Homelessness and People with Intellectual Disability

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presented at

Left out in the cold:
A conference focusing on people experiencing chronic homelessness due to impaired decision making

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Presentation Outline

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1. Introduction

Good morning, my name is Morrie O’Connor. I am the Co-ordinator of Community Living Association (CLA) in Nundah, Brisbane. CLA manages a number of services, including ARROS, Community Living Program (CLP), and Community Connections.

Community Living Program was established in 1989 to support young people with an intellectual disability who wished to move out of the family home and experience independent living. This original orientation changed as the majority of young people who were referred to CLP were young people with an intellectual disability who were living in youth shelters, or exiting some form of state care, control or treatment. In 1999, CLA established ARROS - an outreach service for young people with intellectual disabilities who are homeless.

As we will see today, alongside people with intellectual disability, there are many others who struggle with decision making impairments. For example, people with foetal alcohol syndrome, acquired brain injury, other forms of cognitive disability, autism, and mental health issues. My focus for the purposes of this presentation today, however, we be on the experiences of people with an intellectual disability.

Indeed, this issue of diagnosis is fraught, and is often a feature of the poor service outcomes people experience. Great chasms exist in the artificial spaces that lie between any individual’s diagnoses. There are issues of overlap and confusion - people can have several diagnoses. There may be accompanying hidden agendas - diagnoses can be used to assist the people to whom they are attached, or to exclude them.

A number of people with impaired decision making often have adjectives attached to them such as “high functioning”, or “mild” disability. These labels minimize the impact of an individual’s disability, and deny the significant daily challenges people face, and the often complex support needs they have. The practical impact of these labels is the exclusion of people with “mild” disabilities from service and support, in favour of people whose disability and support needs are recognised (and described) as profound. From our work with people with so-called ‘mild’ intellectual disability, and our witness to their struggles, we would strongly dispute any suggestion that this group have limited need for support. The types of supports people often need can be gleaned, in part, from an overview of the cognitive effects of intellectual disability, which include:

- Limited ability to learn, comprehend, retain, and apply information;
A greater propensity for impulsive behaviour;
Less ability to manage extreme emotions, such as anger;
Less ability to understand and related to the emotions of others;
Less inhibition;
Greater suggestibility;
Poor problem solving skills;
Limited volition;
Poor memory;

Of course, these effects are purely cognitive, and do not address the many other personal, social, economic, and health impacts associated with intellectual disability.

One response to the exclusion of people with “mild” intellectual disability from funded support is offered by the American Association of Intellectual and Developmental Disabilities. In 2002 they recommended that the traditional “levels of severity” classifications that are based on IQ ranges (borderline, mild, moderate, profound), be replaced by a model that reflects the levels of support people require. This classification model is referred to as the ILEP system, and bases the level of support a person requires on their needs - listed as Intermittent, Limited, Extensive and Pervasive - rather than simply their IQ score (AAMR 2002).

Bill’s Story

By way of example I would like to share some of Bill’s story with you. ARROS began working Bill in 2004. Bill is an extremely vulnerable young man, with a family history of abuse and neglect. He has been homeless for a number of years, and is often exploited by others. He is easily suggestible, easy pickings financially, and easily led into crime. Bill’s offending history is also closely linked to times when he has engaged in substance abuse. Bill is currently on probation for 3 years. If he offends again he will receive a jail sentence.

Bill was diagnosed with an intellectual disability at primary school. Testing determined he had an IQ of 62, which put him in the Mild Intellectual Disability range. Following a push by ARROS for Bill to receive support funding from Disability Services Queensland, he was re-tested in 2007. Bill returned an IQ score of 82, which put him in the Borderline Intellectual Functioning range. As Bill was determined to no longer have an intellectual disability, DSQ stated he was not eligible for funded support. This was despite the fact that Bill faces many struggles as he negotiates daily life:
Financial exploitation and poor personal money management
Transience, poor living skills, and homelessness
Poor diet and neglect of personal health
Bill's struggles are daily and they are ongoing. To borrow from the ILEP model, we would determine Bill's support needs to be at least Extensive, if not Pervasive. Yet an assessment based on his IQ found him to have no support needs.

Despite his IQ score, we persisted. This persistence was grounded in our knowledge of Bill's vulnerability and ongoing negative life experiences, and what we saw to be his considerable support needs. We spent a lot of time arranging neuropsychological testing, which ultimately determined that Bill has a 'cognitive disability'. Deemed eligible again under DSQ criteria, Bill is now back on the waiting list for funded support. To date, he is still waiting.

Bill's story also raises complex questions and dilemmas around practice with people with "impaired decision making". It is all well and good to say that neuropsychological reports determine that Bill has a cognitive disability - but what does this tell us about how his decision making is impaired? Is it impaired all of the time or some of the time? What are the consequences of this for our work with Bill? What it means for us, at ARROS, is we respect Bill's right to self-determination, and we work with him to achieve what he wants. But we recognise that there will be times when we will disagree with Bill's choices, and we will not support him in those choices.

2. Homelessness and people with intellectual disability

Key research:
It is nearly 20 years since the release of “Our Homeless Children”, the Report of the National Enquiry into Homeless Children. Also known as The Burdekin Report, “Our Homeless Children” made a number of references to young homeless people with an intellectual disability:

- Intellectual disability was cited as one reason for chronic homelessness;
- Homelessness of some young people with an intellectual disability was referred to as an unintended consequence of deinstitutionalisation policies;
- The report noted that crisis accommodation services for homeless young people were not equipped to provide specialized care for homeless young people with an intellectual disability; and
- The report catalogued many concerns that were expressed in relation young people with intellectual disability, including:

- Poor personal hygiene, including bed wetting
- Drug and alcohol issues
- Exploitation and abuse by family and ‘friends’
- Ongoing offending and involvement in Criminal Justice System
- existing services unwillingness to accept young people with an intellectual disability;
- few if any specialist services existing for this group; and
- young people with an intellectual disability being a “particularly vulnerable group at great risk of exploitation”.

Since The Burdekin Report, a number of other studies\(^1\) have raised the issue of homelessness amongst people with an intellectual disability. A 1995 study by the NSW Council for Intellectual Disability and Opposition Youth Crisis Centre found that young people with intellectual disability are at greater risk of chronic homelessness than their peers, and are overrepresented in the homeless population. These studies, alongside a wide body national and international research, document the multiple disadvantages to which people with an intellectual disability are vulnerable. This includes:

- Significant over-representation in the criminal justice system - as victims of crime; as suspects, defendants and offenders; and in prisons and detention centres (French: 2007; Law Reform Commission of NSW: 1992; Hayes and Craddock: 1992).
- More likely to suffer with under-diagnosed or under-managed health issues (Hammond et al 1995).
- More likely to be unemployed (Ierace: 1989; Coleman: 1994).

**ARRROS Practice:**

The common life experiences of many of the young people ARROS supports, reflects this research. All of the young people we have worked with have experienced some or all of the following:

- Loss of contact with family.
- A history of involvement in the Child Protection system.
- A history of, and ongoing, vulnerability to financial, sexual, and emotional exploitation and abuse.

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\(^1\) Difford, Marshall and Rose (1991); R?? and Spencer (1992); Underwood, Jackson and Lee (1993); The SHIFT Report (1993); The National Evaluation of the Supported Accommodation Assistance Program (1993); Coleman (1994); O’Connor and Coleman (1995); N.S.W. Council for Intellectual Disability and the Opposition Youth Crisis Centre(1995)
• Frequent contact with Police and Justice Systems.
• Lack of relationships with supportive adults.
• Lack of a valued role or position in the community.
• Limited education, and poor or traumatic educational experiences.
• Chronic unemployment.
• Poverty
• High levels of ongoing stress and anxiety, which leads to a high incidence of acquired mental health issues and mental disorders.
• Poor physical health, resulting from poor diet and lack of exercise.
• Lack of stable housing, and have had long-term experiences of homelessness.
• Substance abuse

3. Pathways and experiences of homelessness (focus on Exiting Care)

People with an intellectual disability face particular challenges when they are homeless.

1. Lack of appropriate and effective service support

• Traditionally, this group has high-level contact with crisis response services, but they do not access ongoing support services. As a result, long term intervention does not take place and people often become more deeply entrenched in homeless, mental health, child protection, drug and alcohol, and correctional systems.

• Youth and homeless services often have difficulty supporting this group. They are viewed as ‘too high needs’, or excluded for ‘challenging behaviours’.

• Paradoxically, this group are often excluded from disability services on the grounds that they are ‘too high functioning’. Most young people with an intellectual disability who are homeless fall into the “mild” intellectual disability range. With their disability and support needs minimised by the misnomer of ‘mild’, this group don’t meet the criteria for individualised funding from Disability Services Queensland. This excludes people from the ‘pay-for-service’ supports that are a feature of the disability sector.
2. Lack of appropriate accommodation options

- There are currently few appropriate accommodation options for this group. These young people are vulnerable to exploitation and abuse in homeless and youth shelter systems, and equally vulnerable when couching surfing with ‘friends’ and acquaintances. Traditional disability accommodation services, group homes, and care facilities are not available to this group, and would not meet young people’s need to live what they see as a ‘normal’ life in the community.

3. Lack of supportive relationships

- Poverty, family break-down, unemployment, social isolation, and a lack of supportive relationships mean these young people do not benefit from the web of informal supports that many of us take for granted. Families are often overwhelmed by the demands of supporting the complex needs of a young person with an intellectual disability, and many young people enter the Child Protection system, and graduate from that system into homelessness.

- In our practice at ARROS, relationships have proven to be the key ingredient in all successful work with this vulnerable group. This is a point which cannot be stressed enough. Whether the question is housing, employment, health, social isolation, criminal activity, or anything else, our experiences have demonstrated that RELATIONSHIPS will be the biggest part of the answer.

4. Vulnerability to exploitation and abuse

- When people with intellectual disability become homeless they are highly vulnerable to exploitation and abuse by other service users in the youth and homelessness systems, or by “friends” and acquaintances whom they may depend on for accommodation and other needs. There are a number of factors that contribute to this vulnerability –

  - By virtue of their intellectual impairment, people with ID are easily taken advantage of and ‘conned’
  - They are a financially attractive target, with the Disability Support Pension offering greater financial reward than other benefits;
  - Many people with intellectual disability will have experienced rejection, exclusion, abuse and neglect throughout their lives. As such, they may tolerate abusive behaviours, not feel able to say no or seek help, or not recognise that it is not acceptable for people to be treated in these ways.
  - The need to be loved is at the core of our being. For many people with intellectual disability, experiences of love, friendship and belonging have either been largely absent from their
lives, or fraught by abuse and exploitation. So many people we work with are searching for a place to belong, to fit in, to be accepted. On this most human of journeys, they are, however, particular vulnerable to unscrupulous individuals who readily take advantage of them, and abuse them – be it physically, emotionally, financially, sexually, or through involvement in drugs, alcohol, and crime.

Research demonstrates that there are many pathways into homelessness, and I would now like to give some consideration to these issues. Pathways into homeless for people with intellectual disability are the same as for other homeless people, and include,

- Family Breakdown
- Exiting Child Safety
- Mental Illness
- Involvement in Criminal Justice System
- Drug and Alcohol addiction
- Exiting Corrections

I will focus today on one of these pathways, namely young people who are exiting care.

**Journeys of Exclusion**

In 2006, CLP and ARROS commenced the Journeys of Exclusion Project. This project developed out of the recognition that many of the young people ARROS and CLP work with have experienced a breakdown of natural family support, with many people entering out-of-home care. The Journeys of Exclusion Research looked at the life experiences of 43 young people with an intellectual disability who had exited care. The majority of these young people have experienced poor life outcomes since exiting care, with the research findings demonstrating:

- 59% of the young people had experienced **homelessness**.
- 2 ½ years after exiting care only 1 young person was in the same accommodation.
- The other 42 young people had experienced several accommodation situations, including boarding houses (40%) and homeless shelters (30%). Other housing included the streets, friends homes, prison, nursing homes, and community housing.
- 42% of the young people (all women) had a child within 2 years of exiting care. There was a Child Protection intervention rate of 96% across these 17 families. Only 1 of the 17 families had not Child Protection involvement.
- 17% of the young people had been charged with a **criminal offence**, with 10% being charged with more than 1 offence.
- 71%-88% of these young people have been **victims of crime**. 67% of these crimes were sexual assault and rape. Only 3 perpetrators were convicted.
- 60% of the young people have had contact with mental **health** services.
• 44% of the young people are reported to have engaged in **substance abuse**.

• 94% of the young people are **unemployed**.

Whilst our sample of 43 young people is small, the findings of the Journeys of Exclusion research is consistent with a growing body of research addressing the poor life outcomes of young people who have been in out-of-home care. Recently published preliminary findings from a study by RMIT’s Australian Housing and Urban Research Institute, suggest a direct link between homelessness and being in state care in childhood or adolescence. Of 1,600 people who reported that they were homeless before they were aged 18, 40% of these had been in state care.

I would now like to move on to look at types of responses that are needed to, firstly, prevent people with intellectual disability from becoming homeless; and secondly, assist those people who are homeless to move out of this situation at the earliest opportunity.

**4. Proposals for Change: Prevention and Intervention**

Responding effectively to the experiences of homelessness by people with intellectual disability requires both Prevention and Intervention actions. The biggest single preventative factor that will protect people with intellectual disability from becoming homeless, or help them to move out of homelessness, is the presence of supportive others in that person’s life. To that end, relationships are at the heart of all successful Prevention and Intervention strategies.

**Prevention**

On the homelessness trajectory, there are two obvious points of Prevention where the right interventions can stop people with intellectual disability from becoming homeless:

1. **Supporting vulnerable families with children with intellectual disability**, so that these families are able to function well and support their children; and

2. **Focused support to children with intellectual disability who have lost family support**, and have entered child safety. As evidenced by the Journeys of Exclusion research, young people with intellectual disability exiting child safety at age 18 are at high risk of homelessness and associated issues.
**Tertiary Intervention**

Tertiary intervention can either maintain people in the homeless system, or seek to help them exit it. If people have not been protected from becoming homeless, our next goal, of course, should be to get people out of homelessness, and to that end I advocate the following:

1. **At the tertiary intervention level there needs to be clear direction regarding which government department is responsible for the support needs of people with impaired decision making who are homeless.**

At the present time this responsibility is fractured and passed between Disability Services Queensland (whose support dollar is directed primarily to people with physical disabilities and “profound” intellectual disability); Department of Communities (who fund SAAP services whose short term and limited support model does not fit with the long term support needs of this group); and Department of Housing (who provide housing only – and housing alone is not an effective response for this group).

2. **Services need to have the resources and practical knowledge to support homeless people with impaired decision making.**

Services that come in contact with this group generally find them difficult to work with. There are a number of reasons for this:
- People in this group have multiple issues, and require the support of an holistic practice model.
- The range of issues, the effects of intellectual disability, and people’s entrenched disadvantage mean that interventions require long term work, and are generally slow in pace.
- People with intellectual disability are vulnerable to exploitation by other service users.
- The supports that are offered to people may inadvertently compound their problems – for example, monetary assistance may lead to further financial exploitation; housing without appropriate support may lead to exploitation and abuse (by co-tenants, neighbours, or community members).
- People with intellectual disability do not necessarily learn from their experiences, and may repeat mistakes. This challenges traditional practice ideas of supporting people to take personal responsibility and achieve personal growth.
- People will struggle with decision making and problem solving. Services may have to oppose a person’s decisions or expressed wishes, and may quite rightly struggle with this. Practice
values of self-determination, choice, confidentiality, and free will are often challenged in working with this group.

At both the Prevention and Tertiary Intervention levels, support services must comprehensively respond to the support needs of homeless people with intellectual disability. Whether preventing entry into homelessness, or assisting people to exit and establish an alternative life, the key elements of successful intervention are to:

1. **Support existing, and develop new, ongoing long-term supportive adult relationships:**

   Good relationships give people a sense of worth, purpose and belonging. They are critical in supporting people to make changes that are too difficult to follow through on alone. Good relationships mean that people have someone who is looking out for them and their interests. Being “cared about” has a positive impact on people’s sense of self worth, and also offers vulnerable people great protection from the exploitation and abuse that thrives in environments of secrecy and isolation. An old Czech proverb sums up this idea, saying:
   
   “Do not protect yourself by a fence, but rather by your friends”.

2. **Reduce people’s vulnerability to further exploitation and abuse:**

   - Proactively intervene in exploitative relationships (either observed or suspected).
   - Establish money management supports which can reduce vulnerability to financial exploitation - including financial management by the Public Trustee.
   - Provide sexuality and relationship education, in a way that supports people to learn, remember, and ask questions. This won’t work as a one off sex education lesson, but rather as a process of ongoing discussion and education.
   - Provide appropriate supports to people involved in the legal system, either as victims and offenders.

3. **Support people to develop a meaningful social role:**

   People with an intellectual disability and homeless people, are two groups who often have few valued roles in society other than consumer or recipient. This contributes to their experiencing feelings of uselessness and boredom, which in turn impacts negatively on people’s mental health. People may then engage in substances misuse to alleviate boredom, and to self-medicate depression. Bored and lonely, people are vulnerable to involvement with exploitative people, and engagement in negative activities, including crime. This, in turn, deepens their entrenchment in homelessness.
There are many tensions to be addressed in endeavours to support people to find a meaningful social role. It requires much more than “a job”. We must recognise that people’s level of productivity may be so low that they will find it difficult to succeed in open employment. At the same time, it is our experience that many people will resist the idea of sheltered workshops.

What is needed, are a range of creative mechanisms that allow people to share their gifts. An example from the Community Living Association experience is the Nundah Community Enterprises Co-operative which was established in 2002 to provide meaningful employment to people with an intellectual disability. Furthermore, meaningful social roles are not limited to paid employment – they are almost unlimited, and include roles such as volunteer, friend, daughter, neighbour...

4. **Support people to secure appropriate living situations:**

Responding to homelessness and vulnerability means much more than providing people with a roof and 4 walls. It is our experience that people living alone are vulnerable to abuse and exploitation that may remain hidden. On the other hand, there are many risks facing young people when they live in inappropriate settings with other people, who may exploit or abuse them, such as in boarding houses, hostels, and even with friends and family.

Appropriate living situations must be tailored to the individual, but a key feature will be the active and regular presence of a supportive adult or adults. This may be someone that the person lives with, for example an ex-foster carer, or a supportive co-tenant or landlord. Another model is where supportive people come into the person’s home on a regular basis to assist them with maintaining their accommodation, building social connections, and having a role and structure in their life.

5. **Support people’s physical and mental well being:**

- People with an intellectual disability who are homeless will have experienced much trauma and abuse. They must be supported to process and recover from the abuse and exploitation they have experienced (and in many cases continue to experience).
- Services must support people to access mental health and counseling supports; substance abuse treatment; and physical health care, that is appropriate to people with an intellectual disability.
5. CONCLUSION

To conclude, I would like to sum up with the following key points:

- People with intellectual disability, along with other people with impaired decision making are over-represented amongst homeless populations.
- These groups are particularly vulnerable.
- People are most likely to be homeless if they have somehow lost supportive relationships in their life.
- Prevention and intervention policies should aim at focusing on those points in a person’s life cycle where intervention might make a difference – for example, support to young people with intellectual disability in Child Safety, prior to their exiting this system; support to people exiting Prison.
- Current interventions often maintain people in homeless systems.
- For interventions to effectively support people to exit from the homeless system, they will need to be:

  a) **Holistic:**
  For homeless people with intellectual disability, **accommodation alone will not be the answer.** People will also need comprehensive support to generate an alternative life, and address issues of financial management, meaningful use of time, health and hygiene, cleaning, relationships, addictions, mental health.

  b) **Able to offer long-term commitment:**
  People with intellectual disability will always have an intellectual disability, and will require ongoing support to manage daily life.

  c) **Able to manage complex ethical practice issues:**
  Effective support services must not shy away from complex issues like substitute decision making around issues like money and accommodation. Services will need to challenge people’s destructive choices, whilst holding to and being guided by principles of respect and least restrictive alternative,