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More articles at: www.autismeurope.org















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Dear readers,

e would like to dedicate this issue to the memory of Prof Isabel Cottinelli Telmo who passed away in November 2021. Isabel was President of the Portuguese Autism Association APPDA since 1984, Member of the Council of Administration of Autism-Europe since 1986, and Vice-President of Autism-Europe from 1990 to 2008. We will deeply miss Isabel: her tireless action to promote the rights of autistic people, her expertise as well as kindness and European spirit have inspired many of our members over the years.

In recent months, Autism-Europe has continued its advocacy and projects activities. Autism-Europe has, for example, been selected as one of the members of the new Disability Platform launched by the European Commission. The platform's objective is to cooperate with European institutions and EU Member States to foster the implementation of the EU Strategy for the rights of persons with disabilities 2021-2030. We will make sure that the perspective of autistic people and their families is taken into consideration.

Across Europe, 2021 also saw some milestones regarding the adoption of national autism strategies in several countries across Europe. Autism-Europe welcomes these developments that are in line with its advocacy efforts to promote a coordinated and strategic approach to autism.

This need for strategic approach is also reflected in some of the recommendations of the Lancet Commission on the future of care and clinical research that calls on governments to ensure adequate coordination between health-care, education, finance, and social sectors across the life span, and active inclusion and participation of autistic people and their families.

Our 13th international congress "A Happy Journey through Life" will also focus on a lifelong perspective. Do not forget to register and submit your proposals for presentations! We look forward to connecting with you all in 2022 in person or online – as for the first time this event will be hybrid.

with best wishes,

Director, Aurélie Baranger



President,Harald T. Neerland



In memory

of Prof Isabel Cottinelli Telmo (1930-2021)



Autism-Europe is very saddened to learn of the passing of our friend Prof. Isabel Cottinelli Telmo. Isabel was a Member of the Council of Administration of Autism-Europe since 1986 and Vice-President of Autism-Europe from 1990 to 2008. She was a tireless advocate for the rights of autistic people in Portugal and at the European level. As such, she had a great impact on the lives of many. Until a few weeks ago she had been coordinating our IVEA project to foster access to vocational training and employment for autistic people. Her strength, unwavering determination, combined with optimism and kindness were an inspiration to many across Europe. Many of our members have expressed their gratitude to Isabel. Here we would like to share the tribute of Donata Vivanti, former President of Autism-Europe from 2000 to 2007:

n the sad circumstances of her death on 15 November 2021, at the age of 91, I would like to pay tribute to the life and work of a special person, Isabel Cottinelli Telmo. President of the Portuguese Autism Association APPDA since 1984, founding member and vice-president of Autism-Europe from 1990 to 2008, Isabel dedicated her life, energy and resources to improve the condition of people with autism, in Portugal and in Europe. Professor of Architecture, expert in autism and multilingual, she was a true citizen of the world, with a vast culture resulting not only from her studies, in Portugal and abroad, but also from the travels and the human and professional contacts that she was able to establish and maintain throughout her life.

As a mother of seven children, including one with autism, at a time when parents were being questioned, she did not lose heart in the face of prejudice and the lack of appropriate services and support in her country. Thanks to her keen intelligence, activism and tenacity, from the 1980s onwards she was able to build innovative services for people with autism, fighting for the recognition of their rights and needs, involving public institutions and significantly influencing the social policies of her country, to the point of obtaining a prestigious Medal of Merit from the city of Lisbon.

It would take too long to recall here all the initiatives in the field of autism and disability that she has animated during her life as an activist, from numerous projects to events and congresses at national and European level. However, despite the quality and success of her commitment, Isabel always remained a humble and shy person, who shunned recognition and prestigious positions, preferring concrete actions. Although she deserved it more than anyone else because of her enormous experience, she always refused the presidency of Autism-Europe, but was

always available to contribute significantly to its actions and policies and to support its members in their work.

An essential point of reference for all members of Autism-Europe disappears with her. She leaves a great void in our hearts, but also an exemplary legacy of courage and commitment to the cause of autism that will never fade.

I have lost a dear friend of whom I like to remember the harmony that united us on the many occasions we met and worked together, enriched by her competence and enlightened by her humour. But even more I like to remember the warmth of her large family around a table, to taste together the cod pie prepared by Isabel with all the love and humility of a great woman.

Goodbye dear Isabel, you will always be at the side of those who knew and loved you for your indomitable spirit and the example you set for us."

The IVEA project for the inclusion of autistic people in employment



The Innovative Vocational Education for Autism (IVEA) project aimed at fostering the employability of autistic people and increase their work opportunites thanks to pilot training programmes addressed to autistic people and employers. A European holistic guide and an online application are now available. Running from October 2018 to March 2021, the project was funded by the European Commission's Erasmus+ Programme. IVEA was coordinated by Prof. Isabel Cottinelli on behalf of the FPDA Federação Portuguesa de Autismo (Portugal) with the participation of Autismo Burgos (Spain), Mars autistákért Alapitvány (Hungary), Autisme Europe, Universidade Portuguesa Católica (Portugal) and Intermedia KT (Greece).

IVEA created an active synergy with its partner organizations across different employment and socio-economic sectors. This initiative brought a more modern, dynamic, committed and professional approach through the integration of innovative methods co-produced with autistic people who expressed their concrete needs.

A smartphone application has also been created including an accessible version for autistic people with a learning disability. The IVEA app is available to Download for free via GooglePlay Store.

The European Guide provides:

- Information about the key transversal competences identified for the employment of people on the autism spectrum
- A training course for future autistic employees: "New bridges for professional inclusion of autistic people"
- A training course for employers: "New

- dynamics for professional inclusion of autistic people"
- Testimonies about internships in the chosen organisations
- The result of the synergies of the courses and internships of autistic people in the organisations.

IVEA was awarded the first Award for Equity, Inclusion and Diversity in 2021 by the Erasmus National Agency of Portugal. The success of the project shows that employers are interested in hiring and including autistic people in their organizations. Employers are also eager to learn more about diverse population groups and how they can contribute towards building a more inclusive work environment. According to the project evaluation, the course for employers benefited all participants in the internships.

More information:

www.ivea-project.eu

Lancet Commission on autism calls for adequate policy coordination across sectors

THE LANCET

The Lancet Commission on the future of care and clinical research looked at what can be done in the next 5 years to address the current and urgent needs of autistic individuals and families. It highlights the knowledge gaps that remain, e.g. regarding what interventions and support strategies are effective for whom and when, and which interventions lead to long-term gain for autistic people. It also introduces the concept of "profound autism" to distinguish individuals who have high support needs. The commission has released a series of key messages and actionable recommendations to meet the needs of over 78 millions people on the autism spectrum worldwide.

he Lancet commission brought together stakeholders in autism from six continents and a range of perspectives, including clinicians and other health-care providers, researchers, advocates, self-advocates, and parents to address the future of health care in autism. It highlighted that urgent action is needed so that children and adults on the autism spectrum can have happy and healthy lives. It reaffirms that the complex needs of autistic people can only be met if governments ensure adequate coordination between health-care, education, finance, and social sectors across the life span, and active inclusion and participation of autistic people and their families.

A stepped care and personalised health approach to delivering services

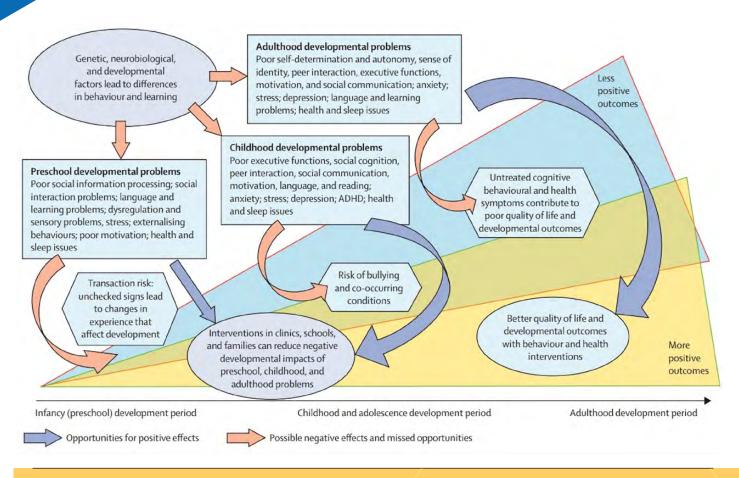
The commission highlighted that the heterogeneity of autism requires personalised, evidence-based assessments and interventions, accessible and affordable to every person to improve the lives of individuals and their families. It notably recommends a stepped care and personalised health approach to delivering services and monitoring effectiveness across time as it provides a framework for efficient and equitable distribution of resources to improve outcomes.

"Recognition of human diversity helps us to better understand autistic individuals... creating stronger and wiser communities and positive social values."

The Lancet Commission on the future of care and clinical research in autism

THE LANCET

The best science for better lives



It means that support is tailored and adapted to autistic people's individual needs and recognises that these needs will change throughout their lives. That stepped care approach starts families with the least cost-intensive appropriate treatment option and funnels children into more intensive services only as necessary. The approach needs to be used in culturally appropriate ways and can be adapted depending on a country's available resources, the report notes. The treatment process should also consider individual preferences or, in the case of young children, those of their caretakers, as well as the time and resources available to the family at home.

The commission also emphasizes that more information about the economic and personal consequences of autism is urgently needed to inform the case for government and societal investment, action, and support worldwide. It also points out that autism and those with other neurodevelopmental conditions have many similar needs, therefore developing appropriate systems of care for people with autism will also improve outcomes for individuals with other neurodevelopmental conditions.

Investing in practical research having an impact on the lives of autistic people

National and international infrastructures should be developed to help prioritize research that goes beyond biology and studies of single interventions. The aim is to focus instead on those that integrate care across systems over time and take into account individual differences within the autism spectrum that lead to better outcomes.

Recent high-quality trials among young children on the autism spectrum have identified psychosocial interventions that can result in changes that could mitigate the influence of autism on development for some people. Research is now needed to identify what factors enable people with autism to live positive,

fulfilling lives, the key elements of effective interventions for children and adults, and the wider environmental barriers to change for people with autism.

"Basic science is often prioritised over more practical knowledge, leaving people living with autism, families, and providers without evidence-based guidance. Individuals with autism are a valued part of society. We urge commitment to greater investments in what can be done for people living with autism and their families now, with a focus on how to build on existing information to answer specific practical questions that will then better inform interventions and services to help people living with autism achieve their fullest potential," says Commission co-chair Prof Tony Charman of King's College London (UK).

Introducing the term 'profound autism'

The Commission reiterates the value of neurodiversity among people with autism - or the natural variability within human brains and minds - to create stronger, wiser communities and positive social values. At the same time, the report formally introduces the term 'profound autism' to refer to autistic people with severe intellectual disability, limited communication abilities or both. The term should not be used for children younger than about 8 years old, and it may be more appropriate for adolescents and adults, the report notes. The authors propose that the designation be used for administrative purposes (rather than a formal diagnosis) in order to encourage both the clinical and research global communities to prioritise the needs of this vulnerable and underserved population. The authors validated the designation of profound autism against three databases and found that it would apply to anywhere between 18% to 48% of people with autism (panel 2).

Key messages: actionable recommendations

Although autism affects at least 78 million people worldwide, formal documentation of their existence is limited to a subset of countries. Formal documentation through governmental health-care, education, and social care systems for people with autism would be a first step in determining the needs and addressing the potential inequalities faced by these individuals.

Autism is a complex but common neurodevelopmental disorder that requires personalised assessments and intervention strategies. A stepped care and personalised health model to assess and direct interventions can increase the effectiveness of approaches. Governments and health-care systems must recognise the need for integration across systems to support the needs of autistic individuals and their families across development.

Autism is a neurodevelopmental disorder that changes with and affects development; a single assessment or a single treatment is never sufficient. Follow-up assessments and personalised treatment plans that focus on individual strengths, difficulties, and changes in contexts and expectations across the life span are needed.

Interventions for autism and for co-occurring conditions should begin as soon as signs are noticed and then monitored with more comprehensive assessment once begun. No one should wait for months or years to start treatment because they are unable to find an appropriate assessment. However, within a reasonable period of time (depending on age and context), assessments do need to be supported and undertaken to identify personalised needs.

institutional level should be prioritised with an emphasis on clinical practice that can increase the understanding of what interventions work, for whom, when, how, with what general outcomes, and at what cost. National and international infrastructures should be developed to help such projects to move beyond single investigator-led (albeit multisite) studies to more integrated attempts that take into account individual differences within autism. Infrastructures should also support studies that build on each other and provide evidence for broader community implementation and effectiveness, rather than simply showing that an intervention is better than a waiting list or treatment as usual.

For Governments and services should monitor access to provision to ensure that underserved groups, including those who are minimally verbal, girls and women, minority ethnic groups, from socially disadvantaged backgrounds, or with severe co-occurring conditions, have equitable access to appropriate services.



You can access the full report of the Lancet Commission on the future of care and clinical research in autism through this QR code.

The Lancet Commission on the future of care and clinical research in autism - The Lancet

"Barriers arise from a combination of factors that impinge on human rights, access, participation, and equity."

Comment: The need to improve autism services in lower-resource settings

THE LANCET

The best science for better lives



New autism strategies are underway across Europe

In the context of the COVID-19 pandemic that impacted autistic people and their families heavily, 2021 saw some milestones regarding the adoption of national autism strategies in several countries across Europe. Autism-Europe welcomes these developments that are in line with its advocacy efforts to promote a coordinated and strategic approach to autism.

United Kingdom



At the end of July 2021, the United Kingdom government approved the national strategy for autistic children, young people and adults in England for 2021 to 2026. It builds on and replaces the second adult autism strategy, Think Autism, published in 2014. The first autism strategy was introduced in 2010 after the Autism Act for England in 2009. The new national strategy for improving the lives of autistic

people, their families and carers, covers mental health, diagnosis, employment, education, public awareness and the justice system. The strategy aims at extending the scope to children and young people for the first time, and includes an implementation plan for 2021 and 2022. It is informed by over 2,700 responses from autistic people, their families, carers and organisations.

The National Autistic Society (NAS), one of Autism-Europe's UK member associations, successfully campaigned for this national strategy to include children and young people. There are many new commitments as a result, including more training for teachers, a new anti-bullying programme in schools and making sure autistic young people can find supported internships and apprenticeships.

AT-Autism, another of Autism-Europe's UK member associations, agrees with the UK government's call to local authorities for

delivering the implementation of the strategy. Yet, this would only work if the necessary resources are put in place which only seems to be the case for the first year of the strategy. AT-Autism is looking forward to clarify funding downstream and hopes this will come with a wider review of the social care system and the legal status of autism in terms of being and whether the disability remains classified as a "mental disorder" under the 2007 Mental Health Act for England and Wales.

For the NAS, the strategy has more money - almost £75 million to the first year of this strategy – than any of the other previous strategies. Yet it does not set out specifically what services will be provided to help people on the autism spectrum. So it will be really important that every council in England talks to autistic people in their area to ask them what they need, and then invest in those services. Getting support from social care is the biggest struggle for many autistic people. In 2019, the NAS found that over 2 in 3 autistic adults in the UK do not get the support they need to carry out everyday activities.

AT-Autism welcomes the objective of the UK government to increase awareness and training. However they wonder what narrative around autism will be spread and whether related trainings will be up-to-date and based on equality. They consider it a missed opportunity if the fundamental issues regarding responses to behaviour of concern would be tackled with generalist behavioral approaches based on poor understanding of the nature of autism which have been shown to be ineffective and traumatising to autistic people. Furthermore, AT-Autism regrets that older autistic adults and models to support them are not addressed.

Malta



Shortly before World Autism Awareness Day (WAAD) this year, the government of Malta launched the country's first ever draft national strategy for 2021-2030. In November the strategy was adopted. It details all the measures and initiatives that the government

of Malta will be undertaking in the coming years with respect to increasing awareness of autism. The Ministry for Inclusion and Social Wellbeing of Malta launched the strategy together with the Autism Advisory Council chaired by Dr. Alistair de Gaetano. This council was advised by the Commission for the Rights of Persons with Disability of Malta, Aģenzija Sapport, medical professionals, educators and others from the University of Malta.

Drafting the strategy was done with the help of people on the autism spectrum and their families across Malta. However, an international perspective was also taken with the Autism Advisory Council engaging in discussion at European Union and United Nations levels.

With regard to awareness raising, Malta's national strategy aims to correct the views on autism still widely hold with the help of the general public and with people on the autism spectrum in order to foster a more accepting and inclusive society.

The Strategy will also work towards the early identification and cataloguing of services available to autistic people, especially young children, and more importantly towards ensuring access to services.

Next to safeguarding the right to education of people on the spectrum, they will also be assisted in their transition to employment. To ensure this, teachers have to be trained and the working requirements of autistic people must be catered for.

Another cornerstone of Malta's first autism strategy is the need for advocacy and self-advocacy. This should include giving a voice to people on the autism spectrum, increasing outreach by disseminating their voice with a large audience, and the need to target decision-makers through updating relevant laws and policies where necessary.

Dr. Alistair de Gaetano from the Autism Advisory Council wants to achieve drastic measures, and while the reality on the ground is much more complex than it is in theory, he hopes for as many entities to join forces to make real change together.

Poland



After WAAD, in mid-April 2021, both chambers of the Polish Parliament passed a resolution to call for a national autism strategy aiming to support and provide equal opportunities for people on the autism spectrum.

The Parliament of Poland recognized that "the State shall provide decent living and working conditions for the people on the spectrum" taking into consideration the needs of the over 1 million citizens, including autistic people, their families and carers. To fulfil this obligation, the Parliament shall support all actions aimed at developing and implementing the future national autism strategy of Poland.

This strategy should be guided by meeting the needs of people on the autism spectrum to:

- break mental, organizational and financial barriers through developing the current support system for autistic people
- to implement their rights in all areas of life, taking into account the level of support they need
- to ensure a dignified and independent status for adults, with particular emphasis on providing inclusive education as well as inclusive and equal opportunities in the labor market.

JiM Foundation, one of Autism-Europe's member organisations from Poland, had been advocating for an autism strategy for the last 3 years in order to provide long-term solutions for improving the quality of life, particularly of autistic adults. Recognizing their advocacy efforts, which have contributed to passing the resolution, the JiM Foundation's representatives have been invited to the Parliament to witness this historic moment for the Polish autism community. JiM was joined by Jakub Wiktor Waliszek "a Polish autistic self-advocate as well as his mother Katarzyna".

Read the resolution of the Polish Parliament on supporting and equalising opportunities for persons on the autism spectrum here in Polish:

https://monitorpolski.gov.pl/M2021000037901.pdf

Germany



In May 2021, a research group from the Munich University of Applied Science led by Professor Dr. Markus Witzmann and Eva Kunerl handed Carolina Trautner, the Minister of Social Affairs of the state government of Bavaria in Germany, a recommendation report on the future autism strategy of

Bavaria. The report draws on national autism strategies across Europe and beyond and firmly echoes demands by Autism-Europe and the Autism Spectrum Disorder in the European Union (ASDEU) project on the needs of autistic people. It was developed in the last 3 years and involved autistic people, relatives, researchers, representatives of welfare associations, funding agencies and the ombudsperson for people with disabilities of Bavaria as well as the state government of Bavaria.

The recommendation report deals with the topics of awareness raising and communications, research, (vocational) training and education, diagnostics and therapy, mental health care, early intervention, schooling, employment as well as living and leisure time.

The recommendation report will be the basis for the Bavarian state government to develop an autism strategy to further improve the lives of people on the autism spectrum in Bavaria. According to the roadmap laid out by the Bavarian Ministry of Social Affairs, the government will table the strategy in front of the state parliament of Bavaria in summer 2022.

As part of the autism strategy, the teacher training for special and regular schools of all levels at Ludwigs-Maximilians-University (LMU) in Munich, will include an optional course as of the winter semester 2021/2022 on how to support autistic pupils in the classroom. This course is unique in Germany as it targets future teachers in all forms of primary and secondary education. The training programme was initiated by Professor Reinhard Markowetz, chair for pedagogy in behavioral disorders and autism at LMU. 65 future teachers mostly for special schools enrolled in the course for winter semester 2021/2022.

Visit our website through the QR code to find more information on the European Disability Strategy, including in Easy-to-Read.



The Strategy for the rights of persons with disabilities 2021-2030

At the European level, the European Commission released in March 2021 the Strategy for the rights of persons with disabilities 2021-2030 (SRPD), which aims to deliver further significant improvements to all areas of the lives of persons with disabilities, including autistic people, within the EU and beyond. Over the coming decade, this Strategy will support both Member States and EU institutions to implement the UNCRPD.

The Strategy builds on the results of the previous European Disability Strategy 2010-2020, acknowledging that persons with disabilities still face considerable barriers and have a higher risk of poverty and social exclusion.

The Strategy takes into account of the diversity of disability, resulting from the interaction between long-term physical, mental, intellectual or sensory impairments, which are often invisible, with barriers in the environment, as well as the increased prevalence of disabilities with age. It promotes an intersectional perspective, addressing specific barriers faced by persons with disabilities who are at the intersection of identities (gender, racial, ethnic, sexual, religious), or in a difficult socioeconomic or other vulnerable situation.

By 2030, persons with disabilities in Europe should:

- enjoy their human rights
- have equal opportunities, equal access to participate in society and economy
- be able to decide where, how and with whom they live
- move freely in the EU regardless of their support needs
- and no longer experience discrimination

The objectives of this Strategy will need to be achieved through a strong commitment by the Member States, by promoting national strategies, policies and actions that will bring about accessible environments, inclusive education systems as well as health care systems of high quality and effective pathways to fair employment for persons with disabilities.



Autism-Europe International Congress 2022: registration open!

The 13th International Autism-Europe Congress hosted by the Jim Foundation will take place on 7-9 October 2022. It is the first time it is held in a hybrid format with high quality online access to its sessions, presentations, workshops, discussion panels and more. Participants can also join in person, in the historical city of Cracow, Poland. The Congress brings expertise from around the world to promote a positive vision for autistic people and their families.

he chosen theme of the 2022
Congress is "A Happy Journey through Life", it highlights the importance of taking a lifespan perspective on autism research and practice, with the promotion of wellbeing for all being as focal point. We plan for the Congress programme to be challenging, diverse, inclusive and to create debate. The Congress is unique in terms of its history and scale. It provides

a platform for researchers, practitioners, students, autistic people and family members to come together.

The programme includes keynote presentations, a diverse range of symposia topics, interactive poster sessions, workshops run by leading practitioners, moderated sessions to discuss challenging questions and "meet the expert" sessions and networking.

During the Congress autistic people and caregivers will be central to proceedings, providing a platform for their voices to be heard and to advocate for change.

We would like to thank our Polish member association Jim Foundation, which will be the host of this exciting Congress. Also, thanks to our social partners who are actively supporting this event of the international autistic community.



Submit an abstract to share your research or experience!

We have been guided by our Scientific Committee, as well as suggestions from the wider community, to create a diverse and exciting programme that will include symposium on the following topics:

- Diagnosing and supporting cooccurring difficulties in the early years
- Reviewing the evidence base to support early communication development
- Research review and practice recommendations in adult diagnosis
- Best practices working with autistic adults with high support needs
- Outcomes for adults on the spectrum: whose quality of life is it anyway?
- Building healthy living: a lifetime perspective
- Better mental health and wellbeing for autistic people and their families
- What is the future of telehealth in autism services?

- Reviewing the evidence: how to create the right environments for autistic pupils in school
- Building positive peer relationships in schools
- How do we support families marginalised by ethnicity, culture, language or finances?
- Gender Identity and autism
- Cognitive neuroscience where are we now and where are we going?
- Sensory differences brain, behaviour and management

For research abstracts, you can make a submission on a symposium topic or a topic that may fall outside of those listed above, which will be reviewed for inclusion as either an oral or poster presentation. Practice and personal accounts must relate to a symposia topic.

For many of the congress sessions, there will be a balance of presentations from researchers, practitioners (i.e. from health, education or social care), autistic people, family members and carers, and those involved with policy or advocacy. At the end of sessions, there will be time allotted for discussion and Q&A.

For more information about the Abstract submission rules, please check the congress website: www.autismcongress2022.org

If you are unsure which type of submission you should make, please email ae.congress2022@jim.org

Register Now!



You can now register to attend the Congress! We offer a range of different options to attend it, both online or in person, so you can decide which option suits you best.

Visit www.autismcongress2022.org for more information!

We celebrate this diversity of perspectives to ensure a "Happy Journey through Life" for everyone.





Keynote Speakers



Petrus de Vries.

Department of Psychiatry and Mental Health, Cape Town, South Africa

The Sue Struengmann Professor of Child & Adolescent Psychiatry, and Director of the Centre for Autism Research in Africa and the Adolescent Health Research Unit at the University of Cape Town.



Professor Connie Kasari,

Professor of Psychiatry at the David Geffen School of Medicine at UCLA and a leading international expert in developing interventions for autistic children and their families.



Catherine Lord

Mind Institute UCLA, USA

The Distinguished Professor-in-Residence School of Medicine at UCLA and a Senior Research Scientist in the Semel Institute for Neuroscience and Human Behaviour.



Ewa Furgal,

Girls on the Spectrum Foundation, Poland

Founder and President of the Fundacja Dziewczyny w Spektrum (Girls on the Spectrum Foundation), organization empowering girls and women on the autism spectrum and creating safe space for them.



Brian Boyd,

University of Kansas, USA

Professor and Director of the Juniper Gardens Children's Project at the University of Kansas, USA. As Director of a community-based, applied research centre focused on child development, he has been heavily engaged in research that involves the most vulnerable, and often marginalized, populations.



Emily Simonoff,

Institute of Psychiatry, UK, USA

Professor of Child and Adolescent Psychiatry in the Department of Child and Adolescent Psychiatry and the head of the Department and Academic Lead for the CAMHS Clinical Academic Group in King's Health Partners.



Isabel Dziobek,

Humboldt University, Berlin, Germany

Professor of Clinical Psychology of Social Interaction and Head of the University Outpatient Clinic for Social Interaction at Humboldt-Universität zu Berlin.

13

Join AE's campaign 2022: "A Happy Journey Through Life"



As you all know, every April 2 marks World Autism Awareness Day (WAAD). In 2022, AE will continue to work with its member organisations and other stakeholders to inform about the needs of autistic people in Europe. AE and its members will launch the "Happy Journey through life" campaign. In line with our International congress 2022, the campaign will promote a holistic approach to ensure that autistic people live happy and fulfilling lives.

What are the objectives of the campaign?

- We will highlight the needs of autistic people concerning various policy priorities across their lifespan: access to education, health, employment, social inclusion, community support services, etc. We will address the EU, national, regional, and local levels.
- At the EU level, we will ensure that the implementation of the new Strategy for the rights of persons with disabilities 2021-2030 and the European Pillar of Social Rights Action Plan take into account the needs of autistic people.
- We will share the voice and testimonies of autistic people and their families about what a good quality of life means. We will also share good practices and initiatives to reach this goal.
- We will have synergies with other relevant campaigns at the EU level. For example, we will back the 2022 campaign of the Social Platform about "decent life for all". It will notably address minimum wages, minimum social safety nets, and empowering services.

Take part in the campaign: call for testimonials

We invite autistic people and their families to share their perspectives regarding what constitutes a "happy life".

- Share your testimony through a survey
- Participate in AE art competition
- Join us on social media #AutismDay2022

Check the campaign page to take part!





The need for careful guidelines regarding psychotropic medications and Autism Spectrum Disorder

The recent guidelines of the Italian Istituto Superiore di Sanità (ISS), published in February 2021, which update the 2011 guideline on the treatment of ASD for child and adolescent, make recommendations for prescriptions of psychotropic medecines that are not based on controlled trials. This is completely inappropriate, because common practice can be very harmful, alerts our Italian member.

n 2013, NICE gave prudent indications on the use of psychotropic medications (https://www.nice.org. ASD: uk/guidance/cg170/chapter/1-Recommendations#interventions-forbehaviour-that-challenges) as well as the subsequent Scottish and European ESCAP guidelines (2020). Only the British Association for Psychopharmacology uses the term co-occurrance to give the green light to the prescriptions of psychotropic medications, albeit not tested in autism (https://www.ncbi.nlm. nih.gov/pmc/articles/PMC5805024/)

In the past years, no experiments have been carried out that can justify the change of practice. If anything, there has been a large increase in the US in court cases that have been awarded compensation for damages from malpractice. Many doctors fear that these appeals will also extend to Europe. Particularly in Italy, where doctors often forget that the prescription of off-label drugs must be authorized in writing by

the patient or his representative, and yet it is forgotten that the physician must carefully and frequently monitor the efficacy and side effects of the drug; furthermore the lack of neuropsychiatrists in Italy prevents frequent checks. If he does not comply with these rules, the prescriber must pay for the drug damages. It is believed that a defensive medicine maneuver is underway in various countries.

In the final recommendations of the ISS, published in February 2021, which update the 2011 guideline on the treatment of ASD for child and adolescent, there is a general tendency to indulge in prescriptions that are not based on controlled trials. This is completely inappropriate, because common practice can be very harmful. This betrays the principle of experimentation that underlies the progress introduced by Evidence-Based Medicine half a century ago, but it would save doctors from court cases.

The 2011 Italian guideline took into consideration not the old antipsychotic drugs, associated with intolerable side effects for children and adolescents, but only two new atypical antipsychotics, Risperidone and Aripiprazole. Risperidone and Aripiprazole were allowed only for moments of crisis, moments with serious problem behaviors and for limited periods.

We translate the first new recommendation "The ISS panel of the guidelines on the Diagnosis and Treatment of Autism Spectrum Disorders in Children and Adolescents suggests using D2 blockers rather than not using D2 blockers in children and adolescents with autism spectrum disorders (conditional recommendation based on a quality of low evidence) "

D2 blockers are the typical, first generation, antipsychotics. In this context the D2 blockers strangely also include antipsychotics such as Aripiprazole and Risperidone, which are widely used in Italy. There is a manifest contradiction in the recommendation on the one hand the recommendation is based on a low quality of evidence, and on the other hand it suggests to use D2 blockers.

Quality of the evidence probably refers to randomized controlled trials, but, since these are drugs on the market for decades, which have been used and abused a lot and for very long periods, often for life, in autism, the effects are known not only through trials, but also, and above all, through real life experience in the short and long term. In autism, and in the intellectual disability associated with it in a large percentage of cases, these drugs have given very few desired effects, often only transitory, in the face of chronic and very long-lasting use, and many very serious undesirable effects: motor, metabolic and cognitive.

Two other recommendations are not acceptable because it is recommended to refer to the guideline of psychiatric pathology only regarding co-occurrence, although there is only trials for co-occurrence between autism and ADHD.

So the recommended treatment for the co-occurring condition is a priori considered in the absence of autism. This contrasts with what is well known: people with autism of all ages, especially children, for whom the use of the drug prolonged for many years is very frequent, tend to have a very peculiar and often paradoxical response to psychotropic drugs.

The dual diagnosis experimentation has so far been done only for autism

and ADHD co-occurring with autism and what the experience has already highlighted is well documented: that the percentage of good responders to drugs, and in particular to Methylphenidate, is much lower while the undesirable effects are much more frequent than in the condition of ADHD alone, for example by increasing aggression. It is therefore necessary to take stock of the positive and negative effects before continuing the administration.

Experimentation regarding double diagnosis should be done for all the psychiatric disorders and it should absolutely not be taken for granted that a subject with autism having other associated psychiatric disorders, will respond to the psychiatric drug indicated for that pathology, in the same way as someone who does not have autism.

Many motor effects are disabling, such as Parkinson's and tardive dyskinesias. Obesity and dysmetabolism, which also leads to type 2 diabetes, predispose to cardiovascular disease, as well as to all the extravascular complications linked to obesity. Cognitive decline, associated with all drugs with Atropine like effect, is the more concerning in a population that already has cognitive impairment of varying degrees. Finally, cardiac arrests for arrhythmias and ab ingestis deaths due to these drugs also occur.

There is an international movement underway aimed at the de-prescription of psychotropic drugs in general and antipsychotics in particular. See project "Stopping over medication of people with a learning disability, autism or both (STOMP)"

https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/

Evenforadultpatients with schizophrenia (without autism), where the evidence of efficacy is much stronger, there is a movement aimed at the deprescription of antipsychotics

https://jamanetwork.com/journals/ jamapsychiatry/article-abstract/2769191

The limited period of drug intake is related to the duration of the trials, but also is linked to the serious danger, which is practically a certainty, of the very serious side effects in long-term recruitment, all the more serious if the drugs are started as children or adolescents and continued for life (See the video Elle s'appelle Sabine): (https://www.youtube.com/watch?v=uyG1giBUx9E&t=124s).

Our associations (A.P.R.I., Tribunale della salute, Aliante, ODV, AGSAS and Associazione Italiana di Analisi e Modificazione del Comportamento e Terapia Comportamentale e Cognitiva - AIAMC) will appeal (http://chnq. it/4PCKz4n6ct) against this update of the Guideline and would like to raise the alert to prevent other new guidelines in Europe from authorizing the misuse of antipsychotics in all people with autism, especially children and adolescents. To write the guidelines, the 2006 UN Convention must be respected: "Nothing about us without us", which the Istituto Superiore della Sanità trampled on.

About the author:

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Daniela Mariani Cerati obtained her M.D. degree at the University of Bologna. She worked at S.Orsola-Malpighi University Hospital (Bologna, Italy) for 30 years.



Daniela Mariani Cerati

Her work has always been geared to integrating the organic, as well as the psychological aspects, of illness, and to finding the biological basis of mental confusion and mental disorders, especially in the elderly. She is now using her experience with elderly people to promote research on the biological basis of neurodevelopmental disorders at any age. She is a member of A.P.R.I. and of Comitato per la Ricerca Scientifica of Fondazione Italiana per l'autismo (FIA) and moderator of the autism biology forum.



A woman holds a girl on her lap, who is wearing a headset to protect yourself from loud noises. They are watching a live show.

Relaxed Performance making culture accessible to all

Going with the family to a concert, a play or a dance performance. A banal act that can turn into an ordeal for autistic people and all those whose disability can lead to atypical behaviour that do not conform to the very standard codes of cultural venues. The looks or reflections of the other spectators at the slightest movement, need to stand up, shout, laugh or applaud out of turn, often discourage them from coming back and trying this experience again. To remedy this cultural and social exclusion, several structures in Europe have developed the concept of "Relaxed Performances" indicates one of the precursors, the French association Ciné-ma difference.

Relaxed Performance is a performance made accessible to people who would otherwise be excluded from the performing arts by the supposedly disruptive behaviour that their disability may cause. More generally, these performances make concerts and shows accessible to all those who would benefit from a more flexible atmosphere, a warmer welcome and a carer's kit to prepare for the cultural event and the venue: families with young children, elderly people with decreasing independence, people who may not be used to going to cultural places...

At these sessions, a welcoming and relaxed environment is set up so that everyone can experience the show and its emotions in their own way, without fear of the gaze of others. Any vocalisations, gestures or even movements from the audience during the show are accepted and kindly received. Chill-out spaces are provided for audience members who may need to take a break should the emotional load during the show beome too great to bear. In some cases, sound and light levels are adapted to reduce their impact or the possibly unpleasant or painful effects of surprise. They seek to appeal to audiences of all ages and offer a range of art forms for all tastes.

A concept born in the early 2000s

The spirit of Relax was born around the same time in France and the UK, starting with cinema. In 2005, the association Ciné-ma différence launched screenings in Paris designed to be accessible to all people, with or without disabilities. In 2006, the Lambeth Autism Group organised sensory friendly screenings in Brixton for its autistic members and their families. In the following years, initiatives were launched on both sides of the Atlantic, mainly in Anglo-Saxon countries.

"A great benefit for disabled audiences attending a Relaxed Performance is to feel, for once, socially accepted."

Rose Edwards, Audience Officer, Royal Shakespeare Company There are common points in all these proposals: the traditional codes of a theatre are relaxed to allow all the spectators' expressions; the whole audience is informed of the relaxed nature of the performance; the reception team of the cultural venue is trained to welcome people with disabilities and is reinforced in number.

There are still differences on some points. In France, the performances are inclusive, the disabled audience shares the room with the regular audience of the venue. Some organisations in the United Kingdom or the Gothenburg Symphony Orchestra in Sweden offer Relax performances dedicated to people with disabilities and their carers.

Similarly, some venues adapt the show by leaving the lights on during the performance or by modifying the staging to take into account sensory specificities, while others do not touch the show but only the social rules.

A relaxation area for momentary withdrawal from the theatre and mediation tools in Easy to Read and Understand generally complete the Relax proposals.

From April 2018 to April 2020, Ciné-ma différence (Paris, France) carried out a comparative survey of sixteen organisations delivering Relaxed-type performances in Canada, the United States, the United Kingdom, Sweden, Switzerland and France. This report presents the findings of the survey, including a chronology and mapping. It describes and illustrates transferable good practice. It suggests recommendations for the implementation of Relaxed Performances.

1

The three key elements of "relaxed performances"

The Relaxed access scheme is based on three key elements:

• Relaxing the etiquette and conventions expected in the venue.

To find out more about the Relax concept and its implementation, you can consult the international comparative study.

It is available in French and English on the website of the Ciné-ma différence association. **Follow the QR code:**





Public on a theater clapping to the performance



participants meeting the Pope

The InSuperAbile relay race 1000 km of solidarity

AE Italian member Diversamente ODV recently took part in a massive relay race called InSuperAbile. The title says it all: Super-Able. It's a 1,000 km journey of solidarity along the Via Francigena to overcome all types of disability and bring a message of re-start and re-birth.

his initiative started in Switzerland's Great St Bernard Pass thanks to Rosa Running Team (#rosarunningteam). In recent years, this organisation has carried out numerous social projects to spread the culture of sport and movement to prevent and slow down the symptoms of many diseases and as psychological support for people with physical and cognitive disabilities.

Diversamente ODV and its amateur sporting association partner, called Progetto Filippide Cagliari, boarded a ship to mainland Italy on September 4th to join the relay in Lazio. They completed the last 140 km walk of the relay through Via Francigena, an ancient pilgrimage route, which means "the road that comes from France" (but has its starting point in Canterbury, England).

Each checkpoint on the road was an excellent occasion for participants with physical and cognitive disabilities to

experience and foster a more inclusive community. They even got to meet the Pope! Before joining the relay, participants completed one month of athletic training, walking 10-15 km every day. The journey of autistic participants ended in Rome on September 12th. Beyond reaching a goal, it was an important milestone towards a full and independent life.

Taking the advice of Pope Francis, they will keep walking and will never stop! Diversamente's President, Pierangelo Cappai, also said: "It was the very first relay for our autistic members, but they've been going trekking for years. They have experienced previous successes on The St Francis' Way twice and the Pilgrimage of Compostela. They enjoy feeling free from social norms and walking in nature. Their participation in InSuperAbile tested their skills again. It improved their self-esteem as it proved that, with appropriate support, they could overcome any challenge".



Two participants sitting on the floor smiling and holding the flag of Sardinia



Participants walking through the forest along the Via Francigena



ANGSA

promotes the rights of people on the autism spectrum throughout Italy

ANGSA APS Onlus - Associazione Nazionale Genitori perSone con Autismo (National Association of Parents of People with Autism) is a non-profit organization constituted mainly by persons on the autism spectrum, parents, family members or legal representatives of persons with autism. It covers the Italian national territory with about 70 associations that regularly meet to identify and promote shared objectives. Our new member ANGSA is actively engaged with the following activities:

Autism information and awareness

ANGSA has been committed since its foundation to make Italian society aware of autism, to ensure information and increase respect, inclusion and to break down the barriers that still prevent the full inclusion of people with autism. Every April 2, on the World Autism Awareness Day, all ANGSA associations throughout the Italian territory organize conferences, events, public information and awareness-raising initiatives on that occasion.

Representation and relations with national and local institutions

ANGSA advocate for autistic people 's rights by working with the institutions where public policies on autism and disability are defined, such as the National Observatory on Disability. ANGSA is an active member of FISH (Federazione Italiana Superamento Handicap) and it is an active member of the school observatory with the MIUR (Ministero Istruzione Univeristà e Ricerca).

Promotion of scientific research: #alprimoposto campaign

ANGSA works to stimulate scientific research and to disseminate the results of national and international research based on evidence of efficacy. The #alprimoposto campaign (#inthefirstplace in English) was an important action organized by ANGSA for the World Autism Awareness Day which followed the motto «Autism in the time of Coronavirus, Research and Health in the first place».

This campaign was the result of a reflection on how much Covid-19 represents a risk with a strong social impact, not only for those most exposed to the infection, but also for those who, like people with disabilities, need specific and coordinated attention, specially autistic people.

Support, assistance, and services for people with autism and their families

The different ANGSA associations are committed every day to support and inform the families of autistic people by connecting families who help other families with forms of support and self-help, training courses for teachers and operators and, when needed, creating services and specialized centers for autism.

Legal Support

ANGSA continues to support its members with a legal service to better defend the right to care and social inclusion of its members to guarantee adequate public policies and compliance with the Italian regulations

ANGSA APS Onlus

is a full member of Autism-Europe

Website: www.angsa.it



A woman health professional is passing a blue ball to a boy who is standing. Both wear a mask.

ASPERGA

promoting a holistic approach to autism in Galicia

ASPERGA, founded in 2006, is the Galician Association of Asperger. The organization is a shared space in which people diagnosed with autism/ Asperger's Syndrome and their families have the opportunity to join forces to defend their common interests and access specialized professional services.

owadays, ASPERGA counts with more than 250 members, and a specialized multidisciplinary team (psychologists, neurologists, speech therapists, occupational therapists, social workers ...) that offers services following state of the art professional criteria. It also offers guidance and counseling, individual and group therapy, comprehensive care at all stages: from social skills programs and socio-labor skills workshops, to adult life programs, early care service, parents' school, leisure, and sports workshops, etc.

Defined as a social-health center, ASPERGA is guided by clear principles:

- 1. Professionalize our services.
- 2. Give visibility and spread the knowledge of autism and asperger's syndrome, of our organization and of the association itself.
- 3. To be the intermediaries with the administrations and other organizations to advance with "true inclusion" and occupy our space, not the one they give us or lend us, but the one that belongs to us.

ASPERGA's mission is to weave a network of families and autistic people with the aim of fighting for a future of inclusion. On our Board of Directors, for example, half of the members are autistic people.

The holistic approach of ASPERGA includes orientation and assessment for people who are on the autism spectrum as well as individual attention through psychological support, occupational therapy and speech therapist care support, aiming to help autistic people in Galicia to become more independent. ASPERGA offers free job orientation, being a special collaborating center with the Xunta de Galicia in the entrepreneurial area.

Young people with autism in Galicia can find educational support in ASPERGA. The association offers a tailored program to improve academic performance, also collaborating with families and schools. Also, ASPERGA promotes access to culture and leisure through its "TEMPO DE LECER" program, organising cultural, leisure activities and workshops for ASPERGA users and members.

ASPERGA

is an affiliated member of Autism-Europe

Website: www.asperga.org

Member Associations of Autism-Europe

FULL MEMBERS

National associations of autistic people and parents

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