RESEARCH IN FACILITATED COMMUNICATION: SHIFTING FROM "IF" TO HOW

Eunyoung Jung
Fernanda Orsati
Casey Reutemann
What do we do?

- **Research**
  - The ICI is an active research institute, and the nation’s leading resource for information about supported typing. Research topics, developed in consultation with scholars and practitioners around the globe have included:
  - Strategies for enabling individuals to become independent in their typing
  - Parent/family experiences
  - The relationship between typed communication and speech development
  - Autobiographies of people with disabilities who use facilitated communication
  - Inclusive schooling and community living
  - Sustainability of communication support in schools
• **Training**

• The ICI provides training at all levels including;

• Introductory workshops and technical assistance for families and professionals new to supported typing

• Skills enhancement for those who will coach or train others using facilitated communication

• “Master Trainer” certification for those with the most developed professional skill in training and assisting in this method
Public Education and Dissemination

The ICI provides public access to the most up-to-date information about supported typing through:

- Publications - Research articles and books by Syracuse faculty, graduate students, and experts
- Training manuals, guides and videos
- Documentaries - Film accounts of individuals who learned to communicate with facilitation, including Academy Award® nominated “Autism is A World” and the upcoming "Wretches & Jabberers and Stories from the Road"
- Lectures and workshops - Seminars and workshops feature regional and national presenters from diverse disability-related fields
If Facilitated Communication …
Review Of FC Research

- The term “facilitated communication” was used as a descriptor in four article databases (Articlefirst, Pubmed, PsychInfo, and ProQuest)

- 174 peer reviewed were found, 104 were retrieved in full text and were qualitatively analyzed

- Quantitative studies:
  - 28 don’t support
  - 8 neutral
  - 7 support
What are the main characteristics of the studies or elements of practice in the studies that do and do not support authorship?
Design of the Task

Practice is offered before, different stimulus and levels of activities, task that is motivating for the participant:

“Objects and pictures were placed in a bag, with their identity concealed from participant’s mother. The clinician then selected one object/picture at a time, showing it only to participant. His mother responded by asking the participant to tell her what he saw and facilitating his response” (p. 4, Ogletree & Hamtil, 1993).

Limited stimulus, poor designed questions:

- Pointing to PPVT-R, which is a psychological test that measures receptive language, the participant listen to a word and have to chose from 4 pictures the one that corresponds to the listened word.

- Open ended questions: “What is your diagnosis? Why don’t you speak?” (Eberlin et al., 1993).
FC User Characteristics

Participant has significant experience with FC prior to the study:

- “participant had to possess the following characteristics: (a) have facilitated for at least six months, (b) be able to spell out at least a single word response using FC, (c) possess a communication evaluation documenting a logical array of communication strategies that had been attempted prior to FC and an anecdotal history of events [...] that the student communicated information via FC that was not known to the facilitator [...]” (p. 232, Cardinal, Hanson & Wakeham, 1996).

- The three participants have been using FC with their facilitators for the past 18 months at least (Sheehan & Matuzozi, 1996).

A person that has verbal speech, a person that is just encountering FC for the first time, a person that is not someone that needs FC:

- Inclusion of participants for 20 hours of training, pre and posttest design: “their speech therapist’s subjective impression that the person may be able to express more through FC than through their already existing communicative forms” (p. 511, Eberlin, et al., 1993).

- “the experimenter informed participants that they would practice their facilitation skills with ‘Jackie’ a 20-year-old individual who ‘was born with a number of developmental disabilities, including inability to speak’ [...] In Reality, Jackie was a normally functioning senior at the University of Connecticut” (p. 72, Burgess et al., 1998).
Familiarity (setting, facilitator, task)

Setting and facilitator that the child knows:

“The uninformed facilitator in the protocol was Kenny’s 1-to-1 school teacher, who accompanied him throughout his regular school day (approximately 30 hours weekly) and had been working with participant for approximately 15 months prior to the first experimental session (p. 222, Weiss, Wagner & Bauman, 1996).

First time in a place, first time encountering facilitator, first time with the task:

“Subjects were taken to the experimental room by their facilitator who requested their participation on their way there.” (p. 348, Regal, Rooney & Wandas, 1994).
Wait time

Most of the studies don’t describe the waiting time.

“For the book Frog Goes to Dinner, two sessions (#9 and #10) were required to complete the discussion using FC” (p. 7, Janzen-Wilde & Ducham, 1995). The three participants have been using FC with their facilitators for the past 18 months at least (Sheehan & Matuozzi, 1996).

“The entire pretest was administered to each participant in one session, duration of the pretest ranged from 30 to 60 minutes. If a participant did not respond to a question by typing on the keyboard within 30 seconds of its presentation, the question was restated and another 30 seconds allowed to elapse” (p. 50, Sheehan & Matuozzi, 1996).
Number and Length of sessions

“Three participants responded to presented stimuli during a total of 14 sessions, each lasting approximately 1 to 1.5 hours” (p. 98, Sheehan & Matuzzi, 1996).

The assessment was conducted over two sessions. This first session lasted about two hours, including multiple breaks. The second session lasted for about 1 hour, including two breaks” (p. 663, Eberlin, Ibel & Jacobson, 1994).
Facilitator Experience

“All facilitators participating were judged to be ‘experienced facilitators’ by the facilitator trainers prior to the beginning of this study” (p. 233, Cardinal, Hanson & Wakeham, 1996).

No experience: “Three facilitators were involved in this study. [...] The first and third facilitators received training[...]” The study was conducted in 10 weeks: every day 5 to 25 minute sessions (p. 48, Bomba, O’Donnell, Markwitz & Holmes, 1996).
Natural conditions

“[...] transcripts or diary records of routinely occurring FC sessions” (p. 99, Emerson, Grayson & Griffiths).

Validation of authorship using a communication profile: unexpected content, atypical spellings, unique phrases, information unknown to the facilitator, oral spelling, self-corrections (Janzen-Wilde & Ducham, 1995).
Methodological Challenges

• From all the 28 quantitative articles not supporting FC, 13 (46%) have one or both of this:
  • Inexperienced facilitators (just being trained, never typed with users; some were not trained);
  • Participants that just encountered FC for the first time on the test.
The publications of the quantitative studies date from 1992 to 1996.

Publication of two quantitative research in the past 5 years:


Moving to the HOW of Facilitated Communication…

- Individuals that started with physical support are now independent;

- Qualitative and quantitative research shows significantly improvement in communication of individuals.
UNDERSTANDING THE SKILLS AND COMPETENCIES OF MASTER TRAINERS IN FACILITATED COMMUNICATION
About the Study…

Gap:

- There are training standards for facilitators (Chadwick 1996), but not for trainers in facilitated communication

Objective:

- This study investigates effective competencies and dispositions associated with being a trainer in order to identify qualities, skills and characteristics of highly effective trainers in the practice of supported typing.

Methods:

- One hour interviews conducted with 9 highly skilled trainers
We Are Interested in…

• How skilled facilitators/trainers describe their practice

• How they approach and carry out their work

• Central characteristics they develop as facilitators that could be taught and used for other facilitators
Themes explored

- What is FC?
- Candidacy
- Getting Started
- Supporting Behavior
- Trainer histories
- Characteristics and skills of facilitators
- Developing independence
- Training metaphors
- Elements of Training
- Training Activities
- Training materials
- Working with Schools
- Controversy
- On-going learning
Support Networks

Critical to both initial training and ongoing development as highly skilled facilitators and trainers

• “It actually took someone who had some experience that actually sit down with me…and this was actually several months later after I had been kind of flailing around trying to figure out what I was doing.” - Pascal

• “I worked with a young man and he was who taught me how to type and so I watched Marilyn for a while and then she asked me to jump in and she coached me and then [the user] provided me feedback to develop my skills.” - Christi
Support Networks

- “I think the biggest thing is spending time with other people who do training because we all do it. We all have a common set of things that we do but everybody does things a little differently and everybody has different sets of skills and expertise so I think that’s a really important part of furthering develop my skills is to make sure I spend time with other people who are doing training.” - Pascal

- “There’s so much that takes you beyond the method itself when you’re trying to help a person become independent that we’ve had to look to each other to kind of figure out what helps, what doesn’t help. What helps one person may not help another. So it really is a steady sense of inquiry within that network”. - Marilyn
Foundations

Consistent discussion of establishing a foundation of knowledge and cultivating positive attitudes towards people with disabilities as crucial to training process

• Modeling:
  • “I think one of the things that I do first and foremost is I engage [the fc user] as an intelligent person… I let them know first and foremost that I want to know who they are and I value what it is that they think, and then I figure out ways to invite that so they can share who they are…. ” - Marilyn
Foundations

Providing

- In looking at providing people with a certain amount of knowledge you know information, education, background, about not just disability but then getting specifically into the practice of facilitated communication history and what it is, what it isn’t, how it fits into AAC, looking at the movement piece and relating that to kind of the bigger picture around movement and disability…And again, that’s information, trying to give people information and educating. - Harvey

- “…we’re training people to understand…I always start with a little bit of background.” Darlene

- “…Getting started really has two different aspects to it and the one aspect is the technique itself, and in talking just about the technique you want to make sure you have good information, you want to make sure you have a good attitude, and you want to make sure you know what the technique is all about.” Marilyn
Independence

Plays many roles in the process: A starting point, goal for user/facilitators pairs in training, and a tool in advancing the method

• **Starting Point:**
  - “So the first thing you’re going to look at is how do they independently communicate so without physical support.”- Darlene
  
  - “Many people are already quite independent and are able to initiate communication but we decrease their independence often for a period of time as part of their acquiring the skills of facilitated communication.” - Mayer
Independence

Goal:
• "…people fading out their support for people is crucial everywhere …And each time you do a task or each time you do an activity you’re going to want to try that differently than the time before.”  - Brady

• “I think it starts with letting people know that the goal of this is independent communication right from the beginning. I think a big part of it is also working [with] individual people around the person to make sure that they understand that it’s a goal. But I think another part of it too is understanding how the person sees independence in general. So it’s not just the independence in communication but how do they see independence in their life.”  - Pascal
Independence

A tool in advancing the method:

• “We know people can get independent. We know that folks are able to pretty quickly learn to type without any physical touch, and so the controversy no longer exists for them.” - Christi

• “So we teach that influence is possible and the way that I avoid influence is to constantly be fading back on the support using that least to most as much as possible” - Darlene
“A WORLD OF DIFFERENCE”: ANALYZING THE DEVELOPMENT OF INDEPENDENCE OF INDIVIDUALS WITH DISABILITY IN TYPING TO COMMUNICATE

- Eight training sessions for achieving physical independence in typing
- Twelve participant pairs: U + F
- **Quantitative portion**: video analysis of the educational training sessions
- **Qualitative portion**: participant observations in educational training sessions and interviews
Quantitative analysis

• Training sessions were analyzed with Studiocode software:

  • **Frequency**: instances during the session that the individual who types to communicate was supported at a specific level (wrist, forearm, elbow, upper arm, shoulder, or typed independently);

  • **Duration**: refers to the length of time of each instance described above at the specific level of support
**Carrie**

**Frequencies: occurrence of support level per session**

- **Y-axis:** Instances of typing periods
- **X-axis:** Session 1 to Session 8
- **Graphs:** Forearm, Elbow, Upper arm, Shoulder, Independent

**Duration: level of support duration per session in minutes**

- **Y-axis:** Time in minutes
- **X-axis:** Session 1 to Session 7
- **Graphs:** Wrist, Forearm, Elbow, Upper arm, Upper arm, Independent
Jessica

Frequencies: occurrence of support level per session

- Wrist
- Forearm
- Elbow
- Upper arm
- Independent

Duration: level of support per session in minutes

- Wrist
- Forearm
- Elbow
- Upper arm
- Independent
Qualitative analysis

• Let’s play
  One recurring theme was the use of games, particularly educational spelling games with the aim of improving typing. The participants described that the opportunity to practice the motor planning and physical motions of typing without having to conceptualize the message was important in gaining confidence in fading support.

• Prompting
  The use of verbal prompts was important, in order to supplement and even sometimes substitute physical prompts. Motivational, reassuring, and positive feedback were consistently utilized by the facilitators in efforts to keep the individuals moving through the activities.
Qualitative analysis

• *Make it interesting*

Besides the use of games, much of the session time was spent in conversation. Individuals who type and their facilitators described that discussing interesting subjects were motivating and promoted increased typing. Familiar subjects were also conducive to fading support, as described by participants.
Qualitative analysis

- Establishment of the skills after the training and generalization of skills to different contexts:

I think it made a world of difference for Carrie and we've seen growth in leaps and bounds toward independence. She's now consistently typing from the shoulder with her new facilitator, and sometimes just a tug at the top of her shirt sleeve… as Carrie becomes more independent in her typing, she's at the same time becoming more independent in everything else… there are a number of things that she's doing on her own that she didn't do before.
LEXICAL ANALYSIS AS A TOOL FOR STUDYING FC USER AND FACILITATOR WRITING

Result

• The characteristics of the written texts of Facilitated Communication users are different from those of facilitators in Italy, in particular in terms of their lexical patterns
  • the texts written by individuals with Autism showed a higher level of lexical richness, a greater proportion of adjectives and a tendency to omit grammatical words.
  • the texts written by individuals with Autism are similar to each other and different from texts produced by other groups
  • the contents expressed in texts written by individuals with Autism are similar to each other and deal mainly with feelings and emotions
Comparative Research

FC user’s text

Facilitator’s text
We’re collecting FC users and facilitators’ written texts produced …

• in training session

• in conversation setting at home, in a school, and etc.

• by an activity of essay writing with a same topic
What the research compares?

Quantitative
- Word type
- Percentage of words appearing only once
- Mean frequency of types
- Grammatical categories (nouns, verbs, adjectives, adverbs, etc.)

Qualitative
- Sematic referents
- Sematic patterns
- Characteristics of discourse
Research method

Lexical richness and grammatical distribution

Text clustering

Correspondence and content analysis
Possible contribution

1. The expansion of Tuzzi (2009)
Our research will show how its outcome can be replicated in the U.S. with English language users.

2. Understanding linguistic characteristics of FC users
Our research will be helpful to understand and show more details about what the written language of Facilitated Communication users and their facilitators looks like.

3. Authorship
Our research will help to build a strong body of research, utilizing a variety of approaches, which address validation and authorship of individuals with disabilities who use FC and encourage more practices in this field.
NARRATIVE ANALYSIS ON EXPERIENCES OF NOVICE FACILITATORS AND FC USERS
About the Study

• Explores the experiences of novice facilitators and FC users training novice facilitators.

• **Participants:**
  • 6 novice and experienced facilitators reflected on being new to this method
  • 4 experienced FC users who have recently typed with new facilitators.

• **Analysis**
  • Facilitators’ and users’ responses were juxtaposed to reveal where perspectives overlap and diverge.
Key Themes

• Comparing users’ and facilitators’ perspectives reveal there are critical areas around which their perspectives diverge.
  • Relationships
  • Expectations of the facilitator’s role
  • Training process
Relationships:

Facilitators cited the importance of shared experiences and interests in building relationships, seemingly using the ideas of “relationship” and “trust” interchangeably.

• “I found something that we shared. Experience together.” – Laura

• “I want her to feel safe with us. She can feel that she can tell us everything, no matter what even, like, you know what, ‘I don’t like you today’” – Judy

Users made clear that relationships are critical, but can exist without trust. Granting trust is a form of self-advocacy.

• “I think I have to trust my thoughts to someone.” – Sarah

• “It takes me a long time to tell if I can pleasingly trust someone enough to type with.” – Sam

• “..simply engage your love of connection and your heart” – Tim
Facilitator's role

Facilitators emphasized the complexities of feeling needed, but presumably as “absent” as possible.

• “..feeling like I am trying to delete myself….I’m trying to make him independent, I’m trying to be accurate, but I’m also trying to move away as much as possible.” – Gina

• “I was scared “am I typing this, am I doing it” and then….you know you’re not. But you doubt yourself because there is so much around it.” – Nancy

• “…be pleasingly pushy but also be sensitive to needs of my body”- Sam

• “…I sing through my facilitators.” – Sarah

• “…confidence and realization that this is the creation of a partnership and construction of a vital connective structure to listen”- Tim

Users focused on the ways that facilitators support them, regardless independence level. They discussed confidence in resisting influence.
Training Process

Facilitators represented training as both coming from external sources as well as a self-driven process.

• “He’s gotten really good at…me not giving him too much [support]. That’s because I made a decision that’s how we’re going to type from now on.” –Jill

• “I have to reach out to people who are doing this work and who have been doing it for a long time and tell them how serious I am and try to find a way to have access to them more.” –Gina

Users highlighted their own roles as trainers and indicated a training partnership is preferred.

• “I tell people always everything that I need to hopefully think more about what my body needs” –Sam

• “I got to be very patient and waiting for the personal bonding to set in. How to be cool and stay calm inspite of all the many bunglings the new facilitator makes is an art I am trying to master.” –Joe
Implications

- Noting where users’ and facilitators’ perspectives diverge suggests a need to develop a structure for an interactive training partnership involving:

  - Ongoing communication between facilitator and user about the typing process
  - Opportunities for positive feedback for facilitators
  - Room for acknowledgement of users’ agency
IMPORTANT VOICES: LISTENING TO THE LIFE STORIES OF MOTHERS OF FACILITATED COMMUNICATION USERS

These mothers’ stories intersect with the story of inclusive education, disability rights and the history of facilitated communication.
Key codes and themes

- Issues of care
- Gender roles
- Shifting professional identities
- Familial and marital life
- School involvement and path to advocacy
- Challenging normalcy in society,
- Use of supported communication to demonstrate competence
Experts/professional arrogance

• All the mothers extensively describe the encounters with doctors, and other professionals like psychologists, and their arrogance, and pessimistic diagnoses, assessments and judgments.

• Here Tammy and Sheila describe the diagnoses and prophecies the doctors gave for their children.

  Tammy says that “when Mathew was diagnosed [with autism] and I know we’ve come a long way but the psychologist and how he delivered that message was so horrendous.”

  Sheila said they “went back to the pediatrician and in the meantime you know we…I mean I’m going to be 62, so back then the Lorna Wing’s “Theory of Mind”. That was very devastating.”
Normalcy

• Describing & Defying

“It’s a society that judges very quickly if you don’t wear the right clothes or you don’t exceed at this sport and my boys are cut from a completely different cloth. Especially being boys in this age in a community where sports and just certain things are the norm and that’s how a lot of families define themselves with their kids and their kids’ sports and there’s nothing wrong with that. That’s just not us.” Tammy
“I know he’s smart”

• Maria explains what she sees from her son Hussani:

“He knows me. I know he knows me and he knows people coming in and going out. I know when he was a year and a half and he goes to the fridge and gets me the peanut butter and the jelly, the bread, then brings them to me. I know he’s smart. Don’t tell me that he does not understand what’s around him.”
Facilitated communication

• Maria describes the first communication of Hussani with FC:

“The first sentence he typed at preschool was “OPEN CABINET.” And they send me that and the communication book. Hussani typed today and he said open cabinet. And when we opened the cabinet he looked at it and he was very upset and he would not communicate anymore. And I said, ‘What the heck is that? Why at four years old would he say Open Cabinet? This does not sound right’… The second day I went and said ‘So which cabinet is that? Hussani said open cabinet?’ And he pointed to the cabinet and it all came home. Because that’s exactly the same cabinet they used to keep the cookies and the stuff in the school in New York City.”
Path to advocacy

- School involvement – advocacy for their children – general advocacy

- Maria says “I had my reputation in that school that here is a pushy mother so if you’re going to deal with any of her kids remember that. You know teachers tell teachers. So I became the bad mom and I before I went to any classrooms with any of my kids I would visit the classrooms and I said, “Hussani or Amit or Ackmin even and I are a team. If you have my son, you have me. If you welcome my son in your classrooms you are welcoming me. Most of the teachers had no problem really.”

- Maria’s story intersects with gender and power issues too
Path to advocacy

• Maria describes her intensive involvement: “I became a parent advocate over here or a parents rep and they told me just read the files and make this decision. I would not take that. I would go to the classrooms of all the kids. I used to travel all over the city to see all the kids. I would be sitting on the CSE meeting and I would talk to their teacher. I would talk to their therapists and I would sit in the classrooms and watch the kids interacting with other kids before I go in and say here’s what the child needs, or if I’m going to support this or support that, which was unheard of in the district.”
Concluding Thoughts

- Research focusing on

  HOW…

  ...independence is achieved

  ...skills are taught and developed

  ...individuals and families advocate and include

  ...individuals learn to pass massages
Thank you!

- ICI – www.ici.syr.edu
- Facebook – Institute on Communication and Inclusion
- EunYoung – ejung02@syr.edu
- Casey – clreutem@syr.edu
- Fernanda – ftorsati@syr.edu