



# Talking to the parent carers of children and young people with disabilities and Special Educational Needs (SEN)

## Contents

Executive Summary and Recommendations .....	2
Introduction .....	4
The Focus Groups .....	4
The discussion.....	5
GP surgeries .....	5
Whipps Cross University Hospital and other hospitals .....	7
Waiting room environment and adaption.....	7
Choice .....	7
Services outside of the borough .....	8
Continuity .....	8
Quality of service .....	9
Wood Street Health Clinic and CAMHS.....	10
Communication.....	10
The range of services.....	12
Systems .....	13
Quality of services .....	14
Waiting room environment .....	14
Continuity .....	14
Transition .....	15
Dentistry .....	15
Lessons learned elsewhere .....	16
The Children and Families Act 2014 .....	17
Summary and recommendations .....	18
Glossary.....	20
References .....	21
Appendix 1 .....	22
Disabled Children's Charter for Health and Wellbeing Boards.....	22

## Executive Summary and Recommendations

This report is a summary of the discussion with parent carers over three meetings in the spring of 2014 and focuses upon children and young people with disabilities or Special Education Needs (SEN). The parent carers discussed their experiences and concerns about health and social care provision in the London Borough of Waltham Forest (LBWF) and elsewhere in London and the South East. Key themes emerged in the discussions, from which these 19 recommendations for change and improvement in how health and social care services interact with parent carers and their children were identified.

### Recommendations:

1. The WF Parent Forum should have a seat on relevant Boards and groups to ensure that its members views and experiences are routinely taken in to account, as appropriate, and their expertise is used to the best advantage.
2. Parent carers should have regular input into the ongoing training and education of staff delivering services to SEN and disabled children and young people.
3. Any changes to SEN and disabled services for children and young people should include meaningful engagement with the service users and their parent carers. This engagement should come as early in the change process as practical.
4. Review of the implementation of the Children and Families Act in Waltham Forest, with regard to SEN and disabled children, should include representation and input from the Waltham Forest Parent Forum and the wider community.
5. The Occupational Therapy treatment offer for children aged 11 and older in Waltham Forest should be reviewed urgently.
6. The CBT offer for children should be reviewed.
7. The feeding pathway should be reviewed.
8. Each child or young person should have a named single point of contact to oversee their use of services and champion their cause if the need arises.
9. Services should coordinate access to medical records to allow easy access, as required, from any site or service used by the child or young person.
10. All correspondence with service users should include clear and current contact details for the service.
11. Services should endeavour to coordinate appointments to accommodate the service users needs. For example, offering same day appointments for multiple services at one site, unless the child prefers otherwise.
12. Services should keep accurate and current notes of the requirements and abilities of SEN and disabled children and young people to ensure they offer a tailored service for appointments, waiting environment etc. They should know who is coming in to the service and how best to support them on the day.
13. Good practice should be routinely identified and shared amongst all service staff to improve services for all.
14. Robust and efficient administration of services should be standard and protocols in place to ensure timely and effective communication with service users.
15. Parents and their children should have ready access to accurate and current information and support concerning the transition to adult services and consideration should be given to a young adult specific service.

16. Services should adapt their approach to focus upon providing ongoing support rather than crisis management, this will improve the long term health and wellbeing of service users
17. Services should offer therapeutic as well as medical choices to service users and support them to make the best decisions for their care.
18. Services should review how they offer their services regularly, in consultation with the service users and their families. For example, rather than scheduled appointments, some parents would prefer drop-in sessions, or a telephone advice line offering targeted support when needed.
19. Appointment booking and waiting systems at GP surgeries should be adaptable, to give appropriate priority to SEN and disabled children to minimise their anxiety.

## Introduction

Healthwatch Waltham Forest is the consumer champion for health and social care services in the borough. Our main activity is the gathering of opinion and experience of services that local people use, and feeding that back to the service providers and commissioners, to ensure that services improve and develop with the service user in mind. We also facilitate local people to get more involved with the development of existing and new services, highlighting opportunities and supporting people to be able to contribute in meaningful ways that best suit them. As part of our work we meet with local people and groups to explore how services they use could be improved and we then report our recommendations for change and improvement to the service providers and commissioners who are statutorily obliged to listen to and respond to our recommendations. This report focuses upon parent carers of children, aged under 25, with disabilities and or special educational needs.

Healthwatch Waltham Forest has been working with the Waltham Forest Parent Forum group to explore the experiences of parent carers of children with disabilities and SEN in the borough. Parent Carer forums have been developed locally across the country and are funded by the Department for Education. Membership is open to any parent or carer of a child or young person with a disability and the aim is to improve services for disabled children and their families.

The Waltham Forest group, has a membership of more than 400 families across the borough, who care for children and young people aged up to 25. It has two aims: to provide support for parent carers and to campaign for change in the design and provision of services for SEN children and young people in the borough.

The group has a strategy for engagement with local health and social care services. They have tried unsuccessfully to encourage the Waltham Forest Health and Wellbeing Board to adopt the [Disabled Children's Charter for Health and Wellbeing Boards](#), which sets out seven commitments focusing on improving health outcomes for disabled children, young people and their families (see Appendix 1). The Board cited financial reasons for not adopting the Charter, which has been signed by 36 Boards across England to date (May 2014).

## The Focus Groups

Healthwatch Waltham Forest arranged two focus groups and a discussion and feedback session with the parent carers from Waltham Forest Parent Forum. All three sessions explored carers' experiences with GP surgeries, the Specialist Children's Service at the Wood Street Health Centre, Child and Adolescent Mental Health Services (CAMHS), Whipps Cross and social care services.

The first session was held in January 2014 and was attended by twelve people; the second was in March and attended by four; and the third took place in May and was attended by 12 parent carers.

This report makes recommendations, based on these discussions, about how services could better interact with parent carers and their disabled and SEN children and young people, to improve their experience of services.

## The discussion

### GP surgeries

Some of the issues raised in the discussion about GPs were common to those of residents across Waltham Forest, such as difficulty getting an appointment and continuity of care<sup>1</sup>. However, these issues are exacerbated by the difficulty of managing a child or young person who cannot wait easily in the waiting room, or wanting to see a GP who has prior knowledge of the child and will not need to be told their history at each appointment. In addition, disabled and SEN children often need to visit their GP more frequently than other children.

### Appointment booking

Appointment booking was discussed and some participants have established effective systems of booking that ensure their child gets an appointment when necessary and that waiting at the appointment is minimised or managed appropriately. One parent spoke about the system of triage at her Redbridge GP surgery, whereby the receptionist takes calls at any time (i.e. not at set appointment booking times), and the GP later returns the call and agrees the next action, either an appointment or a prescription. The parent and child always know when they go to the surgery that they will be seen and when, which helps the SEN teenager to cope with the process. Another attendee has a similar system at her surgery: *“My GP [in Chingford Mount] offers me a great service as he knows my son is autistic. I don’t have to go to the surgery with my son now, but can just call to discuss any issues. He also does a home visit when we need it. Now that the surgery know my son the appointment system works well.”*

However, not all attendees have such good access to their GP. One contributor has to use a general surgery system that requires patients to call at set times to book appointments, which she finds difficult: *“I am trying to get other children ready for school at the time that the GP surgery appointment system opens; it is very inconvenient trying to call at 8am as required to do”*. Another participant now prefers to deal with any illness herself rather than tackle the appointment system and the regular long waits at the appointment. Someone else agreed and said that she and her family delay going to the GP because of the difficulty in getting an appointment. This delay in seeing a GP had serious consequences for her (non -SEN) son, who had a spot on his knee that was eventually diagnosed as Weil’s Disease. It was felt by the group that the impact of delays on the health and welfare of an SEN child or young person could be even more serious where opportunities for prevention and early intervention are missed.

### Continuity

Whilst some attendees were happy to see any GP at their surgery for their own appointments (*“As long as I can see they are listening I am happy with my GP, whoever I get to see”*) they value being able to see the same doctor each time they visit with their SEN child. One attendee generally commended the service at her surgery but did not like their increasing use of locums: *“I want to see someone that knows my child. I don’t want to waste valuable appointment time going over their medical background, I want to talk about the current issue”*. One attendee praised her surgery’s record keeping which meant

---

<sup>11</sup> Our GP survey report was published November 2013 and is available on our website: <http://www.healthwatchwalthamforest.co.uk/reports-and-activity>

she, or her SEN child, need not worry about seeing the same GP each time: “*My GP surgery’s data system is so good that we get continuity of care regardless of who we see*”.

### **Waiting room environment**

The waiting environment at the GP surgery, and other services, was discussed. It was felt that waiting rooms were often particularly unsuitable for SEN children. Some receptionists are accommodating (“*Most know me and my child so give me priority and I don’t have to wait*”), though others felt that their experience varied with different receptionists, which indicates that some practices may not have a standard policy in relation to prioritising SEN patients. At some surgeries, SEN children wait in the waiting room when appointments are running behind, despite the upset this can cause them and the disruption they can cause to other waiting patients. One carer reported that [her] SEN teenager is always seen immediately at the community blood clinic, as staff know and understand that she cannot wait in a busy room for an unspecified appointment time.

### **General comments**

There was some general discussion about GP services that was not limited to parent carers and SEN children issues. One participant spoke about the administration errors that delayed her son’s confirmation of his fitness to enter the army. Another waited all day for a call back from her GP, unaware that the system had been changed and a same day call back was no longer guaranteed. The waiting room at one surgery was described as very “*tired and dirty*”.

The care.data system was discussed at the March focus group, where only one person was aware of it. Her surgery had a notice in reception informing patients they would be opted in unless they opted out, but there was no further information explaining what the scheme was or how it will impact upon patients.

## Whipps Cross University Hospital and other hospitals

Focus group comments about Whipps Cross hospital correspond with those Healthwatch has received from other residents in the borough, expressing both positive and negative experiences and some common themes. However some situations are unique to parents and carers of disabled and/or SEN children and young people.

### Waiting room environment and adaption

Participants at the focus group had experienced long waits in various departments, sometimes in environments unsuited to an SEN child. One child with an outpatient appointment faced a delay upon arrival: *“We waited an hour and he was getting very agitated. I told reception we couldn’t wait, but they couldn’t accommodate us”*. Another SEN child in a similarly-busy A&E was allowed to wait in a cubicle rather than the busy waiting room, but even this adjustment proved unsuitable: *“We waited for over 45 minutes. I was trying to find out how long it would take because my son gets restless waiting. I warned the staff the longer it took the more difficult it would be. After two hours the doctor came, but by then my son was too agitated and he couldn’t be examined.”*

One non-verbal autistic child arrived for a 9am appointment but staff arrived late at 9.30am. After this delayed appointment, there was then another wait for some drops to take effect before seeing the doctor again. *“The waiting room is always very busy and my daughter was really suffering because of the noise. They had no plan for my daughter despite them knowing her condition and that she can’t tolerate environments like that”*.

According to participants, some general departments - such as the blood service - make no concessions for SEN or disabled children: *“Bloods outpatients is much worse and much more crowded. An autistic patient would walk in and walk out.”* Even some services specifically designed for children can fail to accommodate those with SEN or disabilities: *“The [Children’s Outpatients] department is not set up for children with autism as it is very busy and [my child] doesn’t like to be in busy places.”*

### Choice

Choice was raised by several attendees. They wanted to make choices about where and/or when treatment was received so as to best accommodate the needs of their child, but were often hampered by issues such as the range of services available locally, long waiting lists, targets and budget constraints.

One parent experienced frustration when her choices could not be accommodated and the option offered - which would negatively impact upon her child’s already disrupted education - was aimed at meeting an internal target rather than being in the child’s best interests: *“My son was due to have his tonsils out. The process took about three years. We were going between Royal London, Whipps Cross, and Loughton ENT. When we eventually got the date through it was during school time. My son already misses lots of school so I wanted to rearrange for the Easter holiday. I was told they couldn’t do this as it would then be out of the target time. If I chose to do this she’d have to cancel the whole process and make us start again in order for it not to be outside of the target time frame. Eventually we organised for half-term and it was kept within target times. This is not patient-centred care.”*

Another parent, having encountered a Consultant she thought gave excellent care, actively chose to see them in the future when given the choice. *“I prefer to go to St Thomas’ with my son, rather than to Whipps Cross; he receives better and more immediate care there. I met a good Consultant at Roding during a private operation and follow up was at St Thomas’ and I wanted to stay with that Consultant so now choose St Thomas’ when I’m given the option.”*

### Services outside of the borough

Whipps Cross was compared unfavourably with specialist hospitals elsewhere in London and was often not first choice for local parent carers for their disabled and or SEN children; this despite travel out of borough being a costly, time consuming and often fractious undertaking for most parent carers at the focus groups. For their children’s care parents were keen to go where they felt they got a service that best met their children’s needs. Some, as above, followed favourite consultants or went where services were best tailored to their children’s needs, while others had no choice but to go out of the borough because the services they needed are not available locally.

Not all specialist care is available at Whipps Cross all the time and so attendees were having to go out of the borough. One carer who needed to access an ECG service had to go to the North Middlesex as Whipps Cross did not offer the service. Another had to go to the Royal London from Whipps Cross A&E when a specialist was not available, which lengthened her son’s treatment: *“We went to A&E, but the expert on juvenile arthritis was not in so they sent us to the Royal London. Instead of keeping my son in for a day until the expert was available we had to go much further away and three hospitals ended up getting involved.”*

One parent, while praising the quality of service her child received at a hospital out of borough - attended as the service was not available in Waltham Forest - nevertheless found it difficult to get to the hospital. *“There is a difficulty in travelling out of the borough to services. The Maudsley and Springfield are difficult to reach with a special needs child on public transport, requiring several changes”*. She did however appreciate the system of support the Maudsley offers, with telephone and email support as routine, *“We have a once a month meeting via telephone and there is a quick turnaround time to be able to have a telephone consultation between regular appointments if I get worried”*. This means unnecessary travel can be avoided: *“If I’m in crisis I can email them and they call back ASAP. Whipps Cross is also good in a crisis but we need additional help not available there [Cognitive Behavioural Therapy].”*

### Continuity

Going outside of the borough sometimes means that continuity of service is sacrificed. One attendee cited a letter full of errors between her GP, Whipps Cross and Great Ormond Street Hospital that *“resulted in my child being incorrectly told they needed to have their tonsils out”*. In another case, one attendee experienced poor continuity of care between Barts Health sites when her child needed surgery: *“My child needed tonsils and adenoids operations. They had the pre-op at Whipps Cross but I want it done at the Royal London. They [Whipps Cross] did not have thorough notes on the child’s history or heart condition; they had no notes about it at all.”*

Attendees felt that improved administration would allow them to better manage their child's care and would provide an improved experience for the child. One attendee has regular two-monthly appointments but there is no coordination to routinely ensure that they are on the same day.

The need to have an ongoing, joined up service that also kept patients out of crisis was discussed. This was raised at all focus groups and the attendees felt that all services, not just those at Whipps Cross, must work together to keep the children and young people on an even keel rather than only seeing them when they hit a crisis.

### Quality of service

There was some discussion about the quality of service at Whipps Cross. Some individuals were highlighted: *"Children's consultants Dr J Ho and Dr Callahan are absolutely fantastic and brilliant. They should be recognised for the work they do"*. Others compared Whipps Cross unfavourably to services they receive elsewhere: *"A nurse on Acorn Ward always misses the vein. My child always comes out black and blue. At St Thomas' they never have any problems."*

One attendee said her son was sent home from A&E when clearly unwell, was admitted again for four days, but then sent home again, still unwell: *"Why discharge him when he is obviously not fit to go home?"*. Another attendee had had a similar experience on her own visit to A&E with a sore ankle: *"A&E diagnosed a sprain and prescribed painkillers and waiting for it to heal, so I carried on. I went to my GP 8 weeks later still in pain and he said it was a ruptured Achilles tendon. I had crutches, an ultrasound and emergency surgery; it should have been properly treated at the time."*

## Wood Street Health Centre and CAMHS

Wood Street and Child and Adolescent Mental Health Services (CAMHS) provide a multitude of separate services which are closely linked for parent carers who frequently use and rely upon specialist support for their children. Throughout our three sessions with parents they spoke about these services interchangeably, with comments for one often applying to the other. As such they have been considered together in this report but individual services have been identified where specifically named.

CAMHS services are provided in Waltham Forest by North East London Foundation Trust (NELFT) at Thorpe Coombe site in Walthamstow. The community-based service offers help to young people from birth up to the age of 18 who are experiencing emotional, behavioural and mental health difficulties, whether ongoing or temporary.

The Wood Street Health Centre, also in Walthamstow, is a base for specialist children's services provided by both NELFT and the Local Authority to people across the borough. It offers various services (listed below) of particular relevance to the Waltham Forest Parent Forum and was discussed extensively at all focus group sessions.

Services offered:

- Child Development Team
- Community Paediatricians
- Speech and Language Therapy
- Physiotherapy
- Occupational Therapy
- Children's Community Nurses
- Special Schools Nurse Team Leader
- Early Support Team/ Portage
- Child Health Team
- SEN services

## Communication

Almost a quarter of comments about Wood Street focused on communication and the majority were negative. Some issues were common across the group and others were very specific to individuals.

The attendees were concerned that the Friends of Wood Street are no longer active. It was believed that they stopped functioning 2 or 3 years ago because "*the parents stopped caring, nothing changed or improved*". The group is missed by the Waltham Forest Parent Forum who used it to communicate and engage with the staff at Wood Street, and who reporting feeling they now had one less channel of communication.

There was discussion of the communication and support available for children and their parents or carers after diagnosis. Some felt that they were not given sufficient information and support initially, and so found out for themselves: "*Once you have a diagnosis you have to learn as much as you can about it so you can make sure that you know what your child needs and that they receive it.*" There was disappointment that more was not done to promote the Waltham Forest Parent Forum who could offer vital support to parents at

these times. *“You get a diagnosis and a national autism leaflet and you go! Parents with newly diagnosed children are not even told about the support from the parent forum - that is why we were set up! Wood Street should be telling parents they can tap into us for support. Support after diagnosis is crucial, a leaflet is not sufficient.”* Information about services and support was sometimes hard to access: *“When someone tried to advocate for a parent and find out what they do at Wood St no one there could tell them.”*

Communication at Wood Street was described as poor in practical terms, whether letter writing, appointment booking or general correspondence. Parents have waited a long time for yearly appointment confirmation letters. *“I had a letter from Wood Street about my child’s annual review appointment. It is already 5 months overdue, but the letter came so late I can’t attend due to clashes with other appointments.”* Another parent was unaware for two years that her child had been discharged from Wood Street because she had not received a notification.

Parents felt that the administration of the service was poor and hampered their access to services. *“Letters from Wood Street do not have a telephone number for the department to ring. The pathway of contact is crucial, but is not so good”*. They also felt that they had to chase for appointments and the routine administration of appointments was not happening: *“Great when you get there but you have to call and chase for every follow up and treatment or you get forgotten.”* At least one parent felt this was a way of managing the high demand for appointments: *“They are trying to cut the list down by letting people fall off the system rather than reminding existing patients to book a follow up.”* One mother found her child’s appointment timetable slipping - annual reviews were delayed by months, and appointments were made at short notice. However at least one parent believed that while the administration was poor, the care received was good: *“Overall I would rate Wood Street as a real asset to Child Services. Not great on following up on appointments but when you get there or they come to you they can’t do enough for you.”*

Communication and information about treatment was also criticised, parents don’t feel well informed: *“I am not on a pathway for my child, maybe I am but I am unaware of the pathway I am on.”* One parent said of her child’s orthotics appointments, *“Whenever we have an appointment they never tell you what the feedback is and what is or will happen.”* Another parent raised the issue of access to courses: *“Some parents are going to the same classes endlessly. There is no clear pathway for getting on the proper courses or accessing support.”*

One particularly concerning experience, relating to communication, was that described by a parent in relation to treatment changes for her daughter: *“In 2013, I was told my daughter’s funding had been withdrawn. This was for treatment being received through The Maudsley. I could not find out who/how this decision was made, but assume it was made by my local CCG. I was not informed why it had been withdrawn, just that there was no longer funding.”*

The complaints of poor communication also extended to the clinical service received, for instance the lack of information impacted upon a child’s assessment: *“Autism was not on my son’s statement. I requested a test/assessment. It was two hours; it was awful. She*

*couldn't understand what he was saying and mistook words for other things. No one asked me about him, she had no information on him. She told me he did not have autism as he made eye contact. I asked if she knew he was visually sighted [impaired]! She had absolutely no information on him and had no idea."*

Parents felt they were not adequately consulted and that feedback was not routinely collected or acted upon. *"I have been told commissioned services in this borough are based on Better Start in Life and Autism Strategy. These strategies are totally meaningless to us as parents. We did have a bit of input, but there are huge gaps - nutrition, toileting, and more. We want to go through the strategies and see what is being done."* *"I make complaints about Wood Street, but there doesn't seem to be any learning taking place."* One parent said they were unsure how to engage with the service providers, despite wanting to: *"What are the feedback processes at Wood Street? We don't know who's who. Who has the portfolio for Wood Street? Who is the health commissioner contact we can talk to?"*

There was also discussion of good practice in communication. The Community Nursing Support team is considered *"approachable and easy to contact and just very caring"*. In addition, the reception and administrative staff at CAMHS at Thorpe Coombe were felt to be *"very efficient and friendly, they respond quickly to phone calls and e-mails"*.

### **The range of services**

There was a lot of discussion about the range of services available in Waltham Forest. The carers' children have a range of disabilities - and many children have multiple disabilities - so require a wide range of services and support, that is not all supplied locally.

Some services are only available locally for younger children. For example, Occupational Therapy (OT) stops at 11, because as one parent was told, *"there is no clinical value after that age."* Other boroughs served by NELFT do offer OT after this age. Some parents would like to see *"specialist provision for young people with severe learning disabilities who do not have the language or speech skills to access talking therapies."* One child with Tourette's Syndrome also hears voices and needs CBT, but is too young for the local adult service; she has to travel out of borough for her treatment. Her mother commended the local team and said she would prefer that her daughter was treated locally for all of her needs.

One parent was worried about the lack of local support for feeding issues for SEN children. Parents highlighted how they push for treatment at Great Ormond Street because there is no specialist feeding pathway available locally. They indicated a preference for the service to be provided in the borough.

Having a choice of treatments was also raised. One parent would like more therapy for their child, rather than medication: *"I feel the local CAMHS has not been able to support my child except through medication. There is no therapeutic input and no pathway for severe learning disabilities within CAMHS."* Involving parents was also discussed: *"I would like NELFT to work more closely with Children's Services, the Register of Disabled Children, and the Parents Forum to identify the potential level of need. Challenging behaviour is a particular area where I feel that the local CAMHS has not been able to support our family, other than through medication."*

For one mother, being able to accompany her child was important and considered vital by the child, but was not possible locally *“At Maudsley I accompany my daughter but locally the psychologist only works one-to-one therefore my daughter couldn’t get it on the local CAMHS. Maudsley can provide and understand her need to have someone with her, why can’t this be done locally?”*

Existing services, which parents value, have been lost and not replaced or are oversubscribed. In one instance this was due to retirement: *“There was a psychotherapist with a special interest and expertise in severe learning disability, but that role was not replaced when he retired.”* Concentrating on prevention rather than cure was also discussed. One child is regularly treated when in crisis, but her [mother] would prefer she have therapy to avoid the crisis at all. The waiting list for therapy is long. Suggestions were made for changing how services are delivered to improve the service and help parents as soon as they have a diagnosis: *“We would like informal behavioural drop-in sessions to get advice from an expert. We would like a telephone helpline. We want these things before we get referred and sit waiting on a waiting list”*. Targeted sessions were suggested as a way of providing regular, ongoing support: *“Why not run drop-ins for families for each of the different specialisms so that we can bring our children and get bite-sized advice to cope with specific issues - a 50 minute physiotherapy session once in a while is far less use to us than the ability to get 5 minutes worth of regular, targeted advice/exercises to get us over the next milestone. This would enable staff to get through far more children and see them more regularly.*

The suitability of facilities was also considered. When other services cannot provide what is necessary, children *“get sent to CAMHS as there isn’t a service that meets their needs.”* However some find the facilities uninviting and unsuitable for children. *“The physical building at the Child and Family Consultation Service is depressing and not fit for purpose. It is now mixed with the drug and alcohol units so it’s even less inviting. However we have no choice but to go there once a month to get meds and funding, which we cannot get via the GP.”*

## Systems

How patients access the service was discussed and the general feeling was that it is necessary to keep attending in order to ‘stay in the system’, despite a feeling that routine contact was not always the right thing at the right time for the child: *“I have an issue with an annual check up. Is it ticking the box? We are all going to the appointment simply to keep in the system. It does nothing”*. Regardless of whether attendees believed appointments would be valuable for their child, they felt compelled to attend: *“You get forced into taking an appointment. I am under the impression that it is marked down if you don’t make the appointment.”* Overall participants echoed the feeling that the annual appointment system is not as beneficial as it could be: *“My daughter gets seen at Wood Street once a year. Dr X at Wood Street is always cancelling appointments so her 12 month review often becomes 14 months and you’re still chasing and this is despite Great Ormond Street recommending she needs 3-6 monthly visits. I have to follow the process and take my daughter to Wood Street, but they have no input into my child’s care.”*

Similarly, some treatments are given a longer allowance than necessary and may waste resources that could be better deployed: *“[my child] was given 6 weeks of treatment at*

*Maudsley, but we only needed one and the issue [my child had] was rectified. The system needs to be more flexible.”*

### **Quality of services**

Wood Street was perceived as offering a variable quality of service: *“After only seeing my son twice during paediatric review at Wood Street, the doctor recommended he go to special school. Knowing him better I chose to send him to mainstream school, but a carefully chosen one. One year later the doctor apologised and said I made the right decision. At least he recognised his mistake and apologised.”* For another the training offered was poor: *“The quality of training courses for parents of children with special educational needs, both 6 and 12 weeks, are very low and basic. The sleep section for example is not sufficient.”*

However some staff and services were noted as excellent and effective. *“CAMHS are LOVELY. The reception is great. They go above and beyond. My daughter likes a particular room and they always book her in room 11 which is her favourite”.* There was recognition that with budget cuts staff are pressured: *“Staff do their best under very difficult circumstances. They are horribly underfunded and need about three times as many staff for each specialism as they currently have to cope with the needs of our children.”*

### **Waiting room environment**

Many parents raised the issue of the service environments. Some services are housed alongside drink and drug clinics, and even some children-specific services are not felt to be suitable. One issue raised by several people was the lack of appropriate toys and entertainment for older children while waiting for appointments: *“There is only sand and play materials for under 5s. My daughter is 10. You could easily have Wi-Fi then she can sit and watch You Tube clips. Wood St do not have the correct environment for older children to interact. This is totally different at The Maudsley where they have suitable activities and engagement for children of all ages.”*

### **Continuity**

Continuity of care - seeing the same staff regularly - at Wood Street was considered to be difficult to achieve. Often parents will have to wait to see their doctor of choice: *“I will wait for several months to see the same doctor rather than take the next available appointment with any doctor. I rang in January for an April appointment with Dr Attie”.* Staff turnover is also an issue: *“Occupational Therapists come and go at Wood Street. Continuity of care is an issue”.* In general discussion, attendees said they value continuity of care, particularly for children who do not handle change well. While some attendees do experience continuity of care at their GP practice, they would like it at all services they use.

Many parents mentioned the lack of a joined up service across all the health and social care facilities they use, which would improve continuity: *“We could be a lot smarter about how services work together for my child.”* At least one parent would like to see one service or body championing their child’s care to ensure that they get what they need from all the services: *“No one ‘owns’ my child; the communication is missing between services.”*

## Transition

One issue of concern to parents of older children is the transition from child to adult services. Children with learning disabilities can find change hard to manage and parents also worry about the possible falling away of support at this time.

There was perceived to be a lack of information, parents currently talk amongst themselves but want factual, practical guidance about the transition: *“Next year my daughter [with mental and learning disabilities] will be going into adult services. My friend says there is a waiting list for adult services and she is unable to get medication for her child. We need to be made aware of how transition works and how early to sign up/get things going. The system doesn’t allow them to go on the list before they reach the age of 18yr old, but I can’t have a situation where there is no medicine for her. Who should instigate the process?”* The feeling is that *“services start to fall off as children get older”*. One cited issues with prescriptions for her child: *“When you move to adult services prescribing works two ways between GPs and CAMHS but some GPs are not happy to do the prescribing. I want to get things going and be prepared now.”*

Parents would like to see a service between child and adult services: *“There needs to be a young adult service so children don’t go straight transition into adults.”* They would also like this to include a young adult respite service so older children don’t have to go to adult respite care immediately on turning 18, but can have respite care in a better suited environment.

Transition also occurs for younger children as they become old enough for school: *“Feels a bit as though once you get to 5 plus and kids are in the school system, [support] stops, which is a shame as that is when the real problems can start for kids with special needs”*. It was felt that there needs to be a smoother progression for children of all ages so their care is not compromised and they get the support they need in an appropriate setting.

## Dentistry

Dental services were not discussed in detail at the focus groups but several parent carers mentioned the excellent service their children receive at Comely Bank: *“The [Comely Bank] Community Dentist should be given an award. He is AMAZING and really knows what needs to be done working with my child”*. Examples were given of how the dentist works well with the SEN children, and parents would like his good practice to be shared more widely.

## Lessons learned elsewhere

It is clear that the parents and carers we spoke to have a lot of knowledge and experience which they are keen to share with other parents and carers and with service staff and planners. They have a good understanding of how their child will react in various settings and circumstances and understand what the best environment or system looks like. They want to ensure their child gets the best, most effective support; however, most don't feel that they are currently asked or encouraged to give their feedback.

The recent Contact a Family publication [Sharing good practice: parent participation in health settings \(March 2014\)](http://www.cafamily.org.uk/media/769001/parent_carer_participation_sharing_good_practice_in_health_settings.pdf)<sup>2</sup> includes examples of successful collaboration and cooperation between parent carers and service providers, which have all resulted in improved services for SEN children and young people. In each example, it was good and effective communication that helped to bring the improvements.

In some examples, such as GP services in Rutland, it was the simple process of bringing parents and staff together to talk that led to changes in how SEN and disabled children are managed in the surgeries. Staff went on disability awareness courses, the reception protocol was adapted to suit children unable to wait in the waiting area and the parents were encouraged to join the PPGs. Listening to the parents helped the staff to understand the need for change and the type of change necessary.

In another example, parents in Redbridge became involved in a working group of the local authority Overview and Scrutiny Committee looking at services for disabled children. The group looked at neighbouring boroughs to see what good services look like and then wrote a report with recommendations and an action plan for Redbridge. This resulted in a redesigned service, with several teams under one roof and a new code of practice, amongst other things. Having found a way in to talk to the people who make the decisions - in this case the Director of Children's Services - the parents were able to feed in their knowledge and expertise, and bring about real change locally.

The success of each of the nine examples within the report rests on parents being able to get involved and share their own expertise, knowledge and experience. Without this, it is unlikely that services will be able to meet the needs or expectations of the service users and their families. Talking to the Waltham Forest Parent Group members it is evident that they don't feel involved or consulted about the services, and while they are committed to getting what is required and desirable for their children, they currently find it an uphill struggle.

---

<sup>2</sup>[http://www.cafamily.org.uk/media/769001/parent\\_carer\\_participation\\_sharing\\_good\\_practice\\_in\\_health\\_settings.pdf](http://www.cafamily.org.uk/media/769001/parent_carer_participation_sharing_good_practice_in_health_settings.pdf)

## The Children and Families Act 2014

In September 2014 legislation within the Children and Families Act<sup>3</sup> comes in to effect; three items of particular relevance to SEN children and young people are summarised below:

**Education, Health and Care Plans** will replace Statements of Special Educational Needs and Learning Disability Assessments (LDAs). From September 2014, no new statements or LDAs will be available. In stages, over the next few years, children with an existing statement will have their statement transferred to an Education, Health and Care Plan. There will be agreed procedures for the changeover and parent carers and young people will have a say in these. Existing rights, for example rights of appeal, will continue during the transfer.

**Local Offer** every local authority will be required to have a “local offer” which informs parent carers and young people with SEN or disabilities what is provided in their local area, including what to expect from local early years providers, schools, colleges, health and social care. In addition it will include information on how decisions are made about how services are allocated, how to request a personal budget, how to access more specialist support and how to complain or appeal. Local authorities must involve parent carers, children and young people in developing their local offer<sup>4</sup>.

**Information and advice:** Local authorities already have to make information and advice available to parent carers about SEN, through parent partnership services. From September, local authorities must make information and advice available that also covers disability, health and social care and is also available directly to young people as well as parent carers - building on the services (like parent partnership services) they already have in place.

There is a clear statutory duty, under the Act, to involve parent carers and children and young people in the development of services. Currently Waltham Forest council uses the Parent Partnership, based in Chingford to support parent carers in the borough. The Parent Partnership provides independent advice and information freely to those who request it and encourages feedback of parent views to ensure they inform service development. The Waltham Forest Parent Group also offer a similar service, freely providing advice and support gained from practical experience of parenting a disabled or SEN child.

---

<sup>3</sup> <http://www.legislation.gov.uk/ukpga/2014/6/part/3/enacted>

<sup>4</sup> Council for Disabled Children, *The SEND reforms: what parent carers need to know and what they need to do*, 2014

## Summary and recommendations

A common theme in the discussion was a feeling that the parent and child were caught in a system and were being ‘done to’ rather than playing an active part. Parents want to be partners to the process but generally feel side-lined or ignored. Under the Children and Families Act education, health and social care providers will have a statutory duty to involve those who want to be involved. There needs to be more organised, formal engagement between parent carers, their children and young people, and the service providers and commissioners to ensure the patient voice is heard and included.

Communication was also raised at all three sessions and about all services discussed. A few services were praised for their good communication but these stood out as exceptions rather than the norm. Improvements must be made in how services communicate and engage with parent carers and their children, and with each other, in order to offer a joined up effective service. Under the Children and Families Act 2014 local authorities will need to jointly plan and commission services with the health providers to ensure children, young people and their families have what they need.

Availability and adaption of services to better meet the needs of children and young people with disabilities and SEN was clear at all of the focus groups. Parents would like reception staff to be informed and able to anticipate the needs of their children in the waiting room environment, and to have processes in place to support them. This could be as simple as allowing them to wait outside and texting them when the GP is ready for them. How services are delivered was also raised: some parents would like to see drop in sessions or telephone advice lines rather than relying on scheduled appointments. This should be an ongoing dialogue between service users and the service providers.

In a patient-centred health and social care environment the services should be adaptable to the changing needs and expectations of the service user and their family. Healthwatch Waltham Forest would encourage service providers, the Health and Wellbeing Board and the Clinical Commissioning Group to engage more frequently and routinely with the parent carers of disabled and SEN children and young people to ensure they are getting the right services in a suitable format.

Theme	Lead	Recommendation
Engagement	LA CCG Barts Health NELFT	The WF Parent Forum should have a seat on relevant Boards and groups to ensure that its members’ views and experiences are routinely taken in to account as appropriate and their expertise is used to the best advantage.
	LA Barts Health NELFT	Parent carers should have regular input into the ongoing training and education of staff delivering services to SEN and disabled children and young people.
	LA CCG Barts Health NELFT	Any changes to SEN and disabled services for children and young people should include meaningful engagement with the service users and their parent carers as early in the change process as practical.
	LA	A regular review of the implementation of the Children and Families Act in LBWF with regard to SEN and disabled children should include representation and input from the Waltham Forest Parent Forum and the wider community.

<b>Communication</b>	NELFT/LA	Each child or young person should have a named single point of contact to oversee their use of services and champion their cause if the need arises.
	LA CCG	Services should coordinate access to medical records to allow easy access, as required, from any site or service used by the child or young person.
	NELFT/LA	All correspondence with service users should include clear and current contact details for the service.
	Barts Health NELFT LA	Services should endeavour to coordinate appointments to accommodate the service users needs. E.g. same day appointments for multiple services at one site, unless the child prefers otherwise.
	GP providers Barts Health NELFT LA	Services should keep accurate and current notes of the requirements and abilities of SEN and disabled children and young people to ensure they offer a tailored service for appointments, waiting environment etc. They should know who is coming in to the service and how best to support them on the day.
	CCG LA	Good practice should be routinely identified and shared amongst all service staff to improve services for all.
	NELFT	Robust and efficient administration of services should be standard and protocols in place to ensure timely and effective communication with service users.
<b>Service availability and adaption</b>	CCG NELFT	Parents and their children should have ready access to accurate and current information and support concerning the transition to adult services and consideration should be given to a young adult specific service.
	CCG	The Occupational Therapy treatment offer for children aged 11 and older in Waltham Forest should be reviewed urgently.
	CCG	The CBT offer for children should be reviewed.
	CCG	The feeding pathway should be reviewed
	LA CCG Barts Health NELFT	Services should adapt their approach to focus upon providing ongoing support rather than crisis management, this will improve the long term health and wellbeing of service users
	CCG	Services should offer therapeutic as well as medical choices to service users and support them to make the best decisions for their care.
	NELFT	Services should review how they offer their services regularly, in consultation with the service users and their families. For example, some parents would prefer drop in sessions or a telephone advice line, offering targeted support when needed, rather than scheduled appointments.
	GP providers CCG	Appointment booking and waiting systems at GP surgeries should be adapted to give priority to SEN and disabled children to minimise anxiety to them.

## Glossary

**A&E** - Accident and Emergency department

**CAMHS** - Children and Adolescent Mental Health Services

**CBT** - Cognitive Behavioural Therapy

**CCG** - Clinical Commissioning Group

**ECG** - Electrocardiogram

**ENT** - Ear Nose and Throat

**Great Ormond Street** - Great Ormond Street Hospital

**LA** - Local Authority

**LBWF** - London Borough of Waltham Forest

**Maudsley** - The Maudsley Hospital

**NELFT** - North East London Foundation Trust

**North Middlesex** - North Middlesex University Hospital

**OT** - Occupational Therapy

**SEN** - Special Educational Needs

**Springfield** - Springfield University Hospital

**Wood Street** - Wood Street Health Clinic

## References

Children and Families Act 2014 legislation

<http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

Council for Disabled Children - <http://www.councilfordisabledchildren.org.uk/>

Every Disabled Child Matters - <http://www.edcm.org.uk/>

Waltham Forest Parent Forum - <http://www.walthamforestparentforum.com/>

## Appendix 1

### Disabled Children's Charter for Health and Wellbeing Boards

Every Disabled Child Matters have drawn up a Disabled Children's Charter and are campaigning for every Health and Wellbeing Board to sign up to it. The London Borough of Waltham Forest's Health and Wellbeing Board has not signed up to the Charter as yet (June 2014)

The commitments in the charter are:

**1. We have detailed and accurate information on the disabled children and young people living in our area, and provide public information on how we plan to meet their needs**

One of the primary tools Health and Wellbeing Boards have to drive strategic commissioning in their area is the Joint Strategic Needs Assessment (JSNA). The JSNA can only be an effective tool for evidence-based decision making if it is based on accurate and meaningful data. However, data on disabled children is notoriously poor and improving the quality and scope of information on disabled children and young people should be a priority.

**2. We engage directly with disabled children and young people and their participation is embedded in the work of our Health and Wellbeing Board.**

Health and Wellbeing Boards should ensure that the voice of disabled children and young people is always heard when decisions are being made that affect them. The benefits of embedding participation of disabled children and young people are huge and well evidenced. All disabled children and young people communicate and have a right to have their views heard.

**3. We engage directly with parent carers of disabled children and young people and their participation is embedded in the work of our Health and Wellbeing Board**

The purpose of parent participation is to ensure that parents can influence service planning and decision making so that services meet the needs of families with disabled children. The benefits of effective parent participation are well established and Health and Wellbeing Boards should ensure that parent carers are involved in decisions that affect them at a strategic and service level.

**4. We set clear strategic outcomes for our partners to meet in relation to disabled children, young people and their families, monitor progress towards achieving them and hold each other to account**

The Joint Health and Wellbeing Strategy (JHWS) should address how the needs of disabled children, young people and their families should be met and make recommendations on cost-effective approaches to reducing the health inequalities they experience. However, if this group is not identified as a priority in the JHWS, the Health and Wellbeing Board should demonstrate how it is providing strategic direction for partners to meet the needs of disabled children and young people.

**5. We promote early intervention and support for smooth transitions between children and adult services for disabled children and young people**

The importance of early intervention and transitions to life-long outcomes has been repeatedly emphasized. This is particularly significant for disabled children, young people and their families, who often struggle to obtain a diagnosis and access appropriate support at an early age and when transitioning to adult services.

**6. We work with key partners to strengthen integration between health, social care and education services, and with services provided by wider partners**

Disabled children and young people frequently access services across multiple agencies and the failure to effectively coordinate services around them often leads to considerable distress and poor health outcomes. Health and Wellbeing Boards must work with partners, including education providers, to meet the needs of disabled children and young people and ensure seamless integration between the services they access.

**7. We provide cohesive governance and leadership across the disabled children and young people's agenda by linking effectively with key partners**

The role of the Health and Wellbeing Board must be understood in relation to new and existing partnerships, including: local children's trust arrangements, local safeguarding children's boards, learning disability partnership boards, and others. A clear local framework on how these partnerships interact needs to be established to avoid the duplication of effort or even competing for resources.

Health and Wellbeing Boards must also prepare for the new responsibilities being introduced by the Children and Families Bill.

Link to further information:

<http://www.edcm.org.uk/campaigns-and-policy/health/disabled-childrens-charter-for-health-and-wellbeing-boards/disabled-childrens-charter-for-health-and-wellbeing-boards>