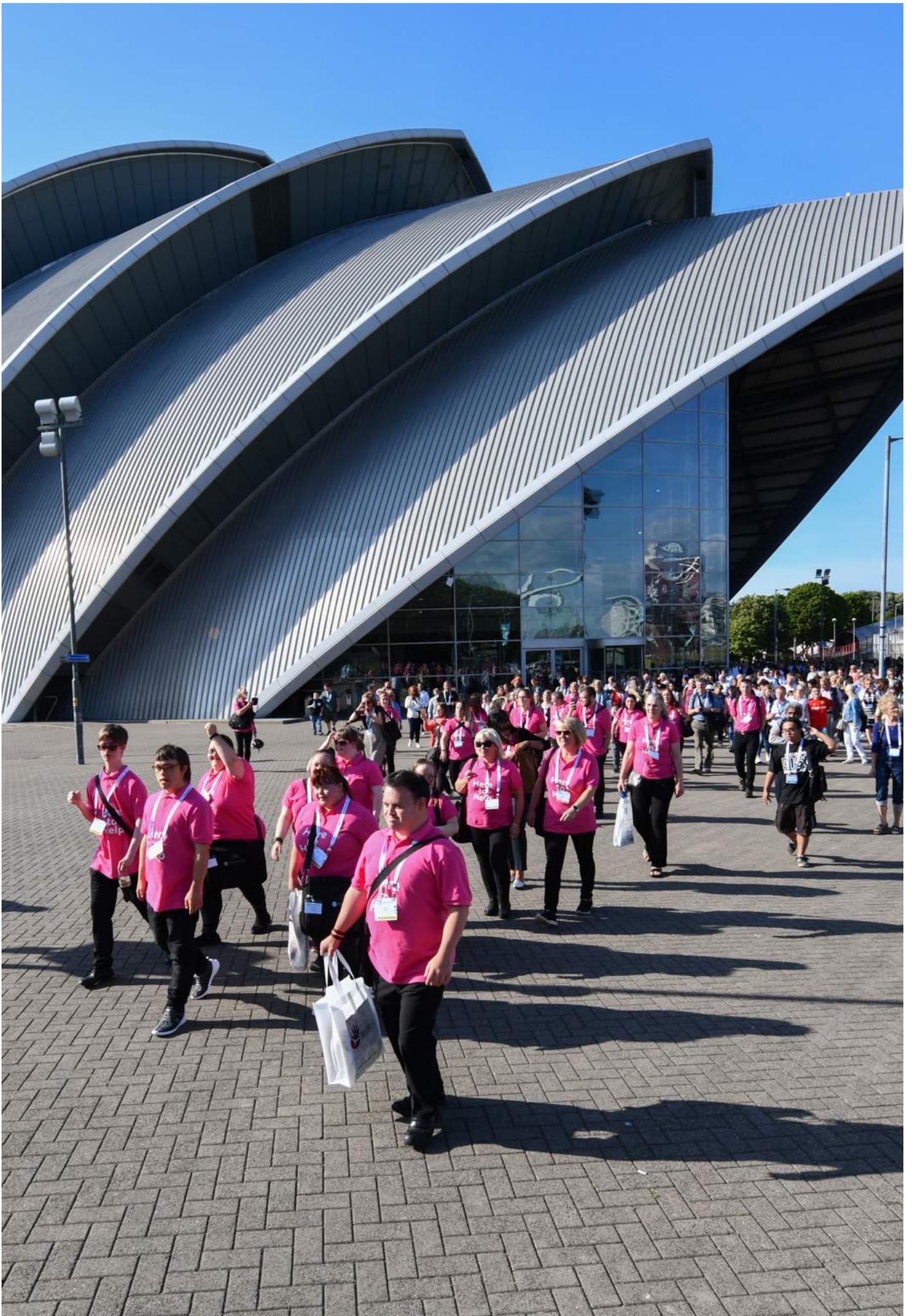


WORLD DOWN SYNDROME CONGRESS







BACKGROUND TO THE PROJECT

Our purpose, as BestCities Global Alliance, is to harness the power of collaboration and community to create positive impact through business events. Our research, initiatives such as Incredible Impacts and the Madrid Challenge, our interactions with clients and destinations - all tell us that education is a priority if the industry is to understand the positive impact that can be created from events and their role in making it happen.

We have created several case studies which we hope will provide inspiration and learning about how a destination has benefited from hosting an international Congress and how the association has moved closer to its mission as a result of holding the Congress.



BACKGROUND TO THIS CASE STUDY

The World Down Syndrome Congress has taken place in five BestCities destinations in the last 20 years – Singapore 2004, Vancouver 2006, Dublin 2009, Cape Town 2012, and Dubai in 2021(online). It was also the recipient of an Incredible Impacts Award in 2018 following its submission from the Glasgow City Marketing Bureau and Down's Syndrome Scotland (DSS) who hosted the event in 2018.

It is a globally rotating triennial Congress attracting over 1,000 delegates. It is a competitive bid

situation whereby the national member bodies present a bid to host the event in their home country and selected city.

The local Convention Bureaux have provided varying levels of support to the national body and Down Syndrome International – mostly support for the bid book, finding and securing venues, securing accommodation, coordination of site visits and promotion of the event. In some cases, financial assistance was also available.

KEY STAKEHOLDERS

Down Syndrome International (DSi)

DSi is a global network of people with Down syndrome and their families, and a network of national organisations in over 140 countries worldwide. Together, they speak up for the human rights of all people with Down syndrome around the world. Their vision is for a better world where people with Down syndrome are fully included in society and have the same opportunities as everyone else.

National Societies

The Congress is held in a different host country and is a platform for the national association to highlight the importance of inclusion for people with Down syndrome in their country.

The local society members who hosted the five World Congresses in the BestCities destinations include, Down Syndrome

Association Singapore, Canadian Down Syndrome Society, Down Syndrome Ireland, Down Syndrome South Africa, Emirates Down Syndrome Association. Down's Syndrome Scotland were the hosts in 2018, the year of the Incredible Impacts Award.

DMO's

Many of the destination partners involved were BestCities partners; Singapore Exhibition & Convention Bureau, Destination Vancouver, Dublin Convention Bureau, Wesgro Convention Bureau and Dubai Business Events. Local PCO's were involved with the different Congresses. Keynote PCO, based in Dublin was interviewed for this case study. Down's Syndrome Scotland, the local host for WDSC 2018 in Glasgow, was also interviewed for this study.



OVERVIEW – WORLD DOWN SYNDROME CONGRESS (WDSC)

The World Congress, originally a biennial, now triennial, is a global event that brings the Down syndrome community together; education and health professionals, social care professionals, families and people with Down syndrome.

The Congress stands out due to its diverse blend of attendees, encompassing not only the national body and professionals but also members, families, and individuals with Down syndrome. The emphasis is on the personal experience of learning and growth, and not limited to the national body and professionals alone. A key objective that runs through the Congresses in the different cities is the bringing together of the Down

syndrome community to learn and share experiences.

DSi also engages in various activities and operates numerous outreach programs and projects, all of which contribute to their overarching goal. One of their key international projects is their self-advocacy work, a project designed to support people with Down syndrome to speak up for themselves and become their own advocates. The Congress provides a golden opportunity to put self-advocacy into practice.



People come to the conference looking for information, looking for ideas, looking for ways to build on their knowledge and have things to take back with them to use. And there's lots of different speakers, lots of different workshops and events that take place that give people those tools.

**Andrew Boys, Executive Director,
Down Syndrome International**



PLANNING FOR LEGACY AT WORLD DOWN SYNDROME CONGRESSES

Moving the Needle Closer to the Mission

This World Congress is an excellent example of a network using its Congress effectively to deliver on its overall mission. In this case, “to improve quality of life for people with Down syndrome worldwide and promote their inherent right to be accepted and included as valued and equal members of their communities.” (Incredible Impacts Programme submission 2023).

This is also echoed at the national host level:



Everything as an objective for Congress has always been in our strategy. We've always had outcomes in respect of making sure that people with Down syndrome are fully included in society, that we will call out discrimination. We will make sure that people have got the access to the right health care, that their human rights are respected, and ultimately that families have access to the right information and the right support at the right time. That's embedded in the core of everything that we do.

**Jo Hughes,
Head of Service Development,
Down's Syndrome Scotland**

Every World Congress puts people with Down syndrome at the heart of the event. In WDSC 2009 Dublin, many of their members with Down syndrome assisted greatly with the running of the Congress, in the provision of entertainment, presentations and generally welcoming the international delegates.

In WDSC Glasgow 2018, they created a network of individuals with Down syndrome called The Commissioners, 12 in total, three of whom were appointed Key Commissioners and became the face of the bid. They were involved in promotion of Glasgow as a host city and travelled to WDSC Chennai 2015 to present Glasgow as the destination for WDSC 2018. This ambition to put people with Down syndrome at the heart of each Congress continues and is being embraced by the organisers of WDSC 2024 Brisbane.

The Glasgow Convention Bureau recognises that the full impact from hosting an international Congress takes time to materialise. In 2023, they revisited WDSC 2018 by following the path of one of the key commissioners, Cher Collins, who was integral to the delivery of the 2018 Congress.

In the five years since her participation in the Congress, the impact on Cher as an individual has been transformative. Her confidence and independence increased as she took on diverse roles, from delivering talks and interviews to actively engaging in workshops. In 2022, she joined DSS as a permanent full-time employee. Cher credits her remarkable journey to the empowering platform provided by the Congress, expressing gratitude for the doors it opened and the enriching experiences it continues to offer. [Glasgow Convention Bureau News](#)

COMMUNITY BUILDING

International conventions facilitate the building and strengthening of relationships and communities and this is a core objective of the World Congresses. DSS made particular mention of this as a hugely rewarding outcome of WDSC 2018, which gave the opportunity for all the people with Down syndrome living in Scotland to exchange experiences with people living with Down syndrome across the world resulting in an amazing network.

DSS actively nurtures and expands the global connections forged with professionals who participated in WDSC 2018, as well as those encountered subsequently and those they look forward to meeting at WDSC 2024 in Brisbane. By fostering and sustaining these connections, DSS actively promotes the implementation of best practices identified during the Glasgow Congress in the local context and encourages the development of innovative practices.



To evidence that and the friendships that were developed from people that have never met before was absolutely incredible. It was lovely to watch and it was very genuine. Friendships were developed and I'm sure there are some people that probably still stay in touch with somebody that they met.

Jo Hughes, Head of Service Development, Down's Syndrome Scotland

KNOWLEDGE SHARING

The power of sharing knowledge and best practice at international events should never be underestimated, and this is particularly prevalent with the WDSC.

One of the key motivations for bidding for the Congress to come to Glasgow was the recognition of the wealth of knowledge and information that is found at a World Down Syndrome Congress. Renowned experts from around the world attend to share best practice and research. Down's Syndrome Scotland (DSS) saw this as an enormous opportunity to bring that knowledge to Scotland, to the

families and the people working in the professional networks of health education, employment and inclusion.

The impact extended beyond the professional sphere; local families experienced significant benefits from the World Congress being hosted in their neighbourhood. They had the chance to attend the event, interact with delegates from around the globe and listen to insights from leading experts worldwide. Something they would never have had the opportunity to do had the Congress been held elsewhere in the world.



I am so lucky she helped me attend the Congress, it was the best thing I have ever done. What an experience, it totally blew me away. My Family Support Service Officer told me she was proud of me for going, and I was so proud of myself too, it was a big thing for me to do on my own....but I really wanted to do it and if I had never had her in my life I wouldn't be where I am now, and I thank her from the bottom of my heart.

Louise Cross, single parent and main carer for her daughter who has a dual diagnosis of Down syndrome and Autistic Spectrum Disorder.



LEGACY ACTIVITIES UNDERTAKEN AT CONGRESS

Each congress starts with a pre-congress session held specifically for delegates with Down syndrome attending the Congress. It took place first in Dublin 2009. The "Synod" was an opportunity for delegates with Down syndrome to talk from their perspective about education, employment and the different issue that they are trying to address at the Congress and globally. This pre-conference activity is an integral part of all World Congresses. In Glasgow it was called The Gathering, in Chennai it was the Panchayat and in South Africa the INDABA.

These important sessions contribute to DSI's self-advocacy work providing a means of strengthening the voices of people with Down syndrome. Together with the many other workshops and activities undertaken at the Congress, these sessions are helping people with Down syndrome to develop their skills, knowledge, and self-confidence to be able to engage with people effectively, take part in work or social situations and understand their rights and responsibilities as citizens.

OUTCOMES

By rotating its Congress around the world, DSI is at the same time creating legacy in each of the host destinations. A significant proportion of the audiences tend to come from the local community in the host destination. The local legacy can therefore be significant. WDSC 2021 Dubai was the first event of its kind to be held in the Middle East. WDSC 2012 Cape Town was a catalyst for the establishment of self-advocacy groups where people with Down syndrome work actively to achieve policy change through advocacy mechanisms.

Hosting a WDSC provides a unique opportunity to raise awareness of Down syndrome in a host city. With support from Glasgow Convention Bureau, DSS conducted training workshops for local businesses, focusing on the hospitality sector, to enhance understanding of Down syndrome in Scotland. The objective was to eliminate stereotypes and prompt organizations to reconsider practices, potentially leading to the employment of individuals with Down syndrome. A total of 155 delegates participated, including 75 Glasgow taxi drivers. All respondents (100%) acknowledged that the session improved their understanding of the needs of Congress delegates, particularly those with Down syndrome.

Each WDSC mark important milestones for DSI, making significant efforts towards inclusivity. In 2022 the "Listen Include Respect" (LIR) guidelines were formally launched. In collaboration with Inclusion International, these guidelines were crafted to promote inclusivity for individuals with Down syndrome. They emphasize active listening, comprehensive inclusion, genuine respect and provide organisations with clear guidance on how to include people with intellectual disabilities in their work. The principles they espouse have been integrated into all recent World Congresses. This could involve providing information in easy-to-understand

formats, offering necessary support for attendance, and structuring meetings to enable full participation. Each WDSC strives to evolve and become more inclusive, enabling individuals with Down syndrome to fully engage alongside other delegates.

World Down Syndrome Day, on March 21, is a hugely important event for the Down syndrome community and was created as a result of people coming together during a World Congress. Around the time of the Singapore WDSC in 2004, a new global awareness day was discussed, which, since 2012, has been officially observed by the United Nations. World Down Syndrome Day has made significant strides in raising awareness, advocating for the rights of individuals with Down syndrome, and fostering inclusion. It has heightened media coverage, contributing to a growing understanding of the challenges faced by individuals with Down syndrome and the telling contributions they make to our society when given opportunities.



WHAT MAKES DSI SUCCESSFUL WITH ITS LEGACY AMBITIONS

As an organisation DSi makes a big effort to track their impact, producing reports and more recently publishing a new strategy, which includes specific impact deliverables and indicators. It takes impact seriously and incorporates it into all its activities, notably into the World Congress.

DSi recognises that making a Congress fully inclusive is not an easy thing to track and it's a very similar challenge with advocacy impact. A lot of advocacy impact measurement has to do with qualitative measurements, based on perceptions people have about whether things are changing. It must be long term.

DSi employs several evaluation methods to assess the Congress:

- In-event surveys integrated into the Congress monitor its progress and effectiveness and provide real-time feedback on the event.
- Follow-up surveys, conducted with attendees post event, play a crucial role in continuous improvement efforts for future events.
- The host country extracts actionable insights from the conference, ensuring that positive changes persist. How the

Listen Include Respect Guidelines have been influenced by feedback from events such as WDSC 2018 being a great example of this.

When asked for three recommendations for associations looking to create legacy from their events, Executive Director Andrew Boys suggested the following:

1. Make sure the event is fully accessible for everyone who attends. All the different types of stakeholders who are there have come to learn and must be given the support that they need to participate fully.
2. Planning for impact. There will be unintended legacy, unintended impact and that should be celebrated. But there is a lot that can be achieved if it is planned, particularly with an event that happens in a sequential period enabling you to undertake comparisons with previous years.
3. Listen to the Locals. Ensure we listen to our hosts and that our hosts listen to their members. It's difficult to judge the impact in countries visited when you are sitting in an office elsewhere, you really need to understand from the people on the ground what impact looks like.

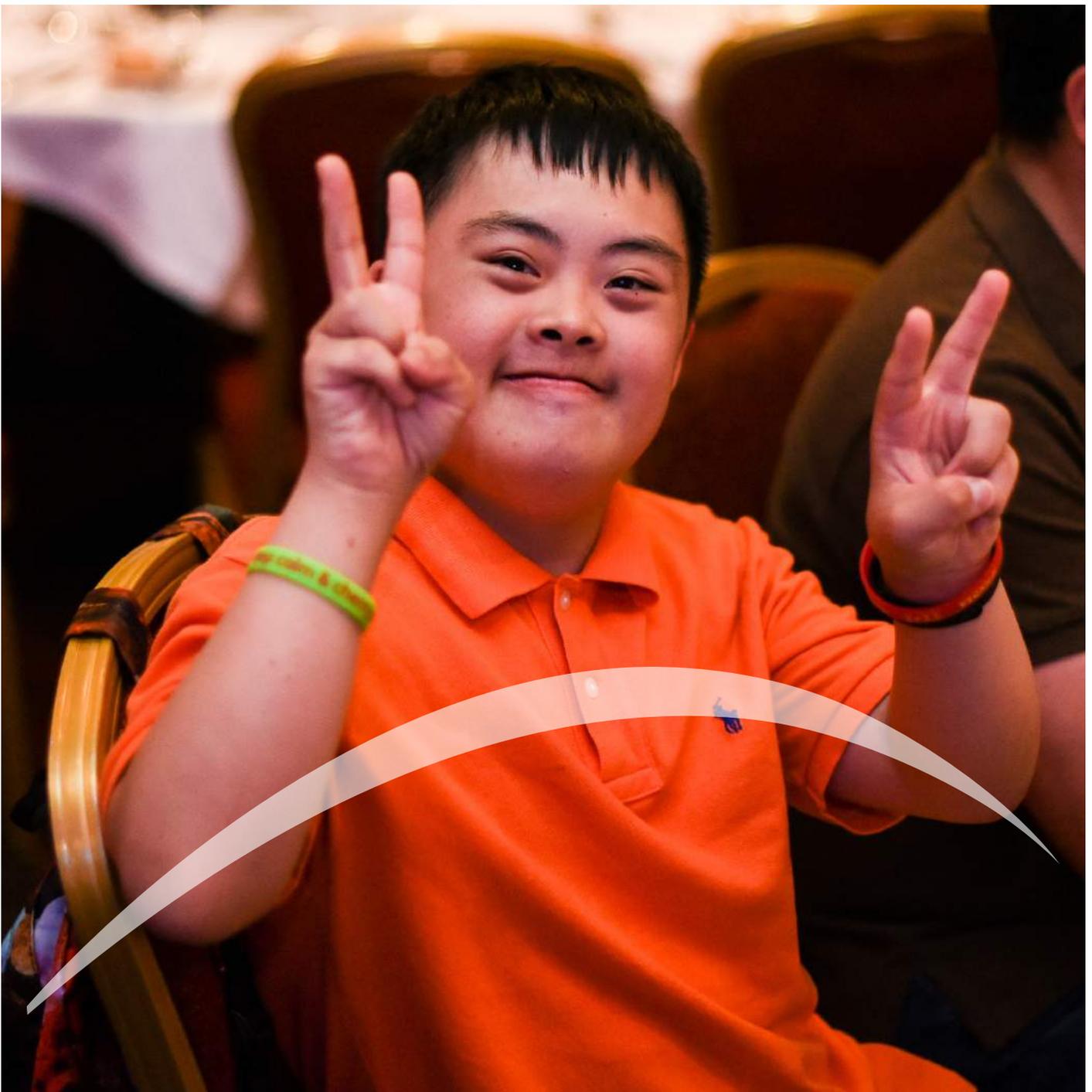


CONCLUSION

WDSC is an excellent example of a global network utilising its Congress as a tool to help deliver on its overall vision, "A better world, where people with Down syndrome are fully included in society" <https://www.ds-int.org/pages/category/who-we-are>

DSi's current ambition is for the organisation to be led by people with Down syndrome and their families in their communities. They recognise that people with Down syndrome and their families know best about what

needs to change in their communities. The World Congress reflects this ambition through the inclusion of local people with Down syndrome in its design and content. Aiming to make changes that are not quick fixes, but long term, contributes to the legacy created by the individual Congresses. Each Congress provides the opportunity for the Down syndrome community to learn and help make the biggest change possible in the lives of people with Down syndrome.



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