

Local Offer Parent Questionnaire

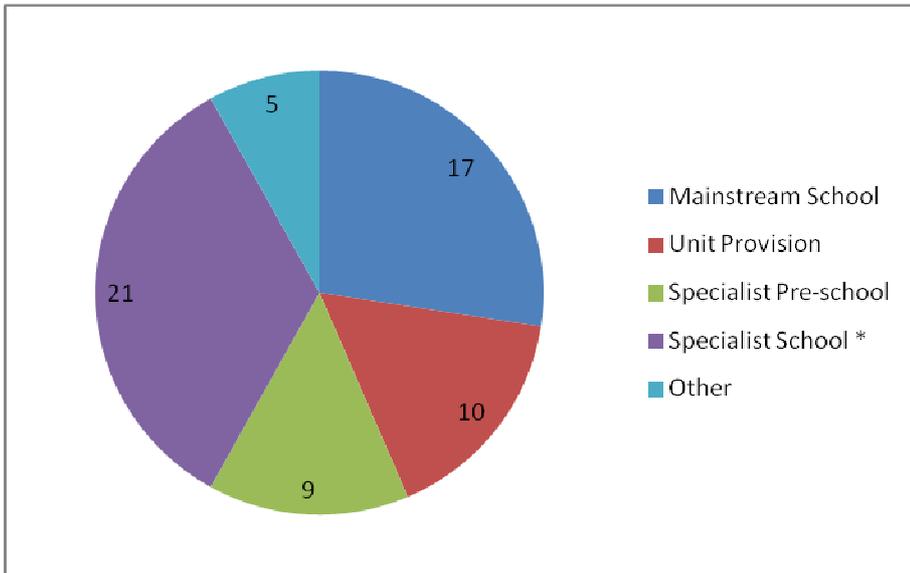
(Results and Report)

Bromley Parent Voice conducted a questionnaire to help inform the Local Offer workstream of the government pathfinder. This report has been assembled from a survey of Bromley parents with children that have Special Educational Needs or Disability. The survey was aimed at children between the ages of 0 and 25, but the responses obtained covered the age range 2 to 17 years.

There were 61 completed questionnaires representing 62 children (46 male & 16 female). The range of disability/SEN included Downs, Cerebral Palsy and Visual impairment. Twenty five of the children (40%) are on the autistic spectrum (some with multiple conditions) with a further 12 suffering global delay.

Ten of the children (16%) do not have a diagnosis. Thirty six (58%) have a statement with two more in the process of obtaining a statement. A further 9 children have either School action or School action plus. The date of diagnosis ranged from birth to age fourteen. Forty one (66%) were diagnosed (or partially diagnosed) by the age of five, this represents the majority of those diagnosed/part diagnosed.

This is the distribution of children amongst various school types:



Other includes 1 home tutored and 4 that are too young for school provision.

* 4 children attend specialist schools outside of the borough.

The following sections contain analysis of the questionnaires completed under the following headings:

1. **Services used by the respondents**
2. **Services that worked well**
3. **Services that could be improved**
4. **Information booklets / resource guides**
5. **Bromley.gov web-site**
6. **Eligibility criteria & decision making**
7. **Time-frames**
8. **Voluntary sector support**
9. **Key worker**
10. **Decision involvement**
11. **Competence of support provided**
12. **Satisfaction scores**
13. **Comments not already covered**

Throughout this report supporting comments from parents are shown in *italics*.

1. Services used by respondents

Parents were asked what services were used by their families.

The numbers show the children who used each service, with percentages rounded.

Pre School Specialist Support Services

<i>Service</i>	<i>Number of children</i>	<i>Percentage</i>
Portage	30	48
Phoenix Pre School	22	36
SIPs	5	8
Petts Wood Pre-school	1	2
Nurse trainer in preschool	1	2
Early Support	3	5
Audiology	2	3
Vision team	2	3
SPEACS	1	2

Therapies

<i>Service</i>	<i>Number of children</i>	<i>Percentage</i>
Hydrotherapy	10	16
Physiotherapy	24	39
Occupational Therapy	17	27
Speech & Language	30	48
Sensory support	7	11
Griffins centre	3	5
Social skills group in school	1	2
Play Therapy	1	2

CAMHS	13	21
Bromley Parent Voice	18	29
Childcare (Universal or Specialist)	6	10
Direct payments	11	18
Short Breaks	9	15
Mencap child minding	12	19
Outreach	2	3
Saturday club and/or holiday scheme (Riverside School)	10	16
Family based overnight short breaks	3	5
Hollybank overnight short breaks	4	7
SEN Transport	26	42

We asked parents to identify any other services used that were not already listed.

Kids crew
Messy Magic
CASPA and CASPA Tots
Phoenix youth club
Wheelchair services
Family fund
Mencap buddying
Key worker
Next steps
Vision support and Griffins vision team
Multiple NHS services
Challenge play scheme in Surrey
Specialist support in mainstream school
Early Learning
POPs group
Holiday scheme at Phoenix centre
Family link Saturday club

2. Services that worked well.

We asked parents to give examples of services that worked well for them and their child.

Portage.

Eighteen parents (29%) identified Portage as an excellent service with comments such as:

Portage was fantastic and welcomed at the first stages of dealing with a disabled infant. Great team.

Portage service gave me lots of ideas and resources to encourage desired outcomes e.g. turn taking that I wouldn't have considered.

Portage was reassuring at the start as stops you feeling so alone at the beginning of the process.

Portage, excellent service that has helped my child become more confident in all areas.

Portage is great, they come to the home and try to coordinate other services.

Portage was an absolute God send provided valuable support & information & guidance.

Portage gave fantastic constant support

Think Portage was our key worker!

Support from our Portage home visitor has been invaluable, don't know what we would have done without it!

Portage & SPEACS know so much and provide support constantly. Makes me worry about once my son is at school.

Outreach.

One parent identified Outreach as being an excellent service whilst another commented:

"Outreach services needs to be better co-ordinated."

Phoenix pre-school

Ten parents (16%) identified the Phoenix pre-school as an excellent service.

Comments from parents include:

The Phoenix centre preschool was fantastic.

Phoenix pre school fab.

Phoenix preschool was amazing and I saw a real general improvement in their learning

Phoenix preschool. Excellent service provision generally felt we were given everything we asked for.

Phoenix pre school where child is settling in extremely well.

Phoenix preschool fabulous with wonderful staff and caring safe learning environment.

Phoenix preschool has been good with helping child develop a little more.

*The Phoenix pre school does **not** need improvement. We need to make sure the Phoenix centre is made available to all children who need it please.*

Very happy with the Phoenix preschool services provided.

The phoenix centre have been a very great support to us. The teacher and head were very helpful and felt could call at any time.

Following on from this are the comments about the Phoenix centre.

I believe early referral to Phoenix centre was vital for all the services we were then able to access.

Support from Phoenix centre was fantastic.

Early learning POPs groups and all other groups/services offered at the Phoenix worked well for us.

Transport

Four parents identified transport as working well for their child. Comments below:

SEN transport is such an important service for us & our son.

After a very rocky first year, transport in the second year (different company) this service is excellent.

SEN transport is vital and I would not want to be without it for my child.

Vision team

Four parents indicated they had found the vision team services worked well for them. Comments below:

Vision team support has been amazing. Any question I have is always answered and my daughter loved the sensory room. The vision has had a massive impact on my family & I am so grateful for all their help.

The support in helping us to understand how our child will develop & advice. Any question or difficulty we have ever had we have always been able to ask the vision team. I don't know what we would have done without them.

Advice, support and (in early days) access to therapies to increase his use of his vision have been exceptional. I don't know how we would have coped without the vision support team and I don't think his child minder or preschool would be able to have him without their support either. Without their support I don't think he would be in mainstream.

Griffin Centre

Three parents indicated they had found the Griffin Centre worked well for them. Comments below:

Griffins (visual support) were excellent.

Sessions run at Griffins for parents helped me to understand my daughter's difficulties and therefore be more understanding.

Sensory support sessions at the Griffins worked well for us.

CAMHS

Two parents indicated they had found the CAMHS worked well for them. Comments below:

CAMHS is vital and I would not want to be without this service for my child

CAMHS were the key to diagnosis

Therapies and school assistance various

This is a list of therapies and school assistance that at least one parent indicated worked well for their family.

<i>Service</i>	<i>Number</i>	<i>Comment</i>
Play therapist		
Hydrotherapy	2	<i>Excellent service which helps support my child's needs</i>
Sensory Sessions		
Physiotherapy	4	
Speech & Language	2	
Occupational Therapy		
Sensory room sessions		<i>When child was a baby</i>
School based social skills coaching		

Comments include:

Very happy with therapies within the school setting.

All have worked well so our son has progressed in all areas. The different therapies have all worked well together, even outside the early support/next steps set up.

The hearing team visited at school. They were able to reassure & give advice to the school including which equipment was best for child. The hearing team made a huge difference to not only my daughter's life at school but also her life outside school.

Child has received extra help since year two with reading writing & mathematics. The extra help has been great. Teacher is wonderful, reading has come on amazingly and handwriting improved.

Regular preschool visits to check on child and advise/counsel parents, Invaluable. Regular school visits to check on child and advise teachers, regular contact with parents throughout. These services are fast, efficient and friendly. I have approached the team for help with exams, courses, bullying, school trips, road safety etc and always had the best possible response

Specialist support teachers/workers have been very helpful at school.

Balgowen Primary have been fantastic.

Riverside

Six parents indicated they had found Riverside worked well for them. Comments below:

Riverside holiday club very flexible (20 days/year) great staff.

Saturday club/holiday club at Riverside worked well for us.

Saturday club at Riverside school worked well for us.

Riverside play scheme worked well for us.

Other services

Parents identified a variety of other services that worked well for their families. With each of the following, at least one parent identified the service as working well for them.

<i>Service</i>	<i>Number</i>	<i>Comment</i>
Children's disability team		
Bromley Parent Partnership		
Hollybank respite service	3	
Direct payments	3	
Short breaks		<i>This service is difficult to access</i>
Kids Crew (Lynne Fletcher)		
Summer play schemes		
Vision support		West Kent Eye clinic
Early support	3	<i>Early support process is very good and well run.</i>
Support in pre-school (SIPs)	3	<i>SIPs support in mainstream nursery worked well. The SIPs service was vital to their successful integration into mainstream nursery.</i>
Holiday scheme		<i>In the past, when he qualified for it, he loved it! It was an excellent service with many benefits for him.</i>
Caspa Tots		
Chucklebox holiday club		
Audiology		
Speacs		<i>This service is amazing, life changing for child & me</i>
Saturday club		<i>This service is vital and I would not want to be without it for my child</i>
Sensory room		
School based social skills coaching		
Mencap	10	

General comment

All services I have had access to have tried their best to help my sons development.

3. Services that could be improved

We asked parents to comment on where improvements could be made with any of these services.

Short Breaks/Direct payments

Direct payments are far too complicated. Could scare people off but process made easier by 3rd party.

Our child was diagnosed with chronic infant insomnia so we are really pleased to have overnight child minder but too much legality.

Perhaps use some of direct payment for other uses – swim lessons- tuition- membership to parks.

The length of time these things take! I started applying for direct payments in April and it is only now just going through

We have no external support whatsoever & rely on hollybank but only get 3 nights per month which isn't sufficient. The lack of support is putting great pressure on our family relationships

Direct payments – found getting a suitable worker quite difficult & too much paperwork.

Short breaks – no liaison to ensure that any short break has been accessed. Our child qualified for short break provision and took over a year to get respite care via Bromley Mencap. There was no liaison or follow up. Direct payments are complicated and not all families are able to use this system.

Short Breaks are hard to access especially when you're already struggling to cope.

The provision of Riverside & Hollybank not enough. Riverside – There should be an opportunity to attend if there are cancellations by other children for a small fee. EG son was offered a space on a Weds for the Sat. He couldn't make it so I'm guessing it wasn't filled and space wasted. We'd be happy to pay a contribution for Son to attend such occasions.

Transport

The transport dept in the council is unsatisfactory. Last minute notice of timings and transport details. The head of this dept is rude and very bad at customer service especially when one needs to go through the whole process for the first time. Her colleagues however, are very good and help you out when needed or try to answer your questions.

SEN transport too late in organizing/do not take into consideration who they are transporting.

Wheelchair services

Wheelchair services – no one thought to refer us and they are working on an 8 to 12 week lead! Now we know we need them, we are having to wait.

Wheelchair services are not equipped to deal with small children, wait times are too long.

CAMHS

CAHMS needs to be more long term for certain children.

CAHMS shouldn't have to be such a fight to access. I had to do a lot of work to get this.

Key Working

Provide support with key worker from birth to school/transition to school.

key worker post age 5

Therapies various

Multi agency meetings & supported 'Next Step' progress with all therapies working together, thus eliminating duplication and over appointments.

Occupational therapy needs to be longer. Children shouldn't be discharged on basis of age.

Ot was changing from social services to Phoenix so took a long time, hopefully now resolved.

I think problem with speech & language and Physio is we never seem to see them enough (guessing due to budgets). Seems more a tick the box you have been than any real continuous support.

We found the speech therapist at Beckenham Beacon very unsatisfactory. She didn't try to talk to my son at all and only communicated with me, except on tasks. Very lacking in warmth, so important for young children in such situations.

SALT at Bromley North Clinic, irregular appointments and different therapist each time

More speech & language input

Waiting list to be reduced to access speech[sic].

There was never enough speech & language therapy, Never enough physio, Never enough O/T. No one offering these services would put anything in writing for me or my husband to adopt as a program of support for our child

Hydrotherapy – would like time for me to take my child as well as have sessions. There is a hydro pool at Orpington which is never used –what a waste of a facility!

OT, Physio, s&l need to have regular sessions of actual therapy ½ a month rather than every term for a catch up. They need to run group sessions (e.g. like Tumbletots) or talking tots) where parents can take a child once a week and have access to facilities as well as the professional who can see what the next steps care for that child. Children change so quickly and often targets become outdated quickly and this is one way parents & professionals make their time the most efficient.

Information.

I wish someone in one of the services had encouraged me to apply for DLA. I'd assumed we wouldn't be entitled as I didn't consider them 'disabled' so we missed out on it for a year. I could have taken a break from work and devoted more time to their learning & development.

My sons needs are not complex enough for him to access any LBB services (other than Phoenix youth club). He is what can be termed as 'able disabled' which is very much a disadvantage for him!

Once your child's special need has been identified having someone to explain how things in Bromley work. Feels very adhoc how you find things out.

I'd like more info on the services available in our area as I have two autistic girls (10 & 13)

I've heard of Parent Voice and signed up online but never heard from it.

Consideration for working parents should be made. As a sole provider and carer there is not much/enough help. I didn't know that some of the listed options existed. Perhaps some sort of selection process is made that dictates what is offered?

More information.

I asked to be referred to the Phoenix centre, who dismissed without even seeing child. Teachers at school have big concerns yet the school (now academy) part time inclusion teacher has filled up her hourly entitlement to assessment for the next year and won't do anything. My child is suffering socially, physically, academically & emotionally.

General comments

Social group for children with social communication difficulties to help with confidence and to make more friendships.

Next Steps needs to be broken down into physical (OT & Physio) other (s&l/Portage/school) to set targets. Often too many adults on one child felt not good use of time on both sides. They need to be up to date with new research within their area.

Joining up! Trying to navigate council & NHS is very hard. We need services to talk to each other, have information and work across boundaries.

More consultation earlier

Focused support/services for teenagers 14-18

DA register [sic]

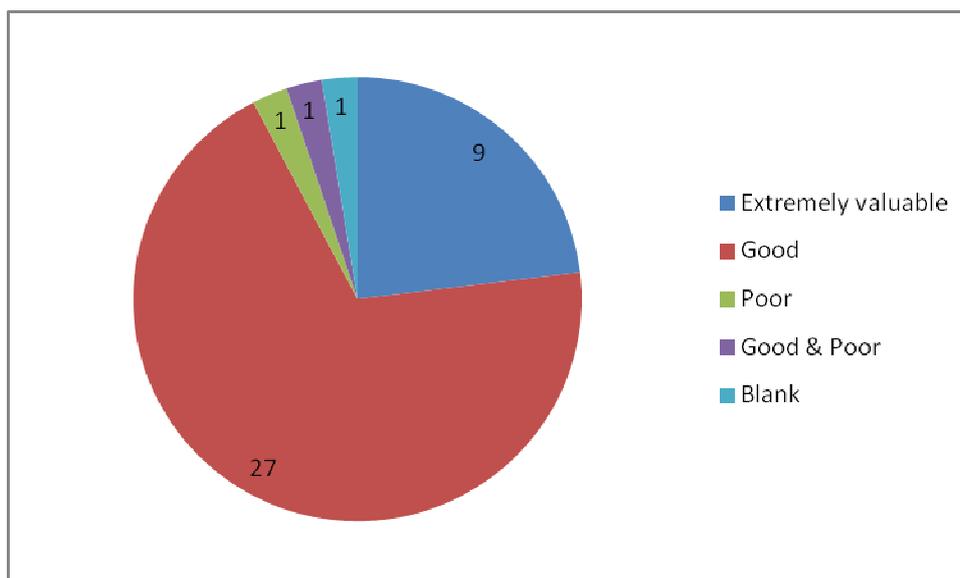
Improve waiting times for appointments

Services have been great but feel government should change intake policy.

Coordination of services.

4. Information booklets / resource guides

We asked if parents were aware of the information booklet/ resource guides that the Local Authority publish. Thirty nine said they were aware of publications (63%). Below is a chart showing how the thirty nine rated these booklets.



We then asked parents to score the publication on a scale of 1 to 10 (1 being poor). Forty three parents (69%) gave a score. Scores ranged across 1 to 10 with the average score being 6.

When asked how useful parents found these publications, we received the following comments:

Although this booklet is great there are still services one is not aware of and we find out through friends who've gone through same experience before us or via Parent Voice (i.e. nappies, volunteer help, Mencap, Maypole etc).

Overall good service. Felt very supported from start and humbled by support/help given to us as a family and our child.

Good though I do worry maybe information overload for parents at time.

Info is not really volunteered.

Not sure how we really got into services, probably via hospital so got all we needed but not via general publications, rather referrals.

We only hear from the vision team.

The information received about things I knew however, I'm sure there are a lot of things I'm unaware of.

Only aware once I got a key worker 6 months ago.

Think it's extremely good all services are under one roof.

Only recently aware.

Problem with booklets/guides is that there is little time to read/digest or work out what services are available or appropriate for your child/family.

They say what they do but don't tell you how to get in touch with someone to help.

5. Bromley.gov web-site

We asked if parents used the Bromley.gov local authority website. Twenty six use the website (42%), Twenty said website is good (77% of respondents), Two said website is extremely valuable (8% of respondents) and Six said the website is Poor (23% of respondents). The two that said the website is poor do not use website, one of which states they do not have internet connection.

Parent comments:

Not that easy to navigate

Not on internet

6. Eligibility criteria & decision making

We asked if parents felt that eligibility criteria and decision making processes are transparent and that services are readily accessible. Forty said no (65%), Three did not comment (5%), Seventeen said yes (27%) and a further two said yes & no (3%).

Parent comments:

Short Breaks/Direct Payments

It was not made clear to me that my child might be eligible for the Short Breaks service or direct payments.

Not everyone knows about the eligibility criteria list. I don't feel some are qualified to know the ins/outs of your child's disability. Or they do a review and leave the service shortly after and you speak with people who don't know your child (high staff turnover) therefore, if you try to change certain criteria it proves hard as it feels like you are begging, but simply want a true picture of what your child is like on the criteria list – which is painful.

Short breaks daughter received a score and was well broken down/transparent how score achieved.

Direct payments stopped without review. Feel that budget dictates, and influences what your child needs.

The eligibility criteria are a mystery and geared far too much towards certain problem issues as opposed to others. despite our son's severe problems we are told we only just qualify for 3 nights respite.

Tried to understand eligibility for short breaks from LBB website and gave up!

Had to fill a CAF form out to access Buddy project.

It's probably unfair to tick no. It is transparent & accessible but such a fight to get an appropriate level. I don't think we received enough, particularly as there are so few other clubs, activities my son can do (he can't do anything independently)

Information is available but eligibility is inconsistent and can be illogical

For Short Breaks I totaled up my family criteria and we were over 20 points yet was only given 50 hours a year.

Diagnosis

We had to struggle to get our child properly diagnosed if it wasn't for our tenacity he would have been left to drift without the necessary support.

It has taken so far almost 2 years to diagnose my child. We still do not have a diagnosis yet and it is like being in limbo.

Felt bewildered by the diagnosis process at Phoenix

It seems there was a lot more help offered to us and my son once he received his ASD diagnosis from CAHMS but this was later in his life. Until then we relied on help and referrals from the SENCO at his primary mainstream school.

General services & Information

I have been told before that there are more needier children than my child and so I cannot have that service. I thought EVERY CHILD MATTERS so we should all have access to services no matter how severe disability.

Services always require a referral of some sort and this can often be time consuming.

Too much mediation, always a battle to get what you need/want.

Services it seems to be random who gets offered (though has got much better over time)

You seem to have to fight to get anywhere.

It's not made easy to recognize.

It's not transparent as I have no way of knowing if its available for my child.

Services not readily volunteered.

Nobody really comes to you and says "do you know you're eligible for.....?"

It is very difficult to find out about services and also very time consuming.

I don't believe that any LBB service (whether you are eligible or not!) is readily accessible! Most information/services are only accessed if you know another parent who has experience in the matter!

Just do not know what is out there.

Have only learnt of some of the services on offer from this questionnaire

Would be hard to navigate without guidance but guidance was readily given to us when contact made.

To be eligible for Early Support felt like climbing a mountain (albeit with a very good guide).

Do not believe eligibility & decision process is transparent. This is largely due to government changes in how support in schools is accessed which are unclear.

Might be because my son is 2 but I don't know what decisions are being taken, by whom or how I can play a part.

Services offered were discovered by chance after consultant referred to speech therapy for a different reason.

There is no clear list of support mechanisms or A to Z process. Too often we are left with being informed by the parents with other children.

Vague & inconsistent

For us the situation was clear as our son is so disabled up until the age of 5 our access to services was clear. Now that he is 8 I am struggling to find services.

Very hard to find about services, end up having other parents to guide me

Too much red tape and no clarity at preschool stage

Decision making processes are based on money being spent!

Cost dependent!

Parents should be more involved in decision making. It seems parents have to fight very hard for additional help when children need it.

At present our child's needs are mercifully few in comparison to others and has access to all the services currently needed. Our concern is will this continue when child reaches school age & beyond.

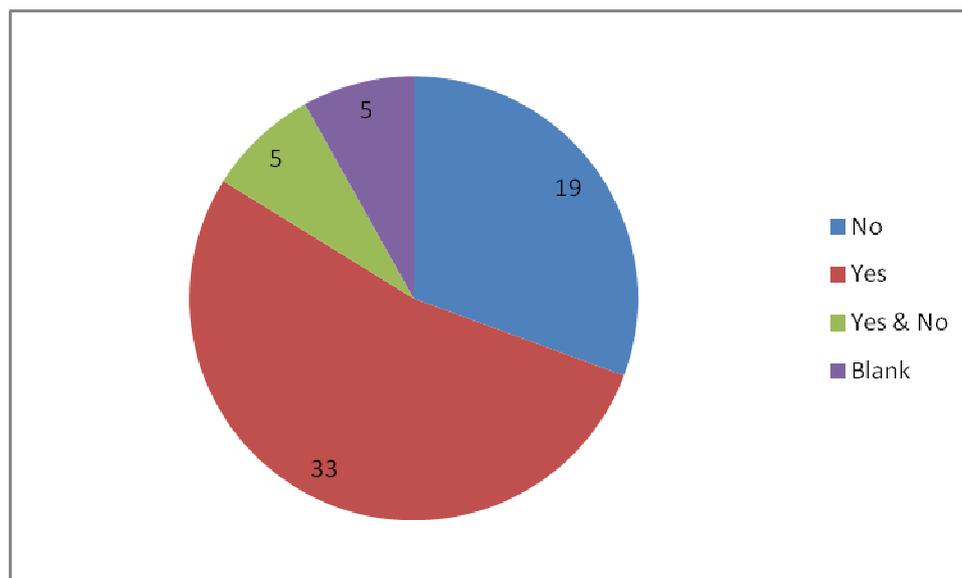
I've always questioned the need for them to be in a unit rather than a mainstream class with ISA, particularly as they affect each others learning in such a small class. I felt a little pressured into it.

Just a year after having a Buddy, funding now scrapped.

Have been lucky with help I have had but I think more information to services, what you entitled to and someone to talk with experience would be beneficial.

7. Timeframes.

Parents were then asked if they felt services are provided within an acceptable time frame. The chart below displays the responses to this question.



Of the nineteen parents that stated services are not delivered in an acceptable timeframe, most of the observations were that processes generally took too long with lengthy waiting lists. See Comments:

*Any services we have had always take a long time to be applied (sometimes too late by then)
It took more than a year to access and a fight to get anyone's attention.
The gap between appointments is too long
Initially services are refused, then we need to go to panel, maybe more than once.*

Some parents highlighted specific services. See comments below, numbers in bracket indicate how many made similar comment upon a particular service.

Wheel chair and equipment services (3)

Wheel chair services clearly are struggling to provide equipment and in early days we waited too long and child had grown out of equipment ordered. Waste of money!

Short Breaks/Direct Payments (2)

*I enquired about Short breaks in June/July 2012 and still waiting to find out eligibility (Nov 2012)
Started applying for direct payments in April- still going through (Nov 2012)*

Occupational Therapy (1)

Diagnosis (1)

Still waiting diagnosis after over one & half years! Hopefully it will come soon as we are now at Phoenix prep school

Statement (1)

It took us a year to obtain child's statement. Not entirely happy with hours of support per week (12hrs)

School related comments (3)

*All parents had placement for school before child, very stressful, it ended well never less difficult.
It took a long time and had the school in the end explaining time frame.
The primary school was very slow. SEN officer not very good at all. Now at Glebe we are very pleased.*

Speech Therapy (1)

Took 18 months before my child had speech therapy

One parent observed that "all things take time however, because of high staff turnover it can take more time than necessary." And another parent commented "It depends if in a crisis any delay is difficult". Four parents made general comments that time delays depend upon service, with one saying *Cost dependent!* [sic]

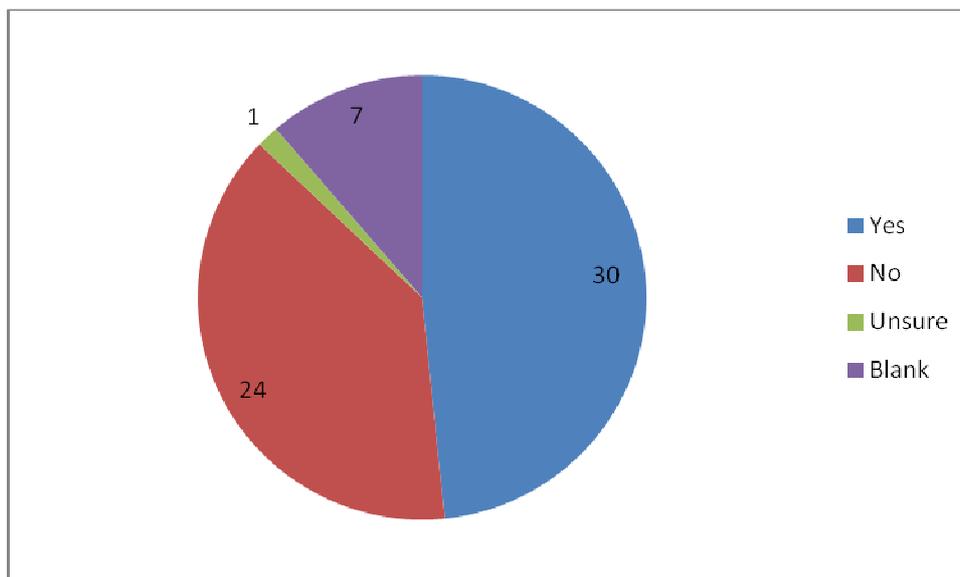
The positive comments on time frames were:

So far we have been satisfied.

Once in the system we were amazed at the speed and regularity with which appointments were sent to us for the various services.

8. Voluntary sector support

We asked parents if they receive support from the Voluntary Sector for example Bromley Mencap, Burgess Autistic Trust or the Maypole Project. Responses are shown on the chart below.



Mencap

Twelve people indicated they had used Mencap services, comments include:

Buddying

Don't cancel Mencap buddying

One parent identified Mencap buddying to be an excellent service.

Childminding:

Use the childminding network.

Bromley Mencap support our childminder and have provided her with training about epilepsy.

Bromley Mencap have been invaluable in providing respite childminder service. If Mencap hadn't have been available we still would be waiting for Bromley to provide short break care!

Mencap child minder services are excellent.

Mencap child minding have been a life saver.

Mencap child minding do not need improvement.

Mencap child minding (reassuring).

General:

Bromley Mencap very good, feel very supported by them.

Bromley Mencap excellent support, family days & DLA form completion

Bromley Mencap assist with DLA form.

Have just joined Mencap and have received info re holiday activities

Had one trip with Mencap last year

*We were introduced by Early support.
Mencap holiday activity scheme is excellent
Sure we will be using Bromley Mencap in the future.
Mencap is great.*

Burgess Autistic Trust.

Twelve people indicated they had used Burgess Autistic Trust services, comments include:

*Used BAT for advice in past
Burgess trust weekly email
BAT I can never get through on the phone as they are always busy
Burgess Autistic Trust have been a very valuable support through school and advice at home too.
Only accessed after his ASD diagnosis
Burgess Autistic Trust supported us to access CAMHS and family support for ASD
BAT are extremely helpful even though we haven't had a formal diagnosis yet, Dr put us in touch
Burgess Autistic Trust offers an excellent service.
Burgess Autistic Trust is very helpful
BAT buddy scheme worked well for us.
Burgess Autistic Trust have been fantastic.*

Maypole

Five people indicated they had used Maypole services or intended to. Comments include:

*Maypole very good, feel very supported by them
Maypole for family days.
Use Maypole art group
We receive regular Maypole project activity breaks
Attended Maypole activity day
Will be contacting Maypole, They were introduced by Early support.*

Bromley Parent Voice

One parent indicated they had used Bromley Parent Voice.

*Bromley Parent Voice Parent Partnership workshop (Early years) was absolutely fantastic.
Lifesaver!*

Bromley Carers

One parent indicated they used Bromley Carers and young Carers and they found them very helpful.

Bromley Children's Project

One parent indicated they used Bromley Children's project and they found them very helpful.

Family Link

One parent stated they had used family link.

There were three general comments where the parents did not specify which voluntary sector they were referring to:

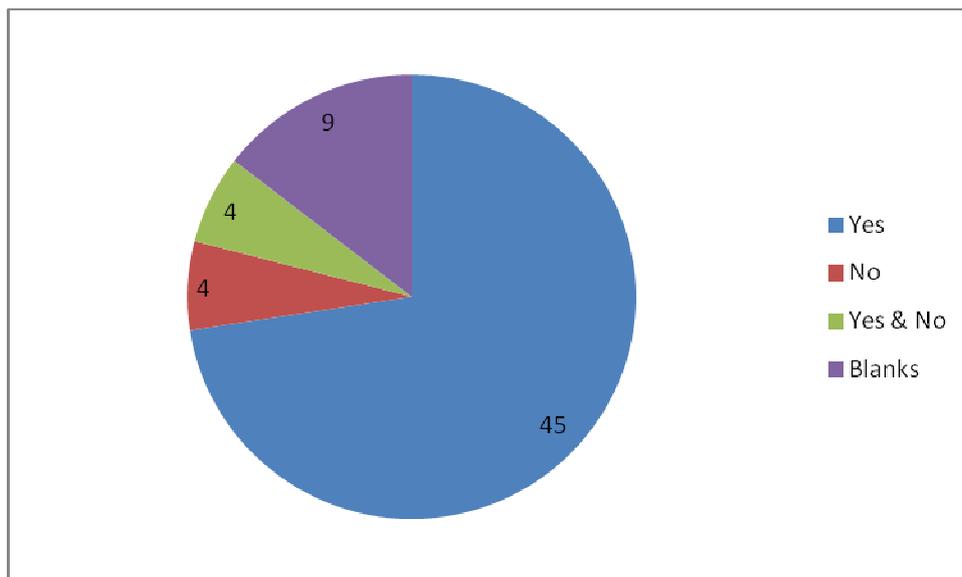
Very helpful, gives somewhere for parents to bounce questions and get feedback.

They are great

All very helpful

9. Key Working

We asked if parents felt that access to a Key Worker would have helped their journey. The following chart shows the responses.



Four parents (7%) indicated they had a key worker for their families. Eleven parents (18%) indicated they felt that another professional had offered this type of support.

The following comments are from the parents that indicated they had used a key worker.

Our key worker was Amazing. Guided us through (from when we moved to borough at 7 months) what was a very difficult time. Everybody should have a key worker from the start.

We have a key worker due to Early support, she is invaluable. I am dreading the start of school and the loss of our key worker.

I never knew/met my key worker, I wouldn't even know how to contact her. If I had problem or question I asked teachers from preschool or other parents

After my child's illness someone associated with the Phoenix centre was allocated – fundamentally useless. The head of the crèche was fantastic and really helped me.

The following comments are from parents who felt that other professionals had offered key working support.

Crèche

The head of the crèche was fantastic and really helped me.

Pre-School

If I had problem or question I asked teachers from preschool or other parent.

(Portage)

Think Portage was our key worker!

Support from our Portage home visitor has been invaluable, don't know what we would have done without it!

Burgess Autistic Trust

I think that as wonderful as Wendy Warne (BAT) is, she can't possibly be aware of every child's needs. To have someone who understands your situation and child's needs would be helpful.

Vision team

Our worker for the vision team acts as a key worker and has been extremely helpful.

I do have a member of the sight team assigned to look after child so I know who to phone for help and child is happy to discuss any problems when they visit the school.

Vision team & Physio

Vision team have been acting as a key worker and now child has started school physio are more relevant [sic].

Hearing team

We have a regular contact advisor within the hearing team. They helped enormously having the same contact has been brilliant for my child.

School

Felt we had a key worker through school.

Health Visitor

Having a constant person that knows you & child after I no longer used health visitor I felt that consistency was lacking.

Pre school

We had key worker preschool which was invaluable[sic]. Would have loved someone to contact once education kicked in.

Pathfinder single plan

We have a key worker to trial a single plan and it has been invaluable.

Three parents (5%) commented they would have liked a key worker but had to find information from other parents.

Like other parents I had to learn and get myself mixed with special need mums. We try and gage each other any information and support [sic].

I would have been shown the right direction instead of having to listen to other peoples experiences to gain an idea [sic].

If I had problem or question I asked teachers from preschool or other parent.

Three parents (5%) expressed they wished key working could continue, having lost the key working support previously given.

I am dreading the start of school and the loss of our key worker.

Having a constant person that knows you & child after I no longer used health visitor I felt that consistency was lacking.

We had key worker preschool [sic] which was invaluable. Would have loved someone to contact once education kicked in.

General comments from parents that felt key working may possibly have worked for their family.

Possibly, although we had few services involved. It would have been useful to be made aware of other services/financial help we would be entitled to/ able to access, particularly as they don't have a specific diagnosis and are not physically disabled.

It depends on the key worker and their designated role.

Possibly, it depends what they could have done!

I would probably be more informed however, there are a lot more people who need major support and I guess there may not be enough key workers.

Think a key worker should have been offered right at the very beginning. They can be a feeder of information about the services etc. Works well that all professionals try to meet once every 6 months about my child.

Gives a chance to voice concerns.

Navigating and chasing, especially the NHS is mystifying & exhausting. It feels as if the responsibility sits with us. We need help.

Help with understanding processes and systems within establishment with greater ease.

A key worker would be able to assist in signposting to appropriate and available services. Most of the time parents who are caring for a disabled child, especially with siblings, and working do not have time to research what is available.

Would have loved advice from a key worker in beginning of journey.

If they were good it may have helped me through difficult journey and the months when I really struggled

Because dealing with the issues we face, getting advice and fighting for support is very difficult and there seems to be a lack of personnel & resources to assist families like ours[sic].

Build up a relationship. They can advise you of everything you are entitled to and help access the services.

Just having that one person to turn to.

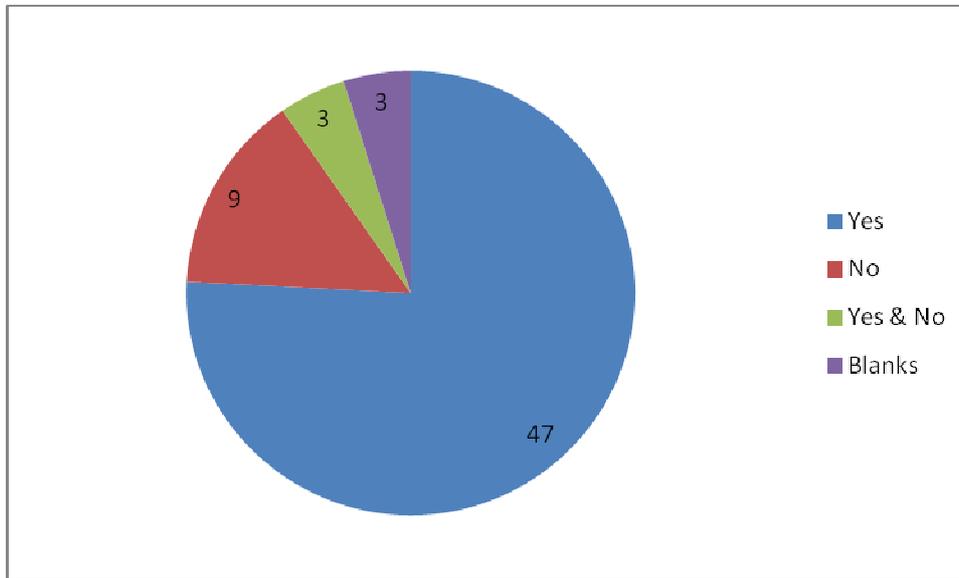
To be able to have more advice feedback & support.

More information is always useful.

One parent commented 'I'm not really aware of services' and another stated 'Communication with school has been sufficient.'

10. Decision involvement

We asked if parents felt involved in decisions made regarding their child. The responses are shown on the chart below.



Eleven parents (18%) commented that they did not always feel involved. Four parents (7%) also stated they felt that decisions had already been made before they were involved.

Comments include:

Involved to a degree but it is not easy.

Involved with some of the issues/situations that affect him. Not included in most of the cost dependant decisions.

Yes but adhoc, not systematic

There has been an incident recently where a professional was discussing our child without our involvement and left us feeling very concerned.

Not always, it feels a decision is made and then you are included in it.

Not always, a decision is made and then I am told about it.

Decisions seem to be made for me and I have to fight to change them

As much as you can but does feel out of your hands and in lap of God. Got no choice but to go along with what is proposed.

Five of the parents that said they did feel included commented:

Being part of Early support/multiagency meetings was empowering as a parent. The key worker was a valuable asset

Have been involved in decisions more so preschool[sic].

Every opportunity the decision was ours

We have been given contact numbers & emails keeping us up to date. Very pleased with the hearing teams communication.

Absolutely every step of the way. We have never felt pressurized or coerced in any decision making regarding our child.

There were a number of comments regarding decision involvement & schools. See below:

Regarding the support that he gets in school I felt involved in the decision making process (i.e. obtaining extra hours support).

I feel that my child's school are not giving enough (no support) and never take on what I say.

I had to be firm what I feel for my sons needs going through diagnosis/schooling.

Luckily for me my sons schools have been very good.

Midfield worked well for me.

The school is very inclusive, the borough is not.

In some part yes, the school keep us informed of the process and some professionals at Phoenix centre advise as well

The phoenix centre [sic] have been a very great support to us. The teacher and head were very helpful and felt could call at any time. Same for the Marjorie McClure staff.

There were a number of general comments about involvement, see below:

I feel that decisions that have been made have been on past and negative.

Parents HAVE to stand up for their disabled child.

I involve myself with decisions whether I'm invited/expected to or not!

Vision team are always open & honest with us and we regularly seek their advice when making school decisions.

I have had to push for a lot of things myself through my own research. Sometimes felt if I voiced something about my child it's not always taken until the professional has observed themselves.

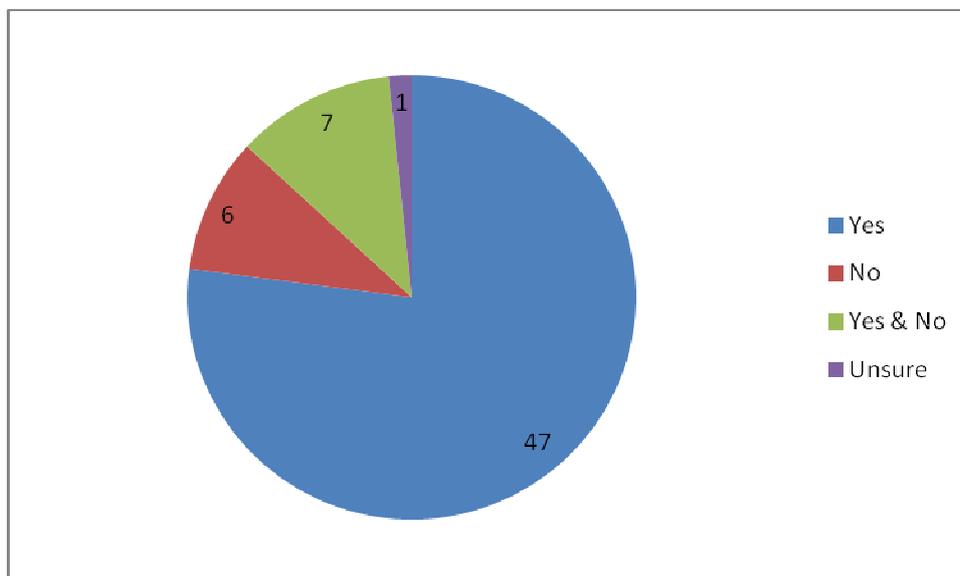
No, might be because he is only two & entering into your services.

Home tuition is great – only service actively involved with our family

You have to be strong enough to push for all your child's needs.

11. Competence of support provided

We asked if parents felt confident that the people working with their families have appropriate training, skills, knowledge and experience. The responses are shown on the following chart.



Parent comments are shown below, separated into confident, not confident, mixed and general comments.

Confident

I am happy with the schools SENCO and the ISA that works with my son in the classroom.

A very high standard, a very un NHS type culture too.

I came across nothing but great people, system sometimes was failing.

Every professional that we have worked with in Bromley have been knowledgeable, skilled and experienced. Where appropriate handovers between staff have been thorough and the transition to school has been smooth.

From the speech therapists to psychologists and the teachers can assume that my daughter is doing [sic] progress.

The carers teachers & professionals are exceptional.

We have been exceptionally lucky that each and every person involved in our child's care has been informative, caring, compassionate, knowledgeable and hugely reassuring.

Not confident

School think they know everything about ASD and fob me off with excuses all the time.

I am trying for my son to get into Riverside as there was too many changes in the unit, he is not coping, I feel that the school cannot fill his needs.

Its concerning that children with mild/moderate issues are being neglected, where they have great potential to lead a full unassisted life.

Concerned that children with lesser needs are being neglected.

Knowledge of fragile X very limited, people do not understand. Try to use more autism tactics to get him to progress.

Not enough training with universal services.

Feel that medics require more bedside manner, need training to deal with families, have empathy behave appropriately etc.

Not all are properly trained

Mixed (confident and not confident)

Apart from the people maybe at the child services who came out and do the reviews[sic]. I praise our Outreach worker and the lady who speaks to me from the office. She is very supportive.

Early years yes, now No. Only the vision team has skills knowledge etc.

Depends upon individual.

Sometimes, There are too many people involved to be able to say a blanket no or yes

As every child is different, they may not have experience of everything. Not all are able to think outside the box and adapt to your child/situation.

Yes, with the exception of our poor experience of Speech therapy

I am happy with the people working with my child but I haven't always been. Sometimes I feel they need to keep more up to date with research, new styles of therapy within that area. Also keep up to date with milestones for children without a disability as these are different to what they were 10 years ago.

Except SEN Transport who haven't a clue and lack appropriate training.

General comments

Happy with Glebe, not so primary school

Generally, but further training/skills good.

Unknown – I can only presume that Riverside (for example) have had appropriate training (have they?)

12. Satisfaction Scores

We asked for parents to state how satisfied they are with the services currently offered by the London Borough of Bromley. Marks were given on a scale of one to ten (one being very unsatisfied, ten being very satisfied).

Forty eight parents (78%) gave scores and these covered the full range from 1 to 10. The average score was 7.

Comments include:

We are pleased, for the most part, with the services we get but feel that there simply isn't enough help available for people like us who have no other support in looking after our disabled child. Frankly we dread the time when our child has to leave school and no longer qualifies for Hollybank respite.

This is difficult to score as some services i.e. Early Support are 10 but transport & short breaks are 2, if that!

9/10 for school, 5/10 GP, clinic & Health Visitor

The services have been very supportive and informative.

Reasonably satisfied but they could do so much better.

13. Comments not already covered

There was a questionnaire returned from one parent, with a *child attending a specialist school, who indicated they were told they did not qualify for Short Breaks, Direct Payments or Outreach. It should also be noted that this SEND child has a sibling.*

Another parent responded "No experience of short breaks, sorry can't comment". This parent has a child with ASD that is being home tutored.

We asked parents if they had further comments upon these services, not already covered by the questionnaire. Their responses have been split into positive, negative and general comments.

Positive comments

The sensory support team are excellent.

Having moved from Lambeth, Bromley was fantastic. We felt very happy with the experience we have had.

10 out of 10 for the vision team.

Negative comments:

My experience at school at present is poor & because my child is not severe is being left behind.

Some things are very frustrating for example, my son is not toilet trained. I knew from your booklet that I could apply for free pads but it doesn't say who to contact. So I called the SEN team at Bromley council. Lady I spoke to never heard of such thing like free nappies. I felt like a fool and had no idea what to do. Only school nurse helped.

I feel it is a funding issue that is the problem & a lot of time & money is wasted that could be put to better use.

Everything has been a fight and if it wasn't for other parents I would not have known what was available most of the time. Any allocated/provided support is scant, underfunded and often under a reduction of services (e.g. SALT)

I appreciate speech therapists are very busy but the wait we have had between appointments was very long (up to 6months). I think Bromley should look to employ more to satisfy demand. I accept that this could be the case across all services.

Feel very concerned in terms of disinvestment and current provision. I.e. transport may be cut also green paper stating improvement of choice – how with disinvestment. How is quality governed [sic].

We are going private in November as no assistance or acknowledgment by school support.

CAMHS I have not heard of this service.

General comments

I think we are lucky this questionnaire will iron out more hiccups. No-one is perfect, asking families is great this can only improve things. I also hope we take families in hardship into consideration as their voices need to be heard too.

Need more information on the statement process. Info needs to be given early on about this process (I am already thinking about it now).

Short Breaks and direct payments comments:

3hours respite nursing for first three months whilst twins on O2.

In process of getting these (Direct Payments).

Previously had these (Direct Payments).

Need support group within Bromley for parents of children with Hemiplegia to meet regularly to share experiences/worries & concerns.

Some things are done well and others are not, which I think is more down to the individuals running those services. As we have said to Sally Harrison it is a shame there is not more of her!