



Inclusion Europe at the World Congress “We Are Inclusion”

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Inclusion Europe

inclusion.eu

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What is the World Congress



“We Are Inclusion” is the name of Inclusion International’s World Congress.

The World Congress is a conference that brings together people with intellectual disabilities, our families, our organisations, and the people who support us.

Inclusion International's 18th World Congress took place in Sharjah, United Arab Emirates, from 15 to 17 September 2025. There were also a Self-Advocacy Summit and Families Summit on 14 September.

Several hundred participants took part in the Congress.

Inclusion Europe at the World Congress

Inclusion Europe represents Region Europe in [Inclusion International](#).

Jyrki Pinomaa and Soufiane El Amrani are members of Council of Inclusion International.

Inclusion Europe organised several sessions at the World Congress:

- **Using data for advocacy.** Inge Volleberg and Soufiane El Amrani presented [Inclusion Indicators](#) and talked about how we use the data to advocate for full rights and inclusion. 20 participants attended the session.
- **Doing deinstitutionalisation.** Milan Šveřepa talked about how the Inclusion movement could change the way we promote transition from institutional to community-based care. 58 participants attended the session.
- **Find Your Voice: Speak Up and Be Heard!** Sandra Marques and László Bercse guided participants through a mix of activities, discussions, and reflections on what it means to speak up for yourself. Participants shared experiences, explored real-life situations through role-play and group exercises, and

developed their own self-advocacy plans. Participants exchanged ideas on how families and professionals can provide support while still respecting each person's voice and choice.

- **JUDY Project** - Sandra Marques and László Bercse shared the results from the JUDY Project, that helped people with intellectual disabilities to build confidence, leadership, and self-advocacy skills. The project trained over 65 self-advocates and reached more than 800 participants across Central and Eastern Europe, showing how inclusive training can support people to move from institutions to community life. Participants heard inspiring stories about self-advocates who became leaders, trained others, and spoke directly with decision-makers to promote real change.
- **Regional session – Europe.** Meeting of European organisations. Guillaume Jacquinot led a discussion about situation in European countries and what we can do about it together. Inge Volleberg gave a brief update about Inclusion Indicators 2025, Freddy Jussien talked about [EU budget advocacy](#). Milan Šveřepa mentioned a new [report on gender equality](#), and invited everyone to Europe in Action conference, which takes place 25 – 27 May 2026 in Italy. There were organisations from Armenia, Bulgaria, Denmark, Finland, Germany, Ireland, Norway, Spain, Sweden, and the UK present at the session.

Inclusion Europe was represented at the World Congress by:

- Jyrki Pinomaa, president
- Jeanne Nicklas-Faust, president-elect
- László Bercse, vice-president, chair of the European Platform of Self-Advocates
- Guillaume Jacquinot, secretary general
- Milan Šveřepa, chief executive
- Inge Volleberg, researcher
- Soufiane El Amrani, self-advocate and accessibility expert
- Sandra Marques, self-advocacy office
- Freddy Jussien, advocacy lead

During the World Congress, Inclusion Europe had many meetings and conversations with people from organisations in Europe and around the world.

What happened at the World Congress and what we think about it

Collection of posts and reflections from Inclusion Europe representatives.

Inge Volleberg before the World Congress

After many weeks of preparing, [Soufiane](#) and I will be leaving to Sharjah tomorrow to attend the World Congress organised by [Inclusion International](#).

We spend many meetings preparing our presentation on the Inclusion indicators, which turned out to be a good exercise to reflect on what we at [Inclusion Europe](#) have accomplished in the last 2-3 years (quite a lot I would say).

But we also had many meetings on what to pack in our bags, what goes in which bag, things we shouldn't forget.

And this is real team work. I remind Soufiane to put his liquids in the checked luggage (ideally wrapped in plastic), while Soufiane tells me I shouldn't forget my travel plug adapter (apparently they have UK plugs in the UAE).

We also went over our travel plan, what time should we meet at the airport, where will we meet and where will we go from there, and informing the airline that Soufiane is travelling with a wheelchair. And we discussed our programme throughout the conference, what are sessions that are really important to attend, when are times to go back to the hotel to rest?

Travelling together or supporting someone at an event abroad is about so much more than only preparing the one presentation or sitting next to each other on the plane. It requires a lot of talking and planning.

But after all this, I believe we are ready and I am looking forward to this next adventure. And it is always an adventure, because no matter how much preparation something unexpected will pop up



([Original post](#))

Saturday

Freddy Jussien, on the way to the World Congress

✈ Spending 6 hours on a plane with your boss could be uncomfortable. But isn't it outside the comfort zone that people do great things? That's what we talked about in the plane.

1. Doing great things:

"At Inclusion, we are doers. That's who we are!" my boss said.

I thought about it...😓 and that's right.

Before nothing was set up for people with intellectual disabilities. Then, they came together with families to advocate for change, and started « self-advocacy ».

They built with others services, jobs and housing to include people.

2. Stepping outside comfort zones:

"We make content understandable, we promote self-advocacy — and we do it in Brussels." my boss said

I thought about it...😓 and that's right.

Brussels isn't designed for clear language or for self-advocates in debates.

But [Inclusion Europe](#) does it anyway. Because that's who we are.

Now I know my role at the [Inclusion International](#) in Sharjah 🇦🇪:

👉 Learn the great things the movement does in the world

👉 See how others step outside their comfort zones

([Original post](#))



Sunday

Soufiane El Amrani after the Self-Advocates' Summit



On Sunday I was at self-advocacy summit in Sharjah.

It took place before the World Congress of Inclusion International which starts today.

There were many self-advocates from all parts of the world.

We heard powerful stories about the right to work, live independently, and have easy-to-read information.

Luis Gabriel Villareal shared about the work he does.

He's vice president of Inclusion International.

Yu Cheng Tseng, self-advocate from Taiwan 🇹🇼, spoke about facing discrimination at school, and how he joined an organisation to share his experiences and promote the CRPD.

He joined a groups of people and together they do beach clean-ups, and visit older people in their homes.

Mia Farah from Lebanon 🇱🇧 spoke about the support self-advocates need and gave inspiring ideas on how to fight for our rights.

We also heard from Mark Mapemba from [Inclusion International](#), who spoke about leadership and how self-advocates can grow into leaders.

Mark said anyone can learn to become a good leader.

I agree!

It was a great day to learn and to meet so many self-advocates.

[\(Original post\)](#)

Jeanne Nicklas-Faust after the Families' Summit

After arriving to Sharjah last night, the family summit is a good start to World Congress of Inclusion International: In a working group with mothers from Nigeria, Taiwan, Korea, Australia, Canada and a sibling from France/Ireland we were discussing what is needed for inclusive communities. Support from families and government are not enough to be included in community - a need for collaboration with organizations of civil society and building more common activities in the community.

([Original post](#))



Freddy Jussien after the Families' Summit

"We don't need to feed Charlie. We need to change the world!" Sue Swenson (President of Inclusion International at the Family Summit)

That sentence says pretty much what families are doing for inclusion of their Charlies (sons/daughters/siblings) with intellectual disabilities.

The family summit had a whole conversation on leadership of families.

Here are my key takeaways from the discussion.

1. Families around the world "must" do amazing things to build inclusive communities

Because there are no other solutions, families must be the first ambassadors of inclusion at community level. So, they organize themselves to find creative solutions, working with allies to build inclusive community.

I was impressed how families:

- have managed to create [a network for supporting the employment of people with intellectual disabilities in Canada!](#) 🇨🇦
- Advocate for [inclusive education in Africa](#).

2. Families around the world “must” support each other to find strength and keep up the good work.

Because there is not enough support, families must support each other.

So, families organisations around the world presented their different initiatives to raise awareness, provide family support and train families.

A new trend is the creation of more sibling support groups. They are the new leaders of inclusion but face [specific challenges](#) that need to be discussed and addressed.

[Mihret Nigussei](#) shared about the first siblings support group in Ethiopia.

3. Families around the world “must” find allies to make inclusion happening

Sue Swenson finished the summit by saying: “Get out there, spread the word, and find allies to build an inclusive world!”.

During the family summit, family agreed to find allies to make inclusion a reality.



Monday

Jeanne Nicklas-Faust after Self-advocacy at UN session

Self-advocacy at the UN! That was for me the Highlight of the day at the World Congress of Inclusion International in Sharjah.

To hear from Carolin Naluwemba from Uganda about research on the participation of Self-advocates at shadow reporting.

From Abanob Tawadros from Egypt hearing about parallel reporting of a group of Self-advocates. And of Joachim Busch on his participation at the delegation of civil society at the state review of Germany in Geneva.

Great insights and amazing Self-advocates!

Rehab Boresli, UN-Committee member from Kuwait highlighted the role of the first Self-advocate in the Committee, Robert Martin.

This was so inspiring and I can't wait to find ways to further enhance the role of Self-advocates at the UN!

([Original post](#))



Milan Šveřepa after Doing Deinstitutionalisation session

As a movement of people with intellectual disabilities and their families, we do a lot of work advocating for deinstitutionalisation. For end to segregation of people with intellectual disabilities in "care" institutions.

1 We keep telling people why institutions are wrong and that they must be closed.

2 We make sure the voices of people who survived institutions are heard. Supporting survivors to tell their stories, learning from their experiences to make deinstitutionalisation reality for everyone.

3 We advocate for good policies and inclusive communities. From inclusive education, through supported decision-making, to housing and support.

!! Yet, there are still so many people with intellectual disabilities segregated in "care" institutions. 800,000 in Europe alone.

Many more around the world.

We need to think about what we can change in our approach to advocating for deinstitutionalisation.

■ We need to make our asks clear and doable, so people understand what we want them to do.

And they need to know they can carry it out.

■ Most people with intellectual disabilities are supported in their homes by their family members. There are many community-based services supporting people.

We know how to support people with disabilities to live independently in the community. There is nothing new to invent in this regard.

■ Many institutions were closed in different countries.

Deinstitutionalisation, it's been done.

There's no need to keep inventing these particular wheels.

There's also no need to play into the governments' hands by agreeing to provide yet more evidence that institutions are harmful or that people benefit from living in the community (duh).

That's settled.

Let's get on with acting upon it.



It was a great privilege to discuss this during my workshop at the **Inclusion International** World Congress, with colleagues from countries as diverse as Australia, Germany, Ghana, Japan, Mexico, New Zealand, Nigeria, Romania to name just few.

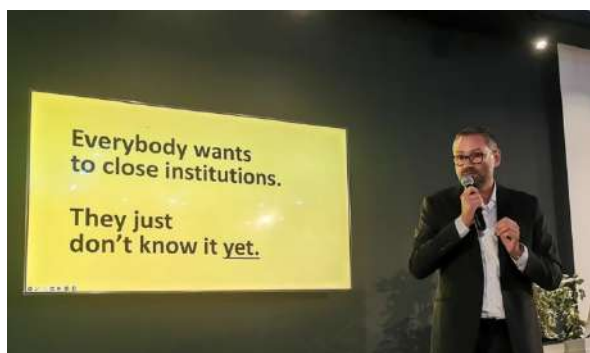
To hear the participants' ideas and experiences.

Thank you!

There were several self-advocates from Japan, who shared their experiences of surviving institutionalisation.

I was moved by them choosing my workshop to do so. I will follow up with a post on what they had to say.

[\(Original post\)](#)



Tuesday

Inge Volleberg after session about siblings

I am the World Congress organised by [Inclusion International](#) in Sharjah, UAE.

The first session I attended was on siblings as leaders in the family, organised by and for siblings.

It was great to hear from and speak with so many siblings from all over the world. We discussed our roles as siblings during childhood, but also now that we are adults, and how we can share care and support roles with our parents.

We also discussed how culture, family structure, and gender play a role. Many of the other siblings shared the extra care responsibilities they had because they are the oldest daughter.

The 90-minute session flew by, and there is still so much more we could have talked about. Hopefully, we will have more opportunities in the coming days to get to know each other.

([Original post](#))



Wednesday

Jyrki Pinomaa after a session on inclusion of people with complex support needs

Today, in the beginning of the final day of [Inclusion International](#) WorldCongress here in Sharjah UAE I felt honored to be one of then speakers in a panel of how we can make sure that people with intellectual disabilities with complex needs will stay visible as part of our global movement.

With me telling their own life stories and discussing were four strong and powerful mothers; [Stephanie Gotlib](#) from Australia, [Sue Swenson](#), the current President of Inclusion International from USA, [Prof. Dr. Jeanne Nicklas-Faust](#), President-elect of Inclusion Europe from Germany and Elena Dal Bo from Argentina.

Our panel was moderated by [Down Syndrome Australia](#)'s CEO [Darryl S.](#)

([Original post](#))



Jeanne Nicklas-Faust after a session on inclusion of people with complex support needs

Inclusion and people with complex needs - how can that be achieved? Five families, six people with high support needs, five countries make different ways and different stories. Most important: All want to be recognised, be part of the movement and equal rights for all.

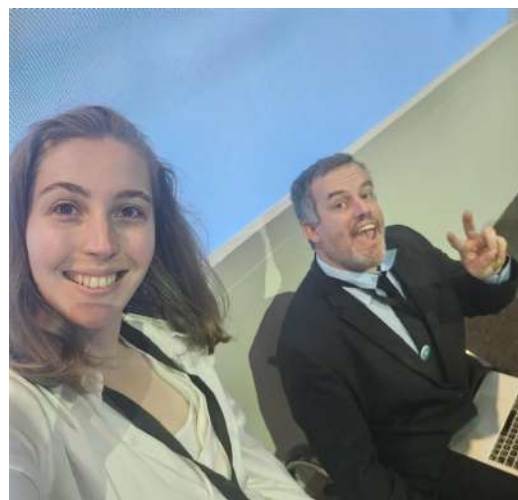
It was great to share this with an passionate auditorium - let's go for solutions!

([Original post](#))



Inge Volleberg after Data for advocacy session

How can we use data in our advocacy?



Soufiane and I talked about the Inclusion indicators. The New Zealand organisation IHC also presented their data projects on health and wellbeing and on poverty.

Soufiane and I presented the Inclusion indicators. We explained the 7 different indicators, why we chose them, and what the data showed us about the situation for people with intellectual disabilities and their families in Europe in 2024.

Soufiane also spoke about how **Inclusion Europe** uses the indicators report in our advocacy: with podcasts and videos, we try to reach as many people; we use the data to inform our reports on housing, employment and legal capacity; and we use it to answer consultations. But it doesn't stop there, we also empower self-advocates by explaining the indicators in easy-to-read with a special issue of Europe For Us. And our members use the indicators report to advocate on the national level, they can say:

"Look! Our neighbour is doing much better than us; we should improve the situation of people with intellectual disabilities in our country!"

Shara and David presented on **IHC Group**'s research projects. They use national data sets that New Zealand keeps on all citizens to do research on people with intellectual disabilities. They discovered that people with intellectual disabilities die up to 20 years earlier than others. People with intellectual disabilities in New Zealand are also more likely to not have enough money and miss out on food, heating, and holidays. They are also more likely to be victims of crime or violence.

Even though this is about New Zealand, we can still use this data in Europe as well. Data like this is missing in many European countries. But we can say: this is the situation in New Zealand, and we have no reason to believe that it is better here.

Thank you to everyone who joined our session and the discussion. Data is necessary in our advocacy work. And we should keep collecting more data, and convince researchers and governments to collect more data too!

([Original post](#))

Jeanne Nicklas-Faust after session for European participants

European members in dialogue was a very lively session of the world congress of Inclusion international: Empowering Self-advocates, dealing with cutbacks and include people with complex needs in our activities were some of the topics. Listening as well as talking respectfully between Self-advocates, parents, siblings and professionals. Most important was the joined understanding of our goal: Equal participation for people with intellectual disabilities and an inclusive society!

Ulla Schmidt, President of [Bundesvereinigung Lebenshilfe e. V.](#) explained the Masterplan to further empower Self-advocates.

([Original post](#))



After the World Congress

Guillaume Jacquinot



What a great few days I spent at [Inclusion International](#) Congress Connecting with the Inclusion network/family.

It has been 2018 since the last Congress in Birmingham and the reunion with all advocates was overdue.

Here are my highlights:

Hearing the powerful stories of self advocates fighting for change in their countries. I had the privilege of moderating a session with advocates like @Ana Martinez from [Plena inclusión](#) Spain, Diane Zgherea from [Keystone Human Services](#) Moldova, Masataka asano and Akio Tsuchimoto from PeopleFirst Japan and [Steven Allen](#) from [Validity Foundation](#) and felt deeply moved by their struggle living in institutions and their lives after, in the community, valued, and in control. I can only wish (and fight) this for my sister, one of the many still on the other side.

As siblings of people with an intellectual, we are now more visible in the Inclusion movement and we are increasingly seen as equal partners to advocate and achieve change and shape our future communities towards more Inclusion. I feel enriched by all the discussions and learning from other siblings like [Steven Allen](#), [Inge Volleberg](#) [Manel MHIRI](#), [Kimber Bialik](#), [Charlotte Pyke Åsa Emtelin](#) [Shabina Bano](#) and many others. [Fiachra O'Connor](#) and [Aoife McGarry](#) as well as my fellow french siblings from [Collectif Fractions](#) should join the conversation ;).

Reconnecting with [Inclusion Europe](#) team [Milan Šveřepa](#) [Freddy Jussien](#) [Sandra Marques](#) and [Soufiane El Amrani](#) [Inge Volleberg](#) and members from many countries and learn from their work on community living, legal capacity, personal support, political participation and see how we can support them and amplify their voices. Many things I will share with [Inclusion Ireland](#) no doubt.

A session with [Sue Swenson](#) [Prof. Dr. Jeanne Nicklas-Faust](#) [Jyrki Pinomaa](#) [Stephanie Gotlib](#) and Elena Dal Bo talking as parents about their support to ensure that their sons and daughters with higher support needs can live a fulfilled life in the community. "If someone cannot speak, it doesn't mean that they have nothing to say!" said brilliantly [Sue Swenson](#).

Great discussions between sessions with amazing advocates and colleagues who I can learn so much from such as [Osamu Nagase](#), [Diane Richler](#), [Jody R. Carr](#), [Cecilia Blanck](#), [Ibaa Khalil](#).

Well done [Jamie Cooke](#) and all [Inclusion International](#) team for such a great event which gave us all lot of food for thoughts and where we want/need to take the whole movement over the next years.

([Original post](#))

Freddy Jussien

Ideas from Africa 💡 to do better in Europe.

Freshly got them from the [Inclusion International](#) [hashtag#WorldCongress2025](#) in [hashtag#Sharjah](#) 🇦🇪.

In Europe, inclusion often gets delayed.
People say there is not enough money, not enough political agreements or sophisticated systems.
It gets delayed because it's "too complex".

So I wanted to understand how do they do it in Africa where:

- political situations are difficult
- money can be a struggle
- cultures and languages are different, sometimes within one country.



I asked African colleagues « how do you deal with the all of this? ». Here are some ideas they shared that can help Europe to do better:

💡 Find new leaders

I have the feeling leadership is getting a bit old in Europe – same approaches, same leaders since a long time ago.

I was amazed how Africa managed to recruit new leaders, finding self-advocates and family

members at very local level, and building inclusion bit by bit with the communities.

👉 see their project for families to become leaders on inclusive education <https://lnkd.in/eq9ZMsKu>.


💡 Together makes own problems weaker

It is tradition in Europe to handle big European folders together, but doing it alone when it comes to national problems.

Africa understood that being together is the best weapon. Even for national problems, they unite and “shame countries into actions”.

👉 see how they challenge west African countries on inclusive education <https://lnkd.in/ebywXXnc>


💡 Time for new allies

In Europe, the support for the movement is getting bad. Governments cut funding and some countries make it harder for NGOs to play their role.
So we complain, a lot...

In the meantime, Inclusion Mauritius , one of the smallest country, with no public funding, managed to bring the biggest delegation (48 people!) in Sharjah.

I asked them « How did you do that!? ».

They answered: target relevant companies, pitch inclusion, train their staff on inclusion, find the win-win situation, and make them play the inclusion game.

👉 <https://lnkd.in/ept5B3MK>

These are just lessons from Africa but I learnt much more from the rest of the world!

So thanks International team! [Sue Swenson](#) [Jamie Cooke](#) [Manel MHIRI](#) [Kimber Bialik](#) [Olivia Schalkwyk](#) [Clay Ballard](#) and Inclusion MENA for putting this together!

([Original post](#))

Milan Šveřepa

Stronger together for full rights and inclusion in Europe 🇪🇺 and everywhere 🌐



Last week at **Inclusion International** World Congress was about meeting people from around the world and learning from all the great work being done for full rights and inclusion.

It's always great to come together, to discuss about our work - to recharge our Inclusion batteries with new, shared energy.

We'll need it.

Because if there's one take away for me, it's this - We need to roll up our sleeves, and dig in our heels.

There are many governments in Europe (and in other places too) making lives of people with intellectual disabilities and their families harder.

Cutting money for support. Allowing worse quality of services. Bringing back institutions.

It's not something I just learned there at **Inclusion Europe** session with European organisations. This has been going on for some time (I often bring it up in my posts or videos).

But hearing it within 15 minutes from literally everyone in the room is another matter.

There were colleagues from Armenia 🇦🇲 Bulgaria 🇧🇬 Denmark 🇩🇰 Finland 🇫🇮 Germany 🇩🇪 Hungary 🇭🇺 Ireland 🇮🇪 Norway 🇳🇴 Romania 🇷🇴 Spain 🇪🇸 Sweden 🇸🇪 UK 🇬🇧 Moldova 🇲🇩 at the conference. Plus the knowledge from our team about Portugal 🇵🇹 Netherlands 🇳🇱 France 🇫🇷 Belgium 🇧🇪 Czechia 🇨🇪.

And the picture was quite clear.

I'm glad for this experience.

Not happy this is being done to people with intellectual disabilities and their families, but glad we could be there together to see it and talk about what we need do about it.

This movement brings together some of the strongest and most resilient people.

We won't accept backsliding.

We'll roll up our sleeves to put up a fight.

We'll dig in our heels to stand against the backward policies so many are trying to normalise.

Together for full rights and inclusion!

[\(Original post\)](#)

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