

CHAPTER SIX

Working with young people with a learning disability

Introduction

This chapter focuses on young people with a learning disability. It explains the needs and issues that young people with a learning disability may face and offers practical advice to help you to work with them. It concludes by directing you to the people and resources that can support you in your inclusive youth work.



It is important to stress that we all have strengths and weaknesses in relation to learning. We all have different ways of learning, different communication styles and different ways of conveying information. Self-awareness on the part of a youth leader on what their strengths and weaknesses are and particularly the tendency they have toward adopting a certain learning/teaching style is helpful when working with young people with a learning disability. It is also important to understand that young people with a learning disability have similar interests, desires, emotions and ambitions as any other young person. As individuals they place their mark on the world in their own way. When you look beyond a disability you see an individual that may have talents and abilities that other people might not have. Youth work is ideally placed to provide environments for young people to express themselves freely and to be involved. It is crucial that young people are included and supported in their

community-based youth groups even if they are also attending specialised services.

In the Republic of Ireland under the **Equal Status Acts 2000 and 2004**, it is unlawful to discriminate against a person on the grounds of their disability in the provision of goods and services, education, sports, access to public facilities accommodation and employment.

In Northern Ireland the **Disability Discrimination Act 1995** and the **Equality (Disability) (Northern Ireland) Order 2000** gives disabled people rights in the areas of the provision of goods and services, education, sports, access to public facilities and accommodation and also in employment. Disability discrimination in education is covered by the **Special Education Needs and Disability (NI) order 2005 (SENDO), as amended**. SENDO applies to schools, education and library boards, amongst other further education bodies. **Autism Act (NI) 2011** means that rights and access of services and benefits will now be based on a person's level of social and communication impairment and function as well as on intellectual or physical ability.



Terminology

This resource has been developed to be used by youth workers on the island of Ireland. At times it is necessary to make distinctions between our two jurisdictions and we had to choose a terminology to reflect this. We have chosen for the most part to use Northern Ireland (NI) and Republic of Ireland (ROI). At times we also use North and South. Additionally, for clarity, where information is significantly different we have used coloured boxes:

Republic of Ireland and Northern Ireland

In exploring how a young person with a learning disability can be involved in your youth group it is important to treat the person as an individual, and to look foremost at what they can do, rather than at what they may have difficulty doing. Ask the young person (and their parents/guardians) about their **abilities** and their **interests**, then what specific learning or functional difficulties they may have that could affect their engagement in youth work. Then look at what **support** they need to be fully involved. This focus on the young person as a young person first is fundamental. Looking at the specifics of a disability, and how the disability might affect the young person, follows only after that fundamental approach.

Terminology relating to disabilities is complex. Terminology changes over time and words can take on different meanings and can become emotive for those involved. Much of the terminology relating to disabilities is linked to categories that have been developed to aid in the assessment of children and young people so that educational supports can be provided. Furthermore, terminology differs both within and between the Republic of Ireland and Northern Ireland. For example, in Northern Ireland the term 'learning disability' is often used whereas in the Republic of Ireland you may also hear the term 'intellectual disability'. In Northern Ireland there is a strong resistance to the use of the term intellectual disability. In the Republic of Ireland the term 'young person with a disability' tends to be used more often, meaning the person is central, not the disability, whereas in Northern Ireland the term disabled person is often used, meaning that the person is disabled by society (this is the definition used by the social model on disability) and it is up to society to put the necessary supports in place to give everyone the opportunity to live inclusive and productive lives. The term 'disability' itself is not used especially in relation to specific issues such as Dyslexia, Dyspraxia etc. This is explained in more detail in the Appendix of this chapter. The best advice is to ask the young person you are working with or



their parent/guardian what terminology they prefer to use or model your terms on the ones they use. We must also remember that how we speak about a disability often determines how young people feel about themselves and their relationship with the world around them. What is important is how we remove barriers in our services to support all young people to achieve their own potential and for the majority of young people with a learning disability this will require challenging attitudes, behaviours and language.

This is encapsulated by taking a **universal design approach** – an approach that caters for people irrespective of their age, size, ability or disability. For example, easy to read documents benefit more people than those who specifically need them; wheelchair access benefits people with buggies; clear signage and instructions makes our spaces safer and more pleasant for everyone including people who have literacy issues, those who are Deaf, and those where English is not their first language, etc.

What is a learning disability?

A **Learning Disability** affects intellectual ability which may mean that a person finds it more difficult to learn, understand and communicate. A learning disability can also affect someone's speech and their ability to communicate verbally. A learning disability will be described by experts as mild, moderate, severe or profound.



The extent of someone's disability varies greatly from person to person. Some people with a learning disability may have additional disabilities. However, with the right support individuals can lead fulfilling and independent lives.

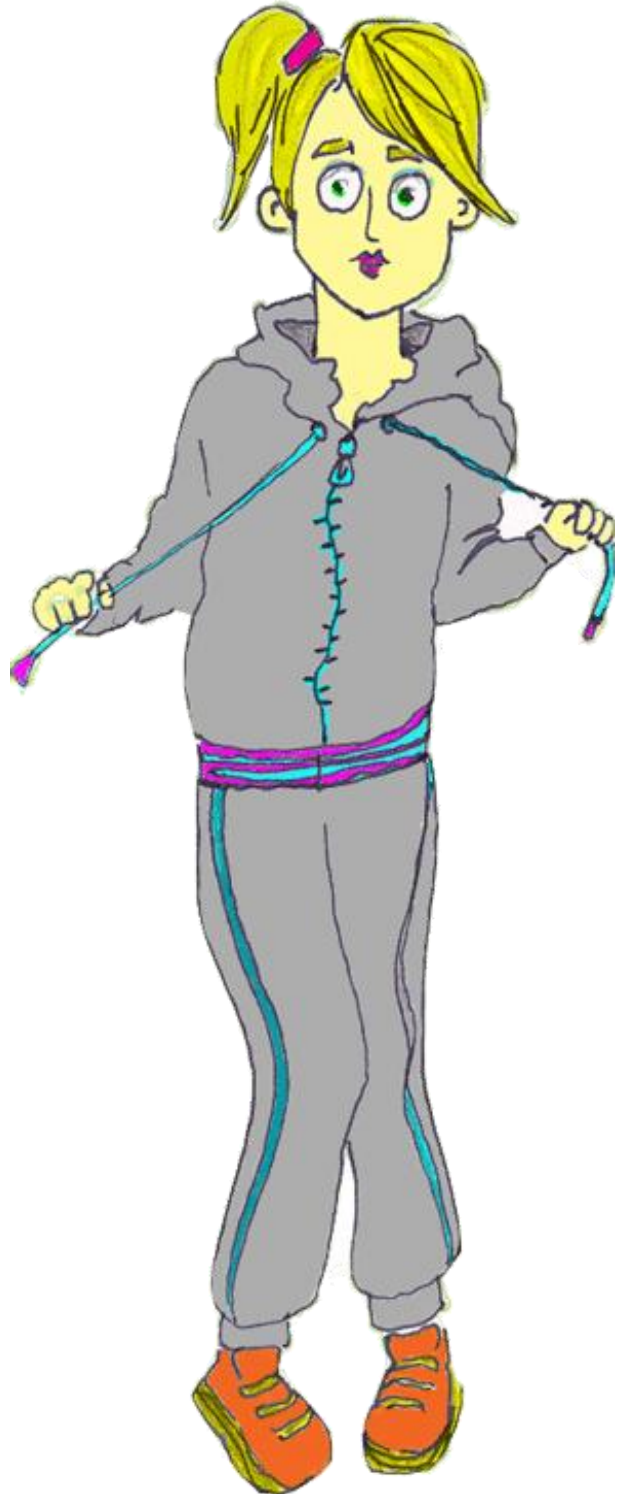
For more detailed information on a range of learning disabilities and related conditions see the Appendix at the end of this chapter or visit

www.mencap.org.uk

Demographics

In **Northern Ireland (NI)** 33,000 have a learning disability and over 20,000 individuals are affected by Autism.ⁱ

In the **Republic of Ireland (ROI)** the National Intellectual Disability Database (NIDD) estimates that the number of people aged 5 to 19 years with learning or intellectual disability is 7.9% of the population (the vast majority of which are specific learning difficulties i.e. dyslexia). Those affected by Autism Spectrum Disorder is 0.6% of the population.ⁱⁱ In all cases boys are affected considerably more than girls.



Needs and issues for young people with a learning disability

Young people with a learning disability like to go out, make friends, be independent and have fun. Your service can offer these things to all young people. Some young people with a learning disability may need some extra support or adaptations to be made to be able to participate in your programmes. This is also the case for many of the other young people who want to use your service.

Young people with a learning disability don't expect you to be an expert or have specialist training. In fact they may want to join your youth programme specifically because they want to be part of what is going on for other young people.

Many young people with a learning disability may have limited social contact. They may go to a specialist school where their friends live far away from them. As little as 1 in 5 adults with learning disabilities are currently in paid employment so being involved in the community can help prevent the social isolation that results from not being an active member of the wider society.ⁱⁱⁱ



A young person with a learning disability may have limited access to transport. Parents may be overprotective of their disabled children until they are assured that they are in a safe environment where their specific needs will be met.

There is a high rate of bullying for young people with a learning disability with 8 in 10 people having experienced bullying in the last year.^{iv} They are twice as likely to be bullied as other children and the negative attitudes that society has towards them can heighten their sense of exclusion.

Barriers

Other barriers faced by young people with a learning disability include:

- **Having access to information**
- **Being included in youth programmes and other services**
- **Lack of choice**
- **What we think can be done instinctively often needs to be "taught" to people with a learning disability. For example, things that we would intuitively do such as asking for help or clarification.**
- **"Environmental" factors can really irritate someone with sensory issues, e.g. overpowering smells (disinfectant, perfume, etc), noise (e.g. alarm going off unexpectedly), touch (difficulty handling certain textures)**
- **Negative attitudes and perceptions directed towards young people with a learning disability**

Negative attitudes and perceptions directed towards young people with a disability result in:

- **Being segregated from others**
- **Being treated with fear and unease**
- **Being patronised**
- **Being treated differently**
- **Not having equal access to services**
- **Being pitied**
- **Having decisions made on their behalf**

Developing disability inclusive practice - working with young people with a learning disability

The following advice relates in general to working with young people with different learning needs as well as those with Autism. See the Appendix at the end of this chapter for advice relating to specific conditions.

Challenge attitudes

The biggest barrier that faces young people with a learning disability is often the negative attitudes of other young people. Remember to model good practice and show respect, acceptance and dignity to all young people, including those with a learning disability. It is important that you work with your group to challenge attitudes and break down stereotypes about all young people with a disability.

Focus on the person as an individual

People who have a learning disability should be treated as individuals defined by their potential and abilities as opposed to their disability. They have the same desires, expectations and ambitions as people without disabilities and they have a right to pursue their dreams as active citizens within a supportive and encouraging environment.



Be supportive

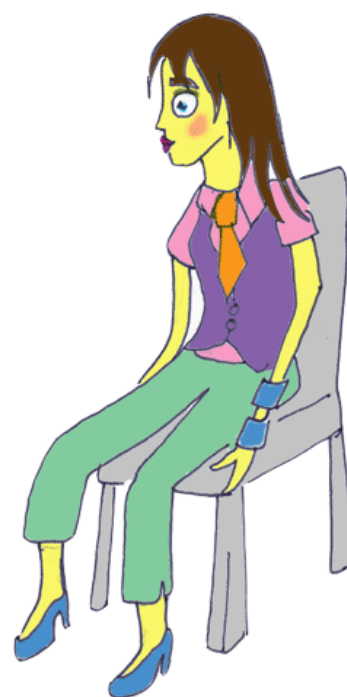
Supporting and involving young people with a learning disability can often be a challenge. The level of support someone needs is ultimately down to their individual preference. It shouldn't be assumed that two young people with a learning disability require the same level or style of support. Don't assume that all young people who are disabled require support as this may not be the case. It is important to ask them what they need.

Young people with a learning disability want to make their own decisions about the type of support they receive. Support might include assisting a young person to write, draw, and speak up in a group, find places or things or by simply building their confidence through encouragement.

Participation

Young people with a learning disability want to participate in activities on their own terms. It may take time for a young person with a disability to build enough confidence to take part. Pressure should not be applied to participate as some young people may be happier at the outset to be present rather than take an active role. Always consider what the young person might need in terms of support or adaptation of the activity. This might mean reducing the number of rules, breaking tasks or activities into shorter manageable bits giving frequent breaks and offering repetition to ensure understanding.

Planning and evaluation is a key part of leading activities. Involving young people in planning and evaluations and using their feedback to improve the way you work is an excellent way to make the service more young person centred.



- **Establish the young person's interests and use this to get to know them and develop skills and social interaction from this.**
- **Obsessions with certain objects or activity can be redirected by allowing them at certain times, e.g. "we'll finish off tonight's session with a basketball game" or " first we will play board games then snack time then you can have a choice between (something the person might be a bit obsessive about) and (something you know that really appeals but is not an obsession)**
- **Build on their strengths and appeal to their better ability e.g. put someone in goals (But not all the time!) as opposed to mid-field as they might be better able to play within a confined space and with a definite focus.**
- **If someone is reluctant to get involved, give them a job "Could you help me with this" something that builds confidence and gives a sense of success etc.**
- **Have fun!**

Communicating with your team

Share information between colleagues where appropriate to ensure they are fully aware of what support is needed for individual young people. Communication is also important so that when organising and planning new events or activities they are planned in a way that is inclusive of all young people - with and without a disability.



Build relationships

Young people with a learning disability might require support to build friendships and relationships with other young people. Barriers and discrimination need to be challenged so that forming friendships and relationships are made easier. This can often be a sensitive area particularly between the sexes or where there is a sexual attraction. It is important to offer support and where appropriate information but remember the young people are young people first relationships are difficult and painful for many young people. Young people with a learning disability may need some additional time and support to understand and learn from their experiences.

Take the time

Many young people with a learning disability have described situations where people have not taken the time to communicate with them or who treat them like a child. When asked about their views on communication young people say ‘talk directly to us, not to parents or carers’ and ‘take your time and make sure you understand what we said’.

Communicate with parents and carers when necessary. The parents and families of young people with a learning disability will often be a key source of information and support to you. They will have vital information on communication and support needs that will help you plan and carry out activities.



Communication

Remember - young people appreciate being spoken to directly as it makes them feel valued ultimately they are the experts in understanding learning disability. Young people who have a learning disability can and will communicate given the right support and resources. However, it is important to remember that long periods of communicating can be emotionally and physically exhausting for both the worker and the young disabled person. It can require a great deal of patience and effort. Several shorter individual sessions held on a regular basis can be more productive than fewer, longer sessions. Working with two staff to one young person can work well when trying to complete a complex task and establish good communication.

- **Find a good place to communicate in**
- **Ask open questions**
- **Give information in a clear, concise, concrete format. Check with the person that they understand what you are saying. A yes or no response is no indication that they understood fully what you are saying. Ask them to repeat in their own way what they have understood.**
- **If the person wants to take you to show you something go with them**
- **Observe the young person and use your intuition**
- **Learn from experience**
- **Take your time, don't rush your communication**
- **Use gestures and facial expressions**
- **Be aware that some people may find it easier to use real objects to communicate but photos and pictures can help too**
- **Try drawing or using digital photos of equipment, people, places etc**
- **If you are struggling to understand what someone is trying to communicate ask others such as their friends or other leaders who are**

more familiar with them to help you understand – don't feel embarrassed.

- **Check with parents if you have concerns about a particular activity**
- **Young people who also have Autism/ Asperger's syndrome can have difficulty with "small talk", they will take things literally, find it difficult to understand subtlety, irony or innuendo. They can adapt socially if given a specific task, e.g. having a checklist to tick off, checking what people want to eat, what people's favourite films are etc.**

Some young people may use different forms of communication. Find out if the young person attending your group uses a different communication system and try to incorporate it into your work. Some examples include:

- **Makaton**

This is a system that uses gestures or signs together with visual symbols as an aid to communication. For more information see www.makaton.org

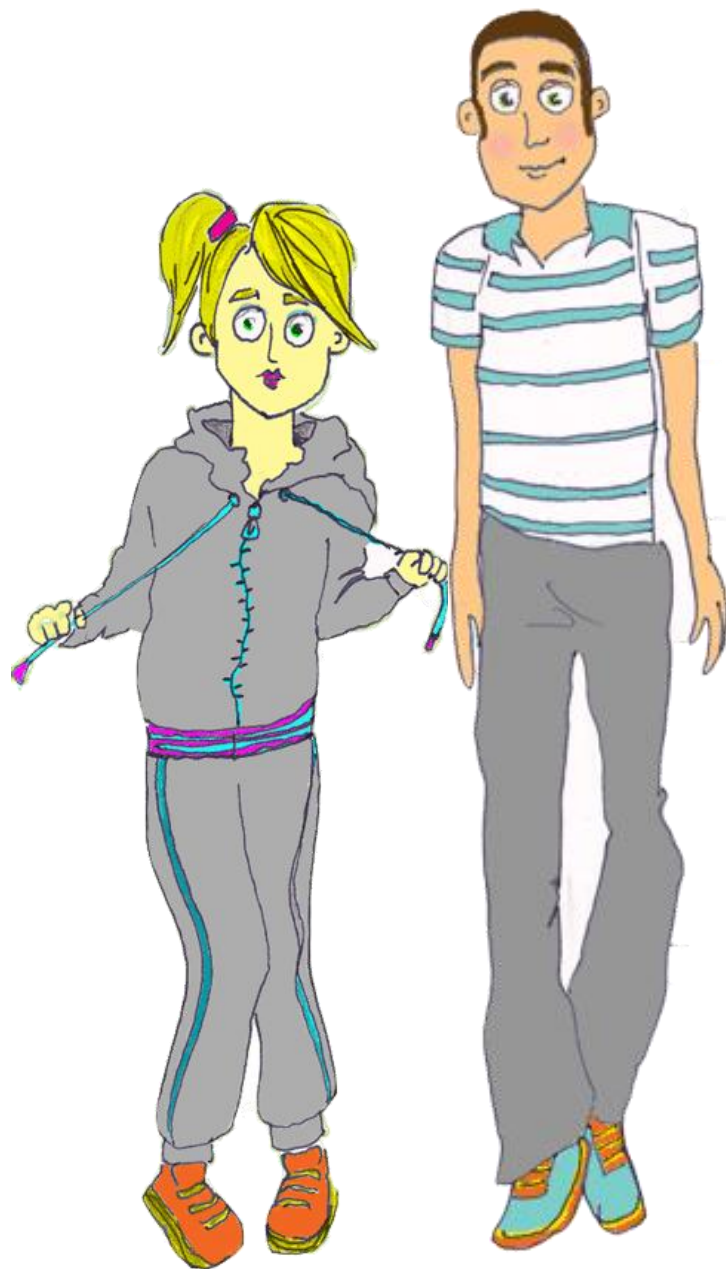
- **Talking Mats**

This is a low-tech, visually-based communication approach which uses Picture Communication Symbols (PCS) as a means of enabling people with communication difficulties, including those with a learning disability, to convey their views and feelings. They can be used, for example, to inform reviews or decisions about services

Become informed

Descriptions giving some specific information on the most common range of disabilities and related conditions that you might see, and how to address them are included in the Appendix at the end of this chapter. You can also consult the contacts at the end of this chapter for support and advice. In all

cases it is important to remember that the expert on a person's ability/disability is the young person themselves. Their parents/guardians will also have useful information that will help you to work with them.



Challenging myths about young people with a disability

One very practical way of challenging attitudes is to be aware of common myths about young people with a learning disability, and having the facts that debunk them. You can use these myths in your youth work activities. You can make sure the people you work with are aware of them. You can print them in large print and put them up for young people to see to increase awareness.

Myth 1 People with learning disabilities are helpless

Don't assume that someone with a learning disability needs your help. A young person who doesn't need help may (understandably) feel very frustrated that other people are constantly trying to take over tasks that they can do themselves. If you think someone needs help, ask them first. If they say yes, ask them what to do before you act. Most young people with a learning disability want opportunities to be independent and have control over their own life. They want to be able to look after themselves rather than be looked after.

Just because someone has a learning disability doesn't mean they don't have abilities. You might be surprised to learn that they have talents and abilities that other people might not have. Don't assume that someone with a learning disability cannot get involved or is not interested in getting involved with your program.



Myth 2 People with learning disabilities need sympathy

People with disabilities do not need sympathy or want pity. They also don't need to be told that they are brave or courageous for living with a learning disability. Some young people with disabilities are brave; some are not, just like everyone else. People with disabilities do not need to be treated as children, they need opportunities to maximise their independence.

Myth 3 People with learning disabilities are sick

A learning disability is not necessarily a sickness. Many people with disabilities are healthy.

Myth 4 All learning disabilities are obvious

Not all disabilities are obvious. In fact it is likely that some young people using your service have a learning disability that you don't know about. Don't assume that you need to know if someone has a learning disability.

Myth 4 People with learning disabilities only want to hang out with each other

The reason most of us make friends with particular people is because we get along well with each other and have common interests. People with learning disabilities are no different. Most like to have a range of friends including those with and without a learning disability.

Myth 5 All people with a learning disability are the same

People with a learning disability are individuals. Not all individuals are the same.

Checklist 6 - How accessible is your organisation to young people with a learning disability?

This checklist can help you to identify how you can improve your service for young people with a learning disability.

Programme planning and delivery

Our programmes are designed and delivered to include the diverse needs and identities of young people with a learning disability

Transport

- Our service considers the transport needs of young people who have difficulty in getting to our service and works to support them YES PARTLY NO

Programmes

- Our programmes and activities are designed with all young people in mind including those with different skills and understanding YES PARTLY NO

Policies and procedures

We have a written commitment to deliver an equal and inclusive service

- Our organisation has a written commitment to equality and inclusion that includes people with a learning disability YES PARTLY NO

Public image

How we present our service to our community

Promoting our service

- | | | | |
|--|------------|---------------|-----------|
| • All written information is easy to read, uses simple English and avoids using jargon | YES | PARTLY | NO |
| • Photos and drawings of young people we use in promotional material feature a range of young people, including young people with disabilities | YES | PARTLY | NO |
| • We involve young people in the production of our promotional material, including young people with a disability | YES | PARTLY | NO |
| • We network with and provide promotional material to a wide range of services, including disability services | YES | PARTLY | NO |
| • Young people can phone, text, email or fax our service | YES | PARTLY | NO |
| • Young people can use Facebook or Twitter to keep in contact with our service | YES | PARTLY | NO |
| • We use clear print in our printed material (see clear print guidelines in Chapter 5) | YES | PARTLY | NO |

Partnerships and networks

- | | | | |
|--|------------|---------------|-----------|
| • We have a referral list of disability services for young people and their families | YES | PARTLY | NO |
| • Our service works in partnership with disability services to make our service accessible | YES | PARTLY | NO |
| • We provide information about our service to disability services | YES | PARTLY | NO |

Professional development

Our staff and volunteers are trained and supported to deliver an inclusive youth service

Staff and volunteer awareness

- | | | | |
|--|------------|---------------|-----------|
| • Our staff and volunteers are trained in basic learning disability awareness | YES | PARTLY | NO |
| • Our staff and volunteers have strategies in place for promoting friendships among young people attending programs, such as group and team activities | YES | PARTLY | NO |
| • We employ an inclusion worker | YES | PARTLY | NO |

Participation

We make sure we include the voices of young people at all levels of our youth service

- Young people with a learning disability have their views and opinions heard and are involved in decision making, such as having input about how services are run. They are involved in consultations at all levels of the organisation such as on the Board, on a youth committee or management committee and these are conducted in ways that are accessible and age appropriate etc

YES

PARTLY

NO

Useful contacts – Northern Ireland

Mencap

Segal House,
4 Annadale Avenue,
Belfast BT7 3JH

Phone: (028) 9069 1351

Web: www.mencap.org.uk

Mencap helpline: 0808 80111

The learning disability helpline is an advice and information service for people with a learning disability, their families and carers

Mencap works to gain support, education, housing, jobs, and recreational opportunities for people with learning disabilities. They also offer supportive services to their families.

Positive Futures

2b Park Drive
Bangor,
BT20 4JZ

Phone: (028) 91 475720

Email: info@positive-futures.net

Web: www.positive-futures.net

Positive Futures for people with a learning disability is a Northern Ireland charity that supports children, young people and adults with a learning disability.

Autism NI

Donard,
Knockbracken Healthcare Park
Saintfield Road,
Belfast
BT8 8BH

Phone: (028) 9040 1729

Helpline: (028) 9040 1729 (Monday, Wednesday and Friday 9.30am-1pm)

Autism NI is a parent led partnership organisation having been formed to promote positive collaboration between parents, professionals and individuals with Autism to address the need for appropriate services.

Cedar Foundation

Adelaide House,
Hawthorne Industrial Estate,
Belfast BT12 6SJ

Phone: (028) 9038 7040

Email: cse@cedar-foundation.org

Web: www.cedar-foundation.org

The Cedar Foundation delivers a range of services which empower and support people with disabilities throughout Northern Ireland to be fully included in their communities, ranging from accessible accommodation for people who have brain injury, physical disability and sensory impairment, as well as for people who have learning disabilities.

Useful contacts – Republic of Ireland

Enable Ireland

**32F Rosemount Park Drive,
Rosemount Business Park, Ballycoolin
Road, Dublin 11, Ireland.**

Phone: (01) 872 7155

Email:

communications@enableireland.ie

Web: www.enableireland.ie

Enable Ireland provides free services to children and adults with disabilities and their families. Their expert teams work with the individual and their family on a plan for each life stage. Their services cover all aspects of a child's physical, educational, and social development from early infancy through adolescence. Children's Services are based in Cork, Clare, Cavan, Dublin (Tallaght & Sandymount), Galway, Kerry, Kildare, Kilkenny, Limerick, Mayo, Meath, Monaghan, North Tipperary, Wicklow.

National Disability Authority

25 Clyde Road,
Dublin 4

Phone: (01) 6080400

Fax: (01) 6609935

Email: nda@nda.ie

Web: www.nda.ie

The National Disability Authority is the independent state body providing expert advice on disability policy and practice to the Minister, and promoting Universal Design in Ireland.

The NDA website has resources, including a paper on the Quality of Life of Young People with Intellectual Disability in Ireland

National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability

Oranmore Business Park
Oranmore
Galway

Phone: (091) 792316

Fax: (091) 792317

Email: info@fedvol.ie

Web: www.fedvol.ie

The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability is a national umbrella organisation for voluntary/non-statutory agencies who provide direct services to people with intellectual disability. Their 62 Member Organisations provide services to 22,000 people with an intellectual disability and their families. The services are founded on the Principles of Inclusion, Choice, Dignity, Respect, Participation and Contribution. They take a rights based perspective that people with intellectual disability have the right to live full and active lives, and be active participating members of their own community.

Inclusion Ireland

Unit C2, The Steelworks,
Foley St,
Dublin 1

Phone: (01) 8559891

Fax: (01) 8559904

Email: info@inclusionireland.ie

Web: www.inclusionireland.ie

Inclusion Ireland is a national association for people with an intellectual disability. The vision of Inclusion Ireland is that people with an intellectual disability live and participate in the community with equal rights as citizens, and live the life of their choice to their fullest potential.

Special Olympics Ireland

Special Olympics Ireland is made up of 5 regional offices and a central office:

Central Office

4th Floor, Park House,
North Circular Road,
Dublin 7,

Phone: (01) 8823972

Email: info@specialolympics.ie

Web: www.specialolympics.ie

Special Olympics Ireland is first and foremost a sports organisation for people with an intellectual disability, but it provides athletes with far more than the physical benefits of sport.

It's about fun, friendships and team spirit; it's about a feeling of belonging, and ultimately improving quality of life.

Through sport, athletes develop both physically and emotionally, they make new friends, realise their dreams, and know they can fit in.

Disability Awareness Training

The Lilac Project

Fleming Fulton School
Upper Malone Road
Belfast
BT9 6TY

Phone: 028 9061 3877

Email: info@lilacni.org.uk

Website: www.flemingfulton.org.uk

The lilac project provides outreach support for disabled children attending mainstream schools.

Disability Sports NI

Adelaide House,
Hawthorne Industrial Estate,
Belfast BT12 6SJ

Phone: (028) 9038 7062

Web: www.dsni.co.uk

Disability Sports NI run a range of events, participation programmes, training courses and services, all designed to give local disabled children and adults the opportunity to lead a full and active lifestyle through sport and physical recreation.

Youth Inclusion Hub

Mencap
Segal House
4 Annadale Embankment
Belfast
BT7 3JH

Phone: (028) 90 691351

Email: Helen.mcvitty-ohara@mencap.org.uk

The Youth Inclusion Hub offers information and advice and free disability and inclusive awareness training both OCN level 1 and non-accredited for youth workers, volunteers, children and young people from across Northern Ireland along with Buddy training for non-disabled young people.

Resources

Information and resources about all aspects on learning disability:

Mencap Resources Centre

www.mencap.org.uk/all-about-learning-disability/resources-centre

KIDS – The disabled children’s charity Publications and Guidance

www.kids.org.uk/information/100428/100623/publications_guidance/

Kid’s charity is developing both the thinking and services that create an inclusive world for disabled children, young people and their families. There are publications and resources available to aid with inclusion

Arts 4 All – a resource pack of creative activities for working with children of mixed abilities

<http://ywicork.com/art4all%20resource%20brochure%20layout.pdf>

Basic Facts for Leaders Leaflets ‘Disability’. *The Boys Brigade*. NI. Millar, C. (2011)

Using Plain English and no jargon

Refer to NALA for advice.

Freephone: 1800 20 20 65

Web: www.nala.ie

A useful guide for “plain English” writing is also available at

www.plainenglish.co.uk/files/howto.pdf and at

www.dest.gov.au/archive/publications/plain_en/writing.htm

A guide to making information clear and easy to read for people with a

learning disability www.mencap.org.uk/sites/default/files/documents/2008-04/make%20it%20clear%20apr09.pdf

APPENDIX

Information and advice on working with young people with a learning disability or conditions associated with a learning disability ^v

Some people with a learning disability also have other physical and emotional conditions, and may receive more than one diagnosis. This could have an impact on the kind of support they and their families need in their day-to-day life. You can find out more about some of the conditions associated with learning disability below, and where relevant some specific advice on working with young people with these conditions. Please note these are general strategies – each young person is unique. Speak to the young person and their parents/guardians in advance to get a better idea of their individual needs.

Global development delay

The term 'developmental delay' or 'global development delay' is used when a child takes longer to reach certain developmental milestones than other children their age.

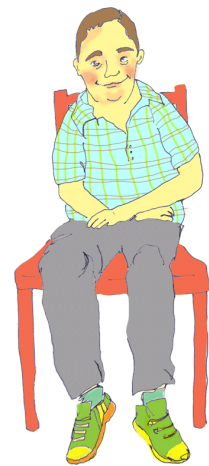
This might include learning to walk or talk, developing motor skills, learning new things and interacting with others socially and emotionally.

Someone with another condition, like Down's syndrome or cerebral palsy, may also have global developmental delay. In some cases, the delay will be short-term and can be overcome with additional support or therapy. However, in other cases the delay may be more significant and the child will need on-going support – this indicates they may also have a learning disability.

A diagnosis of developmental delay can be very confusing for parents – and it's important to remember that every child is unique and will develop at their own pace. Getting an early diagnosis can help to ensure the right support is put in place as soon as possible, to help each person to reach their full potential.

Down's syndrome^{vi}

A person with Down's syndrome may take longer than other children their age to reach certain milestones and to develop certain skills. They may also need on-going support for different aspects of their life when they become an adult. There are some health problems associated with Down's syndrome, such as heart problems and difficulties with sight and hearing. However, these will not affect everyone with the syndrome. Increased awareness and better healthcare also mean the health and wellbeing of people with Down's syndrome have improved greatly in recent years. More recently young people with Down's syndrome along with other young people with a learning disability have undertaken 3rd level education courses through specially designed access programmes.



Fragile X syndrome

Fragile X is a genetic condition that affects both boys and girls, although boys are often more severely affected. Of those with the syndrome, all boys will have a learning disability but only a third of girls. The learning disability could be mild, moderate or severe, which will affect the amount of support the person needs day-to-day.

Most people with Fragile X will need support with their speech and language, and with social and emotional interaction with others. Some people with the condition also develop epilepsy, and a small number have autism. This may also have an impact on the kind of support they need, both as a child and as an adult.

Advice on working with young people with Down's syndrome and Fragile X

- **Be clear and explicit when explaining rules and routines**
- **Communicate directly to the young person, make eye contact, use facial expression and visual tools if it helps**
- **Leave time for the young person to process language**
- **Listen carefully – your ear will adjust to the young person's speech patterns**
- **If inappropriate behaviour occurs ask yourself:**
 - **Was I clear in my instruction – did he or she understand?**
 - **Was the activity/ task at an appropriate level?**
 - **Was the activity/ task too long?**
 - **Did he or she have the support they needed?**

NOTE: Learning disability is the most common form of disability. Many people with a learning disability have other associated conditions. The information that follows is for conditions associated with a learning disability. These are not considered a learning disability in and of themselves.

Autism Spectrum Disorder^{vii}

The three main areas of difficulty which all people with autism share are:

- Difficulty with social communication
- Difficulty with social interaction
- Difficulty with social imagination

ASD can result in the inability to make friends. Young people with ASD often fail to understand words or phrases that are abstract – e.g. “we’ll go swimming later” or “I love you”; or that have a double meaning – for example, if the teacher says to a child with ASD, “clear the table” he may push everything off it. Or the person may interpret things very literally – e.g. “give me a hand”.

Individuals with ASD demonstrate varying degrees of the following:

- **Deficits in communication and language**
- **Intense interest in certain interests or activities**
- **Dependence on routine**
- **Sensory problems**
- **Behaviour problems**
- **Variability of intellectual functioning**
- **Uneven development profile**
- **Difficulties in sleeping, toileting and eating**

Specific advice on working with young people who have Autism Spectrum Disorder - Asperger’s Syndrome and Autism

- **Talk to parents to find out how their son/ daughter responds to different situations**
- **Prepare for any changes to your programme in advance**
- **Always refer to the young person by name**
- **Use visual lists to provide structure for an activity. Reduce the person’s anxiety by talking them through the activity before it happens**

- **Keep verbal instructions short and simple**
- **Be clear and concise in your instructions**
- **Do not bombard individuals with too many instructions at one time**
- **If needed, back up the spoken word with visual supports to give instructions and set tasks e.g. line drawings or a simple sketch - demonstrate what to do**
- **Remember to give individuals time to process the information and give extra time to respond**
- **Observe the person and take your lead from them**
- **Individuals may not know which words to use in a social situation, give examples of the words to use**
- **Develop a 'buddy' or mentor system - Prepare peers before asking them to help**
- **Allow time for discussion with buddies or mentors after the session**
- **Use the young person's ability to learn facts by rote to increase their self esteem**
- **Provide space and time out for the young person to calm down if they are agitated**
- **Small groups within a larger group work best.**
- **Don't expect eye contact and never force them to look at you**
- **Use stories to explain social communication/ instruction**
- **Consider lighting, noise which may be irritants**

Attention Deficit Hyperactivity Disorder (ADHD)^{viii}

ADHD is used to describe children and young people who display over active and impulsive behaviour. Young people with ADHD generally display some of the following:

- **Difficulty in following instructions**
- **Difficulty in completing tasks**
- **Difficulty 'sticking to' a task**
- **Easily distracted and forgetful**
- **Restlessness**
- **Talkative and chatty – often interrupting others**
- **Impulsive**
- **Difficulty contemplating consequences of actions**
- **Difficulty waiting their turn**

ADHD is five times more likely to be displayed in boys than girls and in more severe cases may be treated with medication (e.g. Ritalin)

Specific advice on working with young people who have Attention Deficit Hyperactivity Disorder (ADHD)

- **Make eye contact when giving instructions**
- **Keep it short and simple**
- **Provide the young person with two choices rather than giving them an opportunity to say NO**
- **Set short achievable goals and reward them with immediate**

encouragement

- **Use checklists to help with completing activities or tasks**
- **Provide a space for 'time out' to calm down if tempers escalate**
- **Use large print text that is well spaced out on written communications**

Poor Concentration Skills^{ix}

Recognising young people who have poor concentration skills will help you adapt your approach and offer them support to be involved in your programmes.

Things to look out for are:

- **Easily distracted by background noise**
- **Easily distracted by what is going on around them**
- **Poor eye contact with the person who is speaking to them**
- **Very fidgety, difficulty sitting still**
- **Speaking out of turn**
- **Difficulty following instructions or responding to questions appropriately**
- **Disruptive/ Restless**

Poor concentration skills can affect language and impact on social and emotional development. A young person with poor concentration skills may also have another learning difficulty or disability.

Specific advice on addressing some of the effects of Poor Concentration Skills

- **Keep background noise to a minimum**
- **Don't speak too fast or chop and change what you are talking about**
- **Use visual prompts to help with communication**
- **Make sure activities are at an appropriate level**
- **Pause regularly between sets of instructions**
- **Repeat, rephrase – check that the information has been understood**

Expressive Language Difficulties*

Some young people with a learning disability may have difficulty expressing themselves. Things to look out for are:

- **Over use of labels or non-specific words e.g. 'thingy'**
- **Over use of hesitations/ pauses or fillers e.g. 'em' 'Oh'**
- **Over use of gesture to describe something**

Specific advice on addressing some of the effects of Expressive Language Difficulties

- **Observe – pay close attention to the young person**
- **Wait – do not be tempted to talk or become involved too quickly – give the young person time to speak (count to 10 – or even 30 - if needs be in your head)**

- **Listen – be an active listener and don't assume you know what the young person wants¹**

Moderate Learning Difficulties (MLD)^{xi}

A young person with MLD with generally:

- **Find it difficult to concentrate**
- **Have low confidence levels**
- **Find it difficult to understand instructions**
- **Have difficulties with reading, writing, spelling and numeracy**
- **Have a low IQ (usually 70 or below)**
- **Can have behavioural problems (often used as a way to gain attention)**

Specific advice on addressing some of the effects of Moderate Learning Disability (MLD)

Some people with a learning disability do not have a single diagnosed condition and instead are referred to as having mild or moderate learning disabilities. Often these young people may receive some additional help in education but generally will not be eligible for services from Health.

- **Repeat instructions where necessary**
- **Provide visual prompts to help with understanding instructions**
- **Never directly ask a young person to read, always ask someone to**

¹ Hanen Early Language Programme (2011) *It takes two to talk*.

volunteer to read

- **Use a 'timeout' system if behaviour gets out of control**
- **Give tasks that are appropriate and attainable**
- **Always provide encouragement and reward achievements**

Dyspraxia^{xii}

Dyspraxia involves messages not being properly transmitted in the brain. It primarily affects movement and difficulty in coordination of movements. Approximately 1 in 20 young people display Dyspraxia. Four times more boys than girls display it.

General characteristics include:

- **Difficulties in coordinating movement**
- **Difficulties in throwing and catching**
- **Other activities can pose challenges** – e.g. following sequential instructions, getting dressed and handwriting
- **Confusion over left and right actions**
- **Inability to recognise potential dangers**
- **Can appear awkward or clumsy**
- **Can have difficulty concentrating**

Specific advice on addressing some of the effects of Dyspraxia

- Give clear and unambiguous instructions
- Always check whether the young person has understood an instruction
- Break down activities into manageable steps
- With some young people it might be necessary to avoid games and activities that rely heavily on coordinated movements
- Give regular encouragement and praise

Specific advice addressing the effects of general Mobility and Physical co-ordination difficulties

- Review the equipment you use - some items can be substituted to make games more accessible – a foam ball instead of a football can slow the pace of a ball game
- Introduce new rules – one touch football, tag team games
- Get in the experts – organisations like Disability Sport NI can give advice , deliver games/sports sessions and even lend equipment
- Introduce co-operative games and activities

Receptive Language Difficulties^{xiii}

Having poor, delayed or impaired language skills can impact on someone's social and emotional development. There are many different communication impairments and they can occur alone or with other difficulties (such as hearing loss).

A young person who has general receptive language difficulties may display the following:

- **Poor concentration**
- **Appear withdrawn**
- **Respond to non-verbal cues rather than responding to verbal instruction**
- **Provide answers which aren't relevant to the subject**
- **Repeat back what has been said to them**
- **Mask their difficulty by continuously talking**

Specific advice on addressing some of the effects of Receptive Language Difficulties

- **Keep background noise to a minimum**
- **Make sure you have the young person's full attention**
- **Emphasise key words when giving instructions**
- **Keep communication clear, simple and at a gentle pace**

Dyslexia^{xiv}

Approximately 5-10% of the population has Dyslexia. It affects someone's ability to read quickly and accurately. It can also hinder short term memory or mean that someone has difficulty in processing information. Young people with Dyslexia generally display:

- **Difficulty with recognising and remembering letter names**
- **Difficulty paying attention**
- **Poor short term/ long term auditory memory**
- **Difficulty with spelling, reading and writing**
- **Difficulty in sequencing events**
- **Prone to tiredness**
- **Often display behaviour problems due to frustration**

Difficult behaviour

Some people with a learning disability may demonstrate challenging behaviour. This may include over-reacting, tantrums, hitting or kicking out, throwing things or hurting themselves. For many people with a learning disability this can be a result of difficulty with communication and not being understood, it may be a sign of distress due to an unexpected change in routine, environment or in response to an event. It is not just a 'stage' that they will grow out of but requires consistent and appropriate support to manage it, together with support to develop and address communication needs.

References

- i Taken from Autism NI - [General Facts about Autism](#)
- ii Barron and Mulvany, 2005:20-23;
- iii [Mencap 'Facts about Learning Disability' 2011](#)
- iv [Mencap 'Facts about Learning Disability' 2011](#)
- v Material Adapted from:
 - Millar, C. (2011) Basic Facts for Leaders Leaflets - 'Disability'. The Boys Brigade NI
- vi Adapted from Mencap UK
- vii Adapted from [Autism NI](#)
- viii Material Adapted from:
 - Millar, C. (2011) Basic Facts for Leaders Leaflets 'Disability'. The Boys Brigade NI
- ix *ibid*
- x *ibid*
- xi *ibid*
- xii *ibid*
- xiii *ibid*
- xiv *ibid*