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An Intellectual Disability Outcomes Framework for improving the quality of services for people with intellectual disability

Faculty of Psychiatry of Intellectual Disability

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| Authors

Dr Sujeet Jaydeokar, Consultant Psychiatrist, Barnet, Enfield and Haringey Mental Health Trust

Dr Margherita Tanzarella, Consultant Psychiatrist, East London NHS Foundation Trust

Mr Ashley Guinn, Project Worker, Royal College of Psychiatrists

Professor Angela Hassiotis, Professor, Division of Psychiatry, University College London and Camden and Islington NHS Foundation Trust

Dr Jane McCarthy, Consultant Psychiatrist, East London Foundation Trust

Dr Ashok Roy, Chair, Faculty of Psychiatry of Intellectual Disability, Royal College of Psychiatrists

Executive summary

This report is aimed at health and social care professionals working with people with intellectual disability and commissioners with the responsibility of commissioning services for people with intellectual disability. The Winterbourne View review and the Mid Staffordshire inquiry have highlighted the importance of a safe, high-quality, person-centred service; it is also essential that the provision of such a service is cost-effective.

Although there are a number of policy and guidance documents available for local commissioners on services (in-patient or community-based) for people with intellectual disability, there is not much available in terms of outcomes, measuring value for money and outcomes frameworks. The guidance for the mental health payment by results system and clustering recommends that services collect data on three main types of outcomes: clinician-rated outcomes, patient-reported outcomes and patient-reported experiences.

Measuring outcomes is important for improving quality, and outcomes frameworks provide a context for defining relevant outcomes and performance indicators. They provide a means of accountability to the Secretary of State, commissioners and providers. They can also act as a catalyst to drive up quality by encouraging a change in culture and behaviour. With pressure on resources and funding, it is expected that not only clinical outcomes but other service-level outcomes, such as efficiency, productivity and safe practices, will be achieved.

Three outcomes frameworks are currently available: the National Health Service (NHS), public health, and social care outcomes frameworks. They contain little that is specific to people with intellectual disability. This report interprets these three outcomes frameworks into one Intellectual Disability Outcomes Framework for use in commissioning and providing services.

A literature review was carried out to identify key outcome indicators relevant to people with intellectual disability. Key points are listed below.

Literature review

Premature death of people with intellectual disability

- Circulatory disorders and cancer are the most common causes of death in people with intellectual disability.
- Lung problems caused by swallowing difficulties and epilepsy are the two most preventable causes of death.

- Delays in diagnosis and a lack of appropriate end-of-life care are contributory factors.
- People with intellectual disability and mental health difficulties are more likely to suffer from obesity, diabetes, stroke and respiratory diseases.
- Other factors linked to premature death are poor access to health services, lack of reasonable adjustments, lack of staff knowledge and poor communication.

Enhancing quality of life for people with long-term needs

- People with intellectual disability enjoy better quality of life in their home, rather than in an institution.
- Community integration is important for high quality of life, along with adaptive behaviours of the individual, successful community placements, access to daily activities or employment, and social networks.
- Self-determinism by having opportunity to make choices is an important facet of quality of life.
- Lack of attention to healthcare promotion and reduced access to quality healthcare services decreases quality of life.
- A high level of sensory impairment contributes to communication problems.
- Obesity and poor physical fitness are common problems.
- There is a need for education on healthy living and access to lifespan preventative health practices.
- A lack of social support and isolation leads to increased psychological and mental health problems.

Helping people recover from episodes of ill health or injury

- Clear commissioning arrangements and clear pathways between mainstream and specialist services are necessary.
- Measure quality of service using clinical effectiveness and patient safety as outcome measures.
- Ensure general practitioner (GP) registration, annual health checks and health action plans for people with intellectual disability.
- Promote health screening for common problems such as obesity, diabetes, cardiovascular diseases and epilepsy.
- Primary and community care services such as dentistry, optometry, pharmacy, community nursing and midwifery must be able to make reasonable adjustments.
- Reasonable adjustment in the community to promote integration.
- Identify and manage factors that affect health and quality of life.
- Ensure person-centred planning, with patient and carer involvement.

Ensuring people have a positive experience of care

- It is important that patients are treated with respect.
- Patients want to be listened to and have enough one-to-one time with staff.
- A high value is placed on choice and having a say.
- Consistency of staff teams is thought to be very important.
- Important relationship factors between staff and patients include honesty, trust, caring, and patients feeling safe.
- Staff members need good communication skills.
- There is a need for early intervention and ease of access to prevent mental health crises.
- There should be regular review and liaison among staff and multidisciplinary professionals.
- Adopt a family-centred approach.
- Ensure good interface between intellectual disability and mental health services.

Safeguarding vulnerable adults and caring for people in a safe environment

- Adults with intellectual disability are more likely to experience abuse than other vulnerable adults and adults without a disability.
- The Winterbourne View review revealed poor quality of care, long in-patient admissions, poor practices and poor monitoring of the quality of care.
- It is the responsibility of commissioners to ensure that services meet the needs of the patients in a safe environment.
- The risk of people with intellectual disability experiencing sexual abuse is often underestimated; many cases go unreported.
- Victims' poor communication skills can act as a barrier to action being taken.
- There is a huge discrepancy in responses to allegations of abuse and to victims' needs between different services.

Outcomes frameworks and domains

Following a comparison of the relevant indicators, we were able to distil the three outcomes frameworks into five domains.

- 1 Preventing people from dying prematurely.
- 2 Enhancing quality of life for people with long-term needs and improving the wider determinants of health.
- 3 Helping people recover from episodes of ill health or injury, and delaying or reducing the need for care.

- 4 Ensuring that people have a positive experience of care.
- 5 Safeguarding vulnerable adults and caring for people in a safe environment.

While developing the domains of the Intellectual Disability Outcomes Framework, we have detailed the role of specialist intellectual disability services in achieving these outcomes. For each domain of the framework there is an overarching measure/indicator. For each indicator, we have defined improvement areas and for each improvement area we have tried to identify role of the specialist intellectual disability services.

Given that services being commissioned are assessed for quality by the outcomes they achieve, an outcomes framework is the way forward. This is the first time a framework has been modified to specifically accommodate people with intellectual disability. We believe that this Intellectual Disability Outcomes Framework will provide community intellectual disability services with a structure to define their role based on the local population needs and available resources. Knowing what outcomes to aim for will allow services to define service specifications and ways to improve on these outcomes. By the same token, it will allow commissioners and providers to define key performance indicators that are relevant to people with intellectual disability. This in turn should facilitate relevant data collection and quality improvement and add value to services.

Introduction

The Winterbourne View review (Department of Health, 2012) and the Mid Staffordshire inquiry (Francis, 2013) have highlighted the need for commissioners and providers to ensure high-quality, safe, person-centred services. In the current economic climate, there is a greater scrutiny to ensure that such service provision is cost-effective.

There are a number of policy and guidance documents available for use in commissioning specialist intellectual disability services (in-patient or community-based). There are also reports and documents highlighting the service needs of people with intellectual disability. Commissioners and providers need to be cognisant of these guidance documents and use available outcomes frameworks in commissioning services. Although there are some general outcomes frameworks available for use in commissioning, they contain little that is specific to people with intellectual disability.

Outcome measures

Outcomes are measures of quality in healthcare. They are a powerful tool in the healthcare system, as they can help reduce costs and enhance value (Porter, 2010). Outcome measures should consider the health circumstances relevant to the patient (Porter, 2010). Some of the important properties for patient-based outcome measures are appropriateness, reliability, validity, responsiveness, precision, interpretability, acceptability and feasibility (Thorncroft & Tansella, 2010). Commissioners are advised to consider not just the cost of provision but quality and outcomes as well (Department of Health, 2013a). At the same time 'clinicians will need to demonstrate good outcomes to distinguish themselves in the new market of fixed prices' (Yeomans, 2014).

A statement from the Royal College of Psychiatrists (2014) on mental health and payment systems highlighted that, so far, the payment by results system has rewarded activity rather than outcomes. Compared with some other medical fields, it is difficult to define the concept of outcomes when it comes to mental health services; this is even more the case when it comes to services for people with intellectual disability.

The guidance on mental health payment by results and clustering recommends that services collect data on three main types of outcomes: clinician-rated outcomes, patient-reported outcomes and patient-reported experiences. However, without the benefit of a clearly defined outcomes framework specific to mental health or intellectual

disability services, these might still not reflect actual benefits or lack of them for patients and to the health economy in general.

Measuring outcomes is essential for improving quality. Outcomes frameworks provide a context for defining relevant outcomes and performance indicators. They provide a means of accountability to the Secretary of State, commissioners and providers. They can also act as a catalyst to drive up quality by encouraging a change in culture and behaviour. With pressure on resources and funding, services are expected to combine clinical outcomes with other service level outcomes such as efficiency, productivity and safe practice.

Outcomes and intellectual disability services

Currently there is limited guidance for commissioners on how to define the key performance indicators and outcomes they should be expecting from a service for people with intellectual disability. Anecdotal experience suggests that, although commissioners have been defining key performance indicators for commissioned services using these outcome measures, they did not always reflect actual outcomes for people with intellectual disability.

The UK Learning Disability Consultant Nurse Network worked with the National Development Team for Inclusion, the Improving Health and Lives Learning Disabilities Observatory, people with intellectual disability, family carers, service providers and commissioners to develop the Health Equalities Framework (HEF; Atkinson *et al*, 2013). The HEF measures the effectiveness of service delivery in terms of reducing exposure to the determinants of health inequalities. Although the HEF is not a condition- or syndrome-specific measure, an HEF profile can inform the development of health action plans for people with intellectual disability. Importantly, the HEF also allows the aggregation of data across populations, thus informing commissioning decisions and public health policies. The HEF measures the impact of services on five domains: social determinants, physical/mental health, communication, behaviour/lifestyles and service. These domains map directly on to most of the domains of the three outcomes frameworks and have the potential to yield population-level data.

Without an outcomes framework that is specific to people with intellectual disability and the services they receive, outcomes and key performance indicators will be inconsistent across commissioners and providers. This report interprets the three existing, non-specific outcomes frameworks and summarises the evidence base on the wider health and social care needs of adults with intellectual disability. The resultant Intellectual Disabilities Outcomes Framework is specific for people with intellectual disability and for the services that they receive. Using the principles of outcome- and value-based commissioning, the framework defines the role of specialist intellectual disability services

in achieving outcomes. It will inform commissioning decisions and service specifications for community and in-patient services.

An outcomes framework is not an outcome measure; it is an overarching framework for service delivery and evaluation. Various outcome measures and key performance indicators could be used for service evaluation, such as the Health of the Nation Outcome Scales for People with Learning Disabilities (Roy *et al*, 2002) for measuring clinical improvement and the HEF, which already maps on to the domains of various outcomes frameworks.

There are three outcomes frameworks that commissioners should be taking into consideration while commissioning local provisions (Department of Health, 2013a,b, 2014):

- NHS Outcomes Framework
- Public Health Outcomes Framework
- Adult Social Care Outcomes Framework.

These three frameworks sit at the heart of the healthcare system. Indicators in these outcomes frameworks are grouped around domains. These domains set out the national outcomes that the services should be aiming to improve. For each domain there are small numbers of overarching indicators and for each indicator there are identified improvement areas.

The NHS Outcomes Framework was developed in 2010 and reflected the vision contained in the white paper *Equity and Excellence: Liberating the NHS* (Department of Health, 2010). Its domains are related to effectiveness of care, the patient experience and patient safety.

The Public Health Outcomes Framework aims for the public health system to achieve positive health outcomes for the population. The framework focuses on increasing healthy life expectancy and reducing differences in overall and healthy life expectancy between communities. The public health indicators developed to deliver the main outcomes are grouped in four domains: improving the wider determinants of health, health improvement, health protection, and healthcare, public health and preventing premature mortality.

The Adult Social Care Outcomes Framework was published in 2011 and reflected the principles of care and support in the same white paper. The framework incorporates four domains: enhancing quality of life for people with long-term care and support needs, delaying and reducing the need for care and support, ensuring that people have a positive experience of care and support, and safeguarding people whose circumstances make them vulnerable and protecting them from avoidable harm.

In many parts of the country, community services for people with intellectual disability are spread between health and social care. Therefore, when commissioning services for people with intellectual disability, it is important to consider all three outcomes frameworks.

As considerable overlap exists in the outcomes between these frameworks, they could be usefully combined, thereby not only taking into account the structure of services but also potentially resulting in joining up the health and social care aspects of health delivery in line with the vision articulated in a Government green paper (Department of Health, 2015).

We reviewed the literature in order to identify key outcome indicators relevant to people with intellectual disability. Following a comparison of the relevant indicators, we were able to distil the three non-specific outcomes frameworks into five domains.

- 1 Preventing people from dying prematurely (NHS Outcomes Framework Domain 1, Public Health Outcomes Framework Domain 4).
- 2 Enhancing quality of life for people with long-term needs (NHS Outcomes Framework Domain 2, Adult Social Care Outcomes Framework Domain 1) and improving the wider determinants of health (Public Health Outcomes Framework Domain 1).
- 3 Helping people recover from episodes of ill health or injury (NHS Outcomes Framework Domain 3), and delaying or reducing the need for care (Adult Social Care Outcomes Framework Domain 2, Outcomes Framework Public Health Domain 2).
- 4 Ensuring that people have a positive experience of care (NHS Outcomes Framework Domain 4, Adult Social Care Outcomes Framework Domain 3).
- 5 Safeguarding vulnerable adults and caring for people in a safe environment (NHS Outcomes Framework Domain 5, Adult Social Care Outcomes Framework Domain 4).

For each domain of the Intellectual Disability Outcomes Framework, there is an overarching measure/indicator. For each indicator, we define improvement areas and for each improvement area we have identified the role of the specialist intellectual disability services.

Literature review: health outcomes for adults with intellectual disability

We reviewed the current evidence base around health needs of people with intellectual disability, looking at each of the five domains identified from the three existing outcomes frameworks.

Preventing people from dying prematurely

There have been a number of reports and enquiries into the death of people with intellectual disability. The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (Heslop *et al*, 2013) produced some important figures on death in people with intellectual disability. The most common underlying causes of death were circulatory disorders (22%) and cancer (20%), which are the same as in the general population. The most common final event leading to death is a respiratory infection (21%). However, 43% of deaths in people with intellectual disability are unexpected and 42% happen prematurely. The healthcare standards for people with intellectual disability are poor in comparison with the general population's. While 97% have one or more long-term, treatable condition (the most common being epilepsy, accounting for 43%), 30% have problems receiving treatment and 29% experience difficulty or a delay in diagnosis of the illness that eventually leads to their death. The report also found that there is a lack of recognition for when the patient is approaching end of life, leading to a lack of appropriate end-of-life care. There was poor record-keeping of health measures such as fluid intake, nutrition and weight along, and the Mental Capacity Act 2005 was not always adhered to by health and social care organisations. This significantly reduced quality of life for patients with intellectual disability approaching end of life.

Glover & Ayub (2010) examined death certificates for all deaths that occurred in England between 2004 and 2008. As a group, people with intellectual disability died earlier than the general population. Even people with intellectual disability but no physical disorder died an average of 15 years earlier than the general population. The two most common preventable causes of death were lung problems

caused by solids or liquids going down the wrong way or dysphagia (14%) and convulsions or epilepsy (13%).

Kerr *et al* (2005) looked at physical health inequalities for adults with intellectual disability and mental health problems. As well as with dying younger, this population is also much more likely to suffer from problems such as obesity, diabetes, stroke and respiratory disease. Reasons for this health disparity include social deprivation, receiving fewer health checks and diagnostic overshadowing. There was no evidence that physical health information was used in commissioning services. Kerr *et al* (2005) recommend monitoring and using this information. It also recommends delivering earlier, cost-effective intervention to reduce premature mortality. It is also important to enable access to the same standard of care that the general population receive by building robust disability access and quality standards into contracts with providers in the public, private and voluntary sectors.

Michael (2008) identified many problems that people with intellectual disability face when accessing healthcare. These include difficulty accessing health services, a lack of reasonable adjustments, patient's opinions being ignored, a lack of staff knowledge, and poor communication between intellectual disability services and other services. Several reasons were put forward for these findings:

- people with intellectual disability tend to be non-identifiable to health services;
- there is a lack of awareness of the health needs of people with intellectual disability in primary care;
- compliance with legislative framework covering disability discrimination is not effectively monitored;
- healthcare inspectors and regulators neglect the quality of service for people with intellectual disability;
- timely and appropriate reasonable adjustments are difficult to make because of a lack of knowledge and information;
- there is a lack of education and training of clinical staff on intellectual disability, which leads to a failure to deliver equal treatment.

This report led to the development of the Learning Disabilities Public Health Observatory, which aims to reduce the rate of premature death in this group.

A population-based study in Leicestershire and Rutland found that all-cause and disease-specific mortality was three times higher for those with intellectual disability than for the general population (Tyrer *et al*, 2007). The largest difference in mortality was for people in their twenties: the rate was 9 times higher in men and 17 times higher in women with intellectual disability compared with the age-matched general population. Mortality rates for this group became more similar to those for the general population in older age. This higher mortality rate in younger populations with similar mortality rates in older populations (over 40 years) was also found in a Finnish population study (Patja *et al*, 2001). This age disparity is probably due to the fact

that cardiovascular, respiratory and neoplastic diseases occur more frequently at a younger age in the intellectual disability population. Severity of intellectual disability and urban living were also associated with higher mortality.

Another issue for people with intellectual disability is admission to hospital for possibly preventable emergencies (Glover & Evison, 2013). The most common cause for this is epilepsy or convulsions, followed by constipation, diabetes, influenza and pneumonia. Glover & Evison (2013) suggest that the rate of hospitalisation of people with intellectual disability should be monitored by local services, such as an NHS information centre. Hospitals should tell GP surgeries and community nurses when someone with intellectual disability leaves hospital and people with intellectual disability admitted to hospital for convulsions or a problem related to epilepsy should be able to see a neurologist. Dean (2012) also found evidence of a higher rate of avoidable death and emergency admissions to hospitals for people with intellectual disability, despite an increase in the number of people receiving annual health checks and GPs identifying more people with intellectual disability in their practice lists. Uptake for these annual health checks varies across the country.

Summary

- Circulatory disorders and cancer are the most common causes of death in people with intellectual disability.
- Lung problems caused by swallowing difficulties and epilepsy are the two most common preventable causes of death.
- There is often a delay in diagnosis.
- There is a lack of appropriate end-of-life care.
- People with intellectual disability and mental health difficulties are more likely to suffer from obesity, diabetes, stroke and respiratory diseases.
- People with intellectual disability have poorer access to health services, and face a lack of reasonable adjustments, staff knowledge and communication.

Enhancing quality of life for people with long-term needs and improving the wider determinants of health

Quality of life

Quality of life is an important outcome measure that has become a cornerstone of good practice for intellectual disability services (Ruddick, 2005). In the past quality of life was mainly measured objectively by using variables that were thought to be important indicators of a

person's quality of life; but subjective measures of quality of life have been identified as important. The World Health Organization (1947) defines quality of life as 'a state of complete physical, mental and social well-being and not merely an absence of disease or infirmity'. However, the definition of quality of life has become multifaceted, taking into account physical, functional, emotional, social and cognitive factors along with skills development, activities, psychological well-being and spiritual attitude.

Cummins (1997) looked at measures of quality of life in people with intellectual disability and found that the most promising were the Quality of Life Questionnaire and the Comprehensive Quality of Life Scale. The scale takes into account both objective measures of quality of life (chronic medication use, frequency of physician consultation, presence of chronic disability) and subjective measures (individual perception of the importance of health and satisfaction with health). Both of these aspects of quality of life are important for service provision.

The evidence seems to suggest that people with intellectual disability enjoy greater quality of life when in their home, rather than in institutions. Donnelly *et al* (1996) interviewed 214 people with intellectual disability who were hospitalised and then followed them up 12 and 24 months after discharge. Participants were less depressed and more satisfied at both time-points compared with during their hospital stay. They also reported that community integration was important for quality of life, along with successful community placements, access to daily activities, employment, and social networks. Adaptive behaviours also correlate with better overall quality of life (McVilly & Rawlinson, 1998).

In 2002, an international panel of experts met to discuss the conceptualisation and measurement of quality of life for people with intellectual disability. Some guidelines from this study were proposed (Schalock *et al*, 2002):

- '1. Quality of life measures the degree to which people have meaningful life experiences that they value.
2. Quality of life enables people to move towards a meaningful life they enjoy and value.
3. Quality of life measures the degree to which life's domain contributes to a full and interconnected life.
4. Quality of life measurement is undertaken within the context of environments important to those with intellectual disability; where they live, work, and play.
5. Quality of life measurement for individuals is based upon both common human experiences and individual life experiences.'

Eight core domains of quality of life were identified: emotional well-being, material well-being, interpersonal relations, personal development, physical well-being, social inclusion, individual rights and self-determinism (Schalock *et al*, 2002). Self-determinism is the amount of autonomy and control one has over their own life and has

been found to positively correlate with quality of life (Wehmeyer & Schwartz, 1998).

Nota *et al* (2007) looked at a sample of 141 people with intellectual disability in Italy. They found that increased severity of intellectual disability significantly correlated with reduced self-determinism and quality of life. They also found that using community services over institutions led to increased self-determinism, and that social skills and IQ also predicted quality of life.

Nota *et al* (2007) also found that the opportunity to make choices was important for increasing both self-determinism and quality of life. The impact of choice on quality of life was looked at in more detail by Brown & Brown (2009). Two important aspects of this were the availability of opportunities in terms of breadth and familiarity along with possessing the freedom, initiative and skill to make choices. They suggest a four-step strategy to integrate choice into services.

- 1 Assess acceptance of choice into environment; ensure that the environment is conducive to opportunities to make choices.
- 2 Determine how broad and familiar opportunities can be made.
- 3 Increase freedom, initiative and skill in choice making.
- 4 Increase skill of staff and family to encourage and support choice.

It is important for services to accommodate patients with different needs and levels of disability severity. There are often methodological difficulties with collecting quality-of-life data from people with very severe intellectual disability (Ruddick, 2005). In these cases, proxy measures are often used by asking parents and carers. It has been found that, compared with carers, parents tend to give more accurate assessments of quality of life which are more in line with the patient's views (Schwartz & Rabinovitz, 2003), so their assessment of quality of life is important to take into account.

A Swedish study found that patients, their parents and caregivers tend to have similar perceptions of the quality of care and service received (Larsson & Larsson, 2001). The similarity of their perceptions could be due to the close relationships that exist between the patient, their parents and their caregivers.

Determinants of health

There is a disparity between the health of people with intellectual disability and the health of the general population. Factors such as a higher prevalence of associated conditions, inadequate attention to healthcare needs by carers, lack of attention to healthcare promotion for this group, and reduced access to quality healthcare services have led to unacceptable levels of poor health for people with intellectual disability (Krahn *et al*, 2006).

Treatable conditions commonly go untreated in people with intellectual disability (Sutherland *et al*, 2002). This can be a result of a lower frequency of health screening, atypical presentations of

symptoms and behavioural/communication problems. Furthermore, a lack of health-promoting behaviours, such as good diet and living arrangements and physical activity, can lead to higher morbidity and mortality.

A study examining GP databases found that people with intellectual disability were 2.5 times more likely to have a health problem than people without intellectual disability (van Schrojenstein Lantman-De Valk *et al*, 2000). The most prevalent illnesses were congenital abnormalities, epilepsy and musculoskeletal disability. This study also found that neurological and psychological illness was more common in people with intellectual disability, as were ear and eye problems and general or unspecified illnesses. It was also noted that sensory impairments, which could contribute to communication problems, were much more common in those with intellectual disability.

Obesity and poor physical fitness are also a common problem (Bittles *et al*, 2002). In a sample of 30 adults with mild to moderate intellectual disability, 50% of men and 70% of women were overweight and cardiorespiratory fitness was below the average for the general population (Messent *et al*, 1998).

A report on healthy aging in adults with intellectual disability also offered some relevant recommendations (Evenhuis *et al*, 2001). It recommends taking a worldwide perspective on healthy aging and intellectual disability. Health professionals should take a lifespan approach in order to recognise the progression and consequences of specific diseases and provide effective treatment. People with intellectual disability require expert care to identify developmental disabilities such as epilepsy, cerebral palsy, autism and visual disorders. Education needs to be provided to people with intellectual disability and their carers on healthy living (e.g. nutrition, exercise, oral hygiene, avoiding risky behaviour). They should have access to the same lifespan preventative health practices as the general population. Regular screening for visual and hearing impairments is needed. Psychiatric conditions can have atypical presentations in this population and often go undetected (Gustavson *et al*, 2005). Older-age-at-onset medical conditions are very common in this population, so health professionals should be more alert about detecting them.

Summary

- People with intellectual disability enjoy better a quality of life in the community than in institutions.
- Community integration is important for quality of life, along with successful community placements, access to daily activities, employment, social networks and adaptive behaviours.
- Self-determinism and the opportunity to make choices are important to quality of life.
- There is a lack of attention to healthcare promotion and reduced access to quality healthcare services with resultant poor quality of life.

- A high level of sensory impairment in this group contributes to communication problems.
- Obesity and poor physical fitness are common problems.
- There is a need for education regarding healthy living and better access to lifespan preventative health practices.

Helping people recover from episodes of ill health or injury, and delaying or reducing the need for care

The Joint Commissioning Panel for Mental Health (2013) made some key recommendations to commissioners. It was acknowledged that it can be difficult for people with intellectual disability to access mental health services. At the same time, reasonable adjustments for this group are a legal requirement under the Equality Act 2010. Therefore, clear commissioning arrangements and clear pathways between mainstream and specialist services are needed to help improve access to healthcare services for people with intellectual disability. This report also indicated that it is important to measure the quality of services from the patient's, family's and carer's perspectives. Clinical effectiveness and patient safety were identified as particularly important outcomes. It is also important to provide support and advice during transition between services. Commissioners should work closely with primary care, acute care and public health services in order to provide a successful person-centred service in which treatment is based on a good understanding of the individual and their experiences and needs.

A joint report by the Learning Disabilities Observatory, the Royal College of General Practitioners and the Royal College of Psychiatrists (2013) contained an evidence-based commissioning guide for clinical commissioning groups (CCGs). Aimed specifically at primary care, it recommended that a person with intellectual disability receive health screening along with health promotion for common problems such as obesity, diabetes, cardiovascular diseases and epilepsy. Primary and community care services such as dentistry, optometry, pharmacy, community nursing and midwifery must be able to make reasonable adjustments. Furthermore, the usage and experience of people with intellectual disability using these services should be monitored. There also needs to be improved identification of intellectual disability users in acute settings via a designated intellectual disability liaison function.

To gain independence following an episode of ill health, it was important that the individuals with intellectual disability, along with their family and carers, were involved in service-planning and decision-making across services (Learning Disabilities Observatory *et al*, 2013).

People with intellectual disability have the right to have reasonable adjustments made so they can access local amenities, transport and

cultural and sports/leisure facilities in their community. Additionally, there needs to be better support for getting people with intellectual disability into employment. Less than 10% of people with intellectual disability in the UK are in employment (South London and Maudsley NHS Foundation Trust & South West London and St George's Mental Health NHS Trust, 2010; Public Health England, 2014). Making adjustments would enable better integration into the local community and allow people with intellectual disability to lead more socially inclusive lives. To this end, staff should promote choice and encourage patients to take control of their lives and gain independence, rather than set limitations (South London and Maudsley NHS Foundation Trust & South West London and St George's Mental Health NHS Trust, 2010).

Suicide is a common yet overlooked problem in intellectual disability populations. Lunsky (2004) interviewed 98 adults with intellectual disability and found 11% had attempted suicide. In 23% of these cases, the person's carers were unaware of their suicidal ideation. Factors linked to increased suicide ideation were stress, anxiety, depression, loneliness and lack of social support. Merrick *et al* (2006) also found loneliness, depression and anxiety to be significant risk factors, along with prior psychiatric hospitalisation and having a physical disability. They recommended that interventions should focus on detecting these risk factors and reducing their impact on the person's life. Other intervention methods include therapy for depression and anxiety and setting up a crisis plan agreed by the patient, caregiver and service provider.

It is likely that, with proper interventions, people with intellectual disability can have a similar life expectancy as the general population (Janicki *et al*, 1999). Cooper *et al* (2006) offered 50 people with intellectual disability a health screening intervention and compared them with 50 people with intellectual disability who were offered standard treatment (no intervention). A higher level of health needs was identified in the intervention group, which displayed more health-promoting behaviours and had more health monitoring needs met.

Krahn *et al* (2006) synthesised recommendations from different countries into five guidelines for reducing inequality in the healthcare of people with intellectual disability: promoting principles of early detection, inclusion into quality healthcare services, reducing occurrence of associated conditions, empowering caregivers to meet their health needs, and promoting healthy behaviours.

The Commission for Social Care Inspection *et al* (2009) reviewed nine areas in the UK to investigate how well people with intellectual disability and complex needs were being supported by services. There were some positive findings, for instance that person-centred planning could transform lives because the services met the needs and expectations of patients. Some new contracts required evidence of improved outcomes and there was a move away from large-scale care to more flexible patterns based on the needs of the individual. However, they also found there was a lack of information on available

services and patients had difficulty accessing services. This was because few people had health action plans or access to a health facilitator and patients received too few or no annual health checks from a doctor. Access to and the quality of treatment provided by mental health services was particularly poor and patients and carers reported poor experiences of using these services. There was also a lack of safeguarding arrangements at primary care trusts for adults with intellectual disability and complex needs. It was again identified that improvement was needed in staff competencies and attitudes in dealing with adults with intellectual disability and complex needs. Overall, the report recommended offering personalised services shaped around patients' needs and that the Care Quality Commission should take on board reported recommendations and implement the delivery plan stated in the *Valuing People* report (Department of Health, 2001). Health action plans should follow health checks and be done through primary care and GP practices.

Summary

- Clear commissioning arrangements and clear pathways between mainstream and specialist services are necessary.
- Quality of service should be measured using clinical effectiveness and patient safety as outcome measures.
- Ensure GP registration, annual health checks and health action plans for people with intellectual disability.
- There is a need for health screening, along with health promotion, for common problems such as obesity, diabetes, cardiovascular disease and epilepsy.
- Primary and community care services such as dentistry, optometry, pharmacy, community nursing and midwifery must be able to make reasonable adjustments.
- Reasonable adjustment should be made in the community to promote integration.
- Identify and manage the risk factors that have an impact on health and quality of life.
- Focus on person-centred planning along with patient and carer involvement.

Ensuring that people have a positive experience of care

It is important for people with intellectual disability to be involved in service evaluation and outcome measures. However, research into patient experience with intellectual disability services is somewhat lacking, probably because interviewing and gathering relevant information can be difficult. Despite this, studies have found patients with intellectual disability can give useful and reliable feedback on services (Dagnan *et al*, 1994; McVilly, 1995; Larsson & Larsson, 2001).

Dagnan *et al* (1994) found that overall satisfaction was linked to being able to see a professional, a feeling of being listened to and important topics being discussed. McVilly (1995) interviewed clients with moderate to severe intellectual disability and found that, although interviews were not easy, important provisions were identified by patients. These included staff supporting family ties, facilitating the development of friendships and providing support and information regarding medication, healthcare and finance.

Miller *et al* (2008) interviewed patients and ran focus groups to investigate outcomes that were valued by people with intellectual disability, across three domains: (a) maintenance (supporting quality of life); (b) process (how service is delivered by staff); and (c) change (making things better). In terms of quality of life, important outcomes included activity levels, social contact, having things to do, safety (protection from abuse), and health and well-being (healthy eating and physical activity). These outcomes could be negatively affected by staff shortages and high staff turnover. Untreated health problems could result from staff shortages. For service delivery, it was important for patients to be treated with value and respect. Patients wanted to be listened to and have enough one-to-one time with staff. A very high value was placed on choice and having a say. Services should also be reliable and responsive to patients' needs. Important outcomes based on change included reducing symptoms, increasing mobility and providing opportunities to learn new skills and live independently.

Staff employed by services have an important impact on patient experience. Clarkson *et al* (2009) interviewed 11 adults with intellectual disability and found that a consistent staff team was important to the patients. Key staff–patient relationship factors included honesty, trust, caring and enabling patients to feel safe. On the other hand, traits such as immaturity, inexperience and short-temperedness led to a feeling of discontent by patients.

Feedback from people with intellectual disability in residential services indicates that less restrictive environments lead to improved quality of life. Murphy *et al* (1996) found that patients liked to gain help from staff and enjoy receiving therapy and education but did not like restrictions of their freedom, such as locking their front door or the use of seclusion or restraint.

Kroese *et al* (2013) carried out semi-structured interviews to find out what patients with intellectual disability and a mental health condition thought of mental health services. Staff who worked for intellectual disability services were also interviewed. Focus groups were formed and the interviews were analysed by interpretative phenomenological analysis. The study placed themes under two headings: desirable staff qualities and quality of services. Desirable staff qualities included a genuine interest in working with patients, building up trusting relationships, good communication skills and being honest yet sensitive. Staff should also be aware of relevant background information on the patient's condition. Themes for quality of services included early

intervention and easy access to prevent mental health crises, regular reviews and liaison between staff and multidisciplinary professionals, adopting a family-centred approach, looking after staff (to reduce paperwork and increase productive use of time) and the provision of relevant, ongoing staff training and supervision. Inadequate interface between intellectual disability and mental health services was a theme. This can lead to the person with intellectual disability being unable to access mental health services or receiving a disjointed package of support.

Generic mental health services were found to be the least accessible for people with intellectual disability, especially memory clinics and Improving Access to Psychological Therapies (Kroese *et al*, 2013). To improve this, the authors suggested local referral policies be revised to avoid breaching the disability discrimination legislation. They also suggested that systemic therapy be offered, so that family members can become more involved in treatment.

Summary

- It is important for patients to be treated with value and respect.
- Patients want to be listened to and have enough one-to-one time with staff.
- Patients place a high value on choice and having a say.
- Consistent staff teams are thought to be very important.
- Key staff–patient relationship factors include honesty, trust, caring, and enabling patients to feel safe.
- Staff need good communication skills.
- There is a need for early intervention and easy access to services to prevent mental health crisis.
- There should be regular review and liaison among staff and multidisciplinary professionals.
- Good interface is necessary between intellectual disability and mental health services.
- Services should adopt a family-centred approach.

Safeguarding vulnerable adults and caring for people in a safe environment

Safeguarding is an integral part of patient care, and includes a spectrum of activities that involve multi-agency responses where abuse or harm occurs. Abuse is defined as any violation of an individual's human and civil rights by any other person and can be broken down into physical abuse, sexual abuse, psychological abuse, financial abuse, and neglect. Discriminatory abuse includes racist and sexist abuse and abuse based on a person's disability.

Protection for people with intellectual disability is important in long-stay settings, as institutional abuse can occur, as highlighted by the Winterbourne View case. The Department of Health's (2012) review found that opportunities to reveal poor standards of care were repeatedly missed by multiple agencies. The review found:

- a high number of recorded physical interventions
- evidence of poor-quality healthcare with routine medical problems not attended to
- limited patient access to advocacy
- complaints were not dealt with
- patients were placed in hospital for assessment and treatment for too long
- a lack of care planning and poor-quality care
- a lack of activities for patients
- a reliance on restraint.

The review highlighted the responsibility of commissioners to ensure that services meet the needs of individuals, their families and carers, with a focus on personalisation and prevention.

Adults with intellectual disability are more likely to experience abuse than adults without a disability (Horner-Johnson & Drum, 2006) and other vulnerable adults (Beadle-Brown *et al*, 2010). The most common form of abuse this group is exposed to is physical abuse (Strand *et al*, 2004; Beadle-Brown *et al*, 2010), although sexual abuse is also a prevalent problem (Beail & Warden, 1995; Peckham, 2007). People with intellectual disability can experience abuse within the community: 88% of people are bullied per year, 32% are bullied daily or weekly and 23% have been physically assaulted (Beadle-Brown *et al*, 2014). They are also vulnerable to being taken advantage of financially and being drawn into cultures of drugs and alcohol and gang-related activities. Violence is also common between patients and caregivers or support staff and can be perceived as a normal part of care, especially if the patients display challenging behaviour (Strand *et al*, 2004).

The risk of people with intellectual disability experiencing sexual abuse is often underestimated as many cases go unreported. People with intellectual disability are more likely to have no point of reference to judge motives and they are less likely to make a complaint (Brown *et al*, 1995). Additionally, there is a lack of support for victims (Hames, 1996) and isolation of a service increases the risk of physical and sexual abuse of people within that service (Beadle-Brown *et al*, 2010).

According to the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (Heslop *et al*, 2013), only 11% of their sample of 247 people with intellectual disability had concerns related to safeguarding investigated and 20% raised safeguarding concerns that were not investigated. The report found some evidence that action was being taken to improve safeguarding policies but that, overall, not enough was being done.

Joyce (2003) reviewed 2 years of case notes on sexual abuse cases involving adults with intellectual disability and found many barriers to action being taken. For example, victims often lacked the communication skills to adequately describe what had happened to them. The victim's poor communication skills also meant that staff did not take allegations of abuse seriously (Hollomotz, 2012). Furthermore, investigative interviews with the police can be difficult to complete, leading to low prosecution rates. Victims were not often offered therapy or any form of follow-up after being abused.

Several reports have been published on safeguarding vulnerable adults, including those with intellectual disability. The Commission for Social Care Inspection (2008) investigated the safeguarding arrangements of councils and care services across England. It found that there was little consistency in the support given to abused adults and uneven progress, with a big gap between the best and worst services. Other reports (Healthcare Commission & Commission for Social Care Inspection, 2006; Michael, 2008) on services have raised safeguarding concerns such as staff lacking knowledge of safeguarding issues and the reporting process. Monitoring of safeguarding practice and audit trails of safeguarding decisions were generally poor. Moreover, safeguarding responsibilities were often unclear and contract specifications did not address safeguarding specifically.

Lund (2011) highlighted a need for improved access to prevention and intervention programmes. There was a need for increased collaboration between domestic violence services and disability services. Any intervention programmes should be culturally sensitive and rigorously tested.

Summary

- Adults with intellectual disability are more likely to experience abuse than adults without a disability and other vulnerable adults.
- The Winterbourne View review identified poor-quality care, long in-patient admissions, poor practices and poor monitoring of the quality of care.
- It is the responsibility of commissioners to ensure that the services met needs of the patients in a safe environment.
- The risk of people with intellectual disability experiencing sexual abuse is often underestimated, as many cases go unreported.
- Victims' poor communication skills are a barrier to action being taken.
- Response to allegations of abuse and to victims' needs differs widely between services.

Intellectual Disability Outcomes Framework

Domain 1 Preventing people from dying prematurely^a

Overarching measure and indicator	Outcome measure and improvement areas	Role of specialist intellectual disability services
Potential years of life lost from causes considered amenable to healthcare	<p>Reduce premature mortality from the major causes of deaths in people with intellectual disability</p> <p>Reducing premature death in adults with intellectual disability and serious mental illness/challenging behaviour</p>	<ul style="list-style-type: none"> Supporting primary, secondary and specialist health services with reasonable adjustment, accessible communication Healthcare coordination for people with complex and multiple health needs Facilitate access to mainstream healthcare services Healthcare advocacy Facilitate access and joint working with generic, specialist and in-patient mental health services and out-of-hours/emergency mental health services so that skills, expertise and resources from these services could be utilised Ensure and support monitoring of physical health of people with intellectual disability and mental health/challenging behaviour Health promotion Where appropriate, joint working with community paediatric services
	Reducing deaths in babies and young children with intellectual disability	

a. NHS Outcomes Framework Domain 1 (Department of Health, 2013a), Public Health Outcomes Framework Domain 4 (Department of Health, 2014).

Domain 2. Enhancing quality of life for people with long-term needs and improving the wider determinants of health ^a		
Overarching measure and indicator	Outcome measure and improvement areas	Role of specialist intellectual disability services
Quality of life related to health and social care for people with intellectual disability and long-term conditions	Ensuring people feel supported to manage their condition	<ul style="list-style-type: none"> ● Person-centred planning of care and support needs ● Ensure self determination by providing opportunities to make choices
	Improving functional ability in people with intellectual disability and long-term conditions	<ul style="list-style-type: none"> ● Enhancing independent living skills and activities of daily living ● Enhance access to appropriate day and leisure opportunities ● Health promotion
	Reducing time spent in hospital	<ul style="list-style-type: none"> ● Hospital inreach services ● Healthcare coordination for people with complex physical healthcare needs
	Enhancing quality of life for carers	<ul style="list-style-type: none"> ● Ensuring access to information and advice about support available, including respite care
	Enhancing quality of life for people with intellectual disability and mental illness/ challenging behaviour	<ul style="list-style-type: none"> ● Ensuring access to appropriate day opportunities ● Managing people in the community or appropriate setting ● Skilled long-term support to enable people to live as independently as possible in the community ● Improved access to healthcare services
Admissions to hospital or permanent admissions to residential and nursing care homes due to placement breakdowns	Enhancing quality of life for people with intellectual disability and dementia	<ul style="list-style-type: none"> ● Ensuring people with dementia receive a timely diagnosis and the best available treatment and care with a clear pathway
	Improving outcomes from planned interventions	<ul style="list-style-type: none"> ● Single care pathway, early diagnosis and intervention ● Multidisciplinary team intervention ● Use of care programme approach framework where appropriate ● Facilitate discharge from the hospitals ● Enhanced input to prevent placement breakdowns ● Ensure access to primary care through health advocacy and liaison
	Helping people with intellectual disability to recover their independence after illness or injury	<ul style="list-style-type: none"> ● Healthcare coordination for people with complex physical healthcare issues ● Supporting primary healthcare, rehabilitation and enablement services in providing care to people with intellectual disability ● Supporting social care providers in making reasonable adjustments to ensure proper integration into the community
Reduce the delayed transfer of care from hospitals and reduce delays that are attributable to adult social care	<ul style="list-style-type: none"> ● Effective multi-agency working and coordination to prevent delayed discharge ● Active involvement and coordination in the discharge planning process between community and in-patient services ● Working jointly with commissioners to ensure clear care pathways between mainstream and specialist services 	

a. NHS Outcomes Framework Domain 2 (Department of Health, 2013a), Public Health Outcomes Framework Domain 1 (Department of Health, 2014)

Domain 3. Helping people recover from episodes of ill health or injury, and delaying or reducing the need for care ^a		
Overarching measure and indicator	Outcome measure and improvement areas	Role of specialist intellectual disability services
Admissions to hospital or permanent admissions to residential and nursing care homes because of placement breakdowns	Improving outcomes from planned interventions	<ul style="list-style-type: none"> ● Single care pathway, early diagnosis and intervention ● Multidisciplinary team intervention ● Use of care programme approach framework where appropriate ● Facilitate discharge from the hospitals ● Enhanced input to prevent placement breakdowns ● Ensure access to primary care through health advocacy and liaison
	Helping people with intellectual disability recover their independence after illness or injury	<ul style="list-style-type: none"> ● Healthcare coordination for people with complex physical healthcare issues ● Supporting primary healthcare, rehabilitation and enablement services in providing care to people with intellectual disability ● Supporting social care providers in making reasonable adjustment to ensure proper community integration
	Reduce the delayed transfer of care from hospitals and reduce delays that are attributable to adult social care	<ul style="list-style-type: none"> ● Effective multi-agency working and coordination to prevent delayed discharges ● Active involvement and coordination in the discharge planning process between community and in-patient services ● Working jointly with commissioners to ensure clear care pathways between mainstream and specialist services

a. Adult Social Care Outcomes Framework Domain 2 (Department of Health, 2013b), NHS Outcomes Framework Domain 3 (Department of Health, 2013a), Public Health Outcomes Framework Domain 2 (Department of Health, 2014).

Domain 4. Ensuring that people have a positive experience of care ^a		
Overarching measure and indicator	Outcome measure and improvement areas	Role of specialist intellectual disability services
Patient experience of care and support services including healthcare services	Patient experience of out-patient care	<ul style="list-style-type: none"> Reasonable adjustments to improve access Accessible communication Training to improve staff competency in dealing with people with intellectual disability Person-centred care
	Patient experience of hospital care and accident and emergency services	<ul style="list-style-type: none"> Reasonable adjustments to improve access Accessible communication Provide training Liaison with acute hospital services
	Improving access to primary care	<ul style="list-style-type: none"> Supporting primary care with health action planning Supporting primary care with reasonable adjustment, accessible communication, etc.
	Improving the experience of care at the end of life	<ul style="list-style-type: none"> End-of-life care pathways for people with intellectual disability based on national guidelines
Improving experience of healthcare for people with intellectual disability and mental illness/challenging behaviour		<ul style="list-style-type: none"> Accessible communication Waiting times Person-centred care To ensure good interface between generic mental health services and early intervention and emergency services
		<ul style="list-style-type: none"> Ensure multi-agency transition care pathways Carer involvement and engagement in service delivery and service development
Improving experience of transition services		
Improving carers' experience		

a. Adult Social Care Outcomes Framework Domain 3 (Department of Health, 2013b), NHS Outcomes Framework Domain 4 (Department of Health, 2013a).

Domain 5. Safeguarding vulnerable adults and caring for people in a safe environment ^a		
Overarching measure and indicator	Outcome measure and improvement areas	Role of specialist intellectual disability services
Patient safety incidents including those involving severe harm or death	Reducing the incidence of avoidable harm	<ul style="list-style-type: none"> ● Ensure clinical and practice governance ● Care programme approach processes where appropriate ● Quality assurances through regular audits and quality improvement projects ● Incident reporting and learning from incidents
	Delivering safe care to people with intellectual disability in acute settings	<ul style="list-style-type: none"> ● Health advocacy on behalf of people with intellectual disability ● Training of acute healthcare staff in understanding needs of people with intellectual disability ● Close working and liaison with acute health services
	People are free from physical and emotional abuse, harassment, neglect and self-harm	<ul style="list-style-type: none"> ● Ensure effective safeguarding processes in the service ● Incident reporting ● Active joint working between the in-patient and community services to reduce length of stay in hospital ● Working with commissioners to ensure person centred care in the in-patient and community services ● Liaison and joint working with other agencies (e.g. police, domestic violence unit)

a. Adult Social Care Outcomes Framework Domain 4 (Department of Health, 2013b), NHS Outcomes Framework Domain 5 (Department of Health, 2013a), Public Health Outcomes Framework Domain 3 (Department of Health, 2014).

| Conclusions

Given that the quality of services is assessed on the basis of the outcomes they achieve, defining an Intellectual Disability Outcomes Framework specific to intellectual disability services is an important step. This is the first time an outcomes framework that specifically addresses the needs of people with intellectual disability has been proposed. We believe that this Intellectual Disability Outcomes Framework will allow services to define their role based on local population needs and available resources. Knowing what outcomes to aim for will allow services to define standards and develop ways to improve these outcomes. By the same token, it will enable service providers and commissioners to agree key performance indicators that are relevant to people with intellectual disability. It will also allow commissioners and service providers to evaluate service delivery based on specific outcomes achieved. This in turn should facilitate relevant data collection, quality improvement and improvement in the cost–benefit ratio of the services provided (Lee, 2010). This report has not attempted to identify specific clinical outcome measures or define ways to measure outcomes; rather, it proposes key outcome domains that intellectual disability services should be measuring and achieving.

While the Intellectual Disability Outcomes Framework defines the possible role of specialist intellectual disability services in achieving these outcomes, when using this outcomes framework to commission services it is essential that these outcomes are embedded in regulatory and monitoring requirements for all services, not just specialist intellectual disability services. The Intellectual Disability Outcomes Framework, if used along with specific measures such as the HEF and the Health of the Nation Outcome Scales for People with Learning Disability, along with other measures of safety and user experience, will support effective, outcomes-based commissioning.

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