The concept of intellectual disability, and people with intellectual disability in Corrective Services NSW

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Abstract

Within New South Wales there is a significant focus on people with intellectual disability who come into contact with the criminal justice system. In Corrective Services NSW there was initially an emphasis on identification of this population but more recently the focus has moved to increasing program options both within custody and in the community. The identification and provision of programs has resulted in awareness of significantly more offenders with intellectual disability in the correctional system. It is therefore critical that those working in the system have some understanding of the concept of intellectual disability, and the knowledge and skills of how to interact with people with this label. This paper begins with an exploration of the historical changes in the definition of the concept, briefly discusses the current understanding, and then makes suggestions for staff interactions. Corrective Services NSW (CSNSW) does not limit services to people who fit the strict definition of intellectual disability but uses a broader focus that includes people with 'borderline' cognitive functioning. People who offend who function in the borderline or intellectual disability range (or range of cognitive impairment) are located in correctional centres around NSW, and all staff working within CSNSW are required to understand and meet the additional needs of people with 'cognitive impairment'. CSNSW has set up several systems to assist staff, including State-wide Disability Services and information systems accessible by all staff.

Key words:

Intellectual disability; Borderline cognitive functioning; Cognitive impairment; History of intellectual disability; Offenders with cognitive impairment: CSNSW State-wide Disability Services

Background

Intellectual disability is perhaps one of the longest recognised concepts studied by psychologists and psychiatrists, with qualitative descriptions being found in Babylonian Law Codes around 2500 BC and Egyptian historical records around 1500BC (Berkson, 2004; Tylenda, Hooper, & Barrett, 1987). More recently, the categories of intelligence were at different times referred to as feeblemindedness or Amentia (i.e. dementia that occurred in the developmental period). Australians tend to use the term 'intellectual disability', Americans referred predominantly to 'mental retardation', and the British talk

about 'learning disability'. These terms are used relatively interchangeably to refer to approximately the same concept. The terminology has changed over the past century as can be seen in Table 1.

The term now known as intellectual disability has undergone many changes in name, but has always referred to the developmental period. The expression developmental disability is much broader than intellectual disability, and may include people with epilepsy, cerebral palsy, autism or other disorders that occur in the developmental period. Given this range of terms, it is therefore important to understand the concept of intellectual disability,

and how it has changed over time.

	Terms used commonly today	Historical terms now not used, or derogatory terms			
Australia	Intellectual disability	Mental retardation Developmental disability			
America	Mental retardation Intellectual disability	disability	Feeble minded Amentia		
		mental subnormality			
United		mental deficiency			
Kingdom	Learning Disability	mental handicap			
Approximate IQ range					
Less than 20	Profound		Idiot		
20 - 34	Severe			Cretin	
35 - 49	Moderate	Trainable	Imbecile		
50 - 69	Mild	Educable	Moron		
70 - 80 (85)		Borderline functioning			
50 - 79	Cognitive impairment				

Table 1: Terms used to describe the concept of intellectual disability

One of the difficulties with the term 'mental retardation' which was used in Australia and is currently but less frequently used in America is that it is often confused with 'mental disorder' or 'mental illness'. While 'mental disorder' is a diagnostic term that psychiatrists and psychologists use to describe a variety of cognitive and behavioural differences found in the general population, the term intellectual disability refers primarily to people's significant lower cognitive and behaviour ability. Although intellectual disability is discussed as a single concept this is not always the case. Many people with intellectual disability may have 'mental' or other 'disorders', and terms such as 'schizophrenia', 'depression', 'acquired brain injury', 'drug dependence', etc., may also be used in addition to 'intellectual disability'. Sachs & Barrett (2000) state that intellectual disability can increase the risk of a mental disorder. The compounding effect of having many difficulties or issues that are often difficult to disentangle in practice is beyond the scope of this paper, aside from a mention that they are often part of the disabling impact experienced by people with intellectual disabilities.

Definitions

Definitions set a boundary and framework around the 'things' that are 'studied'. However, in the area of intellectual disability, definitions and labels are also a way of determining whether a person is eligible to gain access to services, or should be excluded from service delivery. The definition of intellectual disability is therefore much more than a point of academic interest, but of major importance to both service providers and persons with intellectual disability and their families. People with intellectual disability may find the label intellectual disability useful in making sense of their world but at the same time the term may also be a stigmatising experience.

Tredgold provided a definition of intellectual disability in 1908 as "A state of mental defect from birth, or from an early age, due to incomplete cerebral development, in consequence of which the person is unable to perform his duties as a member of society in the position of life to which he was born" (Tredgold, 1908, p.2). The advent of the intelligence test allowed for 'objective' measurement of 'intelligence'. One of the inventors of the IQ test, Alfred Binet cautioned that there was a great diversity of intelligence which required qualitative rather than quantitative investigation. Binet wanted to identify students with special needs so they could receive help with the school curriculum. However, the IQ test was heralded as an objective assessment instrument which the 1916 Stanford-Binet manual claimed, contrary to Binet's intentions, could lead to "curtailing the reproduction of feeble-mindedness and in the elimination of an enormous amount of crime, pauperism, and industrial inefficiency" (White, 2000, p. 7). These definitions are an example of the way terms and labelling are a product of the social context.

The first objective definition (i.e. with measurements attached) of 'mental retardation' was published in 1919 by the American Association on Mental Retardation (AAMR), and their most recent definition was published in 2002 (Greenspan & Switzky, 2006). 'Scientific' terms that are commonly and more frequently used tend to be replaced more often than other scientific terms. In the last century reference was made to people with intellectual disability, as 'feebleminded', 'idiots' or 'imbeciles'. They were seen to have 'chronic' conditions, were 'unfixable', and so were socially abandoned (Smith, 2006). Today, it may be argued that people with intellectual disability are not considered to have limitations that are 'embodied' (i.e. within the person), but other factors such as

the effects of poverty and social deprivation may account for some lowered IQ scores. There is more optimism about social integration and more awareness of the disabling effects of society that are encountered by people with intellectual disability.

The definition of intellectual disability in the 2002 AAMR manual includes three criteria: it is "a disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual (reading, writing, money concepts, language and self-determination), social (interpersonal, self-esteem, responsibility, follows rules and avoids victimization), and practical (daily living skills such as cooking, cleaning, hygiene) adaptive skills. This disability originates before age 18" (Luckasson et al., 2002, p. 8).

Intelligence is a multidimensional construct. There are those who claim that there are multiple intelligences (Gardner, 1993; Goleman, 2003), and IQ tests measure only a small part of the various intelligences. Intelligence as measured by IQ tests fits a 'normal curve' where most people fit within the middle of the curve and very few at the extremes. 'Genius' and 'intellectual disability' fall on the two extremes of the normal curve.

Changing the definition

The 'objective' definition of intellectual disability has not remained constant. Some of the major changes are reflected in Table 2. These changes occurred in the areas concerned with IQ scores, with adaptive behaviour, age of onset, and categories of intellectual disability.

Author / Year	IQ cut off	Skill impairment or Adaptive behaviour	Develop -mental period	Severity / support descriptor
Heber,196 1	>1 standard deviation below mean (could include up to 16% of the population)	Only introduced in 1959, and this is first AAMR reference to adaptive behaviour Effectiveness in adapting to environment as reflected in 1. maturation 2. learning 3. social adjustment	birth through age about 16 years	Borderline (68 - 84) Mild (52 - 67) Moderate (36 - 51) Severe (20 - 35) Profound(< 20)
Grossman, 1973	2 or more standard deviations below the mean	Personal independence and social responsibility compared to own age and cultural group. Skills assessed a. <i>during infancy or early childhood</i> 1. Sensory-motor development 2. Communication 3. Self-help 4. socialisation B. <i>during childhood and early adolescence</i> 5. Application of basic academics in daily living 6. Reasoning and judgement applied to master various environments 7. social skills c. <i>during late adolescence and adult life</i> 8. vocational and social performance	upper age limit of 18 years	Mild (52 - 67) Moderate (36 - 51) Severe (20 - 35) Profound(< 20)
Grossman, 1983	70 or below, or up to 75 depending on reliability of IQ instrument	Significant limitations in effectively meeting standards of 1. Maturation 2. Learning 3. Personal independence 4. Social responsibility as expected for age and culture. May be demonstrated in same way as in 1973	upper age limit 18 th birthday	Mild (50 - 55 to about 70) Moderate (35 - 40 to 50 - 55) Severe (20 - 25 to 35 - 40) Profound (< 20 or 25)
Luckasson, et al, 1992	significantly sub-average 70 to 75 or below	Deficits in 2 of 10 skill areas referenced to chronological age 1. Communication 2. Self-care 3. Home living 4. Social-skills 5. Community use 6. Self-direction 7. Health and safety 8. Functional academics 9. Leisure 10 work.	upper age limit 18 th birthday	Intermittent - Limited. Extensive Pervasive
Luckasson, et al, 2002	70-75 or below. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor and behavioural factors	Significant skill deficits in at least one area 1. conceptual (reading, writing, money concepts, language, self-determination) 2. social (interpersonal, self-esteem, responsibility, following-rules, avoiding victimization 3 practical (daily living e.g. cooking, cleaning, hygiene) Also concern with psychological, emotional and social strengths and needs of the individual and limitations in present functioning are considered within the context of community environments typical of the individual's age peers and culture so that profile of supports can be developed	upper age before age 18	Intermittent - support is given on an as needed basis. Limited - regular basis for a short period of time. Extensive - on- going; daily and not time limited Pervasive - constant; and high intensity and intrusive support.

Table2: Changes to AAMR definition of intellectual disability from 1961 - 2002

In relation to IQ scores, the definitions changed, and have consequently affected vast numbers of people, who may be eligible for services, from:

- one standard deviation below the norm (i.e. people with an IQ below 85 points where up to 16% of the population could potentially have an intellectual disability), to
- two standard deviations below the norm (i.e. below IQ 69 points so only 2% of the population could potentially have an intellectual disability), and
- two standard deviations, but allowing for a 'standard error' of the IQ assessment tool of up to 5 points (i.e. people with an IQ of fewer than 75 points or 5% of the population could meet the first criterion of the definition).

Adaptive behaviour has not been immune from changes including:

- impairment with one or more of the following: 1) maturation, 2) learning, and 3) social adjustment
- impairment in two of 10 adaptive skills (communication, self-care, home-living, social skills, community-use, self-direction, health and safety, functional academics, leisure and work), and stated there had to be deficits in two or more of these areas. An important acknowledgement in the 1992 manual was that people have both strengths and limitations.
- the term adaptive behaviour was reintroduced, and 'significant limitations' had to exist in "conceptual, social and practical adaptive skills" (Luckasson et al., 2002, p. 8).

The DSM-IV (American Psychiatric Association, 2000) refers to adaptive behaviour as "how effectively individuals cope with common life demands and how well they meet the standards of personal independence expected of someone in their particular age group, socio-cultural background and community setting" (p. 42)

The concept of age requirement has also changed. In 1961 the upper age for intellectual disability was set at 16, whereas since 1973, it was extended to 18.

The changes in definition do not take into account the technical aspects of IQ tests, where the standard deviation on the Wechsler tests is 15, and on the Binet tests (until the latest revision) was 16. So IQs of 2 standard deviations on the Wechsler give an IQ of 70 points and 2 standard deviations on Stanford-Binet tests an IQ of 68. People could be excluded from services on the basis of the test used. The changes also do not take into account the "Flynn effect" (J R Flynn, 1987) which indicates a rise of IQ scores between 5 and 20 points each generation. These gains occur at all levels of intelligence, including those with intellectual disability (James R. Flynn, 2006). The rise of IQ over time means that while about 2% of the current population would score in the range of intellectual disability, if current norms were applied to people who lived around 1900, then about 1/3 of them would score in the range of intellectual disability. The Flynn effect also underlies the importance of using the most recently normed assessment instruments. If the latest instruments are not used, people may score outside the range of intellectual disability and so be ineligible for services, or could be excluded from the 'immunity' for death sentence due to intellectual disability (Atkins v. Virginia, 2002) in countries where this is applicable.

A criticism has been levelled at the inclusion of conceptual skills as part of adaptive behaviour in the recent AAMR definition of intellectual disability. Conceptual skills are similar to IQ scores, and there can be no 'intellectual disability' without significant conceptual deficits. So, in practice, there needs to be significant limitation in social and practical skills (including skills involved with independent living), as well as difficulties in adapting to a particular environment as shown by the person's behaviour.

There is a debate as to whether adaptive behaviour is a single or multiple construct. Thompson, McGrew, & Bruininks (1999) have found five different areas are used to understand adaptive functioning (personal independence, responsibility, academic/ cognitive, vocational/community, physical/development). They state that there is no single adaptive instrument that measures all these domains.

While there are psychometric scales that measure adaptive deficits, only the Vineland Adaptive Behaviour Scales (VABS) is a valid measure of adaptive behaviour, but it does not have norms that fit the new definitions of adaptive behaviour (Beail, 2003). Other scales that are commonly used to assess adaptive behaviour include the AAMR Adaptive Behaviour Scales (ABS), and the Scales of Independent Behaviour -Revised (SIB), but they have the same difficulties as the VABS in terms of current definitions. Clinical judgement therefore plays a role in determining whether an adaptive deficit exists. Adaptive behaviours are also culturally and contextually determined, and so may vary from place to place. The presence of an adaptive deficit may also not be important if there are appropriate supports in place for the person. For a variety of reasons, it is not possible to assess adaptive behaviour in correctional centres, including the lack of a reliable assessment instrument, the need for a third person to provide evidence of how the person functions as the assessment instruments do not directly measure skills, and the need for different adaptive skills in gaol from those in the community. Reliance on individual self-report can

also be very detrimental to the individual as in the 2002 case of Atkins vs. Virginia. In this landmark American case, the court ruled it was 'cruel and inhumane' to execute a person with intellectual disability. In 2002, based on IQ assessment, adaptive functioning and onset prior to age 18, Atkins clearly met criteria for intellectual disability. But on the basis of 'expert testimony' based on Atkin's self-reported adaptive functioning, a jury in 2005 found Atkins did not have intellectual disability and so could be executed (Perske, 2005). The tendency of a person with intellectual disability to both exaggerate their abilities and deny their limitations adds further need for caution in relying on selfreport (Perske, 2005).

There has been much modification to the concept of intellectual disability from the AAMR. Similar changes to the definition of 'mental retardation' can be found in other leading authoritative manuals, such as the Diagnostic and Statistical Manual (DSM) (American Psychiatric Association, 2000), the International Classification of Mental Diseases (ICD) (World Health Organization, 2005), and the ICF (World Health Organization, 2001). There are presently subtle differences in definition across these authoritative bodies. Schalock & Luckasson (2004) deal with some of the issues involved with naming (assigning a term to someone), defining (specifically explaining a term) and classifying (after a term is defined, stating which groups fit within its boundaries).

About 1.2% - 1.3% of the populations of Australia and America are identified as having intellectual disability, while in the UK there are about 0.5% of the population with this label (Felce, 2006). Using the statistical 'normal bell curve' it would be expected that between 2% - 3% of the population would have intellectual disability, but this is not the case. Does this mean that there are a whole lot of people in the community who have not been identified as having intellectual disability? Does the difference across countries mean that the criteria are more stringent in the UK? Or does the labelling process rather depend on the place, time, culture, and social expectations, with more people likely to be identified as having an intellectual disability if they live in urban centres and technological societies? If so, then 'intelligence' must be linked to culture as claimed by Vygotsky (1978).

Difficulties with the concept of intellectual disability

Intellectual disability is a complex and multifaceted concept. In addition to the definitions discussed above, a further difficulty with the concept of 'intellectual disability' is that it is based on at least two different theoretical models of thought. Those advocating the use of the medical model state that intellectual disability is a 'trait' (i.e. it is something that one is born with and does not change over one's lifetime). Intellectual disability is therefore seen as a physical impairment, the same as a deformed limb, or something that is lacking in the individual, and may well be inherited (Spitz, 2006). Those who claim a medical model is 'right' claim that efforts should be made to prevent intellectual disability, including claims of success in this regard by identification of high risk conditions (e.g. Tay Sachs) and genetic counselling for people likely to have children with 'intellectual disability'. The medical model is often used by rational economists who argue that there are limited financial resources which should be directed to prevention and research that encourages limiting the risk of having people with intellectual disability. Taken to an extreme, the medical model is used by those in the eugenics movement (Brüne, 2007), and was used as a pillar for Nazi behaviour towards anyone who was 'deviant'.

The social model of disability asserts that although a person may have impairment (i.e. the deficit in cognitive and adaptive behaviour in the developmental period); it is society that disables people, not the impairment per se. The social model has gained popularity and strong support by those who are most affected by disability, including intellectual disability. The social model clearly influences the current thinking about the concept. In the introduction to the 1992 AAMR definition, Luckasson, et al., (1992)., state "Mental retardation is not something you have, like blue eyes or a bad heart. Nor is it something you are, like being short or thin. It is not a medical disorder ... Nor is it a mental disorder. Mental retardation refers to a particular state of functioning that begins in childhood and in which limitations in intelligence coexist with related limitations in adaptive skill" (p. 9)

Prior to 1992, the definition of intellectual disability included a distinction between those who were least affected (i.e. they had a 'mild' and 'moderate' intellectual disability), and those who were more affected ('severe' and 'profound' intellectual disability). While this terminology is no longer used by AAMR, Haywood (2006) claims that those with IQs in the 'severe' and 'profound' ranges have multiple impairments and medically are qualitatively different from those with IQs in the 'mild' and perhaps 'moderate' ranges. Haywood claims the latter are much less likely than the former to have verifiable pathology in the central nervous system. Haywood also asserts that people with mild range IQ scores appear to have the same qualitative and sequential cognitive developmental path as those without intellectual disability. People with 'mild intellectual disability' comprise 75% of the population with ID in America, and they tend to be found in the lowest socio-economic parts of society (Greenspan & Switzky,

2006). In a Western Australian survey 87% of those with intellectual disability scored in the mild and moderate ranges (Leonard, Petterson, Bower, & Sanders, 2003). An earlier survey in Western Australia (Wellesley, Hockey, Montgomery, & Stanley, 1992) showed 77% of those with intellectual disability had mild and moderate disability scores, with only 43% in the mild range. It therefore appears that a significant number of people in Western Australia are not being assessed who may fit in the mild range of intellectual disability, which may explain the low overall prevalence rate of 0.76% reported in this study. This underassessment is important in light of Haywood's (2006) conclusion that people with mild and even moderate IQ scores are part of normal variation in IQ distribution across the population, and environment. Experience and cultural variables impact on their behaviour and cognitive ability. The reasoning that Haywood puts forward is similar to that found in the 1983 AAMR manual and is similar to that adopted by the Courts. The situation may best be summarised by the American courts which decided it is unconstitutional as well as 'cruel and unusual punishment' to execute a person with intellectual disability, as "Disabilities in reasoning, judgment, and control of impulses can keep some persons from being as morally culpable as others who commit capital crimes" (Perske, 2005, p. 454). People with mild and moderate IO scores are found in the criminal justice system worldwide, including New South Wales, and are sentenced to terms of incarceration, while those with severe and profound intellectual disability extremely rarely have contact with the criminal justice system.

People with intellectual disability in the NSW correctional system

Correctional centres may be both punitive and rehabilitative. While security and safety are paramount, there is a duty of care that is also crucial. Balancing security and duty of care needs for people with intellectual disability is a difficult process for a number of reasons. Aside from a security perspective, there are two very different approaches towards people with intellectual disability in correctional centre. The first is from a 'clinical' perspective where the disability is considered a trait or characteristic, or something within the person. This type of thinking embraces a medical or statistical model looking either at what is 'wrong' with the person or assessing IQ which is two or more standard deviations from the 'norm'. Within CSNSW the medical model may be used to think about issues of vulnerability and how other offenders may take advantage or stand over an offender with intellectual disability. The other way of thinking about intellectual disability is based on the social model in which disability occurs due to the interaction of the individual and his/her environment. A person is understood to have an intellectual disability based on his/her performance within a specific social system. There is more of a focus on the failures of the social system than the limitations of the person, and concerns what supports are required so the person can function according to her/his strengths rather than limitations. Within CSNSW a social model perspective encourages staff to provide additional supports so offenders with intellectual disability can not only remain in mainstream correctional centres, but also attend mainstream therapeutic and employment programs. Current thinking about people with intellectual disability has moved from a strictly medical and statistical model to include social models. It is important that practice in correctional centres also follows this trend where the two models complement one other.

People with intellectual disability are a heterogeneous group, but in

practice may be considered to be a homogenous group. Two people may have a similar IQ, but are different people. They have different abilities, various support needs and dependant relationships, and different ways of relating to others. When people with 'mild' IQ scores are identified in a correctional centre, they do not necessarily require similar supports. Some are 'street smart' or 'wise to the ways of correctional centre', and adapt to mainstream correctional environments. They may require some supports in the mainstream, but adapt to correctional centres as do most other inmates. Some people, who do not have IQ scores in the 'intellectual disability' range, may have very high support needs. It is critical to identify the support needs of the individual, more so than their IQ. The primary reasons that IQ scores are obtained in a correctional centre are to address the various responsivity issues in programs and correctional centre routine as well as to assess whether the person is eligible for services in the community. IQ scores are the beginning of the process for obtaining community services, and if the person scores in the 'intellectual disability range' then evidence of onset in the developmental period is sought. If IQ and developmental evidence is obtained, then referral to other agencies including Ageing, Disability and Homecare (ADHC) (in New South Wales) is made, and if offending behaviour is frequent and/or severe, then specialised community service (such as the current ADHC Community Justice Program) is sourced.

While in a correctional centre the risk of recidivism, the intensity of a person's responsivity and criminogenic needs is matched to the 'supports' and facilities available. The 'Additional Support Units' within CSNSW were previously used to address risk of harm or 'vulnerability' for people who scored in the range of intellectual disability. However, in line with the National Disability Strategy (NDS) (COAG, 2011) and current thinking within the community, the 'Additional Support Units' are now used to provide programs and services to medium high risk (of reoffending) sentenced people who score in the range of intellectual disability or borderline functioning (cognitive impairment). People with cognitive impairment are housed in correctional centres state wide. It is everyone's responsibility to interact and meet a duty of care with people with intellectual disability and cognitive impairment, so people with cognitive impairment who require intensive support due to 'issues of safety' are managed and maintained within mainstream correctional centres as would be the case for all offenders. However, where offenders require programs which require specific risk, criminogenic needs and responsivity issues to be addressed, they may be eligible for placement in "Additional Support Units' (ASUs). In these ASUs comprehensive case planning is conducted and there are opportunities to acquire employment, educational, functional literacy and other skills that may be useful once they are released from the correctional centre. Specific programs that address criminogenic need are also run in the ASUs. For example, people with cognitive impairment who have committed sexual offences may be eligible for the Self Regulation Program (SRP) for sex offenders that is run in the ASU.

Regardless of where a person is in the criminal justice system, it is vital that staff understand their strengths and limitations and provide the appropriate intensity of support. As the numbers of people with intellectual (and other) disabilities appears to be increasing in the criminal justice system, more staff across the criminal justice system will come into contact with them. It is vital that staff do not contribute to disabling the people with intellectual

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disability, through lack of knowledge, poor attitude and interpersonal insensitivity. Rather than focussing on impairment and limitation, staff may relate on a person to person basis, providing appropriate support while not jeopardising security. Aside from using the Offender Information and Management System (OIMS) screen, staff are most likely to identify that a person has an intellectual disability based on their lack of adaptive behaviour in the correctional centre situation. The person who offends may not demonstrate conceptual skills such as reading and writing, or have a good use of language. The person may show poor social skills such as difficulty understanding and following rules, difficulty with interpersonal relationships, or being victimised, or poor practical skills such as poor hygiene routines. If any staff member becomes aware of a pattern of poor adaptive skills, refer to Statewide Disability Services via the Disability Screen on the Offender Information and Management System (OIMS). Some people who do not have intellectual disability may also have difficulties with adaptive skills in gaol. Adaptive skills deficit alone is not sufficient for them to

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qualify for services for people with intellectual disability. It is important that all people are able to participate in routines and programs to the best of their ability and within the correctional system. The security concerns need to be supplemented with medical, psychological, educational, case management and social supports where applicable. Encourage the person with intellectual disability to use his/her strengths, whilst being aware of but not focussing on the person's limitations. By providing appropriate support and interaction, the person with intellectual disability is able to learn from appropriate role modelling, and over time may learn to apply these new skills in daily interactions. Often people with intellectual disabilities take on 'criminal identities' as this is where they often feel they are being accepted as a person. Where a staff member encourages pro-social behaviour through appropriate interactions, this may change the person's thoughts and feelings about being 'deviant', and may be a starting point to feelings of social inclusion and community reintegration.

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