

INSTRUCTIONS FOR ISAAC COUNCIL REPRESENTATIVES

- ✚ ISAAC Council representatives are encouraged to discuss the released FC documents with their membership. Feedback received from members will need to be summarized by the ISAAC Council representative, so that it will fit into the provided form, found on the next page.
 - ✚ All ISAAC Council submitted feedback must be provided in accordance with the instructions below. ISAAC Council representatives must also include the following information with their feedback:
 - a. Name of the ISAAC Council representative; and,
 - b. ISAAC Council representative member id number.
- Only feedback containing the above will be accepted.
- ✚ ISAAC will check the ISAAC Council representative name and member id number provided to see that the individual is a current (2014) member of ISAAC. Only feedback received from ISAAC Council representatives who are also current (2014) members of ISAAC will be accepted.
 - ✚ Feedback will not be interpreted by ISAAC as a *vote* or a *choice* in any respect to ISAAC's further consideration of the Draft Position Statement.
 - ✚ All feedback will be treated confidentially by ISAAC.

HOW TO SEND IN YOUR FEEDBACK

1. **Use the form on the following page only. Only feedback submitted in this fashion will be accepted.** ISAAC Council representatives are requested to synthesize, in a succinct fashion, the responses received from their current (2014) Chapter (or non-Chapter) members. Please limit your feedback to one (1) page only.
2. In addition to the feedback from 1. above, also provide the requested ISAAC Council representative name and member id number information. Feedback provided without this information cannot be included in the review process.
3. ISAAC Council members are asked to provide completed feedback documents, by 5:00 pm Eastern Time (UTC – 4) on May 30th, 2014, to:

isaac-ahc-2014@isaac-online.org

ISAAC COUNCIL REPRESENTATIVE FEEDBACK FORM

ISAAC Council Representative Name: Kate Louise McCann Anderson

ISAAC Council Representative Member ID Number: 10195

Provide Feedback Below:

Draft feedback on ISAAC FC Position Statement – Australian chapter

Eight out of fifty-six current Australian members submitted feedback on the draft FC position statement. This is a polarising issue in Australia and over 100 pages of feedback were received. I have requested special consideration to submit an extra half-page of feedback for this reason.

Criticisms of the paper (positive and negative):

Two members stated their support of the position statement, viewing it as a thorough, systematic, and unbiased examination of the issue of FC authorship. One member pointed out that the equal exclusion of unpublished evidence both in support of AND in opposition to FC (e.g. anecdotal reports of harm) is a testament to this lack of bias. Three members called for a clearer definition of FC in the report. Two pointed out that FC techniques can play an intermediary role in early communication training for individuals and that this needed to be taken into account. Another member requested inclusion of a warning that FC practices may not always go by that name, but may still carry the risks of facilitator influence. One member also suggested that the primary focus on authorship should be emphasised more clearly in the report, particularly in reference to the term: “communicative intentions”.

A major concern regarding methodological rigor expressed by five members, was that the authors had excluded observational, qualitative, and unpublished evidence from the review, despite having broadened both the terms of reference and inclusion criteria in 2013. One member pointed out that the current review went against standing models of Evidence-Based Practice by ignoring non-empirical evidence sources: “*EBP models ...do not privilege “research” above clinical expertise and client factors.*” The member also illustrated the importance of reviewing this evidence to address the risk of publication bias, quoting Schlosser, Wendt, & Sigafoos (2007): “*A bias through the exclusion of unpublished literature may threaten the validity of the systematic review*” (p141). A related concern was the exclusion of evidence indirectly related to FC (e.g. overlapping populations such as movement/sensory disorders): “*in the absence of quality research specifically targeting FC users, research on overlapping populations ...informs practitioners who work with clients who use FC.*” Two other members expressed concern regarding the absence of legal evidence relating to authorship, or harm caused by the use of FC, and recommended their inclusion within the review.

Two members described substantial methodological inadequacies in the level 1 evidence considered, including the lack of diversity in experimental design, and the emphasis on confrontational testing or message passing in contrived situations, which anecdotal evidence suggests is unfairly challenging for the majority of people using FC. One member also criticised: “Facilitators [in these studies] were poorly trained, “best practice” was ignored, and inappropriate subjects were selected. Experiments featured intrusive ‘controls’ - highly likely to alter both the support needs of the subjects and the nature of support that could be provided.” Two members proposed that similar levels of research scrutiny would find other established areas of AAC lacking, and that ISAAC’s treatment of FC based on this level of evidence was inappropriate. Finally, one member noted that the use of the 5S hierarchy was inappropriate for the nature of this review.

Concerns around the initial review process and current feedback process:

Various members expressed the following concerns regarding the initial and current feedback process for the construction of this statement. One concern expressed by two members was that evidence, including published peer-reviewed papers, submitted to the initial feedback process had been overlooked. One member reported submitting 119 pieces of evidence to the committee initially. Of these, 6 were excluded and 12 included, but the remaining 101 were neither cited nor acknowledged in the report. Four members expressed concerns over a lack of transparency in the process of establishing the committee and gathering evidence, as well as a lack of FC content experts, FC consumers, and a minimum of PWU AAC on the committee. Three criticised the exclusion of non-ISAAC members from the current feedback process, given the ramifications they saw the statement having for

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the general AAC community. Finally, two members viewed the one page limitation as being insufficient length to condense feedback from an entire chapter.

Implications of the paper:

Five members expressed concerns regarding the implications of the paper. One concern was that following the uptake of a position statement by ISAAC, the views and opinions expressed by persons using FC may be discounted and as a result, their rights violated. Two members submitted testimonial reports regarding the improvements in personal safety, independence, and quality of life that access to FC had provided to family members or clients, and emphasised the danger of invalidating FC as a communication tool for these individuals. Three members anticipated that releasing this statement may also result in public misconceptions over the reliability of augmented communication in general. Two members were concerned that a negative position statement may affect funding opportunities for those wishing to receive training in FC techniques, thereby leaving the practice open to misuse by new, untrained facilitators. Finally, two members foresaw damage to the structural integrity of ISAAC resulting from conflict around this report and the procedures that have been adopted by ISAAC's executive in handling this process. One member felt that as a membership organisation, rather than a professional association, ISAAC has no role in engaging in the position statement process at all. Another member felt that ISAAC's focus should be on *"supporting research that helps identify appropriate candidates" for FC rather than producing "a position statement to ban it because we do not yet understand it."*

Three members saw some positive implications from the release of this position statement, including better awareness of the potential harms that can be caused by its inappropriate use. In addition to Article 21, one member identified additional CRPD articles that may be violated by FC including 16 (freedom from exploitation) and article 17 (protecting the integrity of the person), and saw an important role for ISAAC in addressing these violations.

In summary, there was a very low response rate to the call for feedback, and the views of responding members concerning the quality and utility of the report were mixed.