



# **Learning Disability Professional Senate**

## **Rights and Equality Based Outcomes for Learning Disability Services**

### **Introduction**

#### **The professional senate**

The professional senate aims to provide a single voice through which we can lead and inform NHS England, the Department of Health and other strategy leads about the needs of children and adults with learning disabilities. It brings together professional leaders from across the UK, to provide a collective voice of specialist health and social care practitioners, and provide leadership back to those practitioners.

#### **Aim**

We have produced this document to help professionals choose and develop appropriate outcome measures to use in everyday practice. The document is set against the current context of service structure and provision in England but has application for professionals working with people with learning disabilities and their families across the UK.

#### **Outcome Measures**

Outcome measures are an indicator of quality in health and social care systems; they are powerful tools that allow us to evaluate the delivery of services. Measuring outcomes can be misleading if the measures used are not appropriate, reliable, valid, and precise. It is important that outcome measures used are acceptable and feasible in a busy health and social care system. Health and care services are complex and the effectiveness of such systems can be measured in a number of different ways. A good health and care service needs to be outcome focussed; a service for people with learning disability should ensure positive outcomes for all the stakeholders, including individuals with learning disability, their support network, providers, and commissioners. It is important that any service is cost effective and provides value for money. Services also need to ensure that a positive outcome is achieved for most, within the resources available, and not just a few.

## **Policy Context**

From a health and social care services point of view, it is important that outcomes are delivered within current national frameworks and there should be a way to measure whether services are delivering outcomes within those frameworks; this requires outcome data that can be systematically collected and aggregated. At the same time there needs to be consideration to health economics and how those outcomes were achieved; a high quality service would achieve positive outcomes for most within available resources, The Royal College of Psychiatrists have produced a document describing an outcomes framework for improving quality of services for people with learning disabilities (Royal College of Psychiatrist, FR/ID/07). It highlights the role of specialist community services in delivering within the overarching domains of the national outcomes frameworks. The UK Consultant Nurse Network has developed the Health Equalities Framework (<http://www.ndti.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1/>) which measures the effectiveness of services in reducing exposure to the known determinants of Health Inequalities for people with learning disabilities and is cross referenced to the NHS, Social Care and Public Health Outcomes Frameworks. The Professional senate has also produced the document 'Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers' which specifies the role of specialist services. These documents can help form the basis of any key performance indicator data. Finally, the more commonly understood role of outcomes measure is to measure an outcome of an intervention for an individual; we are familiar with clinical outcome measures that are widely available across different professional groups.

These approaches allow us to measure the quality of services, however it is also essential to ensure the protection of rights of people with learning disabilities; we recommend that the protection of Rights and Equality of an individual are important elements on which to base overall assessment of outcome. Achieving symptom relief becomes a pointless measure of success if it was at the expense of quality of life.

## **Outcomes and Rights**

Historically outcomes were conceptualised as clinical outcomes based on a traditional medical model. More recently, a social paradigm of disability has been at the forefront of understanding outcomes. The medical model conceptualises that a disabled individual has a condition (a deficit which is unwanted or which in the past caused something unwanted in the individual); outcomes frameworks that were solely based on this model do not always take into account individuals rights based on liberty, dignity, equality, and entitlement. The social paradigm of disability no longer resides within the individual, but in the 'social, attitudinal, architectural, medical, economic, and political environment' that has failed to adapt to the disparate needs of the community. Again, using such a model exclusively when defining an outcomes framework would be likely to create a false sense of not needing to measure outcomes of therapeutic or clinical interventions. We believe that the best approach to selecting outcome measures is to use a human rights framework with underlying notions of liberty, dignity, equality and entitlement. This is because people with learning disabilities experience inequities across health and social domains, and the human rights of people with learning disabilities are still being ignored. We also need to bring a sociological perspective when defining the outcomes that we want to achieve; inherent socio-cultural, attitudinal, and social hierarchical issues have a significant impact on the way disability gets perceived and how what constitutes a good outcome gets defined.

If we take a Rights and Equality based approach to measuring outcomes for individuals with learning disabilities, and use it as a set of core principles in the delivery of health and social care services, it has the potential to establish services which are truly person centred. It would also effectively address sociological issues of attitudes and discrimination. It would ensure high quality services for individuals with inequalities minimised.

Taking this approach not just ensures delivery against the national outcome frameworks and national policy drivers, such as Building the Right Support; it actively builds on these. A Rights and Equality based approach will not just ensure that outcomes are achieved without violation of any rights but it also ensures that the outcomes achieved are appropriate for individuals and their families.

Below, we have listed a set of Rights and Equality based principles; when measuring outcomes and effectiveness of service delivery, there are two aspects that professionals and teams need to consider:

1. Do the outcomes you are working towards meet the principles below?
2. Do you use outcome measures that are in line with these principles?

## **Rights and Equality Based Outcomes for People with a Learning Disability**

The following principles have been derived from the Human Rights Act, the Equalities Act, the European Convention on the Rights of the Disabled, the UN Convention on the Rights of the Disabled, the NHS England service Model (Building the Right Support), current Department of Health policy development along with existing outcome measures.

The majority of these principles apply to both children and adults although some are more applicable to adults.

### **Rights and Equality Principles for Measuring Outcomes**

#### **I am respected:**

I am recognised and respected as the person I am  
I am free from discrimination and my difference is recognised, accepted and respected

#### **I am safe:**

I am free from abuse and harm  
I am free from degrading, inhuman or cruel treatment  
I am treated fairly by the criminal justice system

#### **I make choices:**

I am supported to be understood and to understand the world around me and the choices I have. I have information that I understand to help with this  
My choices and opinions are respected (even if others do not agree)  
I am supported to participate in democratic processes

#### **I have a place of my own:**

I live in the community of my choice, with privacy and contact with those I choose  
My living standard is adequate for my needs  
I am supported to be part of my community and culture  
I have possessions and property that are my own and are respected  
I am able to go where I want

**I am active:**

I am supported to develop and learn

I have opportunities to engage in meaningful activities, including work

I have time and support to rest and relax and to do things that help with this

**I have fulfilling relationships**

I have a range of relationships of my choosing including personal and intimate relationships

My rights to family life are recognised and supported including marriage

**I am supported to access services – which are reasonably adjusted to meet my needs**

My health needs are met / managed in a way that reduces likely inequality and reflects my choice

My social care needs are met / managed in a way that reduces inequality and reflects my choice

My psychological and emotional needs are met / managed in a way that reduces inequality and reflects my choice

**Applying the Rights and Equality principles to the role and function of Community Teams for People with Learning Disabilities (CTPLDs)**

The previous senate document (Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers) describes the five key functions of Learning Disability teams.

- Supporting positive access and responses from mainstream services
- Targeted work with individuals and services enabling others to provide effective person centred support
- Specialist direct clinical therapeutic support for people with complex behavioural and health needs
- Responding positively and effectively to crisis presentations and urgent demands
- Quality assurance and strategic service development in support of commissioners

This document links these functions with the Rights and Equalities principles above, and gives illustrative examples.

## 1. Supporting positive access and responses from mainstream services

### Example

Cancer screening nurses in Cornwall work with local screening services to put reasonable adjustments in place, making it easier for people with learning disabilities to use them. The best data the nurses have on impact is in relation to breast screening from one of the screening centres in Cornwall. In 2011, the uptake of breast screening by eligible women in the general population was 75%, whereas for women with learning disabilities, the uptake was only 36%. In 2013, the attendance rate for breast screening by women with learning disabilities was 77%, with those that actually achieved screening being 70%. Meanwhile the uptake in the general population remained at 75%

**Relevant principles:** I am respected, I am safe, I make choices, I have access to services,

## 2. Targeted work with individuals and services enabling others to provide effective person centred support

### Example

An individual receiving treatment from the CTPLD for eating and drinking difficulties now needs to attend an acute hospital for a videofluoroscopy.

The CTPLD:

- supports the acute service to provide information about the process in an accessible format, such as easy read information, film of the clinic or visit to look around.
- provides information about the individual's communication needs to support capacity and consent and their involvement in the appointment
- attends the clinic to support any reasonable adjustments required
- contributes to the management plan to ensure reasonable adjustments are made and the plan supports the wider needs of the individual

**Relevant principles:** I am respected, I am safe, I make choices, I have access to services,

## 3. Specialist direct clinical therapeutic support for people with complex behavioural and health needs

### Example

A CTPLD received a referral for a man with learning disabilities who had recently moved into the area following a number of admissions to assessment and treatment units. He had a long history of engaging in behaviours that challenge, including some risk behaviours which had resulted in him going through the Criminal Justice System. There was a history of numerous placement breakdowns and previous interventions had largely involved restrictive practices. There was considerable concern

about the capability of the staff in his new community home to support him.

The CTPLD completed an assessment with the man using a Positive Behaviour Support framework, from which a formulation and Positive Behaviour Support Plan were developed. The formulation highlighted that the man's needs had not previously been well understood, and the plan outlined a number of strategies for the man and the staff to help manage his anxiety, communicate effectively with him and help him stay occupied. The CTPLD used the formulation as a basis for stopping the medications the man had historically been prescribed for his behaviour. Outcomes for the man included an increased range of meaningful activities, more positive relationships, greater confidence from others that he could be supported in his new home, a reduction in the use of restrictive practices and a reduction in the frequency of behaviours of concern to nearly zero.

**Relevant principles :** I am respected, I am safe, I make choices, I have a place of my own, I am active, I have fulfilling relationships

#### **4. Responding positively and effectively to crisis presentations and urgent demands**

##### **Example**

##### **Responding positively and effectively to crisis presentations and urgent demands**

When Omar moved to a new area with his parents, the severe challenging behaviour that had significantly reduced in his previous area, returned with greater intensity. He was excluded from his new school and the short-breaks provision. The new Local Authority and Health Trust proposed placement at a residential school, or inpatient assessment, both more than 250 miles away.

Omar's new Community Nurse, Paediatrician and parents linked with the service in Omar's previous area that had developed a Positive Behaviour Support Plan. The previous service had adopted Sussex Partnership Trust's measures and methods for PROMS, PREMS and CROMS, and Behaviour Grids (see references), which supported the Positive Behaviour Support plan. They advised on elements of the plan which needed particular attention - leisure activities, dental check using the preparation plans which had worked before.

Through the use of a personal budget the new area funded additional support time to implement these plans. This revealed that Omar had a dental abscess which was treated. The positive outcomes (going to the park, activities at school, home and short-breaks) persuaded the Local Authority and Health Trust that Omar could return to school and short-breaks service which was successful.

**Relevant Principles:** I have a place of my own; I am active; I have fulfilling relationships; I have access to services that are reasonably adjusted

#### **5. Quality assurance and strategic service development in support of commissioners**

##### **Example**

In order to improve the quality of health and social care services offered to parents with learning disabilities and their children, an occupational therapy manager in Dorset set up a service development project. By working across the NHS Community Learning Disability Team and the Local

Authority Children's services she facilitated changes in communication and care pathways that benefited both the parent and the children's needs. This integrated, joint working formed a template that commissioners could introduce in other similar services.

**Relevant principles:** I am respected, I am safe, I have fulfilling relationships

The Rights and Equality principles offer a framework upon which the measurement of outcome can be built, they offer professionals and teams the opportunity to assess the impact of their work against the key elements from current policy and legislation.

### **Linking Commissioning Outcomes to the Principles**

The Principles set out in this document provide a useful bridge between the Success Measures that commissioners are currently focussed on and the selection of outcome measure applied by professionals. The following examples of commissioning success measures have been cross referenced to the examples provided above:

- Reduce Admissions, Increase discharges and reduce both bed numbers and length of stay – examples 3, 4.
- Provide robust community services that work alongside other (mainstream) services to 'skill up' staff and improve health outcomes – examples 1, 2, 4, 5.
- Early intervention and building resilience in families and individuals – examples 1, 3, 4, 5.
- Value for money, sustainability, personal health budgets and control – 1, 2, 3, 4, 5.

### **Applying the Rights and Equality principles to choosing and developing outcome measures**

The choice of appropriate outcome measures will be influenced by lots of factors including validity and reliability. A good outcome measure needs to be appropriate, precise, responsive, acceptable, and feasible. We recommend that the Rights and Equality principles form the basis of the selection of outcome measure for professionals and teams. Not only can the principles act as a standard against which the appropriateness of different outcome measures can be assessed, they can also inform interventions and provide a shared (multidisciplinary) and accessible understanding of aims and outcome.

It is generally accepted that outcomes should be viewed from a range of perspectives, including that of the individual and those close to them (Person Rated Outcome Measure PROM<sup>1</sup>, and Person Rated Experience Measure PREM<sup>2</sup>) and that of service providers (Clinician Rated Outcome Measures CROM)<sup>3</sup>. Whatever outcome tools you are using, they should promote and support the Rights and Equality principles; appropriate measures of outcome in learning disability services would reflect positive change against these principles.

It is important to note that when it comes to the fundamental rights of individuals, all the principles are important; focusing on one Rights and Equality principle may be appropriate in specific situations,

---

<sup>1</sup> Patient (or person) reported outcome measure

<sup>2</sup> Patient (or person) rated experience measure

<sup>3</sup> Clinician reported outcome measure

as long as it did not to infringe on other fundamental rights. For example, focusing on safety alone can lead to infringements of other Rights and Equality principles. Often the best outcomes are achieved through multidisciplinary intervention across a range of assessed needs.

For example:

John likes football but his behaviour has made it difficult for his staff to take him out. Alongside the staff team the psychologist and nurse work on a positive behaviour support plan with John (CROM). This helps staff to be more confident about supporting John, and he is now able to go to football matches again (PROM), John and his staff team are very happy with the support and outcome (PREM).

This work means that John is supported to be part of this community and culture, has had opportunities to be active, his social care needs have been met, and he has been able to exercise choice

The diagram at the end of this document demonstrates the relationship between the important elements of measuring outcomes, based on the Rights and Equality principles described. It provides a tool for understanding what outcome measures are required, for what purpose and how they fit together; whilst each profession may have their own outcome measure to assess the impact of their specific intervention (CROM), it is important that these always align with the Rights and Equality principles. The overall impact of multidisciplinary / team interventions can (and should) also be assessed, combining the information provided by the outcome of different professional interventions and individual perspectives.

The two questions identified in the introduction need to be answered:

1. Do the outcomes you are working towards, (as an individual and a team), meet the principles?
2. Do you use outcomes measures that are in line with these principles?

Example:

The Health Equalities Framework has been endorsed by the Learning Disability Professional Senate; it can be used by individuals and teams to measure the impact of the known determinants of Health Inequalities for an individual at any given time and can demonstrate outcome from a range of different multi-disciplinary interventions. It is a good example of an outcome approach that relates specifically to the Rights and Equality principles, maps across the 3 national outcomes frameworks (Health, Social Care and Public Health), can be systematically collected and aggregated and positively responds to the two questions.

<http://www.ndti.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1/>

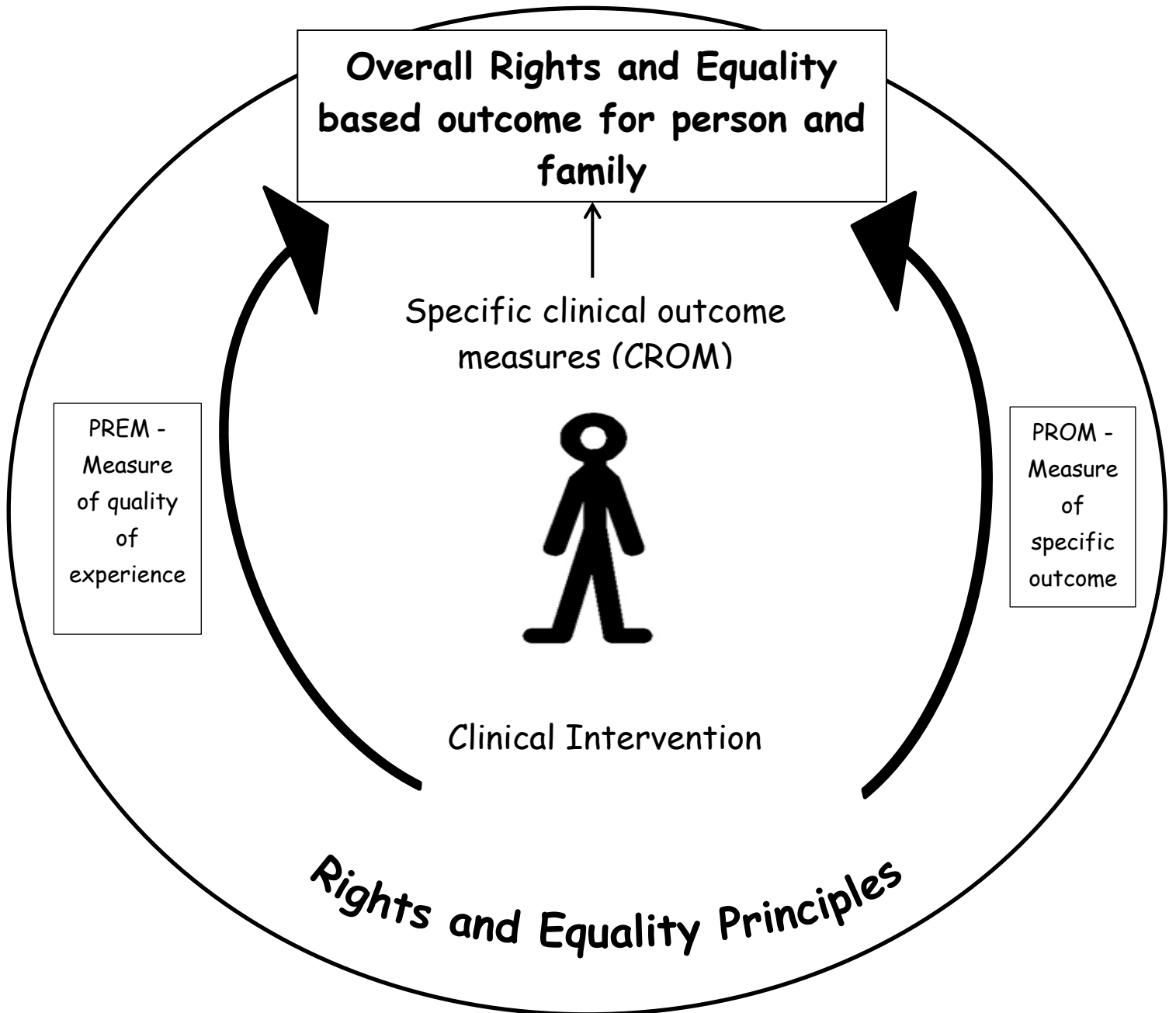


The aggregation of outcome data enables the planning, development and provision of future services to be based on an understanding of both what is needed and what works.

## **Conclusion**

This guidance aims to put human rights and equalities issues at the centre of learning Disability professionals practice. It is not an outcomes framework in itself, but asks important questions about current outcomes and outcome measures in use. By taking Rights and Equalities as the starting point commissioners, service managers and professionals can all understand their responsibilities and accountabilities within the same frame. We hope that the document is used throughout the provision of services for people with learning disabilities to ensure that any approach to outcomes and the measurement of such is Rights and Equalities based and delivered through truly person centred approaches.

# Measuring Outcomes and Experiences



## Bibliography & Further Reading

Atkinson D, Boulter P, Hebron C, et al (2013) The Health Equalities Framework (HEF): An Outcomes Framework Based on the Determinants of Health Inequalities. NDTi, Learning Disabilities Observatory.

Atkinson D, Boulter P, Hebron C, et al (2014) Exposure to Health Inequalities as a measure of outcome. *Learning Disability Practice*. 17 (1) 20-24

Barr, O. 2011, The need for outcomes to be clear – but outcomes of what? *Journal of Intellectual disabilities* 15 (1) 3-5

Beadle-Brown J, Richardson L, Guest C, et al (2014) Living in Fear: Better Outcomes for People with Learning Disability and Autism. Tizard Centre, University of Kent.

Brown I, Brown RI (2009) Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6: 11–8.

Department of Health (2013) The NHS Outcomes Framework. Department of Health.

Department of Health (2013) Adult Social Care Outcomes Framework. Department of Health.

Department of Health (2014) Public Health Outcomes Framework. Department of Health.

Equality Act (2010) [http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga\\_20100015\\_en.pdf](http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf)

Griffiths, P., Jones, S., Maben and Murrells, T. (2008) State of the art metrics for nursing: a rapid appraisal National Nursing Research Unit, London

Hebron, C. Pratt, M. Thomas, J. (2014) Role of an Intensive Health Outreach Team in improving health outcomes. *Learning Disability Practice*, Volume 17. Number 9.

Heslop, P. Blair, P. Fleming, P. et al (2013) Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD). Norah Fry Research Centre.

Human Rights Act (1998)

[http://www.legislation.gov.uk/ukpga/1998/42/pdfs/ukpga\\_19980042\\_en.pdf](http://www.legislation.gov.uk/ukpga/1998/42/pdfs/ukpga_19980042_en.pdf)

Kerr, M. Felce, D. Felce, J. (2005) Equal Treatment: Closing the Gap. Final Report from the Welsh Centre for Learning Disabilities to the Disability Rights Commission. Welsh Centre for Learning Disabilities.

Krahn, GL. Hammond, L. Turner, A. (2006) A cascade of disparities: health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 12: 70–82.

Larsson, G. Larsson, BW. (2001) Quality of care and service as perceived by adults with developmental disabilities, their parents, and primary caregivers. *Mental Retardation*, 39: 249–58.

Law, D. & Jacob, J. (2015) Goals and Goal Based Outcomes (GBOs) some useful information. Chapter on "Using goals in clinical practice : Children and young people with learning disabilities, their parents/carers and networks Children and young people with learning disabilities" by Rossiter & Armstrong. See [https://www.ucl.ac.uk/ebpu/docs/publication\\_files/Goals\\_booklet\\_3rd\\_ed](https://www.ucl.ac.uk/ebpu/docs/publication_files/Goals_booklet_3rd_ed)

Leicester Partnership NHS Trust 2015 "If you listen, you will hear us ". Video at:  
[https://www.youtube.com/watch?v=Hp4PW17U\\_h8](https://www.youtube.com/watch?v=Hp4PW17U_h8)

London & SE CYP-IAPT Learning Collaborative, CORC and CYP-IAPT Outcomes and Evaluation Group (OEG), (October 2014/March 2015) Presentations from the 2 multidisciplinary practice-sharing events on "Children and Young People with Learning Disabilities Measuring outcomes and gathering feedback  
<http://www.corc.uk.net/ldworkshop/>

Michael, J. (2008) Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. Emerald Group Publishing.

Miller, E. Cooper, SA. Cook, A. et al (2008) Outcomes important to people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities, 5: 150–8.

Morris, J., Bush, A. & Joyce T. (2012) Outcome measures for challenging behaviour interventions. Leicester: British Psychological Society.

Morris, C. et al. (2014) CHUMS: Children's Outcomes Measurement Study, Peninsular Cerebra  
<http://www.journalslibrary.nihr.ac.uk/hsdr/volume-2/issue-15#>

Mulligan, B., John, M., Coombes, R. & Singh, R. (2014) Developing Outcome Measure for a Family Intensive Support Service for Children presenting with Challenging Behaviour. British Journal of Learning Disabilities,

NHS England. (2015) Building the Right Support. <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

Nota L, Ferrari L, Soresi S, et al (2007) Self-determination, social abilities and the quality of life of people with intellectual disability. Journal of Intellectual Disability Research, 51: 850–65.

Pencheon, D. (2008) The good indicators guide: understanding how to use and choose indicators. NHS institute for innovation and improvement, London

Phillips, et al. (2013) Are we making a difference? Measuring the value of our work with children and young people with a learning disability and behaviour that challenges their families. In Intellectual Disabilities and Challenging Behaviour, ACAMH Occasional Paper No 32, eds Lovell, M. & Udwin, O.

RCN (2016) Connect for Change, an update on learning disability services in England  
<https://www.rcn.org.uk/professional-development/publications/pub-005525>

Rossiter, R. Armstrong, H. Morgan, S. & Phillips, N. (2013) Same or different? Measuring outcomes in children and young people with learning disabilities, their families and networks. Child and Family Psychology Review, 1, 84-92.

Rossiter, R. et al (2014) Learning Disabilities: collecting and use of feedback with children and young people with learning disabilities. Chapter in Guide to using outcomes and feedback tools with children and young people. Eds Law, D. & Wolpert, M. CORC, IAPT, Evidence Based Practice Unit, Anna Freud Centre, UCL

Rossiter, R. Phillips, N. & Law, D. (2016) Building momentum: who'd have thought ROM's could create such a buzz? Feedback and outcome measures and diversity: children with learning disabilities and neurodevelopmental conditions. Workshop presentation at Children and Young People's Mental Health National Conference, Future In Mind from Vision to Implementation. London. See

<http://www.slideshare.net/cypucl> (slides 5 and 16 for the Sussex Feedback and Outcomes Measures approach)

Roy, A. Matthews, H. Clifford, P. et al (2002) Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD). *British Journal of Psychiatry*, 180: 61–6.

Ruddick, L. (2005) Health of people with intellectual disabilities: a review of factors influencing access to health care. *British Journal of Health Psychology*, 10: 559–70.

Schalock, RL. Brown, I. Brown, R. et al (2002) Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: report of an international panel of experts. *Mental Retardation*, 40: 457–70.

Schwartz, C. Rabinovitz, S. (2003) Life satisfaction of people with intellectual disability living in community residences: perceptions of the residents, their parents and staff members. *Journal of Intellectual Disability Research*, 47: 75–84.

UN Convention on the Rights of Persons with Disabilities (2006)  
<http://www.un.org/disabilities/convention/conventionfull.shtml>