Co-Production in Research

A toolkit for research with family carers of people with a Learning Disability.

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University of Kent

The SPaCE Project
Support for Parent Carers in England

The Challenging Behaviour Foundation

Contents

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Who are we?

This guidance has been co-produced by family carers and researchers involved in the development, delivery and evaluation of support programmes for families of people with a developmental disability. Many of the topics discussed will be applicable to co-production of any kind of research. However, the content has been particularly shaped by the authors' experience of support programme evaluation research, and so may be especially informative for others who are conducting similar research.

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Executive Summary

7 Golden Rules of co-production

1. Work together as peers. Working together in an equal partnership involves recognising and valuing the many different skills and perspectives that family carers and others bring.

- It is vital that family carers are viewed and treated as equal members of the team
- A key way of demonstrating the values of an organisation or project is to model them (e.g., by having a family carer in a permanent or research position and being open about this)
- Acknowledge and harness the many different skills that members of the team (including family carers) bring
- Be aware of, and respect, the different 'hats' family carers may be wearing
- Be clear about the credit and authorship of outputs
- Recognise that there is potential learning for everyone on the team

2. Make it Meaningful. Meaningful co-production values family carer input from the start to the end (and beyond). It is not just a tick-box exercise.

- Meaningful co-production involves the authentic valuing of the views and opinions of those with lived experience
- It can be particularly meaningful if co-production is utilised at all stages of a research project
- Meaningful work may involve making a positive contribution to the wider community
- There are benefits to researchers and the research project from involving co-production partners
- There may also be personal benefits for family carers
- Meaningful co-production requires adequate time and resources to do it well

Executive Summary

7 Golden Rules continued..

3. Listen and keep an open mind. An open and transparent approach builds positive relationships across the team and ensure meaningful contributions.

- Remain open minded to hearing different views and ways in which the project may develop and change
- Be transparent about what has already been agreed in the research and what can change
- Consider creative and constructive ways to manage disagreements

4. Communicate clearly. Use plain and accessible language. A clear remit and expectations of family carers ensures you get people with relevant experience/characteristics for the project. Be clear about the aim of the research and how this will contribute to improving families' lives.

- Use plain and accessible language. Avoid acronyms and jargon.
- Be clear about the remit and role (e.g., family characteristics, time requirements) for example in a 'Terms of reference' document
- Ensure clear communication throughout the recruitment process
- Make it clear who family carers should contact on the research team with any queries
- Explicitly outline the value of co-production and model supportive ways of working (e.g., actively encourage family carer views, develop ground rules in meetings)
- Navigating disagreements in a constructive way is an important role for research staff

5. Pay appropriately. Ensure that family carers are suitably compensated for their time and expertise.

- Co-production partners need to be paid appropriately and fairly. Ensure you include this in the budget for the project
- Consider all the hours involved, including reading time and communication (e.g., responding to emails)
- Ensure family carers are aware that payments (including vouchers) may affect benefits
- Include replacement care costs
- Try to keep the administrative side simple. Be transparent about what is involved and likely timeframes for payment
- There may be additional costs that emerge throughout the project – ideally include a contingency fund for additional hours.

7 Golden Rules continued..

6. <u>Be sensitive.</u> Consider the wellbeing of family carers who contribute their lived experience throughout the research process. Sharing on sensitive topics can bring up a variety of emotions and it is important everybody feels supported.

- **Be aware that family carers may be under pressure.**
- **Be sensitive to their needs and the variety of emotions that certain topics can evoke.**
- **Maintain a non-judgemental stance and familiarise yourself with the world of special needs and disability (including preferred terminology)**
- **Family carers' situations can suddenly change. Recognise that there may be times when they are less able to contribute**
- **Provide support for those with their own additional needs**

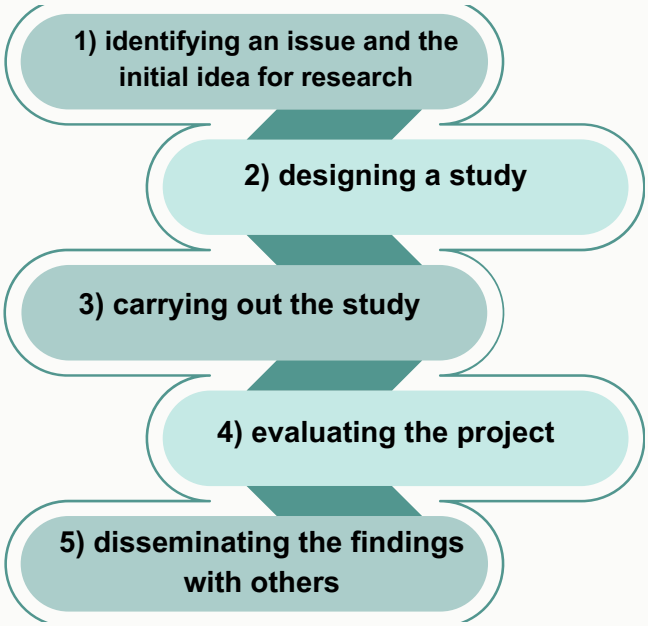
7<u>. Be flexible to support family carers' needs.</u> Think creatively and be prepared to work in different ways to avoid some of the barriers family carers may face.

- **Family carers may be juggling many different things. Discuss their needs with them and offer flexibility**
- **Provide choice around meetings (e.g., evening meetings, attending with cameras off, editing documents by email)**
- **Offer follow up/catch up meetings for those who cannot attend**
- **Explore different ways that people can be involved to ensure a diversity of views and experiences**
- **Work with family carers to consider ways to acknowledge and accommodate some of the challenges that family carers face (e.g. improving digital access, ways to manage if a relative is at home during meetings)**

What is co-production in research?

We define co-production in research as relevant stakeholders (e.g. family carers / commissioners) working as equal partners with researchers, at the earliest stages of a project, to share their lived experience. This ensures research is shaped around real-world experience and can make a positive difference to the lives of people with a learning disability and their families, for example through changes to services and support.

Further details on the research stages



Co-production can be most meaningful when it occurs at all stages of the research process (NIHR, 2021). However, co-production may sometimes be employed in specific stages of a research project. For example, a family support programme intervention might be co-produced with family carers even if the evaluation of the programme is not, or family carers may co-produce resources to share the findings of research they were not initially involved in. If family carers are involved throughout a research project, then it can be said that the project was co-produced. If, however, they were only involved in a particular stage it should only be reported as co-producing that part of the research (e.g., co-producing the design or co-designing the programme).

How does co-production differ from other forms of 'Patient and Public Involvement and Engagement'?

Patient and Public Involvement (PPIE) is a broad term that includes many different ways of engaging with stakeholders in research. For example, PPIE could involve consulting with stakeholders on a specific issue or collaborating with stakeholders in an advisory capacity throughout a project, but with power and decision-making ultimately resting with the researchers. Co-production is different from other forms of PPIE by its emphasis on sharing power between researchers and stakeholders in a mutual and equal partnership.

What is co-production in research?

Why co-produce support programmes?

Co-production can bring specific benefits to the development and evaluation of support programmes. Family carers bring valuable perspectives and expertise in what kind of support would be beneficial, how to ensure its suitability and authenticity, and how to maximise its impact. The authors of this guidance have worked on projects where family carers have also been responsible for delivering programmes, either independently or in partnership with a professional. Evaluations of these programmes have suggested that the lived experience of family carers delivering the programme, and the understanding and empathy this provided, was greatly valued by those taking part (Coulman et al., 2022; Lloyd et al., 2021; Sutherland et al., 2024).

Some quotes illustrating the value of lived experience from participants involved in E-PAtS are detailed below:

"Legitimacy and authenticity, if you haven't lived it, you don't have a clue. Having someone that is in the trenches, you pay more attention to someone who has been through it."

"I found the camaraderie in the sense of, you belonged, you know, your group, and everybody."

"You never get a chance to meet with other parents and the fact that you are actually in a room with other parents for that length of time was good."

Examples of the practical and personal benefits of co-producing support programmes can also be seen in Positive Family Connections. Co-designing and co-delivering the Positive Family Connections programme helped to ensure the programme met the needs and priorities of family carers. In interviews with family carers that took part in the programme, they often emphasised the value of co-production and the way that having the programme delivered by family carers was central to the perceived benefits of the programme for their wellbeing (Sutherland et al., 2024). Enhancing the quality of a support programme would be an example of a practical effect of co-production.

Some quotes from individuals who attended Positive Family Connections groups delivered by trained family carer facilitators are included below:

"It was so much more relatable, so much more relatable and credible, really. And it was refreshing to know that they might be armed with all of this information but some days it just doesn't work you know, it was just nice to have that human touch to it"

"I think it makes a huge difference. Huge difference. Because you believe the people are speaking to you […] I shouldn't compare it to other programmes I've been on but there are times in other programmes when I sit there and I'm like, you don't get it because it's not your life. And they're following like a booklet of information."

"Because they were carers themselves so they got it. They understood the challenges that we face and also they were they were just really approachable. Like you weren't scared to ask a question or speak out."

What is co-production in research?

As well as describing practical benefits of co-production for the programme, family carers involved in co-producing programmes also identified personal benefits such as the fulfilment they gained from supporting other family carers. Some of their reflections are included below:

> ***I think that giving family carer facilitators the freedom to add in our own lived experiences helps develop a feeling of ownership over the programme. For someone creative, like me, it helps bring the programme to life and makes me feel more connected with it and invested in it. I also appreciate that you trust us to bring something valuable of our own to the programme and run with it.***
> **– Positive Family Connections facilitator**

> ***I found working with the CBF on the PETAL programme extremely rewarding. The aim was to develop an intervention designed to support individuals with a learning disability who may display challenging behaviours, their carers, families and service providers to work together to understand the cause(s) of the behaviours and ultimately better meet the needs of the person. From my personal experience I know how profoundly important this can be.***
> **– Family Carer, CBF**

What is co-production in research?

A family carer involved in the Healthy Parent Carers (HPC) and SPaCE project reflects:

Engaging in this project as a parent carer researcher has not only built my confidence but also fostered a sense of personal growth and accomplishment. Knowing that my insights as a parent carer researcher are being heard has empowered me and highlighted the importance of our collective voices. There's a real sense of satisfaction in being able to contribute my experiences as a parent carer researcher and seeing how they positively impact the project.

Being recognised for my worth and input in this co-production project has been immensely gratifying, reaffirming the value of my contributions to improving mental health support for parent carers. Participating in the SPaCE project has empowered me to voice the unique challenges faced by parent carers, ensuring our needs are acknowledged and addressed. The recognition of my input in this project has not only validated my experiences but also fuelled my passion for advocating mental health care improvements for parent carers. Participating in a supportive network of parent carer researchers within the SPaCE project has fostered both professional development and a sense of personal camaraderie.

What is co-production in research?

Reflections from a family carer involved in the SPaCE project:

> **As parent carers, we often inhabit a world where we don't have a lot of control, we don't have a lot of say, we're typically referred to as 'Mum' or 'Dad' regularly by people who aren't our children, and actually you can really feel a sense of a loss of identity. It's not what happens for everyone, but I know that it happens frequently. And so, to actually be involved in something where you're being really listened to intently, it's not tokenistic, and what you say can make real change, can just feel hugely, hugely empowering.**

> **It's just amazing to be able to use that really hard-won experience to actually make change happen. So, to be able to sit in these meetings and see things shift because of what we say, and know it's not tokenistic, it's not tick box, we're respected as equals, is hugely empowering, actually. And interestingly, from a mental health point of view has a really positive impact on my mental wellbeing.**

> **I'm also really conscious to remember when I'm sitting in the meetings, yes I have my own experience, but I'm actually, particularly as a co-investigator, I want to be a voice for the community. Now, obviously I can't speak for everyone, but I know the stories that I've read and the things I've heard and the things that are important to people and so, I try to, where possible, zoom out and remember that this isn't just about my experience or my story. I'm trying to be a voice, as much as possible, for the parent carer community.**

7 Golden Rules for co-production with family carers

We identify 7 Golden Rules which are vital for successful co-production.

1. Work together as peers. Working together in an equal partnership involves recognising and valuing the many different skills and perspectives that family carers and others bring.

2. Make it Meaningful. Meaningful co-production values family carer input from the start to the end (and beyond). It is not just a tick-box exercise.

3. Listen and keep an open mind. An open and transparent approach builds positive relationships across the team and ensure meaningful contributions.

4. Communicate clearly. Use plain and accessible language. A clear remit and expectations of family carers ensures you get people with relevant experience/characteristics for the project. Be clear about the aim of the research and how this will contribute to improving families' lives.

5. Pay appropriately. Ensure that family carers are suitably compensated for their time and expertise.

6. Be sensitive. Consider the wellbeing of family carers who contribute their lived experience throughout the research process. Sharing on sensitive topics can bring up a variety of emotions and it is important everybody feels supported.

7. Be flexible to support family carers' needs. Think creatively and be prepared to work in different ways to avoid some of the barriers family carers may face.

Golden Rule 1: Work together as peers

Working together in an equal partnership involves recognising, and valuing, the many different skills and perspectives that family carers bring.

The authentic valuing of lived experience helps create an equal partnership between researchers and family carers. An equal partnership is enhanced when researchers create a positive environment where they are clear about wanting family carers to be involved and why; when they listen and learn from lived experience (and state this clearly in written and oral communication), and respect family carers as peers. This environment in turn helps co-production to flourish.

The values that an organisation (e.g., a university, charity or public body) embody will also be expressed in their interactions with those around them, including family carers. This includes how family carers and researchers are viewed, and whether family carers are perceived as an equal part of the team or an add-on.

Academia is inherently hierarchical and this may mean, just by the nature of the family carers' role in the project, or even how they are referred to, that they end up feeling like they are bottom of the power hierarchy. However, it is possible to challenge this.

Here is an example of how a family carer was made to feel part of the team and sharing values:

Supporting a family carer to feel part of a team is essential and possible with careful thought and planning. Family carers will often participate in co-production from home which might be a significant distance from the workplace of the researchers. It is important that researchers consider how this might feel for a family carer and what might be needed to enable them to feel connected and part of the team, and not an add on. This will have a time commitment that needs to be factored into any funding applications.

I have been fortunate to work with two academic institutions on co-produced projects. It has been evident from the outset that family carers and families are held in high esteem, that our experiences are valued, trusted, and believed. This is in stark contrast to many experiences in the health, education, and social care systems when families can be made to feel that they are exaggerating, that the needs of the system take priority, or that we simply expect too much.

If I had to describe what it is that makes this experience so palpably different it is the tone and the way I am spoken to. When I describe lived experiences I meet agreement compassion, and validation. When you are heard and believed you feel valued, and this enables you to feel part of the team.

Golden Rule 1: Work together as peers

An organisation's values are vital for ensuring family carers are treated and valued as peers. One key way of demonstrating the values of an organisation or project is to model them (e.g., by having a family carer in a permanent or research position and being open about this). This may involve wider shifts in how organisations support carers – such as enabling flexible working, online working, and supporting carers' leave. Having a family carer in the team, including in a University research department, can bring a wealth of experience and extra perspective on the work.

Furthermore, having co-chairs (one researcher, one family carer) for co-production projects ensures key decisions are made in a way that reflects the equal partnership between researchers and family carers and also sends a clear message about the way lived experience is valued.

It is important for researchers to remember that family carers may not be aware of organisational procedures and structures/departments that influence how a project is carried out. An equal partnership requires researchers to be transparent about these influences as well as being clear about who to expect communication from and their respective roles.

Bringing together different views

At times co-production can involve differences of opinion. Building positive relationships and trust from the start can help ameliorate disagreements where people may feel they are not being listened to or their input is not welcome.

Having a fair and clear pathway of management for resolving disagreement can be valuable for promoting trust and transparency. For example, who makes the final decision? Where there is a joint chair (researcher and family carer), this can help to ensure these are made fairly with all different viewpoints considered. Similarly, being clear about the remit and role of family carers and researchers can help prevent misunderstandings. Reiterating for the whole team that consideration is given to the joint aims of the research project (and ensuring these are co-produced) can help work through differences to find solutions.

Golden Rule 1: Work together as peers

Things to be aware of when working as a group

Researchers and family carers need to be aware of some of the factors that can influence how groups work together.

We all have biases and our views become shaped by our experiences. This may mean that we are not always aware of different perspectives. Similarly, our views can become limited or skewed because of own experience and in turn lead others to think in similar ways. Therefore a group of people start to converge on a particular viewpoint and discount others without fully considering them.

When working together, encouraging different viewpoints means that different perspectives are considered which may go some way to help mitigate confirmation bias (where we only notice things that confirm our view) (Peters, 2022).

When family carers are involved in co-production, they may not always just bring their own experience. They may also bring a snapshot of the experiences of all the other family carers they have had contact with. Inviting these different reflections and seeing a bigger picture can help avoid family carers (and researchers) becoming too caught up in their particular situation or views.

Managing wearing 'many hats' for family carer-professionals.

Researchers and family carers involved on a project may want to consider the different 'hats' (roles/experiences) they are juggling; this could be a useful conversation to have at the beginning of working together.
People are always more than *just* family carers – they are parents, brothers, daughters, with varied values and interests. Many will also have a career, either current or in the past, that can bring a wealth of experience. It is important that they are not labelled as just a family carer. Bringing this experience contributes enormous value to a project.

Sometimes family carers may also want to contribute other relevant skills and experience. Finding out what people's strengths are, and what else they bring to the project, can be a valuable resource. In turn this can develop the family carer who may want to use their experience on a research project on their CV or for career progression. Communication is key and researchers may wish to ask family carers what they want to work on and what their areas of interest are (e.g., writing, IT support). This can help researchers to make best use of family carers' skills, expertise, and interests as well as encouraging family carers' development and agency in a way that reflects an equal partnership.

Family carers often bring particular skills they may have developed through their lived experience, such as project management skills, challenging authority or the status quo, problem solving and the ability to read and dissect documents and policies. Furthermore, family carers tend to have an overview of the whole system and a lifelong approach, whereas often research is focussed only on one element. Family carers will also likely have developed ways of managing stressful situations.
A word of caution: where work and home life overlaps, family carers can be hugely motivated but there is a danger of burnout. As one family carer on this project stated:

'*You can feel that you talk about nothing else apart from learning disability'.*

Family carers may develop different 'rules' (e.g., what they disclose, which email address they use for contact) for themselves in different aspects of their life. In their working life some family carers may share their lived experience as a way of connecting with those they support (for example, supporting other family carers). Others may feel that they would rather not share this information. It is important that family carers have time when they are just being themselves as well.

Golden Rule 1: Work together as peers

Credit and authorship

It is important to credit, acknowledge, and clearly describe the involvement of lived experience partners when writing up the research in order to equally credit their contribution.

It helps to have discussions with family carers early on in the project to clarify the criteria for authorship on dissemination outputs. Generally, if family carers have been involved throughout the project, they should be offered the opportunity to be listed as an author if they wish. Some family carers may choose not to be listed as an author for reasons of confidentiality.

Finding ways to categorise the level of involvement and outlining other options, such as acknowledgements or via other outputs (e.g., lay publications, videos) can be helpful. This may depend on the amount of input, number of times involved, and at what points they have been involved. It may also include what type of input, for example if someone has included a personal vignette then this should be acknowledged (if the family carer wishes, whilst also considering confidentiality and data protection). However, if there are a significant number of family carers involved it can be hard to list everyone and sometimes group acknowledgements may be more suitable.

Peer-reviewed journal authorship may be particularly important for researchers due to the demands of their careers, academic departments and funders. There can be difficulties with peer-reviewed journals for family carers. The sign-up process may require a family carer to include their personal email and involve an administrative burden which may be invasive to their family life. For some individuals, finding other ways to value the input from family carers, such as through dissemination materials or lay articles may be more welcome.

Being clear from the start in the roles/responsibilities/input/time capacity is key. Furthermore, it is important to ask family carers what they want and need and ensure that communication is open throughout the process.

For any research project, it is good practice to write a document early in the process describing who will be involved as authors in the outputs from a project and how that will be decided. Because family carers are a core part of the research team in any co-produced project, they should also be involved in the process of developing and agreeing this document.

Supporting family carers' development

Family carers in the Working Group reported welcoming feedback and supervision for their co-production role in research. This could take different forms, depending on the nature and length of the project.

- A feedback meeting after any co production work could be helpful as an opportunity for family carers and researchers to discuss the project and how it went, and it might be reassuring for families to get and give feedback about the project. As many meetings are conducted online, and it can be difficult to "read the room" so this can provide an opportunity for families to chat through the experience and allay any concerns if there have been any.

- Certificate or concrete acknowledgement of the input of family carers

- Formal Continuing Professional Development (CPD) recognition

- Training for family carers, ensuring that family carers are well compensated for the time they invest.

Golden Rule 1: Work together as peers

Key takeaways

- **It is vital that family carers are viewed and treated as equal members of the team**
- **A key way of demonstrating the values of an organisation or project is to model them (e.g., by having a family carer in a permanent or research position and being open about this)**
- **Acknowledge and harness the many different skills that members of the team (including family carers) bring**
- **Be aware of, and respect, the different 'hats' family carers may be wearing**
- **Be clear about the credit and authorship of outputs**
- **Recognise that there is potential learning for everyone on the team**

Golden Rule 2: Make it Meaningful

Meaningful co-production values family carer input from the start to the end (and beyond). It is not just a tick-box exercise.

Good quality and meaningful research involves different input and considerations. Whilst researchers bring many important and valuable skills, involving lived experience experts brings another perspective which is rooted in day-to-day, real-world experiences. Input from family carers during the conception of a research project helps to ensure research is practical, worthwhile, and addressing stakeholders' priorities. Family carers can help increase researchers' understanding of family carers' experiences and influence future research. Furthermore, family carers can provide real-life examples that may have relevance to the research and help shape the project.

Meaningful 'work' is generally considered to include that which makes a positive contribution to something greater than ourselves which also aligns with our own sense of purpose. Meaningful input from all those involved not only benefits the research itself but can also benefit those involved in the research.

The proposed benefits of co-production are sometimes split into two categories:

- **Practical benefits: These include improving the quality or impact of research. This could be through identifying important research questions, improving the methodological quality of the research, and analysing, interpreting and communicating findings in a way that is impactful for family carers, services, and individuals using services.**

- **Personal benefits: This refers to inherently positive outcomes from the co-production process such as beneficial effects for those involved in co-production. There is also an argument that there is ethical or democratic value in engaging in co-production, besides any practical positive effects it provides. Family carers involved in producing this guidance thought that doing research with rather than to them was crucial.**

A family carer involved in Healthy Parent Carers (HPC):

"Engaging in this project as a parent carer researcher has not only built my confidence but also fostered a sense of personal growth and accomplishment."

"Knowing that my insights as a parent carer researcher are being heard has empowered me and highlighted the importance of our collective voices."

A family carer involved in Healthy Parent Carers (HPC):

"Being recognised for my worth and input in this co-production project has been immensely gratifying, reaffirming the value of my contributions to improving mental health support for parent carers."

"Participating in the SPaCE project has empowered me to voice the unique challenges faced by parent carers, ensuring our needs are acknowledged and addressed."

Golden Rule 2: Make it meaningful

It is difficult to directly evaluate exactly what effect co-production has on practical outcomes because it is impossible to know how a project might have been different were it not co-produced. However, many researchers and stakeholders who have conducted co-produced research identify a range of perceived positive effects on the quality and impact of the work, as well as ways they personally benefitted from the experience.

Some of the potential positives for family carers of being involved in co-production identified by family carers producing this guidance are outlined below:

Increased self-esteem and confidence	**Co-production can boost self-esteem and confidence by contributing to something worthwhile. Feeling that your voice matters is important. It can also be particularly valuable as an opportunity for people who have been out of work for a long time due to their caring role to re-engage with skills and paid opportunities.**
Valuing your own experiences	**Feeling that your experience is useful and making a difference to other people provides a meaningful outlet for some of the challenges that the system brings to family carers. Being heard is important and allows challenging experiences to be put to good use.**
Paid work	**Receiving payment for your input indicates the value and recognition of the level of skill you bring.**
Helping others	**Improving the system for others is often reported as a motivator for family carers to get involved in research. This can also boost family carers' own wellbeing.**
Being part of a team	**Being a family carer can be isolating. Being involved in a co-production project (ideally) allows family carers to become part of a team. It provides an opportunity to connect with other family carers as well as a wider research team.**
Provides hope	**Being involved in a project can provide hope to family carers that there is work going on around the world to improve the lives of families like their own. As one family carer involved in a systematic review project stated: *'realising that there were all these studies looking at family carer wellbeing interventions, really gave me hope. I felt seen'.***
Additional work or development	**Some family carers receive training and access support and equipment as part of their co-production project. Many go on to work on other projects and continue to develop their skills. For instance, multiple family carers who have been paid to train and facilitate E-PAtS have gone on to be trained to deliver other programmes of support and/or gain further related paid employment.**

Golden Rule 2: Make it Meaningful

It is important that co-production is not just a tick-box exercise and must embody an authenticity in the way that families are approached, regarded, and involved in the research project.

As Atkin et al. (2020) state:

'Co-production is much more than a technique or box to be ticked; while there may be many practical guides to the process of co-production, of central importance are relationships, trust and equality, values which underpin co-production in research. We have found that co-production of research takes time; time not only to develop research skills of services users and professional researchers alike, but also time and energy to discover how best to work together. It is these relationships which are vital in supporting and sustaining co-production within research and, as diverse individuals and groups will be involved, we would be ill-advised to advocate one single approach. Good co-production is an organic process that evolves and is shaped and negotiated by all concerned as the research progresses.' (p. 416).

Meaningful co-production in *all* research

Family carers will want to ensure their voice is heard, their experiences valued, and to know what difference it will make to the research project and its' longer-term impact.

Co-production can bring benefits to any research project. For example, if a project is highly technical or 'methodologically heavy', family carers can bring valuable contributions as a fresh perspective such as asking for clarification on issues and thinking through practical problems. Lived experience input may be particularly useful for insight into disseminating research findings and creating impact.

As an example, a recent systematic review carried out at the University of Warwick involved co-production with family carers. One of the family carers involved wrote:

I am a family carer and my career has not had a research focus so when I was asked to be involved in a systematic review, I was not sure that I would have anything to offer.
The process has been both fascinating and enlightening. The researchers painstakingly and systematically (there is a reason that that word is in the title) worked through all the literature that was available on digital wellbeing interventions for family carers. From a starting point of many thousands of papers they ended up with 23 papers to evaluate.

As a family carer it became apparent that I didn't need to fully understand this academic process, that was not the point of my involvement. My involvement and that of my family carer colleague was to view the results from a family carer perspective and to offer comments to the researchers. Again, initially I thought I might not have anything to offer but at every meeting we found there were questions to ask, and we made contributions that were welcomed. To give an example of a question- we asked if the papers specified whether the digital wellbeing interventions were for family carers of adults or children?

If you are a family carer with no background in research and are asked to participate in a research study- please know that you do have something to offer. Your insights from your lived experience will bring a different perspective and your participation is genuinely valued. If you are asked to participate- I do hope you say yes.

Golden Rule 2: Make it Meaningful

Ensuring sufficient time

However, one factor that could affect the meaningfulness of co-production is limited time. For example, if there is a very short timeframe for delivering a project then this may be difficult due to the time required to do co-production well. When this is the case, it should be fed back to funders that the timeframes may be limiting the involvement of family carers; and this is not ideal.

Being realistic about the time frame for a project is key to working with family carers. Researchers commonly report that they wished they had included more hours for lived experience input as it takes time to set things up well and provide the necessary support. In addition, things crop up in people's lives so having a contingency fund and back up plans may help the project run smoothly and on time.

Key takeaways

- **Meaningful co-production involves the authentic valuing of the views and opinions of those with lived experience**
- **It can be particularly meaningful if co-production is utilised at all stages of a research project**
- **Meaningful work may involve making a positive contribution to the wider community**
- **There are benefits to researchers and the research project from involving co-production partners**
- **There may also be personal benefits for family carers**
- **Meaningful co-production requires adequate time and resources to do it well**

Golden Rule 3: Listen and keep an open mind

An open and transparent approach can build positive relationships across the team and ensure meaningful contributions.

In order for the contributions of family carers to be meaningful it is vital that researchers listen and remain open minded. Both researchers and family carers need to be open to hearing different views which may include critiques of elements of a project. Although this can be difficult to hear at times, different perspectives may also add to the quality and richness of the project.

Reflections from a researcher and family carers who worked on the design of Positive Family Connections:

Family carer: The Positive Family Connections programme could have taken many different forms depending on which family carers were involved, it was organic and none of the families involved could have predicted the content of the programme at the start. It really was a blank slate.

Family carer: When working on co-produced projects the most exciting and thrilling aspect is that the shape of the finished piece of work cannot be predicted at the outset. It is a creative experience that unfolds with every conversation. It is important to not only trust the process, but also trust the families to deliver what is needed. Being open minded and trusting are essential components for co-production.

Researcher: There were background theories and evidence that informed the project and the researchers had started to have some initial ideas about how that may translate into an intervention (originally named Positive Families). When we talked these ideas through with the family carers we were keen to emphasise that they were offered tentatively.

Sometimes it is useful to start off with an idea to be moulded/adapted but there is also a risk with this that people just go along with the original idea and we did not want this to happen. By setting the tone as collaborative and emphasising that all feedback was welcome we kept an open mind and really listened to the discussions that developed.

Over several meetings the format we had envisioned significantly changed. Rather than each session being focused on different family relationships, as initially suggested, it developed into different themes for each week (e.g., communication; doing activities together). These could be applied to the relationships for each family carer so the intervention could be personalised to each individual's circumstance.

Sometimes input from family carers may even change the focus and purpose of the research or lead to new projects. An example of this is outlined below.

"Whilst working on a project with a charity on annual health checks, feedback from family carer researchers and participants of focus groups led to a new project being commissioned. This project focused on the experiences of Black, Asian and other ethnic minority communities accessing social care services for their children with disabilities. The annual health check review project allowed us to develop new guidance that is now included in the training provided to GPs through the Royal College of General Practitioners. The social care project is currently in its third phase, and it has reflected the trends experienced by many of the family carer researchers. Co-production in both these projects allowed the researchers and family carer researchers to provide a litmus test of sorts, redesigning questions in real time, ensuring the best way forward."

Golden Rule 3: Listen and keep an open mind

Transparency in decision-making

Transparency in decision-making

Keeping an open mind does not mean that every idea or comment from a researcher or family carer will be actioned or implemented, but it does mean that all comments are listened to and valued. The key is to be transparent about how such decisions will be made. It can be useful to note comments and the response from researchers (for example, an explanation of why a suggestion is/is not taken forward) in a spirit of openness.

There may be some decisions that have already been made, or some non-negotiables in a research project. Where this is the case, being open about this early on in the project can be helpful to avoid family carers feeling disempowered if their views are not acted upon. While it may not be possible to change some things, researchers can remain open-minded about questioning assumptions. For example, if decisions are made because 'we've always done it this way' it might be helpful to question this and consider what will work best for the particular project and those involved in it.

There may be times when certain skills that a researcher or family carer brings that means their expertise is particularly important in making final decisions. It is important that these decisions are explained and shared with the co-production group so that everyone feels they have been meaningfully consulted. Family carers who are involved in co-production will feel reassured if they know that everything said is considered and their input valued.

Sometimes if there are disagreements there can be other solutions to find a way forward. For example, the Challenging Behaviour Foundation (CBF) supported a family carer group for a research study. The group did not like some of the terminology used so a terminology guide was co-produced for the research study for all to use. Where terminology could not be changed (e.g. within research tools) a disclaimer was agreed and used.

Key Takeaways

- **Remain open minded to hearing different views and ways in which the project may develop and change**
- **Be transparent about what has already been agreed in the research and what can change**
- **Consider creative and constructive ways to manage disagreements**

Golden Rule 4: Communicate clearly

Use plain and accessible language. A clear remit and expectations of family carers ensures you get people with relevant experience/characteristics for the project. Be clear about the aim of the research and how this will contribute to improving families' lives.

Researchers should use plain language to communicate from the very beginning and throughout the research process. Using clear and concise language, removing jargon, and explaining research-related acronyms and terminology can also ensure that family carers feel included and valued.

Providing information in a few different formats or using mixed media may also ensure that family carers can easily access information from the start. Highlighting that family carers can ask any questions and stating that 'there's no such thing as a silly question' may help.

Researchers must be clear from the start of a project about what will be expected from co-production partners. Family carers may be juggling many different responsibilities including care for their relative, support for the wider family, and some may also have other paid work. Therefore, clarity and openness about the workload and expectations are crucial. If some aspects of the nature of the work are not already agreed then having discussions with the family carers about what would suit them can help provide a joint agreement.

One way of providing clarity at the start of a project is by having a document that clearly outlines their roles and responsibilities, how they are situated within the research, and what training and support they will receive.

Golden Rule 4: Communicate clearly

Being clear about the remit and role

Getting the right experience for the project may involve recruiting for particular characteristics (e.g., seldom heard voices, family carers of a child or adult of a particular age or diagnosis). A clear recruitment plan, job description and/or person specification will help ensure those with relevant experience are involved in the project.

Outlining the expectations on family carers and researchers from the outset can help to manage time and prevent misunderstandings. Providing "Terms of Reference" – a simple document summarising the key information about the role can help to clarify researchers' and family carers' remit. It can be valuable to discuss and agree the content of the Terms of Reference collaboratively with family carers involved in a project.

The remit may include the number of meetings or timeframes to feedback on information. Ensure there is enough time for family carers to read documents and respond. There is a balance between making the family carers 'conform' to a set of rules and being flexible and mindful of family carer circumstances (see Golden Rule 7 on Being Flexible to the needs of family carers for more information).

It is important that from the outset, the value and role of family carers is clear. For example, stating that a family carer is here as a specialist in their field (of caring and their experience of the system, its complexities and contradictions) and is not required to have an in depth understanding of another part of the project – e.g. statistical analysis. Nevertheless, where family carers have other relevant skills, it can be useful to tap into all the experiences they bring. Many family carers have additional skills that can also add value, for example through their own professional or voluntary roles. However, family carers should be enabled to guide to what extent their role remains focused exclusively on their lived experience if they would prefer this.

Golden Rule 4: Communicate clearly

Terms of reference/role description

As with any role, establishing clear expectations and requirements is vital. Family carers are often dealing with huge volumes of information relating to their relative so it is key to be brief and to the point. Bullet points may work well.

A brief role description and person specification sets clear expectations from the outset, avoiding wasted time for all involved.

Consider including the following information:

What	Why
The purpose of the research What the research is, how it will help, and what difference it may make in the future – e.g. to services. Explain how involving people with lived experience will help shape the work.	As well as this being core to the understanding the research, family carers are often motivated by wanting to help change and improve issues affecting the family carer / disability community.
What skills and experience you are looking for? Set out what experience you need participants to have had. e.g. lived experience of a certain condition. Also make clear the skills needed to take part.	Being specific about this from the outset ensures expectations are clear.
Define a title Consider what the role is going to be called. This will depend on the level of involvement and responsibility required. Previous examples include: Co-investigator, lived experience consultant, specialist lay member. If the project is being co-produced from start to finish, there should be an opportunity to consult with family carers about how they may want to be referred to.	This is important so that family carers have a clearly defined role. In some cases participants may want to reference this experience when seeking other roles / work.
The time commitment Be precise. Include all time that may be involved including any pre or post meeting reading for example. If you are unsure then estimate and make it clear you have done. Also clarify the timetable of the project and various stages, (e.g. it needs to be completed in the next 18 months).	Family carers are often very short of time and need to have a clear understanding of the exact time commitment.

Golden Rule 4: Communicate clearly

Terms of reference/role description

Consider including the following information:

What	Why
Payment Be clear about the pay you are offering and ensure you have accounted for all time involved (including preparation / reading time etc.). It is also important to reimburse for replacement care and travel expenses. Be clear about how payments are organised. If time sheets are needed, and for what. Also if payment is by bacs, what will show up on a bank statement.	As with any role, people need to understand what they will be paid for their time. An example given by one of the family carers who co-authored this document was that they had received a payment but it wasn't clear which project it was for as the payment was an acronym.
How you will gather information? Make clear what the format will be and whether this will be online or in person. Will there be other options such as written testimony, surveys or interviews? In planning all of the above, be flexible wherever possible to accommodate accessibility needs.	This information will give people a chance to consider if the proposed means of involvement meet their own needs, or if adjustments would be needed to enable them to take part.
What the co-production partner will need to do Clearly set out what is expected of the participant. There may be a number of levels of involvement. Try to define these as clearly as you can. Define pay and time commitments accordingly.	This will give family carers the information they need to be able to take time to consider what, if any involvement, is right for them. Defining this from the outset means they do not have the additional admin of contacting you to ask for more information.
Feedback and supervision for families involved in co production	Feedback and supervision for family carers may be helpful, especially when people are involved in extended projects. It can be hard to self-evaluate and providing something concrete, (such as in the context of CPD – Continuing Professional Development) may offer a way of increasing family carer skills and confidence in co-production activities. Having training (and ensuring the family carers are well compensated for the time they invest).

Golden Rule 4: Communicate clearly

Although it is important that the role is defined clearly, there also needs to be flexibility to the needs of the family carer (see Golden Rule number 7). Having an initial discussion to clarify expectations and discuss any queries is key. It may be useful to recruit more family carers than you need to allow for attrition rates (drop out) or times when a role might be considered a 'job share'.

Communication during recruitment process

A robust recruitment process is important to make sure a project is meaningfully co-produced and for ensuring input from individuals with a diversity of experiences. There is considerable variety within family carers' lived experiences. Ensuring different backgrounds, cultures, and circumstances offers varied perspectives and insights that enrich the co-production process. The recruitment process should ensure that the family carers can do the job (or clarify what training is involved to support them) and have the appropriate lived experience to input equally into the research.

Well thought-through and clear screening and recruitment processes can also help to reduce the risk of family carers misunderstanding their role. Rather, it is crucial to recruit family carers who are willing to express their views, including when they are critical, but to do so in a respectful, collaborative way. This might include looking to recruit co-production partners who have the:

ability to communicate views in clear, constructive way.

ability to draw on their personal experiences in a way that connects to other people's needs and experiences.

ability to represent wider views and engage with different perspectives.

Important things to consider when recruiting for co-production with family carers may include:

- **Specifications such as characteristics of the family carer, (e.g. clear diagnosis /age of relative).**
- **Very clear project description.**
- **Practical arrangements (e.g., access to IT/online meetings, ability to travel to in-person meetings etc.).**
- **Skills and abilities: (e.g., being able to talk/write input in some way) while supporting those who have accessibility needs. For example, ensuring flexibility may include the option to use chat, work in small groups, make email edits, edit documents, read and feedback by email, in person, video call, join a meeting with cameras off.**
- **Availability/capacity.**
- **Any prior experience/knowledge required?**

Golden Rule 4: Communicate clearly

Some initial ideas about where to recruit family carers for co-production projects include:

- **Disability charities**
- **Parent Carer Forums**
- **Carers charities**
- **Facebook groups (Contact, Mencap, National Autistic Society) (although you may need to be a family carer to be a member of some of these groups, in this case you could ask the charity that runs the groups to post it for you).**

Talking to the charities and organisations about how they reach a diverse audience with their communications may provide helpful advice.

Family carer:

Researchers for one project wanted to hear from seldom heard voices but didn't know how to achieve this goal. The two lead researchers were men from a White British background. I suggested I use my local community network to recruit participants for these interviews. I also advised about potential barriers that these women may feel whilst talking to a male researcher and said I would chaperone if that helped them feel comfortable. For one interview, I had to invite the participant into my apartment, as she had no access to both WiFi and a laptop. In total, there were five responses and they were all from seldom heard voices. The final report is yet to be released; however, preliminary findings have shown that to ensure there is an uptake of family carer participants in the programme from diverse backgrounds, more direct interaction needs to take place. Relying on email advertisements from the local authority, parent carer forums or charities is not going to be enough.

Golden Rule 4: Communicate clearly

Researchers trying to recruit family carers should ensure that the recruitment materials are accessible. This may include:

- **Effective social media-style graphics**
- **Ability to speak/email someone to answer queries**
- **Straightforward wording and link to further information**
- **Make it easy to read more about a project, ask questions, and to apply.**
- **Consider consulting with family carers and/or organisations that work with family carers when designing the recruitment materials.**

It is also important for researchers to consider in advance how they will manage the response to their recruitment efforts.

- **Researchers may be inundated with interest. In such cases it is important to have clear procedures for shortlisting and selection and to make these clear in the recruitment materials.**
- **There may be critical comments about the topic (particularly if it has not been co-produced with family carers). Be mindful of topic/terminology and try to avoid overly medicalised or non-preferred language. When researchers receive critical feedback on a project, they may wish to consider whether any changes to the project are required.**
- **Have a discussion with the person sharing adverts on your behalf to establish how critical comments/questions will be dealt with.**
- **If you get responses/questions/comments where you recruit – be available to respond to feedback.**

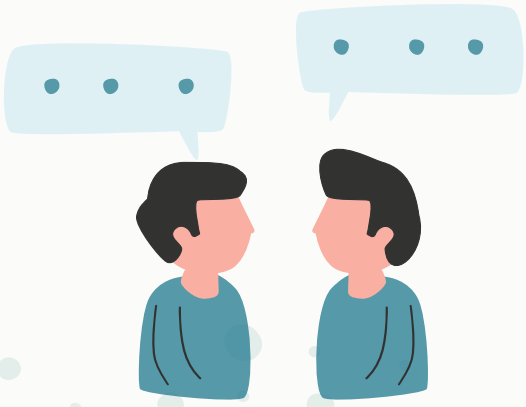
Golden Rule 4: Communicate clearly

Communication during meetings

Practical things can help ensure clear communication with family carers in co-production. This includes communication styles and the way meetings are managed.

Agreeing ground rules at the beginning of your work together may provide a clear framework for the project to progress. These discussions may include:

- **Statement of values/equality (e.g., everyone is equal, no such thing as a silly question, no one is 'just' a family carer, everyone has a right to contribute in their own way).**
- **Agree terminology that will be used for certain diagnoses and needs**
- **Housekeeping, for example, please mute when not talking (if meeting is online), treat others with mutual respect, balancing own input and not taking over, staying on track with the purpose of the meeting.**
- **Confidentiality of the meetings (although important to mention the special case of safeguarding concerns and refer to the organisation's safeguarding policy). It is important to discuss whether or not a meeting is recorded (and if so what the recording is used for, how it is stored, and when it will be deleted).**
- **Guidance/policy on role of family carer and what they have agreed to. The importance of clarifying responsibilities (i.e., sharing power does not mean sharing responsibility in every area of work).**
- **How family carers will be supported and whether any practical help is required (e.g. training, provision of IT equipment).**
- **How actions will be agreed. For example, will family carers be sent a list of things to do and deadline dates following each meeting?**
- **An agreement to leave jargon at the door. This is important to ensure information is accessible to family carers when working with researchers.**



Golden Rule 4: Communicate clearly

A good facilitator can incorporate differences of opinion in meetings. In fact, it may be helpful to encourage different views and to state that not everyone has to agree – as long as views are expressed with respect. Clarity from the start about the way that final decisions will be made will be helpful when disagreements occur. Attending training on mediation, managing conflict, and on understanding family carers' experiences may help lead researchers or those who are chairing meetings.

PenCRU and the Family Faculty, University of Exeter Medical School have written a handbook that includes useful suggestions for ground rules and meetings with family carers.

Key Takeaways

- **Use plain and accessible language. Avoid acronyms and jargon.**
- **Be clear about the remit and role (e.g., family carer of someone with a learning disability, time requirements) for example in a 'Terms of reference' document**
- **Ensure clear communication throughout the recruitment process**
-
- **Make it clear who family carers should contact on the research team with any queries**
- **Explicitly outline the value of co-production and model supportive ways of working (e.g., actively encourage family carer views, develop ground rules in meetings)**
- **Navigating disagreements in a constructive way is an important role for research staff**

Golden Rule 5: Pay appropriately

Ensure that family carers are fairly compensated for their time and expertise.

It is vital to compensate all co-production partners for their time and expenses. Payment recognises the hard and often painfully-gained experience researchers are looking to learn from, and makes it clear that family carers are an integral part of the research team and valued as such. Outlining this commitment in the funding application will ensure all payments are covered.

Points to consider when planning payment:

- **Ensure you are considering all time involved, not just meetings or focus groups. Think about any pre-reading / research required, any liaison in between meetings (beyond planning a date and time for the next meeting), any training required and any significant travel time to / from a meeting if it is not online.**

- **Ensure all out of pocket expenses are covered (e.g., travel expenses, replacement care costs, cost of required equipment).**

- **Consider that payment may affect some family carer benefits and tax contributions. Although Co-production partners are responsible for their own tax affairs and declaring income they have received, the tax and benefit system is complicated, do check in and acknowledge how complex it can be and check that the family carer is confident with everything related to tax and offer support if they are not. Researchers should highlight to family carers that payment (including vouchers) may affect the tax that they owe and the welfare benefits they receive and should support family carers with accessing accurate information. You could direct family carers to Citizens Advice for information about how payment could affect their tax or benefits https://www.citizensadvice.org.uk/. The National Institute for Health and Care Research has more detailed guidance on the employment and tax status of PPI partners, aimed at organisations (NIHR, 2023a) and public contributors (NIHR, 2024), and how co-production could affect welfare benefits, aimed at organisations (NIHR, 2022) and public contributors (NIHR, 2023b).**

- **Make the payment process as quick and simple as is possible. Family carers are often juggling huge amounts of admin. A simple secure form with bank details is ideal. However, researchers are often constrained by their organisations' procedures and cannot alter these. Where this is the case, make sure the process and timeframe is clear, provide support with each step, and do what is possible to minimise administrative burden.**

- **Pay promptly; ideally specify when payments will be made. Never delay and cause a family carer to have to chase this up.**

Golden Rule 5: Pay appropriately

The Challenging Behaviour Foundation have shared their procedures for paying and supporting family carers involved in co-produced research.

We aim for our payment procedures to remove barriers and make the process as easy for family carers as possible.

We inform family carers that any payment could impact on any welfare benefit payments they receive. We also make them aware that they are responsible for ensuring the correct deductions of Tax and National Insurance and to inform HMRC.
Individuals can choose to;

- **be paid directly via Bank Transfer. They are liable to pay their own Tax and National Insurance to HMRC**
- **be paid through CBF payroll software (this does not constitute employment). CBF submit Tax and National Insurance information to HMRC**
- **be paid via e-gift cards. They are liable to pay their own Tax and National Insurance to HMRC**

Limited financial support is available to cover replacement care costs (on request). Reasonable travel costs can be covered with prior agreement.
Travel can be booked in advance. Any other approved travel and/or expenses will be paid by CBF on receipt of a completed and authorised expense form.

Further information from the Challenging Behaviour Foundation is available below:

The resource is called Nothing Without Us and explains how we do co-production at the CBF. It also includes two supplementary resources - a case study of good practice of co-producing the trauma awareness workshop, and a CBF guide to paying family carers who we work with.

Sharing best practice - Challenging Behaviour Foundation
Nothing Without Us (challengingbehaviour.org.uk)
Co-Production Example (challengingbehaviour.org.uk)
CBF-Guidance-on-Family-Carer-Payments-1.pdf (challengingbehaviour.org.uk)

Golden Rule 5: Pay appropriately

As with the whole team, the role of family carers in co-production is a paid role so there are certain expectations about how to behave and a level of professionalism required. In Positive Family Connections, family carers were paid at the level of a post-doctoral researcher and this reflected the level of input and expectation of what they brought to the project. Professionalism includes things like responding to emails in a timely manner and being realistic about your capacity to input to the project. It is still important that researchers ascertain if there is additional support family carers need to carry out the role as well as whether there can be different levels of involvement to encourage a diversity of views.

It is also crucial to be prepared for unanticipated costs. The Challenging Behaviour Foundation, who were co-applicants for the project to produce this document, included a contingency fund for our work (based on previous experience). This was valuable and necessary to help cover unexpected costs, such as additional time for the family carers to write, read and edit large sections of text as well as the production of videos to support the material.

Key takeaways

- **Co-production partners need to be paid appropriately and fairly. Ensure you include this in the budget for the project**
- **Consider all the hours involved, including reading time and communication (e.g., responding to emails)**
- **Ensure family carers are aware that payments may affect benefits (including vouchers)**
- **Include replacement care costs**
- **Try to keep the administrative side simple. Be transparent about what is involved and likely timeframes for payment**
- **There may be additional costs that emerge throughout the project – ideally include a contingency fund for additional hours**

Golden Rule 6: Be sensitive

Consider the wellbeing of family carers who contribute their lived experience throughout the research process. Sharing on sensitive topics can bring up a variety of emotions and it is important everybody feels supported.

Co-producing a research project is likely to involve talking about personal information or experiences. This can add to the texture and richness of research and can be a valuable contribution to a project. However, there can be an emotional toll of discussing personal information. It can be draining to talk about difficult things or family carers may not feel safe to discuss some topics in meetings. It can be particularly upsetting when discussion relates to family carers' own relative's difficulties. People may share more or less depending on the topic or their current circumstances. If a carer is burnt out, stressed, or exhausted, their level of contribution, or the way they contribute, may vary.

It can be helpful if the research team are clear about the project's aims and are transparent about what they are hoping to achieve. Clarifying why the project is being conducted and the limits of the research can assist family carers when they consider what to share and what not to share. It can also be helpful for the researchers to be briefed in advance / receive training about the population with whom they are speaking to help them to discuss topics in a sensitive, respectful way.

Non-judgemental and sensitive approach

A key factor highlighted by the family carers involved in the development of this guidance was the importance of researchers adopting a non-judgemental and reflective approach to working with family carers. Family carers may have experienced challenges or have experienced blame in their contact with services and those in authority (Clements & Aiello, 2021). This can understandably make them wary or concerned about responses from others. If family carers are sharing personal information about their family life and then notice a reaction from a researcher, even a non-verbal one, such as raised eyebrows or shocked face, this can be upsetting and cause them to withdraw.

Golden Rule 6: Be sensitive

Try to be aware of current terminology as well, for example people with Down syndrome prefer a person-first description so to describe someone as a 'Downs boy' for example is outdated and inappropriate. Within the autism field there are differing views but an identity-first approach may be preferred; 'I am autistic' rather than 'I have autism'. Language changes and evolves so it is best to check with the family carers themselves about their preferred terminology.

Researchers and other family carers need to acknowledge that there are many different forms of parenting and caring, and being familiar with the world of special needs and disability in general can help form a shared understanding for the team. In particular, having knowledge about some of the challenges family carers may be experiencing, and developing an understanding and empathic approach, can help to contextualise family carers' experiences. For example, sometimes family carers may communicate bluntly or become angry or upset about a topic. This could be due to terrible prior experiences or having not slept for several days. When people are used to living under duress for a long period of time, living in a certain way becomes 'normal'.

Conversely it is important to be aware of situations where some family carers may overshare, sometimes called the disinhibition effect when working online (Suler, 2004), and to put protections in place to manage this in a sensitive way (e.g., clarifying purpose of meeting, moving to a one-to-one discussion, awareness that there may be regret some time afterwards). Furthermore, rather than finishing a meeting with an abrupt 'goodbye' it may be good practice to check in with everyone about how they are and help them with the transition back into 'real life'.

The need for sensitive, non-judgemental, and reflective support starts from the very beginning of the research process (e.g., recruiting family carers). Researchers may find it helpful to attend training or spend time familiarising themselves with the world of special needs and disability, before starting on a project.

It is important to provide ongoing support so that family carers are clear who they can contact if they have any concerns or are distressed by any aspect of the project. The time for support provided by researchers to ensure this positive approach must be factored into funding bids.

Golden Rule 6: Be sensitive

Information shared by family carers should be kept confidential, unless they have agreed for it be passed on. The only exception to this would be if a family carer discloses something that makes a member of the research team concerned about their own or somebody else's safety. In such cases, the researchers would have a responsibility to understand and implement their organisations' safeguarding procedures.

A researcher's responsibility towards a family carer does not necessarily end once a project comes to an end. Care and sensitivity towards experiences that have been shared continues well after the research has ended. For example, ensuring explicit consent for any further dissemination of material that includes lived experiences.

Family carer:
I participated in research around family support when my son was a child. It was a long study, and I felt we had invested heavily in it. The study ended, and I heard no more. Then by chance a couple of years later I came across a book published about the research and recognised my family as an anonymised case study. I felt it would have been reasonable to at least keep me informed about that.

Recognise the ebb and flow of being a family carer

The journey of a family carer encompasses various phases, each with its distinct challenges and opportunities. The early years are often particularly difficult, as many family carers grapple with uncertainty about where to find support, suffer from sleep deprivation, and struggle to comprehend their child's diagnosis. While these challenges may persist, many family carers gradually develop strategies to manage them more effectively as their child gets older and they develop their own knowledge and support network. However, there can be new challenges that arise throughout the lifespan such as puberty or the transition to adult services.

There may also be current crises or battles that family carers are facing, for example:

- trying to get an Education Health and Care Plan or equivalent
- medical issues (for the carer or relative)
- socio-economic pressures
- housing issues
- feeling isolated
- addressing challenges with the quality of support their relative receives.

Furthermore, there can be variation across the country with better resources offered in different Local Authorities that may mean the contribution they can make will vary. Acknowledgement that people are in different phases and having some understanding and empathy to the ebb and flow of people's resources can be helpful. If people are supported, they can give the most they can at that moment in time (if they feel comfortable to).

Despite their desire to contribute positively, daily responsibilities and emotional tolls may make sustained involvement difficult. This might mean that, despite family carers being highly motivated and keen to engage with co-production, they may struggle with taking time away from their family, or taking on more responsibility and so may find it difficult to be as involved as they would like to be.

Golden Rule 6: Be sensitive

Family carers' own needs

There may be additional complexities if the family carer has their own diagnosis or health needs (physical or psychological). Topics can also trigger emotions from their own childhood/support/lack of support (and this is the case for anyone). Careful consideration as to how researchers support the holistic needs of family carers therefore becomes an essential part of the research process.

Particular care needs to be taken with regards to traumatised family carers and avoiding re-traumatisation. A recognition that trauma is individual to a person and the impact of an experience can be felt and lived with, in a variety of ways, highlights the importance of building a trusted relationship with family carers from the start.

Ensuring a trauma-informed approach can help, which includes:

a. The need for physical, psychological, and emotional safety through trustworthiness and transparency.

b. Opportunities to build a sense of control and empowerment through choice, collaboration, and equality.

There is clear overlap between these aspects and the core aims of co-production: namely working with people in an equal, supportive way that values their experience. Further information on trauma-informed Patient and Public Involvement can be found here.

Personal boundaries and self-disclosure for family carers

Providing guidance or at least having a discussion about self-disclosure at the beginning of a project may help support family carer to consider their own personal boundaries.

Things researchers can encourage family carers to think about:

- What are you happy to share and what you would rather not share?
- Are there times when you will feel less able to share? How can you let others know how to best support you and how can you best support yourself at these times?
- It's okay to say you do not want to discuss something.
- If you would rather make an anonymous contribution that is okay.
- What you share may depend on the type of research project you are involved in (for example the topic of the research or the type of methodology).
- Researchers may need to be aware that if someone keeps missing sessions or withdraws it might be because they are finding the topic difficult. Regular check-in and providing space for family carers to connect or talk to you may help any miscommunications. This may require additional funds for time to support carers 1:1 or offer follow up.

Golden Rule 6: Be sensitive

Conversely, many family carers get used to telling their stories as they have done it many times. It can gradually become easier to fully disclose information. This may mean that very difficult situations are discussed in a calm or seemingly unemotional way as this is how they have developed their capacity to cope. Even in these situations is it useful to encourage family carers to consider how much they want to disclose and it may be valuable to develop guidance for family carers to support them during the research process.

An example of how we did this in Positive Family Connections is included here:

Positive Family Connections
The training for family carer facilitators (who co-designed and co-delivered the programme) of Positive Family Connections included considering using their own lived experience in co-production projects and how to support family carer emotional wellbeing during the process. Family carers were supported to consider what they were willing (or not) to share about their lived experience (personal boundaries). Discussion around what might make people over-share (e.g. feeling uncomfortable with silence, wanting to 'fix' others' problems or to show our knowledge) took place as well as thinking about the impact on other people of sharing our personal experience. Family carer facilitators were encouraged to develop self-guidance on when they might not wish to share personal information (e.g. a current upsetting problem or when feeling sleep deprived).

All family carers fed back that they found this section of the training helpful.

How can researchers help?

Researchers can ensure they do not add to the emotional toll of family carers by considering the following points so that family carers feel valued, listened to, and respected from the beginning of the research process.

- Everyone is an individual and different people may need different amounts of support from the research team. Factor in the hours for support provided by the researcher to ensure a positive approach is taken when developing the research and subsequent funding bids.
- Ensure time to given at the start of the research to develop a positive relationship between members of the team. This may involve organising a one-to-one or small group information session. Explore together what a co-production relationship may look like and examine the role of each of the individuals involved. By allowing time for this relationship to develop family carer can adjust or feel comfortable in their role.

- Being aware that talking about lived experience may raise many different emotions – including anger or sadness. The team may want to plan how they will support family carers in a way that is not shaming or suggestive that they should not express such emotions. It can help to be clear that the family carers involved are not expected to have 'all the answers' or be beyond needing support themselves, due to the ongoing nature of their family members' condition, natural changes across the life span, and challenges accessing appropriate support.

Golden Rule 6: Be sensitive

- Encourage consideration of family carers' boundaries and reflection on what they are happy to share.

- Challenges can arise at any point and it is ok to reach out for support. Discuss strategies or frameworks that may help maintain the long-term engagement of family carers in co-production (e.g. stepping aside for a period, attending only some meetings). This could address issues like burnout, changing life circumstances, and evolving research needs.

- Furthermore, there may be passionate disagreements about certain topics and spending time beforehand thinking how conflict will be managed and mediated. Again, ensuring time at the end of meetings for people to 'decompress' and regular check ins could be useful.

- Some family carers may have been involved in previous projects and allowing time to explore these experiences may also be helpful to new co-production participants and researchers alike.

- Sharing one's own personal experience while also bearing in mind others' differences can take time and practice. No one can speak for 'all family carers' and this needs to be borne in mind.

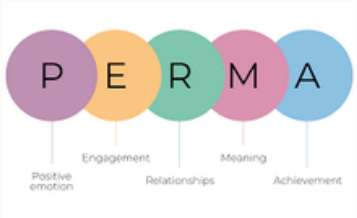
- Furthermore, it is a human trait to compare ourselves to those around us (including our experiences, support network, challenges) which can cause feelings of resentment or envy (i.e. feeling that others have more resources to support them). 'Holding' differences may require sensitive support from the team working with the family carers. The expertise brought by researchers and others in the team (including knowledge based on evidence and theory) can help provide balance to the process. The NIHR INVOLVE principles include reference to the importance of including a wide range of perspectives and skills when working on co-production projects (NIHR, 2021).

- Family carers may require a level of support and adaptation and being open about the researcher(s)' capacity to provide this will ensure there are not miscommunications or false expectations. Transparency about limitations (e.g. other demands on their time, expectations from funders or university departments) with family carers may help identify solutions and harness a sense of being 'in it together'.

- While there are many aspects out of a researcher's control, in terms of funding and commissioning, providing feedback to funders about the need to remunerate good quality co-production (and the time and level of support this requires) is something researchers can encourage.

Golden Rule 6: Be sensitive

The PERMA model: Positive engagement in the process



As outlined throughout the document when family carers and researchers work well together and value each others' input, co production can be meaningful and rewarding.
The Working Group found it useful to refer to the PERMA model of wellbeing (Seligman, 2018) when thinking about what this might look like in practice.

Positive emotions

Encouraging positive experiences in the way people communicate, their appreciation for those working on the project and hope and optimism for the future. For example, the belief that the project can contribute to something helpful for others. Being solution-focused and recognising the strengths that everyone brings.

Engagement

This is where people are fully engaged in the process, and are able to bring their skills and experience to a challenging task. Where people are 'in flow' with a piece of work this can increase wellbeing. Therefore providing opportunities for individuals to contribute (as much as they can) towards the agreed goal can help their wellbeing.

Relationships

Relationships are key to our wellbeing and these can be nurtured through the team project. Group discussions on the project are not just about getting 'input' they are also a chance to speak to other family carers and develop as a team.

Offering times for people to chat (either before, during a break in meetings or afterwards) can help people connect with one another.

Research also suggests that doing things for others increases wellbeing and this may be a key motivator for many family carers who get involved in research. This can be named and nurtured.

Meaning

Contributing to something that is bigger than oneself is known to support wellbeing. Working on research projects that are meaningful and purposeful can boost feelings of self-value, self-esteem and belonging.

Accomplishment

Having a sense of achievement and mastery adds to our wellbeing, in all domains of life. Being clear about the goals of the research, and applying it to real-life examples (i.e., how will this project help peoples' lives), can provide a sense of accomplishment. Reviewing goals throughout the process and having a chance to celebrate/acknowledge what has been achieved at the end of a project can be hugely rewarding as well as keeping the project on track.

Golden Rule 6: Be sensitive

Supporting researchers' emotional wellbeing

Researchers also need to recognise their own limitations in supporting wellbeing and this is where signposting to services of support may also be beneficial for everyone involved in the research process. There are support organisations listed in Appendix I.

Many of the aspects outlined above may, to a greater or lesser extent, be relevant to considering researcher wellbeing. Researchers need to consider balancing work-life balance, self-disclosure, personal impact, and managing other demands on their time.

As outlined above, sometimes family carers are under pressure and may express strong opinions or emotions. Remember to try not to take things personally and understand the broader context which can cause such frustrations. Furthermore, researchers may hear things that are upsetting or traumatising.

Vicarious trauma is possible for those who are in contact with traumatised individuals. Accessing supervision and peer support from other researchers undertaking co-production may help to provide a space to discuss difficulties and identify potential solutions.

Golden Rule 6: Be sensitive

Key Takeaways

- **Be aware that family carers may be under pressure.**
- **Be sensitive to their needs and the variety of emotions that certain topics can evoke.**
- **Maintain a non-judgemental stance and familiarise yourself with the world of special needs and disability (including preferred terminology)**
- **Family carers' situations can suddenly change. Recognise that there may be times when they are less able to contribute**
- **Provide support for those with their own additional needs**

Golden Rule 7: Be flexible to family carers' needs

Think creatively and be prepared to work in different ways to avoid some of the barriers family carers may face.

Having discussions with family carers right at the beginning of a research project (ideally at the project's conception) can help to clarify the decisions about how family carers want to work. Consulting with family carers and discussing options of how to engage can help clarify how the project will progress. People generally like to have some element of choice and agency and this is a good way to involve stakeholders.

In this section we consider i) flexibility of meetings, ii) different levels of involvement, and iii) overcoming barriers to involvement.

i) Flexibility of meetings

Offering flexibility in how meetings are arranged and when they are held can help family carers who may be managing many different demands on their time. This may include evening or daytime meetings and catch-up meetings for those who could not attend. Providing a summary of meetings including the main points discussed and actions agreed can help family carers to keep on top of the role.

Individuals learn in different ways and may have preferred methods of communicating, such as one-to-one, in groups, via email or chat functions. Some people may work best in group meetings while other prefer reading or emailing in their own time. Finding ways to be flexible to the different styles as well as the demands on the family carers' time can ensure a wide range of perspectives and inputs into the research project.

It can be valuable to offer people the flexibility to turn off their camera in online meetings, discuss in smaller breakout rooms, or provide an opportunity to share personal information anonymously rather than in meetings. They may also need time to process what has been discussed in the meeting prior to being able to share their thoughts; so allowing them time to respond outside of the meetings could support this.

Individuals may have different preferences for face-to-face or online meetings. However, these may also be influenced by other constraints such as resources, travel, and the location of family carers and researchers. These all need to be considered and discussed with co-production partners when putting together a funding application.

Golden Rule 7: Be flexible to family carers' needs

ii) Different levels of involvement

In some projects there may be different levels of involvement. This could be because of the nature of the input required or to increase accessibility. For example, some people may struggle to commit to a high number of meetings or consistent input over a longer period of time, particularly if they are dealing with unpredictable challenges at home. The PenCRU Family Faculty enables members to "dip in and out" of research in way that fits with their personal lives without having to justify their varying levels of engagement' (Liabo et al., 2020).

Ensuring that projects are inclusive of different viewpoints might involve a 'second tier' of input.

An example from the Challenging Behaviour Foundation:

We believe it is important to get lots of input from family carers and recognise that some people are not able to commit to regular meetings. To ensure a diversity of voices feeding into projects we are always mindful of finding flexible ways for people to input at different points so we don't exclude people or limit input to people who can make a bigger time commitment. We actively encourage other ways to contribute and support family carers in different ways to feed into projects.

There will be different levels of experience of co-production between family carers. For some family carers the project will be the first time they've been involved with research and may need more support. Others might be involved in many projects and be 'a pro'. All levels of experience are important.

An example from SPaCE project:

In SPaCE, I also involve three parent carers as co-investigators (in addition to our wider working group), so they hold more responsibility and commit more time to the project (always with the understanding that there is a need to be flexible, so there is no expectation in that sense). They attend all Project Management meetings that they are able to, join additional meetings to discuss analysis and interpretation of data, and are involved in discussions about further funding bids. They are also invited to join the team at conferences and meetings to represent the project. We aim to ensure that they have equal status with the researchers in the team in terms of being able to shape the project. They are also paid at a higher rate to reflect this higher level of responsibility. (Gretchen Bjornstad, Researcher)

Golden Rule 7: Be flexible to family carers' needs

Family carers may face many barriers to involvement. Sometimes family carers feel that they cannot get involved in projects because they are concerned that they may not be able to commit to the role (e.g., if their relative is ill or they have lots of hospital appointments). Reassuring family carers that they can work flexibly around these issues and recognising that there may be times when they have to drop out can ensure a diversity of perspectives are included.

Simply saying 'it's ok for you to join a meeting with your relative in the background' or 'we know that there may be emergencies you need to go and attend to' can reassure family carers that they are still able to contribute.

Family carers and researchers still need to think about the confidentiality of the meeting so it can help if the family carer uses headphones or turns of their camera if someone else is going to be in the background.

Here are some of the most common barriers with some suggestions of how to overcome these. Remember that every family carer is different and can have hugely varying care responsibilities and circumstances. Ask the individual what works best for them.

Barrier	Support
Time This will likely be one of the biggest barriers a family carer will face in getting involved. Family carers may be juggling caring for their relative with reviews, appointments, managing medications, form filling and advocating for their family.	Make time commitment clear from the outset and consider all elements of time required (even tasks that may take a few minutes). If meetings are a part of the involvement, then offering them online can really help if they have internet access, equipment and an appropriate private space (see digital access below). It also eliminates any travel time required and more comfortably allows for taking an important phone call for example. If in-person meetings are needed, add facilities to make them hybrid so people can dial in if they prefer, and provide funding for transport and replacement care costs. Ideally do not ask for additional time from family carers once a project has commenced. If you have to, make it clear that it is optional and will be paid. Make any deadlines clear and ensure you caveat by explain that you understand that caring demands may get in the way and for the carer to please let you know if this happens. Keep all communication about the project succinct and to the point. Avoid copying in carers to any unnecessary emails which may fill up their inbox. Time pressure is likely to be greater for single parent families and those families where more than one member needs care. These lived experiences are vital and rarely heard so should not be factors for limiting recruitment. Instead researchers need to understand and allow for these extra pressures on such individuals, especially if relying on a small focus group.
Relative at home In some cases family carers may have their relative at home with them.	Online meetings can enable some family carers in this situation to still take part, if their relative is able to safely be in another room, for example. Offer for people to have a camera off if needs be, at any time. Using a headset may help with any concerns about confidentiality. Other ways of participating such as a phone interview or over email may be helpful. Factoring in replacement care costs in a funding application can ensure there are funds to support families.

Golden Rule 7: Be flexible to family carers' needs

Barrier	Support
Digital access Family carers may not have access to the internet or, if they do, may not have an appropriate device.	Offer a range of ways to take part e.g., a phone interview or an in-person meeting. Consider offering additional payment for mobile data. Providing a device for family carers may be factored into a funding application. Where a family carer is using a mobile phone to access online meetings, be aware that it can be hard to see wordy presentations and slides. Keep things simple and check in that everyone can see what you are sharing and offer to post paper materials to those that would benefit from this.
Transport Family carers may not have access to a car and / or public transport.	Offer alternatives to meeting in person. If in-person meetings are needed cover the cost and time for travel or add facilities to make them hybrid so people can dial in if they prefer.
Schedules and 'head space' The family carer role can be extremely intense. As the co-production involvement is likely to be sporadic, even if regular and planned, it is likely that as soon as a meeting is over the family carer is immersed back into their caring role. If a month passes before the next interaction on the project a family carer may return to the project and need support to recall details about what is happening.	Ask family carers how they want to receive information and offer to post hard copies if required. For those who prefer online resources, provide a central, secure, and easy access (online) resource of project information for carers to allow them to read documents when they have time (which can often be during unsocial hours). Include sheet of acronyms, project details, minutes from meetings, updates, presentation slides, and anything else that the carers need to do the job. Start each meeting with a recap of the core purpose of the research (this has the secondary benefit of helping keep everyone focussed and on topic), what happened last time and what the aims of the meeting / interaction are. Proactively invite any questions and offer people the opportunity to ask these privately if they prefer. Make clear who they should contact for different queries. Help reduce any concern a family carer may be feeling about forgetting things by being clear about why you are doing this; e.g. "We know you all have busy lives and completely understand if you need a recap on any elements at all."
Lacking confidence/skills in certain areas	Training needs - like with any job role it may be necessary to provide training to family carers. This might range from basic digital skills or short online courses such as Good Clinical Practice, to more in depth training from running focus groups to understanding the data.

Golden Rule 7: Be flexible to family carers' needs

Key takeaways

- **Family carers may be juggling many different things. Discuss their needs with them and offer flexibility**
- **Provide choice around meetings (e.g., evening meetings, attending with cameras off, editing documents by email)**
- **Offer follow up/catch up meetings for those who cannot attend**
- **Explore different ways that people can be involved to ensure a diversity of views and experiences**
- **Work with family carers to consider ways to acknowledge and accommodate some of the challenges that family carers face (e.g. improving digital access, ways to manage if a relative is at home during meetings)**

Next steps and future aspirations

This is a working document and we welcome feedback. As co-production with family carers becomes more commonplace, we can continue to learn from one another and share further information.

We considered it would be beneficial for researchers and organisations to link up to share information on recruitment strategies, job descriptions and advertising pathways to develop good practice and widen the pool of family carers who are being reached.

Family Faculty

The PenCRU (Peninsula Childhood Disability Research Unit) at the University of Exeter Medical School set up the PenCRU Family Faculty which is made up of families of disabled children who are interested in their research work.

Their website states:

"Members are mainly parents living in Devon, UK, and then elsewhere in the south west, with a few from further afield. Membership of the Family Faculty involves being informed by email or newsletter about the work that we are doing and to being offered opportunities to get involved in the programme of work the unit carries out.

If you would like to know more about how the Family Faculty or the work we are doing then please get in touch."

However, we also acknowledge that sharing on 'the usual' outlets will only reach certain family carers and considered ways of recruiting to encourage input from a diverse group of family carers.

Finding ways to disseminate information on co-production processes and learning can help raise awareness and encourage ongoing learning. In their co-authored paper with family carers and researchers, Griffin et al. (2023), suggested that disseminating information on how co-production was delivered within a project is crucial part of co-production itself.

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Appendix I: Co-produced research programmes

Below is a brief summary of the co-produced programmes with which the authors' have been involved, and which have informed this guidance.

Challenging Behaviour Foundation (CBF) Positive Behaviour Support workshops

The CBF was founded on the principles of co-production and it is embedded in all CBF work. Many years ago, when a need for family focussed workshops about behaviour was identified, a co-production group was brought together to develop and design the materials. These workshops are co-facilitated (by a trained and supported practitioner and family carer), modelling the equal partnership approach we advocate. The CBF has been involved in multiple initiatives and research projects where co- production principles have been applied, including shaping and contributing to the E-Pats programme (see below) which adopted the CBF co-facilitator model of delivery. CBF has co-produced a guide with practical examples to support this approach which is available here .

Early Positive Approaches to Support (E-PAtS)

Early Positive Approaches to Support (E-PAtS) is a non-commercial group programme for family carers who have a young child (0-5) with additional developmental needs. E-PAtS comprises 8, 2.5 hour long, sessions that support wellbeing and resilience for families, proactive access to services and positive development for children. E-PAtS has been developed through an on-going process of co-production between family carers, researchers and practitioners that began in 2012 led by Nick Gore and Jill Bradshaw at the University of Kent. Family carers and others met to plan and discuss the programme in partnership during face to face workshops and multiple writing rounds to ensure E-PAtS combines the evidence based information families prioritise with accessible and sensitive modes of delivery that place high value on lived experience. All E-PAtS sessions are co-facilitated by a (paid) family carer and practitioner dyad, both of whom receive training and support from the E-PAtS team. E-PAtS facilitators work flexibly, making moment to moment adaptations to how materials and exercises are delivered and discussions are supported to ensure the particular needs of group members are met. Facilitators also help to further refine the programme by sharing their experiences with members of the E-PAtS Community of Support, along with feedback gained through consultation with group members. Multiple family carer facilitators have gone on to train in the delivery of additional programmes and/or gain employment in the context of their expertise by lived experience having gained their initial training with E-PAtS. E-PAtS has been the subject of a qualitative evaluation (Gore et al., 2022) and a feasibility Randomised Controlled Trial (Coulman et al., 2021). A full scale RCT of E-PAtS is currently underway (E-PAtS Study (epats-study.com). Family carers have partnered in each of these studies in the capacity of co-authors, advisors and co-applicants. E-PAtS is provided in third sector, local authority and health service contexts in each country of the UK (and is delivered in parts of Norway and Canada).

The Healthy Parent Carers (HPC)

The Healthy Parent Carers (HPC) programme aims to promote parent carers' engagement with health promoting behaviours (called CLANGERS) to improve resilience, mood, and overall health and wellbeing. It does that through (i) facilitated group-based activities and discussions (delivered in-person or online by trained peer Lead and Assistant Facilitators), and (ii) health-related information and resources (delivered in groups and via printed materials and/or online). The peer-led group-based programme is intended to facilitate change by providing opportunities for and prompting: social and emotional (peer) support, valuing the shared social identity as parent carers who want to look after their health, sharing experiences, and embedding practice of health-promoting behaviours.

Positive Family Connections

Positive Family Connections is a co-produced and co-delivered programme aiming to enhance family relationships and wellbeing in families of children aged 8-13 with a learning disability, who are autistic, or both. The programme is delivered by trained family carer facilitators to groups of family carers online. To read more about the co-production of Positive Family Connections, see Griffin et al. (2023). For the findings from a feasibility randomised-controlled trial of Positive Family Connections, see Sutherland et al. (2024).

SPaCE

Many parent carers of children with special educational needs or disability struggle with their mental health. In the SPaCE study, we want to find out whether parent carers in England are more likely to have mental health problems than other parents, and whether this problem has become worse since the start of the pandemic. We also want to learn what it is about their situations or caring roles that might particularly impact their mental health. We want to see whether parent carers who struggle with their mental health are being identified by the health or social services that they are in contact with, and what kinds of support or treatment they are getting.

We are analysing data from surveys and other health data that already exist to see what we can learn about how many parent carers have mental health conditions such as depression, anxiety and addiction. We are looking at how the Covid-19 pandemic has affected parent carers' mental health by comparing data from before and after 2020. We have also surveyed parent carers to ask them about whether they have been asked about their mental health and if they have been signposted or referred for any help. We have also asked professionals how they identify and support parent carers who may need help for their mental health. Some parent carers also took part in interviews to share their experiences accessing mental health support and treatment. We plan to use the information from this research to develop ideas about how we can improve the ways that services identify and support parent carers who may need more support for their mental health.

Appendix II: Support organisations

Disability/SEND organisations

- **Mencap**
- **The Challenging Behaviour Foundation https://www.cbf.uk.com/**
- **Scope https://www.scope.org.uk/**
- **Contact a Family https://contact.org.uk/**
- **My Family Our Needs. https://www.myfamilyourneeds.co.uk/**
- **Contact www.contact.org.uk**
- **Respond www.respond.org.uk**
- **Affinityhub.uk – www.affinityhub.uk – signposts to emotional support for parent carers**
- **Sibs - https://www.sibs.org.uk/ - UK charity for brothers and sisters of disabled children and adults**

General organisations:

- **Action Mental Health https://www.amh.org.uk/**
- **The Association for Child and Adolescent Mental Health (ACAMH) - Offers resources for both professionals and parents on child and adolescent mental health.**
- **Anxiety UK - A charity aimed at supporting those living with anxiety, stress, and anxiety-based depression. Offers advice and support for families and caregivers.**
- **Carers UK - Provides information, support, and advice for carers, including those caring for individuals with mental health problems.**
- **Family Action https://www.family-action.org.uk/**
- **Mind - A mental health charity who also offer specific resources for managing trauma.**
- **The National Child Traumatic Stress Network (NCTSN) - Offers a wide range of resources and information on understanding and addressing the impact of trauma on children and families.**
- **Parents Helpline by YoungMinds - Specifically for parents and caregivers, offering advice on how to support a child or young person experiencing mental health problems.**
- **Rethink Mental Illness - Provides support and information for anyone affected by mental health problems, including families and carers.**
- **Samaritans - Offers confidential support for people experiencing feelings of distress or despair. Samaritans are available 24/7**
- **YoungMinds - A charity focused on improving the mental health of children, young people, and their parents.**

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TIZARD
University of Kent

The SPaCE Project
Support for Parent Carers in England

The Challenging Behaviour Foundation