## Guide to Co-Design with people living with disability



## "Co-design is a good example of 'by us, for us."

 Jane, member of the co-design group that helped to design this guide

#### What is co-design?

Co-design is an inclusive, collaborative process whereby a diverse range of people with relevant skills, experience or interests come together to provide advice and make decisions on a project, policy, program or initiative.

A meaningful co-design process will run throughout the life of a project – from the planning stage through to implementation and review.

Co-design is used across a range of different sectors and is not disability-specific. When used in the disability sector, it is important that the co-design group includes people with a range of different experiences of disability, in addition to other aspects of diversity (such as age, gender and sexual identity, location, cultural background and language). The remaining members of the co-design group will depend on the nature of the project but could include end-users, beneficiaries, representatives from the funding body (if relevant), affected stakeholders and/or subject matter experts.

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#### Co-design v consultation

Co-design is different to consultation. Consultation is a process whereby relevant stakeholder views are sought but the decisions are made by others. Co-design is a process whereby relevant stakeholder views contribute not only to the thinking but also the making of decisions.

If you are planning to deliver a consultation, we recommend convening a co-design group to support this process. For example, a co-design group could help to advise on outreach and consultation methodology, analyse the data received and formulate recommendations.

# Stakeholder views are considered but decisions are made by others

### Who should use co-design and when?

Co-design should be used by any individual, group, organisation or government body that is making decisions or undertaking work that will affect the lives of people living with disability.

Co-design should be used by any individual, group, organisation or government body that is making decisions or undertaking work that will affect the lives of people living with disability. This includes businesses, service providers, research institutions, public services such as hospitals and schools and all levels of government, including local Councils.

Through the National Disability Strategy 2010–2020, the governments of Australia committed to 'work collaboratively with people with disability and their representative organisations, their families and carers, communities, unions, businesses, service providers, advocacy and other organisations in the development of programs, policies and systems that affect people with disability.' (p67)

Co-design should not only be used for disability-specific projects, policies or programs. People living with disability are an important part of our diverse communities – they access mainstream services and facilities and are affected by laws and policies that apply to the general population. They need to be involved in disability-specific decisions, but also decisions that affect the wider community.

Co-design can be used in a wide range of circumstances such as planning an event, constructing or renovating a building or facility, developing or reviewing a policy or program, conducting research or delivering services. Some examples might include:

- Planning an awards ceremony
- Constructing a new community hall
- Reviewing a policy for after-school care at a primary school
- Developing a new computer literacy program at a local library
- Conducting a needs assessment about people living with intellectual disability
- Developing a new vaccination programme
- Reviewing the way in which customers of a mainstream service receive their bills.

#### Why use co-design?

Co-design can have far-reaching benefits for the organisers, group members, end-users/beneficiaries of a project, disability community and general community. Potential benefits include:

- Achieving a stronger result which draws on a wide range of perspectives, experiences and expertise;
- Encouraging greater ownership of (and interest in) the outcomes by all stakeholders involved, including the disability community;
- Increasing the community's understanding of the reasoning behind key decisions;
- Testing ideas with intended users/beneficiaries;
- Upholding the rights of people living with disability, consistent with the UN Convention on the Rights of Persons with Disabilities (UNCRPD);

UNCRPD, Article 4(3): 'In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, **States**Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations.'

- Reducing the cost of remedying mistakes by designing well from the start;
- Identifying and mitigating potential issues early;
- Demonstrating the organising body's commitment to incorporating the views of relevant stakeholders;
- Providing a platform for networking among different stakeholders; and
- Demonstrating to the wider community the valuable contributions people living with disability can make, as core members of a co-design group.









#### Key co-design principles

- Respect: All participants feel welcome and are treated with dignity and respect.
- Diversity: A diverse range of participants are involved, where possible representing different ages, cultures, languages, locations, sexual and gender identities and experiences of disability.
- Equality: All participants have an equal voice and their contributions are afforded the same weight.
- Safety: Participants feel safe and supported and do not fear retribution for contributing to the co-design process. Group input is not attributed to any individual member without permission.
- Accessibility: The co-design process is accessible to all participants.
- Commitment: The organisers are genuinely committed to co-design throughout the duration of the project – from planning through to implementation and review.
- Authenticity: The process is meaningful; it is designed and implemented in a way that ensures the input from participants is incorporated into the final product.
- Confidentiality: The material shared by the organising body, and by group members throughout the co-design process, is treated confidentially and not discussed outside the group.
- Acknowledgement: The skills and experiences of all participants are acknowledged and valued, including through consideration of payments or honorariums for people participating in a personal capacity.

#### How to run a co-design group

#### 1. Planning

- Ensure sufficient budget to run a co-design process
   (e.g. room hire, catering, honorariums for members contributing
   in their personal capacity, any access needs and transport costs
   of people living with disability).
- Decide who will lead the process and facilitate meetings (facilitators need strong skills in active listening, group facilitation, and reconciling contrasting views to reach agreeable decisions).
- Define the scope of the group's work and expectations of group members.
  - How many times will the co-design group meet? Consider the length of the project, key milestones, key deliverables etc.
  - How could the group most usefully contribute? For example, the group's work could include the following: brainstorming ideas, identifying issues and challenges, developing a project outline, defining methodology, reviewing material, promoting the project, reviewing the outcomes, etc.
  - Ideally, develop Terms of Reference for the co-design group (see template on page 16).
- Identify key stakeholders to join the co-design group (we recommend 6–8 members).
  - Which disability experiences should be represented on the group? Consider the nature of the project, but generally include someone from each of the following cohorts: people living with physical disability, Deaf people, people who are blind or vision-impaired, people living with intellectual disability, autistic people, and people living with acquired brain injury or other neurological conditions.
  - Which other aspects of diversity should be represented in the group? Consider age, gender and sexual identity, cultural background, language and geographical location (i.e. regional/rural/remote as well as metro).
  - Who will be responsible for implementing the project?
  - Who will benefit from/use the final product?
  - Who else will be affected by the project?
  - Who has been involved in similar projects in the past?



## Need help finding co-design participants?

If you don't have sufficient connections with the disability community, contact organisations that represent the cohorts you would like to connect with (e.g. organisations representing blind people, people living with intellectual disability).

JFA Purple Orange has a database of people who have told us they would like to be involved in co-design processes. Feel free to get in touch and we can help you find the right people.



TIP: People living with disability are best placed to know what they need to participate. All you need to do is ask!

You could contact participants with simple questions such as:

- What is the best way to share information with you outside meetings?
- How can we best support you to participate in meetings?
- Do you have any other access needs we should know about to support your involvement?

#### Meeting preparation

- Convene the first co-design meeting as soon as possible in the life of a project, ideally from the conceptualisation stage.
- Offer different ways for people to take part in meetings e.g. online and in person.
- Organise two-hour meetings (maximum) with a break. This allows time for all participants to have a voice, without being too physically and mentally drained.
- Prior to the first meeting, contact all participants and ask whether they have any access needs (e.g. Auslan interpreter, live captioner, hearing loop). Some people might ask to bring their support worker or an assistance dog. Others might ask to have someone sit with them to help them follow the material. Ensure the meeting venue is accessible to all participants, including toilets.
- As a general rule, do not plan meetings at peak times as it can be difficult for people who require an access cab to secure one (e.g. start a meeting at 10am rather than 9am, and finish at 4pm rather than 5pm). Prior to the first meeting, ask all participants which time of day works best for them.
- Communicate with participants living with disability in whichever way works best for them, noting that accessibility requirements can be very personal.
- If you will present information or distribute handouts at the co-design meetings, check with participants living with disability to find out their preferred format. For example, a participant who is blind or vision-impaired might prefer to receive documents electronically beforehand, so they can go through them using a screen reader. Others might need documents printed in larger font. Some participants, particularly those living with intellectual disability, might not use technology or might not be able to read. In these instances, consider mailing out a hard copy or an audio recording, or offer to speak over the phone to read out the material and discuss. Other participants might need material to be converted into Easy English (various organisations provide this service). Consider also the use of graphics or visual aids.
- Send all electronic documents in both PDF and Word.

- Provide an agenda prior to the meeting (see template below)
  and set out clear expectations for participants, including any
  questions they will be asked during the meeting. Some people
  living with disability can feel anxious if they do not have a clear
  idea of how the meeting will proceed ahead of time.
- Make sure that each meeting builds on the last. Begin each meeting with an update on how the group's input has been used so far.

#### 3. Hosting meetings

- Set up the room in a way that is accessible for all participants.
   For example, if you have a participant who uses a wheelchair, leave a space without a desk chair where they can sit. If someone is bringing an assistance dog, leave some extra space for the dog. If someone is blind or vision-impaired, or is Deaf or hearing-impaired, reserve a space in the room that gives that person the best proximity to visual material, audio, interpreter, etc.
- Treat all participants equally, irrespective of their professional status.
- Consider starting the first meeting with a short icebreaker so that participants get to know each other.
- Establish some rules about how participants can contribute to the discussion, for example by raising their hand before they speak. This can be particularly helpful if you are holding the meeting online. Make sure there are alternative ways for people to request to speak if they cannot physically raise their hand. Alternatives are also important if the meeting chair/facilitator is blind and cannot see people raising their hands.
- Speak directly with participants who live with disability, not their support staff (it can be a good idea to ask any support workers to sit at the back of the room). This also applies to interpreters.
- Invite feedback from all participants. It is important not to pressure people, but also to recognise that some may not speak up unless prompted.
- Ask everyone to say their name each time they speak, as
  participants may vary in their capacity to recall people's names
  or read name tags. This will also make it easier for participants
  using live captioning to follow the conversation.
- If you are holding the meeting online, make sure you or someone else from your organisation is monitoring any chat functions in the virtual meeting room.



- If you would like to record the meeting, check whether participants are comfortable with this at the start of the meeting. Before obtaining consent, explain how you will use the recording (e.g. for preparing notes and minutes from the meeting), how you will store the recording (so people know it is secure and private), who else will be able to listen to it and why, and what will happen to the recording once the co-design work is completed.
- Seek feedback from co-design members at the end of each meeting, as they might have useful suggestions to improve the co-design process in future.

#### 4. Follow-up

- Send minutes from each meeting to all participants, in their preferred format.
- Send updates to the co-design group throughout the project, demonstrating how their input has been used e.g. share any reports, policies or procedures that include their ideas.
- If you include ideas generated by the co-design group in a final product, recognise their contribution. This may take the form of a written acknowledgment in a printed publication, a voiced acknowledgment in an audio recording, or a voiced and captioned acknowledgment in a video clip.
- Reimburse any transport costs and arrange payment or honorarium recognition for co-design members participating in their personal capacity in a timely manner after each meeting.

Invite feedback from all participants. It is important not to pressure people, but also to recognise that some may not speak up unless prompted.

### Examples of co-design groups used by JFA Purple Orange

#### • Designing a community garden:

A group of people living with disability, Council staff and representatives from community gardens came together in a one-off co-design meeting to discuss the design of a new community garden, to ensure that a diverse range of access considerations were taken into account.

#### • Developing a new training program:

A group of people living with disability and representatives of local government, state government, community centres and community organisations supported the development of a disability inclusion training program through five co-design meetings over a 12-month period. They gave input on content, methodology, recruitment of trainers and promotion of the program.

#### • Undertaking a research project:

A group of people living with disability formed a co-design group to provide advice regarding methodology, research design and recruitment for a large research project for a Royal Commission inquiry.

#### Carrying out a large-scale consultation:

A co-design group of people living with disability met four times throughout a six-month, large-scale community consultation process to inform a state government's inclusion plan. The group provided advice on methodology for consultation sessions and helped to analyse the data received and convert this into recommendations for government.







#### **Questions or feedback?**

JFA Purple Orange welcomes feedback on this guide. We are also available to provide more detailed advice on how to use co-design in your circumstances. Feel free to contact JFA Purple Orange at 8373 8333 or admin@purpleorange.org.au.



#### Co-Design meeting agenda template

- 1. Acknowledgement of Country
- 2. Housekeeping (location of bathrooms, emergency exit, tea/coffee/water, timing of breaks)
- 3. Introductions and ice-breaker
- Co-design group norms
  - a. Explain what co-design is: Co-design is an inclusive, collaborative process whereby a diverse range of people with relevant skills, experience or interests come together to provide advice and make decisions on a project, policy, program or initiative.
  - b. Set some group norms together (e.g. equal voice, respect for all opinions, constructive input only, one person speaks at a time, confidentiality of content presented to the group as well as opinions offered by group members)
- 5. Background to the project
  - a. Explain the rationale for the project, who has provided funding, the role of your organisation, desired outcomes
- The role of the co-design group 6.
  - a. Explain the expectations of co-design group members and share a draft Terms of Reference for discussion:
    - Duration of project and number/timing of co-design meetings
    - Topics to be covered in each meeting ii.
    - Group tasks, including prior to/after meetings as applicable
- 7. Discussion topic one
  - a. Ask question(s), open the floor, record discussion
- 8. Discussion topic two
  - a. Ask question(s), open the floor, record discussion
- 9. Thank you and close
  - a. Remind the group of the next steps





## Co-Design terms of reference template

#### Context

- Background to your organisation
- Background to the project: funding source, objectives, role of your organisation, deliverables

#### Background to co-design

- Definition: Co-design is an inclusive, collaborative process
  whereby a diverse range of people with relevant skills, experience
  or interests come together to provide advice and make decisions
  on a project, policy, program or initiative.
- Key co-design principles:
  - Respect: All participants feel welcome and are treated with dignity and respect.
  - Diversity: A diverse range of participants are involved, where possible representing different ages, cultures, languages, locations, sexual and gender identities and experiences of disability.
  - Equality: All participants have an equal voice and their contributions are afforded the same weight.
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#### **Membership**

• The co-design group will comprise a range of stakeholders including people living with disability, ... [list stakeholder groups]

#### **Group tasks**

- Co-design group tasks will include (but are not necessarily limited to) the following:
  - Task 1
  - Task 2
  - Task 3

#### Schedule of meetings

- Group meetings will be held on the following dates and will cover the following topics (subject to change):
  - Meeting 1
    - Date and time
    - Topics to be covered
  - Meeting 2
    - Date and time
    - Topics to be covered
  - Meeting 3
    - Date and time
    - Topics to be covered
  - Meeting 4
    - Date and time
    - Topics to be covered
  - Meeting 5
    - Date and time
    - Topics to be covered
- Co-design group members may be requested to review material and provide input outside of formal meeting times.

Co-design is an inclusive, collaborative process whereby a diverse range of people with relevant skills, experience or interests come together to provide advice and make decisions on a project, policy, program or initiative.

#### Format of meetings

• Co-design group meetings will be held [in person or online] at [insert address or online platform].

#### Term of the group

• The co-design group process will commence in [insert month and year] and be completed by [insert month and year].



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