

# TWENTY

realising  
our children's  
rights

parents  
active

2001-2021



**Celebrating 20 Years Together**



# CELEBRATING 20 YEARS OF PARENTSACTIVE

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### **Parentsactive Lead**

Nandini Ganesh

### **Parentsactive Chair**

Mary Melsom

### **Parentsactive Steering Group**

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Claire Foster

Collette Anazodo

Debbie Moses

Helen Soteriou

Ildiko Wurth

Marie Canning

Martin Schouten

Mary Melsom

Siri Lewis

Ageno Ochola



### **Parentsactive Admin & Accounts**

Reema Sharma

# Nandini Ganesh: Marking 20 years of Parentsactive



At a meeting earlier this year Joseph Tobin, who has taken over as the team lead for the DSR key working pilot project, met me for his induction. He had read the Parentsactive website thoroughly, even more than me and remarked "isn't it, your 20th year?". During the pandemic and lockdown, days, weeks and years had merged into one and the remark took me by pleasant surprise. Yes, it was and as we are emerging from lockdown, we need something to celebrate. I thought of an event but with variants lingering in the background, I then thought why not chronicle the 20 years? I joined in 2007 as a nervous coordinator and have survived 14 years to write this piece. I first heard of Parentsactive in 2005 when I was new to the borough and my son was 7 years old. I attended an event in Options around that time and met Amanda Roles who was coordinating the forum as well as advocating for parents. Amanda put me on the membership list, and I used to read her weekly emails regularly. When the job was

advertised as a part-time position in 2007, it suited me as a mum and I applied for it, rest is history, and it has been a good one. What is Parentsactive? Apart from the standard definition of a forum which we will see later, I see Parentsactive as a force that brings parents of children with SEN and disabilities together. While children may have schools, clubs, day centres, what about their parents? Where can they go to voice their fears, their anxieties, their frustrations in a safe atmosphere? For me, Parentsactive is that opportunity. It is the chance for parents of children with different disabilities, varying needs, different schools, and backgrounds to come together for a common cause. Throughout this write up I have touched upon Parentsactive or PA for short, liaising and influencing various services, I do not see this as an achievement, I see it as a work in progress. PA may not have solved everyone's individual problems; however, it is a

collective voice. A voice that has brought the Heads of Services, Leaders, and Councillors in front of parents, so parents can voice their concerns and speak their minds. The forum has bridged the gap between professionals and parents and in the words of our Chair Mary Melsom, rather than Us and Them, it has become Us. Parentsactive has always tried to get information out to parents whether through newsletters, weekly meetings, pestering emails, social media posts or WhatsApp broadcasts, we are everywhere and make sure parents are in the know. I wish PA all the best and here is to 20 more glorious years with enthusiastic members as we stand tall with 500 plus members over the years. My proudest moment was to be nominated for Outstanding Contribution to the Life of the Borough at the inaugural Hammersmith and Fulham Civic Awards in 2018 Thanks PA.





We are 20!

3 Fun Days



Over 10 conferences

500+ members



507 coffee mornings

More than 100 Training events



Founding members

# Stuart and Francesca Walker: 2001 The Early Years



In the early years of 2000, I remember being invited to be on the interview panel by Amanda Roles from Mencap to help appoint a Coordinator for Parentsactive. This took place in Hammersmith where we met and interviewed a young mother called Nandini Ganesh for the role. We were all impressed by her and her commitment to her young son and by her strong desire to help Parentsactive and other families.

I think that the passion she expressed was so convincing and genuine that we offered her the job. We have never looked back and have been rewarded many times. Since that time Amanda Roles and Nandini have worked collaboratively and tirelessly to place Parentsactive in the areas of importance and influence and they have continued to do so with good humour and great drive.

Stuart Walker

Stuart is also the  
designer of our lovely  
Parentsactive logo!

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rights  
**parents  
active**

Back in 2000, a small group of parents, including Stuart and myself met by chance at the Carers Centre in Hammersmith. All drawn together by our mutual need for help, to find some sort of way forward to enable us to do the very best for our young disabled children, all with differing needs.

It was very clear to me then, that the group comprised of parents who were capable of making a real difference.

Gradually the meetings became regular, Nandini was appointed and new equally committed parents joined the group and soon an effective steering group was formed, venues for meetings became established along with a logo and branded T-shirts!

I remember the wonderful Parentsactive Fun Days with all day long entertainment for the whole family and pampering sessions for mums. A great feat of organisation. I remember conferences being arranged and held on many different topics, always fully booked. Quality food and refreshments

always available, such an important detail, never overlooked. At these conferences, it was lovely to catch up with parents who one now felt were friends through our shared experiences, to meet new parents and to secure new contacts and friendships.

Over time Parentsactive under Nandini's inspired and enthusiastic leadership, has secured a way forward to reach out to families and carers of disabled children to inform and support, while at the same time championing and voicing their needs to local authority departments, social care, health and education. It has become a very much respected organisation, and I am proud to feel I have been a very very small part of it. Thank you to Parentsactive and to all the amazing parents that have offered their time, energy compassion and determination to inspire us all to keep striving for the very best for our children whatever their age.

Francesca Walker



# Gina Gerrard:

***I found a much-needed platform from which to share my experiences as well as nurture a strong sense of community spirit. From this group, Parentsactive was born***

26 years ago my life changed when my first daughter was born with profound and multiple needs. This opened up a whole new world to me, initially a very lonely world, as I tried to navigate my way as a mother and full-time carer around the challenges of her disabilities and what I perceived to be a lack of adequate resources to support me. Gradually as I met with other local parents of children with learning difficulties and complex health needs, I found a much needed platform from which to share my experiences as well as nurture a strong sense of community spirit. From this group Parentsactive was born and as a founder member I really hoped that by coming together we could make our voices heard and work together to improve the services and resources for our children and for other families. My main personal aspiration was simply to get health, education and social services around the table together to promote a more holistic and

integrated approach. This did prove challenging! I also wanted to see parental representation at panel meetings together with improved respite and holiday schemes and increased therapy provision with ready access to hydrotherapy.

With a daughter with complex health needs, my focus turned to improving disabled access, resources and professional attitudes within the hospital setting. I became a member of the Learning Disability Steering Group at Chelsea Westminster Hospital and worked closely with the LD nurse on Transition planning for Young People with Complex Health Needs as well as advising around making reasonable adjustments and hospital passports. I have also campaigned with another parent to get overhead tracking in place on the children's wards and in outpatients – no longer do we have to carry out personal care on the floors of consulting rooms. Particularly rewarding

has been my involvement with the installation of the 'Changing Places' on the ground floor of the hospital.

As a member of PA, I have advocated for two families with children with complex needs around education, respite and housing provision. Recognising the lack of local specialised living provision, I have also worked with the CCG, LA and a provider to set up a home in the borough for young adults with high health needs. Sadly, this project is on hold, but I would hope that it will be continued especially as there is currently a lack of unskilled carers and clinical staff to support individuals in their private home settings. Every young adult whatever their needs has a right to choice and if this entails living in an environment that provides the social and therapeutic stimulation that they want, then this should be completely accessible.





## **Mary Melsom: 2021**

### ***A lot has changed in 20 years***

A lot has changed in 20 years. Recently, an old friend has asked me to support her nephew and his wife whose 2-year-old son has just been diagnosed with autism. They live up north and speaking with them has brought back a lot of memories from 20 years ago when my son Tom was also 2. When Parentsactive came into being 20 years ago, I was at my lowest point as a parent. I was frantically trying to get someone to listen to my concerns and secure the support little Tom desperately needed. I was clueless as to what he needed and who to ask. I went from pillar to post only to be put on one waiting list after another never really feeling like I was quite being believed. By the time I

stumbled upon Parentsactive, Tom was already 10 and transitioning to secondary. If only I had found Parentsactive right at the start of Tom's life, I would have been so much better equipped to navigate through the immense challenges of raising a SEN child. All those useful sessions on various aspects of SEN and the opportunity to meet with the professionals responsible for making decisions for Tom would have made such a difference to me. I think most of all I would have loved to have the amazing peer support of parents who are going through or have been through exactly what I was facing. Of course, my first piece of advice for the young family in York was to join their local Parent

Carer Forum so as to be plugged in to all the local knowledge that is so hard to find on your own. Most importantly, I hope that joining their local forum will enable them to meet other families going through exactly what they are. Happy Birthday Parentsactive and thank you to all the members who have made it such a successful forum over the years. I am proud to be the Chair of such a longstanding and resilient forum which has grown and adapted to all the challenges thrown at it over the last 20 years.

**Mary Melsom has been  
Parentsactive's chair since 2010**



Conference 2016

## ***They travelled with us for more than a decade...***

I was introduced to Parentsactive by another parent when my son was 4 and newly diagnosed with Autism. They have been a great help to me as not knowing anything and facing many issues with my son was very stressful. Parentsactive guided me and helped me with many hurdles such as applying for a statement and then moving to an EHCP and school. A few years later I joined the committee and have been a committee member now for many years.

Coffee mornings have always been very informative and it's good to speak to other parents and carers. The professional coffee mornings are very useful - giving an opportunity to talk to them directly, to find out information about what is going on and also a good opportunity to resolve issues.

My Son is 16 now and I still need support and guidance from members; I am grateful for all the support given. Thank you to Parentsactive for the ongoing support. They continue to put in a lot of hard work to resolve issues and try to make things better for parents in the borough.  
Happy 20th Anniversary  
Parentsactive!

Marie Canning

Twenty-five years ago when we arrived in Hammersmith with our severely disabled baby, we had no guidance, no expertise, nothing to help us through the labyrinth that was the mix of social care, health and then education. We immediately saw how parents with special needs children became sucked into a nightmare abyss of form filling, sickness, hospital appointments

and impenetrable and often heartless bureaucracy. It was a situation that ruined lives and families.

Parentsactive was set up by the foot soldiers of this experience, mothers and fathers like us who realized that special needs children needed a local advocate, a collective effort that would fight their corner and spell out to government/council officials what was needed and what was required by law. And most important, practical and moral support for each other.

As Parentsactive grew, the local authority knew they had to take notice. It helped them learn to do their jobs better. It helped parents learn the difficulties of those jobs. It created understanding of a process that, too often, has been described as a battle. It helped parents and the local authority work together to solve problems. It helped children and families move forward to a higher quality of life.

For those, now, whose lives are turned upside down by the birth of a special needs child, Parentsactive is there for you. Thank you to all those, and us, who have made Parentsactive the force for good that it has become today. Thank you Parentsactive for being there and giving very special children the future they so much deserve.

Happy anniversary!

Jonie & Humphrey Hawksley



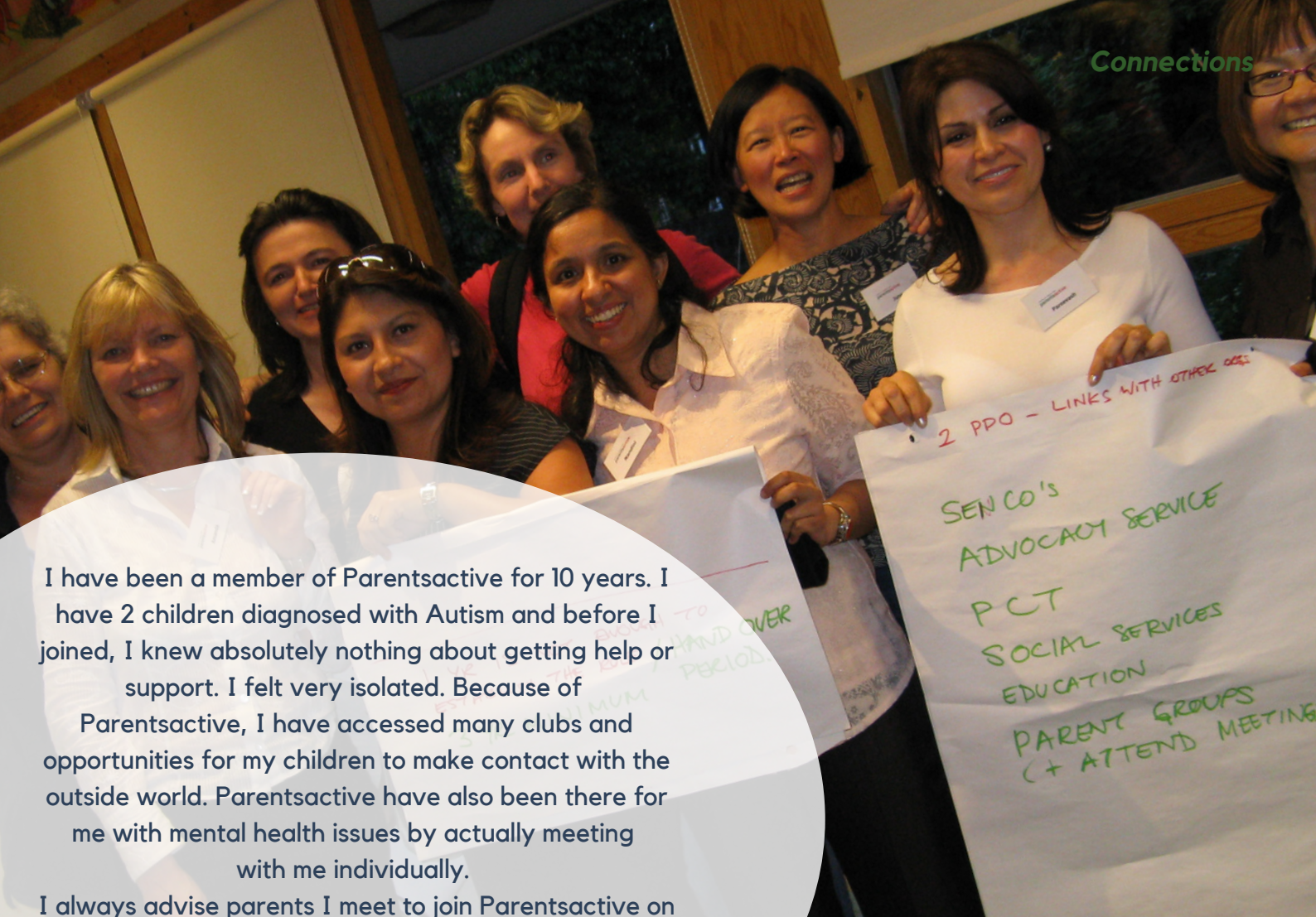
I have been a member of Parentsactive for 10 years. I have 2 children diagnosed with Autism and before I joined, I knew absolutely nothing about getting help or support. I felt very isolated. Because of

Parentsactive, I have accessed many clubs and opportunities for my children to make contact with the outside world. Parentsactive have also been there for me with mental health issues by actually meeting with me individually.

I always advise parents I meet to join Parentsactive on their journey with their children. Things will improve, they will learn so much about opportunities and rights.

I owe Parentsactive a lot, especially to Nandini who is the driving force of Parentsactive. Thank you.

Helen Souteriou





# Parentsactive and HF **mencap**



## ***Growth, Stability and Interconnections for the group under the HF Mencap umbrella***

Parentsactive was adopted by HF Mencap as one of its projects in 2003 by its CEO Teresa McGinn. The stability and structure of HF Mencap has benefitted the forum enormously. It has also encouraged partnership working with all HF Mencap projects such as Advocacy, Play, Early Years, Transitions Practitioner and the My Life Day centre.

In 2002 parents of disabled children approached HF Mencap to set up a Parents Group. I worked with a small group of parents to establish a regular forum where parents could meet together to support one another, to share experiences, and campaign together.

The forum was developed by a group of parents who decided to call the forum 'Parentsactive' which was linked to HF Mencap. The work of Parentsactive complimented the work of other HF Mencap projects. In 2007, as a result of the campaigning by Parents and Carers HF Mencap were successful in gaining funding for a Parent/Carer Advocacy Post. The Parent/Carer Advocate supported individual Parents/Carers to know their rights and challenge decisions made and receive the services and support needed. Over the years, Parentsactive have developed into a excellent resource in the borough, supporting a very wide and diverse group of parents, and are highly

respected by the Local Authority, local NHS services and other borough organisations. Parentsactive are the 'go to' organisation when the views of parents, carers and families are needed. The regular support sessions have been really well attended and very influential. Over the years a number of ground breaking events and conferences have been delivered by Parentsactive. They are very respected by everyone.

I am so proud of the work undertaken by Parentsactive and delighted that they remain part of HF Mencap.

Teresa McGinn  
Chief Executive





***"You absolutely must speak to Amanda Roles and her team. She runs this group called Parentsactive for parents like you and their families. They will sort you out"***

said Bridget, walking briskly behind me as I tried to keep up with my severely autistic 4-year-old son- Nimaro, who could then only be described as "speed". Bridget ran a busy playgroup in Bishops Park, Fulham. Before leaving the playgroup that day, she handed me a piece of paper with Parentsactive's contact details. This was just over a decade ago in 2011.

Parentsactive has been a strong pillar of support to my family. I owe a good part of my sanity to this parents' led group in so many ways. So, with a heartfelt appreciation, I want to wish Parentsactive a very Happy 20th Anniversary celebration and to say below through some reflections just how much it has meant to me in the time I have been affiliated with it.

After first contacting Parentsactive, they were able to refer me to HF Mencap's advocacy service and further down the line and at a breaking point, when I had unsuccessfully tried to access official respite support on my own, a much-needed respite break was granted because of the input from Amanda Roles, the advocate at HF Mencap who represented my family's needs at an official level. Immediately, I felt that

that our personal needs were further validated by having the advocate at HF Mencap, voicing our challenges. Bridget was right, Parentsactive had sorted us out and continues to! I now feel less alone in facing some challenges of raising a disabled child.

Ageno Ochola  
Parent and Steering group member

It has always been wonderful to know that Parentsactive has been there in the borough reaching out to parents and carers. Having been brought up with a brother with Down's syndrome, I have some understanding of the pressures and pleasures families experience. I know how hard people have to fight to get the support, they should, by rights, receive without a battle.

In the past, pre-covid, I have attended some of the conferences Parentsactive has run and I was always impressed with the quality of what was on offer. I know that councillors think highly of all you do. Well done, thank you Parentsactive - here's to the next 20 glorious years.

Julian Hillman  
Chair of Trustees HF Mencap

The Youth Development Project would like to wish Parentsactive a happy anniversary. We are delighted to have been able to work with you over the past 3 years. We hope in 20 years we too are celebrating such a successful project and we look forward to working with you for many years to come.

Kirstin Jamieson  
Youth Development Coordinator





Mencap rounders fun



Parentsactive fun day 2010





# What is a parent carer forum?

## PARENT PARTICIPATION: THE MOVE TO BEING A FORUM

**A parent carer forum is a group made up of parents and carers of disabled children who work with local authorities, education, health services and other providers to make sure the services they plan and deliver really meet the needs of disabled children and families.**

**The forum represents the views of parents in the local area but does not advocate for individual families. There is usually a steering group of parents who lead this and listen to the views of other parents in the local area to make sure they know what is important to them.**

**Forums are keen to make contact with as many parent carers as possible.**

**In England, there are now forums in almost all local areas.**

In 2006 Every Disabled Child Matters was launched, "a campaign to protect the rights and justices of disabled children and their families so that they have access to the right services and support needed" - Council for Disabled Children. This was then built upon in 2007 with Aiming High for Disabled Children, a government agenda to improve outcomes

for disabled children and their families; The Department of Education through the charity Contact (formerly Contact a Family) gave grants to parent/carers forums all over the country. In the years 2008 and 2009 parent/carers forums were formed all over the country. As Parentsactive was already established, we became the forum in H&F. Our forum is affiliated to the National Network of Parent Carer Forums (NNPCF). The money from the DFE is used for activities for the forum to empower families.

Contact administers the grant from the DFE, and we have our own Participation Adviser, Miranda Parrott. Parentsactive is also part of the Northwest London cluster of parent/carers forums with Brent, K&C, Hillingdon, Harrow, Westminster, Hounslow, Richmond, Kingston and Ealing. The cluster meets every term to discuss ideas and common concerns. We feedback our collective concerns to the NNPCF who campaign at the national level. We also participate in national conferences, meetings and have even met the Minister for Children and Families, Edward Timpson, in 2014 along with other parent/carers reps. Our vice-Chair Hayley Wedgbury won the Parent Power award in the 'Contact Together at 40 Awards', while PA was nominated by our Local Authority for Excellence in parent/carers participation at those awards.



Northwest London cluster of Parent Carer Forums group in action

## ***A few words from Contact: On the growth of Parentsactive***

Many congratulations to Parentsactive on their 20th anniversary. I have been the participation Adviser to the Forum since 2017 – and I have had such pleasure in working with Nandini, Mary, Hayley, other Steering Group members and, more recently, with Reema.

The work of the Forum is impressive, and parents are made to feel very welcome – whether at a big conference, at smaller events at the Stephen Wiltshire and Masbro Centres; or online, at virtual meetings and training. I have attended several of these occasions and enjoyed seeing the Forum in action!

This has been a very difficult time for parents and their children, and the Forum has provided a valuable service in offering support and information to guide families

through the changing guidance of the pandemic.

Long may the Forum continue to thrive and grow – providing a vital link between families and service providers in Hammersmith and Fulham. We look forward to hearing of even greater collaboration and co-production in the future – parent views valued and influencing change!

Miranda Parrott - Contact  
Participation Advisor

Congratulations Parentsactive on reaching your 20th year, what an amazing achievement. I have been involved with parent carer forums myself for over 13 years now, from setting one up where I live to now, leading Contact's support offer and grant programme for Parent Carer Forums across England. It has been my privilege to get to know and

work with many parent carers involved in their forums over these years, all of them to passionate about wanting to make a difference for families in their local area and influence change nationally. Parentsactive have always been just that, a very active group of parents! I recall clearly the "We Want to Play Too" survey and report you undertook in 2013 which involved a huge amount of work to gather the views of families on play and respite and led to practical changes in local provision. This was still early days for many parent carer forums and hearing from Nandini about the difference Parentsactive had been able to achieve in Hammersmith and Fulham at the National Parent Carer Forum Conference was inspirational to many others. Your achievements have continued due to hard work and persistence, always keeping the importance of building strong local relationships with families and practitioners at the heart of what you do.

I hope you enjoy celebrating your 20th year and can reflect with pride over what you have achieved, but I also know you won't stop here so I look forward to hearing about the changes you continue to effect for all the families you support now and in the future."

Gail Walshe  
Director of Participation and  
Regional Development





Northwest London cluster group of Parent Carer Forums







Conference 2016

# Parentsactive and Hammersmith & Fulham Council

One of our proudest moments with our Councillors was when Cllr Antony Lillis signed the Every Disabled Child Matters charter in 2009 which emphasised the fact that disabled residents remain the priority of the council over the years.

Parentsactive was part of the Children Education Policy and Accountability committee (CEPAC) since 2014 as the voice for disabled children and their families. The job of the committee is to scrutinise plans and policies relating to schools, education, children, and young people before it is taken to cabinet.

Councillors understood the need for a dedicated centre for disabled children and Cllr Sue Macmillan the cabinet

member for Children and Education, helped with setting up the Stephen Wiltshire Centre in 2018 and this was yet another proud moment endorsed by Cllr Culhane in this 20th anniversary booklet. Parentsactive contributed to the Transitions Workforce set up by the Health and Social care Policy and Accountability committee (HASPAC) and the local authority where our committee member Sarah Markson made valuable contributions in 2017/18 along with Action on Disability, and other stakeholders. The transition work force recognised the challenges faced by young people as they moved on to adulthood and made some key recommendations, though more

remains to be done. The full report can be read on the council website.

In 2018, Parentsactive worked with the councillors on SEN passenger transport through the Transport Working Committee and helped evaluate bids for buses and taxis, resulting in SEN children getting good school transport service.

Parentsactive also worked with councillors over supported employment which ensured that the young people had a choice of supported internships and apprenticeships. Employment for disabled residents remains a priority of the council.

We value the relationship with the Council and our Councillors and appreciate them for attending all our coffee morning sessions, events and for ensuring that co-production remains the key priority of the council.



Ms Nandini Ganesh  
Parentsactive  
H&F Mencap  
65 Aspenlea Road  
London  
W6 8LH

18 May 2021

By email: [Nandini.Ganesh@hfmencap.org](mailto:Nandini.Ganesh@hfmencap.org)



Dear Nandini

### **Letter to Parentsactive**

Congratulations to Parentsactive on this impressive anniversary. You have so much to be proud of and it is a genuine honour to be asked to contribute some remarks to your collective celebration.

Successful organisations do not happen by chance and I know that your achievements are the result of sustained investment of time, effort and passion on behalf of children and young people with special educational needs in Hammersmith and Fulham.

Your Forum has been instrumental in bringing parents and carers together as a powerful and influential voice in the borough and a valued and proactive partner, committed to working productively to find creative solutions that improve outcomes for children and young people.

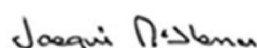
The Forum has built up invaluable knowledge and insight into the local area and been involved in all aspects of the 0-25 experience across Education, Health and Social Care and working closely as a key partner with the different services to inform and shape the way that services are designed and delivered, make the system work better for children and young people's unique needs so they have positive pathways to adulthood.

I am relatively new to the authority but had already been made aware of the magnitude of your work and was therefore very pleased to have early introductions to Mary and Nandini (who was also part of my recruitment!). During this last year I have witnessed directly the central role of the Forum in reaching out to parents and carers across the borough and supporting them to share experiences and, working with education, health and care colleagues to tackle and mitigate the concerns and challenges posed by the Covid 19 pandemic.

After a demanding and worrying year, it is indeed a pleasure and a privilege to mark two decades of achievements.

I know I speak for everyone in Children's Services in thanking and congratulating you and we send the Forum our good wishes for every future success.

Yours sincerely



**Jacqui McShannon**  
Director of Children's Services





Cllr Macmillan at SWC groundworks



Cllr Coleman AGM 2019



Cllr Cowan AGM 2017



Cllr Lillis EDCM Charter 2009



Cllr Culhane AGM 2019



Cllr Cooney and Cllr Binmore SEN information Day 2012



## Happy 20 Years of Parentsactive!

We are delighted to be marking this special anniversary with Parentsactive, who have been working with parents, carers and families for 20 years – always with a focus on how the services and support around them can do better.

In Social Care, of particular importance to us has been Parentsactive engagement in transition and preparing young people with special educational needs and disabilities (SEND) for adulthood. The Forum were a key player in the Transition Task Force report of 2018 and the subsequent establishment of our Transition Team. They have hosted a number of workshops and events which have ensured residents continue to drive, inform and review the way in which we plan and support transition. As experts by experience, their role in co-producing services and support has supported the Council and our SEND stakeholders in focusing on quality, accessibility and inclusion.

We want to thank Parentsactive for their relentless energy and drive and look forward to the next 20 years!

Lisa Redfern

Strategic Director of Social Care



A huge thank you to Parentsactive for 20 years of working to improve the lives of disabled children, young people and their families in Hammersmith & Fulham. The council is determined to make ours the best borough for disabled people of all ages and Parentsactive and its parents and families are playing an essential role in getting us there. Whether in working with us to improve the transition to adult services, develop new pathways to employment as part of our Local Offer or fix the problems we inherited as a new administration with school transport for disabled children and in so many other ways, they are a welcome critical friend and trusted partner. We look forward to working with them in the years ahead.

Cllr Ben Coleman

Cabinet Member for Health and Social Care



# *The strapline of Parentsactive is 'Realising our children's rights'*



CLLR. LARRY CULHANE  
CABINET MEMBER FOR CHILDREN &  
EDUCATION

**I wish we didn't live in a world where this was needed. Wherever you look and however far you go back in history, the treatment of young people with disabilities or special educational needs across the world has been appalling. In Hammersmith & Fulham, we are committed to consigning that to the history books. There is much we have done, and much more to do, but we are much closer to achieving this thanks to Parentsactive.**

If you want to see for yourself just how important a role they play in our borough, head down to Queensmill Road in Fulham. There, you will find The Stephen Wiltshire Centre, a purpose-built specialist centre for young people with special educational needs and/or disabilities (SEND) and their families who live in Hammersmith & Fulham. A storyboard that proudly hangs on the wall

illustrates how their advocacy provided the catalyst for the state-of-the-art centre, built for young disabled residents by young disabled residents.

I am also deeply grateful for the support and critical friendship Parentsactive have given me and my predecessors. I know that no matter how sympathetic and understanding I am in my role, I will never be able to truly understand what it is like to be disabled by society. Working with Parentsactive over the past three years, however, has ensured that young people with disabilities or special educational needs are at the very heart of our decision making through co-production. To put it simply, without Parentsactive the progress we have made so far in Hammersmith & Fulham would not have been possible.





# Parentsactive and Co-production

Parentsactive being the Parent/Carer Forum for Hammersmith and Fulham has enjoyed a good relationship with the Local Authority, we have sat in several committees and influenced a lot of policies and services relevant to disabled children and their families. This has enabled parents to contribute meaningfully to the development of services and have their say. Some of the committees we have sat in over the years are:

1. Short Breaks
2. SEND Board
3. Parents Reference Group
4. SEND Transformation Group
5. Personal budgets
6. Transport Working Party
8. Employment Group
9. Transitions Working Party

We have worked on many policies such as Post 16 guidelines, Transport policy, Direct payments policy, Terms of reference for panels, EHC Plan templates and publications on the local offer to name a few.

We have also sat in interviews and stakeholder panels of SEN keyworkers, Integrated keyworkers, Social Workers, Transition social workers, EHCP Service Manager, Assistant Director of SEND and Disability, Assistant Director of Family Services, Head of Social Care and Director of Children's Services

We have also been the parent voice in evaluating bids on procurement of buses and taxis for SEN Passenger transport, SENDIASS and Mediation.

Being a representative in external committees helps parents understand the system, whilst contributing meaningfully towards the development of services relevant to their children

Parentsactive allowed me to be empowered and vocal in a positive and informed way that has helped me be confident to challenge professionals and pass on my experience to other parents. I am grateful to Parentsactive for embracing me into an organisation that seeks to challenge stereotypes of disabled children and young people and educate the local authority to look beyond the legislation that governs them but see our children as valued members of their community. Congratulations to Parentsactive for their great effects and I wish they continue for many more years to come.

Debbie Moses  
Steering group member

## Connections

It has been an absolute privilege to work with Parentsactive, our wonderful Parent Carer Forum in H&F.

Started by parents 20 years ago as a support group for parents of children and young people with special educational needs and continuing to bring parents and carers together to where you are today as a powerful voice in the local area.

You are always there, no matter what, working with parents and carers, and working with us on innovative ideas to improve the experiences of children/ young people as they grow up.

Applying a unique combination of ruthlessness and sensitivity in the ways you support people and providing a range of opportunities for parents and carers to have their say, empowering them to navigate the complicated systems.

It can't be underestimated how much effort and commitment goes into making this happen but the countless focus groups, training, events, coffee mornings, drop-ins have all made a difference by providing platforms for people to meet one another and to talk directly with professionals, to keep us all touch with real-life experiences and ensure that children, young people and families continue to be at the heart of everything we do.

Thank you Parentsactive for 20 amazing years and are looking forward with enthusiasm to our future working together.

Helen Green

Engagement Planning and Children's services



We were living in another borough when we recognised our son had special needs. It took several years to find our way around the various local services and to gradually develop a local borough support package. When we moved to LBHF the challenge was to transfer the support, schooling and funding to our new borough. Mencap suggested we contact Parentsactive, and they were a tremendous help to get our support package transferred in line with the local LBHF offer. It was the first time we were able to meet other parents encountering similar challenges in getting the required support, and we also found out new ways to help our son.

As a steering group member, I also work with the local council to provide parents' input in the recruiting of LBHF child services staff and in the review of other local children services.

I would advise all parents to join their local parents' groups: Not only can you help other parents, but you will also hear about how they have found new ways to support their children

Martin Schouten





I am thankful as a new member of Parentsactive. I'm learning a lot through other parents' experiences and struggles. I'm also grateful for attending meetings with different topics and hearing advice from experts. And most especially I know I have family and friends I can count on when I need help. Thank you Parentsactive and Happy 20th Anniversary!  
Kenneth Villanueva



Parentsactive has been a lifeline to me as a special needs parent, providing support and guidance on what my child's rights are, and how I should go about it. There have been issues on the way and Parentsactive guided me on whom to contact and how to approach my problems, and to get them sorted. Parentsactive made me feel no longer alone and lost in the system, but supported, and that is so very much appreciated.

With kind regards and many thanks for everything.  
Ekaterina Fields





Opening of ability play equipment 2015

# "We Want to Play too"

Did you know that Parentsactive ran its own Sunday Club funded by Help a London Child every Sunday? The weekly club was originally based in Brook Green, then in Distillery and finally at Bishops Park. The club was run by parents and was intended to alleviate the loneliness that parents face with disabled children especially on Sundays when shops close early. Parents used to meet other parents while children played. This continued till 2009. Parentsactive has always been keen on inclusion, and we went on a mission to make parks, centres and activities to be more accessible for disabled children and their families. We did a survey and wrote a report in 2011 called "We Want to Play too", because of this report an Inclusive Play Coordinator was commissioned and appointed in HF Mencap. The Play coordinator ran play activities for children in many

venues. We also followed it up with another report in 2013 with the same name to make parks more inclusive. As a result of this Mary Melsom, our Chair persuaded Ravenscourt Prep school to choose Parentsactive as one of its projects and the children at the school fundraised for a wheelchair friendly roundabout in Ravenscourt Park in 2015. We also worked closely with the parks department and commented on all improvements in parks. In 2016 Hayley Wedgbury whose daughter Mia is in a wheelchair started campaigning for a wheelchair swing in parks. She successfully fundraised through various sources and managed to get an ability swing in Wormholt park. This also ensured that the Changing Places Toilet in Parkview Medical centre was accessible to park users via a radar key. Hayley also fundraised through Tesco Bag of Life, with the help of Parentsactive,

and got a wheelchair friendly swing in Ravenscourt Park. Hayley managed to raise a whopping 22k!!

Hayley won the Parent Power award at the Together at 40 awards instituted by Contact the National charity for Disabled children and their families. Hayley was celebrated at the Palace of Westminster in July 2019 for her efforts in making parks more inclusive.

Parentsactive also regularly commented on the Summer in the City brochure, H&F's summer activity programme to make it more accessible, sat on Westfield committees as the voice of disability and have also worked with organisations over Changing Places toilets, noticeably in the Lyric, in Stephen Wiltshire Centre and now in the new Hammersmith Town Hall development.







When my daughter was diagnosed with cerebral palsy 14yrs ago my world fell apart. I was so overwhelmed with the news, the many appointments and assessments, I felt completely alone. While the professionals were helpful, I just wanted to meet other parents who understood. I finally attended a Parentsactive coffee morning and met a lovely group of people who made me feel welcome and supported. I never would have thought at that time I would go on to join the steering committee and later become the vice-chair. That was over ten years ago, and although I have recently stepped down from my roles, my daughter and I will continue to benefit from the empowering experiences gained. I have made long-lasting friendships and continue to lean on the group for support. Congratulations to Parentsactive for achieving so much in the 20yrs that they have been serving and supporting our special needs community. May they long continue.

Hayley & Mia





Opening of the Stephen Wiltshire Centre with Stephen Wiltshire 2018



## Short Breaks and the development of the Stephen Wiltshire Centre

Parentsactive was set up by social services in 2001 who encouraged a group of parents to meet and contribute to the development of services. The group used to meet in the Carers centre in the early days. The group then formalised as a committee and approached HF Mencap. In the early days, the Parentsactive committee campaigned for parents to represent themselves in social care panels.

In 2011, Short Breaks Regulations came into effect when all Local Authorities had to write the Statement to outline the arrangements for Short Breaks, Parentsactive coproduced the statement with the local authority.

Parentsactive was involved in the recruitment of the Head of Social services Mandy Lawson in 2015 when Richard Holden retired. Around 2015/16 Sue Macmillan the newly appointed Cabinet Member for Children and Education spoke to the Parentsactive committee. One of the parents commented on how disabled children with their carers were forced to spend time in bus stops and Westfield as there was nowhere to take them. Cllr Macmillan immediately set aside proposals for a new centre for disabled children the Stephen Wiltshire Centre. Parentsactive was involved in the consultations with the architect and the design of the building as well as took part in

consultations around activities in the centre. The building works started in 2017 and the building was completed in 2018. In addition, Parentsactive was involved in the recruitment of the Centre manager, integrated keyworkers and other professionals based at the centre.

Parentsactive regularly comments on and campaigns on all policies related to social care and is currently involved in updating the Short Breaks Statement and the Eligibility Criteria document with the council.



Parentsactive continues not only to meet the personal needs of parent carers like myself in information and training sessions but also as a platform which has also been instrumental in pushing for some long-term positive changes in our local and wider community for the welfare of our special people. A case in point is the Stephen Wilshire Centre located in Fulham. This respite centre is an example of the power of our collective voices in action as guided by our needs. It shows that when we turn our complaints into campaigns, we can affect change because the "personal is the political"

Ageno



Ground works event 2017







## Coffee Mornings, Consultations, Conferences and Training

Coffee mornings and meetings started in 2001 but the regular weekly sessions which formed the backbone of Parentsactive started in October 2008.

Parentsactive approached Masbro children's centre in 2008 wondering if we could have some space to run coffee mornings for parents/carers of children and young adults with disabilities. Our first guest speaker was Caecilia Isadore from Safety Homes in Bishop Creighton House.

We have since then run roughly 507 coffee mornings including the current move to Zoom meetings since the pandemic.

We have invited more than 300 professionals from the Local Authority, local and national charities, voluntary sector organisations on a weekly basis to inform and empower parents. We also host drop-ins and coffee/chats where parents can meet others share tips, concerns and

enjoy a natter over a cup of coffee.

We have organised more than 100 training events on a variety of themes such as; Education, Parental Well Being, Challenging Behaviour, Online safety, Speech and Communication, SEND Law training, as well as talks on autism by Ros Blackburn. We have organised 10 major conferences with more than 100 delegates.

We have organised 3 fun days with activities for children and pampering for parents. Parentsactive also delivered its own training on "Parent Perspectives" to professionals in the local authority over 2015/16. This training was developed with the Triborough in 2015.

The sessions are valued by parents as they have the platform to meet other parents and voice their concerns which then influence the development of services in

the borough. They also help address individual concerns in a timely manner where appropriate. Parents who require further support are referred onto advocacy, the SENDIASS and other services.

So grateful for Parentsactive, a very supportive community, the relevant lectures and making me aware of different resources to support me.

I tried to get an EHCP twice when my daughter was 4. This was turned down by the local education authority as at that time recognising autism in girls was not so well understood.

I muddled through supporting her and financing all her support myself until she had a breakdown at 16.

I felt very unsupported during this time and didn't know how to get the support I needed.

At this point, I had nowhere to go and luckily found Parentsactive.

So resourceful and helpful.

So very grateful.

Made me aware of so many more resources which I have now made use of. Thank you.

Kate Gillies



# ***We hope to see Parentsactive continue their work, supporting disabled and SEN children and their families in the community for many more years to come***



The 20th anniversary of Parentsactive highlights the tremendous work they have done for disabled and special educational needs children and their families in our Hammersmith and Fulham community. At Masbro Children's Centre, we have been grateful to have worked in close partnership with Parentsactive for over 13 years.

For us at Masbro Children's Centre, having Parentsactive deliver their fortnightly coffee mornings has been an invaluable service for families. Over the last 13 years, we have signposted many families who have faced difficulties in accessing support for their children with disabilities or special educational needs to their sessions.

The Parentsactive team have a plethora of knowledge to support families in the right way, understanding their needs and those of their children to make a difference. But to say Parentsactive make a difference is actually an understatement. They do more than this; they change lives.

Their coffee mornings empower families with knowledge about all aspects of their lives, from their child's health and education to their benefits and rights. Families get to

meet other families experiencing similar difficulties to themselves. Difficulties that are often very isolating. Seeing a mother leave the group smiling for the first time in months because she has met someone in the same situation and no longer feels alone is a testament to the wonderful work Parentsactive do. Most importantly they change the lives of the children, improving their journey and making their daily living a little bit easier.

The strong network of the parents attending has seen positive changes happen in the community such as the wheelchair-friendly playground in Ravenscourt Park, Hammersmith. We have directed many families to the facilities who are always overjoyed to experience it with their children and the happiness it brings.

We hope to see Parentsactive continue their work, supporting disabled and SEN children and their families in the community for many more years to come.

**VALLON LEITAO**  
**CHILDREN'S CENTRE MANAGER**





Fun Day 2009



Fun Day 2010





# Parentsactive working together with Health Services

In 2014 Parentsactive did a survey to understand the health needs of disabled children, the results were published in the form of a report called "Health Needs of Disabled Children". We handed over the report to the health commissioner Marie Truman, who advised us to release it formally at an event. We launched our Health report at an event in St Pauls in 2014. Andrew Christie the Director of Children's Services accepted the report and the Clinical Commissioning Group formally responded to the report to say that they will consider the accessibility needs of the disabled children in all their clinical settings. Gina Gerrard our committee member became a member of the Learning Disability board

at Chelsea and Westminster hospital. Gina helped the committee voiced the needs of disabled children in hospital settings, she helped publicise health passports and influenced the design of the Changing Places toilet at Chelsea and Westminster hospital.

Contact and the National Network of Parent Carer Forums also invited us to talk about our Health report at their regional conference and AGM in 2014.

When the Children and Families Act came into being in 2014, Parentsactive was involved in the development of Personal Budgets and helped pilot the personal budgets for incontinence products. We also regularly contributed to the incontinence products

survey and the development of the wheelchair service.

Between 2014-15 we delivered health training to clinicians at various meetings and clinical settings

We were also part of the Patient Reference group for a few years.

In 2020/21 Parentsactive supported Hammersmith and Fulham to bid for a pilot Key Worker project service for those children on the Dynamic Support Register along with Hounslow. H&F won the bid and one of our experienced members, Linda Dolben is the parent representative on the steering committee, Linda has contributed to the recruitment process and helped shape the service.





Health Report 2014

I'm sure that I echo the views of other health colleagues, both past and present, in thanking you for all the work that you have done over the last two decades. You have made a significant difference to the lives of children, young people and their families and the benefits will continue to be realised in years to come. From a CCG perspective, the report on local health services that you wrote and presented to senior leaders in 2014 was very welcome and helped to raise the profile of key issues. We have benefitted from the challenge that you bring in a variety of forums and also the support that you have offered. The partnership working and genuine co-production was evident in the joint Ofsted/CQC SEND Inspection

and it was positive to see this recognised in the inspection outcome letter. Many health teams and commissioners have valued the opportunity to attend your coffee mornings and focus groups over the years to hear directly from parents and carers. The swift move to a virtual offering during the pandemic allowed these essential sessions to continue at a time when they were needed more than ever. Hopefully, we will be able to all meet again in person in the near future. Wishing you all the very best for the next 20 years!

Alison Markwell  
Head of Joint Health  
Partnerships/Senior  
Designated Clinical Officer

I first heard of Parentsactive through a poster in a Child Development clinic. This was back in 2003 and I was to find that, although it was a relatively new organisation, it already had a strong membership and sense of purpose.

My son was premature, and I always believed that he would 'catch up' but that did not happen, and news of his autism diagnosis left me devastated and disorientated. I hope there have been improvements in the way families learn of a diagnosis for their child.

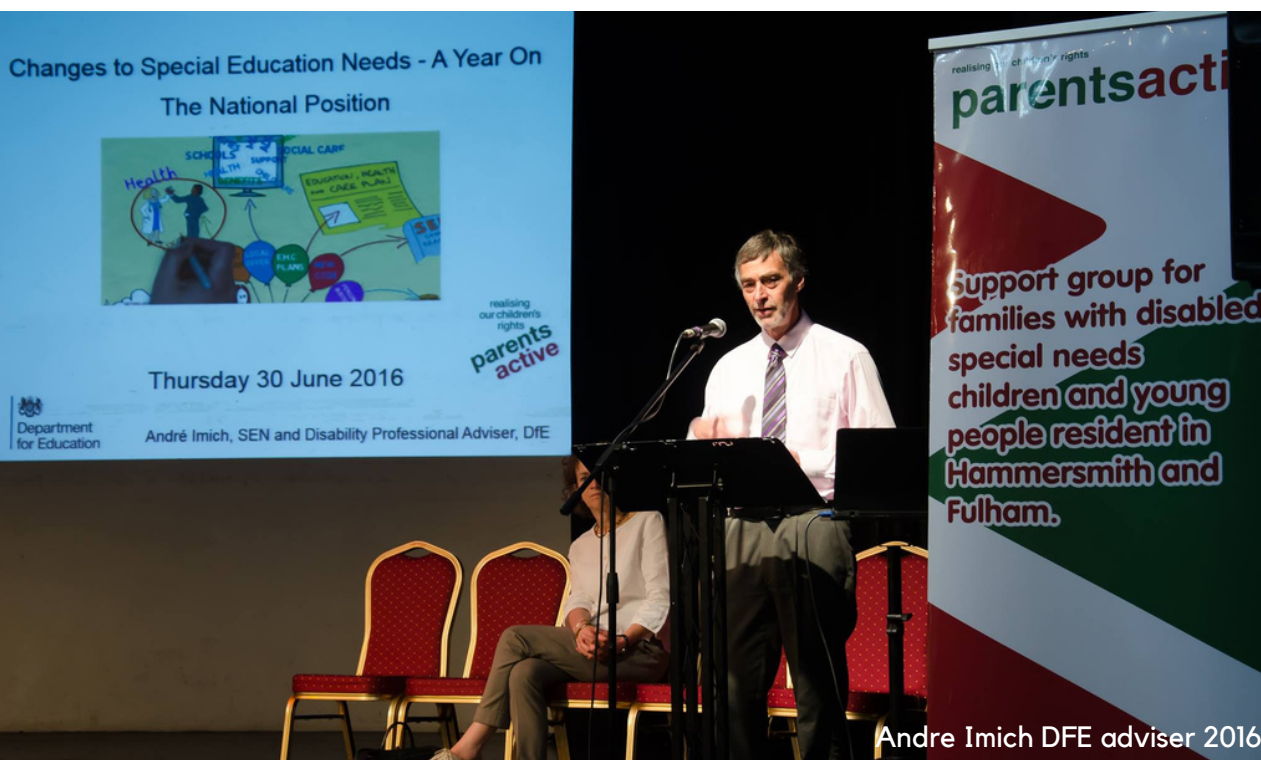
In those early days Parentsactive was a lifeline and I learned so much from the parents who were that bit further ahead in the process than me. It's always been there as a source of help, support and friendship.

One of the strengths of Parentsactive has been to build constructive relationships with all the local agencies but most importantly to keep an independent voice.

Parentsactive has achieved so much but there is still a lot to be done. Through Parentsactive I am now involved in a national project to give extra support to children and young people with autism and/or a learning disability and to reduce rates of admission to psychiatric hospitals.

Linda Dolben (Mum of Rosie  
and Matty)





Andre Imich DfE adviser 2016

## Joining hands with SEN

Parent forums were born out of the principles of the Children and Families Act 2014 with Education Health Care Plans being driven by the Educational needs of children and young people. We work closely with the SEN team on all aspects and closely work alongside the SENDIASS team, formerly Parent Partnership. Parentsactive has always invited the SEN team to all the coffee mornings and has organised SEN Information Days, which includes the Changes from Statement to Plan in 2013 and Changes to SEN – A Year On in 2016. We also organised the Transitions conference in 2018 in partnership with the West London College. We have organised training on

Annual reviews, EHCPs, Outcomes, Stages of Education in partnership with SENDIASS, the Inspire Team and the Local Authority and have worked with the SEN team on the template of EHCPs and various communications to parents. We have sat on interview panels for SEN keyworkers and the Service manager for the SEN team. We have commented on the Post 16 guidelines and the Transport Policy and have influenced the setting up of the SEN duty line 02087531021. We have done surveys on SEN and Mainstream Education in 2019 and published a report. We attend SENCO forums regularly especially since the lockdown and contribute to discussions there and have

visited school coffee mornings whenever invited and speak to parents. We have held consultations on the SENDIASS service in 2010 and 2021 and worked closely with Pat McNair from Insights till her retirement in 2020. We have helped evaluate the tender bids for the new SENDIASS and Mediation service.





It has been a great pleasure to work with Parentsactive over the past 13 years. Parentsactive has been a lifeline in the local community and has empowered and supported so many parents/carers of children with additional needs/disabilities and young people with additional needs/disabilities. I continue to be impressed by the lengths that all members of the Parentsactive staff team go to, ensuring that the service users who contact them feel listened to and get the advice, support and advocacy they need.

Over the years, from when we were known as the Parent Partnership Service and now as SENDIASS, our staff team has developed a very effective and successful, professional partnership with Parentsactive enabling us to reach more families and young people in the Hammersmith & Fulham area and provide an extended level of support.

To Nandini and the Parentsactive staff team: Congratulations on your first 20 years of service and we wish you all the very best for the future !!!

Barbara Quartey MBE  
CEO Insights

I have been tapping into Parentsactive on and off for the last 10-12 years. Alongside other SEN groups, this has been my lifeline. I'm so grateful for the wealth of local knowledge, insight and understanding – especially around how the 'system' works and introduction to relevant professionals and teams. Be it through a newsletter or coffee mornings, informal chats or formal presentations or training.

At times when I have found it hard to navigate key transitions or obstacles, it has given me hope and a feeling of not being alone. It has been a great comfort and moral support - talking to others that are experiencing similar issues and you get honest and relevant help both how to help your child practically but also a degree of belonging and emotional support which I think is difficult to get from friends and family which have not experienced raising a SEND child.

I have now joined the Steering Committee as I feel I would like to give back and feel ready to help others. I also know that within the membership there are other more experienced parents with older children on whom I can lean on with help as Barney transitions into adulthood and we start another chapter!

Many Happy Returns Parentsactive! Well done on the first 20 years and here's to the next 20!!

Thank you ♥  
Siri Lewis





Transition conference 2018

## Parentsactive and young people 18 - 25

We have influenced adult services to some extent, but a lot needs to be done as the forum only goes up to 25. Parentsactive participated in the Transitions Taskforce whose final report made many recommendations in 2017. Transitions is very individual and Parentsactive regularly hold Transitions and Adult services coffee mornings and zoom meetings to help parents understand the process. Parentsactive supported HF Mencap in the Housing Campaign "Can we live here too" in 2014 and have invited professionals from the Independent Living pathways on several occasions. Gina Gerrard is our representative on the Learning Disability Board at Chelsea and Westminster Hospital and continues to contribute to conversations around

transitions to adult health services.

Parentsactive continues to hold conversations with colleagues from adult services to improve service delivery.

Happy 20th Birthday Parentsactive!

I have worked with Parentsactive for nearly 6 years now and some of my happiest memories in work are those working with the Forum. Initially our work focused very much on improving transition to adulthood and the Forums relentless drive to make information, advice and support timely and accessible was a key feature of the Transition Task Force Report and the establishment of our Transition Team. However, inclusive employment is, for me, the area where Parentsactive

have made a huge contribution to the councils work. We established our H&F Supported Internship in 2016 and working closely with Parentsactive, year on year we have improved all areas of our Internship to best meet the needs of our young people with special educational needs and disabilities and their families. The Forum have gone on to champion inclusive employment and our progress is testament to their commitment to this area of our work.

The Forum's focus on detail is what makes them a valued partner to the council, that coupled with their care and compassion

Jo Baty

Assistant director mental health, learning disability and provided services  
Social care



## Connections



Inclusive Learning is very proud to work in partnership with Parentsactive, which has grown over the years to a solid and successful partnership.

This work has included supporting students and their families to achieve their best outcomes as well as working on a hugely successful Transition Roadshow for H&F residents with SEND and their families. This was a particularly successful event that brought together key education, support and community services in one setting for residents and their families. This roadshow alone increased information, opportunities and helped many young adults and their families work towards their Preparing For Adulthood Aspirations.

West London College looks forward to continuing our work together in the future and for the next 40 years.

Sue Jenkins  
Head of Inclusive Learning

Action on Disability (AoD) would like to congratulate Parentsactive for its 20 years, and as long as there is a need, we wish them many happy returns.

Over the course of the last 20 years, Parentsactive led by both Amanda and Nandini has been a key partner to AoD and a vital service to local parents of disabled children and adults.

Parentsactive work has been crucial in that it has given a voice to those who are central to change, local disabled families. They have ensured dignity to those whose rights need to be upheld. They have brought together parents and professionals and ensured that the life of disabled families in Hammersmith & Fulham continues to improve. They have informed, empowered and strengthened the voice of disabled families and continue to highlight the strength in bringing people and communities together.

Hammersmith and Fulham has only been a better place with Parentsactive central to our lives.

Thank you for your 20 years of improving our communities.

John MacNeely  
Youth & Community Services Manager  
Action on Disability





I joined Parentsactive as the second paid member of staff, supporting Nandini with the burgeoning admin along with helping at the coffee mornings, planning sessions and liaison meetings that happen behind the scenes, in late 2019. For 5 months I met parents and regular professionals - finding my feet, and just as we had started a series of parent and professional training with ALLFIE (the Alliance for Inclusive Education) the pandemic stopped everything in its tracks and changed our everyday lives around... It was a challenge converting to online coffee mornings, working from home and only connecting on a screen (whilst also homeschooling my own child with additional needs). Like everyone else, we had no choice and managed the transition, learning Zoom and new ways of working. I greatly miss the organic nature of the face-to-face contact with parents but know that we will return once we can do so, and with that return, we will also bring the new ways that we have learned - providing greater access and convenience to many parents that may not have been able to access our sessions previously, so we will be even better than before.

Collecting the statements and write-ups for the book as well as looking at all the photographs of the fantastic achievements in the 20 years has given me a deeper understanding of the achievements of Parentsactive and all the people that have given to and made it the force that it is. I feel blessed to be a part of its story. In the short time that I have been here, it has also given me a greater understanding and insight into the processes and challenges that families go through in order to make the best possible lives for our children. As a forum, unfortunately, we are unable to pick up individual struggles (but we will always signpost to the services that can) but we pick up those individual issues to thread a pattern of where the gaps lay and use that thread to voice our difficulties and challenges collectively. From attending meetings with other parent carer forums from across boroughs at the National Network of Parent Carer Forums (NNPCF), I have been able to see just how lucky we are in Hammersmith and Fulham to have so many professionals and heads of services wanting to come to our meetings and where parents can engage directly with them.

I look forward to the achievements that I can contribute to moving forward and thank everyone that has come before to be able to write this message marking Parentsactive's 20th year.

Reema





## ***"As a parent carer, you are already active, you are a Parentsactive and you are your child's best advocate"***

I am thankful and proud that during the COVID-19 pandemic, Parentsactive adapted well by keeping in touch with families remotely. Nandini continues to make personal calls to check on parents and ascertain if they are in need of support, which included me. I have a peace of mind knowing that even during periods when I am silent and less active in the group, you are there should we need you and grateful for those occasions when you do pick up the phone and call to check on us. The concern and care for our needs are genuine.

To parent carers contemplating joining Parentsactive, please do not hesitate to join us. As a parent carer, you are already active, you are a Parentsactive and you are your child's best advocate. However, in being a part of a collective group, your needs at the micro level will also help guide and inform strategic policies at the macro level for our special community. Please keep telling and sharing your stories because "the personal is the political". And, we come from diverse backgrounds both culturally and professionally, which makes for exciting team work. I encourage all parent carers

to remain active not only in our formal meetings but the informal ones too. I get the most joy out of the informal coffee mornings, get-togethers because it gives me opportunities to catch up with other parents in a relaxed way. Random parents have at times signposted me to services or useful places and some of those parent carers have become lifelong friends. They have shown up for me and my son at several crisis points in our lives outside organized meetings. Hayley, Marie, Alison and Jenny, thank you not only for the gentle knocks on our door but the mighty support even in hospitals. Such have been the multiplier effect of Parentsactive in my life; it has expanded my social capital beyond official meetings. I also urge parent carers to join our committee body. Not only will you help shape and effect strategic policy making decisions, you will also be treated to some in-house talents and care on our committee. Marie's too-lious cakes are legendary. Hayley's upholstery works are a beauty to behold. And, I am most grateful to Mary for hosting some amazing committee Xmas parties over the years in her beautiful home, which enabled me to experience traditional

Xmas celebrations, not possible in my home due to the severity of Nimaro's autism.

Thank you Parentsactive that on our journey with the "cloud of unknowing"-that is autism, hanging over us, you are a silver lining in that cloud. At several crisis points, when I have been overwhelmed with raw emotions and broken, you not only handed me much needed tissues to wipe my tears but also helped me peel through the layers of those raw emotions like a skillful artist, constructed and articulated them for resolutions, which continues to sustain and give us much needed relief.

As parent carers are often the only constant throughout the lives of their special children, may Parentsactive continually remain relevant in representing their needs.

Happy 20th Anniversary  
Parentsactive, God Bless You!

Ageno Ochola  
Steering group member





# THANK YOU

While every attempt has been made to recreate key moments of Parentsactive's history there may be some errors in the timeline or facts as most of the write up is based on records, emails and anecdotal information. The book is a celebration of the hard work put in by parents despite challenges around their caring role. We also thank the Council, professionals from the local authority, charity sector partners, statutory organisations, schools and colleges who have been our strength and support all these years. Our biggest thanks are to our Steering committee of parents both past and present who have given up their time to make Parentsactive a relevant experience for our membership. A special and affectionate mention to our Chair Mary Melsom who has steered Parentsactive through 10 successful and sometimes challenging phases. Her sense of humour is legendary and has kept the forum smiling despite some dark phases. Hayley Wedgbury our vice-chair has been an inspiration and her commitment to inclusion is spoken of highly as a testimony to successful campaigning.

Amanda Roles coordinated and subsequently mentored Parentsactive for many years and built a strong foundation on which the forum now stands. Her experience has been invaluable, and her advocacy has been appreciated by many parents whom she has helped in some of their most challenging times. Reema Sharma has been a welcome addition to the team since 2019 and has raised the standards of our admin, newsletters database, website by several notches. Affectionately called the "technical wizard" by the non-techies, she does it all with a smile and the future looks secure with her presence. We thank our membership of 400 plus parents who has accessed our events, training sessions and have spoken up for other parents thereby making our sessions lively and interactive. We thank HF Mencap without whom we won't be where we are today. Teresa McGinn and Julian Hillman special thanks to you both for giving us the space to grow. Masbro Children's Centre deserves a huge round of applause for hosting our coffee morning sessions since 2008 and making us a part of their "Confident Parent Happy Child" programme.

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**20**  
YEARS

