

Understanding the transition out of prison for people with intellectual disability

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INTRODUCTORY STATEMENT

This report fulfils the requirements to Grant CRG 26/13-14 funded by the Australian Institute of Criminology. We provide a full literature review, statement of the aims and objectives of the study, report of the methodology and findings, a discussion providing indication of policy implications, and conclusions.

In doing so, we would like to acknowledge the participants of this study, without their generous contributions we could not have made such important observations and insights. Given the difficulty we experienced in recruitment, we are particularly grateful for all participants who went to significant lengths to provide their time and expertise for this study. We would also like thank our two talented research assistants, Mr Nathan Visser in Western Australia and Ms Carmel Blackburn in Queensland, who conducted all interviews and most transcriptions.

Over the course of this grant, our project team has been accepted to four conferences (two as invited speakers), published a letter to the editor and an article for *The Conversation* and been accepted to write a book chapter about ex-prisoners with intellectual disability. We continue to collaborate on this research agenda, and wish to thank the AIC for this seed-funding that has made this research possible.

PARAGRAPH FOR INCLUSION IN ANNUAL REPORT

Approximately 1 in every 10 soon-to-be-released prisoners in Australia lives with an intellectual disability, yet remarkably little is known about their health and justice-related outcomes following their release from prison. This study aimed to understand the health and social needs during transition out of prison for people with intellectual disability across two Australian states: Queensland and Western Australia (WA). We interviewed 17 service providers to seek their perspectives about where gaps in the transition out of prison exist and which specific steps can be taken to address unmet need for ex-prisoners with intellectual disability. Our analysis of key themes identified inadequate life skills, identification of disability, system complexities and combative relationships as crucial gaps to providing comprehensive and effective support during the transition out of prison. Key facilitators to overcoming these gaps included timely planning of transition, continuity of care, relationships and trust, training of service providers and the National Disability Insurance Scheme (NDIS). This arena is complex. Our results indicate that there exist clear differences between policy, service delivery objectives and actual delivery of service to ex-prisoners with intellectual disability. Our findings suggest a clear mandate for modifications and adjustments to current support arrangements (or the creation of support where it is currently absent) and the need for systemic change to address ‘wicked problems’ that hinder the ability of ex-prisoners with intellectual disability to remain out of prison and healthy.

BACKGROUND & LITERATURE REVIEW

In Australia, many more people transition in and out of prison each year than are incarcerated at any given time (Kinner and Avery 2015; Steering Committee for the Review of Government Service Provision 2015). The transition out of prison is likely to be full of challenges, as evidenced by high levels of reincarceration, high prevalence of morbidity across multiple health-related domains, and elevated mortality among ex-prisoners compared with age- and sex-matched community controls (Merrall, Kariminia et al. 2010). After release, people often return to similar—if not identical—circumstances to those they experienced prior to their incarceration (Hammett, Roberts et al. 2001; Baldry and Borzycki 2003). Many ex-prisoners quickly return to behaviours that place their health at risk in the short term, and that may be associated with a return to prison (Kinner 2006). Accordingly, transition out of prison presents an opportunity to improve those circumstances amenable to change, so individuals can be supported to find post-release accommodation, secure a source of income, identify employment opportunities, and build links with community support services (Seal, Eldridge et al. 2007).

However, Australian evidence suggests that transitional planning and support in some adult prisons is poor, particularly for those who have served shorter sentences (Baldry and Borzycki 2003). It may be difficult for ex-prisoners to address their health-related needs if structural barriers (such as homelessness, unemployment and lack of income) have not been addressed. Perhaps the most decisive health-related marker of an ‘unsuccessful’ transition is post-release mortality – particularly death due to preventable causes such as drug-related deaths and suicide (Merrall, Kariminia et al. 2010). Post-release mortality rates in Australia are particularly high for those who have served sentences of less than one year, possibly due to the relative lack of support services individuals receive during a short sentence (Graham 2003).

As at June 2015, Australian adult prison numbers reached a 10-year high with 35,949 individuals incarcerated at any one time and the national imprisonment rate was 196 per 100,000 adult population (Australian Bureau of Statistics 2015). Within 10 years of their release, approximately two in five people will be re-incarcerated, with re-incarceration rates peaking in the years immediately following release (Australian Bureau of Statistics 2010). Individuals experiencing re-incarceration are likely to be younger, male, and/or Indigenous, with re-incarceration particularly high in Queensland and the Northern Territory compared with other states and territories (Australian Bureau of Statistics 2010).

Health and intellectual disability

People with intellectual disability represent approximately 3% of the Australian population (Australian Institute of Health and Welfare 2008), however ascertainment of disability is challenging

and therefore this figure may represent an under-estimate. Definitions of intellectual disability vary (World Health Organization 1992; Cockram 2005; World Health Organization 2012), but the World Health Organization asserts that intellectual disability:

encompasses any set of conditions, resulting from genetic, neurological, nutritional, social, traumatic or other factors occurring prior to birth, at birth, or during childhood up to the age of brain maturity, that affect intellectual development. (World Health Organization 2000, p5)

Intellectual disability is likely associated with challenges in adaptive functioning (e.g., managing daily budgets, organising schedules, paying bills) that can affect independence across vocational, social and personal functions. Clinical definition of intellectual disability may include further categorisation as severe, moderate, or mild, usually according to discrete IQ ranges (Schalock, Borthwick-Duffy et al. 2010). Mild intellectual disability typically refers to individuals who have more independence and fewer support needs.

International and Australian evidence clearly highlights the vulnerability and marginalisation experienced by people with intellectual disability (Beange, Lennox et al. 1999; Ouellette-Kuntz 2005; Emerson 2007). These individuals often experience substantial health inequities across mortality and morbidity (Beange, Lennox et al. 1999; New South Wales Community Services Commission 2001; Lennox, Bain et al. 2007), as well as social exclusion, discrimination and isolation (Ouellette-Kuntz 2005). Many individuals with intellectual disability have unrecognised and poorly managed chronic disease and few receive adequate health promotion or screening (Lennox, Bain et al. 2007). Social disadvantage, difficulties gaining access to services and communication difficulties among this group have been well-documented (Beange, Lennox et al. 1999; Lennox, Taylor et al. 2005; Ouellette-Kuntz 2005; Emerson 2007; Lennox, Bain et al. 2007; Australian Institute of Health and Welfare 2008).

Prisoners with intellectual disability

International evidence suggests that people with intellectual disability are over-represented in the criminal justice system (Fazel, Xenitidis et al. 2008). In Australia, a recent study estimated that approximately 9-10% of soon-to-be-released prisoners had an intellectual disability (Dias, Ware et al. 2013). Recidivism among ex-prisoners with intellectual disability is also elevated compared with the general ex-prisoner population (Klimecki, Jenkinson et al. 1994; Simpson, Simpson et al. 2001; Cockram 2005b; NSW Ombudsman 2008). Ex-prisoners with intellectual disability have a significantly higher rate of rearrest and shorter time to rearrest compared with ex-prisoners without intellectual disability, which may be due to their younger age, greater unemployment and/or increased surveillance by those in the criminal justice system (Cockram 2005; Cockram 2005b). In 1994, Klimecki et al. estimated a 41.3% recidivism rate among 75 offenders with intellectual disability in Melbourne, Australia. Unemployment, substance misuse and psychiatric history were listed as

important antecedents of recidivism (Klimecki, Jenkinson et al. 1994). Fifteen years later, the UK Prison Reform Trust (2009) estimated 61% of adults with intellectual disability were reconvicted within one year of their release from prison, with poor housing and unemployment important predictors (Louks 2006). Prisoners may lose their homes, family contacts, and can be introduced to substance use during incarceration (Kinner 2006; Iorizzo 2012).

Evidence relating to the general prison population suggests that ex-prisoners return to circumstances equivalent to or worse than they experienced prior to their incarceration (Hammett, Roberts et al. 2001; Kinner 2006). Although little is known about the post-release circumstances of ex-prisoners with intellectual disability, recent Australian evidence suggests that homelessness, unemployment, and social isolation are prevalent prior to incarceration (Dias et al., 2013; Dias et al. 2014). Substance misuse both prior to and during incarceration is also common (Hassiotis, Gazizova et al. 2011; Bhandari, van Dooren et al. 2014). Furthermore, the use of certain illicit drugs (Hassiotis, Gazizova et al. 2011) and risk for specific substance-related harms such as injecting drug use and sharing needles in prison (Bhandari et al. 2014), are even greater than their counterparts without intellectual disability

Despite the high re-offending and health needs of those with intellectual disability transitioning out of Australian prisons, submissions to the 1996 NSW Law Reform Commission noted the paucity of appropriate services and supports for those with intellectual disability (see NSW Ombudsman 2008). Article 2 of the *Convention on the Rights of People with a Disability* asserts that ‘reasonable accommodations’ are necessary and appropriate modifications and adjustments that do not impose a disproportionate or undue burden which ensure that persons with disabilities enjoy or exercise, on an equal basis with others, all human rights and fundamental freedom (United Nations 2006). Furthermore, Article 9, ratified by the Australian Government in March 2008, requires the identification and elimination of obstacles and barriers to accessibility to information and communications, and that appropriate measures are taken to promote access to new systems for persons with disabilities (United Nations 2006; World Health Organization, 2011). Feasible modifications and adjustments for people with intellectual disability within the Australian criminal justice system include identifying and eliminating the barriers to accessibility of throughcare programs, and taking appropriate action to promote intellectual disability-specific service access and improved support to carers and family members who help facilitate their transition out of prison (Dias, Ware et al. 2013; Dias, Ware et al. 2014). However, based on limited extant evidence, it is difficult to state with confidence what these needs are, which services are needed and how they are best targeted. For example, our review of the post-release literature elicited no targeted, evidence-based interventions to reduce recidivism or improve health and wellbeing for this marginalised group.

Eligibility for funding for ex-prisoners

Ex-prisoners with intellectual disability have considerable needs and experience considerable inequities which must be addressed. These vulnerabilities were recently acknowledged in Australia by the adoption of the National Disability Insurance Scheme (NDIS). The NDIS is a billion dollar investment from state and federal Governments that aims to offer “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 n.d.). Individualised funding packages will be offered, with control over expenditure resting with the person themselves (or their nominated decision-maker) rather than being managed within a government department by a case worker or other employee (National Disability Insurance Agency n.d.).

Eligibility for funding through the NDIS is yet to be clearly defined for those involved in the justice system. Section 34(1) of the *National Disability Insurance Scheme Act 2013* sets out reasonable and necessary supports in relation to interfaces with the justice system. For people living in the community (i.e., following release from prison) funding appropriate to the NDIS has been noted to include assistance in managing life stages, transitions and supports, and the development of daily living and life skills and behavioural support, as it is specifically related to the individual’s functional impairment (National Disability Insurance Agency 2014). For example, in Part 1 of the *National Disability Insurance Scheme (Facilitating the Preparation of Participants’ Plans – Western Australia) Rules 2014*, it is apparent that prospective participants need to request access to the scheme, with the Chief Executive Officer (CEO) of the scheme deciding whether they meet the criteria. A plan must then be approved by the CEO. Thus, access to the NDIS requires an understanding of the requirements for eligibility and access, the navigation of complex bureaucracy and strategic advocacy for their needs – all activities that may even present challenges to those with mild intellectual disability who do not have assistance from an existing strong advocate or support person.

Following the roll-out of the NDIS across all jurisdictions after the piloting of specific programs in different areas, the Queensland Government will shut its disability department¹; for those without access to the NDIS. 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 for delivery of services (National Disability Insurance Agency n.d.).

¹ WA is currently participating in a two year trial using two different models pursuant to s1.3 of the Rules mentioned above. The scheme is only being trialled in two specific regions of Perth.

It should also be noted that this legislation has a sunset clause, so will cease to exist in 2024, indicating that the implementation of the NDIS could, at this stage, be considered ‘temporary’.

Consequently, outreach services for those who do not have access to a funding source may become untenable for many organisations that will have to rely on their client funding for their sustainability.

As described previously, it is well established that prisoners are a marginalised group with low service access prior to and following their incarceration. It is also well known that those ex-prisoners who avoid alcohol and other drugs, secure stable and safe housing, meaningful employment, steady income and positive social supports are less likely to reoffend and be re-incarcerated (Baldry and Borzycki 2003; Kinner 2006; Seal, Eldrige et al. 2007; Howerton, Burnett et al. 2009; Ogloff 2015). Therefore, the withdrawal of support from agencies who work ‘well’ with ex-prisoners, including those with intellectual disability who are unknown to the disability system, may lead to increased challenges following release from prison, and ultimately higher rates of recidivism.

Benefits of the current study

Australia is on the brink of reformed policy approaches regarding service provision for people with intellectual disability, and the manner in which these reforms will affect key groups – including ex-prisoners – requiring assistance is unclear. It is therefore of critical importance to generate evidence that contributes to understanding how the transition out of prison currently works for individuals with intellectual disability. Such understanding could be used to inform decisions about how the NDIS and service providers ensure that the most vulnerable are not overlooked or excluded from the service provision they likely need to remain out of prison and healthy.

Accordingly, this study qualitatively explored the post-release needs of adults with intellectual disability leaving prisons across Queensland and Western Australia. The current project aimed to (1) understand transition experiences from the perspective of professionals in the criminal justice, health and disability sectors; (2) understand transition experiences from the perspective of individuals with intellectual disability involved in the justice system; and (3) compare and contrast health professional and individual experiences to determine where system gaps lie and what specific steps can be taken to address unmet need. In conducting this study, we aimed to contribute to the evidence base to better inform key decision-makers of the NDIS and other disability and justice organisations that have the potential to improve the justice and health-related outcomes for ex-prisoners with intellectual disability.

METHODS

We chose to address our research aims using a qualitative methodology, which is advantageous to identifying salient issues from service provider and ex-prisoners’ points of view, and variation in individual experiences during the critical re-entry period. It was anticipated that the pervasive themes

described in-depth in our study would lend insight into specific challenges faced by ex-prisoners with intellectual disability upon release and the service providers who support them. Our methodology recognises that to better understand the experiences of people following their release from prison, sociocultural, demographic and incarceration-specific factors that ameliorate or intensify the challenges faced by ex-prisoners are of critical importance.

Participants

Following Lennox et al (2005), who found that 17 levels of ‘gate-keeping’ exist around individuals with intellectual disability by family and other supports (including service organisations), we anticipated that making contact with key informants would build understanding and trust of our research group and study design. By conducting interviews with key informants first (i.e., before recruitment of individuals with intellectual disability), we anticipated that these key informants would themselves become sources of recruitment for individuals with intellectual disability who had experienced the transition out of prison.

We conducted key informant interviews across Queensland and Western Australia (WA). Our key informant narrative interview schedule aimed to determine professionals’ perceptions and experiences within the criminal justice, health, and disability systems. Interview questions related to transitional experiences among ex-prisoners with intellectual disability focussed on how people with intellectual disability are currently supported during their transition out of prison and what constitutes best practice. The interview schedule for participants with intellectual disability with a history of justice system involvement focussed on re-entry challenges through the lived experiences of the participants. Primary areas of focus were social history, experiences before going to prison, and perceived barriers to effective community transition upon release. Given the variation in intellectual capacity and comprehension experienced by this group, participant interviews were conducted in a flexible narrative manner. Additionally, for both participant ‘groups’, specific questions were asked about housing, employment, social support and substance use.

We recruited key informants using purposive sampling of existing networks and known individuals and agencies that interact with ex-prisoners with intellectual disability. Key informants included managers, coordinators, support workers, and case workers. Some organisations for which they worked were tasked with specific outcomes, such as supporting individuals to find employment. Key informants came from two broad groups: i) services from the disability sector (N=6) that work with people with intellectual disability who might come into contact with, or target their services to ex-prisoners, including an agency that had only recently begun working with those involved in the criminal justice system and; ii) services within the justice sector (N=11) who work with prisoners and ex-prisoners, who might come into contact with those with intellectual disability. We note that the

justice sector services were more likely to engage with prisoners and ex-prisoners with mild or borderline intellectual disability, due to funding arrangements that precluded their organisations becoming involved with those formally identified as having a disability, who tended to receive services from disability-specific organisations.

Overall, six adult participants with intellectual disability and a history of justice system involvement were identified by service providers in both states. Service providers ascertained their interest in participating in the research by providing an easy-to-understand ‘plain language’ information sheet. Individuals that were interested in participation were introduced to the researchers. All participants provided informed consent. However, due to privacy concerns in such a small sample, the participants agreed to participate on the basis of anonymity and the non-disclosure of demographic information.

Interviews

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

The two research assistants who conducted the interviews were experienced in working with vulnerable and marginalised population groups. Informed consent was obtained for all participants with intellectual disability by reading the form aloud and cross-checking with further ‘plain-language’ clarifying questions to ensure understanding. All interviews were digitally recorded and later transcribed in full. All Participant Information Sheets and Consent Forms were written in easy to understand English, consistent with the principles of universal design. Our aim was that the interviews with key informants would provide them with insight into the subsequent interview process for participants with intellectual disability.

Interviews with key informants took place primarily at their place of work during business hours and lasted on average 50 minutes. Interviews with participants took place primarily in rooms provided by support organisations and lasted 10-30 minutes.

Analysis

A phenomenological approach guided data analysis, whereby accounts of lived experiences arising out of interviews with service providers and ex-prisoners were analysed to build an account of their interactions with transitional systems across the criminal justice, health, and disability sectors (Ezzy 2002). This approach was intended to allow us to compare and contrast experiences and expectations of both ‘groups’, with a particular analytic focus on individual and structural determinants of reoffending: housing, employment, social support and substance use. Interviews conducted for key informants and participants (parts one and two below, respectively) were manually analysed for

themes. Salient themes identified are illustrated by representative narrative scenarios, which clearly communicate key informants' and individuals' expectations and experiences of the criminal justice systems in Queensland and Western Australia. Because of the small scale of the support network for individuals, including ex-prisoners with intellectual disability, we took extra care to avoid identification of informants.

FINDINGS

In this section, we outline the substantial challenges experienced during recruitment of key informants and participants with intellectual disability over the course of this project. We then present the results for the interviews we conducted (N=23) in two parts, one relating to key informants (N=17) and one relating to participants with intellectual disability (N=6). Key findings and results are followed by a brief discussion indicating implications for policy, practice and research, and a conclusion to this report.

BARRIERS TO RECRUITMENT

The research team encountered substantial obstacles in obtaining primary data during the course of this study. Few service providers responded to telephone or email requests and those who did were often unable or unwilling to be interviewed due to gatekeeping processes. Often the individual expressed interest in the study but advised they could not participate due to a lack of support from their manager or organisation or a lack of resources (predominately time due to the reactive and responsive nature of their work). Those who agreed to participate often rescheduled interviews or had little time to engage in formal interviews, preferring informal phone or face-to-face conversations. Prisoners with intellectual disability were nearly impossible to recruit due to various structural and personal obstacles that we address below.

Consistent with previous research efforts (Ellem, Wilson et al. 2008; Ellem 2010), our findings confirm that the field of intellectual disability is very difficult to investigate because of obstacles to access, resulting in a dearth of much-needed data. The combination of contact with the criminal justice system and intellectual disability produces individuals who are difficult to access and less visible within each of these respective fields. The sensitivity around intellectual disability, a lack of resources and time affecting service providers, and a fragmented funding regime (impacting programme longevity), make the building of trust within this community paramount to effective research. Future studies, whether quantitative or qualitative, which are predominantly questionnaire-based may encounter resistance from the various stakeholders and communities with which ex-prisoners with intellectual disability are associated. Our findings indicate that building trust with

service providers, ex-prisoners with intellectual disability and their carers and significant social circles is of foremost importance in this area. Therefore, a significant scoping phase, likely involving ‘in-principal support’, should be incorporated in the research design of future projects to create and operationalise the necessary relationships to increase project feasibility.

Organisations

Our experience is that the service sector addressing the requirements of ex-prisoners with intellectual disability is fragmented, underfunded, and lacks coordination. There exists a multiplicity of organisations, both governmental and non-governmental, which provide services to the target population. These organisations have different mandates, funding models and programme objectives to fulfil, rendering the sector difficult to profile.

We approached over 50 organisations and found a number of obstacles to conducting our research. These included difficulties contacting service providers within their organisations with access to specific phone numbers and/or email a consistent barrier. Furthermore, when contact was made, interview participation was low. For example, from the organisations approached in Queensland only one in seven service providers (14%) agreed to participate in an interview.

If contact was made, we often encountered gatekeeping by service providers. We noted protectiveness of potential participants (i.e., ex-prisoners with intellectual disability) for various reasons including their perceived vulnerability, past negative experiences with researchers and/or external agencies, perception as to the limited abilities of prisoners with intellectual disability regarding engagement in interviews as well as scheduling and appearing for set interview times. Second, service providers in under-funded and/or oversubscribed services indicated a lack of time to engage in interviews. Third, we experienced unwillingness to undertake a formal interview, but willingness to engage in informal phone or face-to-face conversations. Fourth, we postulated a definitional dissonance between parameters of the study and populations served by organisations (i.e., definitions of intellectual disability vary among service providing organisations, mostly due to screening tools or lack of screening altogether, resulting in poor accordance with even relatively flexible research designs).

Participants

We found recruitment of both service providers and ex-prisoners with intellectual disability to be problematic for the reasons above. In many qualitative studies, the depth of interviews often requires building of trust before formal interviewing can begin. Service providers proved reticent to be interviewed for a variety of reasons, while referral of the research team to ex-prisoners with intellectual disability was rare. The team made several attempts through various governmental and

non-governmental organisations to recruit ex-prisoners with intellectual disability but was only able to secure six interviews.

Identification of ex-prisoners with intellectual disability is problematic. First, there are systemic issues that arise from the lack of consensus on a clear definition of intellectual disability. There are various terms relating to intellectual disability used across services, for example, “cognitive disability”, and various thresholds for IQ as a descriptor of intellectual disability. Related to the identification problem is the existence of poor screening tools and protocols that encompass a multitude of definitions and descriptions. This likely compounds the inability to apply existing intellectual disability diagnostic criteria efficiently and consistently, resulting in lack of reliable identification and/or diagnoses and limit the visibility of this population in the criminal justice system. Agreement among the various service domains associated with intellectual disability (i.e., health, services, and consumer groups) would enable better identification of individuals needing support. However, an added dimension is that cases of intellectual disability are multi-dimensional in complex ways that may preclude clear classification. Additionally, various physical and mental health co-morbidities often render profiling of the population of ex-prisoners with intellectual disability difficult.

Second, there are multiple barriers to access prisoners and ex-prisoners with intellectual disability for research studies likely restricting the implementation of evidence-based policy and the establishment of best practice, leaving their voice unheard and specific needs unmet. Besides physical and mental health implications, personal and social dimensions of the condition promote invisibility. These include hardship, marginalisation, poor health, social exclusion and inadequate social and institutional support. An additional feature in their invisibility is that ex-prisoners with intellectual disability are often unreachable due to lack of post-release service use, poor uptake of available service and service and/or treatment attrition.

RESULTS

Despite these difficulties, we successfully interviewed 23 individuals, including 17 key informants and 6 participants. In this section, we present our results from the interviews in two parts. In Part One, we describe results relating to interviews with key informants, and in Part Two, results for adults with intellectual disability. The results presented are largely descriptive to provide an overview of the tone and content of interviews that we have categorised in overarching themes. In the accompanying *Trends and Issues* paper, we have further thematically analysed content to present a cogent discussion of a more specific research question: *How do health professional experiences determine where system gaps lie and which specific steps can be taken to address unmet need?*. (Also refer to Part Two for a discussion of why we limited the *Trends and Issues* paper to key informants.)

PART ONE: KEY INFORMANTS

In this section, we describe the key informants who were interviewed over the course of the study and outline the type of support they offer to individuals with intellectual disability. We also provide a detailed description of the key informants' reflections on the needs of ex-prisoners with intellectual disability during the transition out of prison, and the system-level issues that create barriers to successful community transition. Finally, we identify recommendations from key informants to overcome barriers and create successful transitions for ex-prisoners with intellectual disability.

For the purposes of this report and to maintain privacy and confidentiality of key informants, we limit the identification of illustrative quotes to the jurisdiction (WA or QLD) and the sector (justice or disability) in which the key informant is based.

We interviewed 17 key informants across Western Australia (N=10) and Queensland (N=7). Time spent in disability and justice sectors ranged from approximately 5 years to 30 years of experience. Most key informants had worked for several different disability- or justice-related organisations throughout their careers.

All key informants described diverse and complex roles that generally involved providing wrap-around support for their clients. This included supporting (and often managing) processes around accommodation, social services and welfare (Centrelink), health assessments, securing other health or social support, and funding arrangements (i.e., if disability funding is available). For example, a key informant working to support employment noted that many other factors have to be addressed before a person could be considered 'employment-ready'.

I might have clients that don't turn up to my appointments, and that's generally because the barriers that I'm trying to address are the barriers that stop them getting to their appointments. QLD, justice organisation.

These other factors are not limited to ex-prisoners with intellectual disability; instead, factors that might also be relevant for successful re-entry among 'mainstream' ex-prisoners, such as *homelessness, drug addiction, alcohol issues, re-integrating back into society after a long time in prison, low self-esteem, family issues* were generally agreed to be compounded by intellectual disability. Consequently, most key informants stressed the practicality of their work, and the need that ex-prisoners with intellectual disability have for practical support.

We do practical stuff. So it might be, OK, you need housing so let's get all the housing stuff, let's get your application sorted let's get you on the waiting list. We also have a list of

psychologists who bulk bill, who have experience in the criminal justice system. QLD, justice organisation.

Organisations varied across those that worked with clients on a voluntary or other (e.g., court-mandated) basis. Many of the key informants, particularly those from the justice sector, indicated that they can only engage and support people who volunteer to engage with them.

They have to want our help. WA, justice organisation.

Support offered

All key informants listed a number of stakeholders across government and non-government organisations (NGOs) with whom they must engage to offer comprehensive and successful support to their clients. These stakeholders included doctors, hospitals, dieticians, corrections, counsellors, psychologists, mental health institutions, public guardians, and administrators such as the public trustee. In Western Australia, key informants were generally positive about their interactions with these different stakeholders.

It has been really clear that everybody is trying to work for the best outcome. So I get in touch with the psychologist once a week or once a fortnight. But between them, the guardian, the psychologist, the disability justice coordinator, and myself, get together every six weeks or so. We just sit in there and see how it is going from each of the perspectives and emails come backwards and forward between that time. It's touching base. This is really beneficial. WA, disability organisation.

The amount of time spent with prisoners and ex-prisoners varied. Some organisations that were not dependent on government funded disability packages could vary their engagement with individuals based on client need.

In general, we work with people for different periods of time. It is really based on need. Some people we see again or for long periods, others find supports and we never see them again. WA, disability organisation.

In relation to individual need, it was generally agreed that support should be intensive in the period directly following release. Organisations in WA described processes where they had access to individuals who were still incarcerated. They could work with their clients in a throughcare arrangement that involved commencing services through a day release program that intensified over time, until release.

First, out in the morning back in the afternoon, then transition into an overnight stay, then 2-3 nights overnight, then potentially a week or two at a time. WA, disability organisation.

However, flexibility in timeframes and intensity of support was limited for some organisations that were reliant on strict government funded disability packages. For these organisations, there was some frustration expressed about the lack of flexibility of these packages, which did not always seem to match the needs of individuals, some of whom were perceived to have ‘too much’ funding and others not enough.

[Our support] starts out quite intensive, and obviously we don't have the funding for that on a continual basis, so it is gradually weaned back so that it fits within the funding model that we have. And, they all have different funding amounts. So, we have the least amount of 22 hours a week and then we have one who has about 70 hours a week, and then anything in between.
WA, justice organisation.

PERCEPTIONS OF NEED

We asked key informants to reflect on the needs of their clients. Consistently, they raised health-related issues, life skills, addressing entrenched disadvantage, overcoming institutionalisation, and challenges in the identification of disability.

Health issues

We asked key informants to describe the health issues that individuals with intellectual disability were likely to experience following their release from prison. The most commonly reported health-related issues included diabetes (particularly given the high representation of Indigenous Australians in prisons across WA) (Australian Institute of Health and Welfare 2013), Hepatitis C (relating to injecting drug use), weight issues (including obesity), epilepsy, medication routines, and dual diagnosis with mental illness.

[On release, health is] generally not that good. Generally, those people with intellectual disability when they come out of prison have been overweight. WA, disability organisation.

In relation to dual diagnosis, ‘diagnostic overshadowing’ (Jones, Howard et al. 2008), whereby clinicians and supports confused intellectual disability for mental illness or *vice versa* was described to be an important issue that might preclude an individual from receiving appropriate care in the community and/or during their incarceration.

People have mental health issues. And then you won't necessarily realise they have an intellectual disability. QLD, justice organisation.

Where I have worked with people with a mental illness and an intellectual disability, often the diagnosis of mental illness is particularly problematic and people would appear to have gone

very long periods of time with poor care provide[d] to their mental health. QLD, disability organisation.

Similarly, it was highlighted that medication could change behaviours of individuals. For staff who have not worked with a person prior to a medication change, it is difficult for them to disaggregate which behaviour is due to this change.

The fellow with intellectual disability, there have been issues with his mental health over recent months. And in the midst of that the doctors had decided to change his medication regime, which outwardly appeared to affect his behaviour. [...] He was presenting as a very different sort of fellow to how he had been before – not dangerous or anything. But that led us to be asking questions of the prison as to what had happened. WA, disability organisation

This key informant went on to reflect:

I don't know whether [their behaviour] is due to the way they are brought up or whether it a prison thing because we don't pick them up until after they've done [their sentence]. WA, disability organisation

Consistent with literature on the health of 'mainstream' prisoners (i.e., not specific to prisoners with intellectual disability) (Hammett, Roberts et al. 2001), individuals with intellectual disability look physical healthier following release from prison. Key informants indicated that it appeared that health improves in prison due to decreased alcohol and drug use; however general consensus was that these improvements are reversed post-release.

Prison creates opportunities to address health needs that might not otherwise be addressed in a community setting due to poor health system access.

This group of people often don't have good access to dentists and GPs get to prison and you get all of that stuff [...] and I'm certainly not suggesting prison is a good place for our clients but in terms of health care, prison can sometimes be the place where health care is best taken care of compared to the person's history. QLD, disability organisation.

Health issues identified by key informants were often related to factors beyond intellectual disability such as social exclusion or low socioeconomic status. This was expressed clearly by one key informant, who indicated there were health issues experienced by *people that have sorta lived on the periphery of society.* QLD, disability organisation.

However, other key informants expressed concerns about the specific health issues relating to the experiences of individuals with intellectual disability during their incarceration:

Not everybody, but quite a few, are not particularly healthy when they come out. And I think that is partly because they don't like the food, and they get harassed inside. A big part of what we do originally when they first come out is educating them in cooking, purchasing their own food, eating routine... all these sorts of things. WA, disability organisation.

Additionally, although the literature suggests ex-prisoners with intellectual disability may experience worse health outcomes than the 'mainstream' prison population, it was highlighted that this evidence may be biased towards those with greater support needs. That is, previous research may have encountered selection bias arising out of recruitment of those with greater needs through reliance on clinical samples or those already 'known to the system'. The following key informant expressed experience with higher functioning individuals with borderline or mild disability:

That's not really been my experience [...] and I guess there is a lot of reasons why that might be the case particularly when we are talking about a group of people with more mild cognitive impairments [...] There is perhaps a possibility that they are able to articulate their health needs in more detail and you know, seek advocacy or support to have their health needs dealt with. QLD, disability organisation.

This speaks to the complexity arising out of the diversity of ex-prisoners' experiences and needs. Key informants stressed that *there is no one model fits all* (WA, disability organisation), because prison experiences and the circumstances into which individuals are released are diverse. Consequently, plans are individualised because of the nature of different court orders and release conditions (including probation and parole) as well as individual needs and preferences. One key informant highlighted that among those with intellectual disability are subgroups with different needs, including Indigenous Australians, young people, women and people from other cultures.

Although more frequently expressed by key informants working within justice organisations, overall, concerns existed that:

There are not enough people taking a holistic view. WA, justice organisation.

Life skills

Discussions of health-related issues were generally followed by descriptions of the additional work that organisations must do with ex-prisoners with intellectual disability to help build fundamental life skills. Life skills mentioned include hygiene, cleaning, cooking, eating well, and healthy routines. These life skills need to be addressed before other issues can be dealt with, because

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.

Key informants described the inability to plan or work out a healthy lifestyle as one of the major consequences of having intellectual disability.

Quite a lot of our guys do not have good hygiene inside prison. So we acquire clothes and all the necessary paraphernalia for having a shower, cooking meals – just generally looking after themselves holistically. So, that starts with very basic recipes and it gets more involved as it goes along. So at least they are starting to feel better and more confident about coming out and living on their own – because all of ours live on their own. They don't live with families. WA, disability organisation.

Community connection was also highlighted as crucial, otherwise extensive social isolation would likely be experienced by ex-prisoners with intellectual disability, many of whom live alone. Here, it was explained that 'mainstream' connections (instead of disability-specific programs) were very important to help build skills around communication and social interactions.

Whenever it is community connection, it is always mainstream. So we have guys that go into play football and things like that. So, that is a mainstream football team that we get them into. And our support staff will go along and mentor them so that they get the social skills, learn the skills and things like that. WA, disability organisation.

Addressing entrenched disadvantage

The lack of life skills of many ex-prisoners with intellectual disability was linked by key informants to the circumstances that individuals experienced prior to their incarceration. Key informants raised issues of neglect, poverty and marginalisation that might stem from unsupportive family backgrounds that were characterised by lack of education, especially regarding fundamental skills it could be assumed that most adults have.

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

All the ones we work with, bar one fella, have all been brought up in horrific environments from home. So they have not had good role models and learnt skills and things like that. So going into prison and having everything given to them has not enhanced anything. WA, disability organisation

Similar to the ‘mainstream’ prison population, ex-prisoners with intellectual disability often come from families with entrenched histories of both 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.

In reference to issues more specifically related to cognitive abilities, key informants described innovative solutions to challenges that could otherwise become difficult and complex. All key informants who raised these issues worked within disability-specific organisations, perhaps speaking benefits of a nuanced understanding of the needs, abilities and complexities of living with intellectual disability. One key informant described the need to support an individual in education around answering the door and understanding who they could safely let into their home. The key informant developed a picture chart beside the individual's front door, with photographs of all the people he is allowed to let through. Another described the development of a picture-based recipe book of healthy, easy meals, helping an individual to cook by alleviating the barrier of reading complex recipes. A third key informant described working with an individual to build a gardening box, facilitating some basic skills to care for chickens and was working towards the individual getting a greyhound as a pet. This individual had been involved with chickens and greyhounds in prison and it was thought this continuity would help ease and facilitate the transition into the community.

Security of basic needs was raised as important, with individuals and organisations aiming to provide *security of housing, security of home, security of nutrition and a 'go to' person who had had the chance to get to know them pre-release* (QLD, justice organisation).

Overcoming institutionalisation

Similar to entrenched disadvantage, key informants reflected on the deficits of institutionalisation developed by individuals with intellectual disability that could hinder successful transitions out of prison. Consistent with research conducted in ‘mainstream’ prison populations, institutionalisation, often compounded by the complexity of community re-entry requirements, can be contributing factors to what has been deemed ‘the revolving door of prison’ (that is, continuous incarceration and release) (Howerton, Burnett et al. 2009; Jacques Baillargeon, Ingrid A. Binswanger et al. 2009):

For a lot of people, particularly if you are coming out on parole, your immediate needs aren't so much your personal immediate needs but things you need to take care of. Like, you know, your bank account, going to parole, navigating through Centrelink. ... For someone who has done 20 to 30 years, this can be quite traumatic. For them. And quite easy for them too, to get frustrated to the point they don't engage. And, we do see a lot of people return to prison just because they can't cope through it.

It is too much of a culture shock particularly for those who have been there for quite some time. WA, disability organisation.

Similarly, some individuals *like it in prison* because they can be more social than on the outside. A key informant described working with one individual who did not want to be released.

He had routine. He was part of the dog program in prison and looked after chickens. He felt secure and safe. WA, disability organisation.

In contrast, for some individuals, social isolation and lack of contact with community, family or friends during incarceration can further contribute to notions of their own worthlessness. Without proper management, perceived isolation or a lack of social support can also contribute to individuals focusing on returning to their home community as an outcome, rather than on the processes they need to address prior to or after their release. A lack of transitional preparation such as securing Centrelink payments or accommodation may leave them poorly prepared for transition out of prison. For example, one individual *has been in here 7 years and not had a single visitor in that time. So it's very challenging. He just wants to go home. [This individual] has no connections. Like I say he has no visitors. He can't read or write so I daresay he doesn't email anyone.* WA, disability organisation.

In both Queensland and Western Australia, participants remarked on the passivity of life in prison, where individuals may not be required to attend courses or gain skills. This is particularly true of those with intellectual disability; limited abilities may lower expectations of participation and lead to exclusion.

Well, the instruction goes in for the 'mainstreamers'. They can learn to read and write and do all the other bits and pieces. Whereas because our guys have an intellectual disability they might want to learn but can't. They can't keep up with the group, so they are excluded. WA, disability organisation.

Consequently, a need to develop targeted programs that encourage participation and inclusion for individuals with intellectual disability, who might otherwise be too scared to participate in mainstream programs.

Well, nothing is going to change if you are just locked up. Because they are scared of the prison guards and they are scared of the mainstreams. Most of them get beaten up and assaulted. So they don't learn. They retreat into their shell, so then you have given them basic survival skills for when they come out, at least they have got that to start with, rather than coming out and feeling worthless. WA disability organisation.

For key informants, a lack of structure, routine and safe program delivery during incarceration made their work difficult, particularly in motivating individuals following their release to attend appointments, work on improving life skills, and to understand the benefits of doing so.

Everything is voluntary in prison so they don't go. It needs to be explained why they need to go. WA, justice organisation

You know, we could have so few going back to prison, if they were treated properly in prison. If they were educated or given a trade. [As it stands, prisoners sit] in a steel yard with nothing to do. Absolutely nothing to do. For 10 hours a day. Then 14 hours in their cell. QLD, justice organisation.

However, it must be noted that difficulties from the loss of routine experienced during re-entry to the community for ex-prisoners with intellectual disability was a significant theme that arose during interviews with other key informants. This transitional loss of routine (including discrete times for meals, lights out, and exercise) may substantially impact on the behaviour of ex-prisoners with intellectual disability making it difficult for support staff to engage with and support them.

When they are in prison they just seem to follow the easiest course. It is very hard for them to assimilate into the mainstream. Just because of their behaviours. WA, disability organisation.

Prison was viewed as an opportunity to work with individuals to upskill and facilitate access to services that they might not receive in the community due to marginalisation, social isolation and inequities in service access. Key informants consistently raised the notion of prisoners as a 'captive audience'.

These guys, they are not encouraged to have a shower, they don't learn any skills, they sort of stagnate where they are. And, I believe strongly that [someone should go in and work with] them when they are a captive audience and teach them their life skills. You know, their reading and writing, their cleaning and cooking, the hygiene side of it. WA, disability organisation.

Day release programs managed by organisations that could continue to support individuals post-release were perceived to be a particularly effective alternative to prison-delivered, mainstream programs. For example, due to work an agency was doing with a prisoner with intellectual disability on day release,

The way he was interacting with prison guards changed. Instead of being rude, or not acknowledging the prison wardens on the way out, I encouraged him to say "I'm back, I've had a good day. How has your day been?" And the guards reacted differently to him, rather than treating him like a piece of dirt. WA disability organisation.

Intensive support in the community post-release, including live-in support, was also identified as a model of care that offered individuals the security and safety they needed following long sentences in prison.

And if it someone who has been in prison for a long time, the support staff with actually live with them for anytime up to a month. [...] We have found over time that if we don't give them at least concentrated assistance in the first month they will gravitate very quickly back into the environment that got them into trouble in the first place. WA disability organisation.

Identification of disability

Understanding intellectual disability was crucial for the services to offer effective support to ex-prisoners with intellectual disability. Key informants, particularly those working in disability organisations, discussed the need to recurrently check-in, and question whether individuals really understood every aspect of complex instructions and processes.

When you're often breaking something down that is not necessarily very simple or basic, but it needs to be in that form for him to be able to grasp it because he would not grasp it in a way if he was having a conversation like you and I are having now. WA, disability organisation.

For those without training in disability, a key issue was the lack of formal identification of individuals with intellectual disability. Key informants, particularly those in the justice sector, indicated their lack of experience and feeling like an 'outsider' to intellectual disability.

If someone has a diagnosed disability and they come out of prison and get on the disability support pension rather than Newstart [allowance], I don't have access to them. So I see people with 'informal' if you like, intellectual disability, but not diagnosed and certainly expected to go out and look for work. QLD, justice organisation.

They often spoke of issues that should occur for all prisoners and especially those with intellectual disability who they considered to be more vulnerable.

But, what I see, as being... y'know... I'm not a ... I've never worked in that sector. Mines only an outsider's perspective of people with intellectual disability. I don't have that background. I don't have that training. QLD, justice organisation.

Prisoners without a formal diagnosis might be identified during incarceration, particularly by other inmates, but do not receive targeted support or funding in the community following release from prison. Therefore, it often rests with community organisations and workers to identify unmet needs.

Justice organisations and staff may *have suspicions* that somebody has an intellectual disability, but remain reluctant to *put labels on them* or flag them as ‘different’.

I could tell you about quite a number of clients that do have intellectual disability ... but that's only my diagnosis. I find you don't generally get people volunteering that information. I think it might get identified by others in the system. Often you'll find that they get placed in protection. QLD, justice organisation.

The need for informal identification is problematic at times in a sector that does not receive any training or education specific to intellectual disability. One key informant seemed confused about intellectual disability in a manner that demonstrates some misunderstanding, likening intellectual disability to illiteracy.

I don't consider illiteracy to be an intellectual disability. But y'know some are illiterate of course, because of their school struggles and maybe never been diagnosed as having difficulties. Or any of those disabilities that we see more often now. QLD justice organisation.

Compounding difficulties for those without training is that many prisoners have learned to effectively disguise their disability, especially in the highly structured prison environment. This can make identifying intellectual disability, and adequately responding to communication and other needs, difficult.

The intellectual disability with this fellow, just to add. He is well practiced at disguising it. If he were sitting in the room here while you and I were chatting he could mimic appropriate responses. WA, disability organisation.

So that stuff gets pushed into the background. You don't discuss that because, y'know, you push that away 'cause any sign of weakness or any sign of sharing that stuff is ... not good for your physical health in prison. QLD, justice organisation.

Beyond personal understanding of disability, it was generally agreed that regardless of diagnosis, intellectual disability could raise the vulnerability of an individual who might not understand social dynamics within prison, or who might be identified by other prisoners as being ‘different’.

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.

I've had other men come out with intellectual disability just saying they spent their whole time in protection because they are absolutely scared. QLD, justice organisation.

In addition to vulnerabilities inherent to intellectual disability, key informants asserted that prisoners might get ‘picked’ on because of the stigma and rumour that surrounds intellectual disability in prison, for example:

If they are in the protected side, it is automatically thought that by the mainstreamers that they are sex offenders so they get met up outside and given a hard time. QLD, justice organisation.

However, one key informant highlighted the diversity of experience of individuals within prison, stressing that not all prisoners with intellectual disability should be considered vulnerable.

You have some who are quite vulnerable and you have some who have come through the system, understand what it’s like in prison, and this is going to sound really terrible, but may have the requisite amount of aggression that can actually mean that they survive within the system. QLD, justice organisation.

Key informant perceptions of intellectual disability, particularly among those working in justice organisations, appeared to strongly influence expectations of the individuals’ knowledge and behaviour, and consequently, how they should be mentored or engaged with. For example, one key informant discussed efforts to work with individuals to better understand their rights with police, in particular, that they don’t need to provide identification when asked by police.

If you have an intellectual or learning disability you don’t know the laws. You don’t know your rights. People with intellectual disability probably wouldn’t be game enough to argue with a police officer about their rights. QLD, disability organisation.

Similarly, there was a perceived need for mentorship around less formal, social interactions such as when it was OK to be ‘teased’ and how to handle this dynamic as other, ‘normal’ people would:

The team members are really accepting about our guys being intellectual disabled. But they are unaware of their histories because we don’t tell anyone about their histories. Some of the team members raze with our guys a bit just like normal guys do. But sometimes our guys take it the wrong way and they get a bit defensive. So then our staff’s job is to diffuse that and explain that it is just blokes stuff and they’re just messing about. WA, disability organisation.

SYSTEM LEVEL ISSUES

In their reflections about client need, key informants raised system level issues that created barriers to (1) their successful engagement with individuals with intellectual disability and (2) successful transition for prisoners and ex-prisoners themselves.

Complexity of system

All key informants highlighted the complexity of ‘the system’ as a potential barrier to effective service delivery and ultimately, a successful transition out of prison.

We help people to navigate the system otherwise they can't. We also support the system in helping people. WA, justice organisation.

In Western Australia, emphasis was placed on the need to work effectively with the Public Guardian, who might act as a substitute decision maker for adults with intellectual disability, as well as the Public Trustee, who might manage individuals’ funds on their behalf. They emphasised that transition depended on the conditions of release when conditional or unconditional orders are in place.

In both jurisdictions, complexities surrounding individuals detained under legislative provisions for those deemed unfit to plead (e.g., Individuals detained under legislation for those with mental illness) further added to difficulties working in the system. Key informants described confusion and frustration that could arise when individuals were treated differently in the community and during their incarceration because of different processes that applied under these conditions.

Before they go in, they can't be charged because they aren't able to... but then inside they are charged. And this just makes them more resentful and they just withdraw further. Thinking, "what's the point of me coming out, I'm always in trouble". WA, disability organisation.

Even when all the necessary programs or processes had been completed, a lack of clear release data was still identified as particularly problematic for individuals detained under mental health legislation.

And whether he knows that or not, but if [he] had been found guilty for the crime he was charged for, he most likely would have been released already. He has done the offender training that was expected of him, he has ticked all the boxes. WA, disability organisation.

However, even for those working with individuals incarcerated under more conventional means (sentenced following a charge), complexities are inherent to the system. A disability-based service that has only recently begun working with individuals in the justice system indicated that:

It is very different dealing with prisons. Prisons need a particular form filled in by 2 o'clock on Tuesdays, whereas in so much of our other support work, there is a lot more flexibility to it because of the regular lives people lead. WA, disability organisation.

Inconsistencies between what is required under court orders on release or probation and parole, and what is realistic or pragmatic in terms of funding or other supports, seemed to further exacerbate an already difficult environment. Generally, it was felt that corrective services focus on criminogenic risk factors and recidivism and ignore disability needs. One key informant described this incongruence in

relation to accommodation and living arrangements for an ex-prisoner with intellectual disability who had been released on specific parole conditions.

He was out and living with people in Ipswich. "Friends" from prison. And, parole had approved that address. They [the "friends"] were standing over him and taking his money off him. They were threatening him. And, of course you can't be homeless on parole. So we scabbled round for three days... four days... maybe a week? Trying to find him accommodation. And putting addresses forward to parole and having them knocked back. He spent another 17 months in jail because he basically said "why would I bother going for parole when they won't approve any addresses". So he did full-time. And when he got out they couldn't tell him where he could and could not live. QLD, justice organisation.

Key informants discussed the need to support individuals so they can meet the requirements of their court orders, thus balancing the competing responsibilities of keeping the individual and the community safe while providing holistic support.

He has a community order and there are all these justice requirements that he needs to meet. He has an electronic tracker, and there are all these places he can go and places he can't go and the police will be watching. WA, disability organisation.

Complexities arising from these divergent requirements left many key informants feeling a lack of control in their own service delivery. For some, the trust and respect of individuals was compromised when they indicated a process would occur within a specific timeframe, but then circumstances outside of their control prevented that process from going ahead.

But I had no control [...] That was a real source of frustration and we had not control over things even though everything was in place. We had met with the prison and had plans in place. WA, disability organisation.

He was released within a very short window with the prison system. And there was not much that we could do about that. When you're not sure of a date you can't put a team in place and be having them paid when there is not someone there. WA, disability organisation.

This lack of control extended beyond individual experiences to system-level changes that could affect organisational funding or access to individuals during their incarceration.

It probably didn't help that Corrective Services last November moved to the Department of the Attorney General and Justice. Whereas before it sat with Community Safety. QLD, justice organisation.

Combative relationships between organisations

All key informants emphasised the importance of effective working relationships. Key informants in Western Australia expressed a positive perspective about collaborations, and relationships with corrective services. In general, it was noted that while the system itself was complex and difficult to navigate at times, individuals working within these systems were striving for the best outcomes for ex-prisoners with intellectual disability.

I have found that everybody has been really good. And the corrective services people I think have done everything that is within their power to do at all times. It is the system that they were working within that was making things a bit tricky at times. But certainly not the people. WA, disability organisation.

In Western Australia, such positivity around relationships may be associated with the fact that, well-defined processes exist for the identification of people with intellectual disability and how to address their needs.

If someone with disability goes into prison, the prison notifies Disability Services Commission (DSC) and then DSC will refer them out after they have had their initial meeting. [When] mainstream workers are working with someone they feel has an intellectual disability, they will often come in and ask if I know them or if they should be in the system. So then I contact DSC. So, there is a bit of collaboration there. WA, disability organisation.

Conversely, in Queensland relationships seemed less effective and at times, even combative. This was particularly true among participants working in organisations that had been involved with ‘the system’ for many years, commenting on newer, larger organisations that had won recent funding tenders.

We don't have any sort of a relationship with those people. They actually tell people at prison – don't have anything to do with [participant's agency], they promise the world and they do nothing. The reality is that it is flipped. This is an organisation that has never worked in prison its life until four years ago. QLD, justice organisation.

Again, key informants identified that the problem was the larger system rather than individuals in the system. However, they maintained their discontent at organisations perceived to be operating successfully within an ‘unfair’ system:

The fault doesn't lie with them so much. My criticism is of corrective services. Giving [this agency] a contract they can't possibly hope to fulfil. People don't even get picked up from prison. And, that's something that we... we picked every single person up from prison. Yes, I'm sure our numbers were a lot lower but that's what they should be. QLD, justice organisation.

Key informants were also more suspicious and critical of prisons in Queensland:

It's a bit like our prisons saying "we offer education programs to our inmates". What they don't say is "if they are doing more than three years". QLD, justice organisation.

This compares to Western Australia, where key informants report trying to establish positive relationships with different stakeholders and individuals working in the prisons.

With the prisons, it is very personality based. If they don't like you they won't accept you. So we try to work hard to build mutual respect, to try and understand the perspective of the other providers and to work together based on mutual respect. We work hard to ensure that relationships stay positive because they are key. WA, justice organisation.

Much of the information we have got, we would get just by having conversations with the officers. For example, some that would know him better would say [...] when we were just chatting, he would say something like: he's changed. He used to come back every day and tell us about all the great things that he had done and about how much he like the guys that we was going out with, and now he doesn't talk about it at all. WA, disability organisation.

In Queensland, the distrust and consequent combative approach to relationships appears to have been exacerbated by recent and historical funding cuts across sectors relevant to the justice system. Key informants were vocal about their beliefs that funding of correctional systems in Queensland was based on ideology rather than best practice or evidence:

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.

It wouldn't surprise me. I was working at [a different NGO] when they were kicked out of the prisons. And that was around a complaint [that was made about the conditions of prisons]. And they were kicked out for a couple of years. QLD, justice organisation.

Such funding cuts have forced organisations to cease some of their long-held advocacy and support activities. For this agency, which has been conducting prison tours for over three decades, a change of activities has been necessary:

Up until last year, we were doing a prisoner tour annually. We got banned from that this year. So what we are trying to do now is go and see individuals. QLD, justice organisation.

Perhaps as a consequence of funding cuts, Queensland key informants reported that they needed to consider professional boundaries to avoid ‘taking’ clients from other agencies they respect.

I’ll look at... you know, I’m quite aware of what [another NGO] offers and I won’t cross that boundary into their area. QLD, justice organisation.

Furthermore, in Queensland there was a clear perception that agencies that were perceived to be advocating on behalf of prisoners or ‘checking up on’ prison processes were not tolerated by funding bodies and those approving access to prisoners:

We’ve always maintained that we are not there to check up on them, we are there to find out what the needs of the prisoners are... to help us better shape our services, to respond to those needs. QLD, justice organisation.

A key informant who worked in government was aware of tensions between services and systems (e.g., mental health, disability and justice) but expressed a desire for these tensions to be put aside for the best interests of clients.

I would say though that I’ve not always seen good relationships across service systems generally [but] I’m happy with the relationships I’ve got. Collaborations are really, really hard work. It’s necessary for us to be able to support this group effectively so I think [...] there is room for various agencies to try and focus less on their agency boundaries. QLD, disability organisation.

For this key informant, funding was seen to be less of an issue than for those working in NGOs recently hit by 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 which 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.

Ultimately, with changes being rolled out through the NDIS, there were some thoughts that 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, among Queensland key informants in particular, there was cynicism about the possibility of positive changes to the system. One participant described the need for throughcare as ‘vital’, but ‘never going to happen’. This person asserted concerns that even with an empirical evidence base, the current situation would not change due to community perceptions of money being spent on prison:

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

Just as participants in Queensland described clashes between agencies, other key informants reported these clashes also extended between service disciplines.

Social workers don't have a good reputation. I went and saw a social worker. And, I lasted 10 minutes before I went and told him to jam his book of theories up his backside. QLD, justice organisation.

Similarly, key informants describe prisoner distrust of professions, and detailed instances where they ‘helped’ prisoners to subvert processes in response to this distrust:

It's problematic because prisoners do not trust psychologists. Because in prison if they disclose anything they'll end up on suicide watch. So, I would keep their face away from the camera, 'cause if they cried during the interview potentially they would go on suicide watch. QLD, justice organisation.

For this key informant, it was important to understand these dynamics because they could impact on his own practice with clients.

Prisoners learn pretty quickly not to trust psychologists, and to tell them what they think they want to hear. So any prisoner that comes to you, you can't be sure they are telling you the reality of their life or what they think you want to hear about their life. Someone with an intellectual disability who has been put on suicide watch because they've said something to a psychologist – you're not going to trust a psychologist again as long as they live. QLD, justice organisation.

Navigating the system

Difficulty in ‘navigating the system’ was a common theme raised by key informants. Specifically, many referred to difficulties managing clients with complex needs who span different systems including mental health, disability and justice. Key informants expressed that prevalent comorbidity often makes it challenging to define and determine mental health versus behavioural issues versus intellectual disability. Furthermore, this ambiguity can make it easy for individuals to fall between the cracks of service sectors.

[...] 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.

In Queensland and Western Australia, key informants highlighted Victoria as a jurisdiction that manages complex needs more effectively compared to their jurisdictions.

Victoria's got a multiple complex needs initiative which has been operating for perhaps eight or nine years and that's been quite a successful example of how good structures, multiple different areas of the system can get together and come up with unique and helpful approaches for supporting people who have slipped between the gaps at other times. QLD, disability organisation.

Currently, in both Queensland and Western Australia, there appear to be difficulties managing disability versus justice funding, while complying with client court orders. For example, one key informant described a client under a court order requiring 24 hours per day supervision by support workers. However, limits were imposed in the amount of support they could provide by agency funding. The funding through disability only allows them to provide support for disability-related needs, not justice needs. The key informant explained that the disability needs of this individual were assessed as insufficient to warrant 24 hour support; however justice decided not to provide funding for this individual.

For another key informant, this system-based complexity translated into concerns about the implementation of the National Disability Insurance Scheme. Concerns were raised that there could be an assumption made that someone else is *picking up the funding and support* of ex-prisoners with intellectual disability, when in practice, neither funding nor support are currently being managed in an elegant manner.

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.

CREATING SUCCESSFUL TRANSITIONS

Key informants identified perceived facilitators of successful transitions. This included both what they believe currently works well in their own practice, and in an ideal world what processes would

implemented to ensure successful transitions for ex-prisoners with intellectual disability. These included early planning and throughcare, changing community perceptions, building relationships and trust, and the NDIS.

Early planning and throughcare

All key informants raised the critical importance of early planning and throughcare as processes *that should happen. Not just for people with intellectual disability but for everyone who comes out of prison.* Quality time with clients and involvement of the ‘right’ people were highlighted as crucial to securing a positive transition experience. Key informants asserted that transitional service timing was critical; the aim was to implement a service model whereby individuals receive the support they need at the time when it is needed.

You know, what I would say is planning for exit from custody is really, really important in terms of psychosocial support. Assisting the person to be the best person they can be regardless of their offending behaviour, all of that stuff needs to be planned for and in-place prior to the person leaving the prison system. QLD, disability organisation.

When agencies have sufficient time to work with individuals in the lead up to release from prison to secure accommodation and other crucial supports, it is easier to identify needs and provide an appropriate level of servicing for transition. Many agencies reported the importance of having continuity of support in the re-entry period. Specifically, key informants expressed the positive impact of having the same worker pick up individuals on the day of release and help them through subsequent days and weeks of transition, gradually reducing support as individuals become more confident.

We knew when his release date was and a place became vacant probably 2 weeks before he was released and they held it open for him. [...] We then got him in touch with [organisation] to get those things he needed. Like bed sheets, pillows, y’know all those cooking implements. QLD, justice organisation.

For ex-prisoners with intellectual disability, the time spent building skills, helping to get them ‘settled’, offering ‘starter packs’ of fundamental supplies such as bedding, and navigating the system may be particularly important. Otherwise, they may come out *dumbfounded because they don’t have these skills. Because that is the hardest things for our guys* (WA, disability organisation).

In relation to the current lack of throughcare,

You don’t treat these people like that. You don’t just kick them out the front door and say “have a good life”. That sets people up for failure. He was set up to fail. And, when he failed,

he was returned to prison. And, that's what the system does. It sets these men up for failure.
QLD, justice organisation.

Early planning and throughcare would ideally involve multiple stakeholders, and for people with intellectual disability and/or dual diagnosis, the involvement of clinicians was viewed as important.

If we can have a clinician and a group of other stakeholders getting together formulating what they think a person's going to need post-discharge ... putting some of those in place you know, pre-release, having the support plans and mechanisms in place... get all that done beforehand then the team can sorta follow the person out and be a constant for them once out there in the community. I think that's the ideal model. QLD, disability organisation.

In addition to clinical and community-based support, it was generally agreed that prisons should be involved in transitional service arrangements and facilitating organisations to be more involved with individuals prior to their release. Information exchange between prisons and supporting agencies was perceived as crucial.

Meetings should be set up regularly. Agencies offering support don't know what is happening. Not enough sharing, for example of medication information. WA, disability organisation.

Discussions of throughcare were generally accompanied by consideration of service delivery costs, with funding often tight or at times, unavailable.

I don't think it needs to be high intensity in terms of man-hours but it needs high intensity in terms of logic. QLD, disability organisation.

However, most key informants stressed the importance of securing funding for their own agency to offer services they felt were necessary.

My dream for prisoners is that the government would decide that, hey, we can afford ten million dollars out of our budget and we'll give that to [his agency] and they can buy houses for accommodation or people coming out of prison. QLD, justice organisation.

In particular, the lack of block funding was regarded as an inefficient and challenging because it provides some individuals with too much and some not enough funding. However since funding flows to the individual, currently agencies cannot further tailor funding to be (re)distributed between individuals.

Changing community perceptions

A common theme across Western Australia and Queensland was the need to change either community perceptions about the need to support ex-prisoners or compel the government to act regardless of

community support. In Queensland, where funding cuts were seen by some key informants to be made based on ideology, there was a consensus that the latter option was most viable.

in conservative political environments i[t']s 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 a lack of community support for prisoners but also extended this to the disenfranchised, poor and marginalised in the community.

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.

Given the over-representation of Indigenous Australians in Western Australia and Queensland prisons, key informants expressed concerns that systems may not change due to racism within government and the community.

Racism, prejudice. In terms of the government. The government is racist. WA, disability organisation.

A bit like racism in Queensland I suppose. It happens every day but everyone pretends no one is racist. QLD, disability organisation.

Building relationships and trust

Most key informants discussed the importance of building relationships and trust with their clients. To build such relationships, quality time was needed, again emphasising the importance of early planning and continuity of care post-release. Key informants believed the earlier the involvement, the better outcomes for the individuals and it was stressed that much more than one visit was required to build rapport and develop trust.

Sometimes it takes a very long time for the guys to realise that they have a voice. And that they can say "I don't want to work with this person without the fear of losing the assistance." I have one gentleman who has only quite recently started to say that "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.

Some key informants in NGOs highlighted that their own experiences in relation to substance misuse and the criminal justice system improved their ability to build rapport and trust with their clients.

I have a good relationship with my clients. My history of drug addiction and crime until the age of 30 has given me a great understanding of stuff that my clients go through. [...] That generally straight away puts them on side with me. I'm someone they can trust. QLD, justice organisation.

I don't think it's vital that you have experience but I think it does give you a level of understanding that would be hard to have obviously otherwise. QLD, justice organisation.

However, the latter key informant felt it was important to judge the appropriateness of sharing their own personal experiences with clients, because *I don't feel like I need to do that to make, make a connection.*

Across Western Australia and Queensland, key informants spoke with pleasure about their ongoing links and relationships with individuals they have worked with. Many found the achievement of establishing trust with and successfully supporting individuals who have experienced marginalisation, social exclusion and institutionalisation rewarding.

We have known many for 20 years or more. Have taken some on 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.

He still contacts us, still rings up every now and then to let us know how he is going. He's found a partner. He's doing really well. QLD, justice organisation.

However, it was highlighted by other key informants that there exists a need for service providers to establish clear boundaries when building relationships with clients. One key informant cautioned that support is to be provided, *not as a friend, in a clearly defined support worker role* (QLD, justice organisation).

Training

In Western Australia, collaborations were generally perceived to be positive and well-defined systems to support the identification of need among ex-prisoners with intellectual disability seemed to be in place. Here, key informants generally thought that staff training was more appropriate than overarching policies given the individualised nature of client situations and existing support networks.

I feel that across the board, targeted training is better and more suitable than across the board policy changes. The reasons for this is because the individualised and dynamic nature

of the work is best met and addressed by staff training than by overarching policies and procedures. WA disability organisation.

However, in Queensland, where collaborations may work less successfully and organisations felt that system-level changes disrupted quality service delivery, it was contended that legislative change was required to improve transitions.

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

For this key informant, a lack of leadership may have contributed to the view legislation outlining a clear protocol for complex needs clients, might compel government and other stakeholders to overcome organisational siloes and boundaries.

Despite differences in opinions about system-level policy changes via training or legislation, some specific training in disability was agreed to be critically important for support and prison staff. Key informants reported that finding the 'right staff' that are qualified, was very difficult. They cautioned about the potential for staff members that feel *they can make a difference but ultimately can cause more damage*. Thus, it was highlighted that undergraduate education in disability and subsequent professional mentoring from those who have been 'through the system' would help develop the next generation of support workers and advocates for intellectual disability in the justice system.

Mentors were needed who could nurture *the next generation of professionals interested in the area*. QLD, disability organisation.

Harnessing the knowledge base – I don't think that what we have 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, the importance of disability training for prison guards was asserted to improve interactions with prisoners with intellectual disability. Key informants noted that prison guards, and most corrective service staff, *don't seem to have a lot of education working with anyone with a disability*.

And they don't understand that if you speak to someone like a pig they are going to answer in the same way because they just mimic a lot of behaviour. WA, disability organisation.

The NDIS

Only one key informant spoke in detail about the NDIS. However, given key informant concerns about the difficulties of working within individualised funding models and the fact that the NDIS will shift more people with a disability to individualised rather than block funding, it is pertinent to note that:

We are not really clear how the NDIA is going to respond to these folk, so I guess I'm saying that whilst we can comment on what state based disability systems and criminal justice systems have learnt over the past few years that's potentially null and void under the federal system, and we need to do some work about making sure that the NDIA is ready to do this work. QLD, disability organisation.

PART TWO: ADULTS WITH INTELLECTUAL DISABILITY

In this section, we describe the participants with intellectual disability who were interviewed over the course of the project.

We recruited six individuals with intellectual disability across Queensland (N=2) and Western Australia (N=4) to participate in the study. We have previously documented the difficulties encountered with recruiting participants in the Findings section; suffice to say that several planned interviews were cancelled due to individuals entering 'crisis' (e.g., sudden experiences of homelessness). It should be noted that the Australian Institute of Criminology approved an extension to this project given the particularly difficult times of crisis reported by service providers over the Christmas period. This extended well into the New Year in 2015.

Despite these challenges, we have begun to establish very good working relationships with a few key organisations, particularly in Western Australia (thanks to the concerted efforts of co-author CC and Mr Nathan Visser, Research Assistant). Recently, we have been approached to conduct further interviews beyond the funding timeframe of this project which we have committed to complete. Furthermore, given the need to establish rapport and trust with participants, we may seek further interviews with some participants who seemed particularly interested in sharing their stories. As discussed elsewhere in this report, a pivotal reflection related to methodology is that an ethnographic approach to this research agenda, whereby researchers spend time with participants over a longer period through follow-up interviews, is warranted. Consequently, we view the interviews described below as 'pilot' interviews for a longer and more detailed subsequent study, where we continue to collect data and build on the themes identified.

Given the smaller number of participant interviews than we originally anticipated and the often short ‘yes’/‘no’ responses of some of those we interviewed, it would be inappropriate to undertake detailed comparison of key informant and participant interviews. Instead, we describe findings from our interviews with people with intellectual disability in the context of themes identified for key informants, where appropriate. Quotations have been limited to three participants with whom our Research Assistant was able to establish a good rapport. Our interviews focussed on descriptions of the transition out of prison from lived experience, rather than on individual demographics and backgrounds. Service providers had highlighted that participants would be reluctant to reflect on their histories and might become distressed by overly personal questions. Therefore, we do not present in-depth demographics for participants and instead identify quotations according to gender and jurisdictions, with an identifying number (1, 2, 3, 4) to help distinguish participants’ quotations.

(Note - given these project limitations we have focused on key informant interviews for the corresponding *Trends and Issues* paper as methodologically it would be inappropriate to draw conclusions from this limited sample.)

Support received from service providers

Participants described the basic support they received from service providers. They echoed key informant descriptions of the provision of fundamental supplies for housing and accommodation.

Umm. Got me furniture. Umm, cutlery. A bed. A fridge, table, lounge. They basically furnished the whole unit. WA, male 2.

They help me with my shopping. They take me places I need to go. And, umm, and they just help me with all different support stuff. WA, male 3.

Participants remembered that on their release they were picked up by their support person, who was often encouraging of their release:

Someone picks me up from [organisation]. That lady came out and see me [sic] and said “oh well, you home”. She turned around and said, “you know, you’re looking healthy. You [are] doing the right thing for yourself for right now. WA, male 1.

Participant descriptions of the support they received on the day of release, including getting picked up from prison, seemed as though it was unplanned (to them) and a surprise: *They just came and helped me* (WA, male 4). This may be indicative of a lack of involvement in the decisions affecting them, and possibly reflecting the fact that processes were occurring around them without their input.

Although participants reflected less explicitly on the notion of ‘control’ than key informants, their narratives suggested a distinct ‘lack of control’ during the transition out of prison.

She lined me up before I even know I was coming up. You know. WA, male 1.

You see, I wasn't quite sure if I was going to be released. The officers came down to me and said "right you're on bail. You can come pack up and go home". And, I didn't believe him. Yeah. Yeah. And then, [support worker], came and picked me up. And I didn't even know that he was going to pick me up. WA, male 2.

When asked to reflect on the preparation received prior to release, the following participant was adamant that there had been no early planning or preparation.

Interviewer: *Was there any preparation before that?*

WA, male 2: *No*

I: *Anyone come and say "you gonna be released, we want to talk about some things?"*

WA: *No.*

I: *Anybody come tell you how things were going to happen after you were released?*

WA: *No. No.*

Lack of early planning

Although one participant indicated that prior to release from prison their support organisation had *come in here and talk to me and stuff like that* (WA, male 3), the majority communicated a clear lack of early planning by their correctional facility:

They let you out the front. You have to find your way home. It's you. No one else. Just you. Get on the phone, ring someone. Get someone to come pick you up. If someone can't pick you up you are on your own. Don't matter what mate. You are on your own. You got to find your own way home. You gotta step out. You can't just walk out and go "I'm home". You can't just like that. You know what I mean? WA, male 1

They try and work you up to it. "You going home next month" "Oh, home! Nah I'm not going home. Doesn't focus to that mate. I still got another 4 years". "Nah, you're going home tomorrow". Well, fair enough good. Get my stuff. Pack my stuff together. WA, male 1.

When asked what might help others in similar situations transition out of prison, practical support from trusted people (i.e., family, friends, and/or organisations) was seen to be crucial: *The biggest*

difference was having support (WA, male 2). Safe and secure accommodation and employment were consistently mentioned as critical to effective support.

Experiences of disadvantage

Participants were not asked to reflect on their backgrounds. However, some offered details conveyed experiences of disadvantage, including physical and mental health issues, challenging family dynamics, being *brought up in government care* (WA, male 3), and experiencing the ‘revolving door of prison’.

It did. To a certain extent. Because, I suffer from depression. And, I get down sometimes. And, I just got to ring [support person] or parole officer and talk to them. But, apart from that I am quite healthy. I smoke. WA, male 2.

But I been in and out too. Ah yeah, I couldn't stay away. In and back. In and back. In back, in back. Gave up. Every couple years. Didn't worry about doing 13 years, 14... say 15 years. WA, male 1.

Yeah. Well, my old man is alcoholic [...] I don't know if he drinks today [...] But I gotta go down and see him sometime. But he's in a wheelchair too see. Bit tricky. Hard for the old boy to go shopping 'cause his electric chair [is] broken. Twit broke down. WA, male 1.

Participants spoke with pleasure about the experiences and positive changes they recently achieved through their own self-motivation and support from service organisations. These achievements included securing employment, purchasing a motor vehicle, learning to read, eating healthy and fresh food, and making it to scheduled appointments independently. Participants valued their freedom and the ability to take positive action in their own lives.

Because [before] I did not have confidence like that. It is not just little steps, it is big steps in the right direction. WA, male 2.

Further, some participants were now taking on a support role themselves, assisting family members with their appointments and health issues, and making active contributions to advocacy and support agencies.

Overcoming institutionalisation

Participants referred to incarceration as claustrophobic, with participants describing feelings of containment and lack of freedom. Many contrasted this experience to leaving prison, where opportunities and new circumstances awaited them.

In a prison mate, you got nowhere to go. Nowhere to hide. Nowhere to run. You [are] stuck. You [are] stuck in a cell like this [referring to small interview room]. You [have a] bed. Toilet. Sink. That's it. That's you. That's all you got. Out here [whistles] you just walk out there and walk out the front door and go out that door to the next step. WA, male 1.

An important theme of key informants was the increased vulnerability of prisoners with intellectual disability, however none of the participants explicitly reflected on their own experiences of intellectual disability in prison. Most participants did describe prison as confronting and frightening, particularly during their first incarceration:

I would say very frightening, because I never been into prison before. Very scary. You didn't know who to trust and you were always looking behind your back. WA, male 2.

Consistent with key informant narratives, prison afforded some opportunities for personal development, although it was reinforced that inmates are not actively encouraged to take advantage of programs instead having to rely on their own motivation to participate.

Yeah. But the system in there is pretty hard. You got to keep the mind occupied. You got to get the job. You know. You got to find time to go down to the sheds or [...] go to concrete. Much to do in there. Work in metal shop. WA, male 1.

Despite feeling scared and isolated, this participant also described the support he received from other inmates. Similar to key informants, he discussed the impact of a lack of routine after release, and how confusing that experience was.

There were quite a lot of prisoners who used to help me because they knew I couldn't read. They used to help me fill out forms and things like that. And, sometimes, depends what officer was on, they used to help me as well. WA, male 2.

Because you're so used to being in jail and having that routine, and then when you come out it hits you right in the face. And, you are just wondering what is going on. And, you get confused and everything. Because when I came out everything had changed. And, when I came out, [support worker] had to show me around. How to do this. How to do that. WA, male 2.

Although prison was emphatically described as a place that participants did not wish to return to, a general sense was conveyed that leaving prison was a confronting and overwhelming experience, particularly due to loneliness and social isolation experienced on the outside.

Because if I have people to talk to I am fine. Because, I get very lonely sometime. And, I just need to go out and talk to someone. Because you get lonely at home and you get bored. Especially when you are living by yourself. WA, male 2.

This same participant described how his supports encouraged him to engage in social activities:

[...] my psych wants me to get out more. So what we are going to do is, I'm going to go to this club [...] because I am afraid of meeting new people. I am frightened they are going to judge me. And [support worker] is coming along with me. Just to be a support. And then he is going to show me what to do. After that I'm all by myself. WA, male 2.

Lack of community connection and isolation from family was reiterated by participants, reinforcing key informants' perceptions that support to engage with others during the post-release period is crucial.

Oh my family. Don't really see them. But sometime I should be seeing them. Only my old man anyways. WA, male 1.

Participants were clear about their desire to avoid contact with past acquaintances and friends from their time in prison, prior periods of intense drug use, or associate with ex-prisoners or those involved in crime (even those they have not met yet). All participants expressed the desire to move on, and felt that such contact would hinder their ability to continue to rebuild their lives.

Relationships and trust

The participants we interviewed appeared to have strong relationships with their support staff, and in some instances, support staff attended the interview to assist the participant to contribute. Given our difficulties in recruitment, we are likely to have experienced some selection bias that may lead to over-emphasis of relationships established between staff and individuals, because staff with stronger client connections may have been more willing to assist us to recruit and interview their clients. However, although early planning was perceived as non-existent, the continuity of care from community-based organisations from day of release to time of interview was highly regarded, *Oh yeah, I couldn't thank them enough* (WA, male 2), and appeared to be based on relationships built over time.

I am saying these are my workers. They help me get out of jail. From juvie [juvenile detention] to adult, from adult to juvie, from juvie to adult. What's that boy gonna do? That boy's gonna turn around and go back to jail. Unless someone gonna be there, with him, and talk to him to no. Right. WA, male 1.

Because I see [support worker] once a week. And we talk about everything. Because I told him when I met him that it was very stressful for me. Very confused. And he just put me on the right track. Said: "we'll do this for you; we'll do that for you. Take you out somewhere".
WA, male 2.

You got a little bit of help. When I needed help. When I'm feeling down. A bit of help or information. WA, male 4.

One participant in Queensland who had close organisational links, through which he was recruited, was more cynical of relationships and reluctant to build trust with individuals, particularly those without a history of incarceration or drug use. This lack of trust was linked to his own poor experiences of family and organisational support in the past. Despite this cynicism, he had been actively involved with and supported by the same organisation for the past decade.

Many family relationships were conveyed as being very complex, particularly in the context of families perceived to be unsupportive or negative. However, unlike key informants who did not emphasise the importance of informal support, participants often reflected on the informal support they receive from family.

I get it from my mum. My aunty. I get it from [support worker] and my parole officer. They're all my support. WA, male 2.

Participants highlighted that engagement with other services or systems could be unsuccessful if they fail to take into account the specific needs of individuals with intellectual disability or those experiencing similar challenges.

The problem is that I have trouble reading and writing. And, when you go into [employment agency], I can't read. And they just take no notice of it. And that's where I get so frustrated with it. Because they are not listening to what I am saying. WA, male 2.

This participant continued explaining that he was told to lodge forms on the computer but since he cannot read, it represented a considerable barrier. In Queensland, another participant also spoke of his reluctance to use computers and telephones when lodging Centrelink forms.

DISCUSSION

Prisoners screening positive for intellectual disability are characterised by greater social disadvantage, increased morbidity and lower preventive health service utilisation compared to other prisoners (Dias, Ware et al. 2013; Dias, Ware et al. 2014). Given their substantial health inequities and elevated rates

of reoffending, it is likely that people with intellectual disability need targeted support during the transition out of prison, particularly in relation to accommodation and employment (Cockram 2005; Cockram 2005b). Most contemporary understandings of intellectual disability rely on terminology to rank the severity of impairment: with those with severe disability requiring a great deal of support, and those with mild and borderline intellectual disability able to live independently, with less or little support (Schalock, Borthwick-Duffy et al. 2010). Those with mild or borderline intellectual disability often experience particular difficulties accessing services because they are not recognised as having (enough of) a disability to qualify for government-based financial support (Baldry, Dowse et al. 2012).

This research agenda focused on understanding the experiences of those with mild or borderline intellectual disability, considered the ‘hidden majority’ of people with intellectual disability. This agenda was chosen because, due to their ineligibility for disability support and barriers to service provision, individuals with mild or borderline intellectual disability are unlikely to be captured by traditional research efforts which are primarily reliant on clinical samples. Our findings suggest that, services for ex-prisoners with intellectual disability are generally underfunded, fragmented and lack co-ordination. Interestingly, these findings mirror those in the Australian Government’s Productivity Commission report recommending the roll-out of national policy change for people with disability in Australia through an insurance-based model (the impetus for the NDIS):

The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. The stresses on the system are growing, with rising costs for all governments. (Australian Government 2011)

Implications for policy and practice

Our results also confirm findings from ‘mainstream’ prisoner research, that sufficient planning prior to release is an important determinant of the post-release success of individuals (Hammett, Roberts et al. 2001; Baldry and Borzycki 2003; Kinner 2006). For ex-prisoners with intellectual disability who may lack fundamental life skills (that may be assumed to be present by service providers), early planning and continuity of care are crucial. Without nuanced and targeted support from those with knowledge of their needs, the barriers to navigating the ‘system’ are likely extensive and insurmountable for many individuals with intellectual disability. Gradual release programs (for a day or two at a time building up to full release) were the preferred reintegration model of many key informants. Some highlighted the need to provide a period of live-in support as necessary for some ex-prisoners. Flexibility of service provision seems paramount, with many instances reported of over- or under-funding of individuals—this should be raised as a crucial issue to the NDIA. The insurance

model of the NDIS has been primarily designed to provide individual funding. However, provisions for systemic funding to address key issues (i.e., during acute periods of crisis or change) that cannot be provided under individual funding models may offer benefits during the re-entry period for prisoners with intellectual disability. The provision of inreach services in prison and outreach services to newly released prisoners with intellectual disability could be considered a systemic concern.

Participants with intellectual disability highlighted the support of informal carers; family members and friends; and at times, their fellow inmates with completing forms and the comprehension of written material during their incarceration. Further investigation into the role that informal networks play for this group and how positive supports during incarceration and early re-entry period can be better facilitated are warranted. .

Institutionalisation, whereby some individuals feel safer, happier, or more secure in prison than they do when living in the community, presents a ‘wicked’ problem for those working to improve the lives of a population group characterised by entrenched disadvantage. The structures and limitations of prison possibly make life simpler and less complicated for individuals with intellectual disability, alleviating many concerns of everyday life such as administrative processes, service navigation and employment. However, prison should not be considered a therapeutic environment, particularly in relation to mental illness and intellectual disability. Institutionalisation can manifest itself through lack of connection with family and community, as evidenced by the social isolation experienced by participants during and after prison.

We have discussed the challenges associated with intellectual disability diagnosis, including diagnostic overshadowing, whereby intellectual disability may be mistaken for mental illness or *vice versa*. The clinical expertise of psychologists and psychiatrists who have expertise and specialised training should be included in pre-release planning. Further training for custodial staff, probation and parole and non-government justice agencies may increase awareness. Furthermore, since intellectual disability is likely substantially overrepresented in prisoner populations (Dias, Ware et al. 2013), intellectual disability-specific training and education is recommended for those working with the justice system in general.

Significant complexities within and across disability, justice and health systems present another considerable problem for those working within these systems, and ultimately, the individuals they support. Already challenging environments are made more complex through the involvement of statutory decision makers such as the Public Guardian and Public Trustee, “Unfit to plead” legislation, and funding models that remove control over service delivery from service providers. Combined, these factors create inefficiencies at best (e.g., where an individual may be over/under funded) and at

worst, substantial and unalterable outcomes for individuals (e.g., who may be incarcerated for a longer period, without conviction, than for those sentenced under ‘mainstream’ courts).

Finally, combative relationships between service providers in Queensland contrasted with more prevalent examples of positive and effective collaboration in Western Australia. This disparity may be explained in part by more well-established processes for identifying intellectual disability and their associated needs in Western Australia. Although key informants from both Queensland and Western Australia highlighted Victoria as the leader in complex care service provision, our findings suggest that Queensland could also turn to the Western Australian model for guidance. However, substantial funding cuts in Queensland and perceptions that organisations advocating for clients may be defunded likely create a counter-productive environment for positive change.

Earlier in this document, we explained that changes to prisoner throughcare programs that address the specific cognitive and social needs of those with intellectual disability, are likely to deliver the most appropriate, acceptable and accessible care. However, pervasive systemic issues (such as those described above) hinder a collective response spanning government and non-government sectors to facilitate such modifications and adjustments. Community perceptions that undervalue or even oppose funding support for ex-prisoners further detract from political impetus to address the issues raised by key informants and participants in this report.

Ultimately, substantial transitional needs exist for ex-prisoners with intellectual disability, and underservicing is pervasive in this group. Formalised protocols of service integration across forensic, health, community and social agency domains are warranted. Additionally, extensive education and training programs across the systems that work to improve the lives of those with intellectual disability should be prioritised. Positive policy change that provides funding commensurate with need; along with adequate structure and governance that allows for flexibility at the service-level is crucial. Perhaps the most critical factor for success appears to be the building of strong relationships and trust between service providers and the clients. There appears to be clear scope and support for education, training and the facilitation of relationship building through the systemic focus of the NDIS.

Implications for future research

Our analysis suggests that investigating ex-prisoners with intellectual disability requires a methodology that allows for building relationships within the prison, health, volunteer and non-governmental organisation sectors. Relationship-building is important because it builds trust and, leads to greater and higher quality access to this population. Furthermore, it allows researchers to understand the specific arena of intellectual disability and experience in the judicial system. This

arena is complex and our results indicate that there are clear differences between policy, service delivery objectives, and actual delivery of services to the target recipients.

Given the paucity of existing empirical information, we suggest an ethnographic approach is required to understand the complexities of the experiences of ex-prisoners with intellectual disability. This approach allows for more time to investigate target populations in their contexts and on their terms compared to other methodologies. Ethnography is broad in scope and encompasses mixed quantitative (e.g., survey) and qualitative (various types of interviews) methods, participant-observation, and a scoping component to gain an understanding of the context in which ex-prisoners with intellectual disability live. Specifically, a scoping phase in which the landscape of institutions, interested parties (including their personal histories), policies, and funding environments is mapped and understood serves the dual purpose of focussing the objects of inquiry and building trust. This phase is important to ensure that a broad and comprehensive view of the justice-disability nexus is captured and understood.

Building relationships within the intellectual disability sector is pivotal to conducting appropriate and meaningful research. This target population is vulnerable and lacks visibility; requiring the development of specific approaches that protect the vulnerable while accessing much needed data. Service providers are often over-worked, under-resourced and lack job security within shifting policy and funding landscapes. In this context, they provide services to a poorly defined population with both high- and specific needs. Trust is essential in establishing relationships with these two groups.

Ethnographic approaches also provide opportunities for an iterative questionnaire design that best addresses participants' key experiences and concerns. It enables recruitment of participants in a just, equitable, and representative manner in which specific vulnerabilities are accounted for in terms of questionnaire design, interview environment and feedback to participants and/or interested parties associated with their care. In terms of service providers, proper mapping of the service landscape maximises representation of different types of organisations, and services as well as roles and various levels of responsibility within service organisations.

CONCLUSIONS

Prisoners with intellectual disability are a disenfranchised, disadvantaged group with poor visibility across research, policy and practice. Our findings suggest a clear mandate for modifications and adjustments to current support arrangements (or creation of support where it is currently absent), and the need for systemic change to address 'wicked problems' that hinder the ability of ex-prisoners with intellectual disability to remain out of prison and healthy. Further research that takes into account the

needs of the sector and individuals in terms of study design, relationship building and methodology is urgently required. We have outlined central themes raised by key informants working within the 'system', and from the lived experiences of ex-prisoners with intellectual disability. However, we view these findings as preliminary, particularly in relation to the latter group. In describing the extensive challenges we experienced during this study, we hope to inform future researchers and build on our own knowledge base as we progress the research agenda commenced here.

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