CHARTER FOR PARTNERSHIP FOR PERSONS WITH LIVED EXPERIENCE OF CHILDHOOD-ONSET DISABILITIES AND PROFESSIONALS IN THE INTERNATIONAL ALLIANCE OF ACADEMIES OF CHILDHOOD DISABILITY 2024 - 2028

This document comprises three parts:

Part A: Charter
Part B: Action plan
Part C: Examples and models

PART A: CHARTER

Preamble:

As Member Academies and the Executive Committee and sub-committees of the International Alliance of Academies of Childhood Disability (IAACD), we affirm our commitment to creating an inclusive organization where individuals of all abilities and backgrounds are valued, respected, and actively engaged. We recognize that it is essential to promote engagement, involvement and participation of persons with lived experience (PWLE) in order to enhance the effectiveness and relevance to our mission and work. Therefore, we commit to actively promoting and modelling involvement, participation and partnership with PWLE in decision-making, programmes, and initiatives of the IAACD.

The IAACD endeavours to make lived experience not only a valuable resource and opportunity for improvement in services but a sharable expertise that may be of use to others and complements evidence-based decision-making .

We acknowledge that the implementation of this Charter will be progressively realized and that each Member Academy is at a different stage in its implementation journey.

Definitions and acronyms:

IAACD:	International Alliance of Academies of Childhood Disability
Persons with lived experience (PWLE):	This term includes individuals living with a childhood-onset disability, their family members and close others. PWLE have authentic first-hand knowledge of the lived reality of childhood-onset disability. The expertise they acquire from first-hand experiences, reflection, and analysis of their and

others' lived experience is essential alongside that of professionals in decision-making.

Participation: In this Charter the term participation refers both to the World Health Organization's ICF meaning of „involvement in life situations" and to the spectrum of levels of participation, which can range from informing → consulting → involving → collaborating to empowering (https://iap2.org.au/resources/spectrum/). Participation should also be viewed as a continuum from an individual level to a social level.

Professionals: In this Charter, professionals include paid or unpaid workers who have acquired specialised skills and are trained to assess, care for, treat, educate, support or perform research involving children or adults with childhood-onset disabilities.

We also recognise that a PWLE may also be a health professional or have other expertise e.g. finance, marketing, communication, which can strengthen the functioning of the IAACD.

Article I: Purpose

The purpose of this charter is to outline the principles and guidelines for partnerships between professionals and PWLE which can be proposed to member Academies and guide the governance and activities of the IAACD, with the aim of fostering a culture of inclusivity, diversity and empowerment to increase the relevance of:

- research programmes
- innovations in therapy and care
- advocacy efforts and initiatives
- evidence-based approach of healthcare and support to people with childhood-onset disabilities
- knowledge transfer initiatives
- educational and training opportunities

Article II: Principles

1. *Equality, and non-discrimination:* We shall uphold the principles of equality, and non-discrimination, ensuring that all PWLE are treated with dignity, respect, and fairness in all aspects of our work.

2. *Equity:* By taking into account the circumstances that might set them apart, we will seek to ensure that PWLE have the same opportunities as everyone else in the activities of the IAACD.

3. *Co-involvement and co-delivery:* Recognizing the value of the complementary perspectives and experiences of PWLE and of professionals, we shall actively pursue co-involvement in decision-making processes and programme development; and where possible co-delivery in advocacy efforts and knowledge dissemination of the Alliance.

4. *Accessibility:* We commit to promoting accessibility in all our activities, including meetings, events, and communications. We shall strive to remove physical, communicational, attitudinal, policy and financial barriers to ensure the full participation of PWLE, ensuring that all voices are heard.

5. *Capacity-Building:* We shall invest in capacity-building initiatives with respect to the development of partnership and co-involvement of PWLE, researchers and clinicians. This includes education, training and mentorship to enhance skills, knowledge, and leadership abilities of all partners, with the goal to enable everyone to contribute actively to the goals and objectives of the Alliance.

6. *Communication in plain language:* We recognize the importance of clear and accessible communication. English is a second language for many IAACD members and PWLE. Therefore, we shall strive to ensure that all communication within the IAACD, including written materials, presentations, and discussions, avoids unnecessary technical and medical jargon, that plain language and easy-to-read versions are available. This commitment aims to promote understanding and ensure that information is accessible to all members, regardless of their background, level of expertise, or first language.

Article III: Implementation

1. *Policy Integration:* We shall integrate disability inclusion principles into the policies, procedures, and strategic plans of the IAACD, ensuring that they are reflected in all aspects of our work.

2. *Representation:* We shall encourage representation of PWLE in leadership positions, committees, and working groups of the IAACD, fostering diversity and inclusivity at all levels.

3. *Consultation and Engagement:* We shall proactively consult and engage with PWLE in the development, implementation, and evaluation of our programmes and initiatives. Where relevant, we may also engage in consultations and partnerships with representative organizations of PWLE.

4. *Resource Allocation:* Recognizing that effective implementation of this Charter requires resources, including funding and technical support, we commit to identifying possible sources of funding and income to make this a reality.

Article IV: Reporting

The leadership of the IAACD shall provide regular reports to the membership and stakeholders on the progress and impact of involvement and engagement with PWLE. These reports shall include updates on activities, achievements, challenges, allocation of resources and recommendations for improvement.

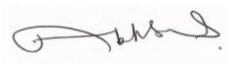
Article V: Review and Amendment

This charter and the goals shall be reviewed annually to assess its effectiveness, relevance and the extent to which the goals have been achieved. Amendments may be proposed by any member of the IAACD and shall be subject to approval by the governing body.

Article VI: Ratification
This charter shall enter into force upon ratification by the Governing Council of the IAACD.

Conclusion
In witness whereof, the undersigned, being duly authorized representatives, have signed this charter 30.07.2025.

Agreed and ratified by the Governing Council and Executive Committee members of the IAACD



Arnab Kumar Seal
President
International Alliance of Academies of Childhood Disability **Date: 30.07.2025**

PART B: ACTION PLAN

To operationalise this Charter, the IAACD Executive Committee and the IAACD's Partnership Working Group (PWG) sub-committees commit to the following goals:

1. By May 2025, the Partnership Working Group (PWG) will have collated baseline data on current involvement of PWLE in all Member Academies through an online survey. This survey will be repeated annually.

2. Recognizing that access to technology and information can be a significant barrier for PWLE, the IAACD will establish a task team by May 2025. This team, comprising members from various Academies will identify barriers to participation of PWLE in IAACD activities and propose solutions. There may be opportunities for academies with successful models of PWLE engagement to provide ideas, help, and mentorship, especially from their PWLE forums and office bearers. It is important that all members feel supported and that we recognize barriers exist in all regions. The task team will report back to the IAACD by December 2025 with updates on activities, achievements, challenges, allocation of resources, and recommendations for improvement.

3. By August 2025, the PWG will have collated a draft budget for the IAACD Executive Committee identifying the resources (financial, human and technical) required to facilitate greater participation of PWLE in IAACD activities and committees.

4. By December 2025, all Member Academies will have hosted at least one webinar or Listening and Sharing sessions co-organized with PWLE.

5. All future IAACD Conferences will be co-organised with PWLE.

PART C: EXAMPLES AND MODELS OF HOW TO WORK TOWARDS GREATER COLLABORATION, ENGAGEMENT AND PARTICIPATION

Suggestions:

- PWG will send out a questionnaire to Member Academies requesting information on what they have done / are currrently doing in terms of involvement and participation of PWLE. This information is then collated and sent to all Academies and is included in the info pack for potential Academies wanting to join the IAACD. This information also serves as a baseline for measuring participation of PWLE at the level of Member Academies.

- In many countries and jurisdictions the imperative to include PWLE is becoming formalized – e.g., health services research grants MUST have formal engagement of PWLE. The PWG will investigate and highlight examples of good practice.

- There are organizations in many countries eg PCORI in the US, James Lind Alliance in UK, SPORs and CanChilD in Canada where active efforts to engage the minds and voices of PWLE are afoot. The PWG will collate a list of these examples with contact information / website addresses.