FULL OF LIFE

SUPPORT GROUP

ANNUAL REPORT 2024-2025

Information, advice and support service

"FULL OF LIFE IS THE FIRST PLACE I GO WHEN I HAVE AN ISSUE OR QUESTION ABOUT MY SON. WE HAVE ALWAYS RECEIVED A BRILLIANT, FIRST-CLASS SERVICE. THANK YOU SO MUCH."

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 as well as young people with disabilities and/or SEN.

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

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 do things 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 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.

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.

> *"IT'S AN EXCELLENT SERVICE, ALLISON, JULIA AND SAM REALLY KNOW AND UNDERSTAND THE LAW AND LOCAL SCHOOL/NURSERIES. I COMPLETELY TRUST EVERYTHING THEY SAY BECAUSE THEY ARE INDEPENDENT OF THE BOROUGH."*
>
> ***FOL Parent***

The Education Advisor organizes regular SEN Surgeries where parents can meet individually with a member of the Management Team of the 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 health, emotional, and practical support. Further, clear communication and a shared commitment to the caregiver's well-being helps in coordinating services and resources efficiently.

> 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.

Feedback regarding Full of Life's Services

Each year, Full of Life encourages parents and carers to give provide their feedback on the quality of our services, rating their experience out of 10. Feedback gathered through our annual survey demonstrates consistently high levels of satisfaction with the support provided.

95%

Of survey respondents rated their overall satisfaction with Full of Life's services as 9 or 10/10, **reflecting strong confidence in the quality, reliability & impact of our work**

AND

95%

Of survey respondents rated the helpfulness of Full of Life's advice & support as 9/10 or 10/10, indicating that families **feel well-informed and supported in navigating complex processes**

These results reinforce the importance of our continued commitment to accessible communication, collaborative working, and high-quality information. They also provide a strong foundation for shaping future priorities and ensuring that the service continues to meet the needs of local families effectively.

Training and Professional Development

During the 2024–2025 period, staff continued to invest in their professional growth through a range of specialist training opportunities. Team members completed Post-16 IPSEA training, strengthening their knowledge of legal entitlements and processes for young people transitioning into further education. They also undertook Child and Adolescent Mental Health training, enhancing their ability to support families experiencing complex emotional or behavioural needs.

Staff attended the IPSEA SEND Law Conference, ensuring they remain up to date with national developments in SEND legislation and case law. Additional training included ADHD awareness and practice development, supporting more informed guidance for families, and participation in a webinar series on the use of AI in Education Law, enabling the team to explore emerging technologies and their implications for service delivery.

Collectively, these opportunities have reinforced the team's expertise and strengthened the quality and consistency of support offered to families.

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 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 provide 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. FOL has a strong history of identifying gaps in provision locally and lobbying for change where needed, and the management of the IASS ensures that the service is confident to bring challenges to the Local Authority where needed.

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 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 already were providing a “one stop shop” for families because of the information and advice roles that had evolved from over time there were 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.

Our staff team has remained stable for many years - providing stability to our community. Our highly trained staff have a wealth of local knowledge on services that will matter to families.

Provision of SEND IASS

Family Support 0-14 years

Operates: Four days a week

Funding Stream: Local Authority & Integrated Care Board

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 years

Operates: Three days a week

Funding Stream: Local Authority 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

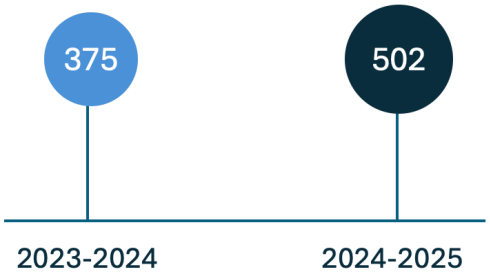
To influence local policy in ways which will bring real positive changes to people's lives across education, health and social care

To encourage dialogue and early resolution of differences

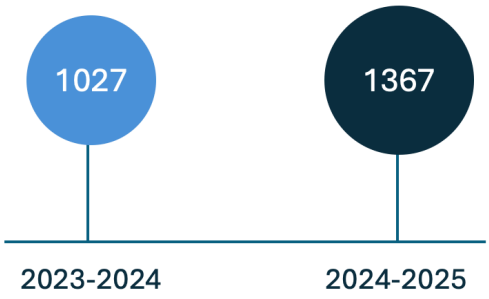
Key Statistics

(September 2024- August 2025)

Total Number of Cases



Total Number of Issues



Full of Life saw a 33% increase in both cases and issues dealt with in 2024-2025

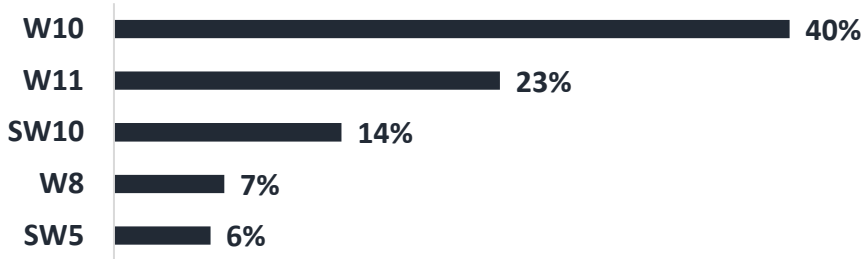
Top 5 Case Types by Primary Need*

Autism Spectrum	64%
Learning Disabilities	9%
On diagnosis pathway	7%
ADHD	5%
Social, Emotional & Mental Health	4%

Top 5 Case Sources of Referral

FoL/Family/Friends/Self	40%
Early Help	13%
Nursery/School/College	7%
Child Development Service or Great Ormond Street	7%
Social Services	5%

Top 5 Postcodes for Cases



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

TOP ISSUES ADDRESSED IN 2024-2025 BY 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. Grant Applications

IASS (Education):

1. EHC Needs Assessments – Information, Guidance, & Support for Parental Requests
2. Issues with attendance – due to school refusal, children out of school completely or part-time timetables
3. Concerns regarding school sanctions
4. Annual review- before, during or after

Carer's Advocacy:

1. Understanding information and general information.
2. Education
3. Benefits/form filling

Key Achievements in 2024-2025

Service Development and Co-Production

- Contributed to the redesign consultation for the Royal Parks playground by gathering feedback from families and supporting consultation activities.

- Supported the redevelopment of the Holland Park sensory provision.

- Contributed to the redevelopment of social care services for disabled children.

- Strengthened links with local services, including delivering a presentation to the SEND Local Authority service.

Partnership Development and Multi-Agency Working

- Strengthened partnerships with youth violence services, raising awareness of IASS and improving collaborative working.

- Continued close partnership working with the Keyworking Service.

- Strengthened links with the Designated Clinical Officer service.

- Strengthened partnership working with Community Nursing and School Nursing services.

- Strengthened links with Ormiston Latimer.

- Supported links with the Bi-Borough Supported Employment Internship programme.

- Developed links with Adult Housing Services.

- Developed connections with Shelter and Money Charity through the Parent Forum, enabling wider support for families experiencing financial and housing concerns.

- Strengthened links with Holmfield House Family Hub.

Early Years & SEND Collaboration

- Developed closer working relationships with Early Years services.
- Regularly attended the Early Years Forum.
- Continued successful SEN Surgery sessions, maintaining strong links with SEN services.
- Delivered a presentation to the SEND Local Authority service, strengthening links and raising awareness of IASS.

Parent and Community Engagement

- Continued active involvement with the Parent Carer Forum. As an integrated service, maintained strong collaborative links with the Chair, including identifying forum topics based on themes emerging from casework.

Strategic Networks & Professional Engagement

- Participated in Neurodivergence meetings.

Our Priorities for the Coming Year

- Increase outreach activity and strengthen engagement with external professionals and partner services, ensuring collaborative working and improved visibility of the service across the local area.
- Maintain regular staff meetings to share feedback, learning, and best practice, supporting continuous improvement and consistency in service delivery.
- Expand and refine the use of WhatsApp communication with parents to help reduce non-attendance rates and improve accessibility for families.
- Develop a concise mini-guide clarifying the distinction between advocacy and representation, supporting clearer understanding among parents, carers, and professionals.
- Update the website and quick-access resources to ensure parents and professionals have clear, up-to-date information about the scope, parameters, and processes of the service.
- Manage increased demand for the service, recognising that delivery across two part-time teams may result in short delays. A response time within a two-day grace period will be implemented to maintain reliability and transparency.
- Explore options for a more user-friendly shared database that can be accessed by all three services, improving efficiency, data consistency, and collaborative working.
- Monitor national developments relating to upcoming SEND reforms and assess their implications for local service delivery, ensuring readiness for future changes

Commissioning, Governance and Management

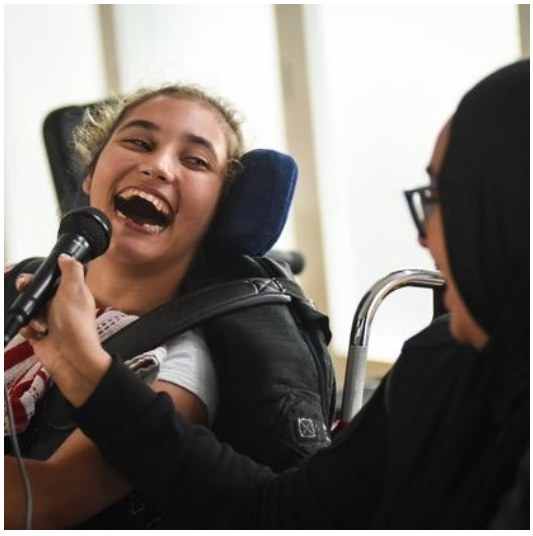
Management: Frank Redmond, Full of Life's Co-ordinator will continue to manage the budget and day-to-day running of the service.

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. We have a memorandum of understanding.

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 in 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.



Report prepared by Catherine Delannoy