Lost in Translation:
Conceptualizations about Collaborative Dialogues between Health Professionals and Adults with Intellectual Disabilities with Significant Needs for Support, Especially in Language

Karina Guerschberg, Gustavo Rubinowicz
Kelsey Kayton, Milagros Albornoz Orfila, Rachel Tucker
Buenos Aires, Argentina

Abstract

In this paper, we focus on creating a dialogue at a Day Centre in Argentina. This Centre provides service to thirty adults with intellectual disabilities between the ages of twenty-five and fifty, who have significant needs for support, especially in communication. The daily institutional work makes us constantly think about quality of life. The dimension of the difficulties that users and families face daily, and the small possibility of being participants in their own lives and break free from pre-established patterns, leads us to this search. We are convinced that seeking the development of collaborative dialogues in a population of adults with intellectual disabilities, is an ethical obligation, but also a challenge because the modalities/ difficulties are not only in the expression or in the output, but in the chain of preexisting meanings. Our institutional experience to establish collaborative dialogues of people with intellectual disabilities, their families, and the professionals. How we are researching and learning the forms of communication of each person, and moving away from the intent to modify their communication in order to prioritize the conversation.

Key Words: intellectual disabilities, collaborative dialogues, research, forms of communication

"I was often unable to express myself completely and relied on another person to 'translate' for me; and if the 'translation' was incorrect, no one understood what I wanted to express" *(*Kelsey Kayton).

> *"Soy la traductora de un idioma que desconozco"* (Susana, *mamá de Mariano*).

Lost in Translation

People identified with intellectual disabilities (PID), in general, have little to no power to make a decision as simple as what to eat, or how or when to tell someone to assist them with personal hygiene, much less complex questions like those about health. Therefore, gaining the full representation of these persons and their rights is difficult. However, our central goal is not to reproduce the oppression that many of these people have experienced through the dominant culture, but rather through our professional work to include all of the voices of the people involved.

In this paper, we focus on creating a dialogue at a Day Centre in Argentina. This Centre provides service to thirty adults with intellectual disabilities between the ages of twenty-five and fifty who have significant needs for support, especially in communication.

To make this possible, we believe these people need reflexive professionals who focus on maintaining open dialogue with people who have evident difficulties in their ability to communicate. In order to promote this dialogue, we work from the perspective of the collaborative-dialogic practices, most importantly by working from certain premises about knowledge and research. From this perspective, we affirm that we do not need specific training to be researchers, nor do we need to be outside the body of research to be objective and neutral. Furthermore, it is unnecessary for our research to occur after the fact, using only certain methods, nor must all of our work include results that are replicable or generally applicable to all support work with the disabled. (Anderson, 2017). We consider ourselves co-investigators with the families and users, and collaborating with our users is the best practice in function with our objectives.

Our use of the word "user" is an intentional choice because we believe there is an imperfect agency relationship between professionals and PID. Labelle at al. (1994) defines a perfect agent as a "physician [who] adopts a role that is congruent with the patient's wishes" (page 356). Is very difficult for us to know their desires because of their difficulties in communication. In contrast, the term client is mostly used to identify individuals obtaining services from a professional, regardless of whether it is paid or unpaid. Furthermore, those who pay for a service are customers, and those who use a service are users. Usually our "clients" don't choose us. They are sent to our Day Center by someone in their family. To make this more difficult, the user's family doesn't pay for this service; the healthcare system does. In other words, those who use the service do not choose nor pay for the service, those who pay for the service do not choose or use it, and those who choose it, don't use or pay for it. Therefore, we choose the term "user" to make this relationship more visible.

We involve ourselves as professionals who reflect-in-action, stop to think and rethink about the theoretical scaffolding, examine and describe their methods, and discuss them with all of the people involved, especially the recipients of our professional services. In constant dialogue, theory influences practice, and practice produces theory. The theory is shared in the same moment it is created and it is "produced with" and not "about." These processes are far from being circular and staggered; they are simultaneous and constant. They involve reading, thinking, executing and reflecting on, returning to think, writing, reading…

We systematize the observation and registry in notes, audio recordings, videos, a variety of forms of communication. These registries are shared among professionals, users, and families. This team reflection, inspired by the concept of a reflective team (Andersen, 1993), pays special attention to reflection, and works toward a transformative action that is generated through the interaction of voices where no one voice has priority over another. These techniques permit us to develop new ideas with greater depth, which Shotter (1993) designates as "performative understanding". We are researchers breaking the dichotomy of researcher/subject, and situating ourselves as participants in a relationship, where we mutually influence each other allowing each of the participants to contribute to the result. It is a decentralized learning process, where those who were seen as the subjects of study, are now considered as the participants in a relationship based on mutual learning (Anderson, 2019). In this work, we do not talk about the others and their texts and contexts, as Ghiso (2009) points out, but with the others and their texts and contexts. We are particularly interested in reflecting on what we have learned and constructed so that the reflection will continue.

Framed in this institutional ideology is that we constantly work with students from diverse fields of study who come seeking to gain experience in the workplace; even, as in the case of Kelsey Kayton, from other countries. Her visit gave us a new look at our reflections on everything that is lost in translation. When the first draft was ready, we asked Rachel to help us adjust the translation. Hers contributions further enriched our experience. And Milagros also worked by comparing both versions and contributing with new dialogues. This article continued to be built with each of these contributions. In this text, we include theoretical reflections about our work and Kelsey's reflections on her own experience. In addition, Kelsey collaborated with the English translation of this article.

We are convinced that seeking the development of collaborative dialogues in a population of adults with intellectual disabilities with significant needs for support, is an ethical obligation, but also a challenge. Ethics is thought of as a joint activity independent of the context and constructed through fluid language that includes the voices of professionals, users, and families (Anderson, 2019 p. 6-7). Our objective is to generate relationally responsible and meaningful actions, where the possibility of intelligibility, internal processes, values, and the feeling of our existence (Anderson, 2019, p.8) is reached through dialogue (Anderson, 2019, p. 8). We want the people participating to be "involved with each other in a mutual or shared inquiry: where they jointly think, examine, question, and reflect" and where we are in a constant search for meaning that is continually interpreted, reinterpreted, clarified, revised, and created. We don't aspire to develop a methodology or new standards, rather we are participating in a constant search in every moment and every situation

We know through our institutional experience that it is possible to establish collaborative dialogues of people with intellectual disabilities, their families, and the professionals working with them, and that this is the most logical way to discover the real necessities of these people.

We center our interest in the dialogue, but only the dialogue that is co-built because it is in the dialogue and/or speech with others where the subject appears, for it is made real by means of the word, in the enunciation and in the meeting of enunciations with another who listens to it (Gerstle, 2014, 26).

Bajtín especially occupied himself in the relationship between subjectivity and language. For the author, to be means to communicate dialogically. (Bajtín, 1979, 324). As Gerstle states, the event of being occurs in the never-ending exchange and meeting among enunciations, in which the voice transports and expresses existential feelings, the value assigned to something by the speaker. Therefore, discourse is not only in the utilization of language but it is the language itself as soon as it comes from thought and speech, as the practice of the language is carried out in singular, contingent, and unrepeatable situations (Haye, 2009, p.3.).

The construction of the subjective is then shared, words are stated to another, emerging from a chain of meanings; meanings which are pre-existing and not final (Bajjtn, 1986).

The People with Whom We Work

The majority of the work we do is with a population that has one or more of the following situations:

- Some lack expressive language expected for adulthood.

- Others express themselves in oral language with the same Spanish vocabulary as the standard population, although in a smaller quantity and with problems in grammar and sentence organization.

- Some use words that are hard to understand in the context, or incomprehensible for people who have not yet accessed the understanding of the "linguistic menu" of the rest of the community. For example, "Ki" for Karina, "turutito" (the original manuscript was written in Argentine Spanish) for a small sandwich; "amamema" for McDonalds, "baturi" for "la combi" (translates to bus in English)

- Spoken Spanish, but with sentences that do not conform to the common use of the language: ¿Fian bien? in order to say "hoy estuve bien" (Today I behaved well.)

- Without oral language and some signs that are or resemble Argentine Sign Language, but which are sometimes "spoiled" by the lack of fine motor skills

- With unconventional sounds and/or guttural sounds.

- Pointing to pictograms or photographs

- Some draw what they want to express almost as if they are creating their own pictograms.

- Some may write discrete words that replicate the characteristics mentioned previously for spoken language. For example, for Dani, "Yarca" is Kari. These words are stable and they are always produced in the same way.

The modalities/difficulties are not only in the expression or in the output, but in the chain of preexisting meanings. At times, this network of meanings becomes evident, but other times many professionals must "go and look for them" in that conversation to guarantee that those words, which are almost inaudible and indecipherable, become a space of dialogue.

Kelsey: *Each member of Senderos del Sembrador expresses him/herself differently from the standard Argentine population: whether gestures, nonverbal sounds, repeated, but discrete words/phrases, words they created, sentence structure that does not conform to standard rules, through Argentine Sign Language, their own variation of Argentine Sign Language, etc…Therefore, it made sense that I had difficulty in understanding what they wanted to tell me. However, the same thing has also happened with anyone else that I have spoken to in Spanish. As previously mentioned, I simply asked for clarification in these situations. If they clearly did not understand what I had meant, I had the opportunity to correct them.*

In the institution, we work under the premise that every repeated **gesture** or **sign** is a word, or a **"complete language."** The same consideration exists for "obscure" sounds or words in the expression of Spanish. This position implies a change, framed in the various institutional movements, which is being made to move toward a user-centered organization. Previously, we

intended for the people with whom we work to correctly articulate words, learn precise gestures, and properly organize sentences.

But then we began researching and learning the forms of communication of each person, and moving away from the intent to modify their communication in order to prioritize the conversation. Because we agree with Bajtim that "the word is not a thing, without the endlessly mobile medium, eternally changing through the medium of social communication" and that it "never leans toward a single consciousness, a single voice". Instead, it happens from person to person, between contexts and even generations. In so doing, it does not "forget its path and can never fully free itself from those concrete contexts which were part of its genesis". Consequently, we understand that "the word is never neutral, but is rather populated by other voices" (Bajtin, 1986, p. 285).

Kelsey: *When I first chose to do an internship at Senderos del Sembrador, I knew that it would involve many challenges, especially in relation to language and cultural differences. Even with that expectation, I was still surprised by the difficulty that I experienced in my first few weeks. During most of that time, I spent time with different groups at Senderos del Sembrador and attempted to interact. My use of the word "attempted" was an intentional choice. When arriving, I feel as though my Spanish-speaking ability was not developed enough to fully communicate.*

Given that the members of Senderos del Sembrador have difficulty in their ability to communicate and each communicate in unique ways, I was hindered by my current level of the language, but also likely by my inexperience with the institution and its members. Anytime someone said something to me that I did not understand (which happened quite often), I listened, tried to make meaning of what they said, and either remained quiet because I was confused or guessed and formed a response. I also tend to do this in my normal experience of speaking Spanish with native speakers so this was not unique to the organization.

Additionally, in my experience here, if I don't understand something that someone tells me, I would ask the person to clarify. However, due to my strong American accent and my hit-or-miss structure, sometimes they don't even understand what I am trying to say. During these situations, I would look to an employee of the organization to "translate" for me and hope that I at least understood what they said. If I did understand, I would attempt to reply to the employee so that they could tell this person my answer. Sometimes, when the employee needed to repeat my answer, he/she would not make the correct interpretation of what I meant to express. I found myself involved in an intercultural game of telephone. Therefore, in a way, my lack of native Argentine spanish-speaking ability in an organization like Senderos put me in a similar situation that the members of Senderos del Sembrador potentially face all the time: I was often unable to express myself completely, relied on another person to "translate" for me, and if the "translation" was incorrect, no one understood what I wanted to express.

If We Understand Them, We Continue Talking

This institutional position was discussed by the professional team from the beginning under the premise that if a person speaks a "private language," this person will only be able to communicate in a reduced environment. This situation exists for all of the users that we work with. On the one hand, as Wittgestein suggests, the existence of a private language is actually impossible, given two "fundamental mistakes:" one, to believe that an experience is by nature "private" would imply that it could not be known by another; the other, regarding the nature of language, is the false belief that words acquire significance in an ostensive manner (Kenny, 1995, p. 149). As a result, at Senderos we work with all linguistic content that appears in whichever type of exchange no matter who it is directed to. The environment in which those words move is **already** reduced, consequently we must prioritize the conversation with whomever is available above a supposed infinite audience.

For example, if someone says "Ara?" and adds the gesture of bringing a hand toward the throat, we work in our institutional conception with the idea of "I am going to Vergara?" (Casa Vergara (Vergara House) is an assisted living house where a group of professionals and users living part-time or full-time) You respond to that statement, request, affirmation, etc. with the same **representational value** of the spoken Spanish language and with complete answers. This person says, "Ara?" and it is answered with, "Yes, today you are going to Vergara". We agree with Sullivan's concept of "consensual validation" (1953, p. 164-165) which refers to the "negotiation of the shared perception of useful truths in dialogue with respect to the others." We recognize and accept the uncertainty of an unknown truth that is neither static nor definitive. The discovery of meaning through respectful dialogue with the users occurs through our offering interpretations of different words, signs, gestures. Through this dialogue, we also search for a consensus among the users so that the conversation can continue. We say then, that the meanings are not given in an arbitrary manner, but that they arise from a sustained dialogue developed over time with the users.

We emphasize this description of the forms of communication because another central institutional change that we have made was to ***abandon*** *the idea of communication as signified-signifier*. We have started to think that the words, as we have said previously, do not have any specific meaning in themselves; they are "interindividual" (Bajtin, 1986, p. 121). They are a method to establish differences in a context and throughout the process of a dialogue. They contribute to specific meanings only in the context of that dialogue. A statement is always said in response to a previous statement and it is limited by a change in the participants in the conversation (Shotter, 2001, p. 268).

Therefore, we do not consider the forms of language that our users use to be a private language. Furthermore, we are not disposed to consider **these variations of language** as a "paralanguage", a "sublanguage," a made-up language, or a language that comes from the disability and lacks value in and of itself. We attempt, in everyday work (and this includes all the people who work in the institution), to collaborate so that the differences are noticed and established and that an honest assessment is made in each one of the intents to **give meaning** to what occurs in the coexistence of the users and the staff (managers, psychologists, artisans, yoga teachers, etc). This takes place without **us proclaiming what each gesture signifies,** since the users' word only has meaning within that shared process.

Shotter (2001, p. 178) states that "what we call our "intuitions' are derived from culture and language. What our forms of speaking represent, as situated "in" the world, are "based on" our form of representing it. This is "ingrained" in our habitual manners of speaking - whose primary function is the constitution of different aspects of life- and acts evolutionarily to complement them, to specify them, or to articulate them even more. This description adheres institutionally. That is why individual practice does not work by **guessing the individual meaning of words or sounds** without intending to learn the conceptual network that it is wrapped in. Through that act, they emerge, creating those "habitual ways of speaking" of the users in some conceptual network.

To value all linguistic exchange is an epistemological decision, based on the consideration that the difficulties that the users present are far from constituting individual character; instead, they are the products of interindividual constructions. We work with adults with intellectual disabilities who have significant needs for support, and although we do not understand the difficulties, our focus is not to work on "what is cognitive" or "what is linguistic." Often, what are called disabilities are defined from a social perspective, as a product of the interaction of the people with the environment. But then, each person **is addressed as an individual phenomenon, relocating the disability into the body of that person**. We believe that the work which considers all difficulty as interindividual is consistent with our proposals, as well as with the guidelines stated in the International Convention on the Rights of Persons with Disabilities.

We fully intend to move away from the dominant micropolitical patterns currently assigned to users, their families, and professionals.

We do not propose creating a space and bonding style which does away with the hegemony of professional discourse, but rather, we advocate exercising vigilance toward the practice itself. This is why the approaches for each one of the users is created for the users and their families uniquely. This action permits us to act as a platform of conceptual networks which support that interchange and professional practice (Gerstle, 2014).

We have previously described that the adult population enrolled in the institution has a serious difficulty in their ability to communicate in the standard manner of the space we inhabit (Argentines speaking in Spanish). Part of the hegemonic majority's knowledge that both participants and their families are subjected to requires the professionals involved to create a description that will be either meticulously detailed or not, given the difficulties in the communications process that occur. And in that tome of deficiencies, the worst of all is deficient language as an indicator of cognitive [in]capacity. Language is associated with cognitive capacity, and therefore, people with serious difficulties in expressing themselves are considered *a priori* less qualified or given a deficient value. This can be illustrated by the family's surprise when we "found out" about family news from one of our adults.

We asked a family if they had sold the Renault belonging to one of their children in payments of 1000 pesos per month. The father asked what we expected him to ask (i.e., How did we know this?), and we responded, "We knew because your daughter told us." However, that story from the user did not have the format, "My father sold the car in payments to my brother," but was pieced together through fragments, single words, and gestures. Silvina wanders around while repeating words or small sentences that make us think she verbalizes her micro dialogue while

talking to herself out loud. She always repeats the same things: "my brother", "the ball", "grandpa", "beating", "the plane". She also makes onomatopoeias. We thought of the significance of each one of those words. "Paliza", for example, is referring to a television show, "grandpa" is what calls her friend that is nearly her age, but appears old to her. Suddenly, some new words appeared. "Dad car . . . Mariano . . . (gesture for pay) . . . 1000 pesos". In the beginning, no one paid attention. She mixed these words with her habitual repertoire, but someone who was listening finally asked her about it. Others had also listened, but could not attribute meaning to what she was saying. The meaning was set up like a complex puzzle and we did not have the full-scale image of the network of meanings to which this word, gesture, and movement referred. We were able to put together the edge pieces, and then we tried to puzzle it out from there. The times of the exchanges were also brief. She said "car...1000 pesos" and someone asked, "Your father bought himself a new car?" She shook her head and left the conversation. Much later, someone asked, "Your father sold the car to Mariano?" She left the conversation again. It took a few days to finish the story. In this work of meaning, the user participated actively by, when she reappeared, saying, "Mariano, 1000 pesos" and someone clarifying and repeating. In this case, we asked her family to meet with us and collaborate with that process; the user was also present.

The classic scene is "Juan, is it okay with you if we call your (mother, father, brother) and ask them about what you are telling us?" Obviously, the user was also present when giving the response. The collaboration request can be realized through audio, a video of the sign, or with a movement that is not understood. In some circumstances, no one knows what the user is communicating except the user him/herself. Then, we hope that in some moment, some context, the meaning will appear.

In order to "encourage this finding of meaning," the distinctive institutional characteristics of the commentary on the car sale should be seen as truthful. This challenges the micropolitical axes (familial and professional) fixed beforehand for that person. We are sure that they are telling us something that is relevant to them. It requires a lot of attention because if the expression of Silvina is taken as a soliloquy or an echolalic speech, no one would listen for distinct phrases and there would be no questions regarding the meaning. Consequently, there would be no possible dialogue.

The process does not end there. When the meaning has been recognized/ co-constructed, the families, by the same means mentioned above, are called as **witnesses** of that event. Then, we probably confirm with a text message, and they might say: "Thank you for the collaboration, you are right. That movement signifies (what the word was). Juan agrees with that." Juan participated in this moment and agreed with a gesture or sound that was included in that message.

Finally, there is another essential step. The user, with a collaborator, tells all of the members of the institution. Then, the scene could be: "Do you know what Juan wants to tell us with this sign? That he is tired." It seems important to highlight that the staff expresses themselves in Spanish with words "said correctly." The professional does not distort language to imitate the user as a gesture of empathy. The user has full capacity to understand (with limitations) the Spanish of the world that surrounds him/her.

Most of the time, what is expressed and meant are not exact meanings, nor are they straightforward. Additionally, it is not an ostensive use of words. The words contain past or present meanings, experiences of all types, and requests for help to solve problems with friends, professionals of the institution, or family.

These moments are not pre-established institutional methods. It is ethical and epistemological work that arises over time and always needs to be revised. It is not identical for all of the users or even for the same user in every moment.

We utilize the micro dialogue or internal dialogue of those "conversations we have with ourselves" or with another "imagined person being" (p.16) in order to support these reflections about meaning. This attention to those thoughts is so they do not control the conversation without "assuming a position of knowledge and authority" (p.16).

We always choose to work in a team to create a context of collaboration in order to facilitate this process of reflexivity and involve people with disabilities in more meaningful ways, generate more ideas, keep listening, and be helpful. This work can be in the same moment (live) or utilized in different moments. For example, we use recordings or other technological resources.

We know that users' speech contains a great deal of content despite the difficulties they have in expressing it. Therefore, we believe that the difficulty of people with intellectual disabilities in choosing aspects of their lives is more related to the form of communication that we have provided to them, than with a cognitive deficit, per se.

Our tenacity for paying full attention to linguistic exchanges is not an end in itself. Benjamin (1988) says that there is no human essence outside the margin of historical context. It can be asserted that most of the users who enter and remain in the institution, experience some aspects of their daily lives "without contexts" and furthermore "the text", may sometimes not even correspond to that experience.

The need for responsible adults who bear witness to the humanity of those utterances or communications is vital. Our choice that those inaudible words consolidate themselves in a dialogical conversation is our **institutional mission**.

Actually, in some sense, the **users "don't adapt submissively"** (fortunately) to the macro-political dominant rules. They use institutional spaces "without permission" and they establish interpersonal links "outside of the standard rules," etc.

They are the ones who frequently question the dominant micropolitical meaning, energizing the ethical norms or frozen values.

The professionals of the institution are those who must accompany that intransigence that is not always welcome nor understood. For that reason, the task of continuous cooperation among the personnel, the users, and their families is the true axis of the institutional spirit.

Kelsey: *Fortunately, I have become a lot better at communicating with many of the members at Senderos del Sembrador through interacting with each of them. Interestingly, I have*

*also noticed a comparison between this and my interactions with the employees. Many of them don't seem to have much experience talking to non-native Spanish speakers. Therefore, in the beginning of my internship, it was fairly challenging to have any conversations with them. It may have been due to cultural and age differences, their focus on their jobs, or my unknown Spanish ability, but **they didn't interact with me very often in the beginning. Even when they did, they tended to use simple and slow questions**. I am not sure if they realized that I did want to communicate and was simply having some difficulty expressing words or getting the courage to speak up. After all, I was in a very unfamiliar situation. They may have also been thrown off by my accent or grammatical structure, thinking that because I did not produce Spanish in the same way as they did, that I must not be able to communicate in the language. Of course, cultural and age differences may have been a further challenge in knowing how to interact with me. Even I had difficulties in knowing what to say to the employees. For example, I would often stay quiet for fear of using "Usted" or "Vos" in the wrong situation since this distinction is not present in English; I also faced other cultural barriers. With practice, I did become better at this and most of the employees also started to interact with me more often.*

A further challenge has mostly come to light when interacting with my supervisor. I communicate with her in Spanish (or English) and have absolutely no idea whether I interpret what she wants to say correctly or if she completely understands what I am trying to say. This mostly occurs during my interactions surrounding my current task, translating a document to English. As a native English-speaker, my task is to read through the paper in Spanish, think about the meaning, and then write it in English. Anyone without this experience would assume the task is as simple as it appears, as did I when I agreed to the task. I expected to be finished in a week or two, have it read over, and move on. This is not what has happened at all.

*I started working on it by talking to my supervisor and her colleague, the other author of the paper, about the significance of each sentence. I read each sentence, focused on the meaning, and so that I could express myself more easily, said my interpretation in English. To my surprise, we spent over two hours discussing fifteen sentences, many of which we put aside for further inquiry. At that point, I had discovered that my previous expectations were false a**nd was left frustrated and exhausted.***

Given the effort and time it took to partially complete those sentences, we took another approach. I spent time reading the text at home and translating it myself. Not surprisingly, this approach had different pros and cons: I had time (without pressure) to think about the meaning of each of the words, but struggled to put it into my own words. Occasionally, this was the result of not understanding the concept, but I believe it also involved my difficulty in switching between languages and the uncertainty if changing the full sentence would remove the full meaning. When talking to my supervisor earlier, I had confirmation from my supervisor that I was most likely interpreting it correctly.

Despite these challenges, it seemed best to continue with the translation and make changes to the text later. I found myself unintentionally using direct translations of

*sentences, which my supervisor and I had discussed is not much better than using an online translator. I continued by trying to use my knowledge of Spanish/English structure and felt as if I had made some progress. Anything I knew that I did not understand, was written in red or highlighted in yellow. After I finished writing the translation, I met my supervisor and her colleague and discussed some of my questions. One of the days, my supervisor and I read through a part of the paper and she checked to see if it was written as she intended. As a continuation of the theme, full sentences that were incorrect, including a few that **I was confident in my translation**. Although I picked up on some variations of grammar rules, I did not catch them all. Some sentences had a completely different meaning than I had thought because I interpreted the use of a comma in the wrong way. There were words that I thought made sense, but sparked long discussions about what we both thought it meant. We continued using "Spanglish" to promote our ability to express our thoughts and ideas. For example, I would sometimes switch to speaking English when I had something more complex to say that I may not be able to express in Spanish. This was because Spanish and English have a different meaning to me. This strategy has worked well since producing words and structures in another language is often a lot more challenging than comprehending it. Using this strategy, we know that we are saying things how we want to say them. However, **there are still always potential problems in interpretation.***

Constructing Meaning

Milagros (facilitator) filmed a conversation with Adrian (user) where she shows him a photo of himself and asks him, "Is this you?" Adrian makes a mild movement by moving his head downward. Milagros sent the video as a message and said, "I see a YES here."

We cannot be sure if he said yes, but we think in accordance with Vigotsky (1979) that the internalization is the "internal reconstruction of an external object," in which a movement that fails in its goal to reach an object, becomes a gesture to be witnessed by another, a gesture for others (Vigostky, 1979, 92-93). That unsuccessful attempt is not in the object but rather in the people. It is a means of establishing relationships which are converted much later into a pointing gesture when the child relates the movement with the act of pointing. Although these theoretical developments were proposed for young children, in the case of adults who have little communicative intention, it is essential for us to be attentive and responsive to each micro gesture. We must be there to make sense of the gesture, but that attitude cannot be innocuous and should not be superficial hat is not verbal as "open to questioning." That quality obliges us to consider the "ability to give an identity to" the non-verbal as a possibility, but also a complex procedure, in which interpretations may be full of wild ideas.

In everyday life, the users are possible, if not probable, victims of being questioned, "*interpelados*," in a superficial, banal or crude way, by relatives, professionals of the institution, or other social agents.

Most of the users express themselves in a full language of iconic and nonverbal messages. This is as common in everyday life as the appreciation, assessment, and appraisal regarding the meaning of that iconicity. The sentence, "He said he cannot stand his mom" is not a dialogical

conversation. Instead, there is a voice of a subject who knows, which cancels out the voice of the user.

The institutional approach that tends to revise all of the constant exchanges is a very complex task for the professionals who work there. Generally, any statement that is said or made with an air of certainty by one of the professionals is then cross-questioned by another professional. In those terms, the sub interpretation of the gesture can be influenced by **hermeneutic injustice,** understood as a gap in the resources of collective interpretation that situates someone in an unjust disadvantage based on the comprehension of their social experiences (Fricker, 2017, 13).

Then, although it is necessary to be present and to give meaning to the gesture, that meaning should be provisional and not remain crystallized into an assigned meaning by the observer.

The Time to Express Themselves

Listening to a person with an intellectual disability can require providing an extended period of time, carefully training patience, and resisting the temptation of filling silences and completing sentences. "Manuel takes a while to answer so give him a while to think", his mom has said. We then notice that many times we asked him something and, faced with a lack of response, we simply continued along with the conversation. For example, we asked him "Did you like the food?" Manuel was silent for fifteen or twenty seconds. He moved his head to the left and right and made repetitive movements with his hands. It is easy to believe that he does not have an answer. If we carry on with the conversation, hopefully we get a yes. After his mother's warning, we tried to wait for a response. After fifteen, twenty, thirty seconds had passed, Manuel said, "I liked the food, but last night we ate the same thing at home." We don't need to describe our surprise.

As a work mechanism, in this example, we show how they are filmed and the exchanges are shared.

Mariano made a gesture by pointing three fingers to his temple. It is clear that he wanted to say something. There are various interpretations for this. Sometimes he said yes and no. For example, we asked "Is that the sign for Mauri?" He said yes. Then, the conversation continued and he was told "Yes, Mauri" and he rejected that. It was not that. A picture of the gesture was taken and sent to his mother to see if she knew that gesture. The mother explained that the sign is the Boy Scout salute. Yes, it is clearly the salute that identifies them, but Mariano uses it to speak about camp. He also uses the salute for a situation when someone sleeps somewhere other than their own home. And because Daniela is moving to another house, he also uses this salute.

The word/sign of Mariano moves among stories and contexts. He has been a Boy Scout, has gone camping, and moved houses. He has lived with other people, in his home and in other homes. Without the attentive look of someone who receives it, without questioning meaning, without open dialogue among family, that word would not have been meaningful. This, in turn, deteriorates the situation of the user. Each person is immersed in a variety of previous relationships in many different contexts. Those relationships influence the supplementation, the process through which a person supplements or responds to the vocalizations or actions of another" (Anderson. 1997, 78). The responses can be a gesture, a word, or an entire sentence.

Those contexts also influence the meanings developed within the dyad and can be transferred to other relationships.

In turn, a single word or gesture can have the meaning of a phrase or complete thought and can also in its intentionality. They can affirm or interrogate, even without a question tone. In other words, they can be at the service not only of telling, but of other searches to obtain information, reaffirm what they think or suppose, realize a longing or desire, and give a "Here!" affirmation of being present. The meanings are not fixed, nor fluid; they are constructed over the course of time (Anderson op.cit). We can't discard or ignore the contexts in which people live. In the shared game of communication, we must be open to other players, to ask and to learn, in order to supplement adequately. The word is a drama in which three characters participate; it is not a duo but a trio (Bajtin, 2011, 0. 310).

But it can also be a monologue. We have observed that some exchanges or ways of organizing conversations have a greater possibility of annulling dialogue. These are ways that appear to be dialogue but are actually monologues that are interpreted by various people. This category includes closed questions that are answered with yes or no or with a single word. For example, "Did you like the food?" or, calling for a single word answer, "Do you want an apple or banana?" We also use sentence stems to be completed with a word. Since these people have difficulty forming sentences, it isn't unusual for someone to form a sentence for them and give them space so that they can complete it with the word that comes out. For example, "Juan, tell them that Saturday you went with your family to . . . . (leaving space so that Juan can say Club)." (The word "Club" refers to the organization's weekly "Club de Sábado" -Saturday Club-activities)

Errors in Comprehension

Diego (user) told us about some problems in his house. It appears that he watches television at a high volume and did something that made his mom upset and embarrassed. He told us the details of the situation. The sentences were organized well, but some words and connectors were left out, and it was necessary to fill in those spaces. He said, "my mom became angry… she didn't let me sleep…I arrived late…She got up early…Wednesday…she gets sad. I don't like her to be sad… She doesn't let me sleep…I don't want her to become sad…watching television all day, I am not watching television all day…I want her to leave me alone". It appeared that he was watching television very late and that this angered his mother and made her upset and embarrassed. Understanding the situation appeared logical to us. We told him to tell his mom about the situation and she told us that she is sad, but for personal reasons. The element that was "bad" was that it was "bad for you to make the bus wait for him."

The more quickly we understand, the higher the risk of interpreting the situation incorrectly as we have just mentioned. We agree with Anderson (2019, pp. 12-13) that "listening is part of the process of trying to hear and understand what someone else is saying from their perspective," and that our challenge is twofold because the users speak in unique ways. Therefore, the idea of participatory activity, in which it is necessary to respond, and try to understand, becomes a more complex task. It requires more time, more patience, more restriction, and the censorship of one's own ideas in order to be genuinely curious.

In Order to Continue Constructing

The daily institutional work with adults who have intellectual disabilities and significant needs for support makes us constantly think about life quality The dimension of the difficulties that users and families face daily, and the small possibility of being participants in their own lives and break free from pre-established patterns, leads us to this search. It is on the one hand a search for a way to create this dialogue. Simultaneously, it is a search for a way to work with the families and reflect about the health systems, as well as to provide continual training for professionals. Furthermore, it leads us to use mothers' discussion groups,, and train professionals in monthly staff meetings which include the parents, brothers, sisters, and the users. These are some of the daily actions of the institution. We might think that these are common activities in any organization similar to ours, but we affirm that the difference is in how we value the words and the meanings that each of these people brings, which have been historically unappreciated because of their disability.

Kelsey: *In general, my experience at Senderos del Sembrador has been very eye opening. Through my interactions with the employees and members of the organization, I have been able to also improve my Spanish speaking ability and knowledge of the culture in Argentina. Furthermore, I have not only learned about people with intellectual disabilities, but through this unique experience, I may be able to understand them better.*

Our objective is for the users to feel like Kelsey: that they can communicate better, that what they want to express is closer to being understood, and that their interests are respected.

Indeed, there is no difference between Kelsey's experience and that of each of the users at Senderos in regards to the human need to communicate. But if the goal of the institution were to repeat the macro-political pattern of considering users and their families as people "who need to be fixed," or "lacking all subjectivity," "without words," "without bodies," the way we do things would become a self-fulfilling prophecy: people with intellectual disabilities and difficulties in communicating turn into / are turned into "people who cannot communicate."

Kelsey can find new horizons using a toolkit of linguistic, emotional and cultural tools. The users at Senderos also have a toolkit, although it in no way resembles Kelsey's.

Professionals would seem to be trained to dismiss the opinions of people with intellectual disabilities, based on the precept that as the deficit is cognitive, the opinions are therefore less valid. (Guerschberg, Rubinowicz, 2019). It is a sort of epistemological injustice, because "prejudice moves a listener to endow the words of a speaker with a lower degree of credibility. It is also a kind of hermeneutic injustice, given the preconception in which the "gap in collective interpretation places someone at an unfair disadvantage relative to the comprehension of their social experiences." (Fricker,2017: 13) These injustices cancel out the ability of certain subjects to transmit knowledge and make sense of their social experiences, discrediting their speech for reasons beyond its contents. This also reveals the ethical and political aspects underlying our ways of knowing and understanding.

Each person in our institution (professionals, staff, users, interns) is expected to pay attention to each of the details involved in the processes of communication. The words stated, the gestures, the tones of voice, the inaudible words, and the body language. We must be committed to the urgent need to understand each of these interactions within the "glossaries" of each of these people. By doing so, we begin to salvage a bit more of what is lost in translation and build dialogue that not only increases communication but indeed, expands our collective humanity.

References

Andersen, T. (1993). *The reflecting team: Dialogues and dialogues about the dialogues*. Nueva York, Norton.

Anderson, H. (1997). *Conversation, language and possibilities: A Postmodern approach to psychotherapy*. New York: Basic Books.

Andeson, H. (2017). Collaborative-Dialogue Based Research as Everyday Practice: Questioning our Myths (en línea)

http://www.harleneanderson.org/articles/newbatch/Collaborative%20Dialogue%20Research%20 Simon%20Chapter.pdf Acceso 10 de enero de 2019

Anderson, H. (2019). Harlene, conversaciones interrumpidas. Rocío Chaveste y ML Papusa Molina, compiladoras. Taos Institute Publications/WorldShare

Bajtín, M. M. (1979) [1982]. "El problema de los géneros discursivos". *Estética de la creación verbal*. Buenos Aires, Siglo XXI. 1

Bajtín, M. M. (1986). *Problemas de la poética de Dostoievski*. México: Fondo de Cultura Económica

Benjamin, W. (1998). «El narrador», en *Para una crítica de la violencia y otros ensayos*, op. cit., p. 118.

Fricker, M. (DL 2017). *Injusticia epistémica. El poder y la ética del conocimiento.* Barcelona: Herder (Pensamiento Herder).

Gerstle Echeguía., V. (2014-03). Psicoterapia Sistémica Relacional Hermenéutica: Hacia una reflexión de la relación y la constitución subjetiva en la Terceridad Sistémica. Disponible en http://repositorio.uchile.cl/handle/2250/135481

Ghiso, A. M. (2009). Investigación dialógica, resistencia al pensamiento único. En Maestros y maestras gestores de nuevos caminos. Educación, conocimiento y poder. Cuadernillo N.º. 50, pp. 12-27.

Guerschberg, K. y Rubinowicz, G. (2019). Presas de una rehabilitación que no pidieron. *Revista Española de Discapacidad*, 7 (I): 111-132

Haye, A. (2009). Acerca de la posición de tercero en el comportamiento humano. Ponencia presentada en Seminario Interno de la Facultad de Teología, Pontificia Universidad Católica

Kenny, A. (1995). Wittgenstein. Madrid, Alianza

Labelle, R., Stoddart, G., and Rice, T. (1994). A re-examination of the meaning and importance of supplier induced demand. *Journal of Health Economics, 13*, 347-368.

Stack Sullivan, H. (1953) *Conception of Modem Psychiatry.* New York: Norton.

Shotter, J., & Sinnott, E. (2001). *Realidades conversacionales: la construcción de la vida a través del lenguaje*. Buenos Aires: Amorrortu.

VygotskyY, L. S. (1979) El desarrollo de los procesos psicológicos superiores. Buenos Aires: Grijalbo.

Wittgenstein, L (1988). *Investigaciones Filosóficas*. México D.F.: Editorial Crítica

Author Note:

Karina Guerschberg
Senderos del Sembrador, Argentina
karinaguers@gmail.com

Gustavo Rubinowicz
Senderos del Sembrador, Argentina
grubinowicz@yahoo.com.ar

Co-authors

Milagros Albornoz Orfila
Senderos del Sembrador, Argentina
m.alborfila@gmail.com

Rachel Tucker
Argentina
tucker.rachel.e@gmail.com

Kelsey Kayton
University of Pittsburgh, Pittsburgh, United States
KRK87@pitt.edu