Paediatric Disability Service City Hospitals Sunderland NHS Foundation Trust

Paediatric Disability department
Sunderland Royal Hospital
Kyll Rd
Sunderland
SR4 7TP

Tel: 0191 565 6256

What is the paediatric disability service?
A team of consultants and trainees with expertise in paediatric disability

What does ‘disability’ mean?
We use the definition from the World Health Organisation’s International Classification of Functioning, Disability and Health (usually known as the ICF). This brings together the ‘medical model’ of disability, which considers health conditions, body structure and function, with the ‘social model’ of disability, which considers factors in the environment that can be disabling, such as physical factors and peoples’ attitudes. Disability is thus something that can affect anyone at any time and can vary over time. Using this definition of disability includes all children and young people with special educational needs as well and may be better understood as the interaction between different factors:

Who can refer to the paediatric disability service?
Any professional who has a concern about a child or young person’s development, learning or where a disability is suspected. Parents can seek referral via their GP, Health Visitor or any other professional involved in their care. If Nursery or School staff are making a referral, it is better for this to be via the GP if possible, in order to optimise communication and reduce the risk of duplication.

Who should be referred to the paediatric disability service?
Any child or young person where there is concern about development, learning or where disability is suspected. This includes all of the following:
Any child who has:
- Lost developmental skills at any age (please fax urgent referral and speak with paediatric disability consultant by telephone)
- Parental/professional concerns about vision (eyesight), fixing or following or a confirmed vision impairment at any age (simultaneous referral should be made to Paediatric Ophthalmology)
- Significant hearing loss at any age, including all infants who ‘fail’ the newborn hearing screening test (simultaneous referral should be made for expert audiological/ENT assessment)
- No speech by 18 months, especially if the child does not attempt to communicate by any other means e.g. gesture (simultaneous referral should be made for urgent hearing test)
- Suspected clinical diagnosis of cerebral palsy
- Complex disabilities
- Head circumference above the 99.6th percentile, below 0.4th percentile or that has crossed two percentile lines upwards or downwards on the appropriate chart, or is significantly disproportionate to parental head circumference
- An assessing clinician who is uncertain about any aspect of assessment, but thinks development may be different from expected
- A parent or carer who is concerned about any aspect of development or potential disability

Any child or young person with “red flags” that might suggest an autism spectrum condition, including:
- Does not point to share interest in something with someone else or draw other’s attention to something (e.g. ‘oh look, there’s an aeroplane!’)
- Does not initiate or start of an interaction with someone else
- Unusual use of eye contact and/or gestures
- Does not show appropriate concern if others are hurt or upset
- Marked insistence on routine and things needing to be the same
- Little evidence of spontaneous, creative, imaginative play
- Restricted range of interests
- Compulsive routines or rituals
- Play with no purpose, repetitive play, does not know what toys are for or how to play with them
- Unusual sensitivities e.g. to noises, textures, smells or tastes
- Unusual sensory behaviours e.g. sniffs, licks or feels things repetitively
- Misreads non-verbal communication
• Concrete or literal interpretation of language
• Failure to develop relationships with other children at a developmental-age-appropriate level
• Limited, repetitive or unusual use of language
• Mannerisms e.g. hand flapping, complex whole body movements etc.

Any child or young person with ‘red flags’ that might indicate a disorder of attention or hyperactivity:
• Marked limitation of attention or concentration span
• Impulsivity
• Hyperactivity – always on the go
• Needs little sleep
• All of the above always there across all settings e.g. home, nursery, extended family etc.

Or any child who is not able to:
• Sit unsupported by 12 months
• Walk by 18 months (boys) or 2 years (girls) (check creatine kinase urgently)
• ‘Walk’ other than on tip toes
• Run by 2 ½ years
• Hold object placed in hand by 5 months of age (corrected for gestation)
• Reach for objects by 6 months of age (corrected for gestation)
• Point at objects to share interest with others by 2 years.

Why should a child or young person be referred to the paediatric disability service?
If there are concerns that a child or young person may have a disability or is following a different developmental journey to other children their age, it can be important to identify any health conditions or diagnoses that can be made. This is so that an explanation can be given for the child, young person and their family as to why they are different, how this might affect them now and in the future.

We know that in the absence of other explanations about why a child is different, parents, especially mothers, tend to blame themselves, thinking it was something they did or didn’t do when they were pregnant or in parenting that has made their child as they are.

Having the right diagnosis or diagnoses:
• Can help the paediatrician to explain what the child’s functioning is likely to be like now and in the future, answering all the important questions that parents want to know: Will she walk? Will he talk? Will she need special support in education? Will she grow up to have a job, have relationships?
• Can help with access to genetic counselling. This means explaining the chances for a family of having other children with the same diagnoses and also explaining the chances of the child themselves having children with the same diagnosis.
• Can help get the management right and to enable early intervention to be put in place, where there is good evidence that this makes a positive difference.
• Can help the paediatrician to think about what else might be going on, that may impact on the child’s ability to take part in everyday activities or enjoy the best possible quality of life
• Stops the need for more tests, which can be painful for the child and inconvenient for the family
Can open doors to the right support and information

**What should referral to the Paediatric Disability Service include?**
Please include a completed background information sheet. These are designed to be completed by the family. If need be, the Health Visitor or the person making the referral can offer support with this. Having all of this information means that the consultation is much more efficient and effective: the family have more idea about why they are attending and hopefully have the chance to share all of their concerns.

The background information sheet for pre-school children can be downloaded from: [www.bacdis.org.uk/policy/documents/PreSchoolBIS.pdf](http://www.bacdis.org.uk/policy/documents/PreSchoolBIS.pdf)

The background information sheet for school-age children and young people can be downloaded from: [www.bacdis.org.uk/policy/documents/SchoolAgeBIS.pdf](http://www.bacdis.org.uk/policy/documents/SchoolAgeBIS.pdf)

For children in nursery or school, it is also very helpful for a **report from nursery or school to be included with the referral**.

For those referred because **medical advice is needed for education**, it is essential for a full report from education to be sent in with the referral, including any **educational psychology reports**.

**What to expect at a paediatric disability new patient appointment**
- The appointment usually takes about 45 minutes
- On arrival, the receptionist will check your child’s and your contact details, GP etc.
- If you need any special arrangements whilst waiting to see the paediatrician, please let the receptionist know
- You will be asked to wait in the waiting room
- One of the nurses or nursing assistants will call your child’s name, so that they can be weighed and measured
- The paediatrician will call you through for the consultation
- We try to keep clinics to time, but sometimes unexpected emergencies arise or a family may need longer than predicted for the doctor to explain everything or make the right assessments. If you are worried about waiting longer than expected, please let the receptionist know. Please be assured that when your turn comes, you will be given the time you need to share your concerns and for your child to be fully assessed
- The paediatrician will ask you about your concerns and go through the background information sheet with you
- The paediatrician will examine your child, explaining what they are doing and why as they do so
- Sometimes one of the trainee paediatricians will examine your child or conduct the whole consultation. Please be reassured that all trainees have careful supervision from a consultant
- We often have medical students in clinics and will ask your permission for them to observe or take part in consultations. If you would prefer for them not to, just let the paediatrician know. This will not affect the care that your child receives in any way
- At the end of the consultation, the paediatrician will explain what they have found and also the plan for next steps
• Sometimes a child may only need one consultation, it may be possible for the paediatrician to reassure you that all is well
• Sometimes the paediatrician may recommend further investigations, including blood and urine tests, x-rays or scans. All will be fully explained to you, including why the tests are being done and when to expect the results
• Sometimes the paediatrician will make referrals on to other experts, who may be other specialist doctors, nurses, therapists, or other professionals
• If the paediatrician thinks that your child may have special educational needs, they have a duty laid out in the Children and Families Act 2014 to share this information with the education team. This will be fully discussed with you
• The paediatrician may need to link with other specialists in other agencies, including education and social care, in order to ensure that your child’s needs are fully assessed and addressed, in their best interests. The paediatrician will explain all of this to you
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• After the consultation, you will receive a detailed letter from the paediatrician, explaining everything that was discussed and found during the consultation and what the care plan is. This letter will, with your consent, be copied to your GP and those professionals who need to know the information, in your child’s best interests

What to expect at a paediatric disability review appointment
• There are different types of disability review clinics and the length of the appointment may vary, depending on the paediatrician and the complexity of the child’s needs. They tend to be between 15-30 minutes long.
• On arrival, the receptionist will check your child’s and your contact details, GP etc.
• The receptionist may give you a form to complete, called the ‘traffic light tool’. This helps you to think about what is going well for your child, what may make their life – and yours – easier and has space for you to write down any concerns or questions. On the back of the form are a list of issues that we know affect many disabled children, regardless of their diagnosis or condition, so you can indicate any that you are worried about.
  You can download the traffic light tool here if you would like to complete it in advance: http://www.bacdis.org.uk/policy/documents/HFWSummary.pdf
• If you need any special arrangements whilst waiting to see the paediatrician, please let the receptionist know
• You will be asked to wait in the waiting room
• One of the nurses or nursing assistants will call your child’s name, so that they can be weighed and measured
• The paediatrician will call you through for the consultation
• We try to keep clinics to time, but sometimes unexpected emergencies arise or a family may need longer than predicted for the doctor to explain everything or make the right assessments. If you are worried about waiting longer than expected, please let the receptionist know. Please be assured that when your turn comes, you will be given the time you need to share your concerns and for your child to be fully assessed
• The paediatrician will ask you about your concerns and go through the background information sheet with you
• The paediatrician may examine your child, explaining what they are doing and why as they do so
• Sometimes one of the trainee paediatricians may examine your child or conduct the whole consultation. Please be reassured that all trainees have careful supervision from a consultant
• We often have medical students in clinics and will ask your permission for them to observe or take part in consultations. If you would prefer for them not to, just let the paediatrician know. This will not affect the care that your child receives in any way.
• At the end of the consultation, the paediatrician will explain what they have found and also the plan for next steps.
• Sometimes the paediatrician may recommend further investigations, including blood and urine tests, X-rays or scans. All will be fully explained to you, including why the tests are being done and when to expect the results.
• Sometimes the paediatrician will make referrals on to other experts, who may be other specialist doctors, nurses, therapists, or other professionals.
• If the paediatrician thinks that your child may have special educational needs, they have a duty laid out in the Children and Families Act 2014 to share this information with the education team. This will be fully discussed with you.
• The paediatrician may need to link with other specialists in other agencies, including education and social care, in order to ensure that your child’s needs are fully assessed and addressed, in their best interests. The paediatrician will explain all of this to you.
• After the consultation, you will receive a detailed letter from the paediatrician, explaining everything that was discussed and found during the consultation and what the care plan is. This letter will, with your consent, be copied to your GP and those professionals who need to know the information, in your child’s best interests.

Specialist paediatric disability clinics
A number of specialist clinics are delivered by the paediatric disability service. These include:
• Special school clinics
• Specialist clinics for children and young people with complex disabilities
• Specialist clinics for children and young people with Down’s Syndrome
• Specialist clinics for children and young people with Neurofibromatosis
• Specialist clinics for children and young people with Neuromuscular conditions
• Specialist joint clinics: Paediatric Disability and Clinical Genetics
• Developmental Vision Clinics: Paediatric Disability, Paediatric Ophthalmology, Orthoptics and Teacher for the Vision Impaired
• Joint postural management clinics: Paediatric Disability, Orthopaedics and Physiotherapy
• Specialist clinics for structured assessments for children and young people who may have autism spectrum conditions (Autism Diagnostic Observation Schedule - ADOS)
• Specialist clinics for children or young people referred from education because of consideration for Education, Health and Care planning. These children and young people will undergo a full paediatric assessment – see the section above on ‘What to expect in a paediatric disability new patient appointment’.
• Specialist clinics for young people referred from the Young Offending Team or Liaison and Diversion Service. The specialist workers in these teams have been trained to identify any children or young people where there may be unmet health needs. These young people will undergo a full paediatric assessment – see the section above on ‘What to expect in a paediatric disability new patient appointment’.
• Home visits are possible where required, especially for those children and young people with the most complex needs and are usually undertaken together with the specialist community children’s nurses.
Where to get support whilst waiting for an appointment, waiting for a diagnosis or in case of any concerns

Contact a Family North East
The Dene Centre, Castle Farm Road, Newcastle upon Tyne, NE3 1PH

Freephone: 0808 808 3555
North East Office number: 0191 213 6300

http://www.cafamily.org.uk/northeast
email: northeast.office@cafamily.org.uk

Sunderland Carer’s Centre
Thompson Park, Thompson Park Road, Sunderland SR5 1SF

Telephone: 0191 549 3768
Email: info@sunderlandcarers.co.uk

www.sunderlandcarers.co.uk

Durham County Carers Support
Unit 1, Hutton Close, South Church Enterprise Park, Bishop Auckland, County Durham DL14 6LG

Telephone: 0300 005 1213
http://www.dccarers.org/contact-us.html
www.dccarers.org

Sunderland, Washington and Coalfields Parent Carer Council
Sunderland Carer’s Centre, Thompson Park, Thompson Park Road, Sunderland SR5 1SF

Telephone: 0191 549 3768
Email: swcpcc@gmail.com

www.swcpcc.co.uk

City Equals
City Equals is a group representing the voice of young people with learning disabilities or difficulties living in Sunderland

Telephone: 0191 561 7401
Email: angela.mills@sunderland.gov.uk


Sunderland Network for Disabled Children
Tel: 0191 520 5553
Email: LifeandFamily@sunderland.gov.uk

Local Offer
The Local Offer is the place to find information for families of children and young people with special educational needs and disabilities (SEND). Here you will find a wide range of useful information with details on services that may help you or your child as they progress into adulthood from birth to 25.

To find Sunderland’s Local Offer, click on this link:
http://sunderland.fsd.org.uk/kb5/sunderland/fis/localoffer.page

To find Durham’s Local Offer, click on this link:
http://www.countydurhamfamilies.info/kb5/durham/fsd/localoffer.page?localofferchannel=0

Disability Matters
www.disabilitymatters.org.uk

This is a suite of free resources that are designed to improve awareness of disability issues for everyone who may work or volunteer with disabled children and young people. Although not primarily intended for parent carers, the resources should be interesting and useful for parent carers as they have all been completely co-produced by disabled young people, parent carers and other experts. Examples of how to make effective reasonable adjustments are given, in order to warmly welcome, include, value and respect all disabled children and young people.

They challenge attitudes and inspire the ‘can do’ attitudes required to support disabled children and young people to achieve the best outcomes that matter to them and their families. The topics were carefully chosen after extensive consultation with disabled children, young people, parent carers and families – they are the subjects that disabled children and young people told us that matter most to them, that they think professionals need to know more about.

The word order ‘disabled children and young people’ is used in all the Disability Matters sessions. This is because disabling factors are most often external to the person and are therefore something that everyone in society can do something about.

Understanding Disability
What is Disability?
This session will explore the meaning of disability, including the barriers that are commonly faced by disabled people and the ways in which perceptions of disability are changing.
https://www.disabilitymatters.org.uk/course/view.php?id=15

Reflection matters
Reflection helps us recognize our limits and then improve. This session allows you to examine your thoughts and attitudes to disability in the past, how you think of it currently and how you might think about it in the future. You will have a chance to think about your experience and what you would do differently next time.

https://www.disabilitymatters.org.uk/course/view.php?id=48

**Hidden Disabilities matter**
This session will help you realize that many disabilities are not always apparent from how someone looks or presents. Such disabilities may still have a huge impact on the individual, their family and others they meet and interact with.

https://www.disabilitymatters.org.uk/course/view.php?id=49

**Disability, Culture and Languages**
This session will help you think about the issues faced by young disabled people who come from ethnic minority communities and how you might adapt your work to offer them the best possible support.

https://www.disabilitymatters.org.uk/course/view.php?id=56

**Deaf Communication Matters**
Deaf children and young people face challenges on a daily basis because of a poor understanding of their communication needs. Using short film clips deaf children and young people share some of the typical barriers they encounter and show us simple steps to take and adjustments to make to overcome those barriers and enable successful interaction with them.

https://www.disabilitymatters.org.uk/course/view.php?id=72

**Learning Disability Matters**
This session highlights some of the specific challenges faced by learning disabled children, young people and their families. It includes positive examples of good practices that have been helpful in improving the experience of everyday activities and accessing services.

https://www.disabilitymatters.org.uk/course/view.php?id=85

**Autism Spectrum Matters**
This session highlights some of the specific challenges faced by children and young people on the autism spectrum and their families. It includes positive examples of good practices that have been helpful in improving the experience of every day activities and accessing services.

https://www.disabilitymatters.org.uk/course/view.php?id=93

**Complex Conditions Matter**
This session aims to demystify complex conditions. A structured approach can identify the many component parts, so that each can be correctly managed as part of the holistic care plan. This can help to achieve the best possible outcomes.


**Person to Person**

**Feelings Matter**
This session will help you realize that any person, whether they are disabled or not, appreciates love, opportunity and encouragement. It will provide some insight into what
being disabled feels like and how people’s reactions to disabled people can affect how they feel.
https://www.disabilitymatters.org.uk/course/view.php?id=50

**See the Person (Celebrate Abilities)**
This session will show that people with physical or learning disabilities also have strengths, ambition and deserve respect for their achievements.
https://www.disabilitymatters.org.uk/course/view.php?id=51

**Confidence Matters**
This session will help us to be more confident in responding to the needs of disabled people of all ages, what they need, and who might help us find out, as we seek to offer opportunity, help and encouragement.
https://www.disabilitymatters.org.uk/course/view.php?id=52

**Building Relationships Matters**
This session helps us understand that a disabled child or young person needs what all children and young people need: a stable background, continuity of care, a listening ear, opportunity and encouragement.
https://www.disabilitymatters.org.uk/course/view.php?id=53

**Communication Basics**
This session explores what we mean by communication – what it is, how and why we do it.
https://www.disabilitymatters.org.uk/course/view.php?id=68

**Understanding Matters for Effective Communication**
This session will help you to improve your chances of being understood and your awareness of whether or not you have been understood when you communicate, including with children and young people with Speech, Language and Communication Needs (SLCN), learning disabilities, social communication difficulties and Autism Spectrum Disorders.
https://www.disabilitymatters.org.uk/course/view.php?id=69

**Three-way Communication Matters**
Communication with disabled children and young people is often a three-way event, involving you, the young person and accompanying adult. This session helps you to plan for and achieve effective three-way communication which focuses firmly on the child or young person.
https://www.disabilitymatters.org.uk/course/view.php?id=70

**Communication Support Tools**
This session explores a range of tools which support direct communication with disabled children and young people about things that matter. It also signposts you towards sources of skilled support and advice and more advanced communication tools.
https://www.disabilitymatters.org.uk/course/view.php?id=86

**Communication Matters in Health**
This session looks at how to enable effective and accurate communication with disabled children and young people about their health needs and care needs.
https://www.disabilitymatters.org.uk/course/view.php?id=87
Communication Matters in Learning
This session looks at how to communicate effectively with disabled children and young people in and about their learning, in educational settings and beyond.
https://www.disabilitymatters.org.uk/course/view.php?id=71

Communication Matters in the Legal System
This session looks at how to enable best communication and best evidence with disabled children and young people involved in legal proceedings as either victims, witnesses, defendants or as parties in civil or family proceedings.
https://www.disabilitymatters.org.uk/course/view.php?id=95

Personal Care Matters
This session will explore the importance of providing personal care sensitively and respectfully.
https://www.disabilitymatters.org.uk/course/view.php?id=96

How Information is Shared Matters
This session gives insight into the impact upon families of how information, particularly in relation to the diagnosis, is shared with them. Case studies will show how positive information sharing can encourage celebration, enjoyment and a ‘can do’ attitude from the outset which can be helpful in contributing to positive outcomes that matter to disabled children, young people and their families.
https://www.disabilitymatters.org.uk/course/view.php?id=88

Family and Society
Rights Matter
This session will describe how everyone, regardless of health condition or impairment, has a right to respect, dignity and opportunity and will explore how these rights are enshrined in national and international law.

Meaningful Inclusion Matters
This session will show how disabled children and young people, with a little thought, planning and ingenuity, can always be included and how the Law may help acquire extra resources when needed.

Inclusion Matters for Organisations and Services
This session will guide you through some of the ways that an organisation can positively include disabled people. We will consider what ‘reasonable adjustment’ means in practice and how to put this in place. We will work towards understanding how real inclusion benefits the person and the organisation.
https://www.disabilitymatters.org.uk/course/view.php?id=57

Working Together Matters
Parents and carers of disabled children and young people are on a constant journey of challenge, discovery and understanding. From the first diagnosis to when the need for caring ends, parents and carers have to react quickly to the changing needs of those for
whom they care as well as the frequent changes in service provision. To support families making this journey, it is vital that professionals and voluntary services work together. This session considers how this can be most effectively achieved. It will also introduce key working and show the benefits associated with this approach. A selection of national organisations will be highlighted, along with advice on locating useful sources of information and other practical resources.

https://www.disabilitymatters.org.uk/course/view.php?id=58

Safeguarding Matters
This session will describe why disabled children and young people are vulnerable to abuse, explore how to respond where abuse is suspected and offer guidance on how to build the resilience of disabled children and young people and their families.

https://www.disabilitymatters.org.uk/course/view.php?id=54

Bullying Matters
This session explores the impact bullying has on life chances, and suggests simple actions that will reduce the impact and incidence of bullying of and by disabled children, young people and those with special educational needs.

https://www.disabilitymatters.org.uk/course/view.php?id=59

Environmental Challenges Matter
This session will give an overview of the environmental challenges that disabled children, young people and their families can face in their daily lives. These include attitudes, policies and rules as well as physical barriers. Positive examples including case studies will explain how you can, by using a bit of imagination, overcome many of these barriers. Disabled people should be included in everything as the default position.

https://www.disabilitymatters.org.uk/course/view.php?id=60

Transport Matters
This session explains the difficulties disabled children and young people face when travelling on their own, or with their families and friends. It provides examples of what people working in public services or the transport industry can do to alleviate this.

https://www.disabilitymatters.org.uk/course/view.php?id=61

Activities Matter
This session looks at how disabled children, young people and their families can enjoy arts, leisure and sporting activities and explains what can be done to ensure they have a good experience.

https://www.disabilitymatters.org.uk/course/view.php?id=76

Family Matters
This session will give insight into the range of challenges and experiences faced by all family members caring for one or more disabled child or young person, and how professionals working in partnership with parent carers and other family members, by listening actively at every step, can contribute to better outcomes that matter for them.

https://www.disabilitymatters.org.uk/course/view.php?id=110

Caring for Parent Carers Matters
This session will give insight into better understanding the needs of parent carers and the importance of supporting parent carers, informally and formally via carers assessments. Getting this right can contribute to better outcomes for disabled children, young people
and their families.
https://www.disabilitymatters.org.uk/course/view.php?id=111

Finance Matters
This session gives insight into the financial impact for families of caring for one or more disabled child or young person. You will learn how families often do not find out about or access the financial support that is available to them, and what you can do to help families access financial support.
https://www.disabilitymatters.org.uk/course/view.php?id=97

Work Experience and Employment Matters
This session will explore the issues faced by disabled young people seeking work experience and employment. Later sections will explore the concept of ‘reasonable adjustment’ and the ways in which employers can benefit by including disabled young people.
https://www.disabilitymatters.org.uk/course/view.php?id=117

Decision-making and Growing Up
Choices and Decision-making matters
This session looks at how to support disabled children and young people making their own decisions in all areas of their life, and what the legal framework is if you believe someone does not have the capacity to make a particular decision or choice.
https://www.disabilitymatters.org.uk/course/view.php?id=73

Mental Capacity Act Matters
This session covers the principles of the Mental Capacity Act and looks at how to assess capacity. There are opportunities to reflect on aspects of the Mental Capacity Act and its practice. 
https://www.disabilitymatters.org.uk/course/view.php?id=62

Best interests Decision-making Matters for Clinicians
This session explores ‘best interests’, what it means for disabled people and how best interest decisions are made for disabled people who lack capacity. 
https://www.disabilitymatters.org.uk/course/view.php?id=63

Advance Care Planning matters
This session discusses Advance Care Planning and decision-making with disabled people of all ages, including using the framework and elements of the Mental Capacity Act. 
https://www.disabilitymatters.org.uk/course/view.php?id=64

Deprivation of Liberty Safeguards
This session explores the Deprivation of Liberty Safeguards (DoLS) to help you understand what they are, their aim and purpose. 
https://www.disabilitymatters.org.uk/course/view.php?id=77

Advocacy Matters
This session explains how professionals from different sectors can help achieve better outcomes for many disabled children and young people by helping to advocate on issues that are affecting the disabled child, young person or their family, or signposting to independent advocates when appropriate.
Supporting Independence Matters
This session will explore how to help disabled children and young people become more independent, including how to address the risks and anxieties that may arise.

Growing Up Matters
This session will describe the changes that take place during adolescence and explore the extra challenges that may be faced by disabled children and young people as they grow up. Later sections will explain how missed opportunities can impact on disabled young people in later life and offer guidance on how to support parents who may be struggling to adjust to such changes.
https://www.disabilitymatters.org.uk/course/view.php?id=65

Transition Matters
Transition is an uncertain time for young people and their families. This session will explore how all those involved can use person-centred approaches to support young people and their families to prepare for adulthood and be confident about their future.
https://www.disabilitymatters.org.uk/course/view.php?id=118

Behaviour and Emotions
The Different Meanings of Behaviours
This session will provide an overview of the possible different meanings of behaviours seen in disabled children and young people from a variety of perspectives. Behaviour changes may be indicators of physical illnesses or they may be secondary to development, communication, mental illness, behavioural disorders and the external environment.

Worry and Anxiety Matter
This session will give insight into what it is like to experience worry and anxiety as a disabled child or young person and what it feels like as a parent carer to be dealing with it. Tips on preventive strategies and interventions will be considered, including behavioural, family interventions and, rarely, medication.
https://www.disabilitymatters.org.uk/course/view.php?id=112

Responding Positively When Behaviours are Seen as Challenging
This session introduces positive behaviour support (PBS), an evidence based approach to meeting the needs of people whose behaviours are seen by others as challenging.

Sexually Concerning Behaviours Matter
This session will investigate the issues surrounding the sexual development of disabled young people and explore when it is appropriate to be concerned about sexualised behaviours.
https://www.disabilitymatters.org.uk/course/view.php?id=119

Self-injury Matters
This session gives insight into self-injury from the perspectives of families who deal with it,
including how the response of others affects their experience and outcomes. Tips on how to respond to self-injury and how to find expert help will be explored.
https://www.disabilitymatters.org.uk/course/view.php?id=89

**Health and Wellbeing**
**Diagnosis Matters**
This session will give insight into the positive difference that having the right diagnosis or diagnoses can make and tips on a structured approach to achieving diagnoses, as well as tips on what to do when no diagnosis is made.
https://www.disabilitymatters.org.uk/course/view.php?id=90

**Health Needs Matter in all Settings**
This session aims to help the learner understand how important health needs are in all settings.
https://www.disabilitymatters.org.uk/course/view.php?id=91

**Equal Access to the Best Health Outcomes Matters**
This session is essential for all involved in the health and care of disabled people. It highlights how inequalities in healthcare can lead to bad outcomes. There are positive tips about how to ensure that the best outcomes are more equally accessible for everyone.
Warning: Some of the case studies in this session are upsetting. They are important because they are real.

**Participation – Movement and Fatigue**
This session will explore the challenges presented by movement difficulties and fatigue and the ways in which we can provide disabled children and young people affected by such impairments with opportunities to participate.
https://www.disabilitymatters.org.uk/course/view.php?id=120

**Participation – Sensory Environments**
This session will explore the way in which the senses can affect the ability of some children and young people to take part in certain activities or situations. Later sections will identify some common examples of sensory challenges and explain how it may be possible to facilitate participation by making adjustments.
https://www.disabilitymatters.org.uk/course/view.php?id=123

**Continence Matters**
Continence is a life skill that some never achieve for lots of different reasons. Issues in this area impact significantly on quality of life for disabled children, young people and their families. This will be demonstrated through case studies, with tips from families and experts about good practice that promotes the best outcomes.
https://www.disabilitymatters.org.uk/course/view.php?id=92

**Vision Matters**
This session will give insight into the:
• Experience of vision impaired children, young people and their families
• Impact of their impairment on their daily lives and access to services
• Top tips on improving outcomes that matter to them
https://www.disabilitymatters.org.uk/course/view.php?id=128

**Pain Matters**
This session will explore some possible causes of pain for disabled children and young people, how pain may be identified and how to get help with pain management to achieve the best outcomes.
https://www.disabilitymatters.org.uk/course/view.php?id=125

**Participation – Social World**
This session will explore how disability can affect a child or young person’s capacity to socialise and offer guidance on how to overcome the barriers that can potentially prevent disabled children and young people from forming new relationships.
https://www.disabilitymatters.org.uk/course/view.php?id=126

**Hearing Matters**
This session will give insight into the:
• Experiences of deaf or hearing impaired children, young people and their families
• Impact of their impairment on their daily lives and access to services
• Top tips on improving outcomes that matter to them
https://www.disabilitymatters.org.uk/course/view.php?id=129