DOING RESEARCH INCLUSIVELY:

Guidelines for Co-Producing Research with People with Disability

UNSW SYDNEY

DIIU Disability Innovation Institute at UNSW

Acknowledgements

We extend thanks to Australia's leading disabled people's organisations, disability representative organisations, co-researchers with disability, and academic researchers with expertise in inclusive approaches to research, who contributed to discussion and debate about the issues presented in these Guidelines.

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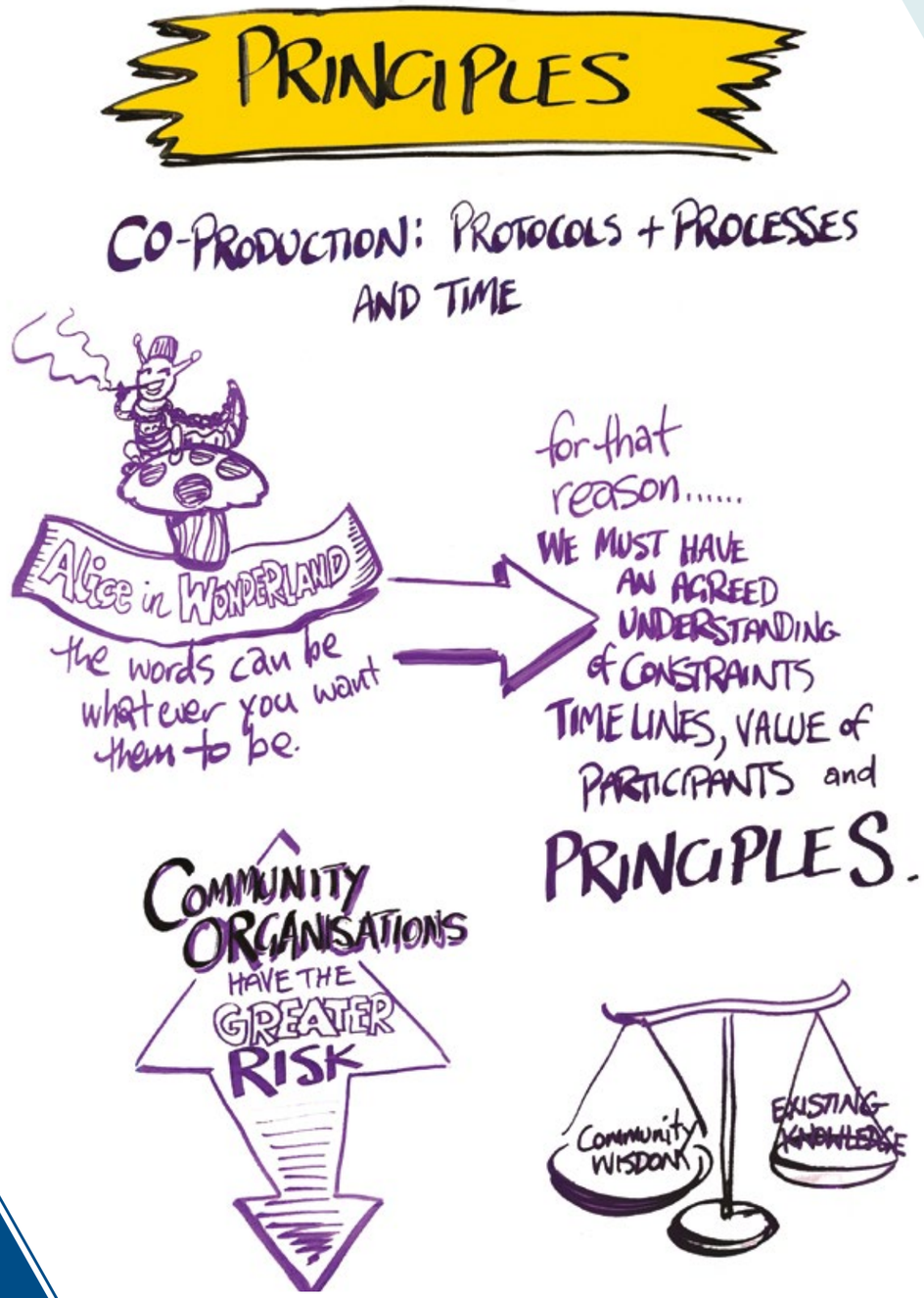
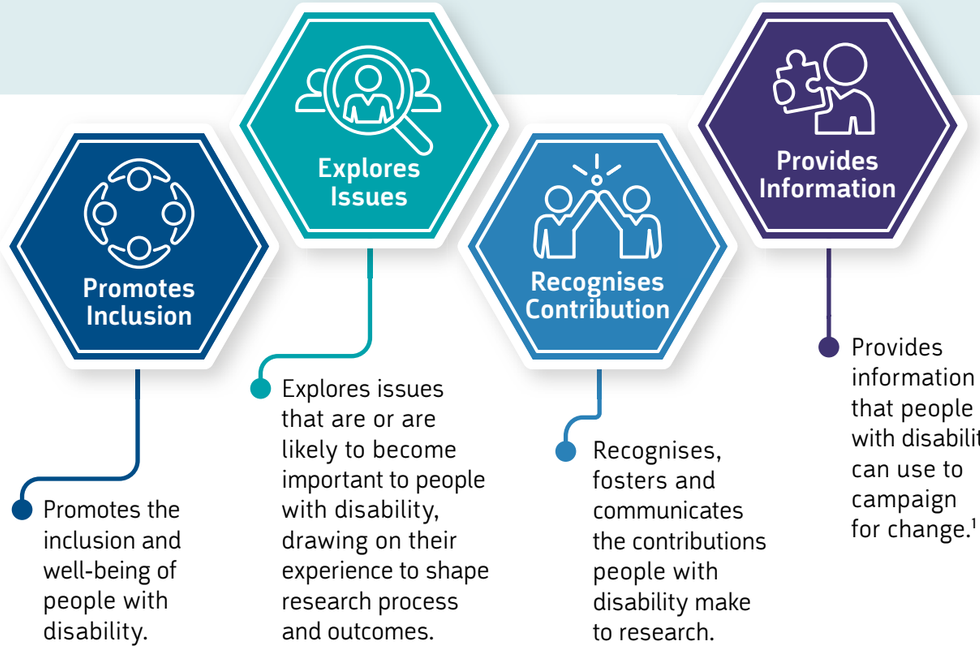


Above: Principles of Co-Production: Protocols, Processes and Time. Live capture illustration from DIIU Co-Production Workshop, November 2019. @lewkeilar

Inclusive Research Practice and Co-Production

The Disability Innovation Institute at UNSW Sydney is committed to a process of co-production to underpin our approach to inclusive research. In inclusive research, people with disability are involved not just as participants, but as co-creators of knowledge. The Disability Innovation Institute recognises that inclusive research:



We understand co-production as a process of collaboration and collective decision-making, which involves changing the relations of research traditionally separating users and producers.[2] Our approach aims to create a shared community of practice in which all stakeholders have a role in knowledge creation.[3] Our ethos is aligned with the fundamental values of co-production in emphasising genuine power-sharing[4] and a democratisation of relationships between the different individuals, groups and institutions involved.[5]

1 Walmsley, Strnadová, & Johnson, 2018.
2 Durose, Needham, Mangan, & Rees, 2017, p. 135.
3 Ryecroft-Malone, Burton, Bucknall, Graham, Hutchinson, & Stacey, 2016.
4 The Disability Innovation Institute held a workshop on co-production in disability research at UNSW Sydney on 12 November 2019, which also informed these Guidelines. At this workshop representatives of Australia's leading disabled people's organisations and disability representative organisations, offered alternative terms to 'power-sharing', such as 'power-taking' and 'power-making', which they suggested as more appropriate. Since 'power-sharing' is more widely understood and used within the literature, we felt that more discussion is needed before a generally approved alternative can be used. In these Guidelines we have therefore continued to use power-sharing.
5 Fisher, 2016.

Purpose of the Guidelines

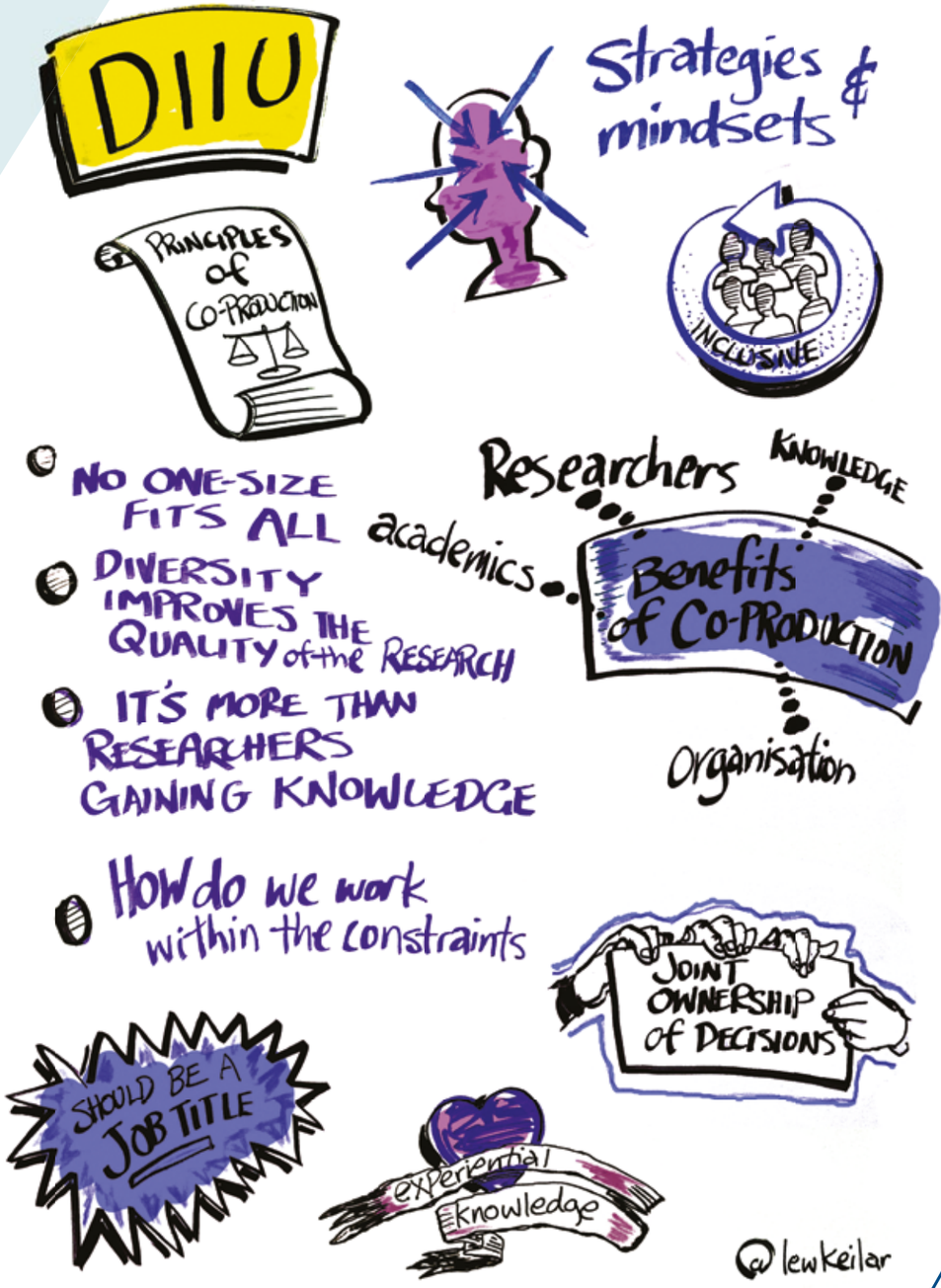
Doing Research Inclusively: Guidelines for Co-Producing Research with People with Disability has been developed for academic researchers at the University of New South Wales (UNSW Sydney) and beyond; people with lived experience of disability; disability organisations; and other stakeholders who understand and appreciate the importance of co-producing research together with people who have lived experience of disability.

This document draws on a comprehensive review of contemporary evidence in co-production. It was developed drawing on the views and experience of a range of Australia's leading disabled people's organisations and disability representative organisations together with disability researchers with expertise in inclusive approaches to research, and was particularly informed by input from participants in a workshop on co-production in disability research held at UNSW Sydney on 12 November 2019.

Terminology

The co-production of disability research brings together people from a range of different and potentially intersecting groups, including but not limited to people with disability, their families and supporters, representatives of disability organisations, practitioners, service providers, and professional researchers. These can be differentiated as academic or professional researchers and co-researchers.

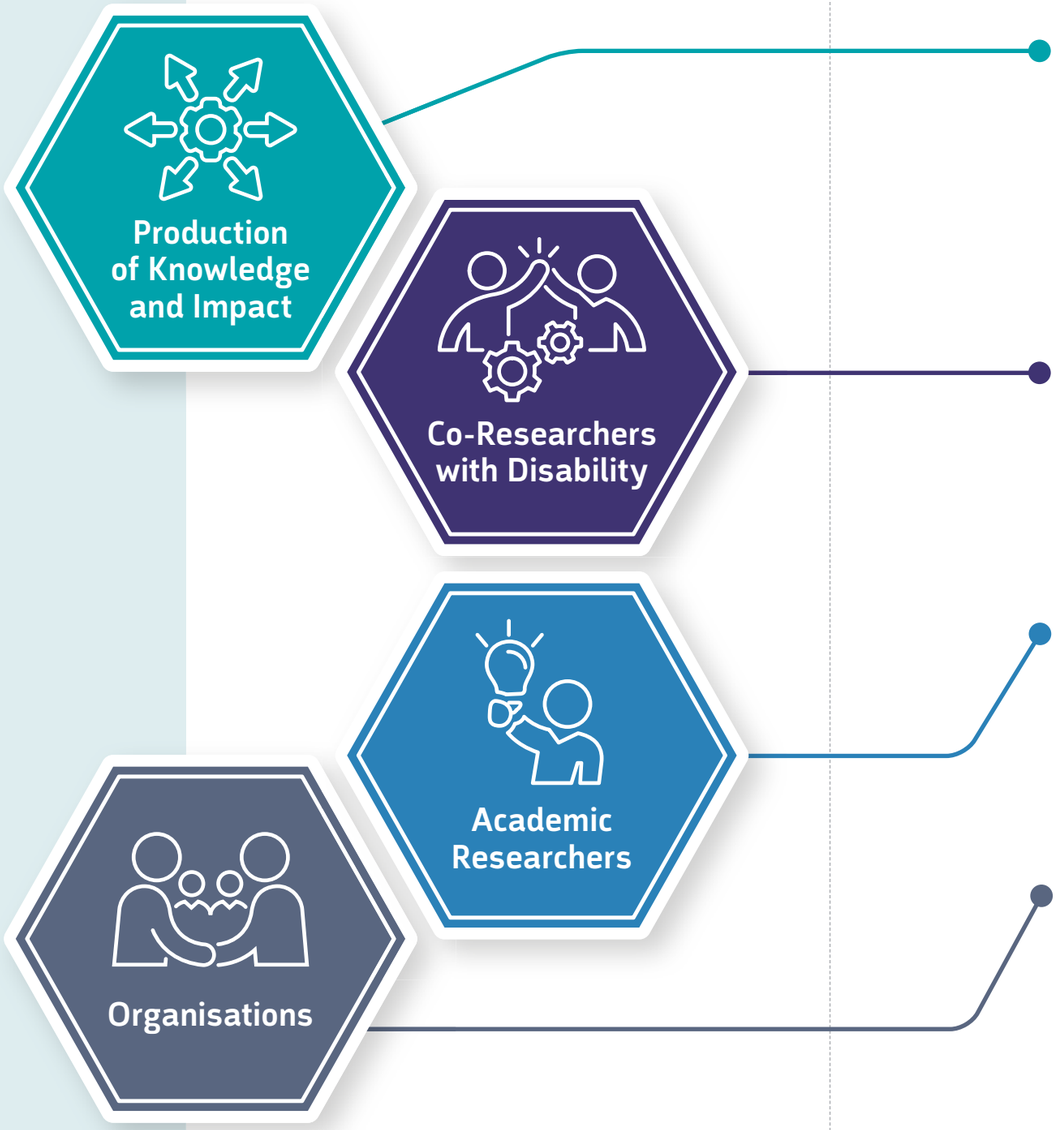
We use the term 'co-researchers' to refer to individuals involved in the co-production of research who represent any of the groups mentioned above based outside of academic or research institutions. In this sense, 'co' suggests an equal but different contribution and has the implication of 'collaborative'. There are other terms used in Australia and internationally, such as 'community researchers', or 'participatory researchers', to name just two.



Above: DIIU Strategies and Mindsets for Co-Production. Live capture illustration from DIIU Co-Production Workshop, November 2019. @lewkeilar

Benefits of Co-Production

Co-production has been shown[6] to have a range of benefits for research stakeholders and for the production of knowledge more generally:



BENEFITS FOR PRODUCTION OF KNOWLEDGE AND IMPACT

The involvement of people with disability and their communities can benefit knowledge production at many stages of the research process. For example, co-researchers with disability might anticipate barriers to participants with disability. In research teams grounded in co-production, research outputs tend to be shared in a more accessible manner and disseminated via the co-researchers' grassroots networks.[7] The co-production of research can help to ensure that the concerns and interests of people with disability and their communities are *central* to a research project, increasing opportunities for real-world *impact*.[8]

BENEFITS FOR CO-RESEARCHERS WITH DISABILITY

The co-production process itself can be a very positive one for people with disability. Research has shown that involvement in the co-production of research has the potential to: (a) empower individuals; (b) give voice and build self-advocacy; (c) provide training, skills and new job opportunities; (d) generate mutual understanding with peers and other team members; and (e) forge long-lasting networks and friendships.[9]

BENEFITS FOR ACADEMIC RESEARCHERS

For academic researchers, the co-production process can be an opportunity for personal growth and the development of new skills. For example, the process can help researchers better understand the community they are producing knowledge with and about, while learning new ways of putting knowledge into action.[10] It can also lead academic researchers to rethink (or reframe) their values, for example by moving towards a human rights perspective.[11]

BENEFITS FOR ORGANISATIONS INVOLVED

The co-production of research can be a chance to facilitate change within organisations through the development of stronger relationships with communities and/or service users. What's more, the co-production of research can help bring funding to organisations via new avenues.[12]

6 See for example Agnew, Ali, Ballentine, Canser, Connor, Jones, Laster, Muhammad, Noble, Sheehan, Smith & Walley, 2016; Amadea, Boylan & Locock, 2016; Frankena, Naaldenberg, Bekkema, Schrojenstein Lantman-de Valk, Cardol & Leusin, 2018; Nind & Vinha, 2012.

7 Community Mental Health Drug and Alcohol Research Network, 2015.
8 Amadea, Boylan & Locock, 2016.
9 Frankena, Naaldenberg, Bekkema, Schrojenstein Lantman-de Valk, Cardol & Leusin, 2018; Nind & Vinha, 2012.
10 Agnew, Ali, Ballentine, Canser, Connor, Jones, Laster, Muhammad, Noble, Sheehan, Smith & Walley, 2016.
11 Nind & Vinha, 2012.
12 National Health and Medical Research Council, 2016.

Principles of Co-Production

Co-production is best understood as a set of guiding principles. It is not a one-size-fits-all approach, nor a strict model with a fixed set of tools or techniques.[13]

Rather, it presents a pathway towards an ideal of authentic collaboration and power-sharing between academic researchers, people with disability, and other relevant organisations, individuals and communities.

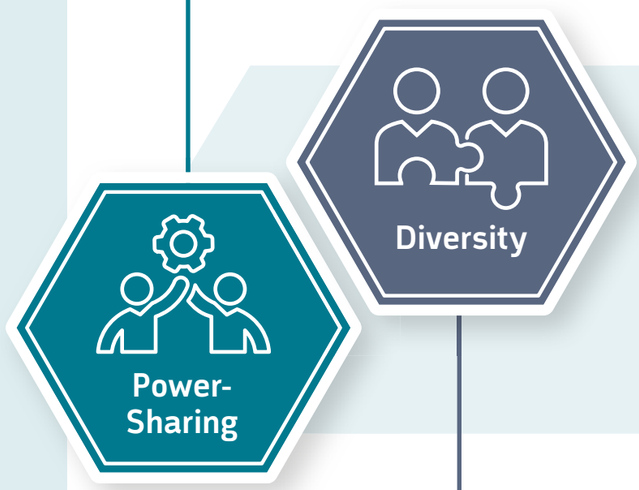
Good co-production involves finding ways of working together that as far as possible suit everybody.[14]

A number of existing guidelines suggest underlying principles that should inform co-production. For a list of these see the *Suggested Resources* section at the end of these Guidelines. The following is a summary of the key principles distilled from the literature.

13 Hickey, Brearley, Coldham, Denegri, Green, Staniszewska, Tembo, Torok & Turner, 2018.
14 Nind & Vinha, 2014.
15 Hickey, Brearley, Coldham, Denegri, Green, Staniszewska, Tembo, Torok & Turner, 2018.
16 Agnew, Ali, Ballentine, Canser, Connor, Jones, Laster, Muhammad, Noble, Sheehan, Smith & Walley, 2016.

POWER-SHARING

Power differentials between individuals and groups need to be acknowledged and actively managed. There can still be leaders, and people will necessarily play different roles within the research process. However, projects should be founded on a sense of shared responsibility and joint ownership, with methods in places to ensure collective control over the direction of the project.[15]



DIVERSITY

Different perspectives and skill sets are brought together in co-production. It is important that all voices are heard and treated with respect. There are many different types of expertise, and all can be valued for their contribution to research. Individuals can also choose to become involved in the aspects of research that best suit their interests, skills and expertise.

ACCESSIBILITY

In order to be inclusive, organisations and individuals must address barriers that may prevent or discourage involvement in co-production. The research process must be accessible. Accessibility can mean ensuring physical access. It can also mean making sure that all information relevant to the research project is made available to be shared in an appropriate way.

FLEXIBILITY

Each co-production project will have its own specific contexts and demands. The particular people and communities involved in a project will dictate the co-production strategies that need to be put in place. For example, there is a large body of literature that looks at the best ways for people with and without intellectual disability to work together in a research team (please see the *Suggested Resources* for more information). Every individual, and every community, will have different needs.

RECIPROCITY

Everybody should benefit from co-producing research. Financial recognition of time, expertise and effort is one way that people can be valued for their contribution. The process of co-production itself can be of value for all stakeholders: for example, learning from each other, building new relationships and skill sets, working towards social goods.

TRANSPARENCY

Co-production should be built on a shared understanding of the context, goals, scope and process, each person's role, and of potential outcomes. Ongoing, open communication and the building of trusting relationships help to maintain transparency. It is important to be open about and reflect on different knowledge and assumptions that individuals bring to a research project throughout the co-production process. For example, an academic researcher might bring advice on particular research methods and data analysis, while a person with a disability might bring knowledge of their community.[16]

Strategies of Co-Production

Co-production can be embedded throughout the research process – from agenda-setting and securing funding, to conducting and disseminating research.

Here, we present some ideas about ways of making co-production work, broken down according to different stages of a project.

Creating a Research Project

AGENDA SETTING

At the heart of co-produced research is the process of co-design, where all involved parties make decisions about the focus and aims of an inclusive research study, and about how these aims can be achieved. This stage also includes applying for funding and forming a team. Frameworks for collective brainstorming, for example deliberative dialogue processes, can provide a useful tool for reaching consensus on research topics and questions.

LEADERSHIP

A co-produced research project can be led by individuals representing different, potentially intersecting groups, including community members with disability, academic researchers, practitioners and/or service providers. An ethos of co-production does not require that research is led by an individual with a disability, but this can certainly be the case.[17] The leadership of a project should represent each core group who has a stake in the research. We acknowledge that the requirements of certain funders or institutions might mean that there is a sole named person as the leader. However, that can still mean that there is more collaborative leadership in practice.

BUDGETING & RESOURCES

Co-production takes time, and resources, to be successful.[18] Thus time and resources need to be factored into the project plan from the very beginning. Simple things to be considered include catering for meetings (snacks are a great way of bringing people together), venue hire, covering the cost of travel and accommodation, remuneration for co-researchers (see *Appendix A*).[19]

RECRUITING CO-RESEARCHERS

Organisations might establish, or already have, a research reference group that is not attached to a specific project. These groups made up of people with disability (and, if relevant, other stakeholder groups too) can provide input into research strategy and agenda setting, and also be part of ongoing training. These reference groups can also serve as a pool of potential co-researchers for specific projects.[20]

17 Community Mental Health Drug and Alcohol Research Network, 2015; Farmer & Macleod, 2011.
18 Roper, Grey & Cadogan, 2018.
19 Community Mental Health Drug and Alcohol Research Network, 2015.
20 Hickey, Brearley, Coldham, Denegri, Green, Staniszewska, Tembo, Torok & Turner, 2018.

THINGS TO CONSIDER WHEN WORKING WITH CO-RESEARCHERS:

Who should be on the team?

- The kinds of groups which need to be represented on the team and the attributes they should have, will depend on the nature of the project. These are important questions to ask in order to ensure a transparent process of recruitment and appointment of co-researchers.
- There is a concern that 'hard to reach' groups are not well represented as co-producers of research.[21] Use the full range of available networks to reach people who may not otherwise be involved (e.g. due to socio-economic, cultural or circumstantial disadvantage).
- How many people should be involved? It is important that there is a clear rationale and justification for the inclusion of each team member, with a clear role description. Each project will have a different optimum number of people involved.

- Clear and concise details about the project should be provided in any information shared with potential co-researchers. This may include role specifications, information about what training and support will be provided, time commitment, and covering the costs of undertaking the role of a co-researcher (see *Appendix B*).

21 Amadea, Boylan & Locock, 2016.

How should co-researchers be paid?

- It is important that people are properly recognised for the time and effort they put into the co-production of research. This is particularly important for co-researchers with disability who are not engaged in the project as part of their regular professional duties.
- Differences in recognition and remuneration for input into the project can have a significant effect on power dynamics within a group. Paying co-researchers with disability for their involvement will also help recruit a more diverse group of people.
- If co-researchers with disability are already employed by a partner organisation, the project budget allocation will recognise partner organisational costs and time. The associated project remuneration will then be undertaken through the co-researchers' organisations/ employers. If they are independent individuals, then they should be employed and paid appropriately.
- The basis on which people are employed in any project will vary and may include entering into a work contract as an employee of the university, employee of a partner organisation, or as an independent consultant. There may be cases where organisational/institutional constraints will affect the way the co-researchers are remunerated.
- Co-researchers with intellectual disability may require a support worker to undertake their work as co-researchers (e.g. prepare for meetings). Time allowance for a support worker will need to be included in a budget.

Conducting a Research Project

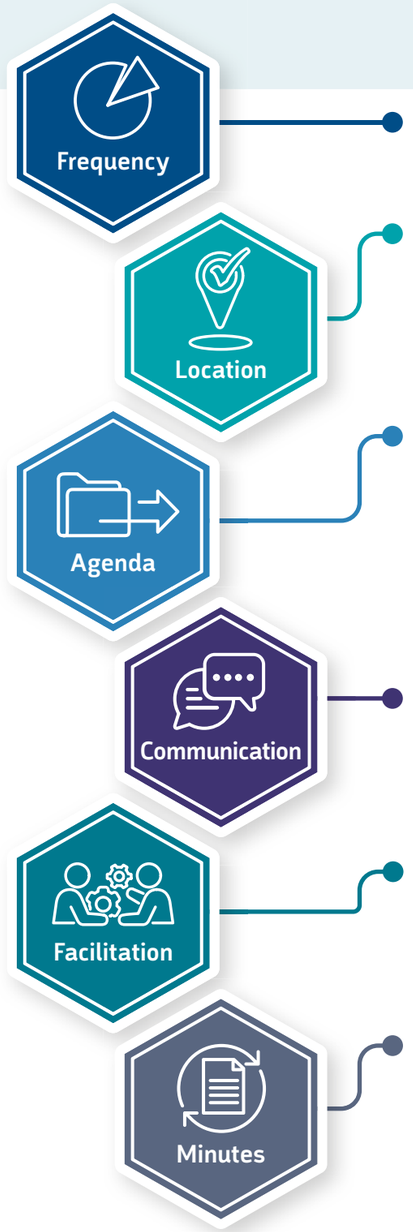
When conducting a research project we suggest attention to five key areas:

1. Planning and Running Meetings
2. Providing Training
3. Navigating Ethics
4. Joint Ownership of Key Decisions
5. Ongoing Support for the Team

1 PLANNING AND RUNNING MEETINGS

Team meetings are a time when a sense of shared ownership and responsibility is established. It is important to create opportunities where everyone can voice opinions, ask questions, provide feedback, find out about progress and future plans, and observe how decisions are implemented.[22]

When planning and running meetings, it is important to consider:[23]



FREQUENCY

Take into account people's other commitments, and fluctuating demands of the project.

LOCATION

Ensure physical access, and ease of access. Is the venue close to public transport? Is there parking on site? Are there accessible toilets near the meeting room? Would remote conferencing via online video or telephone be more appropriate?

AGENDA AND MEETING MATERIALS

Share documents well in advance of meetings and ask for input from all team members; provide documents in forms that are accessible to all participants (e.g. format accessible to screen readers, in Easy Read). Allow sufficient time for co-researchers with disability to work with a support worker to understand the content and formulate opinions prior to meetings.

GENERAL COMMUNICATIONS WITHIN THE TEAM

Make sure that all forms of communication are appropriate and accessible. For example, when planning meetings or research-related activities, it is important to remember that, for example, doodle polls are inaccessible to screen readers.

FACILITATION AND CHAIRING

Who will lead the meeting? How will they make sure that everyone has the opportunity to have a say? Ensure that all participants' accessibility needs are known and accommodated in the meeting.

MINUTE TAKING AND SHARING

Minutes are an essential way of keeping a record of different people's contributions, and how they are being put into action. Who will take the minutes? What form will these minutes be in (are they accessible to everyone)? How will they be distributed?

22 Matthews & Papoulias, 2019.

23 Note: These points have been adapted from a number of other helpful guidances, some relating to specific groups such as people with lived experience of mental health issues and people on the autism spectrum (Agnew, Ali, Ballentine, Canser, Connor, Jones, Laster, Muhammad, Noble, Sheehan, Smith & Walley, 2016; Amadea, Boylan & Locock 2016; Community Mental Health Drug and Alcohol Research Network, 2015; Cooperative Research Centre for Living with Autism, 2016).

2 PROVIDING TRAINING

Training in research skills is important for both co-researchers with disability and academic researchers alike. Training in research co-production can help establish a shared understanding for all involved. Co-production manuals could be developed to guide specific projects.

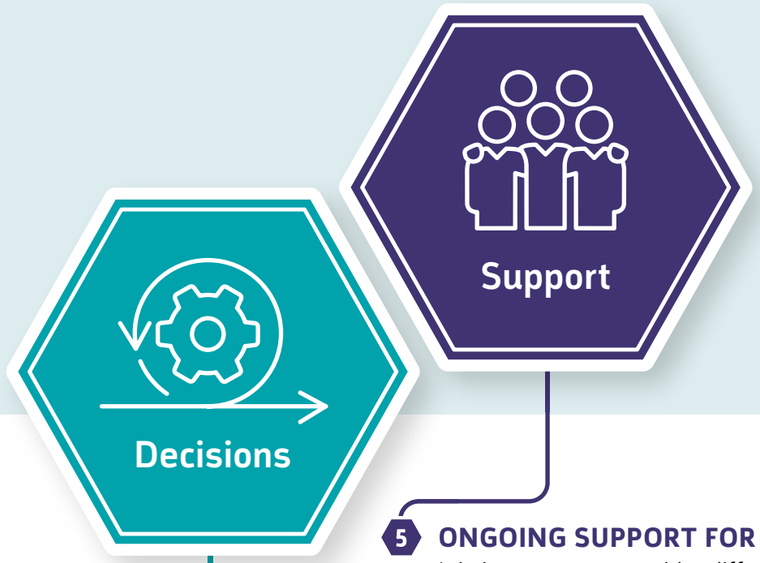
Learning about research methods can be a valued outcome for co-researchers with disability. It can also be an important step in ensuring that everyone has a say in the research design and implementation and can address the 'power imbalance' between academic researchers and co-researchers with disability.[24]

3 NAVIGATING ETHICS

Most research projects will need to be reviewed by an institution's ethical review body. Research ethics consider important things like risk and benefit for participants, and consent. Ethics review panels are generally not familiar with the co-production approach to research. Ethics and governance requirements can pose a barrier to the co-production process, for example by questioning the capacity, vulnerability and/or objectivity of co-researchers with disability.[25]

Some of the ethical principles that apply to research participants may also apply to co-researchers with disability. Ethics committees may be unfamiliar with co-production processes that include people with disability as co-researchers, and may consider co-researchers with disability as especially vulnerable. Thus, researchers and co-researchers may need to be prepared to provide additional information on co-production processes as part of their application for ethics approval.

24 Amadea, Boylan & Locock 2016, 2016.
25 Nind & Vinha, 2012; Smith-Merry, 2017.



4 JOINT OWNERSHIP OF KEY DECISIONS

Not everyone in a co-production project needs to be involved in every decision that is made. What is important is that the collective has a say in who will decide what, and when. Delegating roles and having very clear expectations about who is responsible for which elements of a project is part of this process. The team needs to establish the key decisions in the project and how all co-producers can have input.

5 ONGOING SUPPORT FOR THE TEAM

It is important to consider different forms of support for inclusive research teams:

- emotional support (e.g. access to de-briefing, mentoring or peer support);
- practical support (e.g. assistance with travel arrangements or managing out of pocket expenses); and
- research support (e.g. training and supervision in research practices).[26]

Co-researchers with disability may be supported by academic researchers and/or support workers, for example to lead, to be experts by experience, or at a more practical level with transport or understanding jargon. On the other hand, academic researchers may be supported by co-researchers with disability who provide important insights, access to networks, and help with making research accessible.[27] As co-production is a relatively new approach to research, it may be necessary for academic researchers and co-researchers to advocate together for policy change in instances where policies of universities and funding bodies are not in line with or enabling of co-production processes.

Whilst acknowledging the different ways that people may support each other, in co-production the emphasis is placed on cooperation and interdependence.

26 Community Mental Health Drug and Alcohol Research Network, 2015.
27 Nind & Vinha, 2014.

THINGS TO CONSIDER WHEN WORKING WITH CO-RESEARCHERS:

What are the best ways to engage the team?

- Build rapport among team members through personal check-ins; provide drinks/snacks and schedule social time into meetings (team-building rituals are important).[28]
- In longer meetings, plan for regular breaks and make a space for time out.
- Check in with people about how they want to be referred to in any reports or in meetings.[29]
- It's crucial that people feel supported to participate and be included. Different individuals will have specific support requirements: find out what they are and make suitable adjustments to the process and content.

Continuous reflection on the process of working together can be a source of 'data' about how co-production works.[30] Team meetings focused on reflective discussion about the research and co-production process or reflective diaries are examples of gathering this kind of information.

28 Clarke, Waring & Timmons, 2019; Crompton, 2019.
29 Inclusive Research Network, 2018; Nind & Vinha, 2013.
30 Hickey, Brearley, Coldham, Denegri, Green, Staniszewska, Tembo, Torok & Turner, 2018.

How do I keep the team safe?

- It is important to ensure that people involved in co-production do so on a voluntary basis and understand that they can withdraw at any time.[31]
- Power imbalances within a research project can create instances of potential coercion. For example, when a service provider is involved in a research project, service users might not always be free to leave that service and participation in the project might increase vulnerability.
- It's also important that any risks resulting from the co-production process are managed and openly discussed. For example, a clear plan should be in place that describes how to respond to the potential conflict of interest or emotional distress of team members.[32]
- Co-researchers with a lived experience of disability may find their lived experience both an asset and a potential challenge, particularly if conducting interviews or other forms of primary research with their peers. Self-disclosure is one issue they may need to consider. Clear guidelines can support co-researchers with disability to decide when and how much to disclose; and to reflect on appropriate boundaries.[33]

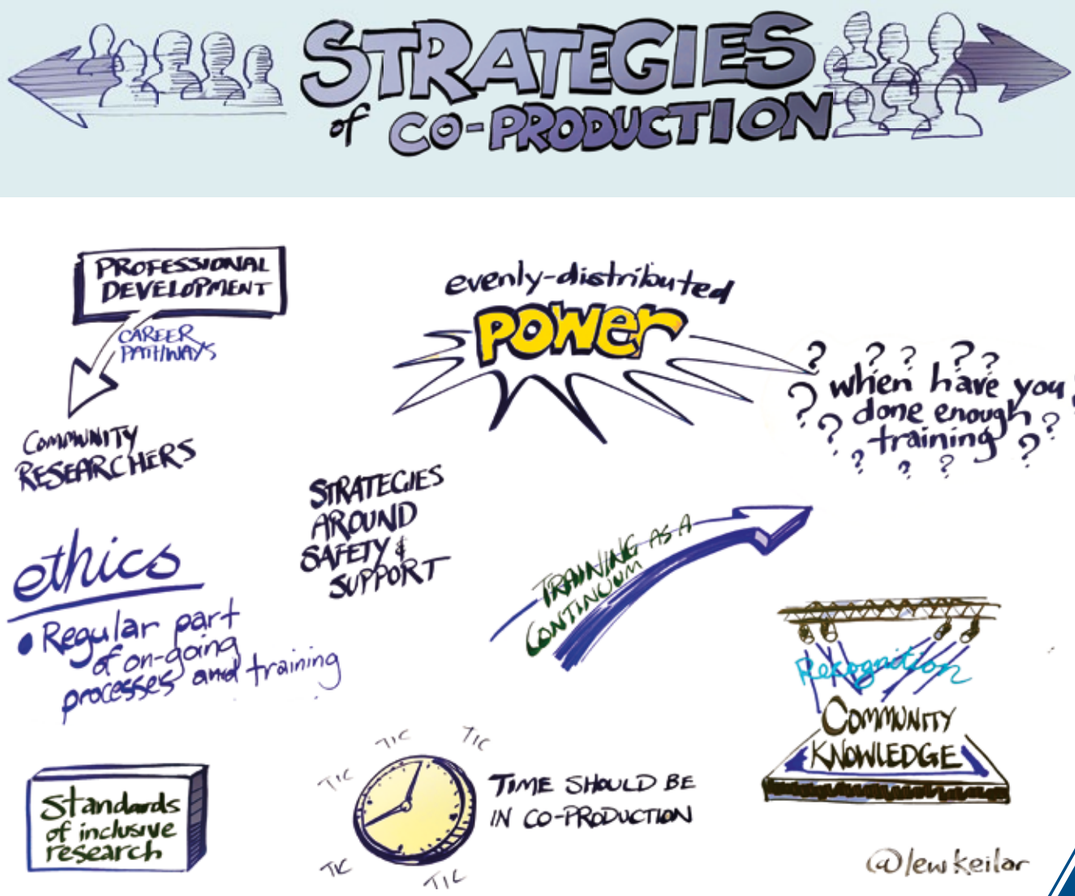
31 Community Mental Health Drug and Alcohol Research Network, 2015.
32 Community Mental Health Drug and Alcohol Research Network, 2015.
33 Community Mental Health Drug and Alcohol Research Network, 2015.

Evaluating the Impact of a Research Project

The impact of co-production in research can be understood on two levels. For one, the process of co-production itself can have intrinsic value for those involved, and its ethos of power-sharing and collective control can have a ripple effect that impacts the culture of organisations and institutions. The process can also have an impact on the outcomes of research – for example, increasing relevance and reach.[34]

It takes extra time and resources to do co-production: assessing impact is therefore an imperative if co-production is to be justified to funding bodies and policy makers. Assessment of impact is also important to improve how co-production is understood, carried out and evaluated.[35]

34 Staley, 2015.
35 Staley, 2015.



Above: Strategies of Co-Production.
Live capture illustration from DIIU Co-Production Workshop, November 2019. @lewkeilar

Evidence Base

Alford, J. (2014). The multiple facets of co-production: Building on the work of Elinor Ostrom. *Public Management Review, 16*(3), 299–316. https://doi.org/10.1080/14719037.2013.806578

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Appendix A

Co-Produced Research: Budget Template

Co-Researcher Compensation	Estimated	Actual	Notes
Co-Researcher 1			
Co-Researcher 2			
Total			E.g. Casual employment at rate X, for N hours

Meeting Expenses	Estimated	Actual	Notes
Venue Hire			
Catering			
Travel and Accommodation for Attendees			
Printing and Other Supplies			
Total			

Research Expenses	Estimated	Actual	Notes
Research Assistant			
Payments to Participants			
Total			

Appendix B

Project Information Template

PROJECT TITLE:	
Project Description:	This co-produced research project aims to address...
About Your Role:	As a co-researcher you will be involved in...
Training and Support:	We value your expertise across all stages of the research, and will support you to access the information and tools you need to complete the project through...
Approximate Time Commitment:	X hours, over N months
Meeting Information:	Dates/times: Location:
Salary:	
Out-of-pocket Expenses Associated with the Role of Researcher/Co-Researcher:	
Contact Information for Project Leaders:	Lead 1: Lead 2:

Notes

For more information and further resources visit:
www.disabilityinnovation.unsw.edu.au

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