



brain in hand

Co-production Best Practice

Using Digital Tech and Innovation
in Health and Social Care

Introduction

Why have we created this guide?

At Brain in Hand, our mission is to **create a fairer, more accessible world**. That drives everything we do.

We want to help create a world where everyone gets the right support for them, in the right way and at the right time. We can only create this world through co-production. We've involved our end users and non-users in the development of our product and service from the start.

We're not perfect. We haven't always got co-production exactly right, but we've always strived to do it as well as possible. Despite our experience, we still want to keep doing better. In the last few years, we've heavily invested in co-production.

We now have a dedicated co-production lead, Connor Ward, who is a consultant on autistic matters, who is himself autistic. He's worked with the National Autistic Society, in theatre and television, and more.

Connor spearheads our efforts to make sure that autistic people are involved at every level, from improving our software to making sure our customer support processes are right.

We're now also in the extremely fortunate position of working in partnership with ADASS (Association of Directors of Adult Social Services) to help support the implementation of the autism strategy. Co-production is an important part of this work.

“ The level of co-production we want to achieve takes a lot of resources, but it's worth it. We invest heavily in making sure our users are involved in everything we do, because it's the only way to be sure we're giving them what they need. ”

– Louise Morpeth, CEO, BiH

What do we want to achieve?

Our goal in producing this guide is for those who support people to **be confident co-producing** their products and services. Our focus is on co-producing with autistic people, because that's where our expertise lies, but we think the principles are generalisable to other groups too.

We want to share the knowledge gained over a decade of co-production in the hope that it'll help others make things better for disadvantaged people too.

We want co-production not to be tokenistic, not to be a box-ticking exercise, but to provide **actionable insights that lead to real improvements**.

We can't tell you exactly what to do, because it'll depend on the specific things you need to achieve. However, we hope that the principles in this guide will help you feel empowered to involve autistic people in everything you do. Even more importantly, we want it to make that involvement truly meaningful.

Asking leading questions designed (even if unintentionally) to give the answers you want to hear is an exercise in tokenism. Co-production has to be about finding out what people really want and need. Then, of course, it has to be about **putting that into practice**. We've found that working to make things inclusive for autistic people tends to make those things work well for everyone.

This document was authored by Brain in Hand, in collaboration with the autistic community:

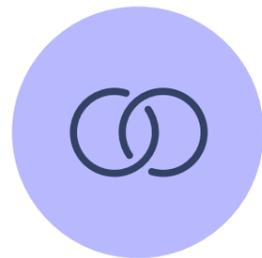


Connor Ward
Co-production Lead
Autistic consultant, trainer
and speaker



Chris Richards
Communications Manager
Author, on autism assessment
waiting list for 2+ years

Contents



Page 6

Section 1 Co-production: What and why?

What co-production is, why it matters, and the benefits of getting it right.



Page 12

Section 2 Accessible Communication

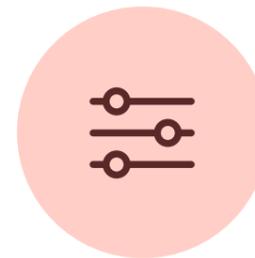
Making your communications clear and accessible for everyone's benefit.



Page 22

Section 3 Recruiting Participants

How to reach the right people, and how to ask them to take part.



Page 32

Section 4 Preparing for Participant Involvement

Designing activities and informing people about what to expect.



Page 40

Section 5 Conducting Co-production Activity Sessions

Get the most out of your invaluable opportunity to learn from your participants



Page 48

Section 6 Post-Session Wrap-up

Acting on the input you've received, and taking continued care of participants

1



Co-production: What and why?

Nothing about us without us

There's a saying that pops up in a few places, but is perhaps most often associated with disability activism: **Nothing about us without us**. That, at its core, is what co-production is about. It's ensuring that when products, services, processes, and spaces are being built, the people who'll use those things are there helping to build them. It's not a single act – you can't 'do co-production' once and be done there. Instead, it's an approach, a way of working.

Co-production isn't the same thing as personalisation

A personalised product, for example, means that everyone who uses it can tailor the product in some way to their own needs, at the point that they access and use it. A co-produced product means that people who use it were involved in building and developing that product. Personalisation is micro; co-production is macro. Of course, some things are both co-produced and personalised.

In support services, co-production is especially important. Providing support for someone is one of the most important things you can do for them. Getting support right means creating something that **truly meets the needs of the person** accessing help. The only way to do that is to involve people who can tell you exactly what those needs are, because they know from their own lived experience.

Improving services improves lives

Although we focus on the benefit to end users, the immediate effect of co-production should be to facilitate better products and services. This in turn should deliver better outcomes for the people who use those products and services. The implications of this simple

chain of effect are huge: a streamlined, more effective service that can better help people is also likely to be less wasteful and more cost-effective. Saving services money saves the taxpayer money, and it also allows for more investment in improving things even further.

Getting co-production right – and the cost of getting it wrong

You're unlikely to find anyone who'll say that co-production is bad, or that it shouldn't be done. But we've seen, through our work with support providers – health and social care services, employers, charities, universities, and more – and through conversations with the people we support, that it's **not always an easy thing to get right**. We've heard people tell us that they want to achieve a high level of co-production, but just don't know how.

At Brain in Hand, our focus is on co-producing with autistic people.¹ This is a group that experiences some of the greatest health inequalities: higher mortality rates, higher likelihood of anxiety issues, and significant risk of self-injurious behaviour, with 66% contemplating suicide and 35% reporting a suicide attempt.

Uncertainty causes a lot of anxiety, too: just thinking about future situations causes worry and stress. Ultimately, autistic people are not getting adequate support for the challenges they experience. The world isn't designed with them in mind, and that's difficult to navigate.

If we work with autistic people to create services for autistic people, we can ensure they have the right help at the right time. We can help them manage their own anxiety, overcome difficulties, and deal more effectively with the challenges that lead to these preventable poor outcomes.

How can we provide good support for autistic people?

By involving autistic people. Historically, the people in charge of designing support products or services have too often tended to assume they know what's best for autistic people. (Or autistic people have been shoehorned into support designed for neurotypical people, which often goes poorly.)

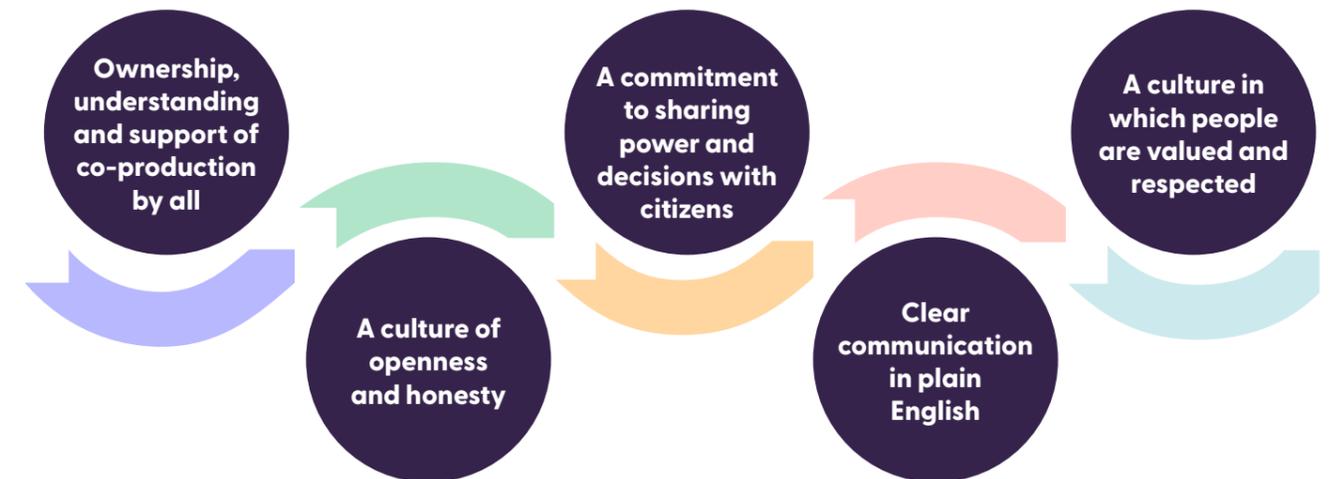
We don't have all the answers. No one person does, not even the most informed autistic consultant. That's why **the only way to get it right is to listen**. In this guide, we hope not to present our own views on how to support autistic people, but **best practice on how to listen to autistic people**.

Co-production guidance to date

In 2016, the Five Year Forward View for Mental Health recommended that new approaches to co-production in commissioning needed to be developed, and the NHS Long-Term Plan pledged to do

more to embed a culture of collaboration.² The NHS points to the Coalition for Personalised Care's resources on co-production, which includes a model with five values and seven steps.

Coalition for Personalised Care model



This infographic originally from: www.coalitionforpersonalisedcare.org.uk/wp-content/uploads/2021/07/C4PCCo-production-model.pdf

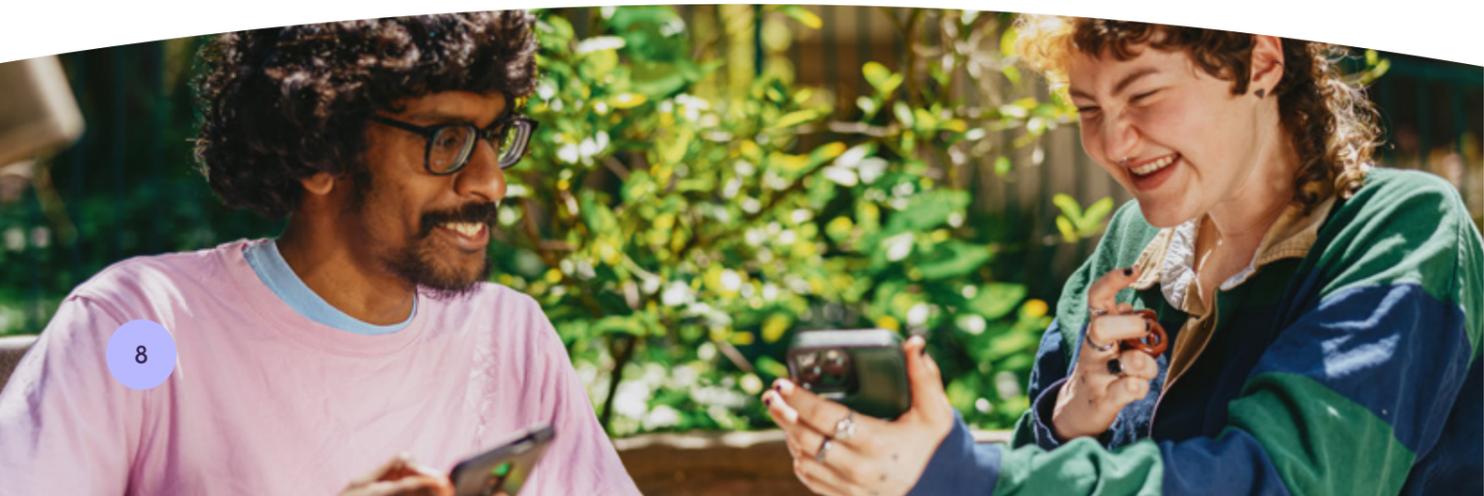
What co-production is and isn't

If you want to say you've truly co-produced something, it needs to have been built with your end user demographic. They need to have been involved in its creation, giving input as early as possible.

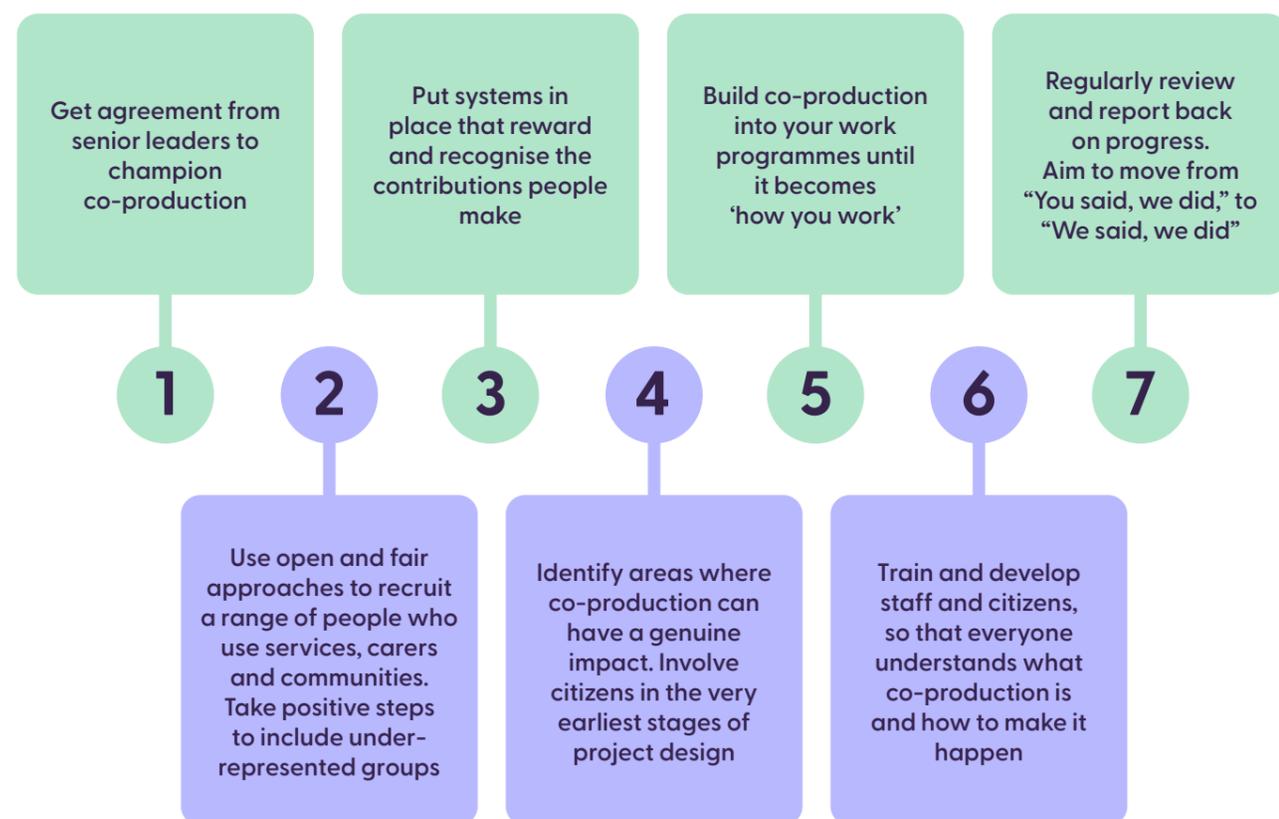
It's not co-production if you create something and then give your users a chance to review it and provide feedback. This is a good step, of course, but it's only one part of the process.

1. It bears acknowledging that many of our end users are not autistic but are, for example, experiencing anxiety-based mental health challenges. We are confident that there is little, if anything, that we would do differently for this community – while our focus is on autistic people because they have historically been under-served and under-represented, doing things in the best way for autistic people is often the best way for everyone.

2. Note that what is often referred to in healthcare as Patient Participation and Involvement (PPI) is broadly similar to our definition of co-production. Certainly, the principles we set out here can be applied to PPI.



The Social Care Institute for Excellence’s co-production guide



This infographic originally from: <https://www.scie.org.uk/co-production/what-how>

The Social Care Institute for Excellence, meanwhile, has its own co-production guide, which breaks the fundamental culture of co-production into four recommendations: Culture, Structure, Practice, and Review.

While these existing guides and models are certainly useful, there is a gap: how, in practice, do you involve people in co-production? This is the link between steps 4 and 5 in the model above – involving

people, and building co-production into work, is a wonderful goal, but it **needs to be done right**.

More than that, it needs to be done with care, especially when co-producing with and for under-represented groups. That’s why we’ve created this best practice guide: to share some of our knowledge and insights from co-producing a support service.

Our focus in this guide is on co-producing with autistic people, because that’s where our expertise lies, but we think the principles are generalisable to other groups too.

We’ve found that working to make things inclusive for autistic people tends to make them work well for everyone³.

Of course, while co-production is necessary to achieve this, it’s not sufficient: it’ll also take an improved funding landscape, the political will to make a difference, and a lot of hard work from support services.

Further resources

Supporting people in the best way also requires a much better understanding and acceptance of the needs of a range of populations: to support someone, you need to understand their relationship to their identity (or identities), the history and context behind those identities, and the language used to talk about them. The National Autistic Society has a wealth of materials and information on these topics, which you can find at <https://www.autism.org.uk/advice-and-guidance>.

Are you ready to begin?

Before you start, you need to know what you want to achieve from co-production. You need to have reflected on why you want to do this, and you need to be ready to act based on what you learn.

The most important question is this: will your co-production work be meaningful? Are you in a position to make real changes as a result? If not, even if you have the best intentions, now may not be the best time to start this work. If you begin before you’re ready, you could end up promising change you can’t deliver, which could jeopardise your relationships and reputation. If you’re sure that all the relevant decision-makers are truly willing to improve things based on learnings from your co-production, you’re in a good position to get started.



3. For example, it’s good practice to provide detailed instructions on accessing a building (including photographs) with the goal of reducing uncertainty and anxiety for autistic people. In fact, everyone benefits – far fewer people get lost, and everyone gets where they need to go more easily. More broadly, the huge range of now-everyday inventions originally designed as accessibility aids includes the audiobook, voice-controlled assistants like Amazon’s Alexa, the typewriter, the electric toothbrush, and even the telephone.

2



Accessible Communication

Clear communication benefits everyone

Everyone is different: what makes sense to one person may not make sense to another. To state the obvious, because it is an important point, each individual person has their own individual needs and preferences. That goes for everyone, whether they happen to be autistic or not.

Embracing the principles of accessible communication benefits everyone. If information isn't clearly presented in a format that suits your audience's requirements, it won't be much use. **Communication is only communication if the other person has understood.** Simply stating something is not actually communicating.

If you want to involve autistic people in co-producing services - and, as we've covered, you do want to do this! - then you'll need to make sure that the way you communicate

with them suits their needs. You need to tell them everything they need to know, and make sure they have a way to easily tell you everything they need you to know.

Reduce ambiguity and uncertainty

For autistic people in particular, ambiguity can cause real problems. When communicating with autistic people, language needs to be clear, precise, and easily understood.

This generally means avoiding idioms, metaphors, and figures of speech, since they can introduce an element of uncertainty about what's really meant. **Uncertainty leads to worry and anxiety**, so the priority should be to reduce that as much as possible.

Tips for written communication
(And useful for all forms of communication)

- ✓ **Keep sentences reasonably short.** The longer a sentence gets, the more unclear it's likely to become.
- ✓ **Make use of spacing between paragraphs or sections to make text easier to read.**
- ✓ **Include clear section headings to help people find the information they're looking for.**
- ✓ **Use bold type to emphasise important phrases** - this can help with readability.
- ✓ **Be very clear about the details when you're asking your reader to act.** This is particularly important if it's conditional or if there are multiple options. (For example, you might need someone to click one of several links to confirm their attendance at a particular session.)
- ✓ **Use active language to make it more obvious who's doing what.** For example, rather than saying 'you will be contacted', a passive statement that doesn't tell the person much at all, try saying 'we will contact you by email in five days'.
- ✓ **Lead with the most important pieces of information.** Anything the person needs to do, or anything that will affect them directly, should be stated clearly up front before going into the detail.
- ✓ **Be careful when using pronouns (she, that, it, and so on). Ensure that it's clear what they're referring to.** Avoid use of the same pronoun more than once in a phrase. For example, a phrase like 'she will take her car' may be unclear as to whether 'she' and 'her' are two different people. Specifying the person by name, as in 'Alice will take Bella's car', or being careful to disambiguate, as in 'Carol will take her own car', will make it clearer.
- ✓ **Finally, keep each communication as concise as possible.** The more information there is to sift through, the more likely it is that something important will get missed.

It's not always easy to consider all of these factors and also keep it short. Just aim to get all the necessary information across, no more or less.

The best way to ensure that your co-production materials will suit the people you want to reach is, perhaps unsurprisingly, to co-produce those materials. At Brain in Hand, insight from our users and Co-production Lead (an autistic consultant), as well as our autistic employees, is invaluable.

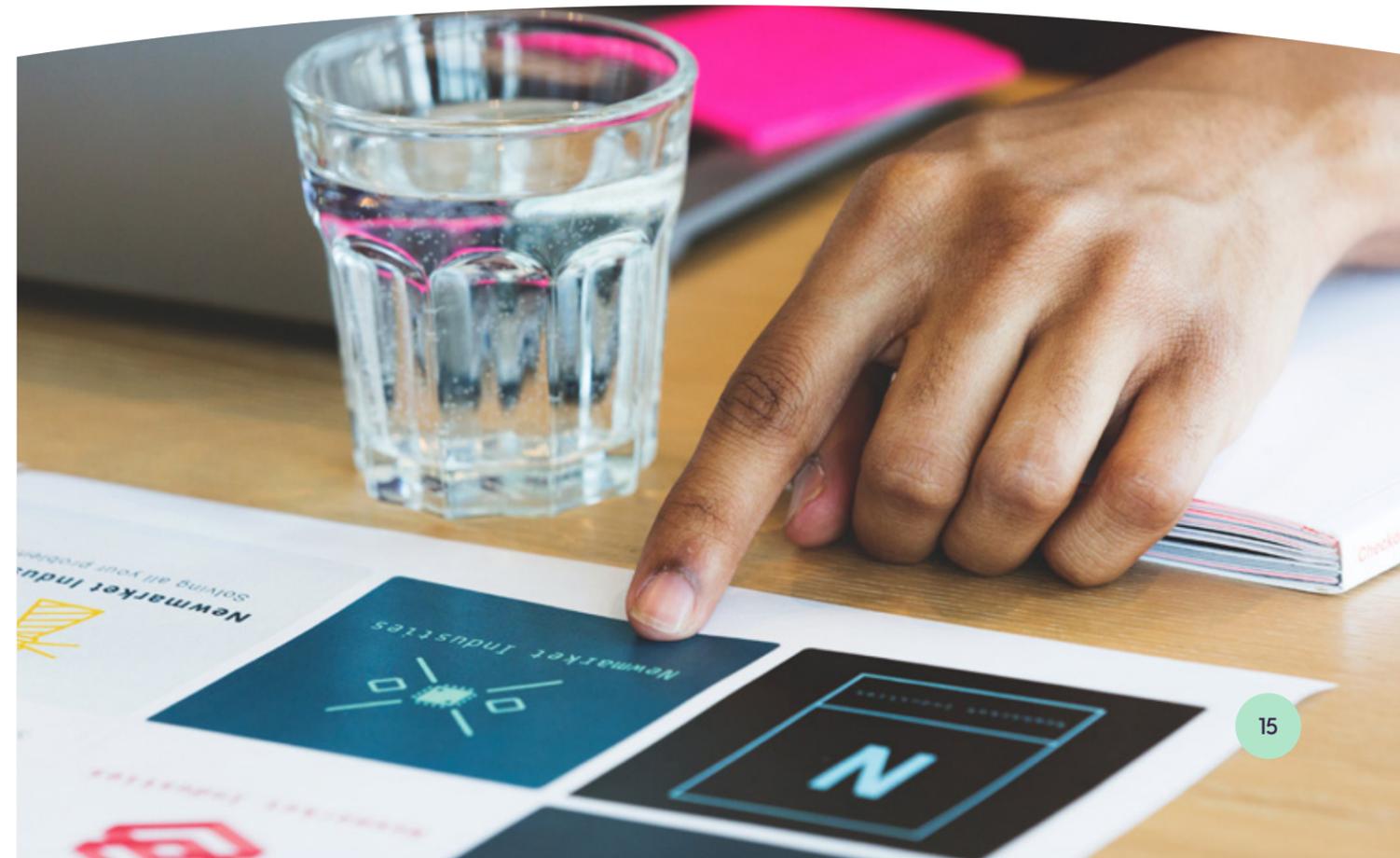
Materials we intend to share with users are co-produced, tested, and reviewed by real users and non-users, giving us a much

better understanding of our users' needs, expectations, and experiences.

In one improvement project, we conducted around 15 testing sessions of a new booking system where users could more easily self-select a time slot for their coaching sessions. The feedback we received led to immediate changes such as adding more frequent booking intervals (every 15 minutes rather than every 30).

“It can be easy to assume that we know what people will need and want, but this often turns out not to be the case.”

– Connor Ward, Co-production Lead, BiH



Consider the five Ws (and 1 H)

- ✓ **Who** is going to act or be involved? If the person needs to act, you need to tell them. If they don't, you need to tell them who will be taking the next action so they're not left wondering.

- ✓ **What** will happen? An agenda with timings will help your participant prepare and feel comfortable.

- ✓ **When** will it happen? Writing out dates in full helps avoid confusion (don't shorten to 5/4/24, for example), as does clearly stating whether a time is AM or PM.

- ✓ **Where** will it happen? Think of where in this case as including digital channels and spaces like emails or video calls.

- ✓ **Why** is it being done in this way? Knowing the reason for a request or point of information can help to reduce uncertainty and anxiety.

- ✓ **How** will it happen? As much detail as possible can, again, help to reduce uncertainty and anxiety.



Present information in multiple formats

Not only do you need to present the right information, you need to present it in the **right format**.

How do you know, then, what that format is? The short answer, unfortunately, is that you don't.

In an ideal world, perhaps you could find out exactly what works for the person you're talking to, then create something tailored to their needs. In practice, however, you need to make sure that each communication works for multiple people, all with their own needs and preferences.

The best way to do this is to **give them the choice between multiple formats**, so they can choose what suits them best.

It's also important to note that there are likely to be **other factors involved in communication** with autistic people. Many, for example, are dyslexic. This is another reason that providing a choice of formats is helpful; easy read documents can also be useful for many neurodivergent people.

Quick Tips

- Make communication as unambiguous as you possibly can
- Keep it short and to the point
- Include all the information someone needs to know
- Remove any non essential information



Communication Formats

As far as is reasonably possible and practicable, it's a good idea to create your communications as: email, PDF or word, web page, infographic, video.

Video

- ✓ Videos should be captioned.
- ✓ In all cases, you should remove as much clutter and distraction as possible.
- ✓ If it's a long video, including timestamps so people can easily find the relevant section can also be helpful.
- ✓ If you're filming yourself talking to the camera, you should find a plain background, wear plain clothes, and not modulate your voice or facial expression too much.
- ✓ Your choice of video platform matters here: YouTube for example, provides a built-in caption function and the ability to add chapters for ease of navigation.
- ✓ Keep movement to a minimum. Gesturing with your hands, for example, can be distracting. All these things can make it difficult to focus on what you're actually saying.
- ✓ YouTube's captions can be switched on or off as the user prefers, whereas captions on a downloadable video file will probably need to be burned in, and therefore on all the time.

Infographics

- ✓ Infographics are particularly useful where you want to explain a process with defined steps.
- ✓ You'll want to refer to accessibility guidelines for visual images to make sure your content works for low vision, colour-blindness, or dyslexia, for example. Some useful principles can be found at usabilitygeek.com/6principles-visualaccessibility-design.
- ✓ Show the flow of activities visually, so the sequence can be clear.

Finally, you should consider the needs of those who may not have reliable Internet access, or who prefer physical communications to digital. If resources allow, a printed-out page may be more suitable for some people than an email.



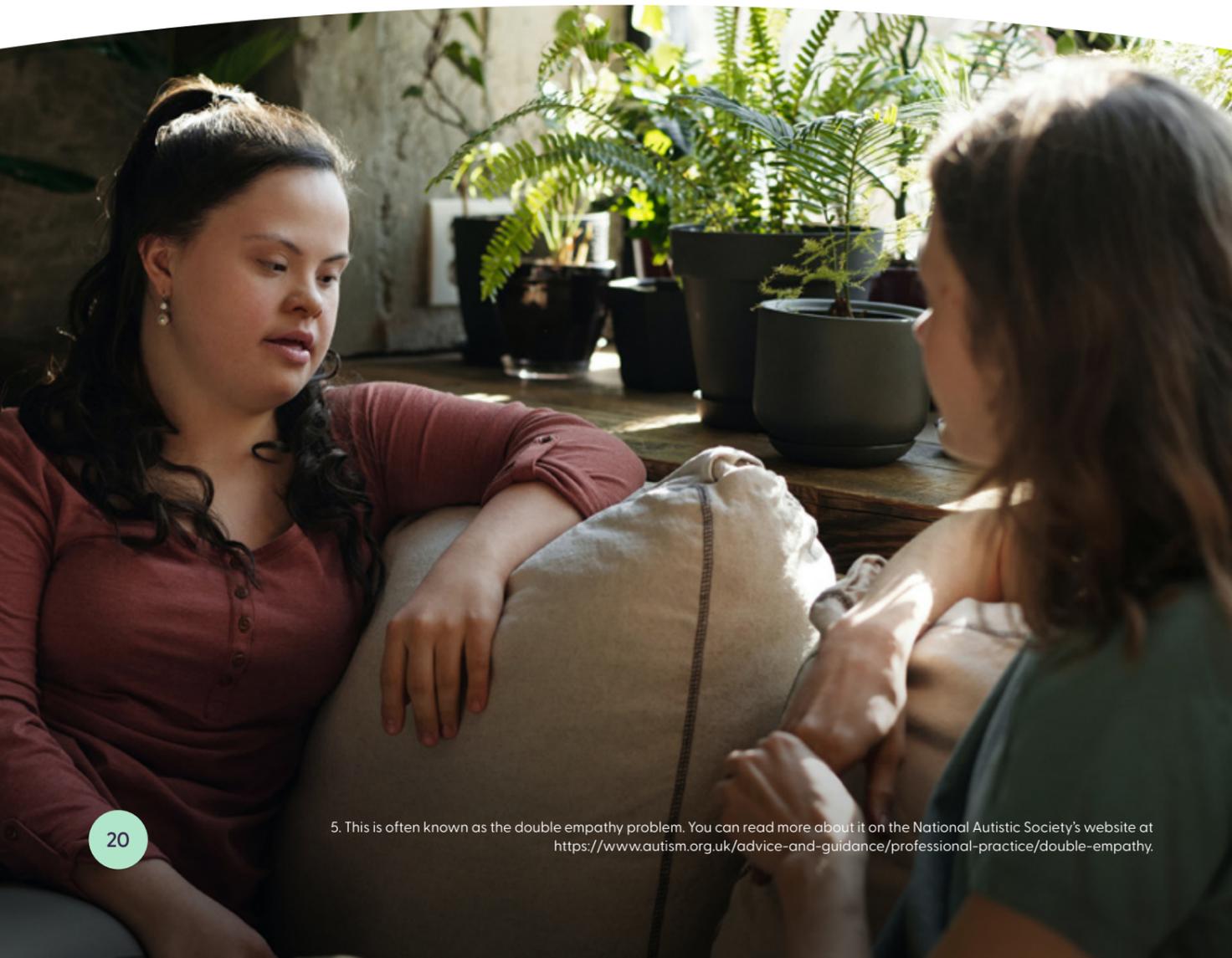
Communication is two-way

For many autistic people, expressing themselves can be a challenge. The pressure to accurately explain what they want to say, in addition to the uncertainty around interacting with people they don't know, can cause a lot of anxiety.

You can reduce the anxiety and difficulty associated with making themselves heard by **ensuring they have options**. Offer them the channel of a phone or video call, email, or text.

We want to stress that the fact that autistic people's communication needs are often different from those of neurotypical people does **not entail a deficit, but a difference**.

Breakdowns in communication come not because one party is wrong, but because each party has **a different way of experiencing the world**⁵.



Remove barriers for as many people as possible

Communication is only communication when all parties understand each other. This can only happen when **everyone can both hear and be heard**.

Some people might find a particular obstacle easy to avoid, or not even notice it; a different person might find that that same obstacle blocks their way entirely. For example, many people will barely notice having to interact with a receptionist to get access to a space, but this extra step could be too difficult for some to navigate.

When you're working one-on-one with someone, directly asking them about their individual communication needs and preferences can be very helpful. However, it's not practical to do this when you're creating

something for a wider audience. It's also not always fair to expect someone to know what their own needs are, or to be able to articulate them clearly on demand.

Rather than endeavour to meet each individual's specific needs one at a time, then, it's best to **provide people with options**, so the need to discuss specifics is minimised. This is proactive accessibility: if you can remove potential barriers, more people will be able to engage.

Ultimately, it's down to you to do as much of the hard work as possible. By the time it gets to your audience, they shouldn't have to be the ones working hard to understand and be understood.

3



Recruiting Participants

Fundamental questions before co-producing with autistic people

1

2

3

Who do you recruit?

How many people do you need, and how do you know who is likely to make a good participant?

Where do you find potential participants?

What are the right places to reach the people you want to recruit?

How do you ask them to take part?

What messages will make people want to be involved?

1. Who do you recruit?

When services generally run consumer testing, the methodology is designed to collect individual feedback from as large a number of participants as possible, then aggregate that feedback. With marginalised people, however, there can often be a tendency to assume that one person can speak for all. It seems self-evident that taking the opinion of a

single neurotypical man would not be a particularly reliable indicator of what all neurotypical men think. Yet there can often be an assumption that one person from a minority group can speak for the whole group, which is a lot of unfair pressure.

When designing products or services for any demographic, the voice of that

demographic has to be **truly represented, not tokenised**. It's not fair on anyone to take a single autistic person and imagine that they can speak for all autistic people.

Each person can only speak for their own views, opinions, needs, preferences, and experiences.

This is extremely valuable, of course, but can't be representative of an entire community on its own. **Be cautious of the label 'expert by experience'**, which can be used to justify relying on a very small number of individuals.

Create services in partnership

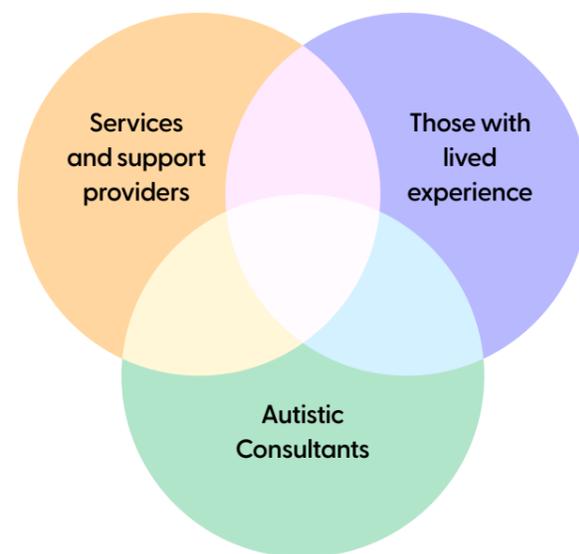
Our recommendation would always be to work with a good autistic consultant as a first step, and to design all your activities and materials with their help.

Then, involve as many people as practically possible from within the demographic you want to serve. This number is likely to be informed by your available resources, as well as the kind of activities you want to conduct. For example, one-on-one interviews will take much more time and effort to undertake and review than a multiple-choice questionnaire. (Note that simply asking for feedback in a questionnaire isn't true co-production. It can be a useful step, but isn't sufficient for creating things in partnership.)

With higher numbers, besides taking more time and resources, you may find that feedback begins to be repeated, which will give you confidence that it is representative of the community.

We say this not to downplay how important and useful it is to hear from every individual person, but because people can only tell you about their own present life experience, which is likely to have some similarities and some significant differences from everyone else's.

A good autistic consultant, on the other hand, makes it their job to **accurately represent the past, present, and future** of the community as a whole. They are an expert based on their own experience of being autistic and an understanding of diverse experiences in the autistic community.



At some point, however, larger numbers will lead to diminishing returns. You'll need to work out the 'right' number for your own needs, but it should be at least seven or eight to give you a good range.

Make your participants relevant to your objectives

What you want to accomplish will affect your choice of demographic for your participants. It's important to be aware that **autistic people are not a homogeneous group**. Like everyone else, they have various intersecting characteristics and identities: age, gender, socio-economic background, and so on. Diagnostic status is also a factor: those diagnosed as adults are likely to have different perspectives than those diagnosed as children, or those who have not been formally diagnosed.

You should look to recruit participants from different areas and social circles. Recruiting within a single Facebook group, for example, is likely to give you multiple people with very similar opinions. Diversifying your sources of input helps you validate that what you learn from your consultants and participants is likely to reflect the needs of the wider community. (Of course, if you're designing something for a very specific group or demographic, recruiting from outside that group is going to be of little use.)

What does a good autistic consultant look like?

An autistic consultant's job is to accurately represent the past, present, and future of the autistic community and its needs. They use their knowledge of the history and current state of things to make informed predictions and recommendations about what can be done to ensure a better future.

As such, they will likely be able to give you a good indication of the right direction, but should be open about the fact that their views will need to be validated and tested with a wider sample of the community.

It is now very easy to find people selling their own view as if it represents everyone, especially as social media increasingly feeds into the notion

of a personal brand, so be cautious. As people discuss their thoughts and experiences with small circles of others in similar situations, views can be reinforced and begin to feel as if everyone must share them.

A good autistic consultant consciously listens to different perspectives, actively seeking out voices with which they may or may not agree from within and without the community – the voices of autistic people, news stories, research, and more. They then apply their breadth of knowledge towards the practical benefit of autistic people. Ultimately, they ensure both circulation and application of knowledge through the dissemination of best practice guidance.

Look for an autistic consultant who can demonstrate that they:

- Engage extensively with other autistic people from a range of backgrounds
- Demonstrate that their input represents expertise of more than just their own experience
- Regularly challenge their own thinking
- Demonstrate an understanding of the past, present, and future of autistic people's needs

2. Where do you find potential participants?

The most obvious place to start looking for people to participate in co-production work is **within your existing client or user network**. If the work you're planning to co-produce is an adjustment or addition to your current service, the people who use that service will

have valuable insight into how any changes might affect it. However, you will also need to **include people who are not already known to you**; they will bring a different perspective than those with some pre-existing knowledge.



One area in which a good autistic consultant can add value is in supporting you to find the people you want to reach. There will be local networks; charities and other voluntary and community sector organisations who likely already have experience reaching autistic people in the area.

Co-production at Brain in Hand

Brain in Hand has a user panel - a group of people who actively use our system and regularly take part in co-production activities - but our approach to co-production is wider than this. We conduct engagement activities with people who no longer use Brain in Hand (either because they achieved what they wanted to or because it wasn't right for them) and people who have never used Brain in Hand at all. This gives us a rounded

view of the needs of not only our current user base, but the wider community we want to reach and serve. Of course, our participants do include Brain in Hand users, giving them a voice and a stake in the product they themselves use. We have a range of touch-points at which we invite users to make their voices heard, including a dedicated 'user voices' inbox and their one-to-one sessions with specialist coaches.

“To find people who would be a good fit for our user panel, I look for people who are already giving good feedback. If they tell us how things could be better or ask about future updates, that's a good indicator that they're motivated to help improve things.”

– Rachel English, Regional Engagement Specialist, BiH

Use digital channels

The Internet is, of course, a good source of potential participants. Contacting the administrators or moderators of **social media groups for autistic people** can be a good option. If you can explain to them that participating in your activity would be worthwhile for their group's members, they may be willing to talk about it in the group.

You could try mentioning compensation for participants or how their involvement could be a way for them to make a positive contribution. This is potentially free advertising with a good chance of drawing engaged and motivated people in the right demographic, as long as you select an appropriate group to approach.

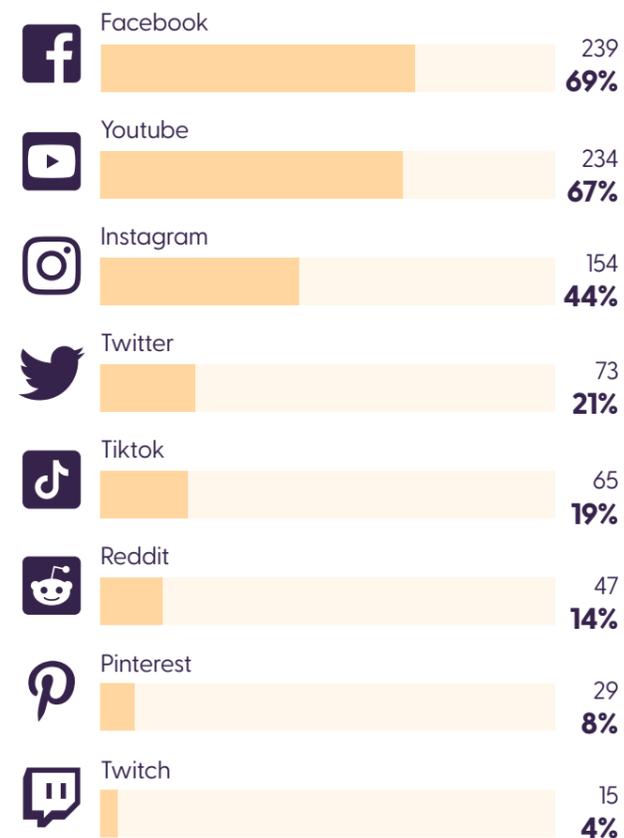
Paid adverts and/or organic (i.e. unpaid) posts on social media can be effective, but they depend on getting two things right: the **audience**, and the **message**.

Paid adverts on Facebook, for example, allow you to target a specific demographic based on age, location, interests, and more. Selecting those who follow pages such as the National Autistic Society or any local support organisations is a good start; it's likely to include people who know someone who might be relevant, at the very least. We'll cover the message in the next section.

Different demographics skew towards different platforms: Facebook, for example, has an older audience than Twitter. You

should consider the demographic you want to reach when picking your channel for advertising.

As part of a survey we conducted with over 400 autistic respondents, we asked them to tell us which digital channels they used most. Their answers were as follows (note that they could select multiple options):



✓ 347 answered - could have chosen up to 4 choices.
 >> 13 skipped. 📺 360 viewed.

While digital channels are extremely useful for reaching people, there are of course a lot of autistic people who don't use this kind of technology, either by choice or because of barriers preventing access. Much of this advice can also be applied to offline interactions, and it's important that we work to address the under-representation of those who are not digitally enabled.

The value of remuneration

We think it's extremely important that people are paid for their participation, where at all possible: participants will bring skills and experience to these activities, and those things have worth. For many autistic people, this could be their first experience of the notion that they could be fairly compensated for what they can offer.

Compensation should be a fair reflection of their contributions (they may have no idea how much they are worth!) – it should also reflect the time and energy that will have been required of them to prepare for sessions, and to recover from them.

Quick Tips

- Think about what you want to achieve, as this will inform the kind of person best suited to helping you
- Don't find all your participants in one place (unless there's a good reason for it)
- Be upfront about why you're looking for input, as this will probably help people trust you and want to take part

3. How do you ask people to take part?

Getting people to engage with you is much the same as with any advert: you need to convince your audience that it's worth their while. There are three kinds of benefit you can focus on – it's worth trying different messages and seeing what works best.

1. The potential benefit to the individual if better services are available to them. Participating gives them the chance to directly shape a product or service that they themselves might access.
2. The benefit to others as a result of their participation. Many autistic people are strongly motivated to improve things for others, not just themselves.
3. Any other compensation, whether a monetary payment or complimentary access to a product or service. We strongly believe that participants deserve to receive compensation for their time and effort.

Converting interest to sign-ups

Following an ad click or referral to you, a potential participant is going to want to know exactly what it is they're signing up for. Here, it's good practice to **have the full information available in a range of formats**. Your ads can direct people to a web page containing everything they'll need to know as written text (both in the page itself and as a separate downloadable document), in the form of infographics if possible, and explained in video and/or audio presentations.

Finally, you **should make it clear exactly how they sign up**. This will most likely involve completing a brief form on your site to provide their contact details, although you should also give the option of contacting you by email or phone. You should also let them know that they can ask you to remove them from your list at any time. You will also have a list of people who have agreed that you can contact them with details of co-production tasks and activities. If you haven't done so already, the next step is to design those tasks and activities.

Quick Tips

- Make it as clear as possible exactly what participating will involve
- Reduce uncertainty and anxiety by giving information upfront and providing a way to easily ask questions
- Make sure it's obvious if there's something the person needs to do – equally, make it obvious if they just need to wait to hear from you

Your messaging to participants needs to cover

Involvement	Purpose	Time
Exactly what they'll be doing: the nature of any potential tasks. Even if you don't yet know the precise details, giving as much information as possible about what you'll ask them to do is helpful.	Why you want their help. Autistic people are often used to being misunderstood or exploited, so you should reassure them that you want their honest input so you can make genuine positive change.	How much time they're committing to spend. At this stage, they're simply consenting to you approaching them with further details of activities, which they can accept or decline; you can therefore make it clear that they'll only have to give you as much of their time as they want to.
Logistics	Data	Accessibility
The practical details of taking part. Whether they might be expected to travel, anything they need to prepare or bring, how you will compensate them – in short, everything they need to know in order to participate.	What you will do with the information they provide. This includes data protection – keeping their personal details secure – as well as your plans for storing and using anything you collect from them during activities (written responses or transcripts, recordings, and so on).	That you will always respect their needs. Stressing that you will endeavour to provide everything they need, to meet any accessibility requirements, and to give them time to prepare and recover, should help people trust you and your intentions.

4



“ We involve users for different reasons at different stages of the process. Typically, what we are doing is testing assumptions about the problem we are trying to solve or the solution (feature) we are working on. If we have lots of data that makes us confident about those assumptions then we may not need to have user involvement. So, when we do involve users, we want it to be for the right reasons, and we want it to matter. ”

– Matthew Arnold, Director of Product Development, BiH

Preparing for Participant Involvement

Preparing to conduct co-production activities

Preparing to conduct co-production activities with your participants consists of two main phases:

1. Designing the activity itself to ensure it fulfils its purpose and is accessible.
2. Enabling your participants to prepare themselves to take part.

In an ideal world, both of these stages would themselves be co-produced, with involvement from autistic people to help you meet your needs and your participants’. That may not be possible in practice –

Remote or in-person?

There are two main ways to do this kind of engagement work: virtual (or remote), and in-person. Virtual is likely to be preferable for both sides (those conducting co-production work and those taking part in it), as it’s more flexible and often more cost-effective. However, you should consider that exclusively virtual activities may exclude those who do not use technology, or cannot access it. This is a group whose voice is often not heard.

co-producing the building blocks of co-production sounds impossibly circular – but it’s still worth making the effort.

It doesn’t have to be perfect first time: if you can find someone to help refine, improve, and iterate, that will add a lot of value in future. Of course, you or your colleagues may well be autistic yourselves. Involving autistic people not just as participants but in the management of the project can be incredibly valuable.

Most of the principles of digital engagement will also apply to in-person interactions. However, special care should be taken when asking people to attend a physical site: it’s inherently harder to control and thus more likely to cause uncertainty.

In fact, the first question you’ll want to ask is: **“Does this need to be in person?”** The answer may well be yes, and that’s fine - if it means you can include those who are not digitally enabled, fantastic. It just means you have

to get in-person engagement right. In a lot of cases, however, you might realise that it's better to conduct an activity remotely.

You want to invest your efforts, and the efforts of your participants, in the right

places. Making sure it isn't just a box-ticking exercise doesn't always mean doing the most extensive possible exercises at every opportunity, but ensuring that you're **responsible in how much you ask** of people.

Activity design

Whether in person or remote, there are a few things you should consider when designing the activities in which you want your participants to take part.

-  **Make sure the nature of the task is easy to understand.** If it requires too much explanation, it's probably too complicated.

 -  **Stay away from open-ended activities.** There should be obvious start and end points.

 -  **Make your tasks as specific as possible so the participant knows exactly what you're expecting from them.** This includes avoiding hypothetical scenarios – saying, for example, 'imagine you are ...' is likely to bring up a lot of questions.

 -  **Try to keep tasks discrete: don't create an activity that consists of multiple steps at once.** Treat each thing your participant needs to do as its own separate task.
-  **If you can't do one-on-one engagement, try to keep groups as small as possible.** Bear in mind that group activities are likely to be more difficult for autistic people, as every new person and interaction creates new uncertainties.

 -  **Create all resources with accessibility requirements in mind.**
- It's worth testing your activities, if you can find some willing volunteers. Colleagues can be helpful, but, if possible, it's often more useful to get an outside view from someone who doesn't have pre-existing knowledge or preconceptions.**

Co-production at Brain in Hand

When we launched a new way for people to refer themselves for Brain in Hand support, we knew we needed to co-produce the approach. We had new social media marketing posts, new landing pages, and a new screening tool. To ensure that the experience was cohesive, we tested this whole journey with each participant. We created discrete and specific tasks for each stage: A/B testing (trying different options and

comparing data to see what worked best) for the social media posts, a directed review of the landing page, and a guided test interaction with the screening tool. Each of these tasks was simple, one-to-one, and had a specific agenda, with participants aware of what we needed from them and why. Because we recognised that this was a more intense task than usual, we compensated participants double the normal rate.

Preparing participants

Having designed your co-production activities, you need to make sure your participants are completely ready to take part in them. You'll need to create something that explains the task and everything it involves as thoroughly as possible. Then send this to your list of co-production participants so they can each decide whether they want to take part.

The key concept to remember here is transparency. If you're **clear, upfront, and unambiguous**, this should prevent misunderstandings and further problems arising. Avoiding potential issues now can save a lot of time and distress later, so it's important to get this part right.

Again, the most helpful thing you can do is reduce uncertainty. You should tell participants what the task will involve in the clearest terms possible, and provide clear instructions for how to take part. Any communication should also include obvious contact details so they can ask questions.

Set expectations around what is and is not expected of participants, and be clear as to the scope of discussion: what is the topic at hand? **Your session should not then introduce anything the participant isn't expecting.**

If you can provide resources ahead of time so participants can see what they'll be doing, that would be extremely helpful. In some cases, you may want to capture an initial reaction without the benefit of foresight; this is perfectly doable, as long as you're open about the fact that the task will involve seeing something for the first time.

Participants **have the right to be informed and decide** whether your activity is something they'd like to do. They should also be given information about whether any aspect of the activity might be optional or possible to adjust for their needs or preferences. Finally, you should make them aware that they can decide to withdraw at any point.

Key points for clear communication

- ✓ Be transparent and unambiguous
- ✓ Set expectations
- ✓ Manage the scope of the activity
- ✓ Provide resources upfront
- ✓ Disclose compensation
- ✓ Inform about what you'll do with input

You should be upfront about the compensation associated with completing the task, and about what you'll do with the information you gather.

You might think it an obvious unspoken rule that, while everything a participant says will be heard, not all of it will be actioned. However, **'unspoken rules' are a common source of uncertainty and misunderstanding**, so you should spell everything out.

Remote virtual engagement

Picking the right software is important, but there are now plenty of video conferencing tools that should work well. Most of these will let you share your screen and attend calls from within a web browser without downloading software, which would be preferable as it requires less work for participants.

If your activity is one-on-one, you could ask participants whether they have a preference for the platform to use. (Of course, your organisation may have specific software requirements, but you should aim to move towards participants' preferences

where you can rather than asking them to work to your requirements.)

More critical than picking a tool is **providing participants with clear instructions** on how to use it. Don't make them wait until the day of the task to send them a joining link; if they need to download software, let them know well in advance.

You should set clear expectations around whether participants will be required to have their cameras turned on or share their screens. You should also let them know whether you will have your camera on and whether you will share your own screen.





Co-production at Brain in Hand

While we work hard to ensure that we give participants all the necessary information ahead of time so they feel comfortable and confident taking part, we recognise that we currently do this mostly in text format.

At present, most of our preparatory information is given by email; we're now working to supply videos with explanations of tasks, pictures of the people that will be interacting with participants, and more.

While we always know we can do better, and will always work to improve how we do things, the fact that we have such rich co-production conversations is what has helped us learn how to make it better.

Without continually talking to real people, we wouldn't have such an insight into how many people would benefit from a more multimedia approach.

In-person engagement

There are a few additional details that you should provide to participants ahead of time when meeting at a physical space. You should give information on:

- **Exact location, ideally with a Google Maps link for ease of reference and to make getting directions easier (or what3words, which gives an even more precise address)**
- **Proximity to train stations, bus stops, and car parking**
- **Proximity to food outlets (especially if you will not be providing food)**
- **Accessibility at the venue: whether there are stairs, non-automatic doors, and so on**
- **A map of the inside of the venue – the room you'll be using should be clearly marked, as should toilets and entrances (ideally, a line showing the route from the entrance would be helpful)**
- **Any dress code the venue might have (explained explicitly – for example, the words 'black tie' don't adequately explain that they also imply a suit or tuxedo – and noted as to whether it's mandatory or flexible)**

Information that works for everyone

Providing this information in multiple formats is extremely helpful. For example, a description of how to get into the building is an absolute must; photographs of the building with clearly marked entrances would be better; a video showing how to get to the entrance, and from there to the activity location, would be even more useful.

Attending your activity **should not financially inconvenience participants.**

In addition to compensation for their time and work taking part, you should pay any travel expenses and consider paying for (or providing) food if it's a long day.

You should tell participants in advance that you'll be covering their costs. It can be extremely difficult and awkward for someone to ask for clarification about this, so you should **address it upfront.**

Best practice accessibility is best practice for everyone

It's worth noting that, while we're focusing on the needs of autistic people specifically, most of what we've talked about is **best practice for everyone.** Not only does it help neurodivergent and neurotypical people alike to have clear expectations, but you never know what someone's needs might be. By **not making assumptions** about whether someone has particular requirements, you can help make things better for everyone.

The obvious objection to doing all of this (or perhaps the obvious excuse people use not to do it) is that getting it right can consume a lot of time and resources, and those are often in short supply. We want to challenge that mindset.

Firstly, even if there truly were no time or resources, that would not be an argument that it isn't still necessary. If something needs doing, it needs doing regardless of other factors.

Secondly, exercises like this should be thought of as **investments, not sunk costs.** Creating strong resources and processes once can make it much easier and faster for the next time. It can also increase uptake and participation and give you stronger outcomes from each activity, resulting in better co-production work. In fact, it might even enable you to get better outcomes sooner, preventing the potential need to repeat a round of engagement and thus potentially saving time and resources.

Ultimately, we think the work required to make co-production better justifies itself. The input you get from co-production work can help you make services and products that **genuinely improve the lives of real people** who need them, and there's no argument against doing that.

5



Conducting Co-production Activity Sessions

Stick to expectations

In the previous section, we covered setting clear expectations for participants about what their participation would involve. This section can be summed up as: **stick to those expectations.**

Don't give people anything to be anxious about. You should have provided a clear agenda ahead of time, explaining what participants will be doing in detail. At this stage, it's incumbent on you to **ensure that that agenda is delivered.**

Be aware, too, that if the session runs over its allotted time – or if any item on the agenda overruns – you should manage expectations where possible. Let the person know how much longer you expect things to take, and be conscious that they may be unwilling or unable to stay longer than the planned end time.

Starting and finishing on time are the two most important things, but not the only important things. You might have attended meetings before where there are still four items on the agenda with ten minutes to go; this can be a stressful situation for anyone, but could cause real anxiety for an autistic person.

If your session is scheduled to run for more than an hour, the agenda should include a break. **You should then have that break at the scheduled time – don't rely on participants to tell you they need one.** In fact, don't even ask whether they want a break, as they may not say yes for a range of reasons.



We begin each testing session by making sure we go through the following things with participants to ensure they'll always be comfortable:

- ✓ A reminder of the context and purpose of the session. Introductions to anyone on the call, including their reason for attending.
- ✓ We will keep to the agreed duration; if we approach the scheduled end of the session, we will ask their permission to extend if necessary.
- ✓ If they don't want to answer anything, for any reason, they don't have to.
- ✓ They shouldn't worry if they don't say everything during the session, as they will have the opportunity to email any other thoughts afterwards.
- ✓ They can take a break at any point, and we may also ask if they would like one.

Help people understand what you need from them

With the right preparation, your participants should be aware of exactly what is required of them, but it is important to restate aims, objectives, and tasks.

Reviewing the aims of the session regularly can help to keep things on track. For each part of the task, give clear instructions about what you need – and, just as importantly, what you don't need.

It is extremely important to be specific when asking for feedback. For example, if you show an autistic person a PowerPoint slide and ask what they think of it, this is likely to be far too big a question. They might

not know whether you want their opinion on the words, the font, the layout, colours, images, even the PowerPoint format itself, and they might not know whether you want those opinions as brief notes or thorough explanations.

You need to direct them: explicitly tell them to exclude things they don't need to look at (if you can't remove them from the materials), and **give direction on the kind of response you want from them.**

Understanding what you will do with the information they provide may help an autistic person to give you the right input,

and reduce anxieties around doing so. For example, if they know you want to produce new visual materials with their input, they will likely feel better able to make observations about their reactions to visual elements.

If, however, they know you want to design an entirely new service process, this may help them ignore details about how things are presented and focus on the bigger picture.

Managing interpersonal interactions

Many autistic people communicate differently to non-autistic people. As such, some of the rules and assumptions used in communication with non-autistic people don't necessarily apply. You should strive to **listen to what an autistic person is actually saying** and disregard your feelings about the way they're saying it.

A lot of autistic people will have spent their entire lives worrying about being misunderstood, and as a result will try very hard to say precisely what they mean.

Paradoxically, this can sometimes be confusing for those used to neurotypical patterns of communication. It can be difficult, for example, for neurotypical people not to feel that someone is being rude or indirect if they don't maintain eye contact, but an autistic person may only be able to express themselves if they're not under the pressure of looking directly at you.

Quick Tips

- Tell people exactly what they're required to do
- Be specific about the feedback you want – and what you don't want
- Tell them why you want their input and what you'll do with it

You should **encourage participants to communicate however works best** for them, and do your best to ensure they're comfortable doing so. Giving an appropriate and accessible way for people to let you know their preferences ahead of time can be invaluable, particularly for those who use non-traditional forms of communication. Remember that they're trying their best to give you a high level and quality of input. If they're having to focus on communicating in a specific way, they'll probably find it much harder to do that. While many autistic people prefer engaging via digital platforms than in-person, video conferencing can introduce problems when interacting with groups. Delays or poor sound quality, as well as a lack of visual cues, can make it more difficult to take turns in conversation. You should therefore be clear at the start of the session about how you will manage group dynamics.



Considerations for video conferencing

- ✓ **Ensure** each participant can only speak when you specifically ask them to (many video call solutions have a 'raised hand' or similar function so they can let you know they want to speak).
- ✓ **Let** participants know whether you will be reading and responding to messages in the meeting.
- ✓ **Allow** people to use the text chat function – it may allow them to express themselves better than speaking aloud.
- ✓ **Give** explicit upfront permission to disengage at any time from a difficult or triggering conversation.
- ✓ **Inform** participants that you will clearly let them know when the dialogue is finished and it's time to move on (you can simply state 'that's the end of this topic').

Don't overlook text chat

It can be a more comfortable mode of communication and make it easier for people to record thoughts as they happen, rather than waiting to speak and potentially forgetting what they wanted to say. Note, however, that text channels can receive a lot of messages quickly; trying to manage them

in conjunction with speaking aloud can be challenging. You should **let participants know** whether you will be reading and responding to messages during the session, or whether you will go back and read them after the fact.

Taking care with carers

In some cases, a user may have a carer present during a session. This can make the interaction a little more complicated, partly because it indicates that the person may

have some additional needs and partly because it's inherently trickier engaging with more people at once.

Where carers are present, you should:

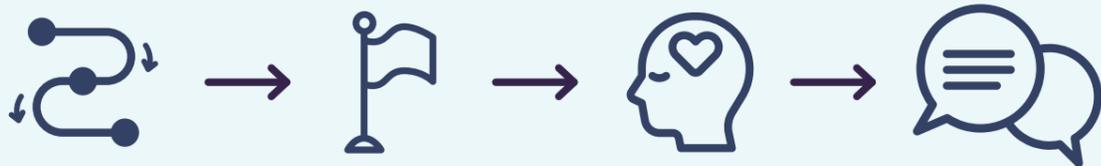
- ✓ allow more time, or at least be aware that you may not be able to cover as much ground
- ✓ test on a larger screen if possible, as two people need to view it – a laptop rather than a phone, for example
- ✓ direct questions to the participant, never the carer
- ✓ check that both parties consent to being recorded and to what they say being used in your work
- ✓ use as simple a technical setup as possible (bear in mind that setting up video calls may be a difficult technical task for this group)
- ✓ keep questions short and direct



Particularly where the carer is a family member, there can be a tendency for them to step in and speak on behalf of the user. This can be useful for clarifying your questions to the user, or for clarifying the user's words to you, but you need to **ensure they're accurately representing the user's views**. You should ask the user directly to check that what their carer has said is what they really want to communicate.

Of course, carers have the best interests of the person they care for in mind; they'll be doing their best to make things as comfortable as possible for them, and to help them say what they want to say. Still, it's respectful to the participant to **always let them have the final confirmation personally**, as long as they're able to do so.

Don't leave a session open-ended



At the end of the session, ensure that participants are clear on what happens next.

If there will be further sessions in this or other activities, let them know. If that's their input finished for now, let them know that too.

Remind them what you will be doing with their input - this can be extremely validating.

If you will be contacting them again, let them know when and how (by email, for example).



1. Acting on the information received

If you undertook a co-production exercise with the right mindset, this part should be easy.

You should have been open to learning, ready to have preconceptions challenged, and motivated to use a co-production approach to make genuine improvements. There are two traps it can be surprisingly easy to fall into at this stage:

1. Congratulating yourself for having ticked the box of 'doing co-production' and assuming that simply having done the exercise must mean everything is good.

2. Deciding that you personally disagree with the participants' input and that you therefore don't need to act on it and your job is done.

Both of these behaviours amount to forms of tokenism, justifying the status quo by superficially including a marginalised demographic.

We're not suggesting that anyone would ever do this on purpose, but being consciously aware of the possibility can help to avoid inadvertently finding yourself in that position.

Post-Session Wrap-up

Once you've conducted your co-production sessions, there are two main things you need to do:

1. Act on the information received
2. Take care of your participants - make sure nothing is left unresolved



The point of co-production is to effect actual change

So it should be possible to trace the input you gathered to meaningful activity. In other words, you should be able to look at your service or resources and identify points where co-production helped shape it. This isn't a simple thing to do: taking all the input you gathered and turning into actionable insights can be tricky, especially where participants had conflicting ideas. You should be prepared to **spend some time simply collating and reviewing** all your data before proposing what actions you'll take as a result.

Reconciling different priorities

Of course, user input – while it is an extremely important consideration – **can't be the sole influencing factor**. Organisational requirements, legislation, the needs of funding bodies, evidence standards, and more will all be important factors in decisions about product and service development.

At Brain in Hand, one of the most important factors in our decisions is research. We want to be able not just to say that we think our system works but that we know it does, and how and why it does. Generating and acting on high-quality independent research is therefore a priority that often intersects with co-production.

We stress for this reason that the **purpose of co-production activity is fundamentally to involve people in a meaningful way**, while

You may find it helpful to focus on the areas most commonly identified as difficulties; if people can't engage with your service or resource, how good it is for those who can use it becomes irrelevant.

Ultimately, this will be worth doing because **it will help more people get better outcomes**, so allocating time and resources to this work should more than pay for itself.

understanding that it isn't possible to act on everything we learn. It isn't tokenistic not to implement every suggestion, as long as your co-production fully involves people and the information you gather is given as much weight as any other factor. You may want to engage an external evaluator or analyst with experience in co-production to help you interpret data, reconcile priorities, and come up with a plan of action.

Unfortunately, there's no simple answer here. When priorities conflict, you'll need to make an informed decision about which is more important to meet. That will probably depend on a range of individual factors. If you can honestly say you've done **as much as you reasonably can to include as much user input as possible**, it's unrealistic to ask for more.



Care through the whole process - and beyond

From the input we get during co-production, we form 'job stories': pillars of understanding about what people actually use Brain in Hand for. We then test these in further co-production activity

to ensure that our understanding reflects our users' thoughts. Once created, job stories are used to inform and direct all our work making improvements to Brain in Hand.

“ Job stories help us make sure that our users' real needs are always at the heart of what we do. They allow us to take the invaluable feedback we get from people and be confident that we really understand what they want and need. We constantly refer to them in all our development work - they help us make sure we're on the right track. ”

– Serin Hartopp, Product Manager, BiH

2. Taking care of your participants

You should have been clear before and during your sessions about what would happen afterwards, including:

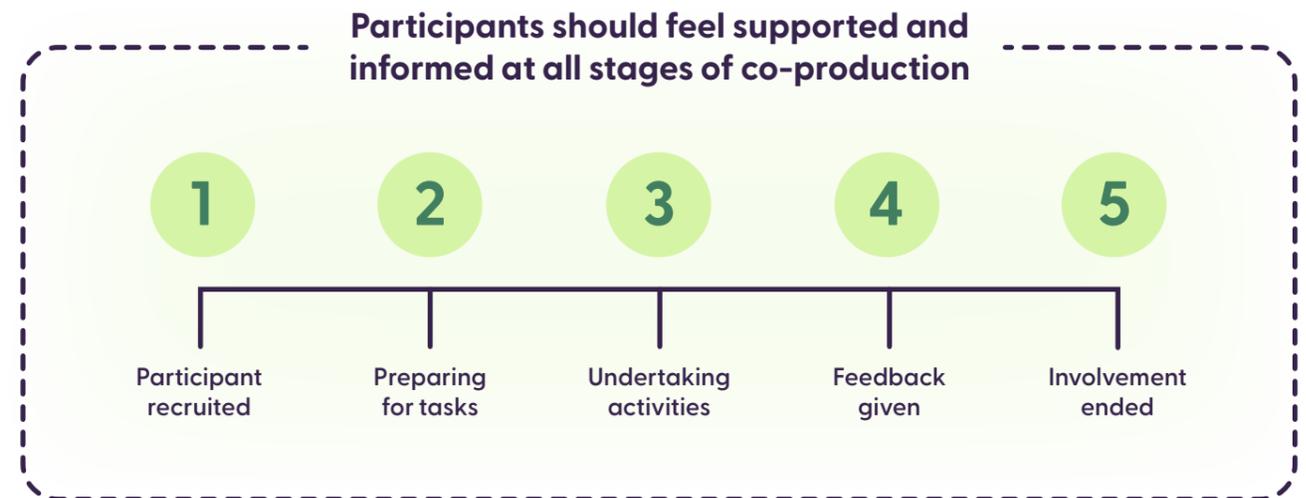
- Will there be more to do on this particular exercise?
- Might they have the opportunity to take part in other exercises in future? If so, how can they find out about these?
- What will happen with the information they provide?

To help participants feel validated, you could contact them with information about your progress since their involvement. You may or may not be able to tell an individual that their input led to a specific outcome, but even if you just show them the work to which they contributed, they will most likely be very appreciative.

Finally, you should make sure **they receive compensation quickly and without having to ask** for it.

Care through the whole process - and beyond

At all stages, including after their active involvement is over, participants should feel that they understand what their contribution is, whether they can expect any further contact, and how to contact you.



Co-production at Brain in Hand

One of the most important parts of our approach to distributing tasks among our co-production participants is ensuring that we spread them out evenly, so people hear from us regularly and don't feel we've forgotten them.

Of course, this is only if they've indicated that they want to keep participating – if they don't, we make sure to respect that.

In future, we would like to be able to send regular communications to our participant group detailing what we heard from them and specifically what changes we have made as a result.

At present, we do tell people on an individual basis when we make improvements based on their input, but we're working to make this more structured and universal.



Moving forward: co-production as business as usual

Nothing's ever perfect for everyone. The point of co-production isn't to get from nothing to flawless, but to ensure that the people who need, use, and benefit from services or products are **continuously involved in shaping those services or products**. It's an iterative process.

Getting co-production right isn't about ticking a box, but about building this engagement and involvement into your regular ways of working. Eventually, this stage should be second nature, just as much a part of how things are done as any other step of scoping, design, sign-off, and so on.

You'll likely find that it gets easier as you do more of it; like any muscle, it gets stronger when exercised.

Unlike a muscle, however, it'll get easier both for internal and external reasons. Not only will you become better at it and more accustomed to building it into projects, but you'll probably find that the first round of task design, resource creation, and

participant recruitment sets you up for the future. You'll still need to revisit and improve on these things – in particular, your participant list shouldn't stay static. It should keep including participants from a range of backgrounds within your service user demographic, and you should always aim to include some new views rather than only ever consulting familiar people. However, you may well find that you get some regular participants who come to understand what you need, and who become very good at providing it effectively.

The truth is that co-production by its nature can never be finished. It's always ongoing. And that's no bad thing, but rather something to aspire to: it just means that you'll always have the opportunity to keep making things better for the people who really need them.





If you would like to learn more about Brain in Hand and our work, please visit braininhand.co.uk. If you're interested in introducing BiH in your area, please contact our commercial director with the details below...

Mat Taylor, Commercial Director

mattaylor@braininhand.co.uk

07872 857337

braininhand.co.uk