Navigating Ever-Changing Seas: An Emergent Theoretical Model Ageing with Intellectual Disability in the Context of ‘Family’

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Overview

- Setting the scene - Background
- Aim & Methodology
- Research Findings
- Discussion & Recommendations
- Overview:

  *Navigating Ever-Changing Seas: An Emergent Theoretical Model*  
  *(Trip, 2015)*

  *(TRIP, 2017)*
WELCOME TO HOLLAND
c1987 by Emily Perl Kingsley

(TRIP, 2017)
Background - The ‘Hidden’ Population

Individuals who continue to reside with a parent past the age of 40 years have the potential for increased vulnerability regarding service access should the caregiving relationship breakdown.

(Dodd, Guerin, Mulvany, Tyrrell & Hillery, 2008)
Informal Carers

- In New Zealand, of ALL informal carers: (Not specific to IDD)
  - 69% are aged 30-64 years
  - 12% are aged > 65 years of age
  - 63% are female (Ministry of Social Development, 2008)

- Informal carers have their own needs in regards to the impact of age and infirmity (Taggart, Truesdale-Kennedy, Ryan & McConkey, 2012)
For some older *parents caregiving is virtually a lifelong ‘career’... There is a wealth of knowledge... that needs to be made publicly available to inform policy, service development and professional practice.

*incl siblings, families AND PWIDD
AIM

To explore perspectives about ageing & future planning for people with an intellectual disability & their family
METHODOLOGY

Constructivist Grounded Theory

An interpretive approach in which the researcher ‘co-constructs’ an understanding of experiences alongside participants. (Bryant & Charmaz, 2010)

Individual, historical, cultural & social lenses informs the interaction as it occurs. (Charmaz, 2008)

- Constant Comparative Process:
  - Theoretical Sampling + Concurrent Data Collection & Analysis
- Data Saturation - Theory Building
- Underpinned by Memo Writing

(TRIP, 2017)
Photo Elicitation

“pictures elicited longer and more comprehensive interviews...
 helped subjects overcome the fatigue and repetition of conventional interviews... it [has an] ability to prod latent memory,
to stimulate and release emotional statements
about the informant’s life…”

(Collier, 1957)
Recruitment & Data Collection

- Non-probability & snowball sampling
- EOI Form - Informed Consent (Participants with ID)

_The above group was invited to bring a photo, image or object to the interview that helped them think about getting older_

- Family were nominated by above participants.
- Interviews occurred simultaneously

(TRIP, 2017)
## PARTICIPANTS (n=47)

<table>
<thead>
<tr>
<th>DEMOGRAPHIC</th>
<th>PERSON WITH ID (n=19)</th>
<th>FAMILY/WHANAU (n=28)</th>
</tr>
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<tbody>
<tr>
<td>Recruitment</td>
<td>Male (n=13) Female (n=6)</td>
<td>Male (n=7) Female (n=21)</td>
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<tr>
<td>Age Range</td>
<td>37 - 58 yrs (means 48yrs)</td>
<td>20 - 83 years old</td>
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<tr>
<td>Co-morbidities</td>
<td>0 - 4</td>
<td>0 - 6</td>
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## RESULTS

<table>
<thead>
<tr>
<th>Codes</th>
<th>Category</th>
<th>Concept</th>
<th>Emergent Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>(n=4)</td>
<td>Reciprocating relationships</td>
<td>Riding the Waves</td>
<td>Navigating Ever-Changing Seas</td>
</tr>
<tr>
<td>(n=3)</td>
<td>Emerging (in)dependence</td>
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<tr>
<td>(n=4)</td>
<td>Taking cognisance</td>
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<tr>
<td>(n=3)</td>
<td>Configuring ageing</td>
<td>Shifting Sands - Changing Tides</td>
<td></td>
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<tr>
<td>(n=6)</td>
<td>Anticipating change</td>
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<tr>
<td>(n=3)</td>
<td>Entertaining possibilities</td>
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<tr>
<td>(n=2)</td>
<td>Creating a good life</td>
<td>Uncovering Horizons</td>
<td></td>
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<tr>
<td>(n=4)</td>
<td>Mastering decisions</td>
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(TRIP, 2017)
Concept: Riding the Waves

The continuous ebb and flow of relationships which enables one to get on with life from day to day and take things as they come.

(TRIP, 2017)
Concept: Riding the Waves

“For me I’ve still got a child. I’ll always have a child who is dependent” (Mother)

“...it’s just another role. It is juggling... You become the parent - it evolves...” (Daughter & Sister)

...can't go to the bank and get my money out, she's [sister] got to go with me and sign for it as well...It’s a bit harder because sometimes she doesn't turn up... might be 2-3days before she turns up...  (Bobby, PWID)
### Concept: Shifting Sands - Changing Tides

<table>
<thead>
<tr>
<th>Code</th>
<th>Category</th>
<th>Concept</th>
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</thead>
<tbody>
<tr>
<td>Defining ageing</td>
<td>Configuring ageing</td>
<td>Concept two</td>
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<tr>
<td>Recognising altered function</td>
<td></td>
<td>Shifting Sands - Changing Tides</td>
</tr>
<tr>
<td>Dying is part of living</td>
<td>Anticipating change</td>
<td></td>
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<td>Looming responsibilities</td>
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<td>Limiting factors</td>
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<td>Feeling disillusioned</td>
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<tr>
<td>Letting go - Enabling others</td>
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<tr>
<td>Unknowing explorers</td>
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<tr>
<td>Evolving expectations</td>
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</tbody>
</table>
Concept 2: SHIFTING SANDS-CHANGING TIDES
Category - Configuring Ageing

“...but it’s [time] too jolly quick...I’d like to have a wand to slow it down but nobody can do that...” (Trevor)

“That’s me when I’m grown old... all the hair around there... It grows out” (Lucy)

(TRIP, 2017)
Concept: SHIFTING SANDS-CHANGING TIDES

Code: Recognising altered function

“...our bones become brittle... frail and brain becomes weak... [the train] got parts that works by steam and wood to make the engine go and it’s the same with our body parts working...” (Jacob)

....dog is “older than humans sleeps a lot... [and] used to run around like a mad idiot - now not so much. ” (Sam)
Concept: SHIFTING SANDS-CHANGING TIDES

Recognising altered function

“Yes I do [wish he had carried on walking but that was] a long time ago [not an option now]... When in my wheel chair... my body that way... a lean.” (Matt)
Concept: Shifting Sands - Changing Tides
Category - Anticipating change

Code: Looming Responsibilities

I’m pretty sure [daughter] would take care of him she wouldn’t put him anywhere...
(Maryellen, Mother)

Code: Limiting Factors

She’s very confident. We never leave her... you couldn’t quite trust what she’d do in a crisis...
(Evelyn, Mother)

Code: Feeling Disillusioned

I had no help from anyone. I went to the disability people they didn’t want to know me...
For almost a year I had [brother] at home... (Teresa, Sister)
**Concept: Shifting Sands - Changing Tides**  
**Category - Anticipating Change**

**Code: Letting Go - Enabling Others**

...co-ordinate with us - see what we do... sort of follow on in the lines that we’ve done... I just want a continuation of what we do... [then] we can just be friends...”

**Code: Unknowing Explorers**

_Honestly don’t know what other services are out there... [or] we don’t know what to ask for..._ (Richard, father).

**Code: Evolving Expectations**

_All I know is that ... She’ll need someone to help teach her to cook... it maybe selfish but I see that as being [service’s] job in a sense_ (Carmen, mother).
Concept: Uncovering Horizons

Whilst daunting, the concept of *Uncovering Horizons* denoted an exciting sense of moving from the present, to the unforeseeable yet inevitable future that holds potential for all.
Concept: UNCOVERING HORIZONS
Category - Entertaining Possibilities

Looking forward

“that was my life as a painter... it was a good life... I liked the job...” (Bob)

Having an identity

“a bit older [you’ll] have to go and find a flat... It was quite a shock and I felt frightened.” (Kate)

(TRIP, 2017)
Concept 3: Uncovering Horizons

Category: Creating a Good Life

Category: Mastering Decisions

Connecting with Others: “I go to Carer Support sometimes to give Stephanie a break... I quite like it. It’s different people and you get used to stuff. (Sam)

Knowing the Person: “...he can judge people and it there’s something about that person I can tell if he doesn’t want to answer a question he’ll change the subject... (Melissa, Aunt)

Facilitating Ownership: You kind of have to guide her to the decision... you’re not making the decision for her... how do you feel about it? (Deborah, Sister)

Engaging the System: “I swallow a lot of things that come through the system and think well he’s at least got a placement so shut up!”

(TRIP, 2017)
DISCUSSION

Mutual benefits, social isolation  
(Parish et al., 2004)

Health status of informal family caregivers cannot be ignored  
(Yamaki, Hsieh & Heller, 2009; Taggart et al., 2012)

Identity & meaning may be linked to role for family member  
(Williams & Robinson, 2001)

The caregiving role between two or more reciprocal parties is often intense and not usually established by choice  
(National Advisory Committee on Health & Disability, 2010)
RECOMMENDATIONS

Lifelong planning & collate information:
What would you like others to know to support you and/or your family member well?

Access to respite care can provide planned breaks, support individuals to develop new skills & may enable opportunity for all parties to seek alternative arrangements. (Gilbert et al., 2008)

Health & disability systems need to work with families to facilitate planning for compounded caregiving - and the emerging role (or not) of siblings and others considered to be family.

(TRIP, 2017)
<table>
<thead>
<tr>
<th>Domain</th>
<th>People with Intellectual Disability</th>
<th>Family/Whānau Networks of Support</th>
<th>Health &amp; Disability Systems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practice</td>
<td>Conversations about ageing in place...</td>
<td>...involving people with intellectual...</td>
<td>...disability in decision-making</td>
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<tr>
<td></td>
<td>Collation of information; life histories...</td>
<td>...update &amp; preferences (bio/psycho/soc)</td>
<td>...to enable timely planning</td>
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<tr>
<td></td>
<td>Development of advance-care plans...</td>
<td>...with each party in caregiving r/s</td>
<td>...across disability &amp; aged care sys</td>
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<tr>
<td></td>
<td>Edn: Rights &amp; responsibility, life skills</td>
<td>...health literacy &amp; facilitating choices.</td>
<td>Support &amp; enable access.</td>
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<td></td>
<td>Increase flexibility in funding...</td>
<td>...and service delivery across the...</td>
<td>...aged care and disability sectors</td>
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<td></td>
<td>Assessments which acknowledge and...</td>
<td>...respond to the needs of all parties...</td>
<td>...in the caregiving relationship</td>
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<tr>
<td></td>
<td>Information about service access and...</td>
<td>...delivery is to be provided to individuals</td>
<td>...and family across the lifespan</td>
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<tr>
<td>Research</td>
<td>Evaluate Navigating Ever-Changing Seas</td>
<td>...across age groups, residential care, SIL</td>
<td>Disability &amp; aged care</td>
</tr>
<tr>
<td></td>
<td>Develop existing formal &amp; informal</td>
<td>...networks of support.</td>
<td>Evaluation of progs implemented</td>
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<td>Explore opportunities to voice choices &amp;</td>
<td>...engage person with ID</td>
<td>...in future planning</td>
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<td></td>
<td>Engagement with photovoice &amp; photo</td>
<td>...elicitation. Decrease gatekeeping &amp;</td>
<td>... increase inclusive research</td>
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</tbody>
</table>
Navigating Ever-Changing Seas: An Emergent Theoretical Model
(© Trip, 2015)

“The map is not the territory”
(Korzybski cited by Bateson, 1973, p. 423)
Navigating Ever-Changing Seas: An Emergent Theoretical Model (© Trip, 2015)
Acknowledgements

To the participants who shared so generously of their lives, their experiences, hopes & realities, past, present and future - which uncovered the dynamics of Navigating Ever-Changing Seas

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(TRIP, 2017)
Thoughts, Comments & Questions…

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