Office of the Chancellor Crouse-Hinds Hall, Suite 600 900 South Crouse Avenue Syracuse New York 13244-2130

Dear Chancellor Syverud,

We, the undersigned, concerned citizens, clinicians, researchers, academics, healthcare professionals, and science journalists, are writing to you about a serious issue regarding the promotion and use of Facilitated Communication at Syracuse University.

On October 1-2, 2018, the Institute on Communication and Inclusion (ICI) will host a <u>2-Day Introductory Workshop in Supporting Communication: Developing Frameworks for Support and Learning to be a Facilitator at the Goldstein Student Center on the Syracuse University South Campus.</u>

Facilitated Communication (FC) (also known as Assisted Typing, Supported Typing, or Facilitated Communication Training) is an unethical practice thoroughly discredited by well-replicated scientific research. FC uses cues from a facilitator's physical touch at the hand, elbow, shoulder, back, or other body part to prompt a non-speaking person to spell words and sentences. FC is a facilitator-dependent technique, and the messages produced have repeatedly been shown to be the words of the facilitator and not the person with disabilities. The most recent controlled study of message authorship during FC (Saloviita et al. 2014) again concluded that facilitators generated the messages, a finding replicated by dozens of experimental studies and eight systematic reviews since 1993 (see the summary of FC research in the enclosed attachment). The prompts from facilitators cannot be faded (gradually eliminated over time) because the facilitator is the source of messages attributed to the person with disabilities. The ideomotor effect is a well-documented phenomenon that explains why facilitators are typically unaware of their influence on the production of facilitated messages.

Facilitators and FC proponents use the technique to promote acceptance, inclusion, and diversity. We share these values. However, facilitators undermine inclusion and acceptance by subjugating the very people they claim have been emancipated via FC. Indeed, facilitators often give credence only to facilitated messages and ignore other communicative behaviors (i.e., vocal protests, walking away, pulling or pushing, etc.) of the person with a disability. Though this is troubling, other serious concerns also merit your consideration.

Facilitated communication has caused serious harms to people with communication disabilities, their families, caregivers, and professionals. Along with significant and costly loss of time, resources, and the opportunity to access effective communication interventions, FC has been the source of numerous false allegations of sexual abuse against innocent people in Australia (where FC originated) and the United States. Recently, the Wendrow family was awarded nearly \$7 million for wrongful prosecution after unfounded allegations of abuse were alleged via FC. Additionally, messages generated with FC have been used by individuals later convicted of sexual crimes who erroneously claimed their victims used FC to consent to sexual contact. For example, caregiver Martina Schweiger of Australia claimed her client requested via FC that they engage in sexual acts. Similarly, a Syracuse-trained facilitator and Rutgers professor Anna Stubblefield pleaded guilty to aggravated sexual contact after she claimed her victim consented to intercourse via FC. Also, Gigi Jordan was convicted of manslaughter after she used FC with her 8-year-old son with autism to request they both commit suicide. These and other well-documented harms make clear that parents, facilitators, DHS workers, law enforcement, and other public institutions are vulnerable to criminal and civil action when FC is used.

There is no way to reduce the risks associated with FC. Accordingly, numerous organizations have for decades issued position statements to discourage the use of FC. In August 2018, the American Speech-Hearing-Language Association's (ASHA) board voted unanimously to adopt an <u>updated position</u> <u>statement</u>, reaffirming its earlier stance, and stating that FC "is a discredited technique that should be not be used" and that "Information obtained through FC should not be considered as the communication of the person with a disability." In their 2014 position paper, the International Society for Augmentative and Alternative Communication (ISAAC) stated, "The use of FC appears to be in violation of several articles of the United Nations Conventions of Rights of Persons with Disabilities (i.e., Articles 12, 16, 17, and 21) as it has been shown to prevent individuals without sufficient spoken language from using their own 'voice.'" Other leading organizations such as the American Academy of Pediatrics, American Psychological Association, and American Association on Intellectual and Developmental Disabilities have maintained for decades position statements denouncing FC as unscientific and unethical. The New York State Department of Health includes the following recommendation on its <u>website</u>:

Because of the lack of demonstrated efficacy and possible harms of using facilitated communication, it is strongly recommended that facilitated communication not be used as an intervention method in young children with autism.

Position statements against FC by numerous other organizations have been widely adopted. A more complete list is included in the enclosed attachment.

It was reasonable to debate FC's effectiveness and argue for further investigation in the early 1990s. However, the scientific community has since conducted dozens of well-designed experiments to test the authenticity of FC. As demonstrated repeatedly, FC and other facilitator-influenced practices simply do not produce authentic communication. Nonetheless, for over 25 years, FC proponents at the ICI have continued to disseminate this widely discredited and dangerous practice at Syracuse University. Dissemination of FC misleads families away from communication methods that are demonstrably effective (e.g., manual sign language, graphic symbols, gestures). FC also obstructs the individual's authentic communication and violates the fundamental right to self-expression.

We do not question the good intentions of families and caregivers who pay substantial fees for these workshops with hope that doing so will enable them to use FC with their loved ones. We also understand that it may be difficult for leading FC proponents to acknowledge that their beliefs directly contradict the overwhelming evidence of facilitator authorship. However, good intentions do not guarantee access to effective and ethical services, as decades of harm associated with invalidated mental health and developmental disabilities practices demonstrate. Further, the rejection of scientific consensus may be considered an issue of academic freedom, but dissemination of unwarranted and harmful beliefs to unsuspecting families is unethical and incongruous with the mission of Syracuse University.

We believe institutions of higher learning have an obligation to seek and promote the truth while dispelling falsehoods. This responsibility is particularly important during an era when facts are obfuscated and citizens are increasingly exposed to misleading information. Syracuse University should reflect a commitment to truth and evidence by halting the spread of false information about FC by its faculty. The University's student newspaper, *The Daily Orange*, reflected this value when it ran a series of articles in 2016 condemning FC. Unfortunately, those articles appeared insufficient for preventing further dissemination of FC at Syracuse University.

We therefore urge Syracuse University leaders to reconsider giving its imprimatur to this invalidated and demonstrably harmful practice at the ICI's October conference. We further urge Syracuse

University to halt fleecing unsuspecting families for training in this dubious method, and to stop all use of University resources allocated for the promotion of FC and related variations.

Please let us know if you have any questions. We look forward to your response.

Sincerely,

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