Attending to the health needs of people with intellectual disability: quality standards

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Abstract

People with intellectual disabilities remain among the most vulnerable members of society and often face many barriers to healthcare. They experience major health problems and risks yet pay a 'disability penalty', the result of social exclusion, discrimination and isolation. If public health strategies are to address the physical and mental health needs of people with intellectual disabilities, attention needs to be given to their particular health profile. Health targets, quality standards and outcome measures must attend to their needs, for the measure of civilisation is how well we treat those who are deemed more vulnerable and less able in society. This article highlights how these issues are being addressed in 'westernised' countries and some of the dilemmas and challenges faced by health care organisations.

Key words: physical health; mental health; intellectual disability; quality; standards

Resumen

Las personas con discapacidad intelectual permanecen entre los miembros más vulnerables de la sociedad y con frecuencia experimentan múltiples obstáculos para el cuidado de la salud. Padecen importantes riesgos y problemas de salud y sin embargo pagan una "penalización" por su discapacidad, resultado de la exclusión social, discriminación y aislamiento. Si las estrategias de salud pública han de enfrentar las necesidades de salud física y mental de las personas con discapacidad intelectual, deberán prestar atención a sus necesidades de salud peculiares. Los objetivos de salud, normas de calidad y mediciones de resultados deben prestar atención a sus necesidades, ya que la medida de la civilización es qué tan bien tratamos a los considerados como más vulnerables y menos capaces en la sociedad. Este artículo subraya cómo se están afrontando estos problemas en los países "occidentalizados" así como algunos de los dilemas y desafíos que encuentran las organizaciones para el cuidado de la salud.

Palabras clave: salud física; salud mental; discapacidad intelectual; normas de calidad

The World Health Organisation (WHO)[1] estimates there are as many as 100 million people in the world with intellectual disability (also referred to as mental retardation, developmental disability and mental handicap). Intellectual disability is not a medical disorder, but rather a state of functioning characterised by limitations in intellectual ability and adaptive skills from childhood. It reflects the 'fit' between the capabilities of the individual and the structures and restricted expectations of the environment (AAMR definition).

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It is more common in developing countries because of associated factors such as poverty, malnutrition and restricted access to good antenatal and perinatal care. From a global perspective, the main causes of intellectual disability can be prevented through relatively simple and cost effective interventions such as the iodization of salt and environmental controls of heavy metals such as lead. The provision of foods fortified with vitamins and minerals can also end micronutrient deficiency.[2,3] Other main causes include chromosomal and genetic abnormalities (thought to make up 50% of ID in developed countries) as well as postnatal infections (e.g. meningitis, encephalitis), head trauma (e.g. head injuries, road traffic accidents, non-accidental injuries), and severe dehydration.

The prevalence of intellectual disability is generally estimated to be between 1-3% of the population, 90% of whom may be mildly disabled (IQ above 50) and capable of living and functioning fairly independently with appropriate community support. People with intellectual disability (PWID) represent a heterogeneous group with a varied range of highly complex needs, yet they remain among the most vulnerable members of society. All too often having a 'diagnosis' of intellectual disability becomes a barrier to services and healthcare instead of being used as a means to identify and address need. The underlying philosophy and principles of care for PWID have undergone radical changes in the USA, Europe, Australia and Canada over the past 40 years[4,5] focussing on civil and human rights, with social inclusion and citizenship free from discrimination.[6,7] There has been recognition of the right to live as normal a life as possible and this has led to the movement towards integration, participation and choice, with the closure of long stay institutions, the development of community based facilities, and growing empowerment and self-advocacy for PWID and their families.[5,8]

Putting policy into action

If there is to be real social inclusion however, PWID should receive the same access to care and support as other members of society, with due consideration given to facilitating equality, autonomy, and independence, even if additional measures are required. This means believing in the human worth and humanity of someone with ID and challenging discriminatory practices and attitudes. When considering intellectual disability, there are also real issues of gender, ethnicity, parenting and meeting their additional complex, physical and mental health needs.

However, the world's general population still believes that PWID should work and learn in separate settings, apart from people without ID. The family is seen as the most appropriate living environment for PWID, a function both of cultural values and availability of services.[9] Such services differ around the world. Westernised nations tend to provide publicly funded services, encompassing residential facilities, productive day involvement, education, training or respite, and some clinical services, whilst charitable organisations provide a high proportion of additional supportive services. However, there are significant differences in the availability and character of ID services, not only among nations but also within nations and within localities. These differences often reflect national and local priorities, cultural considerations and competing utilisation of scarce public financial resources.[5]

Health needs of people with ID

The UK Disability Rights Commission published a detailed exploration of health inequalities and barriers to services for people with ID and/or mental health needs after studying eight million health care records and conducting extensive consultation with service users and service providers as well as evidence reviews.[10] It confirmed that PWID and people with mental health problems are much more likely to have significant health risks. Major health problems include obesity, respiratory disease, heart disease, diabetes and a shorter life expectancy. The report concluded that this higher morbidity and mortality cannot be explained by social deprivation alone. Instead it is seen as a 'disability penalty'; the combination of social exclusion, discrimination and isolation. Therefore it argues that disability equality must be driven through by performance management and strict inspections. For this to work, quality standards and health outcome measures for this population will have to be made more explicit.[11]

Cooper[12] bears in mind that the leading cause of death for PWID is different from the rest of the population. For PWID, death from respiratory disease (pneumonia and aspiration), cardiovascular disease (often from congenital heart disease compared to ischaemic heart disease) and cancers of the oesophagus, gallbladder and stomach are the top three killers. She argues that public health strategies aimed at reducing the main health killers in the general population will not address the main healthcare issues for PWID and indeed may preferentially widen the inequality that already exists.

For PWID there is also a higher risk of epilepsy, sensory impairments and mental health problems as well as the associated health morbidity linked with particular syndromes or conditions. As a result, PWID often need longer and more intense involvement from health

and social care services. Hearing what they have to say about their experiences and addressing their concerns will not only improve standards of care for them but for all who access services. In the UK, PWID have identified the areas of most concern to them.[13] These include:

- Lack of contact with front line community health care services (primary care)
- The way medication is prescribed
- The need for accessible information
- Available treatments for depression
- The care of those with additional severe mental health problems
- Practical support when going into hospital
- Anxieties about being in hospital
- The effect of long waiting times
- Communication between health and social services
- Services for people with high support needs
- Health screening and health promotion
- Informing services when things go wrong

The National Patient Safety Agency[14] highlighted delay in access to treatment and harm related to inability to understand healthcare information as particular issues for primary care. This agency looks at not only how, but who, gets harmed and whether or not there are discriminatory patterns in evidence. The AAIDD has also recently highlighted the health disparity that exists for PWID in the US.[15] This evidence must surely lead to targeted quality standards if they are to be addressed.[16]

Addressing mental health needs of PWID

Mental health is as important as physical health to the overall well being of individuals, societies and countries. Yet in most parts of the world only a small minority of the 450 million people suffering from a mental or behavioural disorder are receiving even the most basic treatment. In developing countries, most individuals with severe mental disorders are left to cope as best they can. Globally, many are victimised for their illness.[17] Good mental health helps people cope with day to day living, major life changing events, and decisions; it is not just about the absence of mental illness. It also includes a positive sense of well being and an underlying belief in one's own and others' dignity and worth.[18]

Mental health problems are common in the general population, affecting one in six adults at any one time.[19] PWID can develop the full range of mental health problems too, with prevalence figures ranging from 25 to 40%.[20,21] These include debilitating condi-

tions such as schizophrenia, depression, generalised anxiety disorder and dementia. The assessment and diagnosis of such problems in PWID has improved with the development of diagnostic tools, and knowledge of their clinical presentation has also increased.[22,23] The association between certain behavioural disorders and specific genetic syndromes has also opened up the possibility of different treatment approaches.[5] The realisation that therapeutic interventions employed in general psychiatry can be utilised, adapted as necessary, in the treatment of psychiatric disorders in PWID has created an atmosphere of therapeutic optimism.[24,25]

In some parts of the world, such as the UK, there are psychiatrists and psychologists specialising in the mental health problems of PWID. In many countries however, this is not the case. General psychiatrists, paediatricians and other professionals without special knowledge may look after PWID and mental health problems. Even where specialist services exist, PWID should have the same access and equality to the full range of mental health care provision as non-disabled citizens. This means including the needs of PWID when planning, organising and delivering mental health care.

Quality standards might include:

- Accessible services – not just physical access but administrative access (i.e. how appointments are made and followed up)
- A safe environment
- Feeling respected as an individual
- Having one's privacy and confidentiality respected
- Good communication – appropriate signposting, literature and written communication and complaints procedures
- Good personal communication – using aids and supports as appropriate; having things explained in a way that is understood
- Being listened to and having one's opinions sought and respected
- High quality, evidence-based clinical care.

These quality standards are needed for everyone, regardless of their cognitive or physical abilities.

Where there are specific mental health standards, there must be a means of ensuring that they apply to PWID too. One example is the National Service Framework for Mental Health in England and Wales,[26] which explicitly states what must be available across the nation for mental health care. It is accompanied by a framework for the coordination and delivery of such multi-agency care in a person centred way.[27] These quality standards are now incorporated into a traffic-light system assess-

ment tool for localities to use, to audit how well local services are providing for the mental health needs of PWID.[28]

The main areas covered include:

a. Local partnerships between mental health and ID services, primary care and PWID and their carers. It requires agreed protocols to be in place to ensure PWID receive the services they need.
b. Key mainstream mental health services that should be accessible to PWID
c. Diversity of provision – including ensuring cultural and gender sensitivity, user led services, and the use of a full range of provision including those provided by the voluntary sector. This might also include using older people's services when a PWID develops dementia prematurely.
d. Programmes and initiatives to support an effective service – such as workforce planning, training and consultancy work, liaison, including PWID in mental health promotion work
e. Planning for the needs of people who often fall between mental health services and ID services – this includes people with autistic spectrum disorder who are functioning above the usual IQ cut off for ID services, adults with Attention Deficit Hyperactivity Disorder who are not yet recognised by general psychiatric services as having a severe and enduring mental illness, those who suffer cognitive impairment in adult life as a result of a head injury / accident.

These standards now form part of the annual quality inspection of all health service providers in England, providing a baseline and benchmark from which to improve mental health services for PWID.[29,30]

Problematic behaviours

Those who present challenging or problematic behaviours may do so because of a number of complex underlying and inter-related factors which may or may not be related to the presence of a mental illness. More often it is a product of environmental and personal factors. In such circumstances it would be important to rule out physical causes such as pain, infection or physical discomfort.

Many PWID with so called 'severe challenging needs' who may or may not have offended, may be sent to live far away from home due to lack of local services to meet their needs,[31] and this, too, is now being used as a quality measure by independent inspecting and regulatory authorities in the UK.

When PWID find themselves in contact with the law they are often discriminated against during their contact with the criminal justice system (e.g. police station, courts and prisons) and their health and social care needs are often overlooked.[18]

Gender, ethnicity & vulnerability

Although most studies have not found an association between gender and mental illness in this population, Cooper et al's recent study in Glasgow[21] did find a positive association with female gender. The World Health Organisation states that:

> across socioeconomic levels, the multiple roles that women fulfil in society put them at greater risk of experiencing mental and behavioural disorders than others in the community. In addition to their expanding and often conflicting roles, women face significant sexual discrimination and associated poverty, hunger, malnutrition, overwork, domestic and sexual violence.[17]

Abuse, whether it is physical, sexual, emotional or financial, can increase an individual's vulnerability to mental health problems as well as cause physical ones. The literature suggests that abuse is more prevalent amongst PWID but the very fact that abuse is hidden means it often goes unreported.[32] PWID may be more dependent and over-trusting of others, they may find it harder to protect themselves, or to communicate their experiences. How such incidents are recorded and dealt with by statutory authorities is also the subject of independent inspection in the UK, with localities agreeing multi-agency 'vulnerable adult' strategies and running adult protection panels led by social services, similar to child protection.

Racism, too, raises important issues for PWID although it is beyond the scope of this article. However, acknowledging the existence of such discrimination and addressing it at every level will go a long way towards tackling the 'double jeopardy' faced by PWID from ethnic minority communities.[33,34] This has also become a focus for quality inspection as regulatory bodies in the UK begin to address the negative experiences of mental health service users from Black and minority ethnic communities.

Families and carers

Another very important aspect to consider and address when thinking about meeting the health needs of PWID is that of families and carers. This too is beyond the scope of this article. However, family and paid carers

often support PWID without proper recognition. They have a significant role in identifying a health need in the first place and are the people involved in the delivery of day-to-day care, including compliance with medication. Clinicians are often reliant on their presence in gaining corroborative histories and in understanding an individual's idiosyncratic, verbal or non-verbal communication. Issues of confidentiality and consent can present dilemmas when focussing on the needs of a person with ID as an adult, encouraged and empowered to make his/her own choices. Sharing necessary information as appropriate to the circumstances, recognising the needs of families and carers and providing information and support remain challenges for all.

Conclusion

This article has focused on PWID of working age (generally meaning 18-65 years). The needs of children with intellectual disabilities or older people with intellectual disabilities must also be considered, separately, and as a continuum. The transition between age-related services needs to be planned and negotiated with care.

When it comes to providing healthcare to PWID, the distinction between physical and mental health needs is an artificial one as far as the individual is concerned. There is a constant interface which needs to be recognised, whether it is the impact of physical health on an individual's mental health or vice versa, whether it is as a result of drugs or treatments given, or whether it is a co-existing or co-morbid condition. PWID have the same right to access healthcare systems as the rest of the community and they expect provision to be made to support and address their special needs if required. Many of these 'special needs' are in fact needs all people have if they are to come away with a good experience of healthcare. Standards and performance measures used to monitor quality and outcome need to be applicable to PWID too, but care needs to be given in order to avoid widening the health disparity that already exists by simply extrapolating public health strategies for the general population.

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