

# Position Statement Policy

As approved at the meeting of  
IASSIDD'S Executive Council,  
20 April 2023

INTERNATIONAL  
ASSOCIATION FOR  
THE SCIENTIFIC  
STUDY OF  
INTELLECTUAL AND  
DEVELOPMENTAL  
DISABILITIES





International Association for  
the Scientific Study of Intellectual  
and Developmental Disabilities

<b>POLICY FOR POSITION STATEMENTS AND RAPID MEDIA RESPONSES: INTERNATIONAL ASSOCIATION FOR THE SCIENTIFIC STUDY OF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES</b> <b>(HEREAFTER REFERRED TO AS IASSIDD)</b>				
<i>Policy Status</i>	New policy	x	Revision of existing policy	
<i>Description if Revision</i>	Minor		Major	
<i>Approval Authority</i>	IASSIDD EXCO FOR COUNCIL			
<i>Policy Owner</i>	IASSIDD			
<i>Approval Date by IASSIDD EXCO</i>	20 April 2023			
<i>Effective Date</i>	20 April 2023			
<i>Date of Last Revision</i>				
<i>Date of Review of Position Statement Policy (Every 5 years or as deemed necessary).</i> <i>Date of Review of Rapid Media Responses Policy</i>	19 April 2028 or earlier as deemed necessary.			

## Position Statements

This draft document was finalised in May 2022 by the Position Statement Committee, hereafter termed the Committee, for approval by IASSIDD's Council via the IASSIDD President (Chair of Council). The Committee's Terms of Reference were agreed in March 2022 and are presented at the end of the document. In summary, the Committee was charged with:

- (1) Defining the scope and types of Position Statements covered by this policy.
- (2) Setting out the procedure for the development of Position Statements prepared for and issued under the auspices of IASSIDD.
- (3) Outlining any other important processes / procedural steps to be considered in the above.

### (1) Defining the scope and types of Position Statements covered by this policy

Within IASSIDD, a **Position Statement** is a concise document that clearly states the official position of IASSIDD on an issue of concern to the organisation, people with intellectual and developmental disabilities (IDD) and their families, and/or those working in the IDD field. Position Statements are based on scholarly opinion and coherence with IASSIDD's core values. As stated on the website, IASSIDD's core values are:

1. Respect for the inherent dignity of all people regardless of disability, age, gender and ethnicity.
2. Openness and tolerance for differences in people, practices and cultures.
3. The right of persons with intellectual and developmental disabilities, their families, advocates and communities to contribute to the research agenda, research processes, and to have access to research findings in a meaningful way.
4. The importance of scientific integrity and methodological rigour in research, within an ethical framework.
5. The importance of policy, practice and education being informed by scientific evidence.

Position Statements are intended to address substantive issues of interest to IASSIDD which are not highly time-sensitive and not related to external events with indirect relevance to IASSIDD.

Position Statements should be supported by a comprehensive scholarly review of the issue, in the form of a Background Paper. Position Statements and accompanying documentation are subject to open review of the issue by the IASSIDD membership to inform both the content of the statement and to inform the IASSIDD Council in its formulation, review and decision on approval. This review and approval process is outlined below.

Generally, the Position Statement will be written in plain language with the following elements where relevant:

- Authors/initiators of the statement
- Introduction to the issue
- IASSIDD's interest and alignment with IASSIDD's core values
- Reason for initiating the statement
- The statement should include:
  - clear definitions of concepts
  - a clearly stated position on the issue
  - scholarly literature and evidence that supports the position
  - recognition of alternative perspectives on the issue (where appropriate)
  - actions related to the statement (where appropriate)
- Date of approval
- Statement on consultation process within IASSIDD prior to approval
- Date for review and consideration of outcomes
- An easy-to-read version is required to accommodate individuals with intellectual and developmental disabilities

**Rapid Media Responses** are a specific type of position statement that address IASSIDD's position on issues of immediate concern, the nature of which do not allow for a long-term process of position development and approval. Generally, these are statements of concern regarding contemporary events which directly or indirectly impact the field of IDD such as armed conflict or global health emergencies such as pandemics which cannot be addressed in the timeframe recommended for a full position statement. Rapid Media Responses should be consistent with IASSIDD's core values and highlight the direct or indirect impact on persons with IDD, their families or those working in the IDD field.

Generally Rapid Media Responses are succinct statements that:

- Highlight the impact/relevance of the issue to IDD
- May contain brief background or information statements highlighting the nature of IASSIDD's concern or interest

## **(2) Setting out the procedure for the development of position statements prepared for, and issued under the auspices of, IASSIDD**

Proposals for Position Statements must be supported in writing by one of IASSIDD's Special Interest Research Groups (SIRGs) or a minimum of ten current members of IASSIDD, termed the 'Working Group'. In cases where a Position Statement is proposed in combination with another association, written or electronic evidence of the agreement is required from the latter's decision-making body at the time of submission. A Position Statement form is available on the IASSIDD website which

requires preliminary information on the scope and position taken. This form is presented in the appendices of this document. Completed forms should be submitted to the Chair of the Position Statement Committee.

### **Development Process for Position Statements**

- On receipt of a completed form, the Position Statement Committee may approve, reject or request revisions. If approved, the Committee will provide the Working Group with a clear charge on the scope, position, length, due date, and format of the Position Statement and any accompanying documents inclusive of the Background Paper and Easy-to-Read version, before they start working.
- This outline is posted on IASSIDD's website and communicated to the IASSIDD membership, inclusive of SIRGs.
- Once the Position Statement and accompanying documents are drafted, they should be distributed throughout the IASSIDD membership for feedback via the following routes:
  - to all SIRGs who are invited to discuss the statement during their regular meetings;
  - to the wider IASSIDD membership, any of whom may request a copy;
  - the Working Group should aim to host at least three discussion fora which are open to all IASSIDD members. These fora may include sessions at IASSIDD conferences, electronic webinars and/or online discussion fora to which all IASSIDD members are invited to attend.
- Feedback from SIRGs, and the wider IASSIDD membership who request a copy of the draft statement, must be provided to the Working Group in writing and within a six-week period from their receipt of the draft submission(s).
- The Working Group is obliged to keep a record of written feedback and that generated at discussion fora and must submit this feedback along with their response to the IASSIDD Position Statement Committee who then collate the submission as an item for an IASSIDD Council Meeting who are responsible for determining approval.
- The full consultation process, from dissemination of the drafts through to receipt of feedback from IASSIDD members, should be completed within a six-month window.

### **Approval Process for Position Statements**

A final draft of the Position Statement, Background Paper, Easy-to-Read document and details of the consultation process with addressed feedback should be collectively sent to the Committee who will forward to IASSIDD Council Members for voting. A quorum of 75% of Council members (one vote per Executive and SIRG) is required to vote on the Position Statement, with a 75% positive response required for approval. Council members may suggest only minor revisions prior to approval. The process from inception to voting should take between six to twelve months.

### **Dissemination of Position Statements**

All approved Position Statements and accompanying documents will be posted to a distinct advocacy section of the IASSIDD website inclusive of the date on which they were formally approved by IASSIDD Council. Working Group members are encouraged to disseminate Position Statements,

Background Papers and Easy to Read versions to other relevant organisations, and where appropriate, in open access academic journals.

### **Review date for Position Statements**

Position Statements are placed on a cycle for review every five years, the due date of which is posted on IASSIDD's website. Council will determine if changes or termination of the Position Statement are required, and if so, will determine the appropriate body to undertake the review and revision process. Substantial changes should follow the consultation and review process for new Position Statements.

### **Development of Rapid Media Responses**

Rapid Media Responses must be supported in writing by one of IASSIDD's Special Interest Research Groups (SIRGS) or a minimum of ten current members of IASSIDD, termed the 'Working Group'. In cases where a rapid media response is proposed in combination with another association, written or electronic evidence of the agreement is required from the latter's decision-making body at the time of submission. A Rapid Media Response form is available on the IASSIDD website. This form is presented in the appendices of this document. Completed forms should be submitted to the Chair of the Position Statements Review Committee. Pictures or images are encouraged but must be submitted with appropriate approvals/permissions.

### **Approval of Rapid Media Responses**

Rapid Media Response are approved in a three-stage process. Firstly, the Position Statement Committee may approve, reject or request revisions to proposed Rapid Media Responses. Secondly, if approved, the Position Statement Committee will identify five experts from IASSIDD's membership to review the submission who may approve, reject or request revisions. If approved, submissions are forwarded to IASSIDD Council members for voting. A quorum of 75% of Council members (one vote per Executive and SIRG) is required to vote on the Rapid Media Response, with a 75% positive response required for approval. Council members may suggest revisions prior to approval. Given the rapid nature of these submissions, the approval process should be completed no later than a 3-4 week period.

### **Dissemination of Rapid Media Responses**

All approved Rapid Media Responses will be posted to a distinct advocacy section of the IASSIDD website inclusive of the date on which they were formally approved by IASSIDD Council. Members are free to disseminate the approved response to media outlets and other organisations.

### **Review date for Rapid Media Responses**

There is no formal requirement for a review date on Rapid Media Responses. IASSIDD members who wish to update a Rapid Media Response should use the process outlined above.

## **(3) Outlining any other important processes / procedural steps to be considered in the above**

Position Statements might be strengthened by one or more accompanying documents such as: (1) academic papers, (2) professional papers, (3) bibliography, (4) guidelines for implementation, (5)

direction to further resources, (6) implementation strategies, and (7) strategies for monitoring impact.

### **Position Statements Committee**

Chair: Christine Linehan [christine.linehan@ucd.ie](mailto:christine.linehan@ucd.ie)

Val Bradley [vbradley@hrsi.org](mailto:vbradley@hrsi.org) (co-opted 14 April 2022)

Vimallan Manokara [vimallan.manokara@minds.org.sg](mailto:vimallan.manokara@minds.org.sg) (co-opted 16 June 2023)

Jenneken Naaldenberg [Jenneken.Naaldenberg@radboudumc.nl](mailto:Jenneken.Naaldenberg@radboudumc.nl)

David Treanor [david.treanor@utas.edu.au](mailto:david.treanor@utas.edu.au)

Former members involved in the establishment and development of the policy:

Ivan Brown [ivan.brown@live.ca](mailto:ivan.brown@live.ca) (Stood down 16 March 2022 after establishing the group)

Levan Lim Heng Fook [levan.lim@nie.edu.sg](mailto:levan.lim@nie.edu.sg) (Stood down 7 April 2022)

Tim Stainton [Timothy.Stainton@ubc.ca](mailto:Timothy.Stainton@ubc.ca) (Stood down 6 June 2023)

<b>Appendix A: Position Statement Form</b>
Proposed title for Position Statement
Name of Proposers (and affiliation to IASSIDD SIRC if relevant)
Contact email for main proposer
Statement of the issue (maximum 600 words excluding references)
Proposed position (maximum 100 words)
Rationale for proposed position citing alignment with IASSIDD's values (maximum 300 words)
Proposed actions if applicable (maximum 100 words)
Proposed format of Position Statement, Background Paper and Easy-to-Read version – (e.g. word count, layout). (maximum 100 words)
Proposed due date (month and year) of Position Statement (6-12 months from inception)
Proposed supplementary documentation (e.g. policy or practice guidance, systematic review) (maximum 100 words)



<b>Appendix B: Rapid Media Response Form</b>
Proposed title for Rapid Media Response Statement
Name of Proposers (and affiliation to IASSIDD SIRC if relevant)
Contact email for main proposer
Statement of the issue (maximum 600 words excluding references)
Proposed position citing alignment with IASSIDD's values (maximum 100 words)
Was Rapid Response Position Statement requested, if so, by whom? (maximum 100 words)
Proposed due date of Rapid Response Position Statement (day, month, year)
Proposed supplementary documentation (e.g. list of references) (maximum 100 words)

TERMS OF REFERENCE FOR IASSIDD COMMITTEE:  
IASSIDD POSITION STATEMENTS AND MEDIA RELEASES

**Background:**

On 15 November 2021, IASSIDD Council mandated the establishment of a Committee to set out the procedure to be followed in the development of IASSIDD position statements. The IASSIDD Executive Committee further requested the Committee to set out the procedure for the rapid release of public and media statements.

**Terms of reference of the Committee:**

1. *Committee name.* The Committee is called the Position Statement Committee (hereafter referred to as “the Committee”)
2. *Committee composition:* The Committee comprises 5 or more current IASSIDD members and is co-ordinated by a Committee Chairperson.
3. *Committee reporting:* The Committee reports to Council via the IASSIDD President (Chair of Council).
4. *Committee term:* The Committee may change membership with other IASSIDD officer and committee cycles. There is no term limit for the members or Chairperson.
5. *Committee mandate:*
  - 5.1 Define the scope and types of position statements covered by this policy.
  - 5.2 Set out the procedure for the development of position statements prepared for, and issued under the auspices of, IASSIDD.
    - 5.2.1 Outline the steps to be taken in developing position statements (including decisions on topic relevance, authors (for example SIRG and other representation) and the draft consultation process).
    - 5.2.2 Outline the Council approval process.
    - 5.2.3 Provide a guide for the dateline (expiry time and review) of position statements.
  - 5.3 Set out the procedure for rapid media response, including posting to the IASSIDD website, about matters of relevance and importance to IASSIDD.
    - 5.3.1 Outline in principle, criteria for matters that are (or are not) appropriate for a media response by IASSIDD.
    - 5.3.2 Outline the process and steps for the development and approval of rapid media responses.
6. Outline any other important processes / procedural steps to be considered in the above.

Approved by the Position Statement Committee

March 21, 2022