



Healthwatch Slough looks at the
Special Educational Needs and Disabilities
(SEND) service.

Questions and Responses from the
Special Voices Focus Group



November 2015



Healthwatch Slough

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

Special Voices

Special Voices is a group of parents/carers of children and young people with additional needs. The main aim of Special Voices is to raise awareness about the rights and needs of children/young people with additional needs and to ensure that they and their families are consulted and involved in any decisions made during planning or developing services for them.

Background

Summer 2015 Healthwatch Slough sought to gather the views and experiences from children and families members in Slough who have used or are using the following services;

- 1) Special Educational Needs and Disability (SEND) Services (formally known as Parent Partnership)
- 2) Slough Borough Council's Local Offer

<http://servicesguide.slough.gov.uk/kb5/slough/services/site.page?id=pQOWLj0rHsE>

Healthwatch Slough engagement undertaken to support the SEND project

- June 2015 - August 2015 Healthwatch Slough Questionnaire on SEND services & the Local Offer this was distributed at 3 community groups and events
- July 2015 - Healthwatch Engagement at a local group Special Voices
- August 2015 - Engagement at the 50-50 Sync CIC Summer 2015 Community Mentoring Programme (CMP)

The Visit to Special Voices

Healthwatch Slough visited the Special Voices coffee morning for a Healthwatch focus group. During the focus group Healthwatch shared the SEND project aims, distributed questionnaires and facilitated a question and answer session. A total of 20 questions were shared with Healthwatch to raise with the relevant services. Healthwatch are pleased to announce that we have received responses from Slough Clinical Commission Group, Frimley Health and Slough Borough Council.

The information shared with providers is anonymous; as part of the provider responses some have requested for further detail or would like to follow up with the individual who shared the question. If you would like to follow up this request please contact Caris Thomas.

Next Steps

The information shared in this paper will be used as part of the Healthwatch Slough Special Educational Needs and Disabilities (SEND) service & Local Offer report.

Thank you for sharing your experience with Healthwatch Slough

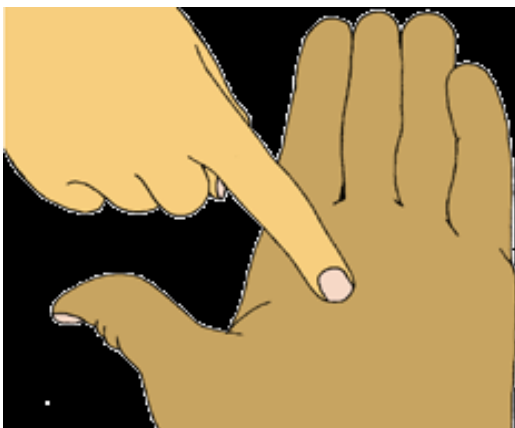
GP access & Hospital appointments for deaf patients

? **Question:** My daughter is deaf she is getting to the age where she will soon need to book and attend a GP appointment without me/a member of the family. What services are available to support her when booking and attending a GP appointment?

Also can the same question be answered for the hospital service?

Response: All services should be accessible to patients with communication or other difficulties. GP appointments can be made online which will help patients with hearing difficulty. It would be advised to ask your practice whether they could add a note on your daughter's record so that they are alerted of the need for an interpreter. When an appointment is being made in advance, it is possible to arrange the support needed. It may be different in emergency situations and it would be helpful for your daughter to carry a card to alert staff of the need for support. Interpreters can be arranged in advance or organised as needed but there is likely to be a short delay at the time

PALS response – Daughter requires equipment to make telephone calls and the response is shown on a screen. Some GP Practices allow you to book appointments online. For attending appointments if enquirer does not use lip reading, and it is required, the GP is responsible for organising someone to use sign language.



Wexham Park Hospital facilities for disabled children

 **Question:** My child is disabled and in a wheelchair, when we attended WPH I always call and check to plan what we will be needed for our visit. I have asked about hoisting equipment and changing facilities. On one occasion I was told to change him on the floor on another occasion I was told that I would be informed when I arrive.

Can you find out why WPH cannot have an allocated area to change and hoist my son and why I cannot be informed of the location before we arrive?

Response: The member of staff from the Children's Ward assured me that they have the appropriate equipment in their area, but this may have been an outpatient appointment.

(Alison Davies | Senior Quality and Safeguarding Administrator)

Please contact Frimley Health or Healthwatch Slough as we would like to discuss this further. Thank you.



GP receptionist training

Query: The reception/front of desk staff should all be given training on autism awareness this will help them have an understanding when dealing with children and their families.

Response: Thank you for your feedback. We can raise awareness at our monthly educational meetings with the practices staff



GP Records

? Question: When you move surgeries where does your information go? How long does it take for the new surgery to get your information as I had to wait months and explain all of my health conditions to the new surgery?

Response: Typically, it can take some weeks for documents to be gathered together and sent from one practice to another if a patient moves. However, with the recent advances in holding records electronically, this should now be much easier. It is important that this is done carefully and appropriate checks and carried out to confirm the patient has moved to avoid inappropriate access



GP & CAHMS SERVICE – SHARING ON INFORMATION

? Question Why can't CAHMS and my child's GP share information about my child. It is important for both professionals to know what is happening, what's changed, the effects of medication. Sometimes these reports and letters have big words some that I don't even understand, it's really important for my child that both professionals come together.

Response: Communications between different parts of the NHS caring for a patient should ensure the patient's GP is aware of all tests and treatment carried out. Traditionally this has been done by writing letters but increasingly other communications are used. It is good practice to copy all correspondence about a patient to the patient. The language used should be clear and if there are any terms used in the letters that you are unsure about, you can contact the author of the letter for further clarification.



IMPROVEMENTS FOR GP APPOINTMENTS

? Question The GPs says that they have improved appointments for people with Long Term Conditions (LTC) so what about my child?

Response: Children would also be considered with LTC management and extended appointments. This is rather specific to a particular surgery to respond helpfully.

GP APPOINTMENTS FOR CARERS

 **Question** it is really important as a carer that we stay fit and well so that we can look after those that we care for. Many people do not see themselves as careers but many do. Our GP surgery knows my situation and still there is no flexibility.

A little while ago I had a cold/flu symptoms with a cough I contacted my GP for an appointment but none was available. I called again on another day and was told to come to the emergency clinic at an allocated time I done this and was given a number. Unfortunately my number was not called in the allocated time so I was told to come back again in the late afternoon. I explained that my son would be home at that time, I was told to bring him with me. My son has disabilities after a whole day in school there are certain care arrangements that I have to do with him. My child should not have to sit in the appointment with me. My child should not have to hear what is happening with me.

On week 2 I finally got an appointment I had now developed a chest infection due to the length of time taken to see a GP. So if I am sick who is there to look after my child this is what GP need to realise.

Response: GPs are now recording on patients' notes whether they have caring responsibilities, so that they can be supported to avoid the situation described here. Please do speak with your practice that can support your needs in the first instance. If you fail to receive an appropriate response please do let us know and we will raise the matter with the practice directly



SLOUGH BOROUGH COUNCIL WHAT IS HAPPENING WITH THE SHORT BREAKS SERVICE?



Question What is happening with the “short breaks” service? What is available for our children? What choice do they have? Please get back to me on what is available for the children with physical disabilities? Where can they go? What is happening with the choice in respite services? How have parents been consulted?

Response: Slough Borough Council continues to provide Short Breaks services for children and young people with SEND. We have a number of providers in (and outside) the Borough, a full list of which can be found here:

<http://www.slough.gov.uk/health-and-social-care/short-breaks-for-disabled-children.aspx> and is accessible to users in and beyond the Borough. 1500

leaflets/flyers have recently been updated and are in the process of being sent out to families and carers known to SEN and children’s social care and to schools with updated details of all short breaks’ providers and provision in the Borough, along with links to the statement.

The Council works closely with Special Voices, a group of parents/carers of children and young people with special/additional needs, trying to ensure that they and their families are consulted and involved in any decisions made during planning or developing services for them. We are planning to work with Special Voices again in the autumn. We do not have details of the numbers of families involved in past consultations.



THE CHILDREN ADOLSCENT MENTAL HEALTH SERVICE (CAMHS) WAITING LIST

? Question The waiting list is far too long we just have to wait for appointments with no help in between.

Response: We agree the waiting times are unsatisfactory. We have invested additionally into the CAMHS services and specifically have been working with them to reduce waiting times for services



WHAT HAS HAPPENED TO THE CARERS REGISTER - GP APPOINTMENTS

? Question - What ever happened to the carers register? To the annual health checks? Do GPs understand what happens when we are sick? We are responsible for someone else many of our children have complex needs we cannot just leave them with a neighbour? The trying to book an appointment at 8am is a real inconvenient time for carers.

Response: We are awaiting a response from Slough Borough Council who leads on the Carers Strategy



GP REGISTERING – I WANT TO CHANGE MY SURGERY

? Question I want to change my surgery I have found a surgery that I would like to register with but they have told me that I do not live in the catchment area even though it is a few minutes in the car. Is this correct as I thought you could register anywhere now?

Response: Pursuant to NHS England guidance on Choice of GP practice, when a patient moves outside of a practice's contractually agreed boundary there are three options:

1. maintain the patient on the patient list as any other registered patient, continuing to provide access to the full range of services;
2. refuse continued registration on the grounds the patient lives outside of the practice area;
3. register the patient as an 'out of area registered patient' with no obligation on the practice to provide home visits etc., assuming it is clinically appropriate and practical to register the patient in this way.

In considering the above, it is important that practices consider applications of patients to register / remain registered on an individual patient basis, taking account of their individual circumstances.

The application of these principles is clearly a matter for the particular practice, it is for them to make a clinical judgement on the specific circumstances of the patient and the practicality of providing the required service, together with how flexible they can be with regard to applying the guidance.



GP APPOINTMENT AT HUB SURGERY

? Question - I went to attend an appointment at my hub surgery and the surgery could not access any of my information, why was this?

Response: We would need to know which hub and practice as some practices share records and others do not operate in the same way.

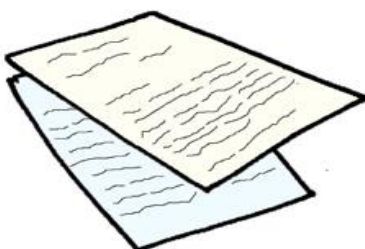


ACCESS TO MEDICAL INFORMATION

? Question - I am trying to get access to my child's medical file at the GPs and I have been unsuccessful. I have requested in person and over the telephone. It is needed for my child's child care I have now been told that the childcare provision will need to request this. I do not think this is right as it's my daughter and I have the right to inform the provision myself. The GP surgery has also told me that I have to request in writing it will then be up to them whether they share or not.

Is this right?

Response: A written request is required as mandatory as requested by the GP practice. Once received this request will be responded to in detail by the GP practice. If the individual still requires further clarification please do not hesitate to contact us via PALS in the first instance



MEDICATION RECALL - PHARMACY/GP SERVICES

? Question - How do you find out if a medication has been recalled? Whose responsibility is it to inform you of what changes you need to make?

Response: Drug recalls are cascaded from the **Medicines and Healthcare Products Regulatory Agency** (MHRA). They go to all pharmacies and hospitals. They are graded depending upon their severity and different course of action apply depending upon this grading. It is then the responsibility of the pharmacy to carry out the action required by the recall, including contacting patients if required. It is quite rare for this to be required as the level of severity is usually lower than this.

Boots have quite a good summary here:

<http://www.webmd.boots.com/medications/guide/drug-recalls-what-are-they>

Anyone can subscribe to receive alerts if they would like here:

<https://www.gov.uk/drug-device-alerts>



MY CHILD WAS MISDIAGNOSED BY MY GP

? Question My GP misdiagnosed my child as my child was labelled with the conditions that the sibling has.

Response: Unable to respond without any detail.



HOSPITAL STAFF NEED TO LISTEN TO PARENTS

? Question To listen and take in what the parents are saying especially when a vulnerable child. A requested a standard procedure for a name tag to be put on my child on day 3 this finally got done.

Response: We will feed this experience through to Wexham Park and our team that monitors quality of services at Wexham to raise the issue with the trust



MY GP MISDIAGNOSED MY CHILD

? Question My GP misdiagnosed my child as my child was labelled with the conditions that the sibling has.

Response: Unable to respond without any detail.

My apologies it appears that ward staff have not followed the admission process and issued/placed a patient ID name band on a child and not responded to the parent's request. I have informed the Senior Sister for Ward 24 about this incident that will ensure ward staff are informed not only to follow process but also to listen to what parents have to say. (Matron for Paediatrics).



Autistic Spectrum Disorder (ASD) Assessments

? Question I am waiting for Autistic Spectrum Disorder (ASD) Assessments Extremely long wait nearly 14 months now what is happening?

Response: We have recognised that the waiting times for CAMHS services including ASD are not acceptable. There has been an increased investment in the service and plans are already underway to reduce the waiting times for all services within CAMHS including ASD.

Service: Out of hours service/ Hesitant to call 999

? Question With all of the information that you hear regarding wasted A&E visits it makes you hesitant and question when to call 999. I called the out of hours service the GP called me back and quite clearly didn't understand my child's condition or surroundings. I was given inappropriate information. I resulted in calling 999 as my child was getting worse. I have the confidence now to ring 999 straight away.

Another parent reported that child with Special Needs often present differently. As parents and carers go with your instinct and explain the situation, use relevant services until you are satisfied with the outcome.

Response: Out of hours (OOH) GP services are there to provide urgent care service for when a GP practices is closed. We have been working with the GP practices and OOH recently to facilitate the sharing of summary clinical records in order to support better management of complex conditions. Saying this if you have noticed a worrying deterioration of your child's symptoms it may be necessary to call 999 for urgent and life threatening conditions.



I was prescribed medication by a receptionist

? **Question** I called the GP for an appointment, there was none available I informed them it was an emergency. The receptionist asked what the matter was. She wanted me to come to the surgery I explained that I was too poorly and that I was caring for my child. I asked if the GP could come out to me the receptionist explained that he couldn't so the receptionist asked my symptoms and informed me that she would have a prescription ready for me.

I think it is scary that the receptionist is able to prescribe and diagnose.

Response: Only GPs and some Nurses can diagnose and prescribe medication. It may be likely that in the scenario above the receptionist may have acted on the directions of the GP / Nurse and in all cases the prescription issues can only be signed by the issuing GP or Nurse. These checks are in place and are followed and monitored by a variety of external checks e.g. pharmacist cannot issue prescriptions that have not been appropriately authorised by a doctor or a suitably qualified nurse.



Use Links

The Local Offer can be found here

<http://servicesguide.slough.gov.uk/kb5/slough/services/site.page?id=pQ0WLj0rHsE>

Next steps and recommendations

Slough Borough Council

- To provide a update on the carers register for Healthwatch staff to inform the community
- To provide Healthwatch with continuous updates on the short breaks services and how parents and children have been involved in any changes to the service

Slough Clinical Commissioning Group

- For Slough surgeries to promote and update their electronic records for children with a learning disability
- For Slough surgeries to promote the health checks for children and their carers and to monitor the number of health checks completed for children with learning disabilities and their carers
- For Slough surgeries to have a clear method for patients to share their feedback and to meet with lead organisations such as special voices to ensure that parents have an awareness of these methods.
- For the GP reception staff and other staff teams to take training around learning disabilities to ensure that children and parents have a better pathway when accessing services.

CAHMS & GPS

- To identify better ways and process for sharing information
- To explore further ideas to promote the use of the CAHMS passports

Hospital Services

- For the patient involvement group at Wexham Park Hospital to identify ways and plan how the patients and carers of special educational needs and disability voice is heard.
- A SEND champion or representative for Frimley Health Trust can be explored.

If you require any further information please contact Caris Thomas directly on -07920 506403 or by email caris.thomas@healthwatchslough.co.uk

Alternatively please contact Healthwatch Slough.



Visit Citizens Advice Slough, 27 Church Street Slough, SL1 1PL

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