

EUROPEAN DOWN SYNDROME ASSOCIATION

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RESEARCH ABOUT DOWN SYNDROME

BRAIN SIGNAL COMPLEXITY IN ADULTS WITH DOWN SYNDROME: POTENTIAL APPLICATION IN THE DETECTION OF MILD COGNITIVE IMPAIRMENT

Abstract

Background: Down syndrome (DS) is considered the most frequent cause of early-onset Alzheimer's disease (AD), and the typical pathophysiological signs are present in almost all individuals with DS by the age of 40. Despite of this evidence, the investigation on the pre-dementia stages in DS is scarce. In the present study we analyzed the complexity of brain oscillatory patterns and neuropsychological performance for the characterization of mild cognitive impairment (MCI) in DS.

Materials and methods: Lempel-Ziv complexity (LZC) values from resting-state magnetoencephalography recordings and the neuropsychological performance in 28 patients with DS [control DS group (CN-DS) (n = 14), MCI group (MCI-DS) (n = 14)] and 14 individuals with typical neurodevelopment (CN-no-DS) were analyzed.

Results: Lempel-Ziv complexity was lowest in the frontal region within the MCI-DS group, while the CN-DS group showed reduced values in parietal areas when compared with the CN-no-DS group. Also, the CN-no-DS group exhibited the expected pattern of significant increase of LZC as a function of age, while MCI-DS cases showed a decrease. The combination of reduced LZC values and a divergent trajectory of complexity evolution with age, allowed the discrimination of CN-DS vs. MCI-DS patients with a 92.9% of sensitivity and 85.7% of specificity. Finally, a pattern of mnestic and praxic impairment was significantly associated in MCI-DS cases with the significant reduction of LZC values in frontal and parietal regions (p = 0.01).

Conclusion: Brain signal complexity measured with LZC is reduced in DS and its development with age is also disrupted. The combination of both features might assist in the detection of MCI within this population.

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NEWS FROM EDSA MEMBERS

Down Syndrome Education International (United Kindom)

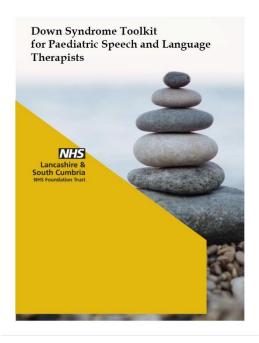


NEW SPEECH AND LANGUAGE TOOLKIT FOR THERAPISTS PUBLISHED

A new toolkit offering guidance for speech and language therapists has been published by a team of therapists working in the UK NHS. They hope the toolkit will inform effective support for young people with Down syndrome.

The Down Syndrome Toolkit for Paediatric Speech and Language Therapists was developed by speech and language therapists at Lancashire and South Cumbria NHS Foundation Trust. Their goal was to provide up-to-date, evidence-based guidance to better support services for young people with Down syndrome.

The toolkit aims to provide evidence-based guidance to speech and language therapists working with children with Down syndrome from birth to 19 years of age. It includes an overview of the relevant literature on how Down syndrome influences speech and language development, provides guidance on therapy approaches and practical tools for assessment and target setting.



Learn more



NEWS FROM THE WORLD

Down Syndrome International



INCLUSIVE EDUCATION

Every child should have access to inclusive and equitable quality education

People with disabilities have the right to inclusive and equitable quality education and the promotion of lifelong learning opportunities.

This is stated in Article 24 (Education) of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, United Nations, 2006).



The challenge

All around the world children with Down syndrome are being failed by education systems.

They are not given the support that they need to succeed in mainstream schools. Many are pushed into special education systems, excluded or segregated from learning alongside their peers.

Many more children with Down syndrome are denied education altogether.

What is inclusive education?

Every child should have access to inclusive and equitable quality education to enhance their opportunities and quality of life.

For children with Down syndrome, this can be realised if:

- full access is provided to education settings, without segregation or exclusion;
- each child is supported to learn and is given the same learning opportunities as others and
- all children have opportunities to develop interests, make friends and gain confidence and independence.

This is also what we expect for any other child.

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NEWS FROM EDSA BOARD MEMBERS

EUROPE DAY: CONVERSATION WITH CORA HALDER



As we celebrate Europe Day, it's important to remember the fundamental values of our continent: respect for human dignity, freedom, democracy, equality, the rule of law, and respect for human rights. These values must apply to everyone, including those with intellectual disabilities. In honour of this occasion, Valueable Network has spoken with Cora Halder – former President of the European Down Syndrome Association (EDSA) from 2008 to 2014, and current EDSA Board member. She has been a long-standing supporter of the Valueable project and now shares her insights on the importance of inclusion and the challenges that still exist.

Cora's interest in the disability field began when her daughter was born with Down syndrome in 1985. Mrs Halder's professional background up to that point was as a special pedagogue, having worked as an educator in Switzerland, Germany and New Zealand. At the time of her daughter's birth, there was not much knowledge or support for families with children with disabilities in Germany. Hence, Cora set up a parents' organisation: the **German Down Syndrome Information Centre**. Being the leader for many years, she helped raise awareness and inform parents through publications, seminars, lectures, working with the press and universities.

According to Mrs Halder, "inclusion starts with school". If children with Down syndrome are not included in regular schools, they will not be used to being around people without disabilities. This will make it difficult for them to switch from the 'special world' to the 'normal world' later in life, but also reduce the chances of their acceptance as full members of society by other people who have not been exposed at all to persons with disabilities.

Today, regrettably, "inclusion in the job world remains a major challenge". In Germany and many other European countries, only a very low percentage of persons with intellectual disabilities are included in the 'first job market'. When companies employ a more diverse workforce it is because of the legally mandated quota systems rather than genuine willingness to commit to inclusion. Most times employers prefer to pay a tax than to employ someone with a disability, or prefer those with physical impairments to those with cognitive ones.

Cora also spoke about the importance of promoting inclusion through multilateral European channels. EDSA brings together different organisations from different countries that can learn from each other, share best practices and import positive



models to follow in their own country. Yet, Mrs Halder was very clear: **"EDSA cannot change the system alone"**. Disability organisations need to continue advocacy, drive protests, and push for change in policies.

"The laws are there, but the implementation is lacking". There is a discrepancy amongst the enforcement of relevant legal provisions across EU member states. For Mrs Halder, whereas Italy and Spain are the leading most advanced examples in safeguarding disability rights, Belgium has the lowest inclusion in Europe. She points to the widespread culture of 'special schools' in many northern European countries, which is difficult to eradicate. Nonetheless, She notes that Austria has indeed closed most of its 'special schools', so progress is slow but possible.

Cora's daughter now lives in her own flat, and they are in frequent contact. Cora believes that we need to focus on inclusion to make a better future for everyone, not just persons with disabilities themselves. With organisations like EDSA and the German Down Syndrome Information Centre, we can learn from each other and drive change.

Benedetta Galeazzi, Valueable Communication Office

Source: Valueablenetwork.eu, May 9th 2023



EU FUNDING OPPORTUNITIES



MOBILITY PROJECTS FOR YOUNG PEOPLE - "DISCOVEREU INCLUSION ACTION"



Under the DiscoverEU Inclusion Action, organisations and informal groups of young people can receive support to carry out projects allowing young people with fewer opportunities to participate in DiscoverEU on equal footing with their peers.

DiscoverEU offers young people who are 18 years' old a chance to have a short-term individual or group experience travelling across Europe by rail or other modes of transport where necessary. The objectives are to:

- give young people the chance to learn about Europe but also to discover Europe's opportunities for their future education and life choices;
- equip young people with knowledge, life skills and competences of value to them;
- encourage connection and intercultural dialogue between the young people;
- foster the young people's sense of belonging to the European Union;
- inspire young people to embrace sustainable travel in particular and environmental conscience in general

Objectives of the Action

DiscoverEU seeks to enhance its inclusion dimension by providing extra support to participants with fewer opportunities to explore Europe.

More specifically, the DiscoverEU Inclusion Action aims to:

- Reach out to young people with fewer opportunities that would not apply on their own initiative;
- Overcome the obstacles that prevent these young people to directly participate
 in the DiscoverEU general application round and provide the necessary support
 that they need so that they are able to travel;
- Trigger and enhance the development of competences and skills of young people with fewer opportunities taking part in DiscoverEU.

Read more



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!

CONTACTS

phone: 0039 06 3723909 e-mail: internazionale@aipd.it

THE STAFF

Carlotta Leonori Paola Vulterini

