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Abstract | People with intellectual disability face a range of challenges on their release from prison due both to their own needs and the complexity of the service delivery system, which can make effective service delivery difficult. This difficulty is exacerbated by the sometimes combative nature of relationships between service providers. These issues could be addressed, at least in part, by improved training and stricter guidelines for those working in the sector.

Representatives of disability and justice-related agencies in Queensland and Western Australia were interviewed for this research. The findings will be useful to policymakers and those who work in corrections, disability support and related sectors.



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Transition from prison for people with intellectual disability: A qualitative study of service professionals

Jesse T Young, Kate van Dooren, Fernanda Claudio, Craig Cumming and Nick Lennox

People with intellectual disability are over-represented in prisons internationally (Fazel et al. 2008); in Australia, approximately nine to 10 percent of soon-to-be-released prisoners have an intellectual disability (Dias et al. 2013). Prisoners with intellectual disability often experience complex comorbid chronic physical conditions and mental health disorders (Männynsalo et al. 2009; Dias et al. 2013; Dias et al. 2014). Substance misuse among prisoners with intellectual disability is also common, both prior to and during incarceration (Hassiotis et al. 2011; Bhandari et al. 2014). Prior research has shown prisoners with intellectual disability are more likely to use certain illicit drugs (Hassiotis et al. 2011). They are also more likely to risk substance-related harm through practices such as injecting drug use and sharing needles in prison than prisoners without intellectual disability (Bhandari et al. 2014).

Although little is known about the post-release circumstances of those with intellectual disability in Australia, many experience homelessness, unemployment and social isolation prior to their incarceration (Baldry, Dowse & Clarence 2012; Dias et al. 2013; Dias et al. 2014). Given their substantial health inequities, social

needs and elevated rates of reoffending, people with intellectual disability are likely to need targeted support during their transition from prison (Cockram 2005a; Ellem 2010).

Recidivism is a substantial issue for those with intellectual disability (Holland & Persson 2011; Riches et al. 2006). Victorian data suggest that ex-prisoners with intellectual disability return to prison at more than twice the rate of ex-prisoners without intellectual disability, with a similar time to reincarceration (Holland & Persson 2011). This may be because ex-prisoners with intellectual disability are younger and more likely to be unemployed and/or are subject to increased criminal justice system surveillance (Cockram 2005a; Cockram 2005b).

Prisoners with intellectual disability share similar needs, such as employment and social support, with their peers without disability; however, prior research has observed they have a significantly greater need for support to address homelessness and literacy after release from prison (Holland & Persson 2011). Providing effective support is complex; previous attempts to implement person-centred planning have yielded inconsistent results (Robertson et al. 2007).

The DSM-5 criteria for the diagnosis of intellectual disability have broadened in scope from earlier approaches that relied primarily on IQ scores (Schalock et al. 2010). They now incorporate three domains of intelligence—conceptual, social and practical—with an increased focus on functional capacity and the need for assistance (American Psychiatric Association 2013). However, individuals with mild or borderline intellectual disability often experience particular difficulties accessing disability-specific services because they are not recognised as experiencing sufficient disability to qualify for government-based financial support (Baldry et al. 2012).

The National Disability Insurance Scheme (NDIS) is a billion-dollar Australian Government program that offers ‘eligible people a flexible, whole-of-life approach to the support needed to pursue their goals and aspirations and participate in daily life’ (National Disability Insurance Agency [NDIA] nd). The NDIS offers individualised funding packages; control over expenditure rests with the person (or their nominated decision-maker) rather than with a government department (NDIA nd). However, the eligibility of those involved in the criminal justice system for NDIS funding is yet to be clearly defined.

It is critically important, therefore, to understand how this group currently transitions from prison. This will contribute to an evidence base that can inform decisions about how the NDIS and service providers ensure those most vulnerable are not overlooked or excluded from the services they need.

Methodology

This paper is based on analyses of data collected in 2014–15 through a grant from the Australian Institute of Criminology (CRG 26/13-14). The research examined how those with intellectual disability experienced transition from prison, and how criminal justice, health and disability sector professionals perceived these experiences.

This paper focuses on the perspectives of professionals working with ex-prisoners with intellectual disability. These key informants were recruited using purposive sampling of individuals, networks and agencies that interact with ex-prisoners with intellectual disability. Interviews were conducted across Western Australia (WA) and Queensland. The narrative interview schedule included questions on how people with intellectual disability are supported during their transition from prison, with the aim of

documenting the perceptions and experiences of those working in the criminal justice, health and disability systems. Interviews primarily took place at key informants' workplaces during business hours and lasted 50 minutes on average.

Two research assistants experienced in working with vulnerable and marginalised population groups conducted the interviews. Informed consent was obtained prior to all interviews and all interviews were digitally recorded and transcribed in full.

Interviews were manually analysed for themes related to the specific research questions, which were:

- Where do health professionals and individuals perceive that gaps in the transition out of prison exist; and
- Which specific steps can be taken to address unmet needs?

Themes are illustrated by quotes from key informants that clearly communicate the individuals' expectations and experiences of the criminal justice systems of Queensland and WA. To maintain the privacy and confidentiality of participants, descriptions of key informants are limited and illustrative quotes are identified only by jurisdiction (Western Australia or Queensland) and the key informant's sector (justice or disability).

This study received ethical approval from the University of Queensland (approval number 2014000225) and the University of Western Australia (approval number RA/4/1/6738).

Findings

Seventeen key informants in Queensland (N=7) and Western Australia (N=10) were interviewed, including managers, coordinators, support workers and case workers. Most key informants had worked for several disability or justice-related organisations over their careers, which spanned between five and 30 years. All key informants described diverse and complex roles that generally involved providing wraparound support for their clients. These roles included supporting and, often, managing processes around accommodation, Centrelink, health assessments and other health or social support, and funding arrangements. The organisations worked with clients on both a voluntary and involuntary (eg court-mandated) basis.

There were two groups of key informants—service providers from the disability sector (N=6) who targeted their services to people with intellectual disability, and service providers from the justice sector (N=11) who targeted prisoners and ex-prisoners. The justice sector group were more likely to engage with prisoners and ex-prisoners with mild or borderline intellectual disability, rather than those formally identified, who often experience more prominent intellectual disability. Often, this was due to funding arrangements that precluded their organisations becoming involved with those formally identified (clinically or otherwise) with an intellectual disability; these people receive services from disability-specific organisations.

Gaps during transition from prison

Key informants reflected on how people with intellectual disability transition from prison and identified some crucial gaps.

Inadequate life skills

One major consequence of having intellectual disability was an inability to plan and/or take action to maintain a healthy lifestyle without appropriate levels of support. Individuals with intellectual disability need support to learn life skills on release from prison, including hygiene, cleaning, cooking, eating well and developing healthy routines. These life skills must be addressed before other issues can be dealt with, as one professional noted:

We are good at telling people what they need to do. But they need practical skills and help to be able to get these basic things done. There are so many competing priorities in their lives (WA justice organisation).

Community connection was also highlighted as critical because of the social isolation that ex-prisoners with intellectual disability, many of whom live alone, would otherwise experience. Connections with general community services, such as Centrelink or the local library, helped build communication and social skills.

Informants noted many ex-prisoners with intellectual disability lacked basic life skills, suggesting that this lack was associated with their personal circumstances prior to their incarceration. Issues like neglect, poverty and marginalisation may stem from unsupportive family backgrounds characterised by a lack of basic skills training and the education assumed to be usual for most adults.

One fella that we had...he did not know how to use deodorant. Did not know where to apply it. Never had had a hot shower. So he obviously had never had one inside. So that says something... The basic stuff that you assume an adult would be able to do was not there. Stuff that we all take for granted that our guys had never had taught to them (WA disability organisation).

Similar to the general prison population, ex-prisoners with intellectual disability often come from families with entrenched histories of disadvantage and incarceration.

I know a lot of their history and I've met a lot of their families. So I know they have not had particularly good upbringings. And, generally the whole family is in and out of prison. So it is like a familial thing that happens (WA disability organisation).

Key informants suggested that a lack of basic life skills, such as maintaining personal hygiene and managing complex social interactions, was a long-term issue that could be traced back to a person's childhood.

Recognising and understanding intellectual disability

Issues related to cognitive abilities were more often raised by those who worked with disability-specific organisations, indicating that a specialised skillset is required for a nuanced understanding of the needs, abilities and complexities of individuals with intellectual disability. A key issue for those without training in disability services was the lack of formal diagnosis of individuals with intellectual disability. Key informants in the justice sector reported a lack of experience and felt like 'outsiders' because they had not received specialised intellectual disability training and were unfamiliar with the disability sector. These informants may not have had prior access to disability organisations or support because their funding models precluded interaction with the disability sector.

Individuals with no formal diagnosis of intellectual disability might be informally identified during incarceration; however, they often do not receive targeted support or funding following release. It rests

instead with organisations and workers to identify their needs. Informal identification of intellectual disability is at times problematic, in a sector that does not receive any intellectual disability-specific training or education. Further challenges arise when those with intellectual disability prefer not to be seen as having an intellectual disability, or do not identify as living with an intellectual disability. These preferences are consistent with key informants' perceptions that intellectual disability may increase the vulnerability of those who might not understand prison dynamics, or who might be identified by other prisoners as being different or easily manipulated.

Other prisoners will sense people's vulnerabilities and weaknesses and yeah, take advantage of that. You know, it's kind of survival of the fittest in there. If you've got an intellectual disability, you're at the top of the vulnerability ladder (QLD justice organisation).

However, masking or failing to acknowledge an intellectual disability can make it difficult to identify cognitive impairment and respond to any associated needs. The diversity of individuals' experience of prison was also noted, with one key informant stressing that not all prisoners with intellectual disability should be considered vulnerable.

System complexities

Key informants raised a common theme of difficulty in 'navigating the system'—that is, in facing the challenges of managing clients whose complex needs span several different systems including mental health, disability and justice. Consequently, individuals were often pushed into gaps within and between service sectors. Failure to clearly identify intellectual disability can cause confusion about which service stream should be primarily responsible for care, which often results in increased complexity of service system navigation requirements and service gaps.

...it can be very, very unclear what's going on for a person if it's clinically complicated, but what magnifies that is service system complications when we're all trying to work out what's happening clinically. All too often there can be a debate between mental health services and disability services and then the person ends up subject to that debate (QLD disability organisation).

This system complexity prompted concerns about the new NDIS; informants worried that it might be assumed that other disability, justice or mental health organisations were already picking up funding and providing support, when no organisation was actually doing so.

There's a risk with the NDIA through not having a lot of experience with offenders with disability. There's a risk they assume that this work has been done by justice or health or other health agencies and then this won't be a requirement of them (QLD disability organisation).

All key informants highlighted the current system's complexity and lack of integration as a potential barrier to effective service delivery and, ultimately, a successful transition from prison.

Practically, emphasis was placed on the need to work with the Public Guardian, who might act as a substitute decision-maker for adults with intellectual disability, and the Public Trustee, who may manage funds on a person's behalf. In both jurisdictions, the complexities around detention under legislative provisions for those deemed unfit to plead—for example, under the *Criminal Law (Mentally Impaired Accused) Act 1996 (WA)*—compounded the difficulty for those working in the system. Key informants described their confusion and frustration at the processes and barriers that applied under these conditions.

Inconsistencies between the requirements of supervised release, and what is realistic or pragmatic in terms of funding or other supports, added to an already difficult environment. Key informants reported tensions between accommodating the support needs of their clients and meeting their legally mandated supervision obligations (which are enforced for the safety of their clients and the community).

These requirements left key informants feeling they lacked control over their own service delivery.

But I had no control...That was a real source of frustration and we had no control over things even though everything was in place. We had met with the prison and had plans in place (WA disability organisation).

Combative relationships within services

All key informants emphasised the importance of effective working relationships. Informants from WA generally expressed more positive perceptions of their collaboration and relationships with corrective services. It was noted that, while the system itself was complex and at times difficult to navigate, those working within the system strove for the best outcomes for ex-prisoners with intellectual disability. Such positivity around service-provider relationships in Western Australia may be associated with the fact that formalised processes exist in that state to identify people with intellectual disability and address their needs.

Conversely, in Queensland, some service-provider relationships were perceived as less effective and, at times, even combative. Most key informants reported that these were problems with the larger system, rather than with individuals. However, most expressed discontent with organisations that were seen to be operating successfully in an 'unfair' system. In Queensland, this distrust and the consequent combative approach to relationships appears to have been exacerbated by historical and recent funding cuts across criminal justice-related sectors.

Y'know they cut all the services that work with people with intellectual disabilities, y'know the drug and alcohol workers, all those things, the early intervention that stopped people going into prison. They told us the state is broke and they cut all the programs (QLD justice organisation).

A key informant from the Queensland government sector was aware of tensions between services and across systems (eg in mental health, disability and justice) but wanted these tensions to be put aside in the best interests of the clients. For this key informant, funding was less of an issue than it was for informants working in non-governmental organisations (NGOs) hit by recent severe funding cuts.

The other thing that would help, and certainly from a government perspective, is for us to understand that regardless of which department or...departments accept responsibility for supporting a person, they will ultimately be a responsibility of the state...so let's not argue over who does it, let's just accept that it has to be done and we can get on and do it...Let's just stop drawing lines in the sand or pointing fingers at each other (QLD disability organisation).

With the rollout of the NDIS, the impetus to work together with other agencies and across systems was stronger than ever.

We will no longer have a specialist state-based disability service system. Our advocacy collectively needs to be towards how the NDIS roll out is going to be in support of this cohort, because some of

our own old battles are not going to be there anymore under a different system. We need to think about that system and not the one we are currently in (QLD disability organisation).

However, Queensland key informants in particular were cynical about the possibility of positive changes to the system, with one participant saying the need for through-care was vital, but it was 'never going to happen'. This person was concerned that, even with a robust evidence base, the current situation will not change because of negative community attitudes to money being spent on prisoners:

And all the research in the world... is not going to change that (QLD justice organisation).

Creating successful transitions

Key informants drew on their own practical experience, as well as what they would like to see in an ideal world, to identify facilitators of successful transition for ex-prisoners with intellectual disability.

Early planning and continuity of care

All key informants raised the critical importance of early planning and continuity of care as essential processes.

Not just for people with intellectual disability but for everyone who comes out of prison (QLD disability organisation).

Service contacts with sufficient 'quality (one-on-one) time' and proper training were highlighted as crucial to a positive transition experience. Aligning the timing and scope of support with the extent of the former prisoner's re-entry needs was also considered pivotal for successful reintegration.

Identifying individual needs and providing appropriate support was seen to be most effective when agencies had sufficient time to work with a person, prior to their release from prison, to plan their transition into supported accommodation. Many agencies noted the importance of having a worker dedicated to client contact on the day of release, and of continued contact in the subsequent days and weeks in the community. Ongoing support can then be tailored to the individual's circumstances and needs.

We knew when his release date was and a place became vacant probably two weeks before he was released and they held it open for him...We then got him in touch with [another organisation] to get those things he needed. Like bed sheets, pillows, y'know all those cooking implements (QLD justice organisation).

Early planning and through-care would ideally involve the collaboration of multiple stakeholders. For people with intellectual disability and/or a dual diagnosis, the involvement of clinicians is important. Additionally, it was generally agreed that prisons should be involved in making transitional arrangements and support organisations to be more involved with vulnerable individuals prior to their release. Information exchange between prisons and supporting agencies was seen as critical to providing effective support in the community.

Discussions of through-care generally included consideration of the costs of service-delivery optimisation, with funding often tight or, at times, unavailable.

The current lack of block funding, in particular, was perceived to be a challenge due to an uneven distribution of funding, wherein some individuals received too much funding and some not enough.

Informants asserted this was because agencies could not distribute excess individualised funding among groups.

Changing community perceptions

The need to either change community attitudes to support for ex-prisoners, or to change policy so that government agencies are required to act regardless of community support, was a common theme in both Queensland and Western Australia. In Queensland, where some key informants believed funding cuts were ideologically based, there was consensus that the latter option was most viable.

[I]n conservative political environments is not going to be a vote winner...maybe it requires action and leadership regardless of whether there is a broad public interest. This topic might not be a vote winner but that doesn't mean you shouldn't do it (QLD disability organisation).

Key informants noted that the lack of community support for ex-prisoners also extended to other disenfranchised, poor and marginalised individuals.

People and the community have the view of locking people up and throwing away the key. The rich are getting richer and the poor poorer. The social divide is getting bigger...these population groups are being devalued (QLD justice organisation).

Relationships and trust

Most key informants discussed the importance of building relationships and trust with their clients. Quality time was needed to build such relationships, further emphasising the importance of early planning and continuity of care post-release.

Sometimes it takes a very long time for the guys to realise that they have a voice...I have one gentleman who has only quite recently started to say...'I'm not comfortable with this person'. And that is huge for him because he has been in prison for so long that he would just do what anyone said (WA disability organisation).

Across Western Australia and Queensland, establishing trust early and maintaining ongoing links and relationships with individuals in the community was considered requisite to successfully supporting the transition of ex-prisoners who have experienced marginalisation, social exclusion and institutionalisation.

We have known many for 20 years or more. Have taken some holiday trips to Bali or to Melbourne grand final days. We try to make things as personalised as possible. Try to be involved in their lives. Have set up a drop-in centre for them with Xbox, computers, art equipment (WA disability organisation).

Improving the system

In WA, where collaborations were generally perceived as positive and there appeared to be formalised systems for identifying the needs of ex-prisoners with intellectual disability, staff training was preferred to overarching policies.

I feel that across the board, targeted training is better and more suitable than across the board policy changes...this is because the individualised and dynamic nature of the work is best met

and addressed by staff training rather than by overarching policies and procedures (WA disability organisation).

However, in Queensland, where collaborations were seen to be less successful and organisations felt that prior system-level changes disrupted quality service delivery, it was thought that legislative change was required to improve transitional support.

I've seen really good leadership in very high levels of government in Queensland around fostering [relationships], that I've got to be frank. I haven't necessarily seen that strong leadership translate into substantive changes at an operational level (QLD disability organisation).

More stringent legislative guidelines may address the issues on the ground in Queensland.

Despite differences in opinion about whether systems-level changes would be best achieved by training or by legislation, most informants agreed that some general training in disability services was critically important for forensic health, prison support and correctional staff. Key informants suggested that finding the 'right staff', with qualifications, was very difficult. Some informants asserted that disability-specific training in undergraduate education should be combined with mentoring from senior professionals who have been 'through the system' to upskill those entering the disability service workforce. This would help to develop high-performing support workers and advocates for the next generation of people with intellectual disability in the criminal justice system.

Harnessing the knowledge base—I don't think that...we have [that] here in Queensland yet, systematically. We need to...have a group of people who are confident with and knowledgeable in this space (QLD disability organisation).

In particular, targeted, disability-specific training for prison officers to improve their interactions with prisoners with intellectual disability was seen as important. Key informants noted that prison officers and corrective services staff did not seem to have access to education relevant to working with people with intellectual disability.

Discussion

Currently, those with intellectual disability who transition from prison must interact with a complex service environment. This research indicates that there are clear differences between policy, service-delivery objectives and the actual delivery of services to ex-prisoners with intellectual disability. The findings suggest there are many reasons for this complexity, including:

- the unique challenges faced by service providers required to meet both legal supervision obligations and the support needs of their clients;
- a lack of formalised coordination between the justice system and disability service providers prior to release; and
- resentment between disability service providers related to perceived funding inequities.

These issues, along with the challenges corrective services staff experience in identifying and working with prisoners with intellectual disability, contribute to service complexity.

This study identified that building strong working relationships among disability and justice service providers is crucial. Managing the various levels of cognitive and social vulnerabilities and support

needs of people with intellectual disability requires an evidence-informed approach. Service providers were often overworked, under-resourced and lacked job security within shifting policy and funding landscapes. In this challenging context, they provide services to a poorly defined population with extensive, complex and highly specific needs. Accordingly, trust is essential to establish collaborative relationships between service providers and their clients.

Heterogeneity among ex-prisoners with intellectual disability (particularly around needs) and the necessity for flexible program delivery was a prevailing theme. If agencies who work well with ex-prisoners—including those whose intellectual disability may be hard to identify—can provide support that meets their needs, this may mitigate some of the challenges to successful reintegration and ultimately reduce recidivism among this group.

Article 9(1) of the Convention on the Rights of Persons with a Disability (UN General Assembly), which was ratified by the Australian Government in March 2008, requires appropriate measures to be taken to promote access to new systems for persons with disabilities. Of particular note is article 9(1)(b), which refers to eliminating barriers to accessing ‘information, communications and other services’. Applied to the context of transitioning from prison, these measures could include assisting individuals with intellectual disability access important services such as Medicare, a disability advocate, a carer and tailored support services. Transitional outcomes for this marginalised population would be improved by stable, individualised support to:

- navigate complex referral and scheduling;
- adopt and maintain healthy lifestyles;
- understand and adhere to medical advice;
- actively participant in healthcare decisions; and
- enhance their capacity for self-management and health-related autonomy (Ellem 2010; Baldry et al. 2013).

However, relatively little is known about the health and related factors that predict successful transitional outcomes among this group; further research on this is warranted.

Given the challenges people with intellectual disability face in areas such as health as they leave prison (Dias et al. 2013), the NDIS has a crucial role to play in supporting this group. Eligibility for NDIS funding has yet to be clearly defined for those involved in the criminal justice system. What is clear is that access to the NDIS means navigating complex bureaucracy and requires an understanding of the requirements for eligibility and access and an ability to advocate effectively for one’s needs. This may be a challenge for those experiencing even mild intellectual disability who have no strong advocate or support person to assist them.

When the NDIS has been rolled out across all jurisdictions, the Queensland Government will shut its disability department. Western Australia is currently participating in a two-year trial using two different models, pursuant to rule 1.3 of the National Disability Insurance Scheme (Facilitating the Preparation of Participants’ Plans—Western Australia) Rules 2014. The scheme was originally to be trialled in two specific parts of Perth, but has been expanded prior to a final decision on the funding model to be adopted from 2017. For those without NDIS access, this closure could have severe consequences. Community support and non-government organisations will no longer receive ‘block’ government funding and will rely on individualised NDIS funding to deliver services (NDIA nd). Consequently, many

organisations that rely solely on direct client funding may not be able to provide outreach services to those who do not have access to a funding source.

Exploring issues such as those raised in this study requires a methodology that allows sufficient time to build meaningful and trusting relationships within the prison, health, volunteer and NGO sectors. When working with vulnerable populations such as ex-prisoners with intellectual disability, it is critical that trust be established between researchers, service providers and consumers to ensure both the rigour of evidence generated and, more critically, to uphold the rights of all participants.

Conclusions

Ex-prisoners with intellectual disability have substantial transitional needs. This group is widely underserved, especially those with mild or borderline intellectual disability. Formalised service-integration protocols across the forensic, health, community and social agency domains are warranted, and there is a clear need for evidence-informed screening and identification processes for people in custody with intellectual disability. Early planning and communication between custodial staff and non-custodial service providers could improve the continuity and quality of service provision during the critical transition period. System-level priorities include:

- providing funding commensurate with need;
- developing adequate structure and governance that allows flexible service provision; and
- more intellectual disability-specific training for the forensic and community workforce.

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