Planning with people with complex support needs
Overview of the presentation

- Intellectual Disability Behaviour Support Chair and Program
- Complexity and complex support needs (CSN)
- NDIS risk factors for people with CSN
- Ecological approach to CSN
- Planning with people with CSN
- Conclusion
Purpose: build the capacity of society to support, include, and improve the lives of people with cognitive disability and CSNs, their families and supporters.

Fundamental need to map the challenges in thinking and working with people with cognitive disability and CSNs.
IDBS Integrated Approach

- Creating & Translating Knowledge
- Learning & Teaching
- Improving Policy & Practice
- Stimulating Informed Debate

Learning & Teaching

Improving Policy & Practice

Stimulating Informed Debate

Creating & Translating Knowledge

UNSW
“No one would deny that the world is complex, that it escapes simplicities. But what is complexity, and how might it be attended to?”

(Mol & Law, 2002, p.1)
Chaos Theory

Emergence
Complexity
Chaos

Image: Shelley Lake, instruments 1986
What are Complex Support Needs?

Multiple, interlocking needs that have both ‘breadth and depth’ because they either span multiple domains and/or involve high levels of need in one or more areas, making the total more than the sum of the parts.

(Rankin & Regan 2004)
Complex support needs

CRIMINAL JUSTICE CONTACT
- Victims of crime
- Contact with police
- Incarceration

DEMOGRAPHIC/IDENTITY ISSUES
- Being Indigenous
- Being female
- Being an older person
- Being from a minority ethnic community

HEALTH AND DISABILITY
- Poor physical health
- Having a physical sensory, behavioural or cognitive disability
- Self-harm
- Having a mental illness

SOCIAL/ECONOMIC ISSUES
- Substance misuse
- Homelessness and rough sleeping
- Unemployment
- Social isolation
- Being in a disadvantaged geographical location (rural, regional)
- Low income/poverty

EARLY LIFE
- Experience of family violence as a child
- Growing up in a low income household
- Early leaving home/out of home care
- Early (teenage) parenthood
- Child abuse and/or neglect
- Poor educational outcomes

‘Natalie’

- Young woman with an ID;
- Various mental health diagnoses;
- History of substance misuse;
- Attended special school - banned for abuse of staff;
- Leaves family home - sexual assault by brother;
- Multiple contacts with Police - victim of DV and assault, multiple AVOs against her;
- First in Juvenile Justice (JJ) custody at age 15;
- No fixed address – OOHC, refuges, homeless - aggressive behaviour;
- Multiple hospital admissions for self-harm/suicide;
- Guardianship/ residential services - malicious damage to property and assaulting carers;
- By age 21 - 3 high risk pregnancies and children removed.

http://www.mhdcd.unsw.edu.au/
**Natalie: Estimated life-course institutional costs**


<table>
<thead>
<tr>
<th>Natalie</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Police</td>
<td>$ 475,179</td>
</tr>
<tr>
<td>DoCS</td>
<td>$ 46,290</td>
</tr>
<tr>
<td>DCS</td>
<td>$ 90,788</td>
</tr>
<tr>
<td>DJJ</td>
<td>$ 103,151</td>
</tr>
<tr>
<td>Housing</td>
<td>$ 13,837</td>
</tr>
<tr>
<td>Health</td>
<td>$ 64,014</td>
</tr>
<tr>
<td>Courts</td>
<td>$ 17,188</td>
</tr>
<tr>
<td>Legal Aid</td>
<td>$ 28,794</td>
</tr>
<tr>
<td>PHDAS</td>
<td>$ -</td>
</tr>
<tr>
<td>Centrelink</td>
<td>$ 113,730</td>
</tr>
<tr>
<td>Justice Health</td>
<td>$ 18,430</td>
</tr>
<tr>
<td>ADHC</td>
<td>$ 4,700</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$ 976,106</strong></td>
</tr>
</tbody>
</table>
NDIS risk factors

- Lack of, or limited, previous contact with disability services (Collings, Dew & Dowse, 2016; Dowse & Dew, 2016);
- Inability to provide proof of disability and previous needs assessment (Collings, Dew & Dowse, 2016);
- Lack of informal supports to assist with NDIS contact (O’Connor, 2014);
- Limited literacy skills to access NDIS information (Clift, 2014);
- Lack of appropriate access to Scheme information and personnel;
- Complex communication needs (Iacono, 2014);
- English as a second language (Soldatic et al, 2014);
- Ill-equipped mainstream services (Soldatic et al, 2014);
- Compartmentalising of supports (Collings, Dew & Dowse, 2016; Dowse & Dew, 2016).
Ecological approach

Bronfenbrenner (2005). Ecological systems model
BEING A PLANNER WITH A PERSON WITH DISABILITY AND COMPLEX SUPPORT NEEDS

Planning resource kit
Research Methods

- Literature review – person-centred planning
- Stakeholder mapping - cross sector: disability, alcohol and other drugs, mental health, criminal justice, guardianship, housing
- Metropolitan and regional perspectives
- Focus groups with 120 practitioners and adults with intellectual disability
- Thematic analysis to identify planning barriers/facilitators
- Action research to develop the planning resource kit
Action Research Cycle

1. Graphic design version of draft resource
2. Test group confirmation
3. Graphic design revision
4. Written and verbal feedback & revisions
5. Test group workplace trial
6. Revisions
Planning

Facilitators & Barriers

» **Person**: interaction between person and planner – relational nature of planning

» **Service**: supports & services the person needs

» **System**: policy, funding, regulations

Process

» **Stage 1**: Pre-planning

» **Stage 2**: Planning conversations

» **Stage 3**: Plan-to-action
Effective planning

For practitioners:
★ Time to build rapport, harness a range of supports & overcome silos and constraints;
★ Organisational support and opportunity to build practitioner skills;
★ Systemwide integration, accountability and creativity.

For the person:
★ Being prepared and learning from mistakes;
★ Having a planner they can trust, who has system know-how and disability understanding.
Mitch is a 30 year old Aboriginal man with an intellectual disability and a mental illness. He has poor physical health, difficulty with verbal communication and low literacy. Mitch lives alone in public housing and finds it hard to look after the house and himself. Although family has always been important to Mitch, due to intergenerational trauma, he is currently estranged from them and has no informal support networks. Mitch is allowed supervised visits with his two children who are in out-of-home-care, but he has not seen them regularly. Mitch has spent time in jail for drug-related offences and is on community orders requiring him to take methadone and medication to manage schizophrenia. Although Mitch is committed to remaining drug-free, his former drug-taking friends live nearby and are his only social contacts. Mitch wants to find work to become more connected to his community and earn money so he can resume former interests such as going to football matches. Mitch has reluctant engagement with multiple services and systems such as corrective services, community mental health, housing and child protection but receives no disability-related support.
Complex support needs flag
Pre-Planning with a person with CSN

- Gather **background information** about the person and the services;

- **Identify people** and other resources;

- **Ask questions** (who, what, where, how) & identify ‘red flags’.
Stage 1: Pre-planning

Questions to consider...

Who?
... does the person regard as important in their life?
... are the person’s existing service providers?

What?
... goals has the person previously articulated or planning have they done?

Where?
... is the most appropriate and least intimidating place to meet the person?
... is a safe place for the planner as well?

How will you clarify information?
... best to build trust and rapport?
... to dress, talk to and interact with the person?
Planning conversations with a person with CSN

★ Identify capacity
  ➢ Build trust/rapport - openness, non-judgmental;
  ➢ Focus on person’s strengths – what’s worked in the past?
★ Identify risks/safeguards
  ➢ Service barriers for people (e.g., mainstream health, mental health, housing supports);
  ➢ Safety concerns (e.g., challenging behaviour, AOD use, criminality, violence, child protection);
  ➢ Social isolation (‘burnt bridges’).
Stage 2: Planning Conversations

Planning conversations

- Identifying capacity
  - Person
    - Formal and informal networks
  - Service
    - Recognise complexity
      - Address complexity
  - System
    - Flexibility | Creativity
- Identifying risks and safeguards
  - Person
    - Formal and informal networks
  - Service
    - Access | Equity
    - Accountability
  - System
    - Resource constraints
      - Silos

Allow time to evolve
(Described in Stage 3, page 68)

Attainable plan
Plan-to-Action with a person with CSN

★ **Build capacity and safeguards**
  - Develop planner CSN awareness;
  - Mentor/educate services (e.g. cultural awareness, CSN, understanding cognitive disability);
  - Coordination/case management;
  - Reconnect with community.

★ **Allow time to reflect, learn and adapt**
  - Trial & error is normal not failure;
  - Long-term approach.
Stage 3: Plan to Action

- Building capacity
- Creating circle of support
- Addressing risks and safeguards
- Pre-empting problems
- Capacity and safeguards working together
- Allow time to evolve
  - Trial
  - Reflect
  - Learn
  - Adapt
What is a circle of support?

“A group of people that comes together, on a regular basis, to assist a person with a disability to design, support and action their goals and aspirations”.

“The group is formed by people who care for, respect and have a common wish to support the individual to achieve ... goals”

Inclusion Designlab 2015
“The best people equipped to support this process are parents, family members, friends, or people that have a meaningful and constant relationship with the person” (inclusion designlab, 2015)
Pre-empting problems

- Matching the service to the person (not vice versa);
- Using systemic advocacy and education;
- Building a Plan ‘B’;
- Brokering a compromise;
- Building relationships with specialist and direct services;
- Finding the ‘go to’ person;
- Knowing how the service system works.
Trial, reflect, learn, adapt
Summary: Effective planning takes...

Person with CSNs:
- Willing to engage in planning;
- Ready to try new things.

Planners:
- Skills, support & time to build rapport with a person with CSN, harness their resources & help them create a dynamic plan.

Services:
- Leadership, collaboration & innovation;
- Investment in planner skills, a team approach & CSN capability.

Systems:
- Accountability;
- Evidence and innovation-focus;
- Integrated approach.


Acknowledgements

The development of this resource kit was funded by the NSW Department of Family and Community Services.

How can I get it?

The Planning Resource Kit and other resources can be downloaded at: arts.unsw.edu.au/research/intellectual-disability-behaviour-support-program

Contact idbs@unsw.edu.au for more information or to inquire about training