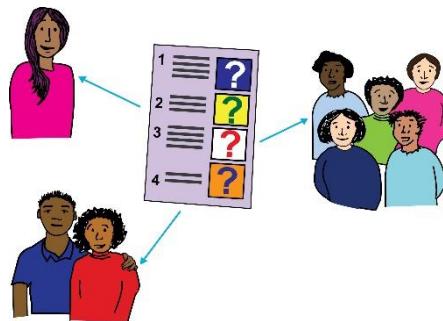




Organisations of Persons with Disabilities are being consulted more but are still not taking part

Consulted, Consult or Consultation: this is when people who might be affected by a change or decision are asked for information about how it will affect them.



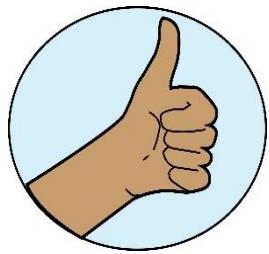
International Disability Alliance Global Survey: Summary Report

International Disability Alliance: this is a group of 14 organisations around the world of persons with disabilities. They push for the inclusion of persons with disabilities at the United Nations.

United Nations: this is a group of countries which work together to push for peace and safety.

Global Survey: here, this is our questionnaire which was answered by organisations of persons with disabilities from over 165 different countries.

1. Acknowledgements, this means people we would like to say thanks to.



The International Disability Alliance wants to say thanks to everyone who works for organisations of persons with disabilities. These organisations work really hard to push for the rights of persons with disabilities.

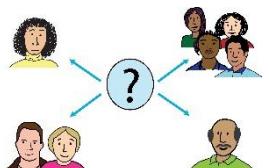


They push to make sure organisations of persons with disabilities take part in making decisions. We have written this report using the experiences they shared with us.



We would like to thank:

- Members of the International Disability Alliance
- Anyone who took part in this survey
- Anyone who helped us to fund this report



Nothing about us without us!



We also want to say thanks these people:

Doctor Joanne McVeigh, Professor Malcolm MacLachlan, Doctor Delia Ferri, Doctor Hasheem Mannan and Iva Sokolovaska. Alexandre Cote and Ailis Hardy.



We want to say thanks to these groups for helping us to fund the survey:

- Ministry for Foreign Affairs of Finland
- Department for International Development of the United Kingdom
- Inclusive Futures programme



The International Disability Alliance are responsible for the views and opinions that are written in this report.



**International
Disability
Alliance**

For more information about how you can use this report, please email: info@ida-secretariat.org.



2. Background information:

How do we make sure persons with disabilities are taking part in making decision across the world?



In a fair society, people must take part in making decisions that affect their lives. It is important that people and organisations take responsibility for their decisions.



Persons with disabilities often face **barriers** when it comes to taking part in making decisions. These barriers are because of things like attitudes, the law and money.

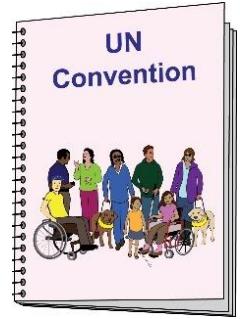


Barriers: in this document, this means the things that stop persons with disabilities living equal lives.

Decisions are often made for persons with disabilities. This means they are left out from all areas of society. When their views are not listened to, policies and programmes do not meet their needs or support them to push for their rights.

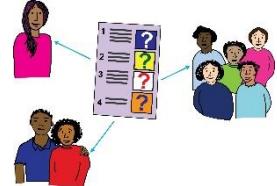


The disability rights movement played a really important role in writing the **UN Convention on the Rights of Persons with Disabilities**. This is why the UN Convention is all about making sure persons with disabilities can take part in making decisions that affect their lives.



UN Convention on the Rights of Persons with Disabilities: this is an international agreement that governments can sign up to, to bring about the full rights of persons with disabilities all over the world.

Article 4.3 says that **decision makers** must consult persons with disabilities and push to make sure they can take part in making decisions. This means children with disabilities too. This means at a local level, across the country and across the world too.



Article 4.3: this is the part of the UN convention that talks about groups and issues around persons with disabilities.

Decision Makers: this means groups that are responsible for making important decisions that affect the lives of persons with disabilities. Such as the government, the United Nations and funding organisations.

The UN Convention says that organisations of persons with disabilities are really important for giving persons with disabilities a voice. These organisations should give a voice to persons with disabilities, so they can talk to decision makers.



Persons with disabilities must also take part in reaching the **Sustainable Development goals**. They must be part of the **UN Disability Inclusion Strategy**.



Sustainable Development Goals: this is a list of 17 goals which the United Nations are hoping to reach by 2030. If these goals become a reality, we will have a better, fairer society.

UN Disability Inclusion Strategy: this means the plan made by the United Nations to push for the rights of persons with disabilities to take part in making decisions that affect their lives.

It's great that our rights are being pushed for more. However, we must make sure that decision makers meet their responsibilities under the UN Convention. We must make sure this work doesn't lead to **discrimination** or bad **stereotypes**.



Persons with disabilities must lead the way to change. They must do this through organisations of persons with disabilities. There is still lots to do.



At the moment, decision makers say they are pushing for more inclusion of persons with disabilities. However, this isn't leading to real change. Persons with Disabilities must have a real and important role in making decisions about programmes and policies that affect their lives.



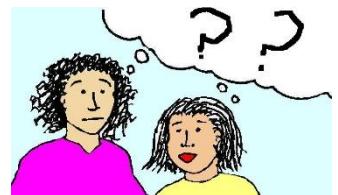
Discrimination: this means being treated unfairly. This could be because of a person's race, age, sex, disability or because of another part of who a person is.

Stereotype: this means an unfair judgement that people make about someone because of their race, age, sex or because of another part of who a person is.

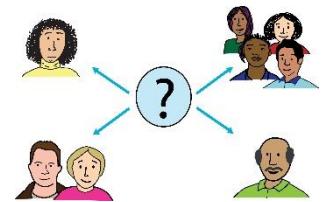
3. The International Disability Alliance Global Survey



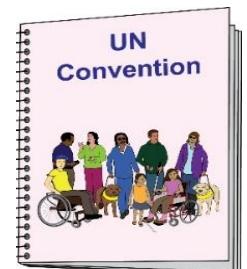
Are organisations of persons with disabilities taking part in making decisions?



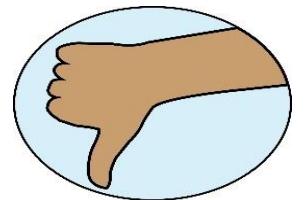
We wanted to find out if organisations of persons with disabilities were really taking part in making decisions.



Our global survey was sent out to make sure that decision makers are meeting their responsibilities under the UN Convention.



At the moment, decision makers are not meeting their responsibilities under Article 4.3 and **Article 32**.



Article 32: this is the part of the UN convention that says that countries must work together to make sure that persons with disabilities can take part in making decisions that affect them.

This survey is part of our plan to make sure that this happens. We want the survey to happen often so organisations of persons with disabilities can make sure this happens.



We wanted to find out if organisations of persons with disabilities were taking part in making programmes and policies with decision makers.



We wanted to ask them if they thought that:

- Their work was a high enough standard
- They were doing enough work
- They were reaching enough people
- They were working on important issues
- Their work was leading to important changes



We wanted to look at what changes have been made. We wanted to look at what is working well and what needs to be done better.

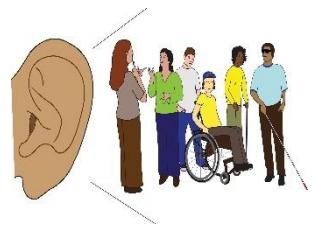


This will help us to make a plan for **advocacy**. It will help us to support more people to take part in making decisions that affect their lives.



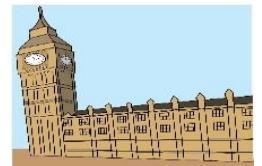
Advocacy or advocates: this means people or organisations that support people to understand their rights and support them to speak up and be heard.

We wanted to listen to the views of organisations of persons with disabilities. We wanted to ask them if they felt like they can take part in making decisions.



We want to talk to them about these groups:

- Governments



- UN agencies

UN agencies: this means organisations that work with the United nations.



- Funding agencies

Funding agencies: this means groups that give funds to organisations to support them to reach their goals.



For organisations of persons with disabilities to take part, there must be a balance between organisations giving suggestions and decision makers consulting with them and listening to their views.



**Our survey aims to look at how to make this better.
We want to look at different areas of taking part,
such as:**

- Which groups of persons with disabilities are invited to take part?



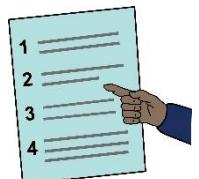
- Which decision makers are working with persons with disabilities?



- At which level of making decisions are organisations taking part? For example, are they working with local authorities or across the country?



- Which issues do decision makers consult organisations about?



- How do decision makers make sure organisations can take part?



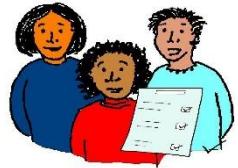
- At which stages of making decisions are organisations asked to take part?



- How often do organisations take part?



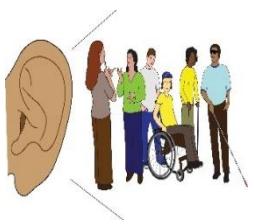
- How do they take part? Is it in a planned way?



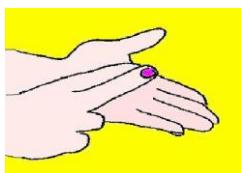
- What role do organisations have when making decisions? For example, do they just give information or are they a really important part of making decisions?



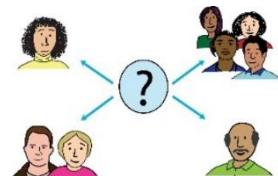
- Do decision makers really listen to the views of organisations? Do their ideas lead to important changes?



The survey was tested on a group of persons with disabilities who also talked about how accessible it was. The questionnaire was written in plain English. It was also sent out online in Arabic, Chinese, English, French, Russian, Spanish and International Sign.



573 organisations replied to the survey. These organisations work across 165 different countries. Over half of these organisations work at the national level, meaning they work across their countries.



4. Key findings: this means what did we find out?

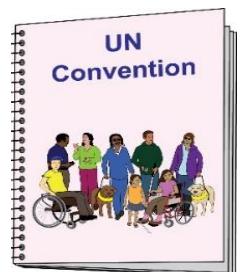
We found out that we are being consulted more and more, but we are still not taking part.



Through this survey, we listened to the voices of organisations of persons with disabilities and people from the disability rights movement.



We asked them if decisions makers were meeting their responsibilities under the UN Convention. Were they consulting and supporting organisations of persons with disabilities to take part in making decisions? Was this being done across different countries?



The results of the survey showed some things that have already been noticed. We had already talked about lots of these things at the International Disability Alliance. Our members had talked about these things before too.



Here are some of the main things we found out:

- a. More and more persons with disabilities are taking part in making decisions. They are doing this through organisations of persons with disabilities.



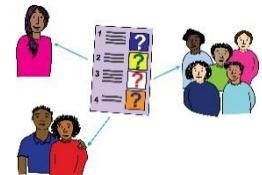
These days, taking part in society and politics is getting harder. However, disability issues are talked about more and more. This might be because:

- Over the last few years, more and more organisations have been pushing for the rights of persons with disabilities across the world.
- There is still a lot of work to do to push for the rights of persons with disabilities.
- Disability is not as difficult to agree on as other human rights issues. So, more work has been done in this area for this reason.



We asked people about how their work with decision makers has changed over the last year. Over half of the people we asked said that compared to last year, more organisations of persons with disabilities are taking part in making decisions.

Over half of the people said that this work was making a difference to policies and practices.



b. Some groups of persons with disabilities are still not being consulted or taking part in making decisions.

Such as **persons with intellectual and psychosocial disabilities**, people with learning difficulties, deaf people, people with deafblindness.



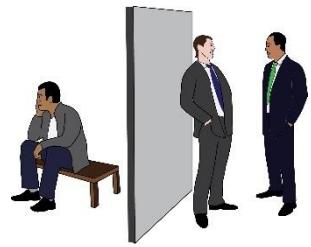
Persons with intellectual and psychosocial disabilities: one of the different groups of persons with disabilities.

As well as other groups of people, such as women with disabilities, **indigenous people** with disabilities.



Indigenous people: the are people from a traditional culture who often face discrimination in their own countries.

One person from Lithuania said that organisations of persons with intellectual and psychosocial disabilities are not being given the chance to take part in making decisions.



One person from the Netherlands said that not enough changes are being made. In the Netherlands, people think disability just means people in wheelchairs. They don't understand how important it is that persons with disabilities have access to making decisions.



C.Organisations of persons with disabilities are still not taking part in making enough decisions.

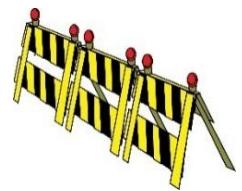
The standards set by Article 4.3 are not being met. Organisations are usually only asked about issues or policies around disability. It seems that disability is not still not being thought about in other policy areas.



One person from Brazil said that persons with disabilities should be able to take part in making decisions, even when the decisions are not about disability. That is what being included looks like.



D. Persons with disabilities still face lots of barriers when working with decision makers.



Decision makers are not doing everything they can to get rid of barriers. Often, buildings and information are not accessible. Lots of people don't know how to talk to and work with persons with disabilities. There is not enough funding to make **reasonable accommodations**.



Reasonable accommodations: this means making changes to get rid of barriers faced by persons with disabilities.

One person from Papa New Guinea said that meetings are often held in buildings that are not accessible. It is often up to organisations to ask decision makers to change the building before the meeting. Persons with disabilities often can't go to meetings because they are not accessible.



We asked people if the government had made changes to support persons with disabilities to take part. We asked them if governments were:



- Making buildings and information more accessible
- Making sure people have a good attitude towards persons with disabilities
- Making sure people know how to talk to and work with persons with disabilities
- Giving funding to make reasonable accommodations



Around 1 in 10 people agreed that these changes had been made. Around 1 in 5 people said that these changes had happened in some ways. Around 1 in 10 people said that these changes had not happened at all.



E.Organisations of persons with disabilities are still finding it hard to get funding.

Around 30% of organisations of persons with disabilities said that they now have more funding than they had one year ago. Organisations need funding to build on their work and reach out to as many people as possible.



Organisations of persons with disabilities support people who face discrimination. Because of this, organisations of persons with disabilities also face discrimination.



Compared to other organisations, they get less access to funding opportunities. They get less invitations to take part in making decisions.



One person from Georgia said that because it's hard for organisations of persons with disabilities to get funding, people have to work and study at the same time as working for organisations.



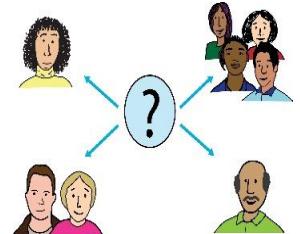
This means people can't take part as much as they would like to. But they are still work really hard to take part in the disability rights movement.



F. Organisations of persons with disabilities say they don't have enough resources, support or time to take part.

Resources: this means money, staff, services or anything else that is needed.

Working with so many different decision makers can be really difficult. Working with different groups can be complicated. Different groups have different ways of working.



Organisations of persons with disabilities don't have enough resources or money to work with different groups. Often, organisations are using all their resources to do this.



One person from Nigeria said that organisations of persons with disabilities don't have lots of resources. This is even more true for organisations in **developing countries**. It is very important that resources are used to do more and reach more people.



Developing countries: this means countries with less resources and money.

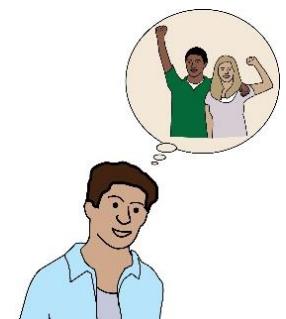
Organisations of persons with disabilities should get training to see the best ways to make change. They must be able to work on systems and structures so they know how to run offices and do things like paperwork. This is really important so they can push for change.



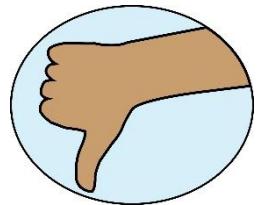
One person from Brazil said that it's important to work on building up organisations. Taking part in making decisions should be easy to understand. Everything that's too complicated won't be accessible to lots of people. Especially in developing countries.



They said that persons with disabilities are the ones who really understand the issues that affect them. Without them we will never make the UN Convention or the Sustainable Development Goals a reality.



G. Organisations of persons with disabilities are taking part in making decisions with the government. However, they are not taking part enough and their work is not leading to enough change.



There is not enough information or chances to make change. Hardly anyone said they had been given important roles in making decisions.



Most organisations said that even though they know about social change, the government don't always tell them about changes that are happening in society.

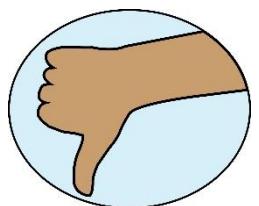


We asked people if they were happy about their work with decision makers:

- Around 30% of people were happy with their work with the UN. 20% of people were not happy at all with the work they were doing with the UN.
- Around 30% people were happy with the work they were doing with the government.



Nearly half the people we asked were not happy at all with the work they were doing with the government.



- Nearly half the people we asked were happy about the work they were doing with funding agencies. Around 20% were not happy about the work.



H.Organisations of persons with disabilities are often left out when working with the United Nations. They don't take part enough, and often don't have enough information about the United Nations.



Organisations of persons with disabilities said they usually have good experiences when they do take part in making decisions with the United Nations.



The **UN Partnership on the Rights of Persons with Disabilities** does include more persons with disabilities than other UN work or organisations.



UN Partnership on the Rights of Persons with Disabilities: this is a piece of work that is run by the United Nations to push for the rights of persons with disabilities.

Organisations who worked with funding organisations said they had good experiences. They could access funding and support. For example, they got support around how to work on changing policies.



Overall, it seems like if organisations have more resources, they will be able take part more.



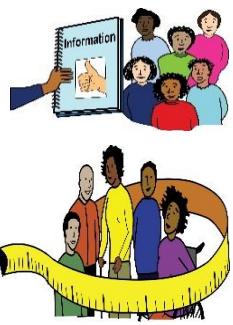
We asked people about their work with the United Nations and the UN Partnership on the Rights of Persons with Disabilities. We asked them about which areas of work they thought were the most inclusive.



Here is what people said were the most inclusive areas when working with the United Nations:



- Around 1 in 5 people said getting data or information was the most inclusive area of work.
- Around 1 in 10 people said **Monitoring** was the most inclusive area of work.



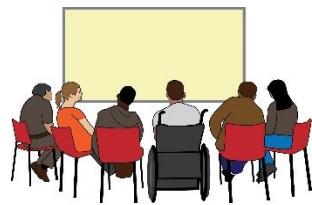
Monitoring: this is how an organisation checks how well something is going. They look to see what needs to be changed or made better.

- Around 1 in 20 people said making decisions about the **budget** was the most inclusive area of work.



Budget: this is a plan of how money will be spent.

- Around 1 in 10 people said putting projects into practice was the most inclusive area of work.



- Around 1 in 20 people said how the UN is run and how decisions are made was the most inclusive area of work.



- Around 1 in 10 people said planning was the most inclusive area of work.



Here is what people said were the most inclusive areas when working with the UN Partnership on the Rights of Persons with Disabilities:

- Around 1 in 5 people said getting data or information.



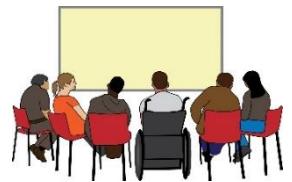
- Around 1 in 5 people said monitoring.



- Around 1 in 30 people said making decisions about the budget.



- Around 1 in 7 people said putting projects into practice.



- Around 1 in 20 people said how the UN is run and how decisions are made.
- Around 1 in 7 people said planning.



I. It is clear that more and more organisations of persons with disabilities are working with decision makers. However, their views and ideas are still not being listened to enough.

Organisations of persons with disabilities have some really important ideas about laws and policies that affect them. They have important things to say about making services more accessible and pushing for rights.



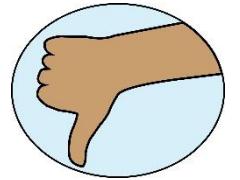
However, organisations of persons with disabilities still say they have bad experiences when working with decision makers. For example, they are often not given reasonable accommodations.



Sometimes, their access needs are not fully met. This often means they are left out or their views are not heard.



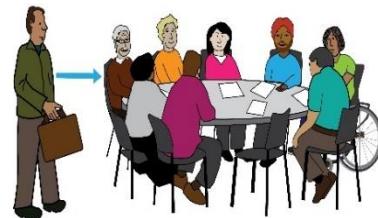
The are also sometimes invited to take part just so that an organisation can say that they have worked with persons with disabilities.



One person from Kenya said that some decision makers are very good at making sure the voices of persons with disabilities are heard. However, others don't understand these issues.



Sometimes, organisations of persons with disabilities are just invited to make it look like decision makers are being inclusive. However, in reality, they can't actually take part properly.



For example, organisations of persons with disabilities were invited to a meeting about changing the law. However, the document was passed around the day before this meeting, meaning that the organisations couldn't actually take part. They were only there to make things look fair. In reality, this was not fair at all.

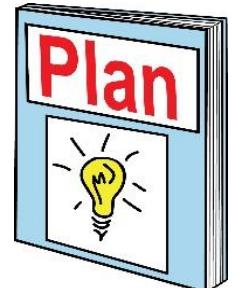


We asked organisations of persons with disabilities about how much decision making they were doing with the government. We asked them about:



Planning:

- Around 1 in 10 people knew nothing about planning.
- Around 1 in 3 people knew about planning but had not been told about it.
- Around 1 in 5 people were told about planning.
- Around 1 in 3 people were consulted.
- Around 1 in 10 people said they made decisions about planning with the government.



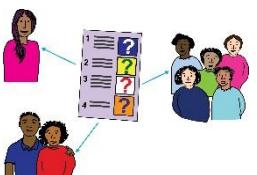
Budget:

- Around 1 in 3 people knew nothing about the budget.
- Around 1 in 3 people knew about it but had not been told about it.
- Around 1 in 5 people were told about it.
- Around 1 in 7 people were consulted.
- Less than 1 in 20 people said they made decisions about the budget with the government.



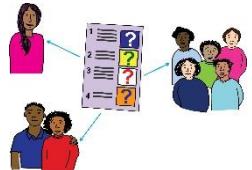
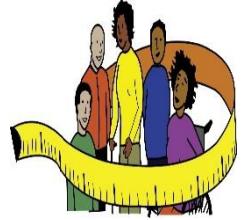
Putting projects into practice:

- Around 1 in 7 people knew nothing about putting projects into practice.
- Around 1 in 3 people knew about it but had not been told about it.
- Around 1 in 5 people were told about it.
- Around 1 in 5 people were consulted.
- Around 1 in 20 people said they made decisions with the government about the putting projects into practice.



Monitoring:

- Around 1 in 4 people knew nothing about monitoring.
- Around 1 in 3 people knew about it but had not been told about it.
- Around 1 in 7 people were told about it.
- Around 1 in 5 people were consulted.
- Around 1 in 20 people said they made decisions about monitoring with the government.



Finding Data or Information:

- Around 1 in 4 people knew nothing about it.
- Around 1 in 4 people knew about it but had not been told about it.
- Around 1 in 5 people were told about it.
- Around 1 in 4 people were consulted.
- Less than 1 in 10 people said they made decisions about the finding data with the government.

