



International Alliance of Academies of Childhood Disability

PARTICIPATION AND LIVED EXPERIENCE STANDING COMMITTEE

(Transition from Partnership Working Group – PWG)

The Partnership Working Group (PWG) was established as a time-limited IAACD Working Group to promote participation of persons with lived experience of childhood-onset disability (PWLE) across IAACD. In 2025, the IAACD Governing Council approved the transition of the PWG into a formal IAACD Standing Committee.

1. Purpose

The purpose of the Participation and Lived Experience Committee is to:

Promote, strengthen and embed meaningful authentic participation of persons with lived experience of childhood-onset disability across all IAACD structures, activities, leadership, and strategic priorities.

2. Vision

The long-term vision is that participation of persons with lived experience of childhood-onset disability becomes a natural and integral component of IAACD governance, research, education, advocacy, and organisational functioning.

3. Objectives

- Promote meaningful and authentic participation across IAACD committees and structures
- Advise IAACD and Member Academies on effective models of participation and co-production (eg sharing examples of models from different Academies)
- Encourage Member Academies to strengthen involvement of persons with lived experience (eg through promoting the operationalization of the Charter)
- Promote integration rather than parallel structures (eg regarding MOUs with partner organizations; the elected PWLE on the EC automatically is a member of the standing committee)

- Identify and address barriers to participation of PWLE in IAACD structures
- Promote mentoring, coaching, and leadership development for persons with lived experience
- Monitor participation of PWLE across IAACD (eg through an annual survey)
- Ensure that lived experience is not only a valuable resource and opportunity of improvement in services, but a shareable expertise that may be of use to others and complements evidence-based decision making.

4. Committee composition and membership

Committee membership will comprise a combination of :

- persons with lived experience of childhood-onset disability
- professionals working in the field of childhood-onset disability
- individuals with dual roles (professional and lived experience)

A mixed model for committee nomination is recommended. This combines nominations from Member Academies with an open call for interested individuals. This mixed model committee nomination ensures that there is a pathway to participation for individuals in areas where there is not yet an Academy. In this situation, the individual will be required to become a member of their nearest geographical Academy.

Criteria for nomination is that the individual:

- can commit to attending 75% of virtual meetings (five meetings per year) and to read any relevant documents prior to the meetings
- is comfortable in expressing themselves in English
- shares the vision of full integration of individuals with the lived experience of childhood-onset disability and family members in all activities of the IAACD
- is excited at the possibilities, power and potential of true partnerships between professionals and PWLE

In line with the IAACD Administrative Procedures Manual, the IAACD Secretary then proposes candidate members to the EC for approval.

The new standing committee will operate and function as per the guidelines in the IAACD Administrative Procedures Manual:

Committee Membership

1. Committee members must be a member of a member academy. Committees will have a minimum of 7 members. Members of Provisional Academies may be appointed as non-voting observers at the discretion of the Chair.

2. Members can be nominated by member academies and by the members and chairs of the sub-committee. Nominations shall be forwarded to the Chair of the sub-committee who will then propose candidate members to the EC having due consideration for expertise, geographic, discipline and gender balance.
3. On an annual basis, members are expected to attend at least 75% of committee meetings and to take on at least one defined task that supports the committee mandate. Failure to meet this minimal requirement will lead to Chair recommendation to EC for removal from the committee.
4. Where a vacancy exists on a committee the Chair will notify the Secretary of the EC and a request will be made to member academies and members of executive and sub-committee members for nominations. The Chair will make a recommendation to the EC on the appropriate candidate to fill the vacancy taking into consideration the existing membership and expertise of the committee. The candidate selected by the EC will fill the term of the vacancy and may be appointed for a second term subject to EC approval.
5. Usual term of office is 3 years, extendable by a further term if the nominating academy requests this.

Appointment of Committee Chair, Vice-Chair and Secretary

1. The chair can be nominated by member academies, the outgoing chair, and other members of the committee. Nominations shall be forwarded to the President who will propose a candidate to the Executive Committee, which will make the final selection and appointment of the chair.
2. If more than one member is nominated an ad-hoc committee of the EC will interview candidates and make a recommendation to the full EC on the most appropriate candidate.
3. The Chair of the subcommittee will be responsible for appointing a Vice-Chair and Secretary for the committee using due process that provides opportunity for committee members to express interest in taking on these roles.
4. The Chair, Vice-Chair and Secretary along with all other members will serve for a term of three years, renewable once with the Chair ensuring staggered terms with no more than 1/3 of the committee turning over each year.
5. Chairs will be non-voting members of the Executive Committee. The Vice-Chair may stand in for the Chair when not able to attend EC meetings.