

Un-scripted: Co-building dialogues between families and professionals

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Abstract

This article tells the experience of a therapeutic support group for mothers of adults with intellectual disabilities in the setting of the services provided by an Adult Day Centre. This group meets weekly gathering around a shared and determined definition of an issue: the care of adult children with important support needs and how, mediated by a professional intervention seeking not to reproduce oppression situations, what we deem an epistemological twist occurs from which these women can critically analyze both the health system journey, where they have been and still are stigmatized and their opinions are devaluated a priori, and its unfulfilled rehabilitative promises, as part of a testimonial injustice practice. Complementarity between professionals and families is sought abandoning all ideas of a 'cure' or 'solution' and appreciating local knowledge. Dialogues that allow for reviewing concepts such as social constructs of disability, medicalization of PWD's lives and feminization of care work are co-built, encouraging a space for resistance to these narratives, for understanding their children as subjects of rights, able to make decisions without responding to the ableist imagination. In this context, new ideas arise about care and how the adult children (and the mothers) 'manage to live their lives'. We are not saying that these women have been and no longer are victims due to our intervention, but that the possibilities to re-think life and to build new narratives have been extended as the group progressed.

This paper is not 'about the mothers', nor 'about being mothers of disabled people'. Instead, this article is about the reflections on how professionals can assist/support people and families in their quest for better lives, in any path they choose.

Key Words: *intellectual disabilities, collaborative dialogues, therapeutic group, epistemic injustice, local knowledge.*

A Therapeutic Group

Our professional intervention takes place in a Adult Day Centre providing services to adults with intellectual disability and extensive support needs. Most of the people we work with has one or several of the following: lack of the expressive language expected for adult age, reduced vocabulary with grammatical structure deficit, use of intelligible words, disrupted structural organization, signs, gestures, guttural sounds, pointing at pictures or images, drawing or writing certain words with the same difficulties as spoken language. They are between 30 and 50 years old, and they further require support both for basic and instrumental activities of daily living as well as behavioural support, usually provided by their female carers, generally mothers who are between 60 and 85 years old. We refer to basic activities regarding the ADLs definition: activities oriented towards taking care of one's own body; we refer to instrumental activities as those related

to IADLs: activities oriented to the interaction with the environment (Rogers & Holm, 1994 in AOTA 2014).

The physical and mental excessive burden involved in this task for the female carers, over the years and with no end on the horizon, is one of the factors deteriorating the quality of life of the family group, the female carers, and the people with disability. Further, it is accompanied in this life stage by the onset of other health conditions in all the family members. Based on this care dyad, we understand that it is not possible to care for our users as isolated subjects. The institution's interest is focused on the observation of how the whole system works, and its purpose is to create supports that take this situation into account.

As one of the ways to collaborate with the families, it was suggested the organization of a group 'for mothers.' It was first designed for the mothers because they have more contact with the institution, they are more used to being summoned in relation to their children's care and to sharing experiences, and they carry the bigger burden of care. Within the institution, there are also groups for fathers and siblings, which differ mostly on how frequently they meet, but are not the object of this paper.

Redefining the Issue

The group is created around a definition of issue: ideas on care of adult children. It aims to generate a dialogic space, defined by Morado (2017) as a relational way encompassing the interaction between someone else's word and one's own, in a reciprocal process of positional delimitation or clarification. These women are asked to talk without a previous idea and, as a professional team, we live this moment of meeting 'from the inside', contributing with a 'know from' with no attempts to normalize any one of the speeches. These women are asked to participate in a space that allows them to move away from domesticated discourses, if there were any, and to try to begin travelling a novel path of their own narrative. Whatever therapists can say is not new; however, it is novel to provide new ways to say what has already been infinitely said about 'your children's disability and your family's experiences'.

In the first meetings there were narratives about disability constructs with a solid stamp of the medical/rehabilitative model: who and when made the diagnosis, or the lack of a diagnosis, extensive explanations about physical problems told with medical terminology, descriptions of medicines including drug names and doses. It seems that talking about their children is talking about their medical records.

We observed how these stories become dominant in the families' lives and, because they are very restrictive, exclude other aspects of the life experience and lead to negative and limiting conclusions about their identity. The 'disability story' is a narrative saturated with problems (White & Epston, 1993), with feelings of hopelessness, frustration and anguish, which prevents other narratives. Part of the group's aim is to promote the surfacing of alternative stories to the official binary narratives about 'being disabled' or 'a mother of', in which the experience includes other moments of life, and the existence of these children surpasses the situation of disability, with the firm conviction that both the women and their children are more than 'disabled' and that those stories, of them as just people, need to arise.

When we are in the midst of the dialogue, we do not expect nor seek any ‘results’, rather we are present in the moment, in the conversation. We try to understand what the women want us to understand, in the best possible way. We try to approach their stories with curiosity, but also with respect, knowing that we are both hosts and guests.(Anderson, 2007)

This text was sent for consideration to the group for mothers and we had a specific meeting to discuss about it. Throughout the text we will include the women’s commentaries with this format (in italics and with indentation).

‘What had caught my attention was this thing of being invited to the meeting. Although I get that you are the ones that organize it, at several times I felt that the meeting was ours and that you are changing places. Like, you are listening and we invite you to come in... other times I felt you are next to us, you are inside the topic we are talking about, and other times I thought you were the hosts’.

We created this space of meeting but, at the same time, we went inside their stories, their lives, with the care pertaining to the Anderson’s Not Knowing stance (1992). We do not know anything nor we claim to understand anything about these women’s lives, because we are abandoning the aspirations of being experts ‘on disability’ that we acquired in our specific university education and our previous professional career in institutions within the rehabilitative model. The institutional space offered is a dialogic space, housing all kinds of experiences regarding what these women feel. The ‘way’ this is offered promotes the appearance of other experiences where, instead of a ‘single trauma’, a network of new conceptualizations can be built relating to what disability means, thus extending or modifying what these women think about their children, particularly in this life stage where the women are elderly adults and they know that the changes promised by the medical/hegemonic system will not happen. We tried to move away from the dominant micro-political patterns assigned to users, families and professionals.

Making available a way to dialogue about these subjects contributes to modifying the narratives on what these women think on the behaviour their children have and will continue to have through their lives.

Developing the Group Experience

This group has been in existence for almost 3 years, and there have been several phases that we have identified as follows: complaint form, listening without judging, and moving away from the script.

In the first phase, the meetings were tinged with the medical record narratives, mentioned above as complaints about their children’s situations or about the services received. The professional intervention consisted in building a new way of listening marked by respect to all opinions, focusing on paying attention and understanding what every person says, not trying to find solutions, but do trying to be responsive, that is, to be at the service of what they are saying in that moment, ‘being in the moment’. Shotter describes this response trait as spontaneous, responsive thinking that becomes available to us in our relations with others, when we can enter into dynamic or dialogical relations with them. Our responses occur spontaneously and directly in our living encounters with an other’s expressions Since are created within the present moment, the dynamic

flow of the conversation, based on what is needed and in the way is needed at the time. A relational receptivity where the conversation ‘is dynamic and the opinions and feelings interweave along the “gap” between us ... joining us through responses created and tailored to that particular instance...’ (Shotter, 2006, p.53).

We consider that this first phase of building a particular way of listening is one of the key elements why there is a change in the communicational logic of the group, where a resolution of the things being said is no longer expected and people start to trust that it is possible to express what you think or feel without being judged. This way of interaction is unusual, which is why it takes time for it to become part of the group’s culture. It involves creating a new form of engaging in a dialogue.

‘One very important thing achieved with the group is that all microphones are on (at the time of writing this article we are going through the COVID-19 pandemic and the meetings are taking place by video conference.) and nobody interrupts when someone else is talking. We were mothers who barely knew each other and such an affinity has been created that we even have a chat group. Sometimes we complain in the chat group, but it is as respectful as during the meetings. A community of mums has been created beyond “Senderos” (“Senderos” is a short familiar way to refer to the Adult Day Centre’s name) and you. I haven’t always experienced this, I’ve been in other groups for mothers where this is not the case. There is affection and respect between the mums. I find this very interesting.’

Starting from the clinical and/or epic narrative of ‘special motherhood’ we can begin a journey through a safe space where other things can be said, things that get “bad press”, such as tiredness, weariness, even saying that the love they feel for their children is not unconditional or constant, or that it is possible to wonder about the existence of that love. And the presence of the other mothers supports them, accompanies them, doesn’t judge them.

‘While you’re the professionals, you put yourselves aside to be able to learn from us. To come into the family, into the lives of every one of us. To listen to a mother saying that she is fed up and not be judged by anyone else... I can say anything I want and I can even not say anything. I can respect the mum who is speaking. The assistance being given is not pity but support even in the silence.’

‘In this group, we are brought together by common life experiences, but there is an openness that leads to other human, personal experiences.... There is space for an emotional side, for philosophy. There are no limits, though it is focused on the experience of “being a special mother”, and it has been interesting for me to question the “special” part of the equation and to look at our children as people, who also have a disability. To see the differences as something shared by all human beings and not to focus on the “special” in them.’

The professional collaboration consists in listening attentively to these narratives, with no conditions to the things each person wants to tell or how they want to tell it. To this end it is sometimes necessary to maintain silence and, other times, to ask questions. Various tools are needed for this to happen, so that the voices and the silences of all mothers can coexist.

'This is a contained space where you are advisers... or goalkeepers... we sometimes kick penalties, and sometimes you catch the ball, other times you don't, but you are there...'
'The silence is also appreciated. No one has the answer, but you feel that you will be understood.'

It is necessary to constantly pay attention to the tones, gestures, and other verbal expressions of every woman. The present and the past live together; stories of overcoming adversity, narratives of new disease, as well as death. And we 'are there,' paying attention so that no one 'falls off the boat'.

'In this group, we sincerely listen to each other. If you do not understand, you insist on it or you wait, but we always try to really listen in order to understand. The things each of us can comment may be more or less useful, but being listened to is really useful.'

'I feel that in this group I can say the things I do not dare to tell in other places. I know that it is not about saying something for the sake of it. The person who speaks really feels what they are saying. I think it goes beyond us having a common issue, for me it has transcended that. I am really surprised every day.'

So that every word is listened to, our contributions are gestural (to do or avoid gestures) or silent, positive connotations, questions that intend to open paths (Tomm, 1987) in order that the person continues speaking, or broadens or expands meanings, or summons other voices (what do siblings, parents, friends say). We never ask questions about details in order to favour what we consider a morbid curiosity. We cannot describe in which moment or due to what situation we choose one or another of these alternatives. These decisions depend on the ethical and philosophical stance before listening that we have previously pointed out, and that is the reason why they happen 'in the conversation' and cannot be previously planned. It is also necessary to pay attention to our internal dialogues.

We consider that social representations on disability create a stigma on the families and particularly on the mothers, resulting in a lack of collective interpretation resources which restricts their understanding of their own experiences; this is what Fricker refers to as hermeneutical injustice (2017, pp. 17-18). The professional world devalues and colonizes the speeches used to narrate these families' lives. Therefore, there are also situations of testimonial injustice, that is, the person who listens (a professional in this case) structurally and systematically discredits the mother's narrative. Thus, within the field of disability, phrases such as 'the kid is pretty okay considering the family he has', or 'we all know how the mothers of disabled children are' are not unusual. The combination of these two situations sets up an epistemic injustice, where someone is 'specifically wronged as a subject of knowledge (2017, p. 45)'. It is not considered that they have knowledge, neither about their children (the reason why behaviors are prescribed) nor about other subjects. We believe that we need fair practices, focused on dialogue, against this injustice.

'What gives me pleasure is that there are professionals who know about the subject and try to learn from the practice and not the books. Generally, the professional manages things based on the detached text in the books and undervalues the mum's position.'

However, you place yourselves in a position to listen to the experiences gained by being mothers for so many years. It usually doesn't happen, the professionals don't usually take the mother's words as valid.'

'There is a respect for the circulating word, the things being said have a weight to them, they transcend. Every meeting leaves a mark and you continue to think...'

Going Off Script

After the first moment where the professional collaboration aimed to establish a form of dialogue, we began a new phase where we shared our professional and theoretical knowledge on an equal footing, proposing texts to read and openly discussing our reflections and ideas about them and their children, as well as our objectives for the group. The different layers of these women's lives -who use this space to reconnect with hobbies, ideas, projects, know-hows- begin to reveal themselves. As professionals, we reinforce our idea of Not Knowing about their lives. And as Anderson says, 'by ethically listening, we do not make an effort to change the other person, but we allow ourselves to be influenced by them'.

We thus stop being restricted by that script (our script on how to be 'professionals' and their script on how to be 'mothers'), leading to enough space for new stories to come on stage. There is a place for humour, for routine and especially for novelty. And there is a place for building a new way to collaborate.

We consider thus that the therapeutic intervention in this group is an epistemological twist, because it resists the social constructs on disability and the power relationships where professionals usually have an epistemically unjust opinion on families devaluing and stigmatizing *a priori* the families' comments.

Planning the Meetings

There is a nodal moment in this experience. When a meeting ends, the coordinators remain talking about and reflecting on the feelings and the experience that each of us has had in regards to their performance. Have we risen to the occasion? Have we been able to understand and assist the group and the mothers who have participated? Is it necessary to contact someone during the week because of a particular suffering? We have to clarify that we do not stay talking 'about the mothers' or their stories, nor we hypothesize or analyze what has been said during the meeting. Sometimes, we have to make an effort not to do so, particularly when the topics that come up are more attractive. This reflection exercise ensures the well-being of everything that occurs in the group, because it condenses the strength of the situation that has just happened. We reflect on our performance based on our objective, to foster dialogue, and the first ideas for the next meeting appear. In some cases, the mothers themselves propose the 'next topic'.

After each and every one of the meetings, while we are reflecting, we begin to receive Whatsapp messages with the repercussions. Some are thank-you messages, others are reflections on the experience, some are joy or strength emoticons. That is why we talk about condensing. The interwoven emotions allow for moving away from the imprisoning narrative and favour the novel one.

'It seems like we are mums of a personality that would not allow domestication'.

A Demanding Group

As we mentioned above, we work with 'our cards on the table'. And so the group starts to demand more and more of our creativity and reflection. In order to include items novel enough to create new dialogues, we resort to theoretical texts, literature, TV shows, music, paintings.

'Something I like, and that is why I'm really happy when you send texts to read, is that I think we need to have a space to stop talking about our children. I think it is really good that we also talk about other things, that we learn from texts, that we give opinions, that we put our heads to work, and that we are women with things inside of us besides the disability.'

Yet the mythical narrative of the disability has such a gravitational force that, when we create too much discomfort or not enough incentive, it comes back and it hijacks the meeting.

Even poetry has had its place, not proposed by us but coming from the work of Laura, one of the mothers in the group, who wrote a text with her group mate's words, as if following the ideas of White and Epston (1989) on therapeutic documents. The poetic language works as 'an act of resistance to the established preconceptions and the social limitations' (Kristeva, 1974).

The Women Say

In the meeting on the 3rd October, 2020, we asked them what they thought of the way the group works and if there was something we could do differently. During the next meeting we offered to send this paper to anyone who wanted to read it and help and collaborate with it. We also organized a special session to discuss the article. This is our way of researching in the practice (Guerschberg, Rubinowicz, 2019) and of co-building knowledge. We included through the text, as quotes, some of the women's words. Other words are transcribed below. As with any editing process, the things left out are in no way less valuable and we are committed to every single word, the ones included and those who are not.

'I think that it is necessary to talk about what we're living; in a pandemic, through Zoom, we are managing to stay in contact, to see each other, to feel that we are together, to end the isolation, to feel that you are in our homes; we are no longer alone. We can talk to other people who also share a similar experience'.

'The account I read on "the meeting of mothers" shows, besides a great professionalism, a deep understanding of the families of people with disabilities and a great respect for the opinion of the mothers, which is very rare in other groups I've been a part of. I completely agree with everything said about feeling that you are being listened to and not judged. I also liked the ideas of adding hints of humour to lighten up painful subjects and of respecting the silences.'

'The word that comes to my mind is communion. There is a union and all of us take the same communion, being a group of mothers so different, there is a union that we have managed to respect, to listen. Even when we disagree.'

'I think you want to generate a change with what you are doing. This is no ordinary group. I know a lot of young mothers with young children with disabilities. The only contact is through social media. And I think, those mothers, those families... Will they go through the same things as we did? Will they have the same model, the rehabilitative model?'

Joint Conclusions

Our conclusion is obvious, but sadly not so much. These women are more than 'mothers.' Their children are in a situation of disability, and there is no possibility for this not to happen. The social model, which assumes that the disability is an interaction between the society and the barriers, is not enough to explain the difficulties, the pain or the effort that their care and support entail. The rehabilitative models have not contributed either, since the promise of normalization (whether explicit or not) results in families dedicating their lives to treatments and putting themselves off until a later time that never comes.

Throughout this text we have chosen not to use theoretical definitions for the issues we have described, such as the decision to prioritise the narrative and the co-building performed between the professionals and the mothers. That is why we did not include the definition of 'feminization of care work' when talking about how the mothers are the carers, nor we specifically identified 'ableism' when recounting the social representation of people with disability. But all those ideas are part of our theoretical expertise, and they are present in ourselves while we intervene in the group, because the Not Knowing stance has to do with each persons' life, not with theoretical subjects that affect everyone's lives. In this text, we took a similar stance to the one we have in the group.

This text has no ending because we hope it will be the source of new dialogue.

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Laura's text

(Laura originally wrote the text in Spanish and we invited her to translate it into English. This translation also belongs to her / us.)

My father-in-law used to tell about a salesman in a warehouse, who when they didn't have something that customers asked for, he answered: "There is but not left"

Much more hopeful than the best known "It is what it is."

In this story there are other women who that Monday could not enter and stay, so this group is not only what is seen but also what is not seen.

Monica says, there is life and death as the jasmine has in itself the white and the yellow; there is guilt and apology in what Cristina points out about her good intentions, then trampled like mushrooms by impatience; there is freedom to choose in the repression according to Alicia who has preferred to leave the anguish locked up in order to go out into the world without relapsing.

There are also those who love and those who do not correspond, like Raimundo and Leo, the characters of Benedetti, as Rosana looks at in the light of that precious anecdote of María Alejandra in front of the mirror rehearsing love over and over again in the sound of the word Apo.

There is union and separation in Graciela's analysis when Leo pats Raimundo: - "Your human accent still shows"-.

For Licia there is a vital sequence in falling and getting up, and from her experience she rescued being attentive, not to prevent the inevitable falls, but to take advantage of sliding smoothly as long as this lasts. It seems like a ski lesson, done in the Alps.

Susana is awake because there is light in her but, even with such clarity, she is faced with areas of shadow and, although more and more she is satisfied with the chocolate ice cream and cookies, she wishes to understand by Franciscan love that of putting herself in the others place.

Ángeles searches and finds a day of glory in which Charly's eyes light up twice and the two of them, lie in the evening sun.

Ana María, Azucena and Liliana choose to be the ones who silently watch the conversation and think of their lives as Cortázar's character.

Milagros tells of her life in Senderos where she is the strand through which simple words, half words, letters, shouts, and sharps gestures or out of focus signals; they hung from her and use her as a trampoline, a snowy mountain, a cat's back, a stairway or a mirror. A strand like a guitar string where communication strums until it can loosen and roll, slide and vibrate, jump and reflect to jerk and shoot; outside the support of the thread, far and without needing to be deciphered.

Gustavo, the psychologist, suggests that he doesn't read Cortázar, but his mother did read him. However, it is remarkable how Gustavo's humor rests on the seriousness of his professional commitment. Something that looks like Cortázar. Gustavo must be told that mothers do their children also reading.

And Karina, "la Karina" proposes, what if we think that not understanding is not a problem?

I think of everything that would answer that question if someone else asked me. No response, a divine door slam, well loud and dispatched. But it's Karina and then yes, I keep thinking, what if it's not a problem? Because there is a good chance that it is not and, as in the story of relapses, the point is that we no longer know where we are

Texto de Laura (originally written in Spanish)

Mi suegro contaba de un mozo de bar de ruta, que cuando no tenían algo de lo que pedían los clientes respondía: "hay, pero no queda".

Mucho más esperanzador que el más conocido "es lo que hay".

En este relato hay otras mujeres que ese lunes no pudieron entrar y quedarse a conversar, por eso este grupo no es sólo lo que queda sino todo lo que hay.

Dice Moni, hay vida y muerte como el jazmín tiene en sí lo blanco y lo amarillo; hay culpa y disculpa en lo que señala Cris de sus buenas intenciones luego pisoteadas como hongos por la impaciencia; hay libertad de elegir en la represión según Alicia que ha preferido dejar encerrada la angustia para poder salir sin recaer. También hay quien ama y quien no corresponde como Raimundo y Leo, según lo mira Rosana a través de esa preciosa anécdota de María Alejandra frente al espejo ensayando una y otra vez el amor en la palabra Apo. Hay unión y separación en el análisis de Graciela cuando Leo le hace la palmadita a Raimundo: - "todavía se te nota el acento humano".

Para Licia hay una secuencia vital en caer y levantarse, y de su experiencia rescata estar atentos, no para impedir caídas, sino para aprovechar deslizarse sin tropiezos el tiempo que esto dure. Parece una lección de esquí, eso que se hace en los Alpes.

Susana se desvela porque hay en ella luz pero, aún con tal claridad, se enfrenta con zonas de sombra y, aunque cada vez un poco más, se conforme con el helado de chocolate y un bizcochito, desea entender por amor franciscano eso de ponerse en el otro lugar.

Ángeles busca y encuentra algún día de gloria en el que los ojos de Charly se encienden el doble y los dos se tienden al sol del atardecer.

Ana María, Azucena y Liliana eligen la mirada que participa en la conversación como silencio y sigue más allá de la charla en el pensar la vida del personaje de Cortázar.

Mili dice de su vida en Senderos donde ella es hilo por donde las palabras enteras, a medias, a letra, a grito, a gesto completo o desenfocado; se le cuelgan y usan de trampolín, de montaña nevada, de lomo de gato, de escalinata o de espejo. Un hilo como cuerda de guitarra donde la comunicación rasguea hasta que puede soltarse y rodar, deslizarse y vibrar, saltar y reflejarse para tomar envión y disparar; fuera del apoyo del hilo, lejos y sin necesidad de ser descifradas.

Gustavo no lee a Cortázar, es psicólogo y su madre sí lo leía, o sea Karina ni te gastes. Sin embargo es notable como en Gustavo juegan el humor con la seriedad del compromiso. Algo que se parece a Cortázar. Hay que contarle a Gustavo que las madres hacen a los hijos también con lo que leen.

Y Karina, “la Karina” dice ¿y si pensamos que no entender no es un problema?

Pienso en todo lo que respondería a esa pregunta si me la hiciese alguien. Ni respuesta, un divino portazo, bien sonoro y despachado.

Pero es Karina y entonces sí, me quedo pensando ¿y si no es un problema? porque hay grandes probabilidades de que no lo sea y como en el cuento es que ya no sabemos dónde estamos.

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