Self-Determination: Adults with Intellectual Disability and the Support of Family

Presented by

Bernadette Curryer (PhD Candidate)

Supervisors

Roger J Stancliffe, Angela Dew, Michele Wiese

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THE UNIVERSITY OF
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Centre for
Disability
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and Policy
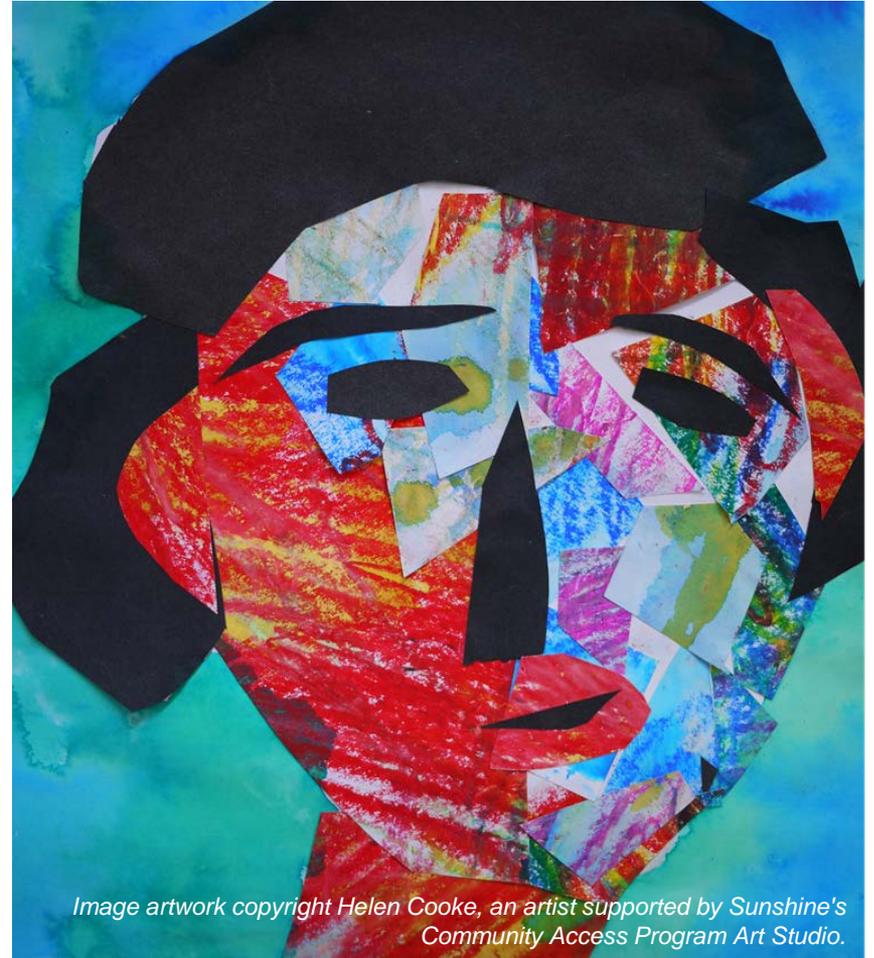
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"I don't know, I will have to ask Mum."
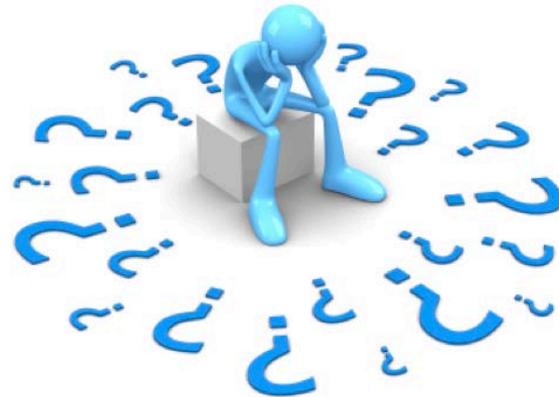
Australian Context

UN Convention on the Rights of People with a Disability

and

National Disability Insurance Scheme (NDIS)

Increased choice and control

for people with disabilities

and their families

Understanding Self-determination

Functional Theory of Self-determination

"acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 2003, p.177).

Understanding Self-determination

Tripartite Theory of Self-determination

"individuals exercising the degree of control they desire over those areas of life they consider important" (Abery & Stancliffe, 2003, p.44)

Importance of family from perspective of adults with intellectual disability

- a sense of place within their family is important (Ward et al., 2003)

- family remains the primary source of care and support (Widmer et al., 2008)

- family relationships makes them happy (Haigh et al., 2013)

Importance of family from perspective of parents

- family have in-depth knowledge and understanding of the person (Hillman et al., 2012)

- family actively guides and enables the decision-making of the individual
  (Saaltink et al., 2012)

- parent as advocates (Dyke et al., 2013)

- care is family business (Knox & Bigby, 2007)

- siblings are important (Jokinen & Brown, 2005)

Barriers to self-determination from perspective of adults with intellectual disability

- overprotective parents (Haigh, 2013; Jahoda & Markova, 2004; Shogren & Broussard, 2011)

- need to constantly prove ability (Jahoda & Markova, 2004)

- support systems not responsive to individual needs (Shogren & Broussard, 2011)

Barriers to self-determination from perspective of parents

- the individual's vulnerability, limited capacity, skill level or understanding of consequences (Mitchell, 2012; Murphy et al., 2011; Power, 2008; Saaltink et al., 2012; van Hooren et al., 2005)

- nature of choices – level of complexity and risk (Mitchell, 2012)

- family is responsible and knows best (Bianco et al., 2009; Dyke et al., 2013; Foley, 2013; Knox & Bigby, 2007; Mitchell, 2012; Saaltink et al., 2012)

Outcomes of barriers

Adults with intellectual disability may

- have little involvement in decision-making (Dyke et al., 2013; Knox & Bigby, 2007)

- be actively persuaded to make decisions based on family values (Saaltink et al., 2012)

Parents may take on

- the role of 'unauthorised decision-makers' (Foley, 2013)

- over-ruling the choices of their adult children (Pilnick et al., 2011)

How can balance be achieved?

Rights
of individuals with intellectual disabilities

Concerns
of parents and family members

Self-determination?

Research Methodology

Qualitative Research

Interpretative Phenomenological Analysis (IPA) approach

— to understand the lived experience of adults with intellectual disability

— to make sense of the way the participants make sense of their experiences

Participants

Name (alias)	Age	Gender		Living Situation
		Male	Female	
Cameron	21	x		Family home
Stacey	29		x	Family home
Helen	32		x	Family home
Stewart	34	x		Family home
Thomas	36	x		Lives by self (rented unit)
Tara	44		x	Lives in unit with a flat mate - run by disability service
Sam	44	x		Lives by self (rented unit)
Rosa	48		x	Lives by self (rented unit)

Research Analysis

Audio-recorded

→ transcribed

→ exploratory comments and notes

→ emerging themes identified

1. Strong connection to family

Life-long tie to family

Family – a place of care, inclusion and equality

Reciprocal relationship

Cameron :
I enjoy staying at home with my family. As the saying goes – 'family first'. Like my brother has a tattoo of that. So I agree with that so much. Like your family always has to come first.

Helen :
I really enjoy my family because family is important to me, that's what I see in life … they always are watching out for us and including us in everything they do.

Stewart :
What is so important about your family? **Um, [pause] they helps a lot.**
Do you think you help them? **Yes , um, doing the housework for them.**

Tara :
Oh yeah and I stuck up for my m couple of times. We have our fig but if anybody goes against her I'll just… clobber them. (laughs)

2. Family as a source of support

Support received

Helen :
I think my parents did a lot of caring and they supported me and everything and they still are supporting me and …I have extended family that can look after me…when mum and dad aren't around.

Negotiating the right support

Sam :
So how did you organise things so that your mum would take that over? [assist with financial management] **Nagged her…I nagged her big time … she knew I would nag her all the time.**

Challenges

Stacey :
Their response is like 'you've got to learn to... to like be with your own friends' or 'you gotta just get along on your own' because they say somewhere down the line …they will no longer be around, and then its hard like when you haven't got family.

3. Developing self-determination

Giving things a try

Cameron :
My mum helps me with a lot of things, but mostly I try and do stuff by myself like if you don't do it yourself you won't learn...let me do it myself and then if I need help I will ask you like I always do.

Life-stage changes

Stacey :
As I grew older then I started to feel like now I can do things I couldn't do before.

Feeling good about myself

Helen :
I think it *[speaking for herself]* **has helped me in both my family and the community...because they can see that I can speak up for myself, I don't always have to have someone talking on my behalf, so I think it is much better.**

4. I am in control of my life, however…

In control

Cameron :
When asked about what he felt in control of -
Things what I do, like I go out with my
friends

Limits to control

Thomas :
Have you planned the wedding? **Well, not yet … I have to wait on her parents, when they say it's gonna go ahead, when it's all going to happen.**

Tara :
I don't think I would pick someone that they wouldn't improve *[sic]* **of.**
What if they didn't approve of him? **Well, then I would have to compromise.**

Helen :
Instead of my mum and dad controlling my life I can control my own now, but I think…when it comes to having too much control then you become to have a big head (laughs) …you think that you …can control everything.

5. Challenges in family relationships

Relationship breakdown

Rosa :
I've got a broken family

**Sam :**
Who would help you if your mum couldn't help you anymore (with finances)?
Mmmm...not me father. He will ...wipe me clean.

Conflict

Thomas :
I love him *[father]* **very much but th... bad, some things…but I just ignore... he does that… because I know he's... temp...**

Negative emotions as a result of fa...

Rosa :
I only have contact with *[brother],* **after what mum and** *[aunt]* **wanted me to do to granny, they are very unpopular with the relations…I don't want to be unpopular with the relations because … I live around them so I expect to get on nicely.**

Stacey :
When they say we want you to move into your own home I feel like they're trying to push me away, they're not wanting me to be there, they're not loving me … it makes me feel really sad.

Summary of results
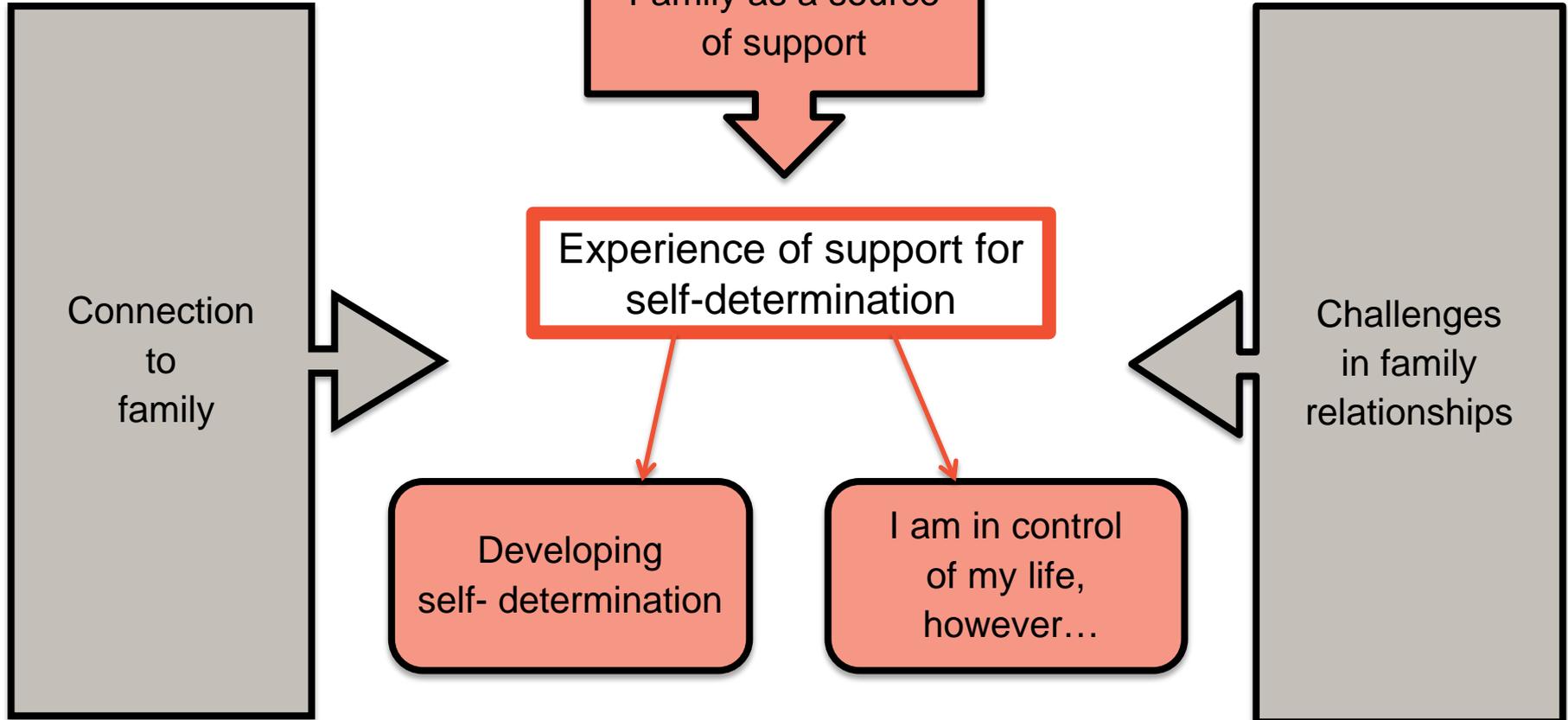
Complexity of family relationships

Tripartite Theory of Self-determination

A degree of control may be 'given away'

- importance to the individual

- expertise and level of skills required

- desire for collaborative decision-making

Back to the Research Inspiration

"I don't know, I will have to ask Mum."

References

– Abery, B. H., & Stancliffe, R. J. (2003). A tripartite ecological theory of self-determination. In M. Wehmeyer, B.H. Abery, D.E. Mithaug & R. J. Stancliffe (Eds.), *Theory in self-determination:Foundations for educational practice* (pp. 43-78). New York: Charles C. Thomas.

– Bianco, M., Garrison-Wade, D. F., Tobin, R., & Lehmann, J. P. (2009). Parents' perceptions of postschool years for young adults with developmental disabilities. *Intellectual and Developmental Disabilities, 47*(3), 186-196. doi: 10.1352/1934-9556-47.3.186

– Dyke, P., Bourke, J., Llewellyn, G., & Leonard, H. (2013). The experiences of mothers of young adults with an intellectual disability transitioning from secondary school to adult life. *Journal of Intellectual & Developmental Disability, 38*(2), 149-162. doi: 10.3109/13668250.2013.789099

– Foley, S. (2013). Reluctant 'jailors' speak out: Parents of adults with Down syndrome living in the parental home on how they negotiate the tension between empowering and protecting their intellectually disabled sons and daughters. *British Journal of Learning Disabilities, 41*(4), 304-311. doi: 10.1111/j.1468-3156.2012.00758.x

– Haigh, A., Lee, D., Shaw, C., Hawthorne, M., Chamberlain, S., Newman, D. W., . . . Beail, N. (2013). What things make people with a learning disability happy and satisfied with their lives: An inclusive research project. *Journal of Applied Research in Intellectual Disabilities, 26*(1), 26-33. doi: http://dx.doi.org/10.1111/jar.12012

– Hillman, A., Donelly, M., Whitaker, L., Dew, A., Stancliffe, R. J., Knox, M., . . . Parmenter, T. R. (2012). Experiencing rights within positive, person-centred support networks of people with intellectual disability in Australia. *Journal of Intellectual Disability Research, 56(11), 1065-1075. doi: 10.1111/j.1365-2788.2012.01647.x*

– JJokinen, N. S., & Brown, R. I. (2005). Family quality of life from the perspective of older parents. *Journal of Intellectual Disability Research, 49, 789-793. doi: 10.1111/j.1365-2788.2005.00753.x*

– Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research, 48*(8), 719-729.

– Knox, M., & Bigby, C. (2007). Moving towards midlife care as negotiated family business: Accounts of people with intellectual disabilities and their families "just getting along with their lives together". *International Journal of Disability, Development and Education, 54*(3), 287-304. doi: http://dx.doi.org/10.1080/10349120701488749

– Mitchell, W. (2012). Parents' accounts: Factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making. *Children and Youth Services Review, 34*(8), 1560-1569. doi: 10.1016/j.childyouth.2012.04.009

– Murphy, E., Clegg, J., & Almack, K. (2011). Constructing adulthood in discussions about the futures of young people with moderate-profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 24*(1), 61-73. doi: 10.1111/j.1468-3148.2010.00565.x

– Pilnick, A., Clegg, J., Murphy, E., & Almack, K. (2011). 'Just being selfish for my own sake...': Balancing the views of young adults with intellectual disabilities and their carers in transition planning. *Sociological Review, 59*(2), 303-323. doi: 10.1111/j.1467-954X.2011.02006.x

– Power, A. (2008). Caring for independent lives: Geographies of caring for young adults with intellectual disabilities. *Social Science & Medicine, 67*(5), 834-843.

– Saaltink, R., MacKinnon, G., Owen, F., & Tardif-Williams, C. (2012). Protection, participation and protection through participation: Young people with intellectual disabilities and decision making in the family context. *Journal of Intellectual Disability Research, 56*(11), 1076-1086. doi: 10.1111/j.1365-2788.2012.01649.x

– Shogren, K. A., & Broussard, R. (2011). Exploring the perceptions of self-determination of individuals with intellectual disability. *Intellectual & Developmental Disabilities, 49*(2), 86-102. doi: http://dx.doi.org/10.1352/1934-9556-49.2.86

– van Hooren, R. H., Widdershoven, G. A., van der Bruggen, H., van den Borne, H. W., & Curfs, L. M. (2005). Values in the care for young persons with Prader-Willi syndrome: Creating a meaningful life together. *Child: Care, Health & Development, 31*(3), 309-319.

– Ward, L., Heslop, P., Mallett, R., & Simons, K. (2003). Transition: the experiences of young people with learning disabilities and their families in England. *Tizard Learning Disability Review, 8(4), 19-28*.

– Wehmeyer, M. (2003). A functional theory of self-determination: Definition and categorization. In M. Wehmeyer, B.H. Abery, D.E. Mithaug & R. J. Stancliffe (Eds.), *Theory in self-determination: Foundations for educational practice* (pp. 174-181). New York: Charles C. Thomas

– Widmer, E. D., Kempf-Constantin, N., Robert-Tissot, C., Lanzi, F., & Carminati, G. G. (2008). How central and connected am I in my family? Family-based social capital of individuals with intellectual disability. *Research in Developmental Disabilities, 29(2), 176-187.*

Email : bcur3628@uni.sydney.edu.au