

EUROPEAN DOWN SYNDROME ASSOCIATION

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BREAKING NEWS



Dietary supplements for children with Down Syndrome: do they really have beneficial effects?

Wednesday, **19 January 2022**, 17.00 CET, per Zoom, Speaker: **Sandra van der Haar Translation:** Croatian, German, French, Turkish and Ukrainian Registration: <u>https://us02web.zoom.us/webinar/register/1416419703369/WN_DIR7DR1jSM6zrz</u> cpOfsmeQ

Dietary supplements are popular among parents of children with Down syndrome. Several manufacturers claim beneficial effects on health and cognitive functioning and parents post on social media about the positive changes they observe in their child due to supplementation.

In the Netherlands, the Down Syndrome Foundation (SDS) often receives questions from parents through their helpdesk about whether or not to provide dietary supplements. Therefore, the SDS asked the Wageningen University & Research (WUR) Science Shop last year to investigate whether there is scientific evidence to recommend dietary supplements for children with Down syndrome.

WUR researchers and students spent more than 6 months working on this study, that consisted of fieldwork and an extensive literature study. As part of the fieldwork a survey was conducted among 234 Dutch parents of children with Down Syndrome to gain insights into patterns of dietary supplement use. In addition, parents and professionals (dieticians, physicians and a supplement manufacturer) were interviewed to explore different points of view regarding dietary supplements for children with Down syndrome. The results of this study have been published in October 2021. In the webinar Sandra van der Haar will give an overview of the main results of the study.

Information in Dutch on the project

website https://www.wur.nl/nl/show/Voedingssupplementen-bij-kinderen-met-Downsyndroom.htm

Information in English: The final research report has the title: Rapport: 'Dietary supplements for children with Down syndrome' and this is the link: https://www.wur.nl/nl/show/Rapport-Dietary-supplements-for-children-with-Down-syndrome.htm

EUROPEAN DOWN SYNDROME ASSOCIATION



Biography



Sandra van der Haar

Sandra van der Haar works since 2017 as a nutrition scientist at Wageningen Food and Biobased Research in the Netherlands (part of Wageningen University & Research).

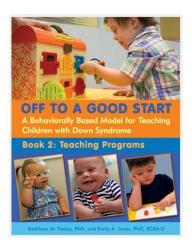
Sandra has a background as a dietician and obtained her masters degree in 'Nutrition & Health' at Wageningen University. The focus of her research group is on the health effects of food products, certain diets and dietary supplements in humans. For the current project she was both the lead scientist and project manager.



BOOK REVIEW

Off to a Good Start: A Behaviorally Based Model for Teaching Children with Down Syndrome

Book 2: Teaching Programs



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Written by Kathleen M. Feeley, Ph.D. & Emily A. Jones, Ph.D., BCBA-D
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Description

If you're the parent, teacher, or therapist of a young child with Down syndrome, you should know that Applied Behavior Analysis (ABA), the evidence-based, gold-standard method for teaching children with autism, is an equally effective strategy for teaching children with Down syndrome! In **Off to a Good Start: A Behaviorally Based Model for Teaching Children with Down Syndrome**, a two-book set, the authors share the compelling research about the benefits of using ABA methods with children with Down syndrome, describe ABA principles and procedures, and provide the ABA-based curriculum they've used for nearly 20 years to successfully teach infants through kindergarteners with Down syndrome. With these books, readers will learn ABA practices for teaching children the all-important foundational skills in motor, social-communication, cognitive, and self-care development.

Once readers understand the ABA principles outlined in **Book 1**, it's time to implement the teaching strategies! **Book 2: Teaching Programs** shows readers how to teach hundreds of essential skills using proven discrete-trial methods with prompts and reinforcement rather than the more informal ways that people typically teach children with Down syndrome. It covers:

- background information on how the teaching programs are structured, how to progress through them, and how to use the included planning and tracking forms
- how to organize materials and yourself, and work teaching into your day
- general information on enhancing the learning environment and helping your child learn throughout the day (e.g., positioning your baby, keeping the environment stimulating, being responsive, ensuring that reinforcement is actually reinforcing, using visual schedules and token systems)



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- comprenhensive information on teaching specific skills to children in four age groups—infants & toddlers, early childhood, preschool, and kindergarten; within each age group, skills are divided into motor, social-communication, cognitve, and self-help development, and organized into teaching programs with specific steps to teach each skill
- using prompts and reinforcement to shape desired behavior and skills
- how to minimize behavior which interferes with learning such as distracting parents/teachers with attention-seeking cute behavior, escaping from demands, or tuning out; using behavior modification tools—functional behavior assessment and positive behavior support—to manage behavior as the child gets older
- how to access community resources and opportunities including early intervention, parent groups, inclusive recreational activities, scoping out preschool and kindergarten programs, understanding special education rights, and communicating with teachers and group leaders about ways to include your child

Check out **Book 1: Foundations for Learning** to learn about (or reacquaint yourself with) using ABA principles and procedures to teach children with Down syndrome.

Written by Kathleen M. Feeley, Ph.D. & Emily A. Jones, Ph.D., BCBA-D

<u>Kathleen M. Feeley</u> is Professor in the College of Education, Information, and Technology and the founding Director of the Center for Community Inclusion at Long Island University. Dr. Feeley has dedicated her career to examining interventions that enable children with disabilities to be successful alongside their typical peers.

<u>Emily A. Jones</u>, Licensed Behavior Analyst, New York, is Associate Professor in the Department of Psychology, Queens College and The Graduate Center, City University of New York. In Dr. Jones' research she examines interventions to improve outcomes for children with developmental disabilities and their families.



RESEARCH

Differential Diagnosis Between Alzheimer's Disease And Hypothyroidism In Adults With Down Syndrome



The differential diagnosis between Alzheimer's disease and hypothyroidism in adults with Down syndrome who begin to show clinical deterioration needs to be emphasised. This study investigated clinical features which could be used to differentiate between the two conditions. Memory loss, mood and personality change, speech and gait deterioration, and slowing down were significantly associated with dementia but not with hypothyroidism. It is recommended that specific questions should be asked to elicit the presence of these features particularly in those individuals in whom assessment of biochemical thyroid status is not possible.

Click On The Link For The Details:

https://library.down-syndrome.org/.../differential...



EU FUNDING OPPORTUNITIES



Opportunities for organisations

Organisations wanting to participate in Erasmus+ may engage in a number of development and networking activities, including strategic improvement of the professional skills of their staff, organisational capacity building, and creating transnational cooperative partnerships with organisations from other countries in order to produce innovative outputs or exchange best practices.

In addition, organisations facilitate the learning mobility opportunities for students, education staff, trainees, apprentices, volunteers, youth workers and young people.

The benefits for involved organisations include an increased capacity to operate at an international level, improved management methods, access to more funding opportunities and projects, increased ability to prepare, manage, and follow-up projects, as well as a more attractive portfolio of opportunities for learners and staff at participating organisations.

Key Actions

Key Action 1: Learning mobility of individuals

Learning mobility opportunities aim to encourage the mobility of students, staff, trainees, apprentices, youth workers and young people.

The role of the organisations in this process is to organise these opportunities for individuals. The benefits for the organisations include an increased capacity to operate at an international level, improved management skills, access to more funding opportunities and projects, increased ability to prepare, manage, and follow-up projects, a more attractive portfolio of opportunities for students and staff at participating organisations, the opportunity to develop innovative projects with partners from around the world.

Key Action 1: Learning mobility of individuals

Key Action 2: Cooperation among organisations and institutions

The cooperation among organisations and institutions is expected to result in the development, transfer and/or implementation of innovative practices at organisational, local, regional, national or European levels.

Key Action 2: Cooperation among organisations and institutions

Key Action 3: Support for policy reform

Opportunities under this Key Action contribute to supporting the overall EU policy agenda, the Education and Training 2020 cooperation framework, and the Youth Strategy.



Organisations will contribute to improving the quality of education, training, and youth systems in Europe, as well as promoting transnational learning and cooperation between authorities. They will also contribute to developing the basis for evidence based policy-making, as well as supporting networks and tools for policy implementation.

Organisations will also contribute to improving the involvement of young people in democratic life and their engagement with politicians.

Key Action 3: Support for policy reform

Jean Monnet

Opportunities for teaching, research, and policy debate on the EU and its policies.

Explore Jean Monnet Actions

Sport

Designed to develop and implement joint activities to promote sport and physical activity, identify and implement innovative activities in the field of sport, and manage not-for-profit events to increase participation in sport.

Explore Sport

Related links

Search the 2022 Programme Guide Download the pdf version in 23 languages Read the press release



WORLD DOWN SYNDROME DAY 2022

Here an article received from the Down Syndrome International for EDSA members about the upcoming World Day campaign, the theme chosen and how it can be interpreted by each organisation and below Edsa proposal for the upcoming World Day campaign.

DSI INVITATION



On World Down Syndrome Day 2022,

Down Syndrome International is asking: What does #Inclusion mean?

We want you to tell us: **#InclusionMeans** ...

¿Qué significa #Inclusión? **#InclusiónSignifica ...** Que signifie #Inclusion? **#InclusionSignifie ...**

Why ask this question?

In its general principles, the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) calls for:

"Full and effective participation and inclusion in society"

There are references throughout the UN CRPD to **#Inclusion**, for example:

"Persons with disabilities can access an **inclusive**, quality and free primary education and secondary education on an equal basis with others."

"States Parties recognize the right of persons with disabilities...to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, **inclusive** and accessible to persons with disabilities."

In 2019, the UN Secretary General adopted the United Nations Disability **Inclusion** Strategy (UN DIS). This provides a path towards disability **#Inclusion** through all areas of the work of the United Nations: peace and security, human rights, and development.



Around the world it is widely accepted that everyone should have the same opportunities, be able to go to the same places, take part in the same activities, and enjoy the same experiences in life.

But the reality is that people with Down syndrome and disabilities today do not benefit from full and effective participation and **#Inclusion** in society.

There are many reasons for this. One reason is that there is a lack of agreed understanding of what **#Inclusion** is and what **#Inclusive** systems look like in practice.

So on 21 March 2022, we would like people with Down syndrome, families, advocates, professionals, organisations and indeed anyone around the world, to tell us:

#InclusionMeans ...

Why does this matter for World Down Syndrome Day (WDSD)?

WDSD is a unique opportunity for the global Down syndrome community to connect every year, so we can:

- share ideas, experiences and knowledge;
- empower each other to advocate for equal rights for people with Down syndrome and
- reach out to key stakeholders to bring about positive change.

From now, up to 21 March 2022, we have an opportunity to share our collective understanding of **#Inclusion**.

In doing this, we can get a global conversation going, which will empower people around the world to advocate for full **#Inclusion** in society for people with Down syndrome and disabilities, and indeed for everyone.

What can you do?

Every year we encourage people with Down syndrome, families, advocates, professionals and organisations to observe WDSD with your own activities.

We want to see this again, more than ever in 2022. We encourage you to:

1. go ahead and plan whatever is possible and safe to do. This could be anything from a social media post to a large organised event...every contribution counts;



- 2. whatever you decide to do, please provide responses that start with #InclusionMeans ... and make sure you advocate for full #Inclusion in society for people with Down syndrome and disabilities;
- 3. let DSi know and we will make sure your voices are amplified.

What will DSi do?

Supporting your activities

DSi will support you in your WDSD activities through the WDSD website, our social media channels and direct communications with our member organisations and the community. We will:

- provide resources to help you plan and organise your activities and
- share details of your activities and amplify your messages.

DSi activities

For our own activities, these will be focused on providing responses that start with **#InclusionMeans** ... from the perspective of the work we do and the amazing work our member organisations do.

DSi is focused on delivering real change. We want to see a world with #Inclusive human systems and we are currently working in 4 key areas that impact the lives of people with Down syndrome:

- #InclusiveParticipation
- #InclusiveEducation
- #InclusiveEmployment
- #InclusiveHealth

Concentrating mainly in these areas:

- we will provide responses that start with #InclusionMeans ...
- we will advocate for full #Inclusion in society for people with Down syndrome and disabilities;
- we will organise the WDSD @United Nations events in New York and Geneva, based on this theme.

Good luck and let us know all about your plans so we can tell the world what #InclusionMeans on 21 March 2022!



EDSA PROPOSAL - POSTER CAMPAIGN



EUROPEAN DOWN SYNDROME ASSOCIATION

Dear EDSA-members!

This year WDSD-Campaign has the motto "Inclusion means ...". The idea behind it is explained on the DSi-website: https://www.worlddownsyndromeday.org/inclusionmeans

For WDSD 2022, let's share our collective understanding of inclusion with a poster campaign on the EDSA website. That will run from march 1st up to march 21st, showing every day a positive Inclusive situation.

We are looking for a GOOD picture, with a person with DS together with another person / or some other persons without DS in an inclusive setting.

Attached are some examples. For the draft-examples we used some older pictures from the campaign in 2019.

That is what we are looking for:

1. Photo > good quality, landscape! format

2. A very short statement in english, telling what the quintessence of the shown situation is.

Inclusion means (Statement not more then 6 to 9 words)

3. A short text > about the person / the situation on the picture, in your own language and in english. The statement on the poster should also be translated in your language

I am collecting your contributions from now on. Dead line: 22. 02. 2022

Questions? halder.cora@t-online.de

Photo and text please as soon as possible to: halder.cora@t-online.de

Not via mailing-list!!

I am eagerly waiting your contribution!

Kind regards

Cora







Inclusion means ... have fun playing together

My name is Aldo. When playing, my friends don't leave me behind. I participate and some times I even lead the game. I am very lucky for the friends I have in the village where I live.

Une jam Aldo. Kur luajmë, shokët dhe shoqet e mij nuk më lënë pas! Unë jam shumë aktiv në lojë dhe ndonjëherë dhe ndonjëherë dhe i udhëheq ata. Unë jam shumë me fat për shokët dhe shoqet që kam ne fshatin ku jetoj.

From: http://www.edsa.eu/wdsd-2019-leave-no-one-behind-albania/



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

