



Global COVID-19 Childhood Disability Tips for Organising and Conducting Listening and Sharing Sessions

The following tips on organising and conducting “**Listen and Sharing Sessions**” has been created by the Global COVID-19 Childhood Disability “Listening and Sharing committee”. We are a collaborative initiative of the International Alliance of Academies of Childhood Disability (IAACD), hoping to assist both professionals and consumers in hosting their own listening and sharing sessions. We welcome input from families, children, clinicians and researchers. Please feel free to email any suggestions to add to this tip sheet to aspittle@unimelb.edu.au

Please note the advice in this document is general and we recommend you check with your local laws, regulations and ethical requirements in regards to privacy and security.

What is a “listening and sharing” session?

“Listening and sharing sessions” are a way to promote open and honest communication across a group of people and provide useful information for taking action. The main emphasis of a **listening and sharing** session is to share experiences, and to do this we need to **listen to a range of perspectives**. Listening and sharing sessions are not webinars (which are usually educational like a lecture).

For a listening and sharing session, it is important to identify the specific topic, the target audience and outcome/s anticipated, and generate conversation and exchange between the audience and organizers of the session.

Who is the audience and how to chose a topic?

It is essential to define the **target audience** for the listening and sharing session, which could include children and/or families of a child with a disability or clinicians/researchers working with children with a disability.

The **topic** will depend on the audience and below are some suggestions.

1. Families of children with a disability

- Experiences of parenting a child with a disability during COVID-19
- Schooling during COVID-19 – home schooling, and returning to school
- Engaging in therapy during COVID-19
- Enjoying your child and seeing them in a new light

2. Children with a disability

- Staying connected with friends during COVID-19
- How to find fun and fight boredom during a lockdown
- Schooling during COVID-19
- Engaging in therapy during COVID-19

3. Clinicians working in childhood disability

- Understanding the impact of COVID-19 on service delivery and staff wellbeing
- Using telehealth during COVID-19: lessons learnt and where to for the future
- Advocating for services for children with disabilities during COVID-19 and into the future

4. Researchers working in childhood disability

- Understanding the impact of COVID-19 on the research landscape
- How can we adapt our research protocols, including assessments, due to COVID-19 restrictions
- What are the research priorities for services for children with disabilities and their families during COVID-19, and into the future (consumer involvement recommended)

Organisation needed prior to the session

Define the goal(s) of your session

- Clearly define goals and expected outcomes of the session. An example for a family session: “Our goal is for families of children with disabilities to listen to one another, and share their experiences in relation to COVID-19, and collectively identify priorities for advocacy”; or for clinicians: “Our goal is for clinicians to share our experiences, to learn what has worked, what has not worked and what learnings we can take into the future”.

Delegate a host and support roles

- Delegate a **host** (a person to lead and moderate the discussion) and **support person/s** (to assist with technology and monitor chat/interactive functions) and keep notes. For the sessions with families, it may be an idea for the host to be a parent of a child/adolescent with a disability to facilitate more open conversations.

Plan the format of the session

- The format of the session is flexible and could include: a number (2-5) of short presentations (e.g., lived experiences of families with children with disabilities, professionals reporting on outcomes of other COVID-19 surveys of families’ responses to COVID-19, and/or other topics) followed by open discussion. You might give the audience a number of questions/themes to discuss during the session (e.g. “Tell us about your experience, what are your worries, what are your challenges, what has surprised you, what should we be advocating for?...”). Ensure there’s plenty of time for open discussion and active listening rather than too many people formally presenting.
- As per above, encouraging participants to complete a short survey with a few key questions prior to the session can allow themes to be identified for the host to lead discussion, and to identify potential future sessions.
- The duration of the session (e.g. 60 minutes, 90 minutes) should be made clear prior to the session so participants know how much time is required. This especially important for families who may need to organise other care arrangements.
- Decide whether you are going record the session (*pros*: the session can be viewed by others post and used for advocacy with consent; *cons*: some people may be conscious of being recorded and therefore not speak honestly). It’s essential to have consent if recording is going to occur and inform participants prior to the session.

Technology

- Technology: examples of useful platforms include Zoom, Webex, Microsoft Teams and Facebook live. Check how many people can join the session and use a password to ensure a secure meeting (for platforms such as zoom). Consider the audience when choosing the platform, families might be more familiar with facebook (although not as private), whereas Zoom/Microsoft teams/Webex maybe more familiar to professionals. It may also be possible to livestream a session to the Facebook or YouTube account of an organisation – this may make the session accessible to more people. Check with your local laws and organisation about privacy and technology regulations.

Advertising and registration

- Registration prior to the session is recommended so that you have contact details of participants. Whilst these sessions are not designed to provide specific medical/therapeutic advice, it is particularly important to ensure you can follow-up on any concerns that are raised during the session that seem to need follow-up (e.g. safety concerns).
- The registration form can include questions such as what the participant's profession is; are they a child or family member; country of participation; and relevant contact details such as email. This could include pre-session questions as per above to survey the audience. If the session is to be recorded, you can use the registration form to gain consent.
- If the session is to be recorded, this should be mentioned in advertising, along with whether participants can watch the session after the live recording.
- Make posters/flyers to advertise on social networks such as Facebook, twitter, and whatsapp groups, to report on: the topic, speakers, date, time, platform to use.
- Allow time (e.g., 2 weeks) for advertising and for people to block out time in their diary/organise care if needed.
- Once registered - email participants, with instructions and the access link to the platform.

Practice/ briefing session

- Listening and sharing on these platforms may be new to many people. To help the presenters/panelists feel more comfortable, it may be useful to have a practice session a day before the live session. This helps familiarise presenters with the platform, and they are introduced to each other.

Inclusion

- To be as inclusive as possible and listen to the views of diverse families – in situations where a parent cannot access Zoom/Webex/Teams and be part of the live session, it may be an idea for a family, child, clinician or researcher to pre-record their presentation on whatsapp and to send it through to the moderator. This obviously limits certain participation, if they do not have access, but at least their views and perspectives will be heard.
- Consider whether you will need captioning and/or extra time to allow children additional time to express themselves (e.g. when using AAC)

During the session

The role of the host is to facilitate the session and inform participants of etiquette of the session.

At the beginning

The host should introduce themselves and the purpose of the session. Explain the ground rules for the session, including:

- Orientate listeners to the platform
- Recording: Let the audience know if you are recording the session. Inform participants they can turn off their video and not participate in chat/online comments if they do not wish to be recorded.
- Mute microphones when not talking – and show people how to do that.
- Turn video off if connection is poor but ideally to keep it on to improve engagement, use of chat/interactive functions
- Explain how people should indicate that they would like to talk next (e.g. put their hand up, or the host will ask people to speak in certain order). Describe the 'chat' function available on most platforms.
- Safe space: everyone should have the right to speak without being interrupted. Everyone's experiences and perspective are important, even though they may differ to our own. If anyone feels uncomfortable during the session, please send the moderator a private message if you do not want to communicate concerns with the wider group
- Purpose of the session: ensure that the participants understand the purpose of the session and proposed outcomes. This is a **listening and sharing session** and will not involve individualised medical and therapeutic advice.
- Outline the format of the session: e.g., brief set presentations, followed by listening, with open questions throughout. Encourage participants to use chat function during session or write down notes to ask during talks for later question time.
- Inform everyone that it might take some time for some children to express themselves (e.g., when using augmentative communication aids).
- Recording the session – remember to press the record button when the session starts. You don't necessarily want to start recording when the meeting opens and participants are coming online; the recording should start when the session starts.
- Host to facilitate questions with the assistance of the moderator. Try to ensure everyone who wants to speak has the opportunity. Some people may prefer to use the chat function rather than speak.
- When opening the discussion, consider using an "icebreaker" question to stimulate discussion, such as (in a session with children) "What's been the best thing about (not) going in to school?"

At the end of session

- Summarise main themes and action points, if any, and who will be involved in the 'action'.
- Provide contact details if further questions, comments, debriefing etc needed
- If the session is recorded, ensure the host saves the recording and let people know where and how the recording will be available.



Post session

- If session was recorded, listen back to session to identify key themes.
- If making the session available to an audience post-recording, ensure all content is appropriate to be accessible. It may be helpful to send the recording to the main speakers and check that they are happy with it, and if anything needs to be edited out.
- Follow-up email to participants as necessary.
- Keep participants updated on possible actions/decisions/advocacy you might undertake
- Identify participants who might want to have continued involvement as appropriate