

Parental and Practitioner Perspectives on Raising an Adolescent with a Disability:

A Focus Group Study

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Abstract

Purpose. To examine the challenges faced by parents of teenagers with a disability to determine the need for a tailored parenting program for this population.

Method. Focus groups were conducted with six parents and nine practitioners with experience supporting parents of teenagers with a disability.

Results. An inductive thematic analysis revealed close agreement between parents and practitioners and eight understandable and relevant themes. The results indicated that parents have difficulty planning and facilitating transitions for their adolescent children, managing behavioural problems due to these problems being unique to this developmental period and because some of the parenting strategies that were useful when their children were younger were no longer applicable. High levels of stress and feelings of grief were also described.

Conclusions. These results suggest that parents of adolescents with a developmental disability could benefit from a parenting program and that an existing evidence-based parenting program should be modified. Implications for program design for this population are discussed.

Keywords

Developmental disability, parenting, prevention, behaviour problems, adolescence.

Parental and Practitioner Perspectives on Raising an Adolescent with a Disability: A Focus
Group Study

Adolescents with a developmental disability are at greater risk of experiencing a range of behavioural, psychological and social issues compared to their nondisabled peers. They are significantly more likely to be diagnosed with a psychiatric disorder such as a conduct or anxiety disorder [1]. They are also more likely to experience lower self-esteem, to require medical treatment after engaging in risk-taking behaviour, and to experience force at the time of their first sexual encounter [2-4]. Adolescents with a disability have been described as having impaired or non-existent relationships with their age related peers and relationships with adults that are ambivalent and *asymmetrical*; that is, relationships that are helpful and supportive, but overprotective and dominant [5]. Parents of adolescents with a disability have been found to be overprotective in the context of receiving little or no practitioner support regarding their adolescents' transition to adulthood [5].

Skär's [5] findings are significant since it is known that the quality of parenting that children receive has a major effect on their development and that sensitively tailored parenting programs based on social learning models are associated with a range of positive outcomes both for families of younger children with developmental disabilities [6-7] and for families of teenagers who are developing typically [8]. To our knowledge, there are no parenting interventions that have been developed specifically for parents raising an adolescent with a disability. However, given the challenges that are known to exist for this population, we believe that such a program is likely to be warranted and to be of significant benefit.

Mazzucchelli and Sanders [9] have suggested that tailoring existing evidence-based programs and interventions to meet the varying needs of consumer groups leads to a greater engagement of consumers, more optimal delivery, and an increase in an intervention's

effectiveness. Both Teen Triple P [10] and Stepping Stones Triple P [11] are examples of effective adaptations of an original evidence-based parenting program, Triple P—Positive Parenting Program [12]. An adaptation of Triple P for parents of teenagers, Teen Triple P, has been demonstrated to be effective in improving teenagers' adjustment, parents' confidence and parenting skills and in reducing parent-teen and inter-parental conflict [10]. Stepping Stones Triple P was adapted for families who have a pre-adolescent child with a disability and has been reported to be acceptable and to result in similar outcomes [13, 14]. Unfortunately, we suspect that neither of these programs would be a good "fit" for this population. The examples and materials in Teen Triple P depict typically developing teenagers and do not address issues unique to families raising a child with a disability. Similarly, although Stepping Stones Triple P was developed for children with a disability, it does not reflect the unique issues faced by parents raising adolescents.

Sanders and Kirby [15] argue that prior to the adaption of a parenting intervention it is important to seek input from consumers in order to gain a thorough understanding of the experiences and needs of the intended consumer groups. Such an understanding is vital in order to tailor the program to optimise its ecological fit and relevance, and to maximise the participation by parents and the fidelity of program delivery by practitioners. These accomplishments are all necessary in order to maximise the achievement of families' behavioural, social and emotional change goals [15].

A previous study by Hubert [16] investigated the views of parents who were caring for a severely disabled teenager in England and their views about institutionalised care. Hubert used an ethnographic method of qualitative data collection that involved unstructured interviews to explore topics with participants in their home environment. Hubert found that caring for a severely disabled young person is a full-time and demanding task that left parents struggling against physical and emotional exhaustion. Contributing to parents' emotional

adjustment was the finding that parents felt there was a lack of services relating to their child's transition to adulthood. It should be noted that Hubert's work focused on the experience of parents raising a young adult with a severe disability who lived in the home and required a high level of care. However, parents of teenagers who have a mild or moderate disability may experience different difficulties and have different views. Thus, further exploration of parental experiences in raising a teenager with a range of support needs is warranted.

The aim of our study was to explore the potential value of a parenting program tailored specifically for parents of teenagers with a disability. We aimed to do this through a series of focus groups to explore the perspectives of both parents and practitioners on the rewards and challenges of raising a teenager with a disability. It was our intention that the results might inform the future development and tailoring of parenting services to this population.

Method

Participants

Parents. Inclusion criteria were that parents were carers of a teenager with an intellectual disability or autism spectrum disorder. Parents were recruited by sending letters to 200 families who met the eligibility criteria, randomly selected from Disability Services Commission of Western Australia's (DSC) client database. Nine parents responded to the advertisement (a response rate of 4.5%) and six went on to participate in a focus group. Demographic details of the parents and their families are presented in table 1. The sample of adolescents (three males, three females) ranged in age from 13-17 years ($M = 14.16$, $SD = 1.67$). Further demographic details of the teenagers who were discussed are presented in table 2. Results obtained from self-report measures regarding each teenager's behaviour and adaptive functioning are also presented in table 2. The general adaptive composite score of

four teenagers was extremely low, one borderline and one below average. Variation was also noted in the results of the DBC-P with three teenagers scoring below the cut-off for a possible psychiatric disorder and three scoring above this cut-off. Together these tables indicate that participants represented a range of disabilities, emotional and behavioural problems as well as family backgrounds.

Practitioners. Inclusion criteria were that practitioners were employed by DSC and were providing a service to families with a teenager with an intellectual or autism spectrum disorder. Practitioners were recruited via internal advertising within DSC. All nine practitioners who volunteered to participate were included. Demographic details of practitioners are presented in table 3. Five of the practitioners were local area coordinators (LACs) who work in the community with families to link them to appropriate services and supports, and the four other practitioners were members of a behavioural support team who work with families experiencing behavioural problems with their child with a disability. The demographic details of the practitioners indicate a range of professions and experience in working with families with a teenager with a disability.

Insert tables 1, 2, and 3 about here

Measures

Two demographic questionnaires, one for parents and one for practitioners, were developed for the purpose of this study. These gathered information relating to family background, nature and severity of each teenager's disability and information relating to each practitioner's experience in implementing and intervening with parents of teenagers with a disability. Two sets of focus group questions (table 4) were developed using the questioning format outlined by Morgan and Krueger [17], one for the parent groups and the other for the practitioner groups.

Insert table 4 about here

The Developmental Behaviour Checklist—Primary Carer Version (DBC-P) was used as a measure of the teenagers' being discussed in the focus groups, emotional and behavioural functioning. The DBC-P is a 96 item instrument of parental or other primary carers' perceptions of behavioural and emotional problems in children aged 4 to 18 years. It shares the structure of the Child Behaviour Checklist [18] in that each behavioural description is scored on a 0, 1, 2 rating where 0 = "not true as far as you know", 1 = "somewhat true", and 2 = "very true or often true." However, the DBC-P items were derived from a study of the medical files of 7,000 children and adolescents with an intellectual handicap seen in a developmental assessment clinic. The instrument has been reported to have good internal consistency, high inter-rater and test-retest reliability, to correlate well with measures of behavioural disturbance within the AAMD Adaptive Behavior Scales [19], and the Scales of Independent Behavior [20], and to discriminate between cases and non-cases [21]. The DBC-P yields a total behavior score (with a designated cut-off of 46 for "caseness") and five subscale scores for disruptive/antisocial, self-absorbed, communication disturbance, anxiety, and social relating.

The Adaptive Behavior Assessment System 2nd Edition Parent Form (ABAS-II; [22]) was used to gain information relating to these teenagers' current adaptive behaviour skills. The ABAS-II is a questionnaire completed by a parent or guardian. It presents the rater with descriptions of adaptive behaviours in a variety of areas in a sequence that reflects an increasingly sophisticated level of adaptive functioning. The rater is asked to indicate if the subject is unable to perform this behaviour, is able to perform the behaviour but never does so at the appropriate time ("Never When Needed"), does it "Sometimes When Needed", or does it "Always When Needed". For each item the rater is also asked to indicate if their response to that item reflects their "guess" rather than their direct observation. The adaptive behaviours of the ABAS-II are grouped into three subscales: the Conceptual Skills

Composite, the Social Skills Composite, and the Practical Skills Composite, which together yield a general score referred to as the General Adaptive Composite (GAC). The ABAS-II has a high level of reliability and substantial evidence supporting its validity [22, 23].

Research Design

A qualitative research design incorporating focus groups was adopted. Focus groups have been used across many domains and fields to obtain insights into various research areas including parenting [17]. Focus groups have been fruitfully used in parenting research across a number of populations including grandparents caring for their grandchildren [24], parents of children with a traumatic brain injury [25] and parents of children with cerebral palsy [26]. In each of these studies researchers were able to gain valuable information relating to parenting strengths and difficulties in each population, practitioner perspectives on what issues need targeting and information relating to what approaches may be effective in population specific parenting interventions [24-26].

Procedure

On arrival at the focus groups, participants filled in the questionnaires. Brief introductions occurred and then the facilitator began the groups. The facilitator asked the questions in the same order in every focus group and ensured all participants provided an answer to all of the questions. The facilitator probed a participant, asking for further explanations or examples, if a participant was unclear. The focus groups were video recorded and then transcribed verbatim.

Analysis

The data was analysed using qualitative inductive thematic analysis as outlined by Braun and Clarke [27]. First, transcriptions of the video recordings were made, these data were then semantically coded line-by-line in units of information that related directly to the research purpose. Codes were then collated into potential themes. A thematic map was

developed to understand each theme compared to each other and to determine each code's appropriateness and consistency. The themes were then refined and extracts from the data were used to illustrate each theme. The analysis of the last focus group revealed no new themes, suggesting that saturation was achieved [28]. The reliability of the categories was confirmed by an independent coder who recoded the data set and identified 19 categories. This resulted in a high level of inter-rater reliability (free marginal kappa, $k = 0.90$).

Results

Informal Record of Need for Parenting Program and Willingness for Involvement

As part of the demographics questionnaire, parents and practitioners were asked whether they believed a parenting program for teenagers with a disability was warranted. Five out of six parents agreed that a parenting program for teenagers with a disability is needed and four out of six acknowledged they would participate if the opportunity arose. All nine practitioners acknowledged the need for a parenting program specifically designed for teenagers with a disability and eight endorsed that they would participate in training for such a program. These results are included as table 5.

Insert table 5 about here

Focus Group Results

The inductive thematic analysis revealed twenty categories that were grouped into eight understandable and relevant themes. See table 6 for an outline of the categories and themes. Table 6 also compares the presence of themes in the parent and practitioner focus groups. All participant names provided throughout the text below have been changed to protect confidentiality.

Insert table 6 about here

Transition to adulthood. Parents and practitioners identified issues relating to the transition of their teenagers to adulthood. One aspect of this transition related to the teenager

becoming independent. Parents and practitioners identified that this transition is difficult for both the teenager who is limited by their ability, but also for the parent who has become used to being needed and relied upon.

He is very dependent on me and I like it, which is a selfish thing. I'm getting older and sometimes I think that dependency I like, that's my issue not his. (Mother of a 16-year-old, Brayden)

Parents and practitioners outlined the need to plan for the teenager's transition to adulthood and expressed the need for information about available services and about the developmental process. Parents acknowledged this transition created a great deal of worry for them which led parents to want to begin to plan for their teenager's transition as soon as they could. This included planning their potential work, where they would live and how they would manage daily tasks.

Those dilemmas around whether their child continues to live with them and if not then where and who do they trust? (Dianne, speech pathologist)

Group homes are no longer the fashion; a lot of them [teenagers] are wanting to live on their own. But then, yeah, what's involved in that? (Lynette, clinical psychologist)

Additionally, both parents and practitioners acknowledged service issues related to the transition for teenagers with a disability to adulthood. Parents told stories about difficulties they had experienced in accessing services and practitioners explained that limited services were available for families. This was a particular issue around the transition from primary school to high school; parents felt isolated, less engaged with services or stopped receiving services all together. Parents and practitioners described less services being available while also describing difficulty getting what they wanted out of the services that are available.

I must admit, in my experience, one of the frustrations I find parents express is when they do get services, and there aren't that many and it's often hard to get any, they would like it for their child. (Divna, local area coordinator)

Social skills and friendships. Parents and practitioners stated that teenagers with a disability go through a difficult period when they begin to notice that they are different from their peers. Related to this realisation is a teenager's difficulty in building friendships with age related peers and having limited social skills to interact effectively.

She is not asking can her friend come over, they are good friends but she doesn't ask. [The other girl] asks her but she never asks. She won't have her own input, she prefers to be on her own. We have friends that have a five-year-old son, they are best buddies.... (Mother of a 13-year old, Karen)

Parents went on to link friendships and socialisation to life skills. Parents discussed the more relationships and friendships that a teenager has, the more resilient they become and the more able they are to distinguish danger. Parents worried about their teenager's ability to safely navigate the community and notice potential danger or exploitation.

You know kids with a disability need to have a variation [in friendships] if they are able to make a judgement and are capable of making a good conclusion.... It's a fear, you know, someone may take advantage, I would hate for someone to take advantage of my son. (Mother of a 16-year-old, Brayden)

Parents have a strong desire for their teenager to develop independence however they often have worries around their teenager's capacity to keep themselves safe. It was identified that parents worry about their teenager's ability to assess potential harm or risky social situations.

Parenting techniques suitable for teenagers and teenager specific behavioural issues. Parents and practitioners raised the issue of the presentation of behavioural issues that

arose in the teenage years that were difficult to manage. Parents and practitioners discussed that the community tends to be more judgemental when teenagers, as opposed to younger children with a disability, misbehave. Additionally, it was noted that teenagers with a disability learn behaviours from their peers, however are unable to navigate social situations well enough to determine their appropriateness. Behaviours mentioned in the focus groups included swearing, slamming doors, emotional tantrums, demonstrations of frustration which included yelling, screaming as well as teenagers ignoring their families, playing video games for an extended period of time, and high school refusal.

I laughed in the questionnaire when it said slamming doors, no one, no one in our family slams doors, but she does when she gets in the mood, where did she learn that? It's strange, she will show frustration, it is trying to understand what she is feeling and what triggered it. (Mother of a 13-year-old, Trudy)

Parents identified that there is a need for parents to learn teenager appropriate parenting techniques. This was raised in the context of their teenager feeling different, discovering their disability and not wanting to be different.

I ask him to do [tasks]. I tried putting a chart of what to do every morning, feed the dog, clean the poo, you know all these things. Sometime he is aloof, is he aloof because of his disability or because he is a teenager? He says, "I don't need a chart I'm not kid." (Mother of a 16-year-old, Brayden).

This also extends to behavioural support techniques. Parents described that previously used behaviour techniques are no longer applicable as their child grows and develops. They described needing new ways of managing ongoing behavioural issues.

She has the added thing of being strong. She is bigger. She can actually push me away. Before I could guide her body and stuff, now she is right up against me and

stuff. What am I going to be able to do, warning, counting, threatening? (Mother of a 13-year-old, Trudy)

Puberty and sexual development. A number of aspects of puberty and sexual development emerged as difficulties for parents. Changes in behaviour were discussed by both parents and practitioners as an issue during this developmental period. Behaviours that arose specifically to do with sexual development included inappropriate touching of themselves in public places as well as significant mood changes for female teenagers around their menstrual cycle. Personal hygiene was also discussed by parents and practitioners. Issues pertained to personal hygiene of emerging body odours, genital areas and at times of menstrual periods. Parents raised concerns around potential emerging relationships and how to discuss these with their teenager in the context of their disability. These three categories were discussed by parents in the context of needing to discuss these issues, ensure their child's health and safety while trying to provide their teenager with the appropriate amount of privacy.

You got to give him privacy whatever he does in the shower, that is his business and I'll leave him alone but at the same time, at the beginning, a few years ago he would get excited at a public place and we had to approach that and say that is not appropriate. He did learn, he has to learn everything. Nothing developed as normal. (Mother of a 16-year-old, Brayden)

Communication difficulties. A teenager's ability to effectively communicate their needs and wants was raised as a difficulty. This was more in relation to those teenagers with an intellectual disability. Parents and practitioners acknowledge difficulty, at times, in understanding what the young person wants or needs. This tends to result in frustrations for both parties. This extended to difficulties for teenagers with a disability to communicate effectively with their peers.

...the person is trying to communicate they have needs or they're trying to get a need met in some other way that's not functional, so it's helping parents to get... all the support to do that and the skills. (Divna, local area coordinator)

Parents raised the issue of compliance and a frustration with their teenager not understanding or following through on their instructions. This relates to limited comprehension as well as difficulties for parents in getting information across.

It takes him so long to process my command.... From when he was little we had to talk like this [face to face]. He always misunderstood, I have to explain all the time, it is so time consuming. (Mother of 13-year-old, Michael)

Parents and practitioners acknowledge a concern about the mental health of teenagers with a disability. Parents discussed wanting their child to discuss their feelings in a meaningful way that would aid parents in determining if mental health is an issue for their teenager. Practitioners raised worries of self-harm and also discussed the need for parents to be educated in the area of mental health given the transitions to high school and adulthood and potential issues with self-efficacy and bullying.

I've even got teenagers with Down syndrome or intellectual disabilities and they know in their gut, they feel it. They know that they're different to the other kids and they start to get depressed. (Daniela, local area coordinator)

Parental and family self-care. Parental self-care was acknowledged as an issue by both parents and practitioners. Parents are often found to be completing many roles for their teenager with a disability, working, having an ongoing relationship as well as potentially looking after other children.

I think for parents of a teenager with a disability the anxiety would be amplified in terms of if they're late home thinking about what's happened. (Lynette, clinical psychologist)

A lot of parents we work with are experiencing burnout. (Dianne, speech pathologist)

Their self-care is being marginalised and [they're] experiencing social isolation themselves. (Dianne, speech pathologist)

This burnout extends to siblings and family units. Parents describe juggling an array of things and sometimes find it difficult to also include services. Parents discussed, at times, needing a break.

In real life we have the phone, work, husband (he's neglected), the dog, the cat, my mother (she is lonely), there are so many other things involved it's not just the person, you have to juggle and make the most of it, and sometimes you need time to yourself.

(Mother of a 16-year-old, Brayden)

This leads to concerns about parental mental health. A number of parents raised the issue of their own anxiety, stress and feelings of being overwhelmed. Practitioners also acknowledged that in their experience, parents raising a teenager with a disability are often overwhelmed which leads practitioners to worry about burnout and parental mental health.

Grief. A period of grief was described and detailed by both parents and practitioners. Practitioners acknowledged that grief has a significant impact on parenting a teenager with a disability particularly around key transitional and developmental points.

I've noticed, it's a bit of a grieving process because I think they can sometimes come to the reality that they will not get a job, not likely to go to university, it's not likely they're going to have a career that makes a lot of money, they may never get married, they may never have a house and money, I think it's grieving, that process. (Daniela, local area coordinator)

Parents expressed a separate unique stage of grief that relates to parents gaining awareness and a realisation that their child may not become independent or have adult

relationships. This grief is felt for their child but also for themselves, their family and their ongoing and future situations.

It is really hard, you go through grief at different times, it just comes out of the blue. I know for a while I was grieving I still have a dependant on me, she is my fifth child.

(Mother of a 13-year-old, Trudy)

Importance of storytelling and connection for parents. Practitioners were able to articulate that they felt parents and families with teenagers with a disability were more isolated and expressed not only the importance of families being connected but felt parents would benefit from being able to connect and learn from each other.

I think it normalises their experience or helps to normalise their experiences. Support can come from having other people around who feel they can understand. As therapists we have to say that we think we understand, but it's not the same as having other parents exchanging stuff. (Lynette, clinical psychologist)

Parents reflected this theme in words similar to practitioners however also in collaboration within the focus group. Parents offered words of encouragement to each other, behavioural suggestions, as well as empathy and understanding. Parents reflected a sense of understanding with each other noting that they didn't think others had gone through the same things they had. This reflection happened through story telling which addressed feelings of isolation, sadness and anxiety for their child. This was in many ways therapeutic for the parents.

I think it is important to talk, to see what parents went through. See for you, your child is sixteen; I can learn from you what I don't learn from others. I have to tell them [practitioners] what I want but it's important to learn from parent mistakes.

(Mother of a 13-year old, Karen)

Discussion

The aim of this study was to gain a rich data set of information from parents and practitioners about the rewards and challenges faced by parents raising a teenager with a disability. A key finding to emerge was that parents feel increasingly isolated and experience a lack of support as their teenager transitions from primary school to high school as well as in their transition to adulthood. Parent burnout and concerns about parental mental health was also identified as a key theme. Both parents and practitioners acknowledged that the challenges faced by parents can be associated with a sense of being overwhelmed and high levels of stress and anxiety. These themes are consistent with those described by Hubert [16] who described limited support services and parental emotional exhaustion as key issues for parents raising a teenager with a severe disability.

Themes relating to emotional expression, mental health and behavioural issues also emerged with parents describing a change in their child's behaviour during the teenage years. This related to mental health concerns, parents viewing their teenager as experiencing lowered self-esteem and the development of different behaviour problems to those exhibited during childhood. This is consistent with research describing adolescents with a disability as more likely to experience psychopathology and to demonstrate more behavioural difficulties compared to typically developing populations [1, 29]. Parents also discussed how communication difficulties increase frustrations and can negatively impact on parent-teen relationships.

Parents and practitioners discussed difficulties in social interactions for teenagers with a disability. This is consistent with research suggesting that teenagers with a disability have difficulty or few relationships with their peers [5]. Parents went on to discuss how this relates to limited resilience and is a considerable source of worry for parents. Parents discussed worries and issues relating to the sexual development of their teenager including potential sexual assault, how to increase safety and how to transition their teenager into having typical

relationships. This is consistent with research suggesting teenagers with a disability are more likely to experience force during their first sexual encounter and the importance of teenagers with a disability exploring their sexuality [2, 30]. Altogether, these findings are taken as confirmation that a tailored parenting program is needed to provide parents of teenagers with disability with information, skills and support. Indeed, when asked directly if a parenting program for this population was required, 100% of practitioners and 83% of parents responded in the affirmative.

A number of the themes identified had implications for the design of a parenting program for families of teenagers with a disability. In particular, the results suggested that a parenting program tailored for parents of adolescents with a disability should: (a) provide information on how parents can best support their teenagers in accomplishing developmental tasks specific to adolescence such as transition to high school, transition to work or other post-school options, and moving out of home; (b) include developmentally appropriate parenting techniques suitable for promoting their teenager's social and protective behaviour skills, decreasing social isolation, and managing emotional and problem behaviour; (c) provide information and ideas to help parents manage their own feelings of stress and grief and reduce parents' sense of isolation. Table 7 suggest a number of adaptations that stem from the themes identified and which relate to current research in the field.

Insert table 7 about here

Although this study identified a number of themes that are consistent with the literature involving teenagers with a disability, the results should be interpreted with caution. First, as is a limitation of all qualitative research, the findings of this study represent the perspectives of only a small number of individuals. Secondly, all of the parents who participated were mothers. Nevertheless, and lending greater confidence to the generalisability of findings was the fact that the sample represented a range of disabilities,

emotional and behavioural problems, as well as family backgrounds. Also, there was good agreement in the issues identified between parents and practitioners. Further, practitioners had many years of experience supporting families with teenagers with a disability and thus represented by proxy the experiences of many more families.

Conclusion

Eight key themes emerged from this qualitative approach to determining parental and practitioner perspectives of raising a teenager with a disability. Although a small number of parents and practitioners were sampled, the key themes and categories were consistent with current literature including outcomes of other qualitative studies. A parenting intervention, such as an adaptation of the Teen Triple P parenting program or an extension of the Stepping Stones Triple P program, may be an appropriate and effective way of addressing the themes raised by parents and practitioners. It is anticipated that this study will aid the development and specific tailoring of such parenting support interventions.

Acknowledgments

We thank Disability Services Commission of Western Australia for assisting with participant recruitment. We also thank Cathryn Prendergast for assisting with data analysis.

Declaration of Interest

This research was supported in part by a grant awarded to Trevor Mazzucchelli and Amy Hamilton from School of Psychology and Speech Pathology Research Allocation Fund, Curtin University.

The Triple P-Positive Parenting Program is owned by The University of Queensland. The University, through its technology transfer company Uniquet Pty Ltd., has licensed Triple P International Pty Ltd to disseminate the program worldwide. Royalties stemming from this dissemination work are distributed to the Faculty of Health and Behavioural Sciences, the School of Psychology, Parenting and Family Support Centre, and contributory authors in accordance with the University's intellectual property policy. No author has any share or ownership in Triple P International. Matthew Sanders is the founder and lead author of the Triple P-Positive Parenting Program, and is a consultant to Triple P International. Trevor Mazzucchelli is a co-author of Stepping Stones Triple P.

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Table 1

Parent and Family Characteristics

Variables	Frequency <i>N</i> = 6
Marital status of participating parent	
Married	4
Divorced	2
Education level of participating parent	
Grade 10	1
Grade 12	
Trade or apprenticeship	1
Diploma or TAFE	1
University Degree	2
Post Graduate Degree	1
Work status of participating parent	
Full Time	1
Part Time	3
Casual	
Looking for work	
Not working (includes stay at home parents)	2
Family financial position	
Can purchase most of the things we want	1
Can purchase some of the things we want	2
Not enough to purchase anything we want	3
Number of children in family	

1 child	1
2 children	1
3 children	2
4 children	0
5 children	1
6 children	1

RAISING ADOLESCENTS WITH A DISABILITY

Table 2

Demographic Characteristics of Adolescent Sample

Adolescent	Participating parent	Gender	Age, years	Diagnoses	Associated health conditions	ABAS-II Conceptual Skills Composite	ABAS-II Social Skills Composite	ABAS-II Practical Skills Composite	ABAS-II General Adaptive Composite	DBC-P Total Behaviour Problem Score
Karen	Mother	Female	13	18 p syndrome, ID	Panhypopituitarism	49*	61*	44*	44*	26
Michael	Mother	Male	13	ASD	Eczema	72	84	81	75	30
Trudy	Mother	Female	13	Down syndrome, ASD, ADHD, ID	Nil	49*	55*	40*	40*	104*
Brayden	Mother	Male	16	Velo-Cardio-Facial syndrome, ID	Congenital heart defect	93	96	83	87	38
Matthew	Mother	Male	17	ASD, ADHD	Nil	61*	66*	82	68*	69*
Sean	Mother	Male	17	ASD, ID	Nil	63*	58*	46*	49*	60*

Note. Names of adolescents changed.

RAISING ADOLESCENTS WITH A DISABILITY

ABAS-II = Adaptive Behavior Assessment System Second Edition Parent Form. ADHD = Attention Deficit and Hyperactivity Disorder. ASD = Autism Spectrum Disorder. DBC-P = Developmental Behaviour Checklist—Primary Carer Version. ID = Intellectual Disability.

* Clinically significant score.

RAISING ADOLESCENTS WITH A DISABILITY

Table 3

Demographic Characteristics of Health Professional Sample

Name	Gender	Discipline	Experience, years	Hours per week consulting with parents of adolescents who have a disability
Lynette	Female	Clinical Psychologist	26	5
Daniella	Female	LAC	5	10
Michelle	Female	LAC	9	3
Divna	Female	LAC	14	12
Steven	Male	LAC	19	8
Jane	Female	LAC / Social Worker	23	38
Margaret	Female	Social Worker	8	12.5
Dianne	Female	Speech Pathologist	8	18.5
Susan	Female	Speech Pathologist	5	12.5

Note. Names of professionals changed.

LAC = Local Area Coordinator.

Table 4

Focus Groups Questions

Question Type	Parent Focus Group	Practitioner Focus Group
Introductory questions	Tell us your name and something you would like us to know about your child—something that they do to make you smile.	Tell us your name and something you find rewarding working with families of a teenager with a disability.
Transition questions	As a parent, what do you think is most different about parenting a teenager with a disability compared to a typically developing teen? What are some of the positive aspects of parenting a teenager with disabilities?	What do you think would be most different about parenting a teenager with a disability compared to a typically developing teen? What do you believe to be some issues facing parents with teenagers with a disability?
Key questions	What do you find challenging in parenting your teenager with a disability in terms of behaviour? What do you find challenging in parenting your teenager with a disability in terms of general development? Should a parenting program for parents of teenagers with a disability be developed? Why?	In terms of behaviour, what do you think would be the biggest challenge for parents in parenting a teenager with a disability? In terms of general development what do you think would be the biggest challenge for parents in parenting a teenager with a disability? Should a parenting program for parents of teenagers with a disability be developed? Why?

	What changes in your teenager's behaviour would be a goal for you if you participated in a parenting program?	What goals for change in their teenager's behaviour do you think parents should have if they participated in a parenting program?
	What change in your own behaviour would be a goal for you if you participated in a parenting program?	What goals for change in their own behaviour do you think parents should have if they participated in a parenting program?
Ending questions	Of all the issues discussed which issues do you think are the most important to address?	Of all the issues discussed which issues do you think are the most important to address?
Summary	Is this an accurate summary?	Is this an accurate summary?
Final question	Have we missed anything?	Have we missed anything?

Table 5

Questions and Responses Regarding the Need for and Potential Participation in a Parenting Service for Teenagers with a Disability

Question	Response
Parents	<i>N</i> = 6
Would you ever participate in a parenting program aimed at helping you manage your teenager's behaviour?	
Yes	4
No	2
Would you like to be contacted about participating in a program for parents aimed at helping you manage your teenager's behaviour problems?	
Yes	5
No	1
Practitioners	<i>N</i> = 9
Do you see the need for the development of a parenting program specifically designed for teenagers with a disability?	
Yes	9
No	0
As a practitioner, would you undertake training to implement a parenting program designed for teenagers with a disability?	
Yes	8
No	1

Table 6

Complete Set of 20 Categories and 8 Key Themes

Theme	Components of theme		
Transition to adulthood	Development of independence. Parents wanting to increase teenager independence but being worried about their safety. Parents finding it difficult to let go.	Planning and information relating to key transitions. Highlighted particularly in the transition from primary school to high school as well as the transition from school to the work force.	Service issues. Not knowing enough about services or there not being a service for the particular issue.
Present in parent focus group	Yes	Yes	Yes
Present in practitioner focus group	Yes	Yes	Yes
Social Skills and Friendships	Limited friends and social interactions instigated by teenagers. As well as services, the community and schools becoming less inclusive.	Friendships and social interactions relate to social competence—how do we build resilience and safety if there is limited social contact?	
Present in parent focus group	Yes	Yes	
Present in practitioner focus group	Yes	No—practitioners did not discuss the link to resilience	
Behavioural issues and teenage appropriate parenting techniques	Newly developed behaviours arise in the teenage years.	What parenting techniques can be used when they are bigger and stronger and what techniques will be viewed by them as appropriate for their age	
Present in parent focus group	Yes	Yes	
Present in practitioner focus group	Yes	Yes	
Puberty and sexual development	Personal, private behaviours such as masturbation or touching in public places.	Personal hygiene issues relating to emerging body odours, cleanliness of genital areas and hygiene around times of menstrual periods.	The development of emerging relationships. How to establish safety as well as normality.

Present in parent focus group	Yes	Yes	Yes
Present in practitioner focus group	Yes	Yes	Yes
Communication Difficulties	Limited ability for teenager to articulate their wants and needs creates frustration in the home and parent-teen relationship.	The added time it takes for teenagers to understand, comprehend and follow instructions.	Mental health issues that arise in the teenage years that relate to limited social interaction, issues around self-efficacy and the teenagers' limited capacity to discuss such feelings.
Present in parent focus group	Yes	Yes	Yes
Present in practitioner focus group	Yes	Yes	Yes
Parental and Family Self Care	Ability for parents and families to take time out and care for themselves. Family's experience limited holidays and express the teenage year as a time in which "burnout" is experienced.	The impact of having a sibling with a disability can have an ongoing impact on the other children in the family that includes increased responsibility and a sense of responsibility.	Parental mental health issues arise due to burnout and the added anxiety and stress around key developmental transitions and grief.
Present in parent focus group	Yes	Yes	Yes
Present in practitioner focus group	Yes	Yes	Yes
Grief	A period of grief that their teenager may never become fully independent. Grief for their teenager's adult life and a sense of loss for their own.		
Present in parent focus group	Yes		
Present in practitioner focus group	Yes		
Importance of storytelling and connection for parents	Parents need to hear from and learn from other parents in similar situations.	Decrease in feelings of isolation and distance for parents raising a teenager with a disability.	Therapeutic nature of storytelling and feeling like you're not alone.
Present in parent focus group	Yes	Yes	Yes
Present in practitioner focus group	Yes	Yes	No

Table 7

Examples of How Themes can Inform Future Parenting Interventions

Consumer Input	Parenting Research	Potential Modification
Difficulties in transitioning their teenager to adulthood	Parents receive little information relating to their child's transition to adulthood [16]	Inclusion of content relating to planning or preparation for transition. This might include how to research and access appropriate services in the community.
Teenagers with a disability often have limited social skills and friendships	Adolescents with a disability have been described to have impaired or non-existent relationships to their peers [5].	Content to assist parents support teenager's social development and manage teenage risky behaviour.
Parenting techniques appropriate for adolescents	When tracked over time, emotional and behavioural disturbance in disability populations remains stable over time [31].	Inclusion of parenting techniques to manage difficult behaviours for adolescents (e.g., acknowledging emotional behaviour, behaviour contracts).
Difficulties in managing puberty and sexual development	Adolescents with a disability should not be excluded from mainstream sexual education [32].	Inclusion of resources and behaviour techniques specific to that of sexual development and puberty.

Need for parent self-care and stress management	Behavioural problems have been shown to have negative impacts on parental mental health, decrease family functioning and increase maternal stress [33].	Inclusion of techniques for parents to reduce their stress such as mindfulness, and relaxation strategies.
Ongoing grief for teenager's and own life.	Grieving is an ongoing feature of parenting children with a disability [34].	Acknowledge and legitimise parents' experience by including information on the nature of nonfinite loss. Also, provide strategies to help parents build emotional resilience and to manage and live with their loss.
