## 'Invaluable to us'

# Examining the Impact of Families InFocus for families of children with SEND in Essex



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### Introduction

Families InFocus (FIF) is a small, independent charity supporting families of children with SEND in Essex. In July 2022, FIF commissioned an external evaluation of the impact of their work, and in particular their Family Support Service (FSS). This report details the findings of the evaluation based on conversations with thirty FIF stakeholders including: families supported by FIF; FIF staff and trustees; and external professionals from the local authority, education, health, and voluntary sectors.

Through the FSS, Family Support Advisors (FSAs) work to address a holistic range of a family's needs across the remits of education, health and wellbeing, social care, finance, and beyond. Chapter 1 of this report looks at how FSAs support families with EHCPs, benefit entitlements, and a range of other issues, and how this is encapsulated by an ethos of empowerment.

As well as supporting thousands of families each year, this evaluation demonstrated the value FIF brings to existing services in the county across local authority, education, health and the voluntary sector. Chapter 2 of this report looks at how FIF creates savings, builds capacity, and enhances the efficacy of other services.

FIF is a small charity and struggles with both operational and strategic capacity, and sourcing the necessary funding to cover the costs of its work. Chapter 3 looks at how these issues threaten FIF's ability to deliver the same levels of impact consistently in the future, followed by a series of recommendations that may strengthen its resilience to the troubles ahead.

The findings of this evaluation are informed entirely by the voices of stakeholders, whose quotes and case studies form the bulk of this report. All names used in case studies have been changed, and all names used in quotations have been redacted.

### Chapter 1: Achieving impact for families

This section of the report looks at how Families InFocus positively impacts the lives of families in Essex. Stakeholders were asked to describe, in their own words, the impact of FIF's support, how this impact was achieved, and the unique value of FIF compared to other services.

FIF's support offer is broad, and encompasses many of the issues that families face when caring for a child with SEND. Most commonly, families received support with: obtaining educational health and care plans (EHCPs), claiming benefit entitlements, managing transitions in their child's life (such as the move to a new school), meetings (such as mediation, appeal, and tribunal), and emotional wellbeing.

Stakeholders explained that this support was made particularly impactful because FIF was: collaborative, knowledgeable, independent, localised, empowering, person-centred, and co-productive. This combination was seen as unique to FIF; an offer that could not be matched elsewhere. Using case studies and quotes from stakeholders, this section looks in more detail at how FIF's combined offer creates valuable impact for families in Essex.

### 'We had to fight': Educational Health and Care Plans

Formal evidence is often required to meet the education, health and social care needs of children with SEND. For many, this takes the form of an Educational Health and Care Plan (EHCP). This is a lengthy process in itself, but families often face additional barriers along the way, including:

- Disagreement as to whether or not the child requires an EHCP
- Delays in beginning, and furthering, the plan
- Delays in gathering evidence of need (such as assessments and reports)
- Disagreement on the content of the report and its final draft

This can be concerning for families whose children often remain in inadequate educational provision until a plan has been formalised. FIF's data indicates that just under half (43%) of all queries to its service relate to EHCPs - an increase from 31% in 2019 and 39% in 2020. This made EHCPs the most prevalent issue for the service in 2021,<sup>1</sup> suggesting that of the 2,032 families FIF worked with that year, around 873 required support with EHCPs<sup>2</sup> - a significant number of children with SEND who are likely not having their needs met in education.

The case studies below demonstrate how FSAs work with families to develop EHCPs in a way that is timely and appropriate to the child's unique needs.

Melinda<sup>3</sup> cares for her grandson, Louis, for whom she wanted an EHCP, as 'whatever was offered in terms of the SEND department was not really working.' The SENCo at Louis' school had 'agreed he needed one,' but it later transpired the process had not been started as the SENCo said she was 'too busy.' Melinda contacted FIF, and an FSA quickly arranged a Zoom call in which she 'decided to take on our case and help us.' The FSA worked with Melinda and the SENCo to draft the EHCP, and

<sup>&</sup>lt;sup>1</sup> Family feedback, via SurveyMonkey

<sup>&</sup>lt;sup>2</sup> FIF performance dashboard, 2019-2021

<sup>&</sup>lt;sup>3</sup> All names in this report have been changed to protect confidentiality

remains involved to keep the process moving. Of FIF, Melinda said, 'They're invaluable to us...I needed somebody to help me, and listen to me in a helpful way.'

Halima worked with her FSA when she felt the school was 'not moving very quickly' in producing an EHCP for her son, Michael. With the help of the FSA, Halima was able to have a draft EHCP agreed by the local authority; the plan was robust, evidencing Michael's suitability for the school Halima had nominated, and everything looked to be going well.

However, Halima said that one evening she received an email from the local authority with Michael's EHCP attached; 'They said 'Is it ok to publish this?'' Halima realised the EHCP had been changed without her knowledge after it was agreed upon by the local authority. She was overcome with panic, explaining that the local authority told her the plan would be published the following morning.

Halima contacted the FSA who advised her to report this to the local authority and arrange a meeting in which Halima and the FSA could lay out the two documents, showing how evidence supporting Michael's suitability for the nominated school had been removed. Halima said, 'It was a really great meeting. We went through the provision one by one, showing what had been removed, side by side.' This resulted in a positive outcome for Halima: 'When it came to the reasons for choosing the school, the local authority said 'We agree with you.''

Most families seeking an EHCP for their child will be unfamiliar with the process, putting them at a disadvantage in knowing their rights and entitlements, dealing with authorities, and making the best case for their child. The support of FSAs undoubtedly leads to greater outcomes for the hundreds of families a year requesting EHCP support, as FSAs can keep the process on track, assist in building evidence, advise on steps for recourse (such as appeal), and problem-solve when something goes wrong.

# 'Having children with SEND is expensive!': Accessing financial support

Families of children with SEND often incur additional costs due to the support needs of that child, which can include:

- One or more parent needing to reduce, or stop, work to provide care
- Specialist equipment and therapies
- Adaptations to the home or garden
- Damage to property, clothes and possessions

While these families may be entitled to various forms of financial assistance, many do not know that it exists, or how they can access it. A large cohort of families that FIF works with come from lower income brackets, and in the words of an FSA, access to benefits 'can determine if a family manages, or if it doesn't.' Year on year, benefit support is one of the leading queries made to FIF (this fell slightly during the course of the pandemic, when existing payments were

rolled over)<sup>4</sup>. FSAs help families identify the support available to them, navigate complex application forms, and assist with renewals, as demonstrated in the case studies below.

Lauren had initially applied for DLA herself, but the financial support she was offered was not adequate for her son, Rueben's, care needs. 'I had applied on my own. The forms are so long and lengthy, but I'd filled them in...and I was offered £80. They said 'He only needs care for an hour a day.'' When Lauren contacted FIF she was told, 'We can help with those forms.' An FSA arranged an assessment for Rueben and worked with Lauren to complete the form based on his needs. Lauren remembers going to bed at 4am one morning, after having spent the night completing the form, and when she woke up at 8:30am the FSA had already sent back comments. 'She gave me some useful phrases to include, she advised me about what - or what not - to put in.' This time around Lauren was able to access more adequate financial support toward Rueben's needs.'

Rebecca had been able to claim DLA on behalf of her son, George, with the assistance of FIF. She said, 'Having children with SEND is expensive! George will only eat certain foods, and then there is the SEND equipment - our food bill is huge!' Rebecca had also left employment, saying, 'I had to stop working...I'm his full-time carer at home. I have to be at home all the time, so we do really need that - that was my wage we lost - not all of it, but it plugs a bit of the gap.' Recently, Rebecca had needed to renew the DLA application, and the FSA she worked with was able to help her present George's case: 'It was my first renewal. She wrote loads of points on Post-It notes for me. Because she knows us so well, she can guide us through it.'

This aspect of FIF's support is essential now more than ever, given the current cost of living crisis that threatens the country's most vulnerable families. Each year, FIF helps Essex families to access roughly one and a half to two millions pounds in Disability Living Allowance and Personal Independence Payments alone, split approximately across 300-500 families whose lives would likely be much more challenging without it.<sup>5</sup>

# 'A huge part of their life, and our work': Important meetings and smooth transitions

Families regularly attend professional meetings when discussing provision for their child's needs. Families described feeling intimidated when facing qualified professionals such as SENCos or local authority representatives, and in legal cases judges and solicitors, to state their child's case. The power dynamic often felt unfairly weighted against families who do not always understand their rights, or legal processes. Therefore, having the option for FSAs to attend meetings meant that someone knowledgeable about the process could advocate for their family. As a member of staff said, 'Appeals are a huge part of their life, and our work.'

Louise had identified a school that she believed would meet the needs of her son, Jason, and had arranged a meeting with the local authority to nominate the school, also attended by the FSA. In the meeting, Louise asked the local authority 'When can we nominate this school?' She said the local authority told her 'You can nominate a school at any time.' However, the FSA informed Louise that nominating the school at this time would revoke her right to appeal. Louise was grateful to

<sup>&</sup>lt;sup>4</sup> FIF performance dashboard, 2019-2021

<sup>&</sup>lt;sup>5</sup> FIF performance dashboard, 2019-2021

learn this because, 'we went through appeal, as it happens.' While she did not believe the local authority were being 'underhand,' having the FSA in attendance prevented her from losing her right to appeal at a later date.

Similarly, when families begin to consider transition points for their children (such as the move to secondary school, a change of school, or a move from child to adult services) FSAs can advise them on preparing for the process to increase the likelihood of things running smoothly. This often involved getting certain paperwork in order that families otherwise might not know about, and FSAs using their network to identify the professionals relevant to each case.

Kayleigh's son, Liam, was due to start secondary school in September. Liam and his class attended two transition days at the new school, but the school had not been informed that Liam had SEND. This meant Liam had faced difficulties, and Kayleigh had to collect him from the transition day early. Liam was now 'quite anti' attending that school. Kayleigh spoke to an FSA who contacted staff at the secondary school to make them aware of Liam's needs. With Kayleigh, the FSA drafted an EHCP for Liam so that the secondary school would have evidence of the support Liam required.

Appeals, tribunals and changes of school are among the most stressful times in families' lives. FSAs work with families to prepare well for these events, mitigating some of the difficulties they may otherwise encounter. Families describe the impact of FIF's involvement as increasing the chances of transitions that are smooth and successful, and empowering them with the knowledge and confidence to make the best decisions for their children when faced with daunting legal processes.

### 'It takes its toll': Supporting the emotional wellbeing of families

It would be impossible to overstate the impact of managing the needs of a child with SEND can have for families. Repeatedly, families described how emotionally taxing it was to witness their child struggling, repeat their story over and over again, feel that they were not doing an adequate job, and feeling uncared for by the services that were supposed to support them.

'Everything is daunting and draining.' (Family member)

'Every so often you have a moment where you're really overwhelmed.' (Family member)

In data gathered by FIF, 75% of families in 2021 felt 'anxious or overwhelmed' before contacting FIF. 55% felt frustrated or unsupported, 45% felt tired or exhausted, 44% felt confused or desperate, and 34% felt alone or socially isolated.

While the practical support FSAs offer play a significant part in improving emotional wellbeing for families, it is often equally impactful for families simply to feel listened to, and cared about. As shown in the case study below, reassurance and understanding provide crucial emotional relief for families who are struggling.

Craig and Jenna are a married couple with an infant son, Daryl. Jenna had stopped working to provide care for Daryl, who often attempted to escape from the home, and had few opportunities to leave the house. Craig explained, 'Jenna is, in a sense, imprisoned in the home. He won't wear reigns, he won't go in a buggy, he likes to walk. But if he pulls away from her hand she can't catch

him. We can't go shopping because he has a meltdown and becomes violent - I have to go on my own - so she is a prisoner in the home seven days a week.' While Craig and Jenna had worked with professionals and even attended specialist courses to support Daryl's needs, this did not detract from the emotional strain the couple were under: 'It takes its toll, one hundred percent. The pressure it puts on our relationship...having our own time...life is really hard at the moment.'

Having contact with an FSA provided emotional support to the family, who simply benefited from having 'someone to go to' when things were tough. Families of children with SEND can often feel guilt and anxiety, but a conversation with an FSA could reassure them that they were doing a good job. Furthermore, during difficult times families may feel invisible and unheard, and simply knowing that they are acknowledged and cared for can relieve some of the emotional strain, 'She's always phoned me up to make sure everything's ok.'

Families also explained that in times of emotional hardship FSA could manage some of their responsibilities, or keep families emotionally composed in important meetings. As well as this, FIF recognised that in documents that required an evidence of need families often had to confront the biggest fears they had for their child, which can be distressing.

'As a parent, you're emotionally attached. You need that calm voice. Someone who's fully on your side who can take over when you're struggling, who, in meetings, can step in when you feel too emotional. It's priceless.' (Family member)

"...the government don't want to give it out to everyone, and quite right, but if you're genuine it's quite a hard thing to come to terms with...you have to put in your worst case concerns about your child. It's difficult to talk about your own child. As a man, I probably struggle with that more than my wife." (Family member)

FIF's data shows that after contacting the charity, 81% of families felt better informed or supported, with 53% feeling more able to support their child and family as a whole. 47% reported improved feelings of positivity and confidence, and 32% experienced improved emotional health and wellbeing.<sup>6</sup> In the year this data was gathered, 2021, FIF worked with 2,032 families, meaning the figures behind these percentages are in the hundreds, or thousands.

By emotionally supporting families, FIF are able to positively impact their mental health in a way that can prevent escalation and crisis. FIF build emotional capacity for families, not only making it easier to cope with their own situations, but to continue to provide for and support their child to the best of their ability.

"... it impacts the mental health of parents. If parents get in the right place, it has a significant impact for that child." (SENCo)

## 'We're all on the same side now': Building collaboration between families and statutory services

Families and professionals described FIF's approach as professional, non-adversarial and collaborative. This was in contrast to some advocacy services that could be 'aggressive' and

<sup>&</sup>lt;sup>6</sup> Family feedback, via SurveyMonkey

obstructive, ultimately breaking down working relationships. Professionals, who were experienced in working with more 'hostile' advocates found FIF to be 'responsible' and 'flexible', and therefore more likely to secure a positive outcome for a family.

'...[other organisations are] more political; FIF is more about advocacy. They don't push an agenda; they provide essential, responsible advocacy.' (Local authority professional)

'They have an ongoing relationship with the [local authority] team, and it just aids it, doesn't it? It demonstrates a good advocate. Some commissioned providers just don't have that good relationship. FIF work co-productively with the local authority; some advocates are more black and white, and less flexible.' (Voluntary sector professional)

For families, this way of working often had a profound impact on the outcomes they achieved. Whereas previously they described having to 'fight' for a solution, viewing themselves in opposition to the local authority, FSAs were conducive to a more harmonious, and therefore productive, relationship:

'We're all on the same side now, but I was fighting before. Now everyone can see we need help. We don't have the same barriers.' (Family member)

'It's not aggressive, it's collaborative. [FSA] wants to encourage a discussion. All of the team work really well and have that manner - all of them.' (Family member)

Families observed the respect services had for FIF, claiming this had resulted in more timely responses from local authorities and schools. This evaluation took place during the summer holidays. In spite of this, schools were still responding to FSAs quickly, and indeed several professionals were willing to interrupt their annual leave to take part in this evaluation. Not only does collaborative working improve cooperation, but it can avoid more stressful and adversarial measures such as tribunal - something that is looked at in more detail in the next section of this report.

#### 'The ins and outs': A thorough understanding of SEND

It's unlikely that families of children with SEND will have pre-existing knowledge of the steps they must take, or the services they must engage, to access the support they are seeking. Families are often still grappling with understanding their child's diagnosis, and many have not been informed about what to do next.

'Information you have to request and ask for. It's really disappointing that it's not freely given. You have to go looking.' (Family member)

'The local authority is very difficult if you don't know the ins and outs...My son is my son. I don't know the technical language. All I know is he needs support in school.' (Family member)

In its twenty-six year history, FIF has amassed a vast knowledge of matters of SEND that is of incredible value to families beginning their SEND journey. Staff remain informed about changes to service provision, or system reforms, so that information is always up-to-date and relevant.

The case study below shows how FSAs can equip families with the information they need to begin putting the relevant support in place.

When his son, Ross, was diagnosed with Autism, Shane told us how he and his wife struggled to know what next steps to take '...it's a hard journey. Well, with Autism there is no journey. We were totally lost. We had no idea what there was, what to do, how to help...'

But when Shane began working with an FSA, he said that he became aware of the range of services he could access that could support Ross. With the support of the FSA, Shane had requested the assistance of a health visitor, speech and language therapist, paediatrician and SENCo. As Ross grew older, Shane and his wife began to feel concerned about the safety of the house they rented, which needed to be adapted to suit Ross' needs. This had been a source of stress and anxiety, but at the time of this evaluation, Ross had spoken to the FSA who had pointed him in the right direction, '...an occupational therapist is coming to risk assess the house, because of [FSA's] advice.'

FIF's knowledge base is a huge asset to Essex families who not only benefit from learning about their entitlements and the types of support on offer, but also what to expect from daunting processes like assessments and tribunals.

## 'Trust is at the centre of everything': FIF's status as an independent charity

FIF is a charity independent from statutory services. While the local authority commissions its own SEND service targeted at providing 'impartial' advice to families, professionals acknowledged that families were less likely to view it as such. Families agreed that it was harder to trust the independence of services run by the local authority, and also had concerns about how their information could be shared across statutory systems.

'[Name of service] is ultimately [local authority] staff - parents don't see them as independent.' (Local authority professional)

'How independent is that, really?' (Voluntary sector professional)

Through being an independent charity, separate from the local authority, families said they could trust FIF's advice as being tailored to the best interests of their child (as opposed to what was most convenient within existing statutory pathways). When families were given information - especially disappointing information - by statutory services, they trusted FIF would tell them if the information was correct, as they had no motivation for doing otherwise.

'You need to know they're not in it for the money, they're not in it because the local authority told them to do it - they do it because they care.' (Family member)

'When they're independent they listen, help you, and can also tell you 'They [local authority] are in the right'...Trust is at the centre of everything.'' (Family member)

This sense of trust is vital to the impact FIF creates for families who feel that in FIF they have a reliable source of information empowering them to make the best decisions for their child.

### 'My neck of the woods': Local support for local families

FIF is a countywide charity, as opposed to a national or international organisation. As such, FIF holds specialist knowledge of provision in the county, and maintains a network of professional relationships. This had a significant impact for families who were connected rapidly to the most relevant services or professionals by FSAs.

"... just dealing with Essex as a whole she knows certain EPs and APs, and if she doesn't: "I'll check with my colleagues to see if they know." (Family member)

FSAs are assigned different localities within Essex, meaning they have in-depth knowledge of local schools, SENCos, and voluntary sector organisations, all of which can form important parts of the support offer for families. This was particularly meaningful for those who felt isolated, or who could not easily travel to other areas of the county; FIF's own data shows that 34% of families reported feeling alone or socially isolated before contacted FIF, and after contacting FIF 27% - almost the same number again - felt less alone.

'They are something in our area of Essex. There's not a whole lot in our sort of area, in terms of SEND support with the children.' (Family member)

'FIF are in my neck of the woods. They know the schools I know; they know the SENCOs.' (Voluntary sector professional)

Comparatively, some families who had worked with national services experienced poorer outcomes as a result of absence of a nuanced knowledge of the locality. In one example, a solicitor pushed a family to tribunal with a school that Ofsted had raised safeguarding concerns about - it was felt that FIF would be aware of the issues at the school, and advise the family appropriately.

Essex is a large county with affluent and deprived, urban and rural dynamics. Understanding these nuances and the local provision landscape is essential in supporting families to make the best decisions for their child in a way that is person-centred and trustworthy.

## 'Giving tools rather than taking over': Empowering families to achieve their own outcomes

Families can often feel disempowered by the large and complex systems they come up against when trying to find the right support for their child. They can be turned away, made to wait for unspecified amounts of time, and outnumbered by experienced professionals in important meetings. This leads to feelings of helplessness, and an inability to do what all parents feel is at the core of their duties to their children: providing for their needs and giving them the best chances in life.

FIF aims to empower families to achieve their own outcomes. This is achieved by building trusting relationships, making the family's decisions central to the goals they work towards, and equipping them with the knowledge to make their own choices. Over time, this develops confidence and resilience.

'[FSA] and I didn't always agree on stuff, but what we did was what I wanted. You feel really involved in it...'doing with' rather than 'done to'...They're giving tools rather than taking over; that's been my personal experience.' (Family member)

'They're very good at empowering parents. Some advocacy services are in danger of 'We'll do it for you.' For want of a better word, they are 'You can do it yourself.'' (Voluntary sector professional)

This does not mean FSAs do not provide intensive support when it is needed - often when a family is first in contact with FIF they describe feeling 'lost,' 'panicked,' or 'exhausted,' and FSAs can support these families by advocating on their behalf. But over time, this dynamic will often shift, with families feeling able to take more of a lead. FSAs told us that at first some families will not speak in a meeting, or attend a meeting alone, but gradually they begin to find their voice.

'As time goes on I feel a bit more confident going into these things [meetings, alone]; since then I know a little bit more about where to get support.' (Family member)

FIF recognises that families are the experts of their children, and what is right for them, and utilise their own skill sets to advance that family's mission, as highlighted in the case study below.

Kasia had identified a school to which she wanted to send her son, Jan. With the support of FIF the process was underway, 'Everything was geared towards trying to achieve that.' But during the tribunal, when Kasia learned more about the school, and the behaviour it demonstrated at tribunal, she began to realise this would not be the best decision.

She said, 'I contacted FIF straight away, saying 'During that meeting I really felt that the school was not right for my son.'' She told us that straight away her FSA began the process of supporting Jan to attend a more suitable school. 'She contacted the relevant individuals in the local authority and advised me on the steps to take. She took care of everything.'

Before contacting FIF, just 2% of families reported feeling 'in control', whereas after contacting the charity 42% felt 'more in control and empowered.' FIF positively impacts, and restores, the confidence of families at a time when they are feeling helpless and unheard. Empowered families will make better decisions for their children, and will have the resilience to reach the outcomes they set for themselves.

#### 'She remembers him and his schedule': Person-centred support

As already discussed, FIF is able to offer person-centred support through its extensive knowledge base, independence, and localised focus. FIF recognises that no two families are the same, and treats each case individually. In building relationships with families, FSAs fit their support around the needs of each family and child. As one family said:

'She remembers him and his schedule. She contacts us when she knows something is happening for him. He starts school in September, so she rang to check everything was ok.' (Family member)

This approach was especially valuable to families who did not have a specific diagnosis for their child, or whose child's needs did not fit traditional definitions of SEND. As well as this, FIF catered to the needs of individual family members, adapting the level of support to suit the needs of families whose first language is not English, or who have SEND themselves. Professionals observed:

'There's a broad approach to SEND, not focused on one area. It's so broad that it's purely focused on that individual parent.' (Local authority professional)

'It's not generic, it's specific to families and that child.' (SENCo)

This person-centred approach creates impact for a broader, diverse range of families who might face barriers to accessing support from other services: perhaps because their child did not have a formal diagnosis, or because they had learning problems of their own. FIF gives these families a way to access the support that may otherwise be difficult for them to access, or to access at all.

### 'Someone who gets it': Co-production and lived experience

Lived experience runs throughout FIF's work: lived experience is present on the Board and staff team, the experience of families informs decisions made about the service, and family voice is shared widely across Essex systems.

'A lot of us have lived experience. The charity supported me before I started - that's my motivation for wanting to be here. I'm so passionate about it because I know how difficult it can be - there is a lack of support out there.' (Staff)

'The experience you have had and how that can drive and determine, and inform, what we do as a charity...be prepared to talk about your experience, and use it in the right way to help us as trustees.' (Trustee)

It's important to note that FSAs without lived experience were achieved the same high quality outcomes as those who did, but anecdotally families said that knowing staff had lived experience was reassuring and inspiring:

'She knows us better than a lot of my family do. Because you get fed up, or feel like you're always moaning. She's a SEND mum herself, so you feel there's no judgement. It's refreshing.' (Family member)

'It's different when you speak to someone with experience...it makes you think you could do it...it gets you thinking how you could help...If there was a job there, I'd take it tomorrow.' (Family member)

FIF runs ongoing surveys to gather the feedback of families, and also informally asks for suggestions about the future of the service. As well as this, the lived experience of families is utilised to provide staff with diverse perspectives and an up-to-date understanding of the issues families face today:

'They had me in, on Zoom, to do a training on Alternative Provision. There's been an upcall in parents asking for non-school alternatives, so I gave a talk on what that looks like, and the journey. They said it was lovely to hear from a parent's point of view; some of them are working with families going through that.' (Family member)

"...they use our case study, anonymously, in training because we've touched so many areas of the process." (Family member)

FIF work closely with decision makers in Essex through steering groups, forums, commissioning panels and wider workstreams. This allowed FIF a platform from which to share the lived experience of the families it worked with in a way that shaped meaningful change in the county.

'They give [local authority] access to parent voice, individually and strategically.' (Local authority professional)

'[FSA] is fantastic, and really champions the issues for families and young people.' (Health professional)

Therefore, the work of FIF and wider Essex systems are constantly used to create impact within the services that families use. Through engaging meaningful with the families it supports, FIF remains relevant, effective, and on course in its mission to improve the lives of families in Essex.

### Concluding thoughts

When considering the impact FIF achieves for families it should be remembered that the charity works with hundreds of families each year (2,032 in 2021), meaning that a considerable number of families in the county live in improved circumstances owing to the work of FSAs. In 2021, 79% of families described FIF's support as 'excellent', 11% describing it as 'very good' or 'good', 2% describing it as 'fair' and only 1% describing it as 'poor.' Through support and guidance that is collaborative, knowledgeable, independent, local, person-centred, empowering and co-productive, families experience uplifts in the support their child receives, financial health, and emotional health and wellbeing. FIF is unique in its offer, and its true value defies quantitative measurement. In the words of a family member, FIF are, quite simply, 'invaluable.'

### Chapter 2: Building system capacity

The primary beneficiaries of Families InFocus' work have always been, and will always be, children with SEND and their families. But in working to achieve a positive impact for these families, professionals described a secondary impact that freed capacity, saved money, added skills, and improved outcomes in existing organisations across the sectors of education, local authority, health and the voluntary sector.

This section of the report looks at the positive impact FIF's work creates for these systems, which in turn improves positive outcomes for the families those systems engage.

## 'We know there are not enough resources': Cost saving and value for money

In 2010, a Social Return on Investment (SRoI) evaluation found that each pound invested in FIF generated an average social return of £6.33<sup>7</sup> (approximately £7.90 for each £1.25 spent, in line with 2021's inflation figures)<sup>8</sup>; based on conservative estimates. Austerity measures throughout the past decade have seen drastic cuts to public service spending, meaning that voluntary organisations are increasingly called upon to deal with the resulting service gaps.

'We know there are not enough resources in the NHS, and so we need that from VCS.' (Health professional)

'People who make decisions and hold budgets are all passionate, but they're facing their own restraints.' (Voluntary sector professional)

Voluntary sector professionals spoke, in general, of the value for money they provide statutory services in the county. Through being less restricted, and more flexible, in their offer charities felt they achieved greater efficiency in creating positive impact for a greater number of people.

'In the third sector there is so much more value for every pound spent. You can be so much more creative...We work with statutory organisations, but they're so limited by being a huge system.' (Voluntary sector professional)

'I think we save a huge amount of money...[local authority] is extremely lucky.' (Voluntary sector professional)

This was echoed by a health sector professional speaking specifically about FIF, who said 'FIF are good value for money. The numbers they're dealing with - they support a large cohort of people.'

As well as supporting hundreds of families each year with a team of just seven FSAs, some of the largest savings FIF demonstrates is undoubtedly associated with their resolution rate with appeals.

<sup>&</sup>lt;sup>7</sup> External Evaluation Report: Families InFocus (Essex), July 2019

<sup>&</sup>lt;sup>8</sup> Bank of England Inflation Calculator, as of September 2022

Appeals can be costly and drawn-out processes for families and the local authority alike, particularly when solicitors are involved. But in cases where FSAs represented a family, an appeal was seen as more likely to reach a satisfactory resolution.

'Within the local authority they lose about 90% of appeals. How much money is wasted? That's the bigger picture of what FIF do. I'm convinced far fewer tribunals go to tribunal because of FIF.' (Voluntary sector professional)

'We work with the appeals team. It's better for them than solicitors, and if parents are left to it on their own it can go back and forth...It's more likely to get an appeal resolved than with solicitors.' (Staff)

The case study below, from a local authority professional's perspective, examines this in more detail.

A professional from the local authority recognised the positive impact FIF's involvement had on the resolution of appeals, saying, 'When a parent was represented by FIF it generally meant the conversation would be managed,' and that families could 'articulate frustrations with the school' in a way that was measured and reasonable, preventing heightened tensions and escalation. Compared to other forms of advocacy and solicitor representation that could be 'single-tracked' in pushing for tribunal, FIF provided a 'sensible voice' that was more likely to reach a positive solution through compromise.

The professional described the appeal process as 'combative,' where the local authority concedes in most cases. However, the process is ideally in place to enable negotiation between parties: 'it should be about making a halfway agreement' between what families' want for their children and what education services can realistically provide within existing limitations. As FIF understood these nuances, and worked flexibly and collaboratively with families and authorities alike, a positive outcome was more likely to be reached and the appeal resolved.

In recognition of this, the local authority had worked with FIF to review the existing tribunal process so that it might work more successfully for both families and authorities.

At present, FIF is involved in approximately 200 appeals a year,<sup>9</sup> meaning the impact of their support is widespread and significant, likely generating large savings for the local authority in terms of staff hours and legal fees. This frees professional capacity and fiscal resources while supporting quicker and more satisfactory solutions for families.

### 'I learned a lot': Knowledge and upskilling

FIFs experience of working holistically with families means they hold a wealth of knowledge about multiple systems and processes. Professionals working within a more rigid system, such as health or housing, may be restricted in their knowledge of other pathways beyond those in their field of expertise. This makes FIF a valuable resource to professionals who can draw from its knowledge to enhance their own work with families.

'We've had GPs and paediatrics asking about DLA, and teachers and the local authority also need support.' (Staff)

<sup>&</sup>lt;sup>9</sup> 'Our strategy - 2022 to 2025', Families InFocus

This is enabled by FIF's collaborative approach to working across existing systems, as already noted in the previous section of this report. Professionals feel comfortable speaking to FIF knowing they will receive a helpful, and understanding, response.

'...they feel confident to ask, knowing they'll get accurate and non-judgemental information - we're not judging their professionalism.' (Staff)

'We're often asked by SENCos about strategies and procedures, because they don't get that training.' (Staff)

The case study below, from the perspective of a SENCo, reveals how FIF's supportive and collaborative style of working develops professional skill and confidence.

When she was new to her role, the SENCo first met with an FSA who was supporting a family at the school. Describing herself as 'a really, really green SENCo' at the time, she felt that along with supporting the family the FSA 'also supported me.'

She explained that new SENCos often feel unequipped for the responsibilities of the role: 'I don't know how new SENCos function. You're in a job a year and you're off to the high court in London to be a witness. I know that six SENCos in our local area have gone this year, and only one has gone to another SENCo role.'

At this stressful time in her career, the SENCo gained experience by learning from the FSA. For example, she now understood how to complete DLA forms with parents, and built further capacity into the education system by supporting other SENCos to do the same. 'Now I support other SENCos. When it comes to tribunal I learned a lot from her. She enlightened and enhanced my knowledge, and I can share that with my school and with parents.'

This is a relatively unsung function of FIF's work, but an important one. Based on referrals alone it is obvious that FIF interacts with hundreds of professionals each year from early years support, mental health provision, health visitors, the local authority, medical practitioners, schools and colleges, social care, and voluntary organisations. These are professionals who are likely as passionate and committed to creating positive outcomes for families of children with SEND as FIF, whose work is enhanced by the knowledge and experience staff impart to all those they speak to.

# 'Double the amount of people': Building capacity in existing services

There are other charities in Essex providing support to families of children with SEND, though this evaluation found that the level of need in the county outweighs the various forms of support. For that reason, FIF works collaboratively with a number of SEND charities to strengthen the Essex offer. As a local authority professional said, 'There's no harm having more organisations doing the same thing,' as this creates 'strategic capacity.'

Not only that, but FIF's offer is unique from that of other services. In this way, charities compliment, rather than duplicate, the work of one another. Referral pathways exist between these charities to ensure families receive the support that is most appropriate to their child's needs.

### '...when it comes to meetings, for example with schools, I hand over to FIF.' (Voluntary sector professional)

FIF is an active participant in a number of successful partnerships across the county, often adding capacity to the voluntary sector in a literal sense through the attendance of FSAs at inperson family drop-in services. This means that more families are able to access the advice and support of FSAs, but also that voluntary sector organisations experience an enhanced capacity to support these families as shown in the case studies below.

Every other week, an FSA attends one charity's drop-in service to provide families with education advice. Like FIF, the charity advised families on claiming benefits, but deferred to FIF on matters of education, trusting them as a source of reliable, good quality information. During lockdown, when FIF had not been able to attend in-person drop-ins, the charity missed the support they provided: 'We're so glad to have them back...When we didn't have them, as a team we really noticed it.'

A community interest company (CIC) hosted regular coffee mornings where families could seek specialist advice around SEND topics. The coffee mornings were always attended by an FSA, increasing the number of families able to access support. The founder of the CIC explained that 'for coffee mornings we get double the amount of people getting specialist advice,' thanks to the attendance of FIF. 'In two hours we probably see eight parents - so it's the capacity we get to give support to.' The charity also worked with FIF to run parenting programmes online, and had coproduced video training resources. The professional told us 'If their funding is not continued...if they're not there...that's all on me, and I can't do that. I wouldn't be able to do the programmes.'

FIF also proved to be a valuable resource to statutory professionals, based on their independent status. Statutory services could be bound by their own internal processes, but could rely on FIF, as an independent charity, to bolster the support the families they worked with received.

'Professionals quite high up in their field will seek our involvement with families who require some independent advice.' (Trustee)

'A number of times we've been contacted by a professional saying 'Can you help us with this family?' For example, a teacher feels that the child is not being supported by the SENCO, but as they work for that school their hands are tied...and they tell parents to get in touch with us.' (Staff)

Furthermore, statutory professionals respected FIF's willingness to contribute to solution-based work streams where possible.

'[CEO] and her team are really great people to work with...the team, I feel, are here to support the system in a productive way...FIF have always been very adaptable, flexible, easy to discuss with and approach, and happy to put their hand up and support when they can.' (Health professional)

'Their approach and culture is such a big thing...To have an organisation with the right culture and attitude; that's our biggest takeaway. We know the system isn't perfect - we know there are legacy challenges as well as new challenges...we want providers who are going to come along and solutionise.' (Health professional)

### Concluding thoughts

It's clear from the SRoI evaluation that FIF creates significant savings for the system, and combined with the other ways in which FSAs build capacity and skill into existing services it's more than likely their value is higher than previously thought. As professionals themselves stated, a number of their offers would be less impactful without FIF. Should the organisation face even a modest reduction in funds the impact for these systems would be costly - as well as the direct support FIF gives to families, the support it gives to the wider system ultimately makes a positive contribution to families who are not even in contact with FIF.

### Chapter 3: Challenges

So far, the focus of this report has been the positive impact FIF creates, although FIF's ability to continue its important work is threatened by a number of challenges. The good news is that these challenges are not unique to FIF, and all of them - with the right planning and dedication - can be overcome. This section of the report looks at the challenges FIF is facing, and why it must act now if it wishes to carry its existing offer into the future.

### 'We need to be concerned about it': Funding and the future of FIF

In March 2023, FIF is scheduled to lose one third of its income as one of its streams of funding comes to an end. This would naturally lead to a reduced service, anticipated to have a devastating impact on families across the county:

'So many families out there are struggling. It's a lot of stress 24/7, 365 days a year...without that support people will not be making the best decisions.' (Family member)

'I honestly believe it would result in much higher levels of tribunals, social care, mental health...' (SENCo)

While trustees acknowledged that, 'We're not burying our heads in the sand. We need to be concerned about,' at present, FIF does not have a strategic plan that outlines how they will manage the shortfall (such as which areas of the service will be cut, or if there will be staff redundancies), and there is expectation and confidence among the trustees that the CEO will be able to find replacement funding in the next six months.

'We have confidence. [CEO] has good quality skills and an understanding of where to draw funding from.' (Trustee)

This is an optimistic view at a time when increasing numbers of organisations are competing for decreasing levels of funds. Historically, the local authority was a large funder of FIF, but statutory organisations have since moved to complex contracting models driven by targets and intensive data monitoring responsibilities. FIF, whose bids staff told us were written by senior team members 'in their spare time,' are competing with charities with robust fundraising strategies that often employ or contract professional bid-writers. As a member of staff said: 'We can't compete with professional fundraisers.'

Professionals involved in commissioning FIF's services commented on the difficulties organisations like FIF faced when trying to adapt to these modes of funding. While these professionals were assured of the impact FIF achieved for families in Essex, the charity was at a strategic disadvantage in bidding for, and maintaining, contracts of this nature:

'It's quite a skill to write a bid. I knew a lot about the service, but you can only use what's written on the piece of paper...If you've got a larger charity, they'll have that funding and whole commissioning team; they can communicate their offer better.' (Voluntary sector professional)

'When we started they had a few concerns about NHS reporting and statutory requirements...if you're going to put your name in future health funding, you need to be confident that you can deliver within the NHS framework. Not that they're not now...but you need to have developed those policies and frameworks.' (Health professional)

Nowadays, charities are also expected to generate their own income and thus embed a degree of financial sustainability into their operations. Funders can be rigorous in assessing the risk of their investment, looking for assurance that the charity will survive alongside, and beyond, awarded funding through independent income streams and levels of reserves. FIF has considered ways in which it can enhance its sustainability, which would largely consist of introducing small, meanstested fees to some of its services.

'We do loads of work that other charities charge for...appeal work, bids for funds...' (Trustee)

However, this was a sensitive topic that had ultimately been decided against, which does limit the ways in which the organisation can self-fund its work. FIF have also considered offering training to professionals in surrounding systems, as the CEO is aware that funders are interested in methods of adding capacity through 'use of technology, training, [and] empowering people with knowledge.' This would undoubtedly be effective; the section above looks at the capacity FIF already adds to the services it works with, but the initiative has not been met with confidence by all FIF staff. While it is natural that people who have been doing their jobs, and doing them well, for a long time are not comfortable with change, the alternative may mean that those jobs cease to exist in future.

FIF has been in existence for twenty-six years, in which time it will have undoubtedly weathered other financial storms, as all charities do. But just because FIF has always survived in the past does not mean it will continue to survive in the future. Today's charities require robust financial strategies and contingency plans, the skill and capacity to manage sophisticated contracts, and a culture among staff to work innovatively and differently than they may have worked in the past.

### 'So overwhelmed': Low capacity and high demand

FIF are a small charity with a large offer; the staff team consists of seven FSAs, the CEO, an Operations & Communications Manager, helpline advisor, activity club coordinator and a small team of volunteers. Not all staff work full-time, and sick leave - or annual leave - can cause instant problems to capacity.

### 'When you take annual leave and you come back, no one's been covering. I came back from annual leave and had over six hundred emails.' (Staff)

Working relationships between FSAs and families can span several years, and events such as appeals often require a large amount of FSAs' time. The long-term history of financial cuts to statutory services has increased a dependence on the voluntary sector, and recent periods of uncertainty such as the pandemic and the cost of living crisis have compounded the increase in demand for FIF's services.

'They're just so needed, more than what they're able to give...What they do is so unique to them, so they're so overwhelmed.' (Family member)

Staff explained that families present a larger complexity of issues than in the past, likely as a result of the austerity measures mentioned above, which can mean a greater dependence on FIF's services, and higher expectations.

'Parents are very demanding now...They're not always kind. Most people here have experienced abuse [from families].' (Staff)

'Some ring every day. There is a lot of parent anxiety...They become quite dependent.' (Staff)

Despite these challenges, staff and trustees spoke frequently of the fact that FIF has no referral criteria or waiting list. This was a point of personal pride for many.

'We don't refuse anyone our service. We have never had to turn anyone away. Our phone message says we'll get back within fourteen days, but that's the worst case scenario. They're always acknowledged...' (Staff)

While this is admirable, families and professionals were well aware that FIF was struggling with capacity:

'What doesn't help is their limited capacity. Someone might say 'I've already spoken to them, but they can't help because they're at capacity,' or, 'I'm on a waiting list, it's going to take two weeks until they come back to me.' (Voluntary sector professional)

'The only negative is...we hear quite a bit that they take a long time to respond...and we do hear that a lot: 'I rung them and they haven't got back to me.'...A parent called at that time because they were in the headspace to deal with it.' (Voluntary sector professional)

Families were immensely grateful for the support they had received from FIF, but said that when they first reached out to the service it was often because they had an urgent request, and therefore waiting to hear back caused considerable anxiety.

'When you are distressed you don't want to be waiting...At that time I was desperate, my son was about to be excluded...' (Family member)

'They do tell you it will take a while to get back to you. It's difficult if you're that parent and you have a deadline.' (Family member)

It's important to note that the feedback FIF collects from families indicates that most (40%) families receive a response within three days, 28% the same day, and 16% the next day, meaning that 84% of families hear back from FIF within the first three days of reaching out. Despite this, it is undeniable that capacity is stretched within the organisation. FIF have attempted to mitigate this in a number of ways, with various levels of success. One has been to deal with simpler issues immediately on the helpline, rather than referring families straight to FSAs, and thus freeing FSAs' capacity to deal with more complex cases, though this has proven difficult. Another has been for FSAs to attend FIF's activity clubs where they can work with multiple

families from one place. However, this is a source of contention, as staff believe this negatively impacts the support they can provide families during the week:

'It's a bone of contention for all of us, I think. In our job description it says we will have to work occasional weekends. But no one wants to work a weekend if you're at capacity all week.' (Staff)

'I've done activity club two weeks on the trot. I don't get overtime, I get a day off. But then that doesn't help families.' (Staff)

Perhaps the most successful measure FIF has taken to build capacity is through running online workshops on common issues such as DLA and school transitions. This was, again, initially met with some resistance from staff, though it was now generally considered to be a 'revelation.'

'Developments like running workshops - speaking to 8-12 people at once, versus face-to-face, is more efficient.' (Trustee)

FIF had also produced helpful factsheets on some of the most frequent issues families sought support with, which empowered more families to achieve outcomes for themselves, thus freeing up FSA capacity. Some stakeholders wanted these handouts and recordings of workshops to be available on the website.

'The resources they share are not clear on the website, or are on the website.' (Family member)

Some of these issues could be resolved at the beginning of 2023, when FIF launches its new website. But, overall, FIF are in a difficult position here - staff say they mostly work 'above and beyond our hours' and have no time to support measures that would ultimately build their capacity (such as providing training or attending activity club) while being resistant to the introduction of referral criteria, or a waiting list. FIF has identified a number of ways to increase capacity across its services, and the next section of the report recommends ways in which these may be embedded into practice.

### Getting the balance right: Operations and strategy

FIF is committed to understanding the impact of its work: as well as independent evaluations such as this, FIF has undertaken social return on investment (SRoI) and practical quality assurance system for small organisations (PQASSO) assessments while gathering ongoing performance and feedback data. This has been useful in assuring FIF of the impact its work achieves, although the charity can struggle to act on the recommendations these assessments make. The same themes emerging from previous evaluations, strategies and feedback gathering were also raised in this evaluation, namely:

- Digital resources (more information shared on the website, accessing online chat)
- Capacity (increased volunteer numbers, working consistently, resolving more issues on the helpline)
- Funding (developing corporate fundraising opportunities, introducing fees, delivering training)

- Raising awareness (increased social media presence, increased work with schools and the local authority)
- Equality, diversity and inclusion (increased representation of the diversity of communities in Essex, increased access for single and working parents)
- Befriending (opportunities for socialising and peer support between families)

Some of the suggestions made by stakeholders included:

'If you're doing webinars, record them to put on the website so they're there for the parents who missed that webinar. That would free up the one-to-one support.' (Family member)

'They could do some CPD...[or] maybe a drop-in centre or a one hour a week phone line for SENCos.' (SENCo)

'Their presence for parents and carers could be improved in a proactive way. When you look at social media, it would be good to see more parents recommend them. They need a stronger presence in social media.' (Voluntary sector professional)

As already discussed, FIF faces challenges to its funding and capacity that, in turn, challenges their ability to meet the goals they set themselves, though work is progressing in some of these areas: a new website launches in January 2023 that will share the resources families have said want to see, and will have inbuilt chat functionality (though this wouldn't be utilised until there was adequate capacity). The CEO is working on a funding and sustainability plan, and the Operations and Communications manager is developing a communications plan. FIF has recently secured funding that will begin to offer befriending opportunities for families of young people and adults with learning disabilities and autism.

FIF knows it needs to work smarter: it wants to increase the consistency of how FSAs work with families (there is currently no handbook for FSAs), its volunteer numbers, and the number of issues resolved on the helpline. At present, raising awareness of its service is not a priority as this would create more demand, and therefore more disappointment, for an organisation at capacity. Other strategic goals that are not currently being progressed include: developing an equality, diversity and inclusion strategy; offering transition to adulthood casework; engaging with young people directly; a consistent FSA presence at weekend activity clubs; respite events for family members to relax and socialise without their children; and increasing early years support.

It is understandable that FIF cannot do everything they want to do, but these issues are important to the families who have suggested them, and remain relevant as evidenced by the fact they each came up again in the course of this evaluation. This means that FIF can miss opportunities to increase its impact, fundability, or capacity. For example, the issue of equality, diversity and inclusion (EDI) was at the forefront of trustees' minds:

'While we do monitor, we are very aware we are not actively proactive...We're very conscious, if you just take referrals, minority ethnic groups are not at the same level of referrals as the percentage of the population is and we're aware of that.' (Trustee)

'Diversity and inclusion is something we should major in more.' (Trustee)

The development of an EDI strategy was part of FIF's three-year strategic plan that launched in 2017, but to date such a strategy does not exist. As such, FIF is not achieving the impact it could be for underrepresented sections of Essex communities. Furthermore, it is now common for funders to ask for an organisation's EDI policy at the point of application, and rightly so; in light of the Black Lives Matter and Charity So White movements voluntary sector organisations are seeking to provide an offer that is equitable and can impact all of the people it aims to support, and it is reasonable to expect the same of FIF.

FIF is not careless, or out of touch with the needs of those it seeks to support, but is restricted in its strategic capacity. The CEO's role is largely occupied by operational issues, restricting the time that can be spent on strategic planning.

'[CEO] line manages almost absolutely everyone.' (Trustee)

'[CEO] takes on a lot - there's clearly not a lot of staff.' (Trustee)

This was of the detriment to FIF as trustees, professionals and staff alike commented on the CEO's strategic value.

'[CEO] is really good. She has a strategic vision...[the third sector is] driven by people like [CEO], with a vision and strategic overview.' (Voluntary sector professional)

'They've got slicker and more professional since the change of CEO.' (Local authority professional)

FIF has a small board of six trustees who meet once every two months. Each has personal connections to the charity itself (for example, as service users), or existing friendships with staff and trustees.

'We do get trustees, by and large, through word of mouth.' (Trustee)

'There is usually a connection between one of us and someone.' (Trustee)

The trustees are therefore highly passionate about the immediate impact of the charity and its day-to-day operations, and while there is a mixture of skills within the Board there are gaps pertaining to FIF's strategic needs outlined above (such as digital, fundraising, comms, and so on). While the Board is trying to recruit more trustees, it is prioritising those with service user experience:

'FIF has always stated clearly that we are parent-led. We must have trustees with lived experience. We are going out to all social media for people who use the charity.' (Trustee)

It is absolutely right that lived experience should inform the strategic decisions of FIF's Board. That being said, focusing on the recruitment of service users can pose a number of problems. As families said themselves in this evaluation, family members of children with SEND do not always have the time to take up an active volunteering role: 'Childcare demands can be so high that they feel they can't take on being a trustee...' (Trustee)

What's more is that this method of recruitment inadvertently rules out potential trustees with valuable skills in areas where expertise is desperately needed. And while service user voice is crucial to a charity's direction, it is also important to note that those who volunteer to be trustees are likely to be the ones who have had positive experiences of the organisation. This means that they are understandably protective of keeping the aspects of the service that benefited their family, which can make it difficult to innovate and grow. Some of these issues are addressed in the next section of this report, which makes recommendations on how FIF could grow its strategic capacity.

### Concluding thoughts

One of the biggest challenges to FIF's work is a culture of resistance to change, both operationally and strategically. FIF staff and trustees know that what the charity does is good, and many have a long history of working for the organisation. It is understandable, then, that doing new things, and doing them in different ways is met with reluctance and concern, but FIF is at a critical point in its history where change is the only option.

#### Recommendations

What FIF does, it does very well - this evaluation demonstrated the powerful impact FIF achieves not just for families in Essex but also across systems of health, education, the local authority and the voluntary sector. However, FIF is at a critical time in its history: the future of its funding is uncertain and the organisation is at capacity both operationally and strategically. Therefore, the recommendations of this evaluation fall into the categories of fundability, operational capacity, and strategic capacity.

#### Fundability

In March 2023, FIF is scheduled to lose a third of its income as one of its largest funding streams comes to an end. It is unclear if, or how, FIF can recuperate this income. This means FIF must return to its earlier conversations about introducing means-tested charges for its services - while this is an emotive topic, the alternative could be worse. At the very least, the organisation should be clearer across all of its communications on the website and in-person about the cost of running its services, emphasising the value of donations where it is appropriate to do so.

Similarly, FIF needs the support of all staff in creating and delivering a chargeable training package. Not only could this introduce financial sustainability to the organisation's work, and thus the ability to retain its current staffing level, but also build long-term capacity through more upskilling systems that are already turning to FIF for advice. Clear communication with staff is necessary to explain the organisation's current financial position, and precisely why changes to working are so important to the charity's survival.

Finally, FIF should consider how it can best place itself to create high quality bids for significant amounts of funding or large statutory contracts. It is up to FIF to determine how this would work

in practice, but could involve consulting professional fundraisers once drafted applications have been produced.

#### **Operational capacity**

Staff are against the introduction of a waiting list or referral criteria, but the only way for this to remain the case will be to make meaningful changes to the organisation's current ways of working. FIF have already identified a number of methods to increase capacity, but not all have the full support of staff. While online workshops have increased the number of families FSAs can support at once, and the new website will share more resources that empower families to resolve issues for themselves, more changes are needed.

An FSA presence at weekend activity clubs allows more families to be supported from one setting, but this is met with resistance from staff who say they are already at capacity. Unfortunately, the only way to free up capacity is to make changes to the current ways of working, and ultimately it is for senior leadership to decide how this is progressed.

Furthermore, there is a need to ensure FSAs work consistently - some work through large caseloads rapidly, whereas others can spend extended amounts of time with just one family. Obviously the needs of each family, and the intensity of support they require, is different in every case, but FIF needs to create clear expectations on what issues they can, and can't, support families with and how relationships can be more centred on empowerment. At present there is no handbook for FSAs, or document for families outlining FIF's offer (and its limitations). Both would be beneficial to building FSA capacity.

More issues need to be resolved on the helpline that do not need to be referred to FSAs. In order to achieve this it would be valuable to compile a list of the most common requests and how they can be resolved, and more helpline volunteers will likely need to be recruited.

#### Strategic capacity

FIF's strategic objectives largely fall across the categories of funding, capacity, EDI, digital resourcing, and communications. Trustee recruitment should seek out specialist skill sets related to each of the above, and recruitment should be advertised broadly by making use of professional and volunteer websites (such as Charity Jobs, LinkedIn, etc). These trustees could support the development and oversight of short strategic plans for each of these areas considering how these objectives can be met and in what timescale. A larger trustee board may also make it more possible to meet more frequently.

Lived experience should remain an integral part of strategic decision making, but this could be better enabled through the creation of a lived experience panel, or forum, where service users could volunteer their time in a more flexible way. The panel could liaise with a named trustee to give feedback on strategic decision making within the organisation, and could recruit participants on a casual and ongoing basis to gather the most current and diverse feedback. This allows service users to continue to shape the organisation at a strategic level while building capacity into the Board to recruit for specialist skills.

Lastly, existing trustees may wish to reach out to some of the charities FIF partners with to understand how those charities configure their boards, how they recruit, how they structure

their meetings, and how they maintain a strategic focus. It may be possible to access funding for this type of developmental work.

### Glossary

AP - Alternative Provision DLA - Disability Living Allowance EDI - Equality, Diversity and Inclusion EHCP - Education Health and Care Plan EP - Educational Psychologist FIF - Families InFocus FSA - Family Support Advisor FSS - Family Support Service NHS - National Health Service PIP - Personal Independence Payment SENCo - Special Educational Needs Coordinator SEND - Special Educational Needs and Disabilities VCS - Voluntary and Community Sector