People with cognitive disability and complex support needs: interaction with the National Disability Insurance Scheme

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Disability Justice Project Leaders’ Forum
June 9th 2016
Presentation Outline

- What does it mean to live with complex support needs?
- How do we understand complex support needs?
- The nature of the National Disability Insurance Scheme
- What are the issues that arise for this group in their interaction with the National Disability Insurance Scheme?
Natalie

- Young woman with an ID, a history of substance and who has had various MH diagnoses including: dissocial personality disorder, ADHD. emotionally unstable personality disorder, histrionic personality disorder, and a psychotic disorder due to the harmful use of cannabinoids.
- Attended special school but left without qualifications.
- Banned from school for abuse of staff.
- Unable to remain in the family home due to aggravated relationship with her brother who has a mental illness – incidence of sexual assault by sibling.
- Multiple contacts with Police as YP - first as a victim of DV and assault.
- First in JJ custody at age 15. The following year had 7 episodes in JJ custody over four months.
- 3 JJ custody alerts during this time for threatening self-harm and escape.
- Often noted as having no fixed address, spends time in OOHC and refuges but placements often break down due to her aggressive behaviour.
- Multiple hospital admissions for self-harm/suicide from early teens.
- Guardianship/ residential services she has multiple contacts with police as a result of malicious damage to property and assaulting carers.
- Has had 3 high risk pregnancies with all children born by the time she is 21.
- The victim of DV in several adult relationships and has multiple AVOs against her.
- Frequent homelessness and custody as a young adult
Natalie: Estimated lifecourse institutional costs


<table>
<thead>
<tr>
<th>Natalie</th>
<th>Total Cost</th>
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</thead>
<tbody>
<tr>
<td>Police</td>
<td>$475,179</td>
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<tr>
<td>DoCS</td>
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<tr>
<td>DCS</td>
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<td>DJJ</td>
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<td>Housing</td>
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<td>Health</td>
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<td>Courts</td>
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<tr>
<td>Centrelink</td>
<td>$113,730</td>
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<tr>
<td>Justice Health</td>
<td>$18,430</td>
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<tr>
<td>ADHC</td>
<td>$4,700</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>$976,106</strong></td>
</tr>
</tbody>
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How do we understand complex support needs?

- Associated with vulnerability and social marginalisation.
- Multiple interlocking experiences and factors that are more than the sum of their parts.
- Includes domains of:
  - Medical diagnosis
  - Health Support
  - Disability
  - Social Disadvantage
  - Risk
  - Justice and Legal issues

Specifically can include:
(a) mental health disorder; (b) cognitive disability including intellectual and developmental disability and acquired brain injury; (c) physical disability; (d) behavioural difficulties; (e) precarious housing; (f) social isolation; (g) family dysfunction; (h) problematic drug and/or alcohol use (i) risk of harm in early life; (k) early educational disengagement etc etc

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

Defining complex support needs

• The need for simultaneous, intense and multiple types of support due to interlocking factors that span disability, health, behavioural and social issues (Rankin & Regan, 2004).

• Some, or all, domains may be experienced by an individual with complex support needs but no ‘generic’ case.

• Domains can change throughout the individual’s life course.

• Not a static or permanent experience. Instead, more likely to arise in certain situations, episodes or life stages such as at key transition points or in times of crisis.

• Exist in the spaces between the individual and their potential or actual support systems – reflecting the relationship between individuals, environments and systems.
An ecological approach to complex support needs
Individual, service and system

- Exist in the spaces between the individual and their potential or actual support systems – reflecting the relationship between individuals, environments and systems

- Individual level
  - Breadth and depth of need
  - Interconnected

- Service Level
  - Risk factors impacting on complexity of need
  - Natural or informal supports do not meet needs

- System level
  - Inability of single service system to provide support
  - Or no current service response
Complex support needs
The nature of the NDIS

- Two key *simultaneous* reforms:
  - Individualisation
  - Marketisation
- Grand opportunity or perfect storm???
People with complex support needs interacting with the NDIS – opportunities and challenges

- Reaching the target audience
- Voluntary engagement
- Eligibility
- Aspirations for a better life
- Gathering Information and making decisions
- Support Planning
- Purchasing products in a competitive market place
- Specialist and mainstream service fit
- A ‘complex needs capable’ workforce?
Reaching the target audience

- Poor track record in accessible information – still struggling to address this
- Exclusion from basic Scheme information
- Particularly intensified for Aboriginal people with disability and their families
- Significant systemic barrier for people
Voluntary engagement

• Presumption that individuals will voluntarily engage with the scheme
• Not safe to assume due to a range of factors
• Lifelong and negative interactions with services
  • Mistrust of professionals
• Issues of identity
  • Do not self-identify as having disability – unwilling or unable
• Hidden in the community
  • Caring for ageing parents
  • In other parts of the social care system (OOHC, AOD, Homelessness, CJS)
Eligibility

- Proving impairment – assessment issues
- Demonstrating functional disability
- For people with multiple diagnosis each of which is ‘mild’ but in combination are very disabling
- What are ‘reasonable and necessary’ supports
Aspirations for a better life

1. Defining feature of the discourse of the Scheme
2. Unrealistic expectations that people with intellectual disability and complex support needs can imagine and articulate this.
3. Culturally specific
Gathering Information and making decisions

- NDIS presumes capacity to navigate referral system designed to determine eligibility.
  - Computer, internet and literacy;
  - telephone and travel,
  - self-advocacy and communication
  - Manage and attend appointments
  - Insight into supports that assist quality of life
  - Capacity to find, approach and manage service relationships

- Decision making and understanding the consequences of those decisions
  - Limited lived experience of decision making and outcomes

- Risk is that these limit the exercise of choice, control and self-determination – all key pillars of the NDIS.
Support Planning

Planning is a process which is now at the centre of the experience of support for people

• » Stage 1: Pre-planning
• » Stage 2: Planning conversations
• » Stage 3: Plan-to-action
Pre-Planning with a person with CSN

- Use referral information wisely to:
  - Learn about the person and CSN
  - Assess risks to them, you, services (e.g. drug use, AVOs)
  - Ask questions (who, what, where, how) & identify ‘red flags’

- NB: Lack of information about cognitive disability
Planning conversations with a person with CSN

- **Identify capacity**
  - Build trust/rapport- openness, no judgments
  - Focus on person’s strengths – what’s worked in the past?
- **Identify risks/safeguards**
  - Service barriers for people with AOD (mainstream health, mental health, housing supports)
  - Safety concerns (e.g., AOD use, criminality, violence, child protection)
  - Social isolation (‘burnt bridges’)
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
Summary of key Lessons: Effective planning takes:

- **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:**
  - Accountable
  - Evidence and innovation-focused
  - Promote integration
BEING A PLANNER WITH A PERSON WITH DISABILITY AND COMPLEX SUPPORT NEEDS

Planning resource kit
Purchasing products in a competitive market place

- Do supports for CSN fit with the itemized, time-bound pricing structure of the NDIS?
- What happens when separate ‘products’ must be purchased from multiple agencies?
- How does the need for cohesion in support services sit with a scheme where agencies are in competition?
Specialist and mainstream service fit: Disability and the CJS

- Interface principles – lines and boundaries of responsibility
  - Program access
  - Assessment for diversion
  - Access and navigation of the justice system
  - Support in police and court processes
  - Supports to meet court imposed conditions
  - Post release support
Challenges for a ‘complex needs capable’ workforce

• At a minimum:
  – Intra and inter-agency collaboration
  – Proactive rather than reactive
  – Comprehensive case management
  – Specialist mental health, positive behaviour and trauma support

• Reliance on mainstream supports
  – Current picture is of significant challenges in capacity
  – Outlook is about ‘inclusion’ but how is capacity built?

• Key Ingredients do exist
  – Best practice guidelines
  – Services and Professional teams
  – Training, supervision and mentoring

• Time and Leadership
Contact details and websites

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Intellectual Disability Behaviour Support Program Website
https://www.arts.unsw.edu.au/idbs

Complex Support Needs Planning Resource Kit
https://www.arts.unsw.edu.au/research/intellectual-disability-behaviour-support-program/support-planning/

People with Mental Health Disorders and Cognitive Disability in the Criminal Justice System Research Project website
http://www.mhdcn.unsw.edu.au/