



Listen Include Respect

Summer School August 2026

This report covers the topics members discussed during the Listen Include Respect Summer School in August 2026.

The sessions brought together members from across our network.

Self-advocates, family members, and organisation staff worked together in the online meetings. At the end of this document, you can find a list of participants.

The group talked through four parts of the guidelines:

- Session 1 (4th August) — Introduction to Listen Include Respect and the eight principles
- Session 2 (11th August) — What good support means
- Session 3 (18th August) — Inclusive meetings
- Session 4 (25th August) — Self-advocacy leadership and inclusive governance

Key topics from the sessions

Under each topic, we have added quotes from the meetings as well as good examples or practices members shared.



Inclusion is a journey

“Inclusion is a Journey” is a principle of Listen Include Respect. It means that inclusion is a long process that takes time. You don't need to be perfect to start your work on inclusion, and the end goal will always be changing.

Members agreed:

“No organisation is going to be ready or is going to be the best even if you want, right away.” (Alejandra, Session 2)

“People and groups can come around, and some will eventually get it, maybe not all, but some, and so it really is a journey.” (Dawn, Session 1)

Examples from members:

- For the first time, Colombia has a National Disability Council member with an intellectual disability. Alejandra said the hard part is keeping it going. Councils *“sometimes forget about intellectual disability. So we’ve got to say, hey, we’re here, we need this support, we need Easy Read”* (Session 1).
- Down Syndrome South Africa. People with intellectual disabilities take part in national and regional committees, planning meetings and awareness campaigns. Maria was honest about what is not there yet: *“They’re not much*

involved in finances, they're not involved much in HR policies, but I think we're getting there" (Session 3).

- At Keystone Human Services, the Listen Include Respect Working Group started to put the guidelines in place. It has grown into a group across the whole organisation, covering intellectual disability services, mental health services and autism services, with leaders, support professionals and people with lived experience together (Courtney, Session 3).
- Asociación Azul began with people Pilar's brother knew from special schools. *"They didn't know how powerful they were. So they started learning that in the peer-to-peer groups" (Session 4).*
- Fundación Visibilia began as a family advocacy movement 20 years ago. *"We grew up alongside our children ... They started learning to be leaders. So inclusive governance for us is natural" (Paola, Session 4).*
- Organisations can be proved wrong. Gamze described people in her organisation who thought a person could not take part. *"They learned they were wrong at the end. That person took part in the team" (Session 1).* Tia said the same often happens after training with self-advocates at SABE: *"They were really surprised how people worked together and did a good job" (Session 1).*



Lack of time most often causes exclusion.

Members said a lack of time, and the pressure to make decisions and do work quickly, is most often what causes people with intellectual disabilities to be excluded:

“The obstacle there is that the world goes so fast ... sometimes as an organisation you have to move on quickly, not to lose a presentation, an opportunity, a grant ... those timings are very different from the value-of-the-process timings.” (Paola, Session 2)

“Time is a key issue when you talk about support. And we live more and more in a hectic world. We are always running. And I think the call of intellectual disability is always to ask us to stop and think.” (Marta, Session 2)

Examples from members:

- Plan for much more time than you think you will need. You will always use it! *“One thing that we could teach anybody to support us is: slow down. Don’t rush.” (Chris, Session 2)*
- Shorten the speaking time, not the content. *“Reduce how long people speak but keep the content, so a person with a disability can still understand and take part” (Stephanie, Session 3).*



- Give the extra time to the people who need it. *“Give more time to the people who need more time ... and less time to the people who can speak faster and tend to speak a lot”* (Pilar, Session 3)

Good support

Members were clear that the person receiving support must share the support they want and need, not the supporter.

“Support is something that can in many ways only be defined by the person who is requesting support ... because that person is the expert at what they need, when they need it.” (Kristine, Session 2)

“For me, what stands out is that it’s okay to tell the support what you need.” (Farrah, Session 3)

Members talked about how hard asking for support can be. Supporters should make it easy for people to do this.

“They must ask for support, but they must feel comfortable to ask for support in a society that’s telling them all the time, you’re not capable.” (Marta, Session 2)

Examples from members:

- Agree on the supporter’s role before the meeting. *“Support people have to have rules clear before the meeting, where*



and when to intervene or not. It is a previous agreement”
(Paola, Session 4).

- Redirect the conversation back to the person, calmly and as often as needed. Pilar described her own practice when people speak to her instead of to the person she supports:
“First of all, I have to keep myself together ... [and be] a calm person who gently redirects the attention to the person with disability as many times as it’s necessary” (Session 4).
- Leaders still need support. *“A lot of times people think that once you’re a leader, you don’t need support anymore. And, boom, your disability all of a sudden disappears. Which is not true”* (Tia, Session 4).

Supporters need support too.

Members said supporters also need space to learn and get help. Members talked about how hard the role is.

“I have been a sister of a person with disability for 36 years ... and still I find myself learning a lot. I’m in the need to open my mind and review myself ... I try to keep an eye on my ableist self that I have, because I live in an ableist society.” (Pilar, Session 3)

“Sometimes you have to say you are sorry, because sometimes you make the mistake and you disrespect

[someone] without knowing, or you went too fast without knowing ... It's good that they know that the support person is not perfect. That we are working together.” (Paola, Session 4)

Examples from members:

- Supporters can be supported by the people they support. Pilar described facilitators helping each other and being helped by the members of Asociación Azul, including emotional support on hard days. *“People with disabilities can support, and they are really good at that” (Session 2).*
- Be clear about what a supporter is not. A paid staff member told Chris she was his advocate. He replied: *“No, you’re not. You’re a paid staff ... I’m the advocate” (Session 2).*
- Supporters should meet and share experiences. Paola suggested a new space where supporters can share what they are learning, because many members are family members rather than trained supporters (Session 4). *“We supporters need to share our experiences to get better” (Paola, Session 4).* Pilar described facilitators supporting each other, and being supported by the self-advocates in her organisation (Session 2).
- Everyone needs to know how to support, not just the support worker. Mark said that in a meeting that includes a person



with an intellectual disability, everyone must speak in an accessible way, rather than leaving the support person to translate (Session 2).

Managing meetings

Members talked about different types of meetings, including leadership meetings. Members talked about running meetings where support needs and communication are different.

“Diversity in intellectual disabilities is really not easy as a facilitator. And each meeting is a new meeting. You never know.”

(Paola, Session 3)

“There are people who are really good at speaking for themselves ... but there are some people that don’t. So I have to make sure all the voices are heard.” (Pilar, Session 3)

The group said meeting chairs and facilitators must be very active to manage power dynamics and ensure all voices are heard.

“It depends a lot on the attitude of the person who leads the meeting ... It has to begin from the top” (Sebastian, Session 3).

The group said it was important that everyone in a meeting knows they are all there to learn and support one another.



“Chair people must feel supported!! They need support to learn!” (Paola, Session 3).

Examples from members:

- Self-advocates can co-run meetings. *“I’m always grateful if the members of the peer group jump in and help me facilitate ... when a self-advocate speaks and says things, it’s more powerful and meaningful than when I do” (Pilar, Session 3).*
- Use two facilitators. *“We generally have 2 facilitators, so one always pays attention to participants, and the other is more attentive to the agenda and timing” “They swap roles naturally during the meeting” (Paola, Session 3).*
- Bring in people who have not spoken. *“Thank you for answering this question. Let’s hear from somebody we haven’t heard from before” (Tia, Session 3).*

Being in the room is not inclusion.

Tokenism is when someone is invited to take part because of who they are, but they aren't given the right support to do so.

The group talked about how common tokenism is and why it is complicated to challenge:

“The presence of a person with an intellectual disability in a meeting or on a board is not enough. True participation



means having a voice, making choices, and playing a role in decision-making, while receiving the support and accommodations needed to enable them to lead and participate effectively.” (Eman, Session 4)

“I have been on boards which they put you on like a check-off box.” (Tia, Session 4)

“Do not invite people to approve a finished process. Include them in creating the process. An inclusive result is only possible when the whole process is inclusive.” (Primrose, Session 1)

Members shared many suggestions and examples of how to prevent tokenism in our own organisations, but explained that it is harder in outside organisations. However, Paola shared that a tokenistic seat in these places is often a first step to inclusion. It may be up to self-advocates and supporters to help organisations learn how to be inclusive:

*“If you want everything perfect from the first moment, then you don’t get there ... Once you are there, you start working more and more. The thing is, what do we do when we see this [tokenism] happening? What will be our strategy?”
(Paola, Session 4)*



Examples from members:

- More than one self-advocate on a board. *“It would be easier for people to feel more comfortable with not just having one person on that board or committee , you could have a couple of people just so they can bounce ideas off each other and support each other during the meeting” (Tia, Session 4).* At Disability Inclusion Rwanda, 5 of the 9 board members are self-advocates, including the vice president (Félicité, Session 4).
- Tia recommended board orientation for all members about roles and what the board does, plus separate preparation and role-play practice with self-advocates on how to speak up (Session 4). Paola’s organisation runs separate leadership training for the administration committee, distinct from self-advocacy training (Session 3).
- Let people observe a board before joining it. *“Give people with disabilities an opportunity to sit in on a board or committee meeting so that they can make an informed decision about whether this is the right board for them or not ... and so they can figure out what supports they need” (Tia, Session 4).*



Inclusion needs a budget.

Inclusion costs something. Members explained that this is often a barrier because organisations have limited money.

“Sometimes good support is based on finances.” (Farrah, Session 2)

Tia said self-advocacy organisations in the United States pay for their own meetings out of project income, because *“not a lot of people want to fund self-advocacy”* (Session 4).

Pilar said reasonable accommodations are the hardest principle for her organisation to implement, because of the economic situation in her country (Session 1).

Members said it is important to plan budgets at the start of any work. An inclusion budget needs to cover people’s time, travel, support workers’ time, and internet data so people can access emails and join online meetings.

Examples from members:

- Ensure self-advocates are part of financial decisions so they can have a say over how budgets are organised. Money is often the last thing organisations include people in, and members were open about wanting to change it. *“The only thing where they are not fully involved is money issues. And I repeat: yet”* (Paola, Session 3).



- Pay people for their expertise: *“In our influencers group we get paid \$20 an hour.” (Farrah, Session 4).*
- Rotate paid opportunities so the same people aren't always the ones who go (Farrah, Session 4).
- At Special Olympics in Panama, the colleague with an intellectual disability is in every staff meeting, *“even financial issues”*. *“We see her participation as normal. Routine. It’s not like, wow, she is participating in this meeting” (Session 3).*

Continuing work on Listen Include Respect.

In the last session, members said they wanted to keep learning from each other. Some places to do this are:

The Listen Include Respect Champions Group.

An Inclusion International discussion group that meets every three months, co-chaired by:

- Courtney Soto (Keystone Human Services),
- Heidi Hatula (Tukena, Finland)
- Anne-Marie Binetti (Community Living Toronto).

It is open to anyone in a member organisation.

- Champions Group sign-up:

<https://s38312.pcdn.co/wp-content/uploads/ToRs-LIR-Champions-Group.pdf>



A space for supporters.

Paola suggested a new space where supporters can share their experience, because many supporters are family, friends or staff members rather than trained supporters. “We supporters need to share our experiences to get better” (Session 4).

Sharing good examples

Members also asked each other to share more stories and examples. If your organisation has a resource or example to share, in any language, please send it to us so we can review and share it.

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Supporting information - Participant list

Name		Country	Organisation
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Freddy	Ortega	Colombia	Asdown Colombia
Paola	Jelonche	Argentina	Fundación Visibilia
Alejandra Vanessa	Pacheco	Colombia	Asdown Colombia
Pilar	Cobanos	Argentina	Asociación Azul
Sebastian	Llobet	Panama	Special Olympics Latin America
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Mia	Farah	Lebanon	Lebanese Association for Self-Advocacy
Eman	Yaseen	Saudi Arabia	Help Center
Monica	Neves Rocha Arten	Brazil	Instituto Jô Clemente
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Dawn	Brunkalla	Germany	Independent
Farrah	Sattaur	Canada	Community Living Toronto
Felicia	Marchese	Canada	Community Living Toronto



Name		Country	Organisation
Jhannet	Guzmán	Bolivia	Asociación de Padres, Madres y Tutores de Personas con Síndrome de Down Luz de Amor Chuquisaca
Maria	Mthmonye	South Africa	Down Syndrome South Africa
Kristine	Koontz	USA	Keystone Human Services
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