



contact *For families
with disabled children*

Policy Forum

Appendix 1 - SEND

Special Educational Needs and Disability

About the Policy Forum

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.

To help Healthwatch across the country understand more about policy issues nationally, and raise issues happening locally, Healthwatch England hold regular Policy Forums to enable staff members to learn and share from one another and partner organisations.

Using Special Educational Needs and Disability (SEND) as an example, we held a Policy Forum to showcase how Healthwatch can have a larger impact through working together with partners such as Contact and the National Network of Parent Carer Forums.

This resource highlights discussions from the day and future recommendations for how Healthwatch and Parent Carer Forums can continue to work together in the future.

About the event

The event was attended by both local Healthwatch staff and representatives from Parent Carer Forums across England.

NHS England joined us on the day to talk about the NHS Long Term Plan (see separate slide pack that accompanies the Appendix).

Lynn Hoppenbrouwers from Contact joined to represent the National Network of Parent Carers.

Desires for learning - why are we here?

- Finding out about good practice and highlighting previous good work
- Meet other parent carers and learn from one another
- How can we work together- Healthwatch England/NNPCF and local Healthwatch and Parent Carer Forums
- How we can formalise a working agreement between Healthwatch and their Parent Carer Forums
- Safeguarding - Healthwatch role on safeguarding boards, ensure SEND is always mentioned when attending safeguarding boards - please can Healthwatch England follow up
- Deprivation of Liberty Safeguarding (DOLS) for young people now over 16-17 but under 18 - please can Healthwatch England follow up

The workshops

During the event we looked at the main issues that both local Healthwatch and local Parent Carer Forums face and working in groups we came up with the top issues.

On policy/health landscape of working together

1. Parent Carer Forums working together across Sustainable Transformation Partnership Integrated Care System areas and so are Healthwatch, how can we do this smarter?
2. A feeling that health services don't engage in participation, it's consultation
3. Clinical Commissioning Groups and Local Authority working together - the way that the Local Authority and the Clinical Commissioning Groups work with STP/ICS is not the same in all areas

4. Local Authority and Clinical Commissioning Groups are pooling budgets or jointly commissioning. Cuts to health and social care specific to SEND make working together and changes to providers more difficult. Relationships have to be rebuilt each time of change
5. Primary Care Networks - positive and negative aspects - ensure that Healthwatch and Parent Carer Forums are part of social prescribing mapping and listed within local provision at Primary Care Network level

It was also mentioned:

- Who is responsible for Personal Health Budgets and funding - creative thinking and funding around local need?
- Battle of funding between Health and Social Care for medical aids - who is funding what? This needs further clarification

On the services provided

1. Local diagnosis / support pathways (AUTISM) - waiting times - lack of support whilst waiting for a diagnosis, lack of support for parent carers (there used to be more). Lack of early intervention
2. Differences in access to eligibility to services over STP/ICS areas - postcode lottery?
3. Transition - preparing for adulthood - when this starts, how it is managed across to adult services. Inconsistency of SEND Support in Health Services. It goes over a “cliff edge” when child has social care involvement and drops off - disconnection between what is adult - Children and Families Act says 0-25 and this is different across Education, Health and Social Care - needs to be uniformity
4. Information and signposting - lots out there but how do you get it? Lack of awareness of what’s available to people
5. Waiting times and access to services - especially mental health services and how social care is integrated with mental health services. Access to support in mental health services before crisis, to be preventative and be clearer with thresholds. Parent Carers being told that “only Autism or ADHD” is not a threshold for access to Children and Adolescent Mental Health Services or a Social Care Assessment.

It was also mentioned:

- Education Health and Care Plans - taking too long, lack of engagement in health input, blockage in time there
- Support and help for families on the diagnosis journey. Good examples of where this has happened
- Autism diagnosis for girls - very difficult
- A SEND-friendly provision/ SEND awareness of services - a lack of person-centred support - too many silos
- Developing support for the whole family
- National Shortage of Learning Disability Nurses
- NICE Guidelines are Advisory, not a MUST
- Children’s Hospices funding has been hit - what are CCGs doing to address this shortfall? See NHS England response here: <https://www.togetherforshortlives.org.uk/nhs-england-protects-25million-for-childrens-hospices-following-together-for-short-lives-campaign/>

Talking through examples

Working in groups we rotated three case studies to discuss suggestions on how to approach the situation through working together. Below we have provided the case studies as well as notes from each group.

Case study one:

Brenda has a daughter aged 15 and feels the paediatrician at her local CAMHS department was dismissive of her point of view and Mum feels that they have been discharged from the service too soon.

Mum would like to make a complaint to her local health provider, but doesn't know where to start?

If the Mum contacted her local Parent Forum or Healthwatch, what courses of action would you take?

Service level ideas/options

- Advise mum to go back to the service and speak to them
- Complain to PALS
- Signpost to complaints advocacy
- Go to CCG and make informal enquiry? Ask CCG for information about their procedures to check if they are followed - make sure Mum has all possible information
- Separate out clinical decision and support in making complaints
- Find out whether they want to complain, or if they want an explanation of more service?
- Ask for a second opinion
- Talk to CAMHS informally through contacts
- Healthwatch can log on their CRM and log with PALS / CCG
- PCF speak to CCG to inform of potential issues.

System change

- How many other cases like this do we know of? Speaking to Healthwatch and Parent Carer Forum if having issues, produce a survey together to provide evidence to CCG.
- Dismissive attitude should be empathy = attitudes to carers - Healthwatch or Parent Carer Forum could do some work about attitudes. Providing empathy and options
- Healthwatch /Parent Carer Forum can help get to the bottom of this.
- Can we do an Enter and View or Survey together?
- Compare data on the service from different sources
- Elevate to Quality Surveillance Group (QSG)
- Feed into HWE about improving complaints system.

Information/individual case

- NHS Choices?
- Follow the lead of Mum - adjust to what she wants
- Daughter is 15 - maybe daughter and mum doesn't agree - what does the daughter want?
- Provide information about other community services for Brenda's daughter
- Understanding the issue and the story - i.e. is it a problem with the service, or is it about developing the service or a service after the initial involvement?
- Is it also about understanding the different tiers of CAMHS and their level of intervention and service levels?
- Refer to community groups
- Peer to peer support for family
- If child is at school can refer via school nurse
- Self-refer tier 2 / Kooth

Case study two:

Healthwatch X and their Parent Carer Forum haven't worked together before. They're both in a rural location with their offices an hour apart and parties have both met brick walls.

Healthwatch X have had budget cuts and 'don't have time for this'.

It one partner is willing; how can we try to build the relationship together?

Working together

- Raise awareness of benefits of working together
- See good practice in working together elsewhere
- Do a project together by finding out their priorities
- Tempt them i.e. offer opportunity to get in there, offer self as speaker at Healthwatch Annual meeting
- Look at offer Healthwatch grant for a piece of work
- Volunteer champions- possible rep on both
- Identify good persons to broker or champion joint working
- Joint training offer
- Value each other's roles
- Forward planning
- Hold a youth led event and both parties attending
- Distance challenge - find a way to communicate more easily using technology such as Skype
- Produce a draft Memorandum of Understanding (MoU)
- Share purposes to reach a common understanding
- Use Facebook to converse
- Share committees you attend so could meet there - don't double up on work
- Add links of other organisations to your newsletter
- At some point ask for something in return and create an obligation.
- Seek funding to have joint projects

- Geographically meet halfway
- Have a mediator if difficult - NNPCF or Contact? Healthwatch England to get involved if relationship is difficult?

Case study three

Local Greenville Parent Forum have tried to join their Advisory Board of Greenville Healthwatch. They're more occupied by retired people, professionals and medically trained.

Greenville Parent Forum feel they don't have a voice with their local Healthwatch. How can they resolve this? They have approached their Healthwatch and met barriers.

Local Forums also report mergers of their local Clinical Commissioning Groups across boundaries. Three counties into one area for health. How can the three Parent Carer Forums engage effectively with Healthwatch?

- Can the Parent Forum sit on the Healthwatch Board?
- Say what they can offer to Healthwatch
- Focus on a specific real opportunity
- Make a complaint to the Healthwatch and the Local Authority Commissioner
- Engage with them in helping the Parent Carer Forum with specific data
- Invite the Healthwatch to the Parent Carer Forum Christmas party and other social events and vice versa.
- Local Healthwatch- make contact to explain Parent Carer Forum and mutual benefits.
- Healthwatch England - sharing good practice with Healthwatch network
- Understanding each other's role
- Healthwatch to know the legislation Children and Families' Act, re social care - short breaks, social care assessments and the Care Act.

Case study four

SEND Code of Practice 2.18 States that Healthwatch offers advice to patients. Are both Parent Carer Forum and local Healthwatch are aware of this and how is the currently organised?

Do local Healthwatch have an entry on their local offer?

How can Forums and Healthwatch work together to ensure this happens?

- Questioned "advice" as written in Code of Practice - more information and signposting
- Healthwatch not aware of parent carer issues - not coming to Local Healthwatch
- Parent Carer Forum signposting to Healthwatch
- Is Healthwatch listed locally on the Local Offer?
- Tell Healthwatch
- Tell the Parent Carer Forum
- Local Healthwatch not aware of the Code of Practice duties in more than one example Healthwatch England to make local Healthwatch aware of SEND Code of Practice (COP) and responsibility <https://www.specialeducationalneeds.co.uk/a-guide-to-the-send-code-of-practice-201819->

ebook.html?fbclid=IwAR0Un7P4sGwkadkuxA5UXtA4cGbYesdMx04dupeRKbAyTn4_1f1mYaqbw5s

- Parent Carer Forum to make Healthwatch aware of forum - giving intelligence, benefits of shared information
- More regional joined up networking with Healthwatch / Contact / NNPCF Regional Reps.
- Include SENDIAS in these events and conversations as well
- Local Offer linking to all services and are Healthwatch aware of their duties and local offer
- MOU or working agreement to clarify way of working
- Ensure Healthwatch is on the local offer
- Encourage Healthwatch to attend local offer events

Case study four

Patsy is a single parent with a newly diagnosed daughter with Autism, aged 2½.

Patsy has no benefits currently, she is not aware of her entitlements, she has no nursery provision and she is waiting to see a Speech and Language Therapist (SALT).

There is over a year wait to see a SALT, and Patsy thinks this is unacceptable. If you were a Parent Carer Forum or local Healthwatch what would you do and who would you refer this to?

Problem solving for the parent

- Talk through issues - a holistic approach
- Does she want to make a complaint? Give advice and support on how to do this - via PALS, via CCG Customer Service or Independent Complaints Advocacy via Healthwatch
- Visit a nursery - see if child likes it - North Somerset example Springboard, or Maisey in Somerset. In Telford - early help referrals, refer to Contact for Benefits.
- Find local children's centres, specialist children's centres?
- Has she had a care plan?

Problem solving for systemic issues:

- What are the NICE Guidelines? <https://cks.nice.org.uk/autism-in-children#!scenario:1>
- "Post diagnosis support does not exist, you just have to get on with it." Is what we hear from parents.
- Is this an isolated case - or is this a systemic case - therefore is the Parent Carer Forum and/or Healthwatch hearing more of these cases and is there a recurring theme? If it is systemic, can this be raised by LHW to Scrutiny?
- Raise to Healthwatch England.
- Publication of report if ongoing issue
- Call out to NNPCF for group examples of where things are working well.
- Call Healthwatch and / or parent carer forum if blockers/barriers
- Local Offer needs to be remembered, used and reviewed.
- Refer to PALS/Healthwatch for being unhappy about Speech and Language Therapy (SALT) waiting.
- *Note the difference between PALS for the service and PALS the CCG.

Information/advice

- National Autistic Society (NAS) website for support / NAS Local Branch
- Has an Education Health and Care Plan (EHCP) be started?

- Refer to local Special Educational Needs Independent Advice Service SENDIAS
- Early health assessment - a referral into everything. Go to a GP for a referral.
- Special funding available to get into a nursery
- Benefits and Disability Living Allowance DLA - more nursery and carers support allowance. Contact Helpline has specialist benefits advisors 0808 808 3555 www.contact.org.uk
- Citizens Advice and Carer's Support in some places
- Could separately fund if a private or charity service available.
- Cerebra website www.cerebra.org.uk have some great resources
- Check if mum knows about the local offer.
- May be local training for parent to help support and navigate - Early Birds/Cygnets and other schemes.
- Autism Education Trust

Feedback from discussions

At the end of the day we had a general discussion where both Healthwatch and those from Parent Carer Forums could raise questions and share feedback.

Here is a summary of what was talked about:

- **Quality Surveillance Group**
Local Healthwatch sit regionally or sub-regionally at the NHS Quality Surveillance Group (QSG) - Healthwatch explained how that works and how pieces of work are discussed and revisited by their local Healthwatch - e.g. Somali Autism, Healthwatch Bristol took this back to Quality Surveillance Group as part of their Impact Tracker - What have you done with this report etc, hold providers to account for system change.
- **Healthwatch Rutland -**
One of the representatives from Healthwatch Rutland mentioned their work and signposted to this link: <https://www.youtube.com/watch?v=9VZ3P6Y4G0w>
- It was discussed at the event that mental health workers in schools are a good idea, but they need to have SEND training.
- The role of champions - we need to encourage people to come forward as they can really change the commissioning of service - the power of one person's case study.
- This led to a discussion on ensuring that Healthwatch and Parent Forums as well as SENDIAS and local support groups are all included within the resources/asset map for Primary Care Social Prescribing.
- **Recognition of the Health impacts on Education.**
For example, lots of appointments can mean loss of school attendance days, parents can often receive sanctions for this by some schools. Also, exclusions can have a serious impact on the mental health of the child/young person. Another participant talked about school refusals by the young person to attend education and the impact it has on their family as the main carer.
- **Highlight the Reports Library at Healthwatch England**
there may be a report done in another part of the country that can help support the work you are about to undertake locally. <https://www.healthwatch.co.uk/reports-library>
- **Healthwatch Greenwich**
Worked on a GP Access for hard to reach communities in 2014, revisited this work in 2018 to see how changes have improved or not.
- Desire to work smarter

- **Healthwatch Herefordshire**
works closely with their Parent Carer Forum and see them as a statutory partner and make recommendations to the board.
- Recognition that local Healthwatch may not be working on SEND as a priority every year/season, but that without the valuable intelligence on SEND specialist feedback, are we missing a trick?
- Are forums part/involved in the commissioning / tendering process of Healthwatch / SENDIAS? If not, why not?

What participants said

As part of our work with the Healthwatch Network, Contact and the National Network of Parent Carer Forums we collected some responses have some of the following quotes/reflections and observations, as well as follow up actions.

“We are independent, we are not campaign groups, we both have that similarity, we should be working together.”

“I sense the frustration of Parents and Carers.”

“The impact of Local Healthwatch on local work and priority areas. I learned a lot about that.”

“We will look at where we can do joint engagement work, sharing of engagement work and take Healthwatch leaflets and resources to Parent Carer Forum events and support groups.”

“It’s a really difficult conversation for Parents and Carers who often have to repeat themselves.”

“We are the eyes and ears of our (Parent Carer) community, so we should be telling Healthwatch.”

“I’m slightly embarrassed that not all Healthwatch networks are engaged with their local Parent Forum.”

“We should be an ambassador for working together for lots of different organisations.”

“Healthwatch England should send a letter to all local Healthwatch advising of their statutory role and help encourage working together, along with the finished policy briefing on SEND!”

“SENDIAS services also need to work with Healthwatch and vice versa.”

“I decided to come only if my local Parent Carer Forum was here with me. We have taken away some great ideas in how to work together going forward.” Healthwatch Swindon

“Where is my local Healthwatch, are they not here today? We have had blocks to joining their Advisory Board, please can you help me Healthwatch England to make this happen?” Consider whether Advisory Group is the best place, but perhaps share intelligence to begin with as shared working.

Recommendations from our participants

“Healthwatch England must cascade the value of this work.”

“Escalate this work to NHS England. The NHS England South West team are already escalating this to the NHS Chief Nurse and Participation teams.”

“Encourage more talking to each other!”

“This is just the beginning; can we do more events like this?”

“Can Healthwatch England come to the NNPCF and SENDIAS National Conferences?”

“Can Healthwatch England feature this work at their National Conference?”

“Relationships are really starting to develop after today, it is important that these are not lost if people change.”

Case study four

Healthwatch England staff would like to thank those who attended the event for their participation and comments. We will consider all of the recommendations made and take them back into our work action plan where possible.