

# QUALITY PRINCIPLES FOR PAEDIATRIC DISABILITY SERVICES

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*on behalf of the British Academy of Childhood Disability*

## **Who this document is for**

The British Academy of Childhood Disability have published this document to make it clear for families, professionals across agencies and commissioners as to what they should expect from paediatric disability services.

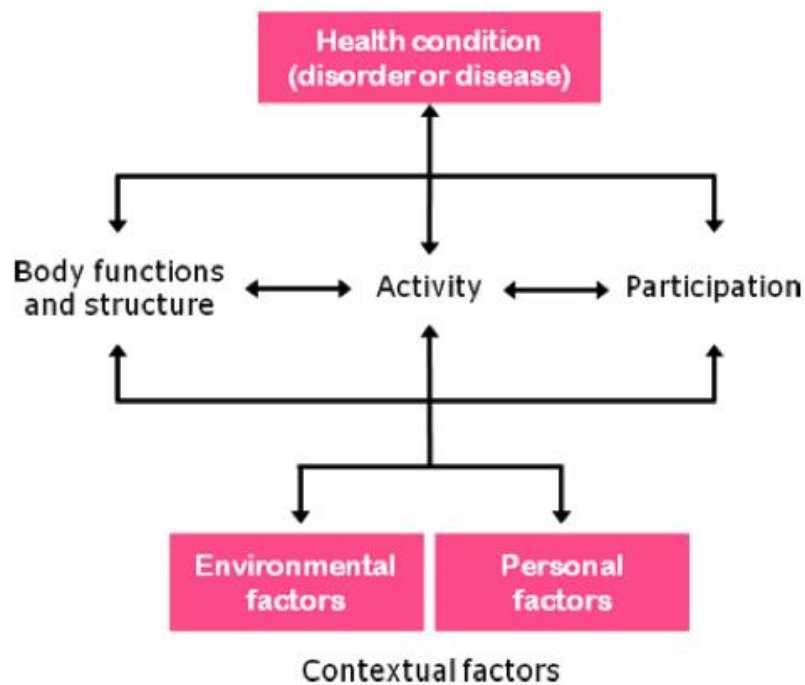
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**What is 'disability'?**

The World Health Organisation's International Classification of Functioning, Disability and Health (usually known as the ICF) definition of disability is used. 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. There are many ways to reduce or exacerbate disability.

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:



**What is the paediatric disability service?**

A consultant led team with expertise in paediatric disability. This team will have clear network arrangements with other paediatric medical and surgical specialists, specialist children's nursing teams, allied health professionals, professionals in education, social care, voluntary and independent service providers. All network partners should work together as a person-centred, family focused team, regardless of employing organisation/s.

**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. It is good practice for the GP to always be notified if a referral is made, to ensure optimum communication.

***What can be measured:***

- Number of referrals
- Waiting times to initial appointment
- Waiting time to diagnosis
- Waiting time for therapies
- Waiting times for other interventions e.g. condition-specific parent carer training

**Who should be referred to the paediatric disability service?**

Any child or young person aged 0-19 years 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 at any age, including in early infancy (early assessment by and advice from physiotherapy, speech and language therapy and occupational therapy essential in this group)
- Red flags suggestive of an autism spectrum condition
- Red flags suggestive of an attention deficit and/or hyperactivity disorder
- Emotions and/or behaviours causing concern to family or professionals
- Head circumference above the 99.6<sup>th</sup> percentile, below 0.4<sup>th</sup> percentile or that has crossed two percentile lines upwards or downwards on the appropriate chart, or is significantly disproportionate to parental head circumference
- Unusual aspects to their appearance, unusual birth marks, skin marks or concern that there may be a genetic or chromosomal condition
- Any clinician who is uncertain about any aspect of assessment, but thinks development, emotions and/or behaviours may be different from expected
- A parent or carer who is concerned about any aspect of development, potential disability, emotions and/or behaviours

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.

***What can be measured:***

- Number of referrals by reason for referral and referral source

**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, as well as any **other factors** that are impacting on the health or wellbeing of the child or young person.

This is so that the best possible **explanation and information** can be given for the child, young person and their family as to how any differences in their health and wellbeing have come about, what to expect for the future and what services and support are available to optimise their health, wellbeing and participation in society

Having the right information about a child or young person's health, wellbeing, diagnosis or diagnoses can help the **paediatric disability team** 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 grow up to have a job, have relationships?
- 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
- Access genetic counselling for the family. This will help families to understand the chances of having other children with the same diagnosis and to be informed about any known associated health issues
- Collaboratively develop, with the child or young person, their family and significant others, a plan to support and enhance the health, wellbeing and participation of the child or young person and their family in daily life
- Manage the child's condition in the best way, based on the evidence of what is known in the published literature
- Put in place any early intervention where there is evidence that this may make a positive difference
- Stop doing further tests that may be painful for the child and inconvenient for the family

The **child or young person and their family** to receive:

- The most evidence-based management for the condition/s and circumstances
- Appropriate information and support, including services provided by charities and online resources

***What can be measured:***

- Numbers of health conditions identified
- Range of functioning for children and young people with each health condition
- Numbers of referrals to clinical genetics
- Adjustments made to enhance health, wellbeing and participation in everyday activities

**What to expect from the paediatric disability service:**

***Respect, value and good communication for the child, young person and family***

- For the best interests of the child or young person to be the paramount consideration at all times, including all aspects of health, wellbeing and safety from harm
- To be listened to, heard and taken seriously
- Appropriate support for communication in the method and language of the child or young person's choosing
- For the views, wishes and aspirations of the child or young person to be taken into account at every encounter and in all decision-making that affects them
- For the views, wishes and aspirations of parent carers to be taken into account at every encounter and in all decision-making about the child or young person. A family-centred approach should value parents as experts in their own children, whilst ensuring the views, wishes and aspirations of the child or young person are always heard in all discussions and decision-making
- To have all aspects of health conditions, assessments, investigations, management, treatments, interventions and onwards referrals clearly explained in lay language, both in person and written down. This should include the outcomes agreed with the child, young person and family and any specific, measurable, achievable, relevant and time-bound actions required to achieve the outcomes and who will deliver these
- Attention to growth and nutrition, with appropriate equipment to weigh and measure children and young people at each consultation and clear referral pathways for expert assessments where there are concerns
- For information, guidance and support to be provided in a coordinated manner, based on the assessed needs of the child, young person and their family.
- Needs-based support, interventions and reasonable adjustments should be implemented without delay as soon as needs are identified and should not wait for a specific diagnosis to be made
- Continuity of care across the lifespan, with good communication, planning and adequate introductions when aspects of care are transferred to different providers, including on moving from paediatric to adult services
- To know that information will only be shared between professionals on a 'need to know' basis, in the child or young person's best interests and to have explained why it is important for this information to be shared
- For reports and clinical letters to be written in language that is as understandable as it can be for children, young people and their families, to be addressed to them directly and copied to professionals across agencies on a need to know basis, with the family's consent, recognising that sometimes additional letters may be needed between professionals
- For children and young people with complex needs to have an Emergency Health Care Plan to facilitate communication in the event of a health emergency. This should include:
  - A statement about agreed levels of intervention, which almost always will be a prompt to assess and manage as per advanced paediatric life support guidance, including full resuscitation and intensive care if needed

- Any clinical scenarios that can be predicted (e.g. breathing issues, seizures, ventriculo-peritoneal shunt malfunction) with step by step instructions about what action should be taken and by whom, from the lay person in the community, the ambulance personnel to the clinician in the emergency department
- Who (person or service) to contact in the event of a health emergency for more information or advice
- Any treatments or signpost to where the latest list can be found
- Review date and signature of lead clinician

***What can be measured:***

- Percentage of disabled children and young people attending paediatric emergency department or admitted to paediatric wards with an Emergency Health Care Plan in place
- Family feedback about experience of how valued and respected they have been, quality of communication and coordination and of care, using tools such as Measures of processes of Care (MPOC-20) (<https://www.canchild.ca/en/shop/1-mpoc-20>)



**Clear information about care pathways**

- Information about locally available services and care pathways across the lifespan clearly published and accessible for families and professionals across agencies and voluntary organisations
- To wait no more than 18 weeks from first referral to receipt of treatment if any is required, based on assessed needs
- To know what early interventions are available for which conditions and how these can be accessed
- To know how to access equipment and assistive technologies when these may be needed, what the waiting times are, how they will be reviewed and how to access maintenance and repair services
- If specialist services are not available locally, to know what and where these are and how to access them, including for specialist management of:
  - Spasticity, including gait analysis and consideration for selective dorsal rhizotomy
  - Complex neuromuscular, neurological, movement, genetic, social communication conditions, pain, epilepsies, communication needs, feeding issues, continence, safety from harm and/or behavioural, emotional, mood issues including for those with learning disabilities

**What can be measured:**

- Family feedback about quality of information about care pathways

**High quality services that network effectively together across agencies and sectors**

All who work in the paediatric disability service should:

- Know the red flags that suggest a child or young person may be disabled or have concerns about their development, emotions and/or behaviours that require further expert assessment
- Undergo regular disability awareness training, including equality, rights, person-centre care and how to make reasonable adjustments
- Undergo regular training in communication, including children with additional communication needs, including in sharing new information
- Be able to proactively plan and make appropriate reasonable adjustments so that disabled children, young people and those where there are concerns about development can be warmly welcomed and included in all services, sectors and facilities and enjoy the fullest possible participation and best possible quality of life
- Collect data at the point of care about the multi-faceted needs of disabled children and young people and record these in the personal electronic record. This is so that data about real time needs in the local population can be:
  - Used locally to inform local assessments of need and the commissioning, design and provision of services across agencies that are fit for purpose to meet identified needs. This will include informing decision-making about how many whole time equivalent doctors, nurses, allied health professionals and staff across education and social care may be required to meet identified needs, which will vary depending on the prevalence rates of specific conditions and needs in the specific local population
  - Reported by NHS provider organisations to NHS Digital as part of the Children and Young People's Health Services dataset (CYPHS) (England) and equivalents in Wales, Scotland and Northern Ireland. This is so that comparative analyses can be undertaken and published by geographical area, to act as a driver for continuous improvement in quality of care and reporting of quality data.For more information about this please see: <http://www.bacdis.org.uk/policy/dataset.htm>
- Work in **operational partnership** with other health, education, social care, voluntary and independent service providers, to produce person-centred care plans that:
  - Minimise duplication of effort for families and professionals – “Do once and share”
  - Wherever possible, efficient and effective, offer combined appointments, joint assessments and team goal-setting in partnership with children, young people and their families
  - Proactively includes the general practitioner in the team around the child, young person and family
  - Communicate clearly and in a timely way across agencies including education teams where a child or young person is identified as having special educational needs or disability
- Work in **strategic partnership** with other health, education, social care, voluntary and independent service providers, parent carer forum and children and young people's participation leads to:

- Plan and design services to efficiently and effectively identify and meet needs in the local population
- Set clear strategic outcomes in relation to disabled children, young people and their families, monitor progress towards achieving these outcomes and hold each other to account
- Strengthen integration of services across agencies and sectors
- Provide cohesive governance across the disabled children and young people's agenda
- Wherever possible pool budgets and resources in order to provide services efficiently and effectively
- Work in **partnership with the local safeguarding children board** to ensure that there are robust mechanisms to safeguard all disabled children, young people and those where there are concerns about development, with easy access to expert inter-agency assessment where there are any safeguarding concerns
- All children and young people with complex needs and their families should have access to a named professional as a single point of contact for all services if they would like one

***What can be measured:***

- Percentage of staff by agency or service who have completed training in recognition of red flags of potentially disabling conditions
- Percentage of staff by agency or service who have undergone disability awareness training, including using Disability Matters: [www.disabilitymatters.org.uk](http://www.disabilitymatters.org.uk)
- Analysis from data collected at the point of care about the multifaceted needs of disabled children and young people
- Data flow to NHS Digital (England) and output reports for NHS providers and Clinical Commissioning Groups and equivalent data reporting arrangements in Wales, Scotland and Northern Ireland
- Notification rates to education teams of children and young people with special educational needs
- Outputs and achievements of local strategic partnerships
- Local arrangements to consistently include the views of disabled children, young people and parent carers in the design of services
- Family feedback about the added value of having a named professional to coordinate their care

**Support and information**

Information should be available for families about how to access when needed:

- Independent advocacy
- Peer support for children and young people
- Parent carer support
- Financial entitlements and income maximisation advice
- Specific support relating to culture or language
- Short breaks, including how to access these locally
- Further expert clinical opinions where there are any concerns about any aspect of care
- The organisation's complaints procedure
- Reports from audits, inspections and reviews of the service

Free **tools** that can support paediatric disability clinic consultations:

- Parents may want to complete these (or similar) in advance to focus their thoughts about what the issues are and what information may be needed
- Professionals may want to encourage and support families to complete these (or similar) in advance of consultations, to ensure that consultation time is as efficient and effective as possible

For new patients of pre-school age: [www.bacdis.org.uk/policy/documents/PreSchoolBIS.pdf](http://www.bacdis.org.uk/policy/documents/PreSchoolBIS.pdf)

For new patients of school age: [www.bacdis.org.uk/policy/documents/SchoolAgeBIS.pdf](http://www.bacdis.org.uk/policy/documents/SchoolAgeBIS.pdf)

For review patients: <http://www.bacdis.org.uk/policy/documents/HFWSummary.pdf>

***What can be measured:***

- Information provided for families
- Information received and understood by families
- How localities include the views of children, young people and parent carers in all decision-making about their care on an individual basis and in the design, management and review of services on an ongoing basis

**Where families can get support whilst waiting for an assessment, waiting for a diagnosis or in case of concern**

National Network of Parent Carer Forums

Telephone: 0207 608 8708

Email: [info@nnpf.org.uk](mailto:info@nnpf.org.uk)

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

Contact a Family

Freephone: 0808 808 3555

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

**Free resources to support disability training across agencies and sectors, including about how to make reasonable adjustments**

[www.disabilitymatters.org.uk](http://www.disabilitymatters.org.uk)

[www.mindEd.org.uk](http://www.mindEd.org.uk)

**Links to quality principles for:**

[Paediatric physiotherapy services](#)

[Paediatric speech and language therapy services](#)

[Paediatric occupational therapy services](#)

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- NHS England Specialist Service Specifications for Paediatric Neurodisability and Paediatric Neurorehabilitation
- Available at: <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e09/>
- NHS England Specialist Service Specification for Paediatric Palliative Care
- Available at: <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e03/>
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