Overcoming ignorance and stigma relating to intellectual disability in healthcare: a potential solution

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Introduction

The Darzi Report (Department of Health 2008) set the target of high quality healthcare through a more personalized approach to care to overcome persisting significant variations in the quality of care. The report aimed particularly to improve services for people who traditionally are less likely to seek help or find themselves discriminated against (Department of Health 2008). At the heart of the proposals for a high quality NHS is the ambition of not only treating illness but also delivering health improvement including tackling obesity through healthy eating and physical activity, raising awareness of vascular risk and the introduction of personalized care plans for those who have long-term conditions (Department of Health 2008). This can only be achieved for people with intellectual disabilities if generic health professionals develop an understanding of the particular issues associated with intellectual disabilities thereby minimizing the risk of stigmatization and consequent discrimination in the health care setting.

A stigmatizing history of care

People with intellectual disabilities have always existed; however, the extent of their visibility within society has
been variable through history and across different cultures. In 1904, a Royal Commission investigated the problem of the ‘feeble minded’ who were considered a threat to the stability of society and recommended institutionalization based on the negative eugenic policies of other European countries. During the 1930s and 1940s, Nazi Germany practiced forced sterilization of an estimated 400,000 people between 1934 and 1937 whom they considered to be mentally and physically unfit (Selgeli 2000). The Nazis were also responsible for ‘euthanasia programmes’, killing thousands of institutionalized disabled people (Proctor 1988, Weindling 1989). Similarly in Sweden a ‘Sterilisation Act’ was passed in 1934 relating to patients who had mental health problems or intellectual impairments and was responsible for more than 62,000 people being sterilized between 1934 and 1975 (Lennerhed 1999). In the United Kingdom, at this time, sterilization programmes were never legalized although some were conducted privately upon those with mental illness and intellectual impairment (Porter 1999).

Changing social influences over time have been reflected in subsequent legislation. The Mental Health Act 1959 ended compulsory certification of people with intellectual disabilities and subsequently provided the means by which people who were detained in the institutions for no legitimate reason could be discharged into the community. The process of ‘normalization’ first emerged as part of the Danish Mental Retardation Act in 1959. Woolfensberger (1972) defined it as ‘the utilization of the means which are as culturally normative as possible in order to establish and/or maintain personal behaviours which are as culturally normative as possible’ (p. 28). His commitment to promoting normalization as a foundation for intellectual disability care was revolutionary and pivotal in the eradication of institutionalization.

The UK 1959 Mental Health Act replaced the term ‘mental deficiency’ with the label of ‘mental sub-normality’ and the 1990 NHS and Community Care Act provided the context for the shrinkage of the institutions and moved responsibility for people with intellectual disabilities away from the NHS to Social Services Departments of Local Authorities. And although people moved into the wider community they were still segregated to some extent into day service provision and group homes. Although Szivos (1992) acknowledged that many good things emerged from normalization, there were three assumptions which needed testing, namely, that assimilation into mainstream society works; that it is a good thing; and that, to be valued, the disadvantaged person should aspire to fulfil societal norms.

Additionally, the health professional’s perception of people with intellectual disabilities has not been helped by frequent ‘official’ changes in terminology. For example, the nursing profession has used various labels over time and moved from the term ‘mental deficiency’ to ‘mental sub-normality’, followed by ‘mental handicap’, and in the days of political correctness ‘learning disability’. This has added confusion to the potential discrimination of this population.

A possible explanation for the frequent change of terminology may lie in attempts to balance non-discriminatory labelling with the need for projecting an understanding of what such conditions comprise but the informal derogatory terminology has also been unhelpful.

Emerging terminology from the United States appears to favour the term ‘intellectual disability’ and this has largely replaced ‘mental retardation’ (traditionally the term used across the United States). The term now appears to have been adopted across Europe and the United Kingdom particularly in research-based journals and by psychiatrists prominent in the field. Interestingly the term ‘learning disability’ is still in use by nurses in the United Kingdom which is unhelpful as it is understandably confused frequently with the educational construct of ‘learning difficulty’ which includes conditions such as dyslexia, dyspraxia, the hyperkinetic disorders and some autistic spectrum disorders.

**People with intellectual disabilities have a higher prevalence of health needs**

People who have intellectual disabilities are more prone to both physical and mental health problems than the general population (Deb et al. 2001, Higgins & O’Toole 2007). In particular, their physical health problems include coronary heart disease (Wells et al. 1997), epilepsy (Stokes et al. 2004), obesity (Marshall et al. 2003), gastro-intestinal and oral health disorders all of which are more prevalent than in the general population (Higgins & O’Toole 2008) whilst auditory and visual disabilities are frequent and often go undiagnosed (Woodhouse et al. 2004).

People with intellectual disabilities also have a high prevalence of mental health and behavioural problems as a result of damage to the brain, specific syndromes, in addition to limited capacity to manage challenging personal situations such as repeated loss and separation issues, poor coping mechanisms and problems with communication and social skills (Fraser & Nolan 1995). People with intellectual disabilities also have the added problem of diagnostic overshadowing where
there is a tendency to attribute symptoms and behaviour associated with illness to the intellectual disability, thereby overlooking the illness itself. In addition, a primary diagnosis (such as epilepsy or psychosis) may result in practitioners assuming that all symptoms in the patient (either observed by others, or described) are attributed to the primary condition thus preventing further investigation of other possible co-morbid conditions.

**Evidence of poor care for people with intellectual disabilities**

‘Valuing People’ (Department of Health 2001a) reasserted the imperative of normalization of healthcare for people with intellectual disabilities and their entitlement to access and use of mainstream healthcare alongside the general population. Indeed, they were not viewed as a distinct group who required a specific National Service Framework (NSF). It could be argued that the reduction of specialist NHS services without the introduction of mandatory training and education in this speciality for generic healthcare professionals was an attempt at true equality with an end to segregation, or alternatively it could be viewed as a money-saving initiative against a vulnerable population who lack a powerful voice.

Krahn et al.’s (2006) systematic literature review of the health problems associated with intellectual disabilities noted that, while there is consistent evidence of health needs, they receive inadequate attention by caregivers, receive less health promotion and have poor access to high quality health services. They argued that it is the compounding effect of these elements that has led to poorer health in people with intellectual disabilities coining the phrase a ‘cascade of disparities’ (p. 80).

The absence of legislation or distinct policies guiding the care and treatment of people with intellectual disabilities within generic services coupled with the readily available evidence of the lack of knowledge held by mainstream NHS staff (Murray & Chambers 1991, Slevin & Sines 1996, Bond et al. 1997) may lead to the charge that the Government is not discharging its duty of care towards this patient group. There are few specialist services for people with intellectual disabilities (Department of Health 2001) so that mainstream NHS professionals are providing care to a diverse group of individuals with whom they have had little previous contact and only minimal related education (Clark & While 2008). The consequent disparities in health and healthcare provision are well documented (Krahn et al. 2006) and were highlighted by ‘Treat me Right’ and ‘Death by Indifference’ (Mencap 2004, 2007) which documented the inadequate treatment of people with intellectual disabilities in the NHS.

‘Treat me Right’ (Mencap 2004) recommended training for health professionals, longer appointment times, annual health checks and the identification of people with intellectual disabilities in patient health records to address health inequalities. However, few of these recommendations have been adopted. Indeed, a formal investigation (Disability Rights Commission 2006) found that people with intellectual disabilities received fewer health investigations than the general population and were less likely to get the healthcare they that needed. Despite this evidence, Mencap (2007) noted that there has been an ‘astonishing lack of response’ in all areas previously recommended in ‘Treat me Right’ (Mencap 2004).

‘Death by Indifference’ (2007) presented six cases of patients with intellectual disabilities who received hospital care with serious deficiencies in the level of care provided by health professionals. An Independent Inquiry was commissioned by the Department of Health as a result of this damning report (Michael 2008) which recommended intellectual disabilities education in all undergraduate clinical courses and as a mandatory element of continuing professional development in addition to better inspection methods regarding how the NHS treats people with intellectual disabilities. Indeed, calls for education in intellectual disability of generic health professionals have been reiterated over the years as a result of research findings (Friedman et al. 1999, Koch et al. 2001, Kerr et al. 2003, Tuffrey-Wijne 2003, Mencap 2004) but the issue has remained largely unaddressed (Michael 2008).

**Attitudes towards people with intellectual disabilities**

Mencap (2007) acknowledged that it was difficult to determine whether any of the individual health professionals involved in the incidents reported in ‘Death by Indifference’ consciously discriminated against the patients whose cases were described. Many of the families involved reported the spoken words of various health professionals which were discriminatory, however, they were not recorded in case notes, although this does not mean that direct discrimination of people with intellectual disabilities did not occur (Mencap 2007).

Ignorance may result in institutional discrimination (Mencap 2007) as a result of policy, practice and procedures not being grounded in knowledge and the evidence base. Mencap (2007) have argued that, by
allowing the high levels of ignorance to continue among health professionals, the NHS is guilty of institutional discrimination. The process of creating discrimination towards people with intellectual disabilities follows a pathway often underpinned by assumptions and fear of the unknown. The terminology and labelling (including diagnostic labelling) associated with intellectual disability is unhelpful which in turn leads to stereotyping whereby the individual is categorized and then subject to the other person’s knowledge base in that area (this could be either negative or positive depending on previous exposure to intellectual disability). Stigma and prejudice which may ultimately lead to discrimination occur when previous exposure to others with intellectual disabilities has been negative or absent (See Figure 1). Goffman (1963) suggested that stigma is created and expressed when people encounter those with undesirable differences with such encounters changing social identity and subsequently creating negative attitudes so that the individual who possesses the differences is disqualified from full social acceptance. Goffman (1963) described the ‘deviancy cycle’ in which devalued people often behave in accordance with the deviant label that society affords them which in turn strengthens society’s existing stereotypical beliefs. The consequent exhibited behaviours reinforce individual notions of the devalued person. Negative perceptions of challenging behaviour and its causes in people with intellectual disabilities is one obvious example of this phenomenon (Kelly 2008).

There is little research which considers the attitudes of health professionals towards people with intellectual disabilities but, where available, more negative attitudes have been found than would be expected from those working in the caring professions (Slevin & Sines 1996, Yazbeck et al. 2004, Oulette-Kuntz et al. 2003) with a lack of education in relation to this patient group being noted as a contributory factor (Bond et al. 1997, Phillips et al. 2004). Murray and Chambers (1991) found that, after placements with clients who have intellectual disabilities, student nurses’ attitudes improved, however, this comparative study also looked at attitudes towards older adults and people with physical disabilities and found that both before and after the placements, intellectual disability was viewed the most negatively of the three groups. A Canadian study of senior resident psychiatrists (Oulette-Kuntz et al. 2003) found that males were more likely to have negative attitudes towards people with intellectual disabilities than females; however, specialist education in the subject improved their attitudes. Stereotypical negative attitudes of some health professionals (in this case student nurses) towards people with intellectual disabilities regarding aggression indicated that they did not view people with intellectual disabilities as similar to other people (Slevin & Sines 1996).

Hollins (2004) has discussed her views on stigma towards people with intellectual disabilities as both a psychiatrist working in the speciality and as a parent of a young adult with intellectual disability and noted that people with intellectual disabilities and those associated with them do not like to be too closely linked with mental illness as it is considered ‘too risky’ (even although there are higher rates of such conditions in this group). Thus people with intellectual disabilities were excluded from the Royal College of Psychiatry Stigma Campaign. However, Hollins (2004) argued that much of what was discussed could have been said about people with intellectual disabilities thus resulting in a potential double stigma.

Stigma and consequent discrimination of people with mental illness appears to have declined in recent years (Porter 2004) with celebrity figures such as Stephen Fry speaking openly about having bi-polar disorder, the popular singer Robbie Williams admitting to suffering from depression and the actress Brooke Shields discussing her post-natal depression. In addition, historical figures such as Virginia Woolf, Sylvia Plath and Vincent Van Gogh having been ascribed the symptoms of bi-polar disorder. As a consequence it is possible that stigma and the discrimination of people with intellectual disabilities may outstrip that of people with mental illness even within the health professional workforce.

Figure 1
The discriminatory process of people with the intellectual disability.
**Improving healthcare workforce attitudes**

Education of the general public and generic health professionals in particular is needed in order to overcome stigma and discrimination. This has been illustrated by ‘Death by Indifference’ (Mencap 2007) and the subsequent Independent Inquiry (Michael 2008) which noted that the situation has reached a point of crisis. Both pre-registration education and continuing professional development in this subject for all health professionals is essential if the health needs of people with intellectual disabilities are to be met (Clark & While 2008). Research and development standards in intellectual disabilities need to be similar to those of other professional groups (RCN 2004) in order achieve equality of care. Regrettably this is not the case with the extent of learning disability nursing research being described as ‘limited in quality and in its ability to provide reliable, generalizable or trustworthy insights’ (Griffiths et al. 2007).

Additionally, the decline in registered nurses specializing in learning disability (intellectual disability) and those studying for the specialty (Department of Health 2007) poses a significant challenge if the expertise and professional wisdom is to be retained for the benefit of people with intellectual disabilities. The UK Learning Disability Consultant Nurse Network 2006 set out their vision of learning disability nurses leading the way to the achievement of positive health outcomes for this client group through a collaborative approach to address barriers to social inclusion. This is perhaps overambitious given that many people with intellectual disabilities are not known to what remains of learning disability services and with the nursing specialty in decline with very limited research and development standards.

**Creating a new framework for nursing**

The need for sufficient expertise in the workforce at the point of contact is not unique to intellectual disability if care is to be of good quality. Thus we have seen the emergence of clinical nurse specialists leading nursing care delivery relating to specific disorders such as diabetes or relating to specific care issues such as incontinence. These clinical nurse specialists are complemented by nurses with special interests within ward teams or primary care teams so that competency is related to a career trajectory (UKADSN & RCN 2005). It is suggested that this ‘disorder approach’ provides a potential model for championing the care needs of people with intellectual disabilities in all areas of healthcare as a policy change alone (Department of Health 2001a) has not been effective.

An organizational ‘sea change’ is required throughout all levels of the NHS as reliance on a dwindling learning disability workforce alone will not be sufficient. Effective leadership is a key component in any change process and should encompass a three-strand approach which incorporates setting the direction, personal qualities and the actual delivery of the service (Department of Health 2001b). Promoting a radical improvement in care of people with intellectual disabilities will require a transformational approach initiated by the Government and then cascaded throughout NHS Trusts and their service provision. Michael (2008) recommended that all NHS bodies should report routinely upon what happens to people with intellectual disabilities using their services. Champions for intellectual disability will be needed at Trust Board and Directorate (or Executive Committee) level to provide leadership thus ensuring quality and safety in care delivery and, while such individuals would not necessarily need to have a good working knowledge and extensive expertise in intellectual disability, they will need to have a desire to bring about positive attitudinal service change in their organizations. These champions would have overall responsibility for education of all sections of the workforce at a variety of levels across the organization as a whole, via the Directorate level to the department and ward level or primary health care team.

Managers will need sufficient knowledge of intellectual disabilities and the essential transformational leadership skills needed to enlighten and engage staff in what is known as a ‘Cinderella’ area often neglected through stigma and discrimination. Simultaneously staff at the ward and department level will need a good working knowledge of intellectual disability and its impact upon individuals and their families together with the necessary core care skills if the quality of care experienced is to be raised. Michael’s (2008) Independent Inquiry observed that staff who did not have training in intellectual disability have a tendency to stereotype, are less likely to listen, or to believe that people with intellectual disabilities have lives worth living. Mandatory training for all health care staff (both professional and administrative) therefore needs to be competency based and applied to practice, and incorporate educational packages that address stigma, labelling, stereotyping and discrimination. Beyond the mandatory education of all staff there is a need for expert staff working as part of every staff team with sufficient knowledge and skills relating to intellectual disabilities that they can provide a resource with care
teams. It is essential that the professional regulatory bodies recognize this need and that universities develop and deliver post-initial education and postgraduate courses for health professionals.

Conclusion

The emphasis upon quality care (Department of Health, 2008) provides the opportunity to address the persistent inequalities relating to intellectual disability and the care of people with intellectual disabilities thereby avoiding another scandal (Mencap 2007) which shames the NHS. The adoption of a similar workforce framework with a recognizable career ladder relating to clinical leadership as that afforded diseases such as diabetes may offer the solution to providing sufficient expertise across the different levels of healthcare so that families of people with intellectual disabilities may be assured of high quality care of their loved ones.

The inclusion of core educational preparation for all healthcare staff both within their initial undergraduate programmes and as part of continuing professional development will be an important first step to addressing the discrimination which exists in many health services despite the espoused rights of equal citizenship for people with intellectual disabilities. It will be important to test the effect of educational packages so that future investment in education will be founded on the evidence that such packages make a difference to patients’ experience of healthcare. The health service cannot afford to invest in staff education if it does not bring about the desired outcomes for patients and service delivery. However, investment in education will need to be accompanied by system changes regarding the governance of service provision for people with intellectual disabilities.

References


