

A GUIDE TO HELP **YOU** ON YOUR JOURNEY THROUGH DISABILITY/ADDITIONAL NEEDS

For Parents by Parents



May 2023



SCAN ME

Why we want to help you on your journey

We, as parents, have worked closely with statutory, community and voluntary services to develop this resource from **US** as an easy read guide for **YOU**, to help signpost you to information, advice and support that you as a parent may need on learning your child has additional needs/a disability. We cannot promise that this resource will meet every need of every parent but we have tried to produce an inclusive guide as best possible.

Receiving the news your child has additional needs/ a disability, diagnosed or not, may have been sudden, you may not have had time to even absorb it properly and you may be experiencing a sense of grief, or loss. As a parent, we often imagine and dream of all sorts of things that our child will do in the future and it can hit us hard with the realisation that life may not progress for them the way we had envisaged it. Some things may not be possible for them or there may be more obstacles in life for them than others. It's ok to have a sense of sadness about this.



Our Journey Parents Group

For some a diagnosis can bring an enormous sense of relief, bringing some ease after dealing with countless organisations/representatives, taking your child to many appointments and taking one step forward and two steps back. Maybe you now feel a sense of hope, that there might be a light at the end of the tunnel, so to speak. For others, your child receiving a diagnosis may come as a shock; you may find it hard to accept it, or you may think that 'they' have got it wrong. This may be because you find it too overwhelming to accept that your child has a disability and all it entails, or you may simply disbelieve that your child has a disability at all. You may be devastated because you hoped that you'd be told that everything is ok.

The most important thing to remember is that everything you're feeling, or not feeling, is natural. Don't dismiss your feelings, because that is part of the process for you as a parent. You may have already been through so much emotionally on this journey with your child.

Often, you can feel like you've been left stranded with this information and not sure where to turn! If you have had interactions with various services, communication can just seem to stop. **What's next? Who can I talk to? Where do I go for help? Will someone contact**

me? All these questions, and more may be running through your mind. Even if there are some explanations/offers of help/instructions at this stage, you may not absorb the information, and/or you may not be ready to move on to the next stage.

That's when this guide becomes a useful tool for you. We, as parents, have all been there and are experiencing many of the same things as you, your child and family may be experiencing. We devised this guide to be a source of help available when it's needed, at whatever stage of your journey. This guide includes information on support services and counselling available along with lots of tips and advice. Check the contents below and we hope you can dip in and out of this guide, to source whatever information and support you may need.



Autonomie Parents Group

NOTE: This document is live online and is continually updated, so the latest version can be downloaded electronically by scanning the QR code on the front cover of the document or at <https://tinyurl.com/YourJourneyGuide>

Key Stages of your Child's Journey

NOTE: *Diagnosis – can come at any stage from birth to your health visitor raising concerns or starting a childcare setting, alternatively it could be pre-school or school.*

Birth /Learning your child has a disability & accessing services

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Important Note: This document has been produced to assist with advice, top tips and signpost to services – CYPSP cannot guarantee immediate access to services. Services vary across Health and Social Care Trust areas and some may hold specific access thresholds.

Birth / Learning your child has a disability or additional needs & accessing services

Emotional Impact -Understanding and accepting your feelings



There's no 'right' way to feel. Acknowledging all your emotions is a healthy thing to do. Finding out that your child is disabled or has additional needs can take time for you to adjust. There's no right or wrong way to feel and everyone reacts differently.

You will experience a range of positive and negative emotions. It can take time to work through these. A disability diagnosis impacts the entire family. However, parents often feel it the most. In fact, many experience a wide range of emotions, including shock, fear, sadness, disbelief, disappointment, self-pity, anger, numbness, guilt, grief, denial, envy and even shame. It's also common to worry about the future, for both your child and your family.

You might feel relieved too, especially if you've been worried about your child's development for a while. A diagnosis means you can ask questions about your child's development and get support from professionals. For more information visit <https://cypsp.hscni.net/emotional-impact-on-parenting-a-child-with-a-disability/>

How can I contact the Health Visiting Team?

Every GP practice has a named Health Visitor. Your Health Visitor will provide you with their contact details which they will write in your Personal Child Health Record (Red book). If this



information is not available, please contact your GP who will provide you with up to date contact information. Health Visitors work as part of a team who provide support and can give information on your child's particular condition, including benefits, support groups, health services and education needs. For further information and resources visit:

Belfast HSCT Health Visiting	https://belfasttrust.hscni.net/service/health-visiting/
Northern HSCT Health Visiting	http://www.northerntrust.hscni.net/services/health-visiting-service/
South Eastern HSCT Health Visiting	https://setrust.hscni.net/service/health-visiting/
Southern HSCT Health Visiting	https://southerntrust.hscni.net/services/children-and-young-people/health-visiting/
Western HSCT Health Visiting	https://westerntrust.hscni.net/service/health-visiting/

[Click HERE to find out what HSC Trust area you live in?](#)

Why childhood immunisation is important

Immunisation prepares the body to fight serious infections that might happen in the future. Young babies are very vulnerable to infections, so they need to be protected as early as possible. Your child needs several different vaccines to be fully protected, so it's important to complete their childhood immunisation programme. For more information on vaccines available and what age your child is given immunisations and how visit <https://www.nidirect.gov.uk/articles/childhood-immunisation-programme>



Child Development Clinics/Community Paediatrics

Child Development Clinics offer an early intervention, child-centred, holistic service to babies and children with complex and significant needs from birth. Community paediatricians work closely with other health professionals such as health visitors, social workers, therapists, psychologists, psychiatrists, dentists, nurses and teachers to manage and support children in the community.

Belfast HSCT CDC	https://belfasttrust.hscni.net/service/community-paediatrics/
Northern HSCT CDC	http://www.northerntrust.hscni.net/services/paediatric-medical-services-community/
South Eastern HSCT CDC	https://setrust.hscni.net/service/childrens-centre-2/
Southern HSCT CDC	https://southerntrust.hscni.net/services/children-and-young-people/childrens-services-pre-school-child-development-service/
Western HSCT CDC	https://westerntrust.hscni.net/service/little-acorns-centre/

[Click HERE to find out what HSC Trust area you live in?](#)

Children's Disability Services

The Children's Disability Services across each Health and Social Care Trust area works to provide services for children with disability and additional needs. They actively



communicate and work with parents, involving and empowering them to cope with the demands of raising a disabled child, and provide a means for families to access a range of information, assessments of need (incl. advice on Social Work Support) and accessing

services. This service is for any child aged under 18. For more information and contact details for services visit:

Belfast HSCT Disability Service	https://belfasttrust.hscni.net/service/childrens-disability-service/
Northern HSCT Disability Service	http://www.northerntrust.hscni.net/services/childrens-disability-teams/
South Eastern HSCT Disability Service	https://setrust.hscni.net/service/childrens-disability-service/
Southern HSCT Disability Service	https://southerntrust.hscni.net/service/children-with-disabilities/
Western HSCT Disability Service	https://westerntrust.hscni.net/service/disabled-children-and-young-peoples-services/

[Click HERE to find out what HSC Trust area you live in?](#)

Peer Support/Counselling

For ease of access we have provided a selection of links to regional and local services below to groups made up of parents who also have children with special needs and other young people who may be able to help support you or your child. Lots more information is available on the **NI interactive Family Support Directory of Services** at <https://www.familysupportni.gov.uk/> (Use Keyword Search 'Peer Support') and the Postcode Search to find services most **local** to you.

Contact Facebook Group *(Regional Service)*

Get to know other parents who are in similar situations. It can help to talk to people who understand what it's like to have a child with additional needs. Welcome to Contact's Facebook group. This is a closed group for parents and carers of disabled children, and is a place for members to chat, listen and ask questions in a **safe and supportive** environment.



Visit <https://www.facebook.com/groups/ContactFamiliesGroup/>

The Parent Rooms Peer Support *(Regional Service)*

The Parent Rooms is a charity that supports parents who are experiencing mental health difficulties to move beyond their struggles and into full and healthier lives. We walk alongside parents as they engage with a supportive community, evolve through learning skills and tools to improve and sustain their mental health, and then empower others to begin their journey to wellness. Visit <https://www.theparentrooms.co.uk/> call us on 02895 38 04 04 or email hello@theparentrooms.co.uk. 



Contact Listening Ear 1-2-1 Support *(Regional Service)*

You might be feeling lonely, tired or emotionally exhausted. Maybe you need practical advice on your child's education, benefits, behaviour, social care or any other areas of concern. Or perhaps you're feeling really stressed and just want to vent without fear of judgement. Whatever it is, the parent carers in our Listening Ear team understand what you're going through and are here to support you through whatever you need. To find out more and to Book a chat at visit <https://contact.org.uk/listening-ear>

Watch our video <https://www.youtube.com/watch?v=aCIU6tRspRI> for more information or click on timelines below:

[0:00](#) Intro

[1:25](#) What is the Listening Ear and how can I book a chat?

[2:29](#) Who will be at the other end of the line?

[3:42](#) What can I talk about during the call?

[6:51](#) How long does the call last and how many can I book?

[8:15](#) What do families think of the Listening Ear?

[9:49](#) What were some of your most memorable calls?

[14:31](#) What advice would you give to parents who are still unsure?



Autonomie Family Voice Hub

(REGIONAL SERVICE)

Caring for a child or young person with a disability can be challenging. Even the most experienced parents and siblings need someone to turn to for help and advice. Families of a child or young person with a newly diagnosed disability can experience shock, fear and attitudes and need practical, emotional and tailored advice.



Services include:



Tailored support through Family Voice Hub helps families cope with life. Parents and siblings can access dedicated support and our work doesn't stop there - we empower families to take part in forums where they can ask questions, share their views, offer peer support and information. Visit <http://www.autonomie.org.uk/family-support-services> for lots more information on services and fun activities available to your family

A drop-in service is available, call in for a cuppa and a chat. We are located right in the heart of South Belfast's Queen's Quarter, with accessible parking on-site at Lilac House, 4 Sandhurst Road, Belfast BT7 1PW. Tel: 028 95918051 Email: autonomieorg@gmail.com

Parent Talk

Down-to-earth parenting advice you can trust.

We're here for you, when you need us. Find answers to parenting questions in our advice articles. Or talk to a parenting coach about anything that's worrying you. It's all free, and no topic is too big, small, or embarrassing.



Featured article: How can I get the right support for my child's special educational needs?

If your child has special educational needs (SEN) you need to be their advocate, to make sure their rights are respected and their needs are met. It's important to listen to your child in this process.



Getting the right support for your child

Mental health and wellbeing



Find out more

Behaviour



Find out more

Stages and development



Find out more

Additional needs and disabilities



Find out more

For parenting advice and support visit <https://parents.actionforchildren.org.uk/> (Regional Service)



(Regional Service)

In Autism NI the Family Support team co-ordinate a number of different types of support groups. There are 20+ support groups based in local communities across Northern Ireland offering support to thousands of parents/carers who have individuals with autism. We rely heavily on our support group network, which continues to be the bedrock of our service steeped in the principles of community development where volunteer parents and carers provide advice and support to other parents.

To find your nearest group visit <https://www.autismni.org/support-groups>

Tel: [028 9040 1729](tel:02890401729) E-Mail: info@autismni.org

We are HERE....

Parentline Team are here to listen to YOU, there are NO silly questions...

My teenager has no respect for me, what can I do?

How much sleep does my toddler need?

How do I keep my child safe online?

My child is being bullied at school, what can I do?

I am worried about managing money over school holidays..

My child hits out, what do I do?

Is it normal if....?

We understand sometimes it is hard to know where to begin or even what question to ask...

I don't know where to start
...lets talk

0808 8020 400

"You've been a star. Thank you so much for helping me push through from negative to positive. Thank you for being brilliant"

"Thank you for your advice, we are reaping the reward now. I'm so glad I reached out."

"It's just so helpful to have a calm voice at the end of the phone"

"Thank you so much for this great service. From the moment I rang I felt supported. I have been spreading the word to everyone at school"

"Thank you for being my safe place to vent all this and get things off my chest"
"Thanks once again. I will definitely be phoning for a top up of support sometime soon. You were super!"



Parent Line NI

0808 8020 400

Children in Northern Ireland

HSC Health and Social Care Board



Parent Line NI

0808 8020 400

Who are we?
What do we do?

Who are Parentline?

Parentline NI are Northern Ireland's FREE and Confidential Helpline for Parent and Carers.

We are a caring, non-judgemental ear to listen and support or guide you wherever you are on your parenting journey.

Get in touch

We are here for you;
0808 8020 400
Monday -Thursday 9am-9pm
Friday 9am-5pm
Saturday 9am-1pm

webchat; ci-ni.org.uk
email; Parentline@ci-ni.org.uk
facebook.com/parentlineNI

Our Mission Statement

Every parent will feel valued, respected and nurtured on every call and are encouraged to both spend time connecting with their children and treating themselves with care and compassion.

How can we support you?

Freephone line-
0808 8020 400

Support, advice, guidance and/or ear to listen. Callers to the helpline can avail of a one off support call or further follow up calls tailored to meet your needs.

One to One parent support

One to one support sessions; tailored to meet your individual needs and circumstances, working alongside one of our dedicated Parentline team.

Web-Chat

When a quiet place to talk may be hard to find, try our webchat at;
ci-ni.org.uk/parentline



Parent Workshops

We deliver a range of workshops on parenting topics and areas of interest.

Parentline Podcast

Your guide to all things parenting. Available through all podcast platforms and free to listen.

Resources

We have a range of helpful resources covering a wide range of parenting topics available to share on request.

Relate NI Referral

Through Parentline's partnership with Relate we can make a referral for up to 10 sessions with Relate NI counsellors.

For more information on how we can support you, give us a call 0808 8020 400

(Regional Service)



Parenting NI is committed to supporting all parents and ensuring that their voices are heard whenever decisions are made that will affect them. We will continue to or endeavour to deliver a range of high quality support and services to meet parent's needs visit <https://www.parentingni.org/>



Parenting Programmes & workshops

Parenting programmes can help you build on your skills and boost your confidence in your parenting. Programmes are fun, interactive and a great way to meet other parents in similar situations.

To find out what's on visit our programme calendar.

Free Support Line & Web Chat



We're here to listen to your parenting worries and offer reassurance. You can also call us find out more about our other services on freephone 0808 8010 722. Click the chat button to talk to us online.

Support Line available Mon - Thurs
9:30am - 3:30pm & Fri 9:30am - 12:30pm.



Parents' Voice

Parenting NI consult with parents to give you the opportunity to have your say on issues important to you and your family. We then make sure your voice is heard to influence government policy, planning and service delivery.

We also carry out research to understand more about the realities of parenting in Northern Ireland and use the findings to advocate on your behalf.

(Regional Service)

CYPSP Parent Support and Parenting Programmes *(Regional Service)*

Your influence as a parent is one of the most significant factors in your child's life chances. We want to support and work with you as the primary care giver and educator for your children to ensure what we offer is meaningful, consistent and available at the point of need. This webpage is designed for Parents and Organisations working to support families using group work approaches – visit <https://cypsp.hscni.net/ebpp/>



Examples of Local Peer Support Services

Helping Hands *(BHSCT Service)*

Helping Hands charity aims to include parents, siblings, carers and families in everything we do. Helping Hands is a parent led charity that is managed by a team of parent volunteers. We have grown greatly to ensure that families are supported when they receive diagnosis of Autism Spectrum Disorder (ASD). As parents of children of young people with ASD we have a greater understanding of the challenges and the journey that families face on a daily basis. Our volunteers support families with children & youth activities each week. We run weekly sessions for different age groups from primary 1 right up to adulthood. Autism Resource Centre, Millars Lane, Dundonald, Belfast, Co Down, BT16 2DA Contact Caroline 028 9620 6286 or 075 4765 6221 Visit <https://www.helpinghandsautism.com/>



Moyle Gateway Youth and Friends *(NHSCT Service)*

Moyle Gateway provides social and learning services for young people with learning disabilities. Weekly club sessions at our club room in Ballycastle allow the young people the opportunity to enjoy various activities, arts/crafts, drama, music, games and sports. Club nights are every Thursday evening from 7 – 9pm at Unit 7, Moyle Enterprise Centre, with transport to and from sessions provided. The club is open to any young people with special needs or learning difficulties, who live within the Moyle area.

Please contact either Ann 028 2076 9009 or Hilary 028 2075 1431 for more details.

Bolster Community Peer Parents (*SHSCT Service*) For more information on practical help for you and your family visit <https://bolstercommunity.org/>



FAMILY
PARENTING SUPPORT GROUP

Being the parent of a newly diagnosed child with a physical or learning disability can be overwhelming. If you are the parent of a pre-school age child with a disability then you and your child would be very welcome at Bolster Community Parent Support Group. The group meet fortnightly in a warm, safe and inclusive environment; where we can offer signposting and advice, support with self-care, friendship or just a listening ear. Come along and meet other parents who are at the start of their disability journey.

Every 2 weeks on a Wednesday morning 10.30am-12noon
Location: The Court Rooms 7 Main St, Markethill, Armagh BT60 1PH

For further information call Catriona on 028 3083 5764

BOLSTER COMMUNITY 



FAMILY
TOTS & TEA

Are you the parent or carer of a pre-school age child with additional needs? Would you and your child like to meet new friends who are on the same journey?

Tots and Tea is a group of friendly mums and children who are all on the first steps of their journey through disability.

Our experienced staff are on hand to offer support and advice whilst you and your child enjoy meeting future friends.

Every 2 weeks on a Wednesday morning 10.30am-12noon
St Malachy's Primary School, Carnagat, BT35 8PJ

For further information call Catriona or Liz on 028 3083 5764

BOLSTER COMMUNITY  Southern Health and Social Care Trust

Newry Gateway Club (*SHSCT Service*)

A group of parents identified a need for young people with learning disabilities/ Downs to have more opportunities to socialise with their peers within their local community. Its key purpose is to provide a social, recreational and respite opportunity for young adults with special needs within the Newry Mourne & South Armagh District area. This was the start of what is now Newry Gateway Club. We have a range of fun filled activities such as Drama, Art, Music and Sports facilitated by our experienced staff and volunteers.

Newry & District Gateway Club
20, Kilmorey Street
BT34 2DE Newry

Newry: 028 3026 8777

info@newrygatewayclub.com



- **G:** genuine
- **A:** ability/achievement/action/admire
- **T:** talent/terrific/trailblazers
- **E:** eager/encourage/energetic/excellent
- **W:** wonderful
- **A:** ability...
- **Y:** young/ youthful

Visit <https://newrygatewayclub.com/> for lots more information

PosAbility (SHSCT Service)

You have the right to an opinion and for it to be listened to and taken seriously – Article 12, United Nations Convention on The Rights of the Child (UNCRC)

PosAbility Aims:

To give children and young people aged 8-25 years old who have a long-term disability or condition, the opportunity to have their say on issues that impact on them and their families.

Their views inform decision makers within local and regional government during their planning processes on issues which impact the lives of children and young people.

PosAbility Objectives:

- To empower young people with disabilities to know and exercise their rights.
- To enable young people with disabilities to influence policy makers and service providers.
- To provide capacity building activities that impact self-esteem, interpersonal relationships, emotional wellbeing and confidence.
- To influence change within our society; locally and regionally.
- To raise awareness of the issues faced by people with Disabilities.

PosAbility is supported by BBC Children in Need, Southern Health and Social Care Trust and the Health and Social Care Board.



Contact details:

The Grange Building
Tower Hill
Armagh
BT61 1DR
Tel: 028 37414541



Believe in children
 **Barnardo's**
Northern Ireland

Sixth Sense

Sixth Sense is a group for young people to learn about their rights and to share their views on issues which affect them and their peers.

The group meets monthly and during school holidays. There are often opportunities for young people within the group to be involved in consultation activities, research and to deliver training to professionals.

Transition and Inclusion Service

Supports young people aged 16-21 with a learning disability, autism and/or physical disability in the Southern Health and Social Care Trust (SHSCT) area as they transition into adult services.

12 weekly sessions offering:

1-1 support

Capacity and confidence building

Consultations with service providers

School and Regional Programmes

Our School's Programme is delivered over 6 weeks to pupils across the 5 health trusts. The programme focuses on empowering young people with disabilities, teaching them about their rights and enabling them to make plans for their future. Representatives from local Health and Social Care Trusts attend to listen to the young people's views about issues affecting them and their peers in their area.

We undertake video conferencing with other youth groups across Northern Ireland in order to share experiences and to discuss issues affecting young people with disabilities.

Peer Coaching

Children in Need fund our Peer Coaching Project. We have trained young people to be peer coaches; they meet with other young people who have similar life experiences on a weekly basis. This is supported by a staff member. The peer coaching programme aims to expand a young person's peer support network, increase their resilience, improve communication and enable them to be involved in decision making. The peer coaching programme has an emphasis on improving emotional wellbeing and mental health for children and young people with a disability.



Clanrye Arts & Crafts Social Café *(SHSCT Service)*



Join us each Monday 1PM- 2.30PM for some crafting & chatting

Location: [Community Mill, Drumalane Mill, The Quays, Newry](#)

Our Arts & Crafts Social Café is open to all those who love to de-stress with arts and spend time being creative. This is a group open to all to socialise and create beautiful art and crafts. This is a FREE group, and we always love to see new faces. To find out more about, please send us a message using the form below, or give us a call on 028 3089 8119 visit <https://clanryegroup.com/book-activities/arts-crafts-social-cafe/> No need to register.

Parent Action *(SEHSCT Service)*

Parent Action is a not for profit organisation, seeking to promote and protect the human rights of children and young people and adults with disabilities/ long-term health conditions in their receipt of health, social care, education, short break and day-care, employment and training support, through the empowerment of their parents and peers as advocates. Parent Action are/will: Promote mutual support of parents by other parents in similar situations; Actively promote and develop parent's skills at speaking up for their and their children's needs; Develop advocacy services in partnership with parents, children and young people; Develop and run small, local, parent discussion groups, and / or home visits to parents and much more. Clare Lodge Centre , 71a Minerstone Road, Downpatrick, Co Down, BT30 8LS Tel: 077 5230 3854 Visit <https://www.facebook.com/parentactionni>



SEN Space Care and Respite Services *(SEHSCT Service)*



We are a non-profit organisation providing support & respite services and much more for children with disabilities in Northern Ireland – for lots more information please visit <https://www.senspace.org.uk/> Tel 02890605977

Circle of Support *(WHST Service)*



Circle of Support for Autism Families is a parent led support group. Our mission is to provide a network of support to Autism families by Autism families. Our Aims are: To offer family support to parents by parents; Develop a 'Community of Autism Families' through our support network; Provide opportunities for children with Autism to meet to develop social and communication skills; Provide support to siblings and the opportunity for siblings to meet and form friendships and much more. The COS Centre for Autism Families, 17a Springtown Avenue, Springtown Business Park, Derry-Londonderry, Co Derry-Londonderry, BT48 0LY Tel 028 7141 7228 Visit <https://www.facebook.com/COS.forAutismFamilies/>

Download All about Me Passport Template Here



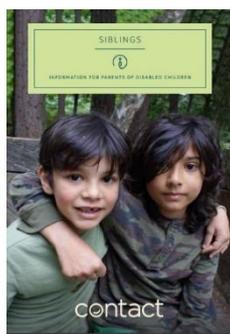
All About ME



Supporting your Family

In this section we have included a number of top tip guides, benefits information and for ease of access we have provided a selection of links to key groups that may be able to help support you. Much more detailed information is available on the **NI interactive Family Support Directory** of services at <https://www.familysupportni.gov.uk/> Services on this website are geo-mapped which will enable you to find services by your postcode which are most **local** to you **see leaflets on how to use the site on pages 34-37.**

Supporting Siblings



Spotlight on siblings

Most of us grow up with one or more brother or sister. As young children we may spend more time with our brothers and sisters than with our parents, and relationships with our siblings may be the most important and meaningful we have. Nearly all children, whatever their disability, spend most of their time with their family. This guide is about supporting the brothers and sisters of children who have a disability or long-term illness. It is written for parents and for those working with families who have a disabled child. Download your copy of this guide now at <https://contact.org.uk/wp-content/uploads/2021/03/siblings.pdf>



Family Support Services for children and families

Family support is a specialist service providing flexible, tailored support to the whole family. Staff and volunteers from these services provide opportunities for children and young people to become more involved in the community and make it possible for parents, brothers and sisters to enjoy fuller lives. For more information visit <https://www.positive-futures.net/what-we-do/children-families-services>

You can access family support through your Social Worker from your local Trust. You can also use your personal budget or direct payment to purchase supports directly from us. *Locations: Bangor, Lisburn and South East Fermanagh (Lisnaskea area).*

Top tips for supporting your sibling child

We have top tips for you as a parent. We know that parents of disabled children already have a lot to do and that extra time is hard to find. We also get a lot of feedback from parents telling us that these things really make a difference to siblings' wellbeing and to the sibling-parent relationship. For lots of advice and information:

[Top Tips for supporting your sibling child](#)

[Supporting your sibling child with their feelings](#)

[When to be concerned about your sibling child](#)

[Your sibling child's experiences](#)

[Free mindfulness course for adult sibling carers](#)



We raise awareness, identify and provide direct support to children and young people who look after or help to look after someone in their family who is unwell or disabled, including children caring for parents who have mental health or substance misuse problems. Visit <https://www.actionforchildren.org.uk/how-we-can-help/our-local-services/find-our-services-near-you/ni-regional-young-carers/>
Phone [02890 460500](tel:02890460500) Email niyoungcarers@actionforchildren.org.uk

Frequently Asked Questions?

contact For families with disabled children

FAQs

Use our Frequently Asked Questions tool to help you find answers to some of the most common questions we get on our helpline



We recommend you visit Contact for families with disabled children Frequently Asked Questions section for advice on Benefits, Education, Diagnosis, Support for your family, preparing for Adult life and other financial help visit

<https://contact.org.uk/help-for-families/faqs/>

Their FAQs are divided into the most popular topics parents ask about.

Choose the topic you're interested in, and keep narrowing down until you see a list of questions. Clicking on the question you're interested in will take you to the section of their site where you'll find the answer.

Getting the right School

Support for my Child's Condition

Aids and Equipment

Support in the Early Years

Planning for the Future

Grants, blue badge & other help with costs

Guides and Resources



Visit <https://contact.org.uk/help-for-families/information-advice-services/> for information on Early years support, Benefits and tax credits, Money and debt, Education and learning, Social care, Health and medical information, Family life work and childcare, Preparing for adult life and much more.



Parents order your free Contact Helpful guide for families with disabled children – email info@contact.org.uk to order your copy now.



Understanding Acronyms!!

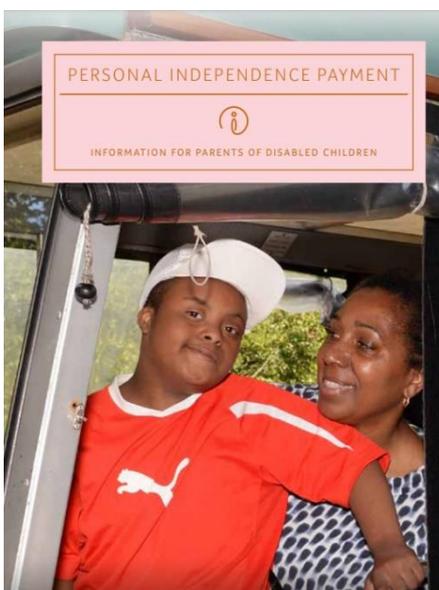
Download you're A-Z Glossary of NI Health and Education Acronyms [HERE](#)



What is DLA Guide?

Disability Living Allowance (DLA) is the main benefit for children under 16 with a condition or disability. DLA helps to meet the extra costs that you might have as a result of your child's disability

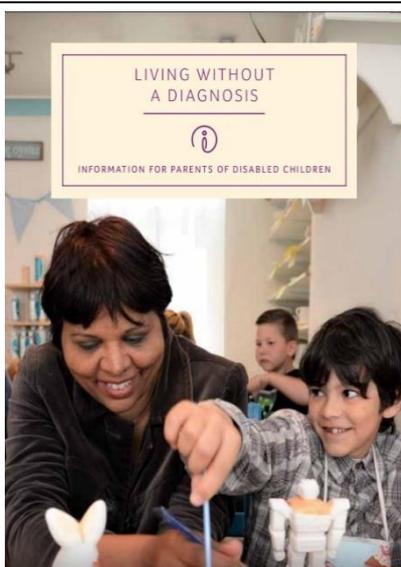
For lots more information and help on applying for DLA visit <https://contact.org.uk/help-for-families/information-advice-services/benefits-financial-help/benefits-and-tax-credits/disability-living-allowance/>



What is PIP Guide?

Personal Independence Payment (PIP) is a benefit that replaces Disability Living Allowance (DLA) for adults. Although PIP looks similar to DLA in some respects, it uses entirely different rules to decide whether you qualify for the benefit, and at what rate.

For lots more information download your guide at <https://contact.org.uk/wp-content/uploads/2021/03/PIP-guide.pdf>



Living without a Diagnosis Guide

This guide is for parents and carers whose child has a learning difficulty or health problem, but do not know its cause. It contains information on:

- why it can be hard to get a diagnosis
- who can help you
- what help & support you can expect
- meeting other parents
- top tips

Download your guide at <https://contact.org.uk/wp-content/uploads/2021/03/Living-without-a-diagnosis.pdf>

Benefits & Funding

Disability Financial Support in Northern Ireland

The links below provide detailed information on all types of disability financial support available – eligibility criteria and how to claim each type of allowance click on each link or visit direct web address.

Appeal a benefits decision	https://www.nidirect.gov.uk/appeal-benefits-decision
Attendance Allowance	https://www.nidirect.gov.uk/articles/attendance-allowance
Carer's Allowance	https://www.nidirect.gov.uk/articles/carers-allowance
Constant Attendance Allowance	https://www.nidirect.gov.uk/articles/constant-attendance-allowance
Diffuse Mesothelioma Payment	https://www.nidirect.gov.uk/articles/diffuse-mesothelioma-payment
Direct payments	https://www.nidirect.gov.uk/articles/direct-payments
Disability Living Allowance for adults	https://www.nidirect.gov.uk/articles/disability-living-allowance-adults
Disability Living Allowance for children	https://www.nidirect.gov.uk/articles/disability-living-allowance-children
Disabled Person's Allowance	https://www.nidirect.gov.uk/articles/disabled-persons-allowance
Employment and Support Allowance	https://www.nidirect.gov.uk/articles/employment-and-support-allowance
Independent Living Fund	https://www.nidirect.gov.uk/articles/independent-living-fund
Industrial Injuries Disablement Benefit	https://www.nidirect.gov.uk/articles/industrial-injuries-disablement-benefit
Payment of disability benefits in other European countries	https://www.nidirect.gov.uk/articles/payment-disability-benefits-other-european-countries
Personal Independence Payment (PIP)	https://www.nidirect.gov.uk/articles/personal-independence-payment-pip



Use our free and confidential Benefits Calculator to find out what benefits you are entitled to claim. In the last year over 2 million calculations have been made by people, like you, looking for information they deserve and need visit

<https://benefits-calculator.turn2us.org.uk/>



Information on the Contact website provides details on benefits you may be entitled to that could help with the extra costs you face including a benefits calculator. For more detailed information and guidance on applying visit <https://contact.org.uk/help-for-families/information-advice-services/benefits-financial-help/>



Family Fund provides families raising a disabled, or seriously ill, child on low incomes with wide-ranging grants for essential items. Whether you need a kitchen appliance, like a fridge, cooker or washing machine, clothing and bedding, sensory or play equipment or technology for your child or a much-needed family break, we are here to help. You can apply for any items that will help meet your child's additional support needs.



Visit <https://www.familyfund.org.uk/grants-apply> to apply for a first grant, apply again to Family Fund and check when you can next apply for grants.



We provide funding towards life-changing equipment for children with a wide range of disabilities or chronic conditions across the UK. Caudwell Children can support with mobility, sports and sensory equipment for disabled children and their families to help with their development, mobility and independence. For more information visit <https://www.caudwellchildren.com/equipment/>



Family Support Services Available

Family Support Hubs *Regional Service*

A **Family Support Hub** is not a single organisation or a building. A Family Support Hub is a network of organisations from across the community, voluntary and statutory sector who provide early help services. There are 29 Family Support Hubs and they cover all of the 5 Trust areas. They receive referrals for families who are in-need of early intervention support who are not currently known to Gateway, Family Intervention or CAMHS. They use their local knowledge to signpost families to local services who may best be suited to meet their needs. Referrals can come from professionals but families can self-refer.



To find your local Hub contact details and for information on how to make a referral please go to the CYPSP website at <https://cypsp.hscni.net/family-support-hubs/> If you would like to receive a copy of the bi-monthly family support newsletter providing lots of information, tips, news and events email cypsp@hscni.net and ask for your name to be added to the mailing list.

SureStart *Regional Service*

SureStart is a programme targeted at parents and children under the age of four. There are 38 Sure Start projects across Northern Ireland. It brings together health, family support and early education services which are designed to support children's learning skills, health and well-being, and social and emotional development. Services are offered both in the home and in group-based settings.

The programme works with parents from pregnancy and provides support for children until their 4th birthday. Involvement with Sure Start helps to ensure that children flourish at home and do well when they get to school. To check if you live in a SureStart area and find out more visit <https://www.familysupportni.gov.uk/Support/94/about-sure-start>

Child and Adolescent Autism Services (HSCTs)

The Child and Adolescent Autism Service is an assessment and intervention service for children and young people up to the age of 18 years, where concerns about autism spectrum disorder (ASD) have been identified. We offer an ASD assessment



and diagnostic service for children and young people. We also provide support for children, young people and their families following an autism diagnosis. For more information and access details visit:

Belfast HSCT Autism Service	https://belfasttrust.hscni.net/service/child-adolescent-autism-service/
Northern HSCT Autism Service	http://www.northerntrust.hscni.net/services/autistic-spectrum-disorder-asd-services/paediatric-asd-services/
South Eastern HSCT Autism Service	https://setrust.hscni.net/service/neurodevelopmental-service/
Southern HSCT Autism Service	https://southerntrust.hscni.net/service/autism-services/
Western HSCT Autism Service	https://westerntrust.hscni.net/service/autism-spectrum-disorder-asd-childrens-service/

[Click HERE](#) to find out what HSC Trust area you live in?

Child and Adolescent Mental Health Services (HSCTs)

CAMHS offer specialist mental health services to children and young people (up to age 18 years) and their families. It promotes emotional wellbeing and delivers mental health services to children and young people. For more information and access details visit:



Belfast & South Eastern HSCT CAMHS Service	https://belfasttrust.hscni.net/service/child-and-adolescent-mental-health-service/
Northern HSCT CAMHS Service	http://www.northerntrust.hscni.net/services/child-adolescent-mental-health-service-camhs/
Southern HSCT CAMHS Service	https://southerntrust.hscni.net/service/camhs/
Western HSCT CAMHS Service	https://westerntrust.hscni.net/service/child-and-adolescent-mental-health-services/

[Click HERE](#) to find out what HSC Trust area you live in?

Carers Support (HSCTs)

Trusts recognise the essential and valuable role that carers play in the delivery of safe and effective care to the person cared for and as such we are committed to ensuring that carers are supported in their caring role.

Belfast HSCT Carers Support	https://belfasttrust.hscni.net/service/carers-services/
Northern HSCT Carers Support	https://www.northerntrust.hscni.net/services/carerhub/
South Eastern HSCT Carers Support	https://setrust.hscni.net/service/carers-support-service/
Southern HSCT Carers Support	https://southerntrust.hscni.net/involving-you/community-development-and-user-involvement/carers-information/
Western HSCT Carers Support	https://westerntrust.hscni.net/service/carers-support-service/

[Click HERE](#) to find out what HSC Trust area you live in?

Autism NI provide support through their helpline, early intervention, family support, support groups and autistic adult services. For more information on all the support available visit <https://www.autismni.org/support2>. They also provide a number of useful factsheets, visuals and resources, Autism awareness card and much more that can be downloaded and printed from their site. Visit <https://www.autismni.org/resources>



FACTSHEETS



RAINBOW RESOURCE KIT



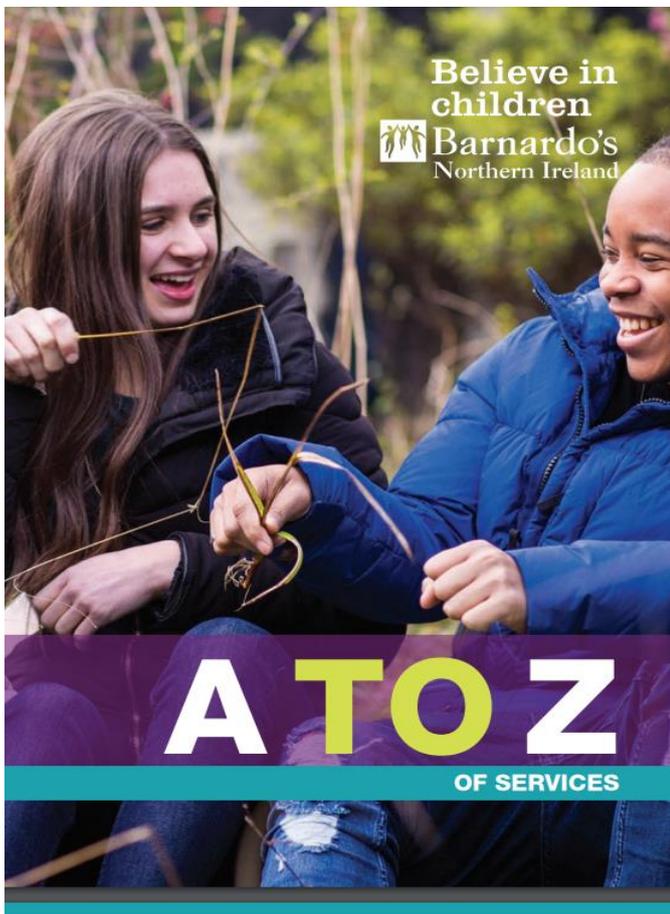
AUTISM AWARENESS CARD



Regional Service

We provide local specialist help, information and care across Northern Ireland for autistic children and adults, and their families. We offer health and social services including support in your home, short breaks and respite, social groups, relationship and health education, and parent groups. For more information on all of our services that we offer in Northern Ireland visit <https://www.autism.org.uk/what-we-do/northern-ireland> You can also contact our advice line Call: 07917 266 487 Or 07917 235 390 or visit <https://www.autism.org.uk/what-we-do/northern-ireland/advice-line>

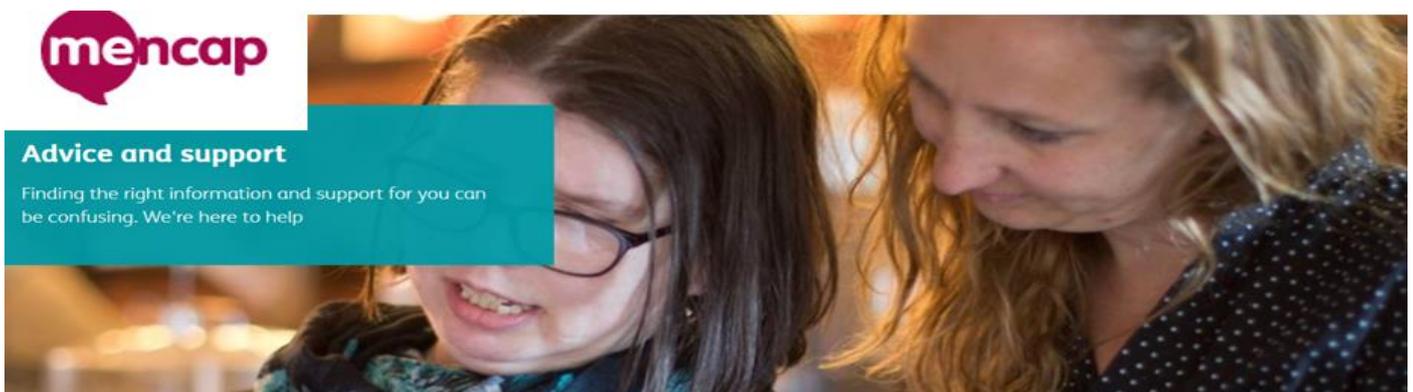




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Download Barnardo's Directory of Services available in NI at <https://www.barnardos.org.uk/sites/default/files/2020-05/barnardos-northern-ireland-a-z-services-2020.pdf> *Regional Service*



Regional Service

Information, advice and support - Learning disability is a complicated subject, and trying to find the right advice for you can be hard sometimes. We can tailor support packages to suit your needs, whatever your needs visit <https://www.mencap.org.uk/advice-and-support> or <https://northernireland.mencap.org.uk/services/children-and-family-services> contact our NI helpline 0808 808 1111 (choose option2) Email: helpline.ni@mencap.org.uk

Regional Service

To access information on services below visit

<https://www.sense.org.uk/places/sense-northern-ireland/>

Email: nienquires@sense.org.uk



We support children and adults with complex disabilities across Northern Ireland. There are around 52,000 people with complex disabilities in Northern Ireland.

	<p><u>Sense services in Northern Ireland</u></p> <p>Sense has been supporting people with deafblindness and complex disabilities in Northern Ireland since 1990.</p>		<p><u>Family support service in Northern Ireland</u></p> <p>Our family support service is for children under 12 with sensory impairments and additional needs.</p>
	<p><u>Friends of Sense NI</u></p> <p>Friends of Sense NI is a support group for people with complex disabilities and their loved ones and carers.</p>		<p><u>Where to find Sense in Northern Ireland</u></p> <p>Find out where to access our services for people with complex disabilities across Northern Ireland.</p>



'...supporting additional needs & autism in Northern Ireland'

Regional Service

Established in 2009, Sólás is a special needs charity which supports children and young people with a broad range of additional needs including autism and ASD. We are based in South Belfast; however, our work extends across Northern Ireland. We have a number of social developments, educational support and parent support programmes. As part of our social development programme we facilitate a range of after-schools, weekend and summer scheme initiatives for children and young people with ASD.

We also facilitate a number of weekly home support and respite initiatives, as well as parent support groups.

As part of our educational remit, we run an early intervention initiative called Back on Track and Kidz Den which provides support to children who have an additional learning need but do not meet the criteria for statutory support. For more information visit

<https://www.solasbt7.com/home> or call **028 90 247600**.

Our Children, Young People and Families team provide support and advice to families, and those supporting children with sight loss or a vision impairment, from birth up to 25 years of age.



We can provide support and services including:

Advice in early years and education; Activities for the whole family; Advice and guidance for young people transitioning from school to further education, work, and independent living and much more. Visit <https://www.rnib.org.uk/nations/northern-ireland/cypf-service-northern-ireland/> for lots more information or Get in touch with a member of our Children, Young People and Families team today at **0303 123 9999** or email us at cypf@rnib.org.uk.



SUPPORTING PARENTS AND FAMILIES IN NORTHERN IRELAND



Regional Service

We support you, as parents and carers with blind and partially sighted children, from the point of diagnosis. We provide you with the tools and knowledge to empower you to make informed decisions for your children and to help them realise their full potential.

How we help you: visit <https://www.angeleyesni.org/>

- To help the whole family come to terms with diagnosis
- To demystify the roles of professionals, who they are and what they do
- To help families understand support that is available and how to access it
- To link families together for peer support at the same stage
- To offer support to parents at every stage of their child's life
- To advocate on behalf of families of sight impaired children
- To strive to make the voice of parents heard by statutory and other organisations that represent the interests of children in Northern Ireland who are visually impaired
- To organise events, some on our own, some with other organisations, to provide information to families and/or to provide a safe, supported environment where children can acquire new skills and experiences
- Monthly clubs for families including online informational workshops, Newly Diagnosed family meet ups and face-to-face family events.



Regional Service

The National Deaf Children's Society provides support to deaf children and young people and their families in Northern Ireland. We run events for families to help them at key points in their deaf child's life and we work to influence the standard and quality of services they receive. With your support, we can create a powerful voice for change and demand a fair deal for every deaf child. Find out more about our work in Northern Ireland and about local groups run by parents and carers of deaf children to give emotional and social support to families. For more info, advice and local groups visit <https://www.ndcs.org.uk/about-us/where-we-work/northern-ireland/>

You can contact the Northern Ireland team at: Tel: **028 9035 2011** (v)

Email: nioffice@ndcs.org.uk

Regional Service



ADD-NI was originally established in 1997 as a support network for children, young people and families of those affected by AD/HD: Attention Deficit Hyperactivity Disorder. ADD-NI provides a unique and specialised service, based in Carryduff. We provide services across Northern Ireland, regionally and now have a satellite office

based in Dungannon, The Hub of the North. Our sole aim is to promote and support the needs of those affected by AD/HD. For more information on support available visit <https://addni.org/> Telephone: [028 90 81 22 22](tel:02890812222) Email: info@addni.org



Understanding Rare Chromosome and Gene Disorders

Regional Service

Unique Families – With a global network of families and professionals, Unique can help you find out more about your child's rare chromosome disorder, copy number variant or single gene disorder associated with learning disability and developmental delay. We can answer many of your questions and match you with other families. You'll also be helping us understand the lifetime effects of these rare disorders. info@rarechromo.org
Helpline: [+44 \(0\) 1883 723356](tel:+44(0)1883723356) Visit <https://rarechromo.org/>



Syndrome without a Name – SWAN Regional Service

Approximately 6,000 children are born in the UK each year with a syndrome without a name – a genetic condition so rare that it is often impossible to diagnose. Without a diagnosis it can be difficult to access basic information and support. We have information leaflets which are available to download. We offer 24/7 information and support through our online forums for registered members. For more information and to register visit <https://www.undiagnosed.org.uk/> Phone 0300 124 0441 Email info@undiagnosed.org.uk

Tel: 01267 244 200 Email: enquiries@cerebra.org.uk Visit <https://cerebra.org.uk/>

Our Services

We offer a range of free services that enrich the lives of children with brain conditions and support their families and carers.



Sleep Advice Service

Advice and support helping you and your child get a good night's sleep.



Toy and Book Library

Borrow specialist books and toys from our free and easy to use library.



Parent Guides

Comprehensive guides to legal, social, financial, educational and health issues.



Cerebra Innovation Centre

See how our dedicated team in Swansea might help your child with an incredible invention.



Legal Rights Service

Get information and help about your legal rights to health and social care services.

Regional Service



We all need advice and support at different times in our lives ...

Do you know where
to find contact details
for various Family
Support Services
throughout
Northern Ireland ?

Check
www.familysupportni.gov.uk
for all types of Family Support services
including statutory, voluntary and
community support services :-



- Adoption Fostering & Looked After Children
- Bereavement
- Carers
- Disability
- Domestic Sexual Abuse
- Drug/Alcohol Misuse
- Eating Disorders
- Ethnic Minority Support
- Family Support Hubs
- Mental Health
- Parenting Support
- Separating Families
- Sure Start

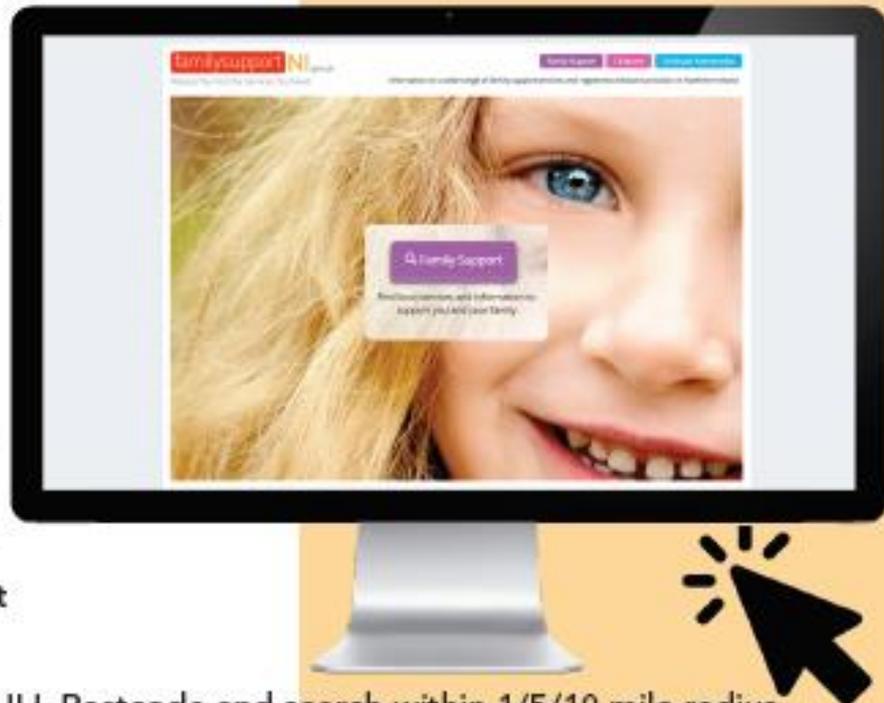
T. 0845 600 6483
E. info@familysupportni.gov.uk
www.familysupportni.gov.uk



@Familysupportni

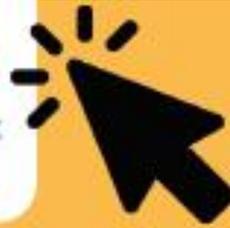
Easy-Steps Search

- Go to Family Support
- Choose a Service from categories listed
- If you can't find what you are looking for in the categories listed you can do a 'Keyword Search' e.g. 'Child Contact Centre'
- Then input your FULL Postcode and search within 1/5/10 mile radius



Other Useful Features:

- TRANSLATIONS – results can be translated into a range of languages at the 'Select Language' option at the bottom of the page.
- Useful articles associated with search are also translated
- Various options can be printed off (in English or other language) and given to people to consider/discuss with their partner/family
- Browsealound functionality
- Dedicated telephone and email which is manned during office hours to respond to queries from the public and/or service providers
- Providers of Family Support services can quickly add/update details of service provision by contacting info@familysupportni.gov.uk



Looking for Childcare/Financial Assistance with Childcare Costs?

ALL **REGISTERED** childcare providers are listed on www.familysupportni.gov.uk the public register of childcare providers, as required by law.

- **Approved Home Care**
- **Childminders**
- **Creche**
- **Day Nursery**
- **Out of School**
- **Playgroup**
- **Statutory Nursery School/Unit**
- **Summer Scheme**



There is also useful related information on this website – including **Financial Assistance with Childcare Costs**

Different types of help towards childcare are available, with support available to working parents through the benefits system, government support schemes or tax relief. The best form of help will be determined by your circumstances

Most working families in Northern Ireland will be entitled to financial support with their childcare costs, although there are some exceptions.

You can only receive help with childcare costs that are being paid to **Registered** or **Approved** childcare providers (as listed on www.familysupportni.gov.uk).



T. **0845 600 6483**

E. info@familysupportni.gov.uk

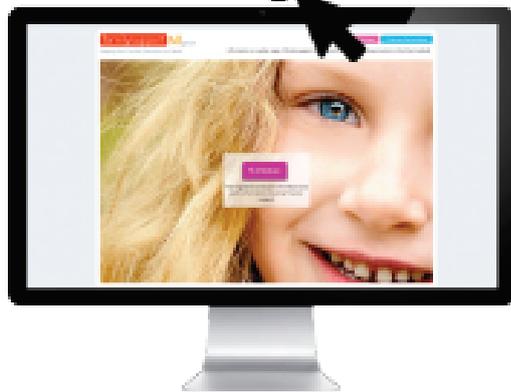
www.familysupportni.gov.uk



@Familysupportni

Easy-Steps Search Guide

Go to Childcare



Select type of provider from Drop-down list.
Then input your FULL Postcode and search within 1/5/10 miles.

Results can be filtered (at left of screen) by :

- ✓ Vacancies
- ✓ School Pick-up or Drop-off
- ✓ Disability/Complex Needs
- ✓ Flexible Working Hours
- ✓ Registered for Tax Free Childcare
- ✓ Accepts Childcare Vouchers
- ✓ Pre-School Funded Places
- ✓ Breakfast Club

Keyword Search – can be used for e.g. town/village or a specific need such as 'autism' or 'epipen' It can also be used If you are looking to contact/ check registration of a particular childcare provider

Help with Childcare Costs

The amount of financial support you may be entitled to receive in each scheme will depend on your circumstances. It can be complicated to work out what is best for you but there is help available with this :-

Employers For Childcare Family Benefits Advice Service – provides free, confidential and impartial advice setting out your best options for support, depending on your specific circumstances. The Advisors are available on Freephone 0800 028 3008, Monday to Friday, 9am to 5pm, or by emailing hello@employersforchildcare.org.

www.childcarechoices.gov.uk is a government website that shows the different types of help available (though not all will be available in Northern Ireland).

Financial help if you have children <https://www.gov.uk/browse/childcare-parenting/financial-help-children> is a government online list of all the main forms of support with the cost of childcare you may be able to claim depending on your circumstances.

www.gov.uk/childcare-calculator – an online calculator that will work out how much money you could get towards registered or approved childcare.

Hospitals and people with disabilities

Visit <https://www.nidirect.gov.uk/articles/hospitals-and-people-disabilities> for information on hospitals for people/ children with disabilities. It includes support in hospital and after leaving, how any financial support you receive may be affected, and support after leaving hospital.

HSC Hospital Passport

This *HSC Hospital Passport* has been developed by the PHA and the Regional General Hospital Forum for Learning Disability for people/children with a learning disability to complete (with or without help) and present to staff every time they have contact with a general hospital. It gives staff important information

on the person and how they prefer to communicate, their medical history and any support they might need while in hospital. Staff can then make any reasonable adjustments in order to provide the best possible care for people/children with a learning disability. Download passport at <https://www.publichealth.hscni.net/publications/hsc-hospital-passport-and-guidance-notes>



The Children's Hospital RVH

The Children's Hospital on the Royal Hospitals site is the only hospital in Northern Ireland dedicated specifically to the care of children. It provides general hospital care for children living in Belfast and provides most of the paediatric regional specialities for children throughout Northern Ireland. For more information visit <https://belfasttrust.hscni.net/hospitals/childrens/>



Blossom Children & Young People's Centre CAH

Our team in Blossom Children and Young People's Centre have put together this video to highlight what you can expect if your child needs to attend an outpatient appointment in the Blossom Centre.



 Watch HERE <https://youtu.be/bSf4IDS5BJE>

School

Choosing a School in Northern Ireland for Children with SEN

Many parents of children with special educational needs and/or disability (SEND) face challenges finding the right school. They can also be faced with making the difficult decision about whether a mainstream or specialist setting is best for their child. National Autistic Society provide advice and information for parents on choosing a school in Northern Ireland visit <https://www.autism.org.uk/advice-and-guidance/topics/education/education-choices/northern-ireland/choosing-a-school>



The **Education Authority** is responsible for delivering education services across Northern Ireland

Pre-School

The SEN Early Years Inclusion Service (SEN EYIS) aims to promote the optimum development of pre-school children with special educational needs by providing advice and support to children, families and pre-school settings. The Early Years Hub (EYH) is the single point of referral to the service. Referrals to the EYH come from Paediatricians for children not attending pre-school and from Educational Psychologists for pre-school aged children. For more information and contact information visit SEN Early Years Inclusion Service (SEN EYIS) | Education Authority Northern Ireland (eani.org.uk)



If additional information is required or any difficulty is experienced, parents can contact the admissions helpdesk Monday - Friday 9:00 am - 5:00 pm Pre-School Admissions Email: preschooladmissions@eani.org.uk

Primary School

Do some research to find out which school might be most suited to your child. If you have any questions, speak to the teachers at a school or health care professionals. The Principal and/or the Special Educational Needs Coordinator (SENCo) at a school can help guide you through the process.

For information on applying for a Primary school place, the Education Authority NI admissions guide will help you understand more about the process and what to expect when applying for a place in a primary school for your child including key dates, how to apply for a primary school place, admissions criteria and more <https://www.eani.org.uk/parents/admissions/primary-admissions-guide> If additional information is required or any difficulty is experienced, parents can contact the admissions helpdesk Monday - Friday 9:00 am - 5:00 pm Primary School Admissions - primaryadmissions@eani.org.uk

If your child has a Statement of Special Educational Needs (SEN), the Statement sets out the child or young person's SEN, describes the provision and supports to help meet those needs, and the educational setting or school they should attend. Your named SEN Link Officer at the Education Authority will contact you to discuss the process and the type of school that has been recommended for your child.

Post Primary School

Special Educational Needs

If your child is undergoing statutory assessment and does not currently have a formal Statement of Special Educational Needs you still need to apply for a Post Primary place.

DO NOT complete an application if your child has a formal Statement of Special Educational Needs. There is a separate admissions procedure where the Post Primary School placement is discussed with you as part of the review of your child's statement. Therefore, application should not be made via EA Connect. Your named SEN Link Officer at the Education Authority will contact you to update you on the process.



For Key information on applying to Post Primary Schools transferring from Primary School the Education Authority NI admissions guide will help you understand more about the process and what to expect when applying for a place in a Post primary school for your child including key dates, how to apply for a primary school place, admissions criteria and more <https://www.eani.org.uk/parents/admissions/post-primary-admissions-guide> If additional information is required or any difficulty is experienced, parents can contact the admissions helpdesk Monday - Friday 9:00 am - 5:00 pm Post-Primary School Admissions - postprimaryadmissions@eani.org.uk

For general queries on SEND, contact the **SEN Helpdesk** by telephone on **028 9598 5960**

The Education Authority provides information and guidance for parents, carers and schools to support improved outcomes for children and young people with special educational needs (SEN).



The first 'EA Plan of its Arrangements for Special Educational Provision' is due to be published in July 2023, which will provide all information in one area on the EA website. A booklet version of the 'EA Plan of its Arrangements' will also be available to download. Information on SEND Services at the EA will be updated on a yearly basis.

NOTE: The links below are active until July 2023 and will be re-directed to the new web area when it becomes 'live.'

[SEN General Information - https://www.eani.org.uk/parents/special-educational-needs-sen/sen-general-information](https://www.eani.org.uk/parents/special-educational-needs-sen/sen-general-information)

General information on Special Educational Needs and how children are supported in schools.

[Stages of the Code of Practice - https://www.eani.org.uk/parents/special-educational-needs-sen/stages-of-the-code-of-practice](https://www.eani.org.uk/parents/special-educational-needs-sen/stages-of-the-code-of-practice)

Guidance that all schools must follow when making decisions about children who have SEN.

[Statutory Assessment - https://www.eani.org.uk/parents/special-educational-needs-sen/statutory-assessment](https://www.eani.org.uk/parents/special-educational-needs-sen/statutory-assessment)

Information on the Statutory Assessment process and online request form.

[Statement of Special Educational Needs - https://www.eani.org.uk/parents/special-educational-needs-sen/statement-of-special-educational-needs](https://www.eani.org.uk/parents/special-educational-needs-sen/statement-of-special-educational-needs)

Information on a Statement of Special Educational Needs, an Annual Review and Transition Planning.

[SEN Annual Reviews - https://www.eani.org.uk/parents/special-educational-needs-sen/sen-annual-reviews](https://www.eani.org.uk/parents/special-educational-needs-sen/sen-annual-reviews)

Information and support for parents/carers submitting Annual Reviews.

[Feedback on EA SEN Decision - https://www.eani.org.uk/parents/special-educational-needs-sen/feedback-on-ea-sen-decision](https://www.eani.org.uk/parents/special-educational-needs-sen/feedback-on-ea-sen-decision)

Ways to provide feedback on an EA SEN Decision.

[Legislation and the new SEN Framework - https://www.eani.org.uk/parents/special-educational-needs-sen/legislation-and-the-new-sen-framework](https://www.eani.org.uk/parents/special-educational-needs-sen/legislation-and-the-new-sen-framework)

Legislation and information on the new SEN Framework.

[Children with Medical Needs - https://www.eani.org.uk/parents/special-educational-needs-sen/children-with-medical-needs](https://www.eani.org.uk/parents/special-educational-needs-sen/children-with-medical-needs)

Information and help on supporting children with medical needs in schools.

[SEN Contact Details - https://www.eani.org.uk/parents/special-educational-needs-sen/sen-contact-details](https://www.eani.org.uk/parents/special-educational-needs-sen/sen-contact-details)

If you have any queries in relation to special educational needs, you can contact the Special Educational Needs Helpdesk.

[Special Educational Needs and Disabilities \(SEND\) Transformation Programme - https://www.eani.org.uk/parents/special-educational-needs-sen/special-educational-needs-and-disabilities-send](https://www.eani.org.uk/parents/special-educational-needs-sen/special-educational-needs-and-disabilities-send)

This programme aims to transform special educational needs and disability services in order to provide the best support.



SEN School Transitions



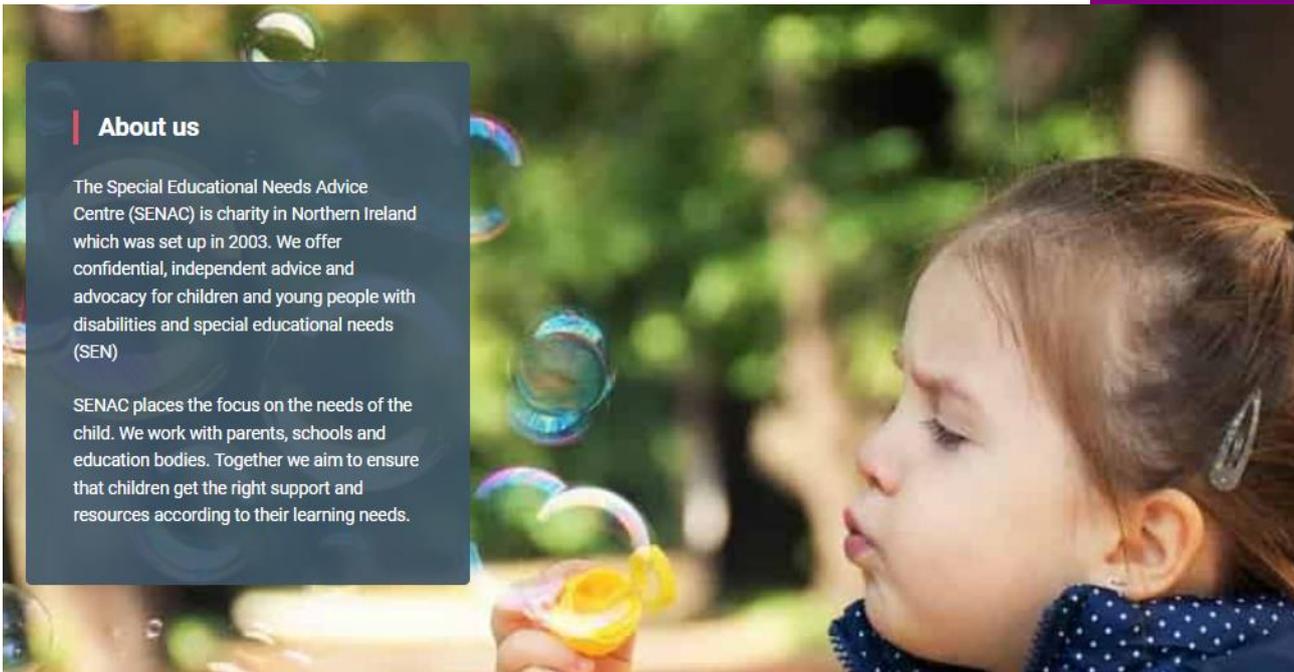
Resources to help prepare your child or pupil with SEN to go back to school or to move to a new school or setting from Pre-School, Primary and Post Primary visit <https://www.eani.org.uk/services/pupil-support-services/transition> also visit <https://www.eani.org.uk/parents/special-educational-needs-sen/transitions-service-14> **for Transition Service for 14+**

Equal Eyes Project

This information provides “at a glance” information to parents and carers about the Special Educational Needs (SEN) framework. This resource was produced as part of the **EqualEyes** project, a collaborative project between the Children’s Law Centre and Angel Eyes. Read more at <https://childrenlawcentre.org.uk/faqs/send-info-sheet/>



Get your child the help they need visit
<https://senac.co.uk/>



About us

The Special Educational Needs Advice Centre (SENAC) is a charity in Northern Ireland which was set up in 2003. We offer confidential, independent advice and advocacy for children and young people with disabilities and special educational needs (SEN)

SENAC places the focus on the needs of the child. We work with parents, schools and education bodies. Together we aim to ensure that children get the right support and resources according to their learning needs.

Advice Line 028 9079 5779 For advice about your child's education please contact our Advice Line to speak to one of our advisers.

Contact: Graham House, Knockbracken Healthcare Park, Saintfield Road, Belfast BT8 8B
Office Enquiries: 028 9070 5654 Office Email: info@senac.co.uk

[Download An introduction to Special Education Needs System in Northern Ireland here](#)

Office email cannot be used for advice queries, for education advice please contact our Advice Line

After Age 14

Important Note: After the age of 14, it is important to be aware of the criteria for access to adult services as your child progresses towards adulthood. Speak to your local Health Trust's Disability Team and/or Education Transition Service for advice and support in respect of this transition process.

Family Support NI

For more information on education support including transport visit <https://www.familysupportni.gov.uk/> (Choose Educational support category) and the Postcode Search to find services most local to you.

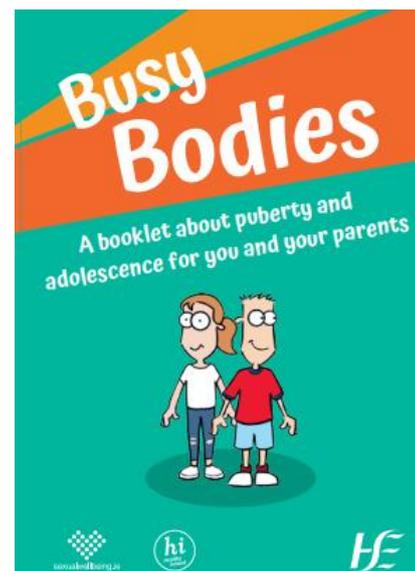
Puberty – How your child’s body will change

Busy Bodies Adolescent Development Programme provides information on the physical and emotional changes that children may experience during puberty, to reassure them that puberty is a normal part of growing up. Busy Bodies is a useful resource to help support both workers and parents in providing information on puberty to children aged between 10 and 14.

[Download Busy Bodies booklet Here](#)

View Busy Bodies videos at

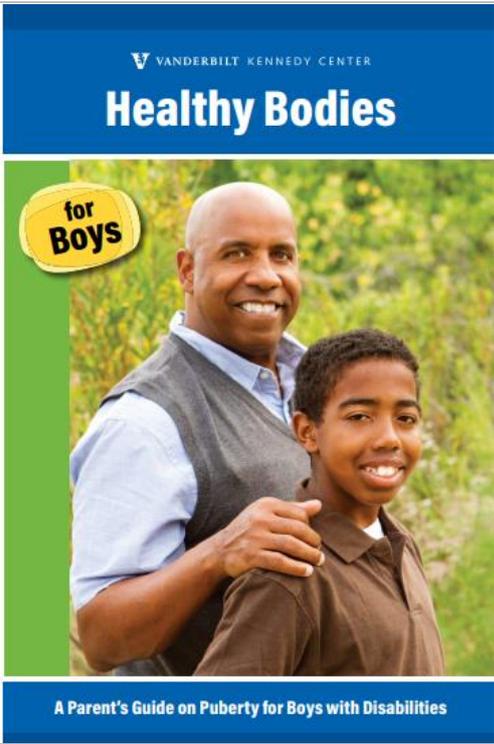
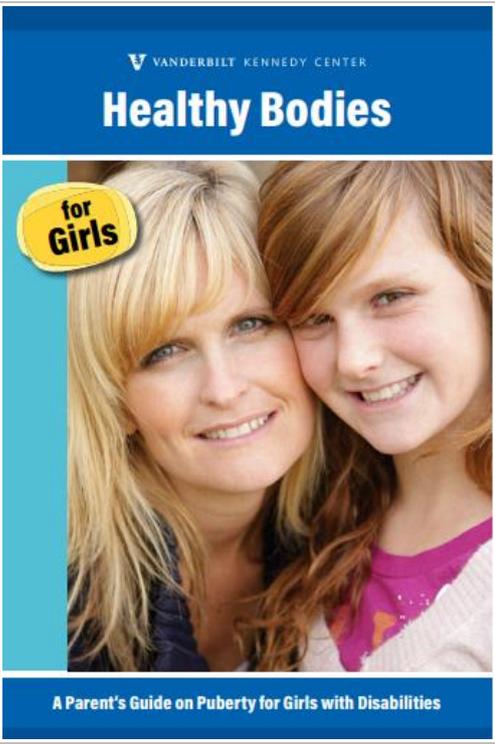
<https://vimeo.com/user/96707063/folder/729017>



Useful GUIDES

[Boys and Puberty – How will my body change](#)

[Girls and Puberty – How will my body change](#)

	
<p><u>https://vkc.vumc.org/healthybodies/files/HealthyBodies-Boys-web.pdf</u></p>	<p><u>https://vkc.vumc.org/healthybodies/files/HealthyBodies-Girls-web.pdf</u></p>

Social Opportunities

contact For families with disabled children

Holidays, Play and Leisure

All children need the chance to play. Many disabled children and young people say that leisure and play – after school, in the holidays and at weekends – is the most important missing element in their lives. Here we have information about what play, leisure, and short breaks options may be available, and where to find more information. For lots of information and ideas visit <https://contact.org.uk/help-for-families/information-advice-services/social-care/play-leisure-and-recreation/>



Mae Murray Foundation Inclusive Beaches

An Inclusive Beach is a beach environment which Mae Murray Foundation has planned so that people of all ages and abilities can take part, have fun, and be included.



Inclusive Beaches will provide access, parking, and disabled toilets. Toilets will always offer hoisting and adult sized changing bench facilities – to full Changing Places standard whenever possible. Inclusive Beaches in Northern Ireland offer free beach equipment loan schemes, operated as a partnership between Mae Murray Foundation and respective beach operators. For lots more information on beaches, equipment and booking visit <https://www.maemurrayfoundation.org/projects/inclusive-beaches/>

Also visit <https://www.maemurrayfoundation.org/projects/> and <http://www.maemurrayfoundation.org/projects/resource-library/> for information on resources, outdoor events, teenagers, early years powered mobility, virtual events, inclusion zone and much more.



Outdoor Events



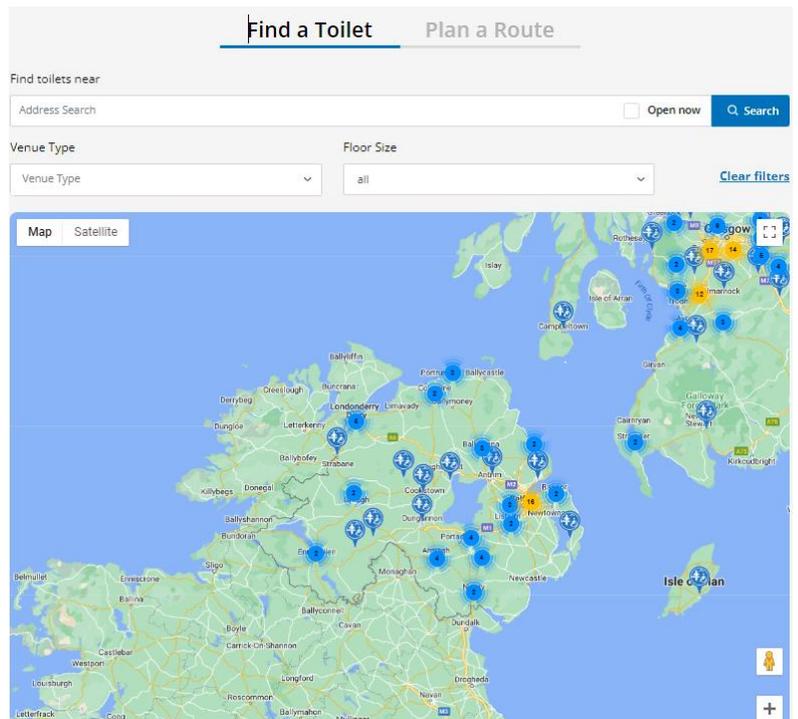
Early Years Powered Mobility



Join us live – virtually!

Changing Place Toilets

A Changing Place (CP) toilet provides sanitary accommodation for people with multiple and complex disabilities who have one or two assistants with them. Without a suitable changing bench, many disabled people have to be laid on the floor to be changed. This is undignified, unhygienic and puts assistants at risk of injury. In the absence of a hoist, assistants are again put at risk when forced to manually transfer a disabled person who is unable to self-transfer between a wheelchair and WC. To find CP toilets in Northern Ireland visit <https://www.changing-places.org/>



Autism Awareness at Belfast International Airport

For many of us, the prospect of going on an aeroplane, especially for the first time, can be daunting in itself. For those with children, it can be even more of an



ordeal – trying to settle nerves, control excitement and quell the fear of the unknown. For those with children on the autistic spectrum, however, the idea of having to travel on an aeroplane can be frighteningly overwhelming. For Guides and more information on assistance visit <https://www.belfastairport.com/special-assistance/autism-awareness>

Special Assistance at George Best City Airport

Special Assistance at Belfast City Airport, ranked one of the highest in the UK by the CAA, is available to passengers with impairments, disabilities, hidden disabilities & reduced mobility. For more information visit <https://www.belfastcityairport.com/Special-Assistance>



Translink

For information on Translink's Accessibility guide for train and bus services as well as concessions on fares visit

<https://www.translink.co.uk/usingourservicesandproducts/accessibility>



Links to Parks and Open Spaces/ Things to do

<u>Antrim and Newtownabbey</u>	<u>Fermanagh and Omagh</u>
<u>Ards and North Down</u>	<u>Lisburn and Castlereagh</u>
<u>Armagh, Banbridge and Craigavon</u>	<u>Mid and East Antrim</u>
<u>Belfast City</u>	<u>Mid Ulster</u>
<u>Causeway Coast and Glens</u>	<u>Newry, Mourne and Down</u>
<u>Derry and Strabane</u>	



Disability Sport NI and Progressive Building Society have developed an exciting partnership to deliver a range of sports and active recreation opportunities for disabled people at a Disability Sports Hub in every council area of Northern Ireland. Within each hub will be a range of disability sports equipment funded by Department for Communities and Sport NI. For information on local activities available across leisure centres visit <https://www.dsni.co.uk/community-sport/progressive-disability-sports-hubs/>



Special Olympics Ulster covers Counties Antrim, Armagh, Derry/ L'Derry, Down, Tyrone, Fermanagh, Donegal, Cavan and Monaghan. There are 1,811 athletes in 58 clubs across the Ulster Region. Contact: Telephone: (+44) 028 9023 9023 Email: so.ulster@specialolympics.ie visit <https://www.specialolympics.ie/ulster> for information on sports programmes and clubs in your area.

Carers Discount on Days Out in Northern Ireland

For information on days out in Northern Ireland where carers can go free or on discount visit <https://sensorykidsni.co.uk/carers-discount/>



Adulthood

Transitions

Leaving School



Resources to help prepare your child or pupil with SEN to go back to school or to move to a new school or setting, including Post Primary and leaving school visit <https://www.eani.org.uk/services/pupil-support-services/transition>

Transition and Me

An information guide for young people with a disability living within the Southern Health and Social Care Trust (SHSCT) preparing for Transition.

- Download Transition and Me booklet
- View Transition and Me Video



Your Transition Plan – preparing for the future

Your Transition Plan is one way you can plan for what you want to achieve in your teenage years, as you move into adult life. A Transition Plan is a document that outlines what you want to achieve in the next few years - and what support you will need to live as independently as possible. For more information visit <https://www.nidirect.gov.uk/articles/your-transition-plan-preparing-future>



Transitions Service

Cedar's Transition Service is an early intervention service that fully involves young people with disabilities and their families to make decisions about their life after school.



Specialist ASD services

Support for young people and adults with ASD to gain practical experience to improve their lives so that they are empowered to become more self-reliant.

Short breaks

One to one social and emotional support to children with disabilities, autism and brain injury to enable them to develop friendships and access social and recreational opportunities at home or within their local community.



Youth Matters

Access to a wide variety of group activities and personal development programmes for children and young people with disabilities, autism and brain injury up to the age of 18.

For more information visit <https://www.cedar-foundation.org/pages/category/children>

Tel. 028 90461834, E-mail: communications@cedar-foundation

Autonomie

SAIL Programme



SAIL Programme

For 16-30 year olds with complex additional needs



Interactive fun learning to help young people with additional needs develop self-confidence through self-awareness.

SAIL (Social Independent and Living) operates across 8 NI local council areas and empowers young people with additional needs to lead fuller and more independent lives through access to free fun and engaging practical activities and emotional support.

 www.autonomie.org.uk
Autonomie, Lilac House, 4 Sandhurst St, Belfast BT7 1PW
Registered Charity No 100421



Find out more!

Email us: autonomieorg@gmail.com Call us: 028 9591 8051

Further Education

Disability Support at College

Further Education can be a great way to pick up new skills, open up new career choices or prepare for higher education. Having a disability or learning difficulty needn't limit your choices. Colleges can offer the support you need to get into Further Education and achieve qualifications. For more information on further education, training programmes, funding/benefits and apprenticeships visit <https://www.nidirect.gov.uk/articles/disability-support-college>



Disability Support in Higher Education

Universities and colleges are increasingly aware of the needs of students with a disability and students with a learning difficulty. They can offer support in a number of ways and you may be able to get extra financial help. For more information on support for students, learning support co-ordinators, help while you are studying visit <https://www.nidirect.gov.uk/articles/disability-support-higher-education>

Clanrye Disability Support Services

Clanrye Group's Disability Support Service (DSS) provides specialised support for young people (aged 16-22) on the Training for Success and Apprenticeship NI Programmes across Northern Ireland. For more information on what is provided and to access support visit <https://clanryegroup.com/services/training-qualifications/disability-support-services/>



Family Support NI

For more information on Education support including transport visit <https://www.familysupportni.gov.uk/> (Choose Educational support category) and the Postcode Search to find services most local to you.

Training and Employment

In this section for ease of access we have provided a small selection of links to key groups that may be able to help/support you. Much more detailed information is available on the NI interactive Family Support Directory of services at <https://www.familysupportni.gov.uk/> (Choose Employment/Training category) and the Postcode Search to find services most local to you. **See leaflets on how to use the site on pages 34-37**



Are you a young person aged 16-22 years who has left school and needs some support in training to achieve your goals? Our experienced and understanding Disability Support Services team located throughout N.Ireland can help, advise and assist you to participate in training as well as gain valuable work experience.

The team provides Disability Support on youth training, working closely with all colleges, training organisations and the Careers Service, across Northern Ireland to enhance the support necessary for disabled people on the Skills for Life and Work programme and the Apprenticeship NI programme. If you would like to find out more about the support we can provide, contact Colin Downey, Disability Support Services Manager on T: 028 9029 7880 or E: colindowney@disabilityaction.org Visit <https://www.disabilityaction.org/help-with-training>



START SOMETHING



Why we are here

The Prince's Trust supports 11 to 30-year-olds who are unemployed or struggling at school to get their lives on track. **What we do** Working across Northern Ireland we support over 8,500 young people aged 11 to 30 each year to develop the confidence and skills they need to live, learn and earn. Our community-based teams work closely with hundreds of delivery partners to provide a variety of support and free courses to help young people develop the life-skills and motivation they need to succeed. Whether you're interested in improving your employability skills, landing a new job or you want to start your own business, there's something for everyone. For more information visit

<https://www.princes-trust.org.uk/about-the-trust/where-we-work/northern-ireland> or Email the team outreachni@princes-trust.org.uk



NOW Group is an award-winning social enterprise - our services focus on supporting people into employment, training and volunteering

We are passionate about supporting people with learning difficulties and autism into jobs with a future. We do this by offering a range of services that support people at whatever stage they are - whether that is just leaving school or college, unemployed, returning to work or graduates. We also offer a family service for new or expectant parents with a learning difficulty or autism and social groups.

Transition from school

Our Transition Service is an individual and innovative service that supports students with different levels of learning abilities in their final years of school to explore future options and gain independence through training, mentoring and sampling work placements.

JAM Card©

The JAM Card© which says 'Just a minute' on one side and 'Please be patient I have a learning difficulty on the other' allows people to ask for a minute of patience in any situation they need it including in shops, restaurants and public transport. It is also available as an app for smartphones that allows users to select what their screen says from options including 'I have autism/Asperger's', 'I have a condition' and 'I have a brain injury'. For lots more information on NOW Group visit <https://www.nowgroup.org/our-services>



Independent/ Supported Living

NIHE Supporting People Service directory

You can search for support in your local area using our online directory. This directory gives you details about housing support services funded by the Supporting People Programme in Northern Ireland. When you search the directory, you will be able to view key details about each service, including: Service and organisation name; Amount of housing support units provided; Thematic group and primary



client group; Service type; Contact information; Referral routes; Service description Visit <https://www.nihe.gov.uk/working-with-us/supporting-people/how-to-find-support-in-your-area>

Cedar Living Options



At Cedar we provide a range of Living Options. Accommodation that is suitably and sensitively designed to meet the individual needs of people who have brain injury, physical disability and sensory impairment, as well as for people who have learning disabilities. Services include Supported Living in independent apartments or bungalows, registered residential homes providing 24-hour care and housing support services. Visit <https://www.cedar-foundation.org/accommodation>



Supported Living Services

Supported Living offers the people we support the opportunity to live where and how they choose – in a home of their own or with people they choose to live with. We work with housing providers to make this possible. <https://www.positive-futures.net/what-we-do/adult-services>

Houses are based in local communities and our teams of Support Workers follow individuals' support plans to provide people with the type of support they need during the day and, if necessary, at night. This means that the people we support can do things in their local community – like going to the leisure centre, using the bus, shopping and going to church – and do as much as they can for themselves, like cooking, shopping, budgeting and personal care. Location: Bangor, Belfast, Coleraine, Cookstown, Enniskillen, Lisburn, Lisnaskea, Magherafelt, Newtownards, Omagh and Portavogie.

Centre for Independent Living

The Centre for Independent Living NI, is an organisation run by disabled people for disabled people. We work to promote the principles of independent living and, in particular, to provide a range of services for people using or considering using Direct Payments and/or Self-Directed Support. The board is made up entirely of disabled people who throughout their working lives have accumulated a wealth of knowledge of government administration, health and social care, governance of voluntary organisations and business. For more information on independent living and services available visit <https://cilni.org/>



Legal Support

Children's Law Centre



The Centre works to protect the rights of all children living in NI particularly those who are the most disadvantaged, e.g. children with disabilities, special educational needs, mental ill health, homeless young people.

- We use the law to access critical services for children and young people and to challenge the discrimination and disadvantage suffered by many of our most vulnerable children.
- We provide a free legal advice service and legal representation for children and young people.
- We also work to create a society where all children can access all necessary services and opportunities they need to enjoy their childhood and realise their full potential.
- We are committed to giving a voice to the most disadvantaged and voiceless children.

For Help and assistance visit <https://childrenslawcentre.org.uk/>

Mencap – Wills and Trusts Service



Mencap Wills and Trusts Service provide helpful information and guidance on how to make sure your child is provided for when you're no longer around. They provide information on specialist solicitors, free resources and planning for the future online seminars providing the opportunity to hear from a solicitor who specialises in this complex area of law and the chance to meet other families who are in a similar situation via zoom. For more information and free guide visit [Wills and Trusts Service for parents and carers | Mencap](#)



The Commissioner's role is to safeguard and promote the rights and best interests of children and young people. The Commissioner uses the [United Nations Convention on the Rights of the Child \(sometimes called the UNCRC\)](#) to guide their work and the work of their staff. All of the Commissioner's work is focused on making sure ALL children and young people have access to these rights in their day-to-day lives, so they have the best opportunity to reach their full potential. For more information on services and contact details visit <https://www.niccy.org/>

Conclusion by Parents

It is important to remember through the difficult times that these conditions do not define your child. Your child will grow, progress and develop. Their path to life may not be a conventional path but it is their path and your family path.

Remember to enjoy every moment and capture every moment, even on the days you struggle you will look back on those memories and smile.

Try not to compare your family life and occasions to other families. You and your family are beginning your journey as an individual family.



Colin Autism Support Group

NOTE: THIS DOCUMENT WILL BE KEPT AS A LIVE LINK AND REVIEWED AND UPDATED AS REQUIRED IF YOU WOULD LIKE TO INCLUDE INFORMATION IN THIS RESOURCE EMAIL: CYPSP@HSCNI.NET