

### Events, Meetings and Reports

# 13th Autism Europe International Congress Cracow 7-9 October 2022. A Happy Journey through Life

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### **Abstract**

This review from the 13<sup>th</sup> Autism Europe International Congress held in Cracow as a hybrid event, has the ambition to showcase three perspectives on the newest scientific trends in the autistic community: perspectives from researchers/academics, practitioners, autistic people and their family members.

Keywords: autism spectrum conditions; happiness; journey through life.

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Autism-Europe (AE) is an international non-profit organization, whose main objective is to advance the rights of autistic people and to help them improve their quality of life. AE as an international association is composed of almost 90 member organizations from 38 countries and represents an estimated 7 million people throughout Europe. It is important to be reminded that self-advocates and families play a central role in the organization. AE is recognized by the European institutions as a key representative network in Europe of autistic people and their families. Last year the Congress took place in a hybrid format with participants able to attend remotely as well as in person in the ICE Kraków Congress Center in Cracow, Poland. The 2 and half days running from the 7-9 October were packed with over 17 oral presentations, over 20 symposiums, posters exhibitions including e-posters, international keynote speakers from the USA, Germany, UK, France, South Africa just to name a few.

The aim of the Congress was to encourage the exchange of knowledge among researchers, medical doctors and other professionals active in the field of autism. As a result, information about diagnosis, therapy, support and education of autistic people became more available to the public – including the parents and caregivers and lived-experiences became key to the central focus and message of the Congress. Organized every three years, the interdisciplinary and transdisciplinary approach to autism remains one of the core features, aiming to provide a balanced selection of events. One of the recurring cultural events at the Congress is the International art exhibition for autistic people by autistic artists. So far, Autismo Burgos has organized 8 International Exhibitions. They had a great impact, not only among the community of autistic people but also among society in general and the world of art. As outlined in the programme, three perspectives were highlighted on the newest scientific trend in the autistic community. These were practitioners, researchers and autistic people and their family members. This brief review is aimed at summarizing key themes and narratives over the last 2 ½ days making a personal selection of key presentations, lessons learnt, reflections, challenges, new conversations and directions for the future.

## A Happy Journey through Life - The Significance of Context, Variability in Experiences and Recognising Differences.

Dr. Connie Kasari (2022) (USA) presented her perspective from the point of view of inclusion, integration and improvements within the education systems and schools in the USA. She talked about the significance of understanding that not all autistic pupils will require so called



'interventions' and that we all need to be mindful of the potential trap 'one size fits all'. Cocreating educational environments that promote and support personalized ways to nurture buddy systems or mentoring that facilitate opportunities for social interactions and social skills based on special interests and characteristics rather than expecting all pupils to 'conform' to a specific timetable or expectation of what playtime should be.

Inequalities both in health but also in opportunities to create social networks amongst autistic community, were highlighted by Dr. Jeremy Parr (2022) from Newcastle University (UK). This recognised inequalities of opportunities can sadly lead and is leading to poor physical and mental health which with the impact of the Covid pandemic has seen a sharp rise of cases.

Dr. Marian Torres-Viso (2022) (USA) provided an overview of the importance for trauma-informed practices and how caregivers, community members, and non-trauma specialists can provide support for neurodiverse children who might have been exposed to significant trauma in their lives. The relevance for meaning-making, and the recognition that trauma is a deeply subjective experience not to be seen as a failure on the part of the individual or their family. Through identification of key stages including realization, recognition, responses and resistance, it was highlighted that agency, a sense of control and empowerment, honoring recovery times encompass the nation of 'doing with' and not doing to autistic individuals who might have experienced trauma.

The use of language and how it is adopted and adapted in different contexts was eloquently highlighted by Prof. Petrus J. de Vries (2022) (South Africa) talking about the importance of family members and caregivers and their contributions in facilitating capable environments that celebrate strengths and capabilities, interests and skills of autistic individuals. He spoke about how certain terms such as 'weaknesses' can perpetuate this notion of fixing or needing to fix someone that is broken or weak, offering an alternative perspective: we ought to speak about weaknesses in the context of systems rather than in autistic individuals and how we can indeed adopt, adapt these.

#### A Happy Journey Through Life - Wellbeing and Quality of Life

The theme of wellbeing, happiness and quality of life was also comprehensively covered in the Congress. Dr. Peter Vermeluen (2022) (Holland) advocated for a complete change of perspective related to measurements of stress levels and anxiety proposing that rather than continuously exploring what makes us unhappy or causes us to be stressed. People ought to



focus on good feelings, positive emotions, relaxation, mindfulness which all have good evidence-practice-base in coping and dealing with intolerance of uncertainty, emotional dysregulation and social anxiety. It was proposed that 'good feeling sensory circuits' and 'good feeling tool boxes' ought to be available in all classrooms and educational environments. The opportunity to harness strengths and abilities even in the face of barriers and adversities. Challenges ought to be part of this journey and welcome that resilience can only be fostered and developed when we are being exposed to these challenges and given the opportunities to build relevant coping skills. If all challenges are taken away, the opportunity will also become obsolete.

Dr. Hilde Guerts (2022) (Netherlands) provided some clarification on the challenges faced by researchers in the field of QoL, and psychological well being, proposing that QoL is multifactorial and needs to be explored within a specific context, as it means different things to different individuals. Looking at predictors of subjective wellbeing it was interesting but not new, to hear that sleep interference, social satisfaction and perceptions of how autistic individuals can and are contributing to society play a role.

Prof. Catherine Lord (2022) (USA) spoke about the importance of early interventions and again the relevance of asking the question of 'what matters?'. She demonstrated through a specific cohort of young autistic children followed-up to 19 years of age, that the neuroplasticity of our brain facilitates steady progress in social communication and expressive language levels. Asking the right questions shows us that hopes for the future from parents, caregivers and young autistic adults may somewhat differ and the importance of answering the question of what matters ought to be continuously rivisted.

On the 2nd day a special session was devoted to Ukraine, the war and autism. Ms. Dariya Orlova-Zhernovaya (2022), Ms. Iryna Sergiyenko (2022) both autistic individuals provided a hard but inspiring overview of the support and creative collaborations that has taken place with Ukrainian families and their autistic children and how the war has and continues to impact them. For those that have fled but also for those that have remained there is still a lot that we can all contribute to in order to alleviate its impact and pave the journey to a happy(er) life.

### A Happy Journey Through Life - Participatory and Collaborative Socially Responsive Research

Dr. Asdis Bergthorsdottir (2022) (Iceland) provided a refreshing reflection on the use of CBT models and CBT therapies with autistic individuals, reasoning and arguing that despite its adaptations the traditional CBT models do not address the autistic experience. It furthermore potentially causes a recurrence of problems, an increased anxiety level, danger of increased self-blame and sense of worthlessness. The argument sat on the notion that the traditional physiological, cognitive, emotional, behavioral CBT model fails to address the challenges that autistic people face with interoception, executive functioning, alexithymia, and the notion of resulting to flight/fight/faw or faint when faced with these challenges. Whilst recognising that easy answers are not available, more collaborative and participatory research is needed, if those models are to be used.

Dr. Zainab Al-Attar (2022) (UK) discussed when autism and ADHD combine and the challenges associated with either mis-diagnosis or lack of it. She promoted the importance of their bi-directional interactions and the danger for clinicians and diagnosticians to hold an hyperfocus on one or the other, leading to reciprocal masking. Concluding reflections led to promoting expectations and benchmarking set at thriving rather than malfunctioning or deficits.

Prof. Brian Boyd (2022) from University of Carolina (USA) covered the difficult topic of 'repetitive behaviors' in the context of its conceptualisation and whether current measures really hold. A need for better conversations are warranted, where the questions of whether intervene or never intervene are explored through 1st person accounts and perspectives. He spoke about co-occurring conditions that ought to be taken into account when trying to better understand these repetitive behaviors. The role played by physical health, sensory sensitivities, sleep and gastro-intestinal issues (GI), the role played by the onset of anxiety, depression and executive functioning. He proposed therefore a reframing in the research agenda, and even if there are different perspectives that ought to be taken into account, there are also commonalities and it is from these that the conversation can start and continue.

Finally Dr. Isabel Dziobek (2022) (Germany) offered an overview of a future that looks at the potential for technology to improve the lives of autistic people. A roadmap that addresses at least partially the sharp increase of autistic individuals who develop mental ill health (70% increase) and risk of suicide (6-10 fold increase) according to her statistics. The use of Assistive

Technology and social robotics in autism looks promising though questions were raised on its feasibility, scalability and accessibility. As proposed earlier this can be the starting point of a conversation that aims to improve and empower autistic communities.

### **Next Autism-Europe Congress:**

The next AE Congress will be hosted in Dublin, Ireland in 2025.

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### **Competing Interests**

The author is an editor of Psychological Thought.

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