



Understanding special needs

Our strategy - 2022 to 2025

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1.0 Who are Families InFocus (Essex)?

Families InFocus is an independent charity, working with families who have a child (or children), or a young person, with any special educational need or disability (SEND). We provide advice and support to families with SEND children on how to access appropriate education, how to apply for an Education Health Care Plan and appeals to the SEND tribunal, as well as providing support with disability benefits, housing and social care issues. We also run weekend activity clubs for SEND children and their siblings to take part in a range of fun, healthy and engaging activities in an inclusive environment, and we are just starting to pilot a peer-to-peer family support service.

We support over 2,000 families across Essex each year, including over 1,500 families with education issues. The majority of the families we work with have a school age child with an autism spectrum condition, but we support with all types of SEND for children and young people aged 0 - 25. Almost all our staff team and our trustees are parents of a SEND child.

It has been the most on point and appropriate support that we have received. It is the first assistance that we have been offered that has completely fulfilled what it said it would and I honestly cannot thank them enough." Parent, 2022

We were founded in 1996 by a group of parents, following research into the needs of families of SEND children. The group was chaired by Dr Gail Bridgman, MBE, who recognised that parents are the experts, and work was needed to find practical solutions to gaps in provision for families. "InFocus" represented: Information, Friendship, Caring and Understanding special needs. Parents and carers have been at the heart of how we have developed, and we are proud to be user-led throughout.

We have recently reviewed and updated our vision and mission, with input from staff, trustees and volunteers. They are now:

Our vision:

A more inclusive society where children and young people with special educational needs and disabilities can realise their potential.

Our mission:

We support the whole family to achieve the best possible outcomes so that children and young people with special educational needs and disabilities and their families thrive and feel stronger, empowered and confident.

Our 2022 impact report

In the year April 2021 to March 2022:

- We helped to bring in £1.4m in disability benefits for families.
- We supported 697 families with benefits, and 1,521 with education issues.
- 93% of families rated us as excellent or very good.
- 87% of parents said the support we provided had a positive effect on the whole family.
- 85% of parents said they felt better after our support more positive, in control and confident.
- 99% of families would recommend us.

2.0 Introduction from the CEO

I am writing this introduction exactly 25 years and a day since Families InFocus were formally registered and incorporated as a charity. We are now an organisation of 13 staff, 15 volunteers, 7 trustees, and with a financial turnover of £400,000 per year.

This plan has been developed to take us through the next three years, following what was for us, and most charitable organisations, a very challenging Covid period.

We have taken time to develop this strategy, and have concentrated on the voices of the families we support, and what they are asking of us. We have reviewed and assessed:

- Our outcomes survey hundreds of responses from families to our online survey over the last two years, asking families about the impact of our work and what families would like to see us do;
- Our own commissioned, first-hand research, undertaken by a funded intern in the autumn of 2021, which gathered views from over 400 parents, both online and in person.
- Discussions with staff and trustees.
- SWOT and PESTLE analysis.

We were also very fortunate to have had the help of two pro bono services, which have been invaluable in helping us to develop our plans:

- Pilotlight the Pilotlight charity matched us up with a team of Pilotlighters senior business leaders who have coached and mentored us over 10 months.
- Statisticians for society run by the Royal Society of Statisticians, who linked us with a volunteer statistician who has helped us to make sense of the data we hold and of the demographics of the county.

Thank you to everyone who helped us to develop these plans.

In developing our plans we are coming from a place of success. Families InFocus is a well-respected, well-known, and valued organisation. Parents and families appreciate us and support us (over 99% of the families we work with would recommend us.)

It's important to us that we continue the things that are working so well, but also be ready to meet future challenges. The Covid pandemic has taught us how difficult it is to plan for the future and predict what may come, however there are things that we know will impact us and the people we support:

- The squeeze on living costs rising prices, higher bills, inflation will all put pressure on households (and charities). Wages are unlikely to rise quickly enough to meet rising costs, and it will be the lowest income families who will be hardest hit.
- Increasing mental health issues, mostly brought about by the pandemic.
- Changes to technology and improvements to mobile networks which will help people and communities to become better connected.
- Changes to how we work Covid has brought home and hybrid working and online meetings to the fore as the new normal way of working, but at the same time we also want to bring back face to face services and events.

This strategy is also set in the context of a changing national picture. Just in the last few months we have had the Education White Paper and the Department for Education's SEND Review, which was announced in 2019 and published in March 2022. If implemented, this will likely have a significant impact on the education of children and young people with SEND over the coming years. In order to do all of the things we want to in the coming three years, we need to make sure we are sustainable long term. Alongside this strategy will sit a fundraising plan, setting out how we will raise income from a diverse range of sources to enable us to deliver our services. This is going to be incredibly important as we face some significant funding uncertainties over the first year of this plan. This is a pivotal time for Families InFocus. Like many charities we have suffered reductions in statutory and grants income, and these will continue over the coming years. Unusually for us, we have no large multi-year funding agreements in place going into the 2023 – 2024 financial year for our main Family Support work (our three-year funding with the National Lottery ends in March 2023, and our funding with Garfield Weston ends at the end of December 2022. We have had nine years of funding from Henry Smith, and are now required to have a three year break, in line with their funding terms). Replacing this lost income will be both time consuming and difficult, and we will need to look at different forms of raising funds, including charging for some services where appropriate.

This strategy will be developed into an operational delivery plan – progress against the plan will be reported regularly to the Board of trustees.

We will measure our success in delivering this plan by review against the delivery plan, and also through regular performance reports and surveys to our users to check how we are doing against our planned outcomes.

We will also commission an external, independent review of our work and outcomes in 2025, following those done in 2019 and 2022.

Like many organisations of our size, we are facing a challenging few years to come – and for us we have the added difficultly of losing a third of our overall income when our National Lottery funding comes to an end in March 2023. I am hopeful that this strategy, along with the hard work of the trustees and staff team, will see us move into 2025 stronger, more resilient, and still delivering the excellent services that we are known for today.

Kirsty Cornell, CEO June 2022



3.0 The need we are addressing

I can't thank T enough for support, being a mum can be scary as it is however having a child with undiagnosed learning difficulties is extremely lonely. T was a friendly voice on the end of the phone who was genuine and sincere when ever we spoke. She made a massive difference to my mental health Parent, 2022

The families we help are often desperate. Their child may have been newly diagnosed, and they are unsure of where to turn and what to do next, or their child may be struggling at school and the parents are finding it difficult to talk to the school about the provision that their child needs at school. Having a SEND child can impact the whole family and place it under enormous strain. The support we provide reduces families' anxiety and helps them to feel their voices are heard. We empower families to take control, feel better able to cope with their circumstances and deal with the issues they face.

Many families who have a child or young person (CYP) with a SEND are under extreme stress, they are struggling to cope, and they are unsure of where to get support and help. The pressure of caring for a CYP with SEND can leave families confused, anxious and in poor emotional health. They are often lone parent households, socially excluded and feeling isolated and unheard. They also have problems accessing services and feel unable to plan for the future. *"Families with disabled children often face high levels of day to day stress and many have high levels of unmet need for support services, which can lead to higher levels of stress / ill health" – Essex County Council research.*

Low-income families are further impacted by caring for a CYP with SEND. The Essex Needs Assessment estimates the annual costs of bringing up a disabled child are three times greater than a non-disabled child. Around 55% of families of disabled children have a low income, and parent carers have limited opportunities to work in order to improve the situation (Contact – 2018). This is compounded in Essex, where parts of the county are amongst the most deprived areas in the UK, with Jaywick, Clacton, Greenstead and parts of Basildon and Harlow being in the 10% most deprived, with many more wards failing into the poorest 20% of communities (as defined by the Office for National Statistics). A number of Essex districts are above the county average of CYP with long term disabilities.

The impact of Covid on families

For the families we support, life was challenging even before the start of the Covid pandemic – whether that is trying to access the right financial support in the form of benefits; dealing with a complex school SEND system; managing complex and challenging behaviour; having the opportunity to meet other parents to get peer support; or finding the right emotional support for the family and for siblings. The Covid pandemic has exacerbated these difficulties for SEND families in many ways. Research from Ofsted, undertaken in October 2020, found that:

- Families found it harder to cope over time because of a lack of established routines; not being able to access family support networks and specialist support services; and for those whose child has a serious or underlying health condition, because of real concerns about the risk the virus poses to their children.
- Services such as short breaks, physiotherapy and occupational therapy could not be continued at a distance which has impacted the CYP's development.
- Some families reported feeling "useless and overwhelmed"; and "like a failure" as they tried to fill in the gaps from lost services.

- Changes to routines for CYP with SEND led to changes in behaviour for some that were physically and emotionally challenging.
- There were increasing numbers of parents reporting negative impacts on their own mental health.
- Home schooling provision was often inadequate for CYP with SEND and not tailored to their specific needs.
- Some children with Education and Health Care Plans were not able to attend school, despite qualifying to attend under government guidance.
- Many CYP with SEND who were awaiting treatment, such as assessments and operations, found these were delayed.

All this is reflected in the increase in demand we have seen. In addition, the referrals we are seeing are also increasing in complexity - families are presenting with increasingly complex issues that are taking a significant amount of time to resolve.

The research all shows that the CYP with SEND we support are more vulnerable as a result of the Covid pandemic, are in greater need of support, and are using our vital support services more and more.

Our unique strength is that we have the skills to support all disabilities and issues that may arise throughout the life of the CYP, and throughout the whole of the county.

The picture in Essex

Essex is home to a very high number of young people aged 10 - 24. There are 90,200 children aged 10 - 14 (the England mean per county is 50,954); 79,900 aged 15 - 19 (compared to a mean of 47,213), and 78,100 young people aged 20 - 24 (mean of 45,729). Overall, this gives us the second largest population of under 25s in England.

This translates into a huge number of children and young people with SEND. There are 32,444 children and young people with SEND in Essex, compared to a England mean of 19,527.

One of the main issues that affects children and young people with SEND is accessing the right support at school and college. The process of requesting an Education and Health Care Needs Assessment, and then ensuring that an Education and Health Care Plan (EHCP) meets a child's needs is long and complex. Where parents then believe that a special school is the best provision for their child, they will usually only secure this in Essex via an appeal to the SEND tribunal. Local government data shows that in 2021, 3.6% of all the decisions Essex County Council made in relation to SEND that could have been appealed, were appealed. This is the fifth highest rate in England and has increased by 140% since 2016.

The 3.6% of decisions appealed equates to 444 appeals registered with the SEND tribunal from Essex in 2021 – in other words, 444 families who need to go through the SEND appeal process each year in Essex. Families InFocus support around 200 of these families. The rate of refusal in Essex is high partly because the Local Authority will usually only place a child in a special school if they are ordered to by a judge at tribunal, and also because Essex County Council refuse a high proportion of requests for an Education and Health Care Needs Assessment (EHCNA).

Families with financial resources will often use solicitors to appeal the local authority's decisions. Those with limited resources come to us for help with the complex appeals process.

Essex families can face delays to the process of applying for an EHCNA, of being assessed for an ECHP, and the EHCP being issued and finalised. The whole process, including the initial stages of support at school should take between 18 months and two years. At the moment we estimate that the process is taking 3 years in Essex. This is due to the high volume of requests the Local Authority receive, the high number of tribunal appeals, and a shortage of Educational Psychologists available to undertake the EHCNAs. Our approach is collaborative – we work with the Local Authority and the family to try and resolve the issues before a tribunal hearing because we know that tribunal hearings can be very difficult and stressful for the family and they can take a long time to reach a conclusion. We work to resolve the issues after an appeal submission but before the hearing with the result that most cases then do not go to a full hearing – 65% of cases are resolved because the Local Authority concedes, and in 24% of cases we help the family to come to another type of resolution (which could be looking at an alternative school).

The delays to the process of applying for, and obtaining, an EHCP in Essex means that children may be out of school, or not attending the most appropriate educational setting for them, which can have long term implications for their learning and educational attainment.

The SEND system in Essex has faced significant challenges and is going through a period of redesign and flux – our support to families helps them to navigate the system and by working together, we help develop solutions that are in the best interests of the child, that reduce the timescales, reduce the pressure on the family and the child, and help families to have a positive relationship with the SEND system.

L made the very complex process of applying for an EHCP seem doable and manageable and her support was invaluable. I cannot imagine how I would have navigated the process without her help. In addition, when the council initially refused the EHC assessment, L was able to successfully guide us through the (equally complex) appeal process. The support provided was so appreciated Parent, 2022



4.0 Our strategy

Our research has shown us how vital families consider our services to be. To continue to deliver our support, we first need to deal with the immediate challenges to our income. This will take a large proportion of our time over 2022 and the first part of 2023. In order to have the time to raise funds, we will need to relook at how we work to free up some time to write funding bids and develop new income streams. We also want to change how we work to make sure we are giving very family the most appropriate level of support for them.

At the moment, we massively over deliver on the targets and numbers we have agreed with funders. This is great in terms of the support we provide for families, but it also means we are dealing with such a high volume of incoming referrals that we do not have the time to plan, and to put in place the things we know we need to do – such as resources for families who can self-service. We need to set up robust resources and information for families, including publishing factsheets and information videos on the website. By delivering workshops for those families who only need light touch support we can use our 121 support for the most vulnerable families who need our help the most. That way we can reach the greatest number of families with the most appropriate intervention for them.

We expect that in order to set those things up, we may need to pull back on our 121 support for a short period of time to focus on developing those resources, and to free up time for identifying and securing new funding sources.

Priority areas for support

Families told us that the most important things they would like to see us concentrate on over the next three years are:

- a) *Education support securing better outcomes for individual children and young people.* Getting support in navigating the education system, support with school meetings, help with education and health care plans, appeals and exclusions.
- b) *Help with financial wellbeing improving family finances*. Accessing benefits and other support, budgeting and planning for the future.
- c) **Bringing people together supporting the emotional and wellbeing needs of families.** People want opportunities to come together online and in person for parents, carers, families, CYP with SEND and their siblings.
- d) **Resources empowering families with access to information** providing information and helping people to know where to go for the right support.

Education support – securing better outcomes	Help with financial wellbeing – improving family
for individual children and young people	fingnces
Our approach to education support is collaborative. We work together, with parents, the Local Authority and schools, to support the family and child to find solutions which will bring about the best and most appropriate education for the child or young person with SEND. There is huge demand for our education support, and we know we could double in size and not meet the demand that is out there. Any growth to our Family Support team needs to be fully funded – a challenging proposition in the current economic climate. We want to increase our work in schools, to share the knowledge we have and to improve the way schools work with parents – improving the experience that SEND families have with their child's school. We will make greater use of the Family Forums' graffiti wall to feed back what families have told us, and we will run workshops on a range of education topics.	Families have told us that one of their concerns is how to plan for the future – what do they need to have in place for when their young person with SEND transitions to adulthood, and also how they plan for the time when they will no longer be around to care for their young person. Of huge importance to families now is the cost of living, and how they will manage the increase in basic living costs, which are further compounded by the additional costs of raising a SEND child. We will build our knowledge around transitions to adulthood and preparing for adulthood, and we will have in place a robust list of where we can signpost people to for support with finance and benefits. We will produce a video resource for families on how to complete the DLA form, and towards the end of our three year plan we will make a successful bid for a benefits and finance worker.
 Bringing people together - supporting the emotional and wellbeing needs of families Another clear request from families in the research was more opportunities to come together - to meet other families who also have a child with SEND, and to be able to get support from each other. To do this, we will set up coffee mornings in the areas of the county that we don't do them at the moment. We will also start a peer to peer or befriending service. We will have a more regular FSA presence at our activity clubs, so families can get some informal support and advice whilst they are there. We will also hold some respite events for parents, where parents can come without their children, to meet other parents and have some space to talk. We have made the difficult decision to stop running Kidzspace, our siblings group. Kidzspace was paused during the pandemic, and after reviewing how and whether to restart the group, we have acknowledged that most of our Kidzspace users have grown up and moved on, and we are also aware that other local charities provide much more wide-ranging programmes and activities. We are therefore focussing on the other areas of our work. 	Resources – empowering families with access to information We know that high quality, trusted support and information can be hard to find. Our goal is to provide support and information in a range of ways that are accessible to as many people as possible. We want people to be able to access information and empower themselves with knowledge – the main way we will do that is through our new website. Our website will contain a range of factsheets, videos and other information – on education and benefits. Our new website will go live in January 2023 (we are very grateful to the support of the Essex Community Foundation for funding the website).

5.0 Enablers

We have identified two steams of work that we need to develop so that we are organisationally resilient and able to deliver our strategy over the next three years.

Enabler 1). More robust systems and processes:

Our ambitions will not be achieved unless we continue to maintain and develop a strong organisation. Families InFocus has strong governance, and good systems and processes. There are some things though that we know need relooking at and renewing, and other things that need to be developed afresh.

- Values we will relook at how we express our values, and what values and ways of working are needed to deliver the new strategy.
- Governance we will recruit new trustees and develop a succession plan for trustees.
- We will move to new, accessible offices.
- We will develop more written policies and procedures about our support a support agreement, a policy for withdrawing support, and clearer information on what we do and don't do. We will develop a "handbook" of how we support, and our approach, which we will use for all new staff inductions.
- Staff wellbeing we will consult on staff wellbeing to see what individually staff need to enhance their wellbeing at work.
- We will develop an equality, diversity and inclusion strategy.
- We will register with the fundraising regulator
- Impact measurement we will better understand the long lasting impact of the work we do with families.

Enabler 2). Financial resilience

To deliver our plans, we need to continue to have financial resilience – meaning we need to raise income and stay sustainable.

We will update our fundraising plan, which will look at a range of income sources, including statutory funding, trusts and foundations, fundraising, and possibly charging for some services. We will need to carefully consider the price point for these.

In the last two years we have increased our reserves, are making progress towards increasing them but we still have some way to go to increase them to three months of running costs, as is in our policy. We want to increase our unrestricted income in order to increase our reserves and give us freedom to choose how we spend that money to best deliver our charitable aims.

Fundraising is difficult for all organisations, particularly now with the increasing cost of living. We will try to maximise income from regular giving (particularly from those who have used our services or been touched themselves by SEND issues). We will register with the Fundraising Regulator.

6.0 Our timeline

	Year one (April 2022 to March 2023)	Year two (April 2023 to March 2024)	Year three (April 2024 to March 2025)
Education support	Making more use of the Family Forum's graffiti wall. Starting to test and develop workshops	Workshops on education topics run. Train up our "experts" in appeals.	Delivering training in schools. We want to have grown our FSA team.
Help with Financial wellbeing and inclusion	We have a centrally held list of other agencies we can signpost to. DLA video is available online. We continue our DLA workshops.	Information sessions for families about planning for their financial future.	We employ a benefits and finance worker
Bringing people together Information resources for families	We start a befriending or peer to peer service. Our new website is live, populated with factsheets and video resources. Developing new video resources with Maze.	Coffee mornings / clinics in: Mid Essex West Essex. Monthly FSA attendance at activity clubs We have increased the support available through our helpline.	Respite sessions for parents.
Robust systems and processes	We are working in new, suitable office premises. We have written values, developed with staff, volunteers and trustees. We have an equality, diversity and inclusion strategy. We have updated our fundraising and sustainability plan.	We have done a wellbeing survey and put in place individual options for staff. We have recruited new trustees. We understand the financial impact of our work.	We are registered with the Fundraising Regulator. We have support policies and a handbook in place. We have increased our reserves year on year.
Finance	Moving to an on online accounts package from January 2023, for full use for April 2023 onwards.	The National Lottery income we lose at the end of March 2023 is replaced.	