

Self-determination of adults with intellectual disability within family relationships - a case study

Presented by

Bernadette Curryer (PhD Candidate)

Co-authors

Roger J Stancliffe, Angela Dew, Michele Wiese



THE UNIVERSITY OF
SYDNEY

Centre for
Disability
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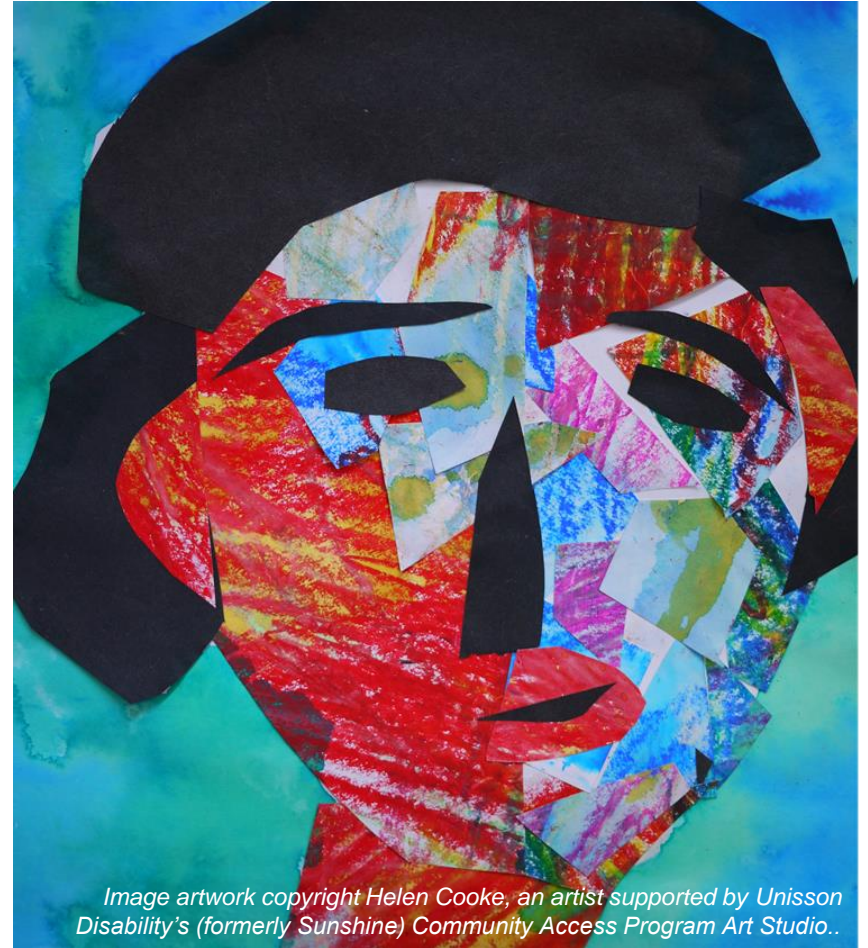


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Context

“Increased choice
and control for
people with disability
and their families”

NDIS (2013)

“Respect for inherent
dignity, individual autonomy
including the freedom to
make one’s own choices”

UNCRPD General Principle
UN (2006)

“Nothing about
us without us “

Self Advocacy
movement

Key components of self-determination

“acting as the **primary causal agent** in one’s life...free from undue external influence or interference” (Wehmeyer, 2003, p.177).

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

Previous findings

**Importance of
family**

**Promotion and
limitations to
choice and control**

**Values and beliefs
direct the support
given**

**Extended family
impact**

Curryer, Stancliffe, Dew, & Wiese, (2018a , 2018b)

Research Focus

Phase 3 : To understand the relationship between a person with an intellectual disability and their key family support person, and the impact this has on the experience of giving or receiving support for choice and control

Research Methodology

Qualitative Research using an Interpretative Phenomenological Analysis (IPA) approach

to explore the lived experience

&

to 'make sense' of the way the participants 'make sense' of these experiences

Case study – Alice (mother) and Lisa (daughter)*

- Mother – Alice (early 70's)
 - Primary carer for Lisa since the breakdown of parent's marriage
- Daughter - Lisa (late 30's)
 - Lisa lives in a privately rented unit by herself
 - loves music
 - has a keen sense of humour

*pseudonyms used

Superordinate themes

Influences on relationship

```
graph TD; A[Influences on relationship] --- B[Values & beliefs]; A --- C[Extended family]
```

Values &
beliefs

Extended
family

The two of us

```
graph TD; A[The two of us] --- B[How we see Alice]; A --- C[How we see Lisa]; A --- D[How we see us]
```

How we
see Alice

How we
see Lisa

How we
see us

Influences on the relationship

Influences on relationship

Values & beliefs

Extended family

“...if we don't have expectations of what Lisa might achieve, then we should not have expectations of what our other daughter should achieve” Alice (mother)

“to strengthen Lisa's personal abilities, to give her more of a bigger outlook on the world” Alice

Being an adult – “I think it means taking responsibility for yourself, your daily care and lifestyle...and your behaviour and not being reactive.” Alice

Influences on the relationship

Influences on relationship

Values & beliefs

Extended family

“...there certainly was a devolving over time of responsibility for Lisa to me...I certainly have taken on more involvement because it's just been the two of us for a while.” Alice (mother)

“Because the decisions that Lisa and I make by the family are not seen as Lisa's decisions. I get very negative feedback about it.” Alice

“...the only way we were going to make any progress was for her to be able to speak for herself because anything I said was a waste of breath.” Alice

How we see Alice



How we see Lisa



Implications – what does it mean?

- **Complexity of family relationships**
- **Self-determination and interdependent relationships?**
- **Negotiation of choices & level of control within this relationship**
- **Effect of personal & family values and beliefs**
- **Impact of individualisation**

**Thank you -
for listening and also to
'Alice and Lisa' who so
generously shared their
story !**

Bernadette Curryer

bcur3628@uni.sydney.edu.au



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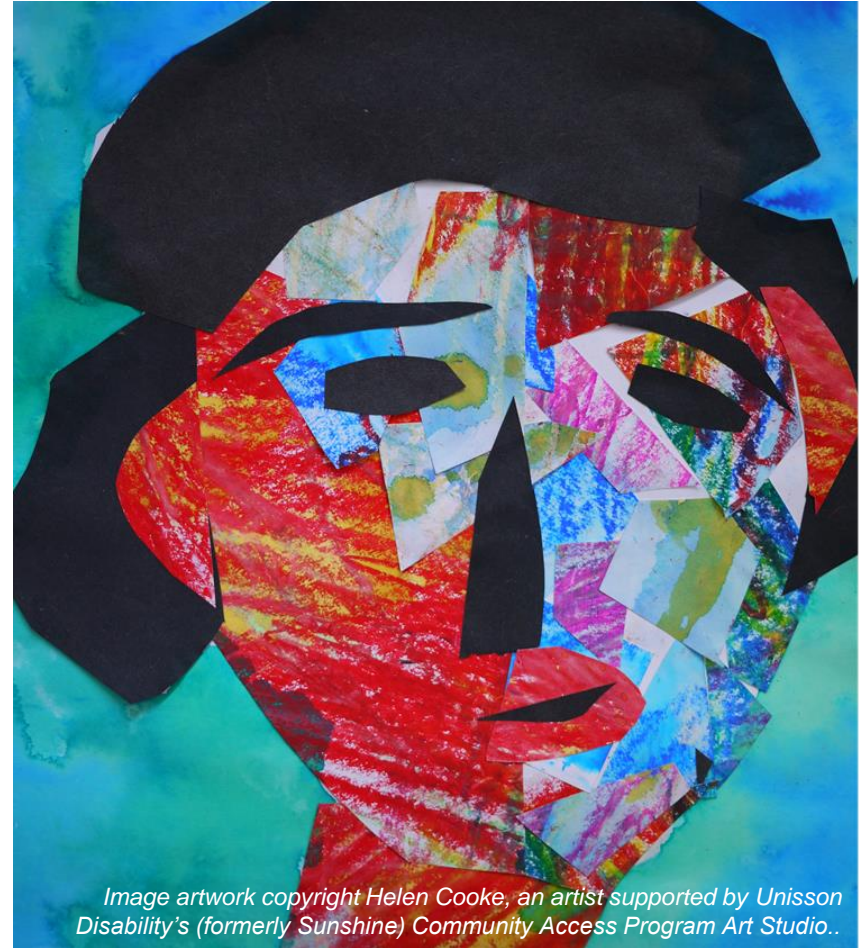


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