



International voices on Childhood-onset disability

A visiting project on 5 continents

in preparation of the

EACD-IAACD congress meeting

2025, 24-28th June

Heidelberg, Germany

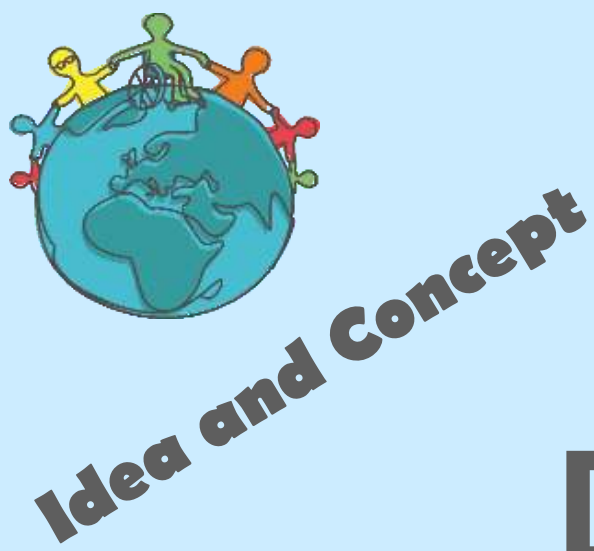
**„Developing networks –
networks for development“**

Introduction

Rainer Blank

President of EACD-IAACD 2025



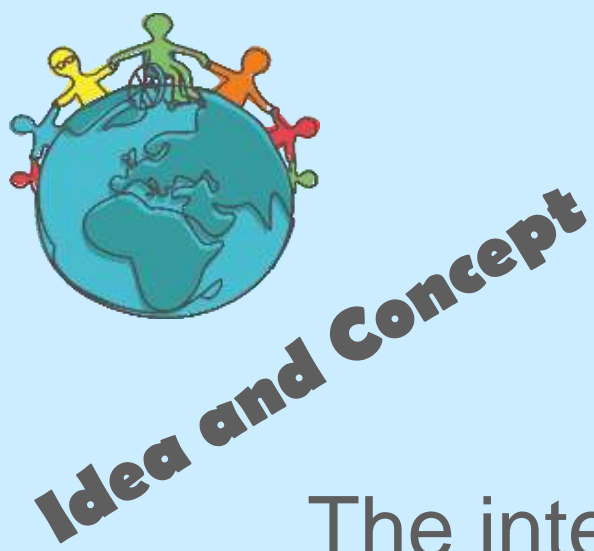


Why International Voices on childhood-onset Disability in the context of an international meeting?

Based on the constitution of the International Allied Academies of Childhood Disability (IAACD) international voices on childhood-onset disabilities were gathered in order to

- to listen to Pwle, Families, Stakeholders and Professionals „onsite from the bottom“ (client-centered) in order to appreciate their issues and themes
- to enable and / or enhance networking within and between professionals, stakeholders, families, advocates and policy makers across countries
- to support partnering and inclusion of parents and users
- to stimulate networking of all health professionals around childhood-onset disability before, during and after the congress meeting
- to strengthen the advocacy for parents, people with lived experiences and stakeholders
- to increase worldwide awareness of childhood-onset disability in health providers, policy makers and the societies

„Developing networks – networks for development“



The outline for the interviews*

The interviews will mainly reflect following issues but all interview partners were free to share any kind of issues they felt to be important with respect to different kind of disabilities and developmental disorders

Parent / caregiver: main themes

- The „story“ to have a child with special needs
- Satisfaction with help and care and challenges
- Possibilities of support incl. psychosocial support
- Disadvantage compensation / barriers in everyday life
- 3 wishes

Child / adolescent (if possible): main themes

- Well-being
- Education and work (schooling, vocational training, integration in a job)
- Friends, other contacts
- Support in everyday life
- 3 wishes

Professionals: different disciplines und functions: main themes

- System of medical care
- System of educational support etc.
- National policies to involve parent representatives and people concerned
- Satisfaction with help and care and everyday challenges
- Special challenges: country-, culture-, policy specific
- 3 wishes

The EACD-IAACD congress 2025 will be a meeting professionals around childhood-onset disabilities including people with lived experience, caregivers and their stakeholders.



Currently, after one year, 12 countries in 5 continents have been visited. So far, around 110 interviews have been recorded. Another 6 countries are planned to be visited in 2024.

The **video clips** with the international voices on childhood-onset disability will successively be presented at the website during the next 18 months until the congress meeting in June 2025.

Before the videoclips of the voices of every country will be shown weekly on our website, there will be some background information about the visit to introduce the country and the people being interviewed. The countries will be presented in the order of the visits.

The goal was to visit about 2-3 countries from every continent outside Europe (IAACD regions).



International Voices on Childhood-onset disabilities
From 18 countries, 5 continents



Selected European countries

**Visits in
EACD Region**

16 Great Britain

15 Belgium

14 France

7 Poland

18 Germany

4 Slovenia

**17 Portugal
(Azores)**

**Visits in
IAACD Regions
outside Europe**





Videoclips

International Voices on Childhood-onset Disability

starting weekly from January 2024 on EACD-IAACD2025.org

Start: 10th January 2024



General information: Congress meeting, acknowledgements, finances and conflicts of interest

Organisational background and acknowledgements:

After more than 15 years of intensive contacts and active involvement within the European Academy of Disability (EACD), I decided to submit a successful bid in 2021 for the 2025 meeting in Heidelberg. After this, there was the rare occasion to bid also for the triennial meeting of the IAACD in 2025, which was successful accomplished at the end of 2021.

From the beginning the bid was greatly supported not only by the EACD, but also by the Management Board and the administration of the Child Center Maulbronn and by the University of Heidelberg, the Department of Paediatrics (Prof. Dr. Georg Hoffmann), the Department of Paediatric Orthopedics (previously Prof. Dr. Thomas Dreher) and especially by the Institute of Genetics (Director: Prof. Dr. Christian Schaaf) and further supported by a highly motivated team.

Representative for this team I would like to thank Christian Schaaf as the Vice-President and later Sebastian Schroeder as my successor at the Child Center and as Chair of Scientific Committee and further Sabine Vincon a long-standing colleague and leading therapist for continuous support from the beginning as well as the IAACD representative for the congress Ros Boyd from Australia; finally, I like to thank the great team of the family, user and stakeholder committee and here especially John Coughlan from the International CP Society (ICPS) sharing a number of international contacts which were extremely helpful for the start of the visiting project.

Copying and sharing

As a Founding member and longstanding Board Member of the stakeholder organisation Children Network Germany e.V. it was my personal motivation and wish to support parents and persons with lived experiences on an international level by giving them a voice and help them to create public awareness and develop further networks. Bearing this intention in mind, it is highly appreciated and welcomed that information of the visiting project „International Voices of Childhood-onset Disability“ is linked within social media and may be used by stakeholders and policy makers. Any sharing for other purposes than being mentioned is strictly prohibited. All film and foto material must not be copied, only links to the EACD-IAACD website and to our social media posts are permitted. Written information can be copied and cited by naming the authors. All further original materials are safely stored according to European data protection rules and not accessible to public. The presented film material is consented and authorized for publication in non-searchable Youtube format on the EACD-IAACD 2025 website by the interview partners themselves and / or their legal representatives if necessary. All further use has to be asked for personal permission.

Financial Support and conflict of interest:

After retirement as a Managing Director and Medical Director of the Child Center Maulbronn, Academic Teaching Hospital of the University of Heidelberg, in December 2022 I made a donation to support the IAACD / EACD project to visit parents and professionals in several countries in preparation of the congress meeting 2025. From this donation, flights and accommodation are largely been paid except for Australia and New Zealand where the complete travel costs have been paid privately by my own. Meal costs and any touristic side activities have been financed privately. As president and project coordinator of the EACD / IAACD I am currently paid part-time by the Child Center Maulbronn until June 2025.

Finally, it is reassured that all information of the interview partners have been given deliberately and freely and provided with their approval. No further conflicts of interests are declared.

Rainer Blank, President EACD / IAACD 2025



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Website / Media / Communication

Accounts for EACD/IAACD 2025:

Instagram Account Name: eacd_iaacd_2025

Twitter Handle: @2025Eacd

Twitter Account Name: eacd_iaacd_2025

Facebook Page Handle: @eacd.iaacd.2025

Facebook Page Name: EACD IAACD 2025

Website: eacd-iaacd2025.org (Revision by February 2024)

Newsletter