

EUROPEAN DOWN SYNDROME ASSOCIATION

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Dear Members,

the 9th of June we had an informal EDSA meeting (not like AGA) and many of you participated.

We had 26 participants from 23 organizations. Thanks to you all.

In the first part of the meeting our president Dinka gave an overview of the activities of EDSA since our AGA last year.

Read <u>here</u> Dinka's presentation.

In Dinka's presentation there is the <u>link</u> to the results of the survey about participation of our EDSA members in EU projects, prepared by José from DownEspana.

Best regards,

Cora Halder

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EUROPEAN DOWN SYNDROME ASSOCIATION

EU FUNDING OPPORTUNITIES

SMALL-SCALE PARTNERSHIPS



Small-scale Partnerships aim to reach out to grassroots organisations or those less experienced in Erasmus+. They are designed to widen access to the programme to small-scale actors and individuals who are hard to reach in the fields of school education, adult education, vocational education and training, youth and sport. They do this by having

- lower grant amounts awarded to organisations
- shorter durations
- simpler administrative requirements
- reduced entry barriers
- flexible formats mixing transnational and national activities to allow smaller organisations to reach people with fewer opportunities

Small-scale Partnerships can contribute to creating and developing transnational networks and linking up local, regional, national and international policies. They also support active European citizenship and bring the European dimension to local levels.

The <u>Erasmus+ Programme Guide</u> is the main source of information on Partnerships for cooperation. It contains all information about the priorities, award criteria, funding rules and more.

Who can apply

Any participating organisation established in a Programme Country can apply for a Small-scale Partnership. This organisation applies on behalf of all participating organisations involved in the project. Any public or private organisation, established in a Programme Country (see "<u>Eligible Countries</u>") can participate in the partnership.

How to apply

Organisations interested in applying should do so through the <u>EU funding & tenders</u> <u>portal</u>.

There is one Call for Proposals taking place in 2021. The deadline for submitting the grant application is 3 November 2021, (12:00 CEST).

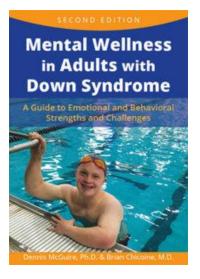
Find out more

You can find a general overview of the programme in the <u>document</u> shown during the last EDSA webinar **ERASMUS + SMALL SCALE PARTNERSHIP. AN OPPORTUNITY.**



NEW BOOK

NEW EDITION: MENTAL WELLNESS IN ADULTS WITH DOWN SYNDROME



Guide to Emotional and Behavioral Strengths and Challenges. Α This thoroughly updated second edition of Mental Wellness in Adults with Down Syndrome is upbeat and accessible in tone, yet encyclopedic in scope. The size of the book reflects both the breadth of the authors' knowledge—acquired as cofounders of the first medical clinic dedicated solely to the care of adults with Down syndrome—and the number of psychosocial issues and mental disorders that can affect people with Down syndrome. It's the go-to guide for parents, health practitioners, and caregivers who support teens and adults with Down syndrome.

Mental Wellness emphasizes that understanding and appreciating both the strengths *and* challenges of people with Down syndrome is the key to promoting good mental health. It shows readers how to distinguish between bona fide mental health issues and common characteristics of Down syndrome—quirks or coping strategies. For example, although talking to oneself *can* be a sign of psychosis, many adults with Down syndrome use self-talk as an effective problem-solving strategy.

The second edition includes new chapters on sensory issues (written by Dr. Katie Frank) and regression, expanded and now separate chapters on communication, concrete thinking, and visual memory, and an extensively updated chapter on Alzheimer's disease citing abundant new research. Other chapters cover a range of conditions and assessment and treatment options:

- What Is Normal?
- Self-Esteem & Self-Image
- Self-Talk
- Grooves & Flexibility
- Life-Span Issues
- Social Skills

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Mood & Anxiety Disorders



- Obsessive-Compulsive Disorder
- Psychotic Disorders
- Eating Refusal
- Challenging Behavior
- Self-Injurious Behavior
- Autism
- Tics, Tourette Syndrome & Stereotypies

Written by Dennis McGuire, Ph.D. & Brian Chicoine, M.D.

In 1992, Dennis McGuire, PhD, and Brian Chicoine, MD, founded the Adult Down Syndrome Center of Lutheran General Hospital in suburban Chicago. The Center, now a part of Advocate Aurora Health, has served over 6,000 adults with Down syndrome since its inception.

<u>Brian Chicoine</u> received his medical degree from Loyola University of Chicago Stritch School of Medicine. He completed his Family Medicine residency at Lutheran General Hospital, where he is now on the faculty. Dr. Chicoine has worked with people with intellectual disabilities in a variety of capacities for more than forty years. He is the father of three, the grandfather of one, and he lives with his wife in Arlington Heights, Illinois.

<u>Dennis McGuire</u> is the former director of Psychosocial Services for the Adult Down Syndrome Center. More recently he served as Senior Consultant with the Global Down Syndrome Foundation in Denver, Colorado. Dr. McGuire received his master's degree from the University of Chicago and his doctorate from the University of Illinois at Chicago. His work experience includes over forty years in the mental health and developmental disabilities field as a clinician, presenter, and writer.

Katie Frank, PhD, OTR/L, is an occupational therapist at the Adult Down Syndrome Center. Dr. Frank received her occupational therapy degree from Saint Louis University and her doctoral degree in Disability Studies from the University of Illinois at Chicago. Most of her work has been with individuals with Down syndrome of all ages. Dr. Frank has experience with treatment and evaluation as well as facilitating groups for people with Down syndrome, conducting trainings for staff, families, and caregivers, and offering a variety of other educational opportunities across the US. Her research is published in peer-reviewed journals.

Mental Wellness in Adults with Down Syndrom

Written by Dennis McGuire, Ph.D. & Brian Chicoine, M.D. Second Edition / Woodbine House / isbn 978-1-60613-285-2 / 2021 / Paperback / 7" x 10" / 466 pages /

Source of the above text:

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https://www.woodbinehouse.com/product/mental-wellness-in-adults-with-downsyndrome-a-guide-to-emotional-and-behavioral-strengths-and-challenges/

Also by Dennis McGuire & Brian Chicoine: The Guide to Good Health for Teens & Adults with Down Syndrome



RESEARCH

GLOBAL MEDICAL CARE GUIDELINES FOR ADULTS WITH DOWN SYNDROME



The GLOBAL Medical Care Guidelines for Adults with Down Syndrome provide first of-kind, evidence-based medical recommendations to support clinicians in their care of adults with Down syndrome.

This life-changing resource as published in JAMA covers 9 topic areas deemed critically important for the health and well-being of adults with Down syndrome and outlines critical future research needs.

Adults with Down syndrome and their caregivers should review the GLOBAL Guidelines with their clinicians to ensure they are receiving care meeting best-practice standards for adults with Down syndrome!

About this clinical practice guideline



This clinical practice guideline focuses on people with Down syndrome due to Trisomy 21, not partial translocation or mosaicism, as even less literature and expertise exist for these latter two subgroups. The biggest challenges for guideline development relate to their intended scope, breadth and depth, and lack of evidence. Down syndrome is not itself a disease, but rather a complex genetic condition involving every major organ-system and life-stage experience. Thus, comprehensive adult guidelines would need to address all concerns and involve every major organ-system.

The first set of key questions addressed by the GLOBAL Workgroup does not cover all systems, all questions, or all health conditions. In this first iteration, the topic areas covered are:

• Behavior

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- Dementia
- Diabetes
- Cardiovascular Disease
- Obesity
- Atlantoaxial Instability
- Osteoporosis
- Thyroid
- Celiac Disease...

All further information on the guidelines, a checklist and a PDF of the full guidelines can be found at: <u>https://www.globaldownsyndrome.org/global-adult-guidelines/</u>



EDSA WEBINAR

Registration of the Webinar: Mathematics for learners with Down syndrome.

The presentation gives an overview of learning mathematics by students with Down syndrome from the early years to adulthood.



Link to the registration: https://www.youtube.com/watch?v=SbEbY_45CwE



NEWS FROM UNITED NATIONS

14TH SESSION OF THE CONFERENCE OF STATES PARTIES TO THE CRPD



The Convention on the Rights of Persons with Disabilities (CRPD) clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced.

Each year a <u>Conference of States Parties (COSP)</u> is held to consider any matter with regard to the implementation of the present Convention.

From 14-17 June 2021, the COSP had met for this purpose.

Theme for the fourteenth session

Building back better: COVID-19 response and recovery; Meeting the needs, Realizing the rights, and Addressing the socio-economic impacts on persons with disabilities.

Sub-theme 1: Protecting the rights of persons with disabilities in armed conflict and humanitarian emergencies;

Sub-theme 2: Living Independently, being included in the community;

Sub-theme 3: Right to education; challenges with inclusive education and accessibility during COVID-19.

Read more: <u>https://www.un.org/development/desa/disabilities/conference-of-</u> states-parties-to-the-convention-on-the-rights-of-persons-with-disabilities-2/cosp14.html



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MAKE THIS NEWSLETTER REALLY YOURS!

Have you got any news that we could publish in EDSA newsletter? Please send us any information you would like to announce and we shall be happy to disseminate it all over Europe!

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THE STAFF

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