

Flexible Family Intervention (FFI)

Provided By Space 2B You for Carers of Those Living with Mental Health and/or Neurodevelopmental Issues in Wirral

Independent Evaluation

July 2023

This report is to share Healthwatch Wirral's independent evaluation methodology, support and findings, including recommendations of the experiences and feedback from people using the flexible family intervention.

Kirsteen Sheppard, Healthwatch Wirral, with thanks to Jenny Baines & Kate Webb.

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EXECUTIVE SUMMARY

It has been a pleasure and provided great insight for Healthwatch Wirral to carry out this independent evaluation focusing on improving the wellbeing of carers from families living with a severe mental illness (SMI) and/or neurodevelopmental disorder (ND).

To understand whether wellbeing, in its broadest sense, improved through a flexible and creative approach to providing therapy by Space 2B You. Healthwatch Wirral were asked to provide an independent, qualitative evaluation through online, face-to-face and/or telephone interviews and a survey.

Results from this independent evaluation highlight overwhelmingly that providing tailor-made support to families and carers of those living with mental health and/or neurodevelopmental issues via Space 2B You's flexible family intervention (FFI) was extremely effective in improving both general wellbeing for carers as well as improvements to their quality of life particularly within the family unit.

This report shares the findings and observations and provides recommendations for consideration by Commissioners.

This subject merits a thorough report, which describes issues that are relevant to multiple audiences.

FOREWORD

HEALTHWATCH WIRRAL

Healthwatch Wirral (HWW) offers a wide range of services to ensure that local provision is the best it can be from the Entering and Viewing of health and social care premises to engaging with the public and professionals, carrying out research to providing independent qualitative evaluations. It's our job to listen to people's experiences and share their views with those who can do something about it.

Our job at Healthwatch is simple, we are here to help make health and social care work better for everyone. Healthwatch is independent and designed to give local people a voice to help them get the best out of their local health and social care services. Whether it's improving them today or helping to shape them for tomorrow. Local Healthwatch is all about helping people to share their experiences to help influence the delivery and design of local services.

Healthwatch Wirral brings unique value to this Pilot, by carrying out an independent evaluation and assessment of the Flexible Family Intervention by the Space 2B You service in Wirral.

www.healthwatchwirral.co.uk

KEY STAKEHOLDERS

Families and carers in Wirral

Norma Currie, Head of Commissioning for Learning Disabilities & Autism, Cheshire and Merseyside, NHS England and Improvement Northwest Senior Strategic Lead (NHSEI) for Transforming Care Programme (TCP).

Project commissioned for Wirral Place as a Proof-of-Concept Pilot

SPACE 2B You is a "not for profit" service set up to find creative ways to meet an identified need for accessible and effective services, particularly for those who might otherwise fall through the healthcare net.

PROJECT AIM

For HWW to provide a brief, qualitative, independent evaluation for the Flexible Family Intervention project involving the provision of a remote, flexible and creative psychological service for carers of those living with mental health and/or neurodevelopmental issues and to ensure that outcomes are shared.

BACKGROUND TO THE PROJECT

In the **Government's White Paper**, 'People at the Heart of Care: adult social care reform' (March 2022) they set out a ten-year vision for adult social care. Their vision puts people at its heart and revolves around three objectives:

- People have choice, control and support to live independent lives.
- People can access outstanding quality and tailored care and support.
- People find adult social care fair and accessible.

Person-centred care is a key theme running through this vision. Genuine choice and control about personalised care and support can enhance quality of life and promote independence.

Unpaid care is provided by people of all ages. Many carers have jobs and other caring responsibilities. Carers are people who often have their own jobs, life pressures and issues that matter to them. We know that the support provided by unpaid carers is often physically and emotionally demanding, with consequences for carers' own health and wellbeing. While many carers enjoy caring for their loved one, it should not define them unless they wish it to.

This Pilot set out to provide participants and their families with an opportunity to engage with therapists, to improve the wellbeing (in its broadest sense) of carers.

1 in 8 adults (around 6.5 million people in the UK) are carers

Every day another 6,000 people take on a caring responsibility – that equals over 2 million people each year.

58% of carers are women and 42% are men.

1.4 million people provide over 50 hours of care per week.

Over 1 million people care for more than one person.

As of 2020, Carers UK estimates there are around 13.6 million people caring through the pandemic.

Carers save the economy £132 billion per year, an average of £19,336 per carer

5 million people in the UK are juggling caring responsibilities with work - that's 1 in 7 of the workforce.

However, the significant demands of caring mean that 600 people give up work every day to care for an older or disabled relative.

The main carer's benefit is £69.70 for a minimum of 35 hours, the lowest benefit of its kind.

People providing high levels of care are twice as likely to be permanently sick or disabled

72% of carers responding to Carers UK's State of Caring 2018 Survey said they had suffered mental ill health as a result of caring.

61% said they had suffered physical ill health as a result of caring.

8 in 10 people caring for loved ones say they have felt lonely or socially isolated.

(REF: Carers UK, 2019, The Public Health England report 'Caring as a social determinant of health' (2021))

Families living with a severe mental illness (SMI) and/or neurodevelopmental disorder (ND) are often under extreme stress, and relationships can become difficult, distant, or conflicted. Familial and informal carers often feel over-stretched, overwhelmed, and ill-equipped to manage their circumstances. Their wellbeing in terms of health (physical and mental), vocational and social outcomes can be significantly affected.

People with autism sometimes describe the way they experience the world as a mass of people, places and events which they struggle to make sense of, and which can cause them considerable anxiety.

Research suggests that caring for an individual with autism can be lifelong and it can be a battle for families to access support. This task alone can act as a barrier to carers seeking support for their own needs choosing to prioritise the needs of the person they care for as a result. Furthermore, autism can have a genetic risk factor and a carer may be supporting multiple family members with the condition or have the condition themselves.

PROJECT SCOPE

Space 2B You were commissioned to carry out a pilot project to offer a remote, flexible and creative psychological service to up to 10 families in Wirral. They used systemic therapy and incorporated aspects of other approaches such as Cognitive Behavioural Therapy, Behavioural Family Therapy and Compassion-Focused Therapy, according to the needs and circumstances of each person or family.

This Pilot project was launched in April 2022 to explore whether a flexible and creative psychological service provided to families in Wirral helps to improve wellbeing for carers. Wellbeing here is treated in its broadest sense to include physical, mental, social and vocational wellbeing.

Their aim was to provide carers (with or without other family members) with a safe and flexible space to:

- Understand their specific challenges more fully and explore their options and preferences.
- Clarify what would help them live more effectively with mental health, neurodevelopmental, and associated difficulties (including other support options).
- Develop new and existing skills and abilities.
- Increase knowledge and confidence to know what to do and when to do it, for themselves and with others within and beyond the family.

They also hoped to see evidence of quality-of-life improvements including:

- Improved confidence to assert needs and access other services.
- Improved engagement with school, services, community.
- More positive communication and collaboration within and beyond the family.
- Families going on holiday where this had not been possible before.
- Restarting or commencing employment.
- Pursuing individual goals.
- Increased leisure and 'down time' activities.
- Reducing substance use.
- Reduction in 'emergency' service use.
- Giving back to the community (e.g., setting up support groups, other voluntary work).
- Improvements in various areas for more than one family member (systemic 'halo' effect).

The Pilot involved providing up to 10 carers/families with a flexible and creative psychological service of up to 120 hours of sessions allowing for

cancellations and Did Not Attends (DNAs) to help further accommodate this group.

Space 2B You carried out comprehensive data gathering in relation to outcome measures with the carers throughout the pilot including the use of:

- Patient Health Questionnaire (PHQ-9)
- Generalised Anxiety Disorder (GAD-7)
- Work and Social Adjustment Scale (WSAS)
- SCORE-15 (family function questionnaire).

METHODOLOGY

HEALTHWATCH WIRRAL - AIM

To provide an independent qualitative evaluation of flexible family intervention (FFI) for those living with mental health and/or neurodevelopmental issues to highlight what commissioners need to know in relation to making reasonable adjustments for carers and to help inform future commissioning.

OBJECTIVES

1. To gather feedback and capture the effectiveness of providing more flexible services.
2. To highlight the impact of the intervention on those that are being cared for by interviewing other family members or asking the carer about the impact on the wider family system.
3. To assess whether the flexible technique used by the therapist at Space 2B You made it easier/more likely for carers to attend the sessions.
4. To explore any impactful, unintended outcomes that add social value to the intervention and wider project.

QUESTIONNAIRE

Healthwatch Wirral designed a questionnaire based on feedback from key stakeholders to ensure that the evaluation:

1. Highlighted the impact on those that are being cared for by interviewing other family members or asking the carer.
2. Assessed whether the flexible technique used by the therapist at Space 2B You made it easier/more likely for carers to attend the sessions.
3. Explored those impactful, unintended outcomes that add social value to the intervention and wider project.
4. Left room for free speech and qualitative free-flow.

The questionnaire design should highlight what commissioners need to know in relation to making reasonable adjustments for carers and what they potentially need to commission in the future.

PARTICIPANTS

We spoke to eight families who had accessed the service (two participant did not respond). Interviews were conducted either over the phone or using Microsoft Teams, they were also given the option to complete a paper-based

version; participants were offered a choice and interviews were arranged at a time that suited them.

Healthwatch Wirral did not receive specific information about participants' families (e.g. who they were caring for) and participants were free to disclose as much information as they felt comfortable with. A majority of the participants were parents caring for school-aged children; some parents attended Space 2B You sessions alone and others attended with their partner. Other participants were caring for adult family members, including caring for a partner or sibling.

FINDINGS & DISCUSSION

Highlights and key themes

Throughout the interviews that we carried out, a number of key themes emerged about the benefits of taking part in the Space 2B You project, including specific advantages that participants felt distinguished this support from other services and outcomes that they identified. Most of the feedback from Wirral participants was extremely positive; the only neutral or negative feedback received focused on occasional technical difficulties or a preference for face-to-face support, and feedback that the whole family could not engage with sessions, which the participant would have found helpful. This feedback has been incorporated into our recommendations.

Skills, experience and knowledge of therapist

All feedback from Wirral participants was extremely positive about the therapist/s. Participants spoke about their skills in conducting sessions online, including making sure that all participants got a chance to speak, where more than one person was attending the sessions; they also highlighted their professional experience and in-depth knowledge of autism, neurodivergence and caring responsibilities as an important aspect of the sessions. Participants felt understood and well-supported.

“The sessions ran well [with me and my husband] – the therapist was good at making sure we both got to speak”.

“I’ve had help from various courses but it hasn’t been as tailored as this with people who really understand the situation as well as their professional experience”.

Tailored service for carers, including organisation and flexibility of sessions – positive response to online/phone service

Although a few participants felt they would have benefited from a face-to-face service, most participants were very happy with the support offered online and felt that it was a significant advantage of the Space 2B You project. Participants cited the lack of travel time, the flexibility of rearranging sessions to suit both parties, and the ability to participate within the home environment as reasons for preferring online (or phone) sessions. Some participants also spoke about the administrative support for the sessions as a helpful factor, including receiving appointment reminders as well as the initial invitation.

“Minimum half an hour travel each way can be very hard to find, but if I can just go into another room for an hour at a time to suit me, has been brilliant”.

“Easier because she fitted around my schedule – she made it so it suited me, didn’t have to leave the house or get a babysitter”.

“Very tailored to the needs that we have as a family”.

Accessible expert information about autism

All participants reported that they had gained a greater understanding of autism from their sessions, including those who had already carried out independent research. Some participants felt that whilst they had a good understanding of autism, the sessions helped their partner to understand their autistic family members better. Many participants spoke about the shift in perspective that they felt as a result of attending the sessions and a new ability to reframe situations.

“The lady we had.... knew what she was talking about. We weren’t sure where to go with my daughter... but the lady gave us another insight from my daughter’s perspective”.

“She helped with my husband – seeing that the children are distressed rather than being naughty, which then changes our behaviour”.

“Talking through everything, breaking down everything, understanding the mind of my child in more detail and how their brain actually works – you can read all this information in books but when somebody tells you directly it sinks in more”.

Improvements in mental health of carer/s

Many participants spoke about their own mental health and the improvements they had felt as a result of the sessions, including those who had previously sought mental health support. They also identified that the improvements in their mental health had also had a positive impact on the rest of the family and helped them to feel more confident in their caring role.

“I felt better after each session I attended, understanding more and more, like a story building about me – every session was facing fears/problems I’d had”

“Being able to prioritise everything that needs doing, account for my energy, look after myself as a priority so I can better help my family”

“Phenomenal difference – incredibly helped my mental health – I’ve previously had support with my mental health but because it wasn’t as

tailored to our specific, very precise needs because of the conditions in the family, the people giving support previously haven't had as in-depth a knowledge despite being good".

"For me, it's lowered my anxiety, because I was anxious about doing the right thing and trying to be very responsible about everything – it's given me some confidence and I'm second-guessing myself less".

Improved communication and relationships

Most participants felt that their relationships and communication had improved with their family members, both with the people they care for and with other family members such as their partners. Where participants had attended sessions with their partner (e.g., two parents caring for their children), they highlighted the positive impact of the sessions on their relationship as a couple.

"Me and my husband communicate better – before, we were clashing every day and since the last session she helped us to realise it wasn't us, that we were fighting, it was the situation and we were taking it out on each other"

"Previously my husband would get irritated by the way our children act but they're not acting that way because they're naughty, it's because of their conditions – they may communicate in different ways, even if it's causing chaos!"

Skills and strategies for coping with difficult situations

Participants felt better equipped to handle difficult situations and family dynamics as a result of attending Space 2B You sessions. Some participants mentioned that they were not yet able to put all the strategies into place due to life circumstances, but still felt that they had better 'toolkits' as carers. Others also spoke of the hope that the therapist had given them - that they might have different options to try, if their current situation changed (e.g., mainstream school placements not working out).

"Not yet able to put everything into practice practically but has definitely helped my mindset... the specifics of how we organise everybody - the situation has been very fluid with helping people to get back into school/education"

"I needed the help realistically – needed tools, strategies, somebody to answer my questions"

"The lady was really helpful and knowledgeable, and supportive – pointed us in certain directions".

FINDINGS FROM THE QUESTIONNAIRE

1) On a scale of 1-10, with 10 being the highest and 1 being the lowest, how helpful did you find the sessions with Space2BU?

5 out of 8 participants rated the service a **10**, with the other participants giving a rating of **8**.

Participants were then asked why they had given that number. Only one participant gave a reason that his rating wasn't higher (he gave a rating of 8): he felt the sessions were very helpful for him and his wife but that their children were not able to engage much with the sessions.

Participants gave a number of different reasons for rating the sessions highly. **Some spoke about the results or outcome of the sessions – one participant described the improvement in her own anxiety:**

"I reached a point where I felt like the anxiety lifted away and I felt not stressed out, not worrying about things I couldn't control".

Multiple participants highlighted the skills of their therapist as a reason for their high rating. **All the Wirral participants gave positive feedback about their therapist:**

"Even though I had up and downs during the therapy, I always looked forward to talking to her".

"The therapist gave the best advice, broke down the problems I was having, explained it all to me and gave me the best solutions".

"The therapist that we had was so knowledgeable about things we'd never even thought about".

One participant spoke specifically about her experience attending online therapy with her partner and how the therapist managed this:

"The sessions ran well [with me and my husband] – the therapist was good at making sure we both got to speak".

The organisation of the sessions was another reason given for a high rating:

"I liked the way the admin worked, they sent out invitations and then reminders which was excellent".

Reminders may be especially useful for carers who are juggling multiple appointments for the people they care for.

A consistent theme throughout our interviews was the **value of tailored support for carers from a therapist who understands not only mental health but autism and other forms of neurodivergence:**

"I've had help from various courses but it hasn't been as tailored as this with people who really understand the situation as well as their professional experience".

2) What did you hope to gain from taking part in the Intervention?

There were three most common answers to this question. Multiple participants didn't have a particular hope or expectation from the sessions as they were not sure what to expect, either because they hadn't attended therapy before or because they knew some members of the family wouldn't be able to engage with the sessions. One participant who didn't know what to expect from the sessions reported that he and his wife "got more out of it than expected, as parents".

Another frequent answer was that participants hoped to **gain a better understanding of autism in particular the perspective of the person/people being cared for:**

"The lady we had, had personal experience of autism and she knew what she was talking about. We weren't sure where to go with my daughter... but the lady gave us another insight from my daughter's perspective".

This couple found it especially helpful to know they were speaking to a therapist who understood autism from personal experience as well as via professional training – this seemed to give them confidence that she understood where their daughter might be coming from.

A common theme from parents caring for a child with autism and other children was a **difference in understanding or opinion between parents,** which the sessions were able to help with:

"She helped with my husband – seeing that the children are distressed rather than being naughty, which then changes our behaviour".

More than one participant felt that they had a better understanding of autism than their partner or were more able to see their child's perspective before the sessions, and that their therapist was able to help get both parents on the same page.

The final most common theme for this question was a **hope for support and to talk to someone who would understand.** One participant spoke about having been offered less specialist support in the past:

“To talk to someone who would understand the situation our family is in and be able to reflect back a professional view on things as well as signposting where necessary – not just a website!”

A participant who attended sessions alone **found it very helpful to have someone to speak to about her experience:**

“For somebody to tell me that I wasn’t crazy and the questions I was asking were relevant and valuable”.

Speaking to someone outside the situation may be particularly valuable for single parents or those who are caring for a partner or other adult family member, to be able to get another perspective. However, participants who attended sessions as a couple also spoke about their hopes:

“Support to help us through a really difficult situation as parents, and as husband and wife”.

This is a recurring theme throughout our interviews – **many participants found that their relationship with their partner improved, as well as their relationship with the person/people they care for.**

2a) Did you gain what you’d hoped for?

All participants answered ‘**yes**’ apart from those who weren’t sure what to expect (and so could not answer yes or no.)

2b) Can you tell me more about why you’ve said Yes or No?

In answering this question, many participants spoke about **gaining more than they had hoped or expected:** one said, *“it’s helped with all areas of my life”.*

Many participants discussed the understanding of autism that they had gained as a result of the sessions, and the benefit of being able to discuss neurodiversity with an experienced professional rather than trying to educate themselves:

“Talking through everything, breaking down everything, understanding the mind of my child in more detail and how their brain actually works – you can read all this information in books but when somebody tells you directly it sinks in more”.

This participant has also highlighted the **advantage of learning about autism through personalised therapy:** she was able to talk about her child specifically and learn more about her unique behaviours and personality, rather than trying to learn about autism more generally and apply it to personal situations.

Multiple participants spoke about the way their sessions had **helped the whole family**:

“Perfectly able to address what we needed addressing where it wasn’t possible for CAMHS to do that directly with the family member. What’s been the ideal is that it’s been able for those issues to be addressed through me”.

This participant felt that the sessions were able to help address issues within the household even though the family member affected wasn’t able to engage with the sessions directly. Another participant felt that the sessions had been **helpful for one of his children who does not have an autism diagnosis** (but has siblings who do):

“It helped my son that wasn’t diagnosed [as autistic] a bit more – he sometimes feels left out by the family”.

It is very positive that the Space 2B You sessions **can help not only carers but children and siblings in a family situation** where there may be many competing needs and diagnoses.

Again, many participants praised their therapist in answering this question:

“She’s extensively educated, professional and yet down-to-earth, easy to talk to”.

“She was very experienced – extremely professional, she understood exactly what I was talking about when I was giving her examples and I found that extremely beneficial”.

Q3) What difference did taking part make to you and those around you?

The main themes highlighted in answers to this question were **improvements in personal mental health for the carer/s and improvements in home and family life more generally**. Many participants discussed their own experiences of mental health and found the sessions extremely beneficial in **addressing often long-standing difficulties**:

“She was able to help me release anxiety and past behaviours – getting off the rollercoaster, breaking the cycle”.

“Reduced stress, taking time for myself: I went from anxious and oversensitive to - take a step back, listen to what the therapist said and put that into practice”.

“Phenomenal difference – incredibly helped my mental health – I’ve previously had support with my mental health but because it wasn’t as tailored to our specific, very precise needs because of the conditions in

the family, the people giving support previously haven't had as in-depth a knowledge despite being good".

The final comment above speaks to the importance for carers of having a therapist or therapist who understands the challenges of being a carer, as well as understanding autism and neurodivergence, even when they are seeking support for their own mental health.

Participants also spoke about the improvements for their family and home life after taking part in the sessions. For some, this took the form of solutions and strategies for coping with difficult situations; others felt that their communication with other family members had improved significantly:

"Me and my husband communicate better – before, we were clashing every day and since the last session she helped us to realise it wasn't us, that we were fighting, it was the situation and we were taking it out on each other".

Many participants felt that the therapist had helped them to better understand their autistic family members, and to have a clearer picture or different perspective on their home situation:

"For me – a better understanding of some of the nuances in Asperger's ... Helped me to better understand my [family member] and how he reacts to certain situations".

"As parents we were always wondering if what she was going through genuine (she's on the pathway but not diagnosed) – we were concerned she just didn't want to go to school and we were being pushovers, but the lady we had helped us to look at it in a different way".

Multiple participants mentioned that before the sessions, they might have felt frustrated by their family members' reactions to situations, or (as with the parents above) worried that they were not reacting appropriately as carers or parents. For these participants, one of the differences that the sessions made was **giving them more confidence in how they respond to situations, as well as the tools to help defuse conflict and approach difficult situations differently.**

Q4) Did any aspects of your life, or the lives of those around you, improve because of the sessions?

All but one person answered "yes" to this question. The participant who answered "no" said that the sessions helped more with a shift in perspective than with practical or outward changes: *"The situation didn't change, just my perspective".*

The improvements seen by participants were similar to their answers to question 3: improved mental health, improved relationships, more confidence in their caring role and the ability to reframe situations.

Participants who are parents caring for their children were especially positive about the **impact of the sessions on their relationships:**

“Me and my wife came away from it feeling a lot better – setting aside time as a couple to talk about things”.

“Previously my husband would get irritated by the way our children act but they’re not acting that way because they’re naughty, it’s because of their conditions – they may communicate in different ways, even if it’s causing chaos!”

Improvements in carers’ mental health is another key outcome from the sessions:

“I’ve received the support I’ve needed and it’s helped me with my mental health”.

One participant even sought an adult autism diagnosis for himself after attending sessions as a carer:

“I’ve always thought I was autistic myself but never been diagnosed – she helped me to go to my doctor and ask for a referral to see if I am autistic, she gave me the confidence to do that”.

It is clear that the Space 2B You support helped participants to understand themselves and their own needs.

- More confidence in caring role
 - *“Life would have been a lot more difficult without the support – a lot of plates need spinning, so I’ve been able to keep myself going and keep the family going”.*
- Reframing situations
 - *“I have a much better understanding of people with Asperger’s. It helped me to step back and have a think “oh, okay” – not somebody being obstinate or difficult, it’s one of the traits [of Asperger’s]”.*

Q5) Have you noticed any changes that you or family members have made since attending the sessions?

Or

Have you noticed you or your family members doing things differently since attending the service?

Yes

No

All but one of the participants answered that there had been changes made or they were doing things differently. Several reported the positive impact talking had on their relationships with their partners.

“My husband is finding it easier to talk to me, I’m finding it easier to talk to him – I’ve learned more about him and I’m able to help him open up more. There is still a lot for me to learn, but it’s been a great starting point”.

The participant who answered ‘no’ reported that they were thinking differently, but perhaps not acting differently.

One participant noted a significant outcome, that their child had been able to go back into school/education.

Another mentioned the impact on lowering anxiety levels.

The other changes noted by participants related to better coping mechanisms.

“I have taken a step back; I can analyse the situation and respond more rationally using the tools and mechanisms that I have been given”.

Q6) How did you find having online therapy?

All participants found online therapy beneficial, and one participant found that online therapy met their needs better than face-to-face therapy. They stated that,

“We find it easier than face-to-face – more down to me than my wife, suspecting to be a bit autistic- not very good with public places, going into an office would have felt daunting”.

Another saw no difference between online and face-to-face interventions.

“With Covid everyone is so used to doing things online and over teams! It didn’t make much difference. The therapist made me feel comfortable. It didn’t matter that we were over camera”.

Whilst one participant took a period of adjustment to online therapy but clearly saw the benefits and adapted well, stating,

“Often it can be better to see someone in person but online has made things possible and flexible on times”. “Different through a screen, but I’ve got used to it – it’s been brilliant”.

Another participant stated that online therapy was fine for them, however their personal circumstances within the home environment made privacy for

the sessions difficult. Thus they were happy with the service as it was, however they felt that a face-2 -face intervention may have been more private.

"I felt a little bit uncomfortable at times. It would have been nice to be able to go somewhere and have a normal appointment, but it worked for the most part".

6B) Were there any advantages or disadvantages for you to accessing this therapy online?

Advantages	Disadvantages
More convenient, allowed for flexibility on times and there was no requirement to source childcare	Setting up technology correctly can sometimes prove a challenge
Reduced waiting times for an appointment as requirement to source a room in a public building was removed	Would have been nice to leave the home and access the community after Covid
Being in the home environment allows for open and honest conversations that are private and safe	Lack of private space in the home environment can make therapy sessions difficult
No travel time required	There can be technology hitches to overcome
Online technology still enables face-to-face conversation that telephone conversations do not allow for	

Two participants saw no disadvantages to online therapy.

Whilst technology glitches did act as a barrier for some, one participant also spoke of being able to adapt to this.

"Occasional technical hitches, but I've got used to it, we can always go to the phone".

There is evidence of slightly contrasting views amongst participants' responses to the appropriateness of the home environment for therapy, and some saw this as positive, whilst just one participant did not find the privacy required. Furthermore, it was evident from the data that multiple participants would have liked the ability to choose their preferred therapy option.

Q7) What made you attend the number of sessions that you did?

Each participant provided a response that was unique to their individual circumstances. One theme was apparent, **many participants valued and prioritised sessions because they recognised the benefits of the therapy.**

"We didn't miss sessions – we prioritised the sessions".

"We knew that the sessions would help".

"Sometimes my husband had been away with a long journey back and he would still make sure to get there".

"I felt better each I attended, understanding more and more like a story building about me....I would have carried on. We both knew by the end I was okay – safe place to finish".

"We tried to attend all sessions – there were a couple, we couldn't because of my circumstances after the first session we were eager to carry on".

One participant valued the flexibility of the sessions making it possible for them to continue with the intervention.

"Would always prioritise attendance – Being able to move them helped me attend".

Whilst another participant valued the **structure of a regular time making it easier for them to attend.**

Space 2B You clearly understood the needs of those taking the intervention and adapted therapy sessions accordingly.

Q8) In the future would you prefer to have face-2-face sessions or online What have you seen the sessions? (Please circle one)

Face-to-Face

Online

6 out of 8 participants answered that they would prefer online sessions.

"Would be lovely to do face-to-face but online means I can fit it in.. makes it happen! Would be nice for people to have the option as to what they preferred but online at the moment makes sense – if someone is ill in the family. I don't worry and it's really practical".

One participant would not mind either way but made a preference to keep the same therapist stating:

"It's more about the person and what the therapist offers. If I needed the help location wouldn't make a difference".

Whilst another participant clearly expressed a preference for face-to-face sessions.

If you chose face-2-face where would you prefer to meet? (Choose up to three)

- **at home**
- **in your GP surgery**
- **in your local hospital**
 - **Arrowe Park**
 - **St Catherine's**
 - **Clatterbridge**
 - **in a Centre in a centralised area across Wirral such as Birkenhead other – please state.**

Only two participants responded to this question both felt it important to attend sessions in their immediate area or where they felt familiar.

One participant had a preference to attend at their local GP/Community Hub.

"Wouldn't be that obvious, little space, easy to get to, no worries about parking, I feel comfortable there (Already familiar with it)".

Whilst the other participant specified home or GP surgery stating:

"As close as possible to home would make the most sense, but would need to be somewhere private somewhere I felt confident it wouldn't be overhead".

At the end of the survey, the participants could add anything they felt necessary that had not been covered by the previous questions, participants were overwhelmingly positive about the intervention.

Many participants took the opportunity to further thank the therapists for their help and support. It was clear from the responses that participants were eager to express the value of the intervention and convey the need for the service to continue to help others in the future.

"Couldn't fault it and couldn't rate it highly enough. Would be great to hear that it's been successful and that they can continue to offer the service because it is very much needed".

One participant particularly expressed that the therapy needs to be introduced as a preventative intervention.

"I was going to write a letter just to say how brilliant it's been, and how valuable – for people in our position it should be there for everybody. By the time you get to the point of where we were accessing CAMHS, you have probably gone beyond where you need this sort of support – this should be available to anybody with family members on the neurodevelopmental pathway – it would be preventative and promote well-being".

There was evidence that the family intervention had supported some participants with achieving wider social outcomes beyond the family Unit.

"Really supportive with transition – school placements – support during that period".

"Gone beyond just the family member that was accessing CAMHS– has enabled me to access an assessment to give me confidence which had been very interesting".

RECOMMENDATIONS

EVALUATION

Healthwatch Wirral are well-versed and suited to obtaining people's views about their experiences of local health and social care services and sharing these views with those involved in the commissioning and scrutiny of care services.

Whilst carrying out the evaluation we were also able to promote and support the people in signposting and providing information to the participants about options and activities available to them locally.

Were Healthwatch Wirral to carry out further independent evaluations of the Space 2B You flexible family intervention, it would perhaps be useful to add one or two questions to explore:

- Whether participants had noted any changes in their quality of life appertaining to the broader social outcomes hoped to be evidenced by Space 2B You in the initial project scope—for instance, achievement of employment etc.
- Who/how many people attended the sessions (e.g., parents and children, both parents/a couple, just the interview participant)
- How many people the interview participant/s care for
- Further details relating to who the participants care for (if they are happy to disclose this information)

This may help to evaluate the benefits of the Space 2B You service for different family set-ups and to explore the impact on outcomes for participants who attended sessions individually or with family members.

Healthwatch Wirral could also obtain information from Space 2B You about how many sessions each participant was offered, how many they attended and the date of their last session in advance of our evaluation interviews, as many participants could not remember the exact answers themselves.

SPACE 2B YOU

Wirral participants gave overwhelmingly positive feedback about the service they had received from Space 2B You. Possible improvements based on the feedback obtained from interviews includes:

- Exploring the expectations of participants in the first session, clarifying who the sessions are for and who they would like to attend. Most participants seemed to have a clear expectation that the sessions were primarily for carers to attend, but one participant had hoped that his children would

be more able to engage with the sessions directly.

- Offering the option of face-to-face sessions if possible, or alternatively help participants to find a private space local to them that could be used to attend online sessions, if this may become an issue for them. Most participants were very happy with attending from their home, but one mentioned that it could be hard to find a quiet, private space. This could be achieved by working with local health care services or third sector groups who might be able to provide space free-of-charge.

Many participants said that they would be very happy to be offered a similar service in the future or that they would benefit from ongoing/long-term support, although they were all satisfied with the number of sessions they were offered and able to attend. The way the intervention was designed also added social value as families had the opportunity to access therapies in a way that suited them from their own homes meaning they had no need to travel or to use transport.

DEMONSTRATING SOCIAL VALUE

Social Value is about the wellbeing of current and future generations and covers three different areas:

- **Social** – the wellbeing of individuals and communities by making services on Wirral accessible for all, especially those who are vulnerable and that can bring about lasting, positive changes. Wirral is a 'Marmot Community' with a committee for the *Core20Plus5 priorities (*see below).
- **Economic** – putting in place economic policies and business practices to improve the wellbeing of society. Ensuring effective utilisation of the Wirral £ by joining services together and avoiding duplication.
- **Environmental** – looking after the social and physical environment and where possible developing more sustainable processes.

By carrying out this Pilot project benefits were demonstrated that had at follow up, had a lasting impact on the families that took part. Providing families with the skills and knowledge to improve their lives highlighted how sustainable improvements can be made that will have long-term effects that will in turn potentially reduce wider costs. During this process we spoke with eight families. We listened to their lived experience and asked them to answer a series of questions about how the service had made a difference to their lives and what could be improved now and in the future.

When carrying out the independent evaluation participants were again given a range of choices to be able to participate. The initiative clearly fitted

with the prevention agenda. Improving population health and preventing illness and disease is key to reducing health inequalities and is at the heart of the [NHS Long Term Plan](#).

*Core20PLUS5 is a national NHS England approach to inform action to reduce healthcare inequalities at both national and system level. The approach defines a target population – the 'Core20PLUS' – and identifies '5' focus clinical areas requiring accelerated improvement. Healthwatch Wirral includes this framework in the work that we do.

Through taking part, families also benefited by being made aware of their local Healthwatch and how they can provide information and advice connecting people to local community assets, services and networks.

Healthwatch Wirral felt that this Pilot demonstrated Social Value and built upon:

- Future service provision avoiding duplication.
- Support for vulnerable people.
- Better use of estates and infrastructure.
- Links between commissioned clinical and non-clinical services so that the Wirral pound reveals more value.

CONCLUSION

Results from this independent evaluation highlight overwhelmingly that providing tailor-made support to families and carers of those living with mental health and/or neurodevelopmental issues via Space 2B You's Flexible Family Intervention (FFI) was extremely effective in improving both general wellbeing for carers as well as improvements to their quality of life particularly within the family unit. However, it is important to recognise the data at the current time does not allow for any conclusions to be drawn with regards to the impact the intervention may have had on the family's wider community engagement and social outcomes. That is not to say that there won't be any impact in the future.

Outcomes included:

1. Improvements in the mental health of carers.
2. Improved communication and relationships.
3. Accessible expert information about autism.
4. Better understanding by carer's of their own needs.
5. High level of satisfaction from carers in relation to the skills, experience and knowledge of therapist/s.
6. Improved integration for a child as they were able to reintegrate into a school/education setting.
7. Participants were able to engage more fully because of this tailored service, including organisation, administration and flexibility in the delivery of sessions.
8. The skills and strategies of carers increased for coping with difficult situations.
9. Understanding increased in relation to autism because of accessible, expert information being provided.

"This should be available to anybody with family members on the neurodevelopmental pathway – it would be preventative and promote wellbeing. I can't speak highly enough about it".

"I'd like to say that I hope they get more funding because it is of massive benefit to people knowing that there's somebody out there who can offer this service – it's amazing".

APPENDICES

Flexible Family Intervention for those Living with Mental Health & Neurodevelopmental Issues - Healthwatch Wirral Qualitative Evaluation (Copy of Questions)

Healthwatch Wirral have been asked to evaluate the sessions that carers took part in with Space2BU. These sessions were designed to improve the wellbeing of carers of people with ASD.

The aim of this research is to find out whether a flexible and creative psychological service helps to improve carers wellbeing and the impact it has had on their families.

Carers are to be asked a series of questions via Teams to help us explore their experiences of these sessions.

Name:

Date:

Number of sessions offered:

Number of sessions attended:

Date of last session:

Question 1

On a scale of 1-10, with 10 being the highest and 1 being the lowest, how helpful did you find the sessions with Space2BU?

1 2 3 4 5 6 7 8 9 10

1A) Can you tell me why you gave that number please?

Question 2

What did you hope to gain from taking part in the intervention?

2A) Did you gain what you'd hoped for? (Please choose one)

Yes No

2B) Can you tell me more about why you've said Yes or No?

Question 3

What difference did taking part make to you and those around you?

Question 4

Did any aspects of your life, or the lives of those around you, improve because of the sessions?

Yes No

Can you tell me more about why you've said Yes or No?

Question 5

Have you noticed any changes that you or family members have made since attending the sessions?

Or

Have you noticed you or your family members doing things differently since attending the service?

Yes No

(Encourage them to speak a little more about this)

Question 6

How did you find having online therapy?

6B) Were there any advantages or disadvantages for you to accessing this therapy online?

Question 7

What made you attend the number of sessions that you did?

Question 8

In the future would you prefer to have face-2-face sessions or online sessions? (Please circle one)

Face-to-Face

Online

If you chose face-2-face where would you prefer to meet? (Choose up to three)

- at home
- in your GP surgery
- in your local hospital
- Arrowe Park
- St Catherine's
- Clatterbridge
- in a centre in a centralised area across Wirral such as Birkenhead other – please state:

That's the end of the survey.

Is there anything else that you would like to add/say?

Thank you so much for taking the time to answer these questions about the sessions that you took part in. Results will be shared with you via email if requested.

FLEXIBLE FAMILY INTERVENTION (FFI) FOR THOSE LIVING WITH MENTAL HEALTH AND/OR NEURODEVELOPMENTAL ISSUES - 'Proof of Concept' Pilot

Problem





Families living with a severe mental illness (SMI) and/or neurodevelopmental disorder (ND) are often under extreme stress, and relationships can become difficult, distant, or conflicted. Familial and informal carers often feel over-stretched, overwhelmed, and ill-equipped to manage their circumstances. Their wellbeing in terms of health (physical and mental), vocational and social outcomes can be significantly impacted. Whilst unpaid carers create significant cost-savings to local and national care budgets, their own needs can become a drain on health and social care services too.

Care and treatment are often focused on the individual, leaving families and carers lacking information, support, or therapeutic input. Additionally, individual family circumstances can vary greatly and those opportunities for support that do exist can be limited in terms of access, scope, and depth. The recent government document, "People at the Heart of Care: Adult Social Care Reform White Paper" (December 2021), highlights the issues faced by these families and, in line with the Care Act 2014, outlines key aims. For carers these include being supported to provide care in a way that accommodates their own need for a life outside caring where their education, employment, health and social needs and aspirations are respected and fulfilled. The paper also identifies that those being cared for should, amongst other things, be able to live as part of a community where they are connected to friends and family, where they are supported to achieve their goals and feel valued for their contributions to society.

Proposal

Introduction

To provide a flexible and creative psychological service to a minimum of 10 referrals. Working remotely, utilizing industry-standard and secure technology to provide psychological clinician-led services which are GDPR compliant. Our aim is to provide carers (with/without other family members) a safe and flexible space to:

-  Understand their specific challenges more fully and explore their options and preferences
-  Clarify what would help them live more effectively with mental health, neurodevelopmental and associated difficulties (including other support options)
-  Develop new and existing skills and abilities
-  Increase knowledge and confidence to know what to do and when to do it, for themselves and with others within and beyond the family.

Our family intervention service is based on systemic therapy and incorporates aspects of other approaches such as CBT, BFT and compassion-focused according to the needs and circumstances of each person or family we work with. Our therapists are trained, qualified, and experienced to deliver these. Current outcome measures include Patient Health Questionnaire (PHQ-9), Generalised Anxiety Disorder (GAD-7), Work and Social Adjustment Scale (WSAS), and SCORE-15 (family function questionnaire).

What we will offer

- 🌈 Up to 12 completed FFI sessions per referral (completed session pool = 120 hours)
- 🌈 Late cancellation/DNA allowance due to unpredictable nature of referrals' lives (up to 20 sessions)
- 🌈 Full discharge summary letter to referral and referrer (including Goal Based Outcomes and ROMs)
- 🌈 Functional assessment as indicated by referral presentation
- 🌈 Liaison with assigned practitioner or MDT as appropriate to individual referral
- 🌈 Up to six 1.5-hour workshops "Coping with Caring" (initially supports referral uptake and then supports individual therapy)
- 🌈 Minimum quarterly project liaison, including interim report summary
- 🌈 Final pilot report
- 🌈 Full administrative support for referral
 - Induction
 - ROMs (baseline, mid-term, completion) collection, collation, and analysis
 - Workshop attendance and evaluation.








Anticipated outcomes

The current service sees improvement in one or more of the measures identified above in the carers/families who complete their intervention. These are alongside quality-of-life improvements such as:

- 🌈 Improved confidence to assert needs and access other services
- 🌈 Improved engagement with school, services, community
- 🌈 More positive communication and collaboration within and beyond the family
- 🌈 Families going on holiday where this had not been possible before
- 🌈 Restarting or commencing employment
- 🌈 Pursuing individual goals
- 🌈 Increased leisure and 'down time' activities
- 🌈 Reducing substance use
- 🌈 Reduction in 'emergency' service use
- 🌈 Giving back to the community (e.g., setting up support groups, other voluntary work)

-  Improvements in various areas for more than one family member (systemic 'halo' effect).

Strategically, we anticipate the following:

-  Improved health and wellbeing of carers
-  Supporting clear pathways into and between services
-  Promotion of inclusivity and diversity
-  Training for carers
-  Championing carers' rights through communications
-  Whole family approach
-  Young adult carers.