A resource about Occupational Therapy with People with Learning Disabilities

Introduction

Occupational Therapy is a profession founded on the belief that occupation is essential to good health and wellbeing (Keilhofner 2007, Creek, 2003). Occupational deprivation affects both physical and psychological health. This can be a particular problem for people with learning disabilities who are more likely to experience social isolation, dependence on others to plan and complete activities and poor access to services (Department of Health, 2001)

People with learning disabilities are more likely than the rest of the population to experience a range of health conditions such as mental health problems, cardio vascular problems, and sensory impairment. As such, our multi-dimensional training puts Occupational Therapists in a prime position to consider the range of difficulties that people with Learning Disabilities might experience.

Occupational Therapists have a key role in helping people with learning disabilities to access occupation; adapting activity, equipment, environment or materials in the places where they live and work. They have specific skills in activity analysis, assessment of function, collaborative goal setting, evaluation and an understanding of the relevance and role of occupation in health and well being (COT 2007).

The most commonly used definition of learning disability internationally is that of the World Health Organisation.

> A condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. (WHO, ICD - 10 version 2010)

The diagnosis will depend on the overall assessment of intellectual functioning by a skilled practitioner. Degrees of impairment are conventionally estimated by standardized intelligence tests supplemented by assessing social adaptation. Intellectual abilities and social adaptation may change over time, and may improve as a result of training and rehabilitation (ICD -10, version 2010).

There is evidence that people with learning disabilities are amongst the most socially isolated and vulnerable groups in society. They are less likely to have jobs (DoH 2009a), less likely to own their own home and often rely on others for day to day support (DoH 2009b). People with learning disabilities are more likely to experience occupational deprivation and social isolation (Stancliffe et al 2007).

They are also at a significantly increased risk of a range of health problems and are more likely to die at an earlier age than the rest of the population (DoH 2007), experiencing a higher incidence of heart and respiratory problems, sensory impairment, epilepsy, diabetes, mental health problems and dementia (Gustavson et al 2005). In light of government drivers promoting the rights of people with learning disabilities to access mainstream services, it is probable that Occupational

Therapists specialising in any field of practice will at some point in their career work with someone with a learning disability.

This paper will consider best practice for both Occupational Therapists working in mainstream services and those specialising in learning disabilities.

Background and context

The four countries of the United Kingdom each have policies or visions for meeting the needs of people with learning disabilities. Occupational Therapy is provided within the context of these policies. Although the emphasis and language used varies slightly in each country, the overall direction is similar.

In England, the *Valuing people* White Paper (DoH 2001) and *Valuing people now* (DoH 2009) focus on rights, independence, control and inclusion with specific reference to addressing needs related to health, housing, work, education and relationships.

In Scotland, *The same as you?* (Scottish Executive 2000) is committed to improving the quality of life of people with learning disabilities, it focuses on importance of social inclusion, equality, fairness and the opportunity for continuous learning. The paper provides information for people about their needs and places people with learning disabilities at the centre of decision making about their care.

In Northern Ireland, *Equal lives* (Department of Health, Social Services and Public Safety Northern Ireland, 2005) bases its recommendations on the five key values of citizenship, social inclusion, empowerment, working together and individual services.

In Wales, *Fulfilling the promises* (National Assembly for Wales Learning Disability Advisory Group 2001) provides a statement on policy and practice (Welsh Assembly Government 2007) based on the principle that people with a learning disability are full citizens, equal in status and value to others of the same age. They have the right to live healthy, productive and independent lives and to decide everyday issues and life-defining matters for themselves. Fulfilling the promises highlights the need for people with learning disabilities to live their lives fully, have support within their community and to have access to general and specialist services.

Occupational Therapists working in mainstream services

Despite a commitment by the respective governments to ensure better access to mainstream services (DoH 2001, Scottish Executive 2000, DHSSPSNI, 2005 and Welsh Assembly Government, 2007) it is well documented that people with a learning disability receive poorer standards of care in mainstream services (Mencap, 2007, Michael, 2008 and Mencap, 2012) due to poor communication, assumptions about quality of life and a lack of understanding by healthcare professionals about their needs (Mencap 2007). Diagnostic overshadowing is thought to contribute significantly to health inequalities for people with learning disabilities and refers to the tendency of professionals to interpret the reporting of symptoms and pain

behaviours to a learning disability or mental health problem (Disability Rights Commission 2007).

Valuing People Now (DoH, 2009) stresses the rights of people with learning disabilities to access mainstream healthcare and *Fulfilling and rewarding lives* (DoH, 2010 p.6) states that people with autism should be able to "depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents."

Occupational Therapists working in both mainstream and specialist services need skills and knowledge to work with people with learning disabilities. The College of Occupational Therapy and College of Occupational Therapy Specialist Section – People with Learning Disabilities have been actively involved in the development of the 'Mencap – getting it right' charter (Mencap 2008) which highlights key activities that ensure equal treatment in mainstream health and social care services. Of these nine activities the following are most significant to Occupational Therapy practice:

- All staff should understand and apply the principles of mental capacity laws.
- Staff should receive ongoing learning disability awareness training
- Staff should listen to, respect and involve families and carers
- Staff should offer practical support and information to families and carers
- Staff should provide information that is accessible for people with a learning disability

Occupational Therapists should offer the same range of assessments and interventions offered to other service users. By law they have an obligation to make reasonable adjustments to ensure an equal opportunity to benefit from the treatment (Great Britain Parliament, 2010, Equality Act).

The following bullet point's offer suggested adjustments:

- Establish the best way to communicate with the person. Mencap (2010) offer the following guidance:
    - Pay attention to facial expressions.
    - Notice gestures and body language.
    - Try pointing to pictures.
    - Try signing.
    - Keep information simple and brief.
    - Avoid using jargon.
    - Avoid abstract concepts as many people with learning disabilities, particularly those with autism have a literal understanding of language, Concepts such as emotions may also be difficult as these do not have concrete meaning.

- Longer appointment times as many people with learning disabilities require more time than most to express their needs and process information (Martin et al 1997, Melville et al 2006).

- Flexible appointment times. Many people with learning disabilities (especially those with autism) find waiting very difficult. In hospital or outpatient settings it may be helpful to offer the first appointment of the day to avoid delays(Brown et al 2012, Brown and Guvenir 2009).

- Assessments of everyday activities should be done in context as many people with learning disabilities have difficulties with generalisation. Replicate the home environment as closely as possible if not assessing at home, use familiar objects and familiar routines as much as possible and assess at the time that person would normally be doing that activity. Things we take for granted may be difficult to comprehend for someone with a learning disability: a commode may just look like another chair to a person with a learning disability; they may not be able to understand that this is the same as the toilet they use at home (Morton-Cooper 2004).

- Use the knowledge and skills of staff or family who can show you how to best communicate and engage with the person (Mencap 2010).

- Seek advice from services, particularly your local Community Learning Disability Team.

Occupational Therapists specialising in learning disabilities:

The College of Occupational Therapy and The College of Occupational Therapist Specialist Section – People with Learning disabilities commissioned a comprehensive research project in the unique role of Occupational Therapy and people with learning disabilities (Lillywhite and Haines, 2010). It can be accessed from http://www.cot.co.uk/publication/books-z-listing/occupational-therapy-and-people-learning-disabilities-findings-research).

Occupational Therapists specialising in the field of learning disabilities have both a clinical and consultancy role (Lillywhite and Haines, 2010).

The Clinical role:

Occupational Therapists have a key role in the assessment and treatment of people with complex needs (people with profound and multiple disabilities, autism, dual diagnosis and behaviour that challenges), those with sensory processing needs, those in transition (moving house, moving from children's service to adult services or adult services into older persons services), those who are becoming parents and in vocational rehabilitation (Lillywhite and Haines. 2010).
Occupational Therapists also have an important contribution described within a range of recent government drivers such as:

- Rewarding and Fulfilling Lives (DoH 2010a) highlights the needs of people with autism to be supported to participate in day to day meaningful activities, in their communities and access employment.

- Raising our sights (DoH 2010b) discusses people with profound and multiple learning disabilities stating the need for highly individualised packages of support and It highlights the importance of accessing assistive technology that enables them to have greater control over their lives.
- Services for people with learning disability and challenging behaviour or mental health needs – (Mansell Report) (DoH 2007) recommendations better day opportunities and environments with staff sufficiently skilled to support people with challenging behaviour and engage them in meaningful activities

Specialist assessment:

Learning Disability Occupational Therapists have a significant role in assessing the impact of an individual's learning disability on their occupational performance i.e. how it affects their life and engagement in the occupations that are important to them.

Occupational Therapists use a wide range of assessments tools in order to gain a broad understanding of a person's needs. These tools include standardised assessments which are robust and provide measurable outcomes.

Assessments should be carried out in a range of naturalistic settings relevant to the individual's life (e.g home, day services, work, college etc...) matched with information from a range of sources such as direct observation, liaison with service user, staff and families Assessments should also include the use of standardised assessments to ensure clarity and objectivity. Assessment can inform services on the support or placement most appropriate for the individual or about the support required to complete daily activities which are relevant and meaningful to the person. This may in turn promote self-esteem and a sense of control, reducing challenging behaviour and promoting skill development.

Lillywhite and Haines found that the main standardised assessments used by Occupational Therapists with people with learning disabilities are:

- The Assessment of Motor and Process Skills (Fisher, 2010)
- The Canadian Occupational Performance Measure (Law et al, 1994);
- Assessments from the Model of Human Occupation (Kielhofner, 2007) i.e The Model of Human Occupation Screening Tool (Parkinson *et al,* 2006), the Volitional Questionnaire (De las Heras *et a,l* 2007), the Occupational Self Assessment (Baron *et al,* 2006) and the Occupational Circumstances Assessment Interview and Rating Scale (Forsyth *et al,* 2005).
- The Pool Activity Level Instrument for Occupational Profiling (Pool, 2007).

Many Occupational Therapists specialising in learning disabilities also undertake post-registration training in sensory integration enabling them to use standardised assessments from within that theoretical framework e.g. The Sensory Integration

Inventory – Revised for Individuals with Developmental Disabilities (Reisman and Hanschu, 1992),

Despite a desire to use these standardised assessments Lillywhite and Haines (2010) found that they were only used for 29% of referrals. This is often due to the complexity of service user need and difficulties with communication. Standardised assessments adapted to be more accessible and applicable to people with learning disabilities (Lillywhite and Haines, 2010, Blount, 2008) are sometimes used and there have been attempts to standardise adapted versions of tools. Examples include activities of daily living or interest checklists, using visual cues such as photos or symbols (Lillywhite and Haines, 2010).

Occupational Therapists are also key contributors in risk assessments (Lillywhite and Haines, 2010).

Specialist treatment and intervention:

Central to intervention is the presumption that the individual should be enabled as much as possible to lead the process, being involved in and taking control over their own Occupational Therapy interventions. Best practice dictates that information about occupational goals is provided in an accessible format (Lillywhite and Haines, 2010).

Learning disability Occupational Therapists should offer a range of interventions including:

- Skills development via 1:1 work (Kottorp et al, 2003), groups (Hallgren and Kottorp 2005) or consultation for those who support the person with a learning disability.
- Development of support profiles which help others to grade activities appropriate to an individual's skills and needs as well as guidance on ways to set up the environment to promote opportunities for engagement (Beadle-Brown et al, 2008, *Stancliffe et al*, 2007).
- Environmental adaption to include the physical environment, sensory and social environment (SIGN 2007).
- Support to develop a range of meaningful occupations, facilitating motivation and promoting choice and control through activity**.** Offering choice and control can reduce challenging behaviour (DoH, 2012) and encourage more passive individuals to take a more active role in their lives (Koritsas et al 2008, Stancliffe *et al.* 2007).
- Work rehabilitation and development of vocational skills (Robertson and Emerson 2006, Winstow and Schneider 2003, Jenkins 2002).
- Developing structures and routines: to create a sense of control and predictability in the day helps orientate people to time and support independence (Jones, 2004).
- Sensory integration therapy**:** Evidence suggests that Sensory Integration Therapy programs can reduce challenging behaviour and self-stimulatory

behaviour (Reisman, 1993), improve interaction with the environment (Green et al, 2003) and improve a person's attention and performance in daily activities (Urwin, 2004).

- Supporting service users to make positive choices about their occupation and listening to service users preferences regardless of communication needs and level of learning disability (Joyce and Shuttleworth, 2001).

The consultation role

Consultation to support staff and families:

Developing a good working relationship with key members of staff who have particular interests or skills can increase the likelihood of recommendations being followed (Emerson et al 2012). Building rapport can take time and may involve educating and encouraging support workers to work in a more occupational or enabling way, requiring long term work to support attitudinal change. Occupational therapists must consider how knowledge is shared across the *whole* team as collaborative working with other members of the multi disciplinary team is vital (Emerson et al 2012, Dobson 2002). Lillywhite and Haines(2010) found that written recommendations in an accessible format clarify the key points discussed and that support workers "emphasise the importance of occupational therapists keeping recommendations down to a minimum". They value involvement in decisions on the format of recommendations transferrable to a whole staff group. This may mean looking beyond written guidelines and recommendations and giving support workers alternative tools, including visual materials such as DVDs (Dunn et al 2006).

Consultation to mainstream services:

Occupational Therapists who specialise in learning disabilities will be involved in consultation with those working in a range of mainstream settings. This will involve supporting colleagues in adapting their practice and communication to ensure the best possible outcome for the person with a learning disability. It may involve advocating on behalf of the person with a learning disability. There are no nationally agreed standards in relation to this role; agreements are made on a local basis.

The consultative role also extends beyond fellow Occupational Therapists to include advocating for people with learning disabilities in support to access services in the community e.g. transport, education and employment opportunities.

Measuring outcomes and auditing good practice

Outcome measures:

Measuring outcomes can be challenging when working with people with learning disabilities. Occupational therapists are required to comply with the *Mental Capacity Act 2005* (Great Britain. Parliament 2005) enabling people to make choices and set their own goals to improve their quality of life. Documenting and reviewing whether intervention goals have been achieved is an important way of demonstrating outcomes. There is a lack of standardised tools that can be used to measure outcomes in relation to people with profound and multiple learning disabilities

therefore detailed observational recording and goal reviewing are essential. Tools with a greater focus on the environment, sensitive enough to measure change in this group of people would be beneficial (Lillywhite and Haines, 2010).

Service user feedback:

The perspective of the person with a learning disability, family carers and support workers on what the outcome should be and whether it has been achieved is particularly important, for example their satisfaction with their own occupational performance (Lillywhite and Haines, 2010). When gaining feedback from service users with learning disabilities much care must be taken. Ball and Shanks (2012) explored how Occupational Therapists specialising in learning disabilities gain feedback. They found that the majority of participants used informal interviews and only just over half considered issues of suggestibility and susceptibility to bias. They offer some suggested ways to increase the reliability of service user feedback. These include:

- Use of tools such as talking mats, cue cards, photographs or the use of multimedia such as DVD's.
- Use of independent interviewers who use photos of the subject of the feedback.
- Clear standardised organisational processes which offer a structure by which to gather and use feedback.

They also recognise the need for more research in to the best ways of gaining feedback, particularly for those with profound and multiple learning disabilities.

Audit tools:

The College of Occupational Therapists Specialist Section –People with Learning Disabilities have produced an audit tool to help specialist Occupational Therapists evaluate their practice. The tool is available at http://www.cot.co.uk/news/cotss-people-learning-disabilities/OT-audit-tool - check

Training issues for Occupational Therapists when working with people with learning disabilities

Whilst it would be impossible to discuss all the possible training opportunities available and appropriate for Occupational Therapists working with people with learning disabilities, this section will describe some of the most relevant.

Undergraduate training:

Despite recommendations in Healthcare for All (Michael, 2008) there is great variation in the amount of undergraduate Occupational Therapy education about the needs of people with learning disabilities (Lillywhite and Haines2010) The College of Occupational Therapists Specialist Section- People with Learning Disabilities has produced the 'Higher education resource pack' (see resources) in an attempt to to support educators.

Mainstream Occupational Therapists:

The Mental Capacity Act (Great Britain. Parliament, 2005).

It is vital that all professionals understand that no one can give consent on behalf of an adult with learning disabilities. There may be a need to adapt information to facilitate capacity and there is a clear process for assessing best interests should a person lack capacity. The act is clear that capacity to consent is situation specific.

The principles of the Act are:

- **Presumption of capacity** (section 1(2) MCA). Every adult has the right to make their own decisions if they have the capacity to do so.
- **Maximising decision making capacity** (section 1(3) MCA). People should receive support to help them make their own decisions.
- **Right to make unwise decisions** (section 1(4) MCA). People have the right to make decisions that others might think are unwise.
- **Best interests** (section 1(5) MCA). Any act done for, or any decision made on behalf of, someone who lacks capacity must be in their best interests.
- **Least restrictive option** (section 1(6) MCA). Any act done for, or any decision made on behalf of, someone who lacks capacity should be the least restrictive option possible

Autism awareness training

The Autism Strategy (DoH 2010) states that all health care professionals should have a basic awareness of the needs of people with autism. There are a range of independent and local organisations able to provide this. Occupational therapists should seek advice from their managers or local community learning disability team.

Specific training for Occupational Therapists specialising in Learning Disabilities:

Assessment of Motor and Process Skills:

The Assessment of Motor and Process Skills (AMPS) (Fisher 2010) is the standardised assessment that is reported by Lillywhite and Haines (2010) as the most used by occupational therapists with people with learning disabilities. To practice AMPS assessments the Occupational Therapist must complete a 5 day training course and be calibrated by AMPS international.

Sensory Integration

The College of Occupational Therapists have produced a briefing paper on the use of sensory integration (COT/BAOT Briefing 70, reviewed 2008).
Sensory Integration is not part of core Occupational Therapy training therefore those wishing to do so must undertake recognised and appropriate training to use this in their work. They do so as extended scope practitioners (COT/BAOT Briefing 14 Extended Scope Practice). The Sensory Integration Global Network and the Sensory

Integration Network (UK) state appropriate levels of training required and stress that competencies in the application of sensory integration theory and skills learned must be maintained. The Network suggests two years of development of clinical experience, mentorship, supervision, ongoing study and guidance for those newly trained and peer support thereafter as a check and balance for best practice.

(*It should be noted that sensory integration therapy is not covered by The British Association of Occupational Therapists indemnity insurance. But would normally be covered by the employers insurance providing appropriate training and supervision is undertaken.)*

Communication techniques

Intensive Interaction
Intensive interaction is an inter-professional approach to communication with children and adults who have severe learning disabilities and/or autism and who are still at an early stage of communication development. Training course information is available on the Intensive Interaction webpage http://www.intensiveinteraction.co.uk/. For an Occupational Therapy based approach, the work of Phoebe Caldwell can be found on: http://www.phoebecaldwell.co.uk/links.html

Supervision, mentoring and locality groups

As with any other area of Occupational Therapy it is important that individuals source appropriate supervision. COT Briefing 55 states that the kind of supervision needed will depend upon the role and level of experience of the practitioner and should be sought from a practitioner with a higher level of knowledge, skills and experience in the same field.

The College of Occupational Therapists Specialist Section – People with Learning Disabilities support local special interest groups who can offer a source of support and advice, involvement in these groups is seen as a valuable continuing professional development exercise.

Research

There remains limited, but growing, published research evidence to support clinical practice. There is a particular need for evidence on the effectiveness of occupational therapy interventions and regarding assessments and outcome measures.

The College of Occupational Therapists Specialist Section – People with Learning Disabilities Strategic Vision and Action Plan for occupational therapists working with people with learning disabilities (2012) gives suggested areas for research. It outlines support for research and evidence based practice. The specialist section also provides support to members who wish to undertake research (COT Briefing 88).

COT/BAOT Briefings and COTSS-PLD resources:

http://www.cot.co.uk/briefings/briefings

Briefing 51: Management of disturbed and violent behaviour (December 2005)
Briefing 55: Management Briefing: Supervision (Revised May 2010)
Briefing 60: Mental Capacity Act 2005 (Revised August 2011)
Briefing 70: Occupational Therapists and Sensory Integration (September 2006)
Briefing 88: Responding to research enquiries: information for specialist sections (Revised September 2011)

Higher Education Resource pack: http://www.cot.co.uk/cotss-people-learning-disabilities/resources

Occupational Therapy Fact Sheet: The importance of occupational therapy to people with Learning Disabilities
http://www.cot.co.uk/sites/default/files/commissioning_ot/public/ot-evidence-learning-disabilities.pdf

Self assessment toolkit: http://www.cot.co.uk/news/cotss-people-learning-disabilities/OT-audit-tool

Strategic Vision and Action Plan for occupational therapists working with people with learning disabilities (2012): http://www.cot.co.uk/cotss-people-learning-disabilities/research

Tips for students: http://www.cot.co.uk/cotss-people-learning-disabilities/resources

SPEaR: http://www.cot.co.uk/supporting-practice/learning-disabilities

Useful websites/ resources:

www.easyhealth.org.uk

www.easyinfo.co.uk

www.plainenglish.co.uk/atoz.pdf

http://www.bildservices.org.uk

www.**mencap**.org.uk (getting it right leaflet and charter)

http://www.pamis.org.uk/

http://www.pmldlink.org.uk/

http://www.pmldnetwork.org/

http://www.intensiveinteraction.co.uk/.

http://www.phoebecaldwell.co.uk/links.html

CAF directory of specific conditions and rare disorders: http://www.cafamily.org.uk/

Challenging Behaviour National Strategy Group Charter:
(Challenging Behaviour Foundation website)
http://www.thecbf.org.uk/campaigns/campaigns.htm

References:

Ball and Shanks (2012) *Gaining feedback from people with learning disabilities* British Journal of Occupational Therapy. BJOT. 75 (10), pp. 471-477(7).

Baron K, Kielhofner G, Iyenger A, Goldhammer V, Wolenski, J (2006) *Occupational self assessment (OSA)*. Chicago, IL: University of Illinois at Chicago

Beadle-Brown J, Hutchinson A, Whelton B (2008) *A better life: the implementation and effect of person-centred active support in the Avenues Trust* Tizard Learning Disability Review 13 (4) 15-24

Blount J (2008) *The Use Of Occupationally Focused Assessment Tools: The Practice Of Occupational Therapists Working With Adults With Learning Disabilities In The UK* College of Occupational Therapist Specialist Section- People with Learning Disabilities (2) 1 pg 8- 17

Brown FJ, Cooper K, Diebel T (2012) *Access to mainstream health services: a case study of the difficulties faced by a child with learning disabilities* Journal of Learning Disabilities

Brown FJ, Guvenir J (2009) *The Experiences of Children with Learning Disabilities, Their Carers and Staff during a Hospital Admission* British Journal of Learning Disabilities 37 (2) 110-115

Creek (2003) *Occupational therapy as a complex intervention.* London: College of Occupational Therapists College of Occupational Therapists

De las Heras CG, Geist R, Kielhofner G, Li Y (2007) *The volitional questionnaire*. Chicago, IL: University of Illinois at Chicago.

Department of Health (2001) *Valuing people: a new strategy for learning disability for the 21st century.* London: Department of Health.

Department of Health (2007) *Services for people with learning disability and challenging behaviour or mental health needs (revised edition).* London: Department of Health.

Department of Health (2009a) *Valuing employment now*. London: Department of Health.

Department of Health (2009b) *Valuing people now*. London: Department of Health.

Department of Health (2010a) *Fulfilling and rewarding lives: a strategy for individuals with autism in England* Department of Health: London

Department of Health (2010b) *Raising our Sights; services* for adults with profound intellectual and multiple disabilities Department of Health: London

Department of Health (2012) *Transforming care: A national response to Winterbourne View Hospital Department of Health Review: Final Report Available at: https://www.wp.dh.gov.uk/publications/files/2012/12/final-report.pdf. Accessed 17.12.2012*

Department of Health, Social Services and Public Safety Northern Ireland (2005) *Equal lives: review of policy and services for people with a learning disability in Northern Ireland*. Belfast: Department of Health, Social Services and Public Safety.

Disability Rights commission (2007) *Equal treatment: closing the gap. A formal investigation into the physical health inequalities experienced by people with learning disabilities and/or mental health problems* Stratford upon Avon: Disability Rights Commission.

Dobson S, Upadhyaya S, Stanley S (2002) *Using an interdisciplinary approach to training to develop the quality of communication with adults with profound learning disabilities by care staff* International Journal of Language and Communication Disorders 37 (1) 41-57

Dunn A Kroese B Thomas G McGarry A Drew P (2006) *'Are you allowed to say that' using video materials to provide accessible information about psychology services* British Journal of Learning Disabilities 34 215-219

Emerson E, Hatton C, Gone R, Caine A, Bromley J (2012) *Clinical psychology and people with intellectual disability 2nd edition* Oxford: Wiley publishing

Fisher A (2010) *Assessment of motor and process skills. 7*th ed. Fort Collins, CO: Three Star Press.

Forsyth K, Deshpande S, Kielhofner G, Henriksson C, Haglund L, Olson L, Skinner S, Kulkarni S (2005) *The occupational circumstances assessment interview and rating scale (OCAIRS)*. Chicago, IL: University of Illinois at Chicago.

Goodman J, Hurst J, Locke C, eds (2008) *Occupational therapy for people with learning disabilities: a practical guide*. London: Churchill Livingstone.
Great Britain. Parliament (2005) Mental Capacity Act 2005. Available from http://www.legislation.gov.uk/ukpga/2005/9/contents. Accessed 17.12.2012.

Great Britain. Parliament (2010). *Equality Act* Available at; http://www.legislation.gov.uk/ukpga/2010/15 accessed on 1.12.2012

Green D., Beaton L., Moore D., Warren L., Wick V., Sanford E., Santosh P., (2003) Clinical incidence of sensory integration difficulties in adults with learning disabilities and illustration of management BJOT 66 (10) 454

Gustavson, Umb-Carlsson, Sonnander (2005) *A follow up study of mortality, health conditions and associated disabilities of people with intellectual disabilities in a Swedish County* Journal of intellectual disability research 49 905-914

Lillywhite A, Haines D (2010) *Occupational Therapy and People with Learning Disabilities: findings from a research study* London: College of Occupational Therapists

Jenkins R (2002) *Value of employment to people with learning disabilities* British Journal of Nursing 11 (1) 38-44

Jones, E. (2004) 'Active support', Occupational Therapists in Learning Disabilities Conference, Cardiff, Wales.

Joyce T, Shuttleworth L (2001) *From engagement to participation: how do we bridge the gap?* British Journal of Learning Disabilities 29 63-71

Kielhofner G (2007) *Model of human occupation: theory and application.* 4th ed. Kingsley.

Koritsas S, Iacono T, Hamilton D, Leighton D (2008) *The effect of active support training on engagement, opportunities for choice, challenging behaviour and support needs.* Journal of Intellectual & Developmental Disability 33 (3) 247-256

Kottorp A, Hallgren M, Bernspang B, Fisher A (2003) *Client-Centred Occupational Therapy for Persons with Mental Retardation: Implementation of an Intervention Programme in Activities of Daily Living Tasks* Scandinavian Journal of Occupational Therapy 10 (2) 51-60

Law M, Baptiste S, Carswell A, McColl MA, Polatajko H, Pollock N (1994) *Canadian occupational performance measure.* 2nd ed. Toronto, ON: CAOT Publications Ace.

Martin, Roy, Wells (1997) *Health gain through health checks: improving access to primary care for people with intellectual disability* Journal of intellectual disability research 41 401-408

Melville C, Cooper S-A, Morrison J, Finlayson J, Allan L, Robinson N, Burns E, Martin G (2006) *The outcome of an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary health care service* Journal of intellectual disability research 50 (1) 11-17

Mencap (2007). Death by *indifference*. Mencap

Mencap (2010) *Getting it right charter.* London: Mencap

Mencap (2012) Death by *indifference*: 74 deaths and counting
A progress report 5 years on. Mencap. Available from
http://www.mencap.org.uk/74deaths accessed on 17.12.2012.

Michael J (2008) *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*. Department of Health. Available from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf . accessed on 17.12.2012.

Morton-Cooper A. (2004) *Health care and the autism spectrum: a guide for health professionals, patients and carers*. London: Jessica Kingsley

National Assembly for Wales Learning Disability Advisory Group (2001) *Fulfilling the promises*: *proposal for a framework for services for people with a learning disability.*

National Association of Occupational Therapists Working with People with Learning Disabilities (OTPLD) (2003) *Occupational therapy services for adults with learning disabilities.* (Principles for Education and Practice). London: College of Occupational Therapists.

Parkinson S, Forsyth K, Kielhofner G (2006) *The model of human occupation screening tool (MOHOST)*. Chicago, IL: University of Illinois at Chicago. Philadelphia, PA: Lippincott Williams & Wilkins

Pool J (2007) *The Pool activity level instrument for occupational profi ling: a practical resource for carers of people with cognitive impairment.* 3rd ed. London: Jessica

Reisman J, Hanschu B (1992) *The sensory integration inventory: revised for individuals with developmental disabilities*. Hugo, MN: PDP Press Inc.

Reisman JE (1993) Using a sensory integrative approach to treat self-injurious behaviour in an adult with profound mental retardation. *American Journal of Occupational Therapy, 47,* 403-11.

Robertson J, Emerson E (2006) A systematic review of the comparative benefits and costs of models of providing residential and vocational supports to adults with autistic spectrum disorder. NAS: Lancaster University

Scottish Executive (2000) *The same as you? A review of services for people with learning disabilities.* Edinburgh: Scottish Executive.

Sensory integration global network; Guidelines for competency in the application of sensory integration theory http://www.siglobalnetwork.org/guidelines.pdf [accesses January 2012]

SIGN (2007) *Assessment, diagnosis and clinical interventions for children and young people with autistic spectrum disorders* Scottish Intercollegiate Guidelines Network: Edinburgh

Stancliffe RJ Harman AD, Toogood S, McVilly K (2007) *Australian Implementation and Evaluation of Active Support* Journal of Applied Research in Intellectual Disabilities 30 (3) 211- 227

Urwin R., Ballinger C., (2005) Effectiveness of sensory integration therapy to improve functional behaviour in adults with learning disabilities,: five single-case experimental designs 68 (2) 56

Welsh Assembly Government (2007) *Learning disability strategy: section 7 guidance on service principles and service responsibilities.* Cardiff: Welsh Assembly Government

Winstow R, Schneider J (2003) *User views on supported employment and social inclusion: a qualitative study of 30 people in work* British Journal of Learning Disabilities 31 166-174

WHO (1996) International Classification of Disease -10 Guide for Mental retardation World Health Organisation: Geneva
Available on http://www.who.int/classifications/icd/en/ accessed on the 17.12.2012.

Written by Jo Ball and Gwyn James
March 2013
With thanks to Amy Harrison and COTSSPLD NEC for support in development