



Understanding Families' Experiences of Self-Direction: Learnings from Queensland Families

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Context

- Australia – National Disability Insurance Scheme from 2013
 - » Individualised funding – self direction
 - » Choice & control
- Queensland last state to implement – NDIS roll out from 2016
- BUT Queensland had various “versions” of self direction, individualised funding
 - » Community agencies – innovative, flexible arrangements
 - » Family driven, long standing in many cases
 - Arrangements for 10 – 15 years
 - » State department ***Your Life Your Choice*** – ramped up in preparation for NDIS



Research agenda – learning together

- What could we learn from the various stages and current “versions” of self-direction in Queensland?
- How could this inform policy and practice?

Griffith team

Margaret Ward
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Michelle Crozier
Pat Dorsett
Donna McDonald
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Partners

Large traditional services
Small family governed
agencies
State government Dept



Study 1 Self Direction and people with an intellectual disability

(Crozier & Muenchberger)

Aims:

Identify perspectives of people with an intellectual disability and their families to explore

- (1) current experiences with services
- (2) aspirations to self-direct
- (3) core skills required to self-direct

To develop an appropriate skills package or tool/s to respond to those findings.

To explore staff understandings of current service practices and concepts in terms of self-direction and service coordination for people with a disability and their families.

Methods – focus groups, survey



Study 1 Self Direction and people with an intellectual disability

(Crozier & Muenchberger)

- **Families:** happy to hand most if not all aspects of service over if they had input into the decision making and planning and had the capacity to change providers in the future. BUT greater choice and involvement was a clear aspiration.
- **People** with an intellectual disability expressed a very low level of interest and motivation to engage about their service experiences so no real interest expressed in taking a more active role in the coordination of them.



Study 1 Self Direction and people with an intellectual disability (Crozier & Muenchberger)

- **Staff** Identified barriers to increased involvement for families and clients

Barriers

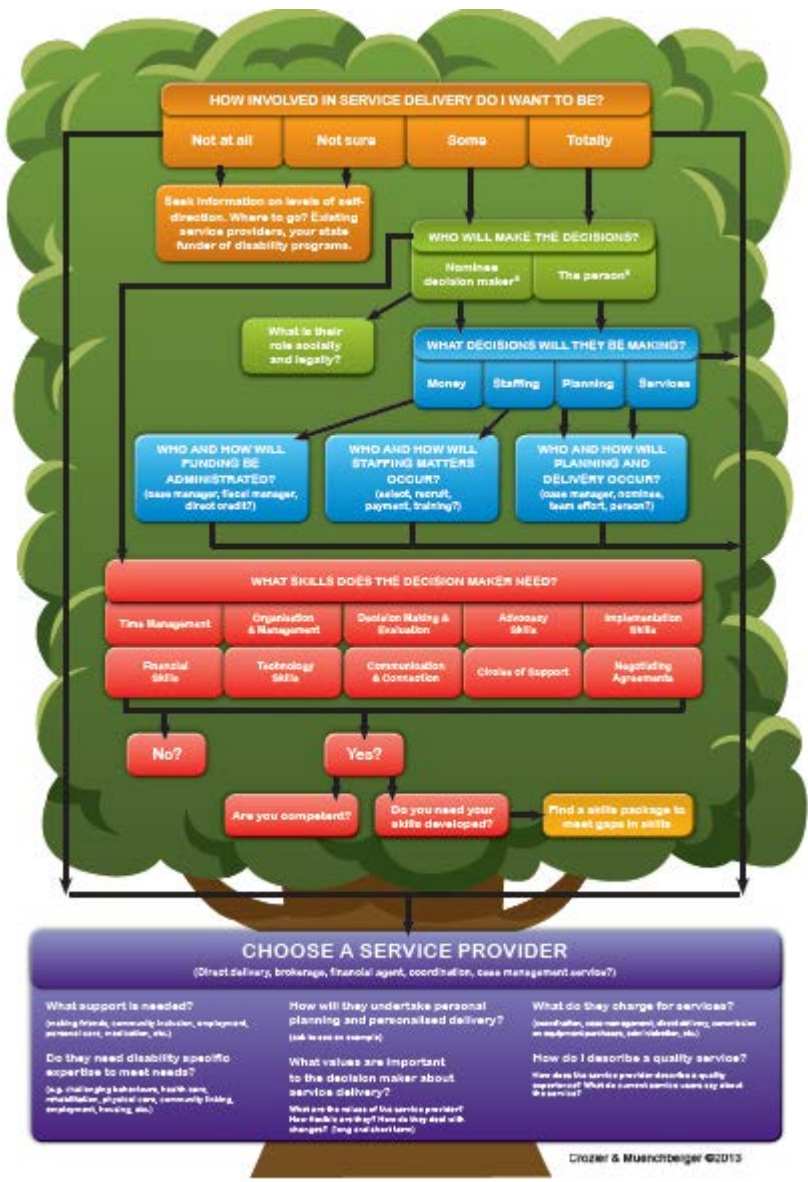
- *service culture focused on deficits*
- *capacities of the staff in terms of time, resources and skills*
- *personal attributes of people with disabilities and families (i.e., personal lack of interest and desire, not understanding what is being asked, limited knowledge of entitlements and levels of involvement, lack of confidence and assertiveness,*
- *geographic distances of families, limited family resources such as money, time, and knowledge*
- *personal impacts of ill health and aging*
- *prior negative experiences with services*
- *power imbalances within services;*
- *being presented with limited options*
- *lack of choices.*



- 23% staff noted organisational incongruence in aspiring to see direction practices but incurring (unspecified) difficulty with proper implementation
- Families did not really need skills but tools and support around decision making
- People with intellectual disabilities needed skills in self-determination particularly in terms of how services work, who to go to for support and assistance and being empowered to do so.

Outcomes

- Decision tree tool developed and implemented
- Adopted by State government
- Research partnership with the organisation - funded research fellow (McDonald) new project



RESOURCES AND DEFINITIONS

WHERE TO GO FOR INFORMATION ON SELF-DIRECTION?

- Endeavour Foundation: www.endeavour.com.au
- Department of Communities & Child Safety: www.communities.qld.gov.au/disability/hey-projects/your-life-your-choice
- National Disability Insurance Scheme: www.ndis.gov.au

INFORMATION ON LEGAL ROLE AND RESPONSIBILITIES (QLD)

- Endeavour Foundation: www.endeavour.com.au
- Department of Communities & Child Safety: www.communities.qld.gov.au/disability/hey-projects/your-life-your-choice
- Adult Guardian: www.justice.qld.gov.au/justice-services/guardianship/adult-guardian
- Guardianship for adults: www.qcat.qld.gov.au/matter-type/guardianship-for-adults-matters
- Guardianship and Administration toolkit: www.qcat.qld.gov.au/resources/fc/ba/ba/daa_-_Guardianship_and_Administration_toolkit.htm
- National Disability Insurance Scheme: www.ndis.gov.au

DEFINITIONS

- Case Manager: paid person who coordinates a range of services and activities
- Fiscal Manager: paid person responsible for financial coordination
- Nominee Decision maker: a person who is nominated to make decisions on behalf of another person
- Person: the individual in receipt of funding and/or services
- Direct Credit: money given directly to decision maker to administer

WHERE CAN I FIND A SKILLS PACKAGE AND PLANNING TOOLS?

- National Disability Insurance Scheme: www.ndis.gov.au
- National Disability Services: www.ndis.org.au
- Endeavour Foundation: www.endeavour.com.au
- Department of Communities & Child Safety: www.communities.qld.gov.au/disability
- ADRCAS Advocacy: <http://support-my-decision.org.au/>

WHERE TO GO FOR HELP?

- Endeavour Foundation: www.endeavour.com.au
- Department of Communities & Child Safety: www.communities.qld.gov.au/disability/hey-projects/your-life-your-choice
- National Disability Insurance Scheme: www.ndis.gov.au



Study 2 Users' experiences of self-direction – voices of experience? (Dorsett Chenoweth Crozier & Rees)

Aim: To document the experiences of people who have been self-directing **prior** to Your Life Your Choice in Queensland, as well articulate the missing evidence on self-direction (people's experiences) within the broader national disability insurance scheme

Methodology: in-depth interviews with family members (n=13)



Study 2 Users' experiences of self-direction – voices of experience? (Dorsett Chenoweth Crozier & Rees)

There are complexities with self-directing but prior wounding experiences of life and service systems are somewhat addressed through a self-directing paradigm

THEME 1: A good life an ordinary life more achievable when self-directing

THEME 2: A lifetime of wounding and service provider failures

THEME 3: Creating a new more personalised culture under Self-direction

THEME 4: Systems and self-direction - different “burdens” but worth it



Study 2 Users' experiences of self-direction – voices of experience? (Dorsett Chenoweth Crozier & Rees)

Outcomes

- Further research into how long term self directing parents are coping and plans for the future
- PhD student enrolled



Study 3 Your Life Your Choice – Quality Health Check (Crozier & Muenchberger)

- **Aim 1:** Develop a snap shot understanding of Your Life Your Choice on participants who have moved from a traditional models of service delivery (or are new to services) to Your Life Your Choice through **two quarters** of payments.
- **Aim 2:** To gain an understanding of the experiences of Host Providers

Methodology

- Participant Interviews (random sample n=63; responses 14 -22%)
- Host providers - Focus groups (15) Interviews (4)
- Survey (informed by focus groups and interviews)



Key themes

- Journey to Your Life Your Choice
- Experiences
- The practicalities - operational



Families' experiences of self direction

- Wide range of experiences in self direction in Queensland families and people with disability
- Many families were new to self direction under the scheme
- No knowledge of self-direction at the start of these studies in the majority of situations BUT
- This increased as YLYC was stepped up and the roll out was accelerated (now approx 2000+ in the scheme) AND other workshops, information sessions made available)
- The pace and scale of rollout often limited choices
- Variable capacity / experience in host providers

Some overall reflections

- Many factors at play in supporting or inhibiting family participation in self-direction and direct payment schemes
- Rolling out a scheme nationally across different state jurisdictions very complex
- Experienced families could tell us a great deal about how families can be prepared for the NDIS
- Some families have been managing funding for their son or daughter for up to 15 years
- BUT we noted some concerns in parents about succession and sustainability into the future
- Particular issues – reaching diversity and minority groups CALD, First peoples, very remote families etc

Some overall reflections

- Readiness of
 - » Person with a disability
 - » Families
 - » Current service sectors (disability and mainstream; NFP and for profit)
 - » Community and business sectors
- Self direction involves having a vision, planning, practical and logistical skills / supports
- Readiness projects need
 - » Start where person/families are – too often “vision” for a good life assumed/imposed – “take a step back”
 - » To involve people with disabilities and families from the start
 - » Experienced families can assist and support others new to SD
- No real attention as yet to community / mainstream readiness

Your Life Your Choice

Spectrum of self-directed support

A person can move across this spectrum depending on what they are comfortable doing, their previous experiences and current situation.

The person accepts full responsibility for planning, budgeting and organising their support. As such, funding is advanced to the person's bank account.

The person accepts most of the responsibilities for planning and organising their support. Additional support is purchased. As such, funding may be advanced to the person's bank account, reimbursed to the person or held by the service provider.

The person accepts some of the responsibilities for planning, budgeting and organising their support. Additional support is purchased.





Crozier, M., Muenchberger, H., Colley, J., & Ehrlich, C. (2013). 'The disability self-direction movement: Considering the benefits and challenges for an Australian response'. *Australian Journal of Social Issues*, 48 (4), 455-471

Crozier, M., & Muenchberger, H. (2013). 'It's your problem, not mine': does competence have anything to do with desire and aspiration to self-direct? *Australian Health Review*, 37(5), 621-623.

Dorsett, P. Chenoweth, L. Crozier, M. & Reese, K. (under review) Users' experiences of self-direction: responding to missing voices.



Thank you

Insert Presenter's name
Presenter's title
Research Program / Theme
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