



Bromley Parent Voice
working in partnership to give parents and carers a voice

Our family, our lives **Unique Journeys**



Families of children and young people with additional needs or disabilities from Bromley, share their journeys.



Our family, our lives
Unique Journeys

Foreword

Bromley Parent Voice is a forum that aims to inform service providers of the needs of children and young people with a disability or additional needs and their families in the London Borough of Bromley. Since September 2011 the forum has supported the London Borough of Bromley who was selected as a partner to the national Early Support Consortium. The Consortium was appointed by the Government to extend and embed the Early Support principles and processes, (which were originally birth to 5) through the age range, birth to 25. The Consortium includes over 50 voluntary, community, statutory and private sector organisations and works with Pathfinders to support national Pathfinder work, to inform the national reform agenda in line with the Government's Children and Families bill. The London Borough of Bromley is one of nine Pathfinder Champions and is supporting other local authorities in an advisory capacity, to implement the national reforms, which will become law in September 2014. Bromley has responsibility for London. A Pathfinder is a public sector organisation or local authority chosen by a department of the Government to develop, test and expand systems and strategies to shape future services.

Families with disabled children have the same aspirations and hopes for the future as other families, but achieving them often presents different challenges.

The London Borough of Bromley are supporting the national agenda as a national Pathfinder by working in partnership with Bromley Parent Voice who undertook research with parents to learn from their Journeys so that their experience could inform service provision, enabling improved outcomes for families. We asked families from across Bromley whose children are affected by a range of disabilities to tell us about their journeys. We wanted to give parent carers a voice to talk about their achievements, acknowledge the challenges and reflect on their hopes and fears for the future. Above all we want to celebrate their family life.

Families want what is best for their children and they dream of a life full of possibilities. Their experience becomes less challenging when parents are given clear and adequate information and are signposted appropriately to where they can access required support at every stage or point of need.

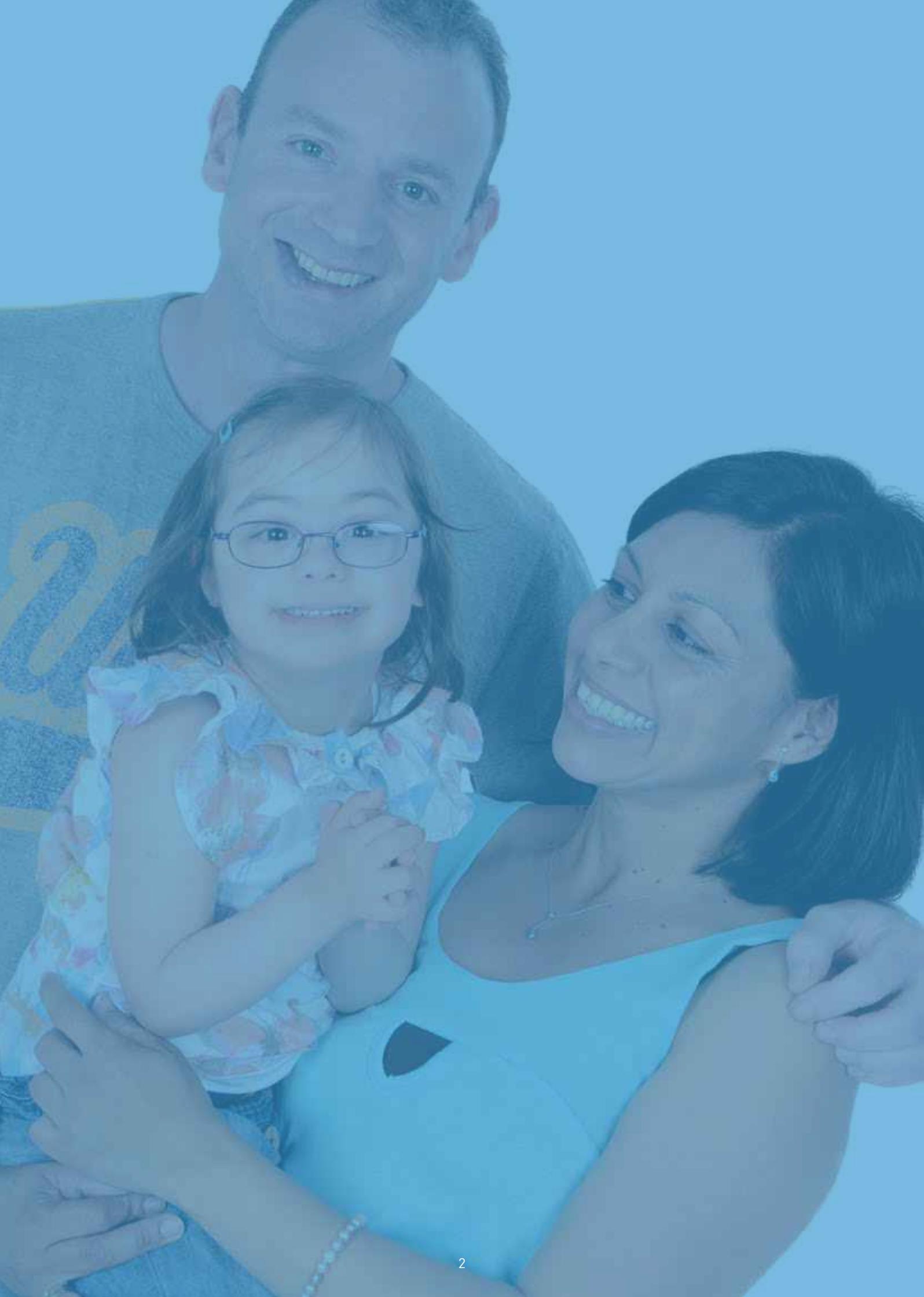
There are positive changes for families with disabled children taking place; parent carers are beginning to be listened to by local decision makers and recognised for their expertise to help shape services for disabled children. Early Support is an approach which aims to place the child and the family at the centre and enable them to live 'ordinary lives'. It also embeds the vision of the Children and Families Bill [subject to parliamentary approval becomes law in 2014] which advocates for "parents to be at the heart of decisions made about their child and feel confident that the support will be put in place".

As these parent journeys show, children and young people with a disability or additional needs and their families are just like other families. They want to make a difference and would like decision makers, budget holders and professionals to recognise and understand the needs of their children and families, valuing the uniqueness of every child and family.

This booklet is a condensed version of each family's experience. Our grateful thanks are given to all the families who chose to share their journey and to Funke Adeloje and Jackie Mitchell who worked on the production of this booklet.

Kay Moore

Parent Participation Officer
London Borough Bromley



Bromley Parent Voice

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Early Support for Children, Young People and Families

What is Early Support?

Early Support is a way of working, underpinned by **10 principles** that aim to improve the delivery of services for disabled children, young people and their families. It enables services to better co-ordinate their activity and provide families with a single point of contact and continuity through key working.

Early Support ensures that service delivery is child, young person and family centred. It focuses on enabling services and practitioners to work in partnership with children, young people and their families.

Early Support is a delivery partner supporting the implementation of the Government's Special Educational Needs and Disability reform agenda and Children and Families Bill which subject to parliamentary approval becomes law in September 2014 . This identified Early Support as a key approach to meeting the needs of disabled children, young people and their families.

Early Support is an approach that brings together the services families need to provide co-ordinated assessment and a single planning process covering education, health and care.



The Early Support Consortium and Bromley Pathfinder

As a Pathfinder, Bromley has been asked to build on the work of its award winning Early Support model which has been successfully running in the borough for ten years, supporting the development of co-ordinated assessment processes and the single Education, Health and Care Plan which is based on the Early Support model of a team around child and family approach.

Bromley has also been invited to contribute to the national work of the Early Support Consortium by working with some parents to write their journeys so that we are able to learn from them to inform service provision and improve families' experiences.

It is the vision of the Early Support Consortium to develop the following areas:

- Working in partnership with parents and carers
- Family support
- Key working at key transition times in a child's or young person's life
- Develop existing Early Support materials and resources for the older age group
- Multi -Agency assessment and holistic support for families.

Furthermore, Bromley has been piloting the Education, Health and Care Plan with children and young people who have complex needs, who require considerable on-going specialist support across Education, Health (including therapies) and Social Care and who will continue to do so to reach their potential in adult life. All of this exciting Pathfinder and Early Support Consortium work compliments each other in developing and improving services for the future for children with additional needs and disabilities.

A group of parents were brought together to bring their valued contributions towards the various reforms. Parents in the group were asked to reflect on their journeys thus far; relating their individual experiences, what has worked, what needs improvement or what has not worked at all? They were encouraged to relay their experiences highlighting the involvement of early intervention, key working and Bromley Parent Voice, as well as their general experience regarding the type of support they have received (or not received) from the various resources available to them within the Borough in the management of their child's disability.

This booklet has been co-produced by the parents' group and we believe it will further help and encourage other families within the borough who are on similar journeys.

“The birth of a disabled child changes everything
It changes the things we think are important
It changes how we see our future
It changes the nature of our daily lives
The birth of a disabled child becomes the central
focus of our every waking moment...
and for a while that's fine.....”

In the end we have to stop; we have to look around us,
at the people in our lives, at the ordinary things
that are still important and we have to work out ways of
reclaiming at least a little of the ordinary in this
new world in which we find ourselves.”

Mark Brown, Parent (extracted from the National Early Support Parent Workshop)

“Whilst I like to think I am relatively intelligent,
I have never walked this path before and I have
no ideas where the twists and turns are,
let alone the pot holes. I know nothing of the hills to
climb and the slopes to slide down. You have no
idea whether the sun is shining or the rain pouring.
This could be a typical day's experience”

Bromley Parent

What our Bromley families have said about Early Support

“Our keyworker helped steer us toward the help and support we needed. Early Support is like a lighthouse guiding us to land.”

Bromley Parent

“Our Early Support Keyworker co-ordinated a fantastic team of professionals who worked with our child with complex needs, they have you and your family’s best interests at heart and I am so sad that I am no longer under their care, they make you feel that you are the only person they are concentrating on and every promise of support is fulfilled and more.”

Bromley Parent

“Thank you to the Early Support Team, without your help and support I don’t know where we would be as a family, it has been an emotional rollercoaster and you all deserve a medal!”

Bromley Parent

“My Keyworker helped with everything, all the things that got done were because of her 100%”

Bromley Parent

“Early Support provides so much to be thankful for, we have benefited immensely. Our Keyworker could not have been more supportive, understanding and easy to relate to.”

Bromley Parent

“Without the services and support we have received, our lives would have been miserable.”

Bromley Parent

Jacqui

Nola (4)

Beckenham

I found out Nola had Down Syndrome when I was about 23 weeks pregnant following a pre-natal scan. I had an amniocentesis done which confirmed this.

I spent the following weeks after this check researching and getting her referred to Bromley Early Support Team at the Phoenix Centre. She was born with an [atrioventricular septal defect](#)* that needed surgery when she got a bit bigger and she had this surgery when she was just six months old.

Nola sort of got lost in the system at the hospital where she had her surgery in 2009, but I had lots of support from the Early Support Team. They saw me before I gave birth to set the ball rolling for her management and this has really been a great help to us. I think I was fortunate to have everything in order before my daughter was born as she started receiving Portage intervention straightaway. Portage worked well for us and has helped my daughter a lot with her development. It has also helped me!

It is still early days for us as she is still very young and just about to start school. We are currently going through the statementing process and choosing an appropriate school for her. This is a bit stressful at the moment and I am really hopeful she will be able to attend the school I would like her to go to. I would also have loved to have more input in what kind of therapy she receives.

My hope for Nola for the future is for her to be able to lead a fairly normal, independent life.

In September 2013, Nola will attend the mainstream placement with additional support that Jacqui hoped for.



* see Jargon Buster page 34

Roz, James

Edward (5)

Orpington

[My youngest son's disability presents in his behaviour. Physically he looks like any other child.](#)

Our entry into specialist pre-school services came when our son reached three years and ten months and lasted for nine months. It stopped because my child started full time education. With what I know now of the services I wish we had identified his needs earlier. We had a few missed opportunities, one was shortly after his birth involving hearing tests and the other was the development check at two and a half. I also regularly attended health visitor clinic for growth checks. He was always non-compliant, showing sensory issues and yet his needs were not spotted. For my part this was due to my lack of clarity at the time and I guess no one "joined the dots".

Looking back Edward's problems were evident from a very early age. He would startle at the slightest noise, barely slept and would scream every time I put the car into reverse (I still tense up when reversing, even when alone). As soon as he could sit he would flap his arms, I used to call him baby bird as it looked as though he wanted to take off. I took to wearing long sleeves as there were always bite marks and bruises on my arms. At a local mother & toddler group I would have to leave before music time else Edward would be running around coshing other children with the maraca.

I was aware he was difficult and certainly didn't understand him. Mostly I put it down to the 'terrible twos' that others refer to; however he didn't appear to be growing out of that phase.

We received a questionnaire for Edward's two and a half year check when he was almost three. We completed the questionnaire without particularly highlighting difficulties such as sleep as we felt things were normal. When my elder child was checked we all saw a health visitor and more importantly she saw us. I am sure that had Edward been seen the health visitor would have referred us onto extra support earlier. Something had to give and the catalyst happened once Edward started in nursery.

Edward started mainstream pre-school in September 2010, to start with he settled in quite well. It wasn't long however before I was pulled aside each time I collected him, to be informed of his latest incident. He was hyperactive, non-compliant and would strike out at anybody who got in his way or tried to stop him. It was suggested that Edward was possibly autistic and I should seek advice when he returned to school after been away due to ill health. We started the assessment process in December 2010, and a formal diagnosis was given in October 2011.

Following a referral to the Early Support Pre-school Panel when Edward was three years and ten months, he started at the Phoenix Specialist Pre-School and had a [SIPS*](#) worker for his days at the mainstream school. We were offered a Portage home visitor following the [SPEACS*](#) assessment and we had a fantastic time with our Portage Worker. Phoenix Pre-School was also supportive especially in the areas of getting an appropriate statement for Edward and getting family support training. This period was a very sharp learning curve for the family.

* see Jargon Buster page 34

We were also sign posted to some voluntary organisations like Bromley Carers, Social Communication Difficulties, Burgess Autistic Trust, Mencap, Maypole, Give to Give and so many others and they all helped to support our family in various ways. Through the Bromley Parent Voice I have also been privileged to be involved with the Pathfinder Project as a Parent Representative and this has given me a better understanding of services available as well as legislative changes and their effects on families. My involvement has helped me to make more friends and useful contacts and I also feel less isolated all in all.

Life is going on well at the moment so I don't like to look too far ahead. I am determined to help Edward achieve the best he can and be as independent as possible. I am anxious over the [SEND*](#) and benefit changes. It is not yet clear how we will be affected. His school have also said they see Edward in mainstream school with support in some time to come; although this is great but very worrying as to whether he would get the right level of support that he needs. Edward was able to attend a swimming course held at Marjorie McClure during summer term 2012. The lessons included sharing games, maths and problem solving; I would love Edward to attend more lessons like this even though I am aware there is huge demand for such now.

There can be lack of understanding from people regarding children with Autism and this can be very isolating. I currently try to avoid places where people do not understand my child. I believe more media coverage on hidden disabilities such as Autism would be good. Maybe a story line in one of the TV soaps, anything that leads to greater understanding of Autism can only be beneficial.



Kay

Luke (17)

Orpington

When Luke was diagnosed with Autism at four years old, there was no Early Support. If I am honest the diagnosis when it came was actually a relief but this was quickly followed by fear of Luke requiring constant care and never progressing. We had entered a new world and our journey had only just begun!

Our journey has been eventful. We were lucky to have excellent support from our family and local services that were there to help us when we needed it. In the early days I benefitted from attending a parents course run by a local voluntary organisation which enabled me to meet other local parents in similar situations and to share in all the ups and downs that life was throwing at us. It was good to know we were not alone. Luke is now 17 and is a happy and outgoing teenager. Despite his [Autism*](#) and learning difficulties which are severe, he enjoys life to the full.

As Luke gets older our aspirations for him are high. Looking forward we hope that Luke has opportunities to work, to be independent and that he will have friends and family around to help him if he needs it.

As a mum I am really excited that as Luke prepares for adulthood the Early Support way of working, training and materials will be available to help our family to make informed choices together, with Luke at the centre.



* see Jargon Buster page 34

Funke and Aj, Teniola (8), Fikunmi (6)

Abigail (5)

Bromley

The turn of events in our life is nothing we bargained for, but we are determined not to allow this take us down the downward spiral of life. This is why we are keeping the family together, facing each day with as much strength and energy as we can receive and try to make each day count!



Abigail was a very healthy and absolutely delightful child from birth. She was growing up normally as any child would until she suddenly convulsed at eighteen months and subsequently slipped into coma. She came round after two weeks and bang...we got a different child altogether! She was diagnosed with presumed viral meningoencephalitis which left her with significant damage to the brain. There had been other offshoots as a result of the initial diagnosis for Abigail along the years and we are managing her condition as best as we can at the moment. We got referred to the Early Support Team in May 2010 and her management and care took a different turn positively since then.

There is no telling our story without a major reference to the timely, efficient and effective input from the Early Support Team through our Designated Keyworker. We were a family new to the UK, Bromley and to the numerous issues surrounding the management of complex needs and disability...altogether green in so many ways! Negotiating our ways through all these alone since we arrived in 2010 would have been unthinkable without the guidance and support from Bromley Early Support. We benefited from joint meetings organised for Abigail, Multi-Agency and Next Step Meetings and we were signposted to some voluntary organisations where we could get support. The co-ordination of professionals involved with Abigail's care within the community also came through our [Keyworker*](#) and everyone has been so supportive.

The availability or non-availability of services, benefits and desired support for families with disabled children is one issue; not being able to access even the available ones due to one limitation or the other is another. Accessing other services beyond the provisions of the Early Support for us could be likened to 'eating from the crumbs that fall from the table' due to the restrictions on our immigration status and the impact of this on our family could be better imagined than narrated. The motivating force despite all the odds has been making Abigail's needs a priority and managing every other event or needs within the family as much as the situation permits. Thus far, the serene look on her face at times, as well as occasional 'smiles' we receive from her make it all worth the while and gives the courage to keep pushing.

We look forward to Abigail having a smooth and seamless transition to a specialist school in September, 2013. The process for looking for a new school, getting the statement and so on have been a bit overwhelming and not void of concerns but we are hopeful that Abigail will continue to receive the high level of care and management which she requires in her new school. There are fears indeed but we are hopeful.

We hope to be a blessing to as many people as we meet in life, despite our situation...hopefully we can make somebody else smile through their pains by the things we have also gone (or still going) through as a family.

* see Jargon Buster page 34

David, Jane, Eliza-Jane and Anya

Samuel (3)



Bromley

All of our children define our family. All 3 are special. Every decision we make for each child, we make with due consideration to the effect on the others. We are eternally grateful for all the support we get; some days it's hard to show that gratitude, but we can assure you it's there!

Samuel arrived a little early, but not early enough to worry anyone. A few days later however he was poorly and went to Princess Royal University Hospital and then transferred to Evelina. Here he was diagnosed as having Enterovirus Sepsis - a common virus he could have got from anyone and anywhere. Although he started to improve and had his liver and kidney functions getting better, an EEG* showed he had had seizures and an MRI* scan revealed there had been swelling and abnormal chemical changes in his brain. We were discharged with Phenobarbitone*.

Samuel was later diagnosed with Cerebral Palsy*. He is visually impaired, has global developmental delay*, increased tone especially in his lower limbs and a very cheeky smile! The support we receive from Early Support, our Keyworker (including all the professionals working with Samuel) and also through the Next Steps* meetings for Samuel are all working well for us currently. The fear of losing all this when he starts school is a concern. He currently attends the Portage play sessions and enjoys his time in the sensory room. We are grateful for the Portage* sessions as they afford Samuel with good experience and also offer invaluable support for me as the mum. The Multi-Agency Meeting* organised for Samuel is a brilliant chance to update everyone, to gently nudge issues that are niggling and haven't been solved, and to ask those 'stupid' questions that you don't know who or where to ask. To have a Family Service Plan* within days is also fantastic as you can move forward straight away. We have absolutely nothing to change with these meetings; I just wish it were possible for more families to benefit from such a wonderful programme. I think the Early Support Team have this sorted!

We are scared as to how we'll cope when Samuel starts school and fearful how to stop him from being lost 'in the system'. We are also concerned about accessing adequate support for his siblings.

We don't think all the Professionals remember that we are living with our situation all day, every day. They are all extremely dedicated and go far beyond all their job requires, but unfortunately we cannot leave our problems at the end of the day. Sometimes the impact of what they say can be far bigger than they realize, coupled with whatever is going on in our lives at that time and other stress or pressure we are under. Also having a child with additional needs means you can't always use friends you might have used for childcare with your other children and this poses another challenge.

Whilst I like to think I am relatively intelligent, I have never walked this path before and I have no ideas where the twists and turns are, let alone the pot holes. I know nothing of the hills to climb and the slopes to slide down. You have no idea whether the sun is shining or the rain pouring. This could be a typical day's experience.

We didn't choose this path, Samuel chose us. We couldn't have chosen to live in a better area, with so much fantastic support from a team with a huge vision for our children, today and tomorrow. Thank you so very, very much.

Maria

Liviu-Stefan (7)

Bromley

Stefan turned three two months after we came to England. We had noticed his speech was delayed earlier; even though some people around us attributed this to the fact that he was growing up with two languages (Bulgarian and Romanian). Moving to England then added the third (English) and our frustration could better be imagined!

My husband noticed a leaflet on Speech and Language Therapy one day at Stefan's nursery school, we read through, made a decision to try it, went in for a drop-in clinic at Biggin Hill and the journey to a new start began for us! We were referred to the Phoenix Centre and our son got a diagnosis for Autism in 2011. We found the staff at Phoenix Centre very helpful and supportive. They gave us advice and further explained the type of help we needed as well as materials to help us understand symbols and ways of communicating with Stefan.

Stefan is now in school. This has helped him to become more sociable and he enjoys many activities. He engages in reading, writing and solving problems in school. He does these activities at home also, listens to music, watch television and making steady progress learning words and understanding the world (especially from the television). He is our 'smiley' little boy!

Our efforts to seek help and address his issues also paid off. I wish I had a friend however (another mum...) to talk about...everything; visit each other, go out and about, holidays, cinemas and do all the 'normal' things of life. But these are luxuries when you have a child needing special attention like our son. We really hope we could prepare our son in advance for the changes that would lie ahead of him in the future; but this seems a bit far-fetched at the moment.

As a parent of a child with Autism you can feel isolated; especially as English is not our first language. This made things even harder for us. Early Support offered us the opportunity to attend their Parent Workshops where we made friends and received helpful information.



* see Jargon Buster page 34

Judith

Noah (5)

Beckenham

Living life taking small steps, jumping over hurdles and through hoops. Eventually reaching huge milestones which need to be celebrated with a golden medal..and.... SMILE!

Noah has a unique chromosome imbalance with four copies of 18q12.3. This means (basically) complex needs and a [global developmental delay](#)*. Noah takes his time in life and because nobody else in the world is known to have this imbalance, all we can do is go with the flow, which is slower than most. Chromosome imbalance or not, Noah is happy and healthy.

As a family we grew stronger and learned what we are capable of. We became even more patient and understanding, preparing us for an unknown journey ahead. We look at what Noah can do, not what he is unable to do. Awareness and communication is important. Working together with other parents and service providers is vital, but this hasn't always been a smooth ride. Service providers do their best I'm sure, but if we can all work together with a positive attitude we can save hardship, money and time, as a lot of this is wasted unnecessarily. We are well looked after by our GP, Health Visitor, Paediatrician, Geneticist, Physio, Speech and Language, Noah's school etc, etc.... We are humbled by the support and care given. The Portage Service has been a major rock in our lives and supported Noah and his needs very well. In our mind, an unfishable piece in this complex puzzle. Once a path full of cobble stones, but now a path cemented with little milestones on the way. The Maypole Project is another service which has been and still is, very important in our lives. They provide support to the whole family. Noah's older sister absolutely loves their activity days. I don't think one realises what an effect these days have on our siblings. Bromley Parent Voice and Pre-School Specialist Support, fantastic services! Last but not least, Bromley Mencap, a powerful partner, who will always be there to help, listen and guide you in the right direction.

Our aspiration for the future is a full night's sleep...!!!

My passion is to raise awareness and inclusion. With all the cuts in services, it has become even more important to work together and deliver an efficient cost effective way of support. Parents also need to work together and support each other wherever possible.

We are a cultural and religious diverse society.... why have we forgotten about our diverse abilities!!!! Local services provide us with a life line and tremendous support. We are so grateful for this, as our lives are turned upside down and we need this support desperately. I would like to see an improvement in communication and co-operation between us, the families and the services we have to access along the way.



* see Jargon Buster page 34

Soshana, Gary

Kayden (7)

Beckenham

Kayden's arrival inspired such love and protectiveness as he simultaneously shattered our world and is constantly rebuilding a new reality. Bringing in the new and taking away the old... Some remaining constant, others forever changing... But always getting stronger, more knowledgeable and understanding that a higher expectation will bring a better tomorrow



Kayden is an endearing conundrum that is the culmination of his many diagnoses; Down's Syndrome, multi-sensory impairment, autistic, asthma, brain damage in the white matter presenting a right side hemiplegia and sleep apnoea. Kayden is a very loving, happy, self-content, undemanding little boy who has severe learning difficulties, communication and motor delays along with many sensory deficits that result in self stimulation. Each year of his life brought a new discovery, adding a new dimension to understanding Kayden and his world. Currently we are reviewing if Kayden is actually asthmatic as he does not represent symptoms in the norm.

With each year comes new diagnosis with its own little battle of knowing something was not right and having to convince professionals that they need to question that which is not "the norm" in a world of "do not compare." Through it all we have had our Early Support Keyworker guiding us, supporting us, giving us the courage to question and the information we need. She has been the nucleus that brought clarity and focus to our issues, meetings and situations. Though she never told us what to do, she gave us all our options, helped me to understand them, leaving me to make a knowledgeable choice that best suited our family. Her support was critical as we had someone to go to for the information post on this journey with Kayden.

With the central support of our Keyworker and later the Keyworker Co-ordinator (who had the very difficult job of supporting and guiding us when things got difficult for Kayden at school), along with Parent Partnership, Parent Voice, Bromley NHS services; GP, Physiotherapy, Occupational Therapy, Sensory Support, the Maypole Project and Bromley MENCAP continue to play critical roles in our journey.

We believe that there is a place that understands Kayden and will be able to meet his needs in order for him to be the best that he can be. Our Early Support Keyworker has been our trusted guide in an otherwise lonely and uncertain journey. The Parent Workshops that Early Support organises have also been instrumental in helping us to build circles of friendship and support for and with other parent carers.

Our journey continues and as all journeys will have its hiccups and we do miss having our Keyworker to go to for information and guidance. We also know that we can call on them for advice and in turn they have made us aware of all other organisations that are there for when the need arises.

Teresa and Karl, Jordan (24), Tayler (21), Ellis (17), Jed (11)

John (17months)

Bromley

John is our 'little ray of sunshine', he has taught us all to acknowledge, appreciate and celebrate every achievement, however small! We no longer take anything for granted and we don't 'expect', we dare to hope and we aspire!

We are Local Authority Foster Carers for another London borough, and in December 2011 we had a call asking if we could collect a 3 day old baby from Hospital, that phone call proved to be life changing! John was discharged into our care as a healthy baby, within 24 hours our world was turned upside down. The first thing we noticed were his eyes, they looked very unusual, it turned out John was unable to see, hear, feed and even breathe properly. Within weeks we had a constant cycle of medical appointments, with trips to Great Ormond Street Hospital, the Princess Royal University Hospital and Beckenham Beacon and the prognosis for John wasn't good! 17 months on, John has 'complex needs' some of which include; global developmental delay, visual impairment, hearing problems, small stature, feeding issues and renal/urinary problems. Although the Geneticist has already found abnormalities on 2 chromosomes' more tests are currently underway and we are still waiting for a formal diagnosis.

After having 4 children of our own we thought our family was complete, and then John came along! The last 17 months have been totally life changing for us as a family. Initially, very stressful and distressing, each day seemed to bring more concerns and worry, John was so fragile and needy and I was exhausted! As time went by and we met all the people now involved in supporting John (and us) things began to slowly improve, John was doing so well, amazing all the professionals involved in his care. The most stressful time for us was yet to come; Social Services began to search for a permanent family for John and as the months went on we began to dread the phone calls from them in case it was to say a new family had been found and he would be leaving. The call never came, without a diagnosis a permanent family wasn't found.

The fantastic people we have met on our journey since having John, both professionals and parents, have helped us to now make the decision to keep John. It has been a decision we had to be sure of because the future for John is still unclear, but every day that goes by reinforces the fact that we made the right decision. John needs constant supervision, he has sensory processing problems so all aspects of his care have to be managed by us as he doesn't feel hungry, thirsty, tired, hot etc. His visual impairment and hearing problems make things much more difficult for him and we are awaiting some surgeries at GOSH, but he is making remarkable progress, he's enthusiastic, determined and interested in all we do. He is very loving, endearing, and very funny! Every day he gives so much back to us!

John was referred to Griffins (Sensory Support Service) for his visual impairment and accessed the sensory room from 4 weeks old, that's where we met the Teacher from the Vision Team and for that we are most thankful, she is now our Keyworker and on a regular basis my therapist and my saviour! Speech and Language/feeding specialist came on board at 8 weeks old due to feeding problems and then we met The Keyworker Co-ordinator who explained everything about Bromley Early Support and what we could expect, she did some referrals and soon John was 'picked up' by Portage, Physiotherapy and Occupational Therapist. The level of support available in Bromley is exceptional and the combination of Multi-Agency and Next Step Meetings along with our Keyworker ensures that John is accessing the correct level of support. The Keyworker Co-ordinator also liaises with Social Services and helps signpost me to the support we need.

Our aspirations for John are high; in the short term we hope that he will continue to amaze everyone with his sheer determination and enthusiasm for all that we throw at him. In the long term we hope that John will continue to receive the level of support needed to be able to reach his full potential, we would like him to have a level of independence and be healthy and fulfilled, but above all we hope that John will be happy!

There is something very special about John, I can't explain what it is, but he has had such a positive impact on our family. Since we made the decision to keep him it feels like a weight has been lifted, we no longer dread the thought of him having to leave and we are now able to look to the future and start to plan for what lies ahead, making sure John has access to all that is out there for him! Every day is different, we never know what it may bring, some days are more difficult than others but, at the end of every day, we always feel blessed to have John!



Brooke's Mum

Brooke (5)

Bromley

I will always fight to get the best for Brooke. Brooke's condition is physical – I would like everyone in contact with her to see past the machinery and see the child that I know and love unconditionally.

Brooke has a diagnosis of Hyper Contractile Muscle Dystrophy due to double mutation on the alpha beta crystallin gene. She cannot take a breath independently and is on full life support. It is important to know that Brooke is fully cognitively able!

Brooke was born a healthy 7lb4oz on 11/07/2008, in Farnborough hospital. I fell in love with her as soon as I saw her beautiful face. We spent an amazing 4 months together before my world was turned upside-down.

At 3.5 months, she started to drop feeds; the health visitor suggested trying solids. Brooke continued to drop feeds so I decided to take her to hospital one day as I suspected she had a sore throat. She was sent home but 2 days later, she was admitted back to the place she was born with breathing problems and low oxygen levels. Overnight things started to deteriorate, so she was then blue-lighted to the Evelina where she spent 10 long months followed by another 10 months at the Tadworth Children's Trust in Surrey, away from home. Brooke underwent a transition into the community plan. Whilst at Tadworth. I was finally contacted by Brooke's neurologist to inform us that her diagnosis was of Hyper Contractile Muscle Dystrophy due to double mutation on the alpha beta crystallin gene and that this was genetic and irreversible. It was a complete shock and how I held it together I still don't know! However, I did, and after a life-changing 20 months get my beloved daughter home where she belonged.

Things that have worked well for us include the community care team and the hospital consultants at the Evelina. The Early Support Team has been fantastic, in particular our Keyworker! Brooke has done really well considering everything she has been through and I am happy she is home with me. We would really like quicker responses from professionals for things like equipment. We need simplified paperwork, for example risk assessments and the decision process takes too long.

We feel anxious about school and we need to find appropriate housing. I think housing should offer more support to families with a child with a disability, especially one who is on life support. It really needs to meet the family's needs.

Brooke's condition is physical – I would like everyone in contact with her to see past the machinery and see the child that I know and love unconditionally.

This is so important to me, Brooke is a bright, delightful girl and I want more focus on the positives and less on the negatives.

Since her birth, Brooke has achieved many things; she has defied the medical profession and lived when they said on many occasions that she wouldn't; she has raised money to help others in a similar position; met celebrities doing the same; shown strength and courage through operations and procedures; been on wonderful holidays with family; thrill rides at theme parks; celebrated 5 birthdays; started school; competed in her first sports day; been in the sea and generally been a star.

She makes everybody she meets happy and thankful for what they have. The one thing that she has achieved that she has no idea about is how she has changed her mum, she has taught me the real meaning of love, compassion, patience and trust. She has made me humble and I will always be in debt to her for this.

My hope is that she lives to understand the profound effect her life has had on mine.

In 2012, Brooke started to attend a specialist provision, she had not previously attended any settings due to concerns over her fragility; she is really enjoying her time at school. Brooke has a multi-agency team who work together across home and school as part of a co-ordinated package, with support from a designated Keyworker.



Meadbh, Brian (Snr), Elsie

Brian (4)

Beckenham

It is important to my family and I that people don't focus too much on my ventilator and my disabilities. And that they focus instead on how I can do things and participate.



Brian was born on 28th of February 2009 at 29 weeks and 6 days. He was ventilated at birth and remained in intensive care for 6 months. He has the following diagnosis; chronic lung disease, spinal cord injury/ cerebral tracheotomy, BIPAP resmed ventilator, multi resistant pseudomonas and gastrostomy fed. Brian was discharged to Great Ormond Street Hospital (GOSH) transitional unit for 10 months. The long term ventilation team at Brompton helped move Brian's discharge process along as an independent group and he finally came home in August 2010.

Our introduction to Bromley Early Support was at the Great Ormond Street Hospital by our Keyworker and from here we knew we had a point of contact in the community. At this stage it was hard to imagine what life in the community would be like. The fear of leaving the hospital and the High Dependency Unit environment to go home was a difficult process for us. Perhaps a discharge to a local hospital might have been appropriate for a week or two before we went home, even maybe some nights there. That way the hospital would have got to know us and we would have built relationship with them.

A team of carers was built to support us at home; as we got introduced to the Phoenix Centre and Portage. Brian had sessions with our Portage Worker at home and enjoyed the music group at the Phoenix Centre. We were well supported by Occupational Therapy, Physio and the Nursing team. We had regular Multi-Agency meetings and Next Steps sessions, where goals are set and followed up. We feel that everyone is working well together and making plans to move forward.

We are well settled in the community. Brian is enjoying being at two pre-schools and we are making plans for a primary school. We feel that everyone is working well together with Brian's best interests in mind.

We hope that Brian will have as much independence as possible as he grows older, learning how to control a computer with eye gazing technology and to drive his own power wheelchair (using his chin) are some goals for the next few months.

In September 2013, it is proposed that Brian will be the first fully-ventilated child attending the family's desired mainstream placement with full healthcare and education support, for four days a week; he will spend one day at the borough's specialist school for children with complex physical difficulties. The transition to school has been co-ordinated by a Designated Keyworker by taking a "team around the child and family" approach across agencies and looking at joint commissioning to determine joint funding splits. The transition of Brian from the Pre- School Specialist Support and Disability Service to school has informed Pathfinder work, he was one of the first children used to pilot the single Education, Health and Care plan.

Elizabeth, Samsondeen, Divine

Faith (2)

Penge

Faith is very intelligent and can have a great future. We would love her to grow up like any normal child, happy and very healthy.

Faith was born in King's College Hospital at 23 weeks and 1 day. We were told immediately that she wouldn't make it. Her dad noticed she was moving her limbs and raised this to the attention of the staff; suddenly she cried out all by herself and immediately everyone sprang into action. She was taken to the Neonatal Unit, and stayed at King's College Hospital for one year and three months. During her time there, she was transferred to St Thomas' hospital where they performed the tracheostomy operation for her breathing. She stayed there for two weeks and, after returning to King's College Hospital, she was transferred to another department where her other needs could be better met e.g. physiotherapy, dietician and to monitor her development.

Once Faith was discharged from the hospital, she was placed in the care of Demelza Children's Hospice and then when she returned home, she began to receive support from Bromley Early Support. She requires ventilation via tracheostomy due to Subglottic Stenosis. She is currently being weaned off CPAP* and is off the ventilator for 12 hours during the day. When she has a nap and overnight sleeps she is on CPAP of 6cm H2O and 1 litre of oxygen. She requires overnight presence of a carer who monitors her ventilation needs and maintains a patent airway when she is asleep. Faith is fed via a gastrostomy; she is also able to cope with small amounts of oral feed, which is being monitored by health colleagues.

We met our Keyworker and she organised everything; she helped at a difficult time, while we waited for our leave to remain in the UK to be granted. When our leave was granted, we were then facing eviction from our accommodation; at that time, our Keyworker and Social Worker gave us vital support. We have had regular Multi-Agency Meetings, where all the team get together to review Faith's needs and the needs of our family. These meetings help us to know what stage we are at, and where we are going. Without the services and support we have received, our lives would have been miserable.

Faith is currently receiving Portage home visits and we are aiming for her to start at the Phoenix Pre-School in September 2013. We are a little worried about Faith's speech, and the fact she hasn't made any noise yet at all; perhaps when her tracheostomy is out, she will. She does appear to be mouthing words and we would love to encourage this.

Our aspiration for Faith is that she is free from her ventilator and has the surgery to remove her tracheostomy soon, that she has a good education, and that she makes a useful life for herself.

In September 2013, it is proposed that Faith will commence a placement at the Phoenix Pre-School Assessment Centre for assessment by a multi-agency team who will be working together to support Education, Health and Care planning.



* see Jargon Buster page 34

Pelin

Leyla (10)

Beckenham

Leyla has a duplication of chromosome 17, which affects her cognitive ability to learn typically and her general physical growth and development. Her condition does not have a name, and we refer to Leyla as a SWAN because she has a Syndrome Without A Name.

Leyla has complex medical issues, despite which do not stop her trying to achieve and overcome the barriers she faces in her everyday life, including; severe myopia (short-sightedness), nystagmus, hearing loss and glue ear, epilepsy and some considerable mobility difficulties. Leyla is thriving in all aspects of her learning and development at a local specialist school in Orpington. Leyla also attends a mainstream out of school club where she enjoys playing and socialising with her friends and peer group.

My pregnancy was a typical one apart from the usual symptoms and there was no reason for me to believe there would be difficulties later on. I was induced at full term due to a major reduction in my amniotic fluid, followed by a caesarean section. Following the birth of Leyla, I struggled to feed her, as she was not able to latch on and I had to find alternative ways to ensure she did not lose any more of her birth weight. She was born a modest 6 pounds, but looked so small and frail. When she was 5 weeks old, she became very seriously ill and had to undergo an operation for Pyloric Stenosis (correction of the opening from the stomach to the first part of the small intestine). We also discovered that she had Pulmonary Stenosis of the heart and it was then that we realised that these symptoms could be part of an underlying syndrome. The next few months would prove a very difficult and testing time for both Leyla and the family. We were fortunate to have a great amount of support from our health visitor, who was there for us if we required support or just to talk to someone about some of the issues we were potentially facing. Leyla eventually became stronger and things settled down. We were offered a Portage Worker and Leyla was able to access the Phoenix Centre sensory room and also went on to receive a course of hydrotherapy sessions.

Leyla was one of the first children in Bromley to be offered the Early Support Programme, which enabled us to receive more support and information that would suit our family's needs. Everyone was friendly and made us feel that we were not alone and help was at hand if we needed it. This was a very vulnerable time for the family and the support was appropriately gauged to enable us to continue focusing on raising a family, albeit with a slightly different twist to how we expected to carry out our duties.

Leyla has a keen interest in horse riding, swimming and riding her bicycle and just generally enjoys being around people. Similarly to my other children, I would have high expectations for Leyla. I am realistic and I understand that Leyla learns and comprehends very differently to typical children, but this does not suggest that she wouldn't be able to follow a 'life path' to suit her as an individual and to maintain her needs and preferences as her character prescribes. My main priority for Leyla would be for her to be able to live and advocate for herself in the most independent way she possibly can. We are lucky enough to have an amazing network of support, which consists of family and friends and most will be aware of the hopes and aspirations we have for Leyla.

We made reasonable adjustments in our lives to care for Leyla and she fitted in well with our family. I do not believe that having a child with a disability is necessarily a tragedy, it's just a different way of living and

loving with different abilities, although in the earlier days I may have initially thought more negatively about this. Through Leyla we have met some wonderful people and gained some meaningful friendships that have enriched our lives in more ways than one.

As a parent, I have been fortunate enough to work within the disability spectrum, which has enabled us as a family to share in the knowledge and understanding which I have learnt of the possibilities and opportunities that Leyla and other children with disabilities can experience through their life journeys. We are very aware that there will be many hurdles to overcome in the future, but we will support Leyla to make those all important life choices where possible to enable her to live the most ordinary life as she knows it.

Leyla was one of the first children in Bromley with complex needs to receive support from a designated Keyworker and multi-agency meetings, placing the team around the child and family.



Laura, Edward and Ophelia

Aiden and Alex (6)

Orpington

Aiden and Alex are loving, inquisitive and cheeky twin boys who are on the Autistic Spectrum, in addition to having learning difficulties, and delays in the areas of speech and language, attention and listening, and some motor skills, due to the fact that they were born extremely prematurely.

They are currently attending a Special Educational Needs Unit attached to a mainstream school, and are slowly integrating into a mainstream class. Unfortunately, being in a small class together means they are together all day, with more opportunities to wind each other up! Their teacher reports that when one is off school through illness, the other is much calmer in class. Both Aiden and Alex have limited imaginative play skills: this means that, unless they are engaged in watching TV, or playing on the PS3 (both of which I try to limit), or an adult is leading their play, they will tend to engage in rather boisterous play with one another, inevitably ending in a huge mess, and someone getting hurt (if not one of them, then their nearly 3-year old sister).

Aiden and Alex were the result of my 3rd In Vitro Fertilization pregnancy. The first sadly ended in the first trimester, whilst in the second pregnancy, we lost twins at 5 months of pregnancy. We were referred to a consultant, who told us that my going into labour at 5 months was probably just “one of those things” as twin pregnancies do carry higher risk, but that he would put a suture into my cervix to hold it shut anyway, and monitor me with fortnightly scans. We were delighted to become pregnant with twins again. However, at 23 weeks, a scan showed that my cervix was becoming shorter, and I tested positive for Fetal Fibronectin, a hormone which indicates that an expectant mother might soon go into labor. We were devastated, and, less than a year after we lost our first twins, convinced we would lose these ones too. I was immediately taken into hospital on bed rest and given steroids at 24 weeks to improve the babies’ lungs, in case they arrived early.

Aiden and Alex were born at 26 weeks and 2 days, weighing 2lb1oz each. They were immediately whisked off to Neonatal Intensive Care, and I saw them 6 hours later; these tiny, fragile little babies covered in tubes and wires, that I couldn’t touch.

Both Aiden and Alex had a stormy neonatal period, on and off the ventilator and CPAP* for nearly 6 weeks, getting infections, Alex had a small bleed on the brain and Aiden narrowly avoided surgery to close his PDA (a small hole in the heart common to premature babies). Having a baby in the NICU* feels like one step forward and two steps back, until one day, they were considered well enough to go to the SCBU*, where they spent another few weeks, before being discharged to the local hospital for 2 weeks, whilst home oxygen was organised, as they both came home with oxygen to support their breathing, via a nasal cannula, which meant bringing two oxygen cylinders with us if we went out anywhere. We also had several medications to give them every day. We were referred for some respite by our respiratory nurse, and subsequently referred to Portage, by our respite nurse.

They started to receive the Portage service when they were around a year old; our lovely Portage home visitor would visit us fortnightly and lend us toys and give us ideas for teaching our special boys through play; skills which tend to come more naturally to typically developing children, such as turn taking, asking for more of an activity, using Makaton to support communication (I had also taken the boys to a Makaton signing class from around 6 months old, but they were always reluctant to sign). Our Portage home visitor was instrumental in



them, and also referred us to the Phoenix Pre-School, an amazing placement, which they still talk about now. They also had a [SIPS*](#) worker at their mainstream pre-school, which they greatly benefited from, and limited disruption to the rest of the class.

When we got the diagnosis for Autism Spectrum Disorder for both boys, I was a little surprised, but in some ways I found it quite reassuring that they had a diagnosis, as in the back of my mind, I couldn't help but wonder sometimes if I just wasn't doing a good enough job as a mother, as they could sometimes be viewed as "naughty" or "weird", which is upsetting, particularly as they are getting older, the differences between them and typical 6 year olds is becoming more apparent.

A short term aspiration for the future would be figuring out some way to get Aiden and Alex to sleep in under the 2+ hours they are currently taking!

I would like to become less isolated as a family; when you have children who go to school on school transport, it's impossible to build up friendships with parents of other children at those settings, and subsequently they rarely see any children outside of school, as we also moved to a new area when they were 1 year old, and have not really met anyone with children (this is compounded by the fact that I work). Some coffee mornings in child-friendly venues for parents of children with additional needs would be very welcome, to build networks with parents in similar situations. I would also like to see greater provision of out of school activities for children with learning needs e.g. swimming, sport, dance. At present the choices seem to be either to watch your child struggle, and take up most of the instructors time, in a mainstream session, or take your child to a Special Needs session, which are few and far between, and never at family-friendly times.

Educationally, I would like to see Aiden and Alex progress into separate mainstream classes, with an appropriate level of individual support, with a view to attending a mainstream secondary school, although as they get older, I am becoming aware that I need to keep an open mind as to where they would most thrive. Long-term I aspire for Aiden and Alex to be happy, and to be given every opportunity to succeed in life and be a productive member of a society that accepts them for who they are.

I feel that our journey to have our special boys has meant that I am more accepting of the boys' additional needs - I was warned even before they were conceived that they were at risk of them, and we were just so thankful to have happy and mostly healthy babies, that it seemed a small price to pay; there was no sudden shock diagnosis, nor gradual feeling of unease as we realised that things weren't quite as they should be.

Having said that, this could have greatly worked against us had Aiden and Alex not come home on oxygen, requiring us to have a respite nurse, who referred to the Early Support Pre-School Panel. They could easily have slipped through the net, and not received the early intervention they so greatly benefited from; we would not have sought services as we didn't know they existed. I dread to think how far down the line we would have finally received some support, especially since, for the first 18 months or so, they were largely meeting their milestones age appropriately. I don't want to imagine how different life could have been without specialist support in our lives.

Sarah

Joshua (9)

Orpington

Josh has Down's Syndrome. A blood test a few years prior to having him confirmed I carried a 'balanced translocation' and that there was an increased chance of having a baby with Down's Syndrome. We were given the diagnosis two weeks after his birth.



Josh goes to a Special Opportunities Unit within a mainstream Primary School. This environment seems to suit him, enabling him to continue progressing. He has regular eye, hearing and thyroid function tests. His hearing is not good at the moment and we have been told he may need grommets or a hearing aid. Josh is a real mixture and can go from being quite indignant and rude, or behaving inappropriately and being unaware of boundaries, to acting quite maturely, being extremely polite, helpful, kind, very funny and great company. He absolutely loves sport, particularly football.

The journey has been well supported with community services. We received Portage services and the regular visits were greatly valued. I was invited to participate in various workshops. Josh attended a play session and then the classrooms at the Phoenix Children's Resource Centre. We were introduced to a Down's Syndrome parent group which has been an invaluable support providing information as well as great friendships. More recently Bromley Parent Voice has held meetings and conferences for parents, supporting us in the changes in legislation.

It turned out our Keyworker for Early Support was the same person we had established relationship with through Portage and this was great. When Josh started at a mainstream nursery our Keyworker was pivotal in providing them with the information and aids to enable them to best support Josh. As a direct result of this the nursery introduced Makaton and more visual support for all of the children. Josh had a SIP worker who was given information on the classroom targets and worked with him on these, providing a consistent approach.

We received help from the Early Support Team with the transition from the Phoenix Centre to Education and our Keyworker also provided advice on the statementing process which alleviated many of my concerns.

My aspirations for the future would be to eliminate stigma and for communities to be fully inclusive and embracing of any differences. I feel one of the ways this could be achieved is for more encouragement and support of integration within education. On a more personal level I would like to see Josh continue to progress in education, go to college, have a fulfilling job, make friends, have relationships, live as independently as possible and feel contented and supported as he approaches old age.

I was really pleased to hear that nationally, the Early Support approach is being extended across the age range. It has been a valuable input for us as a family and really improved the intervention and support Josh received from services. It is good to know it could be available for Josh in the future if and when he needs it.

Annette

Ash (18)

Beckenham

Ash had a late diagnosis and the instruction to get him a special need assessment for statement so he could be moved to a suitable school was not followed through. He missed out on appropriate early intervention in regards to education as a result of this; the situation makes him very angry and sometimes adds to his depression.

Ash now attends school and is willing to improve his confidence and social skills. Although he finds it difficult to cope with new tasks and understand the culture of school life since he has been out of school for so long; I am hopeful this will continue to improve with time. His hygiene and personal grooming has also improved- he now brushes his teeth without fail no matter how he is feeling! He enjoys going to his youth club and this seems his main avenue to socialize. I am encouraging this also because he has no particular friends and I believe he should relate more with what is happening in the community. The cost of travelling is however a major concern for us but we have applied for a taxi card (since he finds it difficult to travel amongst large groups of people). I am not sure if the application will be approved and he is quite worried about this.

Our first contact with the Bromley Early Support and Complex Needs Team team was in 2011 when Ash's was allocated a Keyworker and this has been of help to us.

He is interested in making something worthwhile of himself even though he is not sure what this will be yet.

Since writing this Journey, Ash has relapsed a little bit. He is not engaging with anyone at all at the moment; we are awaiting further assessments and support because of this. Although this could be a slow process but I feel more empowered to support Ash better now.

Ash was part of the vision rolling out the Early Support model to school age children. Ash's transition to adulthood will be supported by a Preparing for Adulthood Co-ordinator whose main focus is to work with young people with more complex needs and families to develop Education Health and Care plans that meet identified need and support long term goals. They will assist in the development of keyworking principles, EHC plans, Personal Budgets and mapping the new pathways which aligns to the Government's legislation across Education, Health and Care.

How did we choose which parents were part of this project?

It was important for us to represent a wide range of experiences which could inform decision making after the project was completed. To aid this, the following criteria were considered while choosing the parent group for the project:

- a) **Early Support involvement with families:** We considered families who have had the involvement of Early Support Full Programme; those who have been on the Early Support Parent Workshops, as well as those with experience of specialist support. These variations gave us a good basis for comparing the positive impact of early intervention for families.
- b) **Age range of the children involved:** families were considered whose children covered the different age range in order to have representations reflecting the new Early Support Key Working focus of birth to 25 years
- c) **Disability range:** care was also taken to involve participants spanning the different disability range represented across the borough. Hence, we had parents of children with cerebral palsy, autism, developmental delays, physical disability, chromosome imbalance and other conditions.
- d) We included families where English is not their first language; and also a fully Looked After Child to ensure wider representation.

Learning through the Parent Journeys

Discussions that took place with the Parent Journey Workshops

- a) The group was informed of the Government's proposed reforms set out in the Children and Families Bill which aims to improve experiences of services and support for children and young people with Special Educational Needs and Disabilities. These were debated, with parents raising their concerns, clarifying grey areas and giving suggestions appropriately. The avenue served as an excellent way of raising awareness and giving information to parents regarding these issues.

The group was able to also review and critique the initiative of having the EHC Plan template on the iPad through the Early Support Application. This app is aimed at parents, young people and practitioners. Its purpose is to provide them with information and also the ability to record important things about themselves that they will then share with others, such as doctors, nurses, teachers and even employers. The practicality and adaptability of the system, as well as how user friendly it is, were all critically looked into and feedback was collated appropriately and sent to the Early Support Consortium. The group was delighted to be joined by Eileen Strevens, Information Co-ordinator National Early Support Consortium at the workshop. It is intended that the app will be trialled to test whether or not it can link with the Government's SEND reform agenda around a single Education, Health and Care Plan.

- b) We also had parents bringing their individual experience to shape future services, improving outcomes for children and young people and their families. The forum provided the parents involved with invaluable emotional support; as parents shared their stories and received encouragement from one another. This has further shown the importance of parent-to-parent support.

What parents told us: key learning evidenced during the Parent Journey research:

- Parents welcome the vision of extending the Early Support way of working to adulthood; to help parents of children and young people with more complex needs make more informed decisions regarding their disabled child as they prepare for adult life
- Parents of children and young people with complex needs were clear that holistic support through Multi-Agency and Next Steps Meetings is effective for better co-ordination and management of the child's progress. Although currently only available for pre-school children, it is intended that the new Education, Health and Care Plan process will incorporate these aspirations
- The Local Offer and Early Support materials and resources will be welcomed as they will provide families with timely information supporting them to make informed choices
- Families value additional support when their child moves on to the next stage of their journey; smooth and seamless transitions, especially to school and when preparing for adulthood. The recent appointment of Preparing for Adulthood Co-ordinators was seen as an exciting new development by parents
- Parents and carers wish to be well informed and want clear and up to date information so they are more empowered to make informed choices, to better support their disabled children
- Families have aspirations for their disabled children, to live, where possible, independent lives in the future

Some families highlighted that they would like:

- More awareness and information about some disabilities such as Autism
- To have Keyworkers to navigate the system for those with more complex needs and more understanding and sensitivity from professionals
- More opportunities and avenues for parents to meet, share and support one another better
- Quicker responses and information from professionals, as well as good and effective communication between services and families
- Simplified paper work and a faster decision making process for issues regarding the disabled child, for example housing, equipment and so on
- Improved access to short breaks

At a time of austerity and significant radical reforms it is more important than ever to modify our working practice to promote meaningful participation. Working in partnership with parents leads to better family experiences and confidence in services, better value for money and better outcomes for children and young people.

Closing Message from Parents

Having a child with a disability is without doubt a unique journey. Each family's experience depends largely on the uniqueness of their child, their individual family and the support available to them. More often it can change our entire outlook on life itself as goals are reviewed, interests changed, dreams redefined (and sometimes lost!!!). The untrodden path of all involved take different turns every now and then in order to accommodate the new demands placed upon us. It is very clear from our different stories how much we take on in addition to the usual demands of life. Interestingly some of us would not have it any differently! Why? because through our journeys we have been able to grow, learn more, acquire new skills and above all love and value our children for who they are.

As a group we have found the process of going through our family journeys helpful. To hear each other's anecdotes has been enlightening, thought provoking and very moving. There have been a few tears and much laughter along the way. It can be humbling to hear other families' stories. We have been supported by Early Support, The Maypole Project and Bromley Mencap during this project, and wish to thank them for the marvellous work they do in supporting our very special families.

The families involved have drawn upon each other's experiences. It is always reassuring to know we are not alone. Whilst all of our journeys are unique, we often face similar situations.

As parents we know that it often helps to talk and share with people who have experienced similar issues. Many of the group are happy to share their experience with you and can be contacted via Bromley Parent Voice in the first instance at: info@bromleyparentvoice.org.uk

We hope you have enjoyed this book and have found it useful and informative.

The Parent Journey research has supported Pathfinder and Consortium work around co-ordinated assessment, the single EHC plan and the local offer.

Jargon Buster

Amniocentesis: *Amniocentesis is a diagnostic test carried out during pregnancy. It can assess whether the unborn baby (foetus) could develop, or has developed, an abnormality or serious health condition.*

Autism: *Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with Autism share certain difficulties, their condition will affect them in different ways.*

Atrioventricular Septal Defect: *is a form of congenital heart disease – a term used to describe a problem with the heart's structure and function due to abnormal development before birth.*

Bi-Level Positive Air Pressure (BiPAP): *A BiPAP machine is a relatively small device that assists with a patient's breathing. It is connected by flexible tubing to a face mask worn by the patient. The BiPAP machine helps push air and oxygen into the lungs and then helps to hold the lungs inflated, thereby allowing more oxygen to enter the lungs.*

Cerebral Palsy: *is a condition in which there may be abnormal brain development or injury to the brain as it develops. This can occur before, during, after birth or during early childhood. Children with Cerebral Palsy have difficulties in controlling muscles and movements as they grow and develop.*

Continuous Positive Airway Pressure (CPAP): *is a treatment that uses mild air pressure to keep the airways open.*

Down Syndrome: *is a genetic condition that typically causes some level of learning disability and a characteristic range of physical features.*

Electroencephalogram (EEG) *is a recording of brain activity it is mainly used to diagnose and manage epilepsy (a condition that causes repeated brain seizures).*

Family Service Plan: *This is a document of current priorities which is family led, written at a Multi-Agency Meeting, in discussion with the professionals and agencies supporting them. Regular review meetings take place to ensure the plan continues to meet the families' needs. Families of children receiving Early Support Full Program will have a Family Service Plan.*

Global Developmental delay: *A child may be described as having global developmental delay (GDD) if they have not reached two or more milestones in all areas of development (called developmental domains). For example: motor skills, speech and language, cognitive skills, social and emotional skills.*

Keyworker: *named single point of contact, usually the person working most closely with a child, who will support the family in co-ordinating help, advice and signposting.*

Magnetic resonance imaging (MRI) *is a type of scan used to diagnose health conditions that affect organs, tissue and bone.*

Multi-Agency: *Multi-agency work involves professionals working together from health, social services, education and the voluntary sector.*

Next Steps: *A play session for a child where the family and professionals can plan goals (Next Steps) and activities together.*

Phenobarbitone: *Phenobarbitone is a central nervous system (CNS) depressant that it mainly used for the management of epilepsy but can also be used as a sedative.*

Portage: *A home visiting educational service for pre-school children who have additional support needs and their families.*

Meningoencephalitis: *Meningoencephalitis is an inflammatory process, most often due to viral infection, involving both the brain and meninges.*

SEND *Special Educational Needs and Disability.*

SIPS: *(Supporting Inclusion in Pre-School Service) A flexible range of support (which may include a grant) can be given to Early Years settings (for children eligible for Free Early Education) to provide additional support for children with severe and complex needs to fully access the Early Years Foundation Stage curriculum in mainstream pre-school.*

SPEACS Service: *(Speech and Language Therapy and Portage – Early Action for Children’s Communication Service) For children who have social communication needs, specialist staff will support the child and family and where appropriate, they will support and contribute to the health assessment process of the child’s social communication and interaction skills.*

Notes

