The Antecedents of Empowerment for Parents and Carers of People with Intellectual Disabilities within the Direct Funding Model

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INTRODUCTION

The last 25 years of the 20th century will be remembered for the unprecedented and rapid change in the way that people with disabilities are viewed (1), as well as in the philosophy, attitudes, and models of providing services and support to these people and their families (2, 3). This transformed vision that people with intellectual disabilities can have "life possibilities" (4) and "a good life" (5) is reflected in increasing reference to concepts such as empowerment, self-determination, choice, control, equity and inclusion.

The provision of services to people with intellectual disabilities and their families has been historically characterised by exclusion and segregation from the community and their families (6, 7, 8). While the nature and degree of this segregation is changing, many people with disabilities have not had the opportunity to engage in good or ordinary life (9). People with intellectual disabilities have traditionally received services and support in ways that reinforced their segregation from the community and their families. These arrangements also seem to assume the need for centralised control through professional intervention, such that people with disabilities and their families have had limited or no choice of services provided (10, 11).

The historical pattern of service delivery for people with disabilities and their families/carers is agency based, that is, it relies on creating agencies to act on people's behalf when it is believed they are unable or unlikely to act on their own (12). The mediator and funders of these services is largely the state, which causes the service system to be characterised as public, collective and politicised (13). Government funding has traditionally been based on directing resources to areas of need through agencies which were often very large and operated in segregated environments (14, 15, 16). A good deal of dis-empowerment potentially comes from the effects of social institutions such as the social welfare and government structure (17). To counteract this, an empowerment strategy would aim to increase the power people have over these institutions and their effects.

The historical dominance of human service systems in the lives of people with disabilities and their families is significant. The lives of people with disabilities and their families have and continue to be, characterised by limited access to required resources which are often of poor quality. The extensive external controls and limited decision making opportunities afforded to people with disabilities and their families remain dominant themes in the literature. These characteristics are reflected in the literature as factors that may have a disempowering impact on the life of a person. A lessening of the control of service systems over the lives of people with disabilities and their families is viewed as a necessary condition for the achievement of greater empowerment (18, 19, 20, 21).

One of the emerging demands of people with disabilities and their families is that resources traditionally controlled by governments and agencies are placed in the hands of the consumers of the services. A substantial amount of anecdotal evidence indicates that this increased control of resources is empowering for people with disabilities and their families 22, 23). The emerging approach to disabilities resource support over the past decade includes new funding mechanisms whereby people receive individualised funding. However, relatively little is known about the ways the emerging support systems of individualised funding approaches enhance or hinder the quality of people's community life experiences (1).

In the context of disability services, individualised consumer funding redirects current resources or allocates them more directly to the consumers of services. Individualised consumer funding is characterised by its philosophical values of choice, control, self-determination and empowerment (24). As a consequence of these characteristics, it also manifests itself in many variations of implementation and the degree of control provided to a person with a disability and/or their family. The individualised funding literature strongly emphasises the concepts of self-determination, choice, impact and competence, which are fundamental concepts of empowerment (25, 26).

Direct Funding is one model of individualised funding (27) and represents a contemporary and challenging paradigm when compared to the predominant funding approaches implemented in human services by governments and agencies. For the past 20 years the Disability Services Commission (DSC) in Western Australia, through the Local Area Coordination (LAC) Program has been considered a sector leader in the provision of individualised funding via Direct Funding to people with disabilities and their families. Direct Funding in Western Australia represents a radical departure from traditionally funded service approaches for people with disabilities and their families. The unique nature of this funding model for people with disabilities and their families, within a government service structure, is internationally recognised (28). The model is being considered and implemented by other government service providers in Australia, the United Kingdom and North America.

There is a paucity of useful models for examining factors that influence consumer empowerment in disability services. This has, in part, led to ill-informed disability policies and services (12, 23, 29) and practical application of research (30). Unless funding organisations address key questions through appropriate research models, there is a risk that the devolution of funding from services to consumers may not necessarily achieve the outcomes demanded by people with disabilities, families, policy makers and governments.

Although the concept of empowerment has received considerable attention in writing in the area of individualised funding there is little or no empirical research on empowerment in this context. In particular, it was not known whether parents and carers participating in the Direct Consumer Funding model experience more empowerment than those participating in traditional disabilities funding/services. Moreover there is a need to develop a much better understanding through empirical research of specific direct funding program characteristics and other factors that potentially influence feelings of empowerment

in the disability funding context. Until recently there have been few studies that examined the concept of empowerment directly and were based on impressionistic findings or using non-validated measures (31). Few studies have examined if empowerment perceptions are influenced by characteristics of the individual or the context (32, 33).

LITERATURE AND RESEARCH MODEL

Empowerment has become a concept with many meanings and interpretations (34) and is a 'buzzword' within disability service provision and design (1, 35), and is in danger of losing any substantive meaning (17). Empowerment is widely used in management literature and many people have talked about the concept without understanding its essential nature (36, 37, 38). Empowerment has suffered a maturation process at such a significant rate that it is almost impossible to gain any rational consensus on exactly what it is (39). However, there is an emerging consensus within the literature that supports the use of a definition of empowerment for this research. The meaning of empowerment has been approached from a number of perspectives which have focussed on the relational vs motivational relationship (40), the psychological vs structural perspective (32, 41, 42), and as a multi-dimensional concept. Empowerment is multi-dimensional and that its essence cannot be captured by a single concept. An alternative perspective on empowerment should be sought distinguishing between the situational attributes and individual cognitions about those attributes. While there is still some debate about the meaning of empowerment a predominant view is emerging from the literature. The growing consensus is that empowerment should be considered as a systematic psychological motivational concept (43).

Researchers (25, 26) propose that empowerment is the intrinsic task motivation resulting from a set of four task-related cognitions pertaining to a person's role supporting the notion the empowerment is multidimensional (32). Empowerment (25) had four dimensions: meaning (26, 44, 45), competence (46, 47), self-determination (1, 25, 48, 49, 50, 51), and impact (25, 52, 53). Each dimension contributed to the overall construct of psychological empowerment or perceived empowerment. This construct of empowerment has been used and validated in further studies (26, 31, 54, 55, 56). Research on psychological empowerment at the individual level has shown that the four dimensions, although related, are still distinct components of empowerment (54). The four dimensions of empowerment are considered to be related because they are likely to be mutually reinforcing (25, 26).

Antecedents of Empowerment

MODEL AND HYPOTHESISES
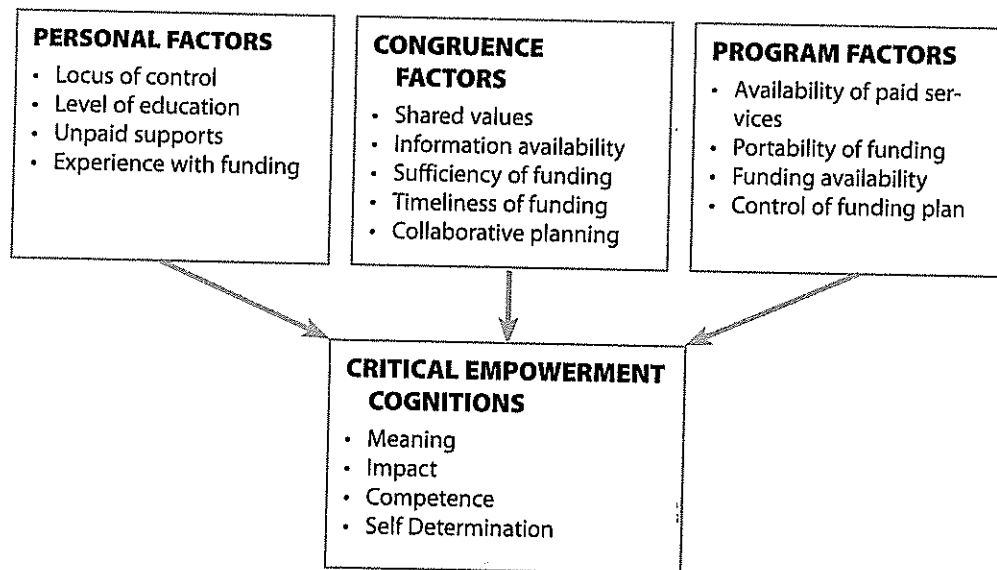
Although in the disability sector there is an emergence of a motivational and psychological perspective to empowerment, it would still appear that a dominant view is based on a relational and structural understanding of the concept. This dominant conceptualisation has the potential to support a belief that control of resources though individualised funding approaches will be strongly associated with empowerment. Such a view makes assumptions that people who are still strongly associated with the predominant service paradigm via the agency model will have low levels of empowerment because they do not have control of resources. This study provided an opportunity to explore the difference in empowerment levels between those people who receive Direct Consumer Funding and those people who do not receive Direct Consumer Funding. It was therefore hypothesised:

Key decision makers for people with intellectual disabilities (parents and carers) who receive Direct Consumer Funding will be more empowered than those key decision makers of people with disabilities who do not receive Direct Consumer Funding.

tional variables that affect the feelings of empowerment. These were called 'critical empowerment cognitions'.

This study uses three groups of influences:

I. The characteristics of the individuals (parents/carers of the person with a disability). Personal characteristics of the individual are believed to influence empowerment and have been widely researched (25, 26, 31, 55,). They represent those things that are intrinsically or extrinsically linked to an individual and not directly influenced by external sources. Until recently, few studies examined the extent to which perceptions of empowerment were influenced by the characteristics of the individual context (31). Contemporary scholars agree that feelings of empowerment are affected by a variety of individual, interpersonal, positional variables including locus of control, eduction, unpaid/informal supports and experience;

II. The characteristics of the program (Direct Consumer Funding). The relationship between an organisation and consumers is seen to be important regarding empowerment outcomes and has been identified as significant for the achievement of empowerment (57). Organisations can help individuals feel more empowered by providing them with the necessary means, ability, and authority to achieve success (31, 58, 59, 60) and by delegating authority and allowing participation in decisions (61, 62). Delegation and their participation to consumers in key programmatic areas may create conditions necessary for empowerment to take place (40). Empowerment is considered, by a range of writers, to be how much people can actually influence service providers and policy makers in key program areas (19, 63, 64, 65, 66); and,

III. Introduces a new set of influences called congruence characteristics where the alignment of organisational and consumer perceptions are con-

Figure 1: **RESEARCH MODEL**

PERSONAL FACTORS	**CONGRUENCE FACTORS**	**PROGRAM FACTORS**
• Locus of control • Level of education • Unpaid supports • Experience with funding	• Shared values • Information availability • Sufficiency of funding • Timeliness of funding • Collaborative planning	• Availability of paid services • Portability of funding • Funding availability • Control of funding plan

CRITICAL EMPOWERMENT COGNITIONS
- Meaning
- Impact
- Competence
- Self Determination

The dominant view of empowerment (25) forms the foundations of the research model found in Figure 1. The model is drawn from research offering one of the few diagrammatic models representing the predictors of empowerment in terms of personal and environmental factors (31). It was identified that the model could research the variety of individual, interpersonal and posi-

sidered. The addition of congruence provides a new aspect to the model (31) who only identify personal antecedents and environmental (program) antecedents. More recently, research has begun exploring the broader notion of congruence between the characteristics of the individual and the characteristics of the organisation (67) which can be viewed as the compatibility between people and organisations (68). In the context of Direct Consumer Funding, the literature supports the inclusion of five antecedents/predictors of empowerment which include: Shared values between the parents/carers of people with disabilities and the Disability, Information (41, 69), sufficiency of funding (70), timeliness of funding (69, 71, 72), and collaborative planning (73, 74, 75).

It was therefore hypothesised:

Key decision makers for people with intellectual disabilities who demonstrate characteristics from the individual, congruency and program influence areas will be more empowered than those who do not demonstrate these characteristics.

RESEARCH METHODOLOGY

Respondents for this study (parents/carers of people with intellectual disabilities) were selected from the databases of the Disability Services Commission of Western Australia. The complete population of people in receipt of Direct Funding was used (n = 508). A random sample of primary carers who were not in receipt of funding (n = 420) was also used for comparative data. Excellent rates of data returned were achieved (with funding = 225, without funding = 199).

The study used an adapted 12 item tool (25, 31, 32) to measure empowerment levels of those people in receipt of direct funding (Table 1). The measure includes the four dimensions of empowerment – meaning, competence, self determination and impact. The scale was chosen as it is a reliable a multidimensional measure of psychological empowerment.

The Psychological Empowerment Scale (51) was adapted and used in the study to compare empowerment levels between people with funding and those people without funding (Table 2). Codes for both scales ranges from 1 = strongly disagree to 7 = strongly agree.

Table 1: Critical Empowerment Cognitions (Direct Funding)

1. The work I do is very important to me	1. Managing my own funding is very important to me
2. The job activities are personally meaningful to me	2. Managing my own funding is personally meaningful to me
3. The work I do is meaningful to me	3. Managing my own funding is meaningful to me
4. I have significant autonomy in determining how I do my job	4. I have freedom in how I use my funding
5. I can decide on my own how to go about doing my work	5. I can decide on how to go about using my funding
6. I have considerable opportunity for independence and freedom in how I do my job	6. I have a lot of say in how I use my funding
7. My impact on what happens in my department is large	7. I have an impact on how I use my funding
8. I have a great deal of control over what happens in my department	8. I have a great deal of control over how my funding is used
9. I have significant influence over what happens in my department	9. I have significant influence on what happens with my funding
10. I have mastered the skills necessary for my job	10. I have learnt the necessary skills to manage my own funding
11. I am confident about the ability to do my job	11. I am confident about my abilities to manage my own funding
12. I am self-assured about my capabilities to perform my work activities	12. I am self-assured about my abilities to manage my own funding

Antecedents of Empowerment

Table 2: Psychological Empowerment Scale (PES)

1. I think I make good choices for the person with a disability that I care for

2. I believe I have the power to make positive changes for the person I care for.

3. I feel I make good decisions about the needs of the person I care for.

4. I think my input has an important influence on how decisions are made about providing services to the person I care for.

5. I see myself as someone who usually achieves the goals that I set for myself.

6. I think I make good decisions about the well being of the person that I care for.

7. I believe that organisational skills are a strength of mine.

8. When I have to get something done, I get right to work on it.

The two groups (people with and without funding) were similar in demographic characteristics. The majority of respondents to the research questionnaire (primary care givers) are the mothers of the person with a disability for both those people who receive Direct Consumer Funding (78%) and those people who do not receive Direct Consumer Funding (82%). The fathers of people with a disability provide only 11% (those with funding) and 9% (those without funding) of the primary carer role. Siblings, friends, and other relatives fulfil other primary caring roles. For those people with funding, 58% lived in the metropolitan area of Perth and 41% lived in rural and remote Western Australia. For those people without funding 62% lived in the Perth metropolitan area and 27% lived in rural and remote Western Australia.

RESULTS

The results show that there is a significant difference between people with funding and those without funding in the areas of level of eduction (t = 3.250, p = .0007), and the use of unpaid supports (t = 3.640, p = .0002). There is a tendency for both samples to be internally focussed. Locus of control did not vary significantly between those people with funding (M = 4.603, SD = 1.156) and those who did not have funding (M = 4.692, SD = 1.004). A t test indicates that there is no significant difference between the two sample groups (t = 1.065, p = 0.8560).

Both the parents/carers who receive Direct Funding and those parent/carers who do not receive funding are very empowered (funding - M = 6.284, SD = 0.662, no funding - M = 6.183, SD = 0.665). Hypothesis 1 predicted that

parents and carers who received Direct Funding would be more empowered than those parents who did not receive Direct Funding. A t test was used which indicated that there was no significant difference between the two study populations (t = 0.982, p = .3270). Hypothesis 1 is therefore not supported.

The 13 variables were tested using a multiple regression because they all were hypothesised to be predictors of critical empowerment cognitions. The results show varying degrees of support for the 13 variables (Table 3). The model predicts 38.4% of the variance (R2 adj = .384). The level of significance was set at 0.5 to reject the null hypothesis. Only four of the 13 items were significant predictors of empowerment within the Direct Funding model which included collaborative planning, availability of paid supports, funding availability and control of the funding plan. The research also shows that locus of control is a high predictor of empowerment amongst those people with and without funding.

DISCUSSION

This study has provided findings that contribute toward the ongoing development and understanding about why current contemporary practices within disability services are empowering for consumers of services. Using an empirical model this study has identified what are the significant influences on empowerment within the Direct Funding model. Research, such as this study, is very important as most research on empowerment in the area of disability has been non-empirical and focused on the outcomes of the concept rather than the antecedents.

The research has addressed two questions. The first question asked if Direct Funding empowered the parents and carers of people with intellectual disabilities, more than those who used traditional funding service models. This study was unable to conclusively answer this question as the empowerment levels of people with and without funding were found to be the same and as equally high as each other. It is very likely that the reason for the similar profiles in empowerment across people with and without funding relates to the type and nature of supports that are provided to all the families of people with disabilities. A primary support service accessed by all families in this study is Local Area Coordination. It would appear that the influence of a contemporary service delivery framework, such as Local Area Coordination has the capacity to facilitate the empowerment of all parents and carers regardless of their support needs.

The second research question explored what were the individual predictors associated with empowerment within the Direct Consumer Funding model. Four significant predictors of empowerment were identified. Feelings of empowerment amongst the parents and carers of people

Table3: Analysis of Multiple Regression Co-efficients: Critical Empowerment Cognitions (people with funding)

Independent Variable	Standardised Beta	T value	Sig.
Personal Factors			
Locus of Control	.107	1.923	.056
Level of Education	.035	.652	.515
Unpaid Support	-.048	-.890	.374
Experience with Funding	.038	.709	.479
Program Factors			
Availability of Paid Supports	.024	.391	.696
Portability of Funding	.082	1.382	.168
Funding Availability	-.173	-2.795	.006
Control of Funding Plan	.414	5.256	.000
Congruence Factors			
Values Congruence	.041	.636	.525
Information Availability	-.058	-.786	.433
Sufficiency of Funding	.115	1.854	.065
Timeliness of Funding	-.009	-.154	.878
Collaborative Planning	.228	3.264	.001

Count = 225
R2 = 0.419
Adjusted R2 = 0.384
F = 11.945 p < 0. 0001

with intellectual disabilities who have funding are more likely to manifest in environments where they believe they are in control of their funding, engage in collaborative planning with the funding organisation, can access services that meet their needs, and believe that if they need required additional funding that it would be available. The emergence of the congruence between organisations and their consumers is an important contribution to the understanding of empowerment. Given that this is not identified in previous research, the findings provide additional insight into how organisations can work to facilitate empowerment amongst its consumers through practices that reflect collaborative approaches.

Empowerment is heavily influenced by the perceptions of parents and carers that they can self determine and control the key issues in their lives. The control of resources, through individualised funding, represents one way that families and people with disabilities can exercise self-determination and control. While these are the directions that people are demanding in service delivery (76, 77) it is apparent that organisations simply providing control of resources is not necessarily enough to ensure people have perceptions of feeling empowered. As this study has indicated, direct funding approaches should be part of a range of strategies including responsive and flexible assistance, personal supports and positive planning processes (78) as is provided by Local Area Coordination.

The complexity of individualised funding should not be underestimated, and although it clearly brings benefits to many people with disabilities and their families, it should be implemented incrementally and cautiously (79, 80, 81). It is realistic to believe that individualised funding approaches such as Direct Funding will continue to grow as a contemporary strategy to support people with disabilities and their families. The challenge that exists for service planners and providers is how such service approaches and current models are further developed and implemented to ensure they facilitate the empowerment of parents and carers of people with disabilities.

Empowerment is a concept loaded with meanings and associations and is likely to remain so, unless organisations claiming to engage in empowerment practices for its consumers, develop a fuller understanding about the actual influences of those practices on empowerment. There is a scarcity of useful paradigms for examining the factors that influence empowerment of people with disabilities and their families (12, 29, 82) and the empirical study of psychological empowerment within area of disability is still in its infancy. Future studies in the area of disability should consider using the predominant view of psychological empowerment which is used in this study (25, 26, 43). The understanding of psychological empowerment would also appear to be inextricably linked to the understanding of its antecedents within specific environmental contexts and not about the concept being the primary objective of research (36, 37, 38). It is therefore essential that future research on the empowerment of people with disabilities shifts from the predominant focus on the concept. Emphasis should be placed on understanding what actually influences empowerment.

Due to space considerations, references have not been included, but a reference list is available from the author at   Angus.buchanan@dsc.wa.gov.au

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