

Co-Production in Research



Guidance for family
carers of people
with a learning
disability

Contents

Introduction	Page 2
What is research?	Page 2
Why is research important?	Page 3
What are some of the challenges in research?	Page 4
What is co-production in research?	Page 5
Co-producing an entire project versus co-producing components	Page 5
How does co-production differ from other forms of Patient and Public Involvement and Engagement?	Page 5
Why co-produce research?	Page 6
What does co-production look like in research?	Page 7
7 Golden rules for co-production with family carers	Page 8
Why take part in a co-produced in research project?	Page 9
What practical guidance do I need to be aware of?	Page 10



Contents

How do I look after my own wellbeing when using lived experience?	Page 15
Where can I find further support?	Page 18
Where can I find out more about co-production?	Page 20
Conclusion	Page 20
Appendix I: Authors	Page 21
Appendix II: Things to consider for family carers involved in co-produced research	Page 22
Appendix III: Jargon-busting: what do these word/abbreviations mean?	Page 24
Appendix IV: Potential barriers to taking part in co-produced research and ways in which family carers can be supported	Page 25



Introduction

This guidance has been co-produced by family carers and researchers for family carers of people with a learning disability who are considering getting involved, or are already involved in, co-production projects in research.

It is designed to either be read altogether as one document, or as a reference document to answer questions you may have about the co-production and research process.

This project was funded by the University of Warwick participatory research fund. The project was led by the Centre for Research in Intellectual and Developmental Disabilities (CIDD). The Tizard Centre, University of Kent and the Challenging Behaviour foundation are co-applicants.

The Authors are listed in Appendix I.

What is research? :

Research is work which aims to generate new knowledge or apply existing knowledge in new ways. This can include work done in a range of settings including universities, government departments, health and social care organisations or community researchers. Often, research involves collecting and analysing data and sharing findings with others.

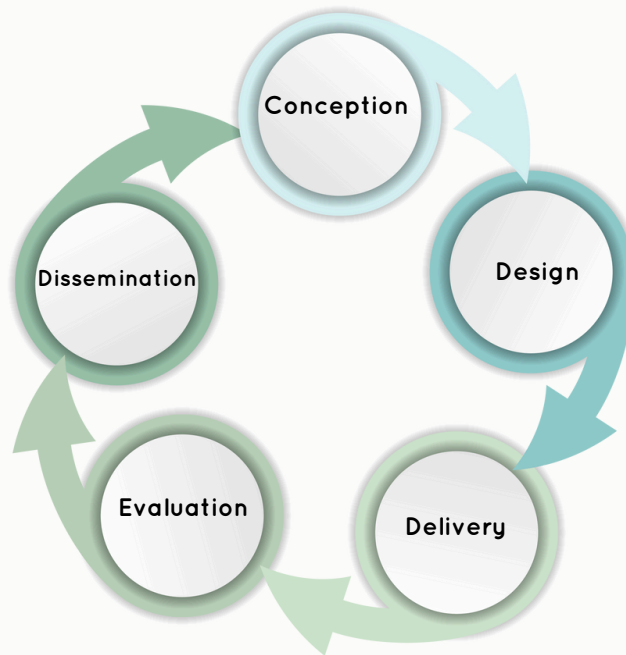


There are generally five key stages in a research process:

- i) **Conception.** This is where the idea for the research is generated and an application for funding may be produced.
- ii) **Design** – where the research process and methodology is designed. How will it be done and who will do what within the team
- iii) **Delivery**– where you actually do the research project (e.g., deliver an intervention, collect and analyse data)
- iv) **Evaluation** – assess and monitor how the project went. What worked well, what lessons were learnt, what could have been done differently?
- v) **Dissemination** – share what the outcomes were and ideally how co-production was implemented for the project.

This does not always follow a linear pathway, for example sometimes the design may be considered before the application for funding.

What is research?



Why is research important?

Research can be crucial for understanding and addressing real-world challenges that affect people's everyday lives. This guidance has been co-produced by family carers and researchers involved in developing and evaluating support programmes for families of people with a developmental disability. In this way, research can lead to improved support for families of disabled people in the future.

Below are links to examples of how research has led to the development of new support for, or knowledge about, families of people with a developmental disability.

Early Positive Approaches to Support (E-PAtS)

<https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/early-positive-approaches-to-support-e-pats/>

Positive Family Connections

<https://cerebra.org.uk/research/positive-family-connections-report/>

Healthy Parent Carers

<https://healthyparentcarers.org/development-of-the-healthy-parent-carers-programme/>

SPACE

<https://sites.exeter.ac.uk/space/>

What are some of the challenges in research?

For people who are new to research, some aspects of research can be frustrating. Research can be a slow process. This can be due to the need for careful planning, waiting for necessary approvals (e.g., from funding panels or ethics boards), and the need to follow strict procedures.

Whilst these can help to improve the quality of research, they also mean the process of getting from an idea to a completed project is often long. Researchers are also often limited by the restrictions of the funding they receive for a project, which may influence (among other things):

- timelines
- the budget they have for co-production
- what they can and can't change about the research



It is important to be realistic and transparent about the limits of research and the academic world. There is not always scope to focus on any topic we choose; it will greatly depend on the priorities of funders.



Being aware of these challenges can help family carers understand when there are delays or certain requirements researchers need to meet in order for the research to proceed.

The language used in research can also sometimes be confusing. There might be terms and abbreviations which aren't familiar to you. We have included a glossary in Appendix I with some common terms. However, researchers should clearly explain terms and make family carers feel comfortable asking for a term to be explained.

What is co-production in research?

The authors of this document defined co-production in research as follows:

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.

Co-producing an entire project versus co-producing components

Co-production can be most meaningful when it occurs at all stages of the research process (NIHR, 2021) - from designing a study to sharing findings. However, co-production may sometimes be employed in specific stages of a research project.

For example, a support programme may be co-produced with family carers even if the evaluation of the programme is not, or family carers may co-produce resources sharing the findings of research which they were not initially involved with. 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 can only be reported as co-producing that stage.

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

Patient and Public Involvement and Engagement (PPIE) is a broad term that describes many different ways of engaging with stakeholders in research.

For example, Patient and Public Involvement and Engagement could include consulting with stakeholders on a specific issue, or stakeholders advising throughout a project, but with power and decision-making ultimately falling to the researchers. What makes co-production different from other forms of PPIE is its emphasis on sharing power between researchers and stakeholders in a mutual and equal partnership.



Why co-produce research?

Good quality research will involve different input and considerations. While researchers bring many important and valuable skills to the work, including lived experience brings another perspective which is based on day-to-day, real world experiences.



To ensure projects are practical and worthwhile for those who the research focuses on, input from family carers whilst first coming up with the idea for a research project helps to ensure research is addressing topics that family carers think are important. Furthermore, family carers can be very good at problem solving and provide real-life examples that may have relevance to the research and help shape the project.

There is considerable diversity within family carers' lived experiences. Ensuring different backgrounds, cultures, and circumstances can offer varied perspectives and insights that enrich the co-production process.

Even at times when family carers might appear to have conflicting experiences there can often be themes in common such as the impact of austerity, the challenge of living rurally. Researchers might be able to identify commonalities even when there may appear to be none.

Feel confident to challenge the researchers - this is why you have been asked to be part of the project. Your role is as a critical friend - you don't need to feel that you have to agree with everything the researchers have suggested and at times you may want to suggest significant changes to a project. Trust your instincts - they have come from a place of reality.

Everyone's views and opinions matter.



What does co-production look like in research?

Co-production can look very different depending on the goals of a project. Often researchers will have funding to do research addressing a question, or to develop a programme addressing a specific need.

They may then work with co-production partners to develop the programme and/or design aspects of the study in greater detail.

Researchers may seek input and suggestions from co-production partners through focus groups, individual meetings, surveys, email, or asking family carers to review or write documents outside of meetings.



In the co-produced programmes that the writers of this guidance have been involved in, family carers developed much of the specific content and, with training and support, facilitated the programmes either independently or along with a professional.

Since co-production can take many forms and involve different responsibilities, it is important that what will be expected of you on a specific project is made clear in advance.

The Working Group developed 7 Golden Rules for co-production to summarise the key points for co-production in research.



7 Golden rules for co-production with family carers

The family carers and researchers involved in the development of this guidance identified 7 Golden Rules for researchers, which are vital for successful co-production.

You may wish to consider if the project you are involved in demonstrates commitment to these rules. Appendix II contains some questions you may want to ask yourself in relation to the Golden Rules.



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.

Why take part in a co-produced in research project?

There can be many different reasons for being involved in co-produced research. Co-production can help contribute to high-quality research that addresses key topics for family carers, such as developing new forms of support and evaluating whether they are beneficial. Co-production can also help to communicate research findings to a broader audience and maximise the impact of a project. Telling people about things that they might find helpful is a key part of research outcomes. Family carers' time is precious so ensuring that they know about evidence-based support is important.

Beyond the positive effects of co-production on the research, being involved in co-production can also have lots of positive effects for family carers themselves. Below are some of the personal positive effects of co-production identified by the family carers who co-produced this guidance:

Increased self-esteem and confidence

Co-production can provide a positive chance to boost self-esteem and confidence by contributing to something worthwhile. Feeling that your voice matters is important. For those who may have been out of work due to their caring role, being involved in research can provide a chance to re-engage with skills and paid opportunities.

Paid work

Receiving remuneration for your input indicates the value and recognition of the level of skill you bring.

Being part of a team

Being a family carer can be isolating. When you are involved in a co-production project you become (ideally) part of a team. This 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 to improve the lives of families like their own.

As one family carer involved in a systematic review stated: 'realising that there were all these studies looking at family carer wellbeing interventions, really gave me hope. I felt seen'.

Valuing your own experience

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 us. Being heard is important and challenging experiences can be put to good use.

Helping others

Learning and 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.

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.



What practical guidance do I need to be aware of?

There are many practical aspects to consider before taking part in co-produced research. In this section we have highlighted some of the key things to think about. Ideally researchers will have considered these topics and provide all the relevant information you need. However, if this is not the case, we hope this is a helpful guide to the types of things you can ask about before taking part.

Payment

It's vital that co-production partners are paid for their time. Co-production partners are an integral part of the research team and should be valued as such. Payment also recognises family carers' hard and often painfully-gained experience.



The payment should include all time involved, such as preparation and planning for a meeting, reading documents, travel time, and any training that is needed. All out of pocket expenses should also be covered (including replacement care costs).

For some families payment (including vouchers) can affect benefits and tax contributions. If you are concerned about this you can seek advice from 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).

Co-production partners are responsible for their own tax affairs and declaring income they have received.

It is important the payment process is quick and simple. Where there may be lengthy timeframes for payments to be made this should be made clear to you from the start. As family carers are often juggling huge amounts of admin you can request a simple secure form with bank details and expect that payment should be made promptly. You should not be expected to chase up payments.

What practical guidance do I need to be aware of?

Role description

A project should provide clear information about what a co-production role involves helping family carers decide whether to take part.

The project recruitment information should set out a description of the role and the lived experience that is required with any additional specifications. It should include the following information:

- A clear explanation of what the research project is about, how it will help family carers, and how it will be shaped by co-production.
- The lived experience needed by participants - for example a specific medical condition, and any other skills required.
- The job title, such as co-investigator, lay advisor, lived experience consultant. This may vary across projects depending on the level of involvement. There should be an opportunity to discuss an appropriate title as part of the co-production.
- The time commitment and payment. There should be enough information for you to work out whether you can fit the role around your other commitments, such as caring. It's important that all participants are paid for their time. Don't be afraid to ask about payment if it is not made clear.
- The type and level of involvement required, such as focus group meetings (online or in person), interviews, surveys etc.
- How much notice you will be given for each meeting and how much time you should expect to be given for each task. You should also be told if it is a short project with tight deadlines or a longer project with more flexibility.
- Transparency between the researchers and family carers can ensure misunderstandings do not arise. For example, being clear about the remit of the project and those decisions that have already been taken.
- Clarifying how your input will be used and acknowledged – if documents are being produced will you be listed as a co-author? You may wish to consider if you would like this, and how your identity will be anonymised if you'd prefer.



What practical guidance do I need to be aware of?

Role description

Everyone's lived experience is different and the researchers may not yet be aware of all the information they require. Therefore, if you feel that your experience would be beneficial to a project, it may be worth contacting the researcher to ask. Also, let the researcher know when applying if you require any additional support for your own needs so that you can still be involved.

It is important that you are honest with yourself (and the researchers) about whether you currently have the time availability to get involved. As with any paid role, co-producing research with involve certain expectations and a level of professionalism required. For example, this could include expectations to reply to emails in a timely manner in order to meet certain deadlines. It is important that any such expectations are made clear to you at the outset.



If you cannot commit to the role as outlined in the job description, some projects may allow different levels of involvement. Either 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, particularly if they are dealing with unpredictable challenges at home. Ensuring that projects are inclusive of different viewpoints might involve a 'second tier' of input.

Attending meetings

Many co-production research projects will involve attending meetings. This may be face to face or online. You may feel comfortable in groups or may prefer 1:1 communication and you can feed this back to the researcher leading the project. If you need any adaptations to enable you to contribute to the project, again, please ask the researcher. Some people prefer just using the chat in online meetings rather than speaking, for example.

Agreeing ground rules at the beginning of a meeting can help provide a clear framework for the project to progress. These discussions may include:

What practical guidance do I need to be aware of?

Attending meetings

- **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).
- **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 doesn't 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** (see Appendix I for a glossary). This is important to ensure information is accessible to family carers when working with researchers, but also to prevent a hierarchy forming.

PenCRU and the Family Faculty have written a [handbook](#) that includes useful suggestions for ground rules and meetings with family carers.

If ground rules aren't introduced at the beginning of a meeting you can ask for them to be included. Starting meetings with a check in and allowing a break in the middle can provide a chance for the team to get to know one another better.

What practical guidance do I need to be aware of?

Attending meetings

Other tips which you could discuss with the lead researcher, include:

- Requesting simple, quick-to-read summaries with key points.
- Requesting 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). This could include a sheet of acronyms, project details, minutes of focus group meetings, updates, slide presentations, and anything else that the carers need to do the job.
- If not already provided, request clear information about who to contact for various questions e.g., about the research, attending meetings, pay, concerns etc.
- Request for communication in between meetings to be short and succinct unless this has been accounted for in the payment and time requirements.
- Where the group has agreed to this, request a recording or transcript of missed meetings.

What are the potential barriers to getting involved and how can these be managed?

There can be barriers to family carers being involved in co-production. These could include finding time whilst juggling all our other commitments and own health needs, having a relative at home, or digital access (e.g., not having a laptop or your internet connection being weak). Researchers should be aware of these barriers and offer flexibility and alternatives where possible. Be honest with the researchers about any concerns you have that might make it difficult for you to fully participate.



How do I look after my own wellbeing when using lived experience?

Looking after yourself during co-production



Part of using lived experience in co-production projects may include 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.

If you are involved in a research project, you can make decisions about how much you feel comfortable sharing. It is okay to say that you do not feel comfortable discussing something, or to ask to contribute something anonymously.

The ebb and flow of being a family carer

The journey of a parent carer encompasses various phases, each with its distinct challenges. The early years are often particularly difficult, as parents 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 over time, many parents gradually develop strategies to manage them more effectively as their child gets older and they develop their own knowledge and support network.

However, it is important to acknowledge that challenges can arise at any point and it is ok to reach out for support.



This may mean that even though you are really keen to get involved in research when you sign up there may be times when you are less able to contribute. At these times you may need to take a step back. Speak to the researcher and explain the situation. If they work in the field of disability and caring they will likely have some knowledge of the ebb and flow of carers' lives.

How do I look after my own wellbeing when using lived experience?

Managing wearing different 'hats' as a family carer

Many family carers also work in different roles, either on a voluntary or paid basis. Where work and home life overlaps, family carers can be hugely motivated but there is a danger of burnout. It is important that family carers have time when they are just being themselves as well.

As one family carer on this project stated:

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

If this is you, you may develop different 'rules' (e.g., what you disclose) in different aspects of your life. In working life some family carers may share their lived experience as a way of connecting with those they support (if in a SEND-related role). Others may feel that they would rather not share this information and this needs to be respected.

It may be useful to spend some time thinking about how much you would want to share in a research project. You can also discuss this with the lead researcher.



What support should I expect from the research team?

The research team also have a responsibility to ensure that co-production partners are supported and to minimise the risk of distress. Here are some things that you should be able to expect from the research team:



How do I look after my own wellbeing when using lived experience?

What support should I expect from the research team?

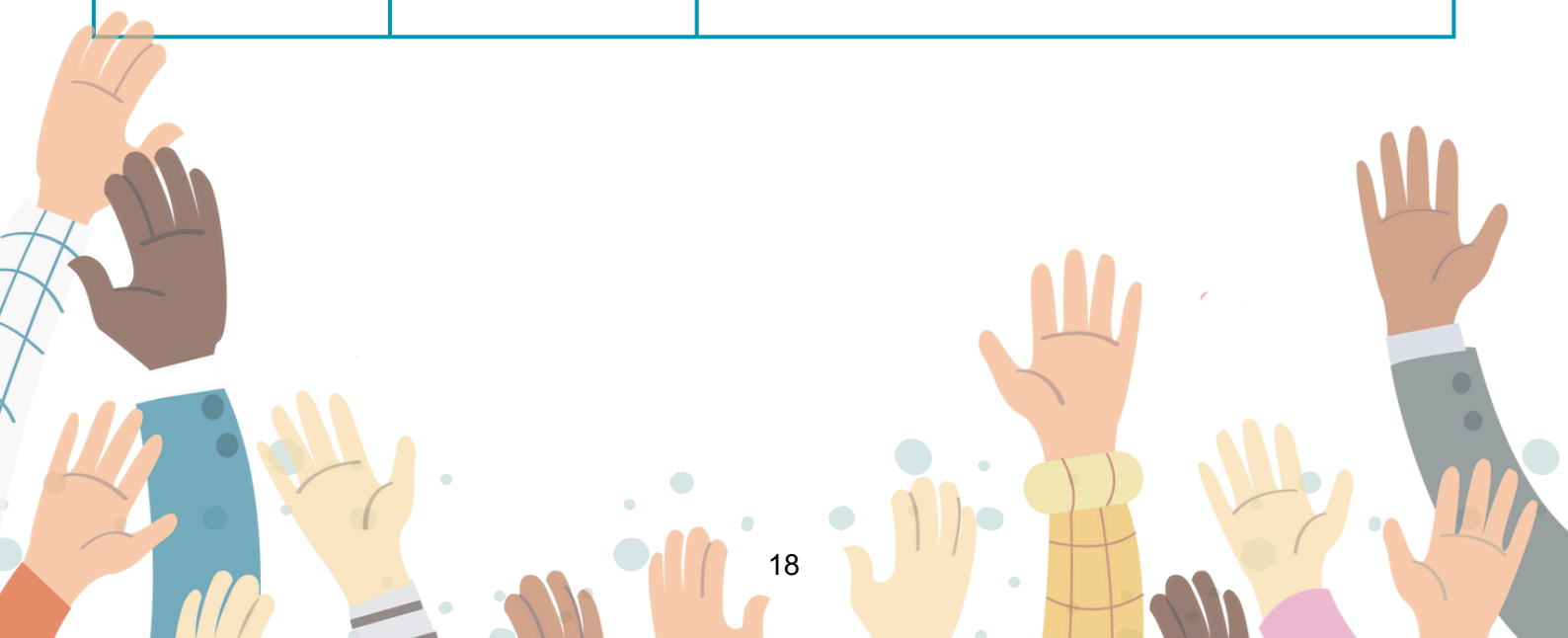
- To be treated in a non-judgemental and sensitive way.
- Flexibility – allowing people to engage in different ways and providing reasonable accommodations to support involvement.
- Opportunity for a check-in/debrief – and clear guidance on who to contact if you become distressed due to the research project.
- Signposting to further support if necessary (see on next page).
- A manageable workload - to not expect unreasonable amounts of work on unrealistic timelines, and to be sensitive to other demands on family carers' time.
- For your views to be listened to, valued, and treated with respect
- To be paid as promptly as possible for all of your time, and for out-of-pocket expenses to be covered.
- Not to be placed under pressure to share experiences that you do not feel comfortable sharing.
- Respect and ethical consideration of personal experiences that are shared
- 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.



Where can I find further support?

There are organisations that may be able to provide information, resources, and support for family carers' wellbeing.

Action Mental Health	https://www.amh.org.uk/	Action Mental Health changes the lives of those living with mental ill health and promotes resilience and wellbeing throughout our community.
Affinityhub.uk	www.affinityhub.uk	Signposts to emotional support for parent carers
Anxiety UK	https://www.anxietyuk.org.uk/	Anxiety UK is a national charity, helping to support people living with anxiety, stress and anxiety-based depression.
Association for Child and Adolescent Mental Health (ACAMH)	https://www.acamh.org/	Sharing best evidence, improving practice. We aspire for ACAMH to become a major portal, access point for anyone seeking the most expertly digested understanding and interpretations of the best evidence available.
Carers UK	https://www.carersuk.org/	We're here for unpaid carers with expert information, advice and support, and also campaign to make life better for carers.
Challenging Behaviour Foundation	https://www.challengingbehaviour.org.uk	We are a UK charity focussed on the needs of people with severe learning disabilities whose behaviour challenges, and their families.
Contact	www.contact.org.uk	The charity for families with disabled children We support families, bring families together and help families take action for others
Family Action	https://www.family-action.org.uk/	Family Action is a national charity working from the heart of local communities across England and Wales. We've been supporting people through change, challenge and crisis for over 150 years
Mencap	https://www.mencap.org.uk/	The Royal Mencap Society is a charity based in the United Kingdom that works with people with learning disabilities.



Where can I find further support?

Mind	https://www.mind.org.uk/	The mental health charity. We're here to make sure no one has to face a mental health problem alone.
My Family Our Needs	https://www.myfamilyourneeds.co.uk/	This is the site for families, carers and practitioners supporting children and young adults with additional needs.
National Autistic Society	https://www.autism.org.uk/	We are the UK's leading charity for autistic people and their families.
Rethink Mental Illness	https://www.rethink.org/	We improve the lives of everyone severely affected by mental illness.
Respond	www.respond.org.uk	Respond supports people with learning disabilities, autism or both, who have experienced trauma in their lives.
Samaritans	https://www.samaritans.org/	Samaritans is a registered charity aimed at providing emotional support to anyone in emotional distress, struggling to cope or at risk of suicide throughout the United Kingdom and the Republic of Ireland.
Scope	https://www.scope.org.uk/	We're Scope, the disability equality charity in England and Wales. We provide practical information and emotional support when it's most needed, and campaign relentlessly to create a fairer society.
Sibs	www.sibs.org.uk	Sibs exists to support people who grow up with or have grown up with a disabled brother or sister. It is the only UK charity representing the needs of over half a million young siblings and over one and a half million adult siblings.
YoungMinds	https://www.youngminds.org.uk/	Whether you want to understand how you're feeling, find ways to feel better, or support someone who's struggling, we're here to help.



Where can I find out more about co-production?

We have also produced guidance on co-production which is aimed at researchers and can be accessed [here](#).

To read more about co-production, you can read the following guidance.

National Institute for Health and Care Research guidance on co-producing a research project

<https://www.learningforinvolvement.org.uk/content/resources/nihrguidance-on-co-producing-a-research-project/ading>

Challenging Behaviour Foundation guidance on co-production

<https://challengingbehaviour.org.uk/wp-content/uploads/2024/04/Nothing-Without-Us-4.pdf>



We have also developed a toolkit for researchers which can be accessed here: <https://warwick.ac.uk/coproductingresearch>

Conclusion

Working with researchers to co-produce research can be a rewarding and enjoyable experience. In this document we have outlined some of the things it is important to consider before taking part, and during the process.

We welcome further feedback on this document and if you would like to contact us you can do so via jo.griffin@warwick.ac.uk



Appendix I: Authors

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.

Jo Griffin, family carer and Assistant Professor, Centre for Research in Intellectual and Developmental Disabilities, University of Warwick

Daniel Sutherland, PhD student and Research Assistant, Centre for Research in Intellectual and Developmental Disabilities, University of Warwick

Debbie Austin, family carer, lived experience expert on E-PAtS and Positive Family Connections

Gretchen Bjornstad, SPACE, Senior Research Fellow, NIHR Applied Research Collaboration South West Peninsula (PenARC), University of Exeter

Jill Bradshaw, Professor of Communication in Intellectual and Developmental Disabilities/Consultant Speech and Language Therapist, Co-lead, Early-Positive Approaches to Support (E-PAtS)

Michael Charles, family carer, lived experience expert and professional facilitator on EPAtS.

Viv Cooper, family carer, CEO of Challenging Behaviour Foundation

Judith Divers, family carer, lived experience expert on E-PAtS

Kate Evans-Jones, family carer, lived experience expert on Healthy Parent Carers

Sharon Foxwell, family carer, lived experience expert on Healthy Parent Carers & SPACE project

Nick Gore, Reader in Intellectual and Developmental Disabilities and Lead for Early-Positive Approaches to Support (E-PAtS), Tizard Centre, University of Kent

Richard Hastings, Professor, Centre for Research in Intellectual and Developmental Disabilities, University of Warwick.

Bel McDonald, Family Involvement Coordinator, Healthy Parent Carers, member of the PenCRU Family Faculty, University of Exeter Medical School.

Saira Minhas, family carer, lived experience expert on Healthy Parent Carers & SPACE project

Ian Penfold, family carer, lived experience expert and Local Champion for the Challenging Behaviour Foundation and on the PETAL programme

Gurdeep Singh, family carer, lived experience expert on Healthy Parent Carers & SPACE project

We are grateful to PenCRU (Peninsula Childhood Disability Research Unit) at the University of Exeter Medical School for enabling collaboration with members of the PenCRU Family Faculty.

Funding

This project was funded by the University of Warwick Participatory Research Fund. The project was led by the Centre for Research in Intellectual and Developmental Disabilities (CIDD). The Tizard Centre, University of Kent and the Challenging Behaviour foundation were co-applicants.

Appendix II:

Things to consider for family carers involved in co-produced research

When deciding whether to be involved in a co-produced project, family carers may wish to think carefully about whether the co-production aligns with the Golden Rules detailed on page 8. We propose that a good or outstanding project would cover the majority of these things. However, that doesn't mean that if all the questions cannot be answered positively the project isn't worth considering. There will be some priorities that are personal to you. We hope the check list and questions are helpful to empower families to know what can be expected from a project.



1. Work together as peers

- Do you feel like an equal partner in the research project?
- Do those you are working with value your experience as a family carer?



2. Make it Meaningful

- Do you feel that the researchers view family carers positively and value their insights from lived experience?
- Are you being asked to be involved throughout the whole research project from start to finish, or will you be engaged in specific tasks?
- Have they considered your skill set and how to use your skills throughout the research project?



3. Listen and keep an open mind

- How will the research/co-production team manage differences of opinion?
- Is the purpose of the research clear?
- Are those you are working with open to negotiating changes to the research project?



4. Communicate clearly

- Have you received information about the co-production role? Are you clear about your remit?
- Is there a key person identified to deal with different aspects of the project (e.g., lead researcher, administrative support)?
- Do the researchers do their best to use clear language and avoid jargon?

Appendix II:

Things to consider for family carers involved in co-produced research



5. Pay appropriately

- Are you receiving payment? Is it clear how much, what for, and how this may affect any benefits received?
- Does the pay feel fair to you? Does it reflect a similar level to university staff with a similar level of expertise. Guidance on payment can be viewed here: [Payment guidance for members of the public considering involvement in research | NIHR](#)



6. Be sensitive

- Do you have any concerns regarding your psychological wellbeing by taking part?
- Do you know where you can go for support, queries, or concerns?



7. Be flexible to support family carers' needs

- Is the time commitment realistic? Does it fit with your current circumstances and the time you have available?
- Are the researchers considerate of, and flexible to, your needs as a family carer?

Appendix III: Jargon-busting: what do these words/abbreviations mean?

- **Principal investigator (PI)** – the senior researcher who holds the grant (funding) for a research project and is responsible for overseeing the project.
- **Quantitative data** – numerical data, including anything that can be counted or measured.
- **Qualitative data** – data that is not represented by numbers. For example, data in the form of text, audio, or images, which may be described using language other than numbers.
- **Randomised-controlled trial (RCT)** – a method for evaluating how effective a programme or intervention is compared with an alternative by randomly (by chance) allocating participants to receive one intervention or the alternative. This is generally viewed as the “gold-standard” way of evaluating whether an intervention is effective.
- **Research design** – the strategy that is used to try to answer the question that a research project is interested in. This is about what a study involves such as what participants will do, what data will be collected, and how the data will be analysed.
- **Statistics** – methods for analysing quantitative data. Statistical analysis methods can help to understand the patterns within quantitative data and interpret their meaning.
- **Impact** – the effect that research has. This includes impact within research (such as influencing other research) but also impact beyond research such as influencing services, families, or policy.
- **Ethics review committee** – before a research project can begin collecting data involving human participants, it must be looked at by an ethics review committee. This committee will decide whether a project is allowed based on whether it meets ethical standards such as not harming participants, protecting participants’ data, and providing participants with clear information to help them decide whether to take part.
- **PPIE - Patient and Public Involvement and Engagement** – a broad term describing a range of ways of involving members of the public in research. This could include co-production, but also other types of involvement such as consulting with members of the public.
- **Expert by Experience** – A term that some people use to describe those who have gained expertise on a topic through their personal experiences.

Appendix IV: Potential barriers to taking part in co-produced research and ways in which family carers can be supported.

Barrier	Support that researchers can provide
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. 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. 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 a 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.
Sickness Family carers often have to deal with unexpected health issues in their relative e.g. sudden hospital admissions. In addition, they may be unwell or need rest themselves, having been up through the night for example. This may mean they will be unable to attend a meeting and cannot give notice of this.	Researchers should make it clear from the outset that they understand that this can happen and that if that is the case, other ways will be found to communicate with you when the situation has passed. Where possible, it can be beneficial for meetings to be recorded.

Appendix IV: Potential barriers to taking part in co-produced research and ways in which family carers can be supported.

Barrier	Support that researchers can provide
Digital access Family carers may not have access to WiFi or, if they do, may not have an appropriate device.	Offering a range of ways to take part e.g. a phone interview or an in person meeting / interview if that is helpful. Consider additional payment for mobile data if that is needed. 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.
Language barriers	Providing information in different languages and supporting those who may need help understanding more technical language.
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, add facilities to make them hybrid so people can dial in if they prefer.

Appendix IV: Potential barriers to taking part in co-produced research and ways in which family carers can be supported.

Barrier	Support that researchers can provide
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.	Central secure 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). This saves printing and adding to the huge amount of filing family carers already have. To include sheet of acronyms, project details, minutes of focus group meetings, updates, slide presentations, and anything else that the carers need to do the job. Consider providing a ‘summary sheet’ of terms, including acronyms, at the outset of a project so that family carers can refer to it throughout. Providing documentation online so people can read in their own time. 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.

