (2019). Developmental delay: Identification and management at primary care level. *Singapore Medical Journal, 60*(3), 119-123. https://doi.org/10.11622/smedj.2019025

Clements, K. M., Barfield, W. D., Kotelchuck, M., & et al. (2008). Maternal socio-economic and race/ethnic characteristics associated with early intervention participation. *Maternal and Child Health Journal, 12*(6), 708-717. https://doi.org/10.1007/s10995-007-0291-3

Cohen, J. S., & Mendez, J. L. (2009). Emotion regulation, language ability, and the stability of preschool children’s peer play behavior. *Early Education and Development, 20*(6), 1016-1037. https://doi.org/10.1080/10409280903305716

Commissioner for Children and Young People. (2019). *Developmental screening*. https://www.ccyp.wa.gov.au/our-work/indicators-of-wellbeing/age-group-0-to-5-years/developmental-screening/#05-health-checks

Cuomo, B., Joosten, A., & Vaz, S. (2019). Scoping review on noticing concerns in child development: A missing piece in the early intervention puzzle. *Disability and Rehabilitation*. https://doi.org/10.1080/09638288.2019.1708296

Curtin, M., Madden, J., Staines, A., & Perry, I. J. (2013). Determinants of vulnerability in early childhood development in Ireland: A cross-sectional study. *BMJ Open, 3*, e002387. https://doi.org/10.1136/bmjopen-2012-002387

Department for Child Protection and Family Support. (2017). *Annual report*. https://www.dcp.wa.gov.au/Resources/Documents/Annual%20reports/Annual%20Report%202016%202017%20Online.pdf

Department of Education and Training. (2019). *Australian early development census national report 2018*. https://www.aedc.gov.au/resources/detail/2018-aedc-national-report

Department of Health Western Australia. (2016). *Child development service referral form*. https://cahs.health.wa.gov.au/~/media/HSPs/CAHS/Documents/Community-Health/ChildDevelopment/CDS%20print%20referral%20form.pdf

Department of Health Western Australia. (2020a). *Child development service*. https://cahs.health.wa.gov.au/Our-services/Community-Health/Child-Development-Service

Department of Health Western Australia. (n.d.). *Overview of the WA health systems*. https://ww2.health.wa.gov.au/Careers/International-applicants/International-medical-graduates/Overview-of-the-WA-health-system

Department of Social Services. (2020). Helping Children with Autism (HCWA) and Better Start for Children with Disability (Better Start). https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability/helping-children-with-autism-hcwa-and-better-start-for-children-with-disability-better-start

Dixit, S. K., & Sambasivan, M. (2018). A review of the Australian healthcare system: A policy perspective. *SAGE Open Medicine, 6*, 1-14. https://doi.org/10.1177/2050312118769211

Eapen, V., Walter, A., Guan, J., Descallar, J., Axelsson, E., Einfeld, S., Eastwood, J., Murphy, E., Beasley, D., Silove, N., Dissanayake, C., Woolfenden, S., Williams, K., Jalaludin, B., & The 'Watch Me Grow' Study, G. (2017). Maternal help-seeking for child developmental concerns: Associations with socio-demographic factors. *Journal of Paediatrics and Child Health*. https://doi.org/10.1111/jpc.13607

Education and Health Standing Committee. (2009). *Healthy child - healthy state: Improving Western Australia's child health screening programs*. Parliament of Western Australia Legislative Assembly. https://www.parliament.wa.gov.au/Parliament/commit.nsf/(Report+Lookup+by+Com+ID)/C03031FD0022E6D548257831003E97D1/$file/Report%202-%20Child%20Health%20Screening.pdf

Education and Health Standing Committee. (2010). *Invest now or pay later: Securing the future of Western Australia's children*. Parliament of Western Australia Legislative Assembly. https://www.parliament.wa.gov.au/Parliament/commit.nsf/(Report+Lookup+by+Com+ID)/62C7619A219CF45B48257831003E9830/$file/EHSC-Child%20Health-final-March2010.pdf

Education and Health Standing Committee. (2011). Follow up questions from public hearing on 23 February 2011. https://www.parliament.wa.gov.au/Parliament/commit.nsf/(Report+Lookup+by+Com+ID)/62C7619A219CF45B48257831003E9830/$file/EHSC+response+from+Public+Hearing+23022011.pdf

Fujiki, M., Brinton, B., & Clarke, D. (2002). Emotion regulation in children with specific language impairment. *Language, Speech & Hearing Services in Schools, 33*(2), 102-111. https://doi.org/10.1044/0161-1461(2002/008)

Geoscience Australia. (n.d.). Area of Australia - States and Territories. https://www.ga.gov.au/scientific-topics/national-location-information/dimensions/area-of-australia-states-and-territories#heading-1

Gerlach, A. J., Browne, A. J., & Greenwood, M. (2017). Engaging Indigenous families in a community-based Indigenous early childhood programme in British Columbia, Canada: A cultural safety perspective. *Health and Social Care In the Community, 25*(6), 1763-1773. https://doi.org/10.1111/hsc.12450

Giannoni, P. P., & Kass, P. H. (2010). Risk factors associated with children lost to care in a state early childhood intervention program. *Research in Developmental Disabilities, 31*(4), 914-923. https://doi.org/10.1016/j.ridd.2010.02.013

Giordano, K. (2008). *Barriers to early intervention services in New Jersey* [Doctoral dissertation, Fairleigh Dickinson University]. ProQuest Dissertations & Theses. http://dbgw.lis.curtin.edu.au:2048/login?url=https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/304403224?accountid=10382

Glaun, D. E., Cole, K. E., & Reddihough, D. S. (1998). Six month follow-up: the crucial test of multidisciplinary developmental assessment. *Child: Care, Health and Development, 24*(6), 457-472. https://doi.org/10.1046/j.1365-2214.1998.00082.x

Glogowska, M., & Campbell, R. (2004). Parental views of surveillance for early speech and language difficulties. *Children and Society, 18*(4), 266-277. https://doi.org/10.1002.CHI.806

Goldfeld, S., O'Connor, M., Sayers, M., Moore, T., & Oberklaid, F. (2012). Prevalence and correlates of special health care needs in a population cohort of Australian children at school entry. *Journal of Developmental & Behavioral Pediatrics, 33*, 319-327. https://doi.org/10.1097/DBP.0b013e31824a7b8e

Government of Western Australia. (n.d.). *Child and parent centres*. https://childandparentcentres.wa.edu.au/about-us/

Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P. M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services. *BMC Health Services Research, 16*(1), 680. https://doi.org/10.1186/s12913-016-1926-0

Guralnick, M. J. (2001). A developmental systems model for early intervention. *Infants and Young Children, 14*(2), 1-18. http://depts.washington.edu/chdd/guralnick/pdfs/dev_sys_model_EI_IYC_10_01.pdf

Hebbeler, K., Spiker, D., Bailey, D. B., Scarborough, A., Mallik, S., Simeonsson, R. J., Singer, M., & Nelson, L. (2007). *Early intervention for infants and toddlers with disabilities and their families: Participants, services, and outcomes*. SRI International. https://www.sri.com/wp-content/uploads/pdf/neils_finalreport_200702.pdf

Heinze, G., Wallisch, C., & Dunkler, D. (2017). Variable selection - A review and recommendations for the practicing statistician. *Biometrical Journal, 60*, 431-449. https://doi.org/10.1002/bimj.201700067

Hendrickson, S., Baldwin, J. H., & Allred, K. W. (2000). Factors perceived by mothers as preventing families from obtaining early intervention services for their children with special needs. *Children's Health Care, 29*(1), 1-17. https://doi.org/10.1207/S15326888CHC2901_1

Human Early Learning Partnership. (2016). *EDI [Early Years Development Instrument] British Colombia: 2016 Provincial Report*. University of British Colombia School of Population and Public Health. http://earlylearning.ubc.ca/media/edibc2016provincialreport.pdf

IBM Corp. (2020). *IBM SPSS Statistics for Windows.* In (Version 27.0) IBM Corp.

IBM Corp. (n.d.). *Visual binning*. https://www.ibm.com/support/knowledgecenter/en/SSLVMB_23.0.0/spss/base/idh_bander_gating.html

Jimenez, M. E., Barg, F. K., Guevara, J. P., Gerdes, M., & Fiks, A. G. (2012). Barriers to evaluation for early intervention services: parent and early intervention employee perspectives. *Academic pediatrics, 12*(6), 551-557. https://doi.org/10.1016/j.acap.2012.08.006

Johnson, J. F. (2011). *An evaluation of the Early Steps Program referral process in Hillsborough County to detect delays in access to early intervention services* (Publication Number 2012-99080-337) [Doctoral dissertation, University of South Florida]. Scholar Commons. http://scholarcommons.usf.edu/etd/3171

Kang, H. (2013). The prevention and handling of the missing data. *Korean Journal of Anesthesiology, 64*(402-406). https://doi.org/https://dx.doi.org/10.4097%2Fkjae.2013.64.5.402

Knudsen, E. I., Heckman, J. J., Cameron, J. L., & Shonkoff, J. P. (2006). Economic, neurobiological, and behavioral perspectives on building America’s future workforce. *Proceedings of the*

National Academy of Sciences of the United States of America, 103(27), 10155-10162. https://doi.org/10.1073/pnas.0600888103

Kummerer, S. E., & Lopez-Reyna, N. A. (2009). Engaging Mexican immigrant families in language and literacy interventions: Three case studies. *Remedial and Special Education, 30*(6), 330-343. https://doi.org/10.1177/0741932508321014

Leiter, V. R. (2001). *Gentle intrusions: Family-centered care in early intervention* (Publication Number 3004966) [Doctoral dissertation, Brandeis University]. ProQuest Dissertations & Theses Global. https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/304681652?pq-origsite=summon

Marshall, J. (2013). *Parent pathways: Recognition and responses to developmental delays in young children: A mixed-methods exploratory study* [Doctoral dissertation, University of South Florida]. Scholar Commons. http://scholarcommons.usf.edu/etd/4534

Marshall, J., Adelman, A., Kesten, S. M., Natale, R. A., & Elbaum, B. (2017). Parents' experiences navigating intervention systems for young children with mild language delays. *Journal of Early Intervention, 39*(3), 180-198. https://doi.org/10.1177/1053815117704958

Marshall, J., Goldbart, J., & Phillips, J. (2007). Parents' and speech and language therapists' explanatory models of language development, language delay and intervention. *International Journal of Language & Communication Disorders, 42*(5), 533-555. https://doi.org/10.1080/13682820601053753

Marshall, J., Kirby, R. S., & Gorski, P. A. (2016). Parent concern and enrollment in intervention services for young children with developmental delays: 2007 National survey of children's health. *Exceptional Children, 82*(2), 251-268. https://doi.org/10.1177/0014402915585563

McAllister, L., McCormack, J., McLeod, S., & Harrison, L. J. (2011). Expectations and experiences of accessing and participating in services for childhood speech impairment. *International Journal of Speech-Language Pathology, 13*(3), 251-267. https://doi.org/10.3109/17549507.2011.535565

McManus, B., McCormick, M. C., Acevedo-Garcia, D., Ganz, M., & Hauser-Cram, P. (2009). The effect of state early intervention eligibility policy on participation among a cohort of young CSHCN. *Pediatrics, 124*, S368-S374. https://doi.org/10.1542/peds.2009-155G

Minister for Health. (2011). *Response to Education and Health Standing Committee*. Education and Health Standing Committee. https://www.parliament.wa.gov.au/Parliament/commit.nsf/(Report+Lookup+by+Com+ID)/62C7619A219CF45B48257831003E9830/$file/40146399.pdf

Nathan, L., Stackhouse, J., Goulandris, N., & Snowling, M. J. (2004). The development of early literacy skills among children with speech difficulties. *Journal of Speech, Language and Hearing, 47*(2), 377-391. https://doi.org/10.1044/1092-4388(2004/031)

National Disability Insurance Agency. (2014). Building the National Disability Insurance Scheme. Progress report: Year one. https://www.ndis.gov.au/about-us/publications/progress-report-2014

National Disability Insurance Agency. (2019). *How ECEI works*. https://www.ndis.gov.au/understanding/families-and-carers/how-ecei-works-step-step-process

Nelson, B. B., Chung, P. J., DuPlessis, H. M., Flores, L., Ryan, G. W., & Kataoka, S. H. (2011). Strengthening families of children with developmental concerns: Parent perceptions of developmental screening and services in Head Start. *Ethnicity & disease, 21*(3 Suppl 1), S1-89-93. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3715307/

Ngala. (n.d.). *About Us*. https://www.ngala.com.au/about-us/

Oberklaid, F., & Efron, D. (2005). Developmental delay - identification and management. *Australian family physician, 34*(9), 739-742.

Offord Centre for Child Studies. *Early Development Instrument in Ontario over time*. McMaster University. https://edi.offordcentre.com/partners/canada/edi-in-ontario/

Pekar, S., & Brabec, M. (2018). Generalized estimating equations: A pragmatic and flexible approach to the margical GLM modelling of correlated data in the behavioural sciences. *Ethology, 124*, 86-93. https://doi.org/10.1111/eth.12713

Persoff, J. R. (1998). *Poverty and early childhood developmental delay: Perspectives from Hispanic mothers* [Doctoral dissertation, University of Denver]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/304432454?accountid=10382

Peterson, C. A., Wall, S. M., Raikes, H. A., Kisker, E. E., Swanson, M. E., Jerald, J., Atwater, J. B., & Qiao, W. (2004). Early head start: Identifying and serving children with disabilities. *Topics in Early Childhood Special Education, 24*(2), 76-88. https://digitalcommons.unl.edu/cgi/viewcontent.cgi?referer=https://www.google.com/&httpsredir=1&article=1041&context=famconfacpub

Phoenix, M., & Rosenbaum, P. (2015). Development and implementation of a paediatric rehabilitation care path for hard-to-reach families: A case report. *Child: Care, Health and Development, 41*(3), 494-499. https://doi.org/10.1111/cch.12194

Phoenix, M., & Rosenbaum, P. (2019). Presenting the model of risk, disability and hard-to-reach families to inform early intervention services. *Disability and Rehabilitation, 41*(2), 244-249. https://doi.org/10.1080/09638288.2017.1385650

Porter, N., & Ispa, J. M. (2013). Mothers' online message board questions about parenting infants and toddlers. *Journal of Advanced Nursing, 69*(3), 559-568. https://doi.org/10.1111/j.1365-2648.2012.06030.x

Pritchard, M. A., Colditz, P. B., Cartwright, D., Gray, P. H., Tudehope, D., & Beller, E. (2013). Risk determinants in early intervention use during the first postnatal year in children born very preterm. *BMC pediatrics, 13*, 201-201. https://doi.org/10.1186/1471-2431-13-201

Ramirez, M. C. (2004). *Latino parents with developmentally delayed children: Perceptions of early intervention services* [Master's thesis, California State University]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/305036959?pq-origsite=gscholar

Rannard, A., Lyons, C., & Glenn, S. (2004). Children with specific language impairment: Parental accounts of the early years. *Journal of Child Health Care, 8*(2), 165-176. https://doi.org/10.1177/1367493504041875

Raspa, M., Levis, D. M., Kish-Doto, J., Wallace, I., Rice, C., Barger, B., Green, K. K., & Wolf, R. B. (2015). Examining parents' experiences and information needs regarding early identification of developmental delays: Qualitative research to inform a public health campaign. *Journal of Developmental & Behavioral Pediatrics, 36*(8), 575-585. https://doi.org/10.1097/DBP.0000000000000205

Rosenberg, S. A., Robinson, C. C., Shaw, E. F., & Ellison, M. S. (2013). Part C early intervention for infants and toddlers: Percentage eligible versus served. *Pediatrics, 131*, 38-46. https://doi.org/10.1542/peds.2012-1662

Rosenberg, S. A., Zhang, D., & Robinson, C. C. (2008). Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics, 121*(6), e1503-1509. https://doi.org/10.1542/peds.2007-1680

Rossiter, C., Fowler, C., Hesson, A., Kruske, S., Homer, C. S. E., & Schmied, V. (2019, 2019/03/01). Australian parents' use of universal child and family health services: A consumer survey. *Health & social care in the community, 27*(2), 472-482. https://doi.org/10.1111/hsc.12667

SAS Institute Inc. (2015). The GEE Procedure. In Author (Ed.), *SAS/STAT 14.1 User's Guide* (pp. 2929-2980). SAS Institute Inc. https://support.sas.com/documentation/onlinedoc/stat/141/gee.pdf

Shannon, P. (2000). *Family-centered practice in early intervention services for infants and toddlers: The experience of families and professionals in one Local Interagency Coordinating Council* [Doctoral dissertation, Virginia Commonwealth University]. ProQuest Dissertations & Theses Global. https://scholarscompass.vcu.edu/etd/5304/

Shapiro, B. J., & Derrington, T. M. (2004). Equity and disparity in access to services: An outcomes-based evaluation of early intevention Child Find in Hawai'i. *Topics in Early Childhood Special Education, 24*(4), 199-212. https://doi.org/10.1177/02711214040240040201

Shonkoff, J. P. (2010). Building a new biodevelopmental framework to guide the future of early childhood policy. *Child Development, 81*(1), 357-367. https://doi.org/10.1111/j.1467-8624.2009.01399.x

Smith, E., Koerting, J., Latter, S., Knowles, M. M., McCann, D. C., Thompson, M., & Sonuga-Barke, E. J. (2015). Overcoming barriers to effective early parenting interventions for attention-deficit hyperactivity disorder (ADHD): Parent and practitioner views. *Child: Care, Health and Development, 41*(1), 93-102. https://doi.org/10.1111/cch.12146

Staudt, M. (2007). Treatment engagement in caregivers of at-risk children: Gaps in research and conceptualization. *Journal of Child and Family Studies, 16*, 183-196. https://doi.org/10.1007/s10826-006-9077-2

Swanson, C. (2013). *Attrition from early intervention: Associations with several child characteristics* [Master's thesis, University of Rhode Island]. ProQuest Dissertations & Theses Global. Ann Arbor. https://search.proquest.com/docview/1476204055?accountid=10382

Telethon Speech and Hearing. (n.d.). *Telethon Speech and Hearing*. https://www.tsh.org.au

Tervo, R. C. (2005). Parent's reports predict their child's developmental problems. *Clinical Pediatrics, 44*(7), 601-611. https://doi.org/10.1177/000992280504400708

Thelen, E., & Smith, L. B. (2007). Dynamic systems theories. In R. M. Lerner (Ed.), *Handbook of Child Psychology: Theoretical Models of Human Development* (Vol. 1, pp. 258-312). John Wiley and Sons.

Twardzik, E., Cotto-Negrón, C., & Macdonald, M. (2017). Factors related to early intervention Part C enrollment: A systematic review. *Disability and Health Journal, 10*(4), 467-474. https://doi.org/10.1016/j.dhjo.2017.01.009

Wall, S. M., Taylor, N. E., Liebow, H., Sabatino, C. A., Mayer, L. M., Farber, M. Z., & Timberlake, E. M. (2005). Early Head Start and access to early intervention services: a qualitative investigation. *Topics in Early Childhood Special Education, 25*(4), 218-231. https://doi.org/10.1177/02711214050250040301

Western Australian Occupational Therapy Association. (n.d.). Find an OT. https://waota.com.au/find-an-ot/?q=search&region=Any&specialty=Any#

Whitehouse, A. J. O., Evans, K., Eapen, V., & Wray, J. (2018). *A national guideline for the assessment and diagnosis of autism spectrum disorders in Australia*. Cooperative Research Centre for Living with Autism. http://autismcrc.com.au/national-guideline

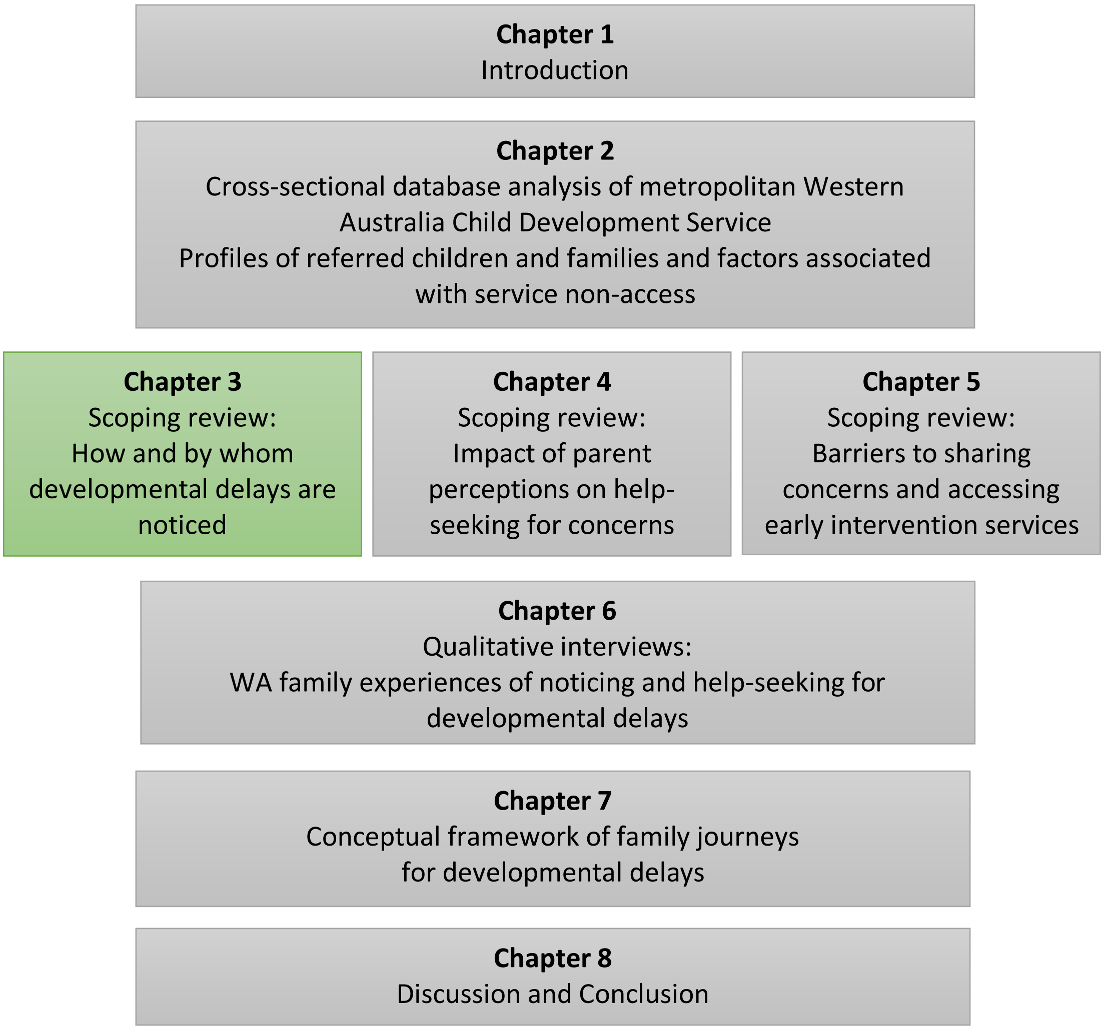
Williams, J., & Holmes, C. A. (2004). Improving the early detection of children with subtle developmental problems. *Journal of Child Health Care, 8*(1), 34-46. https://doi.org/10.1177/13674950401852

Woolfenden, S., Posada, N., Krchnakova, R., Crawford, J., Gilbert, J., Jursik, B., Sarkozy, V., Perkins, D., & Kemp, L. (2015). Equitable access to developmental surveillance and early intervention - understanding the barriers for children from culturally and linguistically diverse (CALD) backgrounds. *Health Expectations, 18*(6), 3286-3301. https://doi.org/10.1111/hex.12318

Chapter 3 Noticing delays

Chapter 2 provided an initial contextual understanding of developmental services in metropolitan Perth, WA. We have gained a sense of who seeks to access developmental services, but not how or why families may experience difficulties in ultimately accessing EI services.

Chapter 3 therefore comprises the first of a series of three scoping reviews that sought to understand different aspects of the help-seeking journey by families for suspected child developmental delays. This review presents a synthesis of current research on the first true stage of family journeys - how and by whom developmental concerns begin to be noticed.



Scoping review on noticing concerns in child development: A missing piece in the early intervention puzzle

Belinda Cuomo[1, 2*], Annette Joosten[1, 3], Sharmila Vaz[1]

[1] School of Occupational Therapy, Social Work and Speech Pathology, Curtin University

[2] CoLab (the Minderoo Foundation), Telethon Kids Institute

[3] School of Allied Health, Australian Catholic University

Corresponding author

Email: Belinda.cuomo@curtin.edu.au

This is an accepted manuscript of an article published by Taylor & Francis in Disability and Rehabilitation on 29 December 2019, available online: http://www.tandfonline.com/10.1080/09638288.2019.1707296

3.1 Abstract

Between 13 to 32% of children in developed nations are at-risk for developmental delays. In order to identify concerns, there is a need to understand the mechanisms that facilitate becoming aware of it. A scoping review was conducted to understand this process of “noticing”, through existing literature on parent experiences. Records from major academic databases and grey literature sources were searched using key terms. Thematic analysis was then conducted to synthesise findings. Twenty papers meeting inclusion were identified. Noticing a delay was found to be an interplay between who notices – parents or other - and how they do so. How concerns are noticed was through two mechanisms: knowledge of child development, and comparison with other children. This review highlights the nuanced complexity of noticing concerns with a child’s development. Understanding how this process occurs and the key ingredients that enable it is vital to supporting early detection of developmental delays.

3.2 Introduction

Child development occurs through complex interactions between aspects of the child, their environment, and the tasks they perform, that together produce a child's unique developmental trajectory (Thelen & Smith, 2007, p. 231). This process evolves as a "dynamic cascade" of risk and protective factors that exist not in isolation but are continuously shaping one another (Thelen & Smith, 2007). The combined and cumulative effects of these interactions shape both immediate and long-term milestone attainment, skill development and growth trajectories. When these interactions are negatively impacted, a child may be at risk of developmental delays (Maggi et al., 2010; Walker et al., 2011).

Developmental delays, or "subtle developmental problems" impact a child's development of cognition, motor skills, speech and language, social-emotional development and/or behaviour (Williams & Holmes, 2004). Children experiencing delays may be largely determined as being in one of three groups: those with established delays in one or more areas; those with diagnosed physical or mental conditions that may result in delay; and those who are at-risk of experiencing delays (Hebbeler et al., 2007). Developmental delay is a recognised global concern, with an estimated 200 million children under five years of age not reaching their developmental potential (Grantham-Mcgregor et al., 2007). Rates of children at-risk for delays in developed nations range between 13 to 32% (Curtin et al., 2013; Department of Education and Training, 2016; Human Early Learning Partnership, 2016; Offord Centre for Child Studies; Rosenberg et al., 2008), with children from vulnerable families or 'at-risk' groups experiencing an even higher risk of developmental concerns (Shah et al., 2015). Failing to support child development can result in associated economic and social costs, including poorer workforce participation, heightened reliance on welfare, and increased healthcare utilisation over the life span (Moore, 2006). Children with delays are however being recognised later than those with diagnosed disabilities (Hebbeler et al., 2007). A longitudinal study of access to early intervention (EI) services in the United States found that families of a child with a diagnosed disability had concerns about their child's development by two months of age, while children with delays were not "noticed" by parents until 11 months of age (Hebbeler et al., 2007). This initial delay flowed through to subsequent EI processes, with children with diagnosed conditions receiving services by nine months compared to 20 months for children with delays (Hebbeler et al., 2007). One reason cited for this is that delays, being more subtle in nature, are often more difficult to detect (Hebbeler et al., 2007; Johnson, 2011; Williams & Holmes, 2004). There is therefore a particular need to understand how concerns are noted for children with or at-risk of delays, separate to those who receive a disability diagnosis. Parent-report of child developmental concerns has been established as a valid indicator of true delays (Glascoe & Dworkin, 1995; Oberklaid & Efron, 2005), and accordingly has been increasingly drawn upon to inform developmental surveillance in addition to more traditional screening-tool based approaches (Dworkin, 1989; Oberklaid & Efron, 2005) The 2006 (reaffirmed 2014) American Academy of Pediatrics policy statement on identifying developmental disorders notes one of the core components of developmental surveillance as eliciting and attending to parent concerns, whereby parents should be explicitly asked about any concerns with their child's development (Council on Children with Disabilities et al., 2006). The formulation of concerns by parents is therefore a critical part of a child's delays being identified; making the noticing of concerns a critical, but currently overlooked, precursor in the developmental surveillance and EI pathway.

A scoping review was therefore initiated. The aim of this review was to understand the process of parental noticing of child developmental delay, to inform this key stage of the EI process and increase awareness of the conditions required for noticing to occur.

3.3 Methods

A review of peer-reviewed and grey literature was undertaken, following the Joanna Briggs Institute scoping review protocol (Peters et al., 2017). Thematic analysis was then conducted to synthesise findings and present key themes of noticing.

3.3.1 Search strategy

A systematic search for literature was conducted in May 2018 (updated August 2019) using key terms related to the research question - "(child OR toddler OR p*diatric OR baby OR infant) AND (developmen* OR delay OR at-risk OR milestones) AND (identif* or notic* OR recogni* OR refer* OR participat* OR engag* OR access OR knowledge) AND early intervention". Truncations were used and combinations exploded to maximize search reach. Records from 1998-2019 from major academic databases (Proquest, ScienceDirect, CINAHL, Ovid and Sage) as well as grey literature sources (Google Scholar, Trove, Mednar, and Agency for Healthcare Research and Quality) were searched. Further snowball searching was conducted through citation tracking of identified articles and hand-searching key child and family journals.

3.3.2 Study selection

Documents were included if: 1) population was children with or at-risk of developmental delays; 2) were concerned with parent identification of concerns with child's development; 3) published in English; 4) conducted in countries classified as developed economies (United Nations, 2019); and 5) published between 1998-2019. All identified results were screened at title/abstract level, with those that appeared to meet the above five criteria extracted for full-text appraisal (see PRISMA diagram for breakdown). Studies were excluded if they focused on children with diagnosed physical or mental conditions, as per the differentiation utilized in U.S. EI services (Hebbeler et al., 2007) if they did not include parental perspectives (professional-focused); or where parental noticing was limited to elicitation through screening tools. Limiting to developed countries accounted for cultural and socioeconomic differences in developing countries that may produce contrasting experiences. As per scoping review guidelines, no restrictions were placed on study design (Peters et al., 2017). Articles or dissertations were included where they consisted of actively conducted research – reviews were excluded in place of identifying original studies. For the purpose of interrater checking of adherence inclusion criteria, a random selection of 20% of abstracts identified for full-text extraction were independently read and then discussed between the first and last authors.

3.3.3 Data extraction and synthesis

Article data were independently extracted by the first author using extraction headings generated in line with scoping review guidelines –author/s, year of publication, country of origin, methodology, study population/sample size, aims/purpose, and findings. Findings were analysed following the 6-phase guide to thematic analysis outlined by Braun and Clarke (Braun & Clarke, 2006); familiarity with the data set; generating initial codes; searching for themes; reviewing themes (and producing a thematic 'map'); defining and naming themes; and producing the analytical report. A process of descriptive inductive coding was undertaken in order to build themes around the experience of noticing based on the sources, with in vivo coding favoured so as to capture the specific language utilized by parents. Codes were then collated into initial themes and subthemes with linkage back to the original source maintained. All coded data were arranged by the first author into tentative themes, which were discussed and refined in collaboration with the second and third authors through a process of independent coding and coming together. A clear audit trail showcasing sources of information was maintained at all times, in order to retain clear connection back to the original sources.

3.4 Results

Twenty studies were included; see Figure 3-1 for PRISMA flow diagram of study selection process and Table 3.1 for overview of included articles. Seventeen studies were peer-reviewed articles while three were unpublished dissertations. The majority of work was qualitative in nature (*n* = 17), with three studies incorporating cross-sectional survey data (parent-report and standardised tools). Figure 3-2 presents an overview of review themes.

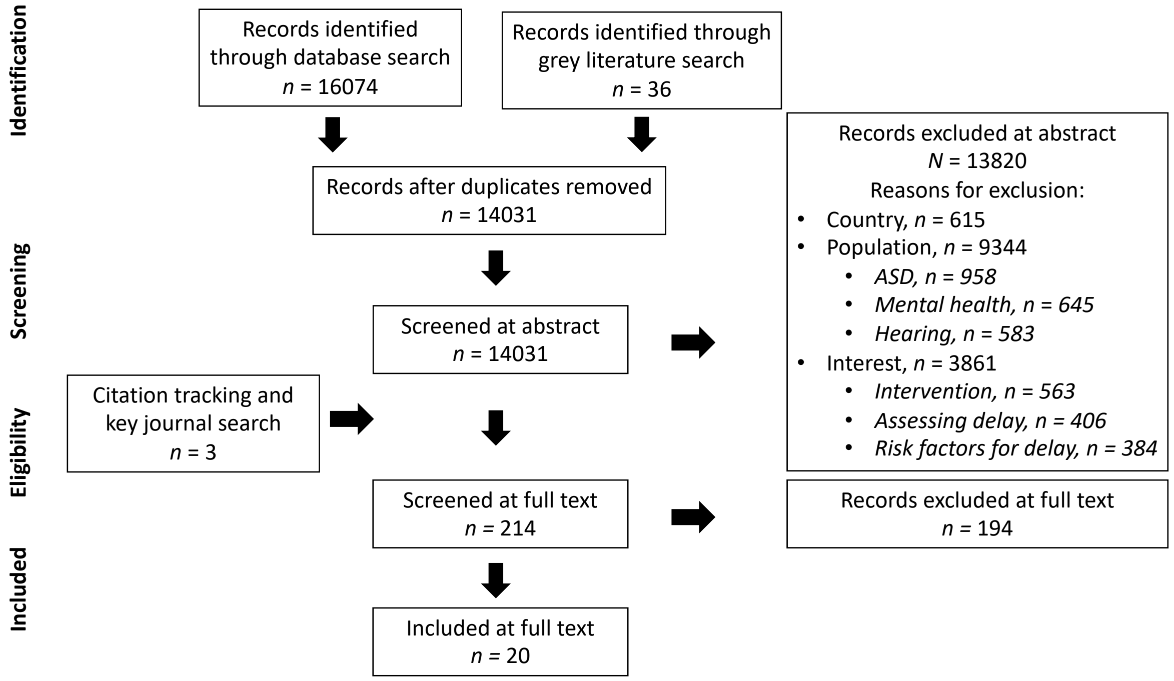


Figure 3-1 PRISMA diagram

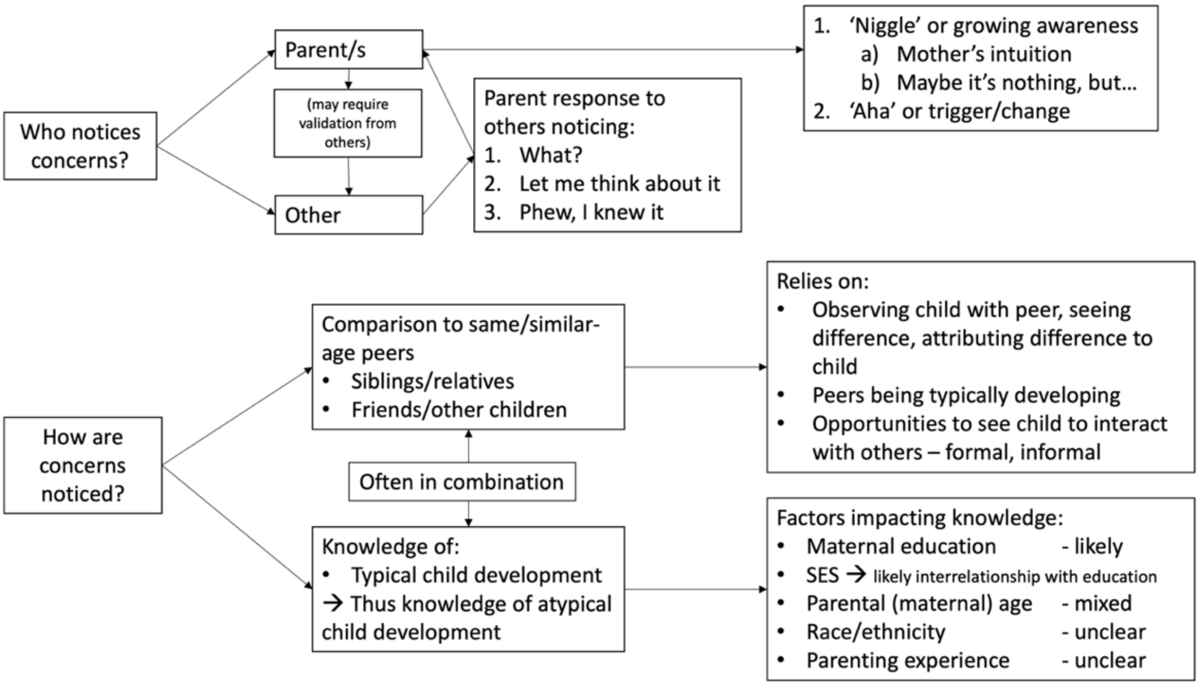


Figure 3-2 Overview of themes

Table 3.1 Summary of studies included in review

Citation	Country of origin	Study design	Participants/ Data Source	Aims/Interest
Glaun et al. (1998)	United States	Descriptive prospective study; Six-month follow up of families using pre-post self-report, through standardised measures and constructed questionnaires	Dyads of parents and pre-school age children with complex developmental delays referred for developmental assessment (*N* = 40)	Assess mothers' recall of their child diagnosis, their opinion on its correctness, and attitudes regarding treatment recommendations. Identify services received post-assessment, service prioritization by mothers, use of complementary or alternative treatments, and overall satisfaction with services. Identify reasons that may have prevented following of recommendations.
Harris (2009)	Canada	Case series; parent-report and standardized developmental measurement	Case series (*N* = 3) of families who had been referred for an evaluation following concerns with their child's motor development	Examine the validity of parents' concerns compared with standardized assessment outcomes Determine whether screening test compared to a comprehensive developmental assessment are congruent in categorization of degree of delay
Hendrickson et al. (2000)	United States	In-depth interviews; descriptive qualitative design with symbolic interaction theoretical foundation	Mothers of children aged three or more years of age with developmental delays, who had not accessed birth-two years early intervention services (*N* = 13)	Experience of mothers of children with developmental delay, who experienced barriers to accessing early intervention services prior to school commencement (birth to two years services)

Citation	Country of origin	Study design	Participants/ Data Source	Aims/Interest
Khan (2013)	United Kingdom	Semi-structured qualitative interviews analysed using discourse analysis	Parents referred to parenting programs for child behavioural concerns (*n* = 44); Parenting program professionals and referrers (*n* = 159)	Understanding of reasons parents seek help for behavioural concerns; barriers to recognizing support needs; differences between parents in their willingness to seek help. Identifying common routes of referral to programs; and factors that help or hinder referrals
Lalbeharie-Josias (2001)	United States	Dissertation. Series of in-depth interviews, phenomenological case-methods approach	Parents of children (*N* = 14) with developmental delays or disability (exclude those with disability; used sample of n = 5)	Exploration of parents' experiences and perceptions of the individualized family service plan (early intervention)
Magnusson et al. (2017)	United States	Semi-structured in-depth interviews, inductive content analysis	African American (*n* = 8) and Hispanic (*n* = 14) mothers of children aged 0-36 months with developmental delay	Understand the role of health beliefs in shaping maternal decisions regarding help-seeking for children with developmental delays Explore differences between African American and Hispanic mothers
Marshall et al., 2016	United States	Mixed-methods; interviews/focus groups - recursive analysis approach based partly on Health Belief Model and Social Support theory; standardized measures – PEDS, Knowledge of Infant Development Index (KIDI)	Parents of children aged 0-5 with signs of developmental or behavioural problems (*N* = 23)	Parent experiences of recognizing and responding to child developmental concerns; cross-sectional assessment of child developmental status and parent knowledge of child development

Citation	Country of origin	Study design	Participants/ Data Source	Aims/Interest
Marshall et al. (2017)	United States	In-depth interviews; grounded theory analysis approach	Parents of children with mild language delay who participated in community-based short-term speech program; Early Discovery Developmental Services Program (*N* = 20)	Experiences of parents of children with mild language delays in navigating the process of assessment and referral and decision to participate/not
McAllister et al. (2011)	Australia	Dissertation; Study 2 findings only. In-depth interviews; phenomenological approach using constant comparative analysis	Parents of children with speech/language difficulties; Study 2 (*N* = 13)	Parent experiences of child speech impairment and accessing services in Australia
Missiuna et al. (2006)	Canada	In-depth interviews; phenomenological approach, descriptive analysis	Parents (*N* = 13) of children with developmental coordination disorder	Explore the parent perceptions of the early experiences and participation patterns of children with developmental coordination disorder
Morton (2012)	United States	Dissertation. In-depth interviews; phenomenological approach, constant comparison analysis	African American mothers (*N* = 8) of children with diagnosed developmental delay	Explore parent's awareness of and reactions to developmental delay in their children

Citation	**Country of origin**	**Study design**	**Participants/ Data Source**	**Aims/Interest**
Mulcahy and Savage (2016)	Ireland	In-depth interviews; interpretative phenomenological analysis	Parents of preschool children whose child had been referred for developmental services (*N* = 15)	Understand the experiences of parents who had expressed a concern with their child's growth or development
Plath et al. (2016)	Australia	In-depth interviews; analysis approach unclear	Parents of school-age children who attended a behavioural program (*n* = 12) and those who did not (*n* = 40)	Experiences of parents in screening and assessment of child behavioural concerns, and engagement in targeted intervention program- differences between those who did and did not participate
Rannard et al. (2004)	United Kingdom	In-depth interviews; life history approach, analysis approach unclear	Parents/guardians (*n* = 40) of children who had received specialist language education (*n* = 28)	Provision of a qualitative account of the parental perspective of children with specific language impairments, with exploration of parental meaning making of detecting their child's language problem and events leading to admission to language education
Raspa et al. (2015)	United States	Focus groups; inductive content analysis	Parents of children with developmental delays (*N* = 74)	Exploring facilitators and barriers to identification of child developmental concerns
Silbersack (2014)	United States	Dissertation. In-depth interviews; phenomenological approach using thematic analysis	Mothers of children 0-5 years with confirmed developmental delays or disabilities (*N* = 18)	Understanding of process surrounding discovery of child developmental issues by mothers.

Citation	**Country of origin**	**Study design**	**Participants/ Data Source**	**Aims/Interest**
Wall et al. (2005)	United States	Case series; in-depth interviews using ecological model frame of reference, and case reviews of Early Head Start participation	At risk families of young children (low income, minority families) (*N* = 32)	Early Head Start participation and impact on likelihood of subsequent early intervention access
Williams (2007)	Australia	In-depth interviews; social constructionist framework, analyses underpinned by semiotics, NeoMarxist and post-structural literary theories	Mothers of children with 'subtle developmental problems' (*N* = 8)	Mothers' experiences of raising a child with developmental problems, and awareness of developmental problems: how and when they noticed.
Woolfenden et al. (2015)	Australia	In-depth individual and group interviews; mix of deductive and inductive approaches	Culturally and linguistically diverse parents of children with suspected developmental delays (*n* = 13) and health and early childhood professionals working with families (*n* = 27)	Family and service characteristics, beliefs and experiences that influence journey of culturally and linguistically diverse families in accessing developmental surveillance and early intervention services

Citation	Country of origin	Study design	Participants/ Data Source	Aims/Interest
Zand et al. (2015)	United States	Cross-sectional survey; demographics and standardized measures (KIDI); analysis via t-tests and bivariate correlations	Mothers of children in EI with or at risk for developmental delay (*N* = 67)	Parent knowledge of child development measured by the KIDI. a) Total knowledge; Total milestone score; Total milestone underestimate score; Total milestone overestimate core score. Analysis: Knowledge scores and comparison of errors types to normative sample; Participant variables that correlate with scores; Regressions to determine variable variance that account for scores

Recognising a delay, henceforth referred to as "noticing", consists of someone beginning to become aware that their child is either developing atypically or delayed in reaching developmental milestones, and subsequently being concerned (Hebbeler et al., 2007; McAllister et al., 2011; Wall et al., 2005). Rather than being a singular, discrete stage, noticing appears to be an iterative process of discovery that evolves over time (Silbersack, 2014). Noticing a delay consists of an interplay of "who" notices and "how" they do so – see figure 2. Key mechanisms for noticing will be discussed, with consideration of implications for the necessary ingredients required for noticing to occur.

3.4.1 Who notices the concern?

3.4.1.1 Parents/Primary caregiver

Most children have multiple stakeholders in their lives who may notice concerns with their development, with the most common being parents or primary caregivers (Raspa et al., 2015). Interviews with families of children with developmental delays found that in the majority of cases, delay was first noticed by one or both parents independently of others (Rannard et al., 2004), through an "incremental awareness of intuitive feelings and nuanced observations" (Silbersack, 2014, p. 90).

Noticing appears to develop in one of two ways: either as a "niggle", or with an "aha moment".

Niggle. A niggling or growing awareness, described by one parent as "coming out piece by piece" (Silbersack, 2014, p. 66) that may catalyse into becoming concerned (Plath et al., 2016). This is further divided into:

'Mother's intuition'. Some parents describe that they "just knew" that something was wrong (Missiuna et al., 2006; Rannard et al., 2004; Silbersack, 2014), even if they couldn't fully articulate or label it– "I thought 'mmm' I don't know…it just didn't feel right" (Mulcahy

& Savage, 2016, p. 339). This was described by some as mother's intuition (Williams, 2007), instinct (Morton, 2012) or gut-based feeling (Silbersack, 2014); which involved parents seeing small or subtle signs. These signs may not initially amount to much; but spark a thought process of something not being quite right (Morton, 2012; Silbersack, 2014). This was described by one parent as "little whispers that got louder" (Silbersack, 2014, p. 50).

'Maybe it's nothing, but…'. Other parents appeared to second guess these niggles and needed time to decide whether they were real (Harris, 2009) – "I was kind of watching for a while. I was saying is it my imagination or is there something here?" (Mulcahy & Savage, 2016, p. 335). This extended to behavioural concerns, whereby parents discussed confusion over whether the child was "just generally naughty" or if there was something of greater concern (Khan, 2013). Some parents described seeing their child experience difficulties – but were unsure as to whether these constituted a "problem"; "…there were very apparent differences. But is that an individual difference or is that a problem per se?...is it just slow development in a boy…or is there a quote, unquote problem?" (Missiuna et al., 2006, p. 10). Due to uncertainty over whether concerns were justified, these parents "watched and waited" to gather evidence before becoming concerned.

"Aha" moment. Some parents describe a sudden change or trigger moment, often at a specific age – an "aha" moment (Marshall et al., 2017; Marshall, Coulter, et al., 2016; Rannard et al., 2004) Triggers were generally specific and behaviour-based, and were identified to include additional signs (e.g. behavioural outbursts) and negative signs, where the child was either lacking in a skill (e.g. limited language) or not doing something it was perceived that they should (e.g. not responding to their name) (Harris, 2009; Hendrickson et al., 2000; Marshall et al., 2017; Rannard et al., 2004; Raspa et al., 2015; Wall et al., 2005).

3.4.1.2 *Other stakeholders who notice concerns*

Other people in a child's life may notice concerns prior to their parents (Harris, 2009; Marshall et al., 2017; Marshall, Coulter, et al., 2016; McAllister et al., 2011; Morton, 2012; Wall et al., 2005; Woolfenden et al., 2015). This may include family members and friends, as well as health and education professionals. Interviews of families of children with delays identified that in a number of instances concerns were first noticed by others (Rannard et al., 2004). While not the focus of the current review, the additional role of developmental screening by professionals in identifying concerns is acknowledged (Glascoe & Robertshaw, 2007; Glogowska & Campbell, 2004; Vitrikas, 2017; Woolfenden et al., 2014).

Parents differed in how they respond to others noticing concerns with their child's development, categorised below:

"What?" – Surprise/shock. Parents may be surprised, having not personally identified any issues (Plath et al., 2016); "So it just didn't occur to me that there any issues and I was flabbergasted. I was completely…and my husband too. We were just totally shocked" (Silbersack, 2014, p. 54). Parents who did not previously hold any concerns may therefore reject noticing by others (Wall et al., 2005).

"Let me think about it" – Reflection. Parents may not immediately accept or reject the opinion of others, but instead require time to consider whether they share the concerns raised. Parents describe being made aware of issues by other stakeholders, which caused them to reflect on and reassess their child's development; upon consideration, all concurred with the concerns noted (Morton, 2012).

"Phew, I knew it" – Relief/validation. For other parents, there was a sense of relief – with others affirming suspicions they already held (Morton, 2012; Mulcahy & Savage, 2016); "We went to a neurologist…he said, everything is fine, but did you know that she has speech delays? It was like, thank you! Yes!" (Silbersack, 2014, p. 63). Some parents

specifically asked others to watch their child, in order to compare notes and determine whether the concern was real (Mulcahy & Savage, 2016). Others may simply wait to see if and/or when concerns are raised by others (Lalbeharie-Josias, 2001; McAllister et al., 2011; Woolfenden et al., 2015). For these families, there is an expectation that others will assist them in noticing (McAllister et al., 2011) – the idea that "if there is a concern, then someone will tell me". Parents place these expectations on stakeholders they deem to have greater expertise than themselves, such as teachers or childcare workers (Lalbeharie-Josias, 2001; McAllister et al., 2011).

3.4.1.3 Waiting for validation

When expectations of assistance from others were not met, parents indicated being frustrated: "I do expect these sorts of things to be picked up at a pre-school… …I feel a bit let down in that respect" (McAllister et al., 2011, p. 260). This also leaves parents unsure as to whether their concerns are in fact valid; "We're just confused... Like, I mean is it a real issue, or…?" (McAllister et al., 2011, p. 261). This is likely to be particularly true for the "Maybe it's nothing, but" families, who are looking for evidence to decide whether their "niggles" are real; if this confirmation is not received, parents may decide that perhaps there is indeed nothing of concern. This reliance on others appears to often be unspoken, and thus raises issues where the stakeholders in question do not in fact have (or lack confidence in) the requisite expertise to identify concerns for parents.

3.4.2 What is needed for noticing to occur?

There appear to be two key mechanisms of noticing developmental concerns that often act in tandem; knowledge of child development, and social comparison with other children.

3.4.2.1 Knowledge of typical child development

To discern whether a child is experiencing a delay, we must know what typical and therefore atypical child development looks like (Zand et al., 2015), through understanding of developmental norms and milestones. Comparing a child's development with their personal knowledge or expectations of 'how children should be' is therefore one key means through which parents notice concerns (Hendrickson et al., 2000; Marshall et al., 2017; Silbersack, 2014; Williams, 2007). As a mother described, she "knew he was behind…because he was not doing the activities he was supposed to" Lalbeharie-Josias (2001, p. 99). In one study this process was likened to putting together a puzzle - fitting the pieces of a child's development together to determine what is and is not "normal" across aspects of development (Mulcahy & Savage, 2016).

Impact of limited knowledge on noticing. If a parent does not have foundational knowledge of normal child development, then their ability to identify whether their child is developing normally is inhibited (Zand et al., 2015). A parent interviewed stated, "I don't know if there's like a certain age, but what age should your child be talking?...I know they say like, you know, words, but when should they be having conversations and talking clear?" (Marshall, Coulter, et al., 2016, p. 109). While this parent knew that children's language develops in stages, not knowing when these typically occur undermines the ability to know if milestones are being met.

What factors influence parent knowledge of development? It cannot be assumed that parents automatically have a certain level of knowledge about development, as this parent articulates: "…and her saying, I can't believe you haven't noticed…I started to get a little annoyed. I was like, look, how would I know? And I think that is the feeling. How would I know?" (Silbersack, 2014, p. 54). When and from where was this parent supposed to have learned such information? Two cross-sectional surveys in fact found that parents of children with suspected developmental delays had lower levels of developmental knowledge compared to a normative sample (Marshall, Coulter, et al., 2016; Zand et al., 2015).

Supporting the development of parental knowledge is therefore a key ingredient to supporting the noticing process. Studies have found that when parents are explicitly educated to increase their understanding of typical child development, they grow their awareness of their child's concerns (Wall et al., 2005). Cross-sectional studies have therefore been conducted to identify factors associated with lower levels of knowledge amongst parents (predominantly mothers) of children with delays, in order to understand who may benefit most from efforts to increase knowledge (Marshall, Coulter, et al., 2016; Zand et al., 2015). Knowledge in this context was conceptualised as consisting of "child rearing practices, developmental processes, health and safety, and child development norms and milestones" (Zand et al., 2015). Although small-scale and only taken at one point in time, these findings enable us to make tentative considerations about the impact of the following factors:

a) Parental education and socioeconomic status. As income and education levels are co-related, these factors should be considered in combination (Zand et al., 2015). Findings from cross sectional studies suggest that both maternal education and socioeconomic status have a moderate to strong, positive relationship with parent knowledge (Marshall, Coulter, et al., 2016; Zand et al., 2015). Further to this, regression analysis found maternal education to be the only factor predictive of knowledge (Zand et al., 2015). This indicates that parent education may play an important role in noticing. However, a disclaimer is required here; it is unclear whether the nature of the education itself is key. Parents whose higher education is not in a child-related field do not necessarily feel that this makes any difference – "It's just I had no knowledge. I'm a lawyer. I don't know anything about this stuff" (Silbersack, 2014, p. 53).

b) Race/ethnicity. Parents who identified as white and English-speaking were more likely to have higher levels of knowledge (Marshall, Coulter, et al., 2016; Zand et al., 2015). In predictive models this association held true for accuracy in estimating developmental timeline, whereby African American mothers were found to be less accurate in their estimations, however overall total knowledge was not significantly different between groups (Zand et al., 2015). As discussed by the study authors, it is important to note the role of cultural differences; it is well established that cultural beliefs, values and practices influence parental expectations of the timing of certain developmental milestones (Pachter & Dworkin, 1997); yet standardised measurement of knowledge does not necessarily account for these cross-cultural differences. Findings should therefore be interpreted with caution.

c) Maternal age. Findings on the relationship between maternal age and knowledge is mixed. Zand et al. (2015) found that older mothers were more likely to have higher knowledge of child development and milestones, whereas Marshall, Coulter, et al. (2016) found no such association. It has been suggested that this association may have more to do with older mothers often having completed higher levels of education or being of higher socioeconomic status (factors which do appear to have a relationship with knowledge); rather than actual age itself.

d) Parenting experience. It is often assumed that first-time parents know less than parents with older children. Experienced parents found this as evidence of knowledge of child development – "Well I already had three daughters. So I know what normal development is and abnormal" (Morton, 2012, p. 77). This is however not empirically supported by either cross-sectional study (Marshall, Coulter, et al., 2016; Zand et al., 2015) . While first-time parents in these studies rated themselves as less confident in their knowledge and those with parenting experience considered themselves more confident, this was not supported by measures of actual knowledge; with no significant relationship found between knowledge and parenting experience (Marshall, Kirby, et al., 2016). See social comparison section for how parenting experience may play into this mechanism.

How much knowledge is actually needed? It has been suggested that strict or "exact" knowledge of development is not necessarily required for parents to know that something is not right (Glaun et al., 1998). Authors found that even when mothers did not recognise the full extent of their child's delay, they still had a strong desire for support; suggesting that "the mere acknowledgement that a problem exists may be sufficient without full appreciation of the nature and severity of developmental delay" (Glaun et al., 1998, p. 469). This was supported in qualitative work, which found that mother's intuition occurred across families of diverse socioeconomic status and educational background (Williams, 2007). Perhaps therefore a baseline level of knowledge is all that is required for parents to notice a concern, with the aim of EI to grow that knowledge further.

3.4.2.2 Social comparison with other children

Noticing through comparison is the juxtaposition of the child against siblings, children of family members/friends, or other children in the community. For example, "I have three kids and I knew that by age four all my kids spoke the same …but my son never happened, I never saw the jump from three to four" (Marshall, Coulter, et al., 2016, p. 109). Interactions with other children appear to present an opportunity to determine whether a child's development appears normal compared to other children; termed by parents as a "yardstick" or "barometer" (Lalbeharie-Josias, 2001; Magnusson et al., 2017; Marshall, Kirby, et al., 2016; Mulcahy & Savage, 2016; Rannard et al., 2004; Silbersack, 2014; Wall et al., 2005; Woolfenden et al., 2015). Some parents indicated that this particularly occurred during social occasions, such as birthday parties or family gatherings – “I just remember there were different little parties. And then you just notice…that’s when you get to see other kids. That’s when it really becomes more noticeable” (Silbersack, 2014, p. 56).

What if peers are not typically developing? An assumption of this mechanism is that the subjects of comparison themselves are developmentally typical and thus will act as accurate yardsticks; as one parent described “When we’d take her out we’d be like, okay, now is she behaving like a typical child…is this typical behaviour? Is this a typical peer?” (Silbersack, 2014, p. 55). If the peer is not typical, this could create a false comparison and undermine this process. This was hinted at by a mother interviewed who indicated that she did not perceive that her son experienced delays as her nephew “took a long time to walk but then started talking instead” (Magnusson et al., 2017, p. 4). While this notion was not extensively discussed in the identified studies, it is an interesting consideration of the validity of the use of comparison.

Challenges to comparison faced by families. Noticing through comparison requires opportunities for a child to interact with others. Families who lack such opportunities talk about lacking “exposure”; “You know, I just don’t have a frame of reference. So I don’t know how other parents figure it out when it’s not something kind of glaring” (Silbersack, 2014, p. 57). This appears to impact on age of identification of concerns; of a sample of parents interviewed, those who had early opportunities for comparison identified concerns at nine months of age on average, compared to 21 months of age by those with limited opportunities (Silbersack, 2014).

Circumstances such as the following are likely to limit, or at the very least change the nature of opportunities for comparison:

- Families who are socially isolated or who have low social capital, and thus limited informal opportunities for interaction (Silbersack, 2014).

- Families who do not engage with formal opportunities such as early years' education, including those who parent only within the home (i.e. no external child rearing) (Williams, 2007; Woolfenden et al., 2015)
- Migrant families, who if newly arrived may have limited social networks and whose extended families may be overseas (Woolfenden et al., 2015); this may be further inhibited by language and/or cultural barriers.
- Working parents, where childcare may need to be shared between parents or grandparents (Woolfenden et al., 2015).

3.5 Discussion

This scoping review was undertaken to bridge the gap in current EI models and discuss the process of noticing developmental concerns. This paper proposes a definition of noticing as follows: a process of emerging concerns about a child's development based on differences or incongruence with personal knowledge of development or by social comparison with same-age children.

This review presents a new first stage to the journey of EI, moving backwards from service contact as a starting point to bringing the focus back to families. Shifting the focus back from services means less emphasis on targeted EI services and requires consideration of a whole-of system approach that includes universal, public health and health promotion structures. Such an approach aligns with perspectives such as the World Health Organization Innovative Care for Chronic Conditions model (World Health Organization Health Care for Chronic Conditions Team, 2002). This model places patients and families in an immediate relationship with community partners and the health care team, supported at the broader level by health care organisations and the community, all of which is surrounded by a positive policy environment (World Health Organization Health Care for

Chronic Conditions Team, 2002). During noticing, community support and resources appear to be most critical – in creating opportunities for comparison, providing resources to build knowledge, and as stakeholders in a child's life who may themselves notice concerns. If we want to support parent noticing, as a first step towards getting children with delays into EI, then we need greater emphasis on the community factors that promote this; and a policy environment that reflects such a priority. Initiatives such as "Birth to 5: Watch Me Thrive!" acknowledge this need; providing resources to strengthen community capacity to support early child development and screening– from education and care professionals, to child welfare and housing providers, as well as advice at the community policy level (U.S. Department of Health and Human Services, 2017). Such efforts are important steps in creating a diversity of pathways for families, particularly through already established touchpoints, to support early noticing beyond traditional health care avenues. This has strong implications in light of findings of the importance of moments for comparison – how can communities create and promote such opportunities for families?

Having an explicit understanding of noticing highlights the diversity of parent experiences, demonstrating that subtle or tentative niggles are as potentially real or valid as more explicit "aha" experiences. In addition, this breakdown generates cues for others, such as professionals, to listen for the way that parents may express concerns without saying it directly – such as "maybe it's nothing, but". Extensive work conducted by Glascoe and colleagues indicates that eliciting concerns from parents should be approached thoughtfully; if not sensitively done, this can lead to both parental confusion and under-identification by professionals - highlighted in Glascoe (2002); Glascoe and Marks (2011). Parent-report screening tools such as the Parents' Evaluation of Developmental Status (PEDS) have been designed as an additional means of opening conversations with parents about concerns they may have (Glascoe & Marks, 2011; Oberklaid & Efron, 2005). A recent study identified that some families may not verbally report concerns when prompted by professionals, despite indicating concerns through written completion of the PEDS, theorized by the authors to be influenced in part by the level of trust and rapport between the parent and professional (Eremita et al., 2017). Findings therefore suggest that use of parent-report tools can capture information that would otherwise not be shared; but also highlights the need for professionals to focus on relationship-building and working in partnership with families in order to create conditions that invite parents to open up to them about concerns.

The literature suggests that who notices is often not singular, but may be a to-and-fro between parents and other people in a child's life. There appears to be an under-confidence in many parents, resulting in a need for validation by those deemed better able to make such judgements. Consequently, there is a critical need for those who interact with young children to recognise the role that parents may be (unconsciously) asking them to take on in monitoring their child's progress. Universal services who interact with everyday families are particularly important, with early childhood education or care providers identified as a key source of information for parents (Baker et al., 2017). Providers need to consider whether they have the requisite knowledge and/or skills to notice developmental concerns, as well as considering how they can build parental confidence in their own role to notice – i.e., to conduct their own developmental monitoring of their child. Further to this, findings on "let me think about it" parents suggests that while parents may not initially respond positively to others noticing, these families may require a period of time to reflect on and come to their own conclusions about their child's development (Wall et al., 2005). As such, there is a need for patience and persistence on the part of professionals in supporting this process, particularly in ensuring there are mechanisms in place to follow up with such families to re-assess their noticing.

The literature also indicates the need to carefully consider expectations of groups considered to have more or less knowledge of child development, particularly in making judgements about first-time versus experienced parents (Marshall, Coulter, et al., 2016; Zand et al., 2015). Instead of having knowledge, experienced parents may simply have more “reference points” through watching other children develop – and thus use comparison, not knowledge. We must therefore be careful in making assumptions about the need (or lack of) for knowledge support for such parents. While efforts to target other particular at-risk groups (such as parents with lower education) seem to hold some truth, we need to ensure that this does not discount the provision of time and resources to those that we deem to be less in need.

Findings highlight the need for parents, professionals and community members to build sound knowledge of child development; but how do they gain this knowledge? Research suggests that parents are increasingly utilising online forums such as parenting websites, message boards and social media to get parenting information and advice (Baker et al., 2017; Hall & Irvine, 2008; Porter & Ispa, 2013; Strange et al., 2018). A survey of Australian parents found that after friends and other parents, parent websites were the second most popular source of information, while social media was a key source for over half of the sample – particularly higher-risk parents (Baker et al., 2017). While many positive benefits are related to the use of online forums such as receiving emotional support, developing connections and sharing experiences (Hall & Irvine, 2008; Strange et al., 2018), there are downsides; with some parents experiencing information as conflicting and even judgemental (Strange et al., 2018). Ensuring that parents (and professionals) have access to reliable, evidence-based information is the modern-day challenge facing our health promotion systems. “Help Me Grow” and the Centers for Disease Control’s “Learn the signs. Act early” campaign are examples of U.S. based initiatives supporting communities to identify vulnerable children and provide centralised access to resources, as well as disseminating information to increase both parent and provider awareness of developmental delays and promote subsequent monitoring of child development (Cornell et al., 2018; Daniel et al., 2009). Preliminary surveys undertaken to evaluate the success of the “Learn the signs” campaign identified significant increases in parent knowledge of important milestones, signs of autism spectrum disorder, and the importance of early help-seeking (Daniel et al., 2009). This demonstrates the positive, powerful impact of such initiatives to raise community awareness of child development and to make the link beyond noticing to connecting in with services.

Comparison to others was identified as a secondary means to noticing. This has significant implications in considering where and how this process can occur for families. Opportunities for comparison may be formal or informal – playgroups, day-care and school all provide natural opportunities for observation of children interacting with peers. However as indicated by the findings, children of families who have limited opportunities for comparison may be at risk of going unnoticed. It is therefore important from an early detection perspective that all families are both encouraged and supported to access frequent, local, easily accessible, no or low-cost opportunities for their child to interact with others (Woolfenden et al., 2015). With the additional benefit of such activities in promoting positive child development, participation thus has a two-pronged impact in facilitating both developmental promotion and surveillance. There should be a particularly targeted approach taken by professionals to explicitly seek out and cater for families identified as being most at risk of limited opportunities – those with low social capital, those who do not traditionally interact with services, culturally and linguistically diverse families (especially newly arrived), and families with significant work obligations. Subsequent to noticing developmental concerns is the next step of sharing them with others – either formally with professionals or informally with family and/or friends - and connecting in with services and supports. Noticing cannot simply occur in isolation; longitudinal work suggests that there is an average time lag of almost 9 months between when children with developmental delays are noticed by parents and when they enter EI services (Hebbeler et al., 2007). Factors influencing decision-making around sharing and acting on concerns is thus an area of significant importance that goes beyond the scope of this work, and is currently being explored through a separate scoping review informed by health behaviour theory.

With the focus of this review on children who were at-risk of or experiencing developmental delays, a deliberate choice was made to not include children with diagnoses or disabilities. The authors acknowledge that rather than being discrete groups, there is often significant overlap between delay and disability– whereby a child experiencing delays may later go on to receive a diagnosis or where an underlying condition may precipitate delays. However, we note that there is an established body of work addressing “noticing” of developmental disabilities that are specific in nature, for example in autism spectrum disorder (De Giacomo & Fombonne, 1998; McConkey et al., 2009; Ryan et al., 2012; Sivberg, 2003) that readers may wish to refer to.

While this scoping review sought to be comprehensive through use of relatively open search terms, it cannot be certain that all relevant literature has been identified. Included studies assessing parental knowledge were only cross-sectional, and therefore can suggest association but not causation. As per exclusion criteria, this review can only posit how noticing occurs in a developed, largely Western context – this process may unfold differently in developing countries or contrasting contexts. Additionally, this conceptual understanding of noticing is literature-based only and has not been empirically tested or validated with populations – future work will seek to do so in the Australian context. Validation in other contexts is recommended.

3.6 Conclusion

This paper highlights the nuanced complexity of noticing concerns with a child's development. Understanding how this process occurs and the key ingredients that enable it is vital to supporting early detection of developmental delays. System-wide support for parent knowledge development and opportunities for comparison is essential, as well as creating conditions that invite parents to share their concerns (niggles or otherwise) with professionals.

3.7 References

Baker, S., Sanders, M. R., & Morawska, A. (2017). Who uses online parenting support? A cross-sectional survey exploring Australian parents' internet use for parenting. *Journal of Child and Family Studies, 26*, 916-927. https://doi.org/10.1007/s10826-016-0608-1

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Cornell, E., Luczak, S., Dudack, D., Sibley, S., Phillip, T., Martini-Carvell, K., & Dworkin, P. H. (2018). *Help Me Grow building impact report*. Help Me Grow National Center. http://helpmegrownational.org/wp-content/uploads/2019/05/HMG-Report-2019-Reference.pdf

Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, & Medical Home Initiatives for Children with Special Needs Project Advisory Committee. (2006). Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics, 118*(1), 405-420. https://doi.org/10.1542/peds.2006-1231

Curtin, M., Madden, J., Staines, A., & Perry, I. J. (2013). Determinants of vulnerability in early childhood development in Ireland: A cross-sectional study. *BMJ Open, 3*, e002387. https://doi.org/10.1136/bmjopen-2012-002387

Daniel, K. L., Prue, C., Taylor, M. K., Thomas, J., & Scales, M. (2009). 'Learn the signs. Act early': A campaign to help every child reach his or her full potential. *Public Health, 123*(Suppl 1), e11-16. https://doi.org/10.1016/j.puhe.2009.06.002

De Giacomo, A., & Fombonne, E. (1998). Parental recognition of developmental abnormalities in autism. *European Child & Adolescent Psychiatry, 7*(3), 131-136. http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=107165221&site=ehost-live

Department of Education and Training. (2016). *Australian early development census national report 2015*. https://www.aedc.gov.au/resources/detail/2015-aedc-national-report

Dworkin, P. H. (1989). British and American recommendations for developmental monitoring: the role of surveillance. *Pediatrics, 84*(6), 1000-1010.

Eremita, M., Semancik, E., Lerer, T., & Dworkin, P. H. (2017). Can we identify parents who do not verbally share concerns for their child's development? *Journal of Developmental and Behavioral Pediatrics, 38*(3), 224-227. https://doi.org/10.1097/DBP.0000000000000426

Glascoe, F. P. (2002). The value of parents' concerns to detect and address developmental and behavioural problems. *Journal of Pediatrics and Child Health, 35*(1), 1-8. https://doi.org/10.1046/j.1440-1754.1999.00342.x

Glascoe, F. P., & Dworkin, P. H. (1995). Role of parents in the detection of developmental and behavioral problems. *Pediatrics, 95*(6), 829-836. https://pubmed.ncbi.nlm.nih.gov/7539122/

Glascoe, F. P., & Marks, K. P. (2011). Detecting children with developmental-behavioral problems: The value of collaborating with parents. *Psychological Test and Assessment Modeling, 53*(2), 258-279. https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/1399542315?pq-origsite=primo

Glascoe, F. P., & Robertshaw, N. S. (2007). New AAP policy on detecting and addressing developmental and behavioral problems. *Journal of Pediatric Health Care, 21*(6), 407-412. https://doi.org/10.1016/j.pedhc.2007.08.008

Glaun, D. E., Cole, K. E., & Reddihough, D. S. (1998). Six month follow-up: the crucial test of multidisciplinary developmental assessment. *Child: Care, Health and Development, 24*(6), 457-472. https://doi.org/10.1046/j.1365-2214.1998.00082.x

Glogowska, M., & Campbell, R. (2004). Parental views of surveillance for early speech and language difficulties. *Children and Society, 18*(4), 266-277. https://doi.org/10.1002.CHI.806

Grantham-Mcgregor, S., Cheung, Y. B., Cueto, S., Glewwe, P., Richter, L., & Strupp, B. (2007). Developmental potential in the first 5 years for children in developing countries. *The Lancet, 369*(9555), 60-70. https://doi.org/10.1016/S0140-6736(07)60032-4

Hall, W., & Irvine, V. (2008). E-communication among mothers of infants and toddlers in a community-based cohort: A content analysis. *Journal of Advanced Nursing, 61*(5), 175-183. https://doi.org/10.1111/j.1365-2648.2008.04856.x

Harris, S. R. (2009). Listening to parents' concerns: three case examples of infants with developmental motor delays. *Pediatric Physical Therapy, 21*(3), 269-274. https://doi.org/10.1097/PEP.0b013e3181b12fbc

Hebbeler, K., Spiker, D., Bailey, D. B., Scarborough, A., Mallik, S., Simeonsson, R. J., Singer, M., & Nelson, L. (2007). *Early intervention for infants and toddlers with disabilities and their families: Participants, services, and outcomes*. SRI International. https://www.sri.com/wp-content/uploads/pdf/neils_finalreport_200702.pdf

Hendrickson, S., Baldwin, J. H., & Allred, K. W. (2000). Factors perceived by mothers as preventing families from obtaining early intervention services for their children with special needs. *Children's Health Care, 29*(1), 1-17. https://doi.org/10.1207/S15326888CHC2901_1

Human Early Learning Partnership. (2016). *EDI [Early Years Development Instrument] British Colombia: 2016 Provincial Report*. University of British Colombia School of Population and Public Health. http://earlylearning.ubc.ca/media/edibc2016provincialreport.pdf

Johnson, J. F. (2011). *An evaluation of the Early Steps Program referral process in Hillsborough County to detect delays in access to early intervention services* (Publication Number 2012-99080-337) [Doctoral dissertation, University of South Florida]. Scholar Commons. http://scholarcommons.usf.edu/etd/3171

Khan, L. P., Michael; Elena Rosa, Brown. (2013). Parenting programmes: identification and referral. *Journal of Children's Services, 8*(3), 194-208. https://doi.org/10.1108/JCS-03-2013-0011

Lalbeharie-Josias, D. P. (2001). *Parents' perceptions of the individualized family service plan* (Publication Number AAI3012154) [Doctoral thesis, University of Massachusetts Amherst]. ProQuest Dissertations & Theses Global. https://scholarworks.umass.edu/dissertations/AAI3012154

Maggi, S., Irwin, L. J., Siddiqi, A., & Hertzman, C. (2010). The social determinants of early child development: An overview. *Journal of Pediatrics and Child Health, 46*, 627-635. https://doi.org/10.1111/j.1440-1754.2010.01817.x.

Magnusson, D. M., Minkovitz, C. S., Kuhlthau, K. A., Caballero, T. M., & Mistry, K. B. (2017). Beliefs regarding development and early intervention among low-income African American and Hispanic mothers. *Pediatrics, 140*(5). https://doi.org/http://dx.doi.org/10.1542/peds.2017-2059

Marshall, J., Adelman, A., Kesten, S. M., Natale, R. A., & Elbaum, B. (2017). Parents’ experiences navigating intervention systems for young children with mild language delays. *Journal of Early Intervention, 39*(3), 180-198. https://doi.org/10.1177/1053815117704958

Marshall, J., Coulter, M. L., & Gorski, P. A. (2016). Parent recognition and responses to developmental concerns in young children. *Infants and Young Children, 29*(2), 102-115. https://doi.org/10.1097/IYC.0000000000000056

Marshall, J., Kirby, R. S., & Gorski, P. A. (2016). Parent concern and enrollment in intervention services for young children with developmental delays: 2007 National survey of children's health. *Exceptional Children, 82*(2), 251-268. https://doi.org/10.1177/0014402915585563

McAllister, L., McCormack, J., McLeod, S., & Harrison, L. J. (2011). Expectations and experiences of accessing and participating in services for childhood speech impairment. *International Journal of Speech-Language Pathology, 13*(3), 251-267. https://doi.org/10.3109/17549507.2011.535565

McConkey, R., Truesdale-Kennedy, M., & Cassidy, A. (2009). Mothers' recollections of early features of autism spectrum disorders. *Child and Adolescent Mental Health, 14*(1), 31-36. https://doi.org/10.1111/j.1475-3588.2008.00495.x

Missiuna, C., Moll, S., Law, M., King, S., & King, G. (2006). Mysteries and mazes: Parents' experiences of children with developmental coordination disorder. *Canadian Journal of Occupational Therapy, 73*(1), 7-17. https://doi.org/10.2182/cjot.05.0010

Moore, T. (2006). Early childhood and long term development: The importance of the early years. https://www.aracy.org.au/publications-resources/command/download_file/id/97/filename/Early_childhood_and_long_term_development_-_The_importance_of_the_early_years.pdf

Morton, D. S. (2012). *Parental descriptions of awareness and associated reactions to developmental delay in children* (Publication Number AAI3545470) [Doctoral dissertation, Capella University]. ProQuest Dissertations & Theses Global. https://www-proquest-com.dbgw.lis.curtin.edu.au/docview/1520325243/B7F1BC2997EB4B37PQ/1?accountid=10382

Mulcahy, H., & Savage, E. (2016). Uncertainty: A little bit not sure. Parental concern about child growth or development. *Journal of Child Health Care, 20*(3), 333-343. https://doi.org/10.1177/1367493515587059

Oberklaid, F., & Efron, D. (2005). Developmental delay - identification and management. *Australian family physician, 34*(9), 739-742.

Offord Centre for Child Studies. *Early Development Instrument in Ontario over time*. McMaster University. https://edi.offordcentre.com/partners/canada/edi-in-ontario/

Pachter, L. M., & Dworkin, P. H. (1997). Maternal expectations about normal child development in 4 cultural groups. *Archives of Pediatrics & Adolescent Medicine, 151*, 1144-1150. https://doi.org/10.1001/archpedi.1997.02170480074011

Peters, M. D. J., Godfrey, c., McInerney, P., Baldini Soares, C., Khalil, H., & Parker, D. (2017). Chapter 11: Scoping reviews. In E. Aromataris & Z. Munn (Eds.), *Joanna Briggs Institute Reviewer's Manual*. The Joanna Briggs Institute. https://reviewersmanual.joannabriggs.org/

Plath, D., Crofts, P., & Stuart, G. (2016). Engaging families in early intervention for child conduct doncerns. *Children Australia, 41*(1), 49-58. https://doi.org/10.1017/cha.2015.5

Porter, N., & Ispa, J. M. (2013). Mothers' online message board questions about parenting infants and toddlers. *Journal of Advanced Nursing, 69*(3), 559-568. https://doi.org/10.1111/j.1365-2648.2012.06030.x

Rannard, A., Lyons, C., & Glenn, S. (2004). Children with specific language impairment: Parental accounts of the early years. *Journal of Child Health Care, 8*(2), 165-176. https://doi.org/10.1177/1367493504041875

Raspa, M., Levis, D. M., Kish-Doto, J., Wallace, I., Rice, C., Barger, B., Green, K. K., & Wolf, R. B. (2015). Examining parents' experiences and information needs regarding early identification of developmental delays: Qualitative research to inform a public health campaign. *Journal of Developmental & Behavioral Pediatrics, 36*(8), 575-585. https://doi.org/10.1097/DBP.0000000000000205

Rosenberg, S. A., Zhang, D., & Robinson, C. C. (2008). Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics, 121*(6), e1503-1509. https://doi.org/10.1542/peds.2007-1680

Ryan, S., Salisbury, H., Ryan, S., & Salisbury, H. (2012). 'You know what boys are like': pre-diagnosis experiences of parents of children with autism spectrum conditions. *British Journal of General Practice, 62*(598), 378-383. https://doi.org/10.3399/bjgp12X641500

Shah, R., Sobotka, S. A., Chen, Y.-F., & Msall, M. E. (2015). Positive parenting practices, health disparities, and developmental progress. *Pediatrics, 136*(2), 318. https://doi.org/10.1542/peds.2014-3390

Silbersack, E. W. (2014). *Mothers' initial discovery of childhood disability: Exploring maternal identification of developmental issues in young children* [Doctoral dissertation, Adelphi University]. ProQuest Dissertations & Theses Global. https://eric.ed.gov/?id=ED557029

Sivberg, B. (2003). Parents' detection of early signs in their children having an autistic spectrum disorder. *Journal of Pediatric Nursing, 18*(6), 433-439. https://doi.org/10.1016/S0882-5963(03)00139-8

Strange, C., Fisher, C., Howat, P., & Wood, L. (2018). 'Easier to isolate yourself…there's no need to leave the house' - A qualitative study on the paradoxes of online communication for parents with young children. *Computers in Human Behavior, 83*, 168-175. https://doi.org/10.1016/j.chb.2018.01.040

Thelen, E., & Smith, L. B. (2007). Dynamic systems theories. In R. M. Lerner (Ed.), *Handbook of Child Psychology: Theoretical Models of Human Development* (Vol. 1, pp. 258-312). John Wiley and Sons.

U.S. Department of Health and Human Services. (2017). *Birth to 5: Watch Me Thrive*. https://www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive

United Nations. (2019). *World Economic Situation and Prospects 2019*. https://www.un.org/development/desa/dpad/wp-content/uploads/sites/45/WESP2019_BOOK-web.pdf

Vitrikas, K. S., Dillon; Bucaj, Merima. (2017). Developmental delay: When and how to screen. *American family physician, 96*(1), 36-43. https://www.aafp.org/afp/2017/0701/p36.html

Walker, S. P., Wachs, T. D., Grantham-Mcgregor, S., Black, M. M., Nelson, C. A., Huffman, S. L., Baker-Henningham, H., Chang, S. M., Hamadani, J. D., Lozoff, B., Gardner, J. M. M., Powell, C. A., Rahman, A., & Richter, L. (2011). Inequality in early childhood: Risk and protective factors for early child development. *The Lancet, 378*(9799), 1325-1338. https://doi.org/10.1016/S0140-6736(11)60555-2

Wall, S. M., Taylor, N. E., Liebow, H., Sabatino, C. A., Mayer, L. M., Farber, M. Z., & Timberlake, E. M. (2005). Early Head Start and access to early intervention services: a qualitative investigation. *Topics in Early Childhood Special Education, 25*(4), 218-231. https://doi.org/10.1177/02711214050250040301

Williams, J. (2007). Learning from mothers: how myths, policies and practices affect the detection of subtle developmental problems in children. *Child: Care, Health and Development, 33*(3), 282-290. https://doi.org/10.1111/j.1365-2214.2006.00690.x

Williams, J., & Holmes, C. A. (2004). Improving the early detection of children with subtle developmental problems. *Journal of Child Health Care, 8*(1), 34-46. https://doi.org/10.1177/13674950401852

Woolfenden, S., Eapen, V., Williams, K., Hayen, A., Spencer, N., & Kemp, L. (2014, Sep 13). A systematic review of the prevalence of parental concerns measured by the Parents' Evaluation of Developmental Status (PEDS) indicating developmental risk. *BMC pediatrics, 14*, 231. https://doi.org/10.1186/1471-2431-14-231

Woolfenden, S., Posada, N., Krchnakova, R., Crawford, J., Gilbert, J., Jursik, B., Sarkozy, V., Perkins, D., & Kemp, L. (2015). Equitable access to developmental surveillance and early intervention - understanding the barriers for children from culturally and linguistically diverse (CALD) backgrounds. *Health Expectations, 18*(6), 3286-3301. https://doi.org/10.1111/hex.12318

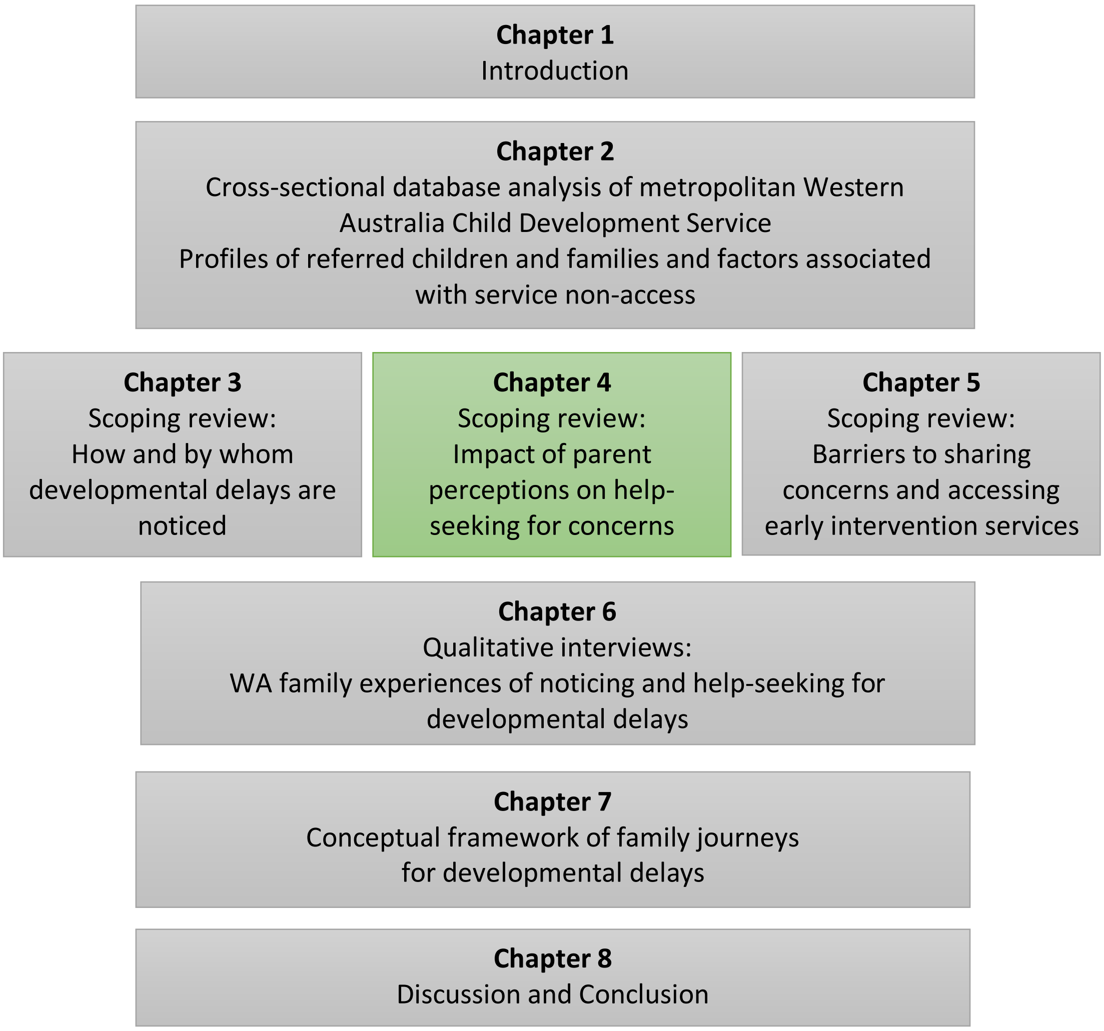
World Health Organization Health Care for Chronic Conditions Team. (2002). *Innovative care for chronic conditions: Building blocks for action: Global report*. World Health Organization. https://www.who.int/chp/knowledge/publications/icccglobalreport.pdf?ua=1

Zand, D. H., Pierce, K. J., Bultas, M. W., McMillin, S. E., Gott, R. M., & Wilmott, J. (2015). Accuracy of knowledge of child development in mothers of children receiving early intervention services. *Journal of Early Intervention, 37*(3), 226-240. https://doi.org/10.1177/1053815115610633

Chapter 4 Parent perceptions

Chapter 3 unpacked how parents and other significant stakeholders in a child's life may begin to notice concerns with their child's development.

Chapter 4 is the second scoping review in the series and is framed by the Health Belief Model (Champion & Skinner, 2008; Rosenstock, 1966, 1974; Rosenstock et al., 1988). This chapter discusses the impact that parental perceptions of developmental delays and early intervention services has on their help-seeking for their child.



Impact of parent health beliefs on help-seeking for child developmental delays

4.1 Abstract

Despite the high prevalence of developmental delays, significant disparities exist between rates of parents with concerns about their child's development and those who access services. A scoping review was undertaken using the Health Belief Model (HBM) to understand how parent beliefs influence their decision to act on suspected developmental delays. A systematic key-word database search was conducted, with 49 studies meeting inclusion criteria. Findings were mapped onto the HBM via deductive coding. Parent beliefs included perceptions of susceptibility (e.g. the influence of family history) and severity. Motivational relevance to act consisted of whether delays were considered problematic and/or 'enough' to warrant action. Perceived benefits of help-seeking included wanting to 'fix' the child, while others' negative experiences and uncertainty about the unknown were barriers. Modifying factors consisted of child/family factors, emotional responses, and low parental self-efficacy. Findings highlight parents' diverse, multi-faceted perceptions of their child's development and how such beliefs influence help-seeking.

4.2 Introduction

Early childhood interventions have long-term impacts on outcomes into adulthood, including overall health and development, education attainment, employment, annual earnings, home ownership, and health and social service utilisation; constituting both individual and systemic benefits (Campbell et al., 2014; Masse & Barnett, 2002; Schweinhart et al., 2005). The rates of return on investment are highest when concentrated during the preschool years (Heckman & Krueger, 2003). Notable examples include the 1960's Perry Preschool Program for disadvantaged children, reporting a benefits-to-costs ratio of 8.74 (Heckman, 2006), and the 1970's Abecedarian Project intensive preschool with 4:1 system returns (Masse & Barnett, 2002). It is thus well-established that early detection of difficulties and prompt commencement of intervention are essential for improved outcomes in children (Doyle et al., 2009; Heckman & Krueger, 2003).

Developmental delays include difficulties or concerns with physical, cognitive, social-emotional, speech and language, and/or behavioural development (Williams & Holmes, 2004). An estimated 13 to 32% of children in developed countries are at-risk of developmental delays (Curtin et al., 2013; Department of Education and Training, 2019; Human Early Learning Partnership, 2016; Offord Centre for Child Studies; Rosenberg et al., 2008), with heightened rates among vulnerable groups such as low-income families (Shah et al., 2015). Despite the high prevalence of delays and the established importance of early intervention (EI), significant disparities exist between rates of concerns about child development and the seeking out of services and supports. For example, population-based data from the United States suggest that despite 39% of parents reporting their child aged 0-5 years experienced one or more developmental concerns, less than 5% of the sample engaged with developmental services (Marshall, Kirby, et al., 2016). Low uptake rates suggest the need to understand why disparities exist between cognitions (i.e., concerns) and actions (i.e., help-seeking). As primary caregivers are typically the gatekeepers of their child's health, understanding how their beliefs and behaviours influence decisions for their child is critical (Kazdin, Holland, Crowley, et al., 1997; Staudt, 2007).

The Health Belief Model (HBM) is a conceptual framework developed from social psychology to explain and/or predict why people take action for their health – based on personal perceptions regarding susceptibility and severity, barriers to and benefits from action, sense of self-efficacy, and influence of other factors (Champion & Skinner, 2008; Rosenstock, 1966, 1974; Rosenstock et al., 1988). The HBM proposes that if a person believes they are susceptible to a particular health outcome with significant and severe consequences, they will believe there is more benefit to taking than avoiding action; and thus are more likely to act to avoid or change the health outcome (Champion & Skinner, 2008). The original HBM and parallel models such as the Transaction Model of Stress and Coping (Glanz & Schwartz, 2008; Lazarus & Folkman, 1984) have been widely used to understand health-related behaviours, as well as to underpin interventions designed to change such behaviours (Champion & Skinner, 2008). While originally designed to understand the influence of personal beliefs on health, in recent years the HBM has been used to understand parent behaviours relating to a variety of child health outcomes including vaccinations, healthy eating, and physical activity (Jacobson Vann et al., 2011; Smith et al., 2011); with a recent review recommending its use to inform strategies for engagement in parenting programs (Finan et al., 2018).

Recent qualitative works have incorporated the HBM and other associated health behaviour models to frame analysis of parent experiences of help-seeking for children with developmental delays (Alexander et al., 2015; Marshall, Kirby, et al., 2016; Woolfenden et al., 2015). There is a need for an overarching understanding across studies of the attitudes, beliefs and perceptions held by parents of children with developmental delays; and what makes some families take action to address their concerns. Due to its widespread historic use, its recent application to child health-based outcomes and explicit use in individual studies exploring developmental delay experiences, the HBM was selected to frame this cross-study exploration. The aim of this study, therefore, was to use the HBM as a ‘lens’ through which to understand existing research on how parent beliefs influence help-seeking for children with or at-risk of developmental delays.

4.3 Method

4.3.1 Design

A scoping review of peer-reviewed and grey literature was conducted as per the Joanna Briggs Institute scoping review protocol (Peters et al., 2017) and PRISMA-ScR checklist for scoping reviews (Tricco et al., 2018). A scoping review design was selected to enable mapping of current evidence from a diversity of sources and methodologies, whilst ensuring data are selected via a systematic search process (Peters et al., 2017).

4.3.2 Search strategy

A systematic search of major academic databases (ProQuest, ScienceDirect, CINAHL, Ovid and Sage) and grey literature sources (Google scholar, Trove, Mednar, and Agency for Healthcare Research and Quality) was conducted in August 2019. Search terms included: “(child OR toddler OR p*diatric OR baby OR infant) AND (developmen* OR delay OR at-risk OR milestones) AND (identif* OR notic* OR recogni* OR refer* OR participat* OR engag* OR access OR knowledge) AND early intervention”. Citation tracking and manual searching of maternal and child health-focused journals were also conducted.

4.3.3 Study selection

Study inclusion criteria consisted of the following: 1) population was children with or at-risk of developmental delays/concerns; 2) studies focused on parent beliefs and/or decision-making regarding help-seeking for concerns with a child's development 3) published in English; 4) conducted in countries categorised as developed economies (United Nations, 2019); and 5) published between 1998 and 2019. Journal articles, reports and unpublished dissertations were included when they reported on active research. Studies were excluded if they focused on children with diagnosed physical or mental conditions as they have different pathways to EI (Hebbeler et al., 2007). Restriction to developed countries accounted for potential cultural and socioeconomic differences. As per scoping review guidelines, no restrictions were placed on study design (Peters et al., 2017). Studies consisting solely of objective analysis of family factors influencing engagement, i.e., not including an explanatory component and/or direct parental perceptions, were excluded as they did not reflect parental beliefs.

All database results were screened at title and abstract level against each of the inclusion requirements, with those meeting criteria extracted for appraisal at full-text level – see figure 1 PRISMA diagram for exclusion breakdown. To ensure consistent adherence to inclusion criteria, a random selection of 20% of abstracts identified for full-text extraction were independently read and then discussed between all authors to determine inclusion.

4.3.4 Data extraction

Article data were independently extracted by the first author under the headings of author/s, year of publication, country of origin, aims/purpose, study population and sample size, methodology, and findings. Analysis of findings followed the six-phase guide to thematic analysis by Braun and Clarke (Braun & Clarke, 2006): familiarity with the data set; generating initial codes; searching for themes; reviewing themes (and producing a thematic 'map'); defining and naming themes; and producing the analytical report. Findings were mapped via deductive coding based on HBM components, with clustering of information to create sub-themes. The four original major headings of the HBM (perceived susceptibility, perceived severity, benefits to action, barriers to action), plus the later introduced concept of perceived self-efficacy were applied (Champion & Skinner, 2008). The concept of cues to action was not included due to being largely poorly defined in the literature (Carpenter, 2010). One additional concept, motivational relevance, was included from the Transactional Model of Stress and Coping – a parallel model that shares core components with the HBM (Glanz & Schwartz, 2008; Lazarus & Folkman, 1984). As the aim was to identify the breadth of the literature and resulting themes, a quality assessment of the articles was not undertaken (Peters et al., 2017; Tricco et al., 2018).

4.4 Results

Forty-nine studies were mapped on to the HBM - see Figure 4-1 for PRISMA diagram and

Table 4.1 for overview of included articles. Study methodologies were predominantly qualitative interviews (*n* = 21), focus groups (*n* = 4) or mixed methods (*n* = 9), as well as content analysis (*n* = 1), cross-sectional surveys (*n* = 4), and longitudinal cohort or prospective studies (*n* = 5). Qualitative analysis of the included studies revealed literature related to identifying concerns, consideration of the extent of concerns and the need for action, perceived benefits and barriers to engagement with EI, and factors determining engagement.

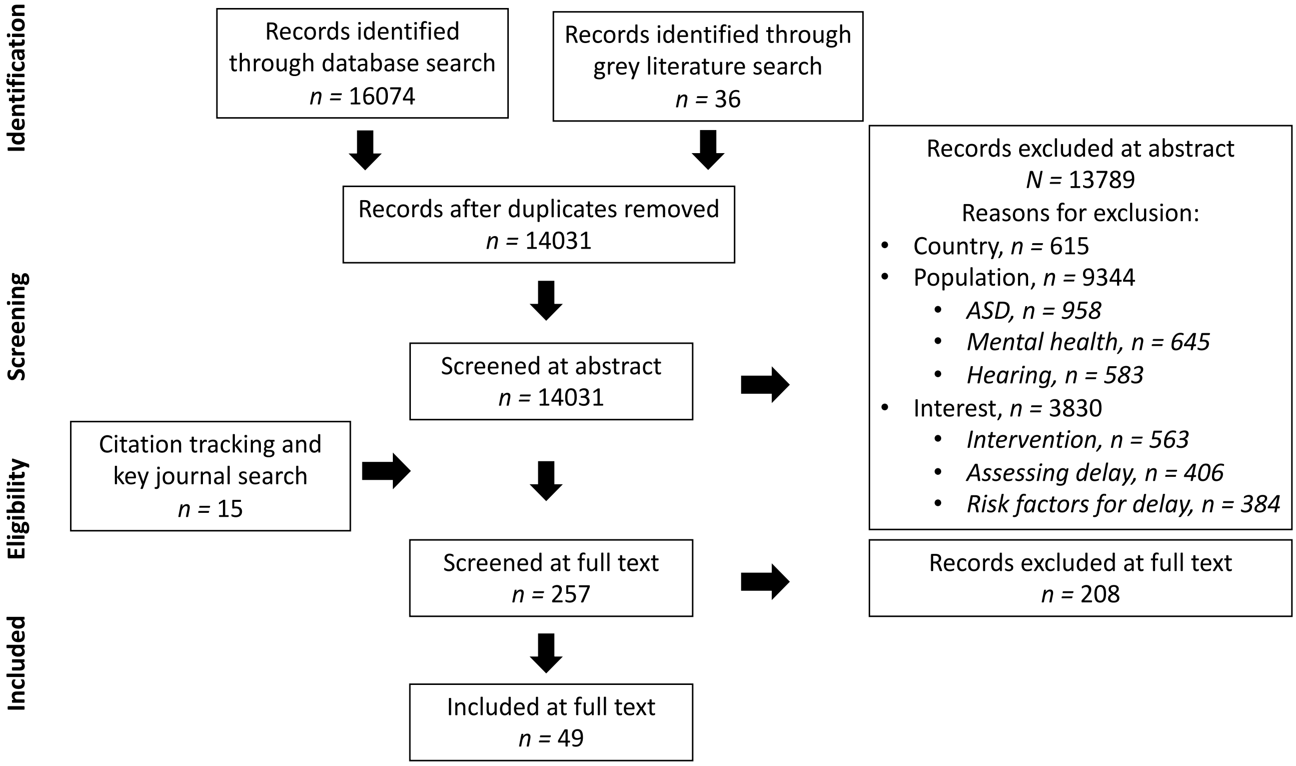


Figure 4-1 PRISMA diagram

Table 4.1 Summary of included studies

Citation	Country of origin	Study design	Participants/data source	Aims/interest
Ahern (2000)	Australia	Article; qualitative interviews	Parents of children with movement difficulties (*N* = 11)	Parent experience of attempts to seek diagnosis for their children
Alexander et al. (2015)	Australia	Article; qualitative interviews	Parents of children 3-5 years from diverse socioeconomic backgrounds (*N* = 28)	Understanding parent access of preventive health care services for child development
Baden (2012)	United States	Dissertation; qualitative interviews	Parents of children with developmental delays participating in EI services (*N* = 20)	Exploring different experiences of mothers and fathers in participation in EI
Beno (2017)	United States	Dissertation; focus groups	Parents and practitioners experienced in working with child protective services children (*N* = 16)	Exploring why infants and toddlers involved in child protective services may not receive EI services
Colgan (2012)	United States	Dissertation; quantitative longitudinal data analysis	Biological mothers of children with developmental delay aged 0-2 years eligible for EI services (*n* = 600) from population-based sample (*N* = 10700)	Exploring the relationship between maternal depression and child developmental delay identification and EI participation

Citation	**Country of origin**	**Study design**	**Participants/data source**	**Aims/interest**
Ellingson et al. (2004)	United States	Article; cross-sectional survey	Birth cohort of 11-39-month olds with identified elevated problematic behaviour symptoms (*N* = 269)	Understand the predictors of parent discussions of early child behaviour problems with paediatric care providers
Feinberg et al. (2012)	United States	Article; quantitative longitudinal data analysis	Biological mothers of children with developmental delay aged 0-2 years eligible for EI services (*n* = 1300) from population-based sample (*N* = 9850).	Examine the association between maternal depressive symptoms and receipt of EI services as infants (9 months) or as toddlers (24 months)
Giordano (2008)	United States	Dissertation; quantitative cross-sectional survey	Parents of children with developmental delays or disability who had (*n* = 70) and had not (*n* = 29) accessed EI services	Explore barriers that prevent families from accessing EI – and differences and similarities in barrier perceptions between families who did and did not access EI
Glaun et al. (1998)	United States	Article; quantitative descriptive prospective study. Six-month follow up using self-report (standardised measures, questionnaires)	Dyads of parents and pre-school age children with complex developmental delays referred for developmental assessment (*N* = 40)	Assess mothers’ recall of their child diagnosis and opinion on its correctness; examine attitudes on treatment recommendations; explore reasons that prevented families from following recommendations

Citation	Country of origin	Study design	Participants/data source	Aims/interest
Glogowska and Campbell (2004)	United Kingdom	Article; qualitative interviews	Parents of children with expressive speech issues (*N* = 20)	Parent experiences of developmental surveillance for early language difficulties
Green et al. (2016)	Australia	Article; qualitative interviews	Primary carers of Aboriginal children aged 0-8 years with developmental delay, attending a child development clinic (*N* = 19)	Aboriginal and Torres Strait Islander parent experiences of accessing child development services
Hebbeler et al. (2007)	United States	Longitudinal study; structured family telephone surveys and service records	Nationally representative sample of children who entered EI (*N* = 3338)	Families experiences in beginning EI
Hendrickson et al. (2000)	United States	Article; qualitative interviews	Mothers of children aged 3+years of age with developmental delays, who had not accessed birth-two years EI services (*N* = 13)	Experience of mothers of children with developmental delay who experienced barriers to accessing EI service
Jimenez et al. (2012)	United States	Article; qualitative interviews	Parents of children referred for EI services (n = 44) and EI providers (n = 22)	Exploring barriers to evaluation for EI
Johnson (2011)	United States	Dissertation; cross-sectional data analysis	Database records of children referred to the Early Steps Program over a 3-year period (*N* = 10688)	Understanding barriers to timely access to EI within the Early Steps referral process

Citation	Country of origin	Study design	Participants/data source	Aims/interest
Khan (2013)	United Kingdom	Article; mixed methods (qualitative interviews, cross-sectional survey)	Parents referred to parenting programs for child behavioural concerns (*N* = 44);	Understanding reasons parents seek support for behavioural concerns; differences between parents in their willingness to seek help; barriers to identifying support needs
Kummerer and Lopez-Reyna (2009)	United States	Series of instrumental case studies – interviews, file reviews, field notes and parent journals	Mexican immigrant families with children with speech/language difficulties; (*N* = 14) with *n* = 3 presented	Perceptions and practices of Mexican immigrant mothers in supporting the language and literacy of their child with communication difficulties
Lalbeharie-Josias (2001)	United States	Dissertation. Series of in-depth interviews, phenomenological case-methods approach	Parents of children (*N* = 14) with developmental delays or disability (excluded those with disability; used sample of *n* = 5)	Exploration of parents' experiences and perceptions of the individualized family service plan (early intervention)
Leiter (2001)	United States	Dissertation; qualitative interviews	Parents of children with developmental delays aged 0-3 years accessing EI services (*n* = 31) and EI service providers (*n* = 19)	Examine how family-centred care is implemented by individual families and EI professionals

Citation	Country of origin	Study design	Participants/data source	Aims/interest
Magnusson et al. (2017)	United States	Semi-structured in-depth interviews, inductive content analysis	African American (*n* = 8) and Hispanic (*n* = 14) mothers of children aged 0-36 months with developmental delay	Understand the role of health beliefs in shaping maternal decisions regarding help-seeking for children with developmental delays. Explore differences between African American and Hispanic mothers
Marshall et al. (2007)	United States	Article; qualitative interviews	Parents of pre-school age children with suspected language delays (*n* = 15) and speech and language therapists (*n* = 9)	Exploration of commonalities and differences in thoughts and perceptions of language development and EI between parents and professionals
Marshall (2013)	United States	Dissertation. Phase 1 cross-sectional data analysis, phase 2 qualitative interviews and focus groups	Phase 1: Parents of children aged 0-5 (*N* = 27566), 2007 NSCH survey Phase 2: Parents of children aged 0-5 (*N* = 23)	Parent recognition and response to child development - child, parent, family, and community-level factors
Marshall, Coulter, et al. (2016)	United States	Article; mixed methods (cross-sectional surveys, interviews/focus groups)	Parents of children aged 0-5 with suspected developmental or behavioural concerns (*N* = 23)	Parent recognition of and response to child developmental concerns; cross-sectional assessment of child developmental status and parent knowledge of child development

Citation	Country of origin	Study design	Participants/data source	Aims/interest
Marshall et al. (2017)	United States	Qualitative interviews, analysed using grounded theory	Parents of children with mild language delay who participated in a community-based speech program (N = 20)	Experiences of parents of children with mild language delays in navigating the process of assessment and referral and decision to participate/not
McAllister et al. (2011)	Australia	Dissertation; Study 1: Quantitative cross-sectional survey and Study 2: qualitative interviews	Parents of children with speech/language difficulties; Study 1 (N = 109), Study 2 (N = 13)	Parent experiences of child speech impairment and accessing services in Australia
Missiuna et al. (2006)	Canada	Article; In-depth interviews (phenomenological approach, descriptive analysis)	Parents (N = 13) of children with developmental coordination disorder	Explore the early noticing and help-seeking experiences of parent of children with developmental coordination disorder
Morton (2012)	United States	Dissertation. In-depth interviews (phenomenological approach, constant comparison analysis)	African American mothers (N = 8) of children with diagnosed developmental delay	Explore parental awareness of and reactions to developmental delay in their children

Citation	Country of origin	Study design	Participants/data source	Aims/interest
Mulcahy and Savage (2016)	Ireland	Article; qualitative interviews using Interpretation Phenomenological Analysis	Parents of preschool children whose child had been referred for developmental services (*N* = 15)	Understand the experiences of parents who had expressed a concern with their child's growth or development
Nelson et al. (2011)	United States	Article; qualitative focus groups	Parents of children with developmental concerns in the Head Start program (*N* = 30)	Parent perceptions of the Head Start program for detection and intervention for developmental concerns
Persoff (1998)	United States	Dissertation; qualitative interviews	Latino families of children with developmental delay (*N* = 11)	Latino mothers' experiences of barriers, stressors and coping skills in accessing EI for their child with developmental delay
Peterson et al. (2004)	United Kingdom	Structured parent interviews and direct child assessment; part of randomised experimental study	Sample of families who qualified for Early Head Start services enrolled in larger experimental study (*N* = 3001)	Understanding the characteristics and experiences of young children with developmental issues and their families
Plath et al. (2016)	Australia	Qualitative interviews;	Children with emerging conduct problems and their parents; parents of children who attended program (*n* = 12) and those who did not (*n* = 40)	Parent program evaluation (those who did and did not attend) of school-based universal and targeted EI program for children with emerging conduct problems.

Citation	Country of origin	Study design	Participants/data source	Aims/interest
Porter and Ispa (2013)	United States	Article; ethnographic content analysis	Online message board postings to parenting magazines of mothers of children aged 0-2 years (*N* = 120)	Explore childrearing concerns reported by mothers via online forums
Pratt (2012)	United States	Dissertation; Mixed-methods case series (interviews, surveys and record review)	Caregivers of children aged 0-3 years with developmental concerns receiving EI home visiting services (*N* = 10)	Parent perceptions and experience of receiving EI home visiting services through the '*Help Me Grow' program* Examine caregiver's experiences with home visitors
Ramirez (2004)	United States	Dissertation; Qualitative interviews	Latino families of children with developmental delay/disability (*N* = 10)	Experience of Latino parents of a child with developmental delay/disability – feelings associated with child's concerns, support systems used, and perceptions of EI.
Rannard et al. (2004)	United Kingdom	Article; qualitative interviews	Parents/guardians (*N* = 40) of children who had received specialist language education	Parental perspective of children with specific language impairments; meaning making of detecting their child's language problem.
Raspa et al. (2015)	United States	Article; focus groups; inductive content analysis	Parents of children with developmental delays (*N* = 74)	Exploring facilitators and barriers to identification of child developmental concerns

Citation	Country of origin	Study design	Participants/data source	Aims/interest
Restall and Borton (2010)	Canada	Article; mixed-method - cross-sectional survey and interviews using a phenomenological approach	Survey: guardians of children entering school (*N* = 290) Interviews: guardians of children identified as developmentally at risk (*N* = 9), all mothers	Understand prevalence of parent-reported developmental risk in children; parental experience of identifying concerns and accessing services
Schumarker-Murphy (2019)	United States	Dissertation; qualitative interviews	Fathers of children with developmental delays or disabilities (*N* = 6)	Fathers' experiences of engaging with EI services
Shannon (2000)	United States	Dissertation; qualitative interviews and observations	Families of children with developmental delay/disability (*n* = 22) and service providers (*n* = 20)	Parent perspectives of family-centred practice implementation
Sices et al. (2009)	United States	Article; qualitative focus groups	Mothers of young children with typical development (*n* = 11); mothers of young children who received EI services (*n* = 18)	Understanding the beliefs and experiences of parents and EI specialists in discussing child development
Silbersack (2014)	United States	Dissertation. In-depth interviews; phenomenological approach using thematic analysis	Mothers of children 0-5 years with confirmed developmental delays or disabilities (*N* = 18)	Understanding of process surrounding discovery of child developmental issues by mothers.

Citation	**Country of origin**	**Study design**	**Participants/data source**	**Aims/interest**
Smith et al. (2010)	United States	Article; longitudinal cohort study (questionnaires, interviews)	Community sample of first-time mothers of high-risk infants aged 12 and 24 months (*N* = 451)	Detection and level of worry about developmental delays by first-time mothers; relationship with formally identified presence of delays; impact of maternal knowledge on worries.
Smith et al. (2015)	United Kingdom	Article; Qualitative interviews with parents and practitioners	Parents of preschool children with ADHD-type problems (*N* = 25)	Parent barriers to accessing and engaging with parenting programs for preschool-age children with ADHD
Tervo (2005)	United States	Article; cross sectional survey	Guardians of children aged 16-70 months at a neurodevelopmental assessment clinic (*N* = 180)	Describe parental reports of concerns with child development. Determine relationship between parent-reported and formally assessed developmental delays.
Wall et al. (2005)	United States	Article; qualitative case studies – interviews and case reviews	At risk (low income, minority) families (*N* = 32)	Early Head Start participation and impact on likelihood of subsequent EI access
Williams (2007)	Australia	Article; qualitative interviews	Mothers of children with 'subtle developmental problems' (*N* = 8)	Mothers' experiences of raising a child with developmental problems
Woolfenden et al. (2015)	Australia	Article; qualitative interviews	CALD background parents of children with suspected developmental delays (*N* = 13)	Family and service characteristics, beliefs and experiences influencing journeys in accessing developmental surveillance and EI services

Citation	**Country of origin**	**Study design**	**Participants/data source**	**Aims/interest**
Worcester (2005)	United States	Article; qualitative interviews	Parents of young children aged 0-4 years experiencing challenging behaviour and/or additional developmental delays or disabilities (*N* = 8)	Parent reports of experiences obtaining services and supports for their children within their local system of care

4.4.1 Perceptions of significance/threat to typical development

The perception of significance or threat consisted of: a) perceived susceptibility or beliefs about the likelihood of a child experiencing development concerns (Champion & Skinner, 2008) and; b) perceived severity relating to beliefs about the seriousness of a child experiencing developmental concerns, and the consequences of not acting on it (Champion & Skinner, 2008).

4.4.1.1 Perceived susceptibility

A family history of developmental delays put families on ‘high alert’ for signs of delays in their child (Alexander et al., 2015; Lalbeharie-Josias, 2001; Marshall et al., 2017; Marshall, Coulter, et al., 2016; McAllister et al., 2011; Rannard et al., 2004; Silbersack, 2014; Wall et al., 2005). Families who had an older child with developmental concerns knew the signs and watched out for them (Alexander et al., 2015; Lalbeharie-Josias, 2001; Marshall, 2013; Marshall et al., 2007; Wall et al., 2005), took concerns seriously (Marshall et al., 2017; McAllister et al., 2011), were already familiar with EI (Baden, 2012), and were more likely to access services (McAllister et al., 2011). Another alerting factor was the child having a history of sickness or poor general health, making parents vigilant about monitoring for developmental issues (Marshall, Coulter, et al., 2016; Morton, 2012). Such children were often already under the care and surveillance of health professionals and thus being actively monitored for concerns (Marshall, 2013; Morton, 2012). For other families, managing their child’s health needs was the priority, and thus, developmental concerns were not pursued (Shannon, 2000). Children with birth complications were considered a vulnerable group for experiencing delays (Barfield et al., 2008; Delgado & Scott, 2006; Hebbeler et al., 2007; McManus et al., 2013; Mills et al., 2018; Mughal et al., 2019; Pevalin et al., 2003; Pritchard et al., 2013; Wang et al., 2009); however, some parents of premature children indicated they did not understand or see the need for EI (Baden, 2012). Parents also held beliefs about the impact of personality, temperament, or the environment on development. For example, that a more outgoing child would speak earlier, or that a child was simply a ‘lazy speaker’ (Marshall et al., 2007); and thus, the child just required opportunity (rather than intervention) to ‘speak in their own time’ (Marshall et al., 2007).

4.4.2 Perceived severity

4.4.2.1 Extent of delay

Parent perception of the extent or severity of their child’s delay was a major consideration in deciding whether to access services (Marshall, Coulter, et al., 2016; Missiuna et al., 2006). For the majority, the more ‘severe’, overt or global the actual delay, the greater the level of concern and thus seeking of services (Giordano, 2008; Hendrickson et al., 2000; McAllister et al., 2011; Shannon, 2000). Parents who did not consider their child’s delays to be severe enough, even when told about them by professionals, subsequently did not seek to access services (Giordano, 2008). Other studies identified a ‘threshold’, whereby parents would not be adequately concerned and thus pursue support until delays reached a certain level (McAllister et al., 2011; Missiuna et al., 2006); or when concerns continued to be ongoing or persistent, i.e., did not resolve with time (Glogowska & Campbell, 2004). However, one study reported some parents of children with severe language impairments believed that their child ‘did not need’ services (McAllister et al., 2011); although it was unclear how parent perceptions of ‘need’ were formed.

4.4.2.2 Nature of concern

Perceptions of seriousness and whether parents then acted on their concerns depended to some extent on the type of delay the child experienced; however, how this translated to action was inconsistently reported. Speech, language, and communication issues were concerns that parents most commonly recognised, worried about and prioritised seeking help for (Glaun et al., 1998; Glogowska & Campbell, 2004; Hebbeler et al., 2007; Jimenez et al., 2012; Marshall, Coulter, et al., 2016; McAllister et al., 2011; Morton, 2012; Nelson et al., 2011; Peterson et al., 2004; Porter & Ispa, 2013; Raspa et al., 2015; Tervo, 2005), even when there were multiple other concerns about their child (Glaun et al., 1998; Peterson et al., 2004; Tervo, 2005). Speech issues were frequently linked to behavioural concerns, whereby the child's communication frustrations led to behaviours such as tantrums; which subsequently resulted in parents' help-seeking (Marshall et al., 2017; Rannard et al., 2004; Raspa et al., 2015; Schumarker-Murphy, 2019; Worcester, 2005).

Social-emotional issues were also a major concern (Marshall et al., 2017; Marshall, Coulter, et al., 2016; McAllister et al., 2011; Nelson et al., 2011; Porter & Ispa, 2013; Tervo, 2005; Worcester, 2005), and often prompted real concern in parents even when delays in other areas were already noted (Marshall, 2013; Marshall et al., 2017). Parents were unlikely to seek support if they believed their child was simply 'being naughty' (Khan, 2013). Parental distress and disruption to family routines caused by the child's behaviour were often the trigger for help-seeking (Ellingson et al., 2004; Khan, 2013; Marshall et al., 2017; Worcester, 2005), as well as the child beginning to be impacted socially (e.g. through bullying) as a result of their delays (Missiuna et al., 2006). Suspicion of developmental disabilities, such as autism spectrum disorder, acted as motivation for some parents to seek help (Jimenez et al., 2012). Other key types of concerns were physical and/or medical, such as issues with feeding and motor milestone attainment (Green et al., 2016; Hebbeler et al., 2007; Khan, 2013; Marshall, Coulter, et al., 2016; Marshall et al., 2007; Porter & Ispa, 2013; Raspa et al., 2015); when concerns were not associated with any medical problems, parents more readily took a 'wait and see' approach (Glogowska & Campbell, 2004).

4.4.3 Motivational relevance to act on concerns

Motivational relevance refers to the perception of whether the ‘stressor’ was considered to have a major impact on the person, i.e. the child (Glanz & Schwartz, 2008), and thus whether further action was warranted. Parental level of motivational relevance appeared to be based on whether the concern was determined to be problematic for their child, and whether it was significant enough to warrant help-seeking at that time.

Not problematic; everything is fine. Concerns may not be seen as atypical or problematic (Glaun et al., 1998; Lalbeharie-Josias, 2001; Marshall et al., 2017; Plath et al., 2016), with the view that children ‘develop in their own time’ (Magnusson et al., 2017). Parents may not understand, or see the significance of the delay (Beno, 2017; Shannon, 2000) – a knowledge issue rather than denial (Marshall et al., 2007; Smith et al., 2010). Also, distant, distracted or insensitive parenting style may result in parents not recognising their child’s needs and thus not seeing the need for intervention (Wall et al., 2005).

At what point should I be worried? Some families experienced difficulty with determining, particularly in the case of behavioural concerns, what was ‘normal’ or indeed something of real concern (Ahern, 2000; Khan, 2013; Missiuna et al., 2006; Porter & Ispa, 2013; Raspa et al., 2015). This struggle led to ongoing self-doubt and thus hesitation in expressing concerns and help-seeking (Ahern, 2000; Khan, 2013; Missiuna et al., 2006; Porter & Ispa, 2013; Raspa et al., 2015); especially in the case of first-time parents (Raspa et al., 2015). Parents described concerns about being labelled ‘overanxious’, particularly where they noticed things that others were not, and thus consulted external sources (particularly family) to try to validate their concerns (Alexander et al., 2015; Missiuna et al., 2006).

I am the expert on my child; I decide. Some parents indicated they were the experts on their child – they knew them best - and because of this, it was for them alone (and not professionals) to determine whether an intervention was required (Jimenez et al., 2012).

Some parents were already working on strategies with their child and thus did not see the need to seek out formal services (Jimenez et al., 2012; Marshall et al., 2007); parents indicated that if issues did not resolve, they would be open to accessing EI (Jimenez et al., 2012).

Someone else told me to. Some parents sought out services at the insistence of others (McAllister et al., 2011; Ramirez, 2004; Raspa et al., 2015; Schumarker-Murphy, 2019), despite not perceiving concerns themselves. This directive was from a partner or family member (McAllister et al., 2011) or health professional (Kummerer & Lopez-Reyna, 2009; Raspa et al., 2015; Schumarker-Murphy, 2019).

Wait and see. The belief that the issue was temporary, would resolve spontaneously or independently without intervention, all prompted a wait and see approach from parents (Glaun et al., 1998; Marshall, 2013; Silbersack, 2014; Wall et al., 2005). Giving a child 'time to outgrow the delay' was a consistent theme (Giordano, 2008; Glogowska & Campbell, 2004; Jimenez et al., 2012; Magnusson et al., 2017; Persoff, 1998; Shannon, 2000; Wall et al., 2005), with the belief (or hope) that any concerns would resolve over time; even if significant issues were noted (Hendrickson et al., 2000). For some parents, there was a specific timeframe or point at which they would seek support (Jimenez et al., 2012), such as by school entry (Glogowska & Campbell, 2004). Others perceived that their child was not 'ready' or too young to cooperate within a therapeutic setting to make EI worthwhile (Glogowska & Campbell, 2004), and that opportunities such as school would help their child to catch up (Marshall et al., 2007).

Want to do the best for my child. Parents described wanting to do the best they could for their child – to find information and learn how to address concerns (Lalbeharie-Josias, 2001; Missiuna et al., 2006; Morton, 2012; Restall & Borton, 2010; Worcester, 2005). Of the families who accessed EI services, the majority believed their child would benefit from services and wanted to receive support (Giordano, 2008; Schumarker-Murphy, 2019), with some parents being proactive in trying to get their child enrolled (Glogowska & Campbell, 2004; Plath et al., 2016). Parents again referred to the importance of school entry; citing this milestone as a sort of 'deadline' by which they needed their child to be ready (Glogowska & Campbell, 2004).

4.4.4 Perceived benefits of engagement with early intervention

A range of parent beliefs were identified regarding potential benefits or positive effects of accessing EI services. Some viewed EI as preventative, "the earlier the better", and a way of getting answers and determining whether there truly was something different about their child (Baden, 2012; Glogowska & Campbell, 2004, p. 6; Marshall, 2013; Morton, 2012). Some viewed they had nothing to lose by trying EI (Mulcahy & Savage, 2016; Persoff, 1998), were open to any support even if they did not know what to expect (Baden, 2012; Ramirez, 2004; Silbersack, 2014), or believed their child would blame them later on in life if they did not attend (Persoff, 1998). A somewhat unhealthy perception was that EI would 'fix' the child (Schumarker-Murphy, 2019; Williams, 2007); one study identified that 70% of parents initially sought EI services to 'fix' their child and 'make the disability go away' (Ramirez, 2004, p. 31). For some parents, positive perceptions were inspired by seeing other children or siblings having positive EI experiences, resulting in them being more likely to access EI for their own child (Glogowska & Campbell, 2004; Marshall, 2013). In contrast, seeing other children who had not received EI and who experienced ongoing issues also appeared to be a motivator for early help-seeking (Glogowska & Campbell, 2004).

4.4.5 Perceived barriers

Previous unsuccessful experiences with EI, negative experiences of other EI services, not knowing anyone else with a similar experience, and feeling unsure of the unknown influenced decisions to access EI (Baden, 2012; Beno, 2017; Glogowska & Campbell, 2004; Magnusson et al., 2017; Marshall, 2013; Schumarker-Murphy, 2019). Some parents were fearful that entering EI would confirm their ‘worst fears’ about their child’s atypical development (Glogowska & Campbell, 2004) or were opposed to their child being ‘labelled’ (Lalbeharie-Josias, 2001). Some families did not know what EI was, or what to expect from it (Beno, 2017; Magnusson et al., 2017), having been told about it by someone such as a health professional (Baden; Magnusson et al., 2017). Many described ambivalence or scepticism of EI need and/or usefulness (Baden; Marshall, 2013), particularly for those whose children had less significant or milder delays (Hendrickson et al., 2000). Other parents were preoccupied or distracted by other issues (Magnusson et al., 2017; Wall et al., 2005), and/or too ‘busy’ (Plath et al., 2016) – whereby they felt they were unable to address their child’s concerns and may thus minimise the significance of concerns.

4.4.6 Modifying factors impacting engagement with early intervention

4.4.6.1 Family factors

A range of experiences, deeply held beliefs, and cultural factors influenced parents’ help-seeking. Child age and gender influenced how seriously concerns were viewed: whether a delay was indeed present in very young children (Mulcahy & Savage, 2016), or simply gender-based developmental differences (Magnusson et al., 2017; Missiuna et al., 2006): “girls can be faster at learning things” (Marshall et al., 2007, p. 541),“boys are slow to talk” (Wall et al., 2005, p. 223), and “boys are always slower” (Rannard et al., 2004, p. 170). Family culture impacted expectations of how children developed, the timing of milestones, and how professional advice was perceived (Magnusson et al., 2017; Marshall, 2013); migrant families sometimes received conflicting advice between their native culture and adopted country, and terms such as ‘autism’ were unfamiliar; all creating confusion and ultimately discontinuation of service engagement (Alexander et al., 2015; Woolfenden et al., 2015). Families who viewed childcare, early learning and support as the role of the parent or mother alone, (Woolfenden et al., 2015); or who perceived services as threatening due to negative past experiences of authority (Leiter, 2001), were each less likely to access services. In contrast, some families went along with referrals to 'avoid trouble' or disagreement with professionals – but were ultimately not engaged in the process (Magnusson et al., 2017).

Parents with 'knowledge and background' of child development and EI services were perceived by other parents to have an easier time accessing services (Marshall, 2013). Understanding professionals' jargon and having a basic understanding of the health care system was viewed as important to engaging with services (Morton, 2012; Shannon, 2000; Silbersack, 2014). Parents with both high legal and clinical knowledge felt empowered for knowing how to access the system and advocate for their child's needs; while parents with low knowledge levels were unsure about their child's delay and EI, did not know how to move through the system as their child's advocate, and may not have been ready to hear (or understand) information about their child (Leiter, 2001). However, parents with higher levels of education also reported that EI was still a foreign world to them (Schumarker-Murphy, 2019, p. 209; Shannon, 2000) and that their backgrounds did not always directly translate to knowing what to do (Silbersack, 2014).

Two studies identified that mothers with depression were more likely to report their child had a special need (Colgan, 2012), to take their child for developmental surveillance or speak to a health professional (Colgan, 2012; Ellingson et al., 2004), and to access EI services for their child (Colgan, 2012; Feinberg et al., 2012) than mothers without depression. It could be theorised that mothers with depression had greater knowledge of the health system through their own personal contact; and that they may be concerned about the impact of their mental health on their parenting, and thus be more vigilant in seeking support to counteract this factor (Colgan, 2012).

4.4.6.2 Impact of emotional response

Parents' emotional responses to their child's developmental concerns varied over time; even when parents were motivated to learn more about their child's concerns, these experiences were often still worrisome (Glogowska & Campbell, 2004). Some parents experienced an initial period of stress, overwhelm, shock, depression (Baden; Raspa et al., 2015; Silbersack, 2014), mourning or grief process (Baden; Persoff, 1998; Raspa et al., 2015; Shannon, 2000; Silbersack, 2014), whereby families are coming to terms with not having the 'perfect child' (Shannon, 2000); resulting in uncertainty, overwhelm and thus somewhat immobilising parents (Baden; Shannon, 2000). Others were in denial, believing the child will 'grow out of it' (Baden), or reluctant to hear negative messages about their child and thus avoidant of taking action (Giordano, 2008; Raspa et al., 2015; Shannon, 2000; Woolfenden et al., 2015).

Negative narratives, shame and/or stigma associated with having developmental concerns made parents fearful of the long-term impact of delays and/or of acting on concerns (Baden; Beno, 2017; Giordano, 2008; Glogowska & Campbell, 2004; Lalbeharie-Josias, 2001; Woolfenden et al., 2015), particularly for social-emotional concerns (Johnson, 2011). Shame or embarrassment relating to the child's behaviour was common (Glogowska & Campbell, 2004; Johnson, 2011; Khan, 2013; Rannard et al., 2004; Smith et al., 2015; Worcester, 2005); parents perceived negative consequences for not only their child but for themselves as a result of their child's behaviour in social situations or from the stigma of attending services (Johnson, 2011; Khan, 2013; Rannard et al., 2004; Smith et al., 2015; Worcester, 2005). The above factors stopped some parents from investigating concerns further and disclosing them to others (Khan, 2013), in part so their child would not be "labelled" (Giordano, 2008), while other parents still connected to services, however with a level of passivity or uncertainty (Glogowska & Campbell, 2004).

Parents often felt guilt about failing their child or about their parenting (Ahern, 2000; Morton, 2012; Raspa et al., 2015; Silbersack, 2014; Williams, 2007) or when there had been delays in noticing concerns or seeking help (Hendrickson et al., 2000; Marshall et al., 2017; Marshall et al., 2007; Silbersack, 2014) – although how these circumstances impacted service access was not consistently reported. In families where developmental concerns may have been caused by maltreatment (e.g. shaken baby syndrome or prenatal substance abuse), feelings of shame and subsequently shutting down or shying away from help-seeking were identified (Beno, 2017).

Parents also feared being judged or blamed: for their parenting skills or discipline style, being a 'bad mom'; or even for the state of their homes during home visits (Pratt, 2012; Shannon, 2000; Sices et al., 2009). Some parents mistook EI for child protective services, and thus were fearful of judgement as a bad parent that might result in being reported (Jimenez et al., 2012; Shannon, 2000; Sices et al., 2009; Smith et al., 2015); particularly for families already involved with child welfare services (Beno, 2017; Shannon, 2000). While parents may blame themselves, they also perceived other family members and health professionals blamed them too (Sices et al., 2009; Woolfenden et al., 2015) – which parents resented (Shannon, 2000). Each of these fears led parents not to want to share their concerns with others (Marshall, 2013; Smith et al., 2015) or to cease pursuing services (Shannon, 2000).

Parents may still seek help when concerned, regardless of, or despite having negative feelings about the process (Morton, 2012; Silbersack, 2014; Woolfenden et al., 2015; Worcester, 2005). Not all parents were resistant to addressing concerns, with some expressing relief and a sense of hope that the earlier something was identified, the sooner it could potentially be resolved (Woolfenden et al., 2015). Some parents also expressed a sense of gratitude that by connecting with services, someone was looking out for their child (Glogowska & Campbell, 2004).

4.4.7 Perceived self-efficacy

Self-efficacy in the HBM refers to expectations about "the effectiveness of one's coping resources" (Glanz & Schwartz, 2008, p. 217). Studies discuss parent perceptions of having low levels of personal confidence in their decision-making, their own parenting skills, seeking out services and advocating for their child (Kummerer & Lopez-Reyna, 2009; Shannon, 2000). Parents who were more tenacious, organised and with higher self-esteem were better able to manage barriers in accessing services and thus successfully engaged in EI (Marshall, 2013; Missiuna et al., 2006; Shannon, 2000). Persistence despite barriers or challenges, as well as in the face of resistance from others, also appears critical (Ahern, 2000; Marshall, 2013; Persoff, 1998; Wall et al., 2005); "I was fighting for things along the way. I have to go out and say, 'Excuse me, but I want this for my child." (Ahern, 2000, p. 195). Past experiences impacted the level of parental advocacy, such as being a health professional themselves (Missiuna et al., 2006), having seen a family member or friend go through a similar experience, or having personal experiences as a person with a delay or disability (Shannon, 2000).

Parents with low personal confidence were viewed as being at a disadvantage in entering a system that required ongoing efforts to have one's needs met (Shannon, 2000). Navigating EI systems required significant effort from parents for whom being vocal in making their needs known does not come naturally and may also place them at risk of being 'railroaded' by others - forcing them to be more assertive (Shannon, 2000). The power of self-efficacy in accessing services is highlighted in the discussion of three categories of parents of children with behavioural concerns: 1) the volunteer parent, who acknowledged their child’s difficulties and were motivated to seek support; 2) the sceptical parent, who did not perceive their child’s concerns as problematic and were ambivalent or unaware of the need for supports; and 3) the overwhelmed or historically disengaged parent, who had complex needs that interfered with their ability to access traditional supports (Khan, 2013).

4.5 Discussion

This scoping review aimed to understand how parent beliefs influence decision making about help-seeking for children with, or at-risk, of developmental delays. This review identified a depth and complexity that accompanies parent thoughts, perceptions and feelings related to concerns with a child’s development, including a range of beliefs that frequently appeared to limit parents’ further exploration of their child’s concerns. This was related to mixed understandings of the nature of child development and the appropriateness and usefulness of EI services.

Findings related to perceptions of significance of concerns identified that not all developmental concerns were viewed equally, with speech and language prioritised and most likely to lead to help-seeking. This finding was consistent with earlier quantitative work (Coonrod & Stone, 2004; Marshall, Kirby, et al., 2016). This, however, does not necessarily fit with population-level findings of the most common concerns: Australian data identified a higher percentage of children nationally who experience physical, social and/or emotional developmental vulnerability (8.4 - 9.8%) compared to language and communication (6.6 and 8.2% respectively) (Department of Education and Training, 2019). These statistics raise questions about why there is a greater focus on language. It might be, that as reported in a Taiwanese study parents were less likely to identify cognitive, global, and behavioural developmental concerns, compared to the more evident speech or communication delays (Chung et al., 2011). This warrants further investigation.

Previous studies on the HBM identified perceived barriers as being the most powerful construct of the model in predicting outcomes (Carpenter, 2010; Champion & Skinner, 2008). In the current review, narratives surrounding barriers centred predominantly around a lack of knowledge or understanding of the purpose of EI and thus not seeing a need for it – reflective of the sceptical parent discussed by Khan, Parsonage and Brown (Khan, 2013). Empirical evidence on the role of knowledge and health literacy suggests that high health literacy and knowledge of child development are significantly associated with legitimate concerns with child development and attendance at EI (Nielsen, 2014; Smith et al., 2010), though others have found no significant relationship (Schmidt, 2013). Perhaps it matters most when baseline knowledge is low; an intervention study found that when exposed to information about EI, low health literacy parents gained knowledge in both developmental delay and EI and were more likely to access services (Jimenez et al., 2017). This finding suggests the need for EI health literacy campaigns.

Health systems are beginning to recognise the importance of health care messaging for developmental concerns. The World Health Organization Nurturing Care Framework for early childhood development emphasises the need for community-level communication strategies in order to inform and empower caregivers (World Health Organization et al., 2018). One such example is the Child and Family Health Service in South Australia - a strengthened universal intervention strategy currently being trialled (Jeyaseelan & Sawyer, 2017). The strategy seeks to improve parental recognition of typical and delayed development; knowledge of risk factors for and long-term consequences of delay; how to find developmental health information; and how to seek professional help; and empowering families to personally carry out interventions (Jeyaseelan & Sawyer, 2017).

The goal is to build parental developmental literacy to support noticing concerns through to help-seeking, with a particular emphasis on self-help beyond a reliance on professionals (Jeyaseelan & Sawyer, 2017). Similar efforts are being undertaken through the 'Learn the Signs. Act Early' campaign in the United States (Daniel et al., 2009). Such work has the potential to address many of the perceived knowledge barriers identified in this review.

A further finding of the current review was a perception that parents needed high parental self-efficacy to ensure they felt confident in accessing services. This appears to speak more to the nature and construction of services themselves – that services were not simple to access, and parents were not adequately supported to access them. A recent Australian study found that only 25% of surveyed mothers attended child and family health nursing appointments (Eapen et al., 2017), despite this service being designed as a major avenue of developmental surveillance and support (Australian Health Ministers Advisory Council, 2013). Other research has found that while high numbers of parents' accessed early postnatal visits, 40% did not currently access the service due to reasons including past negative experiences and not knowing what services were provided (Rossiter et al., 2019); historical distrust of services and experiences of culturally inappropriate care are particular barriers for Australian Aboriginal families (DiGiacomo et al., 2013) and families from culturally and linguistically diverse backgrounds (Woolfenden et al., 2015). Conversely, while in the U.S. approximately 90% of children under six attend well-child visits each year, research suggests that providers do not routinely ask about or screen for developmental concerns (Bethell et al., 2011; Guerrero et al., 2011). These collective findings challenge the early childhood sector to consider how they can more adequately support parents to identify and act on developmental concerns (Coker et al., 2013).

The HBM as an explanatory model needs some critique. Several of its components have not been sufficiently conceptualised (such as cues to action and self-efficacy), while a major criticism is that it does not sufficiently account for external factors such as environmental or economic (Jones et al., 2015; Jones et al., 2014). Without reference to such concepts, findings on motivational relevance must be viewed in the context of motivation theory, and what drives individual human behaviour versus socioecological influences relating to child developmental needs. Maslow's five-tier hierarchy of needs theorises that humans must meet ascending needs relating to physiology and survival, safety and security, belonging, and self-esteem to reach their 'full potential' (Maslow, 1943). If we consider 'full potential' in a developmental sense, then the ability to support a child's development firstly requires fundamental assurance of basic needs of food, water, shelter, safety (and consistency) (Maslow, 1943). Families who experience complex social issues, such as 'overwhelmed or historically disengaged parent' (Khan, 2013), cannot be separated from the factors that may undermine or hinder their ability to act, such as not having these basic needs met (Shannon, 2000). Additionally, the use of the HBM to predict direct effects on behaviour is not supported by evidence; instead, consideration of factors as a whole, including mediation and moderation among the variables is recommended (Carpenter, 2010). We caution against the interpretation of this review in a 'piece meal' way – component findings should be viewed holistically.

The review findings share parallels with frameworks proposed to explain parental engagement levels in child mental health services (Kazdin, Holland, Crowley, et al., 1997; Staudt, 2007). These frameworks highlight the influence of parent perceptions, such as cognitions and beliefs about treatment and level of treatment relevance or acceptability – as dictated by the HBM and identified in this review. The frameworks also consider more holistic aspects, including daily stresses families may experience, external barriers or obstacles to treatment (e.g. financial) and other critical elements such as job loss or relationship breakdown (Kazdin, Holland, Crowley, et al., 1997; Staudt, 2007). Future work should seek to explore whether engagement in EI may be viewed in a similar way.

A common finding across multiple studies was the mixed yet powerful emotional impact of suspected development delays on parents. However, not all studies explicitly explored or considered how parental emotional responses impacted their decision to act. This constitutes a significant gap in the current research evidence – there is a need to understand if and how such feelings influence both social norm perceptions and parent decision-making and actions, to thus enable the design of ways to support them.

Through extensive searching this review sought to include all relevant literature. However, it is possible that some work may have been overlooked. The focus of this review was on parental beliefs; we acknowledge the influence of the beliefs of others and the impact this can have on parent decisions to share and/or act on concerns. Future work should seek to incorporate the influence of others, as well as addressing wider ecological influences on help-seeking.

4.6 Conclusion

Parental perceptions of child developmental concerns are complex, multi-faceted, and can influence their decision to take action for suspected developmental delays. Drawing on aspects of the HBM can deepen our understanding of parents' unique perceptions and how these may influence help-seeking for developmental concerns. However, this must be seen as only one piece of the 'puzzle' in supporting parent access of EI services, recognising the need to understand broader ecological influences, including the accessibility of services themselves.

4.7 References

Ahern, K. (2000). "Something is wrong with my child": A phenomenological account of a search for a diagnosis. *Early Education and Development, 11*(2), 187-201. https://doi.org/10.1207/s15566935eed1102_4

Alexander, K., Brijnath, B., & Mazza, D. (2015). Parents' decision making and access to preventive healthcare for young children: Applying Andersen's Model. *Health Expectations, 18*, 1256-1269. https://doi.org/10.1111/hex.12100

Australian Health Ministers Advisory Council. (2013). *National framework for universal child and family health services*. https://www1.health.gov.au/internet/main/publishing.nsf/Content/AFF3C1C460BA5300CA257BF0001A8D86/$File/NFUCFHS.PDF

Baden, K. M. (2012). *Fathers' and mothers' experiences with participation in Part C of the Individuals with Disabilities Education Act early intervention process* (Publication Number ED551186) [Doctoral dissertation, Walden University]. ProQuest Dissertatations and Theses. https://eric.ed.gov/?id=ED551186

Barfield, W. D., Clements, K. M., Lee, K. G., Kotelchuck, M., Wilber, N., & Wise, P. H. (2008). Using linked data to assess patterns of Early Intervention (EI) referral among very low birth weight infants. *Maternal and Child Health Journal, 12*(1), 24-33. https://doi.org/10.1007/s10995-007-0227-y

Beno, C. (2017). *Receipt of an individual family service plan after reported childhood maltreatment: A mixed-methods inquiry* (Publication Number 10283512) [Doctoral dissertation, University of California]. ProQuest Dissertations and Theses. https://search.proquest.com/docview/1948877934

Bethell, C., Reuland, C., Schor, E., Abrahms, M., & Halfon, N. (2011). Rates of parent-centered developmental screening: disparities and links to services access. *Pediatrics, 128*(1), 146-155. https://doi.org/10.1542/peds.2010-0424

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Campbell, F., Conti, G., Heckman, J. J., Moon, S. H., Pinto, R., Pungello, E., & Pan, Y. (2014). Early childhood investments substantially boost adult health. *Science, 343*. https://doi.org/10.1126/science.1248429

Carpenter, C. J. (2010). A meta-analysis of the effectiveness of Health Belief Model variable in predicting behavior. *Health Communication, 25*, 661-669. https://doi.org/10.1080.10410236.2010.521906

Champion, V. L., & Skinner, C. S. (2008). The health belief model. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education: Theory, research and practice* (4th ed., pp. 45-66). Jossey-Bass.

Chung, C.-Y., Liu, W.-Y., Chang, C.-J., Chen, C.-L., Tang, S. F.-T., & Wong, A. M.-K. (2011). The relationship betwen parental concerns and final diagnosis in children with developmental delay. *Journal of Child Neurology, 26*(4), 413-419. https://doi.org/10.1177/0883073810381922

Coker, T. R., Thomas, T., & Chung, P. J. (2013). Does well-child care have a future in pediatrics? *Pediatrics, 131*(Suppl 2), S149-S159. https://doi.org/10.1542/peds.2013-0252f

Colgan, S. E. (2012). *The role of maternal depression in accessing early intervention services for children with developmental delay* (Publication Number ED551922) [Doctoral dissertation, University of North Carolina]. ProQuest Dissertations & Theses. https://eric.ed.gov/?id=ED551922

Coonrod, E. E., & Stone, W. L. (2004). Early concerns of parents of children with autistic and nonautistic disorders. *Infants & Young Children: An Interdisciplinary Journal of Early Childhood Intervention, 17*(3), 258-268. https://doi.org/10.1097/00001163-200407000-00007

Curtin, M., Madden, J., Staines, A., & Perry, I. J. (2013). Determinants of vulnerability in early childhood development in Ireland: A cross-sectional study. *BMJ Open, 3*, e002387. https://doi.org/10.1136/bmjopen-2012-002387

Daniel, K. L., Prue, C., Taylor, M. K., Thomas, J., & Scales, M. (2009). ‘Learn the signs. Act early’: A campaign to help every child reach his or her full potential. *Public Health, 123*(Suppl 1), e11-16. https://doi.org/10.1016/j.puhe.2009.06.002

Delgado, C. E. F., & Scott, K. G. (2006). Comparison of referral rates for preschool children at risk for disabilities using information obtained from birth certificate records. *The Journal of Special Education, 40*(1), 28-35. https://doi.org/10.1177/00224669060400010301

Department of Education and Training. (2019). *Australian early development census national report 2018*. https://www.aedc.gov.au/resources/detail/2018-aedc-national-report

DiGiacomo, M., Delaney, J., Abbott, P., Davidson, P. L., Delaney, J., & Vincent, F. (2013). ‘Doing the hard yards’: Carer and provider focus group perspective of accessing Aboriginal childhood disability services. *BMC Health Services Research, 13*(326). https://doi.org/10.1186/1472-6963-13-326

Doyle, O., Harmon, C. P., Heckman, J. J., & Tremblay, R. E. (2009). Investing in early human development: Timing and economic efficiency. *Economics & Human Biology, 7*(1), 1-6. https://doi.org/10.1016/j.ehb.2009.01.002

Eapen, V., Walter, A., Guan, J., Descallar, J., Axelsson, E., Einfeld, S., Eastwood, J., Murphy, E., Beasley, D., Silove, N., Dissanayake, C., Woolfenden, S., Williams, K., Jalaludin, B., & The 'Watch Me Grow' Study, G. (2017). Maternal help-seeking for child developmental concerns: Associations with socio-demographic factors. *Journal of Paediatrics and Child Health*. https://doi.org/10.1111/jpc.13607

Ellingson, K. D., Briggs-Gowan, M. J., Carter, A. S., & Horwitz, S. M. (2004). Parent identification of early emerging child behavior problems: Predictors of sharing parental concern with health providers. *JAMA Pediatrics, 158*(8), 766-772. https://doi.org/10.1001/archpedi.158.8.766

Feinberg, E., Donahue, S., Bliss, R., & Silverstein, M. (2012). Maternal depressive symptoms and participation in early intervention services for young children. *Maternal and Child Health Journal, 16*(2), 336-345. https://doi.org/10.1007/s10995-010-0715-3

Finan, S. J., Swierzbiolek, B., Priest, N., Warren, N., & Yap, M. (2018). Parental engagement in preventive programs for child mental health: A systematic review of predictors and strategies to increase engagement. *Peer J, 6*(e4676). https://doi.org/10.7717/peerj.4676

Giordano, K. (2008). *Barriers to early intervention services in New Jersey* [Doctoral dissertation, Fairleigh Dickinson University]. ProQuest Dissertations & Theses. http://dbgw.lis.curtin.edu.au:2048/login?url=https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/304403224?accountid=10382

Glanz, K., & Schwartz, M. D. (2008). Stress, coping, and health behaviour. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education: Theory, research and practice* (4th ed., pp. 211-236). Jossey-Bass.

Glaun, D. E., Cole, K. E., & Reddihough, D. S. (1998). Six month follow-up: the crucial test of multidisciplinary developmental assessment. *Child: Care, Health and Development, 24*(6), 457-472. https://doi.org/10.1046/j.1365-2214.1998.00082.x

Glogowska, M., & Campbell, R. (2004). Parental views of surveillance for early speech and language difficulties. *Children and Society, 18*(4), 266-277. https://doi.org/10.1002.CHI.806

Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P. M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services. *BMC Health Services Research, 16*(1), 680. https://doi.org/10.1186/s12913-016-1926-0

Guerrero, A. D., Rodriguez, M. A., & Flores, G. (2011). Disparities in provider elicitation of parents' developmental concerns for US children. *Pediatrics, 128*(5), 901-909. https://doi.org/10.1542/peds.2011-0030

Hebbeler, K., Spiker, D., Bailey, D. B., Scarborough, A., Mallik, S., Simeonsson, R. J., Singer, M., & Nelson, L. (2007). *Early intervention for infants and toddlers with disabilities and their families: Participants, services, and outcomes*. SRI International. https://www.sri.com/wp-content/uploads/pdf/neils_finalreport_200702.pdf

Heckman, J. J. (2006). Skill formation and the economics of investing in disadvantaged children. *Science, 312*(5782), 1900-1902. https://www.jstor.org/stable/3846426

Heckman, J. J., & Krueger, A. B. (2003). *Inequality in America: What role for human capital policies?* MIT Press.

Hendrickson, S., Baldwin, J. H., & Allred, K. W. (2000). Factors perceived by mothers as preventing families from obtaining early intervention services for their children with special needs. *Children's Health Care, 29*(1), 1-17. https://doi.org/10.1207/S15326888CHC2901_1

Human Early Learning Partnership. (2016). *EDI [Early Years Development Instrument] British Colombia: 2016 Provincial Report*. University of British Colombia School of Population and Public Health. http://earlylearning.ubc.ca/media/edibc2016provincialreport.pdf

Jacobson Vann, J. C., Finkle, J., Ammerman, A., Wegner, S., Cockrell Skinner, A., Benjamin, J. T., & Perrin, E. M. (2011). Use of a tool to determine perceived barrirs to children’s healthy eating and physical activity and relationships to health behaviours. *Journal of Pediatric Nursing, 26*, 404-415. https://doi.org/10.1016/j.pedn.2010.10.011

Jeyaseelan, D. C., & Sawyer, M. G. (2017). Developmental literacy: A universal intervention to help children with developmental disorders. *Journal of Paediatrics and Child Health, 53*, 101-104. https://doi.org/10.1111/jpc.13456

Jimenez, M. E., Barg, F. K., Guevara, J. P., Gerdes, M., & Fiks, A. G. (2012). Barriers to evaluation for early intervention services: parent and early intervention employee perspectives. *Academic pediatrics, 12*(6), 551-557. https://doi.org/10.1016/j.acap.2012.08.006

Jimenez, M. E., DuRivage, N. E., Bezpalko, O., Suh, A., Wade, R., Blum, N. J., & Fiks, A. G. (2017). A pilot randomized trial of a video patient decision aid to facilitate early intervention referrals from primary care. *Clinical Pediatrics, 56*(3), 268-277. https://doi.org/10.1177/0009922816677038

Johnson, J. F. (2011). *An evaluation of the Early Steps Program referral process in Hillsborough County to detect delays in access to early intervention services* (Publication Number 2012-99080-337) [Doctoral dissertation, University of South Florida]. Scholar Commons. http://scholarcommons.usf.edu/etd/3171

Jones, C. J., Jensen, J. D., Scherr, C. L., Brown, N. R., Christy, K., & Weaver, J. (2015). The health belief model as an explantory framework in communication research: Exploring parallel, serial and moderated mediation. *Health Communication, 30*(6), 566-676. https://doi.org/10.1080/10410236.2013/873363

Jones, C. J., Smith, H., & Llewellyn, C. (2014). Evaluating the effectiveness of health belief model interventions in improving adherence: A systematic review. *Health Psychology Review, 8*(3), 253-269. https://doi.org/10.1080/17437199.2013.802623

Kazdin, A. E., Holland, L., Crowley, M., & Breton, S. (1997). Barriers to treatment participation scale: Evaluation and validation in the context of child outpatient treatment. *Journal of Child Psychology and Psychiatry, 38*(8), 1051-1062. https://doi.org/10.1111/j.1469-7610.1997.tb01621.x

Khan, L. P., Michael; Elena Rosa, Brown. (2013). Parenting programmes: identification and referral. *Journal of Children's Services, 8*(3), 194-208. https://doi.org/10.1108/JCS-03-2013-0011

Kummerer, S. E., & Lopez-Reyna, N. A. (2009). Engaging Mexican immigrant families in language and literacy interventions: Three case studies. *Remedial and Special Education, 30*(6), 330-343. https://doi.org/10.1177/0741932508321014

Lalbeharie-Josias, D. P. (2001). *Parents' perceptions of the individualized family service plan* (Publication Number AAI3012154) [Doctoral thesis, University of Massachusetts Amherst]. ProQuest Dissertations & Theses Global. https://scholarworks.umass.edu/dissertations/AAI3012154

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Press.

Leiter, V. R. (2001). *Gentle intrusions: Family-centered care in early intervention* (Publication Number 3004966) [Doctoral dissertation, Brandeis University]. ProQuest Dissertations & Theses Global. https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/304681652?pq-origsite=summon

Magnusson, D. M., Minkovitz, C. S., Kuhlthau, K. A., Caballero, T. M., & Mistry, K. B. (2017). Beliefs regarding development and early intervention among low-income African American and Hispanic mothers. *Pediatrics, 140*(5). https://doi.org/http://dx.doi.org/10.1542/peds.2017-2059

Marshall, J. (2013). *Parent pathways: Recognition and responses to developmental delays in young children: A mixed-methods exploratory study* [Doctoral dissertation, University of South Florida]. Scholar Commons. http://scholarcommons.usf.edu/etd/4534

Marshall, J., Adelman, A., Kesten, S. M., Natale, R. A., & Elbaum, B. (2017). Parents' experiences navigating intervention systems for young children with mild language delays. *Journal of Early Intervention, 39*(3), 180-198. https://doi.org/10.1177/1053815117704958

Marshall, J., Coulter, M. L., & Gorski, P. A. (2016). Parent recognition and responses to developmental concerns in young children. *Infants and Young Children, 29*(2), 102-115. https://doi.org/10.1097/IYC.0000000000000056

Marshall, J., Goldbart, J., & Phillips, J. (2007). Parents' and speech and language therapists' explanatory models of language development, language delay and intervention. *International Journal of Language & Communication Disorders, 42*(5), 533-555. https://doi.org/10.1080/13682820601053753

Marshall, J., Kirby, R. S., & Gorski, P. A. (2016). Parent concern and enrollment in intervention services for young children with developmental delays: 2007 National survey of children's health. *Exceptional Children, 82*(2), 251-268. https://doi.org/10.1177/0014402915585563

Maslow, A. (1943). A theory of human motivation. *Psychological Review, 50*, 370-396. https://doi.org/10.1037/h0054346

Masse, L. N., & Barnett, W. S. (2002). *A benefit cost analysis of the Abecedarian early childhood intervention*. National Institute for Early Education Research. https://files.eric.ed.gov/fulltext/ED479989.pdf

McAllister, L., McCormack, J., McLeod, S., & Harrison, L. J. (2011). Expectations and experiences of accessing and participating in services for childhood speech impairment. *International Journal of Speech-Language Pathology, 13*(3), 251-267. https://doi.org/10.3109/17549507.2011.535565

McManus, B. M., Robert, S., & Albanese, A. (2013). Predictors of receiving therapy among very low birth weight 2-year olds eligible for Part C early intervention in Wisconsin. *BMC pediatrics, 13*. https://doi.org/10.1186/1471-2431-13-106

Mills, I. S., Doyle, L. W., Cheong, J. L., & Roberts, G. (2018). Rates of early intervention services in children born extremely preterm/extremely low birthweight. *Journal of Pediatrics and Child Health, 54*(1), 74-79. https://doi.org/10.1111/jpc.13668

Missiuna, C., Moll, S., Law, M., King, S., & King, G. (2006). Mysteries and mazes: Parents' experiences of children with developmental coordination disorder. *Canadian Journal of Occupational Therapy, 73*(1), 7-17. https://doi.org/10.2182/cjot.05.0010

Morton, D. S. (2012). *Parental descriptions of awareness and associated reactions to developmental delay in children* (Publication Number AAI3545470) [Doctoral dissertation, Capella University]. ProQuest Dissertations & Theses Global. https://www-proquest-com.dbgw.lis.curtin.edu.au/docview/1520325243/B7F1BC2997EB4B37PQ/1?accountid=10382

Mughal, M. K., Giallo, R., Arnold, P. D., Kehler, H., Bright, K., Benzies, K., Wajid, A., & Kingston, D. (2019). Trajectories of maternal distress and risk of child developmental delays: Findings from the All Our Families (AOF) pregnancy cohort. *Journal of Affective Disorders, 248*, 1-12. https://doi.org/10.1016/j.jad.2018.12.132

Mulcahy, H., & Savage, E. (2016). Uncertainty: A little bit not sure. Parental concern about child growth or development. *Journal of Child Health Care, 20*(3), 333-343. https://doi.org/10.1177/1367493515587059

Nelson, B. B., Chung, P. J., DuPlessis, H. M., Flores, L., Ryan, G. W., & Kataoka, S. H. (2011). Strengthening families of children with developmental concerns: Parent perceptions of developmental screening and services in Head Start. *Ethnicity & disease, 21*(3 Suppl 1), S1-89-93. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3715307/

Nielsen, A. M. (2014). *The role of interactive and critical health literacy in appointment cancellations: A quality assurance survey* [Master's thesis, The University of Wisconsin - Milwaukee]. ProQuest Central; ProQuest Dissertations & Theses Global. https://dc.uwm.edu/etd/740

Offord Centre for Child Studies. *Early Development Instrument in Ontario over time*. McMaster University. https://edi.offordcentre.com/partners/canada/edi-in-ontario/

Persoff, J. R. (1998). *Poverty and early childhood developmental delay: Perspectives from Hispanic mothers* [Doctoral dissertation, University of Denver]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/304432454?accountid=10382

Peters, M. D. J., Godfrey, c., McInerney, P., Baldini Soares, C., Khalil, H., & Parker, D. (2017). Chapter 11: Scoping reviews. In E. Aromataris & Z. Munn (Eds.), *Joanna Briggs Institute Reviewer's Manual*. The Joanna Briggs Institute. https://reviewersmanual.joannabriggs.org/

Peterson, C. A., Wall, S. M., Raikes, H. A., Kisker, E. E., Swanson, M. E., Jerald, J., Atwater, J. B., & Qiao, W. (2004). Early head start: Identifying and serving children with disabilities. *Topics in Early Childhood Special Education, 24*(2), 76-88.

https://digitalcommons.unl.edu/cgi/viewcontent.cgi?referer=https://www.google.com/&httpsredir=1&article=1041&context=famconfacpub

Pevalin, D. J., Wade, T. J., & Brannigan, A. (2003). Parental assessment of early childhood development: biological and social covariates. *Infant and Child Development, 12*(2), 167-175. https://doi.org/10.1002/icd.285

Plath, D., Crofts, P., & Stuart, G. (2016). Engaging families in early intervention for child conduct doncerns. *Children Australia, 41*(1), 49-58. https://doi.org/10.1017/cha.2015.5

Porter, N., & Ispa, J. M. (2013). Mothers' online message board questions about parenting infants and toddlers. *Journal of Advanced Nursing, 69*(3), 559-568. https://doi.org/10.1111/j.1365-2648.2012.06030.x

Pratt, A. V. (2012). *Two worlds collide: Caregiver perceptions of their interactions with Help Me Grow home visitors* [Doctoral dissertation, University of Minnesota]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/1027763731?accountid=10382

Pritchard, M. A., Colditz, P. B., Cartwright, D., Gray, P. H., Tudehope, D., & Beller, E. (2013). Risk determinants in early intervention use during the first postnatal year in children born very preterm. *BMC pediatrics, 13*, 201-201. https://doi.org/10.1186/1471-2431-13-201

Ramirez, M. C. (2004). *Latino parents with developmentally delayed children: Perceptions of early intervention services* [Master's thesis, California State University]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/305036959?pq-origsite=gscholar

Rannard, A., Lyons, C., & Glenn, S. (2004). Children with specific language impairment: Parental accounts of the early years. *Journal of Child Health Care, 8*(2), 165-176. https://doi.org/10.1177/1367493504041875

Raspa, M., Levis, D. M., Kish-Doto, J., Wallace, I., Rice, C., Barger, B., Green, K. K., & Wolf, R. B. (2015). Examining parents' experiences and information needs regarding early identification of developmental delays: Qualitative research to inform a public health campaign. *Journal of Developmental & Behavioral Pediatrics, 36*(8), 575-585. https://doi.org/10.1097/DBP.0000000000000205

Restall, G., & Borton, B. (2010). Parents' concerns about their children's development at school entry. *Child: Care, Health and Development 36*(2), 208-215. https://doi.org/10.1111/j.1365-2214.2009.01019.x

Rosenberg, S. A., Zhang, D., & Robinson, C. C. (2008). Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics, 121*(6), e1503-1509. https://doi.org/10.1542/peds.2007-1680

Rosenstock, I. M. (1966). Why people use health services. *Milbank Memorial Fund Quarterly, 44*, 94-124.

Rosenstock, I. M. (1974). Historical origins of the Health Belief Model. *Health Education Monographs, 2*, 328-335.

Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social learning theory and the Health Belief Model. *Health Education Quarterly, 15*(2), 175-183.

Rossiter, C., Fowler, C., Hesson, A., Kruske, S., Homer, C. S. E., & Schmied, V. (2019, 2019/03/01). Australian parents' use of universal child and family health services: A consumer survey. *Health & social care in the community, 27*(2), 472-482. https://doi.org/10.1111/hsc.12667

Schmidt, K. R. T. (2013). *Predictors of parent involvement in Part C early intervention services* [Doctoral dissertation, University of Maryland]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/1399598995?accountid=10382

Schumarker-Murphy, M. (2019). *Fathers' experiences in early intervention: Marooned in the kitchen or member of the team* [Doctoral dissertation, DePaul University]. ProQuest Dissertations and Theses. https://search.proquest.com/openview/26116c4b74bea79c34fd3b4aac10ee77/1?pq-origsite=gscholar&cbl=18750&diss=y

Schweinhart, L. J., Montie, J., Xiang, Z., Barnett, W. S., Belfield, C. R., & Nores, M. (2005). *Lifetime effects: The high/scope Perry Preschool study through age 40*. H. S. Press.

Shah, R., Sobotka, S. A., Chen, Y.-F., & Msall, M. E. (2015). Positive parenting practices, health disparities, and developmental progress. *Pediatrics, 136*(2), 318. https://doi.org/10.1542/peds.2014-3390

Shannon, P. (2000). *Family-centered practice in early intervention services for infants and toddlers: The experience of families and professionals in one Local Interagency Coordinating Council* [Doctoral dissertation, Virginia Commonwealth University]. ProQuest Dissertations & Theses Global. https://scholarscompass.vcu.edu/etd/5304/

Sices, L., Egbert, L., & Mercer, M. B. (2009). Sugar-coaters and straight talkers: communicating about developmental delays in primary care. *Pediatrics, 124*(4), e705-713. https://doi.org/10.1542/peds.2009-0286

Silbersack, E. W. (2014). *Mothers' initial discovery of childhood disability: Exploring maternal identification of developmental issues in young children* [Doctoral dissertation, Adelphi University]. ProQuest Dissertations & Theses Global. https://eric.ed.gov/?id=ED557029

Smith, E., Koerting, J., Latter, S., Knowles, M. M., McCann, D. C., Thompson, M., & Sonuga-Barke, E. J. (2015). Overcoming barriers to effective early parenting interventions for attention-deficit hyperactivity disorder (ADHD): Parent and practitioner views. *Child: Care, Health and Development, 41*(1), 93-102. https://doi.org/10.1111/cch.12146

Smith, L. E., Akai, C. E., Klerman, L. V., Keltner, B. R., & The Centers for the Prevention of Child, N. (2010). What mothers don't know and doctors don't say: Detecting early developmental delays. *Infant Mental Health Journal, 31*(4), 455-466. https://doi.org/10.1002/imhj.20266

Smith, P., Humiston, S. C., Marcuse, E., Zhao, Z., Dorell, C. G., Howes, C., & Hibbs, B. (2011). Parental delay or refusal of vaccine doses, childhood vaccination coverage at 24 months of age, and the Health Belief Model. *Public Health Reports, 126*, 135-146. https://doi.org/10.1177/00333549111260S215

Staudt, M. (2007). Treatment engagement in caregivers of at-risk children: Gaps in research and conceptualization. *Journal of Child and Family Studies, 16*, 183-196. https://doi.org/10.1007/s10826-006-9077-2

Tervo, R. C. (2005). Parent’s reports predict their child’s developmental problems. *Clinical Pediatrics, 44*(7), 601-611. https://doi.org/10.1177/000992280504400708

Tricco, A. C., Lillie, E., Zarin, W., O’Brien, K. K., Colquhoun, H., Levac, D., Moher, d., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., Lewin, S., Godfrey, C. M., Mcdonald, M. T., Langlois, E. V., Soares-Weiser, K., Moriarty, J., Clifford, T., Tuncalp, O., & Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine, 169*(7), 467-473. https://doi.org/10.7326/M18-0850

United Nations. (2019). *World Economic Situation and Prospects 2019*. https://www.un.org/development/desa/dpad/wp-content/uploads/sites/45/WESP2019_BOOK-web.pdf

Wall, S. M., Taylor, N. E., Liebow, H., Sabatino, C. A., Mayer, L. M., Farber, M. Z., & Timberlake, E. M. (2005). Early Head Start and access to early intervention services: a qualitative investigation. *Topics in Early Childhood Special Education, 25*(4), 218-231. https://doi.org/10.1177/02711214050250040301

Wang, C. J., Elliott, M. N., Rogowski, J., Lim, N., Ratner, J. A., & Schuster, M. A. (2009, Jul-Aug). Factors influencing the enrollment of eligible extremely-low-birth-weight children in the part C early intervention program. *Academic Pediatrics 9*(4), 283-287. https://doi.org/10.1016/j.acap.2009.04.001

Williams, J. (2007). Learning from mothers: how myths, policies and practices affect the detection of subtle developmental problems in children. *Child: Care, Health and Development, 33*(3), 282-290. https://doi.org/10.1111/j.1365-2214.2006.00690.x

Williams, J., & Holmes, C. A. (2004). Improving the early detection of children with subtle developmental problems. *Journal of Child Health Care, 8*(1), 34-46. https://doi.org/10.1177/13674950401852

Woolfenden, S., Posada, N., Krchnakova, R., Crawford, J., Gilbert, J., Jursik, B., Sarkozy, V., Perkins, D., & Kemp, L. (2015). Equitable access to developmental surveillance and early intervention - understanding the barriers for children from culturally and linguistically diverse (CALD) backgrounds. *Health Expectations, 18*(6), 3286-3301. https://doi.org/10.1111/hex.12318

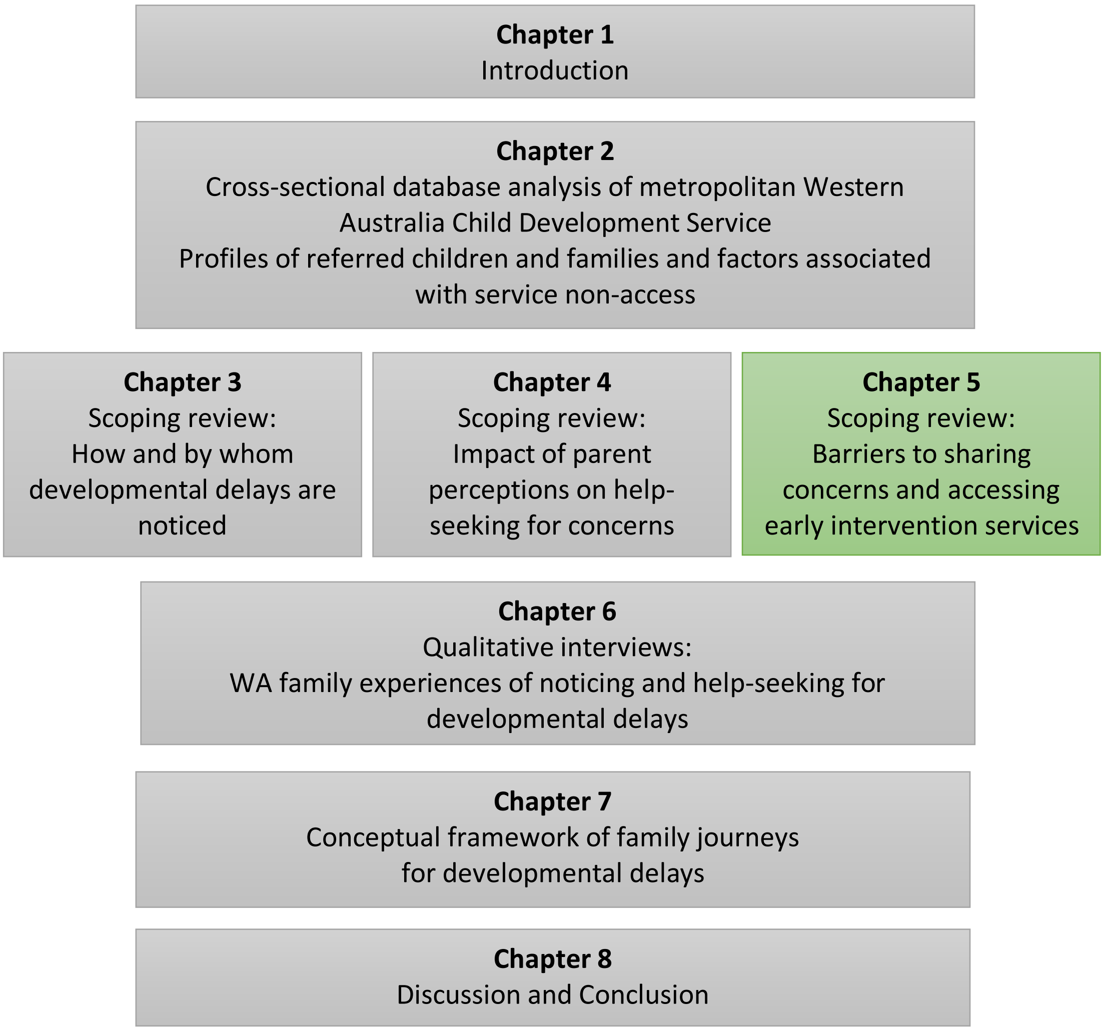
Worcester, J. (2005, 2005). Giving voice to parents of young children with challenging behavior. *Exceptional Children, 74*(4), 509-525. https://doi.org/10.1177/001440290807400406

World Health Organization, United Nations Children's Fund, & World Bank Group. (2018). *Nurturing care for early childhood development: A framework for helping children survive and thrive to transform health and human potential*. https://www.who.int/maternal_child_adolescent/child/nurturing-care-framework/en/

Chapter 5 Barriers to service access

Chapter 4 utilised the Health Belief Model to understand parental perceptions and their impact on help-seeking for their child with suspected developmental delays. We have gained knowledge of the myriad of perceived barriers and benefits, perceptions of susceptibility and severity, motivational relevance, self-efficacy, and family factors that may influence family help-seeking.

This final review focuses on what happens when parents do take the ultimate leap of help-seeking, through sharing concerns with others and attempting to access services. Chapter 5 utilises an established health access framework to unpack current research on both family and service barriers to health service access.



Caregiver experiences of barriers to accessing developmental early intervention services: A scoping review

5.1 Abstract

Significant disparities have been documented between rates of parental concerns about child development and the seeking out of services and supports, with a mismatch between numbers of children identified, referred for and accessing support for developmental delays While families need to firstly be ‘aware’ of developmental delays to initiate the process of help-seeking, they need to secondly be ‘able’ to access early intervention (EI) services themselves – a process that is reported to be problematic. A scoping review was undertaken to summarise research on the barriers families experience in accessing EI services for children with developmental delays via a scoping review. A systematic key-word database search was conducted, with 45 studies meeting inclusion criteria. Extracted data were thematically analysed. Framed using Levesque’s framework of access to health care, findings identified barriers across different elements of family journeys – from initial perceptions of needs and desires for care; health care seeking, ‘reaching’ of services themselves, health care utilisation, and consequences. It is critical that EI services and the sector more broadly reflect and ensure they are taking a genuine family-centred approach that is responsive and flexible to family needs and address the unique barriers that individual families experience.

5.2 Introduction

The United Nations Convention on the Rights of the Child dictates that "every child has the inherent right to life", and that "parties shall ensure to the maximum extent possible the survival and development of the child" (United Nations, 1990, p. 3). The Convention furthers this, by recognising "the right of the disabled child to special care" such as education, health and rehabilitation services to support the achievement of their fullest individual development – such as through early intervention (EI) (United Nations, 1990, p. 7). Despite this, significant disparities have been documented between rates of parental concerns about child development and the seeking out of services and supports, with a mismatch between numbers of children identified, referred for and accessing support for developmental delays (Hebbeler et al., 2007; McManus et al., 2009; Rosenberg et al., 2013). For example, population-based data from the United States (U.S.) suggest that despite 39% of parents reporting their child aged 0-5 years experienced one or more developmental concerns, less than 5% of the sample engaged with developmental services (Marshall, Kirby, et al., 2016). Nation-wide analysis identified that while between 2-78% of young children across the U.S. may have been eligible for EI services, only 1.48-6.96% accessed the services (Rosenberg et al., 2013). Australian data depict a similar picture of unmet need; a 2012 population-level study identified that 18% of children were classed as developmentally vulnerable – yet only 15% of this group had attended EI services (Goldfeld et al., 2012).

Researchers in EI have traditionally sought to understand who these so-called "hard-to-reach" families are, through identifying child, family, and/or community risk factors that negatively impact their services access (Chin & Teti, 2013; Clements et al., 2008; Giannoni & Kass, 2010; Pritchard et al., 2013; Shapiro & Derrington, 2004). The use of 'hard-to-reach' as a label for populations who do not access traditional services has however been criticised in recent years; as a term used almost exclusively by services as opposed to service users, as well as placing emphasis on the individual and framing the access to services as a service user's responsibility (Cortis et al., 2009). Such a focus on the individual fails to consider the role and responsibility of services in access, and the barriers within service delivery that may preclude or undermine the ability for individuals to access them (Cortis et al., 2009; Doherty et al., 2003). There is an increasingly strong narrative from the research community to better understand what makes families 'hard-to-reach' in the first place (Phoenix & Rosenbaum, 2019), and to place the onus on services to provide accessible services for all families.

The scoping reviews of Chapters 3 and 4 provided the context to understand the initial aspects of family journeys to EI services, from how they begin to notice suspected developmental delays (Cuomo et al., 2019) and how parent beliefs may impact how delays are viewed and thus acted upon. While families need to firstly be 'aware' of developmental delays to initiate the process of help-seeking, they need to secondly be 'able' to access services themselves – a process that is reported to be problematic (McAllister et al., 2011). Throughout much of the developmental delay literature parents report that the process of referral and entry into EI services is confusing, complex, and challenging (Marshall et al., 2017; McAllister et al., 2011; Shannon, 2000; Wall et al., 2005). Families who do access services and families who do not access services experience barriers to access, with those who did not ultimately access the services being more likely to identify multiple barriers (Giordano, 2008). A 2017 systematic review sought to identify factors related to EI access, however, focused specifically on the impact of EI policy (Twardzik et al., 2017). What is missing in EI literature is a collective understanding of barriers to service access that is based on the experiences of families. The current study aimed to systematically identify and summarise research on the barriers families experience in accessing EI services for children with developmental delays.

5.3 Methods

5.3.1 Design

A scoping review design was selected to enable a systematic search and inclusion of current evidence from diverse sources and methodologies (Peters et al., 2017). The Joanna Briggs Institute scoping review protocol (Peters et al., 2017) and PRISMA-ScR checklist for scoping reviews (Tricco et al., 2018) were followed.

5.3.2 Search strategy

A systematic search was conducted in August 2019 of major academic databases (ProQuest, ScienceDirect, CINAHL, Ovid and Sage) and grey literature sources (Google scholar, Trove, Mednar, and Agency for Healthcare Research and Quality). Search terms included: "(child OR toddler OR p*diatric OR baby OR infant) AND (developmen* OR delay OR at-risk OR milestones) AND (identif* OR notic* OR recogni* OR refer* OR participat* OR engag* OR access OR knowledge) AND early intervention". Hand-searching of relevant maternal and child health-focused journals as well as citation tracking was conducted to identify any further literature.

5.3.3 Study selection

The criteria for study inclusion incorporated the following: 1) population of interest was families of children with or at-risk of suspected developmental delays or concerns; 2) studies focused on parent experiences of seeking support for their child's developmental concerns; 3) published in English; and 4) conducted in developed economies (United Nations, 2019); published from 1998-2019. There were no restrictions on study design as per scoping review guidelines (Peters et al., 2017). All database results were screened at title and abstract level against each inclusion criteria, with those meeting requirements extracted for full-text appraisal – see Figure 5-1 PRISMA diagram for a breakdown. A random selection of 20% of abstracts identified for full-text extraction were independently read and then discussed between all authors to ensure consistent application of inclusion criteria.

5.3.4 Data extraction

Article data were extracted by the first author under the headings of author/s, year of publication, country of origin, aims/purpose, study population and sample size, methodology, and findings. As the aim was to identify the breadth of the literature and resulting themes (and in line with scoping review guidelines (Peters et al., 2017; Tricco et al., 2018), a quality assessment of the articles was not undertaken. Braun and Clarke's six-phase guide to thematic analysis (Braun & Clarke, 2006) was utilised to synthesise findings, consisting of: familiarity with the data set; generating initial codes; searching for themes; reviewing themes (and producing a thematic 'map'); defining and naming themes; and producing the analytical report.

The conceptual framework of access to health care created by Levesque et al. (2013) was used to structure findings. This framework conceptualises access as a pathway with different journey points, from the initial recognition of health care needs through to health care seeking and ultimately, health care utilisation (Levesque et al., 2013). Transitions between each 'step' in this pathway may present new or unique barriers. There are five dimensions relating to the accessibility of health care services – approachability, acceptability, availability, affordability and appropriateness. In this framework five corresponding 'abilities' of people interact with the dimension of accessibility to generate access. The five corollary dimensions of abilities include the ability to: perceive; seek; reach; pay; and engage (Levesque et al., 2013). The framework of access to health care has been widely utilised across different health care populations to frame literature reviews, as a basis for proposed access frameworks, and/or to structure outcome measurement for interventions to improve healthcare access (Archambault et al., 2020; Foo et al., 2020; Russell et al., 2019).

5.4 Results

Forty-five studies were identified, consisting of 30 peer-reviewed articles, 13 dissertations and two reports – see Figure 5-1 for PRISMA diagram and

Table 5.1 for an overview of included studies. Study methodologies consisted of qualitative interviews (*n* = 27), focus groups (*n* = 3), cross-sectional surveys (*n* = 5), case studies (*n* = 2), longitudinal cohort or prospective studies (*n* = 3), or mixed methods (*n* = 5). The research was predominantly conducted in the United States (U.S.) (*n* = 29) but also included work from Australia (*n* = 9), Canada (*n* = 3) and the United Kingdom (U.K.) (*n* = 4).

Barriers to service access were identified to occur across different points of family journeys, as well as being about both families themselves and services and systems they were engaging with – consistent with Levesque et al. (2013)'s access to health care framework. Findings are presented per Levesque's framework structure – perceptions of needs and desire for care (family ability to perceive, service approachability), health care seeking (family ability to seek, service acceptability), health care reaching (family ability to reach, service availability and accommodation), and health care utilisation (family ability to pay, service affordability), and health care consequences (family ability to engage, service appropriateness). See Figure 5-2 for an overview of findings.

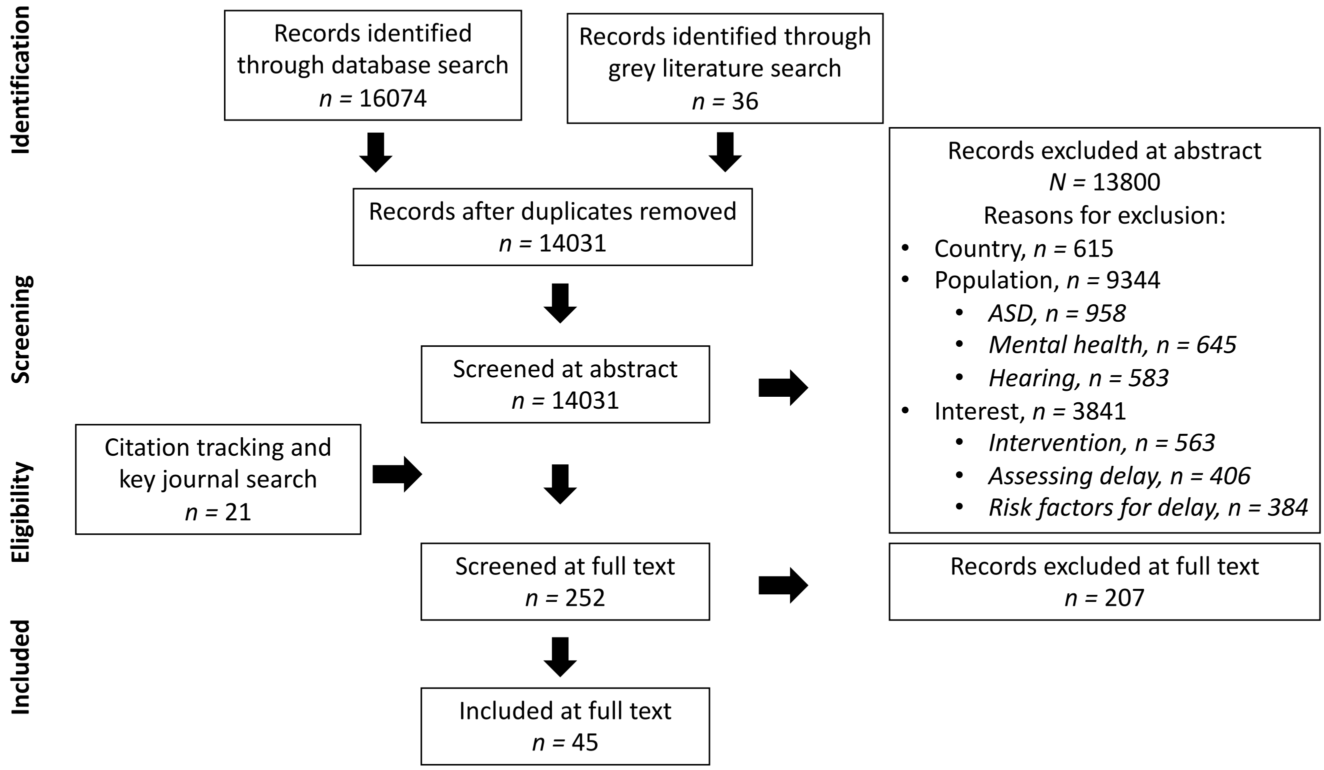


Figure 5-1 PRISMA diagram

Table 5.1 Summary of included studies

Citation	Country of origin	Study design	Participants/Data Source	Aims/Interest
Ahern (2000)	Australia	Article; qualitative interviews	Parents of children with movement difficulties (*N* = 11)	Parent experience of attempts to seek diagnosis for their children
Alexander et al. (2015)	Australia	Article; qualitative interviews	Parents of children 3-5 years from diverse socioeconomic backgrounds (*N* = 28)	Understanding parent access of preventive health care services for child development
Baden (2012)	United States	Dissertation; qualitative interviews	Parents of children with developmental delays participating in EI services (*N* = 20)	Exploring different experiences of mothers and fathers in participation in EI (n = 20)
Eapen et al. (2017)	Australia	Article; longitudinal birth cohort follow-up	Parents of children recruited from postnatal wards (*N* = 2025)	Maternal help-seeking for child developmental concerns
Felt and O'Connor (2003)	United States	Article; quasi-experimental, pre-post questionnaire	Parents of children 15-47 months attending a primary care clinic (*N* = 257)	Assess the use of a parent questionnaire to increase parent identification and discussion of behavioural concerns
Garcia (2015)	United States	Dissertation; cross-sectional survey	Parents of children born prematurely (*N* = 148)	Barriers to EI access and participation for parents of premature children

Citation	**Country of origin**	**Study design**	**Participants/Data Source**	**Aims/Interest**
Gerlach et al. (2017)	Canada	Article; qualitative interviews	Indigenous primary caregivers of children accessing the Aboriginal Infant Development Program (*N* = 10)	Explore impact of AIDP on family and child health and well-being
Giordano (2008)	United States	Dissertation; quantitative cross-sectional survey	Parents of children with developmental delays or disability who had (*n* = 70) and had not (*n* = 29) accessed EI services	Explore barriers that prevent families from accessing EI – and differences and similarities in barrier perceptions between families who did and did not access EI
Glaun et al. (1998)	United States	Article; quantitative descriptive prospective study. Six-month follow up using self-report (standardised measures, questionnaires)	Dyads of parents and pre-school age children with complex developmental delays referred for developmental assessment (*N* = 40)	Assess mothers' recall of their child diagnosis and opinion on its correctness; examine attitudes on treatment recommendations; explore reasons that prevented families from following recommendations
Glogowska and Campbell (2004)	United Kingdom	Article; qualitative interviews	Parents of children with expressive speech issues (*N* = 20)	Parent experiences of developmental surveillance for early language difficulties

Citation	**Country of origin**	**Study design**	**Participants/Data Source**	**Aims/Interest**
Green et al. (2016)	Australia	Article; qualitative interviews	Primary carers of Aboriginal children aged 0-8 years with developmental delay, attending a child development clinic (*N* = 19)	Aboriginal and Torres Strait Islander parent experiences of accessing child development services
Hebbeler et al. (2007)	United States	Report; longitudinal study; structured family telephone surveys and service records	Nationally representative sample of children who entered EI (*N* = 3338)	Families experiences in beginning EI
Hendrickson et al. (2000)	United States	Article; qualitative interviews	Mothers of children aged 3+years of age with developmental delays, who had not accessed birth-two years EI services (*N* = 13)	Experience of mothers of children with developmental delay who experienced barriers to accessing EI service
Jimenez et al. (2012)	United States	Article; qualitative interviews	Parents of children referred for EI services (*N* = 44)	Understand parent experiences with EI referral process in relation to their health literacy levels
Khan (2013)	United Kingdom	Article; mixed methods (qualitative interviews, cross-sectional survey)	Parents referred to parenting programs for child behavioural concerns (*N* = 44);	Understanding reasons parents seek support for behavioural concerns; differences between parents in their willingness to seek help; barriers to identifying support needs

Citation	**Country of origin**	**Study design**	**Participants/Data Source**	**Aims/Interest**
Kummerer and Lopez-Reyna (2009)	United States	Article; series of instrumental case studies –interviews, file reviews, field notes and parent journals	Mexican immigrant families with children with speech/language difficulties; (*N* = 14) with *n* = 3 presented	Perceptions and practices of Mexican immigrant mothers in supporting the language and literacy of their child with communication difficulties
Lalbeharie-Josias (2001)	United States	Dissertation. Series of in-depth interviews, phenomenological case-methods approach	Parents of children (*N* = 14) with developmental delays or disability (excluded those with disability; used sample of *n* = 5)	Exploration of parents' experiences and perceptions of the individualized family service plan (early intervention)
Leiter (2001)	United States	Dissertation; qualitative interviews	Parents of children with developmental delays aged 0-3 years accessing EI services (*N* = 31)	Examine how family-centred care is implemented by individual families and EI professionals
Magnusson et al. (2017)	United States	Article; semi-structured in-depth interviews, inductive content analysis	African American (*n* = 8) and Hispanic (*n* = 14) mothers of children aged 0-36 months with developmental delay	Understand the role of health beliefs in shaping maternal decisions regarding help-seeking for children with developmental delays. Explore differences between African American and Hispanic mothers

Citation	Country of origin	Study design	Participants/Data Source	Aims/Interest
Marshall et al. (2007)	United States	Article; qualitative interviews	Parents of pre-school age children with suspected language delays (*N* = 15)	Exploration of commonalities and differences in thoughts and perceptions of language development and EI between parents and professionals
Marshall (2013)	United States	Dissertation. Phase 1 cross-sectional data analysis, phase 2 qualitative interviews and focus groups	Phase 1: Parents of children aged 0-5 (*N* = 27566), 2007 NSCH survey Phase 2: Parents of children aged 0-5 (*N* = 23)	Parent recognition and response to child development - child, parent, family, and community-level factors
Marshall et al. (2017)	United States	Article; qualitative interviews, analysed using grounded theory	Parents of children with mild language delay who participated in a community-based speech program (*N* = 20)	Experiences of parents of children with mild language delays in navigating the process of assessment and referral and decision to participate/not
McAllister et al. (2011)	Australia	Dissertation; mixed methods (cross-sectional survey and qualitative interviews)	Parents of children with speech/language difficulties; Study 1 (*N* = 109), Study 2 (*N* = 13)	Parent experiences of child speech impairment and accessing services in Australia

Citation	**Country of origin**	**Study design**	**Participants/Data Source**	**Aims/Interest**
Missiuna et al. (2006)	Canada	Article; in-depth interviews; phenomenological approach, descriptive analysis	Parents (*N* = 13) of children with developmental coordination disorder	Explore the parent perceptions of the early experiences and participation patterns of children with developmental coordination disorder
Morton (2012)	United States	Dissertation. In-depth interviews; phenomenological approach, constant comparison analysis	African American mothers (*N* = 8) of children with diagnosed developmental delay	Explore parent's awareness of and reactions to developmental delay in their children
Nelson et al. (2011)	United States	Article; qualitative focus groups	Parents of children with developmental concerns in the Head Start program (*N* = 30)	Parent perceptions of the Head Start program for detection and intervention for developmental concerns
Persoff (1998)	United States	Dissertation; qualitative interviews	Latino families of children with developmental delay (*N* = 11)	Latino mothers' experiences of barriers, stressors and coping skills in accessing EI for their child with developmental delay

Citation	**Country of origin**	**Study design**	**Participants/Data Source**	**Aims/Interest**
Plath et al. (2016)	Australia	Article; qualitative interviews	Children with emerging conduct problems and their parents; parents of children who attended program (*n* = 12) and those who did not (*n* = 40)	Parent program evaluation (those who did and did not attend) of school-based universal and targeted EI program for children with emerging conduct problems.
Porterfield and McBride (2007)	United States	Article; cross-sectional national survey	Parents of children with special health care needs (*N* = 38866)	Parent access of health care for children with suspected and reasons for non-access
Ramirez (2004)	United States	Dissertation; Qualitative interviews	Latino families of children with developmental delay/disability (*N* = 10)	Experience of Latino parents of a child with developmental delay/disability – feelings associated with child’s concerns, support systems used, and perceptions of EI.

Citation	**Country of origin**	**Study design**	**Participants/Data Source**	**Aims/Interest**
Rannard et al. (2004)	United Kingdom	Article; in-depth interviews; life history approach, analysis approach unclear	Parents/guardians (*N* = 40) of children who had received specialist language education	Provision of a qualitative account of the parental perspective of children with specific language impairments, with exploration of parental meaning making of detecting their child's language problem and events leading to admission to language education
Raspa et al. (2015)	United States	Article; focus groups; inductive content analysis	Parents of children with developmental delays (*N* = 74)	Exploring facilitators and barriers to identification of child developmental concerns
Restall and Borton (2010)	Canada	Article; mixed-method - cross-sectional survey and interviews using a phenomenological approach	Survey: guardians of children entering school (*N* = 290) Interviews: mothers of children identified as developmentally at risk (*N* = 9)	Understand prevalence of parent-reported developmental risk in children; parental experience of identifying concerns and accessing services
Schmidt (2013)	United States	Article; cross-sectional survey	Parents of children accessing early intervention services (*N* = 98)	Predictors of parent involvement in early intervention services and their perceived barriers to participation

Citation	**Country of origin**	**Study design**	**Participants/Data Source**	**Aims/Interest**
Schumarker-Murphy (2019)	United States	Dissertation; qualitative interviews	Fathers of children with developmental delays or disabilities (*N* = 6)	Fathers' experiences of engaging with EI services
Shannon (2000)	United States	Dissertation; qualitative interviews and observations	Families of children with developmental delay/disability (*N* = 22)	Parent perspectives of family-centred practice implementation
Sices et al. (2009)	United States	Article; qualitative focus groups	Mothers of young children with typical development (*n* = 11); mothers of young children who received EI services (*n* = 18)	Understanding the beliefs and experiences of parents and EI specialists in discussing child development
Silbersack (2014)	United States	Dissertation. In-depth interviews; phenomenological approach using thematic analysis	Mothers of children 0-5 years with confirmed developmental delays or disabilities (*N* = 18)	Understanding of process surrounding discovery of child developmental issues by mothers.
Smith et al. (2015)	United Kingdom	Article; Qualitative interviews with parents and practitioners	Parents of preschool children with ADHD-type problems (*N* = 25)	Parent barriers to accessing and engaging with parenting programs for preschool-age children with ADHD
Wall et al. (2005)	United States	Article; qualitative case studies – interviews and case reviews	At risk (low income, minority) families (*N* = 32)	Early Head Start participation and impact on likelihood of subsequent EI access

Citation	**Country of origin**	**Study design**	**Participants/Data Source**	**Aims/Interest**
Watson and Chesters (2012)	Australia	Report; mixed methods (cross-sectional survey, qualitative interviews and observations)	Parents who participated in a targeted EI program (*n* = 76 surveys; *n* = 18 interviews)	Understand factors influencing participation of families in a targeted program for vulnerable children
Williams (2007)	Australia	Article; qualitative interviews	Mothers of children with 'subtle developmental problems' (*N* = 8)	Mothers' experiences of raising a child with developmental problems
Woolfenden et al. (2015)	Australia	Article; qualitative interviews	CALD background parents of children with suspected developmental delays (*N* = 13)	Family and service characteristics, beliefs and experiences influencing journeys in accessing developmental surveillance and EI services
Worcester (2005)	United States	Article; qualitative interviews	Parents of young children aged 0-4 years experiencing challenging behaviour and/or additional developmental delays or disabilities (*N* = 8)	Parent reports of experiences obtaining services and supports for their children within their local system of care

	FAMILIES	SERVICES
Perception of needs and desire for care	**Ability to perceive**	**Approachability**
	Influence of informal supports Tensions between personal and community/cultural advice Differing gender roles and perceptions of child development History of negative service interactions Thoughts and decisions around diagnosis	Short appointment times/windows for sharing concerns Non-standard or inconsistent measurement of child development
Health care seeking	**Ability to seek**	**Acceptability**
	Vague presentation of concerns Readiness to answer and ask questions about development Knowledge of available services and eligibility	Professional knowledge of available services Not explaining screening results or referral purpose 'Wait and see' approach Failure to refer onwards Professional communication and rapport
Health care reaching	**Ability to reach**	**Availability and accommodation**
	Complexity and chaos – hierarchy of family needs Needs of other children Child health and behaviour Transport and location Low social capital and isolation Housing and location instability Parental and family issues	Complex referral process Waiting lists Service contact procedures Appointment inflexibility Unclear eligibility
Health care utilisation	**Ability to pay**	**Affordability**
	Insurance coverage Out of pockets expenses Eligibility for free/low-cost services Parent work conflicts	
Health care consequences	**Ability to engage**	**Appropriateness**
	Health literacy Parent self-efficacy and advocacy	Therapist approach Lack of appropriate or sufficient services Lack of service choice

Figure 5-2 Overview of review findings

5.4.1 Perception of needs and desire for care

The first component of the barriers to access model describes the perception of needs and desire for care, comprised of the family's ability to perceive (e.g. their health beliefs, trust, and expectations) and service approachability (level of transparency, outreach, information and screening) (Levesque et al., 2013).

5.4.1.1 Family ability to perceive

Families often shared their concerns with informal supports such as family and friends (Eapen et al., 2017; McAllister et al., 2011). Perspectives of family and friends were both highly valued and influential - at times above and beyond professional opinions (Ahern, 2000; Magnusson et al., 2017; Marshall, 2013; Wall et al., 2005); however, the lack of both emotional and pragmatic support significantly undermined the process of noticing and sharing concerns (Persoff, 1998). Family members sometimes denied that the child had a problem (Woolfenden et al., 2015), they downplayed or minimised the seriousness of the problem (Persoff, 1998; Silbersack, 2014; Wall et al., 2005), or offered rationalisations (Silbersack, 2014). Parents also experienced judgemental and unsupportive attitudes (Khan, 2013; Smith et al., 2015) or blame for the child's delay from family or friends (Persoff, 1998; Wall et al., 2005).

Differences in attitudes could occur between parents and the broader community. This often arose when there was a conflict between respecting community elder advice to wait and see while believing that something was not right with their child (Green et al., 2016). Differences in gender perceptions and roles were noted. Fathers were either not concerned; deferred to the mother; left the bulk of the efforts in seeking services to the mother (Ahern, 2000; Marshall, 2013); took on the role translator for the family and 'filtered' information that was provided to the family (Woolfenden et al., 2015); or exercised the 'power of veto' in deciding whether the child accessed services or not

(Woolfenden et al., 2015). Differences in perception sometimes occurred when families did not see the need for further action (Marshall, 2013), were unsure as to whether to proceed (Hebbeler et al., 2007), did not know anyone who had accessed services (Lalbeharie-Josias, 2001), or when they wished to postpone referral (Glogowska & Campbell, 2004). A disconnect between parental and professional perceptions of a child's development sometimes occurred – whereby one party was concerned and the other was not (Magnusson et al., 2017; Marshall et al., 2017).

Previous experiences with professionals, services and/or forms of authority undermined trust and reduced willingness to engage (Gerlach et al., 2017; Kummerer & Lopez-Reyna, 2009; Leiter, 2001; Woolfenden et al., 2015). Some parents were fearful of being judged as being a bad parent and that this would lead to them being referred to child welfare services. This was particularly in the case of families that had previous involvement with child welfare services (Gerlach et al., 2017; Leiter, 2001; Shannon, 2000; Sices et al., 2009; Smith et al., 2015). This fear resulted in some families answering 'yes' to developmental milestones questions to avoid any suspicion of 'neglect' (Sices et al., 2009).

Families also had diverse thoughts about having their child receive a diagnosis. Obtaining a formal diagnosis for their child positively impacted some families, by validating parental concerns; providing a pathway to seek help; and a 'reason' for the child's behaviour or development (Marshall, 2013; Missiuna et al., 2006). However, families were often nervous about 'labels', and it was reported that the diagnostic process needed to be provided carefully, sensitively, or not until a child was older (Lalbeharie-Josias, 2001).

5.4.1.2 Service approachability

Health services were the most frequently identified source of support including primary care providers (known in Australia as general practitioners, GPs), paediatricians and other developmental specialists, allied health professionals, maternal and child health staff, and paediatric nurses (Eapen et al., 2017; Hendrickson et al., 2000; Kummerer & Lopez-Reyna, 2009; Marshall, 2013; McAllister et al., 2011; Missiuna et al., 2006; Raspa et al., 2015; Shannon, 2000; Woolfenden et al., 2015). Education professionals such as teachers were commonly sought out for support (Marshall, 2013; McAllister et al., 2011; Missiuna et al., 2006; Nelson et al., 2011; Raspa et al., 2015), particularly when a child entered school (McAllister et al., 2011; Walker et al., 2011). Families often identified that their GP was their first port of call (Eapen et al., 2017; Hendrickson et al., 2000; Kummerer & Lopez-Reyna, 2009; McAllister et al., 2011; Shannon, 2000), and commonly the primary conduit for families into EI services (Shannon, 2000; Woolfenden et al., 2015)

Short appointment times were perceived by parents to limit the ability of professionals to pick up and/or address concerns and did not allow time for the conduction of a comprehensive assessment to be completed (Alexander et al., 2015; Marshall, 2013; Shannon, 2000; Williams, 2007; Woolfenden et al., 2015) Professionals may not truly ‘see’ a child, and therefore dismiss concerns (Williams, 2007), and this could result in parents feeling rushed and unable to adequately raise concerns (Marshall, 2013).

Professionals use varied, non-standardised tests to assess for the presence of developmental concerns (Hendrickson et al., 2000; Woolfenden et al., 2015), which could either lead to a dismissal of parental concerns, or a false positive - causing unnecessary distress to the family (Woolfenden et al., 2015). Developmental surveillance ‘books’ in Australia were often used inconsistently and sometimes they were not provided to populations such as migrant families (Woolfenden et al., 2015). On the other hand, some families perceived that use of standardised tests detracted from getting to know the child and family in an individualised, holistic way, with particular concerns about how such measures accounted for cultural differences (Lalbeharie-Josias, 2001; Marshall et al., 2007; Morton, 2012). Checklists were viewed as ‘superficial’, with parents believing that professionals should take the time to probe their responses more deeply to address their raised concerns (Alexander et al., 2015). Some families praised the use of screening tools, as a means of raising their awareness of their child's development (Nelson et al., 2011), while others perceived screening tools as a 'test' or worried about whether they had given the 'right answers' (Gerlach et al., 2017; Nelson et al., 2011). Professionals such as GPs were also reported by families to often fail to ask about developmental concerns and instead focused on medical issues (Morton, 2012).

5.4.2 Health care seeking

The next step of health care seeking consists of the family's ability to seek care (which may be impacted by factors such as personal and social values, culture, gender, autonomy, and capacity) and service acceptability (including professional values, norms, and culture) (Levesque et al., 2013).

5.4.2.1 Family ability to seek

Families sometimes presented their concerns tentatively or via a vague, non-specific question due to low confidence (particularly first-time parents) (Ahern, 2000; Sices et al., 2009). They also downplayed the extent of their child's delays if they did not think they were a problem (Felt & O'Connor, 2003; Glaun et al., 1998). This parental approach meant that the parent was often not taken seriously by professionals (Ahern, 2000; Marshall, 2013). Some families felt reluctant or uncomfortable raising developmental issues compared to discussing medical concerns (Alexander et al., 2015; Marshall, 2013; Morton, 2012; Silbersack, 2014), or felt the need to gather 'evidence' to present (Marshall, 2013). Others simply forgot to ask questions due to feeling overwhelmed or not knowing what to ask (Felt & O'Connor, 2003; Morton, 2012). Parents who made more direct, specific requests for their child received more validating professionals' responses (Ahern, 2000).

Families frequently lacked awareness of both whom to share concerns with, and knowledge of EI service availability (Green et al., 2016; Smith et al., 2015). Families identified that they did not know whom to ask or where to go when concerned, were unsure whose role it was to identify issues, did not know how to navigate health systems, and had not heard of EI services or did not know how to access them until told about them by professionals (Baden; Giordano, 2008; Khan, 2013; Magnusson et al., 2017; Morton, 2012; Ramirez, 2004; Shannon, 2000; Woolfenden et al., 2015). Families had to be persistent in finding out where to go for support (Hendrickson et al., 2000), and often found the EI system 'by chance' (Baden; Shannon, 2000); even those who actively sought out services experienced difficulties (Shannon, 2000), with the search becoming "so discouraging for some families that they gave up trying" (Shannon, 2000, p. 142). Parents with low health literacy reported that their paediatricians did not explain EI and that written materials provided to them were not helpful; while those with adequate health literacy had less difficulty learning about EI as they were able to seek out their own information (Jimenez et al., 2012). Parents sourced information from the Internet, books, and hotlines (Eapen et al., 2017; Morton, 2012; Raspa et al., 2015; Restall & Borton, 2010; Worcester, 2005) and expressed the need for new and creative approaches to access accurate information (McAllister et al., 2011; Wall et al., 2005), including 'more aggressively advertised' EI services (Lalbeharie-Josias, 2001).

5.4.2.2 Service acceptability

Sharing concerns with professionals was frequently reported as stressful, frustrating, confusing, and disappointing (Hebbeler et al., 2007; Hendrickson et al., 2000; Marshall, 2013; Shannon, 2000), and resulted in families relying on informal sources for support (Hendrickson et al., 2000; Williams, 2007; Woolfenden et al., 2015). Families believed that many professionals did not have sufficient knowledge of developmental delay and EI pathways; often lacked confidence in identifying concerns (Magnusson et al., 2017; Porterfield & McBride, 2007; Restall & Borton, 2010; Shannon, 2000; Worcester, 2005); did not provide tailored information (Shannon, 2000); or provided inadequate, conflicting or even incorrect information (Hendrickson et al., 2000; Magnusson et al., 2017; Persoff, 1998; Sices et al., 2009; Worcester, 2005). At times, assessment procedures and results were not clearly explained (Kummerer & Lopez-Reyna, 2009), or families were referred to EI services without the purpose being explained to them (Plath et al., 2016; Shannon, 2000). This caused confusion for families and in some cases was reported to be the reason for failure to follow-through on the referral (Jimenez et al., 2012; Plath et al., 2016; Shannon, 2000). This was particularly a concern for culturally and linguistically diverse (CALD) families, who were reported as possibly misunderstanding recommendations, and as a result were viewed as 'uncooperative' for not following up with recommendations (Kummerer & Lopez-Reyna, 2009).

Families' concerns were not always taken seriously by professionals (Khan, 2013; Sices et al., 2009). This frequently presented as the 'wait and see' approach - whereby parents were told not to worry, that their child would likely outgrow the concerns over time, and to simply 'wait and see' (Ahern, 2000; Giordano, 2008; Hendrickson et al., 2000; Kummerer & Lopez-Reyna, 2009; Marshall et al., 2017; Missiuna et al., 2006; Morton, 2012; Ramirez, 2004; Rannard et al., 2004; Shannon, 2000; Sices et al., 2009; Silbersack, 2014; Worcester, 2005) – with this sometimes occurring even in the presence of significant issues (Hendrickson et al., 2000). Rationales professionals gave to parents to justify a wait and see approach included the child being 'too young to test' (Missiuna et al., 2006; Ramirez, 2004), 'still developing' (Shannon, 2000; Sices et al., 2009; Worcester, 2005), going through a 'phase' (Worcester, 2005), child gender, birth order (Morton, 2012), cultural factors including bilingualism (Woolfenden et al., 2015), or ‘explained’ by other factors (such as the child’s behaviour) (Worcester, 2005). This attitude appeared to many parents as the professional disregarding or not taking their concerns seriously (Hendrickson et al., 2000; Missiuna et al., 2006; Silbersack, 2014), as a lack of willingness to make a referral (Baden; Ramirez, 2004; Worcester, 2005), or as being due to a lack of professional knowledge (Shannon, 2000). Parents expressed that this approach was frustrating and disheartening (Lalbeharie-Josias, 2001; Shannon, 2000) and resulted in children experiencing delays in accessing services (Marshall et al., 2017; Rannard et al., 2004) or being closed out of the EI system due to ageing-out (Shannon, 2000). Professional reluctance to diagnose the child could also have a similar invalidating impact resulting in families seeking out a second opinion (Shannon, 2000; Williams, 2007; Worcester, 2005). Unspecified or generic diagnoses were perceived as unhelpful diagnoses, as they did not make a child eligible for support (Ahern, 2000; Shannon, 2000), made service pathways unclear (Missiuna et al., 2006), or caused families to view the issue as less problematic and therefore not see the need for support (Shannon, 2000).

Some professionals also failed to complete the final step of providing an onward referral to EI services for further assessment and intervention (Magnusson et al., 2016; Rannard et al., 2004; Raspa et al., 2015). The onus for getting a referral to EI services was often placed with families – with professionals deferring to parents to pursue help if they were concerned, but not providing them with the necessary informational support (Marshall, 2013). Sometimes, they were reported to have diagnosed a child but failed to tell the family where to go for help (Shannon, 2000). Some parents had to repeatedly raise concerns (Glogowska & Campbell, 2004; Kummerer & Lopez-Reyna, 2009) or reach a crisis point before action was taken (Khan, 2013) – or resorted to self-referral instead (Silbersack, 2014). Parents had to ‘professional-shop’ in order to find someone who would validate their concerns (Hendrickson et al., 2000; Marshall, 2013; Missiuna et al., 2006; Morton, 2012; Woolfenden et al., 2015). Hendrickson et al. (2000) identified that families averaged 2.83 consultations with professionals before being referred to EI. Invalidation of parental concerns caused some parents to question their instincts and cease to seek further help (Ahern, 2000); or put their concerns ‘on the back burner’ (Missiuna et al., 2006).

Some professionals were perceived not to consider the emotional impact of having a child with delays on a family (Morton, 2012; Shannon, 2000). Families described a lack of meaningful interaction with professionals, particularly GPs – calling them ‘shielded’ and ‘robot-like’ (Marshall, 2013). Others felt that professionals did not listen to them, did not treat them with respect, and did not value their opinions (Morton, 2012). Families appreciated professionals who were caring, compassionate, and followed the family’s lead (Alexander et al., 2015; Sices et al., 2009); and where there was an established trusting relationship (Alexander et al., 2015). Low literacy families were less likely to report that they had continuity of care (Jimenez et al., 2012).

Tone and content of communication had an impact on parent responses to seeking support; a reassuring tone from a paediatrician was sometimes interpreted as an indication that families did not need to pursue services (Jimenez et al., 2012). Other families emphasised that they valued professional honesty and straightforwardness – not ‘sugar-coating’ information, while also not unduly alarming families (Sices et al., 2009; Silbersack, 2014). Clear communication was essential for CALD families (Lalbeharie-Josias, 2001; Persoff, 1998). Many families felt that professionals used too much jargon (Ramirez, 2004), seeing it as a tool used by professionals to ‘cover up what they did not know’ (Persoff, 1998; Ramirez, 2004; Shannon, 2000). Professional ‘blaming and shaming’ of parents was reported, which made parents feel overly paranoid, anxious or like bad parents

(Hendrickson et al., 2000; Missiuna et al., 2006; Shannon, 2000; Sices et al., 2009; Williams, 2007) - “he thought I had a bratty kid and just didn’t want to deal with him” (Hendrickson et al., 2000, p. 11).

5.4.3 Health care reaching

The third step of health care reaching comprised the family’s ability to reach, impacted by their living environments, transport, mobility and social support; and service availability and accommodation due to factors such as geographic location, hours of opening and appointment mechanisms (Levesque et al., 2013).

5.4.3.1 Family ability to reach

Complexity and chaos – the hierarchy of family needs. Families experienced a myriad of pragmatic or practical barriers to attending EI services (Kummerer & Lopez-Reyna, 2009; Marshall, 2013; Marshall et al., 2017; Smith et al., 2015). This was particularly true for vulnerable families, who often had complex needs and who could not focus on their child’s developmental concerns until more basic family needs were met (Watson & Chesters, 2012). Families experienced competing demands on their time (Lalbeharie-Josias, 2001; Woolfenden et al., 2015), were ‘distracted’ by other issues happening in their lives (Wall et al., 2005; Watson & Chesters, 2012); or simply had ‘so much going on’ (Jimenez et al., 2012; Magnusson et al., 2017; Marshall, 2013; Schmidt, 2013). This made families feel too busy, tired and/or stressed to be able to follow through with recommendations (Glaun et al., 1998; Marshall et al., 2017; Schmidt, 2013) or led to them forgetting about appointments (Magnusson et al., 2016; Magnusson et al., 2017).

Needs of other children. Juggling the competing needs of other children, particularly young infants was a major barrier to service access (Green et al., 2016; Hendrickson et al., 2000; Kummerer & Lopez-Reyna, 2009; Lalbeharie-Josias, 2001; Magnusson et al., 2017;

Marshall, 2013; Marshall et al., 2017; Persoff, 1998; Ramirez, 2004; Restall & Borton, 2010; Schmidt, 2013; Shannon, 2000; Smith et al., 2015; Woolfenden et al., 2015). Childcare cost; quality; and availability were frequent issues – for example, for other children during appointments (Persoff, 1998; Shannon, 2000); or for all children to enable parents to attend parent education or support groups, particularly when children were not yet school-age (Shannon, 2000). Families were often forced to juggle competing needs of the whole family – at times weighing up child versus whole-family needs (McAllister et al., 2011; Ramirez, 2004; Shannon, 2000). Families also often had more than one child with concerns to manage (Green et al., 2016; Hebbeler et al., 2007; Hendrickson et al., 2000; Lalbeharie-Josias, 2001; Shannon, 2000), and their other child may experience concerns that may be of a higher priority (Hendrickson et al., 2000).

Child health and behaviour. Studies reported that the child may become temporarily sick and this resulted in appointment absences (Hebbeler et al., 2007; Magnusson et al., 2016; Shannon, 2000; Smith et al., 2015); or the child may experience ongoing health and/or medical issues that require more immediate action and thus take precedence over developmental concerns and EI services (Hebbeler et al., 2007; Magnusson et al., 2016; Shannon, 2000). Managing the child on a day-to-day basis, particularly those with behavioural challenges contributed to families feeling tired and overwhelmed (Silbersack, 2014).

Transport and location. Early intervention services that were at a distance to families or were not conveniently accessible created barriers for access (McAllister et al., 2011; Smith et al., 2015). Lack of transportation to access centre-based services was a key issue (Giannoni & Kass, 2010; Green et al., 2016; Kummerer & Lopez-Reyna, 2009; Magnusson et al., 2016; Marshall, 2013; Marshall et al., 2017; Porterfield & McBride, 2007; Restall & Borton, 2010; Schmidt, 2013; Shannon, 2000; Wall et al., 2005), particularly where families needed to attend multiple appointments spread across different service providers (Green et al., 2016). Lack of private transportation, poor accessibility of public transport with strollers or wheelchairs, costs associated with the use of taxis, as well as difficulties in accessing public transportation during bad weather were commonly reported barriers to access (Green et al., 2016; Ramirez, 2004; Shannon, 2000). Services delivered in the home or in settings such as childcare centres mitigated transportation barriers for some families (Lalbeharie-Josias, 2001; Marshall et al., 2017; Watson & Chesters, 2012). The provision of transportation options was identified as an enabler to access for some families (Ramirez, 2004), however, they varied in their convenience depending on design logistics (Shannon, 2000). Services were additionally not always available in the family's area (Magnusson et al., 2016; Porterfield & McBride, 2007).

Low social capital and social isolation. Families with limited social capital potentially experienced difficulties with both pragmatic coordination of attendance and confidence in accessing services (Morton, 2012; Restall & Borton, 2010). New parents with limited social supports living close by, and migrant families whose own parents lived overseas (particularly if they were newly arrived and thus had limited social networks) experienced social isolation in particular (Watson & Chesters, 2012; Woolfenden et al., 2015).

Housing and location instability. Some families, more often lower-income families, had to move frequently due to limited or unstable income (Shannon, 2000); resulting in housing instability or, at the extreme end, homelessness (Marshall et al., 2017). Moving to a new house meant a change in contact details; therefore, some services lost contact with families (Giannoni & Kass, 2010; Jimenez et al., 2012; Shannon, 2000).

Parental and family issues. Studies reported that some parents experienced personal medical and mental health issues (Marshall et al., 2017; Schmidt, 2013; Smith et al., 2015; Wall et al., 2005). These were chronic or ongoing health problems, such as cancer

(Marshall, 2013) or shorter-term such as pregnancy (Marshall et al., 2017) - as well as the impact of circumstances such as marital separation or a death in the family (Restall & Borton, 2010). Acute mental health issues restricted parents' ability to attend services, as well as parental confidence and self-efficacy (Watson & Chesters, 2012). Parents did not feel confident in seeking out services or engaging in the interactions required as part of attendance (Watson & Chesters, 2012). Other impactful issues that resulted in avoidance of services included experiences of domestic violence (Smith et al., 2015) or substance use, particularly during pregnancy (Shannon, 2000).

5.4.3.2 Service availability and accommodation

Complex referral process. Referral pathways to services were described as inconsistent, frequently changing, convoluted, and filled with contradictory messages, dead ends, and excessive paperwork (Baden; Khan, 2013; Missiuna et al., 2006; Shannon, 2000; Woolfenden et al., 2015). Initial steps of the process often required navigation through new or 'foreign' experiences and interactions with unfamiliar people (Green et al., 2016; Wall et al., 2005) and could take considerable time (Shannon, 2000). Families reported being overwhelmed and frustrated by the process (Giordano, 2008; Shannon, 2000; Woolfenden et al., 2015), resulting in some families never making it through the process "because of the patience it required" (Shannon, 2000, p. 174).

Waiting lists. While some families took the view that waitlists were "a part of life" (Green et al., 2016, p. 5), many families identified long waitlists, especially for public services (Woolfenden et al., 2015), as a key roadblock in the journey to EI (Giordano, 2008; Green et al., 2016; Marshall, 2013; McAllister et al., 2011; Missiuna et al., 2006; Morton, 2012; Woolfenden et al., 2015). Described as the 'gates to service' (Giordano, 2008), waitlists delays were seen by many as detrimental to their child's developmental progress (Green et al., 2016). In systems where services were constrained by age entry cut-offs, delays meant that by the time some children reached the top of the waitlists, they were too old to access the service (Shannon, 2000). The nature of waitlists also meant that when the time came, families generally “only get one shot, ready or not” (Shannon, 2000, p. 146). Having to wait for such extended periods without support could be a stressful experience for families (Glaun et al., 1998; Green et al., 2016), and resulted in seeking alternate private, higher-cost services or complementary treatments (Glaun et al., 1998; Marshall, 2013; Missiuna et al., 2006).

Difficult to make contact with services. Families experienced issues in contacting and communicating with services – including difficulties in making contact (particularly by telephone) (Baden; Jimenez et al., 2012; Marshall, 2013); families misplacing contact details (Jimenez et al., 2012); services not calling back or following-up with families (Jimenez et al., 2012; Marshall, 2013); or services losing paperwork (Marshall, 2013);

Appointment inflexibility. Inconvenient appointment scheduling and difficulty with selecting more appropriate times created barriers (Lalbeharie-Josias, 2001; Magnusson et al., 2016; Porterfield & McBride, 2007; Shannon, 2000; Smith et al., 2015; Wall et al., 2005; Worcester, 2005). Some families had several conflicting appointments and had to make choices about which to attend (Shannon, 2000) or had difficulty with committing to regular attendance where programs spanned over weeks or months (Smith et al., 2015). Services that considered the family’s schedule when planning services enabled access (Lalbeharie-Josias, 2001).

Unclear eligibility. Difficulty with qualifying for services, due to the child age, not being deemed sufficiently delayed, family income level, family location, or services having strict eligibility were significant barriers for families (Baden; Garcia, 2015; Magnusson et al., 2017; Marshall, 2013; Silbersack, 2014). Families reported that when their child was found ineligible for one service, they were often not linked to other services, nor provided with ideas or guidance to implement themselves (Green et al., 2016; Marshall, 2013; Plath et al., 2016; Shannon, 2000). This left families feeling unsure as to what they were meant to do for their child – should they seek out other services, or did this mean that their child was ok? (Plath et al., 2016).

5.4.4 Health care utilisation

The fourth stage of service access, health care utilisation, consists of the family's ability to pay for services (based on income, social capital and health insurance) and service affordability (both direct and indirect costs) – discussed together below (Levesque et al., 2013).

5.4.4.1 Family ability to pay and service affordability

The financial cost of services, both direct and indirect, was a significant barrier to access (Garcia, 2015; Giordano, 2008; Kummerer & Lopez-Reyna, 2009; Magnusson et al., 2016; Marshall, 2013; McAllister et al., 2011; Persoff, 1998; Plath et al., 2016; Porterfield & McBride, 2007; Restall & Borton, 2010; Smith et al., 2015; Woolfenden et al., 2015), including inadequate or no insurance coverage resulting in out-of-pocket costs (Garcia, 2015; Kummerer & Lopez-Reyna, 2009; Magnusson et al., 2016; Marshall, 2013; Porterfield & McBride, 2007; Worcester, 2005). There were difficulties, albeit different ones, for both high and low-income families (Shannon, 2000). Lower-income families often could not afford private services (Alexander et al., 2015; Hendrickson et al., 2000; Lalbeharie-Josias, 2001), but qualified for free support (Lalbeharie-Josias, 2001; Shannon, 2000). Higher-income families had restricted service eligibility due to their income levels (Hendrickson et al., 2000), but were not necessarily able to afford private or out-of-pocket services not covered by insurance (Shannon, 2000). Parent work was a multi-faceted barrier to access. Families were unable to afford to take time off due to financial pressures (Kummerer &

Lopez-Reyna, 2009; Worcester, 2005), or had work schedules or commitments that hindered their ability to attend services (Kummerer & Lopez-Reyna, 2009; Plath et al., 2016; Schmidt, 2013; Shannon, 2000; Smith et al., 2015; Woolfenden et al., 2015).

5.4.5 Health care consequences

The final aspect, health care consequences, refers to the family's ability to engage with services (based on empowerment, information, adherence and caregiver support) and service appropriateness (professional quality, adequacy, coordination and continuity) (Levesque et al., 2013).

5.4.5.1 Family ability to engage

Families did not know what services existed (Garcia, 2015; Hendrickson et al., 2000; Marshall, 2013; Ramirez, 2004) or what their child was eligible for (Giordano, 2008; Hendrickson et al., 2000; Marshall et al., 2017; Shannon, 2000); as well as not understanding the referral process (Jimenez et al., 2012). This was reported to be particularly difficult for families with limited English proficiency and literacy skills (Woolfenden et al., 2015), low health literacy (Jimenez et al., 2012), minority families (Hebbeler et al., 2007), and low-income families (Hebbeler et al., 2007).

Entering into EI services was not equally accessible to all families. The nature of the system created barriers that unduly hampered some families in their efforts to engage with services. Parents were described as needing to be "proactive, persistent and assertive" (Marshall et al., 2017, p. 11) as well as needing to continually researching and fighting to obtain the services their child needed (Ahern, 2000; Restall & Borton, 2010; Silbersack, 2014; Worcester, 2005). Such efforts were stressful for families and seen as an 'ongoing battle'; highly motivated parents overcame obstacles, however, those who were ambivalent were especially vulnerable to attrition when confronted with practical obstacles (Worcester, 2005).

5.4.5.2 Service appropriateness

Families wanted professionals to consult with them, recognise their expertise in their child's life, and empower them to make decisions for their child (Lalbeharie-Josias, 2001; Marshall et al., 2007). They wanted trusting, respectful, honest, genuine relationships and care, where professionals communicated clearly and involved the family in each step of the process (Restall & Borton, 2010; Schumarker-Murphy, 2019). Families wanted information, advice and 'tools' to be able to work with their child at home (Marshall et al., 2007) - but felt that professionals were not always forthcoming with these things (Morton, 2012; Silbersack, 2014).

Lack of services in the families' area of residence (Garcia, 2015), not enough therapy or therapy that was perceived to be ineffective (Rannard et al., 2004), and understaffing due to staff turnover led to delays in services and issues with service coordination (Lalbeharie-Josias, 2001). High demand for specific service options, such as speech therapy for very young children, led to a lack of available professionals (Lalbeharie-Josias, 2001; Shannon, 2000). Families wanted information and the ability to make choices about providers and service delivery (Marshall, 2013), particularly when they were unhappy with or did not get along with the professional (Magnusson et al., 2016; Schmidt, 2013). Some families who were unhappy with what was being offered dropped out from accessing the service, rather than raising their concerns with the service (Shannon, 2000).

5.5 Discussion

This scoping review identified a series of barriers that families experienced when seeking to access EI services for children with developmental delays. Framed using Levesque's framework of access to health care (Levesque et al., 2013), findings identified issues across different elements of family journeys – from initial perceptions of needs and desires for care; health care seeking, 'reaching' of services themselves, health care utilisation, and consequences. The finding suggests that there are both commonalities or shared narratives as well as unique factors that may be barriers to family journeys through to EI service access.

The impact of family perceptions on deciding whether to act on developmental delays was scoped in detail in Chapter 4 of this thesis. This was reiterated here, particularly in relation to the impact of family, friends, and the broader community on help-seeking. It is clear that people in a family's close circle of support may be vital enablers, but they may equally be detractors or inhibitors in their journey of seeking support for their child's concerns. These findings indicate that it is important for services to ask how the delay is perceived by other people in the family, as a means to both better understand the parent and build their own confidence, as well as looking to use this as an opportunity to try to engage other family members in supporting them to see and understand the child's concerns (Wall et al., 2005). Understanding broader support network concerns may also support professional clinical reasoning and decision-making in determining next steps for the child and family unit – for example, if the wider family do not support the need for intervention, then is a home or clinic-based therapy plan the best course of action for this family? The strong influence of informal supports has been widely documented in qualitative work, such as by Ahern (2000); Khan (2013); Magnusson et al. (2017); Woolfenden et al. (2015), and reiterated in the findings of the current review; however, it has been largely absent from formalised policy recommendations or information (Centers for Disease Control and Prevention, 2020a; Council on Children with Disabilities et al., 2006; Lipkin et al., 2020). Given the magnitude of impact that unhelpful family perspectives can have on family journeys to EI services, further work is needed to determine professionals understanding of this barrier – as well as increasing broader community awareness. Acknowledging these experiences and identifying ways to support families (particularly new parents) in managing advice from others is also an essential part of this picture – however is often underrepresented or missing from parenting resources (Kinsner & Parlakian, 2018; Raising Children Network, 2020), and would benefit from greater emphasis.

The response of services, particularly those professionals who families may have initially shared their concerns with, is critical to family progress towards EI services. As this review identified, a significant issue is professionals taking a 'wait and see' approach and/or failing to provide an onward referral. 'Waiting' to see what happens for a child developmentally can mean that a critical window for intervention may be missed, particularly in systems that rely on a diagnosis for qualifying for support beyond the early years. For example, in Australia, children require a formal diagnosis from six years of age to qualify for ongoing support in the disability sector (NDIS, 2019). The finding that many families 'professional shop' to an average of almost three providers suggests that the current wait and see approach is not meeting family needs (Hendrickson et al., 2000; Marshall, 2013; Missiuna et al., 2006; Morton, 2012; Woolfenden et al., 2015). What appears to be needed instead is a 'monitor and review' approach by professionals: whereby families (and other important stakeholders in their child's life) are asked to monitor their child's development closely; are provided with ideas and strategies to promote their development; and are given a specific time frame in which the child will be reviewed, using standardised developmental assessments.

In Australia, taking a monitor and review approach would align with the American Academy of Pediatrics algorithm for developmental surveillance (Council on Children with Disabilities et al., 2006; Lipkin et al., 2020) and the Center for Disease Control's (CDC) promotion of developmental monitoring, screening and evaluation (Centers for Disease Control and Prevention, 2020a). Developmental monitoring is the active surveillance of a child's development by families through looking for and tracking milestone acquisition; while developmental screening is provided by professionals (including health and education providers) utilising validated formal screening tools, and followed up by developmental evaluation via formal assessment, observations and parent-completed questionnaires where concerns are identified (Centers for Disease Control and Prevention, 2020a). It is encouraging to see that such campaigns are also beginning to include resources for families on what to do while waiting for next steps, such as how to support development more broadly or connections to family and parenting support services (Centers for Disease Control and Prevention, 2020b). Of particular note is the added emphasis on sharing findings and obtaining the opinions of other professionals in the child's life, such as child care providers (Centers for Disease Control and Prevention, 2020a), who may be able to provide additional information on the child as well as support both referral processes and/or monitoring for the family.

Such efforts have sought to increase the attention of primary health care to the identification of developmental delays, and while there has been an increase in paediatrician screening rates in the last two decades, the goal of universal screening has not yet been achieved (Lipkin et al., 2020). National, well-resourced campaigns such as these alongside supporting initiatives such as Birth to 5: Watch Me Thrive (U.S. Department of Health and Human Services, 2017) are critical to seeking to changing the wait and see approach in primary healthcare settings – a change that will not come overnight without such concerted efforts. The importance of the early years and supporting pathways to EI has been building momentum in Australia in recent years (Australian Institute of Health and Welfare, 2011; T. Moore et al., 2017), however procedures and models for developmental surveillance particularly in primary care require further development (Ayer et al., 2020; Garg et al., 2018), and would benefit from knowledge from the above U.S. campaigns.

Taking a family-centred approach to service delivery is said to have been a core part of EI services for several decades (Espe-Sherwindt, 2008), with evidence that such an approach generates better outcomes benefitting both the child and broader family compared to more traditional professional-centred approaches(Dunst, 2002). Family-centred practice incorporates both relational and participatory practice elements, consisting of professional attitudes, behaviours and relationship-building with families that is strengths-based and focuses on the family unit; as well as practising in a manner that is flexible, responsive to family concerns and works in genuine collaboration with families (Dunst, 2002). Many EI programs are however providing services that are not genuinely family-centred – instead adopting a 'family-allied' approach that incorporates the necessary relational aspects of family-centredness, however, they are not adequately enabling family choice and action and/or being responsive and flexible to family needs (Dunst, 2002). This aligns with the current review's findings of the myriad of barriers that families experience, particularly in the stages of health care reaching, that EI services are not sufficiently addressing – such as juggling the needs of other children. In line with trying to better enable families to access EI services, services need to reflect on and ensure that they are taking a truly family-centred approach; not just within their face-to-face delivery of services but the processes that sit around this that may then enable parents to access services – such as the availability and provision of child care opportunities within services themselves (Persoff, 1998; Shannon, 2000).

A key focus of the current review was on the privileging the family voice, via inclusion criteria that restricted studies to those that were from the family perspectives only.

Services may make assumptions about why families may or may not ultimately access services; however, these perceptions do not necessarily align with those of families (Giordano, 2008). It is crucial for services to listen to what families are saying; both in terms of the factors that families are consistently experiencing as barriers (such as transportation concerns), as well as those that may be more individualised or only applicable to certain families (such as housing instability or homelessness). Part of this is ensuring that service design is informed by lived parent experience, and thus adequately reflects and meets parents expressed needs rather than those perceived by services (Williams, 2007). Inclusion of consumers in the design and creation of clear channels for consumer advocacy is therefore vital (Williams, 2007).

5.6 Conclusion

Families of children with suspected developmental delays experience a myriad of barriers across the stages of sharing concerns with others, seeking and ultimately accessing EI services. These barriers relate to the abilities of families to engage with the requirements of different elements of their journeys and their own individualised contexts, as well as barriers created by how services are designed and the professionals within them. It is critical that EI services and the sector more broadly reflect and ensure they are taking a genuine family-centred approach that is both responsive and flexible to family needs in order to seek to address the identified barriers.

5.7 References

Ahern, K. (2000). "Something is wrong with my child": A phenomenological account of a search for a diagnosis. *Early Education and Development, 11*(2), 187-201. https://doi.org/10.1207/s15566935eed1102_4

Alexander, K., Brijnath, B., & Mazza, D. (2015). Parents' decision making and access to preventive healthcare for young children: Applying Andersen's Model. *Health Expectations, 18*, 1256-1269. https://doi.org/10.1111/hex.12100

Archambault, J., Cote, D., & Raynault, M. F. (2020). Early childhood education and care access for children from disadvantaged backgrounds: Using a framework to guide intervention. *Early Childhood Education Journal, 48*(3), 345-352. https://doi.org/10.1007/s10643-019-01002-x

Australian Institute of Health and Welfare. (2011). *National outcome measures for early childhood development: Development of an indicator-based reporting framework* (Cat. no. PHE 134). https://www.aihw.gov.au/reports/health-care-quality-performance/national-outcome-measures-early-childhood/contents/table-of-contents

Ayer, C., Eapen, V., Overs, B., Descallar, J., Jalaludin, B., Eastwood, J., Dissanayake, C., Williams, K., Murphy, E., & Woolfenden, S. (2020). Risk factors for non-participation in a universal developmental surveillance program in a population in Australia. *Australian Health Review, 44*(4), 512-520. https://doi.org/10.1071/AH18236

Baden, K. M. (2012). *Fathers' and mothers' experiences with participation in Part C of the Individuals with Disabilities Education Act early intervention process* (Publication Number ED551186) [Doctoral dissertation, Walden University]. ProQuest Dissertatations and Theses. https://eric.ed.gov/?id=ED551186

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Centers for Disease Control and Prevention. (2020a). *Developmental monitoring and screening*. https://www.cdc.gov/ncbddd/childdevelopment/screening.html

Centers for Disease Control and Prevention. (2020b). *What to do while you wait to see a developmental specialist*. https://www.cdc.gov/ncbddd/actearly/concerned-whileyouwait.html

Chin, F., & Teti, D. M. (2013). Infants at double jeopardy: Socioeconomic, medical, and attachment-based predictors of maternal engagement with an early intervention program. *Infant Mental Health Journal, 34*(5), 420-434. https://doi.org/10.1002/imhj.21398

Clements, K. M., Barfield, W. D., Kotelchuck, M., & et al. (2008). Maternal socio-economic and race/ethnic characteristics associated with early intervention participation. *Maternal and Child Health Journal, 12*(6), 708-717. https://doi.org/10.1007/s10995-007-0291-3

Cortis, N., Katz, I., & Patulny, R. (2009). *Engaging hard-to-reach families and children* (FaHCSIA Occasional paper no. 26). http://dx.doi.org/10.2139/ssrn.1728576

Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, & Medical Home Initiatives for Children with Special Needs Project Advisory Committee. (2006). Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics, 118*(1), 405-420. https://doi.org/10.1542/peds.2006-1231

Cuomo, B., Joosten, A., & Vaz, S. (2019). Scoping review on noticing concerns in child development: A missing piece in the early intervention puzzle. *Disability and Rehabilitation*. https://doi.org/10.1080/09638288.2019.1708296

Doherty, P., Hall, M., & Kinder, K. (2003). *On track thematic report: Assessment, referral and hard-to-reach groups*. https://webarchive.nationalarchives.gov.uk/20110506162108/https://www.education.gov.uk/publications/eOrderingDownload/RR475.pdf

Dunst, C. J. (2002). Family-centred practice: Birth through high school. *Journal of Special Education, 36*(3), 141-149. https://doi.org/10.1177/00224669020360030401

Eapen, V., Walter, A., Guan, J., Descallar, J., Axelsson, E., Einfeld, S., Eastwood, J., Murphy, E., Beasley, D., Silove, N., Dissanayake, C., Woolfenden, S., Williams, K., Jalaludin, B., & The 'Watch Me Grow' Study, G. (2017). Maternal help-seeking for child developmental concerns: Associations with socio-demographic factors. *Journal of Paediatrics and Child Health*. https://doi.org/10.1111/jpc.13607

Espe-Sherwindt, M. (2008). Family-centred practice: Collaboration, competency and evidence. *Support for Learning, 23*(3), 136-143. https://doi.org/10.1111/j.1467-9604.2008.00384.x

Felt, B. T., & O'Connor, M. E. (2003). Use of the child development review increases residents' discussion of behavioral problems. *Ambulatory Pediatrics, 3*(1), 2-8. https://doi.org/10.1367/1539-4409(2003)003<0002:UOTCDR>2.0.CO;2

Foo, K. M., Sundram, M., & Legido-Quigley, H. (2020). Facilitators and barriers of managing patients with multiple chronic conditions in the community: A qualitative study. *BMC Public Health, 20*(273). https://doi.org/10.1186/s12889-020-8375-8

Garcia, C. (2015). *Early intervention programs: Preemie parents' perceptions and barriers to participation* (Publication Number 3706896) [Doctoral thesis, The University of Arizona]. ProQuest Dissertations & Theses Global. https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/1695267349?accountid=10382

Garg, P., Ha, M. T., Eastwood, J., Harvey, S., Woolfenden, S., Murphy, E., Dissanayake, C., Williams, K., Jalaludin, B., McKenzie, A., Einfeld, S., Silove, N., Short, K., & Eapen, V. (2018). Health professional perceptions regarding screening tools for developmental surveillance for children in a multicultural part of Sydney, Australia. *BMC Family Practice, 19*(1), 42. https://doi.org/10.1186/s12875-018-0728-3

Gerlach, A. J., Browne, A. J., & Greenwood, M. (2017). Engaging Indigenous families in a community-based Indigenous early childhood programme in British Columbia, Canada: A cultural safety perspective. *Health and Social Care In the Community, 25*(6), 1763-1773. https://doi.org/10.1111/hsc.12450

Giannoni, P. P., & Kass, P. H. (2010). Risk factors associated with children lost to care in a state early childhood intervention program. *Research in Developmental Disabilities, 31*(4), 914-923. https://doi.org/10.1016/j.ridd.2010.02.013

Giordano, K. (2008). *Barriers to early intervention services in New Jersey* [Doctoral dissertation, Fairleigh Dickinson University]. ProQuest Dissertations & Theses. http://dbgw.lis.curtin.edu.au:2048/login?url=https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/304403224?accountid=10382

Glaun, D. E., Cole, K. E., & Reddihough, D. S. (1998). Six month follow-up: the crucial test of multidisciplinary developmental assessment. *Child: Care, Health and Development, 24*(6), 457-472. https://doi.org/10.1046/j.1365-2214.1998.00082.x

Glogowska, M., & Campbell, R. (2004). Parental views of surveillance for early speech and language difficulties. *Children and Society, 18*(4), 266-277. https://doi.org/10.1002.CHI.806

Goldfeld, S., O'Connor, M., Sayers, M., Moore, T., & Oberklaid, F. (2012). Prevalence and correlates of special health care needs in a population cohort of Australian children at school entry. *Journal of Developmental & Behavioral Pediatrics, 33*, 319-327. https://doi.org/10.1097/DBP.0b013e31824a7b8e

Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P. M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services. *BMC Health Services Research, 16*(1), 680. https://doi.org/10.1186/s12913-016-1926-0

Hebbeler, K., Spiker, D., Bailey, D. B., Scarborough, A., Mallik, S., Simeonsson, R. J., Singer, M., & Nelson, L. (2007). *Early intervention for infants and toddlers with disabilities and their* *families: Participants, services, and outcomes*. SRI International. https://www.sri.com/wp-content/uploads/pdf/neils_finalreport_200702.pdf

Hendrickson, S., Baldwin, J. H., & Allred, K. W. (2000). Factors perceived by mothers as preventing families from obtaining early intervention services for their children with special needs. *Children's Health Care, 29*(1), 1-17. https://doi.org/10.1207/S15326888CHC2901_1

Jimenez, M. E., Barg, F. K., Guevara, J. P., Gerdes, M., & Fiks, A. G. (2012). Barriers to evaluation for early intervention services: parent and early intervention employee perspectives. *Academic pediatrics, 12*(6), 551-557. https://doi.org/10.1016/j.acap.2012.08.006

Khan, L. P., Michael; Elena Rosa, Brown. (2013). Parenting programmes: identification and referral. *Journal of Children's Services, 8*(3), 194-208. https://doi.org/10.1108/JCS-03-2013-0011

Kinsner, K., & Parlakian, R. (2018). *'Tis the season…Handling unwanted parenting advice with grace*. Zero to Three,. https://www.zerotothree.org/resources/2555-tis-the-season-handling-unwanted-parenting-advice-with-grace

Kummerer, S. E., & Lopez-Reyna, N. A. (2009). Engaging Mexican immigrant families in language and literacy interventions: Three case studies. *Remedial and Special Education, 30*(6), 330-343. https://doi.org/10.1177/0741932508321014

Lalbeharie-Josias, D. P. (2001). *Parents' perceptions of the individualized family service plan* (Publication Number AAI3012154) [Doctoral thesis, University of Massachusetts Amherst]. ProQuest Dissertations & Theses Global. https://scholarworks.umass.edu/dissertations/AAI3012154

Leiter, V. R. (2001). *Gentle intrusions: Family-centered care in early intervention* (Publication Number 3004966) [Doctoral dissertation, Brandeis University]. ProQuest Dissertations & Theses Global. https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/304681652?pq-origsite=summon

Levesque, J., Harris, M. F., & Russell, G. (2013). Patient-centred access to health care: Conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health, 12*(18). https://doi.org/https://doi.org/10.1186/1475-9276-12-18

Lipkin, P. H., Macias, M. M., AAP Council on Children with Disabilities, & Section on Developmental and Behavioral Pediatrics. (2020). Promoting optimal development: Identifying infants and young children with developmental disorders through developmental surveillance and screening. *Pediatrics, 145*(1), e20193449. https://doi.org/10.1542/peds.2019-3449

Magnusson, D., Palta, M., McManus, B., Benedict, R. E., & Durkin, M. S. (2016). Capturing unmet therapy need among young children with developmental delay using national survey data. *Academic pediatrics, 16*(2), 145-153. https://doi.org/10.1016/j.acap.2015.05.003

Magnusson, D. M., Minkovitz, C. S., Kuhlthau, K. A., Caballero, T. M., & Mistry, K. B. (2017). Beliefs regarding development and early intervention among low-income African American and Hispanic mothers. *Pediatrics, 140*(5). https://doi.org/http://dx.doi.org/10.1542/peds.2017-2059

Marshall, J. (2013). *Parent pathways: Recognition and responses to developmental delays in young children: A mixed-methods exploratory study* [Doctoral dissertation, University of South Florida]. Scholar Commons. http://scholarcommons.usf.edu/etd/4534

Marshall, J., Adelman, A., Kesten, S. M., Natale, R. A., & Elbaum, B. (2017). Parents’ experiences navigating intervention systems for young children with mild language delays. *Journal of Early Intervention, 39*(3), 180-198. https://doi.org/10.1177/1053815117704958

Marshall, J., Goldbart, J., & Phillips, J. (2007). Parents' and speech and language therapists' explanatory models of language development, language delay and intervention. *International Journal of Language & Communication Disorders, 42*(5), 533-555. https://doi.org/10.1080/13682820601053753

Marshall, J., Kirby, R. S., & Gorski, P. A. (2016). Parent concern and enrollment in intervention services for young children with developmental delays: 2007 National survey of children's health. *Exceptional Children, 82*(2), 251-268. https://doi.org/10.1177/0014402915585563

McAllister, L., McCormack, J., McLeod, S., & Harrison, L. J. (2011). Expectations and experiences of accessing and participating in services for childhood speech impairment. *International Journal of Speech-Language Pathology, 13*(3), 251-267. https://doi.org/10.3109/17549507.2011.535565

McManus, B., McCormick, M. C., Acevedo-Garcia, D., Ganz, M., & Hauser-Cram, P. (2009). The effect of state early intervention eligibility policy on participation among a cohort of young CSHCN. *Pediatrics, 124*, S368-S374. https://doi.org/10.1542/peds.2009-155G

Missiuna, C., Moll, S., Law, M., King, S., & King, G. (2006). Mysteries and mazes: Parents' experiences of children with developmental coordination disorder. *Canadian Journal of Occupational Therapy, 73*(1), 7-17. https://doi.org/10.2182/cjot.05.0010

Moore, T., Arefadib, N., Deery, A., & West, S. (2017). *The first thousand day: An evidence paper*. Murdoch Children’s Research Institute. https://www.rch.org.au/uploadedFiles/Main/Content/ccchdev/CCCH-The-First-Thousand-Days-An-Evidence-Paper-September-2017.pdf

Morton, D. S. (2012). *Parental descriptions of awareness and associated reactions to developmental delay in children* (Publication Number AAI3545470) [Doctoral dissertation, Capella University]. ProQuest Dissertations & Theses Global. https://www-proquest-com.dbgw.lis.curtin.edu.au/docview/1520325243/B7F1BC2997EB4B37PQ/1?accountid=10382

NDIS. (2019). *Providing evidence of disability for children*. https://www.ndis.gov.au/applying-access-ndis/how-apply/information-support-your-request/providing-evidence-disability-children

Nelson, B. B., Chung, P. J., DuPlessis, H. M., Flores, L., Ryan, G. W., & Kataoka, S. H. (2011). Strengthening families of children with developmental concerns: Parent perceptions of developmental screening and services in Head Start. *Ethnicity & disease, 21*(3 Suppl 1), S1-89-93. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3715307/

Persoff, J. R. (1998). *Poverty and early childhood developmental delay: Perspectives from Hispanic mothers* [Doctoral dissertation, University of Denver]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/304432454?accountid=10382

Peters, M. D. J., Godfrey, c., McInerney, P., Baldini Soares, C., Khalil, H., & Parker, D. (2017). Chapter 11: Scoping reviews. In E. Aromataris & Z. Munn (Eds.), *Joanna Briggs Institute Reviewer's Manual*. The Joanna Briggs Institute. https://reviewersmanual.joannabriggs.org/

Phoenix, M., & Rosenbaum, P. (2019). Presenting the model of risk, disability and hard-to-reach families to inform early intervention services. *Disability and Rehabilitation, 41*(2), 244-249. https://doi.org/10.1080/09638288.2017.1385650

Plath, D., Crofts, P., & Stuart, G. (2016). Engaging families in early intervention for child conduct doncerns. *Children Australia, 41*(1), 49-58. https://doi.org/10.1017/cha.2015.5

Porterfield, S. L., & McBride, T. D. (2007). The effect of poverty and caregiver education on perceived need and access to health services among children with special health care needs. *American Journal of Public health, 97*(2), 323-329. https://doi.org/10.2105/AJPH.2004.055921

Pritchard, M. A., Colditz, P. B., Cartwright, D., Gray, P. H., Tudehope, D., & Beller, E. (2013). Risk determinants in early intervention use during the first postnatal year in children born very preterm. *BMC pediatrics, 13*, 201-201. https://doi.org/10.1186/1471-2431-13-201

Raising Children Network. (2020). About us. https://raisingchildren.net.au

Ramirez, M. C. (2004). *Latino parents with developmentally delayed children: Perceptions of early intervention services* [Master's thesis, California State University]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/305036959?pq-origsite=gscholar

Rannard, A., Lyons, C., & Glenn, S. (2004). Children with specific language impairment: Parental accounts of the early years. *Journal of Child Health Care, 8*(2), 165-176. https://doi.org/10.1177/1367493504041875

Raspa, M., Levis, D. M., Kish-Doto, J., Wallace, I., Rice, C., Barger, B., Green, K. K., & Wolf, R. B. (2015). Examining parents' experiences and information needs regarding early identification of developmental delays: Qualitative research to inform a public health campaign. *Journal of Developmental & Behavioral Pediatrics, 36*(8), 575-585. https://doi.org/10.1097/DBP.0000000000000205

Restall, G., & Borton, B. (2010). Parents' concerns about their children's development at school entry. *Child: Care, Health and Development 36*(2), 208-215. https://doi.org/10.1111/j.1365-2214.2009.01019.x

Rosenberg, S. A., Robinson, C. C., Shaw, E. F., & Ellison, M. S. (2013). Part C early intervention for infants and toddlers: Percentage eligible versus served. *Pediatrics, 131*, 38-46. https://doi.org/10.1542/peds.2012-1662

Russell, G., Kunin, M., Harris, M., Levesque, J., Descoteaux, S., Scott, C., Lewis, V., Dionne, E., Advocat, J., Dahrouge, S., Stocks, N., Spooner, C., & Haggerty, J. (2019). Improving access to primary healthcare for vulnerable populations in Australia and Canada: Protocl for a mixed-method evaluation of six complex interventions. *BMJ Open, 9*(7), e027869. https://doi.org/10.1136/bmjopen-2018-027869

Schmidt, K. R. T. (2013). *Predictors of parent involvement in Part C early intervention services* [Doctoral dissertation, University of Maryland]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/1399598995?accountid=10382

Schumarker-Murphy, M. (2019). *Fathers' experiences in early intervention: Marooned in the kitchen or member of the team* [Doctoral dissertation, DePaul University]. ProQuest Dissertations and Theses. https://search.proquest.com/openview/26116c4b74bea79c34fd3b4aac10ee77/1?pq-origsite=gscholar&cbl=18750&diss=y

Shannon, P. (2000). *Family-centered practice in early intervention services for infants and toddlers: The experience of families and professionals in one Local Interagency Coordinating Council* [Doctoral dissertation, Virginia Commonwealth University]. ProQuest Dissertations & Theses Global. https://scholarscompass.vcu.edu/etd/5304/

Shapiro, B. J., & Derrington, T. M. (2004). Equity and disparity in access to services: An outcomes-based evaluation of early intevention Child Find in Hawai'i. *Topics in Early Childhood Special Education, 24*(4), 199-212. https://doi.org/10.1177/02711214040240040201

Sices, L., Egbert, L., & Mercer, M. B. (2009). Sugar-coaters and straight talkers: communicating about developmental delays in primary care. *Pediatrics, 124*(4), e705-713. https://doi.org/10.1542/peds.2009-0286

Silbersack, E. W. (2014). *Mothers' initial discovery of childhood disability: Exploring maternal identification of developmental issues in young children* [Doctoral dissertation, Adelphi University]. ProQuest Dissertations & Theses Global. https://eric.ed.gov/?id=ED557029

Smith, E., Koerting, J., Latter, S., Knowles, M. M., McCann, D. C., Thompson, M., & Sonuga-Barke, E. J. (2015). Overcoming barriers to effective early parenting interventions for attention-deficit hyperactivity disorder (ADHD): Parent and practitioner views. *Child: Care, Health and Development, 41*(1), 93-102. https://doi.org/10.1111/cch.12146

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, d., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., Lewin, S., Godfrey, C. M., Mcdonald, M. T., Langlois, E. V., Soares-Weiser, K., Moriarty, J., Clifford, T., Tuncalp, O., & Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine, 169*(7), 467-473. https://doi.org/10.7326/M18-0850

Twardzik, E., Cotto-Negrón, C., & Macdonald, M. (2017). Factors related to early intervention Part C enrollment: A systematic review. *Disability and Health Journal, 10*(4), 467-474. https://doi.org/10.1016/j.dhjo.2017.01.009

U.S. Department of Health and Human Services. (2017). *Birth to 5: Watch Me Thrive*. https://www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive

United Nations. (1990). *Convention on the rights of the child*. United Nations. https://www.unicef.org/child-rights-convention/convention-text#

United Nations. (2019). *World Economic Situation and Prospects 2019*. https://www.un.org/development/desa/dpad/wp-content/uploads/sites/45/WESP2019_BOOK-web.pdf

Walker, S. P., Wachs, T. D., Grantham-Mcgregor, S., Black, M. M., Nelson, C. A., Huffman, S. L., Baker-Henningham, H., Chang, S. M., Hamadani, J. D., Lozoff, B., Gardner, J. M. M., Powell, C. A., Rahman, A., & Richter, L. (2011). Inequality in early childhood: Risk and protective factors for early child development. *The Lancet, 378*(9799), 1325-1338. https://doi.org/10.1016/S0140-6736(11)60555-2

Wall, S. M., Taylor, N. E., Liebow, H., Sabatino, C. A., Mayer, L. M., Farber, M. Z., & Timberlake, E. M. (2005). Early Head Start and access to early intervention services: a qualitative investigation. *Topics in Early Childhood Special Education, 25*(4), 218-231. https://doi.org/10.1177/02711214050250040301

Watson, L., & Chesters, J. (2012). *Early intervention for vulnerable young children and their families through the Parents as Teachers program*. The Education Institute. http://www.theeducationinstitute.edu.au

Williams, J. (2007). Learning from mothers: how myths, policies and practices affect the detection of subtle developmental problems in children. *Child: Care, Health and Development, 33*(3), 282-290. https://doi.org/10.1111/j.1365-2214.2006.00690.x

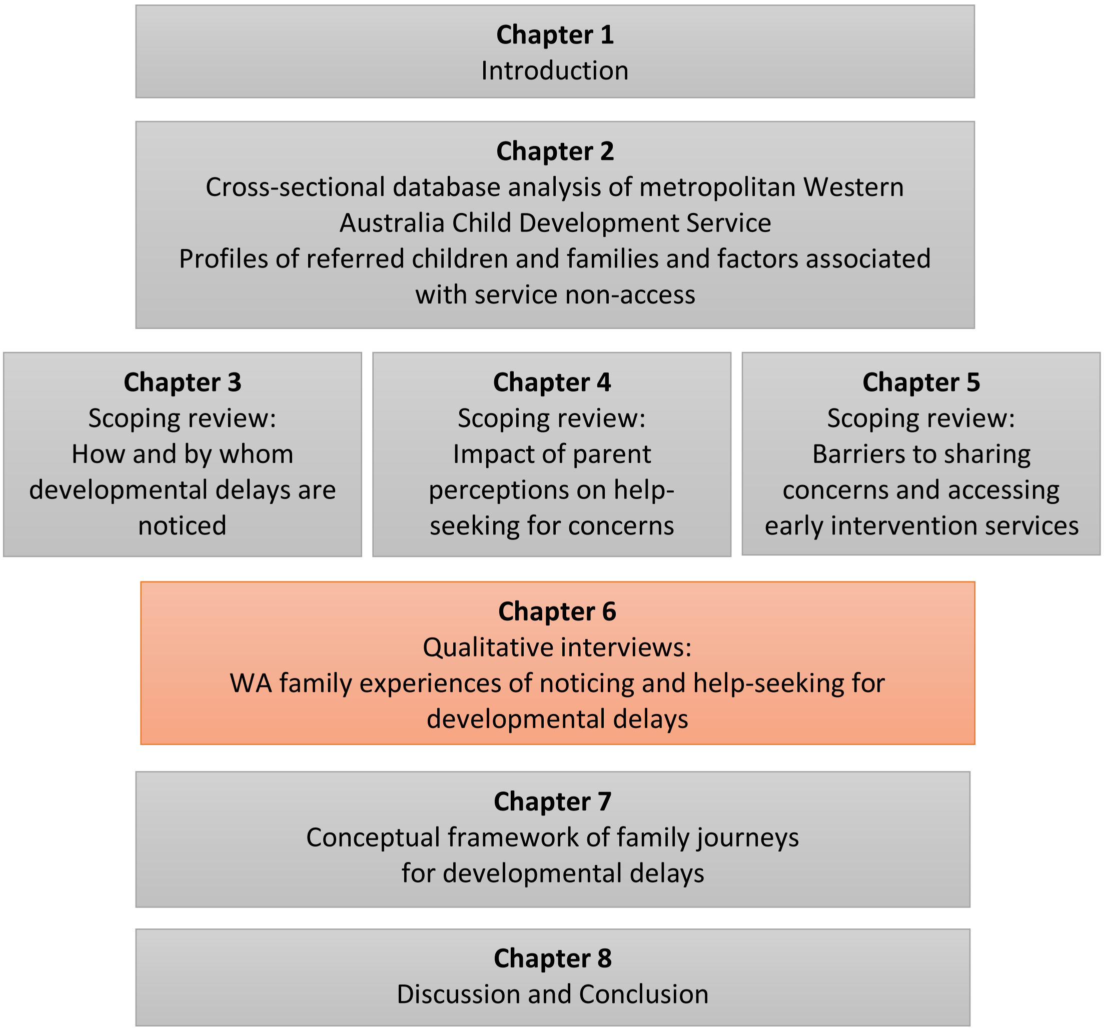
Woolfenden, S., Posada, N., Krchnakova, R., Crawford, J., Gilbert, J., Jursik, B., Sarkozy, V., Perkins, D., & Kemp, L. (2015). Equitable access to developmental surveillance and early intervention - understanding the barriers for children from culturally and linguistically diverse (CALD) backgrounds. *Health Expectations, 18*(6), 3286-3301. https://doi.org/10.1111/hex.12318

Worcester, J. (2005, 2005). Giving voice to parents of young children with challenging behavior. *Exceptional Children, 74*(4), 509-525. https://doi.org/10.1177/001440290807400406

Chapter 6 Family interviews

The scoping reviews presented in Chapters 3, 4 and 5 synthesised current research on the journeys navigated by families of children with suspected developmental delays. We have gained knowledge of how concerns are noticed and by whom; how parent perceptions of developmental delays and EI may impact on help-seeking; and how both family and service factors may act as barriers to successfully sharing developmental concerns and ultimately accessing EI services.

In Chapter 6 we apply this knowledge base contextually to understand what is happening for families in metropolitan Western Australia – beginning to answer the questions raised in Chapter 1 of how and why families experience service access difficulties.



Chapter 1
Introduction

Chapter 2
Cross-sectional database analysis of metropolitan Western Australia Child Development Service
Profiles of referred children and families and factors associated with service non-access

Chapter 3
Scoping review:
How and by whom developmental delays are noticed

Chapter 4
Scoping review:
Impact of parent perceptions on help-seeking for concerns

Chapter 5
Scoping review:
Barriers to sharing concerns and accessing early intervention services

Chapter 6
Qualitative interviews:
WA family experiences of noticing and help-seeking for developmental delays

Chapter 7
Conceptual framework of family journeys for developmental delays

Chapter 8
Discussion and Conclusion

Understanding parent experiences in noticing, sharing concerns and accessing services for children with suspected developmental delays

6.1 Abstract

More than one in five kindergarten-age children in Australia have difficulties with how they move, use their hands, communicate or play and interact with others. Although a significant number of studies have privileged the voice of the family in unpacking their experiences of developmental delay, a relatively small portion of studies relate to the experiences of Australian families. The current study aimed to explore the experiences of parents of children with suspected developmental delays in noticing concerns with child development, sharing concerns with others, and accessing early intervention services. The study was a qualitative design, using a phenomenological approach to explore caregiver experiences via semi-structured in-depth interviews. The thirteen participants were caregivers (predominantly mothers) of children with suspected developmental concerns who lived in Perth, Western Australia. Data were analysed using thematic analysis. Six themes were developed from the data: noticing a difference; making sense of difference; chasing answers; being heard by professional; fighting through the system; and the uniqueness of families. Family experiences, both positive and negative, were critical to how (and if) families progressed through to accessing EI services. While this sample of predominantly mothers were diverse in their backgrounds, many of their experiences contained shared narratives – highlighting commonalities in the factors that may inhibit family journeys to help-seeking.

6.2 Introduction

More than one in five kindergarten-age children in Australia have difficulties with how they move, use their hands, communicate or play and interact with others (Department of Education and Training, 2019). However, many children with developmental concerns or delays are slipping through the net and not receiving early intervention (EI) support (Williams & Holmes, 2005). Significant disparities exist between rates of parental concerns about child development and the seeking out of services and supports, with a mismatch between numbers of children identified, referred for and receiving support for developmental delays (Hebbeler et al., 2007; McManus et al., 2009; Rosenberg et al., 2013). A 2012 Australian study reported that 18% of children at school-entry were considered to be developmentally 'of concern' – yet only 15% of this group had attended EI services, constituting significant levels of unmet needs (Goldfeld et al., 2012).

As was identified in the scoping reviews undertaken in Chapters 3, 4, and 5 of this thesis, families commonly undergo a complex process of noticing suspected delays, determining whether those delays are 'big enough' to act on, as well as a range of experiences when attempting to access services themselves. A significant body of work has sought to privilege the family voice in unpacking experiences of developmental delay (Giordano, 2008; Harris, 2009; Hendrickson et al., 2000; Magnusson et al., 2017; Marshall et al., 2017; McAllister et al., 2011; Morton, 2012; Mulcahy & Savage, 2016; Persoff, 1998; Ramirez, 2004; Rannard et al., 2004; Shannon, 2000; Silbersack, 2014; Smith et al., 2015; Smith et al., 2010). However, only a relatively small portion of the studies relate to the experiences of Australian families (Ahern, 2000; Alexander et al., 2015; Eapen et al., 2017; Green et al., 2016; McAllister et al., 2011; Williams, 2007; Williams & Holmes, 2004; Woolfenden et al., 2015), with the majority of previous research on experience of developmental delays coming from the United States (U.S.) and the United Kingdom (U.K.).

While all three countries share similarities, there are key differences in how each nation funds and delivers their health care systems – such as levels of public system financing, the role of private insurance and the delivery of primary care (Mossialos et al., 2017). Each of these elements will therefore have an impact on the families' experiences in seeking EI supports, with pathways to accessing care and some barriers experienced being context-specific. For example, different age-related eligibility cut-offs for EI services (Giordano, 2008). This consequently means that drawing from research in other developed nations will not necessarily reflect the needs of Australian communities (Williams & Holmes, 2004). Thus, further research is needed to understand the experiences of Australian families of children with developmental delays and begin developing a context-specific understanding of what families need to support their journeys.

Australia's health care system, including the primary health care and community-based services, is largely regulated and delivered at the state and territory level (Australian Institute of Health and Welfare, 2020a). Exploration of family experiences therefore needs to begin with an individual state and/or territory in order to be reflective of and understood in relation to how each system operates. Thus, the 'lens' of this study focused on the state of Western Australia (WA). The study aimed to explore the experiences of WA caregivers of children with suspected developmental delays in noticing concerns with child development, sharing concerns with others, and accessing EI services.

6.3 Methods

6.3.1 Study design

The study was a qualitative design, using a phenomenological approach to understand caregiver experiences via semi-structured in-depth interviews. The in-depth interview method was selected to gain rich information about each parent’s unique experiences (Liamputtong, 2012), prioritising the ‘depth’ of family’s accounts as per phenomenology. Interview format also helps to build one-on-one participant-researcher ‘intimacy’ to facilitate safe disclose of sensitive content (Liamputtong, 2007). Ethical approval was received from the Curtin University Human Research Ethics Committee (HRE2018-0712), see Appendix E.

6.3.2 Participants

Participants were caregivers of children with identified (but not necessarily diagnosed) developmental concerns or delays living in Perth, Western Australia. These caregivers were somewhere along the continuum of having suspected concerns with their child’s development; shared those concerns with a friend, family member or health professional; taken some action towards seeking support (i.e., had been referred to a service); and/or had received some level of EI therapy and/or support services.

6.3.3 Recruitment

Caregivers were recruited from across metropolitan Perth using both purposive and snowball sampling. Targeted recruitment occurred by contacting community organisations such as early childhood education and care centres to discuss the project and families who may meet the eligibility criteria. Organisation staff (e.g. childcare directors) spoke to eligible families within their service about the project, who then permitted staff to provide their contact details to the research team. Recruitment flyers and information sheets (see Appendices F and G) were also disseminated through early childhood networks – including early childhood mailing lists (e.g. Playgroup WA monthly newsletter), websites, and social media. Recruitment continued until saturation was deemed to have been reached; i.e. when limited new data were being generated (Liamputtong, 2013).

6.3.4 Data collection

Interviews were conducted in a setting of the participant's choosing – their own home, their child's childcare centre, a private meeting room in a community library, or café. Interviews took between 45-70 minutes (depending on the caregiver's stage of progression in accessing services) and were all audio recorded for later transcription. Written caregiver consent was obtained prior to interview commencement (see Appendix H). Some of the interview questions were based on findings of three scoping reviews (Chapters 2, 3 and 4) that reported on caregiver experiences of noticing developmental delays, sharing concerns with others and seeking to access services. Other questions focused on asking families to share what had been useful or helpful to them, as well as suggested changes to help facilitate family experiences – see Appendix I for interview guide. A brief demographic questionnaire (see Appendix J) was completed with participants before the interview to provide a rich, 'thick' description of the sample's characteristics and enable determinations of potential for transferability (Liamputtong, 2013). Questions were piloted with a parent of a young child with developmental concerns to test for feasibility, appropriateness and timing. In recognition of the time and effort, participants were given a $20 gift voucher and reimbursed for associated costs such as creche.

6.3.5 Data analysis

Audio recordings of the interviews were transcribed verbatim for analysis. Thematic analysis of transcripts was conducted using NVivo software (QSR International, n.d.), following the six-phase guide to reflexive thematic analysis (Braun & Clarke, 2006; Braun & Clarke, 2019): familiarity with the data set; generating initial codes; searching for themes; reviewing themes (and producing a thematic 'map'); defining and naming themes, and producing the analytical report presented here. Analysis began during the data collection phase to support decision-making regarding sampling and saturation (Liamputtong, 2012). A number of steps were taken to enhance both the rigour and transparency of data collection and analyses, as well as documenting the active engagement of the researchers with the data – in line with the reflexive thematic analysis approach (Braun & Clarke, 2019). An initial sample of transcripts was separately coded by all members of the research team and then discussed collaboratively to identify the range of themes being developed; with ongoing discussions of coding and themes with the research team throughout the analysis. This process ensured a collaborative, nuanced analysis of the data by the research team – as opposed to merely seeking a shared consensus on meaning (Braun & Clarke, 2019). To enhance dependability of the data, a clear audit trail was followed to enable clear identification of links between raw data and final findings and decisions made throughout this process (Liamputtong, 2013). The lead researcher/sole interviewer also maintained a journal to reflect on both interviewing experiences and thoughts throughout the process to track for the emergence of biases and/or initial themes that may later impact the data analysis process.

6.4 Results

6.4.1 Participants

Thirteen caregivers were interviewed. Twelve were mothers, while one was a grandmother and legal guardian.

Table 6.1 provides an overview of participant characteristics.

Participants discussed a wide range of concerns relating to their child’s behaviour, speech and language, motor skill attainment, ear nose and throat (ENT) issues, and physiological concerns (see

Table 6.2). Some suspected these concerns related to specific diagnoses such as autism spectrum disorder (ASD); several were later proven correct. Six participants had multiple children with suspected concerns.

Table 6.1 Caregiver demographics

Parent pseudonym	**Age**	**Relationship to child**	**Location**	**Level of education**	**Profession**
Leanne	35	Mother	South East Metro	University	Accountant
Rachel	38	Mother	East Metro	University	Caregiver (former nurse)
Brooke	33	Mother	South Metro	TAFE	Enrolled nurse
Renee	33	Mother	South Metro	TAFE, some university	Catering, cultural advisor
Sonya	35	Mother	South Metro	University	Caregiver (former teacher)
Helen	29	Mother	South Metro	TAFE, some university	Assistant accountant
Pamela	52	Grandmother, guardian	Peel	TAFE	Caregiver, retiree
Madison	33	Mother	Peel	Secondary school	Caregiver
Janine	27	Mother	South Metro	TAFE	Caregiver
Fadzi	37	Mother	North Metro	Primary school	Caregiver
Melissa	42	Mother	South Metro	TAFE	Caregiver
Jessie	28	Mother	South Metro	TAFE	Caregiver
Sarah	39	Mother	Avon-Midland	University	Teacher

Table 6.2 Child characteristics

Caregiver	**Children's pseudonyms**	**Age**	**Gender**	**Nature of concerns**
Leanne	Alex	4 years	Male	Behavioural (eating, social/emotional; suspected ASD)
Rachel	Jackson	2 years	Male	Feeding/low weight; gross motor; behavioural
Brooke	Henry	6 years	Male	Speech (articulation and lisp)
	James	3 years	Male	Physiology (ankles)
	Ava	9 months	Female	Developmental hip dysplasia
Renee	Ryan	14 months	Male	Gross motor; speech; social/behavioural
Sonya	Amy	6 years	Female	Gross motor; hip dysplasia; speech; behaviour
	Lila	3 years	Female	Gross motor
Helen	Isobelle	13 months	Female	Hip dysplasia
Pamela	Cooper	4 years	Male	Physiology (feet/ankles)/gross motor; ENT issues
	Justin	3 years	Male	Speech; behaviour; ENT issues
Madison	Zac	4 years	Male	Speech; behaviour (ASD diagnosis)
	Jules	3 years	Male	Speech; behaviour; ENT issues; possible ASD
Janine	Brodie	2.5 years	Male	Speech; behaviour; possible ADHD/ASD
Fadzi	Joseph	4 years	Male	Speech
Melissa	James	3 years	Male	Behaviour/play; speech (diagnosis of ASD)
Jessie	Kyle	3 years	Male	Global developmental delay
	Clayton	2 years	Male	Speech; behaviour (diagnosis of ASD)
Sarah	Oliver	8 years	Male	Speech; behaviour (suspected possible ADHD)
	Tabatha	2 years	Female	Speech, physiology (neck)

6.4.2 Findings

Six themes were developed from the data: noticing a difference; making sense of difference; chasing answers; being heard by professionals; fighting through the system; and the uniqueness of families.

6.4.2.1 Noticing a difference

Every participant had positive, loving things to say about their child with several participants acknowledging that every child was different, unique, and developed at different paces. As "Fadzi" stated: "I hope so everything will be all right. Because every child has his, you know, how to goes his life. Sometimes they walk early, or sometime late…you know, different. Every kid is different." However, this posed some difficulties for them as they also acknowledged the fine line between development that was slightly off the norm, within the acceptable timeline of development, or was of real concern. Participants began to suspect differences with their child in two main ways: social comparison; and knowledge.

All participants spoke of comparing their child to others - seeing the diversity of their child's development and the positives in their child. Comparison to the development of their older child was one way three participants realised there might be developmental concerns. As "Melissa" described, "I feel like we had a feeling…because we had Imogen already and she was so easy. And he was completed different." Participants without an older 'reference point' often became concerned when they had a younger child, and they could see the differences between the younger child's development and the development of their first child. Others compared their child to nieces and nephews, children in their mothers' groups, or the broader community. Several participants, like Melissa, spoke of specific moments of comparison:

> So it all came about when I had a play date with a girlfriend who has a daughter around the same age as James… she was picking up all these little plastic vegetables and fruit pieces that she had…and was naming them all and playing with them and I was just going, oh my God, like James is not talking. You know, I got that holy-crap sort of moment…

Several participants mentioned a family history of similar concerns to their children which appeared to function as a sort of comparison – how is that family member now, did their issues resolve – and so what should I do?

Participants constructed knowledge as knowing what was or was not typical development and knowing “where their child should be” based on rough ideas of milestones. Participants began to suspect differences in their child’s development when this deviated from their expectations. As Melissa described:

> …because he has behavioural problems. And they were more than just a typical toddler, you know. It wasn’t just a tantrum. They were massive meltdowns that would last for over an hour and things like that so we knew that it was more than just a normal kid.

Participant knowledge of child development was influenced by their past experiences, particularly level of exposure to children – whether they had friends or family with children, had worked with children, or had younger siblings to learn from. One participant, who was the primary carer of her two grandsons, discussed her experience of raising her own child and having knowledge from that; but then finding that developmental advice had since shifted. Many participants noted that they did not know important information - such as language milestones or diagnoses such as ASD. For “Renee”, information about development made her look at her child differently:

> If we didn’t have a thing where people say kids should be doing it, if I hadn’t read that I’d think he was a fantastic kid…if there wasn’t a thing saying, okay, he’s delayed…I would think he’s just fantastic he’s just so chilled out and happy.

6.4.2.2 Making sense of difference

The process of participant responses to noticing differences in their child's development evolved over time. Many knew or had a gut feeling that something was different but could not quite determine what. Participants expressed undergoing a rationalising process - attempting to understand and explain the differences they saw in their child. Many reasoned that it was something their child may grow out of - that they needed time, experience, exposure - and wanted to allow for this before they acted. "Sarah" explained, "Okay, we'll take a step back, maybe he'll grow out of it, he is a typical boy, boys are always like that, and he's still young...this year we're 'Right, that's it, we're getting him investigated'."

Participants experienced a wide range of emotions associated with the noticing process. Many were confused, worried, in denial, and even grieving for the child they had imagined. Renee explained, "I think you don't want to admit that your child's a little bit, like, slower than others so we kind of put it off for a while and sort of ignored [it]." Almost all felt uncertain because of the unknown and wanted answers; some blamed themselves for why it had happened. Some participants discussed specific social experiences where they had acutely felt the difference between their child and others, like "Sonya":

> All your friends' kids are pulling themselves up on tables and riding little bikes…and your kid just sits there like a bag of potatoes…I just felt miserable because I didn't want to see their kids doing what when mine couldn't.

This extended to the impact of social gaze - having others, at times people unknown to them, making comments about their child - and how awful this made them feel.

Participants frequently discussed suspicions about their child's development with family and friends, and some reported that it was family members who flagged a concern as something that needed action. Some participants reported that although family members did not oppose acting on concerns, many did not think there was a need for further action. Where family members did not share concerns, this confused participants like “Rachel” further: “But then, you know, someone else would say, ‘Oh, he’s just small’.” Other family members, such as partners, were described as being ‘really panicky about it’ or ‘adamant’ about getting support.

6.4.2.3 Chasing answers

All participants spoke about doing their own research to understand their child and what was happening for them. They utilised many sources – family and friends, professionals, informational booklets, research papers, websites, and social media. Mothers’ groups and playgroups were often used (mainly by first-time mothers) as a sounding board for worries. Several participants spoke of a process of discerning what was reputable information and having to ‘wade’ through the advice of others to determine what was trustworthy. “Leanne” expressed, “Sometimes the information, it just rubbish and you think ignore that [laughs] but sometimes some mums, they have very good experience.”

Participants did their research because they wanted specific information – on child development, conditions and services, general parenting, parenting a child with specific concerns, and on how they could support their child. They also wanted to ask questions of others who had similar experiences. Participants reported that information helped them make better sense of their child - at times alleviating their concerns entirely. It also relieved the sense of guilt some participants experienced over how their child’s concerns had arisen. This was “Brooke’s” experience: “I think the biggest thing for me was finding out that, if a child has an underlying speech development issue, then that is that’s own issue and the bilingualism isn’t the problem…So that’s ... I found comfort in that”.

6.4.2.4 *Being heard by professionals*

Participant needs and their level of trust in the source of information determined which professionals they approached for help. Childcare educators and GP whom the families had long-standing relationships with were common sources. Many participants, however, spoke about negative experiences with professionals that made them feel ashamed and judged. There was a shared narrative particularly about child health nursing experiences that resulted in participants feeling shamed, judged and devalued - and therefore not returning to the service. As Melissa described:

> So in those first two or three weeks it was really, really difficult for me and this health nurse that I had was not sympathetic to the cause…So James did have his first few checks but then I was like, 'You know what? I can't see that woman anymore'.

All except two participants reported questioning some aspects of their child's development before professionals raised a concern - but the catalyst for action for many was when the professionals shared the concern or raised other concerns. Rachel sought out her child health nurse to get advice about her son's behaviour – in the course of that interaction, his gross motor development and other concerns were additionally flagged. As "Jessie" discussed*:*

> Because he was so young, we just thought that was his personality…but then I think we went to one of his baby check-ups with the health nurse. And she kind of picked up on a few things…[I] felt like I wasn't crazy…I wasn't the only one noticing it.

In the same way that families and friends often dismissed participant concerns, so did some professionals. Almost all participants told stories of times they had raised their concerns with others and were reassured that there was no need to worry. For some families, such responses caused them to stop questioning - until, in many instances, the concerns did not go away as promised. These families saw such responses as being ‘brushed off’, rather than reassured. As “Madison” explained, “Even when I’ve questioned a few things about Zac’s behaviour, a lot of the time you get told, ‘Every kid’s different, they all develop differently’…it didn’t matter who you talked to, they would just always brush it off.” These experiences forced participants to seek out others to share their concerns within the hope that someone else would take them seriously.

In some cases, this took several attempts or even continued to be an ongoing battle. “Janine” attended four different GPs at two different practices about her son’s speech before one provided her with a referral, but only for a hearing test. Her son was two years old and had seven words of expressive language; “Why did I have to see four different GPs to get one referral? Come on. It shouldn’t matter if I’m an overprotective mother or an overbearing mother. I know him best.” Several participants noted that their child presented differently during assessments, which therefore did not show their ‘true’ self and led professionals to either be unable to make a decision or to determine that all was fine.

6.4.2.5 Navigating through the health system

Participant accounts of connecting with and accessing services were mixed and predominantly negative, a ‘fight’ or a confusing experience. Participants did also speak of positive experiences and what made them successful and expressed hopes and recommendations for both other parents and services.

All participants wanted the best for their child – even if they did not know what that entailed. Many however expressed that what it took to do this was to fight with the system – fight to be seen and heard, get the second opinion, get the referral, and the answers and actions they needed. ‘Fighting’ was uncomfortable for many of the families. They identified that questioning and pushing did not necessarily come naturally to them, but they had to learn to get comfortable doing so – otherwise, they risked not getting what their child needed. Some like Janine, who received much pushback from professionals, emphasised the ‘so what’ aspect – “Get them to do their job because at the end of the day, … if it was nothing, oh well, at least you got it checked…And if it was something, what if you didn’t?” Participants like Madison emphasised that parents needed to trust their instincts - “I think just as a mum you’ve just got to go with your gut and just go, no, something’s not right and, yeah, just keep pushing for answers if you’re not happy with it.” Part of trusting their ‘gut’ was acting on it early – not waiting for others to notice.

Several participants spoke of system ‘hacks’ that made their journeys more successful. This included regularly calling services to check for cancellations; paying extra through private services to bypass public waitlists; requesting rather than waiting for referrals; having ‘ammunition’ through documentation to present their case; and ‘playing up’ a child’s concerns to get higher levels of funding. Some reflected that while knowing these hacks had worked out well for them, they felt for those families who did not know about them. This was summarised perfectly by Renee: “Interviewer: So it’s up to you to fight for your kid?” - “Yeah, but in an ideal world, it’d be good not to have to.”

Pathways to accessing services were often convoluted and involved multiple touchpoints between different services and professionals. Reports of false starts included being referred to an adult rather than a paediatric service and thus requiring another GP visit and referral, as well as multiple accounts of paperwork getting lost by services. As Sonya explained*,* “We put her on the waitlist for PMH. The paperwork got lost, didn’t get my referral and I think within a year we were through PMH … yeah, so that took a while.” In several cases, participants had to work through a ‘process of elimination’ to determine what was happening for their child, such as checking their hearing before exploring speech concerns. In contrast, others had to prioritise resolving health issues first, such as adenoid removal. Services were largely described as being difficult to find – that there is a lack of 'signposting' of what is available – and that they are 'siloed' – only knowing about the services they offered or in the immediate area. This meant that even services did not know about other supports to recommend to families, and so participants like Rachel had to find this out for themselves:

> …and maybe the stuff's not too hard to find, but it just seemed like it was an effort for me…I need to find one, you know, Circle of Security, that's going to be in the evening and then somewhere close…And that was just lucky that I happened to find one.

Participants provided suggestions for how they wanted services to disseminate information better, making it clear that a single solution would not work for everyone. Strategies included word of mouth, having information available from common 'hubs' people access, and having a single online portal where families could access information on services in their area – rather than visiting individual sites.

Waiting lists, especially in the public health system were long and resulted in many weighing up waiting with the cost of alternate pathways. However, not all families had the financial capacity to access private services; as Sonya explained, this highlighted the inequity of the system – that queue-skipping was mostly only possible if the individual could pay for it: "Which makes me, like, feel for people who can't afford to go private and don't have that option…waiting two years is ... in those two years, you could have made a difference." Waiting meant uncertainty and often a building sense of worry about their child, with participants feeling that they were not provided with interim strategies that would support their child while they waited. Many expressed that waiting meant the window of opportunity to access intervention at a critical developmental stage was closing. Madison captures this:

> It’s just sad how long you have to wait in the public system to try and get your child help because the system’s just so … I feel as though it’s broken, to be honest. The waitlist is a joke. Your children need help... it’s just such a precious time for them to be learning and catching up and he’s really, really delayed.

Participants understood that waitlists are system-wide issues and not one that can be resolved overnight – but called for more funding and staffing to reduce them.

Some participants chose the private service pathway but had to later return to public services when they could no longer afford private options. Madison’s family outlaid thousands of dollars investigating her son’s reoccurring ear issues – to the point that her husband had to change to higher-paying, fly-in fly-out work to begin working off this debt. Several participants spoke about high costs for allied health services that their child needed to receive regularly to see benefits. Schemes such as Medicare-covered visits quickly dried up leaving participants to have to cover expenses. Cost also mattered when participants began to receive NDIS funding. Participants spoke about receiving advice to ‘play up’ their child’s concerns in order to qualify for a higher bracket of funding – acknowledging that more funding meant a greater ability to access support for their child, and less out-of-pocket for them. One parent Madison spoke about feeling ‘bullied’ by the NDIS, after she was told they would give her a higher level of funding for her son if she selected a specific provider:

> And then they said, ‘Look, if you go with this one company, we’ll give you that.’ And I thought that was really wrong because we didn’t get to see the rest of the services or anything like that, whereas I was just desperate to get my son the most amount of hours and money to go that way, because no family can really afford that amount of money.

As Madison explained, accessing adequate services for their children was an expense that many families could not afford, even for those who did receive support under different schemes.

Service location and transport were mentioned by several participants, with proximity to their residence making a difference. As Renee reported, this was important if reliant on public transport, as a 30-minute car trip could take two hours by public transport. Location issues were not necessarily negated through the provision of home-based services. Madison explained that receiving therapy at home was more expensive – so she chose to travel to appointments to save on cost.

The public health system created further challenges as participants were commonly automatically allocated appointments, often via mail, on days and times that were not necessarily convenient. Choice in appointment times was important because five participants were in paid employment and eleven had other children's needs to consider. Participants found services with online or email bookings both easier to access and more flexible to schedule - as it was difficult to make contact with the correct person when trying to reschedule appointments via phone call. Almost every participant spoke about having to follow up on something – having to chase services for information, appointments and/or answers. Participants felt that the onus was placed on them to do this – if they left it to the system, their child could be forgotten. Given that one-third of the participants spoke about lost paperwork, these concerns appear well-founded. As Janine expressed:

> I've had my paperwork lost three times…How can you lose it? What are you doing with it?…by chance, we got into [service name] because she's like, "I was walking past the printer and I saw your file and thought we'd call you." Come on. I don't understand their system.

Participants spoke highly of services that provided flexibility in appointment making and those who offered a 'drop-in' style model. These services provided reassurance that if they did have questions, they could readily access professionals in a casual, informal way. This was Sarah's experience: "We have more health nurses there [at the library play sessions] once a week, just wandering and see, and easy enough to contact. E-mails and things. We get e-mails sent out. Anything you mention, she'll just send some information."

Participants also wanted services to acknowledge, consider and begin to accommodate their diversity of needs, such as managing multiple children. As Brooke explains "…it's really hard going with your first child because everything's new, but it's a whole different dimension when you have other children and your newborn baby. It's logistically very difficult as well."

Participants discussed their experiences with professionals' communication style, with many families finding services to be impersonal – from experiences of a centralised booking system through to a lack of continuity due to staff turnover. "Helen" described a negative experience she had in trying to make an appointment for her daughter's hip dysplasia. "…people don't call the hospital cause they're in a happy mood…You don't go there because you're a perfectly healthy human being. So don't then make people's lives harder by being like that." Some participants received mixed messages between professional visits. A therapy team told Fadzi that her son would need to attend a specialist school: she felt uncertain about this, but went away, shared her concerns with others, and decided that she was comfortable with the decision – only to be told that her son could not be referred to the school. Several commented that the information they received from professionals was outdated or inconsistent – which led to confusion as to what was the correct advice.

Participants spoke about appreciating the continuity of care: many had childcare educators or GPs that they had seen for several years, had an established relationship with and thus trusted - and spoke of the value of this. Helen stated, "Find a good GP. Someone who's got your back and will go into bat for you." Families expressed gratitude to professionals who went above and beyond to help them – professionals who actually 'cared'. This was Madison's experience with an ENT surgeon after months of trying to find help:

> So we got this great guy and he said, “Right, I’m on at this time, call me. Here’s my card and we’ll do it.”…it was just really nice just to get someone who actually cared and really worked the system

Participants wanted professionals to treat them with respect – as Helen said, “treating the parent as the one who knows the child best.” Part of this was validating what they were experiencing, listening to their concerns, and affirming that they were doing the best they could. They also appreciated those who considered the needs of the family as a whole. As Jessie explained:

> I definitely notice every appointment we kind of go to, they ask if we’re okay, if we have support …I think we saw a social worker at [service name]. And he was probably the most helpful for us. Like asking what we do to just relax.

Participants also welcomed being giving information on the reality of the situation. For Sonya and Sarah, honesty meant having professionals not ‘sugar coat’ what they said about their child – as honesty then meant action.

All participants talked about the importance of support from family and friends – someone to ‘vent’ to, talk through their experience, provide practical assistance, or simply be there for them. As Madison explained, “Get as much support as possible. Having a good support network is crucial, I think.” This support was not just about their child, but with all the other everyday experiences that families have. Many participants sought out others with common or shared experiences, either in the same situation or who were further along on their journeys that they could learn from - or at least be lost together. Several developed meaningful friendships from other such families who had unique insights into what they were going through.

6.4.2.6 Uniqueness of families

In addition to their experiences related to the child of concern, participants spoke about other factors that overlaid their journeys - some related to their own physical and mental health. Brooke and Melissa experienced peri and/or postnatal depression (PND) – both partly due to unresolved trauma following a miscarriage that they were seeking counselling and support for with varying degrees of success. Brooke, who experienced PND following each of her three pregnancies, strongly expressed the view that to parent her children, she first needed to be well herself and that this was important for other parents to recognise for themselves. Being pregnant with another child when caring for the child of concern also had an impact; Sonya described the time of her second pregnancy as a 'blur', trying to manage her unwellness with supporting her daughter's needs: "I didn't know I was pregnant… I actually thought I had cancer and I was dying [laughs] because I was so sick...I just couldn't believe I'd fallen pregnant and life was just hard with Amy". Fadzi had felt too tired from her pregnancy to bring her son to play sessions and wondered if by not going she inadvertently caused his delays.

Four participants spoke about their education and work backgrounds being positive contributors to how they managed their children's journeys. Brooke's nursing background empowered her to be more questioning of health professionals. Sonya and Sarah spoke of the influence of their teaching experiences provided knowledge about child development and created an awareness of the need for EI – prompting them to want to act on concerns. Helen spoke of how education in general, particularly at a university level, helped her to be critical of information such as on child development**.** However, both Brooke and Sonya believed that other experiences were more impactful on their journeys. Sonya stated, "I think that overrides my education background, like…and being tertiary educated, even having money. I think, having family and friends who have your back is better than anything else."

Five participants spoke of the cultural and linguistic diversity of their families. Both Leanne and Brooke spoke about their beliefs (previous and current) that being from bilingual households had delayed their children’s language acquisition. Fadzi came to Australia from Sudan and spoke about the loneliness and isolation from being away from her family for almost 20 years. Sarah spoke about the influence of her English background on making her want to push to act on her son’s developmental concerns early, while Renee talked of her hopes of accessing early physiotherapy for her son through Closing the Gap funding.

Other family factors influenced the family’s experiences. Janine and Renee spoke about the impact of mainly being their children’s sole caregiver – and how this placed full responsibility on them alone. Pamela and Janine opened up about early harmful environments that they tried to protect their children from, such as domestic violence and in-vitro drug exposure. They worried about the impact of these experiences on their children’s development. Families with several children had to try to balance their child's needs with delays with the others. Jessie talked about feeling unable to engage in public outings due to her son’s meltdowns and how this impacted her older daughter.

Experiences became further complicated for families with multiple children with concerns, such as managing multiple appointments for different children. Madison, Sonya and Pamela spoke about managing the interactions between their children to minimise conflict, describing it as having to ‘referee’ all day – and how exhausting this was. On a more positive note, there was a level of insight that came from already having navigated the pathway for one child – they had knowledge of the system, how it works, what to do, and how to navigate it, and were more confident in seeking out supports early.

6.5 Discussion

This study identified several stages that families of children with suspected developmental delays appear to progress through; initial noticing of the concern; a decision-making process in determining whether to act on concerns; sharing concerns with others including family, friends and professionals; referral to services; before reaching EI services themselves. Through each stage, both positive and negative family experiences and contexts appeared to be critical to how (and if) they progressed to the next stage. While this sample of caregivers was diverse in their backgrounds, many of their experiences contained shared narratives – highlighting that there were commonalities in the factors that may inhibit family journeys to help-seeking.

Findings regarding how families noticed concerns with their children's development align with Chapter 2 (Cuomo et al., 2019). As per scoping review findings, families in this sample began to notice concerns via social comparison with other children or through using their knowledge of typical development. Findings also echoed the notion of 'mother's intuition' about their child (Cuomo et al., 2019), with participants encouraging other families to trust in this feeling despite knockbacks or brush offs they might receive from others. Identifying that WA families also utilised these two mechanisms for noticing has implications for intervention. It means that if developing the capacity to notice concerns is to be promoted in order to initiate help-seeking and EI service access, services need to approach noticing in a two-pronged way – through continuing to provide knowledge of child development through various means, as well as facilitating and encouraging opportunities for comparison.

In 2013-17 the Western Australian State government funded the Child and Parent Centre (CPC) initiative to support the health, development and learning of young children and their families via a series of 'one-stop-shop' centres across the state (Government of Western Australia, n.d.). A 2017 evaluation (while relatively broad brush in nature) identified that the CPC initiative was meeting objectives such as building family capacity to provide nurturing environments and child development outcomes, through providing playgroups, parenting workshops and having access to developmental information via health professionals (Shelby Consulting, 2017) – resources that may facilitate both social comparison and building knowledge of child development. There is a need to evaluate how opportunities like those provided by the CPC initiatives may contribute to noticing delays and also ensure they are accessible (and welcoming) to a diverse range of families.

Many of the caregivers underwent a complex process of making sense of their child's concerns – attempting to rationalise, explain and/or understand what they were seeing in the context of what they knew or understood about child development. This process is in line with previously conducted research regarding parent health beliefs as seen in the Chapter 3 scoping review. Additionally, there is a need to consider and respect the processing that families undertake, which notably includes a vital emotional element. Feelings of guilt were experienced by several of the interviewed families relating to the impact of their actions and parenting skills and how this may have negatively impacted their children. Acknowledging this complex process may go some way to explaining why we see differences in timelines between noticing, help-seeking and service access between children with developmental delays and those with more 'clear cut' developmental disabilities (Hebbeler et al., 2007).

Previous research has identified that caregivers may be reluctant or uncertain about how or who to share their developmental concerns (Alexander et al., 2015; Marshall, 2013; Morton, 2012; Silbersack, 2014). This may relate in part to being unsure about the role of different professionals and the appropriateness of sharing developmental concerns with them – which was expressed by some of the families about the GP's role. Findings also identified that many families had negative experiences with some professionals, resulting in them not having trust and thus precluding them from opening up. It is of great concern that families described experiences that had such an impact that it meant they discontinued accessing services such as developmental health checks with child health nursing (CHN). The discussed finding aligns with 2017-18 data collated by the WA Commissioner for Young Children that identified a steep drop off in routine developmental health checks: while 75-100% of children across the state are seen for their first postnatal check, this drops to 74-91% for 8 weeks, 70-91% for 4 months, 60-53% for 12 months, and only 29-44% for 3-year checks (Commissioner for Children and Young People, 2019). This translates to more than a half of eligible children going 'missing' from their 4-month check until the school entry screening. Concerningly, this has been found to be a consistent trend across Australia; the Longitudinal Study of Australian Children identified that only 32% of 2–3-year-olds and 12% of 4–5-year-olds had attended a maternal and child health nurse appointment (Warren, 2018). There is an urgent need to review the public CHN model and consider whether it is genuinely servicing families' needs in its current form.

Lack of signposting of both sources of information and available services was highlighted by many interviewed caregivers. There continues to be a perception that such resources are 'siloed' and lack the requisite knowledge and awareness of other similar services that they may be able to link families to. Families called for a central source or repository of information, to enable the collation of information in a single point as well as enabling them to search for and find what they were looking for without having to navigate multiple individual sources – such as a specific workshop in a specific area at a specific time. With several families also commenting on the need to 'sift' through information to determine its trustworthiness, such a portal could ensure that what parents are reading is in line with current evidence and best practice. The Telethon Kids Institute Child Development Atlas project may be the beginnings of this, whereby the locations and catchments of service and programs in WA are geographically mapped in an interactive tool (and overlaid with child health data) (Telethon Kids Institute, 2020). While the Atlas' key aim is to understand community needs versus available services to inform service delivery planning, it could be the beginning of bringing together diverse data sources to provide a ‘one-stop-shop’ resource for the wider community to access. Additionally, while the Commonwealth-government funded Raising Children website provides a host of parenting and developmental information (Raising Children Network, 2020), this source does not enable parents to ask questions or provide information on services - which caregivers identified as necessary. The existing structures just described could be further developed and built on to better meet family needs for information.

In line with previously conducted research, many caregivers in this study recounted experiences of ‘brush-offs’ or ‘false assurances’ from family, friends, and professionals about their child’s development. The ‘wait and see’ approach taken by professionals (and particularly general practitioners) has been well-documented as being a significant barrier to EI service access, both for those who do and do not ultimately access services (Giordano, 2008; Sices et al., 2009). It is of great concern that professionals themselves may be strongly impacting the EI journeys of many families of children with suspected delays. There is a need to establish a more effective, standard protocol for such professionals to follow when families raise concerns, as well as the strengthening of connections to services for developmental surveillance. An example of this may be increasing the co-location of GPs and CHNs to provide a ‘soft’ referral within the same physical location for families to connect.

Families discussed service communication, flexibility and accessibility as enablers to successfully engaging with services. With significant waiting lists meaning that appointments are in demand, we understand that the approach that services use to generate appointment times is to ensure that necessary timeslots are filled via allocation. However, as was addressed in the Chapter 2 analysis of CDS referrals and rates of non-access, this approach is not working for all families. There is a need to consider whether greater flexibility in appointment times and more systematic/straightforward processes of cancelling or rescheduling appointments would assist to mitigate the issue of non-access. Many health services have embraced technological advances that enable them to re-think how appointments are scheduled (Atherton et al., 2012). Providing alternate appointment-making systems provides choice to families, enables the swift provision of appointment invitations, confirmations and reminders via electronic media (as opposed to traditional mail which has inherent issues) as well as taking this burden away from staff in attempting to make and take calls and enables redirection of efforts elsewhere.

Waitlists are an endemic issue to many health services, with developmental services being no exception. An Australian Government Senate Inquiry identified ‘long waiting lists’ as one of three major areas of concern in speech-language pathology service provision {Commonwealth of Australia, 2014 #592;McGill, 2020 #550}, and individual states have each ‘grappled’ with how to reduce waitlists for developmental and/or behavioural referrals {Family and Community Development Committee, 2017 #641;Teoh, 2015 #640}. Waitlists in EI have consequences for the individual consumer, professionals delivering services, and broader society due to missed opportunity, particularly during the early years of a child’s life (McGill et al., 2020). To anyone who anecdotally knows the WA EI system, it would not have come as a surprise that service waitlists were a significant issue identified by caregivers. Families spoke of waiting months to years for appointments – such as Sonya, who waited two years to see a public paediatrician. It is of great concern that such waitlists go beyond what was recorded ten years ago via a 2009 state government committee (Education and Health Standing Committee, 2009). It appears not only that waitlists have not improved, but they have worsened further. While CDS introduced a new service model in 2017 that sought to connect families to the service early, such an approach has not yet reduced wait times for service appointments. It has only, as an aside, encouraged families to access private services - which was highlighted by this study as neither feasible nor appropriate for many families. A recent Australian study compared direct speech-language therapy with the provision of advice or website information as waitlist strategies. While there were no significant differences between treatments on outcomes of child intelligibility, language and early literacy or caregiver empowerment, the direct therapy group had higher levels of child speech and caregiver satisfaction (McLeod et al., 2020). The only real solution to wait times is therefore to increase staffing. Wait times for services such as emergency departments and surgeries are a political talking point and thus frequently reported on (Department of Health Western Australia, 2019, 2020b) – why aren't developmental services?

Families emphasised the value they placed on support throughout their EI journeys– with support conceptualised as coming from various sources and serving a range of purposes. Support from families in similar circumstances – who were navigating or had previously navigated similar journeys – was seen as particularly valuable in both getting guidance and support on what to do, as well as the simple nature of having someone who understood what you were going through. There is a myriad of organised support mechanisms for families with children with specific disabilities (such as autism spectrum disorder), however, few if any similar supports appear to be available for developmental delays more broadly – with many of our families finding this through organic or accidental means such as overheard conversations at a local Playgroup. While family's value and want this kind of shared experience support, mechanisms for creating such connection were not scoped. This is an avenue worthy of further investigation.

Even from this small sample, family diversity and complexity were apparent. All identified caregivers had experiences that impacted their journeys with their children. For example, the pragmatics of attending appointments when families have more than one child –

especially multiple children with developmental concerns. Accommodating such families by providing non-clinic-based appointments would go some way to acknowledging these experiences – and comes back to the previously made point around looking at ways to improve service accessibility to enable and improve rates of service access. Linked to this was the narrative about caregivers' 'fight' for their children at different points of their journeys. Some spoke about system 'hacks' they learned or were told along the way. More than anything, this served to show that the current health system does not work for the everyday family. This is particularly true in light of the identified complex family experiences relating to family domestic violence and drug use/in-vitro exposure; are services truly set up to meet the needs of these families? If knowledge of shortcuts is needed to successfully navigate services; if families need to pay high out-of-pocket costs to bypass waitlists; if they require tenacity to repeatedly voice their concerns and attempt to contact services after episodes of lost paperwork; then this precludes the participation of families who do not have the capacity to do so. This means that the families who ultimately miss out on service access are often the ones who need it most (Winkworth et al., 2010). Such findings clearly question whether families are 'hard-to-reach' or services are difficult to access.

This study focused on the experiences of WA families, reflecting Australia's health care system as being predominantly state-managed and thus inextricably linked to the individual state and/or territory services are received in. Further research is needed to understand the experiences of families in other Australian states and territories to determine whether the identified themes are shared nationally. This is particularly important given the introduction of the National Disability Insurance Scheme (NDIS) in recent years, including the Early Childhood Early Intervention (ECEI) program, which has sought to create greater national consistency in disability services provision {National

Disability Insurance Agency, 2014 #563}. In addition, this study focused predominantly on the experiences of families in the WA metropolitan area. It is well established that families living in regional, rural and remote areas can experience significant difficulties in accessing developmental supports. Research from the state of New South Wales identified added challenges of distance, the need for travel, lack of local services and long waiting times for visiting professional visit {Cumming, 2019 #639}. Further research on WA families outside the metropolitan area is required to better understand the unique and/or additional challenges experienced by families in the regions.

6.6 Conclusion

Families of children with suspected developmental delays experience unique yet complex journeys, from initial noticing of differences in their child's development, attempts to make sense of what they are seeing, chasing answers, trying to be heard by professionals, and navigating through convoluted health systems. A myriad of factors may either undermine or facilitate these journeys, with families experiencing barriers, such as the 'wait and see' approach from professionals or significant waitlists; as well as enablers such as the value of social support and continuity of care. Understanding service and system-level issues specific to Western Australian families provides context-specific recommendations for better supporting and enabling EI journeys for these families. Further research should seek to understand family experiences in other states and territories, and in regional, rural and remote areas of Australia.

6.7 References

Ahern, K. (2000). "Something is wrong with my child": A phenomenological account of a search for a diagnosis. *Early Education and Development, 11*(2), 187-201. https://doi.org/10.1207/s15566935eed1102_4

Alexander, K., Brijnath, B., & Mazza, D. (2015). Parents' decision making and access to preventive healthcare for young children: Applying Andersen's Model. *Health Expectations, 18*, 1256-1269. https://doi.org/10.1111/hex.12100

Atherton, H., Sawmynaden, P., Meyer, B., & Car, J. (2012). Email for the coordination of healthcare appointments and attendance reminders. *cochrane Database of Systematic Reviews*(8), Article No. CD007981. https://doi.org/10.1002/14651858.CD007981.pub2

Australian Institute of Health and Welfare. (2020a). *Health system overview*. Retrieved 13 May 2021 from https://www.aihw.gov.au/reports/australias-health/health-system-overview

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589-597. https://doi.org/10.1080.2159676X.2019.1628806

Commissioner for Children and Young People. (2019). *Developmental screening*. https://www.ccyp.wa.gov.au/our-work/indicators-of-wellbeing/age-group-0-to-5-years/developmental-screening/#05-health-checks

Cuomo, B., Joosten, A., & Vaz, S. (2019). Scoping review on noticing concerns in child development: A missing piece in the early intervention puzzle. *Disability and Rehabilitation*. https://doi.org/10.1080/09638288.2019.1708296

Department of Education and Training. (2019). *Australian early development census national report 2018*. https://www.aedc.gov.au/resources/detail/2018-aedc-national-report

Department of Health Western Australia. (2019). *Elective surgery wait list reports*. https://ww2.health.wa.gov.au/Reports-and-publications/Elective-Surgery-Wait-List-ESWL-reports

Department of Health Western Australia. (2020b). Emergency department live activity. https://ww2.health.wa.gov.au/Reports-and-publications/Emergency-Department-activity/Data?report=ed_activity_now

Eapen, V., Walter, A., Guan, J., Descallar, J., Axelsson, E., Einfeld, S., Eastwood, J., Murphy, E., Beasley, D., Silove, N., Dissanayake, C., Woolfenden, S., Williams, K., Jalaludin, B., & The 'Watch Me Grow' Study, G. (2017). Maternal help-seeking for child developmental concerns: Associations with socio-demographic factors. *Journal of Paediatrics and Child Health*. https://doi.org/10.1111/jpc.13607

Education and Health Standing Committee. (2009). *Healthy child - healthy state: Improving Western Australia’s child health screening programs*. Parliament of Western Australia Legislative Assembly. https://www.parliament.wa.gov.au/Parliament/commit.nsf/(Report+Lookup+by+Com+ID)/C03031FD0022E6D548257831003E97D1/$file/Report%202-%20Child%20Health%20Screening.pdf

Giordano, K. (2008). *Barriers to early intervention services in New Jersey* [Doctoral dissertation, Fairleigh Dickinson University]. ProQuest Dissertations & Theses. http://dbgw.lis.curtin.edu.au:2048/login?url=https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/304403224?accountid=10382

Goldfeld, S., O’Connor, M., Sayers, M., Moore, T., & Oberklaid, F. (2012). Prevalence and correlates of special health care needs in a population cohort of Australian children at school entry. *Journal of Developmental & Behavioral Pediatrics, 33*, 319-327. https://doi.org/10.1097/DBP.0b013e31824a7b8e

Government of Western Australia. (n.d.). *Child and parent centres*. https://childandparentcentres.wa.edu.au/about-us/

Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P. M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services. *BMC Health Services Research, 16*(1), 680. https://doi.org/10.1186/s12913-016-1926-0

Harris, S. R. (2009). Listening to parents' concerns: three case examples of infants with developmental motor delays. *Pediatric Physical Therapy, 21*(3), 269-274. https://doi.org/10.1097/PEP.0b013e3181b12fbc

Hebbeler, K., Spiker, D., Bailey, D. B., Scarborough, A., Mallik, S., Simeonsson, R. J., Singer, M., & Nelson, L. (2007). *Early intervention for infants and toddlers with disabilities and their families: Participants, services, and outcomes*. SRI International. https://www.sri.com/wp-content/uploads/pdf/neils_finalreport_200702.pdf

Hendrickson, S., Baldwin, J. H., & Allred, K. W. (2000). Factors perceived by mothers as preventing families from obtaining early intervention services for their children with special needs. *Children's Health Care, 29*(1), 1-17. https://doi.org/10.1207/S15326888CHC2901_1

Liamputtong, P. (2007). *Researching the Vulnerable: A guide to sensitive research methods*. SAGE.

Liamputtong, P. (2012). *Qualitative research methods* (4th ed.). Oxford University Press.

Magnusson, D. M., Minkovitz, C. S., Kuhlthau, K. A., Caballero, T. M., & Mistry, K. B. (2017). Beliefs regarding development and early intervention among low-income African American and Hispanic mothers. *Pediatrics, 140*(5). https://doi.org/http://dx.doi.org/10.1542/peds.2017-2059

Marshall, J. (2013). *Parent pathways: Recognition and responses to developmental delays in young children: A mixed-methods exploratory study* [Doctoral dissertation, University of South Florida]. Scholar Commons. http://scholarcommons.usf.edu/etd/4534

Marshall, J., Adelman, A., Kesten, S. M., Natale, R. A., & Elbaum, B. (2017). Parents' experiences navigating intervention systems for young children with mild language delays. *Journal of Early Intervention, 39*(3), 180-198. https://doi.org/10.1177/1053815117704958

McAllister, L., McCormack, J., McLeod, S., & Harrison, L. J. (2011). Expectations and experiences of accessing and participating in services for childhood speech impairment. *International Journal of Speech-Language Pathology, 13*(3), 251-267. https://doi.org/10.3109/17549507.2011.535565

McGill, N., Crowe, K., & McLeod, S. (2020). "Many wasted months": Stakeholders' perspectives about waiting for speech-language pathology services. *International Journal of Speech-Language Pathology, 22*(3), 313-326. https://doi.org/10.1080/17549507.2020.1747541

McLeod, S., Davis, E., Rohr, K., McGill, N., Miller, K., Roberts, A., Thornton, S., Ahio, N., & Ivory, N. (2020). Waiting for speech-langauge pathology services: A randomised controlled trial comparing therapy, advice and device. *International Journal of Speech-Language Pathology, 22*(3), 372-386. https://doi.org/10.1080/17549507.2020.1731600

McManus, B., McCormick, M. C., Acevedo-Garcia, D., Ganz, M., & Hauser-Cram, P. (2009). The effect of state early intervention eligibility policy on participation among a cohort of young CSHCN. *Pediatrics, 124*, S368-S374. https://doi.org/10.1542/peds.2009-155G

Morton, D. S. (2012). *Parental descriptions of awareness and associated reactions to developmental delay in children* (Publication Number AAI3545470) [Doctoral dissertation, Capella University]. ProQuest Dissertations & Theses Global. https://www-proquest-com.dbgw.lis.curtin.edu.au/docview/1520325243/B7F1BC2997EB4B37PQ/1?accountid=10382

Mossialos, E., Djordjevic, A., Osborn, R., & Sarnak, D. (2017). *International profiles of health care systems*. Commonwealth Fund. https://www.commonwealthfund.org/sites/default/files/documents/___media_files_publications_fund_report_2017_may_mossialos_intl_profiles_v5.pdf

Mulcahy, H., & Savage, E. (2016). Uncertainty: A little bit not sure. Parental concern about child growth or development. *Journal of Child Health Care, 20*(3), 333-343. https://doi.org/10.1177/1367493515587059

Persoff, J. R. (1998). *Poverty and early childhood developmental delay: Perspectives from Hispanic mothers* [Doctoral dissertation, University of Denver]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/304432454?accountid=10382

Raising Children Network. (2020). About us. https://raisingchildren.net.au

Ramirez, M. C. (2004). *Latino parents with developmentally delayed children: Perceptions of early intervention services* [Master's thesis, California State University]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/305036959?pq-origsite=gscholar

Rannard, A., Lyons, C., & Glenn, S. (2004). Children with specific language impairment: Parental accounts of the early years. *Journal of Child Health Care, 8*(2), 165-176. https://doi.org/10.1177/1367493504041875

Rosenberg, S. A., Robinson, C. C., Shaw, E. F., & Ellison, M. S. (2013). Part C early intervention for infants and toddlers: Percentage eligible versus served. *Pediatrics, 131*, 38-46. https://doi.org/10.1542/peds.2012-1662

Shannon, P. (2000). *Family-centered practice in early intervention services for infants and toddlers: The experience of families and professionals in one Local Interagency Coordinating Council* [Doctoral dissertation, Virginia Commonwealth University]. ProQuest Dissertations & Theses Global. https://scholarscompass.vcu.edu/etd/5304/

Shelby Consulting. (2017). *Evaluation of the Child and Parent Centre Initiative*. https://www.education.wa.edu.au/dl/ejzg3o

Sices, L., Egbert, L., & Mercer, M. B. (2009). Sugar-coaters and straight talkers: communicating about developmental delays in primary care. *Pediatrics, 124*(4), e705-713. https://doi.org/10.1542/peds.2009-0286

Silbersack, E. W. (2014). *Mothers' initial discovery of childhood disability: Exploring maternal identification of developmental issues in young children* [Doctoral dissertation, Adelphi University]. ProQuest Dissertations & Theses Global. https://eric.ed.gov/?id=ED557029

Smith, E., Koerting, J., Latter, S., Knowles, M. M., McCann, D. C., Thompson, M., & Sonuga-Barke, E. J. (2015). Overcoming barriers to effective early parenting interventions for attention-deficit hyperactivity disorder (ADHD): Parent and practitioner views. *Child: Care, Health and Development, 41*(1), 93-102. https://doi.org/10.1111/cch.12146

Smith, L. E., Akai, C. E., Klerman, L. V., Keltner, B. R., & The Centers for the Prevention of Child, N. (2010). What mothers don't know and doctors don't say: Detecting early developmental delays. *Infant Mental Health Journal, 31*(4), 455-466. https://doi.org/10.1002/imhj.20266

Telethon Kids Institute. (2020). *Western Australian Child Development Atlas*. https://childatlas.telethonkids.org.au/cda-about/

Warren, D. (2018). *Children's use of health care* (Longitudinal Study of Australian Children annual statistical report - 2017 chapter, Issue. Australian Institute of Family Studies.

Williams, J. (2007). Learning from mothers: how myths, policies and practices affect the detection of subtle developmental problems in children. *Child: Care, Health and Development, 33*(3), 282-290. https://doi.org/10.1111/j.1365-2214.2006.00690.x

Williams, J., & Holmes, C. A. (2004). Improving the early detection of children with subtle developmental problems. *Journal of Child Health Care, 8*(1), 34-46. https://doi.org/10.1177/13674950401852

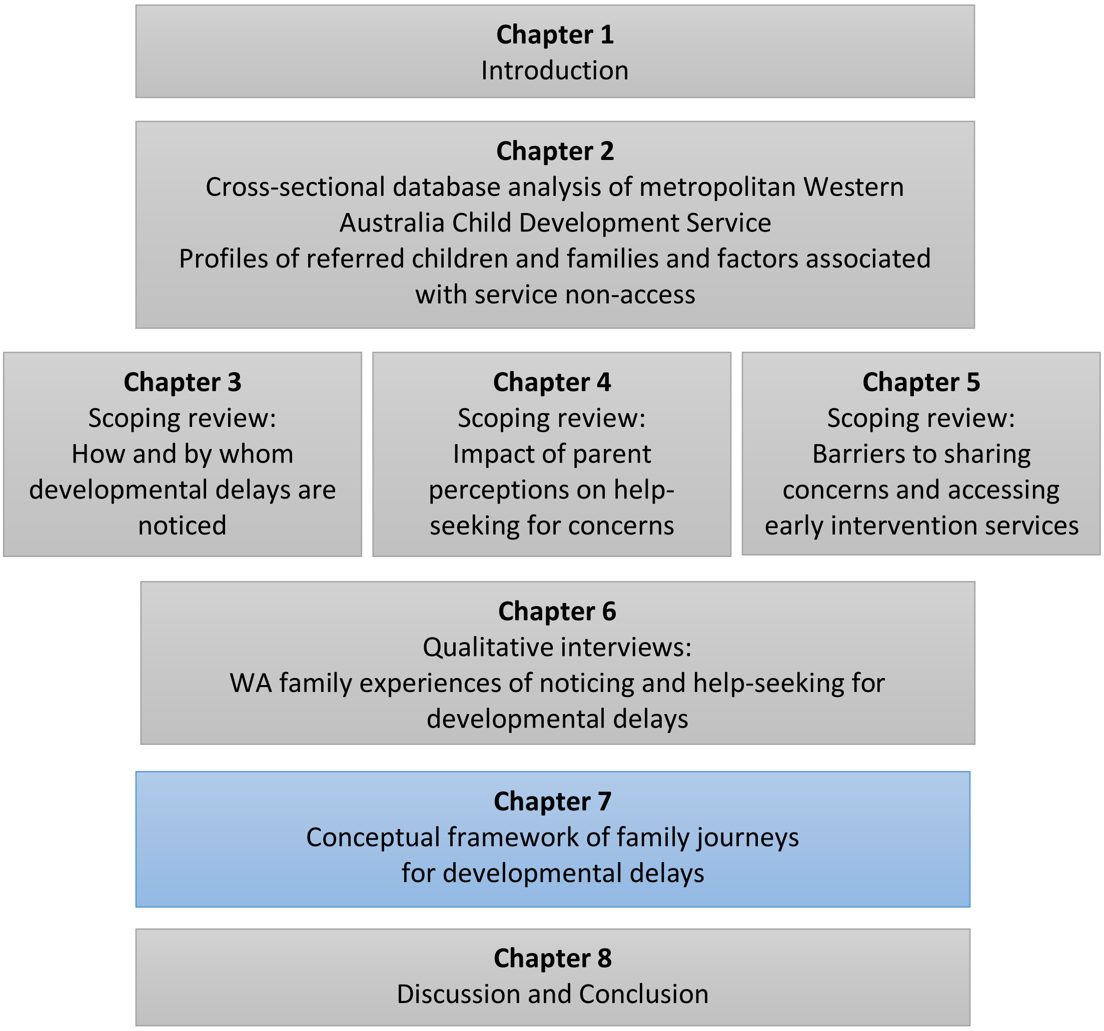
Williams, J., & Holmes, H. (2005). Children of the 21st century: Slipping through the net. *Contemporary Nurse, 18*(1-2), 57-66. https://doi.org/10.5172/conu.18.1-2.57

Winkworth, G., McArthur, M., Layton, M., Thomson, L., & Wilson, F. (2010). Opportunities lost - Why some parents of young children are not well-connected to the service systems designed to assist them. *Australian Social Work, 63*(4), 431-444. https://doi.org/10.1080/0312407X.2010.508170

Woolfenden, S., Posada, N., Krchnakova, R., Crawford, J., Gilbert, J., Jursik, B., Sarkozy, V., Perkins, D., & Kemp, L. (2015). Equitable access to developmental surveillance and early intervention - understanding the barriers for children from culturally and linguistically diverse (CALD) backgrounds. *Health Expectations, 18*(6), 3286-3301. https://doi.org/10.1111/hex.12318

Chapter 7 Framework

This chapter brings together findings from Chapters 2 to 6, culminating in the creation of a conceptual framework of the journeys of families from noticing through to early intervention service access for children with suspected developmental delays.



Developmental delays and service access:
A proposed framework of family journeys

7.1 Background

This chapter presents the Framework of Family Journeys for Developmental Delays (henceforth referred to as 'The Framework of Family Journeys') – a framework conceptualised from this research that seeks to depict family journeys for children with suspected developmental delays. Core principles underpinning the framework, key framework components, proposed framework application, implications for policy, limitations, and recommendations for further research are outlined.

The high prevalence of developmental vulnerability in early childhood populations; the reported mismatch between parent identification of delays and access of EI services; and the myriad of identified barriers and enablers that influence service access; each create an acute need to better understand the pathways of children with delays and their families. As identified in Chapters 2 to 6, pathways navigated by families of children with developmental delays are complex: with multiple (often cyclical or non-linear) stages; potential for breakdown or barriers at different points; and containing several stakeholders with distinct roles. Existing frameworks in similar fields such as broader EI, child mental health, and chronic health contain concepts of importance to understanding developmental delays; however as previously identified each have limitations in their direct applicability to this population. The Framework of Family Journeys seeks to bridge these gaps in the creation of a framework specific to developmental delays that encapsulates the complexity of family experiences.

7.2 Core principles

7.2.1 Family-centred approach

Existing frameworks in child mental health access posit that family factors, beliefs and experiences underpin the success of service access for both the child and the broader family unit (Kazdin, Holland, Crowley, et al., 1997; Piotrowska et al., 2017; Staudt, 2007). The importance of family perspectives in noticing and help-seeking when a child has developmental delays was strongly apparent throughout this research. It was also apparent that it was not a core principle of existing frameworks in areas of child development described in Chapter 1, which were more service or system focused than focused on families.

As well as being ‘focused’ on families, the Framework of Family Journeys and this program of research is underpinned by a family-centred approach. Family-centred practice requires operating in partnership with families in a manner that treats them with dignity and respect; that is flexible, responsive and individualised to family needs; enables informed decision-making through information sharing; honours their values and choices; and provides supports that seek to both strengthen and enhance their functioning as a whole family unit (Dunst, 2002). Both the language and structure of this framework seek to reflect a family-centred approach.

7.2.2 Pathways

A unique component of the Framework of Family Journeys is the representation of different stages of the transition process navigated by families, with the pathway beginning at the point of family noticing concerns through to accessing EI services. The Developmental Systems Model (Guralnick, 2001) and the Connect, Attend, Participate, Enact (CAPE) model of parental engagement (Piotrowska et al., 2017) construct pathways of access to services; however, both these models regard arrival at EI services as the starting point for families. Evident in the scoping review on noticing concerns in Chapter 3; Chapter 4's analysis of the impact of parent beliefs; and reiterated in the account of WA family experiences in Chapter 6, pathways in developmental delays begin well before the point of EI service contact – and therefore this needs to be core to a framework that explains developmental delay experiences.

The concept of 'pathways' is commonly utilised in health care to represent such journeys; however, has been critiqued in recent years (Checkland et al., 2020). A major aspect of this appraisal is that pathways can suggest unidirectionality – that there is a clear order, predictability or a 'right' pathway that should be followed (Allen et al., 2009; Checkland et al., 2020). As the authors state however, "the real world of patient care is rarely that simple" (Checkland et al., 2020, p. 411).

The metaphor of a road is a more apt representation of what family pathways look like for developmental delays. Even in real life, roads rarely occur in straight lines from point A to B: roads wind, they twist, they turn in ways that we were not expecting, and they require (or force) us to make decisions between left and right. There are almost always multiple different routes that one may take to end up at the same destination ultimately. In their description of journeys of Aboriginal families of children with developmental delays and disability, Green et al. (2016, p. 5) described "wrong way signs, roundabouts and roadblocks encountered when accessing services".

As was identified in the family interviews, the road for families of children with developmental delays was rarely linear. They frequently encountered obstacles at different points along the route that sent them in circles, on detours and even off the road entirely. As presented below by the example of Helen and her daughter Isobelle who had suspected developmental hip dysplasia (DHD), families frequently had to share concerns with multiple providers, followed by navigation of different systems and services before finding the right fit (see Figure 7-1). Representing Helen and Isobelle’s pathway as a simple, two-stage ‘share concern-access service’ process would not adequately describe their journey.

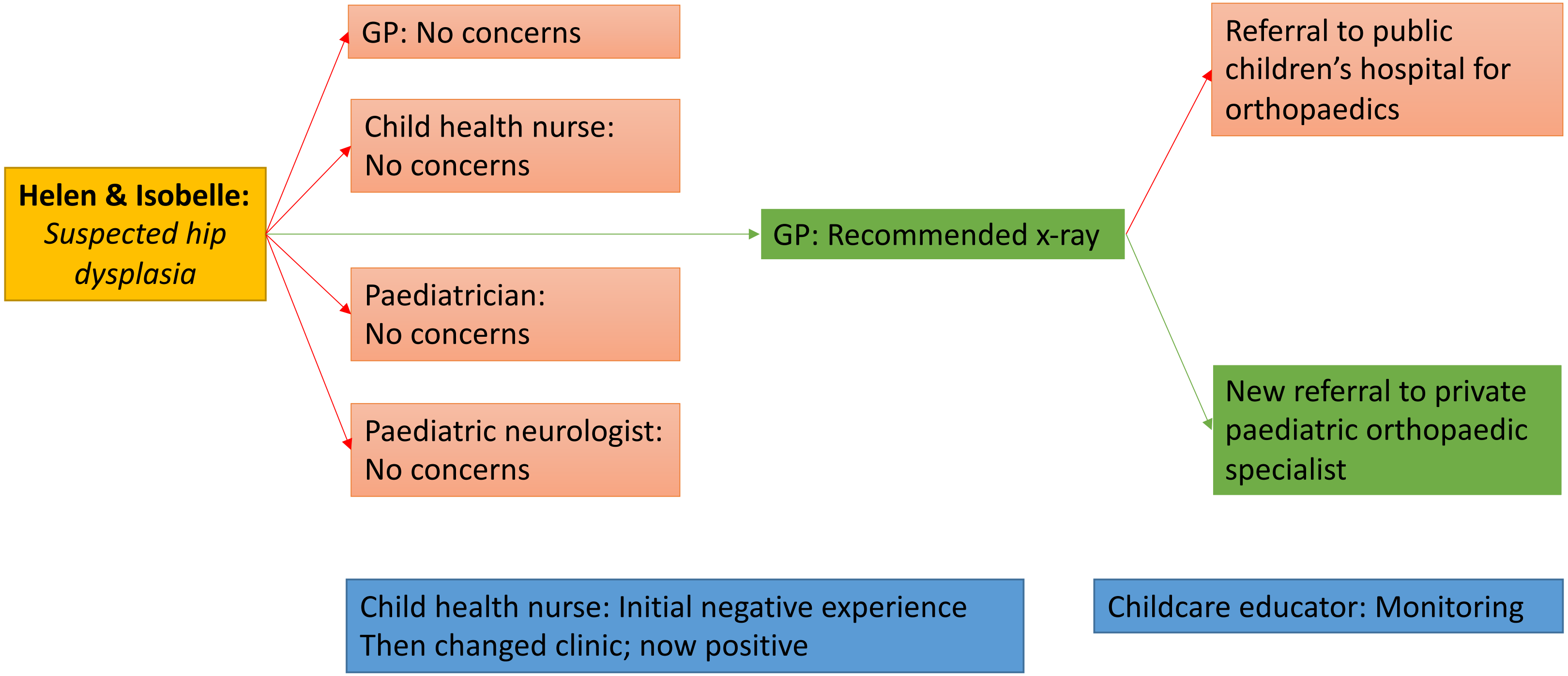


Figure 7-1 Helen and Isobelle's journey to EI services

7.2.3 Services

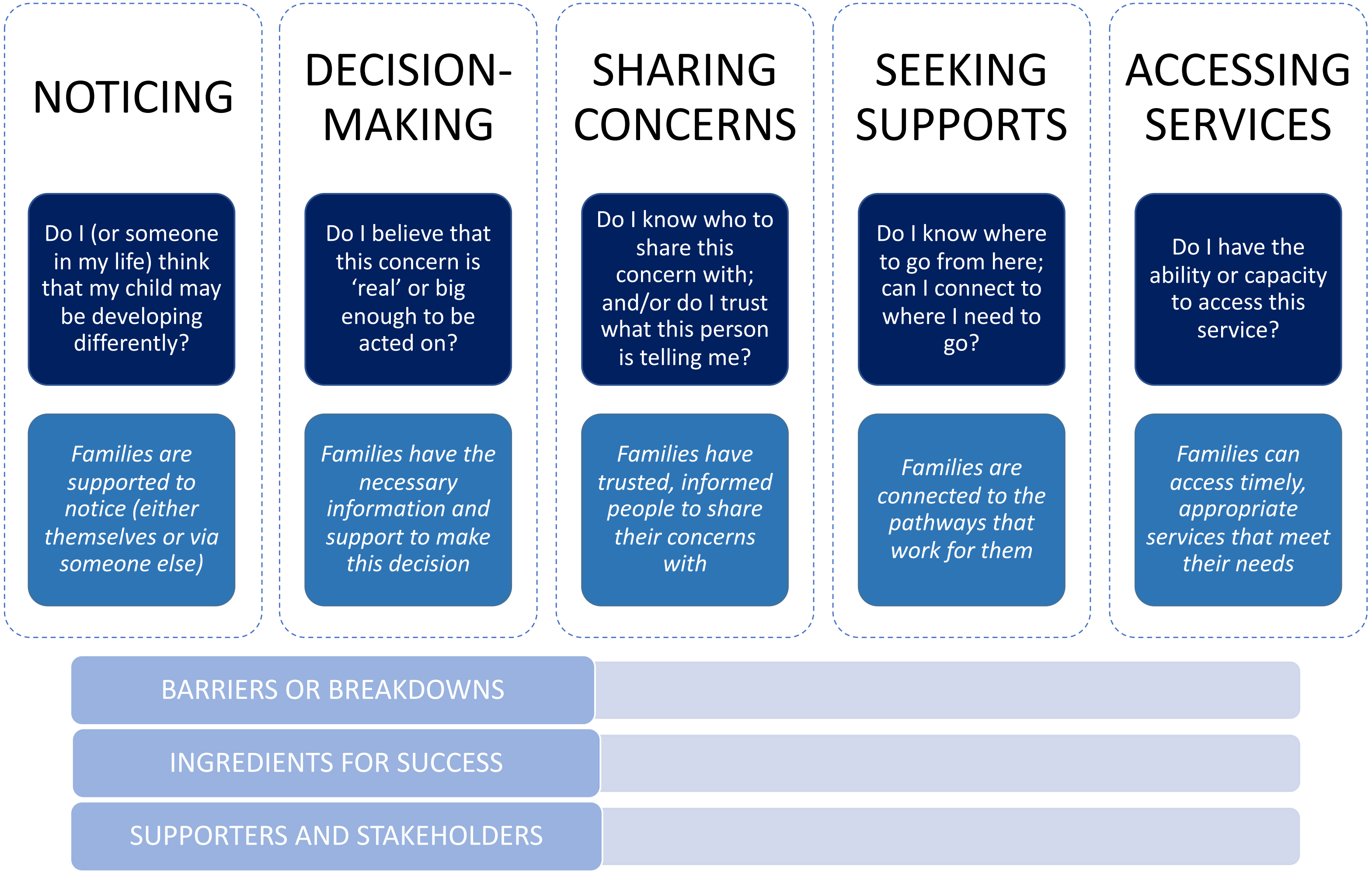
An additional critique of previous models, such as the Developmental Systems Model (Guralnick, 2001) and the CAPE (Piotrowska et al., 2017), is that their ‘services’ focus is largely centred on EI services only – i.e., specialist medical and/or allied health services that provide assessment, diagnosis, and/or intervention. As demonstrated in Isobelle and Helen’s journey, multiple service providers were part of their journey through to their ultimate access of EI services – with both positive and negative consequences. This aligns with findings from both the scoping review series and qualitative interviews regarding the influence of services such as general practitioners and child health nurses on the overall experiences of families. The contribution of these surrounding service providers is therefore equally important to acknowledge and account for. The Framework of Family Journeys terms these services ‘as universal and/or touchpoint services’: services that families are accessing on a day-to-day or universal basis (e.g. for check-ups or developmental monitoring), such as general practitioners, child health nurses, and childcare educators.

7.3 Framework of Family Journeys components

The Framework of Family Journeys is designed to enable services, both universal/touchpoint and EI services, to obtain a deeper understanding of the experiences of families of children with developmental delays. Family experiences are conceptualised here as consisting of the following components: the ‘elements’ or stages of families journeys; if and/or how families progress between these journey elements; and unpacking the barriers, the ingredients for success, and the key stakeholders or supporters who are part of family journeys. This collective information seeks to firstly better inform service providers of the complexity of family journeys; creating awareness and understanding of the difficulties or barriers that families have encountered that have impacted their arrival at the service. Such barriers may have an ongoing impact on family journeys and how they engage with services, and thus framework information may secondly support services to modify or adapt their service delivery to better enable family service access. In simple terms, the Framework seeks to hold services and the system more broadly to account in supporting families in each element; not just at the end stage of EI service access, but also how different providers within the system are supporting other journey elements such as initial noticing, decision-making and sharing of concerns. The Framework may be applied at the micro, individual family to service provider level; through to consideration of macro, whole-community experiences of service provision. How the Framework could be used at the individual family and community levels is explained further under framework application.

7.3.1 Journey elements

The Framework of Family Journeys contains five key elements of family journeys: noticing developmental concerns (N); decision-making regarding whether to act on the concerns (D); sharing concerns with others (S); seeking out supports (S); and accessing EI services (A) – referred to collectively as the NDSSA elements (see Figure 7-2). The term ‘elements’ has been deliberately used instead of steps or stages to represent the non-linearity and unpredictability of family journeys. Some families may spend significant time cycling between noticing, decision-making and sharing concerns with others; particularly where information gathering through sharing concerns with others informs the family’s decision-making process. Additionally, families may move ‘backwards’ or exit entirely based on their experiences within each element. For example, those who receive ‘false assurance’ after sharing concerns may exit the road due to no longer holding concerns. Families may also exit if their concerns do indeed resolve, either via understanding more about normal developmental variability or by their child meeting milestones or; or if they decide to support their child independently of services. It is important to note that not all families should or will move through each element. This journey fluidity is represented through the use of dotted lines surrounding each element.



NOTICING

Do I (or someone in my life) think that my child may be developing differently?

Families are supported to notice (either themselves or via someone else)

DECISION-MAKING

Do I believe that this concern is 'real' or big enough to be acted on?

Families have the necessary information and support to make this decision

SHARING CONCERNS

Do I know who to share this concern with; and/or do I trust what this person is telling me?

Families have trusted, informed people to share their concerns with

SEEKING SUPPORTS

Do I know where to go from here; can I connect to where I need to go?

Families are connected to the pathways that work for them

ACCESSING SERVICES

Do I have the ability or capacity to access this service?

Families can access timely, appropriate services that meet their needs

BARRIERS OR BREAKDOWNS

INGREDIENTS FOR SUCCESS

SUPPORTERS AND STAKEHOLDERS

Figure 7-2 Framework of Family Journeys for Developmental Delays

7.3.2 Journey progress: Family questions and service statements

As opposed to representing parent journeys as a simple transition from stage to stage, key questions associated with progression between the NDSSA elements in the Framework of Family Journeys are proposed (see Figure 7-2). These are questions that parents may face, seek input on, and must ultimately 'answer' – with the answer dictating how and where parents then progress. As opposed to a simple 'yes/no' that then forks families in opposing directions, the 'why' behind the answer to the question is key to understanding pathway progression (or lack thereof). These questions may be directly posed to families by universal and/or touchpoint service providers, or they may simply frame the way that each element is considered. For example, the scoping review in Chapter 3 identified the myriad of reasons that families answer 'no' to whether concerns are real or big enough to be acted on – such as uncertainty of what constitutes 'normal' development or wanting to give the child time to outgrow the delay. Each 'answer' has distinct implications for supports that could therefore be provided to these families – in this case, through supporting developmental literacy and associated parental self-efficacy; or developmental monitoring to actively 'watch' the child's progress.

Paired to each question are simple statements of the requirements that must be met so that parents are able to answer these questions (see Figure 7-2). These statements shift the emphasis away from families and what they 'can' or 'will' do, to encourage service providers to consider how systems, services and supports create conditions that enable families to progress (or not). This notion comes back to ensuring that service providers move away from the idea of families being 'hard-to-reach', to considering services as being 'difficult to access' – and the inherent, systemic inequality that can be created by pertinent service factors. For example, as raised in the interviews, the issues of waitlists creating a divide between those who were and were not able to pay to skip the queues. These families did not have the ability to access EI services – due to the condition of timely, appropriate services that meet family needs not being met. Including these statements therefore prompts service providers applying the Framework of Family Journeys to look more closely at families in understanding the 'real' and individual barriers that are inhibiting their access – rather than making assumptions about the cause of access difficulties.

7.3.3 Journey analysis: the good, the bad, and who's here

Three components support the unpacking of family experiences within and across each NDSSA element: barriers or breakdowns, ingredients for success, and supporters and stakeholders.

7.3.3.1 Barriers or breakdowns

Traditional approaches to understanding family EI service access have taken a 'risk' approach, with service providers largely focusing on factors (particularly family-focused) that may negatively impact or undermine their ability to access services . As was identified through the CDS cross-sectional analysis, risk factor identification does not yield sufficient power to explain how or why such factors may impact family pathways – for example, what is it about being a family living in a lower socioeconomic area that may mean you are less likely to access EI services?

It is essential to go beyond 'hard-to-reach' or group characteristics to focus instead on the specific barriers or breakdowns that may get in the way of successful journeys for families. The series of scoping review in Chapters 3, 4, and 5 and family interviews in Chapter 6 identified a series of such breakdowns that were either unique to certain stages or impactful across the families' journeys. This encompassed both family and service aspects – such as the lack of opportunities for social comparison for noticing; receipt of the 'wait and see' approach from professionals; difficulties with transportation options to attend clinic-based services; and individual factors such as levels of parent knowledge, the number of children in the family, as well as more complex experiences such as family violence. Such a conceptualisation goes beyond making arbitrary judgements of groups to instead attempt to both identify specific factors that individual families experience, as well as reflecting on the barriers services themselves create.

The Framework of Family Journeys provides a talking point prompt for families and services to discuss and thus pinpoint the major breakdowns in their journeys. This may then provide services (both universal/touchpoint and EI) with mechanisms and pathways forward in how to respond to family experiences. For example, family expression of difficulties with transportation would prompt providers to consider service delivery location and timing; while a lack of opportunities for social comparison could encourage conversations about joining a local playgroup.

7.3.3.2 Ingredients for success

Sitting parallel to identification of barriers is the often-overlooked concept of protective factors, enablers, or ingredients for success – when families do have positive experiences, why and how does this occur? Such an approach provides a starting point for understanding what is needed - the 'ingredients' - and thus how services may either begin or continue to facilitate such conditions. This was a key theme identified through the family interviews. Knowing what is or has worked well previously can help service providers to know what a family wants or expects from them – do they value the opportunity to talk through new information? Do they want extra information they can work through in their own time? The Framework of Family Journeys supports service providers to identify these conditions, as well as being a reference to come back to and reflect on in future if difficulties do arise – were the necessary ingredients for success in place for this family to have a positive experience?

7.3.3.3 Supporters and stakeholders

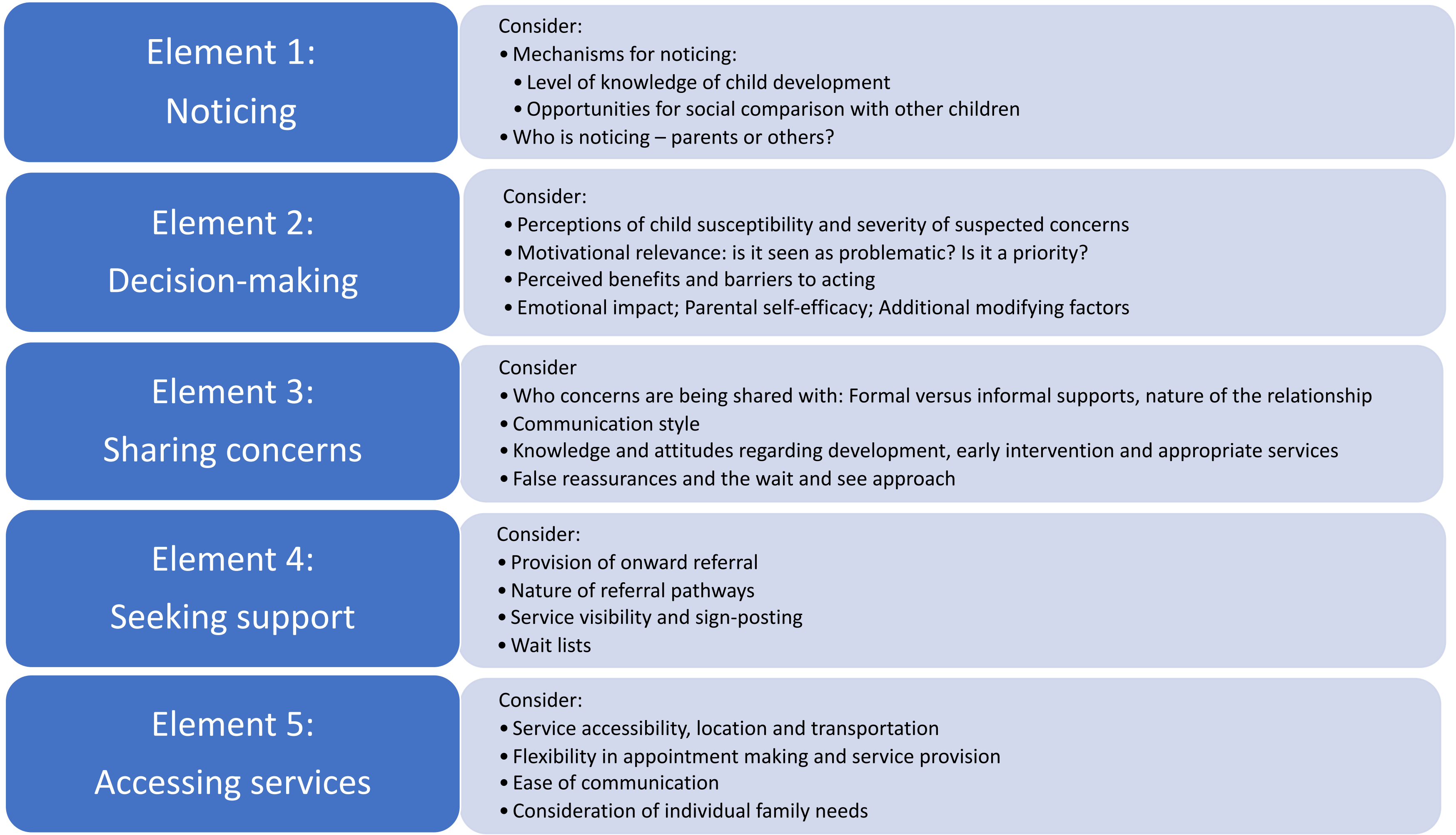
The Framework of Family Journeys component of supporters and stakeholders unpacks who is in a family's 'circle of support' – including family members, friends, community members, and organised services. Social capital does not always directly translate to positive social support – as identified, some people may undermine or invalidate family perceptions and progress (e.g. the wait and see approach). This is particularly important in considering the impact of previous positive and negative experiences on both parent perceptions and their likelihood of progression through further stages. For example, as identified, families may be fearful of blame and judgement from services that leads to the involvement of child welfare services. Such families may be wary of contact with services, and as such would benefit from slow relationship building supported by those stakeholders with whom they have existing, trusted connections.

This component of the framework also promotes the importance of identifying key stakeholders' roles and responsibilities at different stages of the journey; as well as the unique role they play for this specific family. For some families, the role of a GP is to address medical concerns; for others, GPs are a key support for all elements of the family's health and well-being. Understanding who the stakeholders are in a family's life, their relationship, and the role they serve to that family are all vital pieces of information that the Framework collates. Identifying families' unique supports is particularly important when working with culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander families in a culturally secure manner. For example, asking open questions about a family's support networks and the role of different stakeholders (without overlaying 'Western' assumptions of what this may consist of) – are they most comfortable with a family member acting as a translator, or would they prefer that a formal interpreter is involved?

7.4 Framework of Family Journeys application

This Framework of Family Journeys is designed for application either with an individual family or at the community-level, for use by anyone in the early childhood space (see further information in Implications for policy). In simple terms, the Framework seeks to hold services and the system more broadly to account in supporting families in each element; not just at the end stage of EI service access, but in how different providers within the system are supporting other journey elements such as initial noticing, decision-making and sharing of concerns. Application is supported by use of the Framework of Family Journeys element guidance notes, which provide some key points for consideration based on the findings of this research (see Figure 7-3). These guidance notes are not intended to be all-encompassing, nor a ‘tick box’ exercise, but to provide a starting point for thought and discussion.

It is important to note that these guidance notes represent an overview of the major themes that arose throughout this series of research studies. Prior to implementation, further research is recommended to ensure the representation of diverse community needs, such as those of culturally and linguistically diverse (CALD) families and Aboriginal and Torres Strait Islander families. This may result in either the expansion of the current guidance notes, or the development of refined and/or tailored sets that are more specific to certain communities.



Element 1:
Noticing

Consider:
- Mechanisms for noticing:
  - Level of knowledge of child development
  - Opportunities for social comparison with other children
- Who is noticing – parents or others?

Element 2:
Decision-making

Consider:
- Perceptions of child susceptibility and severity of suspected concerns
- Motivational relevance: is it seen as problematic? Is it a priority?
- Perceived benefits and barriers to acting
- Emotional impact; Parental self-efficacy; Additional modifying factors

Element 3:
Sharing concerns

Consider
- Who concerns are being shared with: Formal versus informal supports, nature of the relationship
- Communication style
- Knowledge and attitudes regarding development, early intervention and appropriate services
- False reassurances and the wait and see approach

Element 4:
Seeking support

Consider:
- Provision of onward referral
- Nature of referral pathways
- Service visibility and sign-posting
- Wait lists

Element 5:
Accessing services

Consider:
- Service accessibility, location and transportation
- Flexibility in appointment making and service provision
- Ease of communication
- Consideration of individual family needs

Figure 7-3 Framework of Family Journeys element guidance notes

7.4.1 Family-level application

Family-level application enables the mapping of a family's experiences in relation to the five NDSSA elements and analysis of the three components (barriers, ingredients and stakeholders). This can be performed by anyone in this family's life, at any point in their journey. Coming back to Helen and Isobelle, a mock completion of the framework based on the experiences that Helen discussed during the qualitative interviews is below, as an example of how the framework may be applied on an individual basis.

The element questions and/or statements of the Framework of Family Journeys may be utilised as prompts for initiating discussion with families, particularly as a reference point to ensure that all key aspects of the journey are identified. As Helen's journey depicted in her completed Framework of Family Journeys indicates (see Figure 7-4 and Figure 7-5), much of this information may also be collated through more open-ended, exploratory conversations with families. As highlighted in Chapter 3, there is a strong emotional aspect to noticing developmental delays that demands softness and sensitivity in approach when initiating discussions with families; and as such, less formality and/or structure in such conversations is likely preferable.

To inform analyses of the components (barriers/ingredients/stakeholders), asking families about what has been helpful and what has been difficult is essential. This information helps to form the picture of the ingredients of success – what has helped or would be helpful that can be built on – and the barriers or breakdowns – what do we need to address, change, or work around in order to best support this family. Understanding the role and actions of people who have been involved at different stages is also integral – where and with whom does this family feel safe and supported? This collective information enables the identification of what is currently happening for a family in question and where to go from here, in a systematic yet individualised manner. Unpacking the 'black box' of the key difficulties this family is experiencing enables the development of a pragmatic action plan, even in complex circumstances – what is one thing we can do to try to address the issues getting in their way? Can we facilitate the family’s connection to an appropriate local service? Can we help them to build their knowledge of child development? Can we address other complexities in their lives that need attention before they can focus on their child? Equally, identifying existing supports (or the need to create supports where there are none) is a vital component to ensuring the success of any efforts.

For example, Helen had a previous negative experience with a CHN that had put her off accessing further developmental checks– a barrier experienced during the sharing concerns element. While this CHN experience was invalidating for Helen, she had enough supporters and ingredients for success including her own knowledge of child development that this barrier did not overly impact her ongoing journey with Isobelle. Other families with less such resources may however experience such an interaction as a major barrier; hence the need to understand a family’s unique experiences through each element. It is also important to place this information in context: learning that the family had not accessed CHN checks beyond 8 weeks of age and jumping to conclusions about what this meant for noticing Isobelle’s delays would be wholly incorrect; and would likely produce a further negative, invalidating experience for Helen. Such assumptions are what this framework is seeking to alleviate.

Likewise, learning that Isobelle’s childcare educator worked in partnership with the family to navigate their pathway elements, was an important piece of information to understand about this family’s core supporters. This partnership enabled continuity of support and active monitoring of Isobelle’s development where other avenues of sharing concerns and seeking supports was less successful – ensuring that someone was looking out for this family. Such information provided service providers with ideas of how to ensure this family was supported and maximised the likelihood of experiencing positive, successful outcomes. For example, Isobelle’s DHD is currently being managed conservatively through ongoing monitoring of any gait changes, leg strengthening, and periodic x-rays. Isobelle’s orthopaedic specialist can leverage these supporters through engaging her childcare educators and GPs to be part of this process in supporting Helen and her husband to monitor Isobelle’s development. Not only does this share the load with the family, but it increases the quality of care that Isobelle is receiving. This is the ultimate goal of the Framework: to identify better ways to support families, whatever that may look like for a unique family unit.

NOTICING	DECISION-MAKING	SHARING CONCERNS	SEEKING SUPPORTS	ACCESSING SERVICES
Mother noticed hip 'clunk', dragging of leg when learning to walk. *Family history of allergies, child unwell so in mother 'alert' to any concerns and in frequent contact with health professionals.*	*Mother reports experience with kids, knowledge of development. Confident in accessing, critiquing info. Based on this wanted to ask questions of concerns.*	*Family has set of 3 long-time GPs, trusts them. Initial sharing with nurse, had no concerns. Specialists seen for other reasons had no concerns. Continued asking questions – second GP sent for x-ray, DHD confirmed.*	*Provided with referral to public hospital. Difficulties making contact/appointment with service. Asked for private referral from GP instead, GP facilitated this.* *Childcare educator monitoring child throughout.*	*Public waitlist seen as too long. Dissatisfied with staff approach.* *Family had financial capacity to access private surgeon – waiting time, appointment flexibility, professional approach all met families needs.*

Figure 7-4 Family-level mock application of the Framework of Family Journeys: Helen and Isobelle

BARRIERS OR BREAKDOWNS

- Outdated information, disliked attitude from previous CHN
- Series of professional contacts without noticing child DHD
- Difficulty making contact with public hospital
- Public hospital staff communication style, manner
- Public health service waitlist

INGREDIENTS FOR SUCCESS

- Parent knowledge of development, noticing of hip ‘noises’
- Parent ability to locate, critique information
- Parent confidence in continued raising of concerns
- Active monitoring of concerns by childcare staff
- Family ability to financially access private services
- Private service communication style, flexibility, shorter waiting times.

SUPPORTERS AND STAKEHOLDERS

- Supportive:
  - Partner; Childcare staff; Set of three long-time GPs; current CHN; private surgeon.
- Difficulties with:
  - Previous CHN; public hospital services.
- Other:
  - Two specialists seen who did not identify concerns (however understanding of this).

Figure 7-5 Family level mock application of the journey components: Helen and Isobelle

7.4.2 Community-level application

The Framework of Family Journeys may also be utilised to consider the broader experiences of a community – with community defined by simple geography or by shared characteristics. Such an approach explores both the collective and diverse experiences of community members to identify shared group narratives, strengths and needs. The Framework of Family Journeys can be utilised to 'investigate' stakeholders such as different service providers; asking questions such as, who are the existing services and supports available in the community? Do they provide ingredients for success? What are the barriers or breakdowns that exist? Who leads this investigative process will vary depending on the defined community, but an independent third party who are not providing direct services to the community (and therefore have a reduced conflict of interest) is recommended (e.g. a research institute).

The first step of this process is to seek out the relevant community and ask them to share their experiences; conducting a similar process to the family-level application but on a larger scale with a group of families. This process could be completed one-on-one, as per the family-level application, or through a focus-group style facilitation whereby families come together and collectively share their journeys. The end product of either approach is the collation of element experiences, barriers, ingredients for success, and supporters and/or stakeholders; and the subsequent identification of major 'themes' that arise from this set of data. Conducting this initial process with families enables the community to arrive at this point of identifying what they need to know more about, pinpointing steps forward – as opposed to making assumptions about what the major barriers are for families. For example, from Chapter 6 interviews, there was a common narrative regarding negative perceptions of child health nursing (CHN) services in WA. These findings therefore indicate that a better understanding of CHN services is warranted – and may be selected as a major factor to conduct a deeper analysis on.

The secondary step of applying the Framework of Family Journeys is to focus on one of the identified barriers and explore it in detail. Use of the element guidance notes may be beneficial here as a starting point for reflection by services undertaking this process. For example, in regard to CHNs, the major role of the service largely sits within element 3: sharing concerns – which prompts consideration of aspects such as the nature of the service's relationship with families, staff communication style, knowledge and attitudes, and use of the wait and see approach (see Figure 7-6). These 'questions' should be asked of service users, i.e., families, as well as service providers themselves (both direct providers and management). Families reported that whether the nurses' interaction style was a barrier to family pathways or an ingredients for their success was highly influenced by both the communication skills and the levels of evidence-based, up-to-date knowledge of the staff. Service staff may produce similar answers to families, which would dictate clear steps forward such as staff upskilling in certain aspects of developmental knowledge. Services may alternatively have quite different, contrasting responses to families. Contrasting responses is in many ways the heart of what was elicited in this body of research, with a clear divide identified at times between the perceptions of families and those of services. What becomes important here is that services then take the time to acknowledge, to unpack, and to attempt to respond to the experiences of families.

Element 1: Noticing

Consider:
- Mechanisms for noticing:
  - Level of knowledge of child development
  - Opportunities for social comparison with other children
- Who is noticing – parents or others?

Element 2: Decision-making

Consider:
- Perceptions of child susceptibility and severity of suspected concerns
- **Motivational relevance: is it seen as problematic? Is it a priority?**
- Perceived benefits and barriers to acting
- **Emotional impact;** Parental self-efficacy; Additional modifying factors

Element 3: Sharing concerns

Consider
- Who concerns are being shared with: Formal versus informal supports, nature of the relationship
- **Communication style**
- **Knowledge and attitudes regarding development, early intervention and appropriate services**
- False reassurances and the wait and see approach

Element 4: Seeking support

Consider:
- Provision of onward referral
- Nature of referral pathways
- Service visibility and sign-posting
- Wait lists

Element 5: Accessing services

Consider:
- Service accessibility, location and transportation
- Flexibility in appointment making and service provision
- Ease of communication
- Consideration of individual family needs

Figure 7-6 Community-level mock application of the Framework: Child health nursing

From here, the Framework of Family Journeys process shifts back to a strengths-based focus – looking instead to the ingredients for success and key supporters identified by families across the community. This is where the true value of the Framework of Family Journeys lies: identifying what is working well provides immediate first steps in finding responses for barriers. For example, in reference again to the Chapter 6 interviews, families had positive experiences with CHNs when they were better able to build ongoing relationships with them, and/or when they were more readily and informally available - through opportunities such as the library-based play sessions that some local CHNs regularly attended. This finding therefore suggests that possible solutions may include increasing outreach-style visits to places that families are already accessing; and looking more deeply at organisational factors that may impact the ability to build and maintain family relationships such as appointment-making mechanisms, staff movement between sites and/or overall staff retention, etc. The Framework of Family Journeys does not dictate what these solutions should look like; the community must voice what they need from services.

To generate true insights throughout the journeys of families, the stakeholders that come together for the Framework of Family Journeys application must cross traditional system and service boundaries of education, health and broader community supports. Bringing this range of stakeholders together prompts services to consider where they fit in family experiences, who fits elsewhere, and therefore who do they as a service need to connect with in order to support families. This process also has the additional benefit of enabling stakeholders to learn more about each other, which may inadvertently help to reduce barriers of ‘siloed services’ and better facilitate accurate, timely referral pathways. It may also be beneficial for families as a mapping exercise of the services that exist in their community, enabling them to have better information when seeking services and supports of what is available to them. If completed well, the Framework of Family Journeys may support communities to identify major breakdowns along family journeys, as well as existing and essential supports. This enables communities to strategically direct their efforts of intervention to where it is most needed, and thus maximise the best use of resources.

It is important to consider that while the five NDSSA elements are not strictly linear, they do build upon one another. This, therefore, means that if there are significant issues occurring in the initial stages of noticing and decision-making, then this will have a flow-on impact on family success in sharing concerns, seeking supports and accessing services, and so on. Services at the point of actual EI delivery who experience rates of service non-access, such as CDS from Chapter 2’s cross-sectional analysis, must therefore be part of a process that looks across the elements in considering what is happening for families along the pathway. Where do the key breakdowns exist – is it about a family’s capacity to access the services, issues with knowing how to connect to such services, negative experiences in sharing their concerns with potential referrals – or perhaps all of the above? Answers to these questions have implications for how, where, and thus which services need to act to seek to increase success through to the point of service access as part of a continuous improvement process.

7.5 Implications for policy

Application of the Framework of Family Journeys requires transparency, commitment, and accountability from the involved stakeholders. Transparency in being open and honest about the workings of their service; commitment to engaging in the process, taking the feedback and making plans for change; and accountability to both enacting and showing evidence of said changes. These processes must be therefore be conducted in a manner that actively informs and involves the community throughout each stage, enabling progress to be tracked as well as providing mechanisms for holding services to account. Additionally, while the Framework of Family Journeys is designed to be used by anyone at any point in a family's journey, there is danger that it is used by no one. Thus, there is a need for clear policy-level recommendations regarding delineation of roles and responsibility for the broader support of families.

For Framework application and subsequent implementation of changes to be both genuine and effective, higher level oversight is likely required and thus recommended. Where such oversight originates from is, however, complicated by the cross-sector nature of this exercise. Pathways for developmental delays should incorporate representation from health; education including early learning; community services including social services and child welfare; and other related not-for-profit and community-based organisations, such as playgroups and parenting support services. The creation of a cross-sector working group (or ideally, a Department of Early Childhood), would be required to develop agreements for implementation of the Framework and associated recommendations between and across sectors. What these agreements consists of should be grounded in consideration of how to best meet family needs as an entire sector. For example, whether there should be designated points along family journeys where the Framework of Family Journeys is applied at the individual-level to support family pathways: such as embedded within routine developmental checks administered by CHNs and/or GP's; or alternatively, incorporating the Framework into early education and childcare information gathering. Further research is required to determine both if and how the Framework could be applied by these stakeholders. In the absence of such data, we are reticent to make statements regarding the specific utilisation of the Framework.

As is central to the Framework, such decision-making processes would need to have the voices and involvement of families at its core; as per the mantra, ‘nothing about us without us’.

7.6 Framework limitations and recommendations for further research

The Framework of Family Journeys was created based on the discussed series of research from Chapters 2 through 6. As has been identified through this series of studies, there are a number of limitations associated with this work that therefore apply to the Framework. From a population perspective, this body of research has been confined to the experiences of families in a Western context, with the bulk of previous studies incorporated in the scoping reviews conducted in the United States (U.S.), United Kingdom (U.K.), Canada, and Australia. While some of the scoping review studies and the Chapter 6 qualitative interviews included families from diverse backgrounds such as culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander families, the experiences of these families were blended together with other families. Additionally, there has been limited exploration of the voices of Australian families in regional, rural, and remote areas. As discussed in the framework application section relating to the element guidance notes, further research is required to ensure that the Framework of Family Journeys is genuinely representative of the experiences of diverse families – either through broadening and/or refinement of the Framework in its current form, or through the creation of tailored versions for specific populations. This will require collaboration with different communities to co-design a Framework that meets their needs.

Introduction of the Framework of Family Journeys for use at family or community-level should be accompanied by training in how and when to utilise it and sustain its implementation over time. Such training would need to be balanced between being sufficiently detailed and robust to enable genuine application of the Framework and its concepts; yet accessible to time-poor clinicians. Next steps in the construction of this framework requires the development of an accompanying ‘package’ of information and training materials. This should be performed in collaboration with the professionals and service providers whom the Framework is intended for, as well as the families that it would be utilised with, to ensure that materials meet their collective needs. Following package development, validation of the Framework is required. Small-scale trials of framework application should firstly be conducted to assess its clinical utility, such as appropriateness and feasibility of use; and further refine both the Framework and accompanying information. This would then need to be followed by larger-scale robust trials for assessment of Framework efficacy and effectiveness.

7.7 Conclusion

The Framework of Family Journeys seeks to fill an identified gap in the conceptualisation of the journeys of families of children with suspected developmental delays. Based on core principles of family-centredness and non-linearity of pathways, the framework denotes five elements that families progress through, within a broader context of experiences of barriers or breakdowns, ingredients for success, and supporters and stakeholders. Use of the Framework of Family Journeys to understand family or community-level experiences may provide a starting point for services to determine if and how they are meeting family needs along their journeys through to EI access in a way that is truly family-centred. Future research is needed to evaluate the feasibility, appropriateness, utility, efficiency and effectiveness of the Framework of Family Journeys, as well as exploring the experiences of diverse families and communities to enhance its representativeness of their journeys.

7.8 References

Allen, D., Gillen, E., & Rixson, L. (2009). Systematic review of the effectiveness of integrated care pathways: what works, for whom, in which circumstances? *International Journal of Evidence-Based Healthcare, 7*(2), 61-74. https://doi.org/10.1111/j.1744-1609.2009.00127

Checkland, K., Hammond, J., Allen, P., Coleman, A., Warwick-Giles, L., Hall, A., Mays, N., & Sutton, M. (2020). Road to nowhere? A critical consideration of the use of the metaphor 'care pathway' in health services planning, organisation and delivery. *Journal of Social Policy, 49*(2), 405-424. https://doi.org/10.1017/S0047279419000400

Dunst, C. J. (2002). Family-centred practice: Birth through high school. *Journal of Special Education, 36*(3), 141-149. https://doi.org/10.1177/00224669020360030401

Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P. M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services. *BMC Health Services Research, 16*(1), 680. https://doi.org/10.1186/s12913-016-1926-0

Guralnick, M. J. (2001). A developmental systems model for early intervention. *Infants and Young Children, 14*(2), 1-18. http://depts.washington.edu/chdd/guralnick/pdfs/dev_sys_model_EI_IYC_10_01.pdf

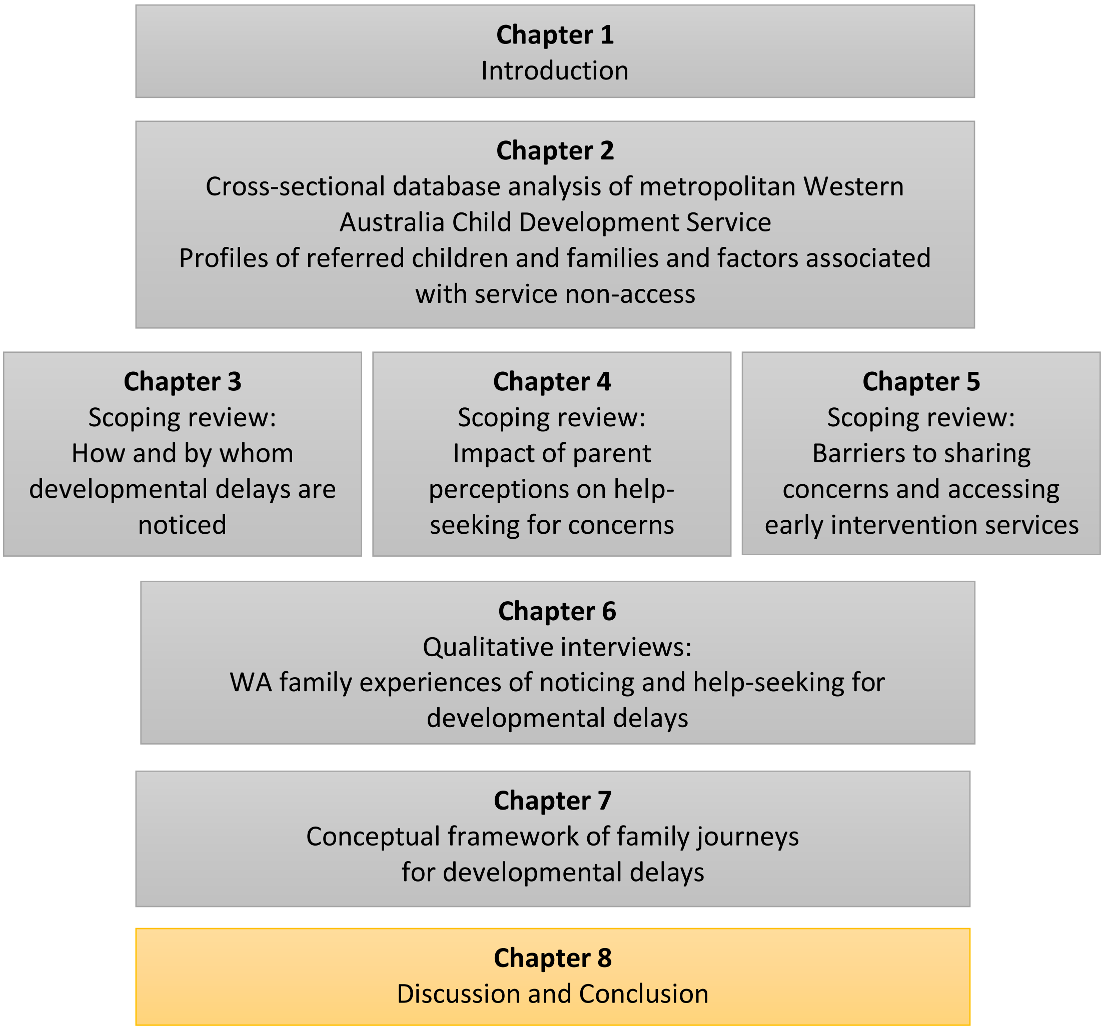
Kazdin, A. E., Holland, L., Crowley, M., & Breton, S. (1997). Barriers to treatment participation scale: Evaluation and validation in the context of child outpatient treatment. *Journal of Child Psychology and Psychiatry, 38*(8), 1051-1062. https://doi.org/10.1111/j.1469-7610.1997.tb01621.x

Piotrowska, P. J., Tully, L. A., Lenroot, R., Kimonis, E., Hawes, D., Moul, C., Frick, P. J., Anderson, V., & Dadds, M. R. (2017). Mothers, fathers, and parental systems: A conceptual model of parental engagement in programs for child mental health - connect, attend, participate, enact (CAPE). *Clinical Child and Family Psychology Review, 20*, 146-161. https://doi.org/http://dx.doi.org/10.1007/s10567-016-0219-9

Staudt, M. (2007). Treatment engagement in caregivers of at-risk children: Gaps in research and conceptualization. *Journal of Child and Family Studies, 16*, 183-196. https://doi.org/10.1007/s10826-006-9077-2

Chapter 8 Discussion

This research set out to answer the question: why are children with developmental delays slipping through the cracks of early intervention (EI) services? Following my clinical experiences as an occupational therapist, I wanted to better understand the experiences of these children and their families, and why seemingly so many are not receiving the services that they need. Through an analysis of a population-level dataset, three scoping reviews of the literature, and exploring local experiences of Western Australian (WA) families, the Framework of Family Journeys was developed to bridge gaps in the conceptualisation of service access journeys of families of children with suspected developmental delays through to and provide preliminary answers to this question for WA families.



This final chapter will discuss the implications of the findings for relevant stakeholders, including families, EI services, associated early childhood organisations and the broader community in informing family-centred developmental EI practice, research and policy. Limitations of the work and recommendations for future research are outlined.

8.1 Conceptualising family journeys

The research focus was initially intended to transition directly into intervention design following the database analysis and one scoping review – with the creation and pilot testing of strategies to increase family service access with the Child Development Service (CDS). As is no doubt clear, this is not what happened. On beginning the search for the scoping review, it became immediately apparent that attempting to address all elements of family journeys in a singular review - noticing, decision-making, sharing of concerns, seeking of supports and EI service access - would not be feasible, nor do justice to the complexity of this area. It was thus decided that such a research question required a series of more targeted scoping reviews that would build on one another.

In undertaking the review series, it became clear that such focused attention had not been previously undertaken in understanding family journeys specific to developmental delays. As the reviews identified, there is a significant amount of work, predominantly qualitative in nature, that has sought to explore family experiences – such as by Magnusson et al. (2017); Marshall et al. (2017); McAllister et al. (2011); Shannon (2000). In addition, some authors had utilised health behaviour models to frame their own results of family experiences (Alexander et al., 2015; Marshall, 2013). However, what was missing was the pooling of results across studies to build a collective understanding of the key elements of family journeys. Arksey and O'Malley (2005) state that a scoping review may be used to clarify conceptual definitions and/or boundaries of a research area, as well as mapping key concepts and available evidence. It was apparent that this was what the research area needed. Utilising such methods to begin the framing or conceptualising of all the elements of family journeys became the overarching aim of this thesis. This ‘mapping’ process has led to a number of significant results, detailed as follows.

8.2 Creation of a set of language around noticing

While ‘noticing’ of developmental delays has been discussed throughout qualitative work on family experiences - such as by Silbersack (2014), Rannard et al. (2004), Missiuna et al. (2006), Morton (2012), and Mulcahy and Savage (2016) - it was a concept that lacked clear definition or conceptualisation. This was, therefore, the overarching aim of Chapter 3 scoping review. This review proposed a definition of noticing as ‘a process of emerging concerns about a child’s development based on differences or incongruence with personal knowledge of development or by social comparison with same-age children’. The review additionally generated a set of terms associated with aspects of noticing, drawn from how families described the process – their ‘aha’ moments, niggles, ‘maybe it’s nothing but…’, and mother’s intuition. The importance of both the definition and set of terms is that it provides language to talk about and listen for ‘noticing’. Parent-report of child developmental concerns has been established as a valid indicator of delays (Glascoe & Dworkin, 1995; Oberklaid & Efron, 2005), and accordingly has been increasingly drawn upon to inform developmental surveillance efforts (Council on Children with Disabilities et al., 2006; Dworkin, 1989; Oberklaid & Efron, 2005). The Chapter 5 scoping review highlighted the fact that parents often experience reluctance or uncertainty in knowing how to raise developmental concerns (Alexander et al., 2015; Felt & O'Connor, 2003; Marshall, 2013; Morton, 2012; Silbersack, 2014); or do so in a way that may appear vague or minimised to professionals - who thus do not take such concerns seriously (Ahern, 2000;

Felt & O'Connor, 2003; Glaun et al., 1998; Marshall, 2013; Sices et al., 2009). Successful parent reporting, therefore, requires that: a) families have the language and terminology through which to firstly identify for themselves when they may be noticing suspected developmental delays, and secondly to communicate those suspicions to others; and b) professionals know and understand the way that families may describe their noticing experiences, in order to identify when families are trying to communicate this to them. The terminology created through the body of work reported in this thesis seeks to begin to fill this communication gap. Future steps forward should include the consideration of how such terminology could be embedded into developmental surveillance efforts – both in the information provided to professionals whom families may be sharing their concerns with, such as GPs, as well as families themselves. The first stage in moving towards this should be consultation with families regarding their responses to the chosen terminology– similar to the efforts undertaken by (Raspa et al., 2015), which utilised parent focus groups to gain feedback on the 'Learn the Signs. Act Early' (LTSAE) campaign. This work identified that parents inherently understood messages regarding the need to 'act early' on suspected developmental delays, but wanted more information on how to act, whom to talk to, and how to have such conversations with professionals (Raspa et al., 2015) – further confirming the need for introducing noticing language.

What is also important is how we frame noticing – whose responsibility is it? The CDC describes 'developmental monitoring' as an ongoing process done by caregivers from birth - to look for developmental milestones, track signs of development and identify concerns (Centers for Disease Control and Prevention, 2020a). Caregivers are encouraged to participate in active surveillance of their child's milestone acquisition, to act in partnership with more formal developmental screening processes through the health care system (Centers for Disease Control and Prevention, 2020a). However, there is a danger in such approaches placing responsibility on families without providing the necessary supports that must sit around them; as well as the potential for ‘pathologising’ differences in development that create parent worry and anxiety. If governments want families to ‘act early’ on developmental delays as per the LTSAE campaign (Raspa et al., 2015), then there needs to be a heavier focus, and associated funding, on a policy program that truly enables this (Williams, 2007) in a way that balances identifying potential delays while acknowledge developmental differences. This notion is discussed further in relation to professional roles in developmental surveillance.

8.3 Developmental surveillance: Whose role?

The Chapter 2 CDS referral analysis identified the major referrers of children in metropolitan WA to EI services: child and adolescent health services; education settings; general practitioners (GPs); other health services; parents/guardians themselves; and ‘other’ such as child protective services workers. These referrers represent the major people/services that families are sharing their developmental concerns with through to referral; however, it does not necessarily mean that these are the only stakeholders that families talk to. For example, Chapter 6 interview findings suggest that who ultimately provides the referral may differ to whom concerns are either initially shared with or spoken about on an ongoing basis, such as childcare educators.

As the Chapter 3 scoping review on noticing identified, some families may consider that suspected delays are ‘maybe it’s nothing but…’ until confirmed by another party – or alternatively may dismiss their concerns if they are not validated by professionals (McAllister et al., 2011). This becomes problematic when stakeholders are either unaware of these expectations or do not perceive themselves to have the requisite skills, knowledge or confidence to identify and discuss suspected delays with families (C. Moore et al., 2017).

It is therefore important for all stakeholders who interact with young children and their families to acknowledge the role that families (explicitly or not) may be expecting them to play in supporting them to notice developmental concerns. While this does not mean that all stakeholders should be expected to singularly provide such a role, findings do raise questions regarding who should – and whether current approaches are working. While Child and Adolescent Health Service - Community Health (CAHS-CH) (which includes child health nursing, CHN) was the largest source of referral for families to CDS, large numbers of Australian families are not accessing routine developmental checks via CHN services beyond the early months of their child's life (Commissioner for Children and Young People, 2019). Interviewed families identified mixed feelings for CHNs, including perceptions of parent blaming and shaming and thus not returning for future checks - consistent with previous research (Alexander et al., 2015). Many Australian families instead identify GPs as their main source of formal support in early childhood (Alexander et al., 2015; Eapen et al., 2017). However, GPs report having insufficient knowledge of developmental screening tools, with this role traditionally undertaken by trained CHNs (Garg et al., 2018).

This links to the important finding of caregivers frequently receiving 'false assurances' via the 'wait and see' approach– which (according to both the interviewed families and scoping review findings) comes from GPs in particular (Ahern, 2000; Giordano, 2008; Hendrickson et al., 2000; Kummerer & Lopez-Reyna, 2009; Marshall et al., 2017; Missiuna et al., 2006; Morton, 2012; Ramirez, 2004; Rannard et al., 2004; Shannon, 2000; Sices et al., 2009; Silbersack, 2014; Worcester, 2005). It is deeply concerning that when families progress to the element of their journey where they feel ready, confident and comfortable sharing their concerns with professionals, that they are then made to feel invalidated and often dissuaded from raising their concerns further. Professionals such as GPs may have genuine, valid reasons for wanting to wait before undertaking further investigation;

however, it is suspected that such a response may sometimes come from a lack of knowledge or training in a role that is not in their traditional remit. Families are thus seeking out developmental support from professionals who do not necessarily have the capacity to fill this role. Either way, current responses of 'wait and see' are inadequate – both for meeting the emotional needs of the caregiver, as well as meeting the child's needs long-term – and need to change.

There is a vital need to review the role and scope of practice of professionals and other stakeholders in developmental surveillance. Families talk about the importance of an established relationship, of trust, and of continuity of care – which is why many seek out their GPs to share developmental concerns (Alexander et al., 2015). If we are to maintain CHNs as the primary providers of developmental screening in the Australian context, then there is a need to find ways for families to build relationships, trust and continuity with these professionals. The co-location of health care services, also known as the medical home, has been considered in recent years as a possible way forward in the provision of paediatric care (Garg et al., 2013; Ginsburg, 2008). While colocation can take many forms, the broad aims are improved coordination of care, efficiency of services and quality of care; through strategies such as shared services, collaborative practice, interdisciplinary training and shared and/or linked patient records (Ginsburg, 2008).

Key mechanisms for creating positive outcomes through co-location are the familiarity it creates for families; the increased knowledge and confidence of professionals themselves; and efficiencies such as more appropriate and timelier referral completion (Ginsburg, 2008); all key issues raised in this body of work. Colocation has also been proposed as a more effective way of providing care for the family unit through addressing holistic needs such as housing issues and food security – reflecting a family-centred approach to care (Garg et al., 2013). Successful co-location is complex and requires consideration of possible organisational, financial, staffing, transport, collaboration style, and data sharing issues (Ginsburg, 2008); yet holds great potential in enabling ‘outside the box’ interventions, particularly in seeking to address the needs of ‘hard-to-reach’ populations (Garg et al., 2013). Further research is required to understand the active ingredients for co-location in different communities; consideration of cost structures and how these new models of service will be funded; as well as building a body of evidence that supports their effectiveness (Garg et al., 2013). Application of the proposed Framework of Family Journeys for Developmental Delays at the community-level would be useful here as a mechanism for identifying what co-location would need to look like for certain communities: who are the services or stakeholders who currently exists in this community, who are families already accessing – and how can we connect and/or collocate other services to those that families already trust. Co-location of CHN alongside and/or within key GP clinics may be a model worthy of trialling.

8.4 From family ‘red-flagging’ to family-centredness

This thesis began with the CDS referral analysis chapter to demonstrate the evolution of this body of research. As stated, the initial aim of this thesis was to conduct initial scoping and analysis, followed by intervention design and feasibility testing of strategies to increase CDS service access. This aim changed during the database analysis, as it became clear that undertaking such a process would not provide the answers that would be needed to launch directly into testing solutions. While the referral analysis did identify some statistically significant factors associated with service non-access – such as the child being female and the family living in a lower socioeconomic area - the odds ratios for each factor were between 0.5 and 1.6 - which are considered as only having small effect sizes (Chen et al., 2010). This means that while these factors may have some impact on family service access, the contribution of each may be relatively small – and thus could not form the basis for intervention. There were also limitations in the data that were available for analysis, meaning factors that have been previous identified as important, such as the impact of parent education level (Giannoni & Kass, 2010), were unable to be considered. Again, this would therefore limit intervention design efforts, as there could not be certainty that all key factors had been identified in order to then be targeted.

This analysis thus revealed that while there were insights to be learned through unpacking such data, there were many questions that remained unanswered through such a process. Previous research has identified that while certain child and family factors may be predictive of service access, they do not necessarily tell the full story (Kazdin, Holland, Crowley, et al., 1997); such as why this is true, what else might be happening for this family, or what to do about it. Unpacking the 'why' behind such factors, rather than making assumptions, was therefore critical to better understanding family service access journeys before any further action could be taken. On this basis the scoping review series was deemed critical to unpacking the 'why' from previous research, followed by circling back to the WA community through exploring the experiences of families here. These studies identified a myriad of reasons why service access can be difficult for families, such as transportation issues, managing the needs of the broader family, and service inflexibility (Giannoni & Kass, 2010; Green et al., 2016; Kummerer & Lopez-Reyna, 2009; Magnusson et al., 2016; Marshall, 2013; Marshall et al., 2017; Porterfield & McBride, 2007; Restall & Borton, 2010; Schmidt, 2013; Shannon, 2000; Wall et al., 2005). As has been found in child mental health service access research, barriers of this nature will not be identified through traditional means of child/family/community risk factor identification, such as by 'red flagging' certain groups at referral (Kazdin, Holland, Crowley, et al., 1997) – which the database analysis initially sought to do. Alternate, additional measures are therefore required to identify family barriers (Kazdin, Holland, Crowley, et al., 1997) – such as via the proposed framework.

The Framework of Family Journeys seeks to conceptualise the key elements of family journeys from noticing through to EI service access, with key questions associated with progression between each element. How families answer each ‘question’ is what is considered most important and insightful. For example, does the family know who to share their developmental concerns with, and do they trust what that person is telling them? Rather than a simple yes/no, the framework prompts consideration of the ‘why’ behind the answers, through application of the three components for analysis – barriers or breakdowns, ingredients for success, and supporters and stakeholders. As the framework stated, this moves the conversation beyond making arbitrary judgements about family groups, to instead taking an individualised approach and understanding of this family’s unique experience: to being family-centred.

The central message of the Framework of Family Journeys lies in considering what it means to be genuinely family-centred. The core principles of family-centred practice include partnership; flexibility and responsiveness; individualisation to family needs; looking beyond the child to considering the holistic needs of the family unit; and the honouring and upholding of family values, dignity, culture, and respect in making informed choices for their family (Dunst, 2002). Family-centred practice is said to have been a core part of EI services since the 1990’s (Espe-Sherwindt, 2008); however, this does not necessarily fit with the reality of practice. Many EI services have not adopted ‘true’ family-centred practice; but instead sit somewhere on a continuum between family-centred and professional-centred (Espe-Sherwindt, 2008). Families have described a lack of information, unequal partnerships with EI professionals, the provision of intervention with limited family input, as well as having demands placed on them without considering the impact on the broader family unit (Dodd et al., 2009). Families who miss appointments continue to be described by professionals as 'unmotivated', with professionals viewing that participation in family-centred services means that families need to ultimately 'do it themselves' (Shannon, 2004). There appears to be a strong dissonance between the guiding principles of what it means to be family-centred, and the reality of how this is interpreted and thus enacted in practice.

This issue appears to relate in part to the nature of systems and services that professionals are practising within. For example, in order for professionals to be flexible and responsive to family needs, services need to be resourced in a manner that enables this – such as through the allocation of sufficient time to be able to meaningfully listen to and respond to families (Dodd et al., 2009). This has parallels to the debate on hard-to-reach families, with shifting attitudes to trying to understand what it is that can make services difficult to access (Boag-Munroe & Evangelou, 2012). Part of this process requires shifting the focus of family EI service access away from the point of services themselves (Guralnick, 2001) to considering the journey in its entirety. The CDS referral analysis identified that over 13% of families did not access any element of the service – therefore having conversations about barriers even during the initial intake appointment (as per the Developmental Systems Model (Guralnick, 2001)) would not have impacted these families. Seeking to be family-centred only at the point of service access is thus insufficient to enable their participation. What this indicates is that if we want to better facilitate service access, then we need to embed a family-centred approach throughout family journeys. This was the underlying principle in creating the Framework of Family Journeys – that each element of a family's journeys is considered in relation to what families are experiencing as the barriers or enablers to success, as well as who are (or could be) their supporters or stakeholders. Such a stance comes back to the principles of family-centred practice and centres those principles as being integral to family success in supporting their child (Dunst, 2002).

This whole-journey approach means looking beyond the EI service providers to asking broader community stakeholders to enter the conversation, including places that families and children are already frequenting – such as CHNs, GPs, childcare providers, and even libraries. For example, several interviewed WA families spoke about The City of Wanneroo It's All About Play (IAAP) initiative, where local libraries run drop-in group play sessions in conjunction with local child health nurses and/or allied health professionals (City of Wanneroo, 2017). These professionals, as well as library staff, are often circulating during activities and thus available as a familiar face for a 'quick question' from families. Families spoke highly of initiatives such as this where they could ask questions of professionals in safe, familiar settings - providing informal, 'soft' touchpoint opportunities. Other similar models in WA include the Child and Parent Centres (CPC), a series of sites located in vulnerable communities across the state that provide playgroups, parenting workshops and access to developmental information via health professionals (Child and Parent Centres, n.d.; Shelby Consulting, 2017). The CPC model aims to increase family capability to provide nurturing environments and improve child development, through enhancing access and participation in services and fostering co-location and coordination of service providers from health, education and social services (Shelby Consulting, 2017). A 2017 evaluation of the CPCs identified that the model is largely meeting its outcomes, however identified areas for improvement such as increasing sites in vulnerable communities, greater resourcing to extend services able to be provided, and ensuring that new or changing needs of the community are addressed (Shelby Consulting, 2017). Use of the Framework of Family Journeys could support each of these areas: as a means of conducting a needs assessment of both new communities where sites may be established, and to frame the re-evaluation of the changing needs of existing communities. Parallel to this, is the need to develop the framework for use as a measurement tool to assess if, when, and how services are meeting identified community outcomes whilst identifying critical points for intervention. Ensuring that all services across family journeys are being provided from a place of family-centredness would be a big, positive step towards supporting EI access.

8.5 Social supports: Conduits for information-sharing

The importance of building knowledge and access to information was a key theme throughout this body of work, particularly through the scoping review series. As identified in the Chapter 3 scoping review, parental levels of developmental knowledge appear to be a key mechanism that enables noticing of developmental concerns (Cuomo et al., 2019). Lack of knowledge or understanding of the purpose of EI and/or not seeing the need for it (the sceptical parent) were also crucial barriers that emerged from the Chapter 4 scoping review (Beno, 2017; Khan, 2013; Magnusson et al., 2017; Marshall, 2013). Families additionally have difficulties in knowing who to share developmental concerns, availability of EI services or how to navigate services (Baden; Giordano, 2008; Green et al., 2016; Khan, 2013; Magnusson et al., 2017; Morton, 2012; Ramirez, 2004; Shannon, 2000; Smith et al., 2015; Woolfenden et al., 2015), identified in the Chapter 5 review.

Each of these findings highlighted the role of information as an ingredient for success for families across several elements of their journey. What is unclear is what ‘useful’ information or ‘sufficient’ access looks like, as well as when, where and how families may gain access. The qualitative interviews identified that families are utilising a variety of different modalities to seek out information; from health professionals, through to online forums and family and friends, with many conducting significant research of their own. A key finding from this research was that families did not want to simply receive information:

they want to be able to ask questions – particularly from other families with shared experiences.

Interviewed WA families identified that learning about EI services and what to expect from others who had already been through the process was invaluable. This was supported by Chapter 3 findings that knowing someone who has been through the journey can be an important enabler for family decision-making to act on delays (Glogowska & Campbell, 2004; Marshall, 2013). Significant previous research has demonstrated the value of established peer support groups for families of children with disabilities, in gaining useful information specific to their day-to-day needs; as a space to safely discuss issues with people they trusted; building their understanding of their child's needs and improving their relationship with their child; increasing self-empowerment such as confidence in advocating for their child; and an overall sense of belonging, reduced isolation, and emotional support (Banach et al., 2010; Baum; Klein et al., 2019; Law et al., 2002). Support groups go beyond providing social support to providing "solidarity-as-care"; a sense of collective identity or comradeship through shared experiences (Klein et al., 2019).

How the interviewed families identified people with shared experiences differed based on the nature of the child's delay. Caregivers of children with suspected ASD were able to link in with established support groups and organisations, such as via the PlayConnect playgroups specific to children with autism or similar communication needs (Playgroup WA Inc, n.d.), and spoke highly of the ability to meet others through these mechanisms. While PlayConnect is stated as being open to children with non-ASD developmental delays (Playgroup WA Inc, n.d.), the wording of its advertising (and the narrative from the caregivers) suggests that it is ASD-focused. There were similar experiences for caregivers of children with developmental hip dysplasia (DHD), each of whom spoke about the 'Healthy Hips' Australia website and social media page that many used to share stories and interact with other families (Healthy Hips Australia, n.d.). Caregivers of children with less specific delays did not have such clear opportunities for meeting others; one mother reported that she met a parent whose child experienced similar language delays through an overheard conversation at a local playgroup.

These findings reiterate the problem of the ‘greyness’ of developmental delays that do not fit with specific diagnoses or disabilities. While families of children with ASD or DHD had distinct places to seek support and solidarity, those with unspecified delays did not have such clear avenues. This has clear implications for considering how such families are being connected together to enable both social support and this sense of solidarity. There must be places where families of children with delays feel that they are both welcome and identify with the other members of the group, which may require the establishment of new support groups or a review of the membership criteria of existing groups. Fostering individual connections may facilitate this on a smaller scale; as part of overarching efforts to support families, services should seek to connect families with shared experiences together. Such mechanisms reduce some of the information and knowledge barriers that families experience, and thus better support journeys through to services.

8.6 ‘Difficult-to-access’ services: Connectivity and waitlists

The Chapter 5 scoping review on barriers and the WA family interviews in Chapter 6 identified that seeking services and supports is not always straightforward. As demonstrated by Helen and Isobelle’s journey diagram in Chapter 7, referrals pathways may be convoluted and require progression through multiple services and systems. Understanding which services are available and what a child may be eligible for can be confusing to navigate; even professionals themselves may misrefer families (Shannon, 2000). This confusion can be compounded when services operate in silos without a clear understanding of the other supports in a community that families may be able to access; which is a source of frustration for caregivers who then have to seek this information themselves. The ChildServ model in Connecticut sought to bridge this gap between identification and service access through establishing a triage, referral and care coordination service: providing a conduit between primary care and services that families needed such as EI, parenting classes, and more holistic needs like housing (McKay et al., 2006). Despite challenges, the model was deemed to fill a critical gap in service delivery (McKay et al., 2006), and has since evolved into the Help Me Grow national initiative that acts as a centralised service access point, conducts outreach to both families and providers, and collects data to enable identification of systemic gaps (Help Me Grow National Center, 2021). Inter-organisation communication is critical for understanding individual responsibilities, reducing duplication of services and creating greater transparency of where resources and supports are being directed (Twardzik et al., 2017). Such approaches are vital to overcoming many of the identified barriers that may inhibit family journeys to service access at the systems-level. Australia would benefit from the implementation of a similar model here.

A significant issue with seeking supports identified across both the Chapter 5 scoping review on barriers and the family interviews in Chapter 6 was service waitlists. Families reported waiting months to years to receive the support that their children needed, which was most problematic in public health systems. Waitlist management is a contentious topic; many services, such as CDS, are seeking to find ways to triage service entry better or to divert families onto alternate service pathways such as private EI services. What was made clear in the Chapter 6 interviews was the inequality and disparity that is created when families are faced with having to choose between waiting for services or paying out of pocket for them. This was echoed in a recent Australian Government Senate Inquiry into wait times for speech-language pathology services (McGill et al., 2020). Families identified that where they could afford it, they would opt to go private in order to enable this queue-skipping; however, this was not an option for families with restricted financial resources. Such inequalities and differential treatment in health care systems create disparities in health outcomes, particularly for groups such as those of lower socioeconomic status (Shonkoff et al., 2009). Research in recent years has sought to explore the efficacy of home programs, website or app-based information, or alternative therapeutic programs as an intermediate 'stop-gap' solution while waiting for services (Armstrong et al., 2020; McLeod et al., 2020). Providing families with some level of strategies and support while on waiting lists is entirely appropriate and needed, especially given the importance of acting early and the negative outcomes associated with delayed service access (McGill et al., 2020). However, while such strategies may yield similar benefits in terms of some child outcomes, direct therapy still delivers better outcomes - particularly for caregiver satisfaction (McLeod et al., 2020); which is an essential component of family-centred practice. Ultimately, what is required is reducing waitlist lengths – which may only be achieved through increased funding for the sector. The Committee response to the Senate Inquiry indeed recommended a cost-benefit analysis of the current level of funding for public speech-language pathology, with specific consideration of the impact of current waiting lists on individuals (Commonwealth of Australia, 2014).

The disability sector in Australia, including the delivery of developmental services, is undergoing significant changes. A 2011 Productivity Commission Inquiry Report identified that existing disability systems were fragmented, difficult to navigate and inadequate. In response to this, the National Disability Insurance Scheme (NDIS) began to be introduced in 2013 (Productivity Commission, 2011). The goal of the scheme was to provide people with disabilities and their families with greater equality, choice, control and individualisation of the services and supports they received (Productivity Commission, 2011). While this thesis did not focus on families accessing the NDIS, those families who did have contact with the system spoke of the exact issues the Productivity Commission raised; issues that the introduction of such an initiative was supposed to overcome. The NDIS is a work-in-progress, review of which needs to include strong consideration of how different populations are able to access the scheme. This is an opportunity to do better.

8.7 Complexity of 'hard-to-reach'

As a work-around to difficulties with accessing EI services, interviewed families spoke about system 'hacks' or shortcuts they used to enable successful journeys, such as making frequent calls to services to gain earlier appointments. Families identified that while these hacks were helpful to them, they felt for those families who did not know about them – and questioned the need to have to use them altogether. Both the Chapter 4 review and the interviews identified that caregivers need a high level of self-efficacy, advocacy and persistence to access EI services successfully. Consistent with previous research, even when services are in adequate supply, there are challenges in reaching all families; often those who are not reached are those who need it most (Winkworth et al., 2010). This comes back to the idea of the 'hard-to-reach' family versus services that are difficult to access and changing the narrative of how we think about families. Instead of families being hard to reach, it is services who are not being sufficiently innovative in attempting to reach them (Boag-Munroe & Evangelou, 2012). Rather than seeking to build families to have the skills to access services, services need to take responsibility for being more accessible to a broader spectrum of the community (Boag-Munroe & Evangelou, 2012).

In 2009 the Council of Australian Governments released the National Early Childhood Development Strategy, 'Investing in the Early Years' (Australian Institute of Health and

Welfare, 2011). The vision of the strategy was that by 2020, ‘all children have the best start in life to create a better future for themselves and for the nation’ (Australian Institute of Health and Welfare, 2011). Under this strategy sits a series of seven outcomes, including outcome six: ‘families are confident and have the capabilities to support their children’s development’. In the development of this strategy the receipt of family support via EI services was identified as important, however, it was not ultimately selected as one of the key indicator areas for which progress would be reported and tracked nationally; focusing instead on family social network and parenting quality/capacity (Australian Institute of Health and Welfare, 2011). Only measuring family outcomes in terms of family-based change does not account for the ecology of services, systems and supports surrounding families that should be the mechanisms for such outcome change. This equally means that failure to meet these outcomes is firmly placed with families, thus perpetuating this family-focused, ‘hard-to-reach’ blaming narrative. Direct outcome measurement of the initiatives that should be generating these outcomes ensures that responsibility for ‘change’ in family confidence and capacity is not placed solely on families themselves.

Additionally, the provision of service-based interventions to support effective parenting or specific developmental problems plays an important role; but is not deemed sufficient to address the level and complexity of developmental need in the Australian community (T. Moore et al., 2017). This is an important distinction for EI services to take note of; rather than focusing on ‘waiting’ for children and families to arrive at their door, we need to ensure that a multilevel approach is taken that includes place-based, community-level programs that build and support families in a more holistic manner (T. Moore et al., 2017). This includes ensuring that broader factors that may impact family and child outcomes are not just acknowledged but considered integral to address as part of this bigger picture, such as housing instability, rather than maintaining a tunnelled focus on developmental supports (Garg et al., 2013). Failure to consider the impact of such factors, and adjust the ways that supports are provided accordingly, will mean that the same vulnerable families will continue to be ‘hard-to-reach’ (Garg et al., 2013).

It is also necessary to consider the less-obvious barriers that families may experience. Critique of the Health Belief Model (HBM) included recognition that parent beliefs about their child’s concerns or EI services may be trumped by other factors that undermine their capacity to act on those concerns (Jones et al., 2015; Jones et al., 2014). Hence, each element of the family journey needs to be understood – at the decision-making element, families may indeed believe the concern to be ‘real’ or big enough to be acted on; but then experience barriers or breakdowns in either sharing their concerns or seeking out supports. A family may be prepared to act, but not have trusted, informed stakeholders with whom to share their concerns with, or are not connected to support pathways that work for them and their unique needs.

This notion of ‘trumping’ factors ties into findings showing the strong, emotional impact of noticing developmental concerns – ranging from feelings of guilt, self-blame, denial, avoidance and fear (Baden; Glogowska & Campbell, 2004; Hendrickson et al., 2000; Marshall et al., 2017; Persoff, 1998; Raspa et al., 2015; Shannon, 2000; Silbersack, 2014; Woolfenden et al., 2015). Emotional impact may ‘tip’ the scales in the determination of whether concerns are deemed ‘real’ or big enough to be acted on – particularly on the balance of considering the consequences of acting. For example, several studies spoke of family fears relating to being blamed for their child’s delays and subsequently being reported to child protective services (Gerlach et al., 2017; Jimenez et al., 2012; Leiter, 2001; Shannon, 2000; Sices et al., 2009; Smith et al., 2015), resulting in some families incorrectly answering developmental questions in order to avoid this chain of events (Sices et al., 2009). Such fears mean that these children slip through the cracks and go unnoticed and unsupported. This was an unexpected finding, yet one of significance. Further research is needed to understand better how such experiences weave into the picture of how and if families act on developmental concerns, and what can be done to support them.

8.8 Limitations and recommendations for future research

The current body of research focused on developmental delays in a desire to extend the knowledge base for this population compared to specific developmental disabilities. Ultimately however delay and disability are not discrete groups, with the reality being that there is a significant overlap between these populations. Different researchers may draw different 'lines' of inclusion and exclusion between these populations than shown in this study series. Whether a child has delays in gross motor development or a diagnosis of cerebral palsy, what is most important is that we are speaking to these families - learning about their experiences and beginning to both better understand and appreciate the diversity and complexity of their journeys.

An explicit choice was made in the design of this research to privilege the family voice. In order to truly understand family journeys, it made sense to concentrate on their experiences alone, rather than including the perspective of others who may overlay their own assumptions. There is a body of literature on health professional experiences and aspects such as developmental screening and monitoring that hold an essential place in this broader conversation - but were not the focus here. Understanding the perspective of other stakeholders is important, such as community partners that parents may share their concerns with and the health care professionals that families seek support or EI services from, and it is recommended that future research seeks to also scope their perspectives.

Through the CDS database analysis process, it was identified and acknowledged that the dataset itself held a number of limitations that impacted the extent and complexity of analysis that could be conducted, as well as the generalisability of findings. Results should be interpreted and understood on this basis. It is worth acknowledging that these limitations are likely to be true of many similar EI services, whose databases are designed primarily for clinical utility and do not necessarily lend themselves to research purposes. In saying this, with a world that is becoming ever-focused on transparency and accountability, systems do need to consider the usability of their data to monitor and track key performance indicators – such as rates of service non-access, who this includes, and the subsequent success of efforts to support service access.

Similarly, utilising data sources such as the AEDC to understand levels of community developmental vulnerabilities hold some limitations. Measurement is conducted in the first year of children’s entry at school, and thus reflects a single point in time for each cohort. Therefore, this means that data comparisons across time are made in relation to different cohorts of children. Longitudinal data measurement of cohorts of AEDC children would enhance our understanding of what happens for these children beyond this data point: whether they catch up to their peers or remain developmentally delayed. Multiple measurements would also enable points of pre-post evaluation of services and supports that may be introduced to support these children, and thus enable the evidence-base for such efforts to develop. In turn, data of this nature would better inform policy decision-making in the early years – for example, through demonstrating the true ‘size’ and thus levels of developmental need to fund developmental services accordingly. The ORIGINS project is a longitudinal birth cohort based in Perth that is tracking 10,000 families over the next decade (Telethon Kids Institute, 2021), and has the potential to provide answers to some of these questions over the coming years.

This study focused on the experiences of metropolitan-based families in Perth, WA. In Australia, geography has a significant impact on service access – with those in regional, rural and remote areas historically facing a different set of barriers to access compared to those in the metropolitan. Future research should seek to understand the experiences of families of children with suspected developmental delays in country areas. Additionally, as discussed in relation to the Framework of Family Journeys in Chapter 7, further exploration of the experiences of diverse families and communities is required, such as CALD and Aboriginal and Torres Strait Islander families, to ensure an authentic and culturally safe representation of their journeys. Further to this, the Framework of Family Journeys requires further research to design accompanying information and training to enables its application, maximise the fidelity of implementation, as well as consideration of its clinical utility, efficiency and effectiveness. First steps in this process need to be the establishment of a working group of both families and service providers to enable the co-design of resources, as well as to begin discussions regarding the best ways to implement the Framework to meet both family and service needs.

8.9 Conclusions

I began this research journey as a clinician who wanted answers on why families were slipping through the cracks in accessing developmental EI services. Through this process, I have come to appreciate and understand the complexity of this issue; the length of family journeys from noticing through to service access, the myriad of barriers that may confront them along the way; the stakeholder who may either support or invalidate their experiences; and the need to shift dialogues away from hard-to-reach families to how services themselves may be prohibiting their access.

Importantly, this body of work sought to bring greater clarity to this research area and provide a way to think and talk about family experiences of developmental delays as a step forward for services and systems. Coming back to family-centred practice, what this truly means and looks like, is integral to taking these findings forward into action. It is my hope that the proposed Framework of Family Journeys provides a platform for services to begin a process of reflection, of identification of where they could and should do better, and ultimately a means of beginning the work of creating change.

8.10 References

Ahern, K. (2000). "Something is wrong with my child": A phenomenological account of a search for a diagnosis. *Early Education and Development, 11*(2), 187-201. https://doi.org/10.1207/s15566935eed1102_4

Alexander, K., Brijnath, B., & Mazza, D. (2015). Parents' decision making and access to preventive healthcare for young children: Applying Andersen's Model. *Health Expectations, 18*, 1256-1269. https://doi.org/10.1111/hex.12100

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology, 8*(1), 19-32. https://doi.org/10.1080/1364557032000119616

Armstrong, J., Girdler, S., Davidson, E., Mizen, J., Bear, N., Wray, J., & Elliot, C. (2020). Randomised controlled trial of a therapeutic playgroup for children with developmental delays. *Journal of Autism and Developmental Disorders, 4*. https://doi.org/10.1007/s10803-020-04580-7.

Australian Institute of Health and Welfare. (2011). *National outcome measures for early childhood development: Development of an indicator-based reporting framework* (Cat. no. PHE 134). https://www.aihw.gov.au/reports/health-care-quality-performance/national-outcome-measures-early-childhood/contents/table-of-contents

Baden, K. M. (2012). *Fathers' and mothers' experiences with participation in Part C of the Individuals with Disabilities Education Act early intervention process* (Publication Number ED551186) [Doctoral dissertation, Walden University]. ProQuest Dissertatations and Theses. https://eric.ed.gov/?id=ED551186

Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social Work with Groups, 33*(1), 69-83. https://doi.org/10.1080/01609510903437383

Baum, L. S. (2004). Internet parent support groups for primary caregivers of a child with special health care needs. *Pediatric Nursing, 30*(5), 381-388.

Beno, C. (2017). *Receipt of an individual family service plan after reported childhood maltreatment: A mixed-methods inquiry* (Publication Number 10283512) [Doctoral dissertation, University of California]. ProQuest Dissertations and Theses. https://search.proquest.com/docview/1948877934

Boag-Munroe, G., & Evangelou, M. (2012). From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Research Papers in Education, 27*(2), 209-239. https://doi.org/10.1080/02671522.2010.509515

Centers for Disease Control and Prevention. (2020a). *Developmental monitoring and screening*. https://www.cdc.gov/ncbddd/childdevelopment/screening.html

Chen, H., Cohen, P., & Chen, S. (2010). How big is a big odds ratio? Interpreting the magnitudes of odds ratios in epidemiological studies *Communication in Statistics - Simulation and Computation, 39*(4), 860-864. https://doi.org/10.1080/03610911003650383

Child and Parent Centres. (n.d.). *About our Centres*. https://childandparentcentres.wa.edu.au/about-us/

City of Wanneroo. (2017). *Early childhood strategic plan*. https://www.wanneroo.wa.gov.au/downloads/file/1333/early_childhood_strategy_and_policy

Commissioner for Children and Young People. (2019). *Developmental screening*. https://www.ccyp.wa.gov.au/our-work/indicators-of-wellbeing/age-group-0-to-5-years/developmental-screening/#05-health-checks

Commonwealth of Australia. (2014). *Senate Community Affairs Reference Committee: Prevelance of different types of speech, language and communication disorders and speech pathology services in Australia*. https://www.aph.gov.au/parliamentary_business/committees/senate/community_affairs/speech_pathology/report

Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, & Medical Home Initiatives for Children with Special Needs Project Advisory Committee. (2006). Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics, 118*(1), 405-420. https://doi.org/10.1542/peds.2006-1231

Cuomo, B., Joosten, A., & Vaz, S. (2019). Scoping review on noticing concerns in child development: A missing piece in the early intervention puzzle. *Disability and Rehabilitation*. https://doi.org/10.1080/09638288.2019.1708296

Dodd, J., Saggers, S., & Wildy, H. (2009). Constructing the ‘ideal’ family for family-centred practice: Challenges for delivery. *Disability and Society, 24*(2), 174-186. https://doi.org/10.1080/09687590802652447

Dunst, C. J. (2002). Family-centred practice: Birth through high school. *Journal of Special Education, 36*(3), 141-149. https://doi.org/10.1177/00224669020360030401

Dworkin, P. H. (1989). British and American recommendations for developmental monitoring: the role of surveillance. *Pediatrics, 84*(6), 1000-1010.

Eapen, V., Walter, A., Guan, J., Descallar, J., Axelsson, E., Einfeld, S., Eastwood, J., Murphy, E., Beasley, D., Silove, N., Dissanayake, C., Woolfenden, S., Williams, K., Jalaludin, B., & The 'Watch Me Grow' Study, G. (2017). Maternal help-seeking for child developmental concerns: Associations with socio-demographic factors. *Journal of Paediatrics and Child Health*. https://doi.org/10.1111/jpc.13607

Espe-Sherwindt, M. (2008). Family-centred practice: Collaboration, competency and evidence. *Support for Learning, 23*(3), 136-143. https://doi.org/10.1111/j.1467-9604.2008.00384.x

Felt, B. T., & O'Connor, M. E. (2003). Use of the child development review increases residents' discussion of behavioral problems. *Ambulatory Pediatrics, 3*(1), 2-8. https://doi.org/10.1367/1539-4409(2003)003<0002:UOTCDR>2.0.CO;2

Garg, A., Jack, B., & Zuckerman, B. (2013). Addressing the social determinants of health within the patient-centred medical home. *JAMA, 309*(19), 2001-2002. https://doi.org/10.1001/jama.2013.1471

Garg, P., Ha, M. T., Eastwood, J., Harvey, S., Woolfenden, S., Murphy, E., Dissanayake, C., Williams, K., Jalaludin, B., McKenzie, A., Einfeld, S., Silove, N., Short, K., & Eapen, V. (2018). Health professional perceptions regarding screening tools for developmental surveillance for children in a multicultural part of Sydney, Australia. *BMC Family Practice, 19*(1), 42. https://doi.org/10.1186/s12875-018-0728-3

Gerlach, A. J., Browne, A. J., & Greenwood, M. (2017). Engaging Indigenous families in a community-based Indigenous early childhood programme in British Columbia, Canada: A cultural safety perspective. *Health and Social Care In the Community, 25*(6), 1763-1773. https://doi.org/10.1111/hsc.12450

Giannoni, P. P., & Kass, P. H. (2010). Risk factors associated with children lost to care in a state early childhood intervention program. *Research in Developmental Disabilities, 31*(4), 914-923. https://doi.org/10.1016/j.ridd.2010.02.013

Ginsburg, S. (2008). Colocating health services: A way to improve coordination of children’s health care? *Commonwealth Fund, 41*(1153), 1-11. https://www.issuelab.org/resources/8730/8730.pdf

Giordano, K. (2008). *Barriers to early intervention services in New Jersey* [Doctoral dissertation, Fairleigh Dickinson University]. ProQuest Dissertations & Theses. http://dbgw.lis.curtin.edu.au:2048/login?url=https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/304403224?accountid=10382

Glascoe, F. P., & Dworkin, P. H. (1995). Role of parents in the detection of developmental and behavioral problems. *Pediatrics, 95*(6), 829-836. https://pubmed.ncbi.nlm.nih.gov/7539122/

Glaun, D. E., Cole, K. E., & Reddihough, D. S. (1998). Six month follow-up: the crucial test of multidisciplinary developmental assessment. *Child: Care, Health and Development, 24*(6), 457-472. https://doi.org/10.1046/j.1365-2214.1998.00082.x

Glogowska, M., & Campbell, R. (2004). Parental views of surveillance for early speech and language difficulties. *Children and Society, 18*(4), 266-277. https://doi.org/10.1002.CHI.806

Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P. M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services. *BMC Health Services Research, 16*(1), 680. https://doi.org/10.1186/s12913-016-1926-0

Guralnick, M. J. (2001). A developmental systems model for early intervention. *Infants and Young Children, 14*(2), 1-18. http://depts.washington.edu/chdd/guralnick/pdfs/dev_sys_model_EI_IYC_10_01.pdf

Healthy Hips Australia. (n.d.). About us. https://www.healthyhipsaustralia.org.au

Help Me Grow National Center. (2021). *The HMG system model*. www.helpmegrownational.org/hmgsystemmodel

Hendrickson, S., Baldwin, J. H., & Allred, K. W. (2000). Factors perceived by mothers as preventing families from obtaining early intervention services for their children with special needs. *Children's Health Care, 29*(1), 1-17. https://doi.org/10.1207/S15326888CHC2901_1

Jimenez, M. E., Barg, F. K., Guevara, J. P., Gerdes, M., & Fiks, A. G. (2012). Barriers to evaluation for early intervention services: parent and early intervention employee perspectives. *Academic pediatrics, 12*(6), 551-557. https://doi.org/10.1016/j.acap.2012.08.006

Jones, C. J., Jensen, J. D., Scherr, C. L., Brown, N. R., Christy, K., & Weaver, J. (2015). The health belief model as an explantory framework in communication research: Exploring parallel, serial and moderated mediation. *Health Communication, 30*(6), 566-676. https://doi.org/10.1080/10410236.2013/873363

Jones, C. J., Smith, H., & Llewellyn, C. (2014). Evaluating the effectiveness of health belief model interventions in improving adherence: A systematic review. *Health Psychology Review, 8*(3), 253-269. https://doi.org/10.1080/17437199.2013.802623

Kazdin, A. E., Holland, L., Crowley, M., & Breton, S. (1997). Barriers to treatment participation scale: Evaluation and validation in the context of child outpatient treatment. *Journal of Child Psychology and Psychiatry, 38*(8), 1051-1062. https://doi.org/10.1111/j.1469-7610.1997.tb01621.x

Khan, L. P., Michael; Elena Rosa, Brown. (2013). Parenting programmes: identification and referral. *Journal of Children's Services, 8*(3), 194-208. https://doi.org/10.1108/JCS-03-2013-0011

Klein, O., Walker, C., Aumann, K., Anjos, K., & Terry, J. (2019). Peer support groups for parent-carers of children with attention deficit hyperactivity disorer: The importance of solidarity as care. *Disability and Society, 34*(9), 1445-1461. https://doi.org/10.1080/09687599.2019.1584090

Kummerer, S. E., & Lopez-Reyna, N. A. (2009). Engaging Mexican immigrant families in language and literacy interventions: Three case studies. *Remedial and Special Education, 30*(6), 330-343. https://doi.org/10.1177/0741932508321014

Law, M., King, S., Stewart, D., & King, G. (2002). The perceived effects of parent-led support groups for parents of children with disabilities. *Physical and Occupational Therapy in Pediatrics, 21*(2), 29-48. https://doi.org/10.1080/J006v21n02_03

Leiter, V. R. (2001). *Gentle intrusions: Family-centered care in early intervention* (Publication Number 3004966) [Doctoral dissertation, Brandeis University]. ProQuest Dissertations & Theses Global. https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/304681652?pq-origsite=summon

Magnusson, D., Palta, M., McManus, B., Benedict, R. E., & Durkin, M. S. (2016). Capturing unmet therapy need among young children with developmental delay using national survey data. *Academic pediatrics, 16*(2), 145-153. https://doi.org/10.1016/j.acap.2015.05.003

Magnusson, D. M., Minkovitz, C. S., Kuhlthau, K. A., Caballero, T. M., & Mistry, K. B. (2017). Beliefs regarding development and early intervention among low-income African American and Hispanic mothers. *Pediatrics, 140*(5). https://doi.org/http://dx.doi.org/10.1542/peds.2017-2059

Marshall, J. (2013). *Parent pathways: Recognition and responses to developmental delays in young children: A mixed-methods exploratory study* [Doctoral dissertation, University of South Florida]. Scholar Commons. http://scholarcommons.usf.edu/etd/4534

Marshall, J., Adelman, A., Kesten, S. M., Natale, R. A., & Elbaum, B. (2017). Parents' experiences navigating intervention systems for young children with mild language delays. *Journal of Early Intervention, 39*(3), 180-198. https://doi.org/10.1177/1053815117704958

McAllister, L., McCormack, J., McLeod, S., & Harrison, L. J. (2011). Expectations and experiences of accessing and participating in services for childhood speech impairment. *International Journal of Speech-Language Pathology, 13*(3), 251-267. https://doi.org/10.3109/17549507.2011.535565

McGill, N., Crowe, K., & McLeod, S. (2020). "Many wasted months": Stakeholders' perspectives about waiting for speech-language pathology services. *International Journal of Speech-Language Pathology, 22*(3), 313-326. https://doi.org/10.1080/17549507.2020.1747541

McKay, K., Shannon, A., Vater, S., & Dworkin, P. H. (2006). ChildServ: Lessons learned from the design and implementation of a community-based developmental surveillance program. *Infants & Young Children, 19*(4), 371-377.

McLeod, S., Davis, E., Rohr, K., McGill, N., Miller, K., Roberts, A., Thornton, S., Ahio, N., & Ivory, N. (2020). Waiting for speech-langauge pathology services: A randomised controlled trial comparing therapy, advice and device. *International Journal of Speech-Language Pathology, 22*(3), 372-386. https://doi.org/10.1080/17549507.2020.1731600

Missiuna, C., Moll, S., Law, M., King, S., & King, G. (2006). Mysteries and mazes: Parents' experiences of children with developmental coordination disorder. *Canadian Journal of Occupational Therapy, 73*(1), 7-17. https://doi.org/10.2182/cjot.05.0010

Moore, C., Zamora, I., Gera, M. P., & Williams, M. E. (2017). Developmental screening and referrals: Assessing the influence of provider specialty, training, and interagency communication. *Clinical Pediatrics, 56*(11), 1040-1047. https://doi.org/10.1177/0009922817701174

Moore, T., Arefadib, N., Deery, A., & West, S. (2017). *The first thousand day: An evidence paper*. Murdoch Children's Research Institute. https://www.rch.org.au/uploadedFiles/Main/Content/ccchdev/CCCH-The-First-Thousand-Days-An-Evidence-Paper-September-2017.pdf

Morton, D. S. (2012). *Parental descriptions of awareness and associated reactions to developmental delay in children* (Publication Number AAI3545470) [Doctoral dissertation, Capella University]. ProQuest Dissertations & Theses Global. https://www-proquest-com.dbgw.lis.curtin.edu.au/docview/1520325243/B7F1BC2997EB4B37PQ/1?accountid=10382

Mulcahy, H., & Savage, E. (2016). Uncertainty: A little bit not sure. Parental concern about child growth or development. *Journal of Child Health Care, 20*(3), 333-343. https://doi.org/10.1177/1367493515587059

Oberklaid, F., & Efron, D. (2005). Developmental delay - identification and management. *Australian family physician, 34*(9), 739-742.

Persoff, J. R. (1998). *Poverty and early childhood developmental delay: Perspectives from Hispanic mothers* [Doctoral dissertation, University of Denver]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/304432454?accountid=10382

Playgroup WA Inc. (n.d.). *PlayConnect playgroups*. https://playgroupwa.com.au/funded-programs/supported-playgroup-services/playconnect/

Porterfield, S. L., & McBride, T. D. (2007). The effect of poverty and caregiver education on perceived need and access to health services among children with special health care needs. *American Journal of Public health, 97*(2), 323-329. https://doi.org/10.2105/AJPH.2004.055921

Productivity Commission. (2011). *Disability care and support* (Report number 54). https://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-volume1.pdf

Ramirez, M. C. (2004). *Latino parents with developmentally delayed children: Perceptions of early intervention services* [Master’s thesis, California State University]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/305036959?pq-origsite=gscholar

Rannard, A., Lyons, C., & Glenn, S. (2004). Children with specific language impairment: Parental accounts of the early years. *Journal of Child Health Care, 8*(2), 165-176. https://doi.org/10.1177/1367493504041875

Raspa, M., Levis, D. M., Kish-Doto, J., Wallace, I., Rice, C., Barger, B., Green, K. K., & Wolf, R. B. (2015). Examining parents' experiences and information needs regarding early identification of developmental delays: Qualitative research to inform a public health campaign. *Journal of Developmental & Behavioral Pediatrics, 36*(8), 575-585. https://doi.org/10.1097/DBP.0000000000000205

Restall, G., & Borton, B. (2010). Parents' concerns about their children's development at school entry. *Child: Care, Health and Development 36*(2), 208-215. https://doi.org/10.1111/j.1365-2214.2009.01019.x

Schmidt, K. R. T. (2013). *Predictors of parent involvement in Part C early intervention services* [Doctoral dissertation, University of Maryland]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/1399598995?accountid=10382

Shannon, P. (2000). *Family-centered practice in early intervention services for infants and toddlers: The experience of families and professionals in one Local Interagency Coordinating Council* [Doctoral dissertation, Virginia Commonwealth University]. ProQuest Dissertations & Theses Global. https://scholarscompass.vcu.edu/etd/5304/

Shannon, P. (2004). Barriers to family-centered services for infants and toddlers with developmental delays. *Social Work, 49*(2), 301-308. https://doi.org/10.1093/sw/49.2.301

Shelby Consulting. (2017). *Evaluation of the Child and Parent Centre Initiative*. https://www.education.wa.edu.au/dl/ejzg3o

Shonkoff, J. P., Boyce, W. T., & McEwen, B. S. (2009). Neuroscience, molecular biology, and the childhood roots of health disparities. *JAMA, 301*(21), 2252-2259. https://doi.org/10.1001/jama.2009.754

Sices, L., Egbert, L., & Mercer, M. B. (2009). Sugar-coaters and straight talkers: communicating about developmental delays in primary care. *Pediatrics, 124*(4), e705-713. https://doi.org/10.1542/peds.2009-0286

Silbersack, E. W. (2014). *Mothers' initial discovery of childhood disability: Exploring maternal identification of developmental issues in young children* [Doctoral dissertation, Adelphi University]. ProQuest Dissertations & Theses Global. https://eric.ed.gov/?id=ED557029

Smith, E., Koerting, J., Latter, S., Knowles, M. M., McCann, D. C., Thompson, M., & Sonuga-Barke, E. J. (2015). Overcoming barriers to effective early parenting interventions for attention-deficit hyperactivity disorder (ADHD): Parent and practitioner views. *Child: Care, Health and Development, 41*(1), 93-102. https://doi.org/10.1111/cch.12146

Telethon Kids Institute. (2021). The ORIGINS Project. https://originsproject.telethonkids.org.au/about-the-origins-project/

Twardzik, E., Cotto-Negrón, C., & Macdonald, M. (2017). Factors related to early intervention Part C enrollment: A systematic review. *Disability and Health Journal, 10*(4), 467-474. https://doi.org/10.1016/j.dhjo.2017.01.009

Wall, S. M., Taylor, N. E., Liebow, H., Sabatino, C. A., Mayer, L. M., Farber, M. Z., & Timberlake, E. M. (2005). Early Head Start and access to early intervention services: a qualitative investigation. *Topics in Early Childhood Special Education, 25*(4), 218-231. https://doi.org/10.1177/02711214050250040301

Williams, J. (2007). Learning from mothers: how myths, policies and practices affect the detection of subtle developmental problems in children. *Child: Care, Health and Development, 33*(3), 282-290. https://doi.org/10.1111/j.1365-2214.2006.00690.x

Winkworth, G., McArthur, M., Layton, M., Thomson, L., & Wilson, F. (2010). Opportunities lost - Why some parents of young children are not well-connected to the service systems designed to assist them. *Australian Social Work, 63*(4), 431-444. https://doi.org/10.1080/0312407X.2010.508170

Woolfenden, S., Posada, N., Krchnakova, R., Crawford, J., Gilbert, J., Jursik, B., Sarkozy, V., Perkins, D., & Kemp, L. (2015). Equitable access to developmental surveillance and early intervention - understanding the barriers for children from culturally and linguistically diverse (CALD) backgrounds. *Health Expectations, 18*(6), 3286-3301. https://doi.org/10.1111/hex.12318

Worcester, J. (2005, 2005). Giving voice to parents of young children with challenging behavior. *Exceptional Children, 74*(4), 509-525. https://doi.org/10.1177/001440290807400406

Bibliography

Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.

Ahern, K. (2000). "Something is wrong with my child": A phenomenological account of a search for a diagnosis. *Early Education and Development, 11*(2), 187-201. https://doi.org/10.1207/s15566935eed1102_4

Alexander, K., Brijnath, B., & Mazza, D. (2015). Parents' decision making and access to preventive healthcare for young children: Applying Andersen's Model. *Health Expectations, 18*, 1256-1269. https://doi.org/10.1111/hex.12100

Allen, D., Gillen, E., & Rixson, L. (2009). Systematic review of the effectiveness of integrated care pathways: what works, for whom, in which circumstances? *International Journal of Evidence-Based Healthcare, 7*(2), 61-74. https://doi.org/10.1111/j.1744-1609.2009.00127

Archambault, J., Cote, D., & Raynault, M. F. (2020). Early childhood education and care access for children from disadvantaged backgrounds: Using a framework to guide intervention. *Early Childhood Education Journal, 48*(3), 345-352. https://doi.org/10.1007/s10643-019-01002-x

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology, 8*(1), 19-32. https://doi.org/10.1080/1364557032000119616

Armstrong, J., Girdler, S., Davidson, E., Mizen, J., Bear, N., Wray, J., & Elliot, C. (2020). Randomised controlled trial of a therapeutic playgroup for children with developmental delays. *Journal of Autism and Developmental Disorders, 4*. https://doi.org/10.1007/s10803-020-04580-7.

Atherton, H., Sawmynaden, P., Meyer, B., & Car, J. (2012). Email for the coordination of healthcare appointments and attendance reminders. *cochrane Database of Systematic Reviews*(8), Article No. CD007981. https://doi.org/10.1002/14651858.CD007981.pub2

Australian Bureau of Statistics. (2016). *Census of Population and Housing: General community profile tables* (2001.0). https://www.abs.gov.au/ausstats/abs@.nsf/mf/2001.0

Australian Bureau of Statistics. (2018). *Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia, 2016* (2033.0.55.001). https://www.abs.gov.au/ausstats/abs@.nsf/mf/2033.0.55.001

Australian Bureau of Statistics. (2019a). *Australian demographic statistics* (ABS cat. no. 3101.0).

Australian Bureau of Statistics. (2019b). *Disability, ageing and carers, Australia: Summary of findings*. https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release

Australian Bureau of Statistics. (2021). National, state and territory population. https://www.abs.gov.au/statistics/people/population/national-state-and-territory-population/latest-release

Australian Health Ministers Advisory Council. (2013). *National framework for universal child and family health services*. https://www1.health.gov.au/internet/main/publishing.nsf/Content/AFF3C1C460BA5300CA257BF0001A8D86/$File/NFUCFHS.PDF

Australian Institute of Health and Welfare. (2011). *National outcome measures for early childhood development: Development of an indicator-based reporting framework* (Cat. no. PHE 134). https://www.aihw.gov.au/reports/health-care-quality-performance/national-outcome-measures-early-childhood/contents/table-of-contents

Australian Institute of Health and Welfare. (2020a). *Health system overview*. Retrieved 13 May 2021 from https://www.aihw.gov.au/reports/australias-health/health-system-overview

Australian Institute of Health and Welfare. (2020b). Primary health care. https://www.aihw.gov.au/reports/australias-health/primary-health-care

Ayer, C., Eapen, V., Overs, B., Descallar, J., Jalaludin, B., Eastwood, J., Dissanayake, C., Williams, K., Murphy, E., & Woolfenden, S. (2020). Risk factors for non-participation in a universal developmental surveillance program in a population in Australia. *Australian Health Review, 44*(4), 512-520. https://doi.org/10.1071/AH18236

Baden, K. M. (2012). *Fathers' and mothers' experiences with participation in Part C of the Individuals with Disabilities Education Act early intervention process* (Publication Number ED551186) [Doctoral dissertation, Walden University]. ProQuest Dissertatations and Theses. https://eric.ed.gov/?id=ED551186

Baker, S., Sanders, M. R., & Morawska, A. (2017). Who uses online parenting support? A cross-sectional survey exploring Australian parents’ internet use for parenting. *Journal of Child and Family Studies, 26*, 916-927. https://doi.org/10.1007/s10826-016-0608-1

Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social Work with Groups, 33*(1), 69-83. https://doi.org/10.1080/01609510903437383

Barfield, W. D., Clements, K. M., Lee, K. G., Kotelchuck, M., Wilber, N., & Wise, P. H. (2008). Using linked data to assess patterns of Early Intervention (EI) referral among very low birth weight infants. *Maternal and Child Health Journal, 12*(1), 24-33. https://doi.org/10.1007/s10995-007-0227-y

Baum, L. S. (2004). Internet parent support groups for primary caregivers of a child with special health care needs. *Pediatric Nursing, 30*(5), 381-388.

Beno, C. (2017). *Receipt of an individual family service plan after reported childhood maltreatment: A mixed-methods inquiry* (Publication Number 10283512) [Doctoral dissertation, University of California]. ProQuest Dissertations and Theses. https://search.proquest.com/docview/1948877934

Bethell, C., Reuland, C., Schor, E., Abrahms, M., & Halfon, N. (2011). Rates of parent-centered developmental screening: disparities and links to services access. *Pediatrics, 128*(1), 146-155. https://doi.org/10.1542/peds.2010-0424

Boag-Munroe, G., & Evangelou, M. (2012). From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Research Papers in Education, 27*(2), 209-239. https://doi.org/10.1080/02671522.2010.509515

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589-597. https://doi.org/10.1080.2159676X.2019.1628806

Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualised: A bio-ecological model. *Psychological Review, 10*(4), 568-586.

Campbell, F., Conti, G., Heckman, J. J., Moon, S. H., Pinto, R., Pungello, E., & Pan, Y. (2014). Early childhood investments substantially boost adult health. *Science, 343*. https://doi.org/10.1126/science.1248429

Carpenter, C. J. (2010). A meta-analysis of the effectiveness of Health Belief Model variable in predicting behavior. *Health Communication, 25*, 661-669. https://doi.org/10.1080.10410236.2010.521906

Centers for Disease Control and Prevention. (2020a). *Developmental monitoring and screening*. https://www.cdc.gov/ncbddd/childdevelopment/screening.html

Centers for Disease Control and Prevention. (2020b). *What to do while you wait to see a developmental specialist*. https://www.cdc.gov/ncbddd/actearly/concerned-whileyouwait.html

Champion, V. L., & Skinner, C. S. (2008). The health belief model. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education: Theory, research and practice* (4th ed., pp. 45-66). Jossey-Bass.

Checkland, K., Hammond, J., Allen, P., Coleman, A., Warwick-Giles, L., Hall, A., Mays, N., & Sutton, M. (2020). Road to nowhere? A critical consideration of the use of the metaphor 'care pathway' in health services planning, organisation and delivery. *Journal of Social Policy, 49*(2), 405-424. https://doi.org/10.1017/S0047279419000400

Chen, H., Cohen, P., & Chen, S. (2010). How big is a big odds ratio? Interpreting the magnitudes of odds ratios in epidemiological studies *Communication in Statistics - Simulation and Computation, 39*(4), 860-864. https://doi.org/10.1080/03610911003650383

Child and Adolescent Health Service. (2018). *2017-18 Annual report*. https://www.cahs.health.wa.gov.au/-/media/HSPs/CAHS/Documents/About-us/Annual-Reports/2017-18AnnualReport.pdf

Child and Adolescent Health Service. (2019). *2018-19 Annual report*. https://www.cahs.health.wa.gov.au/-/media/HSPs/CAHS/Documents/About-us/Annual-Reports/2018-19AnnualReport.pdf

Child and Adolescent Health Service. (2020). Community Health. https://cahs.health.wa.gov.au/Our-services/Community-Health

Child and Parent Centres. (n.d.). *About our Centres*. https://childandparentcentres.wa.edu.au/about-us/

Chin, F., & Teti, D. M. (2013). Infants at double jeopardy: Socioeconomic, medical, and attachment-based predictors of maternal engagement with an early intervention program. *Infant Mental Health Journal, 34*(5), 420-434. https://doi.org/10.1002/imhj.21398

Choo, Y. Y., Agarwal, P., How, C. H., & Yeleswarapu, S. P. (2019). Developmental delay: Identification and management at primary care level. *Singapore Medical Journal, 60*(3), 119-123. https://doi.org/10.11622/smedj.2019025

Chung, C.-Y., Liu, W.-Y., Chang, C.-J., Chen, C.-L., Tang, S. F.-T., & Wong, A. M.-K. (2011). The relationship betwen parental concerns and final diagnosis in children with developmental delay. *Journal of Child Neurology, 26*(4), 413-419. https://doi.org/10.1177/0883073810381922

City of Wanneroo. (2017). *Early childhood strategic plan*. https://www.wanneroo.wa.gov.au/downloads/file/1333/early_childhood_strategy_and_policy

Clements, K. M., Barfield, W. D., Kotelchuck, M., & et al. (2008). Maternal socio-economic and race/ethnic characteristics associated with early intervention participation. *Maternal and Child Health Journal, 12*(6), 708-717. https://doi.org/10.1007/s10995-007-0291-3

Cohen, J. S., & Mendez, J. L. (2009). Emotion regulation, language ability, and the stability of preschool children's peer play behavior. *Early Education and Development, 20*(6), 1016-1037. https://doi.org/10.1080/10409280903305716

Coker, T. R., Thomas, T., & Chung, P. J. (2013). Does well-child care have a future in pediatrics? *Pediatrics, 131*(Suppl 2), S149-S159. https://doi.org/10.1542/peds.2013-0252f

Colgan, S. E. (2012). *The role of maternal depression in accessing early intervention services for children with developmental delay* (Publication Number ED551922) [Doctoral dissertation, University of North Carolina]. ProQuest Dissertations & Theses. https://eric.ed.gov/?id=ED551922

Collier, L. R., Gregory, T., Harman-Smith, Y., Gialamas, A., & Brinkman, S. A. (2020). Inequalities in child developmental at school entry: A repeated cross-sectional analysis of the Australian Early Development Census 2009-2018. *The Lancet Regional Health - Western Pacific, 4*. https://doi.org/10.1016/j.lanwpc.2020.200057

Commissioner for Children and Young People. (2019). *Developmental screening*. https://www.ccyp.wa.gov.au/our-work/indicators-of-wellbeing/age-group-0-to-5-years/developmental-screening/#05-health-checks

Commonwealth of Australia. (2014). *Senate Community Affairs Reference Committee: Prevelance of different types of speech, language and communication disorders and speech pathology services in Australia*. https://www.aph.gov.au/parliamentary_business/committees/senate/community_affairs/speech_pathology/report

Conti, G., Heckman, J. J., & Pinto, R. (2016). The effects of two influential early childhood interventions on health and healthy behaviour. *The Economic Journal, 126*, 28-65. https://doi.org/10.1111/ecoj.12420

Coonrod, E. E., & Stone, W. L. (2004). Early concerns of parents of children with autistic and nonautistic disorders. *Infants & Young Children: An Interdisciplinary Journal of Early Childhood Intervention, 17*(3), 258-268. https://doi.org/10.1097/00001163-200407000-00007

Cornell, E., Luczak, S., Dudack, D., Sibley, S., Phillip, T., Martini-Carvell, K., & Dworkin, P. H. (2018). *Help Me Grow building impact report*. Help Me Grow National Center. http://helpmegrownational.org/wp-content/uploads/2019/05/HMG-Report-2019-Reference.pdf

Cortis, N., Katz, I., & Patulny, R. (2009). *Engaging hard-to-reach families and children* (FaHCSIA Occasional paper no. 26). http://dx.doi.org/10.2139/ssrn.1728576

Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, & Medical Home Initiatives for Children with Special Needs Project Advisory Committee. (2006). Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics, 118*(1), 405-420. https://doi.org/10.1542/peds.2006-1231

Cunha, F., Heckman, J. J., Lochner, L., & Masterov, D. V. (2006). Interpreting the evidence on life cycle skill formation. In E. A. Hanushek & F. Welch (Eds.), *Handbook of the economics of education* (Vol. 1, pp. 697-812). North Holland. https://doi.org/10.1016/S1574-0692(06)01012-9

Cuomo, B., Joosten, A., & Vaz, S. (2019). Scoping review on noticing concerns in child development: A missing piece in the early intervention puzzle. *Disability and Rehabilitation*. https://doi.org/10.1080/09638288.2019.1708296

Curtin, M., Madden, J., Staines, A., & Perry, I. J. (2013). Determinants of vulnerability in early childhood development in Ireland: A cross-sectional study. *BMJ Open, 3*, e002387. https://doi.org/10.1136/bmjopen-2012-002387

Daniel, K. L., Prue, C., Taylor, M. K., Thomas, J., & Scales, M. (2009). ‘Learn the signs. Act early’: A campaign to help every child reach his or her full potential. *Public Health, 123*(Suppl 1), e11-16. https://doi.org/10.1016/j.puhe.2009.06.002

De Giacomo, A., & Fombonne, E. (1998). Parental recognition of developmental abnormalities in autism. *European Child & Adolescent Psychiatry, 7*(3), 131-136. http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=107165221&site=ehost-live

Delgado, C. E. F., & Scott, K. G. (2006). Comparison of referral rates for preschool children at risk for disabilities using information obtained from birth certificate records. *The Journal of Special Education, 40*(1), 28-35. https://doi.org/10.1177/00224669060400010301

Department for Child Protection and Family Support. (2017). *Annual report*. https://www.dcp.wa.gov.au/Resources/Documents/Annual%20reports/Annual%20Report%202016%202017%20Online.pdf

Department of Education and Training. (2016). *Australian early development census national report 2015*. https://www.aedc.gov.au/resources/detail/2015-aedc-national-report

Department of Education and Training. (2019). *Australian early development census national report 2018*. https://www.aedc.gov.au/resources/detail/2018-aedc-national-report

Department of Health Western Australia. (2016). *Child development service referral form*. https://cahs.health.wa.gov.au/~/media/HSPs/CAHS/Documents/Community-Health/ChildDevelopment/CDS%20print%20referral%20form.pdf

Department of Health Western Australia. (2019). *Elective surgery wait list reports*. https://ww2.health.wa.gov.au/Reports-and-publications/Elective-Surgery-Wait-List-ESWL-reports

Department of Health Western Australia. (2020a). *Child development service*. https://cahs.health.wa.gov.au/Our-services/Community-Health/Child-Development-Service

Department of Health Western Australia. (2020b). Emergency department live activity. https://ww2.health.wa.gov.au/Reports-and-publications/Emergency-Department-activity/Data?report=ed_activity_now

Department of Health Western Australia. (n.d.). *Overview of the WA health systems*. https://ww2.health.wa.gov.au/Careers/International-applicants/International-medical-graduates/Overview-of-the-WA-health-system

Department of Social Services. (2020). Helping Children with Autism (HCWA) and Better Start for Children with Disability (Better Start). https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability/helping-children-with-autism-hcwa-and-better-start-for-children-with-disability-better-start

DiGiacomo, M., Delaney, J., Abbott, P., Davidson, P. L., Delaney, J., & Vincent, F. (2013). ‘Doing the hard yards’: Carer and provider focus group perspective of accessing Aboriginal childhood disability services. *BMC Health Services Research, 13*(326). https://doi.org/10.1186/1472-6963-13-326

Dixit, S. K., & Sambasivan, M. (2018). A review of the Australian healthcare system: A policy perspective. *SAGE Open Medicine, 6*, 1-14. https://doi.org/10.1177/2050312118769211

Dodd, J., Saggers, S., & Wildy, H. (2009). Constructing the 'ideal' family for family-centred practice: Challenges for delivery. *Disability and Society, 24*(2), 174-186. https://doi.org/10.1080/09687590802652447

Doherty, P., Hall, M., & Kinder, K. (2003). *On track thematic report: Assessment, referral and hard-to-reach groups*. https://webarchive.nationalarchives.gov.uk/20110506162108/https://www.education.gov.uk/publications/eOrderingDownload/RR475.pdf

Doyle, O., Harmon, C. P., Heckman, J. J., & Tremblay, R. E. (2009). Investing in early human development: Timing and economic efficiency. *Economics & Human Biology, 7*(1), 1-6. https://doi.org/10.1016/j.ehb.2009.01.002

Dunst, C. J. (2002). Family-centred practice: Birth through high school. *Journal of Special Education, 36*(3), 141-149. https://doi.org/10.1177/00224669020360030401

Dunst, C. J., Trivette, C. M., & Deal, A. (1994). *Supporting and strengthening families: Methods, strategies and practice* (Vol. 1). Brookline Books.

Dworkin, P. H. (1989). British and American recommendations for developmental monitoring: the role of surveillance. *Pediatrics, 84*(6), 1000-1010.

Eapen, V., Walter, A., Guan, J., Descallar, J., Axelsson, E., Einfeld, S., Eastwood, J., Murphy, E., Beasley, D., Silove, N., Dissanayake, C., Woolfenden, S., Williams, K., Jalaludin, B., & The 'Watch Me Grow' Study, G. (2017). Maternal help-seeking for child developmental concerns: Associations with socio-demographic factors. *Journal of Paediatrics and Child Health*. https://doi.org/10.1111/jpc.13607

Education and Health Standing Committee. (2009). *Healthy child - healthy state: Improving Western Australia's child health screening programs*. Parliament of Western Australia Legislative Assembly. https://www.parliament.wa.gov.au/Parliament/commit.nsf/(Report+Lookup+by+Com+ID)/C03031FD0022E6D548257831003E97D1/$file/Report%202-%20Child%20Health%20Screening.pdf

Education and Health Standing Committee. (2010). *Invest now or pay later: Securing the future of Western Australia's children*. Parliament of Western Australia Legislative Assembly. https://www.parliament.wa.gov.au/Parliament/commit.nsf/(Report+Lookup+by+Com+ID)/62C7619A219CF45B48257831003E9830/$file/EHSC-Child%20Health-final-March2010.pdf

Education and Health Standing Committee. (2011). Follow up questions from public hearing on 23 February 2011. https://www.parliament.wa.gov.au/Parliament/commit.nsf/(Report+Lookup+by+Com+ID)/62C7619A219CF45B48257831003E9830/$file/EHSC+response+from+Public+Hearing+23022011.pdf

Ellingson, K. D., Briggs-Gowan, M. J., Carter, A. S., & Horwitz, S. M. (2004). Parent identification of early emerging child behavior problems: Predictors of sharing parental concern with health providers. *JAMA Pediatrics, 158*(8), 766-772. https://doi.org/10.1001/archpedi.158.8.766

Eremita, M., Semancik, E., Lerer, T., & Dworkin, P. H. (2017). Can we identify parents who do not verbally share concerns for their child's development? *Journal of Developmental and Behavioral Pediatrics, 38*(3), 224-227. https://doi.org/10.1097/DBP.0000000000000426

Espe-Sherwindt, M. (2008). Family-centred practice: Collaboration, competency and evidence. *Support for Learning, 23*(3), 136-143. https://doi.org/10.1111/j.1467-9604.2008.00384.x

Feinberg, E., Donahue, S., Bliss, R., & Silverstein, M. (2012). Maternal depressive symptoms and participation in early intervention services for young children. *Maternal and Child Health Journal, 16*(2), 336-345. https://doi.org/10.1007/s10995-010-0715-3

Felt, B. T., & O'Connor, M. E. (2003). Use of the child development review increases residents' discussion of behavioral problems. *Ambulatory Pediatrics, 3*(1), 2-8. https://doi.org/10.1367/1539-4409(2003)003<0002:UOTCDR>2.0.CO;2

Finan, S. J., Swierzbiolek, B., Priest, N., Warren, N., & Yap, M. (2018). Parental engagement in preventive programs for child mental health: A systematic review of predictors and strategies to increase engagement. *Peer J, 6*(e4676). https://doi.org/10.7717/peerj.4676

Foo, K. M., Sundram, M., & Legido-Quigley, H. (2020). Facilitators and barriers of managing patients with multiple chronic conditions in the community: A qualitative study. *BMC Public Health, 20*(273). https://doi.org/10.1186/s12889-020-8375-8

Francesconi, M., & Heckman, J. J. (2016). Child development and parental investment: Introduction. *The Economic Journal, 126*(October), 1-27. https://doi.org/10.1111/ecoj.12388

Fujiki, M., Brinton, B., & Clarke, D. (2002). Emotion regulation in children with specific language impairment. *Language, Speech & Hearing Services in Schools, 33*(2), 102-111. https://doi.org/10.1044/0161-1461(2002/008)

Garcia, C. (2015). *Early intervention programs: Preemie parents' perceptions and barriers to participation* (Publication Number 3706896) [Doctoral thesis, The University of Arizona]. ProQuest Dissertations & Theses Global. https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/1695267349?accountid=10382

Garg, A., Jack, B., & Zuckerman, B. (2013). Addressing the social determinants of health within the patient-centred medical home. *JAMA, 309*(19), 2001-2002. https://doi.org/10.1001/jama.2013.1471

Garg, P., Ha, M. T., Eastwood, J., Harvey, S., Woolfenden, S., Murphy, E., Dissanayake, C., Williams, K., Jalaludin, B., McKenzie, A., Einfeld, S., Silove, N., Short, K., & Eapen, V. (2018). Health professional perceptions regarding screening tools for developmental surveillance for children in a multicultural part of Sydney, Australia. *BMC Family Practice, 19*(1), 42. https://doi.org/10.1186/s12875-018-0728-3

Geoscience Australia. (n.d.). Area of Australia - States and Territories. https://www.ga.gov.au/scientific-topics/national-location-information/dimensions/area-of-australia-states-and-territories#heading-1

Gerlach, A. J., Browne, A. J., & Greenwood, M. (2017). Engaging Indigenous families in a community-based Indigenous early childhood programme in British Columbia, Canada: A cultural safety perspective. *Health and Social Care In the Community, 25*(6), 1763-1773. https://doi.org/10.1111/hsc.12450

Giannoni, P. P., & Kass, P. H. (2010). Risk factors associated with children lost to care in a state early childhood intervention program. *Research in Developmental Disabilities, 31*(4), 914-923. https://doi.org/10.1016/j.ridd.2010.02.013

Ginsburg, S. (2008). Colocating health services: A way to improve coordination of children’s health care? *Commonwealth Fund, 41*(1153), 1-11. https://www.issuelab.org/resources/8730/8730.pdf

Giordano, K. (2008). *Barriers to early intervention services in New Jersey* [Doctoral dissertation, Fairleigh Dickinson University]. ProQuest Dissertations & Theses. http://dbgw.lis.curtin.edu.au:2048/login?url=https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/304403224?accountid=10382

Glanz, K., & Schwartz, M. D. (2008). Stress, coping, and health behaviour. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education: Theory, research and practice* (4th ed., pp. 211-236). Jossey-Bass.

Glascoe, F. P. (2002). The value of parents' concerns to detect and address developmental and behavioural problems. *Journal of Pediatrics and Child Health, 35*(1), 1-8. https://doi.org/10.1046/j.1440-1754.1999.00342.x

Glascoe, F. P., & Dworkin, P. H. (1995). Role of parents in the detection of developmental and behavioral problems. *Pediatrics, 95*(6), 829-836. https://pubmed.ncbi.nlm.nih.gov/7539122/

Glascoe, F. P., & Marks, K. P. (2011). Detecting children with developmental-behavioral problems: The value of collaborating with parents. *Psychological Test and Assessment Modeling, 53*(2), 258-279. https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/1399542315?pq-origsite=primo

Glascoe, F. P., & Robertshaw, N. S. (2007). New AAP policy on detecting and addressing developmental and behavioral problems. *Journal of Pediatric Health Care, 21*(6), 407-412. https://doi.org/10.1016/j.pedhc.2007.08.008

Glaun, D. E., Cole, K. E., & Reddihough, D. S. (1998). Six month follow-up: the crucial test of multidisciplinary developmental assessment. *Child: Care, Health and Development, 24*(6), 457-472. https://doi.org/10.1046/j.1365-2214.1998.00082.x

Glogowska, M., & Campbell, R. (2004). Parental views of surveillance for early speech and language difficulties. *Children and Society, 18*(4), 266-277. https://doi.org/10.1002.CHI.806

Goldfeld, S., O'Connor, M., Sayers, M., Moore, T., & Oberklaid, F. (2012). Prevalence and correlates of special health care needs in a population cohort of Australian children at school entry. *Journal of Developmental & Behavioral Pediatrics, 33*, 319-327. https://doi.org/10.1097/DBP.0b013e31824a7b8e

Government of Western Australia. (n.d.). *Child and parent centres*. https://childandparentcentres.wa.edu.au/about-us/

Grantham-Mcgregor, S., Cheung, Y. B., Cueto, S., Glewwe, P., Richter, L., & Strupp, B. (2007). Developmental potential in the first 5 years for children in developing countries. *The Lancet, 369*(9555), 60-70. https://doi.org/10.1016/S0140-6736(07)60032-4

Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P. M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services. *BMC Health Services Research, 16*(1), 680. https://doi.org/10.1186/s12913-016-1926-0

Guerrero, A. D., Rodriguez, M. A., & Flores, G. (2011). Disparities in provider elicitation of parents' developmental concerns for US children. *Pediatrics, 128*(5), 901-909. https://doi.org/10.1542/peds.2011-0030

Guralnick, M. J. (2001). A developmental systems model for early intervention. *Infants and Young Children, 14*(2), 1-18. http://depts.washington.edu/chdd/guralnick/pdfs/dev_sys_model_EI_IYC_10_01.pdf

Hall, W., & Irvine, V. (2008). E-communication among mothers of infants and toddlers in a community-based cohort: A content analysis. *Journal of Advanced Nursing, 61*(5), 175-183. https://doi.org/10.1111/j.1365-2648.2008.04856.x

Harris, S. R. (2009). Listening to parents' concerns: three case examples of infants with developmental motor delays. *Pediatric Physical Therapy, 21*(3), 269-274. https://doi.org/10.1097/PEP.0b013e3181b12fbc

Healthy Hips Australia. (n.d.). About us. https://www.healthyhipsaustralia.org.au

Hebbeler, K., Spiker, D., Bailey, D. B., Scarborough, A., Mallik, S., Simeonsson, R. J., Singer, M., & Nelson, L. (2007). *Early intervention for infants and toddlers with disabilities and their families: Participants, services, and outcomes*. SRI International. https://www.sri.com/wp-content/uploads/pdf/neils_finalreport_200702.pdf

Heckman, J. J. (2006). Skill formation and the economics of investing in disadvantaged children. *Science, 312*(5782), 1900-1902. https://www.jstor.org/stable/3846426

Heckman, J. J., & Krueger, A. B. (2003). *Inequality in America: What role for human capital policies?* MIT Press.

Heckman, J. J., Stixrud, J., & Urzua, S. (2006). The effects of cognitive and noncognitive abilities on labor market outcomes and social behavior. *Journal of Labor Economics, 24*(3), 411-482. https://doi.org/10.1086/504455

Heinze, G., Wallisch, C., & Dunkler, D. (2017). Variable selection - A review and recommendations for the practicing statistician. *Biometrical Journal, 60*, 431-449. https://doi.org/10.1002/bimj.201700067

Help Me Grow National Center. (2021). *The HMG system model*. www.helpmegrownational.org/hmgsystemmodel

Hendrickson, S., Baldwin, J. H., & Allred, K. W. (2000). Factors perceived by mothers as preventing families from obtaining early intervention services for their children with special needs. *Children's Health Care, 29*(1), 1-17. https://doi.org/10.1207/S15326888CHC2901_1

Human Early Learning Partnership. (2016). *EDI [Early Years Development Instrument] British Colombia: 2016 Provincial Report*. University of British Colombia School of Population and Public Health. http://earlylearning.ubc.ca/media/edibc2016provincialreport.pdf

IBM Corp. (2020). *IBM SPSS Statistics for Windows.* In (Version 27.0) IBM Corp.

IBM Corp. (n.d.). *Visual binning*. https://www.ibm.com/support/knowledgecenter/en/SSLVMB_23.0.0/spss/base/idh_bander_gating.html

Ingoldsby, E. (2010). Review of interventions to improve family engagement and retention in parent and child mental health programs. *Journal of Child and Family Studies, 19*(5), 629-645. https://doi.org/10.1007/s10826-009-9350-2

Jacobson Vann, J. C., Finkle, J., Ammerman, A., Wegner, S., Cockrell Skinner, A., Benjamin, J. T., & Perrin, E. M. (2011). Use of a tool to determine perceived barrirs to children's healthy eating and physical activity and relationships to health behaviours. *Journal of Pediatric Nursing, 26*, 404-415. https://doi.org/10.1016/j.pedn.2010.10.011

Jeyaseelan, D. C., & Sawyer, M. G. (2017). Developmental literacy: A universal intervention to help children with developmental disorders. *Journal of Paediatrics and Child Health, 53*, 101-104. https://doi.org/10.1111/jpc.13456

Jimenez, M. E., Barg, F. K., Guevara, J. P., Gerdes, M., & Fiks, A. G. (2012). Barriers to evaluation for early intervention services: parent and early intervention employee perspectives. *Academic pediatrics, 12*(6), 551-557. https://doi.org/10.1016/j.acap.2012.08.006

Jimenez, M. E., DuRivage, N. E., Bezpalko, O., Suh, A., Wade, R., Blum, N. J., & Fiks, A. G. (2017). A pilot randomized trial of a video patient decision aid to facilitate early intervention referrals from primary care. *Clinical Pediatrics, 56*(3), 268-277. https://doi.org/10.1177/0009922816677038

Johnson, J. F. (2011). *An evaluation of the Early Steps Program referral process in Hillsborough County to detect delays in access to early intervention services* (Publication Number 2012-99080-337) [Doctoral dissertation, University of South Florida]. Scholar Commons. http://scholarcommons.usf.edu/etd/3171

Jones, C. J., Jensen, J. D., Scherr, C. L., Brown, N. R., Christy, K., & Weaver, J. (2015). The health belief model as an explantory framework in communication research: Exploring parallel, serial and moderated mediation. *Health Communication, 30*(6), 566-676. https://doi.org/10.1080/10410236.2013/873363

Jones, C. J., Smith, H., & Llewellyn, C. (2014). Evaluating the effectiveness of health belief model interventions in improving adherence: A systematic review. *Health Psychology Review, 8*(3), 253-269. https://doi.org/10.1080/17437199.2013.802623

Kang, H. (2013). The prevention and handling of the missing data. *Korean Journal of Anesthesiology, 64*(402-406). https://doi.org/https://dx.doi.org/10.4097%2Fkjae.2013.64.5.402

Kazdin, A. E., Holland, L., & Crowley, M. (1997). Family experiences of barriers to treatment and premature termination from child therapy. *Journal of Consulting and Clinical Psychology, 65*, 453-463. https://doi.org/10.1037/0022-006X.65.3.453

Kazdin, A. E., Holland, L., Crowley, M., & Breton, S. (1997). Barriers to treatment participation scale: Evaluation and validation in the context of child outpatient treatment. *Journal of Child Psychology and Psychiatry, 38*(8), 1051-1062. https://doi.org/10.1111/j.1469-7610.1997.tb01621.x

Khan, L. P., Michael; Elena Rosa, Brown. (2013). Parenting programmes: identification and referral. *Journal of Children's Services, 8*(3), 194-208. https://doi.org/10.1108/JCS-03-2013-0011

Kinsner, K., & Parlakian, R. (2018). *’Tis the season…Handling unwanted parenting advice with grace*. Zero to Three,. https://www.zerotothree.org/resources/2555-tis-the-season-handling-unwanted-parenting-advice-with-grace

Klein, O., Walker, C., Aumann, K., Anjos, K., & Terry, J. (2019). Peer support groups for parent-carers of children with attention deficit hyperactivity disorer: The importance of solidarity as care. *Disability and Society, 34*(9), 1445-1461. https://doi.org/10.1080/09687599.2019.1584090

Knudsen, E. I., Heckman, J. J., Cameron, J. L., & Shonkoff, J. P. (2006). Economic, neurobiological, and behavioral perspectives on building America’s future workforce. *Proceedings of the National Academy of Sciences of the United States of America, 103*(27), 10155-10162. https://doi.org/10.1073/pnas.0600888103

Kummerer, S. E., & Lopez-Reyna, N. A. (2009). Engaging Mexican immigrant families in language and literacy interventions: Three case studies. *Remedial and Special Education, 30*(6), 330-343. https://doi.org/10.1177/0741932508321014

Lalbeharie-Josias, D. P. (2001). *Parents' perceptions of the individualized family service plan* (Publication Number AAI3012154) [Doctoral thesis, University of Massachusetts Amherst]. ProQuest Dissertations & Theses Global. https://scholarworks.umass.edu/dissertations/AAI3012154

Law, M., King, S., Stewart, D., & King, G. (2002). The perceived effects of parent-led support groups for parents of children with disabilities. *Physical and Occupational Therapy in Pediatrics, 21*(2), 29-48. https://doi.org/10.1080/J006v21n02_03

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Press.

Leiter, V. R. (2001). *Gentle intrusions: Family-centered care in early intervention* (Publication Number 3004966) [Doctoral dissertation, Brandeis University]. ProQuest Dissertations & Theses Global. https://search-proquest-com.dbgw.lis.curtin.edu.au/docview/304681652?pq-origsite=summon

Levesque, J., Harris, M. F., & Russell, G. (2013). Patient-centred access to health care: Conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health, 12*(18). https://doi.org/https://doi.org/10.1186/1475-9276-12-18

Liamputtong, P. (2007). *Researching the Vulnerable: A guide to sensitive research methods*. SAGE.

Liamputtong, P. (2012). *Qualitative research methods* (4th ed.). Oxford University Press.

Lipkin, P. H., Macias, M. M., AAP Council on Children with Disabilities, & Section on Developmental and Behavioral Pediatrics. (2020). Promoting optimal development: Identifying infants and young children with developmental disorders through developmental surveillance and screening. *Pediatrics, 145*(1), e20193449. https://doi.org/10.1542/peds.2019-3449

Maggi, S., Irwin, L. J., Siddiqi, A., & Hertzman, C. (2010). The social determinants of early child development: An overview. *Journal of Pediatrics and Child Health, 46*, 627-635. https://doi.org/10.1111/j.1440-1754.2010.01817.x.

Magnusson, D., Palta, M., McManus, B., Benedict, R. E., & Durkin, M. S. (2016). Capturing unmet therapy need among young children with developmental delay using national survey data. *Academic pediatrics, 16*(2), 145-153. https://doi.org/10.1016/j.acap.2015.05.003

Magnusson, D. M., Minkovitz, C. S., Kuhlthau, K. A., Caballero, T. M., & Mistry, K. B. (2017). Beliefs regarding development and early intervention among low-income African American and Hispanic mothers. *Pediatrics, 140*(5). https://doi.org/http://dx.doi.org/10.1542/peds.2017-2059

Marshall, J. (2013). *Parent pathways: Recognition and responses to developmental delays in young children: A mixed-methods exploratory study* [Doctoral dissertation, University of South Florida]. Scholar Commons. http://scholarcommons.usf.edu/etd/4534

Marshall, J., Adelman, A., Kesten, S. M., Natale, R. A., & Elbaum, B. (2017). Parents' experiences navigating intervention systems for young children with mild language delays. *Journal of Early Intervention, 39*(3), 180-198. https://doi.org/10.1177/1053815117704958

Marshall, J., Coulter, M. L., & Gorski, P. A. (2016). Parent recognition and responses to developmental concerns in young children. *Infants and Young Children, 29*(2), 102-115. https://doi.org/10.1097/IYC.0000000000000056

Marshall, J., Goldbart, J., & Phillips, J. (2007). Parents' and speech and language therapists' explanatory models of language development, language delay and intervention. *International Journal of Language & Communication Disorders, 42*(5), 533-555. https://doi.org/10.1080/13682820601053753

Marshall, J., Kirby, R. S., & Gorski, P. A. (2016). Parent concern and enrollment in intervention services for young children with developmental delays: 2007 National survey of children's health. *Exceptional Children, 82*(2), 251-268. https://doi.org/10.1177/0014402915585563

Maslow, A. (1943). A theory of human motivation. *Psychological Review, 50*, 370-396. https://doi.org/10.1037/h0054346

Masse, L. N., & Barnett, W. S. (2002). *A benefit cost analysis of the Abecedarian early childhood intervention*. National Institute for Early Education Research. https://files.eric.ed.gov/fulltext/ED479989.pdf

McAllister, L., McCormack, J., McLeod, S., & Harrison, L. J. (2011). Expectations and experiences of accessing and participating in services for childhood speech impairment. *International Journal of Speech-Language Pathology, 13*(3), 251-267. https://doi.org/10.3109/17549507.2011.535565

McConkey, R., Truesdale-Kennedy, M., & Cassidy, A. (2009). Mothers' recollections of early features of autism spectrum disorders. *Child and Adolescent Mental Health, 14*(1), 31-36. https://doi.org/10.1111/j.1475-3588.2008.00495.x

McGill, N., Crowe, K., & McLeod, S. (2020). "Many wasted months": Stakeholders' perspectives about waiting for speech-language pathology services. *International Journal of Speech-Language Pathology, 22*(3), 313-326. https://doi.org/10.1080/17549507.2020.1747541

McKay, K., Shannon, A., Vater, S., & Dworkin, P. H. (2006). ChildServ: Lessons learned from the design and implementation of a community-based developmental surveillance program. *Infants & Young Children, 19*(4), 371-377.

McLeod, S., Davis, E., Rohr, K., McGill, N., Miller, K., Roberts, A., Thornton, S., Ahio, N., & Ivory, N. (2020). Waiting for speech-langauge pathology services: A randomised controlled trial comparing therapy, advice and device. *International Journal of Speech-Language Pathology, 22*(3), 372-386. https://doi.org/10.1080/17549507.2020.1731600

McManus, B., McCormick, M. C., Acevedo-Garcia, D., Ganz, M., & Hauser-Cram, P. (2009). The effect of state early intervention eligibility policy on participation among a cohort of young CSHCN. *Pediatrics, 124*, S368-S374. https://doi.org/10.1542/peds.2009-155G

McManus, B., Richardson, Z., Schenkman, M., Murphy, N. J., Everhart, R. M., Hambidge, S., & Morrato, E. (2020). Child characteristics and early intervention referral and receipt of services: A retrospective cohort study. *BMC pediatrics, 20*(8). https://doi.org/10.1186/s12887-020-1965-x

McManus, B. M., Carle, A. C., & Rapport, M. J. (2014). Classifying infants and toddlers with developmental vulnerability: who is most likely to receive early intervention? *Child: Care, Health and Development, 40*(2), 205-214. https://doi.org/10.1111/cch.12013

McManus, B. M., Robert, S., & Albanese, A. (2013). Predictors of receiving therapy among very low birth weight 2-year olds eligible for Part C early intervention in Wisconsin. *BMC pediatrics, 13*. https://doi.org/10.1186/1471-2431-13-106

Mills, I. S., Doyle, L. W., Cheong, J. L., & Roberts, G. (2018). Rates of early intervention services in children born extremely preterm/extremely low birthweight. *Journal of Pediatrics and Child Health, 54*(1), 74-79. https://doi.org/10.1111/jpc.13668

Minister for Health. (2011). *Response to Education and Health Standing Committee*. Education and Health Standing Committee. https://www.parliament.wa.gov.au/Parliament/commit.nsf/(Report+Lookup+by+Com+ID)/62C7619A219CF45B48257831003E9830/$file/40146399.pdf

Missiuna, C., Moll, S., Law, M., King, S., & King, G. (2006). Mysteries and mazes: Parents' experiences of children with developmental coordination disorder. *Canadian Journal of Occupational Therapy, 73*(1), 7-17. https://doi.org/10.2182/cjot.05.0010

Moore, C., Zamora, I., Gera, M. P., & Williams, M. E. (2017). Developmental screening and referrals: Assessing the influence of provider specialty, training, and interagency communication. *Clinical Pediatrics, 56*(11), 1040-1047. https://doi.org/10.1177/0009922817701174

Moore, T. (2006). Early childhood and long term development: The importance of the early years. https://www.aracy.org.au/publications-resources/command/download_file/id/97/filename/Early_childhood_and_long_term_development_-_The_importance_of_the_early_years.pdf

Moore, T., Arefadib, N., Deery, A., & West, S. (2017). *The first thousand day: An evidence paper*. Murdoch Children's Research Institute. https://www.rch.org.au/uploadedFiles/Main/Content/ccchdev/CCCH-The-First-Thousand-Days-An-Evidence-Paper-September-2017.pdf

Morton, D. S. (2012). *Parental descriptions of awareness and associated reactions to developmental delay in children* (Publication Number AAI3545470) [Doctoral dissertation, Capella University]. ProQuest Dissertations & Theses Global. https://www-proquest-com.dbgw.lis.curtin.edu.au/docview/1520325243/B7F1BC2997EB4B37PQ/1?accountid=10382

Mossialos, E., Djordjevic, A., Osborn, R., & Sarnak, D. (2017). *International profiles of health care systems*. Commonwealth Fund. https://www.commonwealthfund.org/sites/default/files/documents/___media_files_publications_fund_report_2017_may_mossialos_intl_profiles_v5.pdf

Mughal, M. K., Giallo, R., Arnold, P. D., Kehler, H., Bright, K., Benzies, K., Wajid, A., & Kingston, D. (2019). Trajectories of maternal distress and risk of child developmental delays: Findings from the All Our Families (AOF) pregnancy cohort. *Journal of Affective Disorders, 248*, 1-12. https://doi.org/10.1016/j.jad.2018.12.132

Mulcahy, H., & Savage, E. (2016). Uncertainty: A little bit not sure. Parental concern about child growth or development. *Journal of Child Health Care, 20*(3), 333-343. https://doi.org/10.1177/1367493515587059

Mumby-Croft, K. J. (2014). *Defining 'hard to reach': The work for health visitors with vulnerable families* [Doctoral dissertation, University of Hertfordshire]. https://pdfs.semanticscholar.org/c3fd/8ad087b3b8478e96a77027a1da309074d072.pdf

Nathan, L., Stackhouse, J., Goulandris, N., & Snowling, M. J. (2004). The development of early literacy skills among children with speech difficulties. *Journal of Speech, Language and Hearing, 47*(2), 377-391. https://doi.org/10.1044/1092-4388(2004/031)

National Disability Insurance Agency. (2014). Building the National Disability Insurance Scheme. Progress report: Year one. https://www.ndis.gov.au/about-us/publications/progress-report-2014

National Disability Insurance Agency. (2019). *How ECEI works*. https://www.ndis.gov.au/understanding/families-and-carers/how-ecei-works-step-step-process

NDIS. (2019). *Providing evidence of disability for children*. https://www.ndis.gov.au/applying-access-ndis/how-apply/information-support-your-request/providing-evidence-disability-children

Nelson, B. B., Chung, P. J., DuPlessis, H. M., Flores, L., Ryan, G. W., & Kataoka, S. H. (2011). Strengthening families of children with developmental concerns: Parent perceptions of developmental screening and services in Head Start. *Ethnicity & disease, 21*(3 Suppl 1), S1-89-93. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3715307/

Ngala. (n.d.). *About Us*. https://www.ngala.com.au/about-us/

Nielsen, A. M. (2014). *The role of interactive and critical health literacy in appointment cancellations: A quality assurance survey* [Master's thesis, The University of Wisconsin - Milwaukee]. ProQuest Central; ProQuest Dissertations & Theses Global. https://dc.uwm.edu/etd/740

Oberklaid, F., & Efron, D. (2005). Developmental delay - identification and management. *Australian family physician, 34*(9), 739-742.

Offord Centre for Child Studies. *Early Development Instrument in Ontario over time*. McMaster University. https://edi.offordcentre.com/partners/canada/edi-in-ontario/

Pachter, L. M., & Dworkin, P. H. (1997). Maternal expectations about normal child development in 4 cultural groups. *Archives of Pediatrics & Adolescent Medicine, 151*, 1144-1150. https://doi.org/10.1001/archpedi.1997.02170480074011

Pekar, S., & Brabec, M. (2018). Generalized estimating equations: A pragmatic and flexible approach to the margical GLM modelling of correlated data in the behavioural sciences. *Ethology, 124*, 86-93. https://doi.org/10.1111/eth.12713

Persoff, J. R. (1998). *Poverty and early childhood developmental delay: Perspectives from Hispanic mothers* [Doctoral dissertation, University of Denver]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/304432454?accountid=10382

Peters, M. D. J., Godfrey, c., McInerney, P., Baldini Soares, C., Khalil, H., & Parker, D. (2017). Chapter 11: Scoping reviews. In E. Aromataris & Z. Munn (Eds.), *Joanna Briggs Institute Reviewer's Manual*. The Joanna Briggs Institute. https://reviewersmanual.joannabriggs.org/

Peterson, C. A., Wall, S. M., Raikes, H. A., Kisker, E. E., Swanson, M. E., Jerald, J., Atwater, J. B., & Qiao, W. (2004). Early head start: Identifying and serving children with disabilities. *Topics in Early Childhood Special Education, 24*(2), 76-88. https://digitalcommons.unl.edu/cgi/viewcontent.cgi?referer=https://www.google.com/&httpsredir=1&article=1041&context=famconfacpub

Pevalin, D. J., Wade, T. J., & Brannigan, A. (2003). Parental assessment of early childhood development: biological and social covariates. *Infant and Child Development, 12*(2), 167-175. https://doi.org/10.1002/icd.285

Phoenix, M., & Rosenbaum, P. (2015). Development and implementation of a paediatric rehabilitation care path for hard-to-reach families: A case report. *Child: Care, Health and Development, 41*(3), 494-499. https://doi.org/10.1111/cch.12194

Phoenix, M., & Rosenbaum, P. (2019). Presenting the model of risk, disability and hard-to-reach families to inform early intervention services. *Disability and Rehabilitation, 41*(2), 244-249. https://doi.org/10.1080/09638288.2017.1385650

Piotrowska, P. J., Tully, L. A., Lenroot, R., Kimonis, E., Hawes, D., Moul, C., Frick, P. J., Anderson, V., & Dadds, M. R. (2017). Mothers, fathers, and parental systems: A conceptual model of parental engagement in programs for child mental health - connect, attend, participate, enact (CAPE). *Clinical Child and Family Psychology Review, 20*, 146-161. https://doi.org/http://dx.doi.org/10.1007/s10567-016-0219-9

Plath, D., Crofts, P., & Stuart, G. (2016). Engaging families in early intervention for child conduct doncerns. *Children Australia, 41*(1), 49-58. https://doi.org/10.1017/cha.2015.5

Playgroup WA Inc. (n.d.). *PlayConnect playgroups*. https://playgroupwa.com.au/funded-programs/supported-playgroup-services/playconnect/

Porter, N., & Ispa, J. M. (2013). Mothers' online message board questions about parenting infants and toddlers. *Journal of Advanced Nursing, 69*(3), 559-568. https://doi.org/10.1111/j.1365-2648.2012.06030.x

Porterfield, S. L., & McBride, T. D. (2007). The effect of poverty and caregiver education on perceived need and access to health services among children with special health care needs. *American Journal of Public health, 97*(2), 323-329. https://doi.org/10.2105/AJPH.2004.055921

Pratt, A. V. (2012). *Two worlds collide: Caregiver perceptions of their interactions with Help Me Grow home visitors* [Doctoral dissertation, University of Minnesota]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/1027763731?accountid=10382

Pritchard, M. A., Colditz, P. B., Cartwright, D., Gray, P. H., Tudehope, D., & Beller, E. (2013). Risk determinants in early intervention use during the first postnatal year in children born very preterm. *BMC pediatrics, 13*, 201-201. https://doi.org/10.1186/1471-2431-13-201

Productivity Commission. (2011). *Disability care and support* (Report number 54). https://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-volume1.pdf

Raising Children Network. (2020). About us. https://raisingchildren.net.au

Ramirez, M. C. (2004). *Latino parents with developmentally delayed children: Perceptions of early intervention services* [Master's thesis, California State University]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/305036959?pq-origsite=gscholar

Rannard, A., Lyons, C., & Glenn, S. (2004). Children with specific language impairment: Parental accounts of the early years. *Journal of Child Health Care, 8*(2), 165-176. https://doi.org/10.1177/1367493504041875

Raspa, M., Levis, D. M., Kish-Doto, J., Wallace, I., Rice, C., Barger, B., Green, K. K., & Wolf, R. B. (2015). Examining parents' experiences and information needs regarding early identification of developmental delays: Qualitative research to inform a public health campaign. *Journal of Developmental & Behavioral Pediatrics, 36*(8), 575-585. https://doi.org/10.1097/DBP.0000000000000205

Restall, G., & Borton, B. (2010). Parents' concerns about their children's development at school entry. *Child: Care, Health and Development 36*(2), 208-215. https://doi.org/10.1111/j.1365-2214.2009.01019.x

Rosenberg, S. A., Robinson, C. C., Shaw, E. F., & Ellison, M. S. (2013). Part C early intervention for infants and toddlers: Percentage eligible versus served. *Pediatrics, 131*, 38-46. https://doi.org/10.1542/peds.2012-1662

Rosenberg, S. A., Zhang, D., & Robinson, C. C. (2008). Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics, 121*(6), e1503-1509. https://doi.org/10.1542/peds.2007-1680

Rosenstock, I. M. (1966). Why people use health services. *Milbank Memorial Fund Quarterly, 44*, 94-124.

Rosenstock, I. M. (1974). Historical origins of the Health Belief Model. *Health Education Monographs, 2*, 328-335.

Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social learning theory and the Health Belief Model. *Health Education Quarterly, 15*(2), 175-183.

Rossiter, C., Fowler, C., Hesson, A., Kruske, S., Homer, C. S. E., & Schmied, V. (2019, 2019/03/01). Australian parents' use of universal child and family health services: A consumer survey. *Health & social care in the community, 27*(2), 472-482. https://doi.org/10.1111/hsc.12667

Russell, G., Kunin, M., Harris, M., Levesque, J., Descoteaux, S., Scott, C., Lewis, V., Dionne, E., Advocat, J., Dahrouge, S., Stocks, N., Spooner, C., & Haggerty, J. (2019). Improving access to primary healthcare for vulnerable populations in Australia and Canada: Protocl for a mixed-method evaluation of six complex interventions. *BMJ Open, 9*(7), e027869. https://doi.org/10.1136/bmjopen-2018-027869

Ryan, S., Salisbury, H., Ryan, S., & Salisbury, H. (2012). 'You know what boys are like': pre-diagnosis experiences of parents of children with autism spectrum conditions. *British Journal of General Practice, 62*(598), 378-383. https://doi.org/10.3399/bjgp12X641500

SAS Institute Inc. (2015). The GEE Procedure. In Author (Ed.), *SAS/STAT 14.1 User's Guide* (pp. 2929-2980). SAS Institute Inc. https://support.sas.com/documentation/onlinedoc/stat/141/gee.pdf

Schmidt, K. R. T. (2013). *Predictors of parent involvement in Part C early intervention services* [Doctoral dissertation, University of Maryland]. ProQuest Dissertations & Theses Global. https://search.proquest.com/docview/1399598995?accountid=10382

Schumarker-Murphy, M. (2019). *Fathers' experiences in early intervention: Marooned in the kitchen or member of the team* [Doctoral dissertation, DePaul University]. ProQuest Dissertations and Theses. https://search.proquest.com/openview/26116c4b74bea79c34fd3b4aac10ee77/1?pq-origsite=gscholar&cbl=18750&diss=y

Schweinhart, L. J., Montie, J., Xiang, Z., Barnett, W. S., Belfield, C. R., & Nores, M. (2005). *Lifetime effects: The high/scope Perry Preschool study through age 40*. H. S. Press.

Shah, R., Sobotka, S. A., Chen, Y.-F., & Msall, M. E. (2015). Positive parenting practices, health disparities, and developmental progress. *Pediatrics, 136*(2), 318. https://doi.org/10.1542/peds.2014-3390

Shannon, P. (2000). *Family-centered practice in early intervention services for infants and toddlers: The experience of families and professionals in one Local Interagency Coordinating Council* [Doctoral dissertation, Virginia Commonwealth University]. ProQuest Dissertations & Theses Global. https://scholarscompass.vcu.edu/etd/5304/

Shannon, P. (2004). Barriers to family-centered services for infants and toddlers with developmental delays. *Social Work, 49*(2), 301-308. https://doi.org/10.1093/sw/49.2.301

Shapiro, B. J., & Derrington, T. M. (2004). Equity and disparity in access to services: An outcomes-based evaluation of early intevention Child Find in Hawai'i. *Topics in Early Childhood Special Education, 24*(4), 199-212. https://doi.org/10.1177/02711214040240040201

Shelby Consulting. (2017). *Evaluation of the Child and Parent Centre Initiative*. https://www.education.wa.edu.au/dl/ejzg3o

Shonkoff, J. P. (2010). Building a new biodevelopmental framework to guide the future of early childhood policy. *Child Development, 81*(1), 357-367. https://doi.org/10.1111/j.1467-8624.2009.01399.x

Shonkoff, J. P., Boyce, W. T., & McEwen, B. S. (2009). Neuroscience, molecular biology, and the childhood roots of health disparities. *JAMA, 301*(21), 2252-2259. https://doi.org/10.1001/jama.2009.754

Sices, L., Egbert, L., & Mercer, M. B. (2009). Sugar-coaters and straight talkers: communicating about developmental delays in primary care. *Pediatrics, 124*(4), e705-713. https://doi.org/10.1542/peds.2009-0286

Silbersack, E. W. (2014). *Mothers' initial discovery of childhood disability: Exploring maternal identification of developmental issues in young children* [Doctoral dissertation, Adelphi University]. ProQuest Dissertations & Theses Global. https://eric.ed.gov/?id=ED557029

Sivberg, B. (2003). Parents' detection of early signs in their children having an autistic spectrum disorder. *Journal of Pediatric Nursing, 18*(6), 433-439. https://doi.org/10.1016/S0882-5963(03)00139-8

Smith, E., Koerting, J., Latter, S., Knowles, M. M., McCann, D. C., Thompson, M., & Sonuga-Barke, E. J. (2015). Overcoming barriers to effective early parenting interventions for attention-deficit hyperactivity disorder (ADHD): Parent and practitioner views. *Child: Care, Health and Development, 41*(1), 93-102. https://doi.org/10.1111/cch.12146

Smith, L. E., Akai, C. E., Klerman, L. V., Keltner, B. R., & The Centers for the Prevention of Child, N. (2010). What mothers don't know and doctors don't say: Detecting early developmental delays. *Infant Mental Health Journal, 31*(4), 455-466. https://doi.org/10.1002/imhj.20266

Smith, P., Humiston, S. C., Marcuse, E., Zhao, Z., Dorell, C. G., Howes, C., & Hibbs, B. (2011). Parental delay or refusal of vaccine doses, childhood vaccination coverage at 24 months of age, and the Health Belief Model. *Public Health Reports, 126*, 135-146. https://doi.org/10.1177/00333549111260S215

Staudt, M. (2007). Treatment engagement in caregivers of at-risk children: Gaps in research and conceptualization. *Journal of Child and Family Studies, 16*, 183-196. https://doi.org/10.1007/s10826-006-9077-2

Strange, C., Fisher, C., Howat, P., & Wood, L. (2018). 'Easier to isolate yourself…there's no need to leave the house' - A qualitative study on the paradoxes of online communication for parents with young children. *Computers in Human Behavior, 83*, 168-175. https://doi.org/10.1016/j.chb.2018.01.040

Swanson, C. (2013). *Attrition from early intervention: Associations with several child characteristics* [Master's thesis, University of Rhode Island]. ProQuest Dissertations & Theses Global. Ann Arbor. https://search.proquest.com/docview/1476204055?accountid=10382

Telethon Kids Institute. (2020). *Western Australian Child Development Atlas*. https://childatlas.telethonkids.org.au/cda-about/

Telethon Kids Institute. (2021). The ORIGINS Project. https://originsproject.telethonkids.org.au/about-the-origins-project/

Telethon Speech and Hearing. (n.d.). *Telethon Speech and Hearing*. https://www.tsh.org.au

Tervo, R. C. (2005). Parent's reports predict their child's developmental problems. *Clinical Pediatrics, 44*(7), 601-611. https://doi.org/10.1177/000992280504400708

Thelen, E., & Smith, L. B. (2007). Dynamic systems theories. In R. M. Lerner (Ed.), *Handbook of Child Psychology: Theoretical Models of Human Development* (Vol. 1, pp. 258-312). John Wiley and Sons.

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, d., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., Lewin, S., Godfrey, C. M., Mcdonald, M. T., Langlois, E. V., Soares-Weiser, K., Moriarty, J., Clifford, T., Tuncalp, O., & Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine, 169*(7), 467-473. https://doi.org/10.7326/M18-0850

Twardzik, E., Cotto-Negrón, C., & Macdonald, M. (2017). Factors related to early intervention Part C enrollment: A systematic review. *Disability and Health Journal, 10*(4), 467-474. https://doi.org/10.1016/j.dhjo.2017.01.009

U.S. Department of Health and Human Services. (2017). *Birth to 5: Watch Me Thrive*. https://www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive

United Nations. (1990). *Convention on the rights of the child*. United Nations. https://www.unicef.org/child-rights-convention/convention-text#

United Nations. (2019). *World Economic Situation and Prospects 2019*. https://www.un.org/development/desa/dpad/wp-content/uploads/sites/45/WESP2019_BOOK-web.pdf

Vitrikas, K. S., Dillon; Bucaj, Merima. (2017). Developmental delay: When and how to screen. *American family physician, 96*(1), 36-43. https://www.aafp.org/afp/2017/0701/p36.html

Walker, S. P., Wachs, T. D., Grantham-Mcgregor, S., Black, M. M., Nelson, C. A., Huffman, S. L., Baker-Henningham, H., Chang, S. M., Hamadani, J. D., Lozoff, B., Gardner, J. M. M., Powell, C. A., Rahman, A., & Richter, L. (2011). Inequality in early childhood: Risk and protective factors for early child development. *The Lancet, 378*(9799), 1325-1338. https://doi.org/10.1016/S0140-6736(11)60555-2

Wall, S. M., Taylor, N. E., Liebow, H., Sabatino, C. A., Mayer, L. M., Farber, M. Z., & Timberlake, E. M. (2005). Early Head Start and access to early intervention services: a qualitative investigation. *Topics in Early Childhood Special Education, 25*(4), 218-231. https://doi.org/10.1177/02711214050250040301

Wang, C. J., Elliott, M. N., Rogowski, J., Lim, N., Ratner, J. A., & Schuster, M. A. (2009, Jul-Aug). Factors influencing the enrollment of eligible extremely-low-birth-weight children in the part C early intervention program. *Academic Pediatrics 9*(4), 283-287. https://doi.org/10.1016/j.acap.2009.04.001

Warren, D. (2018). *Children's use of health care* (Longitudinal Study of Australian Children annual statistical report - 2017 chapter, Issue. Australian Institute of Family Studies.

Warren, D., & Edwards, B. (2017). *Contexts of disadvantage* (Occasional paper no. 53). Australian Institute of Family Studies. https://www.dss.gov.au/sites/default/files/documents/11_2017/occpaper53_contexts_disadvantage_web.pdf

Watson, L., & Chesters, J. (2012). *Early intervention for vulnerable young children and their families through the Parents as Teachers program*. The Education Institute. http://www.theeducationinstitute.edu.au

Western Australian Occupational Therapy Association. (n.d.). Find an OT. https://waota.com.au/find-an-ot/?q=search&region=Any&specialty=Any#

Whitehouse, A. J. O., Evans, K., Eapen, V., & Wray, J. (2018). *A national guideline for the assessment and diagnosis of autism spectrum disorders in Australia*. Cooperative Research Centre for Living with Autism. http://autismcrc.com.au/national-guideline

Williams, J. (2007). Learning from mothers: how myths, policies and practices affect the detection of subtle developmental problems in children. *Child: Care, Health and Development, 33*(3), 282-290. https://doi.org/10.1111/j.1365-2214.2006.00690.x

Williams, J., & Holmes, C. A. (2004). Improving the early detection of children with subtle developmental problems. *Journal of Child Health Care, 8*(1), 34-46. https://doi.org/10.1177/13674950401852

Williams, J., & Holmes, H. (2005). Children of the 21st century: Slipping through the net. *Contemporary Nurse, 18*(1-2), 57-66. https://doi.org/10.5172/conu.18.1-2.57

Winkworth, G., McArthur, M., Layton, M., Thomson, L., & Wilson, F. (2010). Opportunities lost - Why some parents of young children are not well-connected to the service systems designed to assist them. *Australian Social Work, 63*(4), 431-444. https://doi.org/10.1080/0312407X.2010.508170

Woolfenden, S., Eapen, V., Williams, K., Hayen, A., Spencer, N., & Kemp, L. (2014, Sep 13). A systematic review of the prevalence of parental concerns measured by the Parents' Evaluation of Developmental Status (PEDS) indicating developmental risk. *BMC pediatrics, 14*, 231. https://doi.org/10.1186/1471-2431-14-231

Woolfenden, S., Posada, N., Krchnakova, R., Crawford, J., Gilbert, J., Jursik, B., Sarkozy, V., Perkins, D., & Kemp, L. (2015). Equitable access to developmental surveillance and early intervention - understanding the barriers for children from culturally and linguistically diverse (CALD) backgrounds. *Health Expectations, 18*(6), 3286-3301. https://doi.org/10.1111/hex.12318

Worcester, J. (2005, 2005). Giving voice to parents of young children with challenging behavior. *Exceptional Children, 74*(4), 509-525. https://doi.org/10.1177/001440290807400406

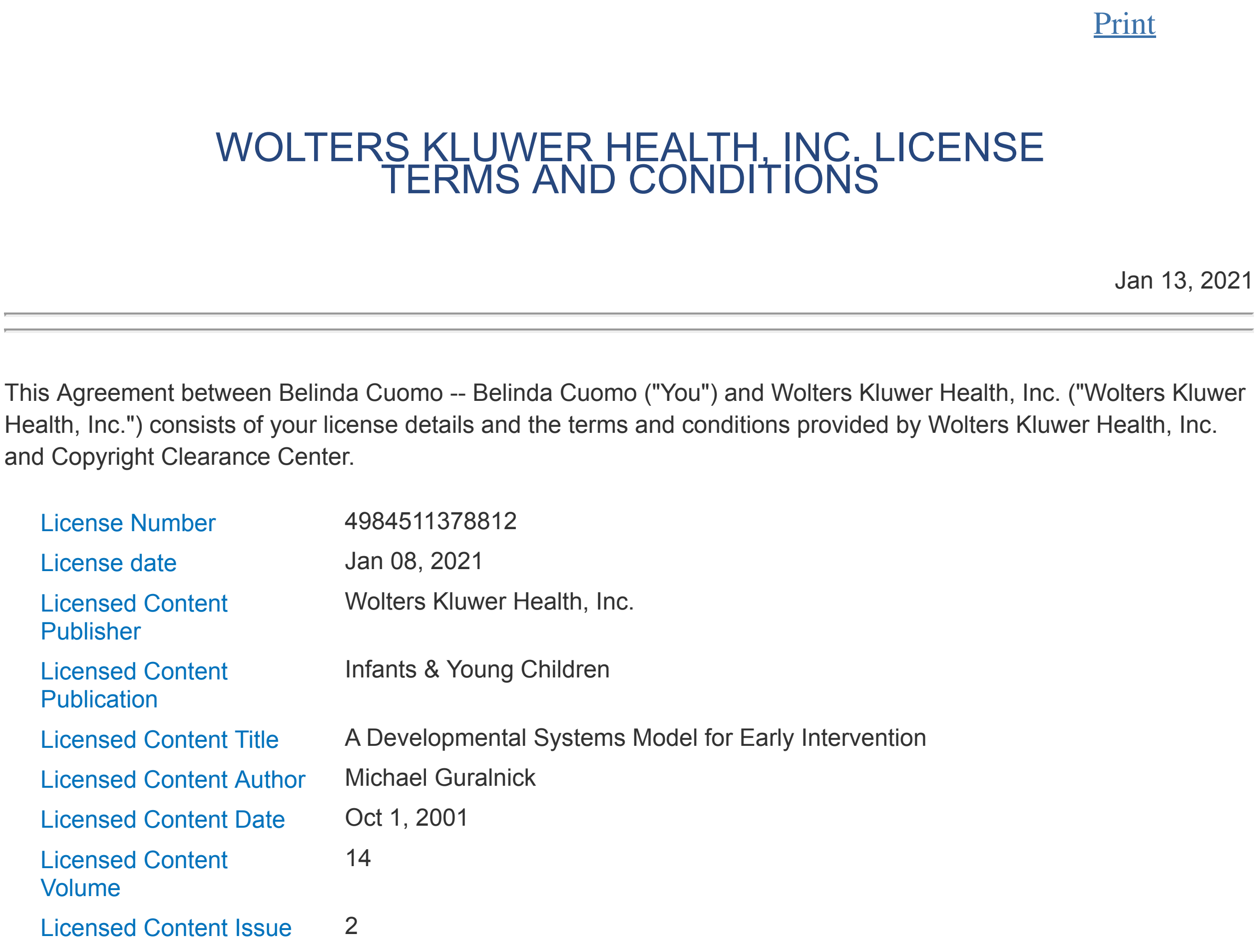
World Health Organization, United Nations Children’s Fund, & World Bank Group. (2018). *Nurturing care for early childhood development: A framework for helping children survive and thrive to transform health and human potential*. https://www.who.int/maternal_child_adolescent/child/nurturing-care-framework/en/

World Health Organization Health Care for Chronic Conditions Team. (2002). *Innovative care for chronic conditions: Building blocks for action: Global report*. World Health Organization. https://www.who.int/chp/knowledge/publications/icccglobalreport.pdf?ua=1

Zand, D. H., Pierce, K. J., Bultas, M. W., McMillin, S. E., Gott, R. M., & Wilmott, J. (2015). Accuracy of knowledge of child development in mothers of children receiving early intervention services. *Journal of Early Intervention, 37*(3), 226-240. https://doi.org/10.1177/1053815115610633

Appendix A Copyright reuse permissions

A.1 Wolters Kluwer Health



Print

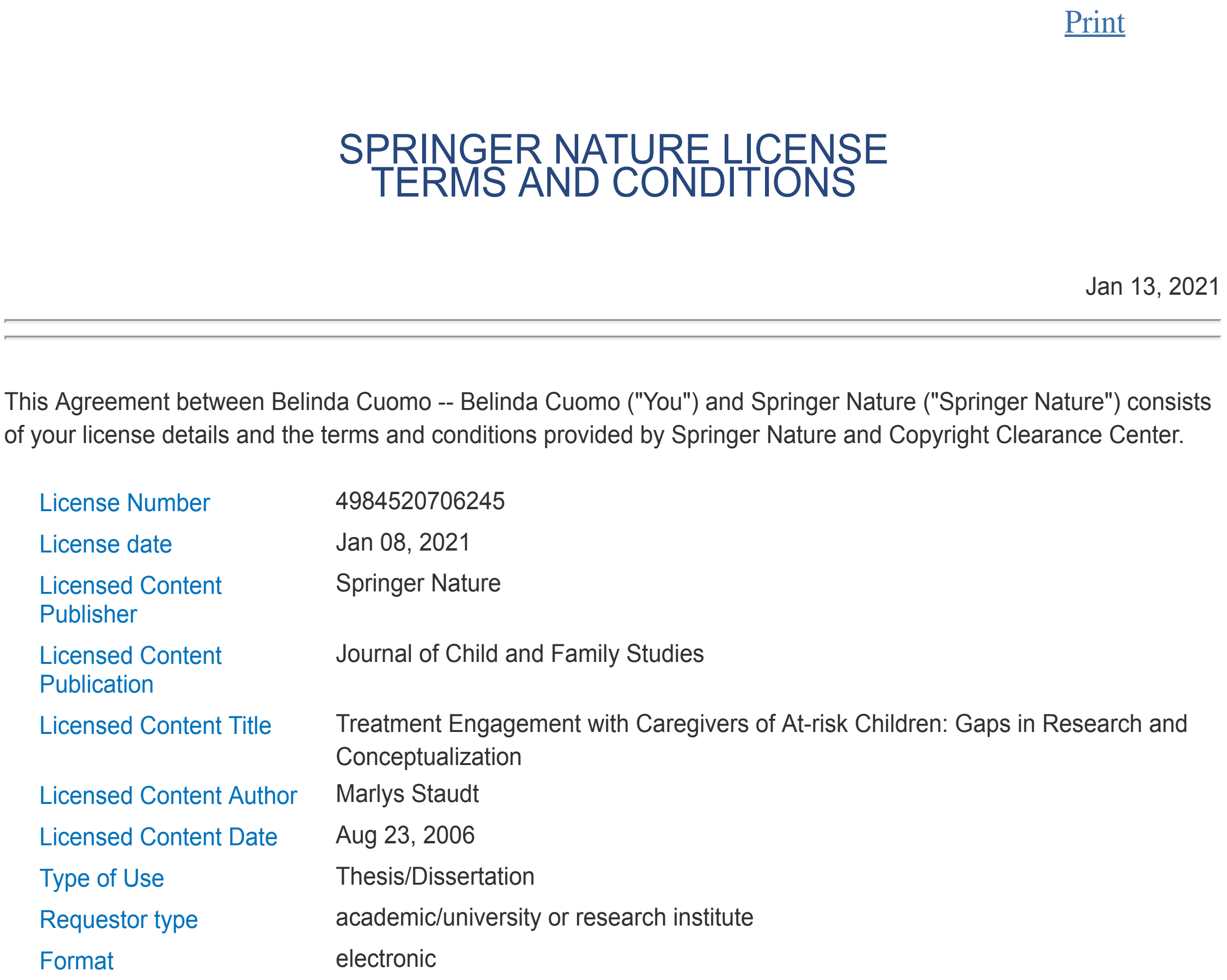
WOLTERS KLUWER HEALTH, INC. LICENSE TERMS AND CONDITIONS

Jan 13, 2021

This Agreement between Belinda Cuomo -- Belinda Cuomo ("You") and Wolters Kluwer Health, Inc. ("Wolters Kluwer Health, Inc.") consists of your license details and the terms and conditions provided by Wolters Kluwer Health, Inc. and Copyright Clearance Center.

License Number	4984511378812
License date	Jan 08, 2021
Licensed Content Publisher	Wolters Kluwer Health, Inc.
Licensed Content Publication	Infants & Young Children
Licensed Content Title	A Developmental Systems Model for Early Intervention
Licensed Content Author	Michael Guralnick
Licensed Content Date	Oct 1, 2001
Licensed Content Volume	14
Licensed Content Issue	2

A.2 Springer Nature



Print

SPRINGER NATURE LICENSE TERMS AND CONDITIONS

Jan 13, 2021

This Agreement between Belinda Cuomo -- Belinda Cuomo ("You") and Springer Nature ("Springer Nature") consists of your license details and the terms and conditions provided by Springer Nature and Copyright Clearance Center.

License Number	4984520706245
License date	Jan 08, 2021
Licensed Content Publisher	Springer Nature
Licensed Content Publication	Journal of Child and Family Studies
Licensed Content Title	Treatment Engagement with Caregivers of At-risk Children: Gaps in Research and Conceptualization
Licensed Content Author	Marlys Staudt
Licensed Content Date	Aug 23, 2006
Type of Use	Thesis/Dissertation
Requestor type	academic/university or research institute
Format	electronic

A.3 World Health Organization

From: permissions@who.int <permissions@who.int>
Date: Saturday, 9 January 2021 at 3:56 pm
To: Belinda Cuomo <belinda.cuomo@postgrad.curtin.edu.au>
Cc: permissions@who.int <permissions@who.int>
Subject: ID: 372350 Permission authorization for WHO copyrighted material

Dear Ms Cuomo

Thank you for your request for permission to reproduce, reprint or translate certain WHO copyrighted material.

On behalf of the World Health Organization, we are pleased to authorize your request to reproduce the WHO materials as detailed in the form below, subject to the terms and conditions of the non-exclusive licence below.

If you have questions regarding this authorization, please contact permissions@who.int.

We thank you for your interest in WHO published materials.

Kind regards,
WHO Permissions team

WORLD HEALTH ORGANIZATION (WHO)

Non-exclusive licence to use selected WHO published materials

You submitted a request, through WHO's online platform, for permission to reprint and reproduce certain WHO copyrighted material (the "Licensed Materials"). This is a legal agreement (the "Agreement") between you and WHO, granting you a licence to use the Licensed Materials subject to the terms and conditions herein.

Read this Agreement in its entirety before using the Licensed Materials.

By using the Licensed Materials, you enter into, and agree to be bound by, this Agreement.

This licence is granted only for original materials belonging to WHO. If any part of the WHO published materials you wish to reproduce are credited by WHO to a source other than WHO, those materials are not covered by this Agreement and are not part of the Licensed Materials. You are responsible for determining if this is the case, and if so, you are responsible for obtaining any necessary permission from the source of those third-party materials prior to their use.

If you enter into this Agreement on behalf of an organization, by using the Licensed Materials you confirm (represent and warrant) that you are authorized by your organization to enter into this Agreement on the organization's behalf. In such a case, the terms "you" and "your" in this Agreement refer to, and this Agreement applies to, the organization.

WHO grants this licence to you based on the representations and warranties you made in the licence request you submitted through WHO's online platform. If any of those representations and/or

warranties are or become false or inaccurate, this licence agreement shall automatically terminate with immediate effect, without prejudice to any other remedies which WHO may have.

If you have questions regarding this Agreement, please contact permissions@who.int.

1. Licence. Subject to the terms and Conditions of this Agreement, WHO grants to you a worldwide, royalty free, non-transferable, non-sublicensable, non-exclusive licence to use, reproduce, publish, and display the Licensed Materials in the manner and using the media indicated in the Permissions Request Form you submitted to WHO (the "Licensed Use"). This licence is limited to the current edition of your publication. Future editions or a different use of the Licensed Materials will require additional permission from WHO. If your request includes translation into different languages, then non-exclusive permission is hereby granted to translate the Licensed Materials into the languages indicated.

2. Retained Rights. Copyright in the Licensed Materials remains vested in WHO, and WHO retains all rights not specifically granted under this Agreement.

3. Mandatory Acknowledgement. In every instance of the Licensed Use, you must make suitable acknowledgement of WHO, either as a footnote or in a reference list at the end of your publication, as follows:

> "Reprinted from Publication title, Vol /edition number, Author(s), Title of article / title of chapter, Pages No., Copyright (Year)."

In addition, If the Licensed Materials originate from the WHO web site, you must also include the URL reference and the date accessed.

Translations of the Licensed Materials should be attributed as follows:

> "Translated with permission of the publisher from Publication title, Vol /edition number, Author(s), Title of article / title of chapter, Pages No., Year."

4. Altering or Modifying the Licensed Materials. As part of the Licensed Use, you may minimally alter or adapt figures and tables in the Licensed Materials to match the style of your publication. Any other alteration or modification of the Licensed Materials (including abbreviations, additions, or deletions) may be made only with the prior written authorization of WHO.

5. Appropriate and Prohibited Uses. You must use the Licensed Materials in a factual and appropriate context. You may not use the Licensed Materials in association with any product marketing, promotional, or commercial activities, including, without limitation, in advertisements, product brochures, company-sponsored web sites, annual reports, or other non-educational publications or distributions.

6. No WHO endorsement. You shall not state or imply that WHO endorses or is affiliated with your publication or the Licensed Use, or that WHO endorses any entity, organization, company, or product.

7. No use of the WHO logo. In no case shall you use the WHO name or emblem, or any abbreviation thereof. Notwithstanding the foregoing, if the WHO name and/or emblem appear as an integral part of the Licensed Materials (e.g. on a map) you may use the name and/or emblem in your use of the License Materials, provided the name and/or logo is not used separately from the Licensed Materials.

8. No Warranties by WHO. All reasonable precautions have been taken by WHO to verify the information contained in the Licensed Materials. However, WHO provides the Licensed Materials to you without warranty of any kind, either expressed or implied, and you are entirely responsible for your use of the Licensed Materials. In no event shall WHO be liable for damages arising from your use of the Licensed Materials.

9. Your Indemnification of WHO. You agree to indemnify WHO for, and hold WHO harmless against, any claim for damages, losses, and/or any costs, including attorneys' fees, arising in any manner whatsoever from your use of the Licensed Materials or for your breach of any of the terms of this Agreement.

10. Termination. The licence and the rights granted under this Agreement shall terminate automatically upon any breach by you of the terms of this Agreement. Further, WHO may terminate this licence at any time with immediate effect for any reason by written notice to you.

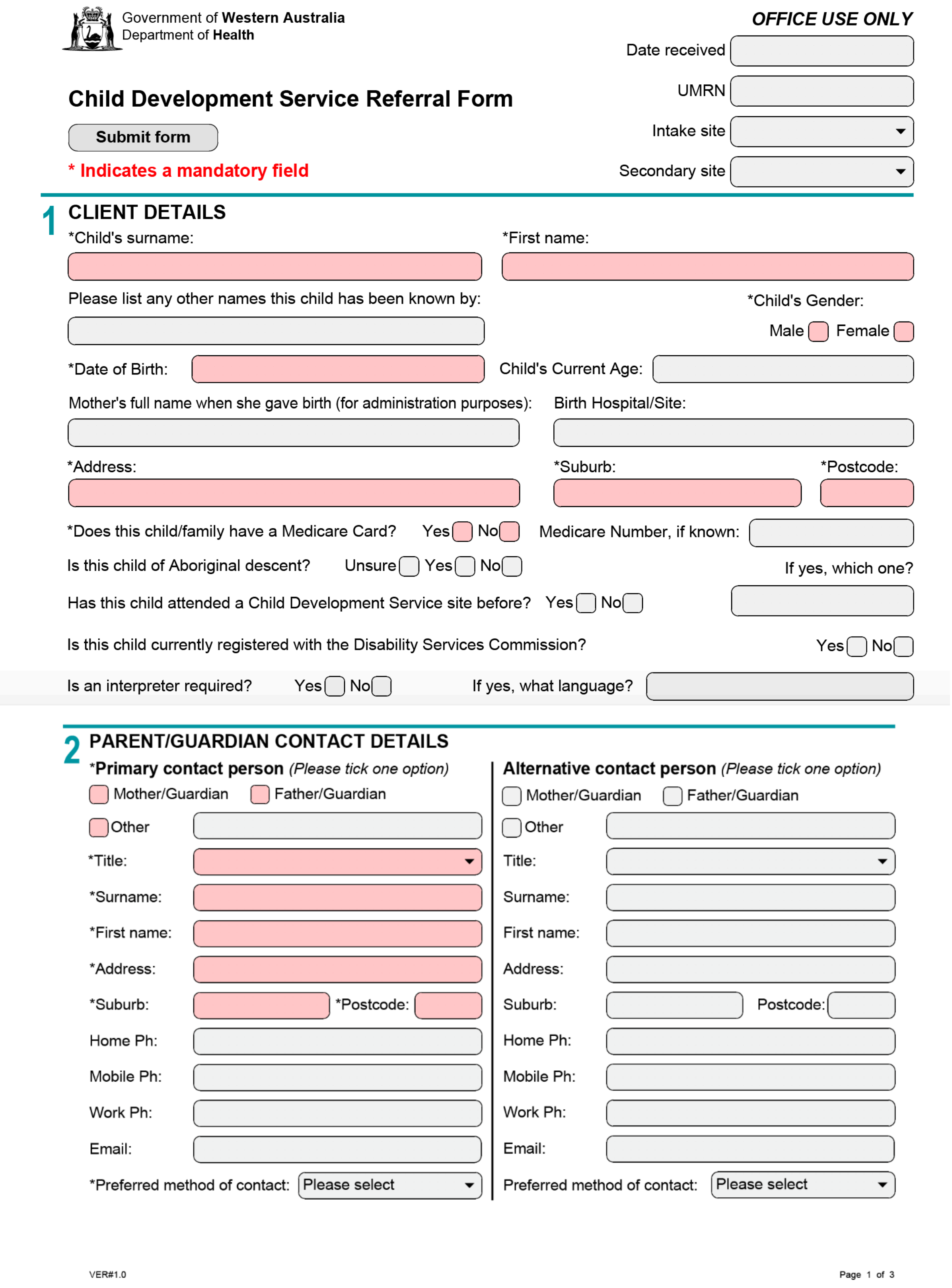
11. Entire Agreement, Amendment. This Agreement is the entire agreement between you and WHO with respect to its subject matter. WHO is not bound by any additional terms that may appear in any communication from you. This Agreement may only be amended by mutual written agreement of you and WHO.

12. Headings. Paragraph headings in this Agreement are for reference only.

13. Dispute resolution. Any dispute relating to the interpretation or application of this Agreement shall, unless amicably settled, be subject to conciliation. In the event of failure of the latter, the dispute shall be settled by arbitration. The arbitration shall be conducted in accordance with the modalities to be agreed upon by the parties or, in the absence of agreement, with the rules of arbitration of the International Chamber of Commerce. The parties shall accept the arbitral award as final.

14. Privileges and immunities. Nothing in or relating to this Agreement shall be deemed a waiver of any of the privileges and immunities enjoyed by WHO under national or international law and/or as submitting WHO to any national court jurisdiction.

Appendix B Child Development Service referral form



Government of **Western Australia**
Department of **Health**

OFFICE USE ONLY

Date received

UMRN

Intake site

Secondary site

Child Development Service Referral Form

Submit form

*** Indicates a mandatory field**

1 CLIENT DETAILS

*Child's surname:

*First name:

Please list any other names this child has been known by:

*Child's Gender: Male ☐ Female ☐

*Date of Birth:

Child's Current Age:

Mother's full name when she gave birth (for administration purposes):

Birth Hospital/Site:

*Address:

*Suburb:

*Postcode:

*Does this child/family have a Medicare Card? Yes ☐ No ☐

Medicare Number, if known:

Is this child of Aboriginal descent? Unsure ☐ Yes ☐ No ☐

If yes, which one?

Has this child attended a Child Development Service site before? Yes ☐ No ☐

Is this child currently registered with the Disability Services Commission? Yes ☐ No ☐

Is an interpreter required? Yes ☐ No ☐

If yes, what language?

2 PARENT/GUARDIAN CONTACT DETAILS

***Primary contact person** *(Please tick one option)*

☐ Mother/Guardian ☐ Father/Guardian

☐ Other

*Title:

*Surname:

*First name:

*Address:

*Suburb:

*Postcode:

Home Ph:

Mobile Ph:

Work Ph:

Email:

*Preferred method of contact: Please select

Alternative contact person *(Please tick one option)*

☐ Mother/Guardian ☐ Father/Guardian

☐ Other

Title:

Surname:

First name:

Address:

Suburb:

Postcode:

Home Ph:

Mobile Ph:

Work Ph:

Email:

Preferred method of contact: Please select

VER#1.0

Page 1 of 3

3 REASON FOR REFERRAL (Please tick all that apply)

☐ Fine motor
☐ Gross motor
☐ Speech/language
☐ Family/relational
☐ Behaviour/emotion
☐ Feet/lower limbs/gait
☐ Head shape/position
☐ Hearing
☐ Functional skills (feeding, toileting, sleeping)
☐ Play skills
☐ Learning
☐ Sensory
☐ General
☐ Attention/concentration
☐ Other

*Please provide a detailed description of each identified developmental concern in the space provided below:

4 CLINICAL INFORMATION

Relevant Health History: (e.g. ENT history for speech & audiology referrals)

Additional Comments:

Date of last hearing test: Result:

Date of last vision test: Result:

Day care/school attending: Yr: Ph:

Teacher's name:

Has this child been referred to/seen by a school psychologist? Unsure ☐ Yes ☐ No ☐

Other agencies/professionals involved:

*Attached documents/reports: Yes ☐ No ☐

Please list attachments/reports:

5 REQUIRED INFORMATION – Parent/legal guardian consent

*(Insert name of parent/legal guardian)

gives consent for this child to be referred to the Child Development Service.

*Relationship to child: ☐ Mother/Guardian ☐ Father/Guardian ☐ Other (state relationship to the child below)

Has the parent/legal guardian consented for the CDS to contact the school/daycare? Unsure ☐ Yes ☐ No ☐

*Date of consent: *Signature: or Verbal consent ☐

Please note: Referral cannot be considered without signed or verbal consent of the legal guardian

6 REQUIRED INFORMATION – Department for Child Protection and Family Support (CPFS)

*Is this child in the care of the CEO of the Department for Child Protection and Family Support (CPFS)? Yes ☐ No ☐

(Insert name of CPFS Authorised Officer)

gives consent for this child to be referred to the Child Development Service.

CPFS Office: Email

*Date of consent: *Signature: or Verbal consent ☐

Please note: Referral cannot be considered without signed consent

7 REQUIRED INFORMATION – Referrer information

***Referrer:** ☐ **Parent/legal guardian.** You are not required to complete the referrer information below.

☐ **Other.** Please complete the referrer information below.

Title: *Surname: *First Name

Occupation: Organisation/School:

*Address: *Suburb: *Postcode:

*Phone: Fax: *Email:

*Date of referral:

PLEASE RETURN COMPLETED REFERRAL
BY ONE OF THE METHODS BELOW

Submit form

Post: PO BOX 1095 West Perth 6872
Fax: 9426 7676
E-mail: childdevelopmentservice@health.wa.gov.au

Thank you for your referral. Please await contact from the Child Development Service.
For more information contact the Child Development Service on 1300 551 827.

Office use only

☐ Accept ☐ Single ☐ Multi ☐ Fast Track ☐ Urgent ☐ Decline RR: AA:

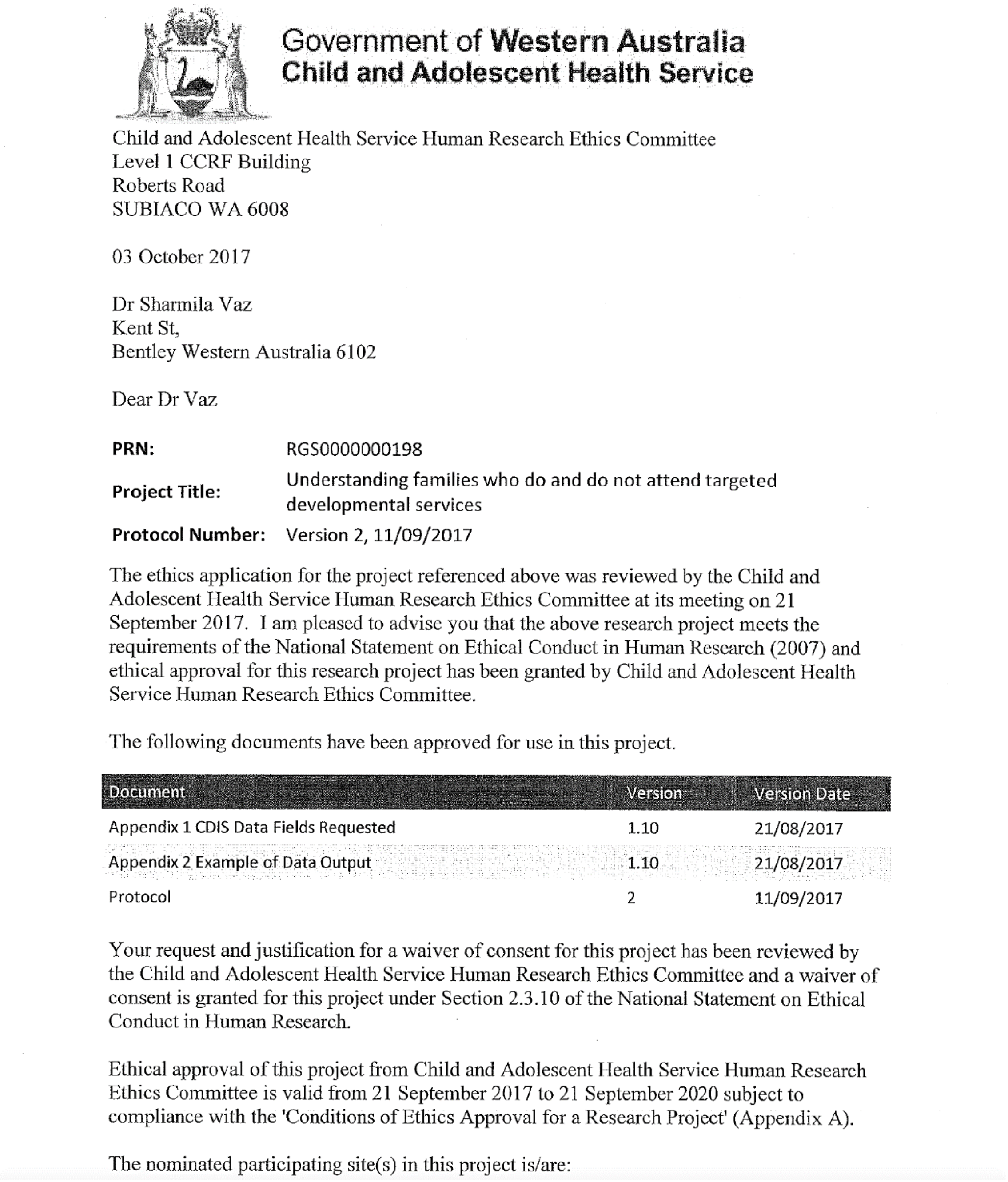
PAQ required ☐ Yes ☐ No Other enclosures/letters:

Client status/history:

Notes:

Data entry: Triage CNS: Date:

Appendix C HREC database, Dept of Health



Government of Western Australia
Child and Adolescent Health Service

Child and Adolescent Health Service Human Research Ethics Committee
Level 1 CCRF Building
Roberts Road
SUBIACO WA 6008

03 October 2017

Dr Sharmila Vaz
Kent St,
Bentley Western Australia 6102

Dear Dr Vaz

PRN: RGS0000000198
Project Title: Understanding families who do and do not attend targeted developmental services
Protocol Number: Version 2, 11/09/2017

The ethics application for the project referenced above was reviewed by the Child and Adolescent Health Service Human Research Ethics Committee at its meeting on 21 September 2017. I am pleased to advise you that the above research project meets the requirements of the National Statement on Ethical Conduct in Human Research (2007) and ethical approval for this research project has been granted by Child and Adolescent Health Service Human Research Ethics Committee.

The following documents have been approved for use in this project.

Document	Version	Version Date
Appendix 1 CDIS Data Fields Requested	1.10	21/08/2017
Appendix 2 Example of Data Output	1.10	21/08/2017
Protocol	2	11/09/2017

Your request and justification for a waiver of consent for this project has been reviewed by the Child and Adolescent Health Service Human Research Ethics Committee and a waiver of consent is granted for this project under Section 2.3.10 of the National Statement on Ethical Conduct in Human Research.

Ethical approval of this project from Child and Adolescent Health Service Human Research Ethics Committee is valid from 21 September 2017 to 21 September 2020 subject to compliance with the 'Conditions of Ethics Approval for a Research Project' (Appendix A).

The nominated participating site(s) in this project is/are:

Perth Children Hospital, Princess Margaret Hospital

[Note: If additional sites are recruited prior to the commencement of, or during the research project, the Coordinating Principal Investigator is required to notify the Human Research Ethics Committee (HREC). Notification of withdrawn sites should also be provided to the HREC in a timely fashion.]

A copy of this ethical approval letter must be submitted by all site Principal Investigators to the Research Governance Office or equivalent body or individual at each participating institution in a timely manner to enable the institution to authorise the commencement of the project at its site/s.

This letter constitutes ethical approval only. This project cannot proceed at any site until separate site authorisation has been obtained from the Chief Executive or Delegate of the site under whose auspices the research will be conducted.

The Child and Adolescent Health Service Human Research Ethics Committee is registered with the Australian Health Ethics Committee and operates according to the NHMRC National Statement on Ethical Conduct in Human Research and International Conference on Harmonisation – Good Clinical Practice.

The Child and Adolescent Health Service Human Research Ethics Committee Terms of Reference, Standard Operating Procedures, membership and standard forms are available from http://www.pmh.health.wa.gov.au/development/resources/ethics.htm. Should you have any queries about the HREC's consideration of your project, please contact the Ethics Office on pmhethics@health.wa.gov.au.

Yours sincerely

Dr Mark Salmon
Director of Clinical Services
On Behalf of the Child and Adolescent Health Service Human Research Ethics Committee

Appendix D HREC database, Curtin University

Curtin University

Office of Research and Development

GPO Box U1987
Perth Western Australia 6845

Telephone +61 8 9266 7863
Facsimile +61 8 9266 3793
Web research.curtin.edu.au

04-Oct-2017

Name: Sharmila Vaz
Department/School: School of Occupational Therapy and Social Work
Email: S.Vaz@curtin.edu.au

Dear Sharmila Vaz

RE: Reciprocal ethics approval
Approval number: HRE2017-0701

Thank you for your application submitted to the Human Research Ethics Office for the project Understanding families who do and do not attend targeted developmental services.

Your application has been approved by the Curtin University Human Research Ethics Committee (HREC) through a reciprocal approval process with the lead HREC.

The lead HREC for this project has been identified as Child and Adolescent Health Service Human Research Ethics Committee.

Approval number from the lead HREC is noted as RGS0000000198.

The Curtin University Human Research Ethics Office approval number for this project is **HRE2017-0701**. Please use this number in all correspondence with the Curtin University Ethics Office regarding this project.

Approval is granted for a period of one year from **04-Oct-2017** to **03-Oct-2018**. Continuation of approval will be granted on an annual basis following submission of an annual report.

Personnel authorised to work on this project:

Name	Role
Cuomo, Belinda	Student
Vaz, Sharmila	CI
Joosten, Annette	Co-Inv
Cuomo, Belinda	Student
Joosten, Annette	Co-Inv

You must comply with the lead HREC's reporting requirements and conditions of approval. You must also:

- Keep the Curtin University Ethics Office informed of submissions to the lead HREC, and of the review outcomes for those submissions
- Conduct your research according to the approved proposal
- Report to the lead HREC anything that might warrant review of the ethics approval for the project
- Submit an annual progress report to the Curtin University Ethics Office on or before the anniversary of approval, and a completion report on completion of the project. These can be the same reports submitted to the lead HREC.
- Personnel working on this project must be adequately qualified by education, training and experience for their role, or supervised
- Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, that bears on this project
- Data and primary materials must be managed in accordance with the Western Australian University Sector Disposal Authority (WAUSDA) and the Curtin University Research Data and Primary Materials policy
- Where practicable, results of the research should be made available to the research participants in a timely and clear manner
- The Curtin University Ethics Office may conduct audits on a portion of approved projects.

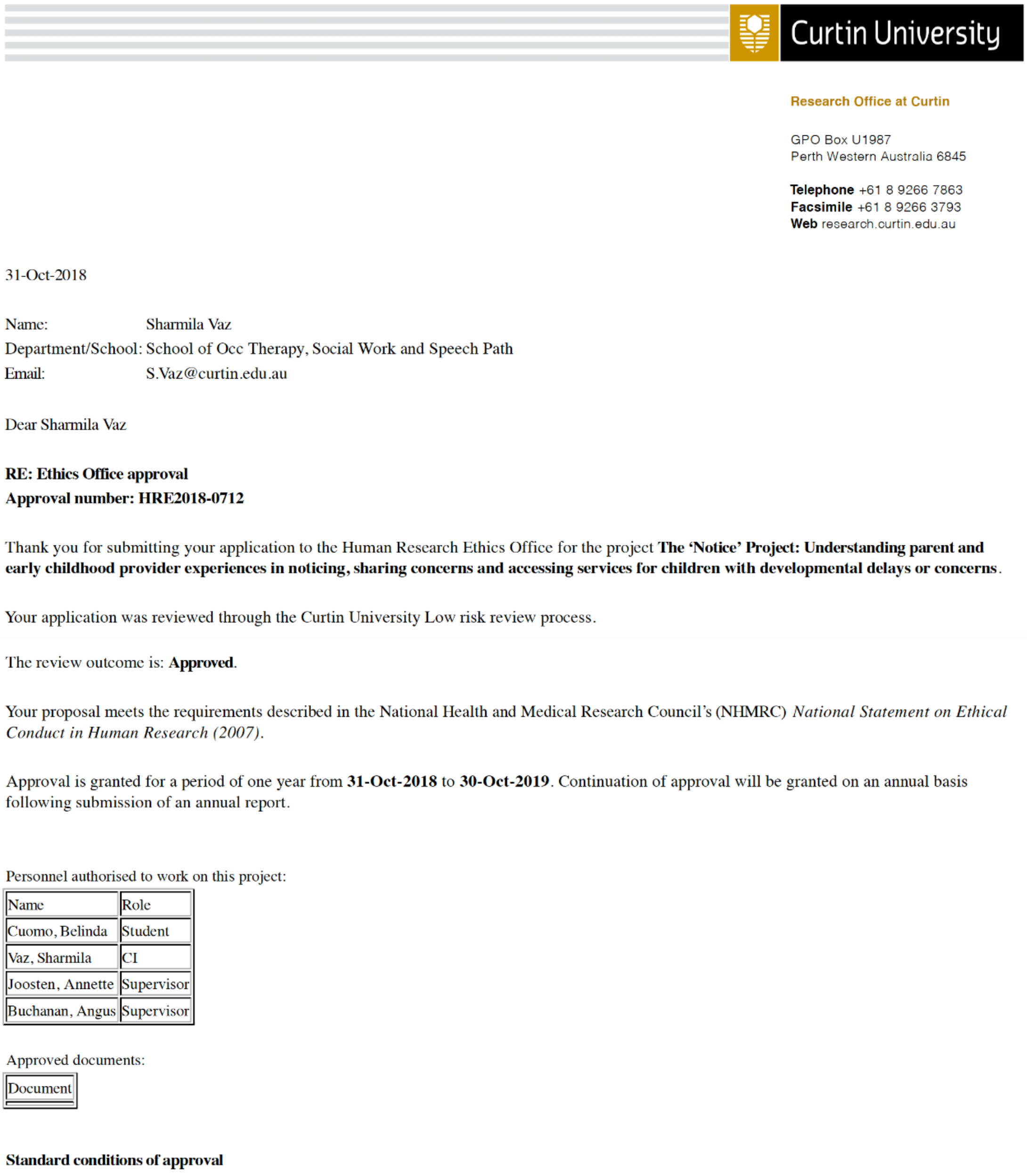
This letter constitutes ethical approval only. This project may not proceed until you have met all of the Curtin University research governance requirements.

Should you have any queries regarding consideration of your project, please contact the Ethics Support Officer for your faculty or the Ethics Office at hrec@curtin.edu.au or on 9266 2784.

Yours sincerely

Professor Peter O'Leary
Chair, Human Research Ethics Committee

Appendix E HREC approval: Interviews



Curtin University

Research Office at Curtin

GPO Box U1987
Perth Western Australia 6845

Telephone +61 8 9266 7863
Facsimile +61 8 9266 3793
Web research.curtin.edu.au

31-Oct-2018

Name: Sharmila Vaz
Department/School: School of Occ Therapy, Social Work and Speech Path
Email: S.Vaz@curtin.edu.au

Dear Sharmila Vaz

RE: Ethics Office approval
Approval number: HRE2018-0712

Thank you for submitting your application to the Human Research Ethics Office for the project **The 'Notice' Project: Understanding parent and early childhood provider experiences in noticing, sharing concerns and accessing services for children with developmental delays or concerns**.

Your application was reviewed through the Curtin University Low risk review process.

The review outcome is: **Approved**.

Your proposal meets the requirements described in the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*.

Approval is granted for a period of one year from **31-Oct-2018** to **30-Oct-2019**. Continuation of approval will be granted on an annual basis following submission of an annual report.

Personnel authorised to work on this project:

Name	Role
Cuomo, Belinda	Student
Vaz, Sharmila	CI
Joosten, Annette	Supervisor
Buchanan, Angus	Supervisor

Approved documents:

Document

Standard conditions of approval

1. Research must be conducted according to the approved proposal
2. Report in a timely manner anything that might warrant review of ethical approval of the project including:
   - proposed changes to the approved proposal or conduct of the study
   - unanticipated problems that might affect continued ethical acceptability of the project
   - major deviations from the approved proposal and/or regulatory guidelines
   - serious adverse events
3. Amendments to the proposal must be approved by the Human Research Ethics Office before they are implemented (except where an amendment is undertaken to eliminate an immediate risk to participants)
4. An annual progress report must be submitted to the Human Research Ethics Office on or before the anniversary of approval and a completion report submitted on completion of the project
5. Personnel working on this project must be adequately qualified by education, training and experience for their role, or supervised
6. Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, that bears on this project
7. Changes to personnel working on this project must be reported to the Human Research Ethics Office
8. Data and primary materials must be retained and stored in accordance with the Western Australian University Sector Disposal Authority (WAUSDA) and the Curtin University Research Data and Primary Materials policy
9. Where practicable, results of the research should be made available to the research participants in a timely and clear manner
10. Unless prohibited by contractual obligations, results of the research should be disseminated in a manner that will allow public scrutiny; the Human Research Ethics Office must be informed of any constraints on publication
11. Approval is dependent upon ongoing compliance of the research with the Australian Code for the Responsible Conduct of Research, the National Statement on Ethical Conduct in Human Research, applicable legal requirements, and with Curtin University policies, procedures and governance requirements
12. The Human Research Ethics Office may conduct audits on a portion of approved projects.

Special Conditions of Approval

None.

This letter constitutes low risk/negligible risk approval only. This project may not proceed until you have met all of the Curtin University research governance requirements.

Should you have any queries regarding consideration of your project, please contact the Ethics Support Officer for your faculty or the Ethics Office at hrec@curtin.edu.au or on 9266 2784.

Yours sincerely

Amy Bowater
Ethics, Team Lead

Appendix F Recruitment flyers

The ‘Notice’ Project

Are you a parent or caregiver of a child 0-3 years of age?

Are you or someone else concerned about how your child is developing?

It can be difficult to know if your child is developing like other children their age. They may not be able to:

- Crawl, walk or run as well as other children
- Do things with their hands, like feeding or drawing
- Express their feelings or talk

Where do you go to get advice or seek help with your child’s development?

WE WANT TO UNDERSTAND YOUR EXPERIENCES.

We would like to interview parents in metropolitan Perth about the often complex process that families go through in deciding if their concerns are real, whether to take any action, and the things that can make finding services or getting help difficult.

Individual interviews or focus groups will take 30-90 minutes at an agreed upon place. You will receive a gift voucher for your time.

For more information or to get involved, please contact Belinda Cuomo at belinda.cuomo@postgrad.curtin.edu.au or call or text 0456 550 321.

CoLab
Collaborate for kids

TELETHON KIDS INSTITUTE

minderoo

Make tomorrow better.

Curtin University

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2018-0712)

Appendix G Information sheet

PARTICIPANT INFORMATION STATEMENT: Parents/caregivers

HREC Project Number:	HRE2018-0712
Project Title:	The 'Notice' Project: Understanding parent and early childhood provider experiences in noticing, sharing concerns and accessing services for children with developmental delays or concerns.
Chief Investigator:	Dr Sharmila Vaz, Senior Research Fellow
Student researcher:	Ms Belinda Cuomo
Version Number:	2
Version Date:	29 October 2018

What is the Project About?

More than one in five kindergarten-age children in Australia are have difficulty with how they move, use their hands, their language, or how they play and interact with others. Early childhood lays the foundation for life – so helping to set children on the right pathways early on is important. However, knowing if your child is where they should be developmentally is difficult. Is it a phase? Are they just different? What does normal even look like? All of these questions can make it difficult for families to know whether to be concerned. This process can also be very emotionally distressing. Added to this are often a range of other problems, such as not knowing who to share your concerns with or how to navigate our often complex health system to get help.

Previous research has tried to understand why families of children who have concerns with their development are not attending therapy services. This has at times placed the blame on families – why aren't you coming? This project aims to look at the situation differently – focusing instead on what makes our system difficult for families to access or engage with?

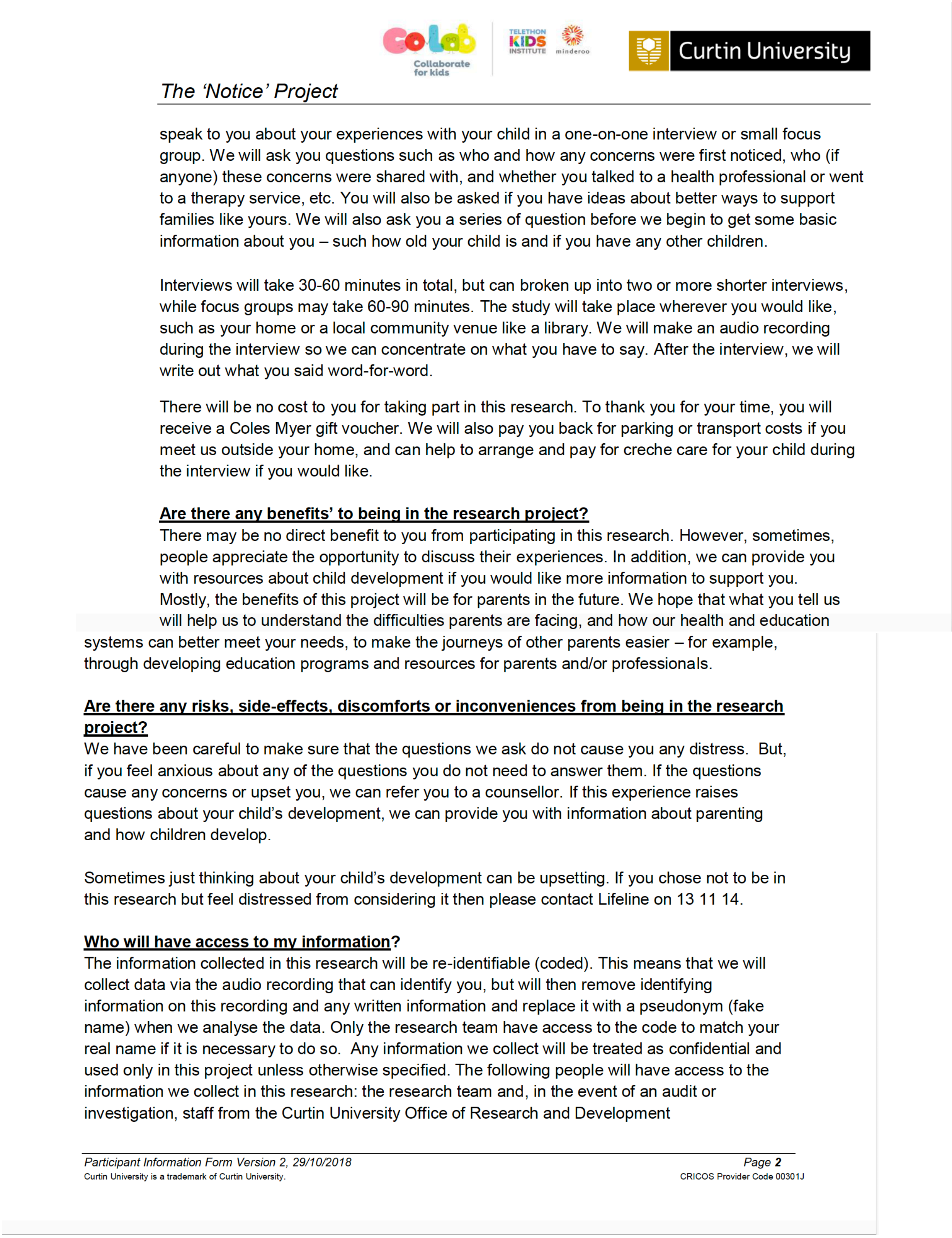
We also want to understand the often complex process that families go through in deciding whether concerns are real and then whether to take any action. This will help us to paint a picture of families of children experiencing developmental delays or concerns in Western Australia, to understand how we can better support families here along key points of their journeys. It is estimated that around 30 parents will take part in this project.

Who is doing the Research?

The project is being conducted by Ms Belinda Cuomo. The results of this research project will be used by Ms Cuomo to obtain a Doctor of Philosophy at Curtin University, who is funded by the University, the Australian government and CoLab through the Minderoo Foundation and the Telethon Kids Institute. There will be no costs to you to be involved. To thank you for your time, you will receive a Coles Myer gift card.

Why am I being asked to take part and what will I have to do?

We are looking for parents of young children who are not yet at school (three years old or younger), who have ever had concerns with whether their child is developing as they should be (or have been told as such) – for example, being slow to start talking or walking. We would like to



speak to you about your experiences with your child in a one-on-one interview or small focus group. We will ask you questions such as who and how any concerns were first noticed, who (if anyone) these concerns were shared with, and whether you talked to a health professional or went to a therapy service, etc. You will also be asked if you have ideas about better ways to support families like yours. We will also ask you a series of question before we begin to get some basic information about you – such how old your child is and if you have any other children.

Interviews will take 30-60 minutes in total, but can broken up into two or more shorter interviews, while focus groups may take 60-90 minutes. The study will take place wherever you would like, such as your home or a local community venue like a library. We will make an audio recording during the interview so we can concentrate on what you have to say. After the interview, we will write out what you said word-for-word.

There will be no cost to you for taking part in this research. To thank you for your time, you will receive a Coles Myer gift voucher. We will also pay you back for parking or transport costs if you meet us outside your home, and can help to arrange and pay for creche care for your child during the interview if you would like.

Are there any benefits' to being in the research project?

There may be no direct benefit to you from participating in this research. However, sometimes, people appreciate the opportunity to discuss their experiences. In addition, we can provide you with resources about child development if you would like more information to support you. Mostly, the benefits of this project will be for parents in the future. We hope that what you tell us will help us to understand the difficulties parents are facing, and how our health and education systems can better meet your needs, to make the journeys of other parents easier – for example, through developing education programs and resources for parents and/or professionals.

Are there any risks, side-effects, discomforts or inconveniences from being in the research project?

We have been careful to make sure that the questions we ask do not cause you any distress. But, if you feel anxious about any of the questions you do not need to answer them. If the questions cause any concerns or upset you, we can refer you to a counsellor. If this experience raises questions about your child's development, we can provide you with information about parenting and how children develop.

Sometimes just thinking about your child's development can be upsetting. If you chose not to be in this research but feel distressed from considering it then please contact Lifeline on 13 11 14.

Who will have access to my information?

The information collected in this research will be re-identifiable (coded). This means that we will collect data via the audio recording that can identify you, but will then remove identifying information on this recording and any written information and replace it with a pseudonym (fake name) when we analyse the data. Only the research team have access to the code to match your real name if it is necessary to do so. Any information we collect will be treated as confidential and used only in this project unless otherwise specified. The following people will have access to the information we collect in this research: the research team and, in the event of an audit or investigation, staff from the Curtin University Office of Research and Development

Electronic data will be password-protected and hard copy data (including audio tapes) will be in locked storage. The information we collect in this study will be kept under secure conditions at Curtin University for 7 years after the research is published and then it will be destroyed.

The results of this research may be presented at conferences or published in professional journals. It will also form part of Ms Cuomo's PhD thesis. You will not be identified in any results that are published or presented.

Whilst all care will be taken to maintain privacy and confidentiality of any information shared at a focus group or group discussion, you should be aware that you may feel embarrassed or upset if one of the group members repeats things said in a confidential group meeting. All focus group participants will be asked to maintain confidentiality as part of signing the consent form before participating.

Will you tell me the results of the research?

After the interview we will provide you with a summary of our understanding of what you said, to give you the opportunity to tell us whether we have understood your experience and make any final comments. We will also write to you at the end of the research (in about 6 months) and let you know the results of the research. These results will not be individual but based on all the information we collect and review as part of the research.

Do I have to take part in the research project?

Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, you can withdraw from the project. If you choose not to take part or start and then stop the study, it will not affect your relationship with the University, staff or colleagues.

Even if you initially consent, you are free to withdraw from the study both during interview itself or prior to approving your transcript that we will send to you. You do not have to give us a reason.

What happens next and who can I contact about the research?

Please contact Ms Belinda Cuomo if you would like to participate, for more information, or if you have any further questions at belinda.cuomo@postgrad.curtin.edu.au or on 0456 550 321.

If you decide to take part in this research we will ask you to sign the consent form. By signing it is telling us that you understand what you have read and what has been discussed. Signing the consent indicates that you agree to be in the research project and have your health information used as described. Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2018-0712). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.

Appendix H Consent form

CONSENT FORM: Parents/caregivers

HREC Project Number:	HRE2018-0712
Project Title:	The 'Notice' Project: Understanding parent and early childhood provider experiences in noticing, sharing concerns and accessing services for children with developmental delays or concerns.
Chief Investigator:	Dr Sharmila Vaz, Senior Research Fellow
Student researcher:	Ms Belinda Cuomo
Version Number:	1
Version Date:	17 October 2018

- I have read the information statement version listed above and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my involvement in this project.
- I voluntarily consent to take part in this research project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by Curtin University Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).
- I understand I will receive a copy of this Information Statement and Consent Form.
- *Focus group participants:* I will maintain the privacy and confidentiality of the other members of the focus group and the information that they share.

☐ I do	☐ I do not	consent to being audio-recorded

Participant Name	
Participant Signature	
Date	

<u>Declaration by researcher:</u> I have supplied an Information Letter and Consent Form to the participant who has signed above, and believe that they understand the purpose, extent and possible risks of their involvement in this project.

Researcher Name	
Researcher Signature	
Date	

Appendix I Interview guide

Interview Guide – Parents/Caregivers

Introduction

- Children develop at different rates. But sometimes we can become worried when children are progressing more slowly compared to others, or when they behave or do things in a different way. This can be because of the way they move around, do things with their hands, how they talk or understand people, or play with others.
- I understand that you are here today because you have a child or children that you or someone else has had some of these worries about.

Noticing

1. Tell me about your child. (Name, age, etc).
    - When did you or someone else first start to notice something was different?
    - How did this happen [probing around specific moment/trigger, niggling sensation]

    Where someone else noticed:

    - How did that conversation go – who noticed, what were their concerns?
    - What was your initial reaction?
    - Did you have any concerns of your own prior to this?

2. At that time of noticing, how would you describe your level of understanding of how children are supposed to develop?
    - Where did you get this understanding from? [resources/other people]
    - What do you think might have influenced this?
        - [probing around previous parenting, time spent with young children, education/work background]
    - Some parents say that they use comparison with other children – siblings, children of friends – as a way to know what is 'normal' is. Have you had this experience?

Appraisal

3. Looking back, was there anything that meant you were already 'on high alert' with [child's name] – such as complications at birth or being unwell as a baby?
    - What about any circumstances with your family, such as a someone having a history of being late to walk or talk?
4. When [type of concern] was first flagged, what were your initial thoughts?
    - On a scale of 1 to 10, how worried were you?
    - What was it about [child's name]'s [type of concern] that made you think, this is/is not a problem?
5. How did you feel at the time?

Share

6. What was the impact of people around you – did you share the concerns with anyone? Family, friends?
    - What were their reactions?

V.1, 17/10/2018

    - How did this influence your beliefs about [your child]?
7. Did you share your concerns with any professionals, maybe your GP or a teacher?
    - Tell me about this experience
        - [probing around professional knowledge/perceptions, confidence)
    - If 'no': [re-iterate no judgement]; did you have any particular reasons for keeping your concerns to yourself/within your family?
        - Sometimes it can be hard to know who to talk to/ask – was this the case for you?

Access

8. Did you take any action beyond this, such as looking into therapy services or things you could do at home with [child's name]?
    - Tell me about this experience.
    - Were there things that made/make it difficult? (prompt around following)
        - Practical barriers – getting there, paying for it, 'life'
        - Perception/attitude - level of concern, influence of family members
        - Emotional
        - Systematic barriers – funding schemes (Medicare), waitlists.
    - If did go: what made it possible?
    - [if not going/dropped out]: What would it have taken for you to be able to take [child's name] to [therapy – whatever service identified].
        - What did you need? (give examples if needed – child care for your other children, to be able to take time off work, for services to come to you, etc)

Overall

9. Thinking about your overall journey with [child's name], from first having some concerns through to now, how would you describe your overall experience?
    - What 3 words best sum up your experience?
10. What has been the most important or most helpful parts?
11. What have been the toughest or most difficult parts of this experience?
    - What did or could have helped you during these times?
12. What would you like [the following groups] to know about navigating the different parts of this journey from noticing concerns through to accessing services?
    - Other families going through similar experiences?
    - People who work with children every day, like playgroups or child care workers?
    - Health professionals like therapists, or GP's who might refer children?
13. What would you like to see happen to better support families like yours?
    - What are some solutions to the barriers that you identified?
    - What information do families/services need?
14. Any further comments?

Appendix J Demographic questionnaire

Participant code: Date:

Demographic questions – parent/caregiver

Interviewee gender: ____

Age: ____

Suburb (name and post code)____

Relationship to child: ____

How many children: ____

Ages of children: ____

Age of child/ren concerned about: ________________________________

Above child's gender: ____

Household composition: ____

Level of education: ____

Employment status/profession: ______________________________________

Work experience with children (Y/N): ________________________________

To be completed after interview (based on interview questions):

Nature of child's developmental concerns:

____

Type of professionals/services accessed or concerns shared with:

____

____

____

V.1, 17/10/2018