

Exploring Complex Support Needs for People with Intellectual Disability and Their Families Across the Lifecourse

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Pushing the Boundaries**

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PAPER 1

Young people with cognitive disability and complex support needs: Service provider views on supporting transitions

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LOST IN RANSITION

Research to improve the lives
of young people with complex
support needs.

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Research
partners:




WE
LIFE WITHOUT BARRIERS
VE



Background

- Young people with Complex Support Needs (CSN) experience lots of transitions
- What are Complex Support Needs (CSN)?
- What is transition?
- Transitions are potentially harder for this group: trauma, inconsistency and less support to navigate them



Method: Experiences of Young People with Complex Support Needs

- 22 focus groups/interviews with 93 frontline workers in NSW, QLD, VIC – including 1 rural/remote site in each state
- No disability specific services
- Workers asked about their perspectives on experiences of transition for YP with CSN and what major issues were for them and YP
- Workers still talked about disability: one of 8 domains coded for
- What did they say?




Age: 18

- At 18 'magically age out of all of their services'— services, workers, doctors and systems are all 'new' (V4_CPDB)
- At 18 young people in Out of Home Care expected to live independently
- Young people with disability support before 18 have some assured funding, but those without a diagnosis transition to 'literally nothing'



Diagnosis

- Better support available for young people (YP) with CSN who have a disability diagnosis before 18
- Particularly the case for young people with complex behaviours like aggressive behaviours and absconding behaviours
- YP with CSN often don't identify as having a disability



Diagnosis/assessment for YP with CSN

- YP with CSN less likely to get a diagnosis: inconsistency in life course and engagement with generalist services (education, health), trauma, drug and alcohol misuse.
- Referrals through education and health often not followed up by families
- Restrictions around assessment in Youth Justice and Child Protection
- Expensive to gather 'the evidence' to get disability support




Problems with Diagnosis and CSN

- How does trauma intersect with disability?
- 'Disability assessments don't capture the complexities of that young person and how their disability actually affects their lives' Q8_CPHL58
- Young people 'on that cusp, on the fringe' of disability support but disability affect everything. Q8_CPHL58
- Assessments need to be thorough – IQ test not account for ASD



NDIS Literacy

- Uncertain, untrained and distrustful of NDIS
- 'NDIS literally comes with a new language'
- Workers and services need to be:
 - 'savvy about the market' of the NDIS (N1_DBED55)
 - 'know what will get funded' (Q2_CP29),
 - 'requires changing the way you think' (V4_CP19).
- You need to have the 'costings in place so you know what to ask for to get the money the person needs.' (V4_CPDB20).
- NDIS plans only include 'what we worked through before hand' (Q5_CP46)




Decoding the NDIS for YP with CSN?

- Requires a case manager to co-ordinate who knows the YP, their needs and who is NDIS literate
- Application is a 'massive process,' case managers often 'mine the records' – particularly around referrals and diagnosis
- YP with CSN 'self-representing' will not explain themselves in a way that gets funding
- YP often not involved in NDIS planning process, case managers 'just do it' because it's inaccessible



NDIS literacy and the case of respite

- "If I would've had these things, you know, before [I relinquished my daughter], I would've been able to care for her". V4_CPDB20: V4_CPDB21
- But respite is becoming an obsolete word in the NDIS – very difficult to get funded as 'respite': 'You never call it respite, it's got to be an opportunity' (L_Fieldnotes28/10/17)
- Framing of NDIS plans mean respite not costed into plans – cost shifting to other sectors like Child Protection: 'why are we paying for this?'
- Emergency Respite places closing down



Disability informed

- 'As case managers, even if referring young people to specialist disability or mental health services, still need knowledge relating to disability' Q1_HL27
- Uncertainty about which assessments to get for YP: is it trauma, mental health, intellectual disability or autism?
- Accessible materials: 'They [Youth Justice] couldn't wrap their head around the idea that he might need to learn it differently. He's not learning it; you've done it seven times.' N4_ADMHRR74



Conclusion

- Productivity Commission (2011) ambivalent about using diagnostic criteria in the NDIS – arguing funding should be based on support and function (p. 172)
- Despite this, and international definitions of disability as ‘interaction’, diagnosis seen as central to being NDIS literate and disability informed
- Importance of diagnosis and plan coordination but the difficulty of attaining it for YP CSN
- Promises of the NDIS ‘remarkably hollow to people experiencing abuse, homelessness, institutionalisation, poverty, decriminalisation and social exclusion.’ (Sherry, 2014, p.)
- Only way promise can be kept for this group is outreach, advocacy and frontline workers who are trained, disability informed and NDIS literate

PAPER 2

Adults with cognitive disability and complex support needs: Using body mapping to explore the planning experience

**Isabella Dillon Savage*, Angela Dew, Susan Collings,
Emma Gentle & Leanne Dowse**

Background



- Strengthen existing good practice
- Identify the specialist skills required to effectively support people with complex support needs to engage in planning
- Provide guidance for practitioners on how to support people with disability to communicate their choices in a respectful and receptive planning process

Safeguarding Conversations in Planning: Project Aim



- Empower and support people with disability and CSN to visualise their goals, develop decision-making skills, and think creatively about their options and how to achieve them
- Develop a planning guide for use by people with cognitive disability and complex support needs, and their supporters, to engage in the planning process

‘Thinking outside the box is hard...you are set in your comfort zone’ (Collings, Dew and Dowse, 2017)

Methodology: Body Mapping



‘Grounded in active, hands-on participation and personal connection that challenge dominant forms of knowledge’
(Orchard, 2017)

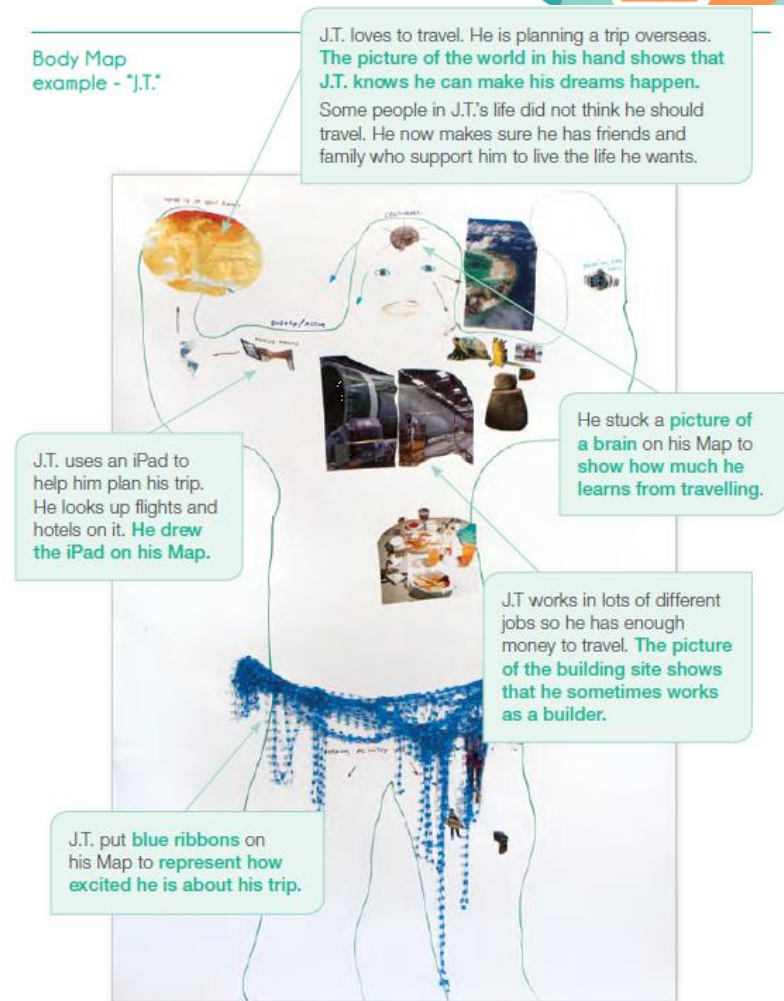
Participants:



- 6 body mapping workshops with 29 adults with cognitive disability (55% female)
- Diverse populations to capture complexity of experience and need (mental illness, sensory impairment, autism spectrum disorder, culturally and linguistically diverse backgrounds, contact with child protection and/or criminal justice systems)
- Metropolitan, regional and rural perspectives (3 metro sites, 1 regional, 2 rural)

Analysis:

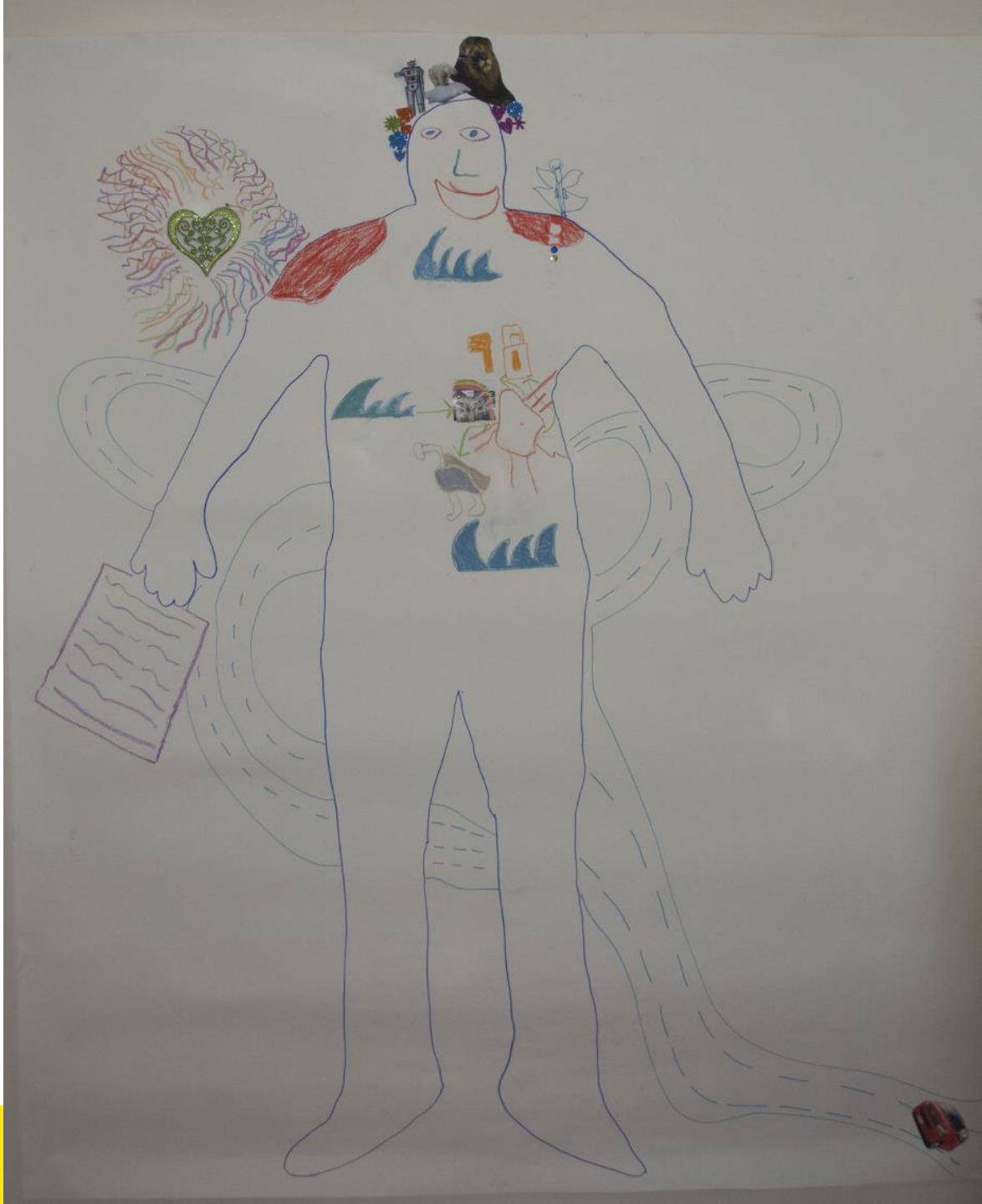
- **Body map:** *symbols, colours, materials, and text drawn on a life sized outline of the participant*
- **Testimonia:** *co-constructed third person narrative*
- **Research field notes:** *capturing the interactions and dialogue facilitated by the mapping process*



Hovi: Day One



'It felt like fireworks were going off'



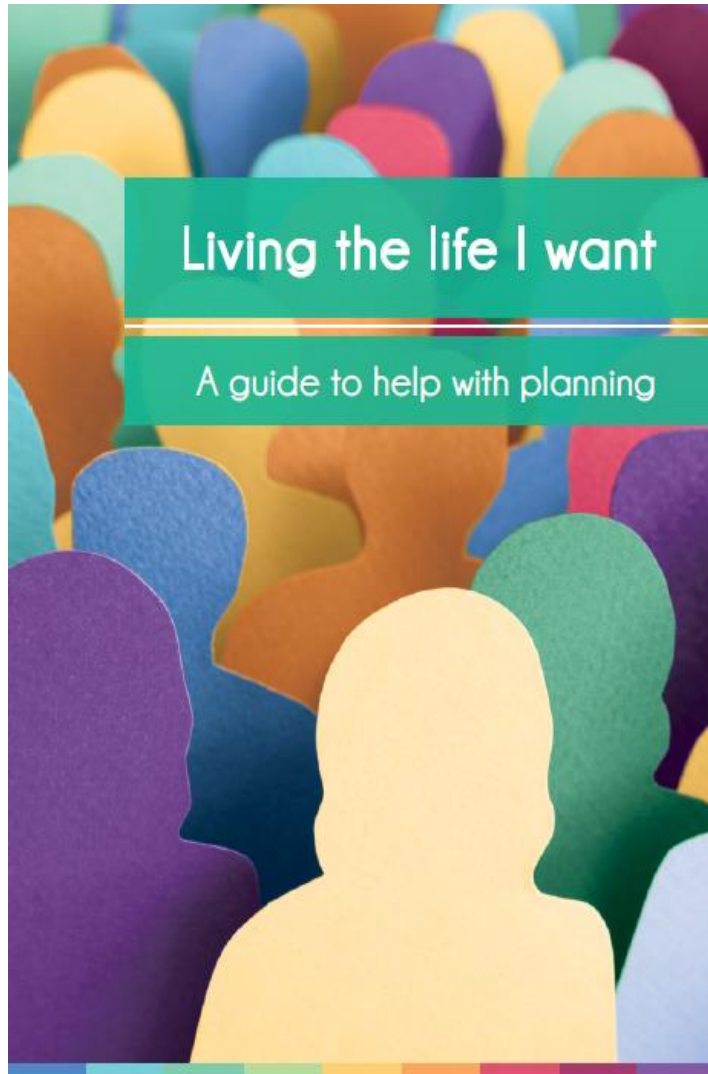
Hovi: Day Two



*'Hovi doesn't need her mum
to be part of the dream of
being in control of her future'*



Significance:



- Participants really enjoyed the process (29/30 came for both days)
- The methodology was highly effective at placing participants at the centre of their experiences
- Revealed the value of using a visual approach like body mapping as a tool for planning

PAPER 3

Families with complex support needs: parent's actions in supporting their family member with challenging behaviour

Leanne Dowse*, Shoshana Dreyfus, Peter Conway, Laura Hogan



Rationale for the study



- In the NDIS context, there are concerns regarding whether people who have behaviour support needs will be able to receive quality behaviour support services in Australia.
- We don't have any research into families' experiences of behaviour support services in Australia
- Preparation of a Discussion Paper “ ***Responding to Behaviour Support Needs in a Disability Services Future***’ bringing together:
 - Inter/national literature
 - Interviews with families who have a member with behaviour support needs
 - Interviews with practitioners
 - Analysis of the policy context of the NDIS



Who has behaviour support needs?



People who have behaviours that threaten their own or others' quality of life and/or physical safety through:

- aggression towards others
- self-harm (including ingesting foreign bodies)
- property destruction
- socially inappropriate behaviour



What is behaviour support?

Behaviour support is a way of helping people to use appropriate ways to communicate, make choices and otherwise participate in the community, rather than relying on challenging behaviours as a way of interacting. Behaviour support aims to reduce the frequency and severity of challenging behaviours in the long term.

This is done in a number of ways including:

- promoting improved quality of life for the person
- managing the environment to reduce triggers
- using focussed strategies to help reduce problem behaviour in the short term
- teaching appropriate behaviours and other life skills (such as coping with change, anger management etc.)
- designing effective strategies for families, school staff and carers to prevent crises but also to respond appropriately to crises when they happen
- establishing effective strategies to support lasting behaviour change.

(http://www.adhc.nsw.gov.au/individuals/support/behaviour_support)



Behaviour Support Services



- comprehensive assessment and analysis of problem behaviour
- development of person-centred support plans
- programs to develop and maintain life skills for individuals
- behaviour support training for families, school staff, carers and others in the support system
- monitoring and review of behaviour support strategies.

What we don't know about behaviour support in Australia

- who gets it
- what works and what doesn't work
- how long it takes
- what the outcomes are
- who provides it
- who funds it
- and so much more.....

What we do know...



Families caring for a member with intellectual disability and challenging behaviour typically face a range of challenges that can include:

- interpersonal violence
- destruction of the home and environment
- sleep deprivation
- high levels of depression, stress
- lower quality of life and
- social isolation

(Biswas, Moghaddam & Tickle 2015, Cummins 2001)

Project Data



- Planned interviews with 50 Australian families about their experiences of behaviour support
- ultimately secured 26 from NSW, WA, Qld, SA (none from Tas, Vic, NT)
- 41% metropolitan; 54% regional; 5% unknown
- 95% were parents
- 91% were female (though two other fathers were present)
- 16% were already in the NDIS; A few were self-managing but still state funded; most were still under block funding arrangements
- All were from an English-speaking background
- Age range of person with behaviour support needs was 4-36 years
- Average age – 23 years



Summary of findings



- there is a great deal of **unmet need**
- **medication** is a common form of behaviour intervention
 - 91% family members on psychotropic medication
- **communication** is often a part of the problem
 - 79% have complex communication needs
- **violence** is a key issue
 - 54% self harm
 - 78% harm others
 - 62.5% harm things (the environment etc)
- **peer support groups** are vital in parents not feeling isolated
- parents show a lot of **resilience and capacity**



Finding out what do families do?

METHOD



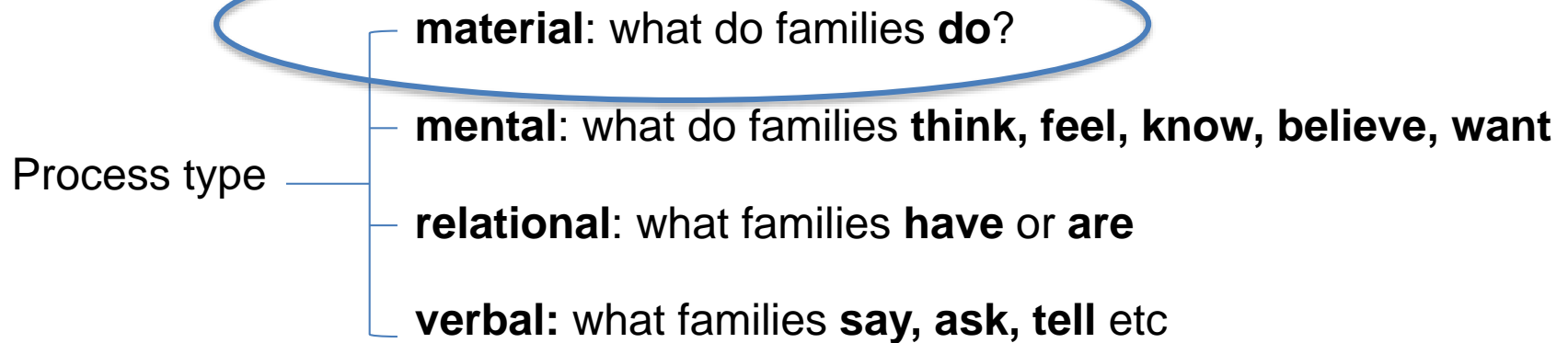
- An examination of the “**I-statements**” that parents say (in relation to questions about behaviour support)
- I-statements comprise “I/we” + verbal group +...

eg

➤ *I really skilled myself up on the AAC stuff*

➤ *We got in contact with someone called Donna Williams who is a lady who is actually on the autism spectrum and runs a support service for people with challenging behaviour.*

Using linguistic theory to guide the classification of i-statements



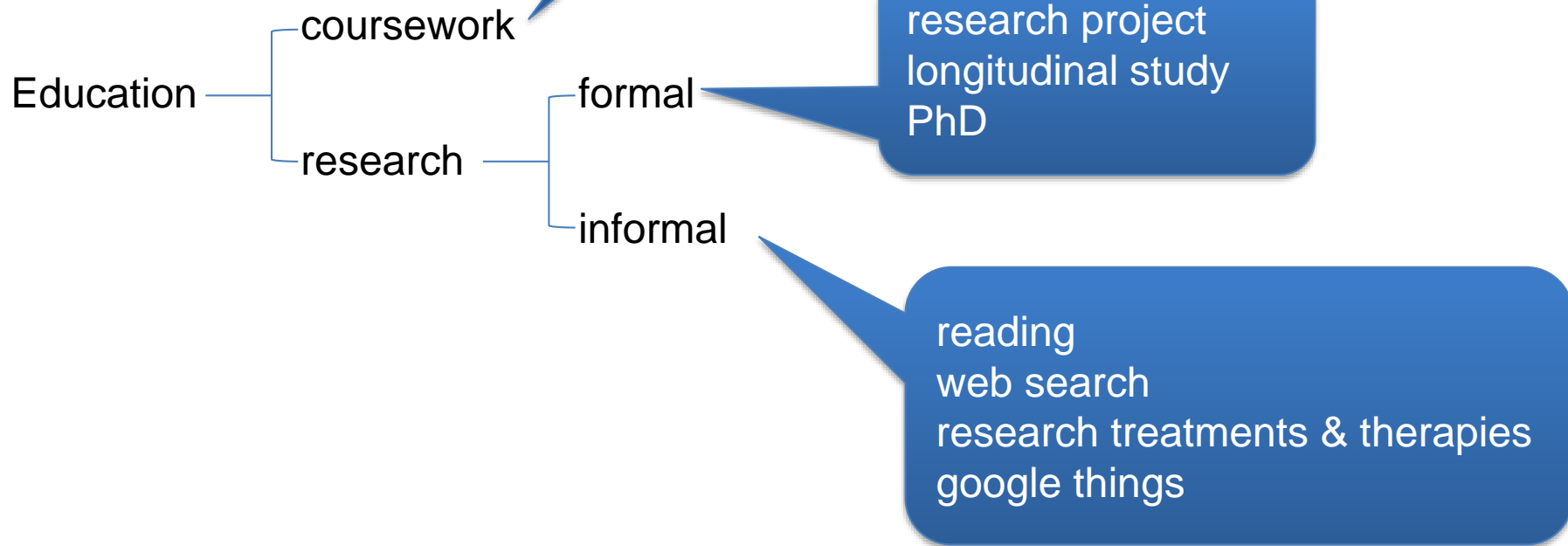
Findings



What families do

- 1. educate themselves (education)
- 2. manage things (management)
- 3. fight/resist (resistance)
- 4. help others (assistance)
- 5. make changes (change)
- 6. get support (support seeking)

1. Education





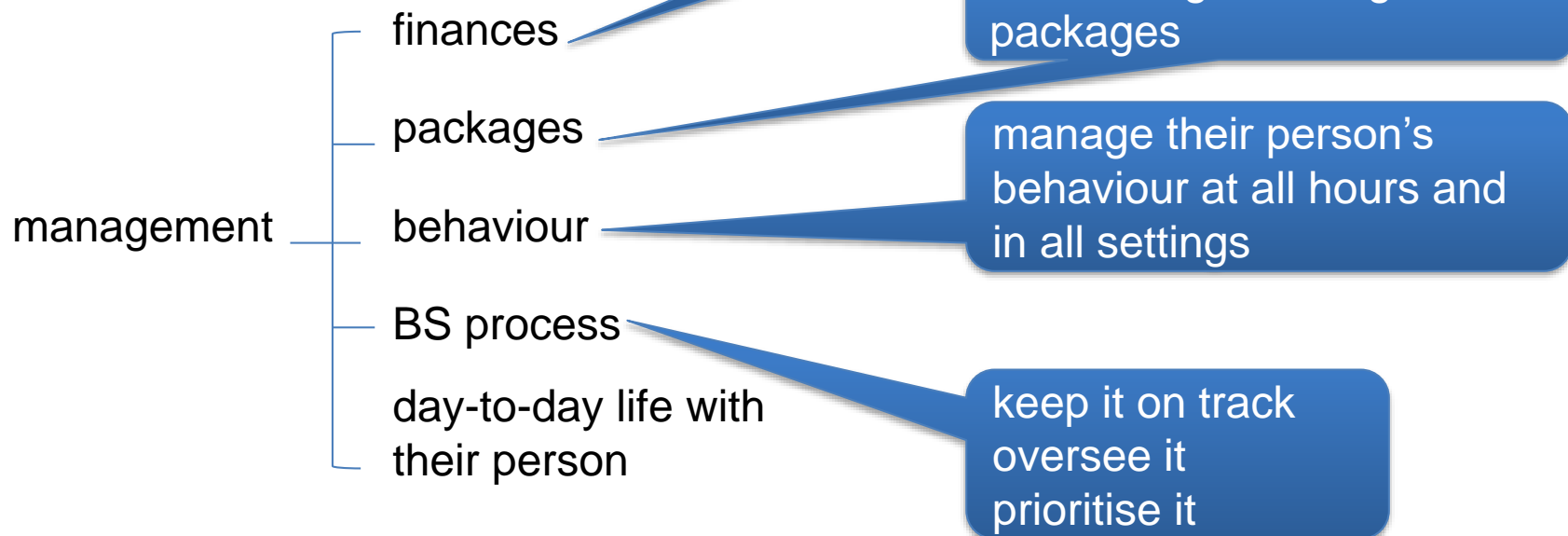
1.1 Coursework

I did a Master of Education in emotional intelligence. A bit of a game changer actually. Really helped a lot.

1.2 Informal research

*Jack was diagnosed at age two when we were living in Newcastle, and I think within a couple of weeks or even a month I **Googled**, worked out that we wanted to do early intensive behavioural intervention.*

2. Management





2.1 Self-manage funding

I self-manage my NDIS funding so I get to choose who my providers are.

2.2 Manage the finances

I do my best to stretch the funding



2.3 Day-to-day life with the person



- admin (eg filling forms)
- attending meetings
- waiting (up to a year or more)
- making LOTS of phone calls
- recruiting and interviewing support workers
- taking the person places
- organising and attending appointments (with schools, doctors, counsellors, psychs, speechies, OTs, BSPs, hospitals, neurologists, Tresilian, police etc)
- interacting and dealing with many people, agencies and organisations in both formal and informal networks



Waiting...

*Once he was diagnosed, it was a whole year and we had heard nothing. Apparently they filed his information and it was just left in a drawer. We received no help with the diagnosis in 2010, 2011, somewhere around there. **I waited the year** and then I rang up.*

Modifying the home environment

There's smashed doors in the house... I've had to put felt on the doors because when he slams the doors the glass smashes, because we've got French doors, and all that sort of thing. If he's got a temper, he'll just kick a door in or he'll smash anything.

Recruiting workers


Identifying them, recruiting them and keeping them is just, a constant, constant battle.

3. Resistance



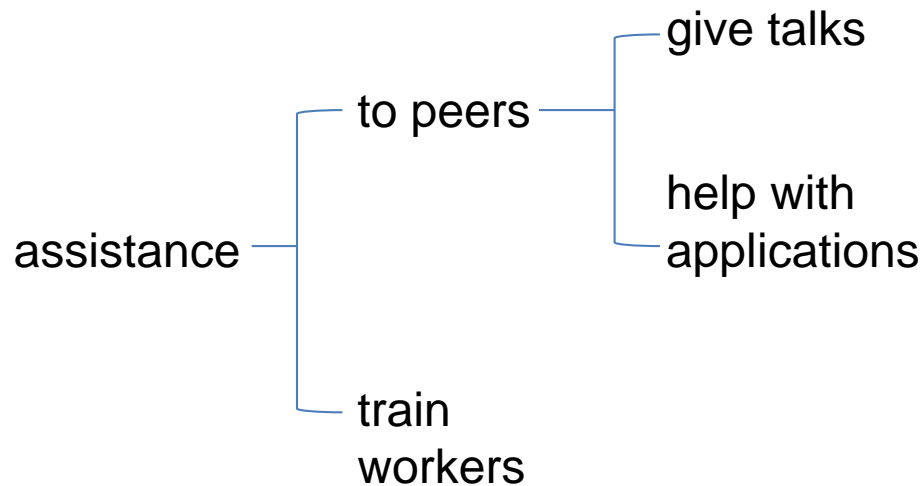
- sending reports back
- asking for internal & external reviews
- taking the NDIS to court
- writing letters to Ministers and local members of Parliament

3.1 Taking on the NDIS



If, when I first started, they had given me \$16,000 to start with, I would have backed right the hell off not knowing any better and bugged off but the more they kept saying no to me and “you can’t” and “we don’t know” and “we’ve given you another planner, don’t ring us or email us, your planner is this”. “Who the f... is that?” “That’s your planner. Get a hold of your planner, don’t talk to us.” I was sent around so much that I thought, you know what, I might as well learn this crap because it sounds like I’m going to be here a while. So I started learning it and the more I learnt the more I realised, you know what, 16,000, I’m not happy with that. I went from \$16,000 to \$42,000 and then up to \$58,000 and I think by the time it’s finished, I should be about \$75,000.

4. Assistance (to others)

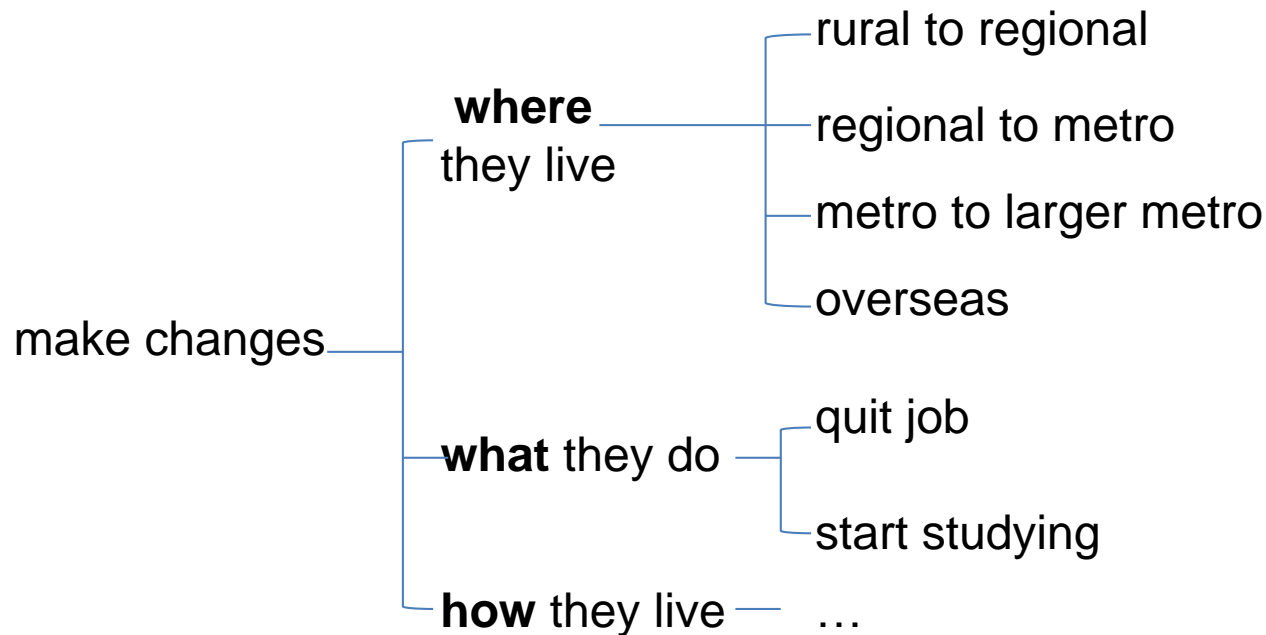


4.1 Train workers



I now train the workers. I train his house workers every few months. I train his day program workers. I go in there with all my PowerPoints. I'm the behaviour support person now, and I've mapped his whole communication system about what means of expressions he uses to bond with people when he can't talk. So, I've got this whole system. I'm it now.

5. Change





5.1 Changes to **where** families live

Then there was support in childcare but it was all very difficult and I decided to move from Adelaide to Sydney in 1995. So, when Annie was three, because there were many more support services available in Sydney at that stage and there was still the Forestville Autism School which took children early and then Giant Steps in Sydney was being founded at that time.

5.2 Changes to **how** families live

It was very repetitive and I put all my time into him, but his schooling doesn't get done during schooling hours. He would mainly do it between midnight and 3:00am. No-one is going to come out at that time to help him, so that's why we did it. When he woke me up, it didn't matter whether I had a migraine, you'd get up and you'd do the school work with him because I didn't know if he'd do it tomorrow. It doesn't matter what was going on for us.

6. Support seeking



- engage an advocate
- get respite
- get a place in pre-school, school etc
- get people involved
- employ workers
- connect with services

Get respite

In the old days we used to get respite before we had support. He used to go to respite. It was supposed to be a secure one and one for people that had high needs but every time he went there he used to break out. They used to have the police out.

Engaged an advocate

Then I got angry. It takes a lot for me to get angry with a lot of their stuff and I thought, you know what, I'm sick of them fucking me around because I've had such good control, and you know how some people get addicted to the control, and I thought, yeah, I'm not having that. Once I got angry, I engaged an advocate and then I just went the whole hog and thought, you know what, if I don't aim high they're going to kick me while I'm down. So I've actually learnt to be mean.

The 'shadow' side of the data



Process type

material: what families **don't/can't** families do

mental: what families **don't/can't** families think, feel,
know...

relational: what families **don't/can't** have or are

verbal: what families **don't/can't** say, ask, tell etc

There's just a lot of things. It is what it is. **I can't change it. I can't cure him.** I'm past that.

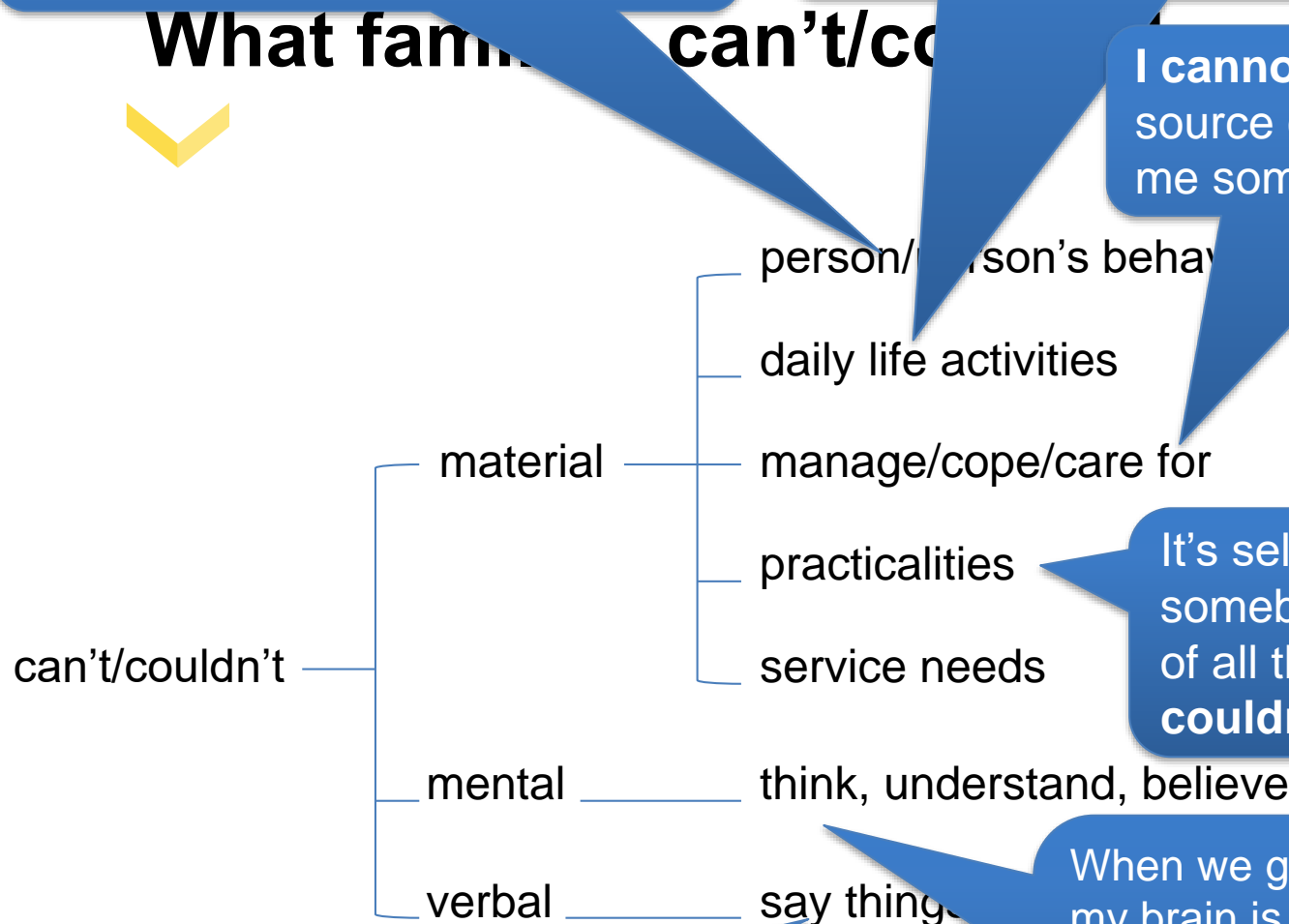
There was times when he was attacking me driving the car, from the back seat of the car and I couldn't drive.

I cannot manage. It is a source of some frustration to me sometimes.

It's self-managed, but somebody else is taking care of all the bills, because **I just couldn't do that**

When we go to these appointments, my brain is so full of information that I actually cannot answer the questions. **I can't think of the information**, the phrasing of their questions and what they're asking


but everyone who's in NDIS, you cannot ask for respite. You cannot say that word (or PTO)





Conclusions and challenges



- Stressors for families cluster and compound and accumulate ‘on top of’ everyday family life  **complex family support needs**
- What families **do** must also be understood in the context of what they feel they **can’t** and **don’t know** or **do**.
- Alignment between **family experiences** and **professional assumptions** about family agency, knowledge and capacity.
- Mismatch between what families **need to do** and the **supports they are able to access** – especially in the context of the marketisation and personalisation of supports for individuals in the NDIS



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PAPER 4

Parents with intellectual disability: addressing complex support needs in the child protection system

**Angela Dew*, Susan Collings, Margaret Spencer,
Erin Cooney & Leanne Dowse**

Background



Intellectual Disability Rights Service: NSW specialist disability legal service

Parents Project

- ★ Advocacy
- ★ Legal representation (limited)
- ★ Legal education
- ★ Volunteer court support

UNSW Intellectual Disability Behaviour Support Program

- ★ Review model
- ★ Use of volunteers
- ★ Future opportunities/challenges for sustainability

Evidence-base

Parents with intellectual disability



- Small in parent population terms (1-2%) (Man, Llewellyn & Wade, 2014)
- Higher rates of child protection involvement (Feldman et al., 2012)
- Higher rates of child removal (McConnell et al., 2011)
- Parenting assessments based on IQ tests (McConnell & Llewellyn, 2000)

Research evidence

Parents' perspective	Practitioners' perspective
Spectators in investigation process (McConnell & Sigurjonsdottir, 2010)	Overstate risks to child (Proctor & Azar, 2013)
Powerless to influence outcomes (McConnell & Sigurjonsdottir, 2010)	Blame parents for service failures (Booth & Booth, 2005)
Difficult to instruct solicitors & hard to understand legal process (Tarleton, 2008)	Pessimistic about keeping families together (Lewis et al., 2015)
Confused about professionals' roles (Tarleton et al., 2006)	Need for specialist support/advocacy to correct power imbalance (Tarleton, 2008; Ward, 2010)
Powerlessness and confusion persist after children removed (Conder, Mirfin-Veitch, & Sanders, 2008)	Need training for child protection workers to engage with parents (Tarleton, 2008; Ward, 2010)
Loss of children a repeat experience (Mayes & Llewellyn, 2012)	
Feel unable to express grief to workers for fear of repercussions / lack trust (Gould & Dodd, 2008)	

Research questions



- How do parents view the difference the parent project made to their experience in the child protection system?
- Does it work to have volunteers support parents during court appearances? What are the limitations?

Parents ($N = 10$)



- Most were **mothers** ($n = 7$)
- Aged 19 - early 40s
- Half had **little or no family support** ($n = 5$)
- Most **lived with a partner** ($n = 6$) or family member ($n = 2$)
- Up to 4 children each (mean = 2)
- Most were **not living with child/ren** ($n = 7$)
- Most children **removed within first year** ($n = 6$)

Past experiences



➤ **Most parents:**

- Out of home care background
- Bullied at school
- Limited work opportunities
- Little informal support

➤ **Most mothers:**

- Experienced intimate partner violence
- Past sexual and physical abuse

Volunteers ($N = 5$)



- 3 women and 2 men
- 3 retired or semi-retired
- 2 volunteers had professional background in education or disability services
- 3 volunteered after ill-health forced early retirement
- All current/past volunteers in criminal justice system

Theme 1: Powerlessness



➤ **For parents:**

- Confusion about process & expectations
- Shut out and ignored by professionals
- Mothers felt punished for domestic violence

➤ **For volunteers:**

- Unfair treatment by courts/CP workers
- Professionals assumed incompetence = disability
- Felt powerless to help parents
- System was stacked against these parents

They said because of my intellectual disability I would not be able to take care of a special needs child. It was hard to swallow.

I want people to know what's going on. Their baby was taken from their arms. It happens today. Talk about the stolen generation.

Theme 2: System-induced trauma



For parents:

- Overwhelming grief and despair
- Some talked of suicidal thoughts (and attempts)
- Over half had no reliable support people in lives
- Mothers experienced removal of newborns as a theft

For volunteers:

- Vicarious trauma – bearing witness to parent's pain
- Risk of burnout
- Feelings of inadequacy and pessimism about justice for the parents

I just want to say to the judge "please give my kids back, I did nothing wrong." It's like they don't want to listen to me

It's sort of a bit cruel to some extent because [the situation is] 'You're not getting them back but let's drag it through [court] for the next two years'

Theme 3: Making a difference



Parents views of **advocate**

- A 'bridge' between them and the system
- Made sure court processes were explained
- Made hospitals teach baby care skills
- 'Like a friend'
- Respected parent for who they are

Parents view of **volunteers**

- Reliable; always there on the day
- They cared about the parent
- Showed them respect and this gave them hope

She says what rights I have, because I have a disability. When I got mixed up with questions she was there to help me explain what they were saying

They explained court in a way that I can understand. They've helped me more than anybody else could.

Theme 3: Making a difference



Volunteers view of **their** role

- Ambivalence
- Being in court made a difference to how parents coped
- Couldn't change the outcome, inevitability of removal
- Needed more training to deal with boundaries (code of conduct)
- Children's court harder than the criminal jurisdiction

We had our general training, but that, I think, didn't really prepare us for what was about to happen.

You're not going to change worlds or anything like that.... You couldn't do it if you were going to be sad.

Implications for practice



➤ **Parents:**

- System abuse - mental ill-health; ongoing trauma
- Individual advocacy makes systems take disability into account
- Advocate- empower parents

➤ **Volunteers:**

- Source of comfort for isolated parents
- Risk of burnout due to emotional demands of role
- Unsustainable longer-term (turnover, skill development needs)

Information and Contact Details



For more information on projects, publications and resources
visit the IDBS website

<https://www.arts.unsw.edu.au/idbs>

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