Dr. Elise Davis-McFarland, Ph.D., CCC-SLP, President, Past Chair, Committee on Committees
Meher Banajee, Chair, ASHA Ad Hoc Committee on FC and RPM
Marie Ireland, Vice President for Speech-Language Pathology Practice, Board Liaison
Diane Paul, ASHA Director, Clinical Issues in Speech-Language Pathology, and Committee Ex Officio
American Speech-Language-Hearing Association (ASHA)
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Rockville, MD 20850-3289 USA

Via electronic mail: dpaul@asha.org

July 2, 2018

Re: ASHA's Proposed Position Statement: Rapid Prompting Method (RPM) and Facilitated Communication (FC)

Dear Drs. Davis-McFarland, Banajee, and Paul, and Ms. Ireland:

We write to voice our concerns about the recently issued proposed position statements of the ASHA Ad Hoc Committee on Facilitated Communication (FC) and the Rapid Prompting Method (RPM) ("Committee"), which the ASHA Board of Directors established in summer 2017.[1] We are deeply concerned that this Committee has failed to engage meaningfully with stakeholder communities, including and especially the self-advocate community. This lack of communication with the individuals most affected by the decisions of the Committee has resulted in proposed position statements that will dramatically undermine access to communication supports for individuals who have no equally effective alternate forms of communication. As a result, the Committee stands to dramatically undermined ASHA's mission of "making effective communication, a human right, accessible and achievable for all."

As autistic self-advocates dedicated to advancing the rights of all people with developmental disabilities - including non-speaking people - we are committed both to ensuring access to a wide range of effective communication supports and promoting research on effective supports. We do not take positions on individual communication support methods or techniques. Nevertheless, we believe each non-speaking person has a right to use the method of communication that works best

[1] The American Speech-Language-Hearing Association (ASHA) Ad Hoc Committee on Facilitated Communication (FC) and the Rapid Prompting Method (RPM) (May 24, 2018). Draft position Statement: Rapid Prompting Method, available at https://www.asha.org/uploadedFiles/Rapid-Prompting-Method-Peer-Review.pdf; *see also* Resolution BOD 10-2017, at http://www.asha.org/ResolutionMotion.aspx?status=considered&year=2017 (resolution to create the Ad Hoc Committee on Facilitated Communication (FC) and the Rapid Prompting Method (RPM)).

for them, as determined by an individualized analysis. Moreover, we believe that no single method of AAC will work for all non-speaking individuals.

The Committee's process has deliberately shut out input from people from disabilities.
When the Autistic Self Advocacy Network attempted in 2017 to learn more about the Committee and offer input, we were denied the opportunity to speak directly to the Committee members or even learn the identities of Committee members. We are also alarmed that to our knowledge, the Committee has never, and never plans to, solicit input from people who use the methods of communication under review, or those who formerly used these methods of communication and then graduated to independent typing. The Committee has also never solicited input from a self-advocacy organization of *any* kind.

The Committee's failure to engage with the community is particularly alarming considering the potential harm that may result from a process that fails to account for the experiences of self-advocates. Due to ASHA's significant influence over speech-language professionals (SLPs), we are aware of cases in which educational institutions have *already* refused to provide support for students' most effective form of communication, citing ASHA's proposed position statement. The likely result of these denials will be isolation from the general education classrooms, exclusion from the general curriculum, and protracted due process proceedings. We are aware of many students who, when denied access to their most effective form of communication, have been forced to move to another district or leave the school system entirely. Denial of communication supports may also result in lack of access to transition-related services, institutions of higher education, and independent living supports. Loss of an effective form of communication can also result in trauma, isolation, and frustration that may in turn lead to escalating "behaviors" and increasingly restrictive interventions.

The Committee's blanket statement that specific forms of communication are *per se* inauthentic robs us of the right to communicate.

The Committee's proposed statement includes the blanket statement that "the use of … facilitator-dependent techniques ... is not consistent with the communication rights of autonomy and freedom of expression because the messages do not reflect the voice of the person with a disability but, rather, reflect the voice of the 'facilitator.'" None of the studies cited by the Committee actually supports such a generalization, nor could they, because no such study ever claimed to evaluate *all* facilitator-dependent techniques or all users of any specific technique.

Evaluations of the authenticity of communication should be conducted on an individual basis, taking into account a variety of considerations. Such individualized analysis is not unprecedented. For example, the medical community has a history of engaging in meaningful discussions on how to

evaluate communication by individuals who, due to motor concerns, cannot communicate effectively without the assistance of a facilitator.[2]

The proposed statement does not meaningfully address the fact that *no other* forms of augmentative communication, including those proposed as alternatives, have been evaluated using message-passing or similar tasks. Nor does it acknowledge that some of the proposed alternative interventions - such as Applied Behavioral Analysis - have been found to have no discernible effects on communication ability,[3] also rely extensively on prompting, and are not themselves a form of augmentative communication. Attempting to wholesale deny the authenticity of a form of communication, regardless of the evidence available with respect to a specific individual, and then assert that unrelated interventions are "alternatives," is unjust and logically inconsistent.

ASHA's proposed position statement prevents a false choice between FC, RPM, and other communication supports.

The proposed statement claims, without support, that use of one form of communication necessarily "supplants" access to other techniques. This inaccurate claim is contradicted by the experiences of countless actual AAC users, many of whom use of a variety of different forms of communication, sometimes simultaneously and sometimes at different times and for different purposes. People who use letter-based communication techniques, such as RPM or FC, often also use methods such as indicating choices among options, pointing to multiple-choice answers or word/symbol banks, yes/no signals, PECS, tablet-based AAC apps, sign language, independent typing, and spoken words or sounds to communicate at different times.

To the extent that people with communication-related disabilities do not use the communication methods that the committee proposes as alternatives, it is often because those methods *do not work* for those individuals. Cutting off access to one form of communication, in the absence of other methods that are equally effective *for that individual*, is unethical and harmful. Although we agree that far too many non-speaking people have not been offered communication supports that are evidence-based and effective, taking away communication options is not the answer. Rather, we urge ASHA to take seriously the evidence that there is a critical unmet need in school districts across the country for effective, wide-scale implementation of robust AAC options, and to focus its efforts on meeting that need.

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[2] *See, e.g.*, Cairncross et al., Assessing Decision-Making Capacity in Patients with Communication Impairments: A Case Study, Cambridge Quarterly of Healthcare Ethics 691–699 (2016), available at http://dx.doi.org/10.1017/S0963180116000414 (discussing efforts to support communication by a woman with traumatic brain injury who communicated by gazing at options on a communication board, with the assistance of a speech-language pathologist who would then point at the option the woman appeared to be selecting. The woman then would confirm the selection with gestures that indicated "yes" or "no.").

[3] U.S. Department of Education, Institute of Education Sciences, What Works Clearinghouse (August 2010). WWC Intervention Report: Lovaas Model of Applied Behavior Analysis, p. 2, *available at* https://ies.ed.gov/ncee/wwc/Docs/InterventionReports/wwc_lovaas_082410.pdf.

The Committee's proposed position statement inappropriately equates absence of peer-reviewed studies with evidence that an intervention is ineffective.

Although we support formal research on communication, a significant number of communication methods have no supporting body of formal research pertaining specifically to that communication method. Rather, SLPs may recommend communication supports based on other sources of evidence, including general research on motor planning and language learning, combined with individualized evaluation of the individual in need of communication supports.[4] Moreover, as noted above, *no* communication support method - including those the Committee recognizes as evidence-based - is supported by double-blind message-passing studies. This includes well-established and promising communication supports that also involve the participation of a facilitator with the goal of increasing independence, such as partner-assisted scanning and Pragmatic Organisation Dynamic Display (PODD).

The Committee's proposal to restrict SLPs' use of a communication method, based entirely on the absence of message-passing studies supporting the specific method in question, therefore threatens to set a dangerous precedent that may obstruct individuals' access to a wide variety of communication supports. This precedent is especially threatening to those who have discovered communication methods that are highly individualized and thus not amenable to formal academic research.[5]

Conclusion

ASAN therefore recommends *against* adoption of the proposed position statements of the ASHA Ad Hoc Committee on Facilitated Communication (FC) and the Rapid Prompting Method (RPM). Adoption of the proposed statements would dramatically undermine the right of all people to the individualized supports they may need in order to communicate.

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[4] *See* Cirrin et al. (2010). Evidence-based systematic review: effects of different service delivery models on communication outcomes for elementary school–age children. *Language, Speech, and Hearing Services in Schools, 41*, pp. 233-264 ("Lacking adequate research-based evidence, clinicians must rely on reason-based practice and their own data until more data become available concerning which service delivery models are most effective. Recommendations are made for an expanded research agenda"); Mullen, R., "Evidence-Based Practice: Opportunities and Challenges for Continuing Education Providers", available at https://www.asha.org/CE/for-providers/Evidence-Based-Practice-CE-Providers/ ("The notion that external research evidence somehow 'trumps' all other considerations is one of the big myths surrounding EBP"); Mullen, R., National Center for Evidence-Based Practice in Communication Disorders (2008). Evidence-based practices. Presentation to the American Speech-Hearing Association, *available at* http://www.nectac.org/~pdfs/Meetings/national2008/1mullenEvidenceBasedPractices.pdf ("It's CLINICAL DECISIONS, not practices, that are evidence-based").

[5] *See* Brady et al. (Nat'l Joint Committee for the Communication Needs of People With Severe Disabilities (NJC)). (2016). Communication Services and Supports for Individuals With Severe Disabilities: Guidance for Assessment and Intervention. *American Journal on Intellectual and Developmental Disabilities, 121(2)*, pp. 121-138 at 123 (noting that "[s]ome individuals with severe disabilities develop unconventional and highly individualized or idiosyncratic means to communicate.").

Sincerely,

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