



**INFORMATIONAL LETTER**

<b>Transmittal:</b>	24-INF-02
<b>To:</b>	Care Coordination Organizations (CCOs) CEOs of Voluntary Provider Agencies Developmental Disabilities State Operations Offices (DDSOO) Directors Developmental Disabilities Regional Field Offices (DDRFOs) Provider Associations
<b>Issuing OPWDD Office:</b>	OPWDD Division of Statewide Services
<b>Date:</b>	April 22, 2024
<b>Subject:</b>	Communication in Developmental Disabilities and Autism Spectrum Disorder: Empirically Supported and Unsupported Communication Enhancement Methods
<b>Suggested Distribution:</b>	Care Managers and Care Manager Supervisors Medicaid Compliance Officers and Compliance Staff Administrative Staff of Fiscal Intermediary Service Providers Support Brokers Care Managers and Care Manager Supervisors
<b>Contact:</b>	Division of Statewide Services, Bureau of Psychology and Behavioral Health at: <a href="mailto:psychologyandbehavioralhealth@opwdd.ny.gov">psychologyandbehavioralhealth@opwdd.ny.gov</a>
<b>Attachments:</b>	

<b>Related ADMs/INF</b>	<b>Releases Cancelled</b>	<b>Regulatory Authority</b>	<b>MHL &amp; Other Statutory Authority</b>	<b>Records Retention</b>
N/A	N/A		Mental Hygiene Law, §§ 13.07, 13.09[b], 16.00	

## **I. INTRODUCTION**

OPWDD strongly advocates for the rights of all people with developmental disabilities to have their own voice, thoughts, and opinions to be heard and respected. Communication that reflects the thoughts, will, and opinions of the person is essential to ensure maximal individual autonomy and decision-making. This includes individuals who are non or minimally verbal who may be able to communicate via different methods or with the use of technology. However, communication methods vary, and it is critical to understand which methods have empirical support.

## **II. BACKGROUND**

OPWDD supports and encourages the use of evidence-based methods that enhance communicative abilities of people with developmental disabilities.

Augmentative and Alternative Communication (AAC) interventions have a long history of acceptability and research-based support in helping people with severe speech or language limitations to communicate via alternative communication systems.<sup>1</sup> The specific system used is individualized to the person based on their abilities and may include low or no technology (such as sign language, picture exchange, etc.) or high technology systems (such as speech generating devices). The AAC approach is a clinically driven intervention that presumes competence, emphasizes independent communication, and has substantial empirical support in peer reviewed studies. As used here, “empirical support” refers to AAC interventions that have adequate and controlled scientific research evidence that demonstrate effectiveness and validity of the approach in enhancing a person’s ability to communicate independently.

Some communication methods, however, do not have appropriate evidence to support their use and purpose. Methods that require assistance, prompts, or dependence on other people lack research evidence to support their efficacy and validity. OPWDD does not support communication methods lacking appropriate scientific evidence to support their use, including Facilitated Communication, Spelling to Communicate, the Rapid Prompting Method and other functionally similar methods. Communication methods that lack a scientific or research evidence base are considered experimental treatment. Here, “experimental,” means a treatment or functional communication enhancement approach that does not have adequate and controlled empirical research demonstrating the effectiveness and validity of the approach in enhancing a person’s ability to communicate independently.

## **III. DISCUSSION**

### **1. Supported Communication Methods**

Some communication methods that have appropriate evidence for OPWDD to support their use include, but are not limited to:

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<sup>1</sup> Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder (2020). <https://ncaep.fpg.unc.edu/sites/ncaep.fpg.unc.edu/files/imce/documents/EBP%20Report%202020.pdf>

- Sign language;
- Picture Exchange Communication System (PECS);
- Independent use of speech generating devices (SGDs);
- Communication independently typed/written by the person without the aid or cuing of a facilitator or communication partner; and
- Other methods based on the clinical and scientific approach of augmentative and alternative communication (AAC) techniques.

These OPWDD-supported communication methods are legitimate augmentative and alternative communication (AAC) techniques. They have a well-established scientific base, research support, and focus on ensuring authentic independent communication.

## 2. Unsupported Communication Methods

Some communication methods that lack appropriate evidence for OPWDD to support their use include, but are not limited to:

- Facilitated Communication;
- Rapid Prompting Method (RPM);
- Spelling to Communicate (S2C);
- Informative Pointing;
- Typing to Communicate;
- Supported Typing; and
- Letterboarding.

Facilitated Communication (FC) is a technique whereby a person types with the aid of a facilitator who has physical contact with their typing hand, arm, elbow, or shoulder.<sup>2</sup> FC may also be known as “Typing to Communicate.”<sup>3</sup>

FC has been widely discredited as a false and invalid method for communication.<sup>4</sup> Properly controlled research studies have repeatedly demonstrated complete, if unintentional, control of the communication by the facilitator.<sup>5,6,7</sup> This phenomenon is most convincingly observed in studies where the person was asked a factual or personal experience-based question that the facilitator had no knowledge of, or the facilitator was intentionally given different information. If the facilitator didn’t know the correct answer, the answer was not provided, not correct, or only

<sup>2</sup> Schlosser, R.W., Hemsley, B., Shane, H. et al., (2019) Rapid Prompting Method and Autism Spectrum Disorder: Systematic Review Exposes Lack of Evidence. *Rev J Autism Dev Disord* 6, 403–412

<sup>3</sup> <https://disabilityinclusioncenter.syr.edu/communication/typing/> (retrieved 091523)

<sup>4</sup> Jacobson, J. W., Mulick, J. A., & Schwartz, A. A. (1995). A history of facilitated communication: Science, pseudoscience, and antiscience science working group on facilitated communication. *American Psychologist*, 50(9), 750–765.

<sup>5</sup> Szempruch, J., & Jacobson, J. W. (1993). Evaluating facilitated communications of people with developmental disabilities. *Research in Developmental Disabilities*, 14(4), 253–264.

<sup>6</sup> Wheeler DL, Jacobson JW, Paglieri RA, Schwartz AA (1993). An experimental assessment of facilitated communication. *Ment Retard*, 31(1), 49-59.

<sup>7</sup> Montee, B.B., Miltenberger, R.G. and Wittrock, D. (1995). An experimental analysis of facilitated communication. *Journal of Applied Behavior Analysis*, 28: 189-200.

reflected what the facilitator believed to be true.

The Rapid Prompting Method (RPM) was originated by the parent of a child with autism spectrum disorder who developed the technique to teach her son to communicate. Training on the RPM has been available since 2001 to parents and other caregivers as a separate and specialized intervention typically geared to people who have developmental disabilities and are non or minimally verbal. The RPM is described as a “method that empowers a student with the means to express his/her learning, understanding, reasoning and thoughts” and involves training “the student to respond by selecting between correct and incorrect choices, or spelling on either the large letter stencils, full letter stencil, full letter board, keyboard/device, handwriting, or speech.”<sup>8</sup> The more recent emergence of a method called “spelling to communicate” (S2C) is virtually identical in technique.

The RPM and S2C are noted to have considerable similarities to FC. The difference with the RPM is that the facilitators hold the letter board, instead of having physical contact with the person, prompting concerns that the techniques are functionally the same.<sup>9</sup>

### **3. Conclusion**

Based on a review of the currently available research evidence, OPWDD finds that there is a lack of evidence to support the use of FC, RPM, S2C and similar techniques as a means of developing communication or leading to independent communication. This conclusion is reached based on the existing research on facilitated communication and the near complete absence of properly controlled research support for other similar methods (despite RPM's existence for more than 20 years as a treatment method claiming to teach communication to people with or without developmental disabilities).

In the absence of appropriate scientific research, these approaches, and others like them are considered experimental. These approaches may not accurately reflect a person's thoughts and beliefs. Any expenses related to these methods (e.g., training, treatment, coaching, teaching, supporting) will not be funded by OPWDD.

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<sup>8</sup> <https://www.halo-soma.org/what-is-rpm>. Retrieved 09/06/2023.

<sup>9</sup> Tostanoski, A., Lang, R., Raulston, T., Carnett, A., & Davis, T. (2014) Voices from the past: Comparing the rapid prompting method and facilitated communication, *Developmental Neurorehabilitation*, 17:4, 219-223.