



Information Report

Children and Young People with Special Educational Needs & Disabilities (SEND): Speaking Up Report

January 2016

Children and Young People with Special Educational Needs & Disabilities (SEND):

Speaking Up Report

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Children and Young People with Special Educational Needs & Disabilities (SEND): Speaking Up Report

1. Introduction

1.1 What is Healthwatch Slough?

Healthwatch Slough is the independent consumer champion for health and social care in Slough. We are here to understand the experiences of people who use health and social care services in the borough, and to make sure their voices are heard and responded to.

1.2 Purpose of this report

Healthwatch Slough has gathered the views and experiences of local children and young people with special educational needs and/or disabilities (SEND), and their parents and carers. We asked the question: **“What is it like for families in Slough seeking SEND information and support?”** This report aims to speak up on their behalf to the organisations involved: Slough Borough Council (SBC), Slough Children’s Services Trust¹, local health services and the voluntary sector. This feedback and our recommendations will help them identify gaps in services and information, and shape future changes.



¹ Slough Children's Services Trust is the independent non-profit company established by the Dept. for Education to provide social care and support services to children, young people and families in the Borough.

2. About the project

2.1 Background

One of Healthwatch Slough's priorities for 2015/16 is ensuring a strong voice for children and young people; another is monitoring the implementation of the Care Act.

In June 2015, Slough Borough Council (SBC) was invited to deliver a presentation to Healthwatch on the impact of the Care Act and other recent legislation on SEND services in Slough. The presentation was delivered by SBC's Interim Head of Early Years & SEN, Nandita Sirkir, and Samia Baig, Children's Social Care (Disability Service). They outlined plans to reform the SEND process through collaborative working, taking into account the views and aspirations of young people and parents. In response, Healthwatch Slough discussed the following queries with the presenters:-

- How do Slough families hear/find out about SEN support and resources? How well-publicised and how accessible is the 'Local Offer'?
- What experience of personal budgets is there?
- How does SBC involve young people & families in designing services/shaping change?
- How is the transition between child and adult services handled in Slough?

To follow up this discussion, Healthwatch Slough set out to gather the views and experiences of SEND families themselves about these issues, to check their perspective and ensure they had a strong voice.

2.2 What the project involved

Healthwatch Slough undertook three tasks:

- We tested out for ourselves what it is like for new enquirers seeking information about SEND and the Local Offer (see below) in Slough via an online search
- We made contact with children and young people with SEND, their parents and others involved in supporting them, and asked for their views and experiences.
- We studied SEND feedback already reported to us (stored on our database)

3. SEND definitions

3.1 What do we mean by children and young people with SEND?

SEND is short for Special Educational Needs and Disabilities. . The legislation relating to SEND (Children & Families Act 2014 and Care Act 2015) specifies the age bracket for children and young people with SEND as being from birth up to the age of 25.

3.2 What is the Local Offer?

Every Local Authority in England is required to publish information about the services in their area for children and young people with SEND (and services outside the area which local children may access). This is known as the Local Offer and has been mandatory since September 2014.

The Local Offer presents all information about education, health and care services, voluntary agencies, leisure activities and support groups in one place. It has two main purposes: to provide clear, comprehensive and accessible information about the support and opportunities available, and to make provision more responsive to local needs. Slough's Local Offer can be found on [Slough Services Guide](#), SBC's online directory.

3.3 What is the Slough SEND Advice and Support Service?

Slough's SEND Advice and Support Service is a free, impartial and confidential service that provides information, advice and support to children and young people with SEND and to their parents and carers. Every local authority must have this type of service by law. In Slough it provides information, advice and support on:

- All aspects of SEND from initial concerns and identification to ongoing support
- The law on SEND, health and social care
- Slough's local policy and practice
- Personalisation and personal budgets
- Resolving disagreement and mediation
- The Local Offer

3.4 What is a personal budget?

A personal budget is when an individual or family is put in charge of a sum of money allocated by the local authority and/or health service to pay for some of the support identified in their EHCP (see below).

They can take charge of the money in any (or a combination) of the following ways:

- by telling the authorities how they would like it spent
- by receiving the money themselves so they can directly pay for the support needed (a direct payment)
- by asking another individual or organisation to do it on their behalf

3.5 What is an Education, Health & Care Plan (EHCP)?

An EHCP is an integrated support plan. It an official document that describes a child or young person's learning, health and care needs, and sets out the help required to meet those needs. Children and young people with SEND who have EHCPs are those who have been assessed as having the most complex/profound support needs.

4. Finding the Local Offer

4.1 What we did

Healthwatch Slough carried out an internet search for Local Offer information. We conducted the test over a five minute period including interruptions to simulate the experience of a parent caring for a child.

Our online search took us to two key web pages which will be referred to in this report as:

- i) **Local Offer page**
- ii) **Children with SEND page**

The Children with SEND page contains a link to the Local Offer page but itself contains valuable guidance about the Local Offer not found elsewhere.

Both pages could be found within the target time period, although the search may take longer for an enquirer not using the exact terminology.

A screenshot of each webpage and its Healthwatch Slough review, with recommendations for improvement, can be found overleaf.



4.2.1 Children with SEND page - screenshot

Accessibility Cookies Help

www.slough.gov.uk

www.slough.gov.uk
Slough
Borough Council

Resident Business About the Council

Enter Search Text

Planning & building control Council tax Housing Schools & learning Parking, roads & travel Bins & recycling Libraries Jobs More

Home Schools & learning Educational support services Children with special educational needs or disabilities

Children with special educational needs or disabilities

Navigation

- ▶ Educational support services
 - Autism
 - Educational psychology
 - Parent partnership
 - School attendance
- ▶ **Children with special educational needs or disabilities**
 - ▶ Continuing education - post 16 support
 - ▶ SEN - our approach
 - ▶ Special schools & SEN resources in schools
- Sensory impairment support

Information for families who have a child or young person with Special Educational Needs or Disability (SEND)

Every Local Authority in England is required to publish information about the services in their area for children and young people from birth to 25 with special educational needs and/or disabilities (SEND); it also has to include services outside of the area which children from their area may use. This is known as the 'Local Offer' and has been required since September 2014.

The Local Offer has two main purposes:

- to provide clear, comprehensive and accessible information about the support and opportunities that are available
- to make provision more responsive to local needs. The Local Offer will put all the information about education, health and care services, voluntary agencies, leisure activities and support groups in one place.

Slough's Local Offer can be found on the [Slough Services Guide](#). It has been developed in partnership with parents and other agencies in Slough.

The information in the Local Offer is divided into six sections:

- **Education, Learning & Development** - this includes information about schools, other education providers and contains advice and guidance about Education, Health & Care Plans and other useful information.
- **Health and Wellbeing** - this section includes information about the health services that you may need to access and it will give details of how to access them and the eligibility criteria.
- **Care and Support for Families** - this section includes information about social care and about other support services that are available in the area. It also contains information about national support groups.
- **Becoming an Adult, Transition 14+** - the move from children's to adult service can be difficult. This section aims to provide information on what services might be available to young people and the eligibility criteria. It also provides information about Slough's policies.
- **Childcare** - families may wish to access childcare for their children. This section provides information on childcare providers in Slough.
- **Things to do** - there's lots to do in Slough and this section gives you a list of activities both universal (for all children) as well as targeted. The information will allow you to choose activities that are suitable for your child or young person.

The Local Offer also has an [Events, News & Consultation](#) section where you can find out what's new both in the Slough area and nationally.

If you offer services or events you can add them to the Local Offer. Please contact Slough Family Information Service (FIS) for information on how to do this – 01753 476589 or FIS@slough.gov.uk.

How to use the Local Offer

The Local Offer should have all the information you need included in it. You can find the information you need in several ways:

- use the **sections** in the Local Offer - click on the section you are interested in. You can view all the service records and the information and advice in that section and decide which is most useful to you.
- use the **search** - keyword boxes. If you are looking for something specific then you can put the title or name or a word that relates to what you are looking for in the "keyword" box at the top of the page. When you click on "search" a list of services that meet your keyword will be displayed. You can also add a postcode or location here to give you information that is close to that postcode.
- use the **filters** - on the left hand side of the page there is a list of filters such as age, postcode or type of need. You can use these filters to narrow down your search results.

Records that are part of the Local Offer are identified by the KITE symbol in the top right hand corner of the record. Service providers have been asked to be very clear in the information they provide so that you can see if they are relevant to you.

What happens if I can't find what I'm looking for?

If you need help to find the information or service you want, you can contact Slough Family Information Service on 01753 476589 or FIS@slough.gov.uk. Alternatively you can contact us by clicking on the "contact us" button on the website and completing and submitting the form.

It may be that there isn't a local service that meets your need directly. There may be a service in a neighbouring area that you can use or there may be a national organisation that can help. Part of the purpose of the Local Offer is to highlight what services are needed in the area. We will use the information you provide to help us plan, monitor and develop appropriate facilities and services for disabled children and their families.

The Local Offer must be updated and reviewed regularly to include information about any new services or information that will be of use to families. We welcome your feedback on the Local Offer. You can contact us by using the 'Contact Us' form on the Slough Services Guide or you can contact the FIS by phone 01753 476589 or email FIS@slough.gov.uk.

Related pages

- [Family Information Service](#)

4.2.2 Children with SEND page - review

<http://www.slough.gov.uk/schools-and-learning/children-with-special-educational-needs-or-disabilities.aspx>

Enquirer might find by typing 'Special Educational Needs and Disabilities' into search box on Slough Borough Council website www.slough.gov.uk. First option provided is link to this page. Reviewed by Healthwatch Slough as follows.

We found

- Lots of text
- The way in which the information is written assumes awareness of SEND services available. Can make desired message unclear
- Page contained 'hidden treasure' - invaluable information for helping people find out about & use the Local Offer tool and the services available. It was refreshing to know that information and services are available for support. However, the information was not prominent enough.
- We believe this information should be written in a clear way for everyone.

We recommend

- Consulting with a range of people who might access this page, and using their views to develop the content available
 - Highlighting that the Slough Services Guide/Local Offer information is an online tool
 - Displaying the Local Offer logo
 - Adding the image of the Slough Service Guide Page
- 'How to use the Local Offer' (Section 2) - a key hidden treasure**
- Presenting this info in step by step form, with supporting images
 - Producing a video clip
 - Including the information on the Slough Services Guide
- 'What happens if I can't find what I'm looking for' (Section 3)**
- implementing the feedback gathered in the consultation
 - adding a picture of the Family Information Service Team.
 - promoting the facility to call and speak to a team member
 - developing the request for feedback

We want to see (outcome)

- ✓ Wide range of views (including children, parents and professionals) captured to support ongoing development
- ✓ Logos and images in place to help with recognition and consistency
- ✓ SBC process and resources to support families clearly presented
- ✓ More informed choice for SEND families
- ✓ The opportunity to be part of the planning and future services for SEND

4.3.1 Local Offer page - screenshot

The screenshot shows the Slough Borough Council website's Local Offer page. The header includes the URL www.slough.gov.uk and the council logo. A navigation menu contains links for Resident, Business, About the Council, and Slough Services Guide. A secondary menu lists various service categories like Home, For Family, For Youth, For Adults, For Community, Health & Wellbeing, What's On, Sign in / Register, and Contact Us. A search bar is present with a language selection dropdown and a Google Translate link. The main content area is titled 'Local Offer' and features a large purple banner for 'Special Educational Needs and Disability'. This banner contains several buttons for 'Education, Learning & Development', 'Health & Wellbeing', 'Care & Support for Families', 'Becoming an Adult - Transition 14+', 'Childcare', 'Things to do', 'Disability Register', and 'Events, News and Consultations'. A sidebar on the left provides a welcome message and a 'More Info' button. The footer includes an 'A TO Z OF SERVICES' index.

www.slough.gov.uk **Slough** Borough Council

Resident Business About the Council **Slough Services Guide** Shortlist (0 items)

Home For Family For Youth For Adults For Community Health & Wellbeing What's On Sign in / Register Contact Us

Services Guide Local Offer Select Language Powered by Google Translate

Your feedback on the Local Offer will help us develop and improve the site. [Click here](#)

Search for Keyword(s) in Location Search Clear

Local Offer

Welcome to Slough's Local Offer

The Local Offer is part of the reforms that are happening as a result of the new Children & Families Act 2014 and the new SEN reforms. The Local Offer contains information about Education, Health and Social Care services that are available in Slough for children, young people with SEND and their families.

Your feedback on the Local Offer will help us develop and improve the site. [Click here](#)

[More Info](#)

Special Educational Needs and Disability

- Education, Learning & Development
- Health & Wellbeing
- Care & Support for Families
- Becoming an Adult - Transition 14+
- Childcare
- Things to do
- Disability Register
- Events, News and Consultations

A TO Z OF SERVICES A B C D E F G H I J K L M N O P Q R S T U V W X Y Z 0-9

4.3.2 Local Offer page - review

<http://servicesguide.slough.gov.uk/kb5/slough/services/localoffer.page>

The Local Offer page (on the Slough Services Guide), is reached by an enquirer who types 'Slough Local Offer' or 'Slough Service Guide SEND' into Google or similar internet search engine. Or by searching for 'Special Educational Needs and Disabilities' on Slough Service Guide.

We found	We recommend	We want to see (outcome)
<ul style="list-style-type: none"> - Information displayed clearly, inviting to the eye including colour - A welcome to the local offer with short and clear explanation of what it is - Clear clickable buttons for each category of local offer service (e.g. childcare) - Information on how to send feedback with a direct tab to link - instant accessibility alternatives: different languages and Browsealoud (spoken version) can be selected 	<ul style="list-style-type: none"> <input type="checkbox"/> adding to the website information on what has changed since SBC's consultation and feedback exercise in 2014-2015 <input type="checkbox"/> creating a new contact details button, highlighting the key sources of SEND information and signposting e.g. <p>Website - Slough Service Guide</p> <p>In person - St Martins Place, Special Voices, Destiny Support</p> <p>By phone - SEND Advice & Support Service 01753 787693</p> <p>By email - SENDASS@slough.gov.uk</p> <ul style="list-style-type: none"> <input type="checkbox"/> including downloadable PDF leaflets, starting with the SEND Advice and Support Service leaflet. <input type="checkbox"/> including the facility for feedback to be anonymous 	<ul style="list-style-type: none"> ✓ Users informed about issues raised and changes made as a result of feedback ✓ Clearer pathway for people to access available information, whether seeking independently or via another agency. ✓ Enquirers better informed more quickly thanks to greater range of information available to read online or download ✓ More people providing feedback

5. How did Healthwatch Slough gather the views of SEND families in Slough?

5.1 Who did we want to hear from?

During summer 2015 Healthwatch Slough sought feedback from children, young people, parents and carers in Slough who had used the following resources:

- the Local Offer
- SEND Advice and Support Service (formally known as Parent Partnership)
- services for children and young people with SEND, their parents and/or carers

5.2 How did we find them?

In to reach out to this audience, Healthwatch Slough attended the Slough Special Educational Needs and Disability (SEND) Open day; and also arranged engagement visits to:

- Special Voices²
- 50-50 SYNC³ Summer 2015 Community Mentoring Programme (CMP)

5.3 How did we invite and capture their feedback?

Data was collected via a variety of methods:

- questionnaire (offered on a one-to-one basis)
- feedback forms
- focus group sessions

We also searched our database for all the feedback stories relating to SEND already reported to us through normal Healthwatch Slough channels.

5.5 What did Healthwatch Slough do with all this feedback?

This report presents the survey findings and draws together feedback from questionnaire respondents (Section 6) the Special Voices focus group, (Section 7), and our database (Section 8).

Feedback specifically about the 50-50 SYNC holiday club⁴ received during our visit was written up at the time and passed directly to 50-50 SYNC and its commissioners. This previously published report is available on our website⁵.

² Special Voices is a local parent-run forum providing advice and support to parents and carers of SEN children

³ 50-50 SYNC is a social enterprise which works with vulnerable children, young people and adults using interactive mentoring

⁴ 50-50 SYNC holiday club feedback consisted of positive comments from the children and their parents, with a small number of suggestions/criticisms from the children (e.g. lunch break should be shorter).

⁵ http://www.healthwatchslough.co.uk/sites/default/files/healthwatch_slough_-_special_voices_report4_-_november_2015.pdf

6. Our survey results

6.1 Who completed our questionnaire?

21 people completed the Healthwatch Slough SEND Questionnaire.

Questions 1&2: Profile information

90% of respondents described themselves as children, young people or families with Special Educational Needs or Disability (SEND).

10% of respondents described themselves as representing a group or organisation providing support to SEND families.



Education, Health & Care Plan (EHCP) / Statement of SEN⁶

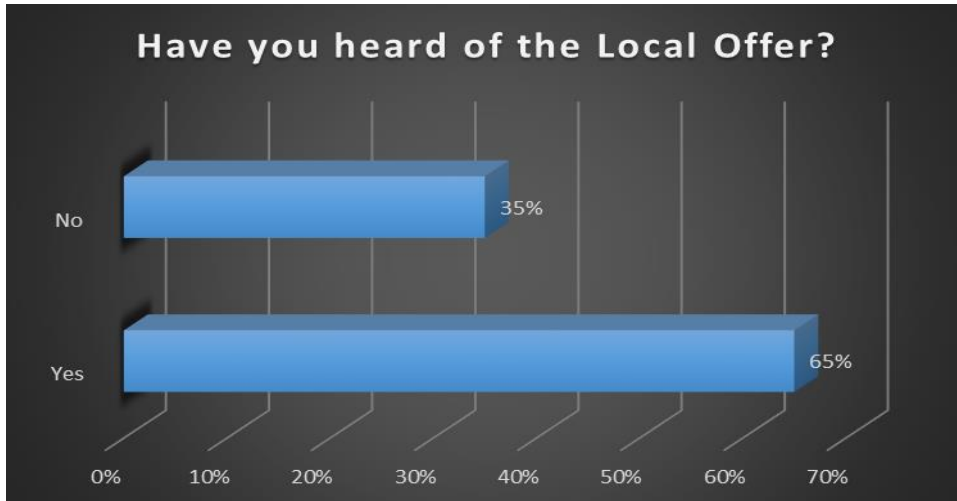
75% of respondents indicated 'I have a child or young adult in my care with SEND **with a statement/EHCP**⁷ [*i.e. they have been assessed as having the most complex/profound support needs*].

25% of respondents indicated 'I have a child or young adult in my care with SEND with no statement/EHCP.'

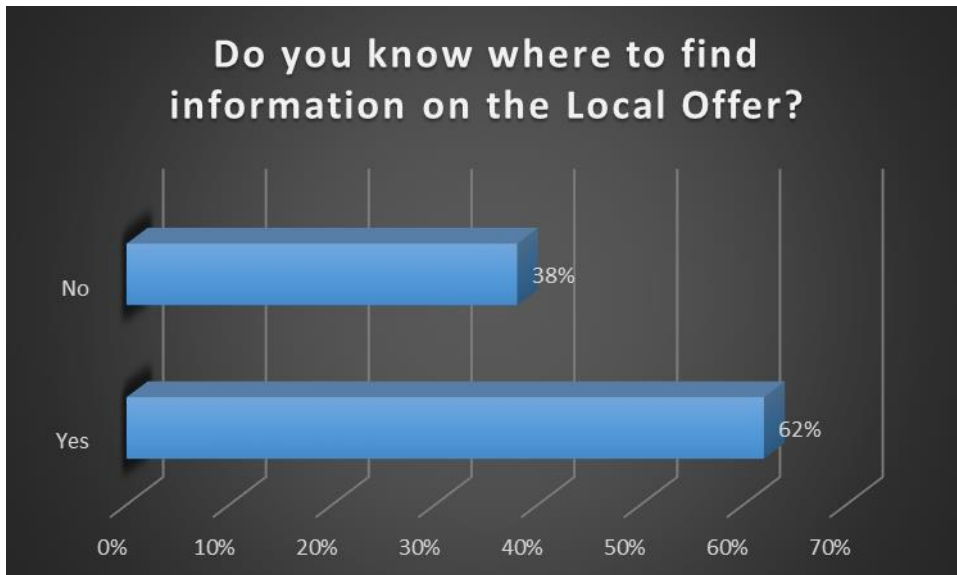
⁶ 'Statement' is a term from an older system which EHC plans replaced.

6.2 What did survey respondents say about the Local Offer⁸?

Question 3



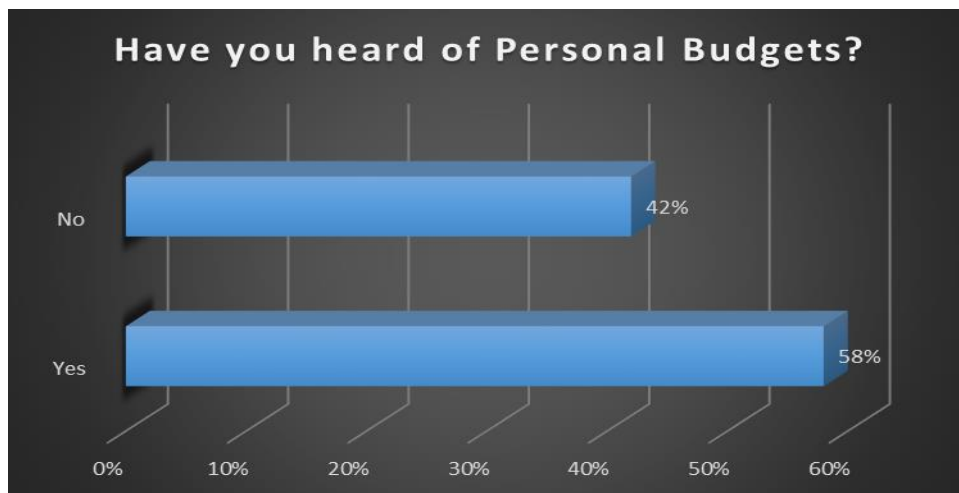
Question 4



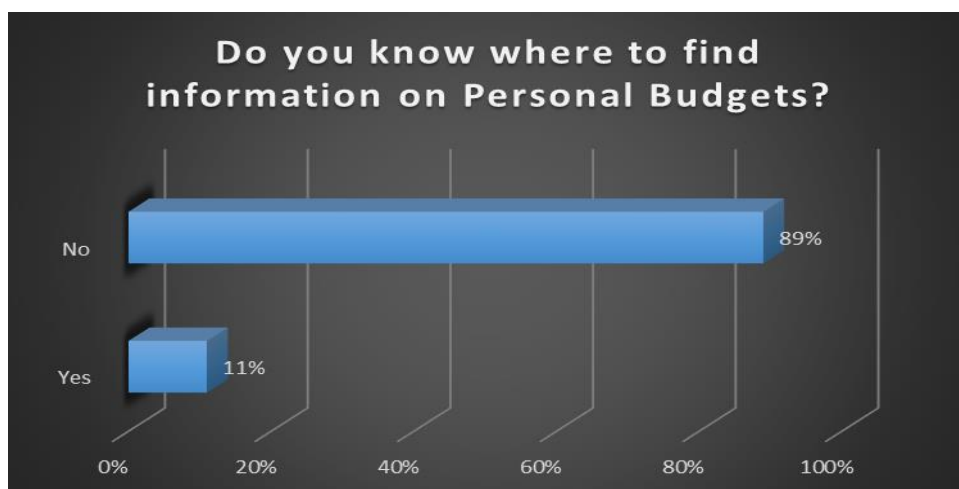
⁸ For a definition of Local Offer, see Section 3 of this report.

6.3 What did survey respondents say about Personal Budgets⁹?

Question 5



Question 6



Question 7 - Do you have a personal budget?

100% of respondents stated No

⁹ For explanation of personal budget, see Section 3 of this report.

6.4 Respondents' views and experiences - key themes

The questionnaire ended with four open-ended questions. Individual responses are attached at Appendix 1. We extracted key themes from responses to these questions, as shown below.

Q8: How have you been involved in sharing your views, ideas and experiences with the Special Educational Needs and Disabilities Service or Parent Partnership?

- 👍 Many people were involved in sharing their ideas, views and experiences as part of the Special Voices Group.
- ☹️ Some issues around parents not feeling able to work with the school and council effectively.

Q9: What is working well for children and families in Slough?

- 👍 50/50 SYNC, Well Woman's Support Group, Sure Start Centres, and Parent Partnership were quoted as working well for children and families in Slough.
- 👍 On the whole families are happy with the level of support they receive from these groups.

Q10: Where are the gaps in service?

- Information is hard to find
- Lack of support for those with certain conditions
- Long waiting lists
- Access to services
- No support for other family members such as a non-SEN sibling
- Lack of supported living accommodation
- Lack of understanding of individual circumstances from professional services
- Accessing GP appointments
- Lack of respite care and activity clubs

Q11: What would you like to shout out about?

- ✂ More access to social activities
- ✂ Lack of funding for services, which in turns leads to lack of support
- ✂ Agencies should work collaboratively to reduce waiting times and provide a better service
- ✂ Better/more training in all schools on SEN
- ✂ More support groups needed
- ✂ More recognition of carers
- ✂ To be listened to and for individual needs to be understood
- ✂ No funding available for young person from the age of 20

7. Feedback gathered at the Special Voices Q&A session

7.1 Receiving and responses given

Individual parents at the Special Voices focus group raised specific questions for response by Healthwatch Slough (in its signposting capacity) and relevant providers. Full details of the questions and answers given are available in a report published on our website in November 2015¹⁰.

7.2 Feedback breakdown

Analysing the questions raised (see table below) provided valuable information to help us identify the issues of importance/concern to SEND families in Slough.

Area of concern	Issue/details
GP appointments	- for carers (recognising responsibilities/restrictions)
	- for deaf young people (access, independence & privacy)
	- for patients with long-term conditions
	- at hub surgery (records access issue)
GP receptionists	- need for autism awareness training
	- apparently 'prescribing' over the phone
Changing GP surgery	- choice
	- records transfer
GPs & CAMHS	- information-sharing
CAMHS	- waiting times
Short breaks service	- information/ choice
Pharmacy/GP	- notifying patients of medication recalls (responsibility)
Out of hours services/emergencies	- ensuring grasp of situation/how children with SEND may present differently
Hospital	- disability access & facilities (WPH)
	- security/response to requests & complaints

7.3 Key themes

Recurrent issues and underlying themes were identified as follows:

- ☞ Long CAMHS¹¹ waiting times [this was acknowledged in the report by SBC. Berkshire Healthcare Foundation Trust (BFHT) are working to address this problem]
- ☞ Importance of listening to parents - respect and tap into their knowledge of child's needs/condition/symptoms
- ☞ Carers' challenges - make it easier for them and their child to access services and attend appointments etc.; address barriers (training, equipment, timing etc.).
- ☞ Coordination (between services, and with patients/parents) - better sharing, transferring/accessing information = critical

¹⁰ http://www.healthwatchslough.co.uk/sites/default/files/healthwatch_slough_-_special_voices_report4_-_november_2015.pdf

¹¹ Children & Adolescent Mental Health Services (NHS mental health service for children and young people)

8. Feedback recorded on the Healthwatch Slough database








8.1 Receiving and recording feedback

Since April 2015 we received 36 feedback stories relating to SEND via normal Healthwatch Slough channels. These are recorded on our database on which they are categorised by topic and sub-topic.

8.2 Feedback breakdown

- Feedback was predominantly from relatives and carers
- The three organisations providing the services which most of the feedback related to were (i) Berkshire Healthcare Foundation Trust, (ii) Slough Borough Council and (iii) local GPs
- The main topics we heard about were Patient Pathway and Access to Services which were mostly negative in sentiment
- The most commonly featured sub-topics were Access to Information and Access for those with a Disability. The majority of these were mixed in sentiment (i.e. featuring both negative and positive feedback)

8.3 Key themes

-  Lack of information about support groups open to parents, particularly opportunities to meet other parents in similar situations
-  More local social activities and clubs for SEND children needed
-  More support needed from schools
-  Lack of respite care
-  Long waiting lists for assessment
-  Lack of same-day/priority GP appointments
-  Lack of co-ordination between health and social care professionals and schools

9. Healthwatch Slough's recommendations

9.1 Accessing information

Healthwatch Slough has identified a number of ways in which the Local Offer (on SBC's Slough Services Guide online directory) might be made more user-friendly, as listed in Section 4. We recommend implementing these improvements. In addition, we would encourage SBC to run short information training sessions to inform the families, faith groups and local agencies within the community about the SEND services and support and to increase awareness of the Local Offer.

9.2 Innovative ways in which children and young people can share their views

In its future plans to involve young people in shaping its services, we would like to see Slough Borough Council use a variety of channels such as animation, video, workshops and open meetings to encourage children and young people to speak up about their views and experiences. Healthwatch Slough would recommend that these mechanisms should be designed and shaped by local groups who regularly work with this young target audience.

9.3 Encouraging parents and carers to speak up

Existing Local Offer feedback channels should be enhanced by adding the option to submit feedback anonymously. In addition, Healthwatch Slough recommends that SEND families' feedback and its response/impact should be shared by organisations using 'You Said/We Did'-style communications.

9.4 Reducing CAMHS waiting times

HWS urge SBC and Slough CCG to continue work to reduce assessment and appointment waiting times, and to ensure progress is rigorously monitored.

9.5 Smoothing the transition pathway

Healthwatch Slough notes that Berkshire Healthcare Foundation Trust (BHFT) has a target to improve the experience of transition (when a young adult moves from children's to adult services) across all children's services this year. We welcome and would encourage ongoing efforts to investigate and improve young people with SEND's experience of transition. In particular, Healthwatch Slough recommends that BHFT follows through plans to introduce 'transition passports'¹² for every young person with SEND.

We also ask that, over the coming months, BHFT monitors the impact of its improvement efforts by seeking feedback from young people and their parents after they have been through the process, and that BHFT publishes the results.

¹² A transition passport is an 'All About Me' document, based on the principles of person-centred planning. It is designed to help young people think about and communicate what is important to them including their preferences, needs and aspirations for adult life. It can be used as a tool in transition planning. An example produced by Norfolk County Council can be found at http://www.preparingforadulthood.org.uk/media/190584/1035_passport_15_march.pdf

9.6 Personal budgets awareness

Our survey indicated that 42% of people did not know about personal budgets and 89% of people did not know where to access information about them. We urge SBC to invite appropriate organisations such as Adviza and Enham Trust to carry out a joint piece of work in partnership with Slough SEND Advice & Support Service to develop clear and accessible information material for SEND families in Slough on the topic of personal budgets. The information could then be used online as part of the Slough Service Guide and in printed leaflets.

9.7 Increasing activities and groups

Feedback shows that clubs and activities used by SEND children, and peer support opportunities for parents, are highly valued. Many SEND families have told us there is a need for more. HWS recommends that SBC and local providers look at ways of increasing the number and diversity of activities and groups for/accessible to SEND families in Slough. Resources such as these are vital in helping families manage the challenges they face.

10. Conclusion

Who is listening? Are we being heard? Where is the change?

As Healthwatch Slough carried out this project, we learnt about the information, resources and services to support SEND families in Slough. We have uncovered hidden treasures and scope for improvement, both online (in our webpage review) and in people's feedback about the benefits and limitations of the services available in our borough.

Overall, the challenge we are most keen to address is a recurring sentiment we heard again and again during our engagement with SEND families. It is captured here in the words of one parent:

“We speak to people, we highlight the problem, information gets noted, and that’s it - you don’t hear anything else, nothing changes, we are left to get on with it. You can only speak so many times and then you just get by on your own.”

Healthwatch Slough invites the organisations and groups involved in supporting and providing information to SEND families to take up this challenge - firstly in response to our recommendations, and secondly whenever individuals speak up in the future.

Healthwatch has found that that one consumer's voice often reflects the views, experiences and situations of many others. Listening to and acting upon the voices of SEND children, young people, parents and carers is the key to making improvements which would benefit the whole community.

Healthwatch Slough believes every voice counts.

Healthwatch Slough
January 2016

Appendix

Individual responses from the Healthwatch SEND Questionnaire

Question 8 - How have you been involved in sharing your views, ideas and experiences with the special educational needs and disabilities service or parent partnership?

- I have used parent partnership to attend meetings at my son's school as I found it difficult to work with them in particular the SENCO.
- No [x 2]
- Yes [x 2]
- Through a range of services
- Yes through the nursery
- Parent Partnership
- yes I have attended meetings at special voices
- Parent partnership, Support meetings
- I have spoken to lots of people but always been let down by Slough. They could have done more. I would like one of the council managers to come with me for a day and see what I do.
- No I haven't really
- I belong to Special Voices
- I belong to the special voices group
- I belong to special voices group
- Through Special Voices

Question 9 - What is working well for children and families in Slough? (16 comments)

- 50/50 has been a huge benefit to my son. He was referred because of his behaviour was very negative. Within a couple of weeks he showed enthusiasm for the first time and wanted to go. He responded so well and wanted to earn his medals. It was so nice to be able to collect him and hear positive things, rather than complaints about him
- 50/50 I found out about this group from the parent support worker at my sons school. She works with us. This is the first time that my son has been to a club without me.
- 50/50 Slough well women's Support Group (run by Jackie & Vickie) Sure Start Centres
- Sharing support between friends/colleagues
- Advice
- Parent Partnership is all I know about
- Events like today (SEND open day) so you can come and get information and support
- Parent partnership
- it's just so hard at the moment there is just so much to do we are going through the statement process
- Support work - supporting people to chase other people if you need support in something
- The support services groups
- The out of hours service are happy to see my special needs child
- Nothing
- Nothing
- Not a lot as not getting help that my boy needs
- Sharing information

Question 10 - Where are the gaps in service? (22 comments)

- Once my son was diagnosed by CAMHS I felt left to get on with it, being told to go and look at a website. Most services are out of the area
- I haven't heard of a lot of the services that are happening. Information is really hard to find.
- Professionals not taking parents views or knowledge of their children into account. Family Therapy No support groups for families affected with foetal alcohol syndrome. Crossroads lack of funding for summer trips Lack of funding for weekend respite No outcomes when working with parent partnership and SEN
- sharing information, communication
- training information available, waiting lists too long, access to services, Delay in diagnosing speech and language - families need support with this
- Activities for children with autism.
- A specialist school that is in between mainstream and Arbour Vale
- Guidance. Unless you know where to go you don't know where to go. If you're in the know you're ok.
- clubs for physically disabled children. There is none, nothing in between that deals with a range. Our children do not have any choice
- People to help me with letters and attending meetings.
- booking a GP appointment. Hands on approach in supporting the family including schools for the siblings of the SEN child. My child has yet to receive a statement so we are doing all of this on our own. It affects the whole family. When my other children come home from school they cannot sit down in a quiet environment and complete their homework, you have to understand that all of my children are my priority but the needs and support of my child with additional needs takes up much of the focus. My family has to have different priorities.
- There are lots. People just don't listen, they don't understand. You can only talk so much. I don't have the energy or the fight to keep complaining or even challenge or query I just go along with it. Main services hospital, GPs, shops, housing our children our different its hard work, continuous hard work some of our children do not even sleep, stay in one place for 1 minute. People don't realise and it's easy to ignore us so there are many like me we just continue to struggle and accept even when we know things are not right.
- Supported living, better communication, no plan, the staff do not have the knowledge and experience to deal with SEN children.

The supported living accommodation should support the young person needs- for example a sensory room should be available.

Autism specialist centre - a team of staff to be accessible.

- Appointments at the GP surgeries
- Need more information and ways of how to access it
- Ease of getting a GP Appointment
- G.P appointment for carers (impossible to get the same day appointment) GP has prescribed wrong dose of medication.
- Respite for holidays and weekends
- Lack of respite, services and benefits
- school and professionals
- There are no social activities clubs or short breaks that cater for a child with profound disabilities; needing a hoist or changing facilities in Slough that cater for physically disabled children with complex needs and normal cognitive abilities.
- Finding out about the local offer it is not obvious that all providers cater for all disabilities e.g. 20/20 sync don't deal with epilepsy. (Healthwatch believes this to be referring to 50/50 Sync)

Question 11 - What would you like to shout out about? (21 comments)

- The fact that my sons school (name provided) are unwilling to apply for a statement for my son, to the point they refused point blank for 2-3 years. It was only once I threatened to sue the school that they agreed to apply.
- I get a lot of support and information from the parent support worker at my son's school
- When I know what is best for my child and other professionals also know my son, but because of funding the SEN have just shrugged their shoulders. Won't allow funding for transport. It's not what's best for the child, their needs, and their future, rather it's all about money
- More money - stop cutting money in the wrong places. If you invest and train more staff this will help money training available where to go when desperate. Mobile App information for parents. Misdiagnosis. Everyone all agencies coming together reduce all of the waiting lists
- Our children actually matter you cannot keep brushing us under the carpet. We need support groups available in the day
- CAHMS diagnosis with autism. Support for parents of children with learning disabilities. More support groups at the moment we just have parent partnership & special voices and still a lot of families do not know about these services.
- Schools and teachers to be trained with actually listening to the parents and taking time to understand the child. I just want to be heard
- Just to be listened to and helped

- The doctors just don't get it. They should work with the agencies to help deliver the best care for our children. You can never get an appointment a body part needs to be falling off before you get seen. It's not an easy road for us but who actually listens?
- Everyday things like shopping, opening your front door, getting your child to school - is hard work. People need to understand and be aware of autism and an autistic child's needs.
- My son is over 20. I understand that he needs his independence; however, the family are still the ones supporting his needs and looking after and out for him, it is important keep the family involved, we should have access to the experience and qualifications that the staff have who are caring for our loved ones.
- Reviews with all key people are important but this does not happen.

Appointments

the CAHMS waiting list is horrendous

- Getting suitable assistance and information
- No telephone appointments or appointments at cluster surgeries
- Lack of respite services for school holidays and weekends
- When the young person turns 20, parents loses the money even when the young person is in full time education
- No statement when it's clear the child needs one
- My son would like to be able to access social activities that meet his physical disability (hoist and changing areas) combined with stimulation to meet his mental abilities
- Give carers more recognition at appointments doctors/hospital.