ANNUAL REPORT

2020-2021

INFORMATION, ADVICE AND SUPPORT SERVICE

Annual Report

September 2020 – September 2021

Learn more about our work at www.fulloflifekc.com/sendiass

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

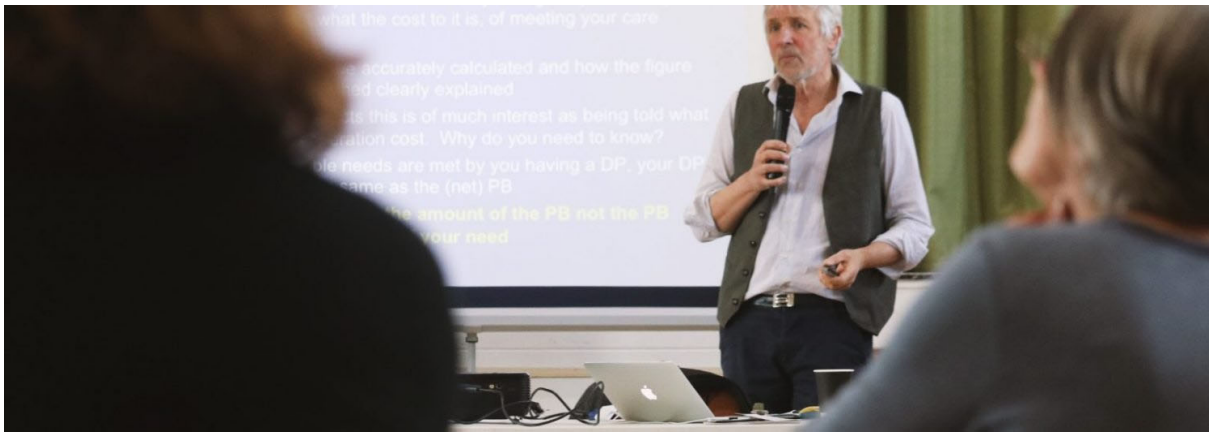
FOL has hosted the parent carer forum (now the Parent Participation Group or PPG) in one shape or another since we started as an organization. This group now offers training and mutual support to the next generation of parents. The parent carer forum works closely with the IASS to plan and organise training 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.



IASS staff 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.

The IASS Officer 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 Support Working Group meetings as well as Young People's Participation Group meetings and SEN coffee mornings in local schools.

The Family Support Worker attends a monthly Early Years SEN meeting with the Head of Bi-Borough Early Education and Childcare Services. She also is part of the Team Around the Family Hub Network and attends SEN coffee mornings in various Early Years Settings.

The Carer's Advocate will be participating in a monthly Adult Social Care steering group which is a new group looking at the ongoing development of services when young people reach 18.

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.

Our staff team has remained stable for many years - providing stability to our community when there has been so much change. We've gone from a single Borough to Tri-Borough, then back to Bi-Borough, as well as enduring the tragedy of Grenfell and its difficult aftermath, Covid-19 and, more recently, the north of the borough has experienced severe flooding; many families known to the IASS were displaced from their homes due to this.

OUR CURRENT SERVICES

Family Support Service

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 parents with issues relating to Social Care, Education and Health; helping families with benefits, form filling, preparing for meetings, appeals, complaints and accessing additional support.

Information Advice and Support Officer

Operates: Three days a week

Funding Stream: LA SEN

The IASS Officer 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 officer has offered training to the PPG as well as to groups of professionals to explain the role of IASS. The IASS Officer 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.

Carers Advocacy Service

Operates: Five days a week

Funding Stream: Health

Full of Life's Carers Advocacy Service works in line with the Children and Families Act to provide support to parent carers and young people from 16 upwards and offers free, impartial support in relation to Education, Health and Care plans and the process.

The Carers Advocacy offers a holistic approach. In line with the Care Act, the service offers full support with community care issues from transition onwards. The service does not stop at 25 and will support parent carers who care for adults over the age of 25. The service offers support with Benefit Issues, Housing and Health.

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

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.

Achievements 2020-21

Website

During Covid-19's lockdowns, we wanted to get even more information on the IASS section of the FOL website. We produced new mini-guides on choosing a school with and without an EHC Plan, and on tribunals. We have also updated our Transition Guide and written and commissioned a short animation explaining IASS, which was also put on the website.

In the area of social care, we were really pleased to commission a lecture series by Luke Clements, Cerebra Professor of Law and Social Justice at the School of Law Leeds University, on Community Care Law. This is available on the front page of the FOL website.

We will continue to add to the IASS section of the Full of Life website and hope to include even more mini-guides as well as some new animations that are currently in the pipeline!

Resilience during Covid

As a staff team, we supported each other during lockdown and while working from home. The IASS staff continued to work closely together, referring service users to our colleagues where appropriate. We also participated in monthly staff sessions with Dr Jo Stubley from the Tavistock Clinic, which focussed on sustaining our own strength as a team and helping us to think of how we could optimise the support we were providing to families during the lockdowns.

In fact, our case numbers during the Covid period show that as a service we actually reached more families during that time than we had during the previous 18 months.

IASS staff have continued to work closely with colleagues from SEN, Health and Social Care to help achieve good outcomes for families, keep parents' children and young people with SEN

on the agenda, and bring forward any concerns. We continued to attend strategic meetings with colleagues in Education, Health and Social Care which helped to shape services and support for families as the Covid crisis evolved, they also helped to keep our IASS team up to date on any local developments or changes because of Covid.

Technology was incredibly helpful to us throughout the Covid-19 period, and allowed us to continue our work seamlessly. We have been supporting families using video calls (Zoom), sending documents via email, and through telephone appointments. We have also used our building as a dropping off point for documents, with staff members stopping in to collect them. Our case numbers did not drop during Covid; if anything, they were higher than last year for Family Support and Carer's Advocacy.

Early on in the crisis, it became clear to the IASS staff team that parents and carers were bearing an enormous weight of responsibility during the lockdowns, and therefore we needed to be sensitive to the extreme stress that families were under. We made sure to book telephone and Zoom appointments with longer times so parent weren't rushed, and felt supported. We were all able to attend many virtual meetings such as annual reviews and network meetings. In fact, we were able to attend more of these than before Covid as the travel time between meetings was cut out. IASS staff regularly attended virtual parent participation groups and were able to connect with new parents in this way.

Although it is not something that is within our area of expertise, housing came up as a major issue for so many families during lockdown as it must be mentioned in this report as a huge challenge for families with children with SEN and Disabilities locally. IASS staff made links with Nucleus Law Centre to put parents directly in touch with their housing advisors and secured a housing workshop by the Law Centre for the Parent Participation Group. In fact, IASS staff worked closely with the Parent Participation Group, as we were seeing the stress and isolation of carers during the first lockdown. The Parent Participation Group responded by providing twice-weekly mindfulness sessions via Zoom.

At we began coming out of the 2021 winter lockdown, IASS staff were very concerned about the mental health of parents and carers following so many months of holding it all together. When Full of Life commissioned a survey of the mental health of parents/carers, the IASS staff worked in partnership with Catherine Delannoy from Alder Tree Research and Dr Jo Stubley, Consultant Psychiatrist in Psychotherapy at the Tavistock Institute in writing the content of the survey. The results of the survey were communicated to officers, and Full of Life has subsequently been awarded funding for counselling. We are currently developing this service in partnership with the Tavistock Institute who were also extremely helpful for families following the Grenfell Tragedy.

COVID-19 SUPPORT DATA

Covid-19 had an enormous impact on the parents and carers associated with Full of Life. Isolation felt by parents and carers was worsened by the crisis, as were issues with finances, education and housing.

Family Support Service:

From March 2020 to August 2021, our Family Support Service supported 178 families.

The top two Covid-related issues were:

- Isolation
- Housing

IASS (Education):

From March 2020 to August 2021, IASS (Education) supported 118 families.

The top two Covid-related issues were:

- Child falling further behind in learning, social skills
- Annual Review and Draft Amended EHC Plan

Carer's Advocacy:

From March 2020 to August 2021, our Carer's Advocacy service supported 175 families.

The top two Covid-related issues were:

- Financial Strain
- Isolation

IASS Data for Period of Annual Report

(September 2020- August 2021)

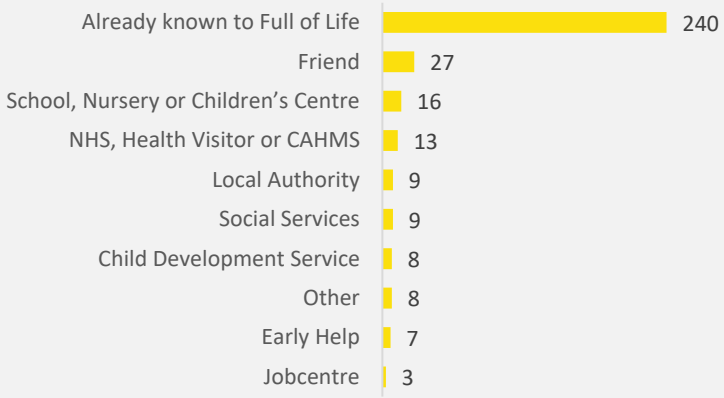
39

Number of families accessing IASS support who have two or more children with SEN

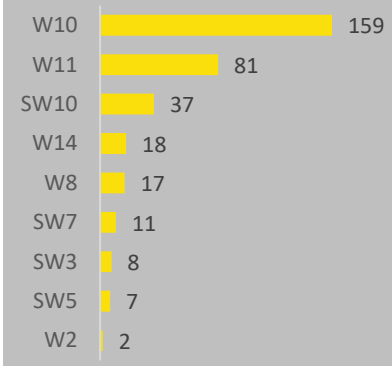
Total Cases

- Family Support - 119 families
- IASS (Education) - 94 families
- Carer's Advocacy - 127 families

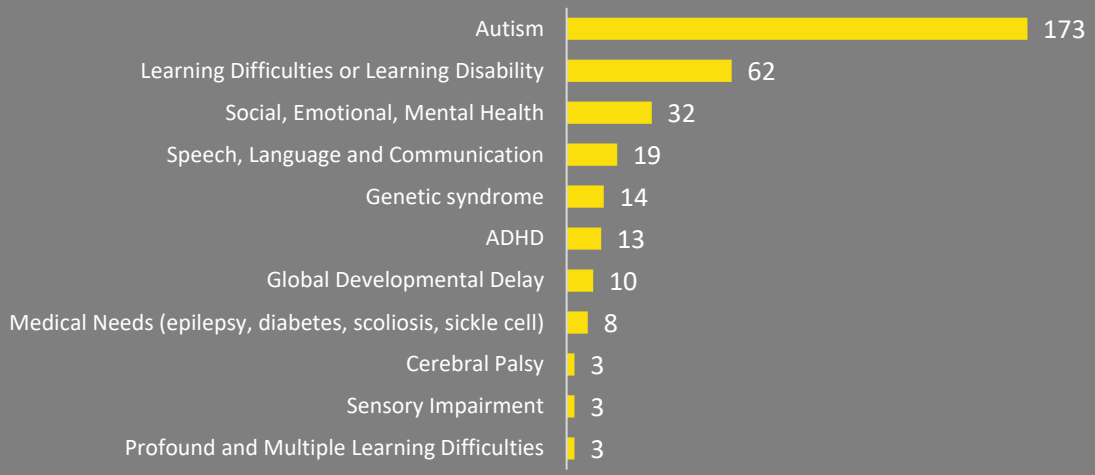
Source of Referrals



Number of Cases By Postcode



Number of Cases By Primary Need



TOP FOUR ISSUES FOR EACH SERVICE

Family Support Service:

1. DLA (including change of circumstances, mandatory reconsiderations & appeals)
2. EHC Requests
3. Social Services (Care Packages, Needs Assessments)
4. Housing

IASS (Education):

1. Communication with School
2. Annual Review/Draft Amended EHC Plan
3. Secondary Transfer
4. EHC Needs Assessment Request

Carer's Advocacy:

1. Benefits and form filling
2. Preparation for meetings
3. Advice on EHC plan and process
4. Information on colleges and next steps

FEEDBACK

We gather feedback using the standardised IASS Service User Evaluation, which we have a link to on our website. We regularly encourage parents to complete this by sending them a link (with their permission). However, it is a challenge to get service users to complete this, and the responses we get tend to be consistently positive, without information about how we could improve. We will be exploring how to gather more specific feedback from parents in the coming year when we create our Development Plan.

Here are some examples of direct feedback we have received during the period of this Annual Report:

Thank you so much Julia, appreciate all your time and help.	*Thank you very much for your help, have a great weekend.*
Thank you Julia for your support, it's very helpful, so kind.	*Thank you so much for everything. I greatly appreciate your help and support.*
We are delighted with the outcome, and I am personally grateful for your time when we reached out	*Thank you so much for your time today, spending a lot of time reviewing all the plan with me and answering all my questions*
Thank you very much for your time just now on the call about SEN and EHCP for primary schools!	*Thank you for your help and advice. It was so useful to me*
Although we only corresponded a few times, I want to let you know that your advice was invaluable to us	*We did it! Thank you so much!*
Thank you for all your help, and so happy we were successful	*Thanks again for your help all over again. You are truly amazing. I really don't think I could do this without you*
I wouldn't have been able to do it without the support you have given so many thanks	*Thanks for your call yesterday. I find your advice is very helpful*
I would really like to thank you for all your support over this stressful time as I could not have got through it without all the support	*I would like to thank you for your precious advice over the telephone. We finally got an EHCP for our son!*
I have worked with Sam for a number of years (and 2 potential Tribunals), regarding my daughter, and her very real and very difficult issues with her schooling and her various school placements. It doesn't matter how many times I call Sam or how many times I email, she always responds within 24 hours and calmly and patiently explains processes and next steps.	*I would like to say thank you so much for all your help and hard work.*

Our Priorities for the Coming Year

- Helping families to navigate through re-opening following lockdown. Many children and young people are struggling to return to school. Children are further behind than they were, and many parents feel the gap between their children and their peers has widened over lockdowns.

- One of our priorities now that things are opening up will be a focus on strengthening parents' mental health. Full of Life have secured a year of funding from local CCG for counselling for parents. We liaised with the Tavistock Institute who will work with us to shape this service. The Tavistock Institute provided vital support to our families post-Grenfell and throughout lockdown; ultimately gaining parents' trust. Many of our families are experiencing PTSD as well as raising a child with SEN/disability - many families continue to be affected by Grenfell and, more recently, this summer's localised flooding. Some of our families have experienced traumatic experiences in their home countries or in the UK before they were known to us. Mental health is a huge area for development locally; for adults, as well as for children and young people.

- The IASS needs to re-establish and strengthen connections with local schools, colleges, nurseries. It is vital that these settings refer parents and young people into the IASS so that we can support them before major problems arise. One way we will be doing this is by sending information packs to local schools and colleges. We are also designing a poster that will be sent to all providers of education, health and social care for display.

- We will continue resource-building- we have commissioned Sophie Lodge to create short animations on Problem Solving, Parent Participation and Post 16. We will also produce more mini-guides, based on feedback from parents. All new resources will be added to the IASS section of the website.

- We are looking at finding a safe way to re-open for face-to-face meetings but in the meantime have access to Zoom/Teams and telephone appointments. We have started regular in-person staff meetings.

- Our first SEN Surgery of this academic year is scheduled for 18 October. Others will be scheduled regularly throughout the year, and will help to sort out tricky cases before they escalate.

- We will also focus on more regular gathering and analysis of feedback from service users. This is be covered in our Development Plan.

- We will continue our participation in working groups with colleagues in Health, Education, and Social Care.

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 such as the Grenfell Tragedy and COVID 19. Full of Life is the foundation families rely on and it's something we are extremely proud of.