



# **EACD Strategic Plan**

## **2023-2026**



The presented actions and outcomes in this document were discussed and decided during the EACD Strategic Planning Meeting, 25-26 November 2022, Brussels, Belgium

**Present at the EACD Strategic Planning Meeting:**

Arnab Seal	(AS)	GMC Chair
Bernard Dan	(BD)	GMC Chair-Elect
Therese Millar	(TM)	GMC Treasurer
Elegast Monbaliu	(EM)	GMC Secretary & President EACD Bruges 2024
Jackie Casey	(JC)	GMC Member
Jeroen Vermeulen	(JV)	GMC Member
Mercedes Martinez-Moreno	(MM)	President EACD Barcelona 2022
Katja Groleger Srsen	(KGS)	President EACD Ljubljana 2023
Niek De Taeye	(NDT)	Family & Users' Forum Coordinator (Ex-officio GMC Member)
Teresa Mano da Costa	(TMC)	Family & Users' Forum Coordinator (Ex-officio GMC Member)
Christopher Newman	(CN)	Chair of Scientific Committee (Ex-officio GMC Member)
Sylvain Brochard	(SB)	Technology & Innovation Task Force lead (Co-opted GMC Member)
Annemieke Buizer	(AB)	Prospective Chair of Scientific Committee
Erika Cloudt	(EC)	Early Career Researchers' Forum representative
Inti Vanmechelen	(IV)	Early Career Researchers' Forum representative
Marco Konings	(MK)	Back-office coordinator (EACD Staff)

**Apologies received for absence:**

Elisabet Rodby-Bosquet	(ER)	GMC Member
Oleh Kachmar	(OK)	Edu.EACD.org webmaster (Co-opted GMC Member)

*Abbreviations: GMC: General Management Committee; ExCom: Executive Committee*



# EACD's Mission, Aims and Values

The **European Academy of Childhood Disability (EACD)** is an international not-for-profit association founded in 1989, and is an organisation for anyone with a clinical and/or scientific interest in childhood-onset disabilities in Europe.

EACD is a multidisciplinary, welcoming, constructive academy, consisting of like-minded members who want to build together a better future for people with childhood-onset disabilities. Education, ethics and social commitment are of paramount importance to EACD, bridging cultural, societal, economical, and lingual differences across the entire European region for the benefit of people with childhood-onset disabilities.

**EACD's Mission** is to promote excellence in research and services for the benefit of people with, and at risk for, childhood-onset disabilities, and to provide multidisciplinary, state-of-the-art education for professionals active in the field of childhood-onset disabilities in Europe and beyond.

**EACD Aims:** In furtherance of our mission, the EACD shall engage in the following aims and activities:

- To promote and extend excellence in research in all aspects of childhood-onset disability, and to facilitate the dissemination and valorisation of such research.
- To ensure regular education and knowledge exchange on all aspects of childhood-onset disability through meetings, congresses, symposia, working groups, training courses, online events, exhibitions and publications.
- To support the use of the latest evidence-based practice and evidence-based medicine into the care, treatment and services for people with childhood-onset disabilities and their family caregivers.
- To foster cooperation between those active in the field of childhood-onset disabilities in Europe and elsewhere for the benefit of people with childhood-onset disabilities.
- To raise awareness of the needs and rights of people with a childhood-onset disability, their families and close others
- To encourage people throughout Europe to become professionally active in the field of childhood-onset disabilities.
- To maintain the highest possible ethical and scientific standards in all EACD activities, and to encourage the use of the highest possible ethical and scientific standards by those working with people with childhood-onset disabilities.

**EACD's values are:** Collaboration, Knowledge, Inclusion and Integrity



# EACD's Strategic Planning Meeting

The EACD's has scaled up its involvement over the recent years from an annual scientific meeting organiser to a broader range of activities for the benefit of people with childhood-onset disabilities including the areas of Education & Training, Technology & Innovation, and Advocacy, with the ambition to be the leading organisation in respect to the area of childhood-onset disability at European level with a clear mission and vision. In order to fulfil EACD's Mission, Six key areas have been identified and discussed during the EACD Strategic Planning Meeting on 25-26 November 2023 in Brussels, Belgium for the period 2023-2026:

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## Key Area 1: To promote Excellence in Research in the area of childhood-onset disability in Europe (and beyond)

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Focus areas include:

### **(i) To organise high-quality EACD Annual Meetings in terms of scientific and organisational standards**

The Annual Meeting is the hallmark of the EACD. The programme of the Annual Meeting has to be distinctive and have an European stamp, preferably including a local flavour from the hosting country in both the scientific and social programme. The key objectives of an EACD Annual Meeting include knowledge exchange, networking, cross-fertilization of ideas, and a local legacy. To achieve these objectives, EACD perceives it to be important to create an opportunity every year for people active in the area of childhood-onset disability to meet in person. In addition, EACD recognises the potential benefits in allowing online participation to its annual congress to promote wider participation, in particular for people from countries with less resources and/or from geographically distant locations. At the same time, it is noted that a hybrid meeting can be challenging from organisational perspective, being required in practice to organise two events (online and on-site) simultaneously, with a substantial financial cost involved for the online platform and technical aspects. As such, it is EACD's ambition to find a sustainable model for virtual participation to the Annual Meeting that capitalises the strengths of virtual participation, tailored to the needs of the online attendee and without discouraging in person participation, rather than creating an "online version" of the on-site meeting.

#### **Action points:**

- Develop a standardised evaluation method to assess the EACD Annual Meeting  
The evaluation method should assess the scientific quality; the provided networking opportunities, the cross-fertilisation of ideas, and the local legacy of the EACD Annual Meeting;
- Explore the introduction of late-breaking abstracts.  
Late-breaking abstracts should contain new information that was not yet known or fully available by the abstract submission deadline (i.e. the late-breaking abstract deadline is not an extension of the abstract submission deadline) and the data in the abstract must not be published prior to the meeting.
- Introduce guided poster tours to increase attractiveness of poster presentations  
Guided Poster Tours will take place during the EACD Annual Meeting. Each tour will be led by a moderator. The presenting authors shall be present by their poster during the time of their presentation and will stay after their presentation to participate in the rest of the tour. Each tour of physical posters will commence at the poster listed first in the programme book. Each poster presenter will have 1-2 minutes for presentation and 1-2 minutes for discussion. All attendees are encouraged to interact with



the presenter and tour moderator. To further improve the attractiveness of the posters, the option to split the Best Poster Award into a jury vote and popular vote will be explored.

- Organise an online event after the annual congress with the congress highlights +/- 3-4 months after the congress; target audience: people who could not attend the annual meeting, e.g. people from lower-income countries, families, etc.
- Improve the participation numbers of underrepresented professions e.g. educators, social workers, nurse specialists, dieticians, paediatric dentists, ...
- Inclusion of Early Career Researcher Award winner(s) in next year's EACD Annual Meeting programme

Provide platform for winner Early Career Researcher Award in preceding year to present research to a wider public, e.g. via plenary session

- Reconsider the format of the 'Gala Dinner' to allow wider participation.  
The Gala Dinner is seen as a highlight of the EACD congress, but is seen as expensive. Small working group will be set up to reflect on format. Key focus on lowering costs (e.g. via walking dinner) to become more inclusive; potential re-branding to 'Networking Dinner' or something equivalent
- Implement ways to increase the attractiveness of the congress to local audience e.g. include a special track during the congress in the local language to support the efforts to use the EACD congress as a catalyst to bring the local community together and/or Reserve dedicated slots (e.g. Instructional courses, mini-symposia) for local participants
- Explore possible ways to reduce costs for Annual Meeting  
The main costs of a congress involve venue, catering, PCO. A careful reflection will be made where costs could be saved without affecting the quality of the congress
- Consider the inclusion of "How to ... / Methodology" discussion sessions (e.g. how to deal with low number of participants?)
- Consider wider participation in both design, delivery and engagement of professionals and users
- Explore the option for joint keynote sessions with a senior "big name" and upcoming talent
- Ambition to have a broader focus than only cerebral palsy during Annual Meetings
- Work out a strategy to facilitate networking during the Annual Meeting e.g. mentorship programme; 'meet the expert' session; Special Interest Groups; academic speed dating

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## **(ii) To provide networking opportunities to researchers active in the area of childhood-onset disabilities from all career stages**

In the era of internationalisation, EACD recognises the value of networking in international contexts as a way of fostering research collaboration, cross-fertilisation of ideas, mobility exchange and curriculum improvement from an European and even global perspective. In addition, networking is increasingly recognised as a vital component of a successful career in academia and higher education. However, while many established researchers already seem to be part of that successful net of connections, especially those who are at the beginning of their academic careers may struggle to find their own way to build professional relationships that will lead to effective collaboration. EACD agrees it should support initiatives and activities which are intended to support in particular early career researchers in building relationships both with peers and with more experienced scholars, and to support EACD members in



building and developing their careers to promote capacity building, collaboration and networking. EACD foresees a key role for the Early Career Researchers' Forum in this process.

**Action points:**

- Anchoring the Early Career Researchers' Forum within EACD as the central platform for the Early Career Researchers community across Europe active in the area of childhood-onset disability

- Identify (networking) priorities for each career stage (early – mid – late).

E.g. what kind of support / initiatives / activities would be needed to further advance their career at that stage; Possible ideas: (i) Start organizing regular 'How to' workshops; (ii) activities for mid-stage career to continue establishing research networks and contacts in the field; (iii) Fixed Early Career Researcher session at the EACD conference; (iv) Set up (safe, low-bar) community forum where (Early Career) researchers can post questions, discuss and share knowledge

- Develop a strategy to facilitate networking between junior and senior researchers

Possible ideas: mentorship programme; online symposium or pre-conference symposium on specific, focused themes; webinars; summer schools; joint research forums with other organisations) – Both formal and informal

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**(iii) To stimulate excellence in research and the use of good research practices**

Stimulating excellence in research is of the utmost importance to push the frontiers of science and for the world to produce the knowledge needed to meet current and future challenges experienced by people with childhood-onset disabilities, their families and close others concerned. Good research practices apply throughout all phases of a research project and career, be it while doing research, preparing publications, collaborating with partners, performing assessment, undertaking societal outreach, supervising other researchers or leading a research unit. EACD should actively promote good research practices to ensure the highest standards of integrity, ethics, and professionalism are observed while doing research.

**Action points:**

- Develop a sustainable model for organising EACD Training Schools at regular intervals (e.g. Summer Schools for Early Career Researchers)

- Deliver education and training opportunities stimulating excellence in research and good research practices at regular intervals

Suggested formats to promote excellence in research: Journal club; "Breakthrough session", in which very recent high quality recent paper(s) can be presented; "How-to sessions" (e.g., writing a paper, writing a grant, writing a literature review, methodological considerations for study set-up, open science practices, how to design a high level clinical trial, etc.)

- Identify tools needed to define knowledge gaps and/or areas of attention that need to be encouraged / promoted (and the level of evidence needed)

e.g. explore the option to create a working group for high-level international systematic reviews on innovative & promising topics;

- Promote stakeholder (e.g. users, families) involvement in design and conduct of research

- Consider whether EACD should start commissioning/facilitating its own research

Identified to be a possible area of interest for EACD, but only if there is the availability of funding resources to support this.

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## **Key Area 2: To facilitate Knowledge Transfer from research to (clinical) practice and to deliver state-of-the-art educational material and events**

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Focus areas include:

### **(i) To identify education and training needs across Europe, and to develop appropriate formats to address such needs (e.g. webinars, e-courses, etc.)**

One of the core missions of the EACD is knowledge transfer from research to clinical practice. Traditionally this has been through our Annual Meetings and website, but EACD would like to broaden up its activities in this regard, for example via webinars and e-courses. The development and implementation of a structured approach to identify and prioritise the knowledge gap and training needs for EACD will be critical. First steps have been taking already in this direction by the set-up of the EACD Education & Training Committee, including assigned GMC Member post. This process will be continued with the aim to deliver regular, high-quality education content and material, bridging cultural, societal, economical, and lingual differences across the entire European region for the benefit of people with childhood-onset disabilities.

#### ***Action points:***

- Identify gaps in education and training needs across Europe

Develop a mechanism on how we quantify gaps in education, how we define priority areas for identified gaps, and how we measure progress; Various aspects need to be taken into account here: level of urgency, (professional) background, type of condition, geographical/economic factors, local languages, cultural translations, etc.; Next step will involve the preparation of a survey among the EACD member base to identify training needs and priorities;

- Organise appropriate formats to address the identified education and training needs.

e.g. following formats were identified as potentially interesting: Lectures / Webinars on topics based on suggestions / voting by EACD members; Joint webinars with partner organisations with shared interest; E-courses on hot topics at regular intervals; listening & sharing sessions on specific themes.

- Develop a framework in which EACD delivers educational events and content at regular intervals, but with the flexibility to adapt the format and frequency of delivery to the content-wise objectives where appropriate.

- Actively encourage researchers to think about the relevance and impact of their research for users and families.

e.g. by asking submitting authors to include short statement during abstract submission and to include slide on relevance for users/families at the end of oral presentations.

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### **(ii) To encourage the development and implementation of evidence-based best practice consensus statements**

Evidence-based practice is necessary for improving the quality of health care as well as patient outcomes, and is an ongoing, collaborative approach to making decisions about the provided services. This requires the consideration of the best available basic and applied empirical research evidence when making decisions about health services provided to people with childhood-onset disabilities, plus the consideration of the limitations of the available empirical evidence, especially given contextual factors such as developmental level, community/cultural



needs, the settings in which the services occur, barriers to services, and the strengths and assets of individuals and communities. Evidence-based practice includes also ongoing measurement and evaluation of the impact of services and, if necessary, outcome-informed adjustments to services that are intended to maximize their effectiveness. Service providers serve as a guide for collaborative decision-making in evidence-based practice, integrating different sources of information, including recipients' values and preferences, as well as the provider's competence and the organization's capacity to provide effective services. In this perspective, EACD aims to have a leading role in the development of evidence-based best practice consensus statements at European level, and to assist where possible in the integration process of evidence-based practice into the curricula of undergraduate, postgraduate, and continuing professional development health programs across Europe.

**Action points:**

- EACD should have a leading role in the development of best-practice consensus statements at European level

Assign specific people to bring this action forward; Encourage the development of best-practice consensus statements at European level. If possible in terms of resources and capacity, the provision of consensus statement grants could possibly be considered.

- Create a practical framework for the translation of research findings into practice and policy, and to develop tools or formats that facilitate this process.

Define what we mean by Knowledge Transfer, with whom and what our editorial process, curating and archiving process will be. Five key questions identified will need to be addressed: 1) What should be transferred?; 2) To whom should research knowledge be transferred?; 3) By whom should research knowledge be transferred?; 4) How should research knowledge be transferred? 5) With what effect should research knowledge be transferred?

- Facilitate the process from international guidelines and consensus statements to local implementation

Find and map current (local) guidelines and consensus statements; Linked to local implementation process, two-sided focus: 1) focus on policy-makers; 2) focus on practitioners/therapists; Explore possibilities linked to whitepaper CP in France to European context (nice to have)

- Need for knowledge brokers – implementation science experts

Identify tools or formats to facilitate and accelerate the translation of research findings into best clinical practices, health care services and policies across Europe

- Develop a strategy to increase the effectiveness of clinical practices and services for the benefit of people with childhood-onset disabilities of all ages over their entire life course.

Install a Lifespan Working Group to (a) facilitate the co-ordination of long term outcome information on a range of common childhood onset neuro-disabilities; (b) Consider the service gaps and knowledge gaps in this area and produce a strategy applicable for European countries to bridge the gap (c) Raise awareness among professionals and users regarding possible implications of the life-course approach which could have long term impact on health and non-health outcomes for children with childhood onset disabilities

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## **Key Area 3: To facilitate adoption and application of Technology & Innovation with respect to childhood-onset disability practices**

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Focus areas for the next years include:

### **(i) Consolidate the current efforts of the Technology & Innovation Task Force**

Following the Hackathon at the EACD Paris 2019 meeting, a Technology & Innovation Task Force was set up in 2020 to develop a vision at the European level by making visible the needs for people with childhood-onset disabilities and by promoting innovation targeted on this group. As part of the work from the Task Force, EACD introduced a special interest session on Technology & Innovation and the opportunity to present innovative products during the annual congress, including a Technology & Innovation Award. Furthermore, EACD rolled out the cross-European RehaTech4Child Survey to identify the digital technologies that are used, or not used, in clinical practice. Key priority for the next years will be to consolidate these effort of the EACD Technology & Innovation Task Force into a sustainable model within the EACD organisation.

#### ***Action points:***

- Continue the 'EACD Technology & Innovation Award' as recurrent EACD Meeting Award to celebrate excellence in the development of innovative products and technologies for the benefit of people with childhood-onset disabilities
- Provide platform during EACD Congress for (start-up) companies to present their products and innovations  
e.g., via Demonstration posters presenting an innovative product or technology; or via hands-on session for congress attendees to try products during congress
- Continue the Special Interest Group on Technology & Innovation
- Organization of new hackathons dedicated to individuals with a childhood-onset disability. The option for organising a hackathon around the EACD Bruges 2024 meeting will be explored as big European event linked to Technology & Innovation

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### **(ii) Accelerate innovation for people with childhood-onset disabilities at European level.**

To promote and facilitate innovation for the benefit of people with childhood-onset disabilities, it will be essential to make their needs and priorities visible for (bio-)engineers, innovators, developers, entrepreneurs, researchers and industry partners. At the same time, we may need to think how EACD could facilitate knowledge transfer across professional boundaries to identify, capitalise, and accelerate the potential benefits from technological and medical breakthroughs and innovations relevant to our field in the shortest possible timeframe. This may require a focus on creating and strengthening structural, sustainable and integrated networks across Europe, and to provide the opportunities for dissemination of new technologies and innovations via conferences, symposia, blogs, publications, etc.

#### ***Action points:***

- Develop a potential partnership model with industry partners to promote new technologies & innovative solutions that fits within EACD's mission and values



Explore the possibilities for partnerships with industry to promote new innovations and technologies for the benefit of people with childhood-onset disabilities. Consider the potential ethical implications for working with industry partners. As partnerships with industry are most likely to happen, EACD needs to think how we manage as EACD to collaborate with such partners in an ethical, integer way.

- Share success stories on successful innovative solutions for the benefit of people with childhood-onset disabilities.

This would include providing the opportunities for dissemination of new technologies and innovations via conferences, symposia, blogs, publications, children talking how technology helped them, etc. This asks also for a strategy to identify products and/or partners of interest who are working on new technologies and innovations in the area of childhood-onset disabilities relevant to the European region;

- Focus on the co-creation of educational tools for health professionals, (bio-)engineers and families on how to partner with each other.

EACD should be active in knowledge transfer across professional boundaries. The EACD should also actively bring together users and all relevant professional groups together to ensure that the advances make a difference in people's lives as quickly as possible i.e. shorter translation times. At the same, there should be a strategy to co-express ones needs between health care professionals, families and engineers, and to identify the needs for a better participation. A final step would focus on setting up an e-Platform to engage at a macro-scale level.

- Work out a vision as EACD on the use of big data
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## **Key Area 4: To co-advocate for their rights with people with childhood-onset disabilities, and their families, throughout Europe and beyond.**

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Focus areas include:

### **(i) To co-advocate for their rights with people with childhood-onset disabilities, and their families, throughout Europe and beyond following the OHCHR Framework**

There has been agreement in the EACD GMC that advocacy for the rights of people with childhood-onset disabilities in the European region should be an explicit key area of focus for EACD. This is a shift in thinking as traditionally advocacy has not been prominently featured by EACD. However, it should be recognised that EACD has been participating already in various advocacy projects over the past years on ad-hoc basis (e.g. austerity survey, COVID-surveys, EACD Advocacy group for Ukraine). There are perceived to be roles for EACD in academic advocacy and social/policy advocacy. However, it is emphasised to be important that EACD remains its political impartiality, and to ensure EACD's voice is used with a clear focus on the rights of people with childhood-onset disabilities, their family caregivers and/or their care/service providers only. As such, there is a need to work out what mechanisms EACD needs to validate what we are saying as an organisation, and to identify our priorities in this area.

#### **Action points:**

- Support and contribute to advocacy projects for research, healthcare and related issues important to both professionals and families

e.g. accessibility and quality of health and social care services for people with childhood-onset disabilities; COVID-surveys; EACD Advocacy group for Ukraine

- Work out what mechanisms EACD needs to validate what we are saying as an organisation, and to identify our priorities in the advocacy area.

Is there a need for a separate committee on this? A key role is envisioned here for the EACD Families & Users' Forum

- Consider a revisit of the constitution to reflect EACD's activities

To reflect EACD's advocacy work; In addition, a reflection on used terms and languages as EACD is warranted. E.g., use of childhood or childhood-onset; disability or development;

- Raise awareness on the stigma on disability that still exists in many European countries  
Explore possibilities to roll out awareness campaign

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### **(ii) Develop a strategy to optimise internal and external communication and cooperation with all involved stakeholders, including people with lived experience, policy makers and media**

There is increasing recognition of shared communication with engineers, scientists, basic science researchers, education, social care, policy makers, politicians, civil servants, etc. A key ambition should be that we become the 'point of reference' / 'go to organisation' for any matters relating to childhood onset neurodevelopmental conditions for professionals in our field, professionals outside our field, users/people with lived experience, policy makers and media. A strategy is needed on how we aim to achieve this and which steps we need to take.



**Action points:**

- Create a practical framework for the translation of research findings to policy-makers and media

Reach out and form partnerships with individual stakeholder groups, particularly those stakeholder groups with whom we are less invested. Engage actively with wider partners & stakeholders (e.g. engineers, scientists, basic science researchers, education, social care, policy makers, politicians, civil servants etc.)

- To use all forms of (social) media to connect to members, families, colleagues and organisations;

EACD is currently using Twitter, Facebook, LinkedIn and Instagram as social media tools. In addition, monthly email newsletters are sent out to the membership, and recurring blogs are published on the Edu.EACD website

- To provide regular updates from networks and academies from across Europe;  
Include 'Update from country' as fixed topic in monthly newsletter

- To create a practical framework for a better accessibility and translation of state-of-the-art knowledge to persons with lived experience, their families and close others concerned

Develop strategy to communicate relevant scientific knowledge to users/families in an understandable way

- To continue to develop excellent and accessible educational resources for our members and partners

Maintain Edu.EACD as the knowledge hub for the latest EACD Educational content, including keynote lectures by the leaders in the field, our EACD Annual Meeting archives, resources.

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## **Key Area 5: To foster the development of International, Regional and National Networks**

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Focus areas include:

**(i) To continue EACD's leading role in developing a global perspective and collaborations with partner Academies around the globe as part of the ongoing work and initiatives with the International Alliance (IAACD).**

The EACD is one of the founding members of the International Alliance of Academies of Childhood Disability (IAACD). IAACD is an assembly of academies of childhood-onset disability globally, and aims to capitalize on the efforts of colleagues from around the world who are leading regional childhood-onset disability clinical and educational initiatives to support the best outcomes for people with childhood-onset disabilities and their families. It is envisioned here that the international alliance would combine individual strengths to close the global gap in access to this expertise – providing an environment for interdisciplinary collaboration, advancing best practices through research and training, and advocating for the service needs of these children and their families – and promote the development of professional capacity, being accessible by families and policy makers and sensitive to the cultural, social, geographic and political realities of their country or region.

There is agreement within EACD on the complementarity of EACD and IAACD, and EACD agrees clarity exists in general sense on what is IAACD's authority/responsibility and what is not. In which IAACD plays a pivotal role in understanding the health needs from across the globe better, in contributing to international knowledge transfer and research initiatives, and is among other an extension of EACD's traditional area of attention for addressing and dealing with differences between high- and low-resources regions. The EACD recognises the IAACD has been working hard to establish a sustainable framework and governance structure for long-term global partnerships, and EACD will continue to support these efforts. Finally, the EACD has global membership, and our activities have a global reach. There is agreement that EACD's role in the IAACD does not prevent us from fostering other global partnerships and/or activities if they are relevant.

**Action points:**

- To contribute to the governance structure and initiatives of the IAACD;  
Continue to monitor there is a balanced approach in terms of power, influence and contributions provided between Academies and regions within the IAACD; To contribute to international knowledge transfer and research initiatives via IAACD, among other via our acquired experiences and expertise at European level on how to deal with cultural and lingual differences
- Inform IAACD that EACD would be willing to collaborate with academies in other parts of the world.  
e.g. via hosting of joint online events; EACD agrees that the promotion/advocacy of partnership between academies from other parts of the world should go in first place via IAACD.
- Set up a framework for the nomination, selection and feedback process for the EACD representatives at the IAACD sub-committees  
Install a mechanism to get feedback at regular intervals (e.g. 1-2x per year) from the EACD representatives at the IAACD sub-committees; develop a system on nomination process for IAACD sub-committee members on behalf of EACD



## **(ii) To actively promote the development and strengthening of national and regional multidisciplinary networks of professionals in the European region**

The EACD agreed to adopt the WHO list of countries from the European region (<https://www.who.int/countries>) as operational approach to define as EACD what is meant by 'Europe'. This involves a total of 53 countries. Due to the wide variety in culture, language and health care systems across the European region, there is a key role for the EACD National Coordinators to promote the development and strengthening of national and regional multidisciplinary networks of professionals. Therefore, optimal communication and collaboration between EACD and National Coordinators/ Academies is crucial. In recent years, EACD has increased its number of meetings with the National Coordinators from once per year (at the congress) to three times per year (at the congress + two online meetings). EACD will continue this approach and agreed that during the EACD Annual Meeting a "traditional" update meeting with the National Coordinators should be foreseen, plus an interactive discussion session. EACD is also willing to actively support regional partnerships between countries and to support national and regional meetings, for example via the provision of an "EACD speaker". Finally, efforts will be employed to facilitate knowledge transfer from European / international guidelines to local settings and vice versa.

### ***Action points:***

- Identify local networks and organisations from countries from the European region without National Coordinator.

Check via contacts in neighbouring countries (e.g. via Turkey, Georgia)

- Reflect on the role and requirements EACD has towards its National Coordinators

What are expectations as EACD towards the national coordinators: should they be (primarily) networkers, knowledge brokers, representatives/ambassadors, event organisers, ...? How could EACD empower the national coordinators and improve their visibility (e.g. ask national coordinators to make a short, pre-recorded introduction video of themselves)?

- Provide regular updates from networks and academies from across Europe;

e.g. via EACD newsletter or other media channels from EACD

- Develop a strategy to facilitate knowledge transfer from European / international guidelines to local settings and vice versa.

e.g. how to deal with cultural, lingual (local language and jargon), geographic and economic challenges towards such knowledge translations; Identify current national / regional guidelines of best practice

- Foster regional partnerships between countries

To facilitate collaboration and knowledge exchange between national and regional networks and groups of health professionals; proactive role for EACD to explicitly communicate this to the National Coordinators.

- Support the organisation of activities by local/regional academies/networks

Proactive approach by EACD to encourage national coordinators/local academy to include EACD representation (e.g. via a speaker) into their local meetings; Explore opportunity to have joint activities with local/regional academies/networks. E.g. local/regional meetings, endorsing local initiatives, rotating activities like summer schools to different regions

- Raise awareness on challenges to provide appropriate care in rural areas

Identify how is being dealt with this in different European countries

- Encourage a meaningful partnership and knowledge exchange of the national and regional networks and groups with local user and family organisations.



Create links between the National Coordinators and the Families & Users' Forum

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**(iii) To rekindle the collaboration with leading European and International organisations, networks and authorities in the European region**

Without collaborations with leading European and International organisations, networks and authorities in the European region, it will not be able for EACD to have a wider influence outside our own community. There is a need to clearly define our expertise as EACD (and what we are not experts in). In this respect, EACD's expertise in research and our (multidisciplinary) network are perceived as our main assets for partnership with other organisations. Initial efforts have been employed to anchor and maintain partnerships with European networks with shared interests. There is a need now to develop a framework that allows us to identify the relevant networks and organisations, and to identify which type of partnerships EACD offers to engage with such networks and organisations.

***Action points:***

- Develop delineated plan for collaboration as EACD with UNICEF – Europe & WHO – Europe

Potential partners in sharing of ideas in areas as advocacy & technology, bringing in EACD's expertise in research and our (multidisciplinary) network as our main assets for partnership with these organisations and for further discussion.

- To consolidate EACD's current partnerships with European networks with shared interests With EPNS, ESMAC, EPOS, ERN-RND, European Palliative Care Network – CYP group, Elsass Foundation, Mac Keith Press, La Fondation Paralysie Cerebrale; Identify possible other partners of interest: e.g. ESCAP (European Society for Child and Adolescent Psychiatry), European Pain federation; Actively approach 1 or 2 partner organisations per year for a joint event/initiative (e.g. shared webinar)
  - Identify and validate which type of partnership EACD offers and set up partner program tiers  
e.g. with professionals organisations, patient organisations, advocacy groups, industry partners, European institutions? At national / regional / European level? What do we offer to partners; what do we expect from them?
  - EACD should aim to be more inclusive on all childhood-onset disabilities in the long-term Identify potential diagnosis-based organisations as possible partners
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## **Key Area 6: To continue to build a stable and sustainable organizational and financial structure**

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Focus areas include:

### **(i) Identify new revenue streams to support EACD's ambitious plans.**

With our ambition to be (and present ourselves as) the leading organization in respect to the area of childhood-onset disability at European level, there is a need for adequate operational and administrative support to ensure continuity and a stable organizational and financial structure as organisation. This requires the EACD to protect its existing funding streams and generate new funding streams. This is a key priority that needs constant attention as if EACD plans are not underpinned by the generation of sufficient income streams over the medium term, EACD's ambitions are admirable but likely not sustainable in the medium to long-term.

#### ***Action points:***

- Improve and maintain relationships with congress sponsors and industry partners  
Implement a proactive strategy for follow-up with sponsors after the congress - Were they satisfied? Did they reach their goals? What could be done better?
- Explore the options for long-term engagements as EACD with industry partners and/or philanthropical organisations  
Going beyond only annual congress sponsorship, creating a partnerships with mutual benefit with an outlined, clear and transparent strategic vision on the (ethical) red lines as EACD
- Develop business cases for webinar programmes, online courses, training schools, etc.  
Ensure operational templates are available on the organisational and financial aspects of the various educational formats
- Create a framework for a rolling programme of courses and events organised by EACD throughout the year  
Spread risk over multiple initiatives, allow flexibility in framework for adapting the used educational tool/format to the end goal

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### **(ii) Implement new attractive membership offerings in order to retain and attract members.**

EACD is a member organisation. A membership scheme allows us to bring together all the people who are interested in what we do, while also providing an important income stream for our organisation. Membership can be invaluable in generating a constant stream of revenue, providing more income flow certainty. It is important here to balance the need to draw funds from our members with the need to keep them engaged and satisfied, and to ensure the return on investment for individual EACD members is perceived to be appropriately matched with EACD annual membership fee.

#### ***Action points:***

- Organise regular education- or research-related webinar programs and/or e-courses, with significant discount (or for free) for EACD members





- Explore hosting special interest group meetings under the umbrella for EACD

With participation to special interest group meetings for EACD members only

- Identify strategy to reach underrepresented stakeholder groups or therapy groups in the EACD membership

We should reach out and form partnerships with individual stakeholder groups, particularly those stakeholder groups or therapy groups with whom we are less invested. e.g. educators, dieticians, nurse specialists, ...; Identify which organisations or partners could assist in order to reach out more to persons interested in other childhood-onset disabilities than cerebral palsy, or develop a strategic plan to involve these people more within EACD.

- Evaluate the current EACD Membership Categories

Currently, EACD has a Regular member and Honorary member category. Is there a need to install a different membership category, for example for people outside the European region?

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### **(iii) Governance, organisational structure and accountability**

Clarity and transparency on the governance procedures, organisational structure and accountability lines is essential with the growing number of committees and activities within EACD. The organizational structure and accountability lines should define how roles, and responsibilities are assigned within the organisation. It helps determine who reports to whom, who makes decisions about what, and is all about setting and holding people to a common expectation by clearly defining the EACD's mission and values. The EACD GMC agreed to explore measures to open up the application process for posts in EACD committees, thereby increasing the pool of available talent. However, it was agreed that the Committee Lead should always be someone active in the European region.

#### ***Action points:***

- Organize regular (weekly) meetings with the Executive Committee (Chair, Secretary, Treasurer)

To map progress on strategic goals and daily management

- Install a framework which allows EACD to critically reflect the Ethical Considerations of EACD's activities and other relevant research, healthcare and related issues important to both professionals and families

Continue the set-up of Ethics & Compliance Committee; someone needed with legal expertise; Systematically ask committee members to (re-)fill in their Disclosure form, incl. scientific interests

- Nurture and develop a Meaningful User-Professional Partnership with people with lived experience, their families and interested others in EACD activities and governance procedures.

Anchoring of the Families and Users' Forum within EACD with participation of people with lived experience, their family members, and close others in the organized plans and actions of EACD; Identify the needs of people with a childhood-onset disability, their families and close others to ensure new (and existing) initiatives EACD sponsors/supports are aligned to a family/user priorities. To do this there will need to be support (logistic, scientific, financial, manpower)

- Overtly state accountability process for all committees and groups within EACD

Determine which committee/group report to whom and who makes decisions about what, and clarify EACD's organisational structure and role of its committees to its members base (e.g. on the website and/or with short videos).



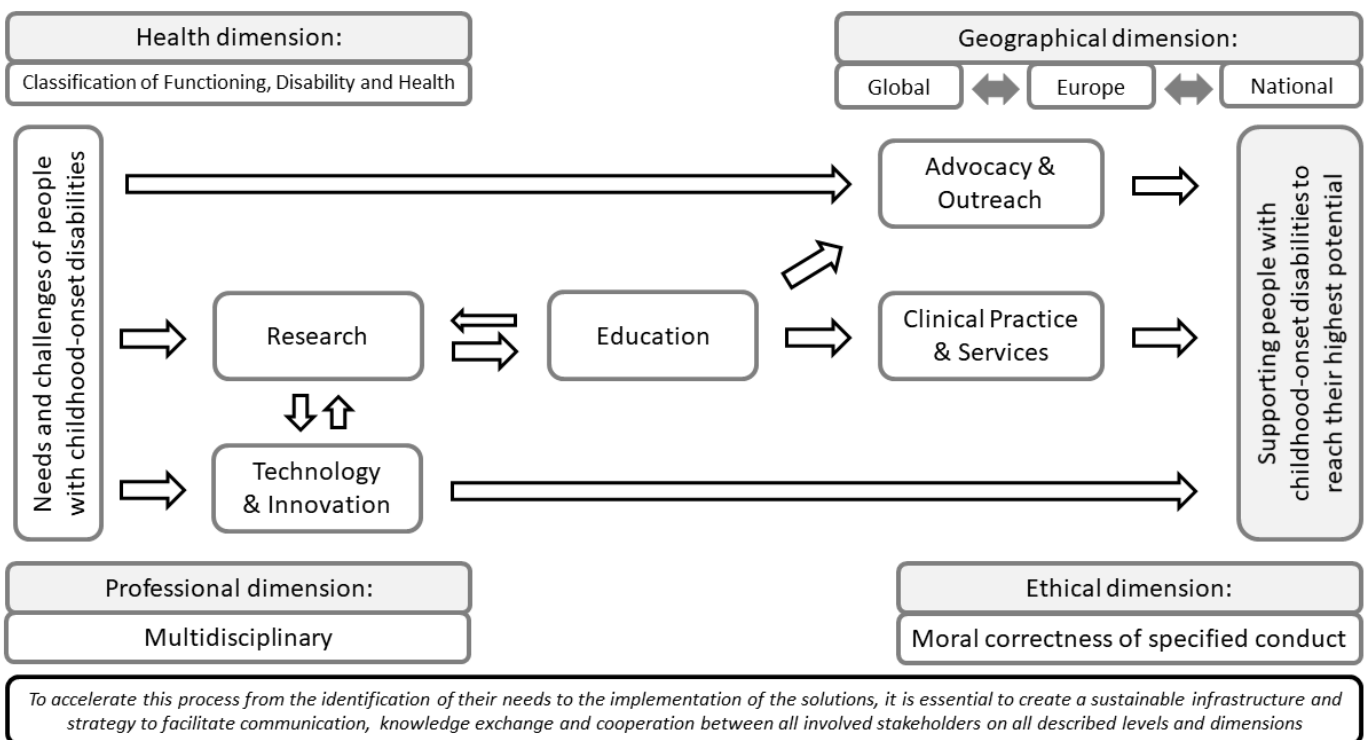
- Consider the need for setting up sub-groups or working groups within specific committees and the subsequent accountability lines

e.g. scope of the certain committees covers a very broad range of tasks and responsibilities. E.g., the Education & Training Committee currently is tasked with identifying and prioritising knowledge gaps in education and training needs across Europe, organising appropriate formats to address the identified education and training needs, and facilitating the development of best practice consensus statements. As such, there is a need to consider if delegation of certain tasks to sub-groups or working groups within specific committees may be warranted to keep it feasible for all involved

- Implement measures to open up the application process for EACD committees

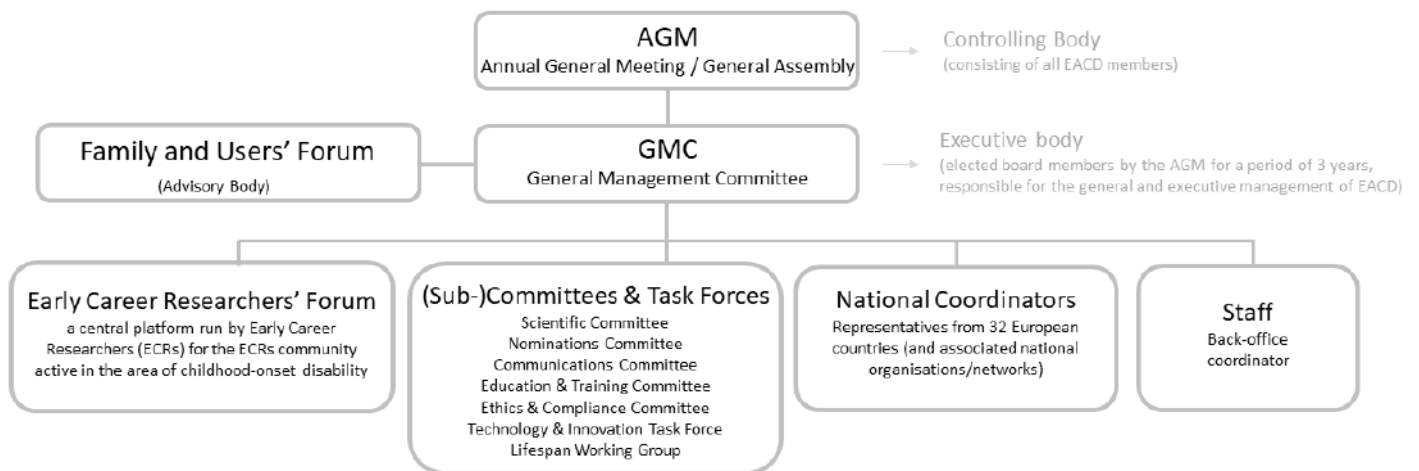
Allow EACD members to indicate in their profile that they would be interested to be part of a committee, or to indicate they would be willing to be an “EACD speaker” based on their areas of interest. Final decision on selection of (sub-)committee member posts resides with EACD GMC.

**EACD’s Mission is to promote excellence in research and services for the benefit of people with, and at risk for, childhood-onset disabilities, and to provide multidisciplinary, state-of-the-art education for health professionals in Europe and beyond.**





# EACD Organisational Structure



## General Assembly / Annual General Meeting

The General Assembly, the highest governing body of EACD, consists of all EACD members and meets at least once a year at the Annual General Meeting. At an AGM, the GMC present an annual report containing information for members about the organisation's performance and strategy, and members can question and vote on current issues (e.g. election of board members and the future annual meeting location, or amendments in the constitution)

## EACD General Management Committee

Elected board members by the AGM responsible for the general and executive management of EACD

## Families & Users' Forum

The body through which persons with lived experience, their family members, and close others participate in the organized plans and actions of EACD.

## Other Committees & Task Forces:

### *Executive Committee*

Responsibility: Daily management of EACD on behalf of the GMC (members: Chair, Secretary, Treasurer);

The Executive Committee is accountable to the GMC

### *Scientific Committee*

Responsibility: A) To ensure a rigorous process to ensure that any scientific material published or presented under the auspices of the EACD has the appropriate level of scientific merit. B) To support Local Organisers of the EACD Annual Meeting and/or other EACD Events in producing a programme which is original, has excellent scientific credential and has the right mix of original research and evidence-based instructional practice.



The Scientific Committee is accountable to the GMC

### ***Nominations Committee***

Responsibility: To assist the GMC in finding suitable people for nomination to the General Management Committee

The Nominations Committee is accountable to the AGM

### ***Communications Committee***

Responsibility: To ensure EACD will be highly visible to families, clinicians and academics in the field of childhood-onset disability, and to ensure EACD will provide high quality, accessible information, education and resources to enable best practice for individuals with childhood-onset disabilities and their families.

The Communications Committee is accountable to the GMC

### ***Education & Training Committee***

Responsibility: To identify the needs for education and training across Europe, and to facilitate regular education and training initiatives bearing on all aspects of childhood-onset disabilities.

The Education & Training Committee is accountable to the GMC

### ***Ethics & Compliance Committee***

Responsibility: To ensure EACD maintains high ethical standards in all its activities

The Ethics & Compliance Committee is accountable to the GMC

### ***Technology & Innovation Task Force***

This Task Force aims to develop a vision at the European level by making visible the needs for people with childhood-onset disabilities and by promoting innovation targeted on this group

The Technology & Innovation Task Force is accountable to the GMC

### ***Lifespan Working Group***

This working group aims to develop a strategy to increase the effectiveness of clinical practices and services for the benefit of people with childhood-onset disabilities of all ages over their entire life course

The Lifespan Working Group is accountable to the GMC

### ***Early Career Researchers' Forum***

The Early Career Researchers' Forum is intended to be a central platform run by Early Career Researchers for the Early Career Researchers community across Europe active in the area of childhood-onset disability

### ***National Coordinator Network***

National Coordinators play a crucial role in supporting the work of EACD at national level in promoting communication, mutual learning and support between professionals with an interest in childhood-onset disability. The National Coordinator can be of any professional discipline who has an interest in childhood-onset disability