



World Psychiatric Association (WPA) report on mental health issues in people with intellectual disability

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Special Issue Papers

World Psychiatric Association (WPA) report on mental health issues in people with intellectual disability[†]

Paper 1: Intellectual disability and mental health: an overview

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ABSTRACT

Characterised by impairment of global mental activities, intellectual disability as a term has replaced learning disability. Although in many countries terms such as mental handicap and mental retardation are still being used, the term intellectual disability is to be preferred. Intellectual disability has different significance across cultures and has three levels of severity: mild, moderate and severe. The causes of intellectual disability are divided into pre-natal, peri-natal and post-natal. Assessment and management of intellectual disability need broad multi-factorial approach. Rates of physical co-morbidity are very high and need careful evaluation.

Introduction

Intellectual disability (ID) is a condition that is characterised by the impairment of global mental abilities and the consequent limitations in the individual's adaptive functioning. The latter is broadly based on the person's ability to perform day-to-day activities and involves three main skills (American Association of Intellectual and Developmental Disabilities, 2016):

- (1) The ability to conceptualise, which includes the ability to use language, read and write, mathematical skills, general knowledge, memory and reasoning.

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- (2) The ability to socialise, which is demonstrated by the person being able to empathise with others, make social judgements, have appropriate interpersonal communication and make and keep friendships.
- (3) The ability to perform practical tasks and be able to manage oneself in areas such as managing their own money, finding and holding a job, taking part in recreational activities, caring for their personal appearance and hygiene and generally being able to organise their school- or work-related activities.

The term ID is used in all the papers in this series. However, it has been described using a variety of terms, including mental retardation and learning disability.

Evolving terminology

The evolution of different terms used to describe ID has been elegantly described (Harris, 2013) and is summarised below. The global impairment of mental abilities used to be described as ‘feblemind- edness’, ‘idiocy’, ‘mental sub-normality’ and ‘mental handicap’. These terms became pejorative and stigmatising labels and were slowly replaced. The term ‘mental retardation’ was then introduced by the American Association on Mental Retardation in 1961, followed by the American Psychiatric Association, which incorporated it into its *Diagnostic and Statistical Manual for Mental Disorders* (DSM). The World Health Organisation (WHO) used the same term for its *International Classifi- cation of Diseases* (ICD) (WHO, 1992). Over time, this term too came to seen as a pejorative label. Even while the DSM and ICD continued to use the term, the UK government and academic bodies like the Royal College of Psychiatrists, responding to feedback from people and families, started using the term ‘learning disability’. This occasionally gave rise to confusion, particularly in international circles outside the UK, because of the risk that it may be confused with ‘specific learn- ing disability’ (SLD or dyslexia), which is a completely different condition.

International bodies subsequently started using the term ‘intellectual disability’. The International Association for the Scientific Study of Mental Deficiency became the International Association for the Scientific Study of Intellectual Disability, the *Journal of Mental Deficiency Research* became the *Journal of Intellectual Disability Research* and the Faculty of Learning Disability became the Fac- ulty of the Psychiatry of Intellectual Disability at the Royal College of Psychiatrists. Now, the inter- national classificatory systems – the DSM-5, published in 2013 (American Psychiatric Association, 2013) and the ICD-11, due for publication soon – have also replaced the term ‘mental retardation’. The DSM-5 uses the term ‘intellectual disability’ and uses the phrase ‘intellectual developmental dis- orders’ (ID/IDDs). The ID/IDD description in DSM-5 is very similar to the ICD-11 proposal to call this condition ‘intellectual development disorder’. While the absolute emphasis on a specific intelli- gence quotient (IQ) is no longer there, both systems conceptualise ID as a condition with both intel- lectual and adaptive function deficits (Cooray et al., 2015).

Clinical assessment of ID and degrees of ID

The International Classification of Diseases classifies ID into categories based on IQ with a score less than two standard deviations below the population mean of 100 as the cut off (i.e., $IQ < 70$) (see

Table 1. Degrees of intellectual disability (ID).

Degree of ID	IQ	Mental age equivalent (years)
Mild	50–69	9–12
Moderate	35–49	6–9
Severe	20–34	3–6
Profound	< 20	< 3

Table 1). It is important to remember that the term ID represents a very heterogeneous group of individuals with a varying range of abilities from being completely dependent on carers to being reasonably independent and needing only occasional support. The diagnosis of ID depends on a systematic assessment of both intellectual and adaptive functioning. It is often problematic to carry out an IQ assessment and, therefore, clinicians rely on the assessment of adaptive functioning in order to ascertain the degree of ID. Traditional measurements of IQ in children with developmental problems are not routinely carried out in many countries, and this is especially true of low- and middle-income (LAMI) countries. Hence, there is a need to base sub-classification on adaptive functioning rather than IQ measurement. The Glasgow Level of Ability and Development Scale (GLAD) scale is a tool that may be used for this purpose (Cooray et al., 2016). It is important to establish a diagnosis of ID and its degree when a clinician sees the person for the first time as part of a detailed clinical assessment with emphasis on early development. Collateral history is important and, hence, when there is a suspicion of ID, the clinician has to make sure that there are informants available (family carers, professional carers or both) who can provide a detailed developmental history and an account of the person's current level of functioning. If the individual is presenting in a crisis, it is useful to assess the premorbid functioning (best possible functioning) and also what a typical day for the person is like from the time of waking up to the time of going to bed, asking questions at each stage as to whether they need any prompting or assistance in carrying out such activities. The pointers listed in Table 2 can assist with clinically determining the degree of ID.

Causes of ID and epidemiology

Specific causes for ID are more common and more easily identified in people with moderate to severe ID. Clinicians need to make every attempt to establish a possible cause for the ID. This sometimes becomes essential and will not only contribute to the assessment but aid in the management of the person with any specific genetic conditions that show an association with physical and mental health-related problems. For example, a common finding in individuals with Down's Syndrome is the association with depression, hypothyroidism and dementia. Establishing the underlying cause is not always possible (approximately 50%). The principal causes for ID are broadly summarised in the Table 3. The prevalence rates vary depending on the definition, parameters used and the classificatory system. While only 0.47% of adult population use specialist ID services (administrative prevalence), a global prevalence of 1–3% has been reported (Harris, 2006). In a recent meta-analysis (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011), the overall prevalence was 10.37 per 1000 population and the study concluded that prevalence is almost two times more in LAMI counties compared to high-income countries. Of all people with intellectual disability, 85% have mild, 10% moderate, 4% severe and 1–2% profound intellectual disability (King, Toth, Hodapp, & Dykens, 2009). There is usually a male excess in the ID population and the reasons include genetic disorders that tend to mainly affect men (e.g., Fragile X syndrome).

Mortality and morbidity in people with ID

Individuals with an ID have a shorter life expectancy than the general population (Tyrer & McGrother, 2009). There are several reasons for this such as congenital malformations, neurological conditions, genetic disorders and iatrogenic conditions. In addition to this there are other contributory factors that increase the risk and these are associated with poor environment, delayed diagnosis and the barriers in accessing good quality health services. Individuals with ID have more health problems than the general population with a shorter lifespan. Ensuring good quality healthcare for individuals with ID in acute care settings can potentially reduce the mortality and morbidity. Appropriate training for professionals working in these settings will reduce this further.

A commonly employed measure in mortality studies is the *standardised mortality ratio* (SMR), which is the ratio of observed deaths in the population of interest to the expected deaths using

Table 2. Clinical assessment of degree of intellectual disability through adaptive functioning.*

		Mild IQ (69–50)	Moderate IQ (49–35)	Severe/profound IQ (34–0)
Mental age equivalence (years)		9 – <12	6 – < 9	3 – < 6
Proportion of the group (%)		85	10	3–4
Language acquisition	Some delay in acquisition.		Slow in developing comprehension and use of language. Eventual achievement is limited but variable. From just enough language to communicate basic needs to simple conversations with limited vocabulary. May learn to use manual signs to compensate.	Acquire little or no communicative speech in early childhood years but may develop some speech during school-age period. Limited to a few words only or absent speech. May indicate choice through nodding or pointing.
Expressive language	Most achieve the ability to use speech for everyday purposes, hold conversations and engage in clinical interview. Executive speech problems may persist and interfere with development of independence.		Limited to simple instructions Limited	Very limited understanding if any Rudimentary
Comprehension	Reasonable			
Non-verbal communication	Good			
Self-care and continence	Most achieve full independence in washing, eating, dressing as well as bladder and bowel control.		Can attend to personal care with moderate assistance from carers. Mainly continent.	Achieve elementary skills only. Full support of carers needed. Mainly incontinent.
Independent living	Full independence in practical and domestic skills possible. May be able to cook simple meals, participate in household chores, operate common household appliances (television, telephone, microwave, washing machine, etc.). May travel independently, do everyday shopping and use money. Regression in skills is common under unusual social or economic stress.		Will need supervised living arrangements. Limited mastery of domestic tasks; will require support and assistance. Unlikely to shop or use public transport without support.	Full 24-hour supervision required.
Academic skills	More likely to have left school without any qualifications; achievements up to approximately the sixth-grade (late primary school) level. May learn to read, write and do simple maths but can have problems.		More likely to have attended a special school; achievements unlikely beyond the second-grade (early primary school) level. May develop some reading, writing and math skills.	Familiarity with the alphabet and simple counting. May be able to do simple sight reading of some words. May learn to copy write.
Adult work	Capable of work demanding of practical rather than academic skills.		Simple practical work with supervision.	Simple visuospatial skills.
Motor skills	Normal mobility. Generally without problems with motor dexterity.		Delayed but usually fully mobile.	Most not capable of this. Frequent musculoskeletal abnormalities. Often severe restriction.
Social and emotional development	Some immaturity is present, which can make demands of marriage, child-rearing or fitting in with cultural traditions and expectations difficult.		Interaction may be as usual but difficulties in understanding social conventions may interfere with peer relationships.	Maybe very limited. Autism common.
Associated deficits	Organic aetiology identifiable in only a minority. Minimal sensorimotor impairment. Other deficits as in normal population.		Organic aetiology identifiable in a greater proportion. More frequent sensorimotor impairments with increase in Central Nervous System disorders like epilepsy.	Organic aetiology frequently identifiable. Increased central nervous system disorders such as epilepsy and sensorimotor deficits, including visual and hearing impairments.
Autism and other pervasive developmental disorders	Present in varying proportions.		Present in a substantial minority and can impact clinical picture and type of management needed.	Increased prevalence affecting presentation and management.

*For the benefit of the readers, we have combined severe (3 years to < 6 years) and profound (< 3 years) ID categories together. However, descriptive elements in the Table are more applicable to the severe ID category.

Table 3. Causes of intellectual disability.

Prenatal	Perinatal	Postnatal
Malnutrition: • Intrauterine growth retardation Iatrogenic: • Radiation • Drugs • Alcohol Intrauterine infections: • TORCH (Toxoplasmosis, Other, Rubella, CMV and Herpes) Genetic syndromes: • Angelman syndrome • Down's Syndrome • Fragile X syndrome • Lesch-Nyhan Syndrome • Phenylketonuria • Prader-Willi syndrome • Tuberous sclerosis • Williams Syndrome	Traumatic birth delivery: • Brain haemorrhage • Anoxia • Hypoxia	Kernicterus Meningo-encephalitis Prolonged seizures Hypoglycaemia Lead poisoning Malnutrition Hypothyroidism Neoplasm Head trauma Cerebrovascular incident Educational, social and economic deprivation

the general population death rate. In 2009, a study in a population of adults with ID (Tyrer & McGrother, 2009) found an all-cause SMR of 2.77 (95% confidence interval: 2.53–3.03). The group that was particularly disadvantaged included those with congenital malformations and co-morbid disease of the nervous system (including epilepsy) and sensory organs, with their overall SMR noted to be 16.3. The SMR for men and women with ID and active epilepsy is noted to be 3.2 and 5.6, respectively. Sudden death in epilepsy (SUDEP) in patients with ID is a major cause for premature deaths in the population and SMR for SUDEP in males and females was 37.6 and 52.0, respectively (Kiani et al., 2013).

Major health problems increase with increasing degree of ID. Secondary health issues may also arise due to underlying primary conditions or poor lifestyle choices (see Table 4) (van Schrojenstein Lantman-de Valk & Noonan Walsh, 2008). Common conditions like constipation, if not identified and treated early, can lead to further health problems such as pain, nausea, faecal incontinence, anal fissures, haemorrhoids and even rectal prolapse (Coleman & Spurling, 2010). There is also a reported high prevalence of poor oral health, including dental caries (58%). Hence, vigilance around health checks is very important given the background problems of communication difficulties (Hoghton, Martin, & Chauhan, 2012). Untreated physical health issues with associated pain or discomfort may present as challenging behaviour as these patients may not be able to verbalise these concerns.

Psychiatric problems are three-to-four times more common in those with ID in comparison with the general population. Cooper, Smiley, Morrison, Williamson, and Allan (2007) found a lifetime prevalence of all mental health problems to be around 49.2%. Prevalence of dementia in people

Table 4. Physical health problems in individuals with intellectual disability.

Physical health	Prevalence (%)
Hearing disorders	8–100*
Constipation	70
Visual impairment	2–67**
Obesity	13–58
Gastro-oesophageal reflux disease	48
Fractures	32
Edentulous	23
Epilepsy	18

*Prevalence increases with age and is higher in people with Down's Syndrome.

**The large variations are usually due to differences in methodology and settings of studies.

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Table 5. Mental health problems in individuals with intellectual disability.

Mental Health Problems	Prevalence (%)
Overall prevalence	40
Dementia	20
Depression	4
Schizophrenia	3
Bipolar affective disorder	1.5

with Down's syndrome is at least three times higher than the general population (Cooper et al., 2007). Similarly, Schizophrenia is reported to be approximately two-to-three times higher in people with ID than that in the general population (Table 5).

Clinical challenges in the assessment of health problems

Assessing co-morbid health problems in individuals with ID is challenging. Doctors, nurses and allied health professionals working in hospitals may find it difficult to undertake a complete assessment and arrive at a diagnosis if they are not appropriately trained. The main difficulties are a lack of awareness of the presentation of individuals with ID, attitudes of professionals and difficulties with communication. It is important that healthcare professionals and carers are made aware of the risk of diagnostic overshadowing – that is, the tendency to attribute symptoms to the ID rather than investigating an underlying health problem.

In addition to this there is a delay in the diagnosis, which results in a poor outcome. Some people with ID may be unable to understand the significance of their symptoms and may not be able to report them early. Others may have a higher pain threshold due to their background sensory perception problems (seen in some individuals with autism). Atypical presentation of symptoms is common. Any distress, either physical or psychological, could have an atypical presentation due to the underlying communication difficulties. These can include refusal to eat or drink, withdrawal from daily activities, deterioration in baseline skills and challenging behaviour (head banging, bruxism, self-injury, aggression etc.).

At times, reaching a diagnosis in a very unwell patient with ID might be extremely difficult due to the co-occurrence of physical and mental health problems, and these often co-occur. The challenges of obtaining a good history and performing a physical examination in people with ID can be overcome to some extent by having a good understanding of the communication principles in these individuals. It is important to be empathic and treat the person with respect and dignity, focusing on their abilities and using accessible information materials to improve their understanding. Sometimes, a clinician can only arrive at a provisional diagnosis for mental disorders and only with the passage of time do things become clearer and the working diagnosis finalised. It is important to identify the individual's normative pattern of behaviour and any shift from it due to illness in order to establish optimum treatment response and the target state to be achieved. Observing the patient is key to identifying changes in behaviour and making a differential diagnosis.

General principles of management strategies

The recognition of ID happens usually at the primary care services, where professionals are the first point of contact for most families. Subsequently, referrals from the primary care to child developmental clinic or community paediatric teams are not uncommon. Health inequalities for people with ID have been reported from all over the world. Due to the complexity of the healthcare needs and the lack of communication, the quality of care received by this population leaves much to be desired. Avoidable mortality and morbidity due to poor care has raised concerns globally and emphasis has been on recognising the basic principles of respect, dignity and inclusion for the individuals in all healthcare settings. When treating such individuals, personalised care

pathway-based approaches, including the use of patient outcome and experience measures, have been found to be most useful.

When a patient is first referred to the specialist service, it is important that the clinician gathers appropriate information from all relevant sources, including family, educational and day-care providers. Once the assessment and diagnostic process is completed, the results are shared with the patient and their family in a user-friendly format. The psychiatrist may need help from the speech and language therapist to facilitate this effectively. The management plan should include a package of care provided by a team of multidisciplinary professionals consisting of culturally sensitive bio-psychosocial components and addressing areas of both health and social care needs. Ideally, it should also include a clear plan for skills development in the individual. Drug treatment for mental health problems is provided as per the evidence base that exists for general population. However, caution should be exercised in relation to monitoring drug side-effects (through observation, interview and carer feedback) as there may be a propensity for development of unacceptable side-effects, which are not always reported due to communication difficulties. For this reason, starting treatment at a low dose and gradually titrating upwards is advised (Royal College of Psychiatrists, 2016).

Services for people with ID

Ensuring the availability and accessibility of high quality healthcare for individuals with ID should be made an international priority. The WHO survey suggests that in-patient care, primary care, specialised services and physical rehabilitation are now available in most nations. However, there is a variation in their provision in that high-income countries have a higher provision (80–90%) and low-income countries have a lower provision (60–70%). Primary healthcare provision is available in most countries, although low-income countries are noted to have a lower provision (75% for children and adolescents and 70.3% for adults). The availability of specialist services is distinctly less for adults living in South East Asia (50%), Africa (60.7%) and the Western Pacific (61.1%). This discrepancy highlights the need to make reasonable adjustments for individuals with ID so that they can access mainstream health services. Making this a priority is the way forward to improve their health status. For the majority of people with ID, regular health checks at the primary healthcare level can identify their health needs and can be followed by the provision of necessary treatment or signposting for access to treatment in secondary care. Given the great burden of health problems within the population, the treatment gap in LAMI countries and co-occurrence of physical and mental health problems, integration of care into primary care is essential. The WHO service organisation pyramid (see [Figure 1](#)) is a useful tool that promotes integrated primary mental healthcare, with support from other levels of care such as hospital and community services (WHO, 2008a). The model promotes collaboration, information sharing, education and patient involvement, with self-care being reflected in all levels.

Mental health services provided by primary care should be the first level of care, which should include early detection through thorough assessment and treatment of common mental health conditions and low-level behavioural problems, where risks can be managed in primary care. An emphasis should be placed on continuity of care and regular health checks, including physical health, at this level. Community services for those with intellectual disability may include day centres, therapeutic and residential services, support services and carer services. People receiving good community care have been shown to have better health and mental health outcomes, and better quality of life, than those treated in psychiatric hospitals. To maximise effectiveness, strong links are needed with other services up and down the pyramid of care. In addition, input from social care is often beneficial for their extensive social needs. It is imperative to develop a co-ordinated and personalised care plan that includes input from all health professionals and social care. A small minority of people may need specialist psychiatric care in general or specialist hospitals, for example people with treatment-resistant conditions, complex presentations or where risk posed to self or others is significant. In-patient care may be provided for at the secondary care setting with appropriate support from the carers.

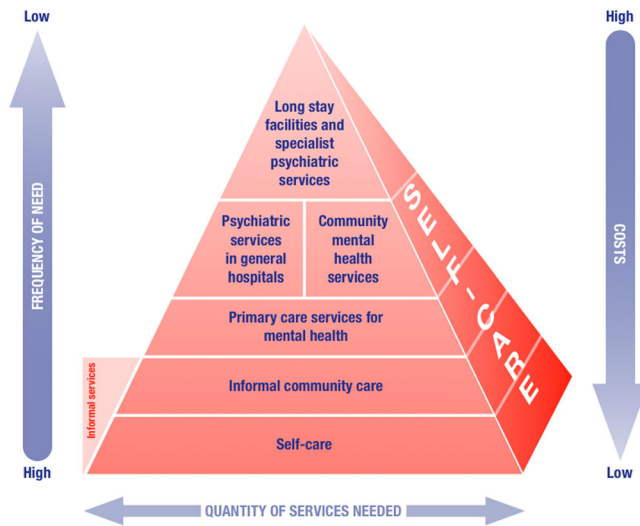


Figure 1. The WHO service organisation pyramid.

Stepping down from in-patient care to community care is another difficult transition time, which should be appropriately supported by the healthcare providers.

In high-income countries, specialist ID services aim to provide care within the community setting for treatment of psychiatric disorders, epilepsy and other long-term conditions. Many providers have provision for a short-term admission and assessment unit to deal with acute mental health problems that pose a high risk. A *stepped-care approach* (see Figure 2, Royal College of Psychiatrists, 2011) might be beneficial, with basic health needs being addressed at the primary healthcare level through primary healthcare workers or equivalent. With increasing complexity, it may be necessary to provide joined-up care together with the nearest available mental health or acute care service staff. In addition, input from social care is often beneficial for their extensive social needs. Inpatient care is needed for a very few individuals and may be provided for in the secondary care setting, with appropriate support from carers. It is therefore imperative to develop a coordinated and personalised care plan, which includes input from all health professionals and social care. Stepping down from in-patient care to community care is another difficult transition time, which should be appropriately supported by the healthcare providers. Institutional care is not considered to be the norm for these countries; however, such care is still being provided in some countries where there is a paucity of health resources and ratio of mental health professionals to the population is very low. Several reports of abuse and exploitation in institutional care have been published, and every effort is being made at present to replace institutional care, where possible, with the model of community care. The WHO promotes the enhancement of services provided in general hospital, community mental health services and primary care as oppose to specialist psychiatric hospitals.

Key policy drivers

Every LAMI (low- and middle-income) country is expected to have a Disability Discrimination Act, which establishes protection and rights for people with disability. The fundamental principles of any policy that supports care for people with intellectual disability should include a wide range of areas, for example: education, housing, social support, access to health services and supported employment. These policies can be based on the fundamental principles of choice, inclusion, rights and independence. However, it is important to bear in mind that the policy on paper does not always implement into practice; there must be a legal obligation of fulfill policy requirements, otherwise

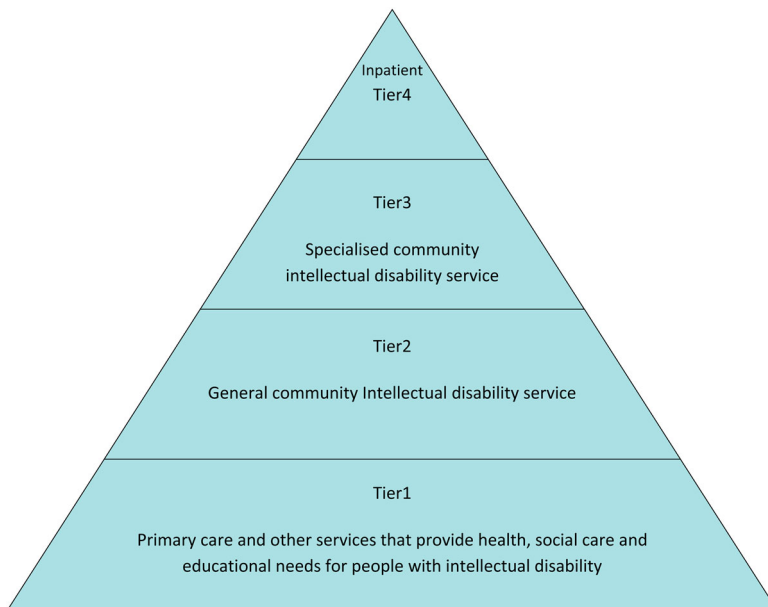


Figure 2. Tiered/stepped model of care for learning disability services (adapted from “Future role of psychiatrists working with people with learning disability”, Faculty of Learning Disability Report FR/LD/1 of the Royal College of Psychiatrists, January 2011).

the misery and lack of support will continue. We also cannot forget that in LAMI countries, the main support tends to be provided by family members and local community at large. For them to be valued and to be included in the choice and decision making process is crucial. Policies should also include support for such families, either financially or through material benefits, in addition to reduction of the burden of care and stress.

Training and core competencies

Psychiatric training programmes are present in 62.5% of countries worldwide, with significant regional variation (47.4% in Africa and 94.1% in Europe) and significantly reduced availability in LAMI countries (WHO, 2005). Expansion of Psychiatric training is needed in almost all LAMI countries. The World Psychiatric Association, along with the World Federation of Medical Education, through a core curriculum committee, developed detailed guidelines for the ‘Core Curriculum in Psychiatry for Medical Students’ (World Psychiatric Association and World Federation for Medical Education, 1998). The main recommendation that Psychiatry should occupy a major part in the medical curriculum is now generally agreed (Kallivayalil, 2012). So far as our understanding goes, only a few LAMI countries provide any meaningful training in ID as part of training in Psychiatry. In this context, we suggest the following:

- (1) Effective teaching in Psychiatry and Intellectual Disability Psychiatry in medical schools and postgraduate education for primary care physicians is a key area to focus on; LAMI countries should adopt minimal standards and adopt Psychiatry into core curricula for medical student and primary care physicians. Strengthening teaching standards and research in LAMI counties could also drive improvements in education.
- (2) In recognition of a treatment gap in mental health, the World Health Organisation (2008b) launched the Mental Health Gap Action Programme (mhGAP) in 2008. The programme emphasises the delivery of pharmacological and psychosocial interventions in non-specialised healthcare settings such as primary care using a teaching manual and an intervention guide.

Table 6. Core competencies required for professionals dealing with mental health problems in individuals with intellectual disability.

1. Ability to recognise the presence of an intellectual disability using either structured screening instruments or through history taking that focuses on intellectual ability and adaptive functioning.
2. Ability to categorise the appropriate degree of intellectual disability (mild, moderate, severe or profound) using either structured screening instruments or through history taking that focuses on intellectual ability and adaptive functioning.
3. Awareness of the common physical health conditions affecting people with intellectual disability that may present with behavioural difficulties.
4. Awareness of the common mental health conditions affecting people with intellectual disability that may present with behavioural difficulties.
5. Ability to either treat these conditions or signpost the patient to services which can manage them better.
6. Awareness of issues of abuse and neglect that make people with intellectual disability, an especially vulnerable group.

It has proved highly successful and has already been delivered in a number of LAMI countries. The mhGAP-ID was launched in 2014 and, following a successful pilot and consultation period, future training will involve cascading to primary care physicians who manage ID in the community. This will facilitate early recognition and intervention of health needs within the ID population. Training in primary care should target not only doctors, but also nurses and allied health professional who work in primary care and are often the first contact for people with intellectual disability in LAMI countries (Gumber et al., 2015).

The core competencies required for professionals who work with people who have an intellectual disability and mental health problems are summarised in [Table 6](#).

Equality and human rights

Adults with ID are more likely to be liable to social exclusion, poverty and isolation and efforts to improve their lives so far have had little impact on some. To create a culture of human rights will need a positive and proactive approach with the introduction of a positive duty on public authorities to promote respect for the human rights of people with ID. This will encourage a move away from negative attitudes and stereotypes that are still prevailing in many societies. Individuals with ID, whether at home or in other residential settings, often suffer neglect, abuse, discrimination and indifference. The removal of an individual from one care setting to another often leads to a serious risk of a breach of the rights of individuals.

In addition, recent research suggests that in some societies, hate crimes against people with ID are gathering momentum. This can only be redressed with confidence through appropriate action from the authorities and development of confidence in the criminal justice system that takes a proactive approach to protect and support individuals with ID. Another measure that can be useful is to reduce the barriers to the enjoyment of ordinary life by people with ID through the production of more accessible information, independent advocacy, communication equipment and support services. All providers of health and social care for this group of individuals can be subject to the duty of compliance with convention rights. The practical steps to promote the rights of these individuals in mainstream public services may need appropriate legislative changes and the involvement of equality and human rights commission, which can ensure that the voices and views of adults with ID are heard and can play a central role in the work environment.

The Convention on the Rights of Persons with Disabilities follows the work carried by United Nations to change attitudes and approaches to persons with disabilities. The convention provides individuals with rights and considers them capable of claiming those rights in making decisions for their lives based on their free will and informed consent and for being active members of society. In short, this convention provides support for people with ID in claiming all human rights and fundamental freedoms. The convention also allows adaptations to be made for people with ID to

effectively exercise their rights. Most countries have ratified this optional protocol and the numbers are still growing.

Criminal justice system

People with ID who come into contact with the criminal justice system are deemed to be more vulnerable in situations where they have to face interrogations, court proceedings and so on. The reasons for this include their limited communication skills, inability to express themselves, high degree of suggestibility (Clare & Gudjonsson, 1993) and inability to comprehend the consequences of some of their actions. Wherever possible, countries should try and develop a criminal justice system (CJS) bypass system for people with ID, and this can be supported by the employment of a liaison officer. Police interrogations should take place in the presence of an appropriate adult, who needs to monitor the style of questioning and should emphasise the avoidance of leading questions. There are many reasons for people with ID to commit an offence, and these may include underlying mental health problems or personality disorder, motives related to revenge, trying to impress peers and sometimes trying to please others or under duress. The key is to avoid unnecessary admission for a crime the person may not have committed and the person to be supported as far as practicable to bypass the usual CJS pathway (i.e., being remanded in custody or being in prison where these options might expose the individual to be exploited by others and being subject to abuse) (Royal College of Psychiatrists, 2013, 2014).

Ethical and social considerations

A person with ID is likely to face rejection and may often be socially isolated and segregated. The additional issues of mental health problems, epilepsy and high dependency needs also contribute to increasing the risk of discrimination, stigma and exclusion. There is a high risk of potential abuse, and to safeguard the individual's interests, the ID services in the UK have adopted a model of advocacy that is available in most local authority areas. There are also teams located within health and social care settings dealing with safeguarding issues.

Conclusion and the way forward

Not all professionals need to become experts in the area of ID. However, it is expected that the majority will be able to identify the condition and will be fully aware of the risks of associated comorbidities and their impact. They should also be fairly conversant about sign posting when an ID is identified and take the necessary steps towards reasonable adjustments when they are involved in providing care to these individuals.

There is very little evidence base, especially in the areas of treatment of mental illness and challenging behavior, for people with ID, and further research is needed in this area. In such cases, treatment and management strategies should be based on evidence available for the general population. One way ahead might be to consider inclusion of people with ID in future research proposals that are specifically aimed at assessing effectiveness and outcomes of interventions. Alternatively, research proposals that deal with the applicability of an intervention method that is already in use with strong evidence base in the general population can be extrapolated to the population with ID.

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Appendix: Organizations and websites

Organisations/websites	URL address link
American Association of Intellectual and Developmental Disabilities	http://aaidd.org/
Anticipatory Care Calendar	http://anticipatorycarecalendar.org/
Association for Persons with Developmental Disabilities and Mental Health	http://theadd.org/
British Institute of Learning Disabilities	http://www.bild.org.uk/
Down's Syndrome Association	http://www.downs-syndrome.org.uk/
European Association of Intellectual Disability Medicine	http://www.mamh.net/
Improving Health and Lives Learning Disabilities Observatory	http://www.improvinghealthandlives.org.uk/
International Association for the Scientific Study of the Intellectual and Developmental Disabilities	https://iassid.org/
Mencap	http://www.mencap.org.uk/
National Autistic Society	http://www.nas.org/
Palliative care for people with learning disability	http://www.pcpld.org/
People with profound and multiple learning disabilities	http://www.pmlnnetwork.org/
Royal College of Psychiatrists Faculty of Intellectual Disability	http://www.rcpsych.ac.uk/workinpsychiatry/faculties/intellectualdisability.aspx
SeeAbility, seeing beyond disability	http://www.seeability.org/
Sense for Deafblind people	http://www.sense.org.uk/
SUDEP aware	http://www.sudepaware.org/
The Australasian Society for ID	http://www.asid.asn.au/

Paper 2: Health promotion in people with intellectual disabilities

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ABSTRACT

As has been well described, intellectual disability carries significant psychiatric and physical morbidity with it. Mental health and physical health strongly influence each other, thus any attempts at health promotion require careful consideration. Thus any programmes for health promotion for both aspects in persons with intellectual disability have to be developed in an easy-to-understand manner so that families, their carers and individuals themselves can benefit from them. In this group in particular, health inequalities associated with physical and mental health problems will play a role, which needs to be understood and tackled at a universal level. The aim has to be both on mental health promotion and on prevention of ill-health. In this paper some of the key underlying issues are described. For mental health promotion it is vital that suitable living conditions are available, along with social support and sufficient resources.

Introduction

Health promotion in people with intellectual disability (PWID) involves both physical and mental health issues and the interface between them. Health inequalities associated with physical health problems including morbidity/mortality and interface with mental health problems have been discussed

earlier and hence this chapter focuses on the aspects of mental health promotion in people with intellectual disabilities.

Health promotion and people with intellectual disabilities

Mental health promotion involves actions to create living conditions and environments that support mental health and allow people to adopt and maintain healthy lifestyles. Though people with intellectual disabilities are exposed to abuse, stigmatisation, marginalisation, humiliation and discrimination, there has been a delay in developing and applying appropriate norms to meet their needs. Constituting 2% of the population, they are a vulnerable group with complex comorbidities, who experience significant health inequalities when compared with the general population (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Scheepers et al., 2005). There is also a dearth of robust evidence-based studies on health promotion in PWID (Van Schrojenstein Lantman De Valk, Metsemakers, Haveman, & Crebolder, 2000). Research undertaken by Beange, McElduff, and Baker (1995) in the 1990s highlighted unmet healthcare needs of people with ID. van Schrojenstein Lantman-de Valk, Linehan, Kerr, and Noonan-Walsh (2007) emphasised the need for evidence-based data on the types and amounts of these inequalities that permit comparisons with the general population and to target and monitor the effects of health programmes. Krahn, Hammond, and Turner (2006) defined a range of contributing factors responsible for the poor health of people with ID. These include: complex health conditions that are poorly managed, frequent changes in direct care that result in inattention to health status and care needs, poorly understood and managed problem behaviours, insufficient attention to individual health promotion behaviours and difficulty in implementing clinical preventative services. McGuire, Daly, and Smyth (2007) have argued that where the healthcare is generally good, the ID population has experienced increased longevity, with an increased risk for health problems that are experienced by the elderly population.

There is a pressing need to return to the foundations of health promotion as laid out in the Ottawa Charter by the World Health Organisation (WHO) (1986). We have picked out the following four key issues from the charter that are pertinent to PWID: enabling positive lifestyle changes; health screening and other interventions; mental health; and the WHO response.

Enabling positive lifestyle changes

Activities that promote healthier behaviours for people with disabilities should include education and support for making healthier choices, thereby improving their quality of life. People with disabilities may not have had the same opportunities to learn about the importance of healthy lifestyles including maintaining normal weight, maintaining a good diet, ensuring regular exercise and the risks and implications of smoking, alcohol consumption and other drug use. Regular Medical Reviews and appropriate investigations are critical to health maintenance and health promotion for people with developmental disabilities. Raising the awareness of primary healthcare staff, educational establishments and non-governmental organisations will ensure that health promotion is kept high on the agenda of all initiatives undertaken by these organisations. In addition, having opportunities to participate in healthy lifestyles and being supported in that process by the carers, family members and ‘champions’ should be available for all PWID. Carer education and information regarding healthy lifestyles and their positive impact is crucial to enable this to happen in addition to the provision of user friendly information for PWID (e.g., importance of physical exercise, making right choices regarding food and regular walking if possible). These patients therefore require advocacy and a structure to ensure regular medical reviews through annual health checks.

Health screening and other interventions

According to the WHO *Disability and Health Fact sheet N°352* (2013b), health promotion and prevention activities seldom target people with disabilities. For example, PWID receive less screening for

breast and cervical cancer than women without disabilities. People with intellectual impairments and diabetes are less likely to have their weight checked. Adolescents and adults with disabilities are more likely to be excluded from sex education programmes. There is also a dearth of robust evidence-based studies on health promotion in PWID. Specific syndromes may be associated with an increased risk of certain conditions (e.g., Down's Syndrome and thyroid disease, leukaemia, depression and dementia). Being aware of these associations may lead to regular screenings in order to prevent these comorbidities. Whilst undertaking screening, it is important to bear in mind that PWID may have difficulty in interpreting and/or describing symptoms. Symptoms and signs must be actively sought, observed and explored, and carers may be very helpful in providing information, which may suggest particular symptoms (e.g., food refusal may suggest nausea). The indications for screening tests – including breast examinations, mammograms, pap smears, rectal examinations and PSA, and colonoscopy – are the same as the rest of the population. People with intellectual disabilities may have some difficulty understanding the reasons for such testing therefore health promotion must include careful explanation and preparation may be required and staff or family members may provide valuable support and assistance in this ensuring information should be provided in an accessible and user friendly format.

Mental health

The incidence of mental health problems for PWID is much greater than for the general population with rates of over 50% being reported in studies (Royal College of Psychiatrists, 2013, 2014, 2016). This may be related to biological factors including genetic and hereditary conditions, psychological factors such as rejection, segregation, stigmatisation, restricted life experiences and social factors such as poverty, limited social support networks, rejection, segregation, stigmatisation and the risk of emotional, physical and/or sexual abuse. Mental Health promotion should include (Taggart & McKendry, 2009):

- promoting a positive sense of self
- providing opportunities to learn and apply new skills to enhance autonomy and participation
- enhancing the environment to improve access, inclusion, understanding, respect and support.

When planning for mental health promotion, recognising barriers is crucial. These include:

- individual barriers due to the lack of knowledge of ill health or where to seek help
- carer barriers where carers lack the ability to recognise early indications or triggers for mental ill health
- professional barriers where primary care professionals lack the experience in dealing with people with intellectual disability.

To address this, the UK Department of Health has suggested a two-stage model that aims at: (1) reducing risk factors such as poverty, deprivation, unemployment and so on and (2) increasing protective factors such as increasing self-esteem and empowerment, promoting social participation, improving environments and so on (Department of Health, 2001). This is a model that has relevance across the world.

The WHO response

The WHO response includes the creation of a comprehensive mental health action plan for 2013–2020 (WHO, 2013a). The plan's overall goal is to promote mental wellbeing, prevent mental disorders, provide care, enhance recovery, promote human rights and reduce the mortality, morbidity and disability for persons with mental disorders. It focuses on four key objectives, namely to:

- (1) strengthen effective leadership and governance for mental health
- (2) provide comprehensive, integrated and responsive mental health and social care services in community-based settings
- (3) implement strategies for promotion and prevention in mental health
- (4) strengthen information systems, evidence and research for mental health.

In order to achieve these objectives, the implementation of the action plan requires clear actions for governments, international partners and the WHO. Ministries of health will need to take a leadership role and the WHO will work with them and with international and national partners, including civil society, to implement the plan. As there is no action that fits all countries, each government will need to adapt the action plan to its specific national circumstances. If implemented, the action plan will enable persons with mental disorders to access mental health and social care services with greater ease and treatment will be available in general health care settings. The World Health Organisation's Mental Health Gap Programme (mhGAP) (WHO, 2008) facilitates this process. This has been further supported by the development of mhGAP action programme for PWID (RCPsych, WPA, WHO) which can be rolled out to all healthcare professionals in general healthcare settings (Gumber et al., 2015).

Conclusion

We conclude that: (1) substantial health disparities exist between people with and without disabilities and that there is an emerging paradigm shift from disease and disability prevention to prevention of secondary conditions, (2) health promotion is fundamental to empowering PWID to gain equitable access to healthcare – an integral component of basic human rights and (3) developing innovative strategies globally that promote health among this population has emerged as an important public health priority.

Disclosure statement

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Paper 3: Domestic gender inter-personal violence and people with intellectual disability

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ABSTRACT

There is considerable evidence in the literature that persons with intellectual disability are not only stigmatised against but are also often victim of inter-personal violence, which is often linked with gender but also with perceptions that these individuals are more violent. Gender-based violence can be both acute and chronic. The role culture plays in gender development and gender roles is well described. Gender roles and gender role expectations are important in clinical understanding of individuals' needs and cultures play a major role in this. Culture also plays a role in the understanding of intellectual disability thus creating a complex web of social and cultural understanding. There seem to be various varieties of violence: physical, sexual, emotional and exploitative among others. Clinicians need to be aware of how persons with intellectual disabilities are abused and how to assess their needs, but more importantly how to set protective aspects of intervention in place.

Definition

Gender-based violence (GBV) is violence involving men and women, in which the female is usually the victim and which is derived from the unequal power relationships between men and women. Violence is directed specifically against a woman because she is a woman, or affects women

disproportionately. It includes but is not limited to physical, sexual and psychological harm (including intimidation, suffering, coercion and/or deprivation of liberty within the family or within the general community). It also includes that violence which is perpetrated or condoned by the state (UNFPA, 2001). Gender-based violence needs to be looked at in the wider context of atrocities against women, which are classified broadly within the following categories:

- (1) physical violence
- (2) sexual violence
- (3) verbal violence
- (4) social disadvantage
- (5) emotional exploitation
- (6) financial exploitation/dependence
- (7) other forms such as denial of education, denial of reproductive rights, female genital mutation, gender-based foeticide/infanticide and access to basic facilities like healthcare.

Although there have been some positive transformative changes for women in the last decade, resulting in greater visibility, more education and employment opportunities as well as better access to healthcare, society is far from being in a position of achieving gender equality. Some groups of women are particularly vulnerable to exploitation, including GBV. These women are those who are single, widows, orphaned women and women with long-term disability or health conditions, as well as women from deprived backgrounds.

There is a very limited literature globally on GBV with regards to people with intellectual disabilities. This briefing paper has therefore focused on the key learning messages from the wider literature on GBV that may be relevant to women with intellectual disabilities.

Prevalence

Around 15% of adults worldwide have a disability. A recent systematic review (Hughes et al., 2012) found that the pooled prevalence of any (physical, sexual or intimate partner) recent violence was 24.3% (95%CI: 18.3–31.0) in people with mental illnesses, 6.1% (95%CI: 2.5–11.1) in those with intellectual impairments and 3.2% (95%CI: 2.5–4.1) in those with non-specific impairments. The pooled crude odds ratios for the risk of violence in disabled compared with non-disabled individuals were 1.50 (95%CI: 1.09–2.05) for all studies combined, 1.31 (95%CI: 0.93–1.84) for people with non-specific impairments, 1.60 (95%CI: 1.05–2.45) for people with intellectual impairments and 3.86 (0.91–16.43) for those with mental illnesses. This suggested that adults with disabilities are at a higher risk of violence than are non-disabled adults, and those with mental illnesses could be particularly vulnerable.

Risk factors

Van Der Heijden (2014) highlights a number of risk factors for violence against women with disabilities:

- (1) Women with disabilities are marginalised from society so making them more at risk to be exploited or experience violence.
- (2) Physical, social and social dependence make them exposed to multiple perpetrators.
- (3) Social and cultural myths around disability increase the likelihood of victimisation.
- (4) Women's mental health increases their risk for interpersonal trauma and women with intellectual disabilities are vulnerable to mental health problems (McCarthy, 2010).
- (5) Women with disabilities are less likely to disclose violence or seek help.

Prevention, interventions and good practice

There are interventions to prevent violence against women that are shown to be effective (WHO, 2010). While there is insufficient evidence that these interventions will work for women with intellectual disabilities, there is no evidence to say they will not either. There is some limited evidence on interventions to prevent sexual violence for women with intellectual disabilities (Lund, 2011; Wacker, Macy, Barger, & Parish, 2009).

In order to consider any preventative interventions or good practice, we need to acknowledge there are few specialist services in low-to-middle-income countries for adults with intellectual disabilities. Preventative interventions may also be easier to implement and more acceptable in urban areas. Any interventions to prevent or address gender-based violence would be best directed through resources such as non-government organisations available to the wider population of women. In addition, better access to education and employment for women not only improves the status of women, including those with disabilities, but also the sociocultural outlook of the society. While a focus on more effective legislative framework is seen as easy solutions to reducing GBV, in the absence of significant changes in sociocultural outlook the law is unlikely to be enacted in the way it is expected to.

Interventions that reduce dependency and increase both economic and social empowerment, including more knowledge on their rights and healthcare needs, seem more effective. In addition, challenges to social and cultural myths needs to take place around women with intellectual disabilities through the wider education of the public. Evidence to date indicates that different types of approaches are required to educate the wider public using awareness campaigns to change social norms that deny the sexuality of women with intellectual disabilities. School-based interventions that focus on personal relationships and sex education should be available to girls with intellectual disabilities as they are for all school-aged girls. Successful interventions will strengthen the resilience of women with intellectual disabilities with a focus on social empowerment to protect them from being at risk from GBV.

Conclusion

Currently few violent and abuse prevention efforts at a global level are geared to women with intellectual disabilities and this needs to change to include women with intellectual disabilities. Any intervention needs to be informed by the evidence on what increases risk of violence against women with intellectual disabilities. Further evaluations are needed to identify this vulnerable group of women in each country and the ongoing recording of their risk for GBV.

Recommendations

We offer the following three recommendations:

For future training of doctors

The undergraduate and postgraduate curriculum for all doctors should include knowledge of GBV. The training should include awareness of the reasons for the increased vulnerability for people with intellectual disabilities from GBV. The students should know the signs and symptoms of GBV and demonstrate an understanding of the interventions required to support people with intellectual disabilities to prevent further GBV.

Practical implications

Every doctor should know that women with intellectual disabilities are at increased risk of GBV.

Every doctor assessing a woman with intellectual disabilities presenting with recognised physical signs and/or any mental health problem should routinely enquire about GBV.

Research implications

There is need for further research to screen for intellectual disabilities among women presenting to mental health services with a history of GBV in order to recognise their increased vulnerability as well to monitor the rates of GBV among this group of women, including the effectiveness of interventions to reduce the risks.

Disclosure statement

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Key international guidance & research documents for further reading:

1. Ending Violence Against Women Globally: International policies, programs, and approaches http://www.vawnet.org/global/summary.php?doc_id=3232&find_type=web_desc_SC
This special collection brings together selected documents that focus on international policies, programs, and approaches to prevent and intervene in violence against women.
Authors: Sheetal Rana (2012). National Online Resource Center on Violence Against Women (VAWnet.org)
2. Perera, J. P., Gunawardane, N., & Jayasuriya, V. (2011). *Review of research evidence on gender based violence (GBV) in Sri Lanka* (2nd ed.). Colombo: Sri Lanka Medical Association. This is a compilation of research published between 1982 and 2011 on Gender Based Violence (GBV) in Sri Lanka and is a valuable source of information for all those wishing to understand the evidence base on GBV.
3. Heart and Minds of Women of India Speak, Shaping the post 2015 development discourse and agenda; UN Women, United Nation's Entity for Gender Equality and the empowerment of women, Published 2013.

Paper 4: Child sexual, physical and emotional abuse and intellectual disability

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ABSTRACT

It is well acknowledged and understood that children who have been sexually, physically or emotionally abused are likely to experience psychiatric disorders in adulthood. Persons with intellectual disability who have been through abuse face a more complex double or even triple jeopardy because of mental illness, intellectual disability and abuse. They are more likely to be vulnerable to further exploitation and manipulation. Prevalence of disability is linked with development of mental ill-health and distress compounded by experiences of sexual, physical or emotional abuse. Clinicians need to be aware of the role abuse may play and must be sensitive in exploring history of abuse as well as any ongoing difficulties. Legal frameworks wherever available should be used to protect vulnerable individuals. If such protection is not available it is imperative that clinicians and policymakers work together to set up these frameworks.

Introduction

The rights of disabled children to protection from abuse are enshrined in the UN Convention on the Rights of the Child and all work to protect and safeguard disabled children should be grounded in the Convention. Article 19 provides for the protection of the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment and maltreatment or exploitation, including sexual abuse. Article 2 addresses the rights of all children, without discrimination of any kind, to all rights enshrined in the Convention, irrespective of the child's or his or her parent's or legal guardian's disability. Article 23 recognises the right of the disabled child to enjoy a full and decent life in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

The UN Convention on the Rights of Persons with Disabilities reaffirms that all disabled people must enjoy all human rights and fundamental freedoms, and Article 7 states that all necessary measures should be taken to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. Article 16 details the right of all disabled people, in accordance with the Convention, to be free from exploitation, violence and abuse (Miller & Brown NSPCC, 2014).

Prevalence

The presence of disability is associated with risk of all forms of abuse, especially neglect. In a systematic review and meta-analysis of observational studies, Jones et al. (2012) found a prevalence of 20.4% (OR: 3.56) for physical violence and 13.7% (OR: 2.88) for sexual violence against children with disabilities, but the authors noted huge heterogeneity across the sample. A population-based epidemiological study in Nebraska found a rate of maltreatment of 31% with children with

disabilities, with disabled children being ‘maltreated multiple times and in multiple ways’ (Sullivan & Knutson, 2000, p. 1258). This study included all forms of disability, including intellectual disability, physical disability, sensory problems, communication disorders and autism. There is thought to be significant under-reporting, however the extent of the problem is unknown.

The impact of age, gender, social and cultural factors on the relationship between disability and abuse is poorly understood. Unlike the pattern associated with non-disabled children, disabled boys are at greater risk of maltreatment than girls. Children with communication disorders, sensory impairments, learning disabilities and behavioural disorders have increased risk, however some of the disability and behaviour may be secondary to the maltreatment (Stalker & McArthur, 2012). Children in residential care are also thought to be at increased risk (Miller & Brown, 2014). Disabled children are more likely to be abused by an immediate family member and are more likely to be abused at a younger age (Sullivan & Knutson, 2000). In a population study of all children born in Western Australia between 1990 and 2005 (total 397,345), there were 3.4% of child maltreatment allegations. In the non-aboriginal families, children with an abuse allegation were more likely to be female and three times more likely to be disabled (O'Donnell et al., 2010). Aboriginal children with an intellectual disability had almost double the risk of a substantiated allegation of abuse. There are limited studies regarding child abuse in low- and middle-income countries and those that were included in reviews were very limited in their sample ascertainment.

Risk factors

The report from the National Society for the Prevention of Cruelty to Children (NSPCC) ‘We have the right to be safe’ (Miller & Brown, 2014) identified factors that increase risk and lessen protection for disabled children. They include:

- (1) attitudes and assumptions – for example a reluctance to believe disabled children are abused; minimising the impact of abuse; and attributing indicators of abuse to the child’s impairment
- (2) barriers to the disabled child and their family accessing support services
- (3) issues related to a child’s specific impairment – for example dependency on a number of carers for personal or intimate care; impaired capacity to resist/avoid abuse, difficulties in communicating; and an inability to understand what is happening or to seek help
- (4) limited opportunities for disabled children to seek help from someone else
- (5) a lack of professional skills, expertise and confidence in identifying child protection concerns and the lack of an effective child protection response.

It is known that those who have been subjected to abuse can demonstrate increased risk of psychopathology and behavioural difficulties. The major difficulty noted in the review of the literature regarding clinical effects of sexual abuse on people with intellectual disabilities (Sequeira & Hollins, 2003) is that persons with intellectual disabilities may not be able to report symptoms for reliable diagnosis. Researchers have therefore relied upon informant measures, therefore missing the internal subjective experience of the person. Therapeutic work should be grounded in research that takes account of the emotional, social and developmental factors that are the integral part of psychopathology of people with intellectual disabilities.

Signs and symptoms that might suggest that abuse is occurring

The following are examples of altered behaviour that might give rise to the suspicion of abuse. It is essential to remember that, while they call attention to the possibility of abuse, their presence does not inevitably indicate abuse nor do they necessarily occur (RCPCH, 2015). Trigger factors, particularly in the presence of autism or other behavioural phenotypes, are particularly open to misinterpretation (McNicholas, Slonims, & Cass, 2000).

A change in the child's behaviour such as:

- (1) withdrawal from friends or family, a loss of interest in their usual activity or outright depression or anxiety
- (2) increased disturbance whether aggression, hyperactivity, self-injury or self-harm, which may extend to suicidal behaviour
- (3) a change in school performance, a reluctance to go home or to enter the transport and leave school activities, as if he or she doesn't want to go home, absenteeism.

Indications of physical abuse:

- (1) injuries that are either unexplained or for which the explanation does not quite fit
- (2) recurrent injuries
- (3) signs of neglect – untreated medical or dental problems, poor growth or weight gain and poor self-care.

Indications of sexual abuse:

- (1) sexual behaviour that is inappropriate to the child's circumstances or age
- (2) pregnancy
- (3) sexually transmitted infection
- (4) any indication of genital injury or pain (including genital bleeding in prepubertal girls)

Indications of emotional abuse:

- (1) delayed development of emotional responses and self-confidence
- (2) difficulty with developing relationships – being detached or else over-close
- (3) appetite disorders
- (4) parental behaviour that suggests an unusual unconcern for the child (including an inappropriate standard of performance)
- (5) parental violence towards the child.

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Recommendations

We offer the following 10 recommendations:

- (1) There should be an accepted safeguarding programme to keep vulnerable children safe from abuse and exploitation.
- (2) Personal safety skills activities, including sex and relationships education, that raise disabled children's awareness of abuse and ability to seek help.
- (3) Peer support, which can have a beneficial effect on reducing bullying and enabling children to explore issues and make decisions.
- (4) Creative therapies, which can provide children with opportunities to express themselves through indirect and non-verbal means.

- (5) Share and build on existing knowledge and good practice and work together towards ensuring equal protection for disabled children
- (6) Develop a wider and deeper evidence base to help better understand the vulnerability of disabled children to abuse and how they can be protected.
- (7) Raise awareness about the abuse of disabled children and challenge attitudes and assumptions that act as barriers to protection.
- (8) Promote safe and accessible services
- (9) Raise disabled children's awareness of abuse and ability to seek help including access to personal safety skills training
- (10) Agencies to build on good practice and measures already in place that help ensure the effective delivery of child protection and criminal justice services for disabled children.

These recommendations are drawn from the NSPCC report that is referenced in this chapter (Miller & Brown, 2014).

Recommendations for future training:

- (1) All people working with children should have an understanding of physical, sexual and emotional abuse and neglect for all children. They should be aware of the reasons for increased vulnerability for children with disabilities. They should know the signs and symptoms that would indicate the possibility of abuse and know the safeguarding procedures within their organisations.
- (2) Non-governmental organisations working with children will need to have clear protocols for reporting and managing risk of potential abuse within their own organisations.
- (3) The curriculum in medical undergraduate and post-graduate training should include knowledge of physical, sexual, emotional abuse and neglect in children.

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Paper 5: Prisoner mental health care for people with intellectual disability

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ABSTRACT

Persons with intellectual disabilities are likely to be misdiagnosed and end up in prisons for petty offences. The rates of criminal behaviours will be influenced by social and cultural factors. What is seen as illegal behaviour in one society may not be so in another. Cultures also play a major and significant role in defining deviant behaviour and defining what is abnormal. Thus relationship between intellectual disability and criminal behaviour deserves better understanding and research. In hospital or care settings as well as in prisons, clinicians must be sensitive to the role intellectual disability may play in contributing to mental ill-health and behavioural problems. Clinicians must have the skills to identify intellectual disability and its consequences. Wherever possible, depending upon local needs, court diversion schemes and pathways be identified and developed through all agencies who may be involved in caring for persons with intellectual disability.

Introduction

Much has been written about mental health morbidity in prisons internationally (e.g., Fazel, Xenitidis, & Powell, 2008), and in the last few decades this has contributed greatly to a better understanding of the needs of the prison population. However, there is still a limited understanding of the prevalence and needs of those with intellectual disability (ID), defined as significant impairment of intellectual functioning and adaptive behaviour originating before the age of 18 years, or of the larger group referred to as those with learning difficulties (Talbot, 2008). A range of developmental conditions, such as attention deficit hyperactivity disorder and autism spectrum disorder as well, as those functioning within the borderline range of intellectual functioning, is often considered along with this group. People with ID in prisons receive insufficient support and treatment. They experience greater difficulty coping in custody, are vulnerable to bullying and are less likely to participate in or benefit from prison treatment and rehabilitation programmes.

Prevalence

In one of the largest studies of its kind, looking at 10 prison surveys across four countries involving almost 12,000 inmates, Fazel et al. (2008) found substantial heterogeneity and hence did not undertake a summary estimate of prevalence. The results suggested that typically 0.5–1.5% of prisoners were diagnosed with ID (range 0–2.8% across studies). A recent study from Norway (Søndenaa, Palmstierna, & Iversen, 2010) suggested that up to 10% of sentenced prisoners had ID. Few studies have looked at the prevalence of people with ID in non-western countries. An exception is a study by Ghubash and El-Rufai (1997) in United Arab Emirates, which found that 4 out of 142 prisoners had an ID.

Identification of people with ID in prisons or in police custody

All people in police custody should be assessed in order to highlight whether they are likely to present any particular risks either to themselves or other people. Even for experienced professionals working with people with ID, it is not always easy to recognise those with ID, particularly in a setting away from home, such as prison or a police station. Screening questions may help, but current practice does not usually include questions regarding ID. However, even when screening does take place, for instance in police custody, it is suggested that some people with IDs are not being identified (McKinnon & Grubin, 2013). In research articles a number of questions have been used such as whether the person had 'reading problems or learning difficulties' or 'had been to special school' (Murphy, Harnett, & Holland, 1995). Questions like this, while being irrelevant in many developing countries, can also include a large number of people with borderline ID.

The screening questionnaire 'Learning Disability Screening Questionnaire' (McKenzie, Sharples, & Murray, 2015) is limited in rating ID. More recently, the Glasgow Level of Ability and Development Scale (GLADS) (Cooray et al., 2016) has been shown to be able to categorise ID accurately and to have good psychometric properties. It is quick to administer and popular with professionals. The GLADS may therefore be particularly useful in lower- and middle-income countries where specialist services are not available.

Simple (untested) screening could include questions such as:

- (1) Does the interviewer think the person has ID?
- (2) Does the person, the family or carers think he or she has ID?
- (3) Does the person have any problems in reading, writing or filling in forms?
- (4) Has he or she been to special school or special educational support in mainstream school, or has he or she had to drop out of mainstream school?
- (5) Is there any history of ID or of contact with ID services (community services, hospital)?
- (6) Is the person capable of living independently? Does the person need support from family or carers to support him or herself?
- (7) Does the person have the ability to travel independently?
- (8) (If applicable) Is the person able to use technology such as mobile phones, the Internet, television, radio and so on?

Associated conditions

About a third of people with intellectual disability have mental health comorbidity (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Deb, Thomas, & Bright, 2001). For those who are treated within hospital settings, rates of major mental illnesses may be even higher, at up to 50% (Alexander, Piachaud, & Singh, 2001). This is in addition to other comorbid conditions such as autism spectrum disorders, attention-deficit hyperactivity disorder, personality disorders and substance misuse. For individuals treated within or referred to forensic (i.e., secure) hospital services for those with ID, similarly high figures are reported. Up to half have a personality disorder, up to a third have an autism spectrum disorder, about a third to half have a major mental illness, about a third to half have substance misuse/dependence and about a fifth have epilepsy (Alexander, Crouch, Halstead, & Piachaud, 2006; Plant, McDermott, Chester, & Alexander, 2011). It is clear therefore that the clinical presentation of offenders with ID is often a complex mix of ID, mental illness, other developmental disorders, personality disorders, substance misuse and physical disorders, including epilepsy. Some of these conditions present with challenging behaviours, whereas others do not (Royal College of Psychiatrists, 2013, 2014, 2016). Often these conditions are unrecognised because of 'diagnostic overshadowing' of the ID. Contact with the police may be because of a new presentation of one of these conditions, and professionals dealing with offenders should consider this.

Pathways of care

Ideally, all prisoners and people in police custody should be screened for presence of intellectual disability, for instance by using the GLADS (Cooray et al., 2016). Those who have screened positive to a screening questionnaire should be referred to mental health care staff, preferably with experience, training and knowledge relating to assessing and treating people with ID. Those people with ID who may have mental health needs associated with their ID should then be referred to a psychiatric team able to deal with people with ID. In cases where there is doubt that the person has ID, a referral to a psychologist for psychological testing may be appropriate. In the case of those thought to have ID, it is important that the professional working with the offenders with developmental disorders in prison has a good relationship with local health and social services providing for those with ID. In countries and settings where such specialised services are not available, identifying the intellectual disability by screening and then seeking help from any health or mental health professional with some expertise in that area is important.

Vulnerability

Those with ID are likely to experience greater difficulty coping in prisons and to be vulnerable to bullying and financial, physical and sexual abuse. There are likely to be issues in respect of prison treatment programmes, court attendance and parole hearings. It has been suggested that those with ID are more likely to respond to bullying with physical aggression, which could result in transfer to more restrictive secure settings (Cooray, 2012, personal communication). People with ID can vary widely as to their level of functioning and ability, which can further complicate things. They may have little long-term perspective and limited ability to understand the consequences of their actions. They may be easily manipulated. They often make no attempt to disguise what they have done. In trying hard to please authority figures, they may confess to what they have not done and may show evidence of increased acquiescence (Finlay & Lyons, 2002). It is important to note that while ID is not a mental illness, many people with the condition, particularly those who come into contact with the criminal justice system, may have additional mental health problems including other developmental disabilities, mental illness, substance misuse disorders and so on. (Alexander et al., 2011). When a person in police custody appears to be suffering from mental health problems, including ID, or look like they need clinical attention, then appropriate help must be sought as soon as possible.

Recommendations

We offer the following 6 recommendations:

- (1) People with ID should have equitable legal and civil rights as other people. Those who are at risk of offending should also have a right to be held accountable for intentional actions, to have fair boundaries set and to have the full range of sentencing options available to them, if convicted. In view of their vulnerability and limited understanding, they may have difficulty in exercising their rights within criminal justice systems, and they may consequently need extra support.
- (2) Local pathways should be developed in conjunction with all agencies involved in the management of offenders with ID, in particular with regards to diversion from custody, including formal court diversion schemes.
- (3) Prisons and police stations should adopt reception screening to allow for early recognition and assessment of ID.
- (4) There should be standards on health and social care provision for offenders with an ID, with clear lines of accountability and explicit mechanisms for addressing any apparent gaps in service provision. Particular attention should be paid to developing a range of inpatient and community services that will allow people with ID who offend to be managed safely in the least restrictive setting.

- (5) There also needs to be greater clarity in the use of terminology (e.g., intellectual or learning disability, learning difficulties, mental retardation, etc.).
- (6) Doctors who work with people with ID need to be competent in the operation of mental health legislation with regard to offending behaviour. In addition, a detailed knowledge of relevant mental health, criminal and equality legislation and understanding of their potential involvement in proceedings throughout the various elements of the offender's journey is required.

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