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Toolkit for working with people with learning disabilities

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Thanks also go to the Salford and Trafford Palliative Care Subgroup for Information and Communication for reviewing the toolkit, and Sue McKenna, Project Manager, Cancer and You Information Project for editing it.



Introduction

Background

The idea to develop a toolkit to enable healthcare professionals provide and deliver individualised, appropriate support and information about cancer, to a person with a learning disability developed directly from an experience of such a client calling into the Cancer and You Macmillan Information and Support Service in Trafford, asking for help.

To develop this project I contacted Simon Bailey, the Regional Project Manager for Mencap. Together we developed a plan of action to address the needs of people who are learning disabled, and are living with cancer.

Our plan was to research the following specifically in relation to people with a learning disability:

- Cancer information resources
- Specific needs of this client group
- Government initiatives, reports and standards
- Best practice in communicating with people with a learning disability.

We would collate this information into a toolkit. The aim of this toolkit would be to act as a resource for healthcare professionals, who were called upon to give a person with a learning disability information about cancer. The toolkit could also be used by cancer information services.

The Cancer and You Macmillan Information and Support Service

The Cancer and You Macmillan Information and Support Service is funded by the Big Lottery Fund and its main objective is:

To provide an integrated and accessible Cancer Information Service ¹

This includes ensuring that the service is accessible to people with a learning disability. In the Macmillan Information Materials Guide ⁶, the accessibility of appropriate information, sensitively given is stressed, and is something that every Macmillan Information Service is addressing.

A New Strategy for Learning Disability for the 21st Century, 2001, (The White Paper) describe the health needs of people who are learning disabled as follows:

Many people with learning disabilities have greater health needs than the rest of the population. They are more likely to experience mental illness and are more prone to chronic health problems, epilepsy, and physical and sensory disabilities. The Government's objective is to enable people with learning disabilities to have access

to a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard and with additional support where necessary. ²

Defining a learning disability

The White Paper, 2001 describes a learning disability as

- *A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;*
- *A reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development.*

This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support.

An assessment of social functioning and communication skills should also be taken into account when determining need.

Many people with learning disabilities also have physical and/or sensory impairments.

The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence, such as some people with Asperger's Syndrome...

'Learning disability' does not include all those who have a 'learning difficulty.' ²

Mencap defines a learning disability as being:

A learning disability is a lifelong condition, acquired before, during or soon after birth, that affects an individual's ability to learn.

The causes of many learning disabilities are not known, but the most common example is Down's Syndrome.

People with a learning disability find it harder to learn and understand than other people. As a result, some need support with everyday practical skills like getting dressed or cooking, or social skills like holding a conversation. Others with more severe learning disabilities - often coupled with physical disabilities - require 24-hour care. Many, however, are able to live fairly independent lives.

It's important to understand that people with a learning disability are individuals with unique personalities, likes and dislikes, goals and aspirations.

*A learning disability does not prevent someone from learning and achieving a lot in life, if given the right support.*³

Learning disabilities and cancer

The British Institute of Learning Disabilities (bild) has carried out a review of the experiences of people with a learning disability and diagnosed with cancer. This was achieved by reviewing evidence from published studies and examining people's experiences from cancer services. The following quotes identify some key questions the report was able to answer and summarises the needs of people with a learning disability when accessing cancer services.

Is the tumour profile of people with learning disabilities different from that of the general population?

There are no comparative studies that would enable us to answer that question in a general sense. Should any be undertaken, it would be desirable to differentiate specific syndromes associated with cancer... There is, however, a persistent finding... that gastro-intestinal cancer has a particularly high prevalence among people with learning disabilities... With respect to specific learning disability aetiologies, we know the incidence of certain cancers is high.

Is aetiology related to incidence and types of cancer?

It is clear that there are important linkages between aetiology and the occurrence and types of cancer. A different tumour profile has been demonstrated for people with Down's syndrome, and has a very significantly increased risk of childhood leukaemia. Specific cancers in this group have been found to have differing incidences from the general population... There are also several low incidence genetic conditions in which the occurrence of cancer is evident...

Is healthcare surveillance with particular reference to cancer adequate for people with learning disabilities?

The evidence we have on involvement in screening programmes and health surveillance initiative generally is limited, but suggests that both women and men with learning disabilities are poorly served. With respect to cancer specifically, this is certainly the case as limited evidence from studies of women and breast and cervical cancer screening indicates that only a minority receive these services. Where specific linkages have been suggested, as between stomach cancer and ulcers and H Pylori, people with learning disabilities who show a high prevalence of this bacillus may be particularly disadvantaged by existing medical protocols.

Conclusion

We did find a lack of good accessible information for people with learning disabilities about cancer, and also, where we did find materials, staff were not often aware of their existence, and were not able to carry out systematic searches for relevant information.

We found a lot of evidence of barriers to effective screening, diagnosis and treatment... We would suggest that these barriers occur where there is a lack of knowledge, information and adequate planning systems... 4

Recommendations

In order to provide an accessible cancer information service to people with learning disabilities certain themes emerge. The need for:

1. Clear appropriate resources about cancer for people with learning disabilities
2. Health professionals to be aware what resources are available for people with learning disabilities
3. Health promotion to raise awareness of cancer and screening for cancer amongst this client group.
4. Clear referral protocols to ensure cohesion between different provider organisations.
5. Clear policies and protocols around how to provide cancer information to people with learning disabilities.
6. Training for cancer information givers when working with people with sensory impairments and disabilities.

Summary

The following toolkit will address these points by:

- Listing what resources are available for people with learning disabilities
- Examining how we can make services accessible to people with a learning disability at all stages of the cancer journey

It is hoped that the development of this toolkit will help services to:

- Provide cancer information to people with a learning disability.
- Run health promotion events to raise awareness of cancer prevention and screening.
- Reduce the incidence of cancer.
- Improve the experience of cancer for this vulnerable client group.



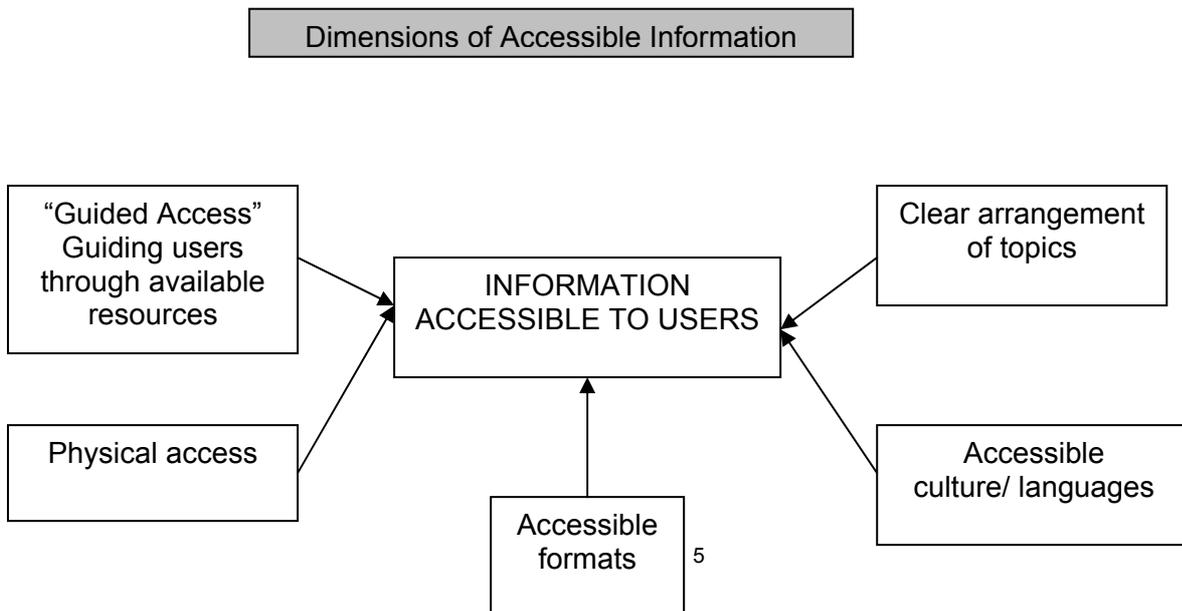
Accessibility for people with a learning disability

The White Paper, 2001 states:

The Government's objective is to enable people with learning disabilities to have access to a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard and with additional support where necessary. ²

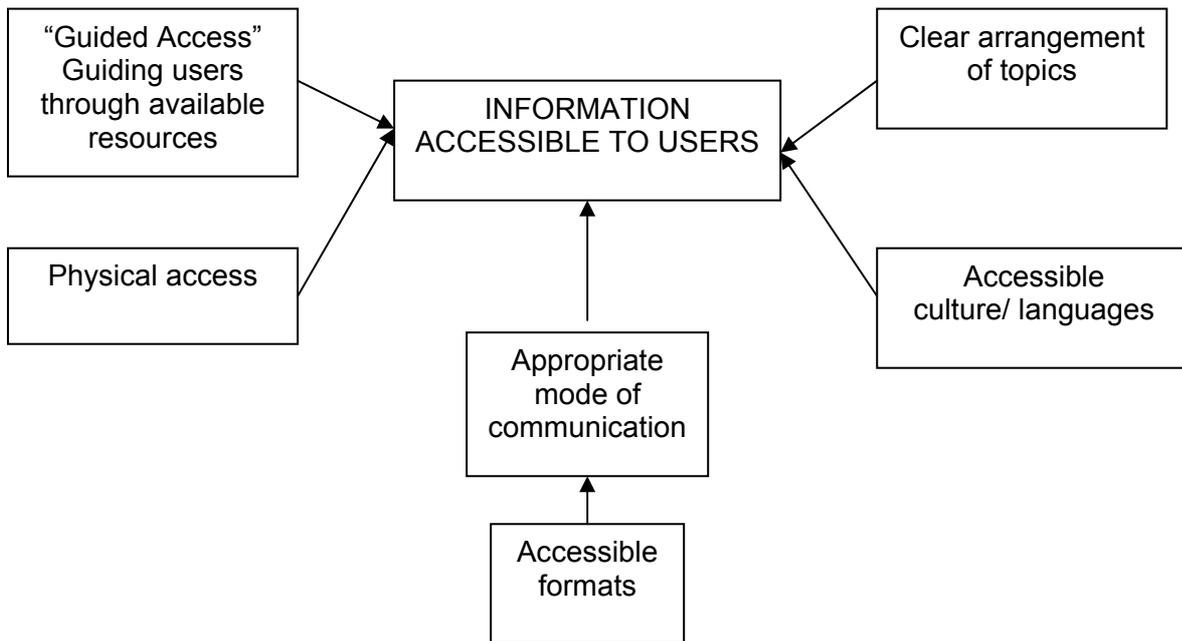
What does this mean in practical terms when it comes to people who are learning disabled?

Macmillan's model Dimensions of Accessible Information describes the different areas of accessibility.



When looking at this model in terms of people with a learning disability an additional component needs to be added. This component is how we communicate the information in the accessible format to the person with the learning disability. The Macmillan model would then look as follows:

Dimensions of Accessible Information for people with learning disabilities



The skills of people with learning disabilities to process information are as varied as the people themselves. Having information in a particular format alone may not be sufficient to communicate this to individuals.

To ensure an information service is accessible to people with learning disabilities two things must be in place:

- 1) Information in an accessible format
- 2) The means of communicating this information

The section in this toolkit, Accessibility Resources and Initiatives, lists resources that have been designed specifically for people who have a learning disability.

Communicating information

To communicate with a person who has a learning disability we need to know how that person communicates. The way that people communicate is so varied we need to identify what the best way is for that individual. This can be gathered from various sources, e.g. the referring agency. It also involves carrying out an assessment to discover how best to communicate and then developing a plan on how to communicate with the individual taking into account their specific learning needs.

Action for Health- Health Action Plans and Health Facilitation, 2002

This action plan points out that, *Health workers may lack experience in talking with service users with sensory impairments and/or profound and multiple learning disabilities, who may have limited communication skills and be anxious and unforthcoming... Health care workers may therefore need specific information from key supporters about the person's method of communication, prior to their appointment.*

More general suggestions include:

- *If people can explain their symptoms and history, this must be encouraged. It may be time-consuming, but busy health workers should be discouraged from just talking to supporters, not service users.*
- *Many people need interpreters (for example language interpreters, British Sign Language interpreters) and extra time will be needed to work with them. There may also be informal 'interpreters' (such as family or staff) who understand the ways the person communicates. The patient must be included in all discussions.*
- *Information concerning the person's method(s) of communication should be conveyed to key people to avoid creating unnecessary stress when accessing health care. The consistency of support available to the individual may influence their ability to co-operate with treatment and improve the likelihood of a successful outcome.*
- *Behaviour that challenges may express anxiety in frightening environments (such as clinical settings). People may need intensive support before their behavior presents difficulties and reduces their ability to benefit from opportunities available.*
- *If a person has particular communication needs, then a 'communication passport' can give details of important things to know when communicating with them. This can be in written and symbol format, or on videotape. Ownership and confidentiality of passports must be considered. It would be helpful for the communication passport to include a summary of what their impairment(s), and family background may mean for them.*
- *Whilst some people may prefer to receive information verbally and to depend on supporters they trust, others will require information in different formats – such as leaflets in 'Easy English' or relevant language, illustrated material, taped booklets. People may want more than one format so they can 'read' the information with a supporter and by themselves.⁶*

Current statutory requirements state that:

Health facilitators will be appointed from each local community learning disability team to support people with learning disabilities in getting the health care they need. We will ensure that all people with learning disabilities are registered with a GP and have their own Health Action Plan. 2



Putting theory into practice

In order to meet the information needs about cancer for people who have a learning disability we need to:

1. Have information about cancer in an accessible format.
2. Make links in local areas with organisations and individuals who can help us to communicate this information. Such as:
 - a. Learning Disability Nurses
 - b. Health Facilitators
 - c. Local Health Promotion Services (Health promotion services may have health promotion materials and resources available to use when running awareness events.)
3. Have the tools to “translate” information into an accessible format for the person with a learning disability
4. Have additional training around how to communicate with a person with a learning disability.

To do this you could:

1. Using the Accessibility Resources and Initiatives section following this compile a folder or box with cancer information in an accessible format for people who are learning disabled.
2. Contact the learning disability nurses and other local and statutory groups working with people with learning disabilities in the local area to establish a two-way referral pathway.
 - A pathway for you to access them in order to aid you in communication with the person with a learning disability
 - A pathway for them to access you in order to obtain information about cancer in an accessible format for a person with a learning disability.
3. Purchase software such as Writing with Symbols 2000 (a language, literacy and communication tool that uses symbols, speech and activities to help anyone read and write) in order to be able to translate information into a more accessible format.
4. In your Personal Development Plan set a goal of having training around how to communicate with a person with a learning disability.
5. Develop an accessibility policy describing how to make your service accessible to a person with a learning disability.

6. Develop a patient and public involvement strategy plan describing how to involve people with learning disabilities in the development of the service.



Accessibility Resources and Initiatives

FAIR Multimedia

<p>About the Resource</p>	<p>Information</p> <p>This organisation produces a wide range of information for people with learning disabilities.</p> <p>Copywriting, design and illustration</p> <p>Fair can edit, and illustrate your reports, leaflets or brochures to make them accessible to people with learning disabilities</p> <p>Training</p> <ul style="list-style-type: none"> • Mind your language Half a day course for anyone who is writing or commissioning written materials for people with learning disabilities • Moving on Three half day courses for staff who support people with learning disabilities
<p>Resources provided</p>	<p>Publications</p> <p>Guide to checking your breasts Guide to examining your testicles Guide to having a healthy heart Guide to a healthy mouth Men's guide to keeping clean Women's guide to keeping clean Women's guide to having a period Guide to having a smear test</p> <p>These booklets are priced at: 1-50 copies of one title: 50p each 50-100 copies: 40p each 100+ copies: 35p each</p> <p>Guide to checking your breasts CD-Rom (includes booklet) £3.50 Guide to examining your testicles CD-Rom (includes booklet) £3.50</p> <p>Holiday help £5.50 Information about holidays including funding and insurance A working life £10 Report of 3 year project, helping people with learning disabilities find and keep jobs</p>
<p>Contact Details</p>	<p>Fair Multimedia, 25-27 West Nicolson Street, Edinburgh, EH8 9DB Tel: 0131 662 1962 Fax: 0131 662 9468 multimedia@fairadvice.org.uk</p>

Macmillan Cancer Relief and the Royal College of Psychiatrists

<p>About the Resource</p>	<p>Macmillan has worked with the Royal College of Psychiatrists to produce resources for people with learning disabilities. There is a series of books called the beyond words series.</p> <p><i>Books Beyond Words</i> is a series of picture books that has been developed to make communicating easier for these people, and to enable discussion about difficult topics. Supporting text and guidelines are also provided for carers, supporters and professionals.</p>																				
<p>Resources Provided</p>	<table> <tr> <td>Health</td> <td></td> </tr> <tr> <td>Getting On With Cancer</td> <td>£10</td> </tr> <tr> <td>Getting On With Epilepsy</td> <td>£10</td> </tr> <tr> <td>Going into Hospital</td> <td>£10</td> </tr> <tr> <td>Going to the Doctor</td> <td>£10</td> </tr> <tr> <td>Going to Out-Patients</td> <td>£10</td> </tr> <tr> <td>Keeping Healthy Down Below</td> <td>£10</td> </tr> <tr> <td>Looking After My Breasts</td> <td>£10</td> </tr> <tr> <td>Looking After My Balls</td> <td>£10</td> </tr> <tr> <td>Michelle Finds a Voice</td> <td>£10</td> </tr> </table>	Health		Getting On With Cancer	£10	Getting On With Epilepsy	£10	Going into Hospital	£10	Going to the Doctor	£10	Going to Out-Patients	£10	Keeping Healthy Down Below	£10	Looking After My Breasts	£10	Looking After My Balls	£10	Michelle Finds a Voice	£10
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<p>Contact Details</p>	<p>The Royal College of Psychiatrists, Book Sales, 17 Belgrave Square, London, SW1X 8PG. Tel: 020 7235 2351 ext. 146 Fax: 020 7245 1231 www.rcpsych.ac.uk/publications/gaskell/index</p>																				

NHS learning disability website

About the Resource	<p>This project is funded by the New Opportunities Fund in collaboration with Plymouth Hospitals NHS Trust for three years, from October 2001 until October 2004.</p> <p>The Goal is to improve Cancer Services for people with Learning Disabilities, their Carers, Young Carers and people who do not use English as their first language.</p> <p>They have done this through the development of a website.</p> <p>This website has a full range of downloadable PDFs.</p> <p>The website also has a useful links page which links in with national organisations involved with people with learning disabilities.</p>
Resources Provided	<p>Downloadable PDFs</p> <p>The PDFs include the following:</p> <ul style="list-style-type: none">• A health promotion pack• A cancer journey pack
Contact Details	<p>www.learningdisabilitycancer.nhs.uk</p>

Northern Cancer Network Project

<p>About the Resource</p>	<p>This network has a website with information about cancer on it. Next to this information a little man appears whenever the information is in a format for people with learning disabilities. You can download this information as a PDF. The Macmillan specialist nurse for the learning disabled has produced these fact sheets.</p> <p>This service also offers</p> <ul style="list-style-type: none"> • Support with screening, prevention and early detection • Health promotion • Accessibility to cancer services • Support if you are living with cancer
<p>Resources Provided</p>	<p>Downloadable PDFs</p> <p>Another Northern Cancer Network plan is the development of a CD-rom, which has photos, and images of a person going through the cancer journey. Bev Collins 01928 753 502 produces this</p>
<p>Contact Details</p>	<p>Macmillan specialist nurse for the learning disabled</p> <p>1st Floor Learning Disability Office Monkwearmouth Hospital Newcastle Road Sunderland SR5 1NB</p> <p>Tel: 0191 565 6256 ext. 48249 email: ashley.murphy@stw.nhs.uk</p> <p>www.cancernorth.nhs.uk</p>



Website Links

Disclaimer: Throughout researching this project the organisations listed in Accessibility Resources and Initiatives had useful website links. This list is comprised of a lot of those links. These websites are listed for information only, it is recommended that they be reviewed before they are included in any services recommended website list.

A2A Access to Acute

www.nnldn.org.uk/a2a

The A2A network has been in existence since 1999 and has grown to become a national forum for people interested in improving the access to acute hospital care by people with learning disabilities.

Access Travel

<http://www.access-travel.co.uk>

A tour operator which specialises in holidays for disabled people, in particular wheelchair users

Acting Up

www.acting-up.org.uk

Provides information about training and development of people with communication difficulties so that they can express and represent themselves

Association for Residential Care (ARC)

www.arcuk.org.uk

A national umbrella charity of organisations providing residential and other services to people with a learning disability.

Aidis Trust

<http://www.aidis.org>

We provide computer communication equipment for severely disabled people of all ages who are without the means to purchase it themselves

British Council of Disabled People

<http://www.bcodp.org.uk>

The British Council of Disabled People is Britain's national umbrella organisation for groups controlled by disabled people

British Deaf Association

<http://www.britishdeafassociation.org.uk>

The national charity organisation representing about 70,000 Deaf people in the UK

British Institute of Learning Disabilities (BILD)

www.bild.org.uk

A major research organisation BILD is committed to improving the quality of life to all people with a learning disability. They provide general information, articles and publications about learning disabilities.

Challenging Behaviour Foundation

www.thecbf.org.uk

Provides information and advice on challenging behaviour in people with learning disabilities.

CHANGE

www.changepeople.co.uk

A national organisation run by disabled people. CHANGE fights for the rights of learning disabled people especially people with learning disabilities who are deaf or blind.

Citizen Advocacy Information & Training (CAIT)

www.citizenadvocacy.org.uk

Citizen advocacy offers friendship by one citizen to another. CAIT is the national resource agency for citizen advocacy.

Community Living (UK)

www.community-living.net.

The independent quarterly journal devoted to supporting the rights of all people with learning difficulties.

Computers For The Disabled

<http://www.cftd.co.uk>

Second hand PC's & parts supplied to the disabled and the housebound

Department of Health website on learning disabilities

www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilities.

Website on learning disabilities

Disabled Living

<http://www.disabledliving.co.uk>

Our services may be useful to disabled and older people, their families and carers

Disabled Living Centres

<http://www.dlcc.co.uk>

A national network of local disabled living centres which provide disability equipment, information and advice throughout the UK

Down's Syndrome Association

www.downs-syndrome.org.uk

Exists to support people with Down's syndrome, their family and carers as well as providing information for those with a professional interest

Down's Syndrome Scotland

www.dsscotland.org.uk

Down's Syndrome Scotland, formerly the Scottish Down's Syndrome Association, is a membership organisation which works to improve the quality of life for everyone with Down's syndrome in Scotland.

Employment Opportunities

<http://www.opportunities.org.uk>

A national charity helping people with disabilities find and retain work

Enable

www.enable.org.uk

Promotes the welfare of children and adults with learning disabilities, establishes mutual help and support amongst parents and carers, and encourages research and provision of services. Scotland's equivalent to Mencap.

English Sports Association for People with Learning Disability

www.esapld.co.uk

A national registered charity and the recognised governing body of sport for people with learning disabilities.

The Elfrida Society

www.elfrida.com

Works with people with moderate learning difficulties. Their aim is to identify and promote the best ways of supporting people to live their lives in the way they want to.

Full Circle Arts

<http://www.full-circle-arts.co.uk>

We are an agency who believe, that as Disabled People we should determine on our own behalf decision making

Headway

<http://www.headway.org.uk>

Aiming to promote understanding of all aspects of head injury with information, support and services for people who have suffered a head injury, their family and carers

Holiday Care

<http://www.holidaycare.org.uk>

If you are disabled, an older person or carer, Holiday Care can help you take a break

Irish Society for Autism (IE)

www.iol.ie/~isa1/

ISA provides services for people suffering from and dealing with Autism. This encompasses support groups for parents, providing information on Autism, lobbying for the rights of people with the condition and, most importantly, providing services for people with Autism

12 Jigsaw

<http://www.buryjigsaw.co.uk>

A social group for young people and adults with disabilities in the Bury area

LD Resources

www.ldresources.com

Resources for the Learning disability community

Learning Disabilities UK

www.learningdisabilitiesuk.org.uk

LDUK aims to be the most informative and up to date Learning Disability related site in the UK.

Malcolm Rowley Trust

<http://www.malcolmrowleytrust.eng.net>

The story of Malcolm Rowley, who died unnecessarily in the care of Salford Social Services in 1998

Manchester Disabled People's Access Group

<http://www.mdpag.org.uk>

Organisation of disabled people which campaigns, trains, consults on access issues, carries out access audits and surveys

Manchester Jewish Community Care

<http://www.mjcc.org.uk>

A leading organisation dedicated to supporting and enabling local Jewish people to cope with a variety of disabilities

Manchester Learning Disability Partnership

<http://www.mldp.co.uk>

Manchester Learning Disability Partnership support people to lead independent lives and assist them in improving their skills.

Mencap

<http://www.mencap.org.uk>

Mencap works with people with learning disabilities to fight discrimination

Mental Health Media

www.mhmedia.com

Uses a range of media to promote people's voices in order to reduce the discrimination and prejudice surrounding mental health and learning difficulties

National Association For Bikers with a Disability

<http://www.nabd.org.uk>

A small group of people in Manchester who believe that disabled people should have the enjoyment of motorcycling

National Autistic Society

www.nas.org.uk

Charity for people with autistic spectrum disorders and their families. Publications and information available.

National Development Team

www.ndt.org.uk

An independent not for profit development agency that wants new opportunities and inclusion in ordinary life for all people with learning disabilities.

Paradigm

www.paradigm-uk.org

A consultancy and development agency. Their work includes health, housing and social care services for people with learning disabilities.

Pavilion

www.pavpub.com

Pavilion is committed to promoting and developing good practice for all those involved in health and social care. Pavilion provides a range of training materials, courses, journals, conferences and exhibitions surrounding Mental Health and Learning Disabilities.

People First

www.peoplefirst.org (Birmingham) and www.peoplefirst.org.uk (Central England).

A self advocacy organisation run for and by people with learning disabilities. People First organisations in: Birmingham, Bristol, Carlisle, Central England, Ely, Leeds, London, Liverpool, Manchester, North Herts, Scotland and Sunderland.

Phab Club England

<http://www.phabengland.org.uk>

This is a national charity dedicated to promote and encourage the coming together of disabled and non-disabled people

Scope

<http://www.scope.org.uk>

The disability organisation in England and Wales whose focus is people with cerebral palsy

Scottish Consortium for Learning Disability

www.sclld.org.uk

SCLD is made up of 13 Partner Organisations who have joined together with funding from the Scottish Executive.

SCOVO

www.scovo.org.uk

An umbrella voluntary organisation promoting ordinary lives for people with learning disabilities in Wales. Their work includes development, campaigning, information and policy. In addition, they have projects focussing on planning the future for young people, direct payments, user participation and advocacy.

The Disabled Living Foundation

<http://www.dlf.org.uk>

Our vision is to provide the best possible choice for people who use equipment to live a more independent life

The Drake Music Project

<http://www.drakemusicproject.com>

A national charity that is committed to providing the opportunity for disabled people to explore, compose and perform their own music

The Dyslexia Institute

<http://www.dyslexia-inst.org.uk>

Information about dyslexia services

The Dyspraxia Foundation

<http://www.dyspraxiafoundation.org.uk>

We support individuals and families affected by developmental dyspraxia

The National Autistic Society

http://www.oneworld.org/autism_uk

The UK's foremost charity for people with autism and Asperger syndrome and their families

The National Network for Learning Disability Nurses (UK)

www.nnldn.org.uk/index.asp

The NNLDN is a 'network of networks' which aims to support networks and nurses within the field of learning disability. It facilitates networking and sharing of practice, promotes user and carer perspectives, encourages information exchange and engages with central bodies to highlight needs and achievements within learning disability nursing.

Values into Action (VIA)

www.viauk.org

Non-profit organisation campaigning for citizenship for and with people who have learning difficulties.

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