

Guidance Note on the
Meaningful Engagement of Organisations of Persons with Disabilities
in IDDC Task Groups

December 2023

For questions about this resource, contact the OPD Partnership Task Group: IDDCOPDPartnership@iddcconsortium.net

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# Introduction - What is the Guidance Note?

IDDC is the International Disability and Development Consortium. IDDC is a network made up of many organisations who come together in Task Groups to do work on different topics.

This guidance note is a tool for IDDC Task Groups.

It helps to explain how Task Group Coordinators can make sure that organisations of persons with disabilities (OPDs) can take part in the work of IDDC’s Task Groups.

OPDs are organisations or groups that are led by persons with disabilities. They represent persons with disabilities and they work for disability rights. Most of their members should be persons with disabilities. More information about what an OPD is in the [CRPD Committee’s General Comment 7](https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhsnbHatvuFkZ%2Bt93Y3D%2Baa2pjFYzWLBu0vA%2BBr7QovZhbuyqzjDN0plweYI46WXrJJ6aB3Mx4y%2FspT%2BQrY5K2mKse5zjo%2BfvBDVu%2B42R9iK1p#:~:text=The%20Convention%20on%20the%20Rights%20of%20Persons%20with%20Disabilities%20recognizes,involve%20persons%20with%20disabilities%20(art.).

This guidance note was created because IDDC thinks it is important to actively work with OPDs - especially OPDs in the Global South where IDDC members are working.

Although IDDC’s rules say that OPDs are already able to take part in the work of Task Groups, OPDs are not very involved in most groups yet - either as members or leaders.

One of IDDC’s big goals is to have better participation of OPDs in IDDC’s work. This goal is part of IDDC’s [Strategic Framework](https://www.iddcconsortium.net/wp-content/uploads/2023/05/1294_IDDC-Strategic-Framework-2023-infographic-A3_tagged-PDF-artwork_v2.pdf).

IDDC wants to make sure that it is removing barriers that keep OPDs from being part of our work and make sure not to create any new barriers. IDDC also wants to make sure that our policy and advocacy work are in line with what OPDs want.

IDDC also knows that when OPDs are part of our work, we get better and more inclusive results.

The information in this guidance note will help Task Group Coordinators to plan their work in a way that makes sure OPDs can fully take part.

This guidance note asks Task Group Coordinators to think about new ways of working, and to run IDDC Task Groups in a different way.

Starting to work towards meaningful engagement of OPDs will be a learning process for all Task Groups - we know that we won’t get it right from the very beginning!

There will still be many challenges for Task Groups as we try to move towards more meaningful engagement, but this guidance note can help us try to plan for more OPD engagement and learn from what works and what doesn’t.

It is important to understand that this guidance note is about working with organisations of persons with disabilities, not working with individual persons with disabilities.

Many task groups make efforts to make their work inclusive of individual persons with disabilities. While this is also important, engaging individual persons with disabilities is different from engaging a representative of an OPD.

With an individual person with a disability, they only represent themselves. With an OPD representative, they are participating on behalf of their organisation or movement and represent all persons with disabilities in their community.

This guidance note is specifically about the engagement of OPDs, not individual persons with disabilities.

This guidance note was created by the members of the OPD Partnership Task Group. They worked with a paid Steering Group of OPD Representatives from around the world to collect advice on what should be in this guidance note.

This guidance note has 5 sections:

1. [What is meaningful engagement?](#_6jmezqrjsykn)
2. [What are the big ideas IDDC Task Groups need to think about?](#_d9ilgqs7wo4h)
3. [What does good OPD engagement look like?](#_seg1j2wljdsm)
4. [What resources can help to make the work more inclusive?](#_4eh2mthcl08w)
5. [What challenges might IDDC Task Groups face?](#_3zsx6t12z0ir)

Each section of this guidance note will give Task Group Coordinators clear information about how to make sure OPDs can take part in their work.

# Section 1 - What is meaningful engagement?

All of the member organisations of IDDC agree that we want a world with full inclusion. Inclusion means that persons with disabilities can take part fully in all parts of their community, on an equal basis with others.

One way that IDDC members can make inclusion happen is by making sure that OPDs can take part in the work of our organisations.

When organisations make an effort to include OPDs and take steps to make sure everyone can take part fully in their work, we call this meaningful engagement.

Sometimes it is also called inclusive participation.

Different organisations describe meaningful engagement in different ways. There is no one agreed way to describe it.

For IDDC, we will use the same definition that the International Disability Alliance (IDA) uses.

[This comes from IDA’s report about inclusive programming](https://www.internationaldisabilityalliance.org/sites/default/files/executive_summary_inclusive_programming_v3_cp.pdf).

Meaningful engagement:

* Respects and values the role of OPDs
* Makes sure everyone has an equal opportunity to contribute
* Makes sure that OPDs share decision-making on big issues that affect them

When people say “meaningful engagement” they are usually talking about engaging groups or organisations like OPDs, and when people talk about “inclusive participation” they are usually talking about engaging individual persons with disabilities. Meaningful engagement and inclusive participation both refer to the same big idea - making sure that barriers are removed so that everyone can take part equally and feel respected.

The big goal for any organisation that wants to include OPDs should be to make sure full participation happens every time.

Unfortunately, this doesn’t always happen. Right now, OPDs are not getting equal opportunities to take part in the work of organisations.

For example, sometimes OPDs will only be told about an activity happening at the last minute. Or they might be asked to give ideas, but there are still things that keep them from taking part - like the event not being fully accessible or not being given enough time or resources. There are some good examples of the type of things that keep OPDs from fully taking part in [this report from the International Disability Alliance](https://www.internationaldisabilityalliance.org/blog/%E2%80%9Cnot-just-ticking-disability-box-meaningful-opd-participation-and-risk-tokenism%E2%80%9D).

The situation with meaningful engagement also might be different from one activity to another. If an organisation has two activities, one might fully meaningfully engage OPDs and another might exclude them.

For IDDC Task Group Coordinators, it is important to be able to recognize which level of engagement our activities are at.

There are 4 levels of OPD engagement that Task Group Coordinators should be aware of.

This table gives a summary of the four levels of engagement - being excluded, being informed, being consulted, and being meaningfully engaged. It explains what each level means.

**Levels of OPD Engagement**

| **Level** | **What does this level look like?** |
| --- | --- |
| Excluded | This is when OPDs are not part of the activity. This can also be when an OPD is invited to take part in the activity but the organisers did not make an effort for anything to be accessible or inclusive - this means that OPD representatives are in the room, but they don’t have what they need to take part.  |
| Informed | This is when OPDs might be invited to take part in the activity, and the activity might have accessibility support, but OPDs don’t have real inputs or give feedback - they are only being given the chance to be passive participants. |
| Consulted | This is when OPDs are invited to give ideas for what the activity should focus on, or they give feedback about the activity, but they are not a decision-maker. |
| Meaningfully Engaged | This is when OPDs are fully involved in the planning and decision-making. OPDs are included in every part of the activity. |

True meaningful participation happens at level 4 - when OPDs are fully involved in planning and making decisions. When OPDs are engaged at this level, they feel listened to, feel like they have been fairly compensated, and feel that their time has not been wasted - they feel like a true partner in the work.

Sometimes organisations will say that they have done “meaningful engagement” with OPDs when they have really only informed OPDs or consulted with OPDs.

IDDC is committed to making sure that we only describe our work as meaningfully engaging OPDs if it really meets the criteria for the meaningful engagement level.

OPDs gave us some examples of some ways to tell if the activity has reached meaningful engagement or if it has only reached a lower level.

These are some things that OPDs told us need to happen for there to be meaningful engagement:

* **Information is accessible** - All information is accessible to everyone - meaning it is easy to understand and measures are put in place so that everyone can access information easily (for example, translation or interpretation or captioning). The activity should work for people who communicate in different ways.
* **Timelines work for OPDs** - When the activity is planned, enough time is given for OPD representatives to prepare and to consult their networks.
* **Extra support is available** - for example, OPDs are comfortable coming to the organisations to ask questions or to ask for extra support, like a pre-meeting.
* **Support people are welcomed** - OPD representatives are able to bring their personal assistants, supporters, or interpreters to help them be fully included. These supporters are paid for their work.
* **Costs are covered** - OPD representatives do not need to pay out of their own pocket to participate (for example, transportation costs) and OPDs are paid for their expertise.
* **Everyone’s opinions are valued** - OPDs are free to contribute, and when they speak, everyone listens.
* **OPDs are treated as equals** - OPD representatives are not just seen as people to consult or people to deliver work on the group - they are seen as real partners and equals by NGOs.

Remember that meaningful engagement is about both what the participation looks like while you are planning the activity (the process) and the participation of OPDs you get at the end (the outcome).

Each stage of the activity - from planning the concept note all the way to doing the final activity - should aim to have meaningful engagement at each stage.

If OPDs are involved in the work from the beginning, it is easier to achieve meaningful engagement because OPDs have the knowledge and experience to make sure an activity is inclusive.

# Section 2 - What are the big ideas IDDC Task Groups need to think about?

IDDC asked OPDs for some of the big ideas that Task Group Coordinators should be thinking about when they are planning their work.

These are the things that OPDs said Task Group Coordinators should be thinking about from the beginning of their work:

**Decision-making power** for OPDs is something that organisers need to think about from the beginning. For many OPDs, equal decision-making power is a core part of what partnership means. Is there a commitment to take action on suggestions and feedback that OPDs give? Will OPDs share equally in the decision making? If the goal is true equal decision-making, it is important to remember that this should not just kick in part way through the process - real shared decision-making power begins with co-creation of the work.

**Roles for OPDs** should be clear from the beginning. How will OPDs be involved in each stage of the work? Roles for OPDs and expectations should be agreed together and should be clear to everyone.

**Underrepresented groups** are the groups that are often excluded from activities. OPDs representing persons with intellectual disabilities, persons with psychosocial disabilities, and persons with deafblindness are underrepresented groups - so are women, girls, youth, and children with disabilities. In different countries, other groups can also be considered underrepresented in their context too. It is important to think about how to make sure these groups can be included - it is a big problem that some activities will only include the groups that are seen as easiest to include, like persons with physical or sensory disabilities.

**Accessibility** is what you do so that everyone can fully take part. Everyone can use these measures. For example, writing in easy to understand language or having captioning or sign interpretation are all examples of accessibility - everyone who is taking part in the event has access to these things.You plan to do them before you know who is participating in the activity - it is “proactive.” Think about how the activity can support different ways of communicating.

**(Reasonable) Accommodation** is something that you do for a specific person who is taking part in the work. Usually, the person will ask for this support directly, but it is important for organisers to always ask if anyone needs any support to take part. For example, this could be having a pre-meeting with someone before an activity to help them understand better, or giving someone extra time to meet a deadline. It is “reactive,” meaning it will respond to something you didn’t plan for ahead of time. Remember that when accessibility is good, usually this means fewer people need reasonable accommodation later on!

**Paying for OPD expertise** should be considered at the beginning. If OPDs are leaders in the activity and are contributing their knowledge and experience, it may be appropriate to pay them for that role. Whether or not payment is necessary will depend on the activity. For example, OPDs would usually not expect to be paid for something small like filling out a survey, but if you are asking someone to give advice, deliver work for you, or do other things that could be considered a consultancy role this should be paid. This is especially important if you are working with an OPD that does not have paid staff, because the representatives you are working with may be taking time away from their day jobs to work with you.

**Planning for access costs** - budgets need to include costs that OPDs will need covered, and accessibility costs like captioning and interpretation. An example of costs that OPDs need covered could be something like data costs if you are asking someone to join a virtual consultation or transport costs to come to an in-person session. It is becoming common practice to save 5% of a total budget for accessibility and accommodation costs.

Once the Task Group is clear on big ideas like decision-making power and how much money they have for the work, then OPDs as partners in the work can help them think through the other big ideas and start making plans.

# Section 3 - What does good OPD engagement really look like?

This chapter talks about what good OPD engagement for IDDC Task Groups should look like.

We will use the 4 levels of OPD engagement explained in Section 2 to talk about this - where OPDs are either excluded, informed, consulted, or meaningfully included.

This section will help Task Group Coordinators to figure out what level of engagement their Task Group’s activities are at now.

It will also help you think about how to get to the meaningful engagement level. The next section will talk about what specific actions Task Groups can do to make their activities engage OPDs better.

As a starting point for thinking about what level of meaningful engagement the Task Group is at, it is important to check in on what OPD engagement in your Task Group already looks like.

For example, are there any OPDs who are already taking part as members of your Task Group? Could you encourage them to have a leadership role in the future?

You can also encourage the IDDC members in the group to invite their OPD partners working on the group’s topic to take part in the group. All IDDC Task Groups are open to the partners of IDDC members - even Co-Chair roles are open to these partners, as long as a majority of the Co-Chairs still come from IDDC members directly.

As you open up the Task Group to more OPDs, the activities that the Task Group does will also need to engage OPDs within and outside the group.

To help show what a meaningful engagement level of OPD engagement could look like in different types of IDDC work, we will use examples.

This first example is about an event that an IDDC Task Group is running. It is an online event.

The example talks through the process of planning for an event that meaningfully engages OPDs, and mentions all of the specific points when the organisers considered different things.

Example 1: Planning an IDDC Event

| **What could a fully inclusive IDDC event look like?** |
| --- |
| Level 4 - Meaningfully Engaged | A Task Group has an idea to plan a COSP side event. It will be a webinar.**Finding Partners**Early on, the Task Group informs a diverse set of OPDs about their idea for the event. They share their detailed timeline for the planning. They make a point to reach out to diverse OPDs to find partners for the event. They know that they want to include OPDs representing persons with deadblindness for this event because they are underrepresented, but they do not know where to find national level groups. They contact the World Federation of the Deafblind (WFDB) to ask for contacts in their region of interest, and also reach out to some cross-disability umbrellas in the region to get contacts for these smaller groups. This helps them find other partners that they might not have been able to connect with otherwise.**Agreeing on Roles**Two of the OPDs they contacted are interested in being partners in the event. The Task Group agrees with those OPDs on clear roles and responsibilities. They look at their budget and consider paying OPDs depending on the size of the role they have taken on. They have a conversation with the OPD about costs they might need covered to be able to participate.**Co-Design**The Task Group meets with their two OPD partners to think about the goals and key messages for their event. They work with the OPDs to understand what key advocacy messages the OPD movement already has on the topic of their event. This helps them make sure that the event is in line with the positions of OPDs and doesn’t go against any of their key messages. They also talk about what their “non-negotiables” are - these are the things that each group needs to be included or excluded in the work for them to participate.The Task Group and the OPDs work together on a Concept Note. They write their Concept Note in plain language so it is easy to understand for everyone. They also make sure that their document is screen reader friendly and they send it in Word Doc format so that everyone can adjust the size as they need. Even though there isn’t an OPD representative in their planning group who has an intellectual disability or who uses a screen reader, they still make the Concept Note accessible because they want to make sure everything is already accessible for when they share an event invitation later.If there is something that the OPD partners suggest that the Task Group isn’t able to put into the Concept Note, the Task Group Coordinators have a conversation with the OPDs about this. They explain which comments were taken into account, which ones were not, and why. This task was easier because at the beginning of their partnership, the Task Group and the OPDs each shared their non-negotiables for the work together - this meant that everyone was clear about each other’s goals, and the OPDs knew that the Task Group already agreed on the points that were most important to them. This meant that during the edits to the concept notes, none of the big or important issues were on the table because they had already been agreed to.The Task Group and the OPD Partners brainstorm who they want to speak at the event. They make sure that enough OPD speakers have slots to speak. They make sure to give space to speak for underrepresented groups. **Accessibility**The Task Group Coordinator makes a budget for the event. The budget includes money for accessibility and reasonable accommodation. They book captioning and sign language interpretation. With their extra money, they think about whether they should book translation of a spoken language used in a region where there is lots of OPD activity on their event topic. They also save some money for any reasonable accommodation requests.**Spreading the Word**The invitation is sent out at least two weeks before the event. The OPD partners who have helped to plan the event are listed as equal co-hosts alongside the Task Group.They share the event invitation with international, regional and national, disability-specific and cross-disability OPDs, OPD partners of IDDC Members, and specialised Mailing Lists. The invitation includes a clear and easy to understand agenda for the event and tells people where to send any reasonable accommodation requests. **Getting Ready**During the registration, the Task Group got two requests for reasonable accommodation. One was a request for pre-meeting to help someone understand and prepare ahead of time, and the other was a request for translation into a national sign language. They fulfil these requests. The pre-meeting support did not cost anything to fulfil, and the Task Group paid for the national sign language support out of the rest of their accessibility budget.Before the event, the Task Group has a pre-meeting with all of the speakers and the moderators. They make sure everyone understands the agenda and how long they have to speak. They give everyone a briefing about what accessibility measures will be there. They also talk to everyone about how to make their presentations more accessible - like using easy to understand words and explaining complicated ideas. They check the presentations ahead of time to make sure things are accessible.**Running the Activity**During the event, Task Group makes sure the session is inclusive. They start with explaining housekeeping rules so everyone knows how to use Zoom. They do accessibility check-ins and give sensory breaks. When someone uses language that is complicated or hard to understand, the moderator asks them to simplify or explain it. During the Question and Answer part of the session, the Moderator saves a few question slots for OPDs that represent underrepresented groups.**Feedback and Follow Ups**After the event, the Task Group shares a recording of the event and the captioning transcript with everyone who signed up. They invite everyone who took part to provide feedback on the event. The Task Group also books a follow up meeting with the two OPD partners to do a debrief and get feedback for next time. When they are thinking about what questions they want to ask their OPD partners, they think back to the outcomes of good meaningful engagement - where OPDs feel listened to, respected, fairly compensated, and like their time was well used. These big ideas help frame the feedback conversation.**Documenting Lessons Learned**The Task Group documents the feedback they received. They make a plan for which suggestions will be followed in the next event, and which ones will not be taken up and why. They share this plan with their OPD partners.They also share this plan with the other Task Group Coordinators, so that everyone can learn for their own future events. |

The goal of this guidance note is to give all IDDC Task Groups the tools they need to be operating at this 4th level - meaningful engagement - for all of their activities and partnerships.

This requires more input, and planning ahead, but the result is an event that is not just more inclusive, but is also better quality because it has diverse inputs and participation.

Here is a real example of an IDDC Task Group activity that reached the meaningful engagement level. This example is split into the same steps as the previous example.

| Case Study: Guidance Note on OPD Engagement |
| --- |
| **Budgeting for Inclusion**As a first step, the Task Group Coordinators made a budget for all of the costs of a fully inclusive process for creating a guidance note on OPD engagement. The Task Group decided that a Steering Group of OPDs should guide the writers of the note. The Task Group Coordinators budgeted for the 10 Steering Group members to be paid for their work, with the option to also have a paid personal assistant join them on the calls. This decision to pay OPDs was made because they would be asked to give input over an 8 month period, and would be asked to review documents. This is something that organisations would pay a consultancy fee for, so this meant that OPDs should be paid for this work. Then the Task Group made a budget for captioning, sign language interpretation, and interpretation into 2 spoken languages (to be decided based on the final group) for each of the 6 meetings planned with the Steering Group.Once the costs were planned, the Task Group Coordinators asked the members of our Task Group if their organisations could support the work to design the Guidance Note in an inclusive way, and found funding through one of the group members.**Finding Partners + Spreading the Word**The OPD Steering Group was recruited. The Task Group Coordinators started by making a briefing document that explained the project and who we were looking for to join the Steering Group. [The briefing document](https://docs.google.com/document/d/1aVCsLl0TjLIJzn3SmjDsT212GtJIQ_nO5ehTz3uRz8s/edit?usp=sharing) was written in question and answer format to be easy to understand, and it also used plain language.The call for Steering Group members was sent out via IDDC Task Groups, IDDC members, IDA email lists, and any other OPD mailing lists available. OPD Representatives had over 1 month to apply to make sure there was enough time for anyone who wanted to take part to respond. 52 eligible applications came through from OPD Representatives. They came from every region, and represented every impairment group. To make a decision about which 10 to select, the Task Group formed a 5 member working group to review applications. Priorities were agreed ahead of time - the group wanted OPDs who had a connection to IDDC, representation from every region, at least 50% women representatives, and space for underrepresented groups. The final group of 10 was made up of 50% women, 40% youth, 70% underrepresented groups.**Agreeing on Roles**Because the briefing document was clear and easy to understand, the roles were clear for the Steering Group members.In the first meeting, everyone reviewed the roles together. Expectations for the decision-making power OPDs would have was also made clear - the Task Group decided that they would not submit the final guidance note unless the OPD Task Group had validated it. If they were not happy with the final version, it would go through more edits.**Co-Design**Co-design of the guidance happened during the OPD Steering Group sessions. The group met 6 times to give feedback and suggestions. They gave suggestions about the structure, how we define meaningful engagement, how OPDs want to be engaged in IDDC work, and more.Each session, OPDs came prepared to share their thoughts in response to some easy to understand prompts, and their feedback framed the guidance note.As the guidance note developed further, the group’s role in co-design moved from just framing the document to also giving directions on the content that should be part of the guidance note.**Accessibility**For each feedback meeting for the Steering Group, to make sure the meetings were accessible the Task Group Coordinators took a number of steps.Before each meeting, the Task Group Coordinators:* Sent a save the date and a calendar invitation for the meeting a minimum of 2 weeks ahead of time
* Sent a full agenda which included all of the questions the Steering Group would be asked during the meeting a minimum of 2 weeks ahead of time.
* Sent all of the PowerPoint slides, other resources, and things to read ahead of time a minimum of 2 weeks ahead of time.
* Wrote all materials in simple, easy to understand language - this includes the agenda, discussion questions, PowerPoint slides, etc.
* Booked interpretation and captioning well in advance of the meeting and made sure participants knew what accessibility measures would be in place a minimum of 2 weeks ahead of time.

**Running the Activity**During each meeting, Task Group Coordinators:* Stuck to the agenda that the group used to prepare
* Used easy to understand language for the discussion - this required reminding the participants to make sure that they did the same.
* Did a re-cap at the end of each section to make sure we understood correctly the feedback the group was giving us.

**Feedback and Follow Ups**After each meeting, Task Group Coordinators:* Sent out meeting notes in easy to understand language.
* Shared when the next meeting would be.
* Told the group what we would be working on before the next meeting and when they can expect to see the materials.

The final OPD Guidance Note credits all of the members of the OPD Steering Group for their work in the acknowledgements.**Documenting Lessons Learned**During our first meeting, one representative of a global OPD federation said: “Thank you to everyone who did the prep and the materials – in my long years of experience, it has been really different with different organisations, and you are the first who made the effort to make me feel included as a deafblind person with the materials and the approach.”Running the meeting in an accessible and inclusive way also meant that the OPD representatives were more comfortable speaking up from the beginning.Our inclusive process helped us build trust, and we got better feedback as a result.We documented the process that we followed and what worked - this can help us follow the process again in the future and learn from what went well. |

These two examples help explain what the process of planning an activity that meaningfully engages OPDs could look like.

This will look different for different Task Groups based on the type of activities they deliver, but there are always some common elements:

* Budgeting for inclusion from the beginning,
* Looking for OPDs from diverse groups to work with,
* Making sure that key messages or advocacy points for the activity are in line with the OPD movement’s goals,
* Making sure accessibility is in place,
* Giving enough time for people to take part,
* Collecting feedback about the process,
* Documenting the experience to learn and improve.

At the end of this document, you can find [a tool that you can use to document how following these steps worked in your Task Group activity](#_scwst3w78vj0).

It is important to note that the two examples that are used in this section are both for short term pieces of work - an event and a project. One time activities are the way that many Task Groups are working now, but this is not the only way that Task Groups can be working with OPDs.

Task Groups can also think about how to work with OPDs in a more consistent way. If Task Groups find an OPD that wants to work together and works on the same topic, Task Groups and OPDs can also engage in longer-term partnerships - for example, developing a shared workplan for a series of activities together across the year, or having an ongoing advising relationship. These less transactional ways of working can give IDDC Task Groups stronger connections to the OPD movement and help make sure that their work is inclusive.

While there is no example in this section for setting up a longer-term partnership with an OPD, the same ideas and steps in the two examples here could also be used for starting a long term partnership.

# Section 4 - Where can I find more resources to help make sure my activities are inclusive?

For more information, OPDs and other organisations have also created many other tools and pieces of guidance that Task Group Coordinators can use.

A good starting point for Task Group Coordinators is to think about the big ideas outlined in section two of this report. Once the Task Group has already started thinking about the OPD partners they can bring on board and how to budget for accessibility and reasonable accommodation, these resources can help Task Group Coordinators deliver fully inclusive events.

These resources are not all how-to guides on how to deliver meaningful engagement of OPDs - these resources focus mostly on practical tips for making the event inclusive, which is Step 2 after beginning the meaningful engagement of OPDs.

| What is it? | Who made it? | Where can I find it? |
| --- | --- | --- |
| IDA’s Technical Paper about Inclusive Programming talks about working with OPDs as equal partners and how to follow the CRPD in projects. | International Disability Alliance | [Link to the full report](https://www.internationaldisabilityalliance.org/sites/default/files/ida_crpd_based_inclusive_programming_iw_experience_aug_2022.pdf) (in English) |
| Listen Include Respect Guidelines have detailed how-to guides that explain how to plan inclusive meetings, inclusive events and consultations, how to do inclusive communications, and other areas of an organisation’s work etc. | Inclusion International and Down Syndrome International | [Link to Listen Include Respect website in English](https://www.listenincluderespect.com/)[Link to Listen Include Respect website in Spanish](https://www.listenincluderespect.com/es) |
| The UNDIS Guide on Consulting with People with Disabilities explains the steps that organisations should take to make consultations fully inclusive. | United Nations Disability Inclusion Strategy (UNDIS) | [Link to the full guidance](https://drive.google.com/file/d/1FlMelB_T9c6oEHNZ-7NGruZhuDpWsnX1/view?usp=sharing) (in English) |
| IDA’s discussion paper for the Global Disability Summit talks about OPD engagement. It explains what the current situation is for OPD participation, and gives examples of what good OPD engagement looks like through case studies. | International Disability Alliance | Link to the full report in [English](https://www.internationaldisabilityalliance.org/sites/default/files/opd-engagement-paper-2022-ok1.pdf), [French](https://www.internationaldisabilityalliance.org/sites/default/files/opd-engagement-paper-2022_fr.pdf), [Spanish](https://www.internationaldisabilityalliance.org/sites/default/files/opd-engagement-paper-2022_spa.pdf), and [Arabic](https://www.internationaldisabilityalliance.org/sites/default/files/opd-engagement-paper-2022-arabic.pdf) |
| The Inclusive Participation Toolbox has information about how to engage persons with disabilities and OPDs. | CBM | [Link to the Inclusive Participation Toolbox website in English](https://participation.cbm.org/) |
| IDA’s Report “Not Just Ticking the Disability Box? Meaningful OPD Participation and the Risk of Tokenism” talks about what the situation is now for OPD engagement in projects, and how to improve. | International Disability Alliance | Link to the full report in [English](https://www.internationaldisabilityalliance.org/sites/default/files/full_ida_global-survey-2022-final.pdf), or the Executive Summary in [French](https://www.internationaldisabilityalliance.org/sites/default/files/executive_summary_2nd_global_survey_french.pdf), [Spanish](https://www.internationaldisabilityalliance.org/sites/default/files/executive_summary_2nd_ida_global_survey_spanish.pdf), [Arabic](https://www.internationaldisabilityalliance.org/sites/default/files/executive_summary_2nd_global_survey_arabic.pdf), and [International Sign](https://youtu.be/CorRaOO3Z3s%20). |

In addition to bigger resources about meaningful engagement and inclusive participation, many OPDs have tools that give advice on how to make sure an activity is accessible to specific groups. Some examples include:

* [Guidelines from the International Federation for the Hard of Hearing (IFHOH) on accessibility for people who are hard of hearing](https://www.efhoh.org/wp-content/uploads/2021/04/Accessibility-Guidelines-IFHOH-Position-Paper-1-1.pdf)
* [The World Federation of the DeafBlind’s Inclusive guidelines for including people with deafblindness in meetings](https://docs.google.com/document/d/1KceZooXsvCNUDEDNclnpbggMwrH4u21X/edit?usp=sharing&ouid=114434434768142434416&rtpof=true&sd=true)
* [Inclusion International and Down Syndrome International’s Listen Include Respect resource on how to produce information that is accessible to persons with intellectual disabilities](https://www.listenincluderespect.com/information)

Task Group Coordinators should also use each other as resources! Use the Task Group Coordinator mailing list to ask for advice on how other Task Groups have found OPD partners, accessibility service providers they recommend, or tips for inclusive events.

# Section 5 - What challenges might IDDC Task Groups face?

This section will talk about some of the big challenges that Task Group Coordinators might have when they try to meaningfully engage OPDs.

There might be conditions that Task Groups are working under that make it difficult to meaningfully engage OPDs in the work all of the time.

Facing challenges that make it difficult to meaningfully engage OPDs does not mean that Task Groups shouldn’t do the activity at all - it just means that Task Groups can’t describe these events as meaningfully engaging OPDs. It is also an opportunity for the Task Group Coordinators to plan ahead and think about how to break down barriers for next time.

This section talks about some of those common challenges and what Task Groups can do to try and address them.

**Budgets** - Task Groups are working with a very small accessibility budget, and accessibility services like captioning or interpretation can be very expensive. This means that one event might use all of the accessibility budget for the year. Some strategies for managing this could be:

* Picking and choosing what stays in the budget - for example, if a Task Group is working with an OPD that represents persons who are hard of hearing on an activity, captioning might be more important to prioritise in the budget than sign language interpretation, for example. The OPDs you work with should help to make these budget choices.
* Teaming up with another Task Group that hasn’t spent their accessibility budget yet for a joint activity.
* Asking members of the Task Group if their organisations can contribute to helping make an activity accessible. IDDC members with flexible funding are often able to help supplement Task Group Accessibility Budgets when their initial budget runs out. Having group members who are actively engaged helps with this request!

**Short Timelines** - When Task Groups are doing activities and create the timelines themselves, it is important to always build in enough time for OPDs to meaningfully engage. Often Task Groups are up against external deadlines where they are not able to control the amount of time given. Some common examples are requests for feedback or consultation from UN Agencies or other global organisations. If Task Groups are not able to meaningfully engage OPDs in the time given, IDDC’s role as an ally to the disability movement is important. When Task Groups are given an external deadline that does not allow for consultation, they can respond by:

* Pushing back and telling the organisation that the timeline is not reasonable. Task Groups have a role in making other organisations aware that there is a responsibility to consult our network and OPDs that we work with, and to call for fair timelines in the future.
* Task Group Coordinators can still respond to a short timeline request for feedback, but not without asking for a change next time.

**Lack of OPD contacts** - Task Group Coordinators may not have contacts for OPDs working on specific topics or on specific countries that are relevant to the group’s work. Finding an OPD to engage with might take some research. This can be particularly challenging for OPDs of underrepresented groups, who are likely to be smaller organisations and may be more difficult to find online. Some strategies for managing this could be:

* Crowdsource contacts - IDDC members are working all over the world. If you are looking for an OPD to work with that represents a specific impairment group, country, or that works on a particular topic, ask other IDDC members for contacts of OPDs they work with that fit the criteria.
* Ask global OPDs for recommendations - IDA’s global members have networks of thousands of OPDs that work all over the world on different topics. Global OPDs representing specific impairment groups also typically have close relationships with their members and can provide an idea of which OPDs in different countries are working on certain topics. If you don’t know where to look, ask a global umbrella organisation for help - particularly if you are looking for underrepresented groups.
* Contact national umbrella OPDs - if you are looking for OPDs focusing on underrepresented groups working at the national level, national umbrella organisations will usually have contacts for these OPDs. They will also know if those groups don’t exist in the country you are looking at. They can point you to other places where you could look.

**Deciding between OPD partners** - Task Groups might face a challenge when having to decide which OPDs to work with. Moving away from the “usual suspects” and wanting to work with different groups is important, but partners should be chosen strategically. Respond to this by:

* Think about the level - if your work is global in focus and does not require country examples, work with a global or regional OPD. If you want to use case studies, national level groups might be a better fit.
* Think about the topic - some regions or impairment groups have a focus on different topics which can help make the decision about who to work with easier. For example, OPDs representing persons with deafblindness would have an important perspective if the topic is accessibility. OPDs representing persons with intellectual disabilities tend to be leaders on inclusive education, while OPDs in Africa tend to have a stronger focus on inclusive health than other regions. What makes sense for the topic?
* Think about the voices you want to hear - for some activities, underrepresented groups will be most important to hear from - plan for when you want underrepresented groups to be in the lead.
* Make strategic choices based on the Task Group - For example, if most of the Task Group members have their work focused in Latin America, OPDs in Latin America might make the most sense this time. If Task Group members have a country of work in common, it might be useful to think about OPDs from that country. Choose OPDs that align well with the work your group members are doing and your goals for the year - if the Task Group has some regional or national focused work coming up, link up with OPDs in those places.

**Working with small OPDs** - With the move to work with OPDs from underrepresented groups, this also may mean Task Groups are starting to work with smaller OPDs. This could also mean OPDs that are not registered yet, or who are operating informally. Small OPDs typically have smaller budgets, fewer or no staff, less formal structures, and may be newer to work at the international level. Smaller OPDs may mean Task Group Coordinators need to change the approach to meaningful engagement with these groups. For example, this might mean:

* Helping the OPD understand the international context - you might need to provide more information about the topic than you normally would at the beginning of the work together. Some OPDs have suggested that a “buddy system” where a new OPD participant is assigned an experienced member of the group to support them is a good way to make them feel comfortable working in a new environment and make sure they have a way to ask for more information and support.
* Getting rid of jargon - the acronyms and terms we use at the international level might be new to smaller groups who have never been involved in global work before. Make sure you are explaining things clearly and don’t use acronyms without explaining what they mean. Make sure the OPD knows from the beginning that it’s okay that they are new to this level of work - create a safe space where they feel comfortable asking if they don’t recognize a term.
* Adjust timelines - small OPDs are more likely to have only one staff person playing all of the roles, and many are run only by volunteers who have day jobs. Make sure you are giving them enough time to take part and give feedback.
* Think about compensation - if you are working with an OPD whose representatives are volunteers and they need to take time away from their paying day jobs to work with you, this is even more important.

**Questions about representativeness** - Working with umbrella groups or cross-disability groups can be a good way to get the perspectives of an entire OPD network in all of its diversity. But sometimes the leadership of these groups might be dominated by the groups of persons with disabilities who are least excluded. This not a reason to avoid working with cross-disability or umbrella groups, but some ways to deal with this challenge are:

* Setting expectations - when you begin working together, make it clear that diversity is important for the activity. Tell the OPD you are working with that you want to make sure the perspectives of women, youth, and underrepresented groups also come out in their advice. Even if these groups aren’t represented in the umbrella group’s staff or leadership, they will know where to find these voices to get inputs and bring them into the work.
* Ask questions - if you think you are getting inputs that don’t capture the thoughts of underrepresented groups, ask for more information about this in a follow up.
* Complement with more voices - working with umbrella groups does not mean not also working with underrepresented groups. You can supplement the perspectives by also bringing on an OPD representing women, children, persons with intellectual disabilities, etc. to take part in your work alongside an umbrella group.
* Talk about feeding back - there can also be a challenge here around making sure that your work with an OPD is feeding back into the movement, instead of just sitting with one individual. For example, have open conversations with the OPD partner about how you could help with documenting the lessons so that the whole OPD network can learn from the partnership. It is useful to think about how work with local groups feeds up into the umbrella group, and how work with umbrellas feeds down into the member OPDs.

**Safeguarding Issues** - Task Groups have a responsibility to keep the people they work with safe - this includes OPD partners and the OPD members that they might be engaging on your behalf. OPD partners have a right to be kept safe and comfortable during their work with Task Groups - both the individuals and the organisation. Some ways to manage this challenge are:

* Thinking about context - if you are working on a controversial topic, think about potential risks to the OPDs you want to engage. For example, OPDs in some political contexts might not be able to work on topics like political participation and gender and could pose risks from being seen to be involved in those conversations.
* Use resources - good resources on safeguarding are available and are important to look at ahead of time if you are partnering with an OPD on work that involves children or vulnerable people. [Able Child Africa and Save the Children’s Disability-Inclusive Child Safeguarding Toolkit](https://ablechildafrica.org/wp-content/uploads/2021/08/Able-Child-Africa-Safeguarding-Toolkit.pdf) is one example.
* Ask the experts - if you aren’t sure if the work your Task Group wants to do could be a safeguarding risk, ask for support. IDDC’s Safeguarding Task Group could give advice or point you in the right direction.

When thinking about these big challenges, within the Task Group Coordinators and within IDDC members more broadly there are experts with solutions to some of these problems.

Task Group Coordinators should remember to use the knowledge of the network and ask for support or advice from other members when needed to help solve challenges together!

This guidance note was produced during 2023. It is a living document and may be updated with new examples and information as Task Groups try to engage more OPDs in their work.

To share lessons that your Task Group learned which could be included in an updated version of this guidance note, contact the OPD Partnership Task Group Co-Chairs at IDDCOPDPartnership@iddcconsortium.net

## Tool: Documenting Meaningful Engagement

Task Groups can follow the steps in this form when planning an activity. Document the steps you are taking and the plans you are making as you go using this resource, and it can help to document what works and become a resource for the future!

| **Step** | **Your Process** |
| --- | --- |
| Budgeting for Inclusion | What costs did you identify for your activity to be fully inclusive? |
| Finding Partners | Where are you looking for OPDs to work with? How did you choose which OPDs to target? How are you making sure your onboarding process is inclusive and accessible? |
| Agreeing on Roles | How did you negotiate decision-making power and non-negotiables with your OPD partners?What were the agreed roles? |
| Co-Design | How did you plan the key messages for the activity? Do they line up with the disability movement’s key messages?Was all of the OPD feedback taken? If not, how did you handle that?What did the joint planning process look like? |
| Accessibility | What accessibility features did you plan for, and how did you choose these? |
| Spreading the Word | How did you advertise for the activity?How did you make sure you were spreading the word in an accessible way? |
| Getting Ready | How did you support the people taking part in the activity to get ready?Did you get any requests for reasonable accommodation? Were you able to fulfil them? |
| Running the Activity | How did you make sure the activity was fully inclusive?What did you do during the activity to make sure everyone felt comfortable to take part? |
| Feedback and Follow Ups | How did you collect feedback?What feedback did you hear?How did you make sure OPD partners were comfortable sharing their true feedback? |
| Documenting Lessons Learned | What would you change for next time about the way you organised the activity?What worked?What didn’t work? |

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