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Position Statement.

The Importance of Physical and Mental Health for People with Intellectual Disabilities in the Criminal Justice System

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President: Dr Jacqueline Small
Vice-President: Prof Julian Trollor

C/- QCIDD, Level 2, Aubigny Place, Mater Hospitals, South Brisbane Qld 4101
T: +61 (7) 3163 1589 | F: +61 (7) 3163 2445
E: AADDMsecretariat@gmail.com | W: http://aaddm.com.au
ABN: 61 039 294 522

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Summary

- People with intellectual disability (ID) often experience psychosocial disadvantage and are significantly overrepresented within the Australian criminal justice system.
- People with ID have significantly higher rates of health conditions that may not have been diagnosed or treated and these may lead to challenging behaviours.
- People with ID (particularly those in the criminal justice system) have significantly higher rates of mental health problems that can present as challenging behaviour and can have specific treatment implications.
- Accurate diagnosis and treatment of physical and mental health problems can result in improved behaviour outcomes for people with ID.
- A significant proportion of people with ID display challenging behaviours which pose risks to their own safety or the safety of others.
- Providing positive behaviour support with a focus on skill building and with the aim of reducing the need for restrictive practices for people with ID (as recommended by the Australian Psychological Society) is best clinical practice and can effectively reduce challenging behaviours.

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Recommendations

1. The health and day to day support needs of people with intellectual disability (ID) are comprehensively assessed on entry to the criminal justice system and are reviewed on an annual basis.
2. Where there are concerns that a person in the criminal justice system with ID has either physical or mental health problems, they have a timely review by medical practitioners with access to advice from specialists in ID to determine appropriate treatment and management.
3. For any people with challenging behaviours, including all people for whom restrictive practices might be considered for safety, a positive behaviour support plan should be implemented under the guidance of a professional trained in developing positive behaviour support plans.
4. Support and training should be provided to staff in criminal justice systems to effectively deliver the supports the person needs and to consistently implement positive behaviour management strategies.
5. Independent restrictive practices authorisation panels should be established within all Australian detention facilities to monitor and regulate the implementation of any restrictive practices. Panel composition should include at least one external member.
6. As recommended by the Australian Law Reform Commission, a national approach should be adopted to the regulation of restrictive practices across settings including the disability sector, residential care facilities, hospitals, schools and detention facilities.
7. Effective liaison should occur with the disability sector and National Disability Insurance Scheme (NDIS) to provide suitable expert supports for people with ID as they leave the criminal justice system. Such supports should be sustained in order to reduce the risk for recidivism and improve inclusion in the community.
8. Ensure practices and procedures within the Australian criminal justice system comply with human rights treaties such as the United Nations Convention Against Torture and the Convention on the Rights of Persons with Disabilities.
9. Regular public reporting of policies and practices within the criminal justice system against human rights and other relevant instruments.
10. Suitable sanctions are implemented where breaches of practice guidelines or abuses have occurred.

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The Importance of Physical and Mental Health for People with Intellectual Disabilities in the Criminal Justice System

The overrepresentation of people with intellectual disability (ID) within Australia's criminal justice system has been well established in the literature. In NSW, people with mental health disorders and/or cognitive impairment are estimated to be 3 to 9 times more likely to be incarcerated than the general population (McCausland, Baldry, Johnson, & Cohen, 2013). People with ID who also have mental health disorders appear to be particularly overrepresented. For example, a recent study examining co-occurring mental health disorders and ID in a large sample of Australian prisoners found that approximately 1 in 10 had ID (significantly higher than the general population prevalence), and of these, more than half had also received a mental health disorder diagnosis (Dias, Ware, Kinner, & Lennox, 2013). Although there are likely to be many reasons for this, psychological and socio-economic disadvantages together with behavioural disturbances which place individuals with ID at increased risk of contact with (and unfavourable treatment within) the justice system are undoubtedly key contributors.

The same disproportionately high prevalence of ID has also been found in incarcerated adolescents and young people. While current Australian prevalence data is lacking, a 2003 report on young people in custody in NSW described that 17% of young detainees had cognitive functioning consistent with a possible ID (NSW Department of Juvenile Justice, 2003). Detained children and adolescents are becoming increasingly recognised as one of the most vulnerable groups in the Australian population with high levels of need and specific health risks. Indeed, the Royal Australasian College of Physicians has strongly emphasised the need for children to undergo comprehensive physical and psychosocial health assessments and treatment during and after incarceration, including screening for the presence of developmental or intellectual disabilities (RACP, 2011).

Dias and colleagues (2013) found that approximately 1 in 10 Australian prisoners had ID, and of these, more than half had been diagnosed with a comorbid mental health disorder.

A small but significant proportion of people with ID in both correctional and community settings display challenging behaviours which pose risks to their own

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safety and the safety of others, including aggression, self-injury and destructive behaviour (e.g. Emerson et al., 2001; McClintock, Hall, & Oliver, 2003). The aetiology of these challenging behaviours varies considerably from person to person, and is likely to be influenced by a range of environmental, interpersonal and intrapersonal factors, including (but not limited to):

- Physical health problems (e.g. May & Kennedy, 2010)
- Mental health problems (e.g. Holden & Gitlesen, 2008)
- Environmental stimulation (e.g. Matson, Bamburg, Cherry, & Packlawskyj, 1999)
- Social contact (e.g. Hastings & Remington, 1994)
- Quality of sleep (e.g. Brylewski & Wiggs, 1999)
- Receptive and expressive communication skills (e.g. Kevan, 2003; McClintock et al., 2003)

Effective and ethical behaviour management strategies should aim to address all contributing factors to reduce the frequency and severity of challenging behaviours and promote more appropriate alternative behaviours. A goal should be maximising the person's potential for inclusion and participation in their community. Within the context of the criminal justice system, a related goal would be reducing recidivism among offenders with ID.

Human Rights Violations in Current Behaviour Management Practices

Recent reports from the Australian Human Rights Commission have exposed systematic patterns of abusive and restrictive practices towards people with ID and challenging behaviour in Australian correctional facilities, including the repeated use of chemical, mechanical and physical restraints and seclusion (e.g. see AHRC, 2013). These restrictive practices are out of keeping with best practice guidelines and are in direct violation of the *United Nations Convention Against Torture* (ratified by Australia in 1989) and the *Convention on the Rights of Persons with Disabilities* (ratified by Australia in 2008), which includes a specific article relating to the right of freedom from torture or cruel, inhuman or degrading treatment or punishment for individuals

All practices and procedures involving people with ID in the criminal justice system must comply with the UN Convention Against Torture and the Convention on the Rights of Persons with Disabilities.

with disabilities. In the context of the Australian criminal justice system, these conventions compel state parties to ensure that people with ID are protected by the law and are able to participate within the legal system on an equal footing with others in the community, with appropriate recognition of any individual capacities and limitations.

In 2014 the Commonwealth, state and territory disability ministers across Australia endorsed the *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* which highlighted the need for person-centred, data-informed practice in managing challenging behaviours in people with ID. The Australian Law Reform Commission has highlighted the need for a national approach to the regulation of restrictive practices across other settings outside the disability sector, including residential aged care facilities, hospitals, schools and prisons (ALRC, 2014). Sadly, progress in this area has been slow, and abusive practices have been allowed to continue. While there is a dearth of literature on the long-term impact of abusive practices within the criminal justice system for detainees with ID, intuitively it is clear that rehabilitation with a view towards productive community participation is highly unlikely to be achieved while these continue.

The Australian Law Reform Commission has highlighted the need for a national approach to the regulation of restrictive practices across all government settings. Unfortunately, however, progress in this area has been slow and abusive practices have been allowed to continue.

Contributions of Health Problems to Challenging Behaviour in People with Intellectual Disability

In Australia, there already exists a strong relationship between incarceration and poor health (AIHW, 2011). For people with ID in the criminal justice system, this association is likely to be even stronger, as people with ID are known to have significantly higher prevalence rates of a range of chronic health conditions compared to the general population, as well as higher rates of premature mortality and preventable deaths (Jansen, Krol, Groothoff, & Post, 2004; Taggart & Cousins, 2014;Trollor et al, 2017). Specific conditions which are particularly

Physical health problems such as pain and illness can affect behaviour both directly and indirectly in people with ID. Medical screening for physical health issues can determine whether these might be contributing to challenging behaviour.

overrepresented in people with ID include epilepsy (estimated prevalence 16-26%; Morgan, Baxter, & Kerr, 2003; McGrother et al., 2006), cardiovascular disease (around 14%; Van Den Akker, Maaskant, & Van Der Meijden, 2006), gastro-oesophageal reflux disease (up to 50%; Böhmer, Klinkenberg-Knol, & Niezen-de Boer, 2002), osteoporosis and osteopenia (approximately 17% and 50% respectively; see Zylstra, Porter, Shapiro, & Prater, 2008), oral health problems such as periodontitis (approximately 80%; see Morgan et al., 2012), hearing impairment (approximately 30%; see Meuwese-Jongejeugd et al., 2008) and visual impairment (approximately 14%; see Van Splunder, Stilma, Bernsen, & Evenhuis, 2006).

The relatively poor health of people with ID is likely to be associated with differences in health and lifestyle behaviours, such as smoking status and maintaining a healthy diet (McGuire, Daly, & Smyth, 2007; Taggart & Cousins, 2014). Additionally, psychosocial disadvantage and disparities within health care settings and systems experienced by people with ID are likely to play a significant role, including inadequate attention to the health care needs of people with ID, little focus on appropriate health promotion and poor access to quality health care services (Krahn, Hammond, & Turner, 2004). As people with intellectual disabilities often cannot explain health complications they are experiencing in the same manner as other adults, their health problems can go undetected and untreated, with studies showing that mild and severe health needs are often unmet in people with ID (Baxter et al., 2006). It is pleasing to note that the disparities in health care delivery for people with ID are receiving increasing recognition in the health sector, and in New South Wales a service framework to improve health care of people with ID has been developed which outlines the specific health care needs and health risks for this population (NSW Health, 2012). Implementation of this framework is in its infancy, however, and people with ID continue to experience poorer health outcomes than the general population.

Physical health problems such as pain and illness can affect behaviour both directly and indirectly in people with ID. For example, a study examining self-injurious behaviour in

nonverbal children with severe ID found that self-injury was significantly more likely to be directed towards or near the site of chronic pain, such as head-hitting in those with facial pain (Breau et al., 2003). People with ID may therefore use self-injurious behaviour to signal the presence or location of pain, or alternatively may engage in self-injurious behaviours in an attempt to temporarily relieve pain in the affected area. Pain or illness can also affect behaviour by changing the value of a reinforcer. For example, a person who was previously motivated to behave appropriately by opportunities to socialise in a group setting may no longer wish to be in a busy, noisy environment if they are suffering from an ear infection and may engage in challenging behaviours as a means of escape (May & Kennedy, 2010). Functional analysis of challenging behaviours in people with ID should always include medical screening for physical health issues to determine whether pain or illness might be contributing (Waite et al., 2014).

Knowledge of the underlying cause of disability can assist with understanding health conditions and behaviour phenotypes (that is, behaviours typical of a particular condition or disorder). Sometimes certain behaviours can be characteristic of (but not specific to) particular syndromes or conditions, such as self-injury in Lesch-Nyhan syndrome (Waite et al., 2014) or excessive eating in Prader Willi syndrome (Bouras & Holt, 2009). Behavioural phenotype research has shown that environmental, developmental and biological factors can interact in specific conditions associated with ID to create a ‘causal pathway’ to challenging behaviour, illustrating that there are multiple stages at which behaviour can be influenced and therefore multiple levels at which interventions might be successful (Waite et al., 2014).

Within the criminal justice system, important disorders to consider are foetal alcohol spectrum disorders (FASD), a group of neurodevelopmental disorders arising from prenatal exposure to alcohol. While there is a paucity of research on the prevalence of FASD in Australia’s criminal justice system, a previous study in the United States showed that approximately 60% of individuals with FASD had experienced trouble with the law, with half experiencing confinement in prison or inpatient settings throughout their lives (Streissguth et al., 2004). Significant structural brain changes are known to be associated with FASD, including reduced overall brain size, additional reduction in the cerebellum and basal ganglia and abnormal development of the corpus callosum (Archibald et al., 2001; Mattson et al., 1992). These structural changes are related to a range of neuropsychological problems

which include reduced overall intellectual functioning (IQ) as well as specific deficits in attention, memory, language, executive functioning and social and adaptive functioning (Riley & McGee, 2005). The neuropathology of FASD gives rise to a specific behavioural phenotype of impulsivity, oppositional behaviour, a lack of social judgment and failure to learn from experiences (Koren, 2015). Understanding this phenotype has important implications for which behaviour support strategies are selected in this population – for example, people with FASD are likely to need lots of support to regulate their behaviour due to impulsivity and are unlikely to learn from punitive response-cost behaviour management approaches.

Health assessment with appropriate tools, such as the Comprehensive Health Assessment Program (CHAP), will be essential immediately upon entry to the criminal justice system for people with ID to explore the potential contribution of health issues to challenging behaviour.

It is clear that the potential contribution of health to challenging behaviour in people with ID in the criminal justice system warrants further exploration. As such, thorough health assessment with appropriate tools will be essential immediately upon entry to the criminal justice system with regular scheduled reviews for detainees with ID. One such tool would be the Comprehensive Health Assessment Program (CHAP), which has been developed by Professor Nicholas Lennox at the Queensland Centre for Intellectual and Developmental Disability (Lennox et al., 2007). This is a two-part, structured questionnaire requiring a comprehensive health history from the person with ID and any carers or support staff followed by a guided medical review leading to the development of a health action plan. Across Australia, this is widely considered the gold standard in meeting the health care needs of people with ID living in the community (Gordon, Holden, Ware, Taylor, & Lennox, 2012). Such a program could be readily incorporated into health assessment practices in the criminal justice system.

Mental Illness and Challenging Behaviour in People with Intellectual Disability

In addition to physical health problems, people with ID also have disproportionately high rates of mental illness compared with the general population. In Australia, more than 30% of people with ID are estimated to also have a mental illness, well above the general population prevalence of 20% (Morgan, Leonard, Bourke, & Jablensky, 2008). Within the criminal

justice system, the estimated rates of mental illness for people with ID are even higher at 52.5% (Dias et al., 2013). Mood and anxiety disorders are common, however schizophrenia appears to be particularly overrepresented in people with ID, with prevalence estimates ranging between 1.3 and 5.2% (e.g. Bouras & Holt, 2009; Deb, Thomas & Bright, 2001; Morgan et al., 2008;) compared to approximately 0.4% in the general population (McGrath, Saha, Chant, & Welham, 2008).

It can be difficult to differentiate challenging behaviour and psychiatric illness in people with ID, as challenging behaviour can represent an atypical presentation (or "behavioural equivalent") of a psychiatric disorder (Allen & Davies, 2007). For example, it has been proposed that in some cases self-injurious behaviour may be an expression of obsessive compulsive disorder symptomatology in people with ID (King, 1993). Alternatively, behavioural disturbances such as aggression may occur secondary to psychiatric illnesses (Allen & Davies, 2007). Sometimes, challenging behaviour in people with ID might be better conceptualised as a mental health problem requiring a treatment and management approach.

Mental illnesses require assessment by a psychiatrist for accurate diagnosis and treatment. A mental health approach which aims to assess and treat mental illnesses in people with ID should be considered as an alternative to incarceration where appropriate.

The Positive Behaviour Support Framework

The Positive Behaviour Support framework has been recommended by the Australian Psychological Society as best clinical practice in managing challenging behaviours in people with ID. This framework is the standard of practice in the disability sector but has yet to be adopted within the criminal justice system.

The Positive Behaviour Support (PBS) framework has been recommended by the Australian Psychological Society as evidence-based and best clinical practice in managing behaviours of concern in people with disabilities (APS, 2011). This framework has been widely accepted for years as the standard of practice for clinicians working within the disability sector (e.g. see DADHC NSW, 2009) but has yet to be adopted within the criminal justice system. PBS incorporates a number of key elements

underpinned by a commitment to the rights, dignity and quality of life of people with disabilities and includes a comprehensive behavioural assessment and support plan developed under the guidance of a professional trained in PBS principles, such as a psychologist. Where medical or mental health concerns are identified or suspected, referral to an appropriately trained medical practitioner with experience in ID for assessment and treatment would be an essential component of that person's ongoing management plan.

While the PBS approach does not specifically preclude the implementation of restrictive practices (including the use of seclusion and physical, mechanical, chemical and/or psychosocial restraints) where unavoidable for health and safety purposes, the aim is to reduce and ultimately eliminate the need for these practices over time (APS, 2011). This is accomplished through imposing strict conditions on the use of any restrictive practices, including: selecting these practices only as a last resort, selecting the least restrictive option, limiting the time-frame of implementation, recording and monitoring all instances of implementation, and reviewing the practice at regular intervals (at least yearly) to assess whether or not the restrictive practices can be faded out in favour of more positive approaches. The focus is on maintaining the person's safety and the safety of others while respect for the person and their dignity remains paramount. Restrictive practices as a means of discipline, coercion or retaliation are unacceptable and ineffective.

Assessment and Implementation of Support Needs for People with Intellectual Disability

People with ID are likely to have a range of extra support needs which may be relevant to a positive behaviour support plan. However, the nature and extent of these needs will vary significantly from person to person, and as such comprehensive assessment by a range of health professionals may be necessary to understand how best to support the person. Some key areas to explore in relation to challenging behaviour in people with ID are mentioned below, however it should be noted that this is not an exhaustive list.

Communication

It is widely recognised that people with ID have difficulties in communication, including receptive communication (difficulty understanding speech) and expressive communication (difficulty expressing themselves using speech). People with more severe ID may only be

able to communicate by gestures such as pointing. It is widely recognised that people with ID with limited expressive language can engage in challenging behaviours if a more appropriate form of communication is not available to the person (Carr & Durand, 1994). Furthermore, when there are receptive language issues, challenging behaviours may occur due to a mismatch between the level of communication directed towards a person with ID and that person's level of skill (Kevan, 2003). Assessment by a speech pathologist may be necessary for people with ID where communication issues are identified to establish whether Augmentative and Alternative Communication (AAC) strategies might be of benefit, such as visual aids, symbols or key word signing.

Sleep

Although there is limited research on sleep disturbance in adults with intellectual disability, a previous study suggested that as many as 17% of people with ID might have clinically significant sleep problems (Gunning & Espie, 2003). It is widely recognised that chronic sleep debt decreases frustration tolerance and reduces the efficiency with which people process information (Brylewski & Wiggs, 1999). These are already most likely areas of difficulty for people with ID given their reduced cognitive proficiency compared to the general population and as such people with ID and sleep disturbances would be particularly vulnerable to displaying challenging behaviour. Indeed, previous research addressing sleep disturbance and challenging behaviour in children with ID has shown strong associations between sleep problems and the frequency and severity of daytime problem behaviours (Didden, Korzilius, van Aperlo, van Overloop, & de Vries, 2002; Richdale, Francis, Gavidia-Payne, & Cotton, 2000). Psychologists and medical practitioners may be able to provide behavioural and/or medical intervention to improve sleep which may reduce challenging behaviour.

Social Contact and Stimulation

Adults and children with ID are vulnerable to social isolation and loneliness, with evidence suggesting that up to 50% of people with ID are chronically lonely (Gilmore & Cuskelly, 2014). Challenging behaviour can often be an effective means of eliciting reactions and social contact for people with ID, particularly when more appropriate means of social interaction are not available. There is an emerging body of evidence to suggest that engagement and occupation can reduce challenging behaviour in people with ID (Ball &

Fazil, 2013). As such, providing people with ID with meaningful things to do in any environment may reduce opportunities and motivations for challenging behaviour to occur.

Conclusion

In summary, the degrading, coercive and abusive behaviour management practices in Australia's detention facilities has shown that our nation is failing in its duty to uphold the human rights of people with disabilities. To address this, it will be important for our government to invest resources in appropriate education programs and other initiatives to ensure the basic needs of people with ID in the criminal justice system are adequately met. Such initiatives would likely require ongoing collaboration between the health, disability and justice sectors. Priorities will be facilitating fair and equitable access to specialist medical assessment and treatment for people with ID, comprehensive behavioural assessment and the development of positive behaviour support plans for people with ID where indicated, and the establishment of independent restrictive practices authorisation panels within criminal justice facilities to monitor the implementation of any practices which might unduly limit the rights and freedoms of people with ID.

We can, and should, do better.

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