

Ujink

Autism-Europe N°78 / December 2022

**Autism-Europe's
13th International
Congress 2022**

**Support Autism-Europe's
campaign for World Autism
Awareness Day 2023!**

**Interview with
William Theviot,
the 'Atypical Pianist'**

**Spotlight on the
United Kingdom: new advocacy
and policy developments**

**Guidelines
for participant-friendly
autism research**

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More news at: www.autismeurope.org



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Edito



Dear readers,

In this edition, you will discover some snapshots from our 13th International Autism-Europe Congress that took place on October 7th- 9th 2022. Our member, the JiM Foundation, hosted AE International Congress in the historical city of Krakow, Poland. Throughout these 3 days, more than 1,300 participants exchanged and debated about the notion of 'A Happy Journey through Life' with experts from around the world, in order to promote a positive vision for autistic people and their families.

Creating a vision to shape a society that works for autistic people is also the objective of the ambitious Moonshot project launched by our member, the National Autistic Society (NAS) in the UK. The NAS has extensively consulted with autistic people and their families to get their insights about the society they want to see. Their objective is for the Moonshot project to support the wider autism movement and governments in achieving their goals. Therefore, in this edition, we also took the opportunity to look more closely at the recent policy developments across the UK, notably in Scotland and Northern Ireland, which are taking place thanks to the work of our members.

Finally, in 2023 we will be celebrating the 40-year journey of Autism-Europe. Under the motto 'Building an inclusive society for autistic people', we will conduct a campaign to reflect on the advances made so far for the autism community and the work that remains to be done to improve the lives of autistic people. We therefore invite all of our members and the autism community to join the campaign for #AutismDay2023 and take part in the various activities. We hope you will join us!

Best regards,

Director,
Aurélie Baranger



President,
Harald T. Neerland



Dance performance on stage at AE's 13th International Congress



Autism-Europe's 13th International Congress in Krakow: the biggest European event on autism in 2022

The congress delivered more than 70 hours of presentations, over 466 topics, 306 poster sessions and 106 speakers – all in just 3 days! Hosted by the JIM foundation, Autism-Europe's International Congress was held in Poland in 2022 for the very first time, with the theme 'A Happy Journey Through Life'.

The theme emphasised that autism is a journey, as it lasts a lifetime, pointing out that whether this journey will be a happy one depends on whether autistic people receive adequate support throughout their lifetime. The theme illustrates the will of the congress to address all the stages of the life of an autistic person.

The congress welcomed over 1,300 people

from all over the world, as participants came from Poland, the USA, the United Kingdom, France, Germany, Ukraine, Iceland, and even Japan and Cambodia, among others. Approximately half of the attendees (600 people) participated online.

The keynote speakers included prof. Isabel Dziobek – head of the University Social Interaction Clinic in Berlin, prof.

Petrus de Vries – director of the Autism Research Centre in Africa – and Ewa Furgal – an autistic woman and founder of the Girl on the Spectrum Foundation. In addition to numerous lectures, seminars and discussions, as well as poster sessions, the programme also included several non-standard activities, such as an art exhibition, or the joint planting of a memorial tree.

Speakers and participants were able to exchange ideas and experiences with each other in the auditoriums and common areas. The distinctive feature of the 13th edition of the Congress in Cracow was that each topic was discussed from three different perspectives: an autistic person or their relative, a researcher and a practitioner all provided their viewpoint during each intervention. The programme intended to be challenging, diverse, inclusive and open to sparking debate. Thanks to this, academic knowledge has been enriched with practice and life experience. An interdisciplinary approach to autism is indeed one of the hallmarks of Autism-Europe congresses.

“On a daily basis, all these groups separately strive to improve the situation of people on the autism spectrum around the world. We gave them a chance to exchange experiences and knowledge so that the solutions developed in the future would take into account the perspective of autistic people. Let their voice be heard.” –

said Tomasz Michalowicz, president of the JIM Foundation.

In total, 106 speakers took part in the congress. The topics covered in these lectures included diagnosis, education, therapy or work. Other presentations explored more specific issues, such as the subject of affirmative care for neurodivergent individuals who are gender expansive, understanding persistent school absenteeism in girls through a narrative approach or how toxic relationships can hinder an autism diagnosis.

“The Autism-Europe congresses held every three years are of great importance to the autistic community around the world. First of all, they provide an opportunity to exchange experiences and knowledge. At the same time, they help in building awareness, including awareness of the real needs of people on the spectrum. Topics discussed equally by scientific authorities along with autistic people enable us to work together to build a better world for autistic people.” –

said Tomasz Michalowicz, president of the JIM Foundation.

Additional challenges linked to the Covid-19 pandemic and the war in Ukraine made this year's congress unique in terms of its history, scale and applied solutions. This is the first time the event has had a hybrid configuration, which provided participants with the option to attend on-site or online, according to their preference.

One of the main outcomes of the congress has been to provide focused attention to the needs of the autistic community. It is important to listen to the voices of autistic people and learn from their point of view, as research should concentrate on improving the lives of autistic people and their relatives.

We already look forward to the next Autism-Europe International Congress that will take place in 2025 in Dublin, Ireland. It will be organised by ASIAM, Ireland's National Autism Charity.

Photo above: Tomasz Michalowicz, President of the JIM Foundation, and Ira Sergiyenko, Director of the Ukrainian organisation Child with Future, at the opening ceremony of AE's 13th International Congress

Visit the dedicated AE's 13th International Congress page



AE's 13th International Congress reception



Workshop on 'Autism and happiness: Mission (im)possible' given by Dr Peter Vermeulen (Belgium) at AE's 13th International Congress



Autism-Europe and JIM Foundation staff at AE's 13th International Congress



Interview with 'Atypical Pianist' William Theviot

William Theviot is a young autistic musician from France who describes himself as being an 'atypical pianist'. Trained in classical music, he now works as a pianist, giving concerts – including for audiences from disadvantaged areas – and advocating for a greater inclusion of disabled people in the cultural scene.

Question: You describe yourself as an 'atypical pianist' on Twitter. When did you become aware of the fact that you were atypical and autistic?

William Theviot: I became aware of being atypical when I realised that my way of approaching music, musical practice and musical study in general was not academic and not truly scholarly either, as it is more free and full of artistic byways. This approach is perhaps paradoxically more demanding than the 'typical' method, which is an almost athletic type of training, where the student is coached in mechanical movements, or rather conditioned into them, as it is a kind of work that is devoid of passion, muscular and detached from the substance of artistic expression. Of course, these two approaches are not incompatible, but I had the impression that there was little room left for open-mindedness, for being different, for alternative pathways, for the questioning that can bring about work that, at its core, searches for singularity – a type of work that might bring about public success if it reaches a certain universality. The main thing is to find one's own musical and intellectual honesty, not to lie about one's own unformatted singularity, [and to stay away] from the eye of the cyclone that would like to carry us away into banality. This strength, which is as much about self-preservation as it is about self-destruction when it comes to staying 'firmly' in the place one considers appropriate, can perhaps be found in autism, as it is almost a guarantee of an independent mind.



Pianist William Theviot joining AE's campaign for World Autism Awareness Day 2022, 'A happy journey through life'

Pianist and autistic activist William Theviot at the piano



Question: Has being autistic influenced your music and creative process?

WT: If being autistic has influenced some of the work I tackle on a regular basis, I wouldn't be able to estimate the percentage as an expert analyst could. I would say that working upholds a mind that can only stand upright when it is over-stimulated, body-built, a bit like in an old type of therapy called 'patterning'. Rather, I would say that it is the loneliness that comes from being autistic that, because of its very nature and intolerance, leads me to overcome my distress through a kind of hyperactivity and 'overcompensation'. It is a bit like the characters in *Philoctetes* or Stefan Zweig's *The Royal Game*, who can somehow resist social rejection by developing abilities that they would not have otherwise explored, because, as the expression goes, if at first you don't succeed, try, try again. However, if work equals self-realisation, then when it is not necessary, I am not sure, because being a happy, contemplative person might be better than being somewhat of a prolific and dissatisfied 'genius', given the solitude that always follows you and catches up with you in the end.

Question: How do you combine your artistic career with your autism awareness and activism work?

WT: I try to get the cultural and disability worlds to meet. They are both like arrogant mountains, and indeed as they say, only mountains don't meet. I try to be a pilgrim, going from one mountain to the other, but it is quite exhausting and dangerous. The few initiatives that do exist often put the people concerned, namely autistic people, to the side, when they often have skills which are neglected and not taken seriously, maybe because their spontaneous nature seems insolent, whereas some people spend years doing theoretical study only to end up mostly with a great ego and without a true sense of diversity.



Question: What are your main demands as an activist?

WT: My main demands would be to allow people with disabilities to have a professional access to culture, not only as spectators who fill the seats at festivals, but to enable them to be actors. Artists who know nothing about disability should not be those who are given priority without considering those who are concerned in the first place. [...]

This January 2023 for example, the County Council of Gironde presented a so-called '100% inclusive roadmap 2022-2025', which did not entertain the possibility of including professional support for disabled artists, who are left to fend for themselves in a world where codes and presentation matter more than coherence, openness and diversity.

I would like if autistic people would be made to feel comfortable in airports for example, in places of transit, and that it not be a fake 'HR policy', but that projects truly include them, that we support and encourage them constructively in awareness-raising efforts. It would also be good if they were not overly medicalised, and that teachers, people in positions of authority and the general public were more welcoming and less stigmatising towards them. Rather, we should provide them with opportunities to allow them to deal constructively with their anxiety about not fulfilling their true potential.

Question: And finally, do you have any plans for World Autism Awareness Day 2023?

WT: For autism awareness month, I am planning to give a concert at the Château Labottière in Bordeaux (at the Bernard-Magrez Cultural Institute), as well as at the Town Hall of Bordeaux. I will perhaps also play at the Opera of Bordeaux because at the beginning of January I suggested to the pianist Khatia Buniatishvili that I play the first part of a concert she will be giving at the start of the month of April, autism-awareness month, in Bordeaux, not far from where I live.

Visit William Theviot's website here:



BUILDING AN INCLUSIVE SOCIETY FOR AUTISTIC PEOPLE



#Autismday2023



World Autism Awareness Day 2023: Building an inclusive society for autistic people

Each year, Autism-Europe (AE) works with its member organisations to conduct a Europe-wide campaign to raise awareness of autism and the rights of autistic people. To mark both World Autism Awareness Day (WAAD) and AE's 40th anniversary in 2023, the theme is 'Building an inclusive society for autistic people'.

As always, Autism-Europe (AE) is celebrating World Autism Awareness Day (WAAD) on 2 April and throughout the month of April. This edition is particularly special, as AE celebrates its 40th anniversary in 2023. Thus, under the motto 'Building an inclusive society for autistic people', this year's campaign will be an opportunity to reflect on the advances made so far for the autism community and the work that remains to be done to improve the lives of autistic people.

It is in this context that AE invites all of its members and the autism community to join the campaign for #AutismDay2023 and take part in its various activities. First

of all, AE launched a photo competition to illustrate the perspectives of autistic people and the ways in which society can be more inclusive. The deadline to participate is the end of February 2023, and each participant could submit up to five original photos.

Additionally, AE launched a call for video-testimonies to further amplify the voice of autistic people and to share their lived experiences, as well as their vision to continue building a more autism-friendly society. So, the organisation invites its members, partners and general public to share their testimonies by mid-March 2023. The video-testimonies will be shared on AE's social media channels,

and AE invites all of its members and supporters to relay these messages throughout the month of April.

Then, on 28 March 2023, to mark WAAD 2023, AE is co-organising an event alongside MEP Rosa Estaràs at the European Parliament in Brussels (Belgium). This event will include a conference, a photo exhibition to display the winning pictures from the competition, and other activities.

Follow Autism-Europe's campaign to mark World Autism Awareness Day 2023 here:



Join us to mark Autism-Europe's 40th anniversary!

Forty years ago, Autism-Europe was founded to promote the rights of autistic people and their families across Europe. Even though much remains to be done, AE and its members have come a long way together!

To celebrate this milestone, AE invites all of its members to join this campaign and also to use its anniversary logo for the occasion. You can find and download the logo and campaign visuals scanning the QR code below.

Translations of the visuals will be available upon request. If you have any questions, please feel free to contact Carmen Clemente, AE's

Communications and Campaigns Manager, at communication@autismeurope.org.

AE looks forward to seeing you all join World Autism Awareness Day 2023, always using the hashtag #AutismDay2023 on social media!



IVRAP project kick-off meeting in Brussels (Belgium) in 2019



'Learn to learn' by Immersive Virtual Reality as a Tool for Autistic Pupils and Teachers (IVRAP)

Running from September 2019, this two-year project has developed, disseminated, and assessed an Immersive Virtual Reality (IVR) educational tool to teach students on the autism spectrum and with learning difficulties how to 'learn to learn'. It includes all the necessary elements of an Individual Work System (IWS), together with the powerful supports provided by means of virtual reality.

It is estimated that 32-50% of autistic people also have an intellectual disability/learning difficulties. Autistic students progress much better when specific educational supports are provided. Visual supports for both receptive communication (daily agendas, individual work systems, task panels, task structures, etc.) and expressive communication (alternative communication systems based on picture-exchange to communicate what they need, and to share ideas with others) are examples of autism-specific supports which have proven effectiveness.

What exactly is IVRAP and why is it beneficial?

The Immersive Virtual Reality as a Tool for Autistic Pupils and Teachers project (IVRAP) is based on the combination of one of the most extended models of autism intervention in education (named Individual Work System or IWS) with the power of Immersive Virtual Reality (IVR) and Hand-Tracking sensors tailored to virtual environments. The individual work system is defined as a visually organised space where children practice acquired skills.

A work system visually communicates at least four pieces of information to the student including (1) the tasks the student is supposed to do, (2) how much work there is to be completed, (3) how the student knows they are finished, and (4) what to do when they are finished (or 'what's next'). The work system provides a structured opportunity for students to practice skills

deliberately and independently. Individual work systems may also promote students' generalisation of skills across settings.

Advantages of using virtual reality for Individual Work System (IWS) include:

- Attracting a learner's attention by highlighting relevant information at each step (by increasing prominence or salience of items to be handled) with additional light or sounds
- Error-free learning, not allowing incorrect handling of objects in early stages of system use
- Control of sensory load, starting with little or no competing stimuli and moving towards more realistic scenarios in later stages of system use to facilitate generalisation and transition towards real (non-virtual) scenarios

Immersive Virtual Reality also has the potential of transferring and generalising knowledge very rapidly, not only for autistic learners, but also for teachers. It can particularly help those geographical areas where access to qualified autism intervention training is very limited. With a Virtual Reality environment, many elements of an autism intervention can be easily incorporated into the daily practice of a teacher who now will also have a powerful tool to boost the learning of autistic students with an intellectual disability.



Policy recommendations for policy-makers and other key decision-makers



AE prepared a report of policy recommendations for policy-makers and other key decision-makers across the EU, including recommendations based on the overall findings of the project as well as good policy and practice across the EU.

Research report about the feasibility, usability and safety of IVRAP Toolkit



This study aims at verifying that the software created in the IVRAP project in its current version, used in Oculus glasses Quest 2 is a safe, viable and usable tool. This document also explains the use of the IVRAP tool as a teacher and as a student.

Massive Open Online Course (MOOC) about Virtual Reality and Autism



Another outcome of IVRAP is a MOOC about how to use virtual reality technologies with autistic students, which will be soon available in English, French, Turkish and Spanish.

Partners:

University of Valencia (coordinator), University of the West of England, Adapta Foundation, Koynos Cooperative, Cambian School, SOBE Foundation, Autismo Ávila, CEFIRE, Konya li MEM, Autism-Europe

What did teachers like the most about the IVRAP tool according to the feasibility study?

- It made it very easy to plan the sessions
- The contents is very motivating for users
- It is really flexible and allows customisation
- Being more interactive as you can use your hands (much better than with controllers)
- Faithfull to reality
- Very well structured and organised
- Enthusiastic to use VR for many other areas in the curriculum
- Comfortable, motivating and fun space

What functions would teachers most like to use IVRAP for?

- For classroom activities where visual support is very important
- Very useful for students with important learning disabilities
- For training students on logic/mathematics and literacy skills

A total of 6 teachers and 14 students tested IVRAP (3 teachers and 7 students from CAMBIAN School in the UK and 3 teachers and 7 students from Trebol School in Spain). All 14 students completed all the tasks they were offered (a total of 127 tasks, 9 tasks per participant on average) which indicates the feasibility of IVRAP toolkit as an intervention tool for autistic students.

The feedback from teachers after using the IVRAP tools was very positive, highlighting 'the realism of everything. More specifically, the activities with animals' and the fact that 'it made it very easy to plan the sessions, it is very flexible and it allows customisation'.

After the interviews and analysis of the experiences, we were happy to learn that both teachers and students found IVRAP highly usable, showing a lot of enthusiasm about the use of this tool in their classroom.



Autism on the Line!

ALERRT training on autistic people in emergency situations held in Cyprus in June 2022

Educating first responders on how to interact with autistic people in the case of an emergency

It is crucial to train first responders to understand and communicate adequately with autistic people so that they are prepared to respond effectively and safely in the case of an emergency. Therefore, Autism-Europe joined from October 2020 to September 2022 the ALERRT Erasmus+ project with health, education, and VET professionals from Spain, Italy, Portugal, Cyprus, and the Czech Republic, to pilot a training on autism for first responders, which included the use of virtual reality.

In August 2022, in České Budějovice, Czechia, an incident involving police officers and a young autistic man at a political rally for the 2023 presidential election made headlines across the country and beyond. Police in plain clothes knelt on the autistic man in order to restrain him after the officers failed to comprehend his behaviour. It was the latest of many events that made the news in recent years where first responders' behaviour led to escalation when interacting with autistic people in

what was perceived as a threat – when it is usually due to miscommunication or misreading behaviour of autistic people.

First responders are seven times more likely to come in contact with a person on the autism spectrum. Evidence shows that first responders are not adequately trained to recognise and respond to autistic people in appropriate ways. All of this points to the importance for first responders to have a sufficient understanding of autism, how people on

the autism spectrum (re)act, and how to best handle incidents involving autistic persons. The barriers are mutual as for people on the autism spectrum learning how to interact with first responders is also critical.

The 'ALERRT – Autism on the line' pilot project promoted autism awareness among first responders and the development of mutual trust between autistic people, their families, and first responders.

At the ALERRT final online conference in September 2022, where the results of the project were presented, Member of European Parliament (MEP) Chiara Gemma from Italy highlighted the added value of projects like ALERRT. It specifically trains a range of professionals including police officers and firefighters and equips them with adequate strategies to meet the needs of autistic people. The MEP welcomed such training programmes as it addresses pressing needs, as evidenced by a vast survey she conducted in Italy. She also welcomed the innovative learning format of the training course and expressed her willingness to promote the availability of such training in Italy. MEP Radka Maxová from Czechia also emphasized how crucial it is for first responders to have an adequate understanding of autism, how it may present in a person, and how best to handle incidents involving autistic people.

During the event, Kirstine Peterson from Autism Denmark, Autism-Europe's Danish member association, also introduced a related initiative, the Inclusive Emergency project – an Erasmus+ project focusing on how to interact with people with various disabilities in cases of emergencies.



To implement this Erasmus+ project, an international partnership of six partners from six different countries was created. The project coordinator, GESEME (Spain), closely worked with the International Centre for the Promotion of Education and Development (CEIPES, Italy), the Universidade Lusófona (Portugal), STANDO LTD (Cyprus), the European Development Agency (EUDA, Czechia), and Autism-Europe in Brussels.

In the framework of ALERRT, a vocational education (VET) trainer curriculum and a manual for first responders, notably police officers, firefighters, and medical

emergency/ambulance workers, was developed covering everything from autistic people's rights, needs and behaviours all the way to concrete practical tips for first responders. Another major output developed by Universidade Lusófona was two virtual reality training scenarios – one where an autistic person was in a car accident and the other where a person on the autism spectrum was trapped in a house fire. Additionally, project partners created a safety kit for autistic people and their families and consolidated the developed learning materials on an e-learning platform created by EUDA.

Part of the project was to pilot the training which was prepared in Palermo, Italy in May 2022 and which was delivered in Larnaca and Nicosia, Cyprus in June 2022 to firefighters, police officers, educators, health and autism professionals recruited by CEIPES (in Italy), GESEME (in Spain), EDA (in Czechia) and STANDO (in Cyprus). They gave overwhelmingly positive feedback.

Follow Autism-Europe's campaign to mark World Autism Awareness Day 2023 here:



Invitation to Autism-Europe's 2023 Annual General Assembly

In accordance with the statutes for our organisation, we are pleased to invite you to attend Autism-Europe's Annual General Assembly, which will take place in Stockholm, Sweden, on May 6th 2023.

An Autism-Europe Council of Administration meeting and a study visit will also take place in conjunction with the General Assembly.

All the working documents related to these meetings will be emailed to registered participants at a later date.

Agenda:

- Presentation of the Executive Committee report
- Presentation of the activity report: 2022
- Presentation of the financial report: 2022
- Presentation of the work programme: 2023

For more information, please contact Autism-Europe's Secretariat: secretariat@autismeurope.org

Vi.Co Hospital:

a new app to enhance accessibility of hospitals and medical treatments

Vi.co Hospital is an app available for Android and iPad mobile devices created by the Children and Autism Foundation (Italy), in collaboration with the Hospital of Pordenone (Italy), to help autistic people access healthcare and undergo health procedure. The app makes medical examinations for autistic children and adults much more accessible.

In recent years, an increasingly large number of scientific contributions have framed the problem of access to healthcare faced by autistic children and adults. Admission to hospitals and health centres is sometimes an issue for both autistic patients and the healthcare workers, due to a lack of staff training to deal with this disability and to the fast-paced rhythm of hospital activities often requested by emergencies.

So, how to ensure that autistic people can access essential healthcare services, given that their conditions require specific accommodation – notably in terms of communication – compared to neurotypical patients?

The network led by the Children and Autism Foundation (FBA, an accredited Italian health organisation recognised by the Italian Ministry of Health) has been taking care of autistic people in a global and transversal way for the past 25 years, giving attention to all aspects of their physical and mental well-being. So, the FBA research team strived to address this challenge in collaboration with the Hospital of Pordenone (Italy), creating the Vi.Co Hospital app (where 'Vi.Co' stands for 'Visual Communication').

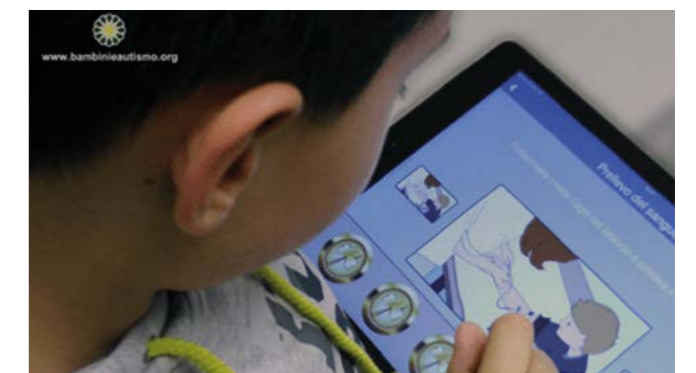
Based on the principle that healthcare workers' training in autism and proper patient preparation for medical treatments is a fundamental element in guaranteeing adequate medical care, the app offers a communication interface between autistic people and the healthcare workforce, therapeutic providers, family members and caregivers with the aim to facilitate medical treatments and procedures. Developed in 5 languages and including 16 medical procedures, Vi.Co Hospital offers the possibility of using a visual communication (via icons, photographs, videos) to show in detail, through different steps, how medical procedures take place.

Vi.Co Hospital was tested on a group of autistic patients who had to undergo a blood sample analysis at the hospital. At the beginning of the test, the healthcare staff worked on the patients' knowledge of the medical procedure by showing them the overall

procedure (i.e., not divided into steps) to explain them how to go through it. Then, patients were asked to reproduce step by step what they saw via the app, using verbal or physical language. As patients proceeded successfully, they earned a token for each successful step. The test reached its conclusion when patients proved to be able to perform all the steps of the procedure for four consecutive sessions.

During the ensuing blood test at the hospital, 80% of the patients proved to be cooperative during the whole procedure. No resistance, problematic behaviors, disruptive or aggressive reactions were observed. Patients' families and healthcare staff evaluated the whole experience in a positive way, because it enabled medical procedures to be planned and delivered better since the communication needs of patients were addressed.

Indeed, the use of Vi.Co Hospital during the patient preparation and the exam phases at the hospital made it possible to create a familiar and predictable situation, minimising contingencies and providing patients and healthcare staff with a shared protocol in a safe environment. The app has proven to be an effective tool to provide autistic people (and people affected by communication problems in general) a fair access to healthcare treatments and prevention pathways.



Vi.Co Hospital app interface

Read more:

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Guidebook for
**PARTICIPANT-FRIENDLY
CLINICAL TRIALS**
in **AUTISM**
for investigators, researchers, clinical trials
staff, and the autism community



The Clinical Trials
in Autism Guidebook
was issued in June 2022

Designing participant-friendly autism research

Participating in clinical trials can be a challenging experience for autistic individuals and their support networks. However, it is important for members of the autism community that their perspectives be taken on board for the collaborative development of all clinical trials, autism or other. Making clinical trials in autism accessible and participant-friendly requires understanding the autism community and their journeys, but also appreciating the unique barriers and challenges faced during the research process and across the community. Members of the autism community and Roche have co-created a Guidebook for Participant-Friendly Clinical Trials in Autism, outlining what steps and recommendations professionals can follow to ensure their research is inclusive of autistic participants when designing and conducting clinical trials. The team has also developed an Autism Guide for Study Participants.

Understanding the need for inclusive research

Diversity characterises neurological conditions on multiple levels: there can be vast differences in the way people present symptoms, on how their lives are impacted and the type of support they require. Exploring these differences with confidence and even celebrating nuances within the community requires a cultural shift – the pharmaceutical industry and academia need to embed inclusivity in all areas of the clinical trial process, from trial design and site selection to post-study communications.

The community should always, and to the largest extent possible, be included in all important decisions about their health, particularly in the early stages

of clinical trial design to ensure the research addresses the most pressing unmet needs in a way that encourages participation. While some considerations to make research more participant-friendly are general and apply to all research design, others are specific to the therapeutic area being studied.

Co-creating a guidebook to address the needs of autistic people and their families

To help ensure that clinical trials consider the requirements of autistic people and their support networks, representatives of the autism community collaborated with Roche to co-develop a freely accessible guidebook. The personal experiences and

opinions of the autism representatives were combined with literature reviews and existing Roche insights and research to create the guidebook as a resource for the autism community. To provide insight into the motivating factors, obstacles, and the emotional perspectives of autistic individuals and their families, caregivers or support staff, two illustrative journeys were developed, representing the experiences of autistic people and their support networks from birth to adulthood. Importantly, the guidebook provides guidelines and considerations for autism and non-autism focused clinical trial organisers to ensure that future trials are truly accessible to autistic people.

The Guidebook for Participant-Friendly Clinical Trials in Autism highlights

the diverse needs within the autism community, and how we can overcome or reduce the barriers participants face when taking part in clinical trials. It highlights the need to conduct research for underserved groups within the autism population. It provides both general and specific considerations for designing, conducting, and supporting participants in autism and non-autism clinical trials depending on the level of support needed. The Guidebook has been co-created alongside eight global representatives from the autism community over the past year, including autism organisation representatives, parents of autistic children and self-advocates.

One of the key recommendations was to co-design clinical trials with members of the autism community. For example, if a clinical trial targets autistic people who have gastrointestinal problems, then autistic people with gastrointestinal problems should be included in the study team. Additionally, if a study involves

minimally verbal autistic individuals, then involving caregivers in the design process may also be useful.

Recommendations for conducting accessible participant-friendly clinical trials

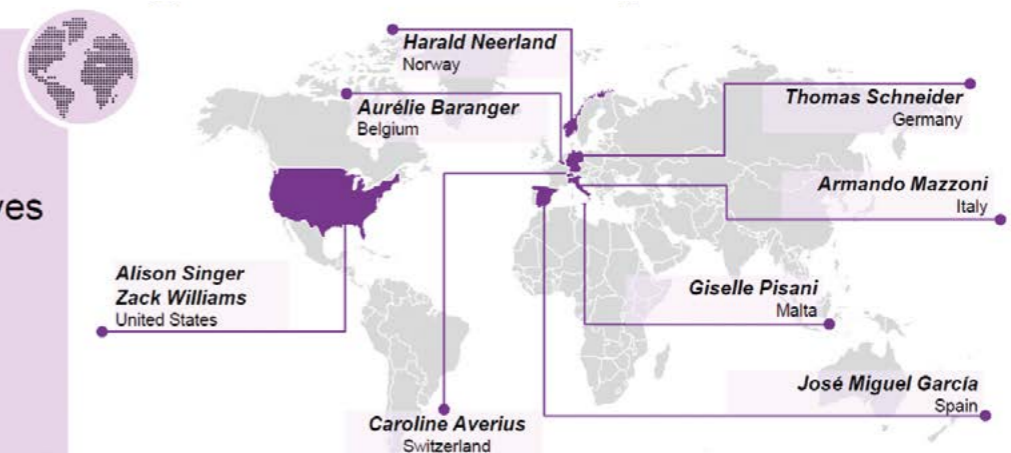
Entering a trial site for the first time can be a nerve-racking experience for many as unexpected events may arise, but it can be more so for autistic people and their families. For example, if an autistic child and their parent enter a hospital for a clinical trial and have had no prior information regarding the layout of the hospital, the location of the trial or where the study team is, this could be a particularly distressing scenario. Researchers can take steps to make that first visit easier. If a person is told ahead of time what to expect from the first visit, how to get around and whom one will be meeting, this can have

a huge impact on the experience for the participant. For instance, the participant and the person accompanying them could be given additional information as to who they are meeting, when they will be meeting them and what they look like (a photograph could be provided). This example illustrates just one of the many ways the experience of a clinical trial can be improved.

Making clinical trials participant-friendly does not necessarily involve complicated guidelines, as it is more so about making the participant feel valued and comfortable. Some useful examples would include ensuring that the trial site – apart from taking equipment and staff considerations into account – adapts to the needs of the participants and those accompanying them, given that participating in clinical trials implies a great deal of time and effort. These accommodations may include providing optional home visits if possible, baby-sitting facilities, validating parking, offering lunch vouchers, etc.

How was this guidebook developed?

Our team included **9** representatives from **8** different countries



Existing Roche insights and research



Literature searches



Online video meetings to share insights



Discussions via the Roche iADVISE virtual platform

Insights on the Guidebook development

The guidebook allows researchers to easily access these recommendations, ensuring that clinical trials are implemented in a participant-friendly manner in a much more robust and sustainable way. The guidebook also contains recommendations pertaining to the post-trial phase, explaining for example how follow-ups should be conducted and how to provide additional information to participants should they have further queries.

Fostering understanding for a more personalised approach to care

Co-created tools like these guidelines can pave the way for more successful research in clinical trials as the improved experience will also lead to better trial adherence and retention. If trial participants are treated in a more human-centred way, they will also be willing to participate more actively in the trial by sharing feedback for example. Pharmaceutical companies

and academia have the responsibility to integrate community perspectives and insights into their core decision-making in order to deliver a truly personalised approach to care in autism.

The team behind the guidebook hopes to see an increasing volume of trials in the field of autism research. Autism research, in general, has an evidence problem: there is a lack of good evidence for a lot of the interventions, and that stems from a lack of funded trial research. There are very simple trials researchers could run — such as whether certain types of antidepressants work to treat anxiety or depression in autistic people. For many of these trials, the setup is essentially the same, which is why the clinical trial guidebook is relevant for all of those kinds of research, and it can help make sure researchers are running these trials optimally and to their highest potential. By implementing the considerations in the guidebook, the team also hopes that clinical trials in other areas can become more inclusive of autistic participants, such as trials on high blood pressure or oncology for instance.

Participating in autism research studies is critical for scientific breakthroughs that improve lives, but there are often lots of questions from families and participants around clinical studies in autism regarding expectations, relevance and information.

To address these queries and raise awareness on the value of science, the team also decided to create a user-friendly ‘Explainer’ clinical guide for autism study participants. The team hopes that people see that by getting involved in research — not only as study participants, but also at the level of trial design — they can help focus the research on what is meaningful to them. We must show people that actively participating in clinical trials can be a positive experience that can improve their lives.

The Guidebook and Explainer are accessible as open-source materials available for researchers to implement in their work and for the autism community to use as tools to advocate for participant-friendly trials.

The Guidebook for participant-friendly trials in autism was created by:

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The Guidebook for Participant-Friendly Clinical Trials in Autism is available to download here:



The Autism Guide for Study Participants is available to download here:



Spotlight on the United Kingdom: new advocacy and policy developments

Recent policy and advocacy developments in the United Kingdom are paving the way for a more autism-inclusive society. From the Moonshot project in the UK – developed by the National Autistic Society – to the Scottish ‘Autism, Learning Disability and Neurodiversity’ Bill and the ‘Autism Amendment’ Act in Northern Ireland, it is safe to say that the UK is making great strides to

strengthen the rights of autistic people and better the services and support that are available to them. The following articles take stock of the current policy and awareness-raising efforts in autism across Northern Ireland, Scotland and the UK as a whole, where autistic people are at the centre of the decision-making process of both recommendations and legislation.

Big changes ahead for Northern Ireland as new autism legislation is introduced

Autism NI is Northern Ireland’s longest established autism charity formed in 1990, providing services for over 35,000 autistic individuals and their families throughout Northern Ireland. The charity is the main ‘change driver’ within Northern Ireland and has provided the secretariat for the All Party Group on Autism at the Northern Ireland Assembly since 2008. It has led the lobby campaign for not one, but two pieces of autism legislation within the past ten years, and it is at the forefront of creating real change for the autism community. The Autism Amendment Bill was passed in March 2022 at the Northern Ireland Assembly with unanimous cross-party support. The new Private Member’s Bill is the most comprehensive piece of single disability legislation within the United Kingdom.

The Bill’s public consultation process attracted more than 1,800 responses in October 2020, receiving one of the biggest consultation responses in Northern Ireland history. The legislation will amend the Autism Act (NI) 2011 to enhance the effectiveness of its provisions.

The legislation will introduce vital changes in Northern Ireland including:

- **Expanding on autism data collection to include prevalence data on adults**
Prior to this legislation, the Northern Ireland Department of Health collected data on children only. The new legislation will therefore introduce data collection on adults too which will aid future planning and service provision for the autistic adult population of Northern Ireland.
- **Development of an autism training strategy**
A new autism training strategy will be introduced to raise awareness and understanding of autism across agencies and professionals who work directly with the autism community, such as teachers and mental health professionals.



Kerry Boyd with local politician and MLA Pam Cameron and Hannah Armstrong, pictured at the Northern Ireland Assembly after the passing of the Autism Amendment Bill in March 2022

- **Development of a regionally consistent early intervention service.**

A regionally consistent early intervention service will be introduced across Northern Ireland to ensure every autistic individual will receive early tailored support and access to resources to best support them.

- **Development of a regional information service.**

A regional information service will be introduced for autistic adults and families to receive the support and access to local services within their area.

- **Development of a regionally consistent range of adult support services.**

The introduction of adult data collection will improve the capacity to map the needs of particular services including employment, education and social opportunities.

- **The autism strategy will have measurable targets and outcomes.**

The new autism strategy will include measurable targets to assess the effectiveness of services and improvements that need to be made to achieve overall goals.

- **The autism strategy will be developed in consultation with the autistic community.**

Northern Ireland's autism community will have a voice in the development of the autism strategy. Autistic people and their families as well as the voluntary and community organisations that represent them will have an input into priority areas.

- **The introduction of an annual budget report.**

All government departments within Northern Ireland will produce a report on the funding of the services delivered within the Northern Ireland Autism Strategy. The report will also evidence the matching of data against investment: for example, matching investment to the rise of autism prevalence rates.

- **The introduction of an independent scrutiny body, known as an Autism Reviewer.**

The Autism Reviewer will have the following duties:

- To monitor the implementation of the Northern Ireland Autism Strategy and to advise the Assembly on its effectiveness.
- To assess the effectiveness of the funding arrangements regarding autism.
- To review the adequacy and effectiveness of services provided for autistic individuals and their families.
- To commission independent autism research.
- To issue a monitoring and evaluation report annually on the progress of the Autism Strategy.

CEO of Autism NI, Kerry Boyd commented that:

'After years of lobbying for better services and leading the campaign for this legislation, I am delighted that this legislation

was passed with support from all political parties. Autism NI has worked extremely hard to ensure that the content of the Bill reflected the needs of our autism community here. The new legislation will end this postcode lottery by strengthening the current Autism Act (NI) and introducing an independent scrutiny mechanism to drive forward regionally consistent autism services. The views of autistic adults, families and the wider autism community were considered when developing this new legislation which I am confident will deliver better outcomes for everyone. It is time for person-centred autism support services to be delivered, which are easily accessible from childhood right through to adulthood'.

Census results confirm prevalence

Another piece of news from Northern Ireland is the release of new autism statistics. In December 2022, the Northern Ireland Statistics & Research Agency published the autism prevalence results from the recent Census. For the first time ever, and as a result of the Autism Act of 2011, the Census included a question to record autism figures. The statistics consequently showed that 35,367 people stated that they have an autism diagnosis. It is the first time in history that the overall autism prevalence has been accounted for.

The statistics show that there may be a significant number of undiagnosed adults, for example 5.25% of 0-14 year olds have a diagnosis of autism, compared to the 0.32% of 40-64 year olds.

Autism NI's CEO stated that:

'The possible reason for this contrast between child and adult diagnosis may be due to autism assessments only beginning in the late 1990s in Northern Ireland. Therefore, many autistic adults were 'missed' as children. It is therefore important that adults have access to diagnostic services within a reasonable timeframe, as well as follow up support services that will enable them to live happier and healthier lives. Hopefully these statistics will be an opportunity for our government to be able to plan for autism services much better'.

Autism prevalence statistics for Northern Ireland taken from 2021 Census (<https://ukdataservice.ac.uk/2022/12/21/second-phase-of-northern-ireland-census-data-released/>)

Age	Percentage	Ratio
All age ranges	1.86%	1:54
0-14 years	5.2%	1:19.2
15-39 years	2.3%	1:43.4
40-64 years	0.3%	1:333
65+ years	0.09%	1:1111
40+	0.24%	1:417
Under 40	3.34%	1:29



The debating chamber of the Scottish Parliament building

Autism policy development in Scotland: building bridges and bridging gaps

More than a decade after the Scottish Strategy for Autism was launched (spanning from 2011 to 2021), and 2023 being the year the Towards Transformation Plan – aiming to better and empower the lives of autistic people and people with learning or intellectual disabilities – ends, Scotland is at a pivotal point in its autism policy development. Recent surveys have highlighted that much remains to be done to address the needs of autistic people in Scotland. So, what does the future of autism policy development in Scotland look like?

While Scotland is often considered one of the leaders in terms of legislative successes for autism, the impact of past strategies is nuanced by the autistic community, their families and professionals working in the sector. Indeed, they point out that these measures do not always translate effectively or meaningfully into the lives of autistic people. Here we look at the next steps in terms of autism policies in Scotland.

Working towards the 'Autism, Learning Disability and Neurodiversity' Bill

Scotland's main policy development is the 'Autism, Learning Disability and Neurodiversity' Bill, which is currently under way. The Scottish government committed to the drafting of this bill after the 2021 Scottish parliamentary election, during which several Scottish political parties included it in their manifestos. The objective of this bill is twofold: first, to ensure that the rights of autistic people, as well as people with learning disabilities and other neurodivergent people, are protected in law, and second, to ensure these rights are being upheld in practice by creating a commissioner role.

The work for this bill builds on the lessons learned from the Ten Year Autism Strategy, which has fallen short of expectations, as

revealed by a survey carried out by the Scottish Parliament's cross-party group on autism in *The Accountability Gap* report (2020) that reviews the impact of the Strategy. Indeed, over half of respondents considered that the Autism Strategy had had no impact on their lives, and over three quarters noted that they had not received the support they needed.

With this bill, the Scottish government is hoping to adopt a human rights-based approach in the areas of health – £2 million are being allocated for annual health services for people with learning disabilities – employment, education, data collection, deinstitutionalisation and care services (by implementing a national support service during diagnosis and post-diagnosis). The bill's core strategy is for it to be designed with the input of autistic people, people with learning disabilities and other neurodivergent people, as well as the wider community. Three panels – a lived-experience panel, a stakeholder panel and a professional panel – will be working alongside the Scottish government to ensure that the bill answers the needs of the people it represents.

Will the bill deliver the needed measures and support?

While there are different perspectives and opinions regarding the measures

that should be provided, the proposal of this bill has been welcomed in Scotland. A survey by Scottish Autism and National Autistic Society Scotland, published in the *Closing The Accountability Gap* report, including the opinions of over 1,200 autistic people, family carers and professionals, revealed that 96% would be in favour of creating a commissioner role. In turn, respondents expect the commissioner to not only hold Scottish authorities to account and ensure they deliver on legislation, but to also take on a research and educational role as well.

So, although the bill is highly anticipated and the preparatory work is expected to provide a tailored approach to the needs of autistic people, it is imperative for the bill to finally provide effective and tangible results, despite its timeline inevitably delaying this process. In the meantime, we hope that Scotland will become an example to others, showing that cooperation and accountability are key to providing services that truly meet the needs of autistic people.

Download the report on Views from autistic people, family carers and professionals on the Scottish Government's proposed Commissioner here:





Looking at the future for autistic people: the Moonshot Project shows us what a better society should look like in the UK and beyond

On the charity's 60th anniversary, the National Autistic Society (United Kingdom) launched its new vision for a society that works for autistic people, built on their direct contribution. The outcome is the ambitious Moonshot Project, which aims to change attitudes about autism and transform their lives.

The National Autistic Society (NAS) launched their project at the beginning of 2022, calling it 'Moonshot' since its goal is shooting for the moon: autistic people deserve a society that works and is fair for them, without exception. So, the NAS put together a plan to consult widely and accessibly over 500 people with different needs and backgrounds in the United Kingdom and beyond, including autistic people, their families, professionals working with autistic people, NAS staff members and partners, key decision-makers and influencers. The NAS reached out to them through social media, workshops, surveys, interviews, discussions and non-verbal creative activities such as videos and drawings.

After having collected their thoughts about what would make society work for them, the NAS turned those insights into the ideas and goals which fed the Moonshot Vision by looking at various everyday scenarios as experienced by autistic people, and considering what these might look like in an autism-friendly future. Additionally, the NAS ran a series of 'Future Gazing' workshops to identify future trends in British society. Increased use of technology, new ways to engage with the National Health Service (NHS) and people's increasing openness to diversity show that new opportunities to achieve the Moonshot vision are arising.

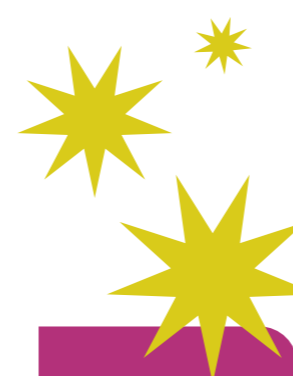
The NAS was therefore able to come up with some key principles for society, namely five desirable Future Realities that came from the research. These key themes describe a society that:

- ▶ Values autistic individuals, by understanding and appreciating what autism is and how it is unique for each individual;
- ▶ Maximises autistic power, by recognising that autistic people are empowered to control their lives and can make distinctive contributions that influence the world;
- ▶ Guarantees support, by providing seamless diagnosis, support and care for autistic people from all backgrounds throughout their lives;
- ▶ Adapts public spaces and services, by designing spaces and services that are autism-inclusive, with flexible adjustments which recognise that not all autistic people have the same preferences;
- ▶ Is free from discrimination, by rejecting stereotypes and stigma.

From these Future Realities, the NAS moved on to the Blueprint for getting there – to the project's own moon. In its recently launched report, the Moonshot Vision describes the short, medium and long term milestones that society needs to reach for autistic people across key areas of life such as work, education, diagnosis and specialist services.

'We hope these will be useful to advocates and organisations up and down the country - and beyond!', declared Tim Nicholls, Head of Influencing and Research at the NAS. 'Although the National Autistic Society led on this research, we don't consider this our vision. It's everyone's – to use and shape the world they want to see, as they see fit. We hope that collectively it supports the wider autism movement and governments to achieve their goals. By launching the Moonshot Vision, we want to start a conversation!'

As highlighted by Caroline Stevens, CEO of the NAS, 'the next step for the National Autistic Society is to develop and share a new strategy that defines our role in achieving a society that works for autistic people. This work is already well under way, and we look forward to sharing our new strategy in 2023!'



Read more about the Moonshot Vision here:



Future Realities

A society that works for autistic people and their families:



Values autistic individuals



Maximises autistic power



Guarantees support



Adapts public spaces and services



Is free from discrimination

The five future realities identified by the Moonshot Vision for a society that works for autistic people and their families



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