

CHAPTER 1
INTELLECTUAL DISABILITY AND MENTAL HEALTH
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OVERVIEW

This chapter will examine health and social policy with special reference to people with intellectual disabilities in the UK, and explore the severe health inequalities they experience. It will also discuss the need for psychological and other therapies for people with intellectual disabilities who have mental health needs.

Learning objectives

- To contextualise the health and social care policy directives
- To highlight the health inequalities and discrimination
- To explore resilience and interventions

INTRODUCTION

Community living have laid to rest the myth that the emotional problems experienced by people with intellectual disabilities (ID) are the result of institutionalisation alone, and that living in the community would somehow 'remove' or 'cure' such problems. In fact, living in the community has resulted in additional stressors for people with ID, such as negative attitudes, social exclusion and lack of appropriate and meaningful employment. For many people with ID this has also resulted in increased exposure to alcohol and illicit drugs, and made people more vulnerable to abuse and exploitation. Furthermore, the lack of leisure and social opportunities, and a lack of adequate help and support to allow them to access and fully participate in such activities in the community, frustrates many people with ID. Such stressors, when combined with the limited coping and problem solving skills often found in this population, are likely to result in maladaptive ways of coping and mental health problems. However, it is a sad fact that many mental health disorders, such as anxiety and depression, often go unrecognised due to the phenomenon of diagnostic overshadowing i.e. the assumption that mental disorder and ID are mutually exclusive categories rather than overlapping.

In fact, research evidence over the last two decades consistently shows that around 40% people with ID experience a range of mental health disorders during their lives, and that for most of the common mental health disorders, the estimated prevalence in people with ID is far higher than the general population.

Another issue in diagnosis is that people with ID often show severe behaviour problems or challenging behaviours, which pose a serious challenge to services (Emerson, 2001), but the extent of overlap between such challenging behaviour and mental health disorders has a significant impact on detection and diagnosis. For example, the violent behaviour sometimes apparent in paranoid schizophrenia, and social withdrawal accompanying clinical depression, can both be described as challenging behaviour. The problems of differential diagnosis of challenging behaviour and mental health disorder may therefore have serious consequences in understanding the therapeutic needs of people with ID.

The extent of this overlap between challenging behaviour and mental health disorders has been examined from different perspectives and been the subject of many debates. Moss *et al* (2000) conducted a study to determine the proportion of people with challenging behaviour who have additional psychiatric symptoms. They surveyed 320 people with ID, with and without challenging behaviour, for the presence of psychiatric symptoms using the Psychiatric Assessment Schedule for Adults with a Developmental Disability Checklist (PAS-ADD) (Moss *et al*, 1998). Their results indicate that an increasing severity of challenging behaviour is associated with increased prevalence of psychiatric symptoms. For example, the study found that depression is four times as prevalent in people whose challenging behaviour was more demanding than in people showing less challenging behaviour. Moss *et al* suggest that this strong association with depression is significant because this condition is often undetected in the general population and in people with ID. Based on this association, they highlight that there may be many people with ID and challenging behaviour who may also have unrecognised psychiatric symptoms.

It should be noted that the complex nature of this overlap should be taken into account when diagnosing mental health disorders in this population. Dosen (1993) argues that the area of overlap is broad and that this should not be a reason to abandon efforts to distinguish between challenging behaviour and mental health disorders. Multidisciplinary assessment processes using both behavioural observation and psychological states may therefore be the best option for establishing appropriate diagnosis and treatment.

POLICY DIRECTIONS

The Department of Health's *Valuing People* white paper (DH, 2001) and its recent update *Valuing People Now* (DH, 2009) outline the strategy for improving the lives of people with ID and their families. The agenda is based on the recognition of their rights, as citizens, to be socially included, and to have choice in their daily lives and opportunities to achieve independence. In many respects, *Valuing People* challenged the way services are organised for people with ID, and more importantly the way in which professionals and other service providers work with this population.

Some of the key changes in this area that we have seen over the past decade include:

- the development of real partnerships between services and people with ID and their families, thus promoting inclusion
- a focus on the health of people with ID and the need to improve their health and well-being through focused action, such as the health improvement plans and health facilitators
- the availability of easy-read information on all aspects of health and social care, enabling and empowering people with ID and their families to make informed choices
- increasing the range of housing options and the closure of the NHS campus service provisions
- promoting a personalisation agenda, underpinned by the principles of person-centred planning, by working in partnership with the user and a range of service providers in the locality
- increasing employment opportunities for people with ID.

These initiatives need to be fully supported and maintained to observe its long-term impact on improving the lives of people with ID.

With regard to mental health needs, *Valuing People* highlighted that most psychiatric disorders are common in people with ID and suggested that the *National Service Framework for Mental Health* (DH, 1999) was applicable to people with ID of working age. *Valuing people* advocated the use of mainstream mental health services in combination with a range of specialist services for people with ID.

However, mainstream mental health services continue to pose major barriers for people with ID, whose experiences of such services are far from satisfactory. One of most common uses of mainstream services by people with ID is the admission to general adult wards in mental health hospitals, and here:

- Many find the general psychiatric wards too busy, chaotic and threatening, having come from quieter protected environments such as the family home or residential care.
- Nurses and other professionals on such wards do not usually have the training or skills to meet the needs of the person's intellectual disability.
- They might expect each patient on the ward to quickly learn appropriate routines such as meal times, times for medication rounds, days of ward rounds, days when occupational therapy activities are available and so on.
- A person with ID may have poor literacy skills and time sense, and thus be unable to read or tell the time.
- The staff on the wards may be too busy with unpredictable acute emergencies to have the time to help people with ID adjust to being in a new environment.

As a result, people with ID may feel more confused due to the lack of individualised care and attention. More importantly, these people may feel more vulnerable in general adult ward settings, and many may be prone to abuse and exploitation.

Services have therefore argued for more collaborative working models with people with ID who have mental health needs. A recent study (Bhaumik *et al*, 2008) stresses the need for close collaboration between mainstream mental health and specialist service providers to improve the experiences of people with ID. It also stresses the importance of a clear pathway for people with ID and mental health problems to ease the transfer between specialist and generic mental health services, and the importance of a protocol for joint working where input from both services is required.

In order to improve access to mainstream mental health services, the Green Light Toolkit (GLT) (FPLD, 2004) was introduced with the aim of measuring how the *National Service Framework for Mental Health* (DH, 1999) is being implemented for people with ID in England. This audit tool provides standards that local mainstream mental health and specialist ID services, in collaboration with key stakeholders, can measure their services against using a 'traffic light' scoring system. It also provides guidance on how services can be improved and covers areas such as local partnerships, planning, accessing services, care planning, workforce planning and diversity. It can be a useful tool for services, helping them to identify gaps in their service for meeting the mental health needs of people with ID, and helping them to plan and develop a service strategy (Eastwood *et al*, 2009). However, very little is published about the use of GLT and its impact on service development.

The service structures for people with ID who experience mental health disorders are fraught with confusions, complexities and conflicts: confusion in terms of the nature and manifestation of mental health problems in people with ID; complexity in terms of the challenges for appropriate detection, diagnosis and intervention approaches; and conflicts in terms of the service structures and processes that work against the needs and wishes of users and their carers. As a result, people with ID and mental health needs face severe inequalities. What is required is a truly inclusive mainstream service accepting people with ID and mental health needs and offering appropriate therapeutic services.

The development of an inclusive mainstream mental health service will consist of a number of factors, which should be allowed to grow and flourish over a period of time so that its effectiveness can be closely monitored. It is difficult to provide an exhaustive list, but the key factors are as follows:

- User and carer involvement in the development of services and their functioning.
- Effective communication systems at all levels of the service.

- Accessible information for people with ID, their carers and other professionals, about the types and nature of services and the therapeutic interventions offered.
- A clear vision in the service of the requirements of people with ID and mental health needs, and how they can address these requirements.
- Appropriately trained and qualified professionals who are confident and competent to address the challenging issues of assessment and intervention.
- Joint training of learning disability and mental health nurses.
- Multi-professional education/training programmes for all professionals working in this area.

The new mental health strategy, *No health without mental health* (DH, 2011), sets out the coalition government's ambition to mainstream mental health and to establish parity of esteem between services for people with mental and physical health problems. This strategy outlines six broad principles:

1. More people of all ages and backgrounds will have better well-being and good mental health. Fewer people will develop mental health problems – by starting well, developing well, working well, living well and ageing well.
2. More people who develop mental health problems will have a good quality of life – greater ability to manage their own lives, stronger social relationships, a greater sense of purpose, the skills they need for living and working, improved chances in education, better employment rates and a suitable and stable place to live.
3. Fewer people with mental health problems will die prematurely, and more people with physical ill health will have better mental health.
4. Care and support, wherever it takes place, should offer access to timely, evidence-based interventions and approaches that give people the greatest choice and control over their own lives, in the least restrictive environment, and should ensure that people's human rights are protected.
5. People receiving care and support should have confidence that the services they use are of the highest quality and at least as safe as any other public service.
6. Public understanding of mental health will improve and, as a result, negative attitudes and behaviours to people with mental health problems will decrease.

(DH, 2011, p6).

This policy is relevant to everyone, from children and young people, to those of working age and older. The mental health of people with ID is also specifically mentioned in this document, and it highlights two key aspects for the improvement of mental health services for this population and for people with autism:

- inclusivity of mainstream mental health services for people with learning disabilities who have mental health problems; and
- development of appropriate skills and provision of adjustments to meet the individual needs of people with learning disabilities and autism (recognising the increased risks of a range of physical and mental health problems for this group).

ACCESS TO PSYCHOLOGICAL THERAPIES [A-Head]

People with ID experience severe health inequalities in terms of access to and use of appropriate therapeutic services, and recent evidence highlights continuing discrimination in receiving adequate health interventions from mainstream health services. A national newspaper in the UK reported that, '*the National Health Service is accused of causing or contributing to the deaths of at least 74 patients with a learning disability because of poor care that reveals enduring "institutional discrimination" among doctors and nurses*' (*The Guardian*, 2 January 2012). This discriminatory attitude has been the

topic of discussion over the last five years and a number enquires and reports published have argued for 'reasonable adjustments' to be made by services for people with ID. As to how these adjustments work for people with ID is to be monitored and evaluated over the next few years, when we might have reasonable evidence of its implementation.

The National Institute for Clinical Excellence (NICE) guidelines on anxiety and depression (NICE, 2007; 2009) recommend a range of therapeutic approaches to treat people with anxiety and depression. Access to psychological therapies is a major component of the recommended interventions.

Improving access to psychological therapies (IAPT) is a major initiative for people with mental health needs. For many people with ID, however, this initiative is not fully implemented and it is not able to evaluate the effectiveness of applying the most common psychological therapies to this population. According to IAPT, the key barriers in accessing psychological therapies for people with ID include:

- professionals lack confidence in working with people with ID
 - they have concerns about their ability or skills to build a therapeutic relationship
 - they consider that psychological therapies would be better used on people with greater cognitive abilities.
- (IAPT, 2009)

The positive practice guide for IAPT (DH, 2009) highlights the need for proper and effective engagement with people with ID, and it recommends:

- monitoring uptake of IAPT services by people with ID
- identifying the successful and unsuccessful referral pathways
- recognising that Community Learning Disability Team staff, support staff, family members, carers and advocates can play an important role in identifying mental health problems in people with ID, and that they should be a key part of the referral pathway into the IAPT service
- recognising that people with ID themselves may be a potential resource to the IAPT service (eg. as volunteers or paid workers including playing a part in recruiting staff)
- advertising psychological therapies in ways that are accessible and meaningful to people with ID, such as providing leaflets or audio/DVDs in easy-to-understand formats
- commissioning local voluntary sector and advocacy groups specialising in ID to raise awareness and support people with ID to access IAPT services.

The evidence base for many psychological and other interventions for people with ID is limited. This calls for more practice-based evidence models that may help to highlight the factors contributing to the long-term sustainability of these interventions. Person-centred approaches to care and intervention is multi-dimensional as it involves family carers, teachers, frontline support workers and range of health and social care professionals. For example, a person with ID living in a supported group home may receive help and support from frontline staff and a range of professionals such as nurses, psychologists and psychiatrists. This may involve anxiety management when at home, at work, or when shopping or engaging in any social or leisure pursuits. Whilst providing this person-centred approach, it is important for health and social care professionals to identify and record all the intricate processes involved. This detailed and careful documentation of the nature and experiences of the user, carers and professionals will help to build a rich and valid picture of the much-needed practice-based evidence for working with people with ID and mental health needs.

Disablism, risk and resilience [B-Head]

Disablism [C-Head]

The Demos Report (2004), *Disablism: How to tackle the last prejudice*, was intended to put the word 'disablism' in the context of the political and social agenda, alongside racism and sexism. It defines disablism as, '*discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others*'. Emerson (2010) argues that disablism contributes to poor health outcomes for people with ID, and in a major study using secondary data to explore the possible impact of exposure to discrimination in everyday life on the health status of people with ID, he highlights that exposure to overt acts of disablism contributes to the health inequalities experienced by this population. Emerson concludes that health and social policies aimed to reduce health inequalities are likely to be more effective if they are specifically tailored to the social and cultural experiences of high-risk groups such as those with ID.

People with ID have a multiplicity of health and social care needs that require specialist help and support. O'Hara (2010) argues that, '*people with ID have a constellation of negative health determinants, including minimal education, low income, unemployment and poorly developed social networks, which are risk factors in their own right for poorer health outcome*' (p4). Moreover, people with ID from minority ethnic communities experience exclusion and discrimination in terms of accessing and use of our health and social care services (Raghavan, 2009). Evidence also demonstrates that people with ID have limited social networks and only a few people play important roles in their lives (Grant, 1993). It is also suggested that their membership of social networks is rarely static, and that they may be very much limited to the key carers in their lives, with little opportunity to form friendships outside the family. This lack of a circle of friends and limited social networks is also echoed by Emerson & Hatton (1998).

Risk [C-Head]

ID is a 'risk factor' that increases the likelihood of adverse outcomes, but it cannot predict future behaviour in itself. A combination of factors — personal, familial and social — determine whether individuals with ID will have successful academic, social and employment outcomes (Cosden *et al*, 2002). Nevertheless, people with ID are at a greater risk of developing mental health problems and being exposed to social disadvantage than their non-disabled peers (Emerson and Hatton, 2007), and they often experience serious intra- and interpersonal problems such as loneliness and depression, which can exacerbate the challenges presented by the intellectual disability itself (Cosden *et al* 2002). However, focused interventions in building resilience will provide people with ID with a buffer against these negative experiences, and Emerson and Hatton (2007) suggests that building the resilience of children with ID and their families can help reduce the personal, social and economic costs associated with mental health disorders among them.

Resilience [C-Head]

Resilience is the term used to refer to the maintenance of positive adaptation by individuals within the context of significant adversity (Luthar *et al*, 2000). It is a dynamic process involving interactions between various risk and protective processes, both internal and external to the individual, that act to mitigate the influences of adverse life events (Margalit, 2004). It encompasses three areas:

- individual characteristics
- their families
- the societies in which they live.

In societal terms, the most important influences are those of school and the broader social environment. Given that it involves an interaction between the person and their social and physical ecology, resilience is always contextual and can be achieved in a variety of ways across contexts and cultures (Didkowsky *et al*, 2010).

The resilience model shifts focus away from deficits, looking instead at the strengths in individuals and systems, and is therefore more useful for educators and therapists. It is also useful from policy

and practice perspectives since it can help to inform guidance on prevention and intervention efforts (Murray, 2003). By identifying what it is that makes some people resilient, it should be possible to foster those skills in those who are less resistant. In fact, many intervention programmes using school-wide approaches based on a resilience model have proved effective in reducing maladaptive behaviour and promoting competency in students (Miller *et al*, 1998). While the resilience of non-disabled individuals who have been exposed to severe adversity has been widely researched (Howard *et al* 1999), this has not been matched by research into the ways individuals with ID construct resilience for themselves.

Resilience-building activities should be carefully linked to the types and range of interventions offered and their effectiveness in building emotional well-being in people with ID. Luther (2000) provides a set of guiding principles that are very relevant to people with ID:

- Interventions must have a strong theoretical base
- Interventions must have a strong basis in theory and research of the particular group
- Efforts should be directed not only toward the reduction of negative outcomes or maladjustment among targeted groups, but also toward the promotion of dimensions of positive adaptation or competence
- Interventions must be designed not only to reduce negative influences (vulnerability factors) but also to capitalise on specific resources within particular populations
- Interventions should target salient vulnerability and protective processes that operate across multiple levels of influence (influences stemming from the community, family as well as from the individual)
- Interventions should have strong developmental focus
- The contextual relevance of the overall intervention aims, as well as of the specific intervention strategies, must be ensured
- Intervention efforts should aim at fostering services that eventually can become self-sustaining
- Wherever possible, data from interventions groups should be compared with those of appropriate comparison groups.
- There must be careful documentation and evaluation of the interventions (of all the gains and unanticipated problems).

CONCLUSION

Enabling people with ID to develop emotional well-being is both an art and a science. It is an art because of the diverse roles that professionals and carers have to play when engaging with people with ID. Experienced professionals should reflect on their work with a person with ID and through publications, provide stories of the art of implementing such interventions. These stories will highlight the processes and the complexity of implementing and evaluating some of the much needed psychological interventions for people with ID. We should not limit the exploration and use of psychological and other appropriate intervention strategies for this population because of the lack of evidence base. Imagination is a key asset here, as it helps to explore and combine a range of methodologies and approaches that can be implemented easily and cost effectively. This will undoubtedly help the advancement of professional practice and contribute to the development of evidence based on practice models. As Albert Einstein once said, *'Imagination is more important than knowledge. Knowledge is limited. Imagination encircles the world.'*

Summary

- Providing services for people with ID with additional mental health need is a challenge for our services. Health and social policy directives identify the gaps in our mainstream mental health services and identify the need to provide appropriate therapeutic services for people with ID with mental health needs.

- Access to psychological therapies for people with ID need to be fully explored and appropriate modifications/ adaptations should be made.
- Building resilience is paramount in enabling and empowering in people with ID with additional mental health needs.

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