FULL OF LIFE
SUPPORT GROUP

ANNUAL REPORT 2023-2024

Information, advice and support service

"ALL THE PEOPLE AT FULL OF LIFE HAVE BEEN SUPER HELPFUL AND SUPPORTIVE. THEY GIVE ADVICE OR SEND YOU IN THE RIGHT DIRECTION. TRYING TO GET INFORMATION ON THE INTERNET IS OFTEN OVERWHELMING AND HAVING THE RIGHT PEOPLE TO HELP MAKES SUCH A LIFE DIFFERENCE."

FOL Parent

WHO ARE WE?

The Information, Advice, and Support Service at Full of Life is a free, impartial and confidential service for parents and carers of children and young people with special educational needs and/or disabilities.

The IASS at Full of Life is made up of three strands: Family Support, SEN (Education), and Carer's Advocacy.

"FULL OF LIFE HAVE BEEN THE BEST SERVICE AND SUPPORT WE HAVE RECEIVED SURROUNDING THE JOURNEY PRIOR TO/AT/SINCE THE DIAGNOSIS OF OUR SON'S AUTISM."

FOL Parent

History and Development of the Information, Advice, and Support Services

1994 – The Beginning

Full of Life (FOL) started as a small parent support group in 1994, holding coffee mornings. From the start, the organization wanted to be pan-disability, and accessible to all parents and carers. The group's focus was to enable and empower parents to understand the system in order to get the best support for their children and families. Sharing expertise between parents was also an important aspect of Full of Life from the beginning. The organisation soon

began working with local authority officers on local planning and collaborated with officers when RBKC's Disabled Children's team was being set up.

As the organization evolved, Full of Life successfully bid for National Lottery funding. This allowed them to employ a coordinator and a family support worker; an early incarnation of the current Family Support Service. This role has grown over the years to meet the challenges facing families.

As a result of observed gaps in support for families, FOL also lobbied for voluntary organization funding and was successful. They obtained a small office in Notting Hill where parents could come for advice and support.

Early 2000s – Parent Partnership Service

In the early 2000s, the head of RBKC SEN Department approached FOL to ask if it would be interested in managing the Parent Partnership Service (PPS), offering support to families around the education system for children with Special Needs and Disabilities. Outsourcing the PPS was considered best practice even then, and FOL worked with RBKC to establish this service from 2002. This made our PPS one of the first in the country to be parent-managed. The PPS at Full of Life started as a two days a week service, growing to three days a week around 2007. The PPS at FOL developed a strong reputation for impartiality thanks to its early establishment away from the Local Authority.

2004 – Carer's Advocacy Service

As the Parent Partnership Service began to take shape, Full of Life could see how support for parents, carers and young people seemingly disappeared when young people reached age 16. They began negotiating with social care and health about funding for a Carer's Advocacy service to fill this gap. By 2004, the service was up and running, offering support and advice to parents and carers, and their young people, on matters in relation to social care and health. The service later extended its remit into education as well.

2009 – Information Service

As the support services at FOL evolved, it became apparent that the organization held a lot of knowledge and information about SEN in one place. FOL successfully lobbied for funding for an Information Service and in 2009 were given three years funding to develop this service, which was really a pre-cursor to what is now the Local Offer.

Now – Providing information and support to parents and carers across RBKC

FOL are proud to have been an early source of centralized information on a wide range of subjects in relation to SEN/Disability, shaped by parents' knowledge, experiences, and feedback. Much of the information we have amassed over the years contributed to the building of the Full of Life website, which continues to be a source of independent information for families. It has also helped us build evidence to shape and develop services that matter to families.

Parent Participation and IASS

FOL has hosted the parent carer forum (now the Parent Participation Group or PPG) in one shape or another since we started as an organization. This group now offers training and mutual support to the next generation of parents. The parent carer forum works closely with the IASS service to plan and organise training and support subject matter so that it is relevant and useful to the changing needs of families. IASS staff often attend PPG meetings so that they can offer support, answer questions and meet new parents, and IASS staff have also delivered training in PPG meetings.

Working with Other Professionals

Over the years, Full of Life staff and parent members have been identifying gaps in provision and taking these up with local officers and councillors. Some of the local services FOL families and staff have been instrumental in shaping have been inclusive local play provision, Behaviour and Family Support Team, St Quintin's Centre, Short Breaks Services, the Full of Life Centre for Young People with Complex Needs and others.

Full of Life have also been involved in training over 5,000 hospital staff in working with children and young people with special educational needs and their families. Their partnership work with Chelsea Westminster Hospital led to the development of the Learning Disability Flagging System and Learning Disability Hospital Passports.

The staff at Full of Life IASS have established close links with schools, nurseries, and colleges as well as NHS providers, local councillors, and Local Authority Officers. Our links with local child development specialists who provide childhood assessments and diagnoses have helped make sure our contact details are provided to all parents whose children have received new diagnoses. We have also taken part in the Law Commission's review of disabled children's social care.

"EXCELLENT HELP AND ADVICE ALWAYS. A LIFELINE TO ME AND MY FAMILY."

FOL Parent

Family Support and IASS Education Advice.

Full of Life's Family Support Service offers practical help, emotional support, independent advice and information for families of children from birth to 14 years old. The service can support you with issues relating to Social Care, Education and Health helping you with benefits, form filling, preparing for meetings, appeals, complaints and accessing additional support.

IASS education advisors regularly participate in a range of meetings and working groups within the areas of education, health and social care. This provides us with regular opportunities to share the experiences and views of local children, young people, and parents/carers that we have worked with.

"JULIA AND ALLISON HAVE BEEN AN IMMENSE SUPPORT… THEY HAVE BOTH EMPOWERED ME IN SUCH A HUGE WAY AND WE WOULD BE LOST WITHOUT THEM."

FOL Parent

97%

of parents rated their satisfaction with SEND IASS as a 9/10 or 10/10

91%

of parents rated the difference the advice or support from SEND IASS had made for them as a 9/10 or 10/10

The Education Advisor organizes regular SEN Surgeries where parents can meet individually with a member of the Management Team of the Local Authority SEN Department to discuss their child or young person's case. She also attends the Parents Reference Group - a quarterly meeting attended by parent representatives from the PPG as well as representatives from SEN, Health and Social Care. In addition she attends SEN coffee mornings in local schools.

Transition to Adult Services

Our carer's advocate helps young people and their carers through their transition into adult services. Working with other professionals, ensuring that the needs of caregivers and those they support are met effectively, is a crucial part of the role for our Carer's Advocate. Collaborating with NHS providers, social workers, and community organizations allows for a holistic approach to care, integrating medical, emotional, and practical support. Further, clear communication and a shared commitment to the caregiver's well-being helps in coordinating services and resources efficiently.

100%

of parents felt the support offered by the carer's advocate helped them to solve the problems they had.

85%

of parents rated the support from the carer's advocate as 8/10 or higher for reducing anxiety and stress.

SAM KNOWS HER BRIEF AND IS ALWAYS WELL INFORMED. SHE UNDERSTANDS THE URGENCY OF THE SITUATION FOR PARENTS, CARERS AND THEIR CHILDREN AND YOUNG ADULTS."

FOL Parent

By fostering strong relationships with these professionals, the carer's advocate facilitates access to necessary support systems, addresses challenges more comprehensively, and ensures that caregivers receive the recognition and assistance they deserve. This work ultimately enhances the quality of care provided and supports the resilience and well-being of both caregivers and those they care for.

The Carer's Advocate will participate in a monthly Adult Social Care steering group which looks at the ongoing development of services when young people reach 18. We have also held a post-16 local offer conference.

Strength in Community

The Royal Borough of Kensington and Chelsea is a small Borough, but it is a very diverse area in terms of ethnicity and economic background. FOL has always strived to reach as many families as possible, and to ensure that everyone is included and encouraged to participate in shaping local services.

Full of Life's position within the community has helped the IASS service to include many "hard to reach" families among our service users. Its established history in the community ensures that FOL is often recommended from parent to parent. The IASS staff meet many of our new families this way. FOL's building and signage near a large supermarket, located in an area of deprivation within the borough, also provides a visible presence in the community.

From an initial group of 8 parents, Full of Life has grown to now having over 750 families on their database, most of whom are current or former service-users of the IASS service. FOL has a strong history of identifying gaps in provision locally and lobbying for change where needed, and the management of the IASS service ensures that the service is confident to bring challenges to the Local Authority where needed.

"THEY HAVE ALWAYS BEEN THERE FOR ME TO GIVE THE RIGHT INFORMATION, GUIDANCE AND ANYTHING ELSE THAT I NEED HELP."

FOL Parent

One of the most important values of Full of Life is that funding goes where it will have the most impact - on front line services offering practical support to families, children and young people. The FOL IASS service therefore places an emphasis on front-facing support that makes a difference to the lives of children and young people.

When the 2014 Children and Families Act came in we were already providing a "one stop shop" for families, and we did not have to make any changes to comply with the Act. We already had staff in place to deal with education, health and social care from 0-25 and beyond.

All of our IASS staff have completed SEND training to IPSEA Level Three, in addition to undertaking other legal and practical training as needed.

As an organisation, Full of Life is also outwards facing. Some of our recent work has included partnership with local housing developers, such as Ballymore and the Earl's Court Development Company. We are also very proud of our partnership work with the Royal Parks, consulting on the redevelopment on their playgrounds, ensuring they are completely

inclusive. IASS advisors have links to local charities including Clement James Centre and Rugby Portobello.

> "FULL OF LIFE, ALL OF THEM, ARE AMAZING, VERY HELPFUL AND INFORMATIVE. THEY ALWAYS SUPPORT ME IN DIFFICULT TIMES TO FIND A SOLUTION."
>
> ***FOL Parent***

Provision of SEND IASS

Family Support 0-14

Operates: Four days a week

Funding Stream: Children's' Social Care

Full of Life's Family Support Service offers practical help, emotional support, independent advice and information for families of children from birth to 14 years old. The service can support parent carers with issues relating to Education (0-5 years), Health and Social Care; helping families with benefits (DLA, Carers Allowance, Universal Credit), grant applications and general form filling, understanding reports (Diagnosis, Speech & Language, Occupational Therapy, Needs/Carers Assessments etc), preparing for meetings, appeals, complaints and accessing additional support.

SEND IASS Education Advice 5-16

Operates: Three days a week

Funding Stream: LA SEN

The Education Advisor deals with matters in relation to education for children and young people from age 5-16. The service will continue to work with young people aged 16 and over if they remain in a school setting. They do not have to have a diagnosis or EHC Plan, in fact many service users have children on school-based SEN support or are wondering how to get initial support for their child.

This service offers support around communicating with schools and the local authority, understanding SEN support and navigating through the SEN support system, EHC Needs Assessment requests, EHC Draft Plans, Annual Reviews, Appeals/Tribunals, Phase Transfers, Exclusions and more.

The Education Advisor has offered training to the PPG as well as to groups of professionals to explain the role of IASS. The Education Advisor answers calls and returns messages left on the 24-hour voicemail. She also attends meetings in a supportive role with service users where capacity allows. She liaises with other professionals as needed to take forward larger issues that she sees arising through the course of her work.

Transition to Adult Services

Operates: Five days a week

Funding Stream: Health

The Carers Advocate plays a vital role in assisting young people and their carers through their transition into adult services, starting from the age of 14. The service provides invaluable support with issues related to health, benefits, and social care, and extend their expertise to educational matters from the age of 16. Importantly, the Carers Advocate's support doesn't end at 25; they continue to assist carers with any issues that arise, ensuring ongoing guidance and support to navigate the evolving needs and challenges they may face.

	This comprehensive support ensures that both young people and their carers are well-equipped to handle the complexities of transitioning into adulthood, promoting a smoother and more informed shift into adult services. The Carers advocacy services approaches each issue with the aims, values and mission of Full of Life at the forefront of any activities. The CA services works in line with the Care Act 2014, Care Act code of Practice 2014, Children's and Family Act 2014 and SEN code of practice 2001 and any relevant guidance and legislation.

IASS Aims

To empower parents/carers, children and young people with the information they need in order to participate as fully as possible in decisions around their/their child's education, social care and health care provision.

To enhance awareness and understanding of local and national policy and practice; to increase participation of parents/carers, children and young people in planning provision.

To improve outcomes for children and young people in education as well as in health and social care

To influence local policy in ways which will bring real positive changes to people's lives across education, health and social care

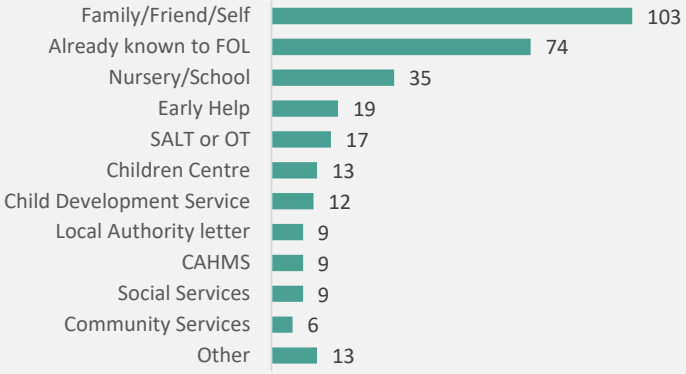
To encourage dialogue and early resolution of differences

Key Statistics

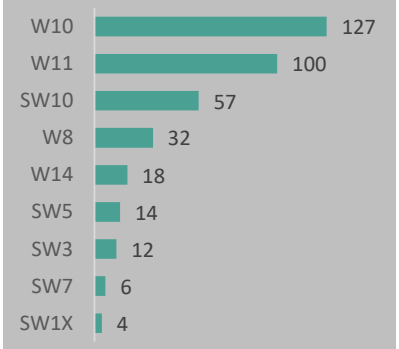
(September 2023- August 2024)

375	1027	56
Number of total cases	Number of total issues	Number of families accessing IASS support who have two or more children with SEN*

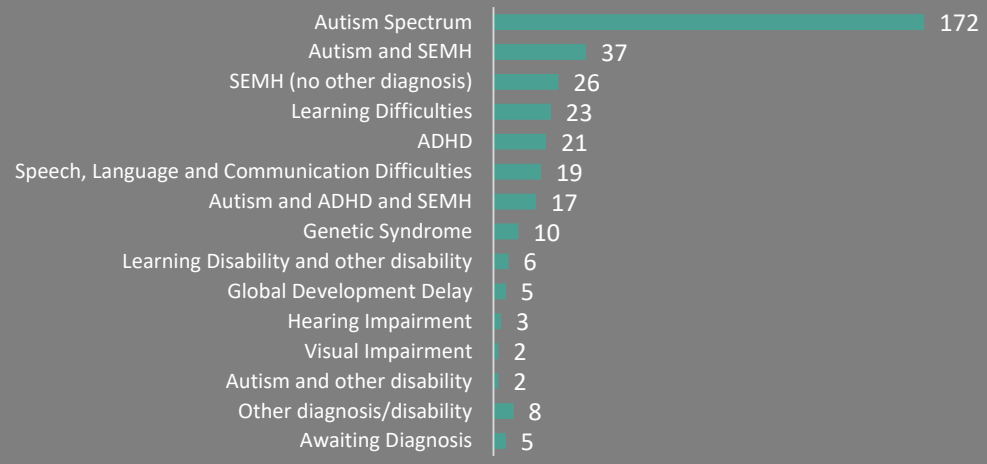
Source of Referrals



Number of Cases By Postcode



Number of Cases By Primary Need



*This only refers to children aged 0-16. People older than this still receive support from Full of Life but are not classified as children.

TOP FOUR ISSUES FOR EACH SERVICE

Family Support Service:

1. DLA (including change of circumstances, mandatory reconsiderations & appeals)
2. Benefits (Universal Credit, Carers Allowance)
3. EHCP (Parental Requests, Section A)
4. Housing (Health & Disability Needs Assessments, Council Register Applications)

IASS (Education):

1. Child not in school or very poor attendance
2. Communicating with school regarding progress, support and incidents
3. Information, advice and support for either parental or school EHCNA request and through the EHCNA process
4. Annual review- before, during or after (including support with draft amended plans)

Carer's Advocacy:

1. Understanding information and general information.
2. Preparing for meetings and going through documentation.
3. Benefit/form filling
4. Advice on timeline and procedure for EHC plan.

Key Achievements 2023-2024

We have revised mini-guides on website, and re-printed and distributed them widely to parents and professionals.

We now provide a specialist counselling service via the Tavistock NHS Trust for parents.

Our Local Offer conference was held in June with a Post-16 focus. This was well attended by parents and local services.

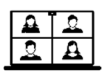
Full of Life were key to the development of the Changing Lives strategy, which we hope will improve the lives of people with learning disabilities and their parents in RBKC.

We organized meeting between parents and carers with local housing developers Ballymore regarding the redevelopment of the area around Ladbroke Grove Sainsburys, discussing how it may affect their lives.

We created a poster advertising the SEND IASS service and this was sent to all schools.

We developed two short animations for our website about problem solving and parent participation.

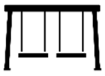
SEN surgeries with case officers from the Local Authority SEN service have continued.



In response to parent feedback, we now offer flexible appointments for parents – in person, online (Teams) or over the phone.

Our email signatures have been updated to include a direct link to our feedback survey. Our gathering of feedback has now improved, and this year we gathered a record amount of feedback.

Alongside parents and carers, we have participated in the reshaping of the Speech and Language Therapy service with a whole-systems approach.



We have worked alongside the Royal Parks, getting local parents/carers involved in redevelopment of Princess Diana Playground in Kensington Gardens. In addition we have worked with staff from Holland Park to introduce parents to their sensory garden and the facilities they have available for children with additional needs.

Full of Life recruited Parent Champions to promote and explain the Local Offer and the Speech and Language Therapy service.

Our Priorities for the Coming Year

We will be focusing on Post-16/Transition Education, Social Care and Health as we see this as least well developed area of local offer. We will hold a series of focus groups where parent/carers and professionals can have constructive discussions about life for young people after 16 including colleges, apprenticeships, internships.

We will also facilitate parent engagement with local services by holding other focus groups on topics such as Early Years, SEN Support in Mainstream Schools, Special Schools

We are facilitating the participation of local families in the reshaping of Occupational Therapy service

We will aim to strengthen local links by continuing to work closely with Early Help, establishing closer links with Family Hubs, SENCO forums and other local professionals' networks.

We will revise and re-print Education, Health and Care Guide, the Early Years Guide and the Transition Guide.

Commissioning, Governance and Management

Management: Frank Redmond, Full of Life's Co-ordinator will continue to manage the budget and day-to-day running of the service.

CPD: This will be developed over the year with Sue Redmond and Virginie Isbell, Joint Chairs of Full of Life.

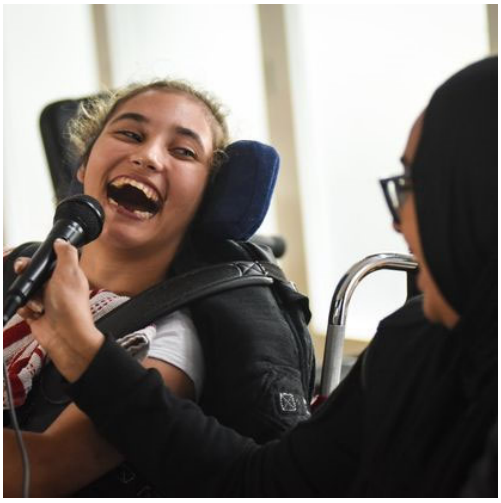
Termly reports to Full of Life's management committee will continue and each service will present their report in future committee meetings. We regularly review the service in line with the minimum standards. Our service is jointly funded by the NHS, Education and Social Care. A memorandum of understanding is in place.

"THIS IS A GENUINE AND FRIENDLY SERVICE WE'VE BEEN RECEIVING TO SUPPORT OUR DISABLED CHILDREN IN MANY AREAS IN PARTICULAR EDUCATION AND SOCIAL SERVICES. SO, PLEASE MAXIMISE YOUR SUPPORT TO FULL OF LIFE AND PROVIDE ITS HELPFUL AND GENUINE MEMBERS OF STAFF WITH ALL THE NECESSARY SUPPORT FOR THEM TO KEEP GOING AND MOTIVATED HELPING FAMILIES AND CHILDREN."

FOL Parent

THE IMPORTANCE OF OUR WORK

Our experience as a service and an organisation as a whole is that families need frontline services that are independent, that offer stability and support with people they can trust. We have learnt this over the years from our direct work with families through business as usual, as well as crises.



KENSAL HOUSE ANNEX • 379 LADBROKE GROVE • LONDON • W10 5BQ
TEL. 020 8962 9994
http://www.fulloflifekc.com. Email: office@fulloflifekc.com.
Registered Charity No: 1125525 Company Registration No: 6643013

Patrons: Lady Puttnam: Dr Sarah Brewer MB BChir: Ms Lindka Cierach: Ms Clare Mackie:
Ms Esther McVey: MP