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Contents

The rights of people with autism and intellectual disabilities	3
Participatory design	4
The working group	5
Mission statement	6
Work plan September 2017 – August 2018	7

The rights of people with autism and intellectual disabilities

The United Nations Convention on the Rights of Persons with Disabilities states that parties undertake a number of general obligations, including:

To undertake or promote research and development of universally designed goods, services, equipment and facilities ... which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities.

To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost.¹

The UN convention was ratified by the European Union in December 2010, marking the first time in its history that the EU became a party to an international human rights treaty.

The EU's European Disability Strategy 2010-2020 seeks "to empower people with disabilities so that they can enjoy their full rights, and benefit fully from participating in society." To achieve this, the strategy recommends, among other things, the importance of considering the needs of people with disabilities during the design of products, services, environments, education, and training.²

It is estimated that between 5 and 15 million EU citizens have an intellectual disability.³ While the complexity of diagnosis, and the potential co-morbidity of Autism and intellectual disability make it more difficult to determine the exact prevalence of Autism, it is believed to be of a similar magnitude.⁴

This represents a substantial group of EU citizens whose unique needs and preferences must be considered during the design of products, services, and environments. The inclusion of these individuals' perspectives is an essential factor in the realisation of their fundamental rights, their empowerment, and their full participation in European society.

¹ UN Convention on the Rights of Persons with Disabilities, Article 4

² EU Communication COM/2010/0636

³ POMONA Final Report. <https://goo.gl/fEvzJa>

⁴ Some elements about the prevalence of Autism Spectrum Disorders (ASD) in the European Union. <https://goo.gl/wjPpJt>

Participatory design

Participatory design refers to any process in which the end users of a product or service are involved in its development, not merely as testers or by informing a user model, but as *design participants*. In this role, they make decisions about the nature of the product or service, and collaborate with designers so that the users' perspectives and preferences are incorporated into the outcome. Originating in Scandinavia in the 1970s, participatory design has a uniquely European heritage as a political movement for inclusion and democracy in design.

We believe that participatory design represents an exciting and effective way to ensure both the participation of people with autism and intellectual disabilities in society, and the effectiveness and availability of products, services, environments, and technologies for this population. Participatory design for people with autism and intellectual disabilities may therefore prove to be a key factor in ensuring the rights of people with disabilities and implementing the EU Disability Strategy.

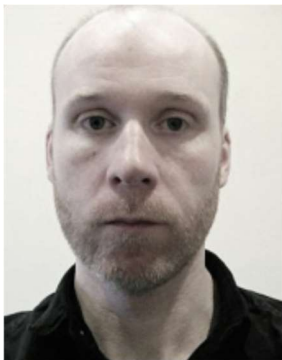
However, participatory design with neurodiverse populations presents unique challenges. Imagine that your co-designers have social/communication difficulties. Or that they are completely non-verbal. Or perhaps they are not primarily focused on sight and sound, and so require multisensory stimulation and communication. These and other challenges must be met if we are to fully realise the participation of people with autism and intellectual disabilities in design, and, by extension, society.

A growing body of exciting research is addressing these challenges. However, neurodiversity in design is still in its infancy. It is far from mainstream practice, and an enormous range of outstanding issues – from the practical to the political – must urgently be addressed. To accelerate the state of the art in this field we have founded the ***Neurodiversity in Design European Working Group***. Our overall aim is to build a rich and productive network of participatory design for neurodiversity research, and to expediate the translation and communication of this research to broader society, so that people with autism and intellectual disabilities can actively influence the design of the products and services they use.

The working group



Dr. Yurgos Politis completed a Physics degree at the University of Athens, qualifying as a Physics teacher. He then undertook a Masters in Education and a PhD in Education in University College Dublin. He is currently a Marie Curie Fellow with the ASSISTID programme, spending two years at Michigan State University and one at University College Dublin. His project, Virtual Learning for people with ASD, will offer training on communication skills through a Virtual World. He will develop an intervention personalized to the needs and preferences of each participant to ease their transition from education to independent life.



Dr. Nigel Robb received his PhD in philosophy from Queen's University Belfast. He also holds a Master's degree in software engineering. His research is focused on the effects of video games on learning and cognition, and the application of games as interventions for people with disabilities. He is currently a Marie Curie ASSISTID Postdoctoral Fellow at University College Dublin, and a Visiting Scholar at Michigan State University. He is currently developing an inclusive online multiplayer game for children with intellectual disability, with children participating in the design process.



Bryan Boyle is currently a Marie Curie ASSISTID Postdoctoral Fellow at Trinity College Dublin. He has an extensive background in clinical practice supporting children with disabilities through the application of technology in therapeutic and educational settings. His research interests are focussed on the relationship between children with disabilities and the technology they employ to support participation. His current research focuses on inclusive design practice and on the application of virtual world technology on collaborative learning for children on the autism spectrum.

Mission statement

The aims of the Neurodiversity in Design European Working Group are:

1. To advance the state of the art in participatory design for people with autism and intellectual disabilities.
2. To develop a European-led global collaboration between participatory design researchers and practitioners.
3. To raise public awareness of, and knowledge about, the many roles people with autism and intellectual disabilities can play in design.
4. To facilitate participatory design with people with autism and intellectual disabilities by making practical resources and guidelines accessible and easy to use.
5. To promote a “one size fits one approach”, by cultivating agile, inclusive, responsive approaches to design.
6. To stimulate debate on ethical issues, policy, and practice relating to the nature of participation, including issues relating to the rights of persons with disabilities, and gender issues.

Work plan September 2017 – August 2018

Sep-17	Launch of website, neurodiversityindesign.eu
Oct-17	Draft founding document release
Nov-17	
Dec-17	
Jan-18	Pre-launch event with guest speaker (tbc)
Feb-18	Grant application submission for dissemination event; Submission of Interactive Workshop proposal to Participatory Design Conference 2018 (to be held in Belgium in August 2018)
Mar-18	Formal launch of the working group in Dublin
Apr-18	
May-18	
Jun-18	First official meeting of the extended working group, involving researchers from across Europe; Release of Work Plan September 2018 – August 2019
Jul-18	Journal article submission: "A review of participatory design for people with autism and intellectual disabilities"
Aug-18	Participatory design conference 2018, Belgium