Family Ambassadors Evaluation

Final report

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Introduction

In 2019 the NHS formed a Quality Improvement Taskforce with the aim of improving Children and Adolescent Mental Health (CAMHS) in-patient services. This included establishing a Parent Council, a group of parents who have provided expert by experience input to the Taskforce. The Family Ambassadors programme has been developed in co-production with the Parent Council members and is the largest project within the Taskforce. Funding was initially allocated to cover the first-year costs of the Family Ambassador role and an independent evaluation of the effectiveness of these roles.

It was agreed that two levels of Family Ambassador roles would be implemented in the system as part of the NHS England Regions and Provider Collaboratives:

- Regional Family Ambassador (RFA): The plan was for there to be one Regional Family Ambassador for each of the seven NHS England regions. These individuals would provide oversight of, and support for, the Local Family Ambassador (LFA) roles. Additionally, they would be using learning from the work of LFAs to input into Provider Collaboratives and regional Children and Young People (CYP) pathway development programmes to support quality outcomes.
- Local Family Ambassador (LFA): Each Lead Provider Collaborative (LPC) was given an allocation to recruit into posts, with the aim being to recruit approximately 35 posts across England. This role was planned to work directly with the families/carers whose children are admitted to inpatient services. They were to be a resource for families, helping from admission to discharge, including transfers and transitions by providing guidance, information, and emotional support.

The Family Ambassador roles were designed to champion ‘parents as partners’ to empower parents and carers to be actively involved in the care of their child. The plan was for them to work alongside clinical teams in the units to support them to build pathways and opportunities that ensure parents and families are treated as partners.

In May 2022, NDTi responded to an invitation to quote to undertake an evaluation of the Family Ambassadors project. NDTi was awarded the work in June and once a formal contract was in place (August 2022), the evaluation work began.

Methods

The interim report in December 2022 was informed by:

- Learning shared as part of the development day held in December 2022 which included discussions about what was working well and what the challenges and opportunities were within the roles.
- Collection of change stories - a total of 14 were included in the analysis for the interim report.
- Monitoring data from LFAs and RFAs.

This final report has been informed by a period of data collection (February to April 2023) which included:

- One-to-one online interviews with RFAs (n=5, 100% of RFAs appointed).
- One-to-one online interviews or small focus groups with LFAs (n=12, 86% of LFAs who were in post and whose contact details were provided during the data collection period).
- One-to-one online interviews with Taskforce members (n=5).
- An online survey for clinical team members (n=17, including allied health professional, nurse, psychiatrist, psychological therapist, ward manager, clinical psychologist, peer support worker, social worker, family therapist)
- One-to-one phone interview with family carer (n=1)
- Anonymised feedback from family carers collected by Family Ambassadors (n=30, across 3 regions – note that the format for collecting the feedback varied, but all included qualitative responses)
- Monitoring data including time in post and number of families supported from LFAs (n=4).

Limitations

A number of challenges were experienced which have resulted in some limitations to the data we have been able to collect in this evaluation phase:

1) The evaluation contract start was delayed and some evaluation activity was postponed due to NHS England guidance on the period of mourning of Queen Elizabeth II in September 2022. As a result, the data collection period was both later and for a shorter period than originally proposed.

2) Proposed fieldwork was revised in response to the evolving situation around RFA and LFA recruitment and delivery of support in the regions.
3) As the evaluation team and Taskforce had no direct contact details of family carers or clinical team members, we were reliant on the co-operation of Family Ambassadors to recruit participants. The timing of the data collection (February to April 2023) was a period when many of the Family Ambassadors faced uncertainty over the future funding of their posts and some left their jobs. This may have affected their willingness and/or capacity to support data collection and participant recruitment.

These have contributed to the following limitations:

1) We were only able to interview one family carer. While sampling criteria was amended to extend to a larger pool of family carers and repeated requests made to LFAs, these were not successful. The restricted timescale meant that we were unable to attempt alternative approaches to recruitment. While we have received family feedback through other methods, there will be a need, in any further evaluation to address this limitation and work with LFAs to co-design an alternative approach to ensure the voice of family carers is central.
2) Due to the restricted time period for data collection, the decision was taken to focus qualitative fieldwork on Family Ambassadors, family carers and the Taskforce. The survey responses from clinical team members have been valuable, but future evaluation will benefit from getting more in-depth responses from clinical team members.
3) There has been no requirement for Family Ambassadors to report any routine monitoring data such as number of families supported to NHS England. Despite several requests directly to LFAs, only 4 LFAs provided the evaluation team with basic monitoring data in April-May 2023. As a result, we are unable to report or reflect on the reach of the Family Ambassador programme.

Developing a Theory of Change

A Theory of Change is a description and illustration of how and why an intervention is expected to lead to change in a particular context. A Theory of Change guides the evaluation and shapes data collection. As a new intervention with clear intentions to generate change, the evaluation of Family Ambassadors started with the development of a programme Theory of Change.

Process of developing the Theory of Change

The Theory of Change was developed with a group of people involved in the design and delivery of the programme including:

- LFAs and RFAs
- Members of the Parent Council
- Representatives from the Taskforce

It was developed through two online workshops facilitated by NDTi evaluators.

Session 1 covered:

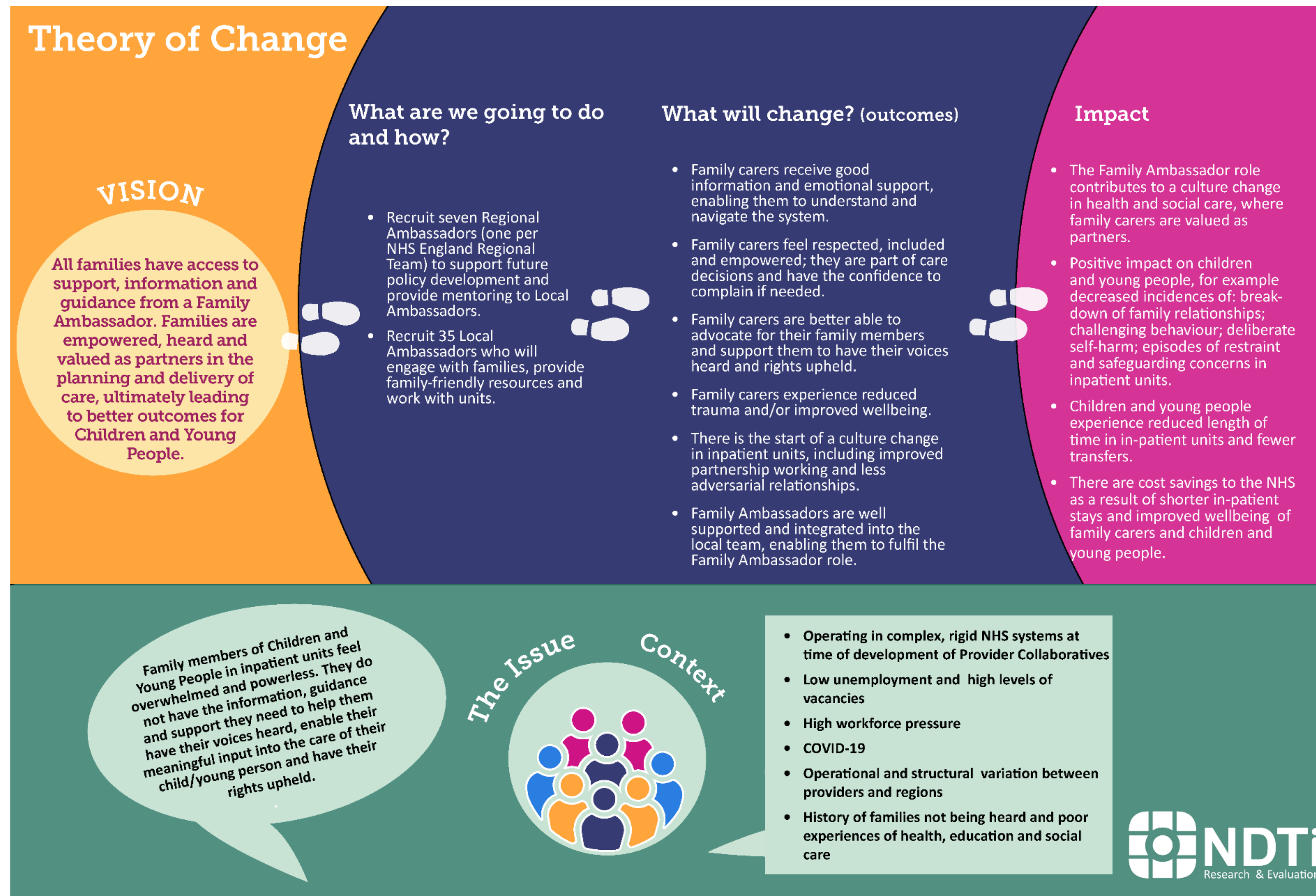
- What is the issue that Family Ambassadors is aiming to address?
- What is the overall vision for Family Ambassadors?
- What do we need to be aware of (the context that Family Ambassadors is operating in)?

Session 2 covered:

- What do we expect to change in the life of the project? (Outcomes)
- What do we expect to change in the longer-term? (Impact)

Following each session, the NDTi evaluators developed the relevant sections and invited feedback from the group before producing the final Theory of Change. The Theory of Change is shown on the next page.

Figure 1: Theory of Change



What have we learnt about setting up the Family Ambassadors programme?

The interim report discussed some of the initial challenges in setting up the project, which included problems with recruiting to the Family Ambassador posts and establishing effective systems for families to access the service. Progress has been made with recruitment, meaning more family carers are being supported:

Summary of Family Ambassadors appointed

It was envisaged that there would be up to 7 Regional Family Ambassadors (one in each region) and up to 35 Local Family Ambassadors.

In total 5 Regional Family Ambassadors were appointed. It is our understanding that one region decided not to appoint a Regional Family Ambassador and reallocated the funding and, in another region, an alternative post of Quality Improvement and Family Ambassador was created. Two of the 5 Regional Family Ambassadors are no longer in post.

Recruitment to Local Family Ambassador posts started at the end of 2021 and at the time of writing (May 2023) some newly appointed Local Family Ambassadors have yet to start in post. Through this 18-month period, some posts have ended and some individuals left their jobs. Some roles were part-time and some full-time. In total, including those who are yet to take up their roles, 27 individuals have been appointed as Local Family Ambassadors[1]. Regions have had between 3 and 8 Local Family Ambassadors.

[1] This excludes the Midlands region as we have not received information about those in post in that region.

Number of families supported

We requested information from all LFAs about the number of families they have been in contact with in total and how many of these had been multiple contacts. We recommend that a systematic way of collecting data about the number of families being supported is implemented whilst the project continues.

Project update

The Family Ambassador programme had initially been designed to run until March 2023. We welcome the following update from NHS England:

> "By the end of March 2023, we currently had over 50% of all Family Ambassadors in post. The evaluation was challenged as people were coming into post at different stages and this limited the amount of evidence available to NDTi. However, NHS England are delighted to see that early evaluation findings are demonstrating a positive impact. Whilst the CYP Quality Improvement Taskforce itself formally closed at the end of March 2023, there is recognition of the importance of the project. As such the Quality Transformation Team for Mental Health, Learning Disability and Autism inpatient services (QTT) will be continuing to support the programme. The QTT recognises that the evaluation completed by NDTi is a first wave and that further evaluation needs to take place to ensure there is a robust evidence base for the role going forwards. The QTT is going to support a second wave of evaluation to achieve this. In recognition of the financial challenges Provider Collaboratives and NHS Regions are experiencing, the QTT will be offering a salary contribution towards all Family Ambassador posts. This salary contribution will fund all Family Ambassador posts up until 31st March 2024. Where posts have initial Quality Improvement Taskforce remaining, this funding offer will be for the remainder of the financial year. This funding is specifically for Family Ambassador posts created within the Quality Improvement Taskforce and is pro rata. We hope that the important work done by the Quality Improvement Taskforce and the NDTi can be built upon over the coming year."

In the first part of this report, we have intentionally focused on the challenges faced in the design, set-up and roll-out of the Family Ambassador programme. We have identified problematic issues ('What we heard' presented in pink) and reported what has already been done to address these or suggestions that could be explored in next phase of the work ('What could help' presented in green). We have used quotes or examples to illustrate these points. Whilst some of the issues raised can be addressed as the programme continues, some are reflective learning which could inform future developments of new programmes in NHS England. The issues and potential solutions identified cover:

a) Recruitment and initial rollout
b) Supporting the Local Family Ambassador roles
c) Delivering the Local Family Ambassador service
d) Looking forwards: Delivering a national service

In the second part of this report, we will focus on what the LFAs have achieved since they have been in post and progress towards the desired outcomes identified in the Theory of Change for the Family Ambassador programme. Some of the issues and solutions presented in section one are discussed in more detail in section two.

1. Recruitment and initial rollout

Who Family Ambassadors are employed by

The introduction of Provider Collaboratives and the shift from the original vision of Family Ambassadors being employed by NHS England has contributed to a significant variation in the experiences of Family Ambassadors. This variation has been evident, not only between regions and Provider Collaboratives, but also between units, wards and teams. Therefore, rather than reaching a conclusion about who Family Ambassadors should be employed by, or where they should sit, the next four sections identify key issues and factors that need to be in place to successfully support Family Ambassadors in their posts regardless of who they are employed by.

A concern was raised by members of the Taskforce involved in developing the roles that being employed by Provider Collaboratives would mean that Family Ambassadors would feel unable to challenge clinical team members, this has not generally been raised as a concern by the RFAs or LFAs. Feedback from families is that they felt the Family Ambassadors were on their side, irrespective of who they were employed by.

Recruitment

What we heard

The job descriptions lacked clarity, have been interpreted in different ways and expect a lot from one person.

Concerns that the banding for the roles is too low (particularly for the LFA roles).

"The job description was not clear and has not been considered very well I don't think." (RFA)

"It [job description for band 7] is asking for an awful lot." (Taskforce member)

"You can't put Band 4s in place and go, here you go, develop a service." (RFA)

What could help

The job description and banding for the Family Ambassador roles should be reviewed.

"I think that the job description should be reviewed because we first wrote them from an idea, and now that there are actually people doing the jobs, I think it would be really good to have a consultation with them about what the role does involve and what are the most important aspects. I think it's due for a reality check." (Taskforce member)

What we heard

Using standard procedures to recruit for a non-standard role is ineffective.

"The NHS system doesn't allow for flexibility." (Taskforce member)

"How do we find people that don't know that they want a job yet? They must exist but how do we reach them?" (RFA)

What could help

The NHS recruitment process should allow flexibility when a non-standard role is being recruited.

The recruitment process should be informed by those with lived experience and extend beyond traditional NHS routes including contacting user partnership groups, sharing via social media, Tier 3 services and Trust Communications leads.

"As the Parent Council that is our role, we are the conduit to talking to families, we know where they go, what they look at and respond to." (Taskforce member)

When recruiting LFAs, regions can learn from those areas where this was successfully done, using specifically designed materials and ensuring local targeting.

Lived experience

There was consensus that lived experience enhanced the RFA and the LFA offer, but there was no agreement on the specific type of lived experience that was needed. The requirement for lived experience was interpreted differently (and dropped) across different areas of the pilot. Several interviewees said a flexible, non-prescriptive approach to lived experience was needed to recruit the right person. All agreed that getting support and supervision right for employees with lived experience was crucial, as boundaries and burnout could be an issue.

What we heard

Understanding of, and support for, the lived experience of family carers can be lacking in existing services.

"Families working with professionals, often say 'that person doesn't understand'." (LFA)

"Families say things like 'I know I can tell you this'. 'I know you won't judge me on this'... They [families] can't say that to the nursing staff or anybody else because they feel they're going to be judged." (LFA)

What could help

Family Ambassadors with lived experience can engage with, and give good support to, family carers. The focus on the parent perspective means the support offered feels different.

"We don't want anything from the families. Everybody else working with them wants something from them." (LFA)

"LFAs need to have some form of lived experience because they are in direct contact with families...they need to know that somebody understands on some level." (RFA)

"They [Family Ambassador] shared their own experiences and lived experience which made us feel understood." (Family feedback)

"The FA has been so supportive towards my situation she was able to give me brilliant advice through her own experiences and really made me feel that someone was there to help me through a difficult period." (Family feedback)

What we heard

Being prescriptive about the nature of the lived experience required for the Family Ambassador limits potential job recruits.

"X area are having a harder time recruiting because they're very, you know, strict on this criteria [lived experience], which I think is right because it's a totally unique experience." (LFA)

"It is such a massive ask at a band 4 level to expect someone to have the perfect lived experience but also to be bright, to be mature in their thinking to be able to slot into a system where you are going to face so many barriers." (RFA)

"I find it difficult when people are quite rigid about the requirement of it [lived experience] being a parent." (LFA)

What could help

The consensus was that LFAs should have some lived experience, but there was no agreement about what type, such as being a parent, sibling, or a previous in-patient.

"I think lived experience is an essential part but I think it depends on what sort of lived experience and it doesn't have to be parent or the carer of a child who has been through the system but that is a huge advantage because as we know it is a very complex system." (Taskforce member)

"Certainly my lived experience has helped as it has resonated with some families, I've connected, engaged with them... Where you are a parent it's helpful, but not essential." (LFA)

What could help

A flexible approach to lived experience with a focus on the right person may work best for the LFA role. Family Ambassadors with a range of lived experiences, including an understanding of complex services, were all valued.

"...your experience of services no matter what they are is really important...you need more in your toolbox than just being a parent, a lot more." (LFA)

"What I'm getting from families, just having lived experience of a child having difficulties... having a child that doesn't fit down your typical pathway is what they relate to... your lived experience is very similar, you're able to help them." (LFA)

"Within our team there's such a wide range of different lived experience. Personally, I think that makes it all the richer. I think we have benefited so much from having different perspectives in our lived experience." (LFA)

"I'm in contact with lots of people with different experience...they bring different elements to the role...I don't think you can pigeonhole it to parents..." (LFA)

What we heard

There was an awareness that lived experience may bring boundary issues, especially if the Family Ambassador has recent experience that has not been processed. Burn-out was also identified as an issue in this emotionally demanding role.

"I think it's really interesting because sometimes I think the lived experience can be a barrier. It almost gets in the way because you can't see past your own lived experience to sort of imagine that somebody else might be experiencing a similar situation but in a different way and having a different response and a different viewpoint to your own." (LFA)

"That's the only thing of having this lived experience, if you connect with someone with similar experiences, as you can get drawn in and you need to be mindful of this." (LFA)

What could help

Good support and supervision can help Family Ambassadors manage the demands of this role and the emotions around their own lived experience.

"The passion that lived experience brings is really helpful but it needs managing to make sure it doesn't become something else that becomes out of control." (LFA)

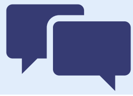
"The FA local members have been very well supported and this was one thing that I had concerns about because these are individuals with lived experience and I wanted to be sure that they were also getting the right support for themselves because it's a role that can be very overwhelming. So they have been very well-supported I mean they have multiple layers of support." (RFA)

What could help

Family Ambassadors said that having distance on their own lived experience in terms of time having passed helped.

"I think it really helped me that... I hadn't come straight out of that experience, that lived experience..." (LFA)

"I couldn't have done it [the job earlier]. There's still too much psychological work going on with [child] and the family." (LFA)



Communication with clinical teams

What we heard

A 'top down' approach to communication where ward staff were unaware of, or unclear about, the Family Ambassador project and roles.

The clinical team survey found that only just over a quarter of respondents (29%) agreed or strongly agreed that there was clear communication about the Family Ambassador roles before the LFA was in post.

"I don't think it [communication] went to the people on the shop floor who deal with the young people coming in day in, day out, the ward clerks, the nursing staff, the support workers." (Taskforce Member)

"I am still finding that there are still three wards that are still not sure who we are, and they will not let us in." (RFA)

"At times I think it felt for teams that we'd kind of come out of nowhere." (LFA)

What could help

Clear communication with clinical teams about the Family Ambassador roles, expectations and boundaries.

"I think there should have been something where they had sat down and made sure that all of the ward, those who needed to know knew, so ward managers and the responsible clinician, psychology team, psychiatry team social worker, OT and all of those people knew that what I was coming in to do and what that would look like." (LFA)

"We thought we needed to do a couple of sessions aimed at ward-based staff about the Family Ambassador role, but unfortunately we just didn't have the time available to us...we definitely did miss a trick." (Taskforce Member)

What we heard

Lack of awareness and advance notice prior to Family Ambassadors starting meant that they had to 'sell' their role to teams.

"Basically, what we spent the first 3, 4, 5 months doing was knocking on metaphoric and physical doors." (LFA)

"I felt like it was, we were sent in to do the communication of what the role was gonna be when we probably didn't know what the role was gonna be either." (LFA)

What could help

When a ‘respected’ person within the clinical team promoted and supported their role in advance.

“Our line manager took us around the wards and explained to ward managers and everybody who we were…we’ve got a clinical supervisor who is the family therapist at one of the units…she explained to a lot of people who we were.” (LFA)

What could help

Where RFA was employed first, they spent time on outreach, spreading the word about the LFA role.

“I have been meeting with social workers, family therapists, within the units who are very much on board with it, willing to link in and willing to promote me and share me with their contacts and welcome me to parent/carer forums.” (RFA)

“Where it is working well and it is starting to develop, I have asked those wards to speak to other wards.” (RFA)

What we heard

Some resistance was experienced by Family Ambassadors due to lack of awareness and misunderstandings

“[They were] feeling threatened by me, not wanting me to be there. I was basically told that my job role would be better suited at the [other units] and not there because they had social workers and the others didn't. But my job’s not a social worker.” (LFA)

“[There] was a lot of resistance... when I started calling people to say oh, this is who I am, they were very sceptical sharing information with me because they weren't aware.” (RFA)

What could help

Clarity on how the LFA roles differ from existing roles, such as social workers, family therapist and advocates (see section on clarity and boundaries of role).

Ensure teams understand how they can benefit from the Family Ambassador role e.g., the LFA can ease the strain on existing staff, and help address local service needs.

“I think it was communicated in a really helpful way. I think it was, you know…. nurses don't have time to do the clinical role …they have massive amount to do and they would like to be able to talk to parents a lot, but they simply don't have the time. And the Family Ambassador is going to provide that role. So actually it's going to enhance the work that we do here.” (LFA)

2. Supporting the Local Family Ambassador role

Induction and training

What we heard

There was limited induction into the Family Ambassador roles.

"They said that there was gonna be a Family Ambassador specific [training course] and that never materialised." (LFA)

What could help

Centralised agreement over clear induction expectations for the roles.

Develop specific induction training for the LFA role.

"What we could really have done with is having someone, you know, 'I'm gonna talk you through all the things you need to do'." (LFA)

What we heard

There was limited induction to the wards that LFAs were working on.

"They [the ward] didn't know what to do with us or what to tell us." (LFA)

"The ones at the units I have to arrange with them and say right, I need these ward inductions and chase down who was the person to do it. But I've done all that myself." (LFA)

What could help

Organisations employing LFAs should provide ward inductions for each ward or unit the LFA will be working in.

"I would like to have had a, some kind of enforced time really working on the ward or being down at the ward to see what goes on... to do a little bit of shadowing would have been quite nice." (LFA)

What we heard

There was variation and inconsistency between regions in the training received, with most Family Ambassadors self-directing their own training.

"Training wise it was all self-driven. We asked our supervisors to have training on the Mental Capacity Act and Gillick competence because it came up a lot... We attended lots of training in the end, but it was all sort of self-directed." (LFA)

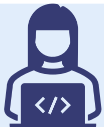
"We've not really done that much training. We've done like e-Learning and things like that... a lot of the training that we've probably done is... what we've signed ourselves up for." (LFA)

What could help

Centralised agreement about standardised, required training.

Centralised agreement over clear induction expectations for the roles to identify recommended core subject area training (for example Mental Capacity Act, autism, learning disabilities, boundaries, peer support, suicide awareness, eating disorders).

"There wasn't any mandatory training, but it would have been quite helpful I think." (LFA)



Access to space and systems

What we heard

LFAs had a lack of appropriate physical base and access to private meeting space.

"The wards that I work on, there isn't a co-working space available... so if I want to physically go and work on the ward... I need to sit in the MDT room where I sometimes overhear conversations that I definitely shouldn't be overhearing... Also I have to kind of perch on the end of a desk... there isn't actually a place for me anyway, so it's physically uncomfortable." (LFA)

"There's nowhere for me to go. The only place I can go and sit is the public areas that would be available to a patient or a visitor, that obviously is not a confidential space..." (LFA)

What could help

Employing organisations need to ensure LFAs have access to private meeting spaces (as stipulated in the SOP).

"I have an office to myself... [staff member] said you need to not be in office with other people, so you can talk freely and so clinicians and that aren't listening in." (LFA)

"We need somewhere where we can keep everything for families and where if families are coming to the unit and they need to just have a quick chat with us, something's come up or we've seen that they're upset following a visit, we can just pull them into our office where there's got a nice, cosy little space. We can give them a cup of tea." (LFA)

What we heard

LFAs had lack of access to buildings, systems (including IT systems), documents, contact details and family carer data.

"Because one of the hospitals is not in the Trust that I work for, I can't actually use the Wi-Fi or open the doors or log on to anything. So I can't actually work there at all." (LFA)

What could help

Having access to the shared systems.

"I can Teams message people, we're on the same intranet. All of these things just make your life so much easier." (RFA)

Local working agreements between Trusts within Provider Collaboratives to ensure Family Ambassadors can access all buildings and systems.

What we heard

There is variation in practice around LFAs having access to information in the young person's case files.

"[the Trust is] very, very absolutely [clear] - you're not going anywhere near any clinical system." (LFA)

"Because we've got access to the [NAME] system." (LFA)

"No, we don't want all that [access to clinical system] because again you don't wanna be reading information that's got nothing to do with you and then you start thinking about that information." (LFA)

"Now, because the Family Ambassadors are employed to support families, they need never, in my view, access clinical care records... They just need to be able to support the families in whatever the challenges the family feels are important to them." (Taskforce member)

What we heard

There is variation in practice around FAs recording information in the young person's case file.

[about being expected to write notes about interaction with family in the young person's clinical notes] "I don't think it's right and I've asked several times, you know, should this be discussed further, but I've been told no, this is ok... so it's still not resolved." (LFA)

What could help

Local Provider Collaboratives should secure legal advice regarding FAs accessing, and recording in, patient information systems and use this to develop clear local guidance for FAs to work within.

Support and supervision

What we heard

Family Ambassadors have different employers with different organisational boundaries and systems. This means different line managers, and varying levels of supervision and support.

"It's confusing as who we go to for what [support] and sometimes there'll be conflicting information." (LFA)

"This role, certainly where I am doesn't have the support around it. It's very isolated.... It doesn't have the support in place so you hold a lot of what's said to you.. ...I work from home most of the time because there is a lack of understanding about my role...the role would be better if it was placed somewhere else." (LFA)

"Different regions have different support in place for FAs." (Taskforce member)

What could help

Consistent approach to supervision and support is needed.

"as PCs and regions develop the role... the supervision offer definitely needs looking at... There needs to be a consistent approach to support – areas need to join together on this." (Taskforce member)

What could help

Family Ambassadors can get good support and supervision within their Trust.

"We have a clinical supervisor as well...and then we also have a peer support supervisor who does our well-being supervision... we've got so much of the support within the Trust, we haven't needed to pull on the regional. Whereas I think if we didn't have as much support as we already do, we probably would have had to." (LFA)

What we heard

The nature of the LFA role and caseload requires good line management, supervision, emotional and practical support. Who provides this skilled support needs careful thought.

"The way that the roles developed ...in reality means that they [LFAs] need a lot more supervision... it's a lot of traumatic information to hold..." (Taskforce member)

"There's so much emotion that parents offload onto you... you need to do something with that... there is only so much you can absorb, you need to go somewhere with that." (LFA)

What could help

Supervision and support from somebody who 'gets it' – addressing the emotional impact as well as caseload management. This support can be from multiple sources.

"I'm kind of alright. I have clinical supervision every four weeks, which is great and that keeps me going." [Also has supervision from the family therapist who] "gets it and that's really important to me." (LFA)

"I know what I need to do, this is just unpacking the situation... I do talk to her [RFA] and her support has been really useful." (LFA)

"I think lived experience roles really do need to be supervised by a lived experience practitioner. Because it can be really uncomfortable trying to explain why something is tricky to somebody who doesn't get that. It can be quite invalidating." (LFA)

What could help

Peer support – a community of practice where LFAs meet for informal support.

"That [peer support] been really great...It's meant that we've been able to hear about different practice in different areas ... But also have been able to support each other... sometimes things are really tricky and there isn't a natural person in your immediate vicinity to talk to about it." (LFA)

"I think we're really good at and then also us a team as well, we can speak to each other and offload. You know we've always said like if you having a tough day or whatever you know just ring one of us and we can speak to each other as well...Personally I think we've got a good balance." (LFA)

The role of the Regional Family Ambassador

Although we interviewed every RFA this evaluation has only limited evidence on how this role is working. This is because the majority of the RFAs had not had LFAs in place when we were undertaking fieldwork. Part of the RFA role is to engage with the themes and issues identified by the LFAs and work at a strategic level to promote changes. Currently our learning is limited to where they sit and how they can work with their LFAs rather than how they can influence system change.

We conclude that phase 2 of the evaluation could collect more learning about how this role can work in practice once the LFAs in their region are delivering a local service.

What we heard

The lack of agreed timetable resulted in some regions recruiting LFAs before the RFA was in post which caused some issues.

"I only became aware when it was time for interview and when I looked at the people who were shortlisted, they didn't even meet the lived experience requirement, but we had to go ahead with the interview because we had already planned that. So, we couldn't appoint anyone at that point." (RFA).

What could help

RFAs should be in post and directly involved in the recruitment of LFAs.

"I think that the value in having the band 7 first and getting them to recruit the band 4s with the Provider Collaboratives probably would have worked better for the integration." (Taskforce member)

What we heard

RFAs are inhibited in their ability to support LFAs as a result of having different employers.

"It just doesn't work is the bottom line, for many reasons... I can honestly say they [LPCs] neither understand my role nor wish me to be involved on any level." (RFA - sits within NHS England)

"When we first met with our Regional, there was no way of us sharing things with her because she was from a different Trust. So it was like, how do we have a sharing base?... straight away there we've come up against this because we're in totally different Trusts and we can't share information." (LFA)

"If I were the lead for them within the Provider Collaborative and was line managing them, then I guess it works well. But I don't have any of that managerial. I only have the oversight of the role really." (RFA)

"I think that's been really difficult because again, she's [RFA] not our line manager. She's not, she can't do a lot for us, in the sense of actually from a job point of view." (LFA)

What could help

RFAs and LFAs work closely together; being employed by the same organisation facilitates better support and a better service for families.

"The whole point of this job is intensive work with the [local] FAs. That is how we will find out what the themes are, what the issues are that families are facing." (RFA)

"I feel like I am working as a part of a team with shared goals in terms of the quality side of services.... What's working well is I am part of the collaborative. I'm very much viewed as part of the collaborative." (RFA employed by PC)

"If the original post was sat in the Provider Collaboratives then there would have been more control. So, we'd have saved time, would have been able to pursue things much quicker... the Regional, in hindsight, could have been placed with them for better control, better management." (RFA)

"I also think that whilst there was a good reason to have the distinction of having the Band 7 in NHS England and a bit removed, in reality that's not been a positive thing." (Taskforce member)

What could help

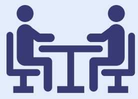
RFAs are well placed to provide practical and emotional support to LFAs, but they need to be accessible and have the right training.

"She's just very accessible.... And so that's been that's been really helpful in terms of saying, I don't know what to do with this situation. Can I talk about this particular case?" (LFA)

"The RFA needs to have a lot more training to be able to support them [LFA]." (Taskforce member)

"There are people around me... but it's not the right support. I think there is real value for the RFA having a place for you... I'm going to have to try and find that support somewhere else." [when RFA is no longer in post] (LFA)

3. Delivering the Local Family Ambassador service



Access to Family Ambassador support

The Standard Operating Procedure (SOP) states that all families of young people admitted should be contacted by the LFA to offer support. However, in order to comply with information governance, some units have required family carers to consent to a referral before contact details are passed to Family Ambassadors. These different approaches have been referred to as 'opt-out' and 'opt-in' systems. While the 'opt-out' approach has been more successful in generating referrals, it is unclear whether this complies with information governance.

What we heard

There is a conflict between guidance provided in the SOP and the application of information governance in some areas resulting in significant variation in the number of referrals.

"Well we did have opt-out and then information governance said no that doesn't fit with the policy so then we reverted back to an opt-in." (LFA)

"soon as we know a family or a young person's coming in or is already being admitted, we just contact the family ourselves… we don't have to rely on somebody telling us that there is a referral or somebody been admitted overnight, we can find that information out for ourselves." (LFA)

"So I think this is where had we done the engagement and the development of the role a bit better and with a bit more time with our providers, that we might have been able to overcome - because you know the minute everybody's employed by an NHS Trust, everybody starts thinking, information governance, what can you, can't you have access to." (Taskforce member)

What could help

A centrally agreed, legally compliant approach to referrals needs to be prioritised.

"It would be useful if FAs would be able to make contact direct with parents and carers at the start of admission, rather than the rather clunky method of having to get ward staff to seek consent from parent/carer to be approached" (Clinical team)

This piece of work should be co-produced with Provider Collaboratives, Trusts and family carers.

What we heard

The ‘opt-in’ approach creates a risk of clinical teams’ gatekeeping referrals.

“It really is driven by what the ward feels is useful.... So I think there is a bit of gatekeeping.” (LFA)

“I've never had [a referral] from a doctor or consultant. It's always been social workers, family therapists and nurses... So even though they're in all of the meetings, they had all of the presentations, they know that I am supporting families. They'll still never refer me.” (LFA)

What could help

An ‘opt-in’ system can be supported by having one point of contact between the clinical team and the LFAs who has responsibility to go through all admissions and identify those suitable for referral.

Example:

In one area there is a Case Manager who assesses all admissions and where appropriate makes a referral to the Family Ambassador with the relevant consents from the family carers. The LFA is confident that this system is working and does not experience the challenges that other areas using an ‘opt-in’ system describe.

What could help

An ‘opt-in’ system can be supported by LFA attendance at admissions meetings which can provide an opportunity for families to be introduced to the LFA and the support available.

“We just attend that five day admission meeting and right at the beginning introduce ourselves and ask a family whether they want us to stay and support them in the meeting and 100% at the time they said yes.” (LFA)

What we heard

The 'opt-in' approach requires LFAs to spend time building relationships in order to generate referrals.

"[Opt-in] put a lot of pressure on us, making sure we had those relationships and that rapport with the wards because we were depending on them for referrals and for getting the word out." (LFA)

"That's why I went into the [unit] so often at the beginning... just to remind them that I exist... you know I'm here and that's what I do. So if you want to refer them to me - but it's still just not as effective as being able to call them ourselves." (LFA)

"How are we gonna bring in referrals?... Some weeks you don't have space for it because you're so busy. But then as soon as your numbers drop down a bit, it's like, right, how are we gonna bring them up again? And it's like a constant battle really." (LFA)

What could help

Where an 'opt-in' system is adopted, the LFAs role in building relationships with clinical teams should be acknowledged in the LFA job description and time allocated for this as an essential part of the role.

Right time for support

There was a strong feeling among people interviewed that support should be available to family carers of children and young people prior to, and post admission, (which has previously been described as being in Tier 3 services) and that support should continue in the community. As the Family Ambassador project was commissioned as part of the Quality Improvement Taskforce with the aim of improving CAMHS in-patient services this section focuses on the right time to support family carers of children and young people in in-patient services.

What we heard

Getting the time right for support to start was difficult.

"In an ideal world, I would start it I would say just after the first week, once all emotions are coming down a bit. So I would say possibly within the second week, just so that they're not overloaded with too much information... But then again, I think some families have really found that first week quite helpful. I do think it's just on an individual basis and you can't really predict that." (LFA)

"Could really have done with this a year ago on our child's first admission to [ward name] but I understand it's a new (and vital) role." (Family feedback)

"I found the support of the family ambassador invaluable particularly in the early months of my daughter's admission." (Family feedback)

What could help

There is broad consensus that the support works best when it is offered as close as possible to the first contact with the ward or unit. There will be inevitable variation depending on whether the admission is planned or crisis.

"When that happens [making first contact within 24 hours of admission] it works really well... If we don't make contact within those first 24/48 hours then a lot happens and the FAs end up trouble shooting and unpicking issues rather than supporting the families in the way they are there to do." (RFA)

"I think that it's a good starting point after admission because there has to be a starting point. I think that's a good one. Any earlier and it starts confusing things." LFA

"I would have liked her support as soon as my child was admitted and continued after discharge." (Family feedback)

"They engaged as soon as their role started. it would have been lovely to have this role start sooner during the admission." (Family Feedback)

What we heard

Getting the time right for support to end was difficult.

"I realised very quickly discharge is one of the most tricky times for families… important that the relationship doesn't just end abruptly." (RFA)

"You are still bewildered when your child comes out… It is a very, very scary time as normally nor you or child feel ready for discharge." (Taskforce member)

"I felt cut adrift after X had been discharged. There were still lots of issues but I have no one to talk to. X has a social worker – I have no one." (Family feedback)

What could help

There is a broad consensus that support should not end abruptly at the point of the young person's discharge but should continue for up to 4 weeks to provide support during what is often a difficult time for families.

"Within two weeks, everyone disappears and you're left with a child in crisis again, and no one to help. So I think the four weeks is absolutely essential. Again, that's from my personal experience." (LFA)

"I think the family ambassador's role needs to continue for longer on discharge as our experience of several inpatient discharges is that the support is not adequate and/or not ready on discharge or nobody is giving you guidance on what you need to do proactively to get the right help. So the discharge fails and your child is back in hospital again." (Family feedback)

The SOP was updated to recognise the need for support following discharge and now states that follow-up support should be available to families for up to 28 days post-discharge.

What we heard

Stopping support when a young person transitions to adult services at 18 (including to adult inpatient units) was an issue.

"The whole process of that because you go from a CAMHs unit where you've got routine and you've got structure and you've got things to be doing all the time to it literally the next day to an adult where you've got nothing and you don't have any routine." (LFA)

What could help

Family carers of young people should be offered support for up to 4 weeks (as in discharge) to provide some continuity of support.

"If the young person gets transferred into an adult inpatient unit, I think we should stay on. Because there's nothing for families there, and families still need that support... that transition is already hard enough for the young person from a children's unit into an adult's unit and then to take away our support ....you're just gonna end up with crisis again." (LFA)

"We have been the only people on that call that knows anything about this family and what's happening with the young person." (LFA) *[in relation to supporting an inpatient YP with a move to an adult unit the day after their 18th birthday]*

Clarity and boundaries of the role

What we heard

Difference between what is recommended in the SOP (that LFAs do not attend meetings) and what is happening in practice.

"[Trust] are very strict on what's in the SOP. I'm not to attend meetings, clinical meetings." (LFA)

"The whole point of this role is not to go to meetings.... and yet that is what happened." (RFA)

LFAs found that offering attendance at meetings provides a valuable form of support for families.

What could help

Agreement on LFA's role in meetings is needed.

If attendance at meetings is agreed as part of the role, there needs to be clear direction about the role of the LFA within the meetings.

"If we just need to go in so they know that they've got somebody on their side who's listening to them and who actually cares, with them and not say anything, then we need to be there." (LFA)

"Some really want that support during the meetings with the with all the jargon and with how many people are in the meetings as well... I'm more of a supporting role. I don't really speak." (LFA)

"It was extremely stressful at the time and so I felt reassured and that nothing would be missed as at a very big professional meeting FA attended and took notes for me." (Family feedback)

What we heard

There is a lack of understanding about how the Family Ambassador roles fit, and whether there is overlap, with other roles.

"Especially at the beginning when we was going in, the family liaison or the family therapists would be like have their back up and like this is my, this is my job." (LFA)

"In the beginning there was some confusion about designation and remit (not at all the LFA's fault) but it felt that this should have been agreed before the posts started so that they could have been working as they are now from an earlier stage." (Clinical staff)

"It can be difficult having another separate person supporting a family when they already have a lot of input - these are families that already make use of lots of resources and so it can be become uncontained." (Clinical staff)

What could help

Continuing education and awareness raising of the unique role of the LFA as the only role solely to support the family carers.

"We just have to make it really clear, like we're not there for the whole family, we're there for the parents really... we're not there to do an intervention with the full family." (LFA)

"It's just about sort of explaining what our roles are and what we can and what we can't do." (LFA)

"It would be good for some clarity around the difference of family ambassadors and Peer supporter who work with the family in CYPS then there isn't confusing for the family/ clinical staff." (Clinical staff)

What could help

Work with other professionals to agree roles and boundaries.

"I think mine [role] is quite clear cause I've kept, I've kept boundaries very, very tight. There is, there is potentially a bit of overlap, but not in a negative way, with the work that the social worker does and the family therapist." (LFA)

What we heard

The inconsistency in practice around the role of the LFA in meetings and the lack of understanding about how this role fits with others has led to some examples of LFAs drifting into the role of an advocate.

"At times this role appears to have stepped into that of an advocate which is not what I expected. This has been very difficult to navigate at times." (Clinical team)

What could help

Improved understanding and awareness of Family Ambassadors about the role of an advocate.

Information and training for Family Ambassadors on understanding and different types of advocacy, the law around who has a legal right to advocacy and awareness of local advocacy provision.

4. Looking forwards: Delivering a national service

National consistency

What we heard

There is conflict between the need for consistency of service for families and the varying local needs.

"The consistency is very important because one of the major difficulties that the families have experienced, that has led to the Family Ambassador approach coming into place is a lack of consistency, lack of clarity." (RFA)

"To be the same across nationally… that will be really reassuring to parents." (LFA)

"Some level of consistency is important, but I think to try to enforce the same thing, even in the same region, won't work." (RFA)

"I don't think it matters, I think collaboratives need to work according to their local needs. Needs are different locally… working consistently doesn't matter, you just need the same sort of ethics, respect for families - we work according to what the needs are." (LFA)

What could help

Work should be done to identify the key principles and core elements of the service, while allowing for flexibility to adapt the service to reflect local populations, needs and issues.

"a model that then leaves enough space for people to be able to shape it for themselves and adapt it to their localities." (Taskforce member)

"It is a dynamic role and will keep evolving… Consistency is important but also flexibility." (RFA)

What could help

The SOP should be updated to reflect the agreed key principles and core elements and set out which elements should be decided locally.

A national Family Ambassador booklet or leaflet should be produced for families setting out the key principles and core elements with a section to describe how the support works locally.

"We spoke about writing a Family Ambassador booklet or unit booklet, you know, as one national one that would be consistent across the board." (RFA)

"I've always talked about things like having a national welcome booklet, so everyone's got the same information. So yeah, particular unit's information will be different, but your general standard about sectioning, about your rights...." (LFA)

What we heard

With the Taskforce ending and Provider Collaboratives set to be taking over funding Family Ambassador roles there is a risk of drift from the original purpose of the role and further inconsistency.

"Especially with the Taskforce ending... the money will be coming out of the pockets of the LPCs, which means they will feel a sense of understandable power and control over what that role looks like and maybe we'll shift things to our demographics, our communities or you know, our bed management for example. So yeah, I like consistency. I'm not sure how that would happen now." (LFA)

"Other local Provider Collaboratives have totally changed the model at the local level... And some regions have got nothing still or just starting to recruit when other regions are at the end of their pilot and ending the role. So I think the consistency ship sailed." (LFA)

What could help

There should be ongoing opportunities for LFAs and RFAs to continue to meet to support a level of national consistency.

"I think it's important to have that consistency... which is why I pushed for us to have the weekly Tuesday meetings where we all come together and discuss everything." (RFA)

The online community of practice on the Future NHS Collaboration platform can be used for discussion and for sharing of resources.

What could help

Any discussions and planning should incorporate the views of Provider Collaboratives.

"It would be good for the Provider Collaboratives to also plug into that, you know... also joining that meeting maybe once in a while and discussing maybe for a few hours discussing and breaking things down to say, OK, we're gonna all work together like this." (RFA)

What could help

LFA specific induction training should be developed to support a level of consistency (see page 20).

"I think that [Family Ambassador training] should have been developed before we started employing Family Ambassadors... What one area is doing is completely different to another area and there needs to be consistency across the country, not just across one Trust to the next." (LFA)

"Think it would have been nice for all of us to [have Family Ambassador training] as Family Ambassadors, because we're all doing things differently." (LFA)

Leadership

What we heard

Dissatisfaction with central leadership exacerbated by the Taskforce coming to an end.

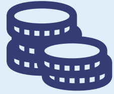
"There needs to be more leadership, scrutiny and direction to address the problems. We need a strong central lead and clear boundaries." (RFA)

"There was no support from the Taskforce...which was really disappointing."[2] (LFA)

"The lack of communication from NHS England..... actually when we wanted that information, it wasn't there... There's quite a lot of us and, you know, I think we all felt the same." (LFA)

"What it risks is the vision drifting. I always felt it should have some kind of national ownership. It's a massive investment of money that doesn't have one central point. At end of Taskforce – where does it belong?... It just feels like potentially a massive waste of money if it doesn't get centrally held and centrally nurtured." (Taskforce member)

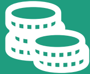
[2] The Taskforce endorsed, funded and supported the creation of the Family Ambassador role and had responsibility for multiple projects, including the Family Ambassadors programme, and it should be noted that these were being delivered in a very challenging context.



Timing and resources

What we heard

Some level of ongoing, central leadership is needed to oversee and support the programme.

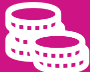


"I think for the five years there should be dedicated support from a team... there's obviously the quality transformation team that I know have agreed to support the project for a period of time going forward, but I think it should be dedicated." (Taskforce member)

"My hope is that it is owned centrally, that this evaluation will mean that we will have the opportunity to make it better, to make it more stable, to give it a national support structure, and to feel that it's a consistent core service." (Taskforce member)

What we heard

Initial funding period was not long enough to allow time to embed new roles and see change.



"Right from the beginning of this project it became really obvious early on that we needed time to implement this.... It's taken time to spread the word, it taken time for people to allow us in." (RFA)

"At the end of the day, it is money isn't it?... This is classic NHS, where you know it is the best solution long-term but we can't do it in the short-term so we don't do it and outcomes don't improve." (Taskforce member)

"That is my biggest fear, that you don't get the time in the NHS to prove these concepts." (Taskforce member)

"Funding is the biggest, without a doubt... with hindsight, 12 months funding wasn't enough to make it a significant project for individual Provider Collaboratives." (Taskforce member)

What could help

Funding by Provider Collaboratives to allow the work started to become embedded.

"My fears are that Provider Collaboratives don't continue the roles and it just disappears and people look back and say look we poured all that money into it and it didn't work, and therefore damaging the principle." (Taskforce member)

"I think that the FAs should become permanent roles. The ongoing uncertainty regarding the post means that it has been more likely that FAs will leave their roles, making the post harder to embed within the teams. The widespread feedback from the nursing team and the MDT is that the Family Ambassador role should be made a permanent fixture and they would be extremely frustrated if this service was cut." (Clinical team)

"Thank you for piloting this service. Please keep it. You have no idea how important it is." (Family feedback)

What we heard

There is insufficient resource in some areas to support all families.

"They need more people, now they need more hands because they get in too many, you know, families to support ... we're gonna need more Family Ambassadors." (RFA)

"We do need more of us. We can't possibly, the stuff that we do for our families, we can't possibly do that for all of the families. It just, there's just not enough time and there's just not enough of us." (LFA)

"I cannot physically, possibly support every single family that's on the unit and I'm starting to get very anxious about that because you know, how do I choose which family I work with and which family doesn't get that support." (LFA)

"More family ambassadors in services, they could really help a lot of people." (Family Feedback)

What could help

Sufficient funding by Provider Collaboratives that is used efficiently to resource the roles adequately.

Family Ambassadors need to collect robust data about the number of families being supported and the amount of support received to evidence the need for additional posts.

"The FA was someone I could contact if I need advice, assurance or help. She was always there if I needed her." (Family feedback)

Processes (such as referral systems) need to enable efficient use of the LFA resource.

Progress towards outcomes

The findings presented in this section are drawn from the three regions that had a team of Local Family Ambassadors in place for a substantial period by the time the data collection took place (February to April 2023). In each of these three regions we have analysed data from family carers, Family Ambassadors and clinical team members.

1. Family carers receive good information and emotional support, enabling them to understand and navigate the system.

This section builds on the emerging findings that were identified in the interim report around providing information and emotional support to family carers and supporting them to navigate the system. The data and evidence collected from interviews with Family Ambassadors and the Taskforce, survey responses from clinical staff members and feedback from family carers shown here strengthens and validates the findings described in the interim report.

Information and signposting

There is evidence of the valued role that Family Ambassadors are playing through providing information for families. Family carers value the information they receive and the help finding resources at a time when this is difficult to do themselves:

> ***"[LFA gave] information that I didn't have the headspace to look for myself. I am very grateful"*** (Family feedback)

> ***"The FA was the most supportive and informative individual on the ward"*** (Family feedback)

Specific examples of the information shared include benefit entitlement such as DLA and PIP, travel information and information about mental health conditions and the law relating to mental health.

> ***"We let them know what benefits they're entitled to, because a lot of them do not know, and once they know that and they're like 'this can help so much'."*** (LFA)

> ***"Since the family ambassadors have come into post they have… sourced and shared information around sections and tribunals and other things I have asked for"*** (Family feedback)

> ***"They brought us information about mental health and helped us understand more about what our child was experiencing"*** (Family feedback)

There is particularly strong evidence about the signposting role that Family Ambassadors are providing, as described by family carers, Family Ambassadors and by clinical staff:

> ***"The family ambassador made us aware of a large number of resources, groups and contacts that we had no idea about and would have had real difficulty finding ourselves"*** (Family feedback)

> ***"It was great to have a listening ear and a professional who was able to do the background research and advice [sic] me on activities or services in our areas."*** (Family feedback)

> ***"Parents and families have spoken very highly of [Family Ambassador] citing a number of ways in which they have been supported:… [including] having support in thinking about next steps and outlining practical + emotional support available in the community"*** (Clinical team)

Family Ambassadors have given examples of services they have signposted families to such as the Carers Trust, PALS, family therapy and peer support organisations.

It was highlighted by Family Ambassadors that having the time to do the research around organisations and services to signpost to was something that other professionals involved with the family may not have:

> ***"Lots of signposting. They appreciate that… There are actually so many wonderful charities and organisations out there helping that you need to sort of know about to be able to signpost to. We've had the ability to research these."*** (LFA)

Emotional support

Local Family Ambassadors spoke about their role in providing much needed emotional support for family carers during a difficult time. Some of the ways they offer this support is through regular check-in calls (which can be more frequent during crisis situations) and face-to-face meetings. Feedback from families show how much they value this emotional support.

> ***"[Family Ambassador] was amazing. I really don't know how I would have navigated such a difficult time without her support and understanding."*** (Family feedback)

> ***"She was a beacon of hope during our time. It is an incredible supportive service."*** (Family feedback)

Often, families appreciate the value of simply having someone to listen to them:

> ***"It was very beneficial to feel listened to and understood. I would fully support the continuation of this role."*** (Family feedback)

> ***"It's not necessarily the parents needed anything, but they just wanted to offload. Sometimes you could be on the phone for half an hour and not really speak, let them speak...and then they'll be like 'I feel so much better now'."*** (LFA)

The emotional support was strengthened by family carers seeing Family Ambassadors as 'someone who gets it', who understands, can be trusted and won't judge them, which was explicitly linked to the lived experience they have:

> ***"It was nice to have someone to talk to who fully understood what you were going through as a parent."*** (Family feedback)

> ***"You don't get the same understanding or sympathy from family or friends who don't see what we are going through first hand. The FA gets it and it's so helpful."*** (Family feedback)

> ***"The sense that they were "on my side" was utterly priceless and made a really horrible situation more tolerable and gave me hope actually."*** (Family feedback)

Feedback from family carers emphasised some of personal attributes of Family Ambassadors that they particularly appreciate, including being understanding, caring, supportive, patient and knowledgeable:

> ***"I am immensely grateful of her soft quiet wisdom and support as I could then pass it on to my own family."*** (Family feedback)

> ***"The FA is a wonderful human being, So, so compassionate and professional."*** (Family feedback)

Practical support

> ***"[Family Ambassador] gave the most practically helpful, encouraging and positive support that we've had so far on this long and painful journey."*** (Family feedback)

As well as giving families the time and space to share their stories, experiences and concerns we have also heard examples of ways in which the Family Ambassadors provide practical help such as support with form filling, benefit applications and financial support to travel to hospital for visits.

> ***"very helpful and effective in helping us to apply for financial help and resources."*** (Family feedback)

> ***"The FA helped with filling in form when I know for a fact that it would be overwhelming."*** (Family feedback)

Family Ambassadors are able to provide practical support that is tailored to the specific needs of the individual family,

> ***"I helped find a GCSE centre because the ward had refused to let the young person take their GCSEs there and so finding somewhere for them to do their exams and things like this."*** (LFA)

This individualised support, specific to their family's need is highly valued by family carers:

> ***"Help offered was never generic and always relevant to our needs… FA has gone above and beyond to help us."*** (Family feedback)

> ***"I felt more supported through this service rather than the parent's group as it was more bespoke to our needs."*** (Family feedback)

Support to navigate the system

A key aspect of the original vision was around support to navigate a system that is overwhelming and confusing; something that a family member confirmed is needed:

> ***"You feel such fuzziness and misery you feel.. need someone to who can be there for you.. help you negotiate this bewildering system.. explain the basics. Like when can I visit. What will my young person be doing during the day… treatment plans – that sort of thing."*** (Family feedback)

Family Ambassadors have helped family carers to navigate the system by giving advice on who the appropriate people to speak to are, explaining procedures and processes, demystifying language and terminology, and navigating transitions both from CAMHS to adult services and discharges.

> ***"We really didn't understand how things worked and the FA took her time to explain. We felt supported and heard. We really couldn't have done without her."*** (Family feedback)

> ***"On previous admissions when I didn't have the family ambassador service, it was exhausting and I did not know or understand how to navigate this world or what to expect. I do now thanks to the FA."*** (Family feedback)

> ***"They explained to us about what the inpatient service looked like and what was allowed and prohibited on the ward, explaining why items might not be... They helped to explain people's roles and what they did so we knew who to direct our questions to."*** (Family feedback)

Reflections from Family Ambassadors show that this is an important aspect of the support that they provide for families:

> ***"A lot of the stuff that we hear all of the time is 'Thank you so much for your support'... and 'If it wasn't for you then we wouldn't know anything. We would be lost.'"*** (LFA)

This is further confirmed by observations from clinical staff about how the Family Ambassador role has supported families:

> ***"The family ambassador has been able to build relationships and support the families of the young people in our care."*** (Clinical team)

2. Family carers feel respected, included and empowered; they are part of care decisions and have the confidence to complain if needed.

One explicit aim of the Family Ambassador programme is to "enable them to be 'parents as partners' in their Children and Young People (CYP) healthcare needs."[3] The data collected for the interim report highlighted the crucial role that Family Ambassadors can have in improving communication. The interim report highlighted that when a Family Ambassador facilitates improved communication this may also assist with other desired outcomes, such as better participation in care decisions.

Analysis of the much larger dataset, from a wider range of sources, has confirmed that facilitating better communication between the family and the clinical team continues to be a vital part of the Family Ambassador role. There is evidence from the family feedback that the support provided by LFAs can help families feel respected, included and empowered to become more involved in the care of their child. This could include making complaints,

[3] Family Ambassadors: in Children and Young People's mental health inpatient services (Standard Operating Procedure)

although evidence from all sources highlighted the role of Family Ambassadors in de-escalating and avoiding complaints.

Improving communication

The feedback from the families was very clear that facilitating better communication is a valued aspect of the Family Ambassador role; many of them reported this as something the Family Ambassador had helped with:

> ***"Communication between ward and family was terrible. FA helped improve this and made it a 2-way system with more regular contact."*** (Family feedback)

> ***"Before her [LFA] involvement it felt like everything was an uphill struggle but she was able to explain policies and feedback to the ward on my behalf."*** (Family feedback)

Improvements in communication between the clinical team and the family has resulted in families feeling better informed about their child's daily life whilst they are in hospital. Several family carers have talked about the importance of knowing feeling included in their children's lives and knowing what they are up to:

> ***"In past admissions, myself and my child have had to experience my child being sectioned, I have felt very isolated as a parent due to lack of information and communication from the unit, I haven't known what my child was doing on a daily basis or getting any feedback which has led me feel anxious and sitting wondering about what they are doing."*** (Family feedback)

One LFA has encouraged the Occupational Therapists to give each family a timetable of the young person's activities for the week.

Respecting and empowering families

Some family carers said they needed support from the Family Ambassador to have their voices heard. At a time when many parents feel upset and powerless, we found some evidence of families supported by LFAs playing a more active role. There were examples of improvements after the LFA had intervened,

> ***"The mum rung me back within the hour and said... thank you so much. Since you've spoken to them they've had a real kick up the bum... she was just really grateful."*** (LFA)

> ***"The LFA has helped managed parents anxiety by feeling more included in decision making or understanding processes."*** (Clinical team)

LFAs and clinical staff agreed that good relationships between families and the clinical team benefitted everybody:

> ***"There's a feeling that things run more smoothly when we're working with the family...that communications are sort of more streamlined and there's less backwards and forwards."*** (LFA)

Not only can families benefit from being listened to by the clinical team but they also have something to offer. LFAs gave many examples of valuable knowledge that parents have shared that can help in the clinical management of their child. This included families being able to explain about what their young person will find distressing and what reassures them.

Not all families felt respected and listened to by the clinical team. In the direct family feedback, one family member commented that the "FA [was] excellent at their job, without them we would have been voiceless as parents" but they also said they had not been empowered to be an equal partner in their young person's care despite the efforts of the family ambassador.

Family Ambassadors described their role in helping families know the input and quality of service they should expect. This could involve supporting families to make a complaint. Families agreed this support could be helpful:

> ***"Helping families have a voice also vital. If I had decided to complain about things, I think it would have been great to have the FA support."*** (Family feedback)

One LFA noted that when she first started, she felt the team were worried she would be "raising complaints and helping families complain. And that is what I can do and I will do if I need to. But most of it is about let's, let's find resolution for the young people and the family."

In some areas a reduction in complaints has been noted:

> ***"Since our role's been out that we've had zero complaints, not even a PALS issue."*** (LFA)

It is positive to see evidence that LFA input, by improving communication and empowering families to be involved in care decisions, has avoided concerns escalating into complaints (see Outcome 5).

Supporting family members in meetings

The SOP clearly states "Family Ambassadors **will not attend meetings** with family members. The role of the Family Ambassador is to facilitate and empower families to have their own voice, not to speak on their behalf. Family Ambassadors may raise concerns with clinical staff but **will not** represent

families in clinical meetings." (page 7). Despite this explicit statement, we know that many of the LFAs have been supporting family members in meetings in a range of ways:

> ***"I think it would be quite difficult to do this job without going to some of those meetings with the parent... I'm not there to contribute or to speak for them or anything like that. I'm there to sort of provide moral support, I guess."*** (LFA)

The LFA role in meetings has varied from simply note-taking and debriefing after, to supporting families to ask questions, to fully participating within the meeting.

We found several reasons given for LFAs joining meetings; some reported this as a way to make contact with the families when referral systems were not up and running:

> ***"When we first started, it was our way in....and introducing ourselves because we were just really struggling to, to, to get in to, to speak with the parents and to get in there."*** (LFA)

Many LFAs spoke about the need to attend meetings in order to be able to debrief the family carers and provide appropriate ongoing support:

> ***"It's essential, that's how you know what's going on with families... it doesn't make sense not to... I can't understand why they felt we shouldn't be at meetings."*** (LFA)

Primarily, the LFAs that attended meetings spoke about it being what families said they need:

> ***"In our SOP it says that Family Ambassadors are there to support and empower families to have their voice heard. Then in the next sentence, it says Family Ambassadors WILL NOT attend meetings in capitals. But you've just said that they're there to support and empower families to have their voice heard. Some families are that exhausted and that burnt out that they can't physically verbalise."*** (LFA)

If family carers are struggling to speak for themselves then they may well benefit from the support of an advocate. In such situations, the LFA should make an introduction to a local advocacy service.

The need for support in meetings has been strongly evidenced by the feedback from families who identified a range of benefits from the Family Ambassador's attendance at meetings:

> ***"When we found ourselves too emotional to speak [LFA names] were there to make sure our concerns were addressed. After the meetings we***

always had a catch up to make sure we understood everything that had been discussed in meetings and to make sure we got what we needed from those meetings." (Family feedback)

We have found evidence that the support in meetings had helped some families to engage in a more positive way with the clinical team:

"Having the meeting [CeTR] about my daughter was very difficult, and the FA's attendance ensured I could concentrate on what was being discussed. It was also useful to her experiences of other meetings." (Family Feedback)

It is not only the families that have identified LFA input into meetings as a positive aspect of the role. Our survey of the wider clinical team found this was reported as a benefit by multiple respondents:

"They have spoken to family members and provided further information and support during meetings that have been difficult due to family members disagreeing with the MDT team." (Clinical team)

"A supportive presence in meetings, helping the family understand and keep track of plans by summarising outcomes from meetings." (Clinical team)

The Family Ambassador role was not designed to advocate on behalf of family. Several responses from the clinical team specifically noted the value of the LFA in terms of advocacy at meetings suggesting there has been some misperception about the role:

"Families are better advocated for in team meetings and treatment reviews." (Clinical team)

"The family ambassador has been able to build relationships and support the families of the young people in our care. They have helped them navigate meetings and advocated for them." (Clinical team)

In summary, the evaluation data has indicated that the role LFAs can play in meetings is beneficial to both families and the clinical team but does need clarification. If it is agreed that LFAs can provide useful support to families through being at meetings, then there needs to be transparency about exactly what their function is in meetings, to ensure they are not working outside of the intended role. LFAs should be ensuring that family carers have their voices heard and their rights upheld, without stepping into the role of an advocate. Rather, they should have the appropriate skill to gauge when a family carer needs the input of an advocate and the knowledge about how to signpost them to a local service.

3. Family carers are better able to advocate for their family members and support them to have their voices heard and rights upheld.

The Family Ambassador role was not designed to provide advocacy for the family, rather they should be empowering the family to advocate for their family member.

LFAs said this distinction is important:

> ***"I believe in my role as Family Ambassador, I empowered the family to get their voice heard and enabled them to use the tools they already had."*** (LFA)

> ***"I'm alongside them, sort of helping them to find their own strengths and sort of ability to manage these situations themselves and speak for themselves and understand what's going on. So it's more about support, I think, rather than advocacy."*** (LFA)

We have heard explicitly from some family carers that the FAs have helped them to advocate for their family members:

> ***"I have more confidence and knowledge moving forward to advocate on behalf for my daughter, to make sure I get my voice across. The parent is important too in this journey."*** (Family feedback)

Although Family Ambassadors are there to provide direct support to the family carers of the children and young people, ultimately it is hoped that this will lead to better outcomes for the young people themselves. Benefits for the young people might include reduced time in inpatient units or fewer transfers for example. One respondent to the wider team survey was unsure they had yet seen a direct impact in young people yet but said:

> ***"Validating the parents will give them more space to understand their child/young person."*** (Clinical team)

The survey responses showed that the staff team can see how the support given to the parents can benefit them and their children:

> ***"The LFA has helped managed parents' anxiety by feeling more included in decision making or understanding processes. This has in turn supported them to feel more confident in managing leave and working towards discharges."*** (Clinical team)

> ***"The young people benefit from the support, advice and guidance provided to their parents. Risk management and successful discharge from inpatient care is more likely when parents are provided with***

adequate support, so that they can then contain and manage their child's anxieties." (Clinical team)

Families have also recognised benefits to the young people of the LFA's input:

> ***"I feel more confident supporting my child and have a better understanding of the support that is available to myself and my child."*** (Family feedback)

We were told that some of the interventions put in place by Family Ambassadors have benefitted the young people and the family as a whole. In one area LFAs worked with the wider staff team to set up a monthly family event which has enabled families to spend some quality time together:

> ***"The young people have come up from the wards and they've had that time with the families… a bit of a normal environment, they've played pool, they've sat in the caff. A bit of normality back."*** (LFA)

> ***"The carer's events that the allied health professionals arranged with the family ambassadors were a huge comfort to us as a family. They meant that all of us could get together in a way similar to home, that the ward environment doesn't allow for."*** (Family feedback)

We did not expect to see evidence of these long-term changes during the evaluation period. However, we are encouraged to note there are already signs of change that indicate better involvement of family carers can result in benefits for young people, with most of the positive examples relating to discharge.

Whilst there is some feedback from all sources suggesting that the LFA role helps families have more confidence and knowledge about their family members rights and care, there is less robust evidence that this supports parents to advocate for the benefit of their family members. This could be explored in more depth in any further evaluation.

4. Family carers experience reduced trauma and/or improved wellbeing.

As described in Outcome 1, the emotional support provided by Family Ambassadors is highly valued and appreciated. As well as providing reassurance and a listening ear, for some family carers this support has helped them to deal with the trauma they are experiencing and led to an improvement in their wellbeing.

Reducing stress and anxiety

Both clinical staff and Family Ambassadors have observed the impact that the support of the Family Ambassadors has had in reducing the stress, anxiety or worry that the family carers experience:

> ***"it's amazing seeing the connections we build with families and just for them to have an emotional space to offload... you just see the benefits, like the first time they speak to us, they're so anxious and sad and they just slowly open up and sort of relax."*** (LFA)

> ***"Parents and families have spoken very highly of [Family Ambassador] citing a number of ways in which they have been supported: [including]... given a space to talk through intense feelings brought about by the MH crisis and also the admission."*** (Clinical team)

This is confirmed by feedback from family carers:

> ***"The FA was absolutely fantastic she provided me with a shoulder to cry on whilst going through such a worrying time."*** (Family feedback)

> ***"It was extremely stressful at the time and so I felt reassured."*** (Family feedback)

Coping in a difficult and scary time

Family members particularly referred to feeling scared or fearful and how the support of the Family Ambassador had helped them to cope through such difficult times:

> ***"[Family Ambassador] helped and supported us as a family during our most devastating time. Her constant support and kindness helped me navigate my hopelessness and desperation."*** (Family feedback)

> ***"[Family Ambassador] has been a lifesaver and helped us when we needed the most. Having our son at hospital turned our lives completely upside down and I don't know how i would have coped without (LFA name's) help & support."*** (Family feedback)

> ***"Having time with [Family Ambassador] at this point has been much needed, she has given me the space to process my feelings and helped lift my spirits so I don't go home and dwell for the rest of the evening."*** (Family feedback)

Promoting self-care

Family Ambassadors also support the wellbeing of family carers by promoting self-care. In a period and environment that is focused primarily on their young person, the Family Ambassadors play a role in reminding, guiding and directing family carers to actively take care of themselves.

> ***"I always ask them…What support have you got?... Because you wanna be your best self when your young person comes out and you wanna be able to support them the best. They're being looked after now. So it's time to look after yourself as well."*** (LFA)

> ***"I would not have had the opportunity to discuss my own well-being as previously everything was centred around my child's feelings and problems. Without this service I would have struggled to cope."*** (Family feedback)

> ***"Having the support really helped with my own well-being and as a single parent I felt that it gave me the opportunity to voice how I was feeling and coping."*** (Family feedback)

Family Ambassadors do this by signposting to organisations and groups as well as gentle encouragement:

> ***"[I had] weekly check in calls with YP's father where he would talk about how he was supporting his YP and family... he spoke of having time in the fresh air to process what had been happening to his YP. Had plans to continue doing this [bike rides] as he had felt the benefit of exercise and time to himself."*** (LFA)

> ***"I think seeing the effort I made [making suggestions about his wellbeing and support] helped encourage him to take the steps he needed."*** (LFA)

Supporting a sense of hope and optimism

As well as helping family carers to deal with their current situation and feelings, Family Ambassadors help family carers to feel a sense of hope or optimism about the future:

> ***"[Family Ambassador] helped me see the positives and progress despite the weekly setbacks we all endured... always left me better off at the end of each conversation."*** (Family feedback)

> ***"their availability and readiness to help in whatever way I needed... made a really horrible situation more tolerable, and gave me hope actually."*** (Family feedback)

In response to a question about what they would have done if they hadn't met with Family Ambassador, family carers responded:

> ***"Continued to drift aimlessly and feel entirely hopeless."***
> (Family feedback)

> ***"Been more miserable and less hopeful and more bewildered."***
> (Family feedback)

Wider family wellbeing

There are some indications that the Family Ambassadors have been able to promote family wellbeing more widely by providing support to multiple family carers or working with other clinical team members to arrange events for the whole family:

> ***"Whilst our child was admitted in the inpatient unit, we also had other things going on with our other children as they had also been affected by this. [Family Ambassadors] contacted their schools and helped us to help them which was really helpful for all of our family... They understood that this didn't just affect us it affected my whole family."***
> (Family feedback)

> ***"What's been lovely is that the siblings, the younger siblings have come together, there's a big sports hall [they] played football, they've done gymnastics they've done colouring in... And then the young people have come up from the wards and they've had that time with the families."***
> (LFA)

Being able to extend their support to the wider families does of course depend on the capacity and provision of Family Ambassadors.

5. There is the start of a culture change in inpatient units, including improved partnership working and less adversarial relationships.

The interim report indicated that the Family Ambassador role was having an impact on clinical staff in terms of their awareness and understanding of the family perspective. Subsequent findings have confirmed this and provided examples of changing attitudes and better communication, leading to improved relationships between staff and families. Our findings indicate the start of a culture change in some areas, where the Family Ambassador role has helped facilitate mutual understanding and less adversarial relationships with families. Respondents agreed that culture change takes time and it will be

important to continue and build on the work that has been done by the Family Ambassador role.

Awareness and understanding

Family Ambassadors and clinicians said they had noticed a shift in awareness and understanding of staff towards family carers.

> ***"I do think that clinicians are now much more aware of the family life, what goes on beyond... There's a lot more compassion and flexibility."*** (LFA)

> ***"The staff on the ward were like well we've changed that because of what you said they're hearing straight from the parents that said, you know, it didn't work like well, you know it could, it could it work better this way."*** (LFA)

In our survey, 71.5% of clinicians agreed or strongly agreed that the LFA has helped them understand the experiences and challenges faced by family carers.

Working differently

Family Ambassadors said that as well as increasing awareness they were role modelling how to interact with and to support families, as partners.

> ***"There's developed a culture here of if a parent is raising something, we're all much more interested as a team now of let's get this resolved so the parent can feel at ease and that their child is supported."*** (LFA)

Some LFAs said they were supporting culture change by simply being working in their role and demonstrating good practice:

> ***"I think even just being called a Family Ambassador and sitting in the same room as them can help them sort of be more mindful about what they're discussing and saying, and their language they're using when they're talking about a person who's going through such a horrible time."*** (LFA)

It was encouraging to hear examples where wards are beginning to make systemic changes that will benefit all families. One LFA shared that she has managed to get agreement that the rule of 'no parents' in the ward can be lifted. This means that families can now see where their child will be living and sleeping.

Two-way relationships

We were told that by understanding and communicating better, working in partnership with families, the clinical team and families find themselves in a

less adversarial relationship. Over half the clinicians in the survey agreed that LFA role has led to improved working relationships between their clinical team and family carers. Family feedback also supported this:

> ***"The FA helped me communicate with the ward, when I was getting nowhere. I felt relief knowing that my voice was being heard in ward rounds'*** (Family feedback)

> ***"The support they [FA] gave us in meetings helped us to feel really supported and able to speak freely and openly to clinical staff."*** (Family feedback)

Clinicians and LFAs said that their role helped resolve issues amicably and could avoid matters escalating. Examples were given of families who did not feel the need to make a complaint after support and intervention from the LFA:

> ***"I think that at that particular time in the process for them, things were going wrong and meeting the family at that particular time in the process, my involvement prevented and already challenging situation from escalating."*** (LFA)

> ***"The LFA has brought any concerns to the attention of the ward team straight away to allow these concerns to be heard and dealt with in a timely manner to prevent any further escalation in the formal complaints process."*** (Clinical team)

Although some could see a shift, respondents were aware that it was early days, with some way to go in terms of culture change and partnership working with families. Some families said they were not listened to and were excluded or ignored by the clinical team.

> ***"Yes, the young person is their patient, but they don't understand how important the parent is in this scenario…the parent's role is unmistakably paramount in the young person's recovery."*** (Family feedback)

There were also examples of teams resistant to the LFA role, where attitudes and practice had not changed (see Outcome 6 below):

> ***"(FA Name) is a lovely person and it is clear that she truly wants to help families. Sadly, the ward does not listen to anyone so she cannot make an impact."*** (Family feedback)

6. Family Ambassadors are well supported and integrated into the local team, enabling them to fulfil the Family Ambassador role.

Embedding a new role into a clinical team inevitably takes time. In the interim report we were able to identify a few examples of progress towards this outcome with some Family Ambassadors reporting they felt their interventions had been welcomed by the wider staff teams. We now have more robust evidence from interviews, feedback forms and the survey for clinical staff members.

The quantitative data from the survey showed that despite a lack of agreement around communication of the Family Ambassador roles before they in post, almost all respondents (93%) agreed or strongly agreed that they now clearly understand the role and purpose of the LFA. Moreover, most respondents agreed or strongly agreed (71%) that LFAs make an important contribution to the clinical team.

Another indication of the LFA role being valued and integrated is direct requests for their input and opinion:

> ***"I think they value my opinion. I'm often asked, like, whether I think that the young person is ready for discharge from the family's point of view and things like that."*** (LFA)

It was noted in the clinician's survey that the parent workshops facilitated by the LFAs have received excellent feedback. LFAs spoke about how managers of the units are starting to want to use them for service developments, such as addressing CQC report recommendations about working with families.

Only a small number of survey respondents did not think they had a LFA in their area (N=3), but all of these people agreed or strongly agreed they would welcome this role within their team. Moreover, there has been interest from other teams about the potential of the role in other settings:

> ***"I had people from acute hospitals reaching out to me to say…we also want the Family Ambassador involved from the acute hospital perspective."*** (LFA)

> ***"When I talk to the staff in Tier 3 CAMHS services they can really see a massive value in the FAs."*** (RFA)

A further indication that the work of the Family Ambassadors is being valued and supported by the wider clinical and social care team comes from a social worker nominating their LFA for an award with the local area (The LFA won a highly commended award).

Despite the general evidence of progress towards Family Ambassadors being supported and integrated into local teams there are variations between the different settings and some of the family feedback indicated there is more work to be done towards this in some places:

> ***"I also feel that the ward should value and respect the role of Family Ambassador more.... the ward should be recommending and support the Family Ambassador's service. I got the impression that they did not value or really care about this service.."*** (Family feedback)

> ***"The ward did not listen to our ambassador."*** (Family feedback)

What helps with integration?

As discussed earlier, Family Ambassadors have spent a lot of time on promoting their role. It is evident that time has been needed for Family Ambassadors to build relationships with their local teams:

> ***"As time goes on, they are getting to understand role...... on our side we gradually built up this relationship, we didn't impose ourselves on them, it was gradual."*** (LFA)

> ***"The longer we've worked in the role, the more people are starting to understand and call on us for our support if you get what I mean, seeing the benefits of it."*** (LFA)

One RFA shared how she had assessed progress in her region from a family-focused point of view. She noted how on her first visit only a few of the staff team spoke to her but the second time the whole ward team chose to engage with the process.

There is some indication that face-to-face contact and physical proximity has assisted FAs getting to know, and integrate with, their wider team:

> ***"For me I've had the same 2 wards since I started, so I've had the same base and been able to build those relationships up."*** (LFA)

> ***"I'd say me being able to have access to or push past the resistance to be able to physically go to this unit and spread the word about it."*** (RFA)

One LFA spoke about the benefits of having an office in the unit which means she can be easily introduced to families and better fulfil her role.

As discussed in progress towards Outcome 2, some LFAs commented that attending meetings has helped them to build better relationships, with one saying it has helped the clinical team to understand her role whilst improving her knowledge of their various roles.

Another factor identified by LFAs as helping them to build relationships with the team has been sharing good practice and positive feedback:

> ***"One of the things I was encouraged to do is to share positive things that staff have done. So if I hear something good, I'll just nip out and go 'so and so has said this about you, I'll e-mail it to you and you can use it for your professional development'."*** (LFA)

> ***"Some wards have some great ideas that they are happy to share with other wards."*** (RFA)

What are the benefits of integration?

The role of the LFA is being valued by other staff. Below we present evidence of specific benefits identified by other staff, which included benefits for the clinical team, the families and even the children and young people:

> ***"It's acknowledged that I'm useful to the parents and that I bring something different to what the ward can offer to anybody else on the team. And so I think that they've really understood the value of the role, the Family Ambassador role."*** (LFA)

> ***"They're really getting on board, now they know the role, how it can be helpful to them."*** (LFA)

Freeing up time

A number of the responses in the survey noted that having the LFA in place to provide support and information for the family freed up some of their time:

> ***"The FA provides containment and information to families, therefore allowing me more time and space to offer clinical sessions and therapeutic work."*** (Clinical team)

> ***"Some families require a lot of time that would otherwise be spent caring for their family member - the LFA has reduced the need for this contact and therefore increase the time spent with the young person."*** (Clinical team)

One LFA said the family therapist had noticed the impact of her role, commenting they had less outstanding work when they returned to work following sick leave, because of her contact with the families. It is encouraging to see the examples of how the support and input from the LFA has reduced time demands on the wider staff team; this was described by one of the Taskforce as being a desired outcome. We would expect that such direct

benefits for staff will help with their engagement with the role in terms of referrals and partnership working; some of the LFAs have already reported this:

> ***"I think they now see the value in having additional people to take some of that kind of difficulty and work with it and support through that."*** (LFA)

Better support for families, children and young people:

There was evidence that the staff could see the value of the role for the families being supported:

> ***"As a consultant, I absolutely appreciate the extra support, which I don't always have time to offer."*** (Clinical team)

> ***"Some of the OTs have said to us they've seen a difference in the families that have been supported by us than the families that are not being supported by Family Ambassadors."*** (LFA)

> ***"Definitely a valuable addition to the service and starting to see wonderful changes and interventions with carers to feel included."*** (Clinical team)

It was noted in the clinician's survey that the parent workshops facilitated by the LFAs have received excellent feedback. LFAs spoke about how managers of the units are starting to want to use them for service developments, such as addressing CQC report recommendations about working with families.

Many examples were given of the LFA sharing information (with permission) that helped the wider staff team better support families and their young people. LFAs talked about the importance of learning from the parent about what is traumatic for their child and what soothes them. We heard about LFAs sharing information about people's life stories as well as practical information about their situation and what will or won't work for them:

> ***"We all kind of work together on that to try and find out the best support for them. So, I'll chip in ... 'you know you might have planned leave for 3 o'clock in the afternoon, but she's picking up the other kids from school, so that's not going to work'."*** (LFA)

> ***"When I get information from parents I will type it up with, you know, with permission and send it out to that child's team. So they're getting loads more information now than they ever got before about the child's background and things that they find difficult."*** (LFA)

As well as staff teams recognising the direct support that FAs can help provide for families and young people, we also heard how the LFA working in partnership with the wider team has led to more efficient working:

> ***"So often after meetings we will get together and go right, you know which families are you speaking to this week to make sure we're not all phoning at the same time."*** (LFA)

There was a specific example given where the LFA had facilitated better partnership working between the CAMHS and adult service by bringing the teams together to address issues raised from two of the families they were supporting:

> ***"Two of the Social Workers have actually told their bosses that they have never worked like that before and how successful this was."*** (LFA)

It is evidence of the impact of the LFA role that the services are now looking at how this can be implemented across the region.

Discussion and recommendations

The evaluation has found almost unanimous consensus from Taskforce members, Family Ambassadors, family carers and clinical teams that the Family Ambassador role is both valued and urgently needed. The interim report presented early data that indicated the benefits of the role and the difference it was starting to make. The main fieldwork, which incorporated the views of a wider range of stakeholders, including families themselves and clinical teams, has now confirmed and strengthened those early findings.

There have been considerable challenges for those setting up this exciting programme. COVID resulted in inevitable initial delays and while there was a subsequent two-year extension this was agreed in three time-periods (12 months, 6 months and 6 months) inhibiting the ability of the Taskforce to plan over a longer timeframe. Other major changes such as the introduction of Provider Collaboratives and Integrated Care Boards meant there were many interim roles and a huge amount of flux within the teams the Taskforce was trying to work with. The decision to roll the programme out nationally was positive recognition of the needs of family carers, but it was ambitious and perhaps contributed to some of the problems with the timing and some aspects of the programme not being fully in place, including:

- insufficient communication to LPCs and those working in local teams
- delays in recruiting to RFA and LFA posts
- the Family Ambassador training not being available
- systems and processes such as referrals and data access and management not being clearly agreed.

In spite of the challenging conditions in which this programme has been delivered, there is now a strong body of evidence of progress towards all the desired outcomes. Overwhelmingly positive feedback from family carers emphasises how well supported they feel and the difference the Family Ambassador's role has made to them at an extremely difficult time in their lives. Furthermore, the evaluation has captured some early indicators of positive changes in relation to the longer-term impact the Family Ambassador programme hoped for, including signs of cultural change within teams and some benefits for the young people.

Recommendations

Given the agreement for extended funding for Family Ambassador roles and evaluation, there is a great opportunity to build on the positive outcomes we have found so far. This report has presented strong evidence of progress towards the desired outcomes but also flagged a number of issues that need to be addressed in the next phase of this work. Addressing these will ensure the Family Ambassadors are able to operate efficiently, to their full potential and provide vital support to the family carers who need it. Some of the issues identified can be addressed by the SOP being implemented as intended and we have highlighted these below. We also have evidence of some aspects of the SOP that may need to be reviewed in partnership with central teams and programmes of work, local Provider Collaboratives and Family Ambassadors. Finally, we have drawn together some recommendations for work that can be done on a local level to improve the service being provided, as well as thoughts for the next phase of the evaluation. We think that addressing these recommendations would give the Family Ambassador programme the best opportunity to flourish.

Aspects of the SOP that need to be consistently implemented:

- Local induction for LFAs - including an introduction to the wards and units they will be working with.
- Bespoke training for new LFAs – to be developed and implemented as soon as is feasible and built into the induction process.
- Meeting space -LFAs need a private meeting space to talk to families.
- Access to units - LFAs need to have physical access to the units they support.
- Data collection - a minimum dataset (number of families supported; type of contact made; satisfaction surveys) should be collected and shared with the evaluation team. There may be a need to centralise this system.
- Family contact - LFAs should aim to have initial contact with family carers within the first week of admission and throughout the stay where required.
- Post Discharge support - LFAs should provide follow-up support to families for up to 4 weeks after discharge.
- Promoting rights and signposting - LFAs should recognise the need to signpost to advocacy for family carers when needed.

What needs to be reviewed or actioned:

- Opt-out approach - the updated version of the SOP states that an opt-out approach should be implemented. Our evidence suggests most people would prefer an opt-out approach and that this approach generates a greater number of contacts. However, some LPCs are not permitting this saying it is not in-line with NHS information governance requirements. It is imperative to establish if an opt-out approach is legally compliant.
- Meetings - the SOP states that LFAs will not attend meetings with family members or represent families in clinical situations. Our data shows overwhelmingly that Family Ambassadors, family carers and members of the wider clinical team see benefits when LFAs attend meetings. The evidence suggests LFAs should attend meetings to provide emotional support, take notes and provide a debrief for family carers. The SOP position on meetings should be reviewed in light of these findings.
- Job descriptions and banding - these should be reviewed to consider what has been learnt about the roles since the job descriptions were written, including reflecting on the exact criterion for lived experience for the LFA.
- Transition - consideration should be given to treating transition to adult services as a discharge and that accordingly, LFAs should provide follow-up support to families for up to 4 weeks after transition.
- Recording day to day interactions - this could be a decision for local areas but we believe national guidance on where LFAs can record this type of information in accordance with information governance would be helpful.
- Training - the recommended core subject area training should be reviewed to assess if it meets the needs of those working as Family Ambassadors.
- Key Family Ambassador service principles - work should be done to identify and specify the key principles and core elements of the Family Ambassador service. The SOP should allow for local decisions to be taken on adapting the service to reflect local populations, needs and issues.
- Oversight – once the Family Ambassador service becomes Business as Usual, there would be a benefit in establishing a central mechanism to support consistency across regions where needed.
- National Family Ambassador booklet or leaflet – once the above decisions have been taken, a booklet or leaflet setting out the key principles and core elements should be produced with a section to describe how the support works locally.
- Awareness and sharing good practice - it is important to continue to educate clinical teams about the purpose of the Family Ambassador role. This could be done by sharing good practice examples illustrating the unique role of the LFA and the benefits that clinical teams are reporting.

Decisions for local areas:

- Recruitment - we have made recommendations about the most effective way to recruit LFAs in terms of advertising and timely involvement of the RFA. Areas should use the knowledge of people with lived experience to tap into relevant local networks.
- Line management - LFAs need a line manager within their organisation, but this should be someone with the appropriate skills and understanding of their role and the specific issues for people with lived experience.
- Keeping clinical teams informed - local areas should have a strategy for sharing up-to-date and accurate information about the purpose of, and referral process for, the Family Ambassador programme.
- Referrals - if an area is taking an opt-in approach for referrals, then there should be a clear referral process and a named point of contact.

Recommendations for phase 2 of evaluation:

- RFA role – as most of the RFAs did not have LFAs in post, the function of the RFA role should be explored once it is up and running as envisaged.
- The next phase of evaluation should look in more depth at the role of LFAs in meetings and explore whether their role can provide useful support for meetings, without stepping into advocacy.
- Family interviews - the family feedback has been very powerful, but we were only able to interview one family carer. There is a need to hear the voice of families directly. The phase 2 evaluation team should work with LFAs to establish an effective and sensitive recruitment process. When LFAs have been in post for longer there will be a larger number of potential family participants to draw on.
- Clinical team interviews - due to time-limitations, we collected information from clinical teams through a survey. The data from this has been very useful but richer, more narrative data should be collected.

Conclusion

Given the great progress made, despite the many obstacles, we are delighted that there is a continuation plan for the Family Ambassador programme. Taskforce members and Family Ambassadors have acknowledged how many years it can take to properly embed a new role and to prove the value of it. We heard fears that the programme would not be given the necessary time for this and concerns that the challenging time at which it was being delivered could jeopardise the impact of the work. It is heartening that benefits of the programme are already being seen, and we hope that the learning from the evaluation could strengthen its impact.

In conclusion, there were factors that made it very difficult for Family Ambassadors to come in and do their jobs effectively. Despite this, it is impossible to overstate the gratitude that family carers have expressed in relation to the support they have received and the strength of feeling from all sources that the work of the Family Ambassador programme needs to be continued:

"Please continue to commission this service!" (Clinical team)

"This is a much needed service that will help a lot of parents/carers." (Family feedback)

"I think it would be a huge shame to stop things before it has had a chance to show how successful it can be. I really do feel people will think in a few years how did we ever do without a Family Ambassador?" (RFA)

"The FA was a light in our most darkest moment. Having our son in hospital was a scary time and we felt so lost" (Family feedback)

"We've spent a year trying to embed the role as best we can and supporting families, and they've all said how valuable it is." (LFA)