



contact *For families
with disabled children*

Working with partners

Special Educational Needs and Disability

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About this resource

Healthwatch aim to reach every section of their community to gather evidence and insight about people's experiences of health and social care in their communities.

Using Special Educational Needs and Disability (SEND) as an example, this resource explains how Healthwatch can use this insight to have a greater impact and influence in areas outside of health and social care by working with partners.

It provides information about SEND and how Healthwatch can work with SEND and Parent Carer Forums locally to improve services for their community.

This resource was produced with Contact and National Network of Parent Carer Forums.

Working with partners

Working with partners can help you to:

- Deepen your understanding of an issue by working with experts
- Reach a wider audience with your work, helping your work to have more of an impact and build your brand reputation
- Effectively use resources to tackle common local issues together rather than duplicating time and effort
- Better understand how other organisations work and their roles to enable you to work well together

How Healthwatch England can help facilitate partnerships

Healthwatch England can work to help broker relationships with national organisations and help highlight local Healthwatch as resource of invaluable local insight to people's experiences.

In relation to SEND, Healthwatch England has met with the National Network of Parent Carer Forums and Contact to discuss how we can work better together and use Healthwatch as a way of sharing evidence and insight about SEND provision to providers of health and social care.

To help facilitate partnerships across the Healthwatch network, Healthwatch England has:

- Held webinars for:
 - representatives of Parent Carer Forums to find out more about Healthwatch and how we can work better together
<https://ukdoh.webex.com/mw3300/mywebex/nbrshared.do>
 - local Healthwatch about Parent Carer Forums and the benefits of working together
<https://ukdoh.webex.com/ukdoh/ldr.php?RCID=68b45064110d20197cab219a8360cadd>
- Held an event for representatives from Parent Carer Forums and local Healthwatch to learn from one another

What is meant by Special Educational Needs and Disability?

Special Educational Needs and Disability are grouped together under the term SEND.

Local authorities and clinical commissioning groups use this terminology when referring to a service user or patient who may have additional learning and access needs for Education, Health and Care.

A child or young person has special educational needs and disabilities if they have a learning difficulty and/or a disability that means they need special health and education support, we shorten this to SEND.

The Children and Families Act 2014 came into force on 1 September 2014. This brought in changes to how children with special educational needs have additional rights and entitlements for help and support, and is more holistic in health, education and social care.

Special educational provision should be matched to the child's identified needs. Children's special educational needs are generally thought of in the following four broad areas of need and support (see Chapter 6 of the SEND Code of Practice, 0 - 25, paragraph 6.28 onwards, for a fuller explanation): <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>.

- Communication and interaction
- Cognition and learning
- Social, emotional and mental health
- Sensory and/or physical needs

In practice, individual children or young people often have needs that cut across all these areas and their needs may change over time.

The legislation in more detail and SEN Help additional reading can be found here:

- <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>
- <https://www.gov.uk/children-with-special-educational-needs/extra-SEN-help>

Education, Health and Care Plans

- Many children with special educational needs will qualify for an Education, Health and Care Plan (EHCP).

This is a legal document made up of various parts of the child/young person's requirements. It replaces the old system of Statement of Educational Needs. Parents and carers as well as the child or young person will be consulted through the process of development of an EHCP.

- This law does not stop when a child reaches the age of 18, but spans to the age of 25, to consider that some people with learning delays can result in outcomes taking longer to achieve.
- Even if a child does not reach all the criteria to receive an EHCP, they may have the other tier of support called SEN Support. This means that support is awarded within the place of education, but may also involve additional health, therapies and social care such as short breaks*. *Sometimes families who have disabled children and/or health conditions benefit from a break from their caring responsibilities. Local authorities now

have duties to provide short break services and make clear how families can access these.

Special Educational Needs and Disability Independent Support Service

In each local authority area there is a Special Educational Needs and Disability Independent Support Service (SENDIAS) which supports parent and carers with any difficulties they have in getting the support their child needs.

Although these support services mainly focus on education, they also work with other partners, such as Healthwatch on health and social care issues.

Find out more

Find our more information on SENDIAS services on their website.

<https://cyp.iasnetwork.org.uk/>

Why partner with SEND?

Since the launch of the Children and Families Act in 2014, Healthwatch have been hearing more about issues relating to services and support for children and young people with special educational needs and disabilities.

There has been changes to the legislation that aim to put children and young people at the centre of SEND services, providing a more holistic approach to Education, Health and Social Care.

This puts different duties on different providers including time limits on processing Education, Health and Care Plans (EHCP), which replaces a Statement of Educational Needs (SEN).

Although Healthwatch are not the experts in education, there is the opportunity through working with their local Parent Carer Forums to develop a strong partnership to help create stronger evidence and insight to ensure services meet their duties.

Our partners tell us that Children with SEND often have to 'battle' and 'fight' or their voice can be lost in the system of getting the right provision for their child. It is the role of Healthwatch to amplify the voice of those who find it difficult to be heard, so another reason how our joint voices can be heard better.

SEND in context

National strategy

The NHS has produced a ten -year plan, setting out all the things it wants health services to do better for people across the country.

In this plan, there is a strong focus on improving care for people with learning disabilities and autism.

It includes:

- Increasing access to support for children and young people with an autism diagnosis
- Developing new models of care to provide care closer to home and investing in intensive, crisis and forensic community support
- A commitment to providing support closer to home by reducing inpatient provision for people with learning disabilities or autism to less than half of the 2015 level by 2023/24.
- Expanding services for children and young people in line with the proposals outlined in the Green Paper on young people's mental health including the creation of 'mental health support teams' in schools

To support these changes, the NHS has committed to spending more money on providing support for children and young people's mental health

As well as specific mentions of SEND, the following parts of the Long-Term Plan will also impact on families of children with SEND.

Integrated care and population health

The Long-Term Plan highlights a shift towards a more coordinated and integrated approach to providing care that meets the needs of local populations. Integrated Care Systems (ICS) will be the main way of achieving this.

The plan says that ICSs will cover all areas of England by April 2021 - and will increasingly focus on population health. It also includes the development of a new ICS accountability and performance framework that includes patient, carers and public in the measurement of how well integrated the local area is.

Reducing health inequalities

The plan also states a commitment to a 'more concerted and systematic approach to reducing health inequalities', with a promise that action on inequalities will be central to everything that the NHS does. SEND comes under this, so it is important to remember this when working with Parent Carers.

Personalised Care

The roll out of the Comprehensive Model of Personalised Care which includes more personal health budgets, more social prescribing including 'link workers' to navigate local options. As people with SEND are more likely to have complex medical conditions, this is a positive step forward for SEND.

Participation

The Long-Term Plan states a need to create genuine partnerships between professionals and patients. To help facilitate this, is commits to training staff to be able to have conversations that help people make the decisions that are right for them.

National timelines

The NHS Long Term Plan sets out the priorities for the SEND workstreams:

1. Confirm national funds and programme support by end of July 2019
2. Define and confirm SEND deliverables with government partners and regions by end August 2019
3. Complete and present SEND Programme Transition Report to the Children and Young People Transformation Board in October 2019
4. Fully reporting to Children and Young People Transformation Board in October 2019
5. Draft next four years' deliverables by end of January 2020

Find out more <https://www.longtermplan.nhs.uk/implementation-framework/>

Children and Young People Transformation Programme Board

Section 5.10 in the NHS Long Term Plan is the only specific reference to SEND. However, SEND is also part of the workstream within the Children and Young People's Transformation Programme Board.

This is a newly created part of the NHS Long Term Plan and a sub-group of the NHS Assembly. The NHS Assembly brings together a range of individuals from across the health and care sectors at regular intervals to advise the joint boards of NHS England and NHS Improvement on delivery of the NHS Long Term Plan.

The Children and Young People Transformation board meets quarterly and reports to NHS England and NHS Improvement Executive Boards. This information is then shared with the NHS Assembly.

The Board is expected to produce a report on SEND transition to adulthood in late 2019.

Local timelines

Local systems are working hard to develop draft versions of their five-year strategic plans (by mid-September), with final versions submitted by November 2019. These plans will clearly describe the population needs and case for change in each area, then propose practical actions that the system will take to deliver the commitments set out in the NHS Long Term Plan.

These proposals should clearly set out how proposals for people with learning disabilities and/or autism align with their plans for mental health, special educational needs and disability (SEND), children and young people's services and health and justice.

Top issues parents and carers seek help for

The disabled children's charity Contact shared the top health issues parents and carers contact their helpline for:

- **Transforming Care Partnerships**

the way in which care for the disabled is worked from a bottom up approach, using participation both individual and strategic to enable change/transformation.

- **Access to Child and Adolescent Mental Health Services**

People often report long waiting times for access to support their child needs. In addition, people often face issues around the thresholds for accessing support.

- **Getting an Autism diagnosis**

People say that they are made to wait too long for their child to be assessed and receive

a diagnosis. They also say there is little information about the support available whilst waiting for a diagnosis.

- **Access to therapies**

People tell Contact that they face difficulty accessing therapeutic intervention and often face a lengthy wait. They have also shared that they feel that their child has been discharged from a service too early, without them receiving the ongoing support they need.

Working with Parent Carer Forums

The National Network of Parent Carer Forums (NNPCF) is a network of Parent Carer Forums across England.

The NNPCF is a membership-led organisation. Membership is made up of 152 local parent carer forums where they are in receipt of the 'Parent Carer Participation Grant' which is currently administered by [Contact for Disabled Children](#).

These member forums are arranged into nine regions, these follow the same regional breakdown as the Department for Education, with each of the regions appointing a regional representative to act as their regional steering group member.

There are over 80,000 parent carers within the network who contribute to local, regional and national developments and discussions.

Find out more

To find your local Parent Carer Forum, take a look at the NNPCF website.

<http://www.nnpcf.org.uk/about-the-nnpcf/>

The data that goes to NNPCF from all the local Parent Carer Forums, is also shared with the national body, and enables NNPCF to identify national issues. Where these are significant, the NNPCF works with Contact and often creates campaigns and raises these issues with the Department of Health and Social Care/Department for Education.

What is a Parent Carer Forum?

There is a Parent Carer Forum in each local authority in England. They are commissioned by the local authority and have advisory powers to the Clinical Commissioning Group, Joint Strategic Needs Assessment and NHS England. They also report to Contact and the Network of Parent Carer Forums.

These forums include parent carers of children and young people with special educational needs and/or disabilities. They have valuable experience and insight into how health, education and social care services are working for their children and how they can be improved.

Similar to Healthwatch, Parent Carer Forums are independent and are strategic partners of local authorities and health partners in the planning, developing and evaluating services for disabled children and young people and act as a collective voice for parent carers in their local area.

Find out more

In 2019, the National Network of Parent Carer Forums published their 'State of the Nation' report. This report provides an overview of the experiences of families of children and young people with special educational needs and disabilities a year after the end of the implementation of the Children and Families Act.

Read the report: <http://www.nnpcf.org.uk/wp-content/uploads/2018/06/State-of-the-Nation-2019.pdf>

Benefits of Healthwatch and Parent Carer Forums working together

When organisations work together in partnership, they can often have a bigger impact on improving the way services are designed and run and improve people's experiences.

Benefits for Healthwatch	Benefits for Parent Carer Forums
Parent Carer Forums are the experts when it comes to all matters about SEND in the 0-25 age group. As Education is outside of local Healthwatch remit, they're able to provide expertise in this area and know SEND law in detail.	Healthwatch has a seat on the Health and Wellbeing Board and local Joint Strategic Needs Assessment
Parent Carers have in-depth knowledge and data about local issues and can supply a rich source of information when Healthwatch are working on certain projects.	Healthwatch has statutory powers and therefore Parent Carers can get their voices heard and their issues via their local Healthwatch
Parent Carers are experts in supporting parents and signposting parents to SEND support around education.	Healthwatch can be on Parent Carer Forum Advisory Board to help steer local issues and keep SEND as a priority workstream
Parent Carers make excellent advocates for their children and are often passionate about their voices being heard. Many go on to volunteer, so there may be opportunities for parents and carers to become Healthwatch volunteers.	Working with Healthwatch can mean that representation at meetings and strategic boards can be shared, reducing impact on resource.
There are potential cost savings for joint meetings and focus groups joining together.	Healthwatch is intelligence and data-led, and national and regional trends can be formed based on local intelligence.

Parent Carer Forums are often the one consistent element within the SEND agenda locally and have links to local, regional and national networks and all the intelligence and information sharing this can achieve.

Parent Carer Forums understand what is happening on the ground for families and they know what works and what doesn't work.

Forums should be working at a strategic level with ALL area partners so can offer insight into the effectiveness of these strategic processes for participation.

Parent carer Forums are a mechanism for getting service and policy design, processes and pathways, and engagement opportunities right for the wider SEND community from the beginning

Top tips for working with your Parent Carer Forum

Working together can be difficult in practice when both organisations often have competing priorities and tight resources. We have created some top tips for Healthwatch and Parent Carer Forum who keen to work together but they aren't sure how within the time and budget limitations.

Making initial contact

- Raise awareness of the potential benefits of working together in partnership, highlighting the additional expertise you can add
- Highlight the benefits in other areas where joint working has had tangible results
- Have a conversation to find out what their priorities are and where there may be joint areas of interest you could collaborate on.
- Before you start working together, draft a Memorandum of Understanding outlining how you aim to work with one another outlining boundaries and expectations.
- Identify people within both organisations who could broker or champion joint working.

Opportunities to share resources

- Share the committees that you attend to avoid doubling up on work.
- Seek funding to work together on joint projects
- Develop a joint training offer for both Healthwatch staff and Parent Carer Forums representatives to better understand each other's roles.
- Use volunteers or patient champions to represent for both organisations
- Hold a joint event to engage with the public

Maintaining the relationship

- Use each other's communications channels such as social media, websites and newsletters to share relevant information with key audiences
- Consider providing a community pot grant to support SEND work within a Parent Carer Forum
- Hold a youth led event and both parties attending
- Try different methods of communicating more easily so you don't have to physically meet, such as teleconferences, webinars or take it in turns to visit each other.
- If your relationship becomes difficult, having a mediator such as Healthwatch England can help ensure the relationship remains positive.

Work in practice

Including Parent Carer Forums on a Healthwatch Board

Healthwatch Somerset

To help fulfil their commitment to work with children and young people each year, Healthwatch Somerset has added the Chair from the Somerset Parent Carer Forum to their Advisory Board.

The Parent Carer Forum regularly sends feedback from Somerset parents and carers about health and social care issues they are facing.

As well as being used locally, this information is also shared with Healthwatch England and the National Network of Parent Forums. This allows the data we collect to have a bigger impact as it's shared more widely.

“I see the parent forum as another member of the team, Ruth regularly sends me updates. We have made a commitment to work with children and young people every year, and we want to make sure that children and young people with additional needs do not have their voice lost in their feedback. It is an essential relationship that continues to build on our shared values.”

Healthwatch Somerset Manager

Making services work better for children and young people with SEND

Healthwatch Rotherham

In Rotherham, Healthwatch work closely with their local Parent Carer Form and regularly share local regional or national intelligence that may benefit one another.

Working together, they have used what children and young people and their families have said to inform the development of Rotherham's All Age Autism Strategy and how it is implemented locally.

They have also worked to influence the restructuring of the Rotherham Children and Adolescent Mental Health Services (CAMHS) Neurodevelopment Pathway as well as establishing a regular meeting with CAMHS and partners from across health and social care to provide an opportunity to share what they're hearing from local people.

Helping children and young people with special educational needs and disabilities feel involved in their care

Healthwatch Newcastle

In 2017 a new system designed to assess and plan support for people with a high level of special educational needs and disability was introduced in Newcastle.

Healthwatch Newcastle wanted to find out more about people's experiences using this new service to find out how it was working.

During a ten-week Healthwatch Newcastle ran two surveys aimed at

- Young people between 16-25 with Educational Health and Care plans or statements
- Parents and carers of children and young people between 0–25 years with Educational Health and Care plans or Statements, in Newcastle. The questionnaires were a mix of closed and open questions

People told Healthwatch Newcastle that they often felt that they were not involved in decisions being made about their care. As changes with legislation were meant to make things more person-centred, they were hearing that services had not yet caught up with the differences in working together in practice.

Healthwatch Newcastle presented their findings and recommendations for improvement to the local authority and local stakeholders.

The recommendations were categorised into the four main areas:

- Involving children and young people and their parents and carers using the service as much as possible in decisions about their own care.
- Providing better information and support to help people feel involved and participate in decisions about their care.
- Preparing effectively for adulthood
- High quality provision to meet the needs of children and young people with SEND

In response to the recommendations, Newcastle City Council developed an action plan that included:

- A 'who's who' guide was developed to help people better understand the roles and responsibilities of who they can contact for SEND support
- A tracker was introduced to monitor attendance of professionals at education, health and care planning meetings/review meetings. It will now be used to compile an annual review of attendance
- A training and information event about Preparing for Adulthood outcomes was held
- Development of a 'Life skills' checklist which is being used in schools across Newcastle
- Two post-16 providers changed their curriculum to have a greater focus on Preparing for Adulthood outcomes

In April 2018, Ofsted and the Care Quality Commission carried out an inspection of SEND services and some improvements were highlighted. As a result, Newcastle City Council (NCC) and Newcastle Gateshead Clinical Commissioning Group (CCG) produced a 'Written Statement of Action' outlining what they intend to do.

Healthwatch Newcastle is supporting the council and CCG to improve how people can share their experiences and have their say about local SEND Services.

In addition, Healthwatch Newcastle is now invited to some of the meetings that fall within the SEND governance structure in Newcastle and are working with partners to help deliver the action plan created by Newcastle City Council.

‘There is much for local services to celebrate, but clear challenges too, and the recommendations contained in this report should serve as a reminder that there is still much to be done, and that the needs of children and young people with SEND should remain an absolute priority for commissioners and providers of services in the local area – Healthwatch Newcastle has produced an excellent report!’

Dr David W Jones, Newcastle Gateshead Clinical Commissioning Group

‘The findings of this report will form part of the discussions with Newcastle and Gateshead CCG and the SEND programme board to ensure that the service delivered by the trust provides a quality service for children and young people with SEND.’

Rebecca Campbell, Northumberland, Tyne and Wear NHS Foundation Trust

Find out more

Read Healthwatch Newcastle’s report, Spotlight on SEND

<https://www.healthwatchnewcastle.org.uk/wp-content/uploads/2015/10/Spotlight-on-SEND.pdf>

Working together in Enfield

Healthwatch Enfield

In Enfield Healthwatch and the local Parent Carer Forum work closely together to ensure that those with children with special educational needs have their voice heard and acted upon. They do this collectively by:

- Ensuring that local parents and carers of children and young people with special educational needs can have their say in local consultations about changes to health and care services.
- Involving parents in their work as volunteers and staff
- Helping health and social care staff become more disability aware by delivering training sessions to providers and staff.
- Encouraging parents and carers of young people with special educational needs and disabilities along with adults with learning disabilities in sharing their experiences of health services to help inform how the NHS develops locally over the next ten years.

Helping people get the right benefits

Contact

A parent got in touch with the Contact Benefits Helpline (0808 808 3555) to discuss whether they were getting the right financial support. They were unable to claim working tax credits as one parent earned over £40,000 per year. This meant that they were also unable to receive help for travel costs to get to help them get to college.

Contact advised the individual to stop claiming Child Benefit for that child, but to switch to a Universal Credit claim instead. This was successful, and the child now receives £500 per month to help with their travel costs to access their further education.

Find out more

Get in touch with Contacts benefit helpline

<https://contact.org.uk/advice-and-support/our-helpline/>

#AVeryDifferentConversation

Healthwatch Suffolk

Healthwatch Suffolk and the Suffolk Parent Carer Network are working together to ensure that families are at the centre of how services are designed and delivered for children and young people with special needs. Through their joint working they have been able to collectively reach more people, raise awareness of who they are and what they do and have a bigger impact locally.

Healthwatch was invited to share their findings from their latest mental health report at the Suffolk Parent Carer Network conference, one of the largest in the country. This then led to a series of opportunities for Healthwatch to share their work, including additional conferences and providers across the county.

They have worked in partnership with a range of organisations across the county on a campaign aimed to transform mental health services in East and West Suffolk. Healthwatch facilitated the design of the survey with a range of partners, while Suffolk Parent Carer Network worked led on the engagement and events which reached over 5,000 people.

This partnership has led to Healthwatch Suffolk inviting those partners from the A Very Different Conversation project group to submit a pre-inspection report to CQC on the local mental health NHS trust. This will be the first time in Suffolk where a comprehensive report with a range of local voluntary sector organisations have shared their perspectives and the voices of those they are there to support.

“We know that the change that is needed can only happen if each and every one of us plays our part in making this work.”

Anne Humphrys, Co-Chair, Suffolk Parent Carer Network

Additional work Healthwatch has done on SEND

- **Healthwatch County Durham**
<http://www.healthwatchcountydurham.co.uk/news/shining-light-transitions-services>
- **Healthwatch St Helens**
https://www.healthwatchsthelens.co.uk/sites/default/files/report_-_listening_to_the_experiences_of_young_people_with_ldd.pdf

Useful resources

- **Cerebra**
Cerebra is a charity for children with brain conditions. They have factsheets, support, sensory lending library and information about adaptations and aids to help children who are disabled.
www.cerebra.org.uk
- **Contact**
Contact is the charity for families with disabled children. Their website includes factsheets for parents and carers and they're able to help and support with access to benefits and education. ~
www.contact.org.uk
- **The Council for Disabled Children**
This is the umbrella body for the disabled children's sector bringing together professionals, practitioners and policy-makers.
<https://councilfordisabledchildren.org.uk/>
- **The Disabled Children's Partnership**
This is a major coalition of more than 60 organisations campaigning for improved health and social care for disabled children, young people and their families.
<https://disabledchildrenspartnership.org.uk/>
- **Independent Provider of Special Education Advice (ISPEA)**
ISPEA provides free and independent advice and support to help get the right education for children and young people with special educational needs and disability. Their website has sample letters and additional support.
www.ispea.org.uk
- **National Network of Parent Carer Forums**
The National network of Parent Carer Forums coordinates, promotes and delivers parent participation locally. Find your local parent forum and get in touch
www.nnpcf.org.uk
- **SEND Code of Practice**
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf
Code of Practice Guide in a more condensed version for parents and carers
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/417435/Special_educational_needs_and_disabilities_guide_for_parents_and_carers.pdf

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