

When Family Language Policy Meets Crip Linguistics: An Autoethnographic Study of a Russian-speaking Transnational Family With a Non-Speaking Autistic Child in Sweden

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Abstract

This autoethnographic study describes the dynamics of multimodal communication in a Russian transnational family raising a non-speaking autistic child with an intellectual disability in Sweden. Grounded in the principles of Crip Linguistics, the research challenges modality chauvinism of dominant language policies, emphasizing the fluidity of communication and the importance of linguistic care work. The study documents the family's journey through various communication methods, including Picture Exchange Communication System (PECS) and Augmentative and Alternative Communication (AAC) technologies. It examines the gradual shifts in the language policies adopted by the family, revealing the complexities of maintaining Russian at home while navigating the Swedish educational system's expectations. The narrative explores the institutional and societal challenges experienced by the family, focusing on the lack of support for AAC in minoritized languages, and the broader implications for access to communication for autistic children. By presenting a personal narrative through a lens of broader social issues, this study advocates for a more inclusive and flexible approach to language policies that respect the diverse communicative needs of autistic people and their families. It suggests that effective support systems and recognition of the multimodal nature of communication are crucial for maintaining their linguistic and social well-being.

Plain Language Abstract

This research shares a personal story of a Russian family living in Sweden, raising a non-speaking autistic child with an intellectual disability. It looks at how the family has learned to communicate in many different ways and how it does not always match with what the schools and language policies expect. The study also talks about the struggle to keep using Russian at home while dealing with a system that mostly supports Swedish. The study highlights how hard it can be to find support for communication in a language that is not used by most people in the country. It shows why society needs more flexible and inclusive language policies that respect many ways people communicate. This research encourages everyone to make sure autistic kids and their families get the support they need to communicate and thrive both at home, at school, and in their communities.

This paper is a reply to the call by late Jon Henner and Octavian Robinson (2023) to use *Crip Linguistics* through the notion of disidentification—the act of distancing oneself from normative linguistic identities and expectations (e.g., “fluent speaker”, “native speaker”, “language delay”) that often privilege spoken, monolingual, and linear language acquisition and use. Crip Linguistics is “a resis-

tance against monomodal, spoken language only policies, and the belief that there is one *right* way to language” (Henner & Robinson, 2023, p. 15) that promotes different understanding of language and language competence (Canagarajah, 2023). In Crip Linguistics, disidentification also refers to the process of challenging normative assumptions about the ways disabled people

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use and experience language. It contests the deficit models of communication that label disabled ways of communication as “deficient,” celebrating the unique, and multimodal ways that disabled people engage with language.

This is not my first attempt to write about the nuances of multimodal communication in families with non- or minimally speaking autistic children. My MA thesis focused on Family Language Policy (FLP) (Spolsky, 2012) in transnational families with bilingual autistic children, and the issues of *recognition* and *redistribution* (Fraser & Honneth, 2003) when it comes to access to healthcare and education. During my MA research, I decided to take on the identity of a strict and cold researcher, the one who always maintains a researcher status and uses their “detached ethnographic voice” (Behar, 1997, p. 17). While I enjoyed conducting that research and interviewing families in similar, yet always unique situations to mine, I could not stop thinking about my authorial voice and my *heteroglossia* (Bakhtin et al., 1994)—coexistence of multiple voices and perspectives as a researcher, observer, immigrant, caregiver, and a member of autistic community.

Reflecting the multiplicity of my voices, this paper is structured as a continuous narrative without any chapters or visually separated introductions or a conclusion. As much as we like to compartmentalize our lives into epochs and periods, I do not see my autoethnographic research as a “voyage through the long tunnel” (Behar, 1997, p. 8), but more as a chaotic movement through a continuous loop of both hope, love, expectation, and despair. The main goal of this structural choice is, hopefully, to give the reader an opportunity to reflect about potential “solutions” to the described challenges, or inability to find any.

I focus on my attempts to approach the study of multimodal communication and the dynamics of FLP and Language Policies and Practices (LPP) (Spolsky, 2012) in Swedish Special Education using autoethnography as the main method of analysis, which “should be ethnographic in its methodological orientation, cultural in its interpretive orientation, and autobiographical in its content orientation (Chang, 2016, p. 48)”. In this essay, my goal is not to be the voice of a whole autistic community, but to present a perspective of a Russian-speaking transnational family raising a non-speaking autistic child with an intellectual disability in Sweden. Similar to Behar (1997), I believe that presenting a larger problem through a lens of a personal story is more accessible to a reader as “personal voice, if creatively used, can lead the reader, not into miniature bubbles of navel-gazing, but into the enormous sea of serious social issues” (p. 14). This attempt could be potentially critiqued for prioritizing my subjective experience above a collective one, but I decided to situate myself firmly with Behar’s (1997) belief that the beauty and unique nature of autoethnography is in the fact that you are always present. This presence can make it visible how caregiving, communicating, and epistemic struggles are shaped by societal ableist systems and linguistic norms.

In its traditional meaning, autoethnography is “a qualitative research method that utilizes ethnographic methods to bring cultural interpretation to the autobiographical data of researchers with the intent of understanding self and its connection to others (Chang, 2016, p. 56)”. Autoethnography, as practiced in this study, is not just a narrative technique, but a methodological and ethical orientation. My experience as a neurodivergent immigrant mother of a disabled child in Sweden leads to a unique positionality as both insider and outsider of the institutional structures I critique, as well as a Crip co-languager. I draw on Behar’s (1997) framing of the *vulnerable observer* as a researcher who acknowledges that their emotions, lived experiences, and physical presence can influence the research process. This framework recognizes all the emotions of witnessing, and the impossibility of neutrality in observations close to one’s personal and political stakes.

While an ethnographer can always pack suitcases (Behar, 1997, p. 8) when the data collection is over, the vulnerable observer stays with it and continues to live it, laminating the brief encounter with oneself or their life. As a result, autoethnography transitions from a researcher’s “voyage” (Behar, 1997, p. 8) to a stay-in and, similar to sociolinguistic ethnography, “carries a strong orientation to the discovery of the local, uncertain, unpredictable and changeable positioning of the participants in interaction” (Pérez-Milans, 2015, p. 103). Rather than claiming neutrality or distancing myself from the collected data, I write from within the beauty and messiness of caregiving, emotional and communicative labor, and bureaucratic entanglement. My subjectivity is not a methodological weakness, but a tool of knowledge production in a unique context, that can help recognize care work and research not as opposites, but overlapping forms of attention.

When I think of my reader, I am speaking to both the neurodiversity movement, parents with different attitudes and levels of acceptance of neurodiversity, and every policymaker and corporate entity responsible for alleviating or burdening the lives of autistic people and their families as my main audience. While they might be quite familiar with the types and principles of Augmentative and Alternative Communication (AAC), I feel that I owe an explanation of some key terms to my reader, making this paper more accessible.

What happens if an autistic child never speaks, develops a small set of spoken words, or goes through periods when they cannot speak or choose not to speak? In many families, including ours, these scenarios lead to the introduction of alternative ways to communicate. About one quarter of autistic individuals remain non-speaking (Reichow et al., 2025). In general, the choice to introduce alternative communication depends on a number of factors: the person’s motor and cognitive profile, fine motor skills, family or school preferences, access to services, and, just as importantly, the family’s socioeconomic situation, the public or private nature of healthcare and education in their country, and national language policies.

AAC is usually divided into two broad categories: unaided AAC, like gestures, sign language, or key word signs, and aided AAC, which uses external tools such as picture cards, communication boards, writing systems, speech-generating devices (SGDs)¹ or apps that can be installed on an iPad or other tablets (Ganz et al., 2014). The success of these tools varies depending on the individual, the presence of other additional diagnoses, and how well AAC is introduced, supported, and maintained (Reichow et al., 2025).

One of the most researched and widely used communication tools for non-speaking autistic children is the Picture Exchange Communication System (PECS) (Bondy & Frost, 1998). It was designed to support independent communication through exchanging picture cards, and it is often described as a method that does not rely heavily on prompting or formal training (Reichow et al., 2025). However, in my experience as a parent who received unofficial online PECS training from a Belarusian speech pathologist in Russian and paid for it from my own pocket, I find this to be an oversimplification, especially when it comes to community partners like educators and aids. PECS consists of six structured phases, from Phase I, which teaches children to exchange single pictures for corresponding items or activities, to building short sentences and responding and commenting to questions in later stages (Suchowierska et al., n.d.). Reaching every stage takes time, support, and a lot of repetition. For many families, progress is not linear: they often have to “repeat” one phase or another depending on the day, setting, or level of support available.

In the case of our family, the PECS training was only received by me, and it was not part of the formal certification process offered by the Pyramid Educational Consultants (Bondy & Frost, 1998). My instructor had a PECS Implementer Certification, despite the challenges of obtaining one if you are located in a country like Belarus or Russia. Currently, the Pyramid Educational Consultants has no office in either Russia, nor Belarus, offering its support through the German distribution center. It offers training in Russian only for Phase I, and in English with Russian subtitles for Phase II. Thus, the official training in Russian is limited only to the phases that teaches requests as the main communication goal.

Similarly, although I was guided through all PECS phases, I received follow-up support only for the initial two. Due to the lack of professional guidance and my son's difficulties with picture discrimination and sentence building, we have not progressed beyond the early phases. This appears to be a common experience with PECS, as autistic children, particularly those with intellectual disabilities or other co-occurring diagnoses, often progress through the first three phases but face increas-

ing barriers in later stages without consistent support and resources (Wannapaschaiyong et al., 2025). While it is often described as a structured system for promoting functional communication, in practice, the boundaries between “formal” and “informal” usage blur—especially when access to training is fragmented, language materials are limited or unavailable, and parents are left to work with the protocols on their own. It is also unclear how families with autistic children in Russia are expected to order PECS materials or training from the official webpage, as the only available payment method is PayPal, a payment system currently inaccessible due to sanctions.

This lack of infrastructure is not unique to our transnational experience, nor is it limited to Russia or Sweden. It reflects broader systematic issues in how AAC is conceptualized, implemented, taught, and supported. In both countries, despite the fact that Sweden does not have to deal with geopolitical barriers in accessing AAC, formal training in alternative education is scarce, can be expensive, and is rarely offered in languages other than the national majority. Follow-up support is minimal or non-existent. As a result, much of the burden of implementing and sustaining AAC falls on families, their finances, initiatives, research, and time. What appears as a matter of “choice” and preference is, in reality, the product of neoliberal logic of self-responsibilization (Braedley & Luxton, 2010), where individuals internalize responsibility for care as their own rather than the state's, turning care into a private responsibility. This is a major language hegemony issue, embedded within national and global AAC infrastructures that continue to prioritize normative, monolingual, and speech-centered modalities of communication.

High-tech AAC, like SGDs or communication apps on tablets, is also not an exception and has a learning curve. Unlike PECS, there are no standardized or evidence-based training protocols for using these systems (Alzrayer, 2020). Most guidance comes from the manufacturers' webpages, which vary in depth and quality. Many community partners² and members of the autistic community prefer high-tech AAC tools partly because they, unlike PECS, are not linked to applied behavior analysis (ABA). Despite the increasing promotion of high-tech systems, research suggests that both PECS and high-tech AAC are equally effective for supporting basic communication skills like requests (Agius & Vance, 2016; Boesch et al., 2013). Some studies even support using the PECS protocol for transitioning to high-tech AAC (Alzrayer, 2020). To summarize, research supports the use of aided AAC systems over unaided ones (Ganz et al., 2014), but also emphasizes that there is no one-size-fits-all solution. Choosing the right AAC and getting the right

1 Also occasionally referred to as voice-output communication aids (VOCAs) (Lancioni et al., 2007)

2 I am using this term for family members, educators, and other practitioners that communicate with and about an autistic individual

support to use it remains a complex decision, especially for immigrant families.

Before our family got access to an AAC app in Sweden, we used PECS in Russian with my son. The materials we used were not adapted to our multilingual context. This AAC system requires constant access to materials like paper, a printer, a laminating device, a special digital library with pictures, Velcro bands, and an album to store all the cards. While most of our strategies mirrored PECS' structured format, we lacked access to official PECS materials, certification, or regular in-person instruction. This highlights a broader issue of limited access to structured AAC training for families outside dominant language and geographic centers of the communication system. One of the reasons our family decided to switch to high-tech AAC was the need to frequently replace lost or damaged cards, and the vocabulary limits of such a method, as the album could only fit up to 200 cards. In contrast, a robust high-tech AAC can support tens of thousands of words as a fringe vocabulary tied to particular categories (e.g., animals, foods, feelings), allowing the user to navigate by topics (see [Figure 1](#)(right)), routines, or environments and providing morphology support and grammar scaffolding, like color-coding parts-of-speech (see [Figure 1](#)(left)).

The main reason for the switch, however, was our realization that PECS could mainly support only one communication need: a request. While both PECS and high-tech AAC can support a wider range of communication functions, such as commenting, asking questions, forming a phrase or a sentence, PECS takes more time and motor skills. In addition, PECS cards are literally laminated as part of conversations with autistic children. At the same time, pictures in high-tech AAC are digital representations of such "laminations" that can be easily adopted and changed if you need to change a suffix in a verb or use a plural form of a noun. That being said, PECS remains our son's favorite mode of communication, and he still prefers using it alongside vocalization for requests over high-tech AAC.

In case of pictures used for both PECS and AAC, the symbols on them usually resemble what they represent, helping the users to understand the meaning more easily (see [Figure 1](#)(left)), for example, a picture of a glass might indicate that the child wants to drink a glass of water. Thus, the symbols chosen by an AAC user indicate a specific message (indexicality) and often visually resemble the object or a concept they represent (iconicity). As a result, *indexical iconicity* (Silverstein, 2003) showcases that symbols used are often effective in enabling a communication process, as they both point to a specific meaning and resemble what they represent.

Returning to my son, he was born in Moscow, Russia, to a family of Russian first language (L1) speakers. From early days he was also exposed to English, as our family always preferred watching movies in the original language, rather than the Russian dubbed versions. My son received his diagnosis two years after his birth. The main worrying sign for us to seek a specialist was a sudden disappearance of his speech around 14 months. After re-

ceiving his diagnosis, he attended a mainstream kindergarten in Russia with daily support of a speech pathologist. The main focus of this schooling was to develop his speech, so this period of his life was characterized by predominant modality chauvinism (Henner & Robinson, 2023) that favors spoken language as the "norm". In 2018 my husband was accepted to a doctoral position in Sweden, and we joined him several months later.

Soon after arrival, we encountered our first major challenge: confirming our son's diagnosis in another country. I will not go into the complicated bureaucracy behind it, but the entire process took about a year. During that time, our son did not have access to any specialists or specialized education. He was attending a mainstream school with a personal assistant, who did not have any professional training to work with autistic children, nor did she share any common language with him. Moreover, the school did not provide him with any form of alternative communication in any language.

At home, my husband and I tried to support him by continuing lessons in Russian under an online guidance from a specialist in Moscow. Unfortunately, it was not enough. Over that first year, our son's ability to maintain his previous communication and social skills was constrained by the lack of care. To support our children's wellbeing, we decided to continue using Russian language at home, making it the main language of our family. This became our primary FLP (Spolsky, 2012) at home.

Spolsky (2012) explains that FLP can be understood in terms of three areas: what languages families use in daily life (language practices), what they believe about those languages (language ideology), and how they try to navigate language use (language management). In our case, we spoke Russian and used PECS with Russian text with our son. We believed it would be easier to maintain our family routines in our own language, creating an island of stability for our kids after their school day.

According to Slavkov (2021), this kind of language setup is called a *Minority Language at home* (ML@H) policy. It is one of the most common approaches adopted by families in multilingual situations, along with *One Person-One language* (OPOL) that assigns one consistent language to each caregiver or environment, using the majority language at home, or mixing their languages in daily life (Mixed Model) (De Houwer, 2021; Slavkov, 2021). We followed the ML@H approach until our son was officially diagnosed in Sweden and placed in a specialized school (Swe: anpassad grundskola). Without knowing it at the time, we were using one of the most advantageous language policies for autistic children, since research shows that using your first language at home can lead to more meaningful interactions than switching to a language you are less comfortable with (De Houwer, 2021).

Flashforward to 2019: our son has been attending a specialized school for almost a year. While most specialists were recommending that we continue using Russian, we started including more Swedish in our daily lives by reading aloud and watching cartoons in Swedish. In



Figure 1. Augmentative and Alternative Communication App

Note: (left) A typical home screen of an AAC app; (right) inside a thematic folder of an AAC Tobii Dynavox app.

addition, we also updated our communication tools and started using PECS with bilingual text written in both Russian and Swedish. We also began relying on visual schedules and schemes from the rehabilitation center (see [Figure 2](#)). The latter were in Swedish only³, signaling a *dual indexicality* (Kerfoot & Tatah, 2017) from the educators and specialists: while supporting our home language, the provided materials were in Swedish only, signaling alignment with the hegemonic order of the mainstream education (Karrebæk, 2013) and indicating “slippage” (Collins, 2011, p. 417) between their expectations and real language policies of Swedish specialized education and manufacturers of these materials.

During our almost six-year stay in Sweden, our son has changed several different specialized schools. Each of these schools has tried to support his communication and socialization into transsemiotic monolingualism (Swedish in all modalities) through speech, gestures, and various forms of visual communication, ranging from communication boards to AAC. However, depending on qualifications of personnel, some schools developed different levels of modality chauvinism, often prioritizing speaking or forms of AAC they were most familiar with.

In the early years of our stay in Sweden, most community partners supported our decision to use Russian at home. However, after about four years, we noticed a shift. Our language choices started to be questioned more frequently, especially during the visits when my husband, who does not speak Swedish, was present. Questions of our language use at home are now raised more often, with subtle inquiries into why our family does not use AAC in Swedish only, and prefers using it in English for high-tech AAC, or Russian and Swedish for low-tech AAC. In summary, as of today, our son is 13

years old and uses the following communication methods to varying degrees of independence and prompting at home: spoken words (less than five, some in Russian, some—in Swedish), vocalizations, facial expressions, pointing gestures, gestures of refusal, PECS for requests with text in both Russian and Swedish, communication boards in Swedish or without any text, visual timetables and activity sequence schemes, and an AAC app from Tobii Dynavox LLC on an iPad in English.

Unlike mainstream education in Sweden, the status of mother tongue education in specialized education is unclear (Skolverket, n.d.). Interestingly enough, English is still taught as a foreign language, and I have met our son’s classmates who chose English as their dominant language and were communicating in it freely. Despite that observation, our reasoning for using AAC in English has always been questioned, regardless of our remarks that it does not make sense to focus on Swedish only due to our precarious residential status and the nature of academic work that requires frequent relocations.

This tension has only intensified since Russia’s invasion of Ukraine, which has led to increased scrutiny and suspicion toward Russian speakers in some public and institutional settings. Given this context, we now see English as the most practical option for high-tech AAC, as none of the robust high-tech AAC apps currently offer a proper localization in Russian, making it difficult to use the language effectively through these tools. As shown in [Table 1](#), most leading AAC companies prioritize European languages, including regional variants of the same language, while overlooking widely spoken languages like Russian. While some companies claim to support Russian, it is limited and does not represent proper localization with culturally relevant symbols, accurate gram-

³ The print-out in the bottom right picture is in English and replicates the home-screen of the AAC app we use; I printed and laminated it myself.

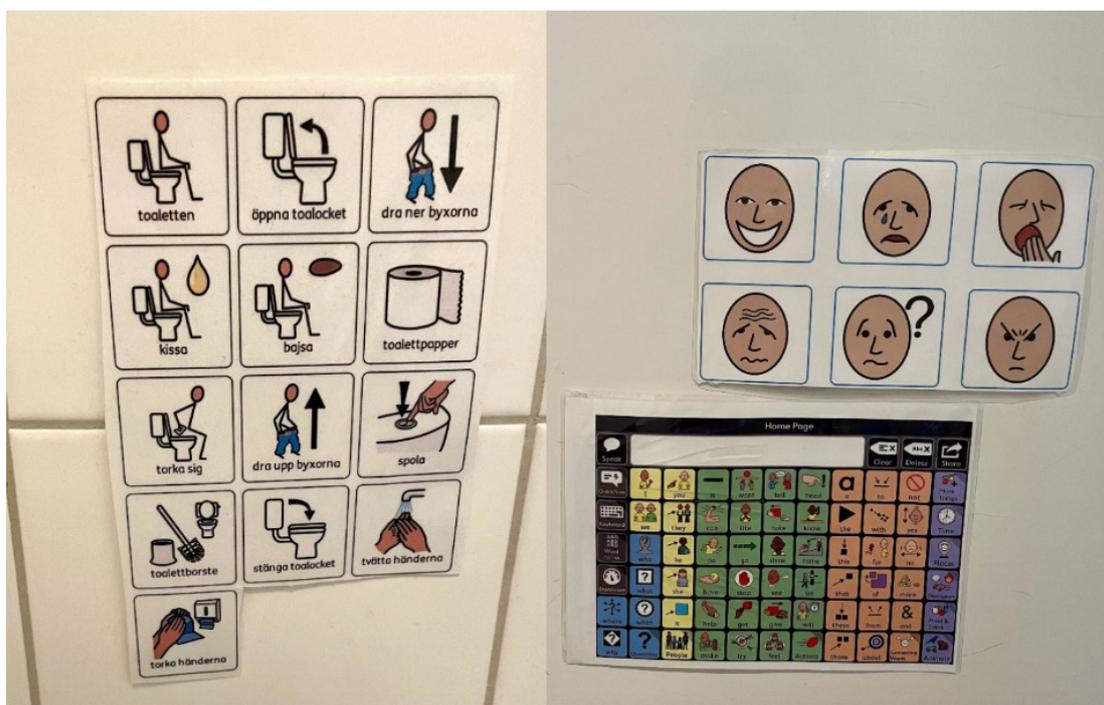


Figure 2. Schemes and Communication boards used by my son

Note: Photos made by author using WidgeOnline and Tobii Dynavox displays

mar structures, and region-specific vocabulary, relying instead on basic automated translations through tools like Google Translate. These translations miss essential linguistic features like verb conjugation and adjective agreement, making communication awkward or incomprehensible. Additionally, these AAC options typically lack the same range of synthesized voice outputs available in other languages, providing limited choices in terms of gender, age, and vocal tone, which are important for making speech-generating AACs feel personal and usable.

On a personal note, I once volunteered to translate communication boards into Russian for Ukrainian refugees and reached out to a major European high-tech AAC provider; they politely refused, stating that the communication boards will only be available in Ukrainian. Such an excluding and narrow approach to languages as belonging to nation-states does not acknowledge complexities of bilingualism and disability, moving further away from the policies and actions of *linguistic care work*—“time taken in being patient, in supporting and providing semiotic resources, in seeking, expanding, and claiming our own semiotic resources, in calibrating to each other in seeking mutual understanding (Henner & Robinson, 2023, p. 27)”. The refusal of linguistic care work highlights how language ideologies are reproduced even in spaces that claim to support communicative access. My example illustrates a tendency to prioritize geopolitical alignments over inclusive communication practices, reinforcing the modality chauvinism and linguistic nationalism that Crip Linguistics attempts to challenge. This episode also reflects a deeper issue within the AAC landscape that tools, systems, and discourses surrounding

them are often shaped by dominant language communities, commercial interests, and state narratives, rather than by linguistic care work and communicative realities of disabled people and their families.

While high-tech AAC systems are presented as neutral tools, their design, distribution, and available language settings mirror broader market logic. Most of them are created by for-profit private companies in the Global North, with limited or no transparency about how languages are selected, prioritized, or why certain languages are excluded. This way, AAC companies do not participate in *Crip technoscience* (Hamraie & Fritsch, 2019)—practices of modification and reinvention of material-discursive world with and by disabled people.

As shown in [Table 1](#), many AAC apps are also transitioning to subscription-based models. This will continue to further restrict access for Russian-speaking families, particularly those in Russia and Belarus, where sanctions and the lack of access to payment systems like Visa or Mastercard make it difficult or impossible to purchase these tools. Unfortunately, while some countries invest into developing AAC apps in their nation language(s), efforts in Russia remain limited. A few enthusiasts have attempted to introduce high-tech AAC, but these initiatives are not led by teams with expertise in linguistics or speech-language pathology. Instead, they often rely on Google Translate, use low-quality synthetic adult male voice, or mimic paper-based PECS formats without offering the full functionality of a robust high-tech AAC system. Based on these factors, it could be reasonably argued that there is currently no robust, fully functional high-tech AAC app available in Russian.

Table 1. Language localizations available in major AAC apps

App/Device	Languages	Bilingual Settings	Price (USD)
Proloquo2Go	English, Spanish, French, German, Dutch	Yes	249.99
Proloquo (AssistiveWare)	English, Spanish, French, German, Dutch	Yes	
TouchChat HD	English, Spanish, French (CA), Hebrew, Arabic	No	149.99
LAMP Words for Life	English, French (CA), Spanish	English (CA/ French)	299.99
CoughDrop	English	Yes	9.00/month or 295.00
Avaz AAC	English, Spanish, Hindi, Tamil, Marathi	Yes	9.99/month or 199.99
GoTalk NOW	English, Albanian, Arabic, Czech, Danish, Finnish, French, German, Greek, Italian, Japanese, Polish, Portuguese, Simplified Chinese, Spanish, Swedish, Turkish, Ukrainian	Yes	119.99
Sono Flex	English, Swedish, Portuguese (BR)	No	99.99
TD Snap	Arabic, Chinese (simplified), Czech, Danish, Dutch, English (US/UK/CA), Finnish, French (FR/CA), German, Hebrew, Icelandic, Italian, Japanese (Hiragana/Kanji keyboard), Norwegian (Bokmål), Portuguese (BR/PT), Spanish (LA/MX), Swedish, Swiss German, Turkish	English (US/ Spanish) English (CA/ French) Spanish (LA/ MX)	9.99/month
MetaTalk	English (US), German	No	179.99
WeaveChat	English (US)	No	free
Grid	English, Afrikaans, Arabic, Croatian, Czech, Danish, Dutch, Finnish, French, German, Greek, Hebrew, Italian, Norwegian Bokmål, Polish, Portuguese, Slovak, Spanish, Swedish, Ukrainian, Welsh, Russian ^a	No	9.99/month or 399.99

^aWhile Grid claims to support Russian, it uses a machine translated version with many mistakes and inaccurate translations of only one page setting, this setting is also not a robust AAC, same applies to the apps not mentioned in the table.

The politics of access in relation to AAC is further exacerbated by temporal linguistic benchmarks (Henner & Robinson, 2023) and normative time expectations on a macro level, which presume a child to acquire certain skills by a certain age. These benchmarks are especially difficult to transfer to disabled children. In contrast, Crip linguistics “urges us to think about the fluidity of time and the capacity of the bodymind to develop language, achieve understanding and communication (Henner & Robinson, 2023, p. 25)”.

The need to challenge the normative structure of time is, luckily, often understood by special educators in Sweden on a meso level. For example, one of the schools our son used to attend was labelling its grades not by numbers, which immediately indicates some form of a linear progression, but colors. Our son went to the Orange class. The door to his class did not have any numbers, but a bright orange card on it. Such a seemingly small change in the indexical order (Silverstein, 2003) made an escape from a paradigm of temporal benchmarking. In the times of social acceleration, which describes the speeding up of technical processes, social change, and the pace of life (Rosa, 2013), and is also visible in education, specialized education suffers the most. It should take time, patience, care work, and *ethics of care* (Copland & Creese, 2015; Kerfoot, 2016), instead of being subjected to the

enormous amount of metrics, and gruesome audit culture (Shore & Wright, 1999) that looks into a child as a set of parameters and checkboxes to be filled. Investment of Crip time should be a priority in specialized education, as it allows for delayed, recursive, or paused forms of connection.

In the case of our son, he is not an active high-tech AAC user (yet), with me being the primary user of his AAC device in modeling my speech and prompting. Modeling is one of the most important stages in introducing an AAC app, as an AAC user learns when they see their device being used by their community partner in real situations, not just for requests (Biggs et al., 2018; Sennott et al., 2016). Modeling can lead to increases in communication turns, receptive and expressive vocabulary, increases in multi-symbol turns, and morphology structures (Sennott et al., 2016). Thus, AAC modeling altercasts an autistic child as a communication partner (Goffman, 1979, p. 22). Meanwhile, prompting is used to give verbal or gestural cues to help the AAC user navigate their device. Both stages are important in achieving language brokering and communicative relationship building.

Although this paper uses autoethnographic reflections on my lived experience as a parent of a non-speaking autistic child and did not involve physical interventions,

risks to participants, or external participants, I recognize that including my child in this narrative raises ethical questions that must be addressed. My son is not able to provide conventional assent or consent due to his profound intellectual disability. He does, however, communicate preferences and boundaries through body language and vocalization. Both as a parent and an autoethnographer, I am attentive to his communicative cues and avoid recording or sharing any interactions that he appears to be distressed by or does not wish to participate in.

Throughout this work, which included data collection that lasted for several days in Spring 2024, I have made constant efforts to center care, dignity, and relational ethics. The decision to include the interaction in [Excerpt 1](#) from our live was guided by an ethic of relational accountability, grounded in my dual role as a researcher and a mother. While I constantly refer to my son by name, I decided to anonymize his name in support of long-term protection. It is also important to acknowledge that consent is an ongoing and situated responsibility. This work is not about *speaking* for my child, but about sharing the ways we attempt to *communicate* with each other across constantly shifting modalities and systems.

The transcript of our brief interaction (see [Excerpt 1](#)) using high-tech AAC showcases the need of escaping the normative time expectations and to rely on Crip time, instead. This interaction lasted only two minutes, but included three AAC-produced turns in lines 31, 38, and 45. Out of these three turns, only one was initiated by my son through prior prompting. This excerpt is both multimodal, multilingual, and includes the AAC device as an animator in a communicative act (Goffman, 1979). Moreover, all three AAC turns have different functions in epistemic reciprocity (Hedman et al., 2024). Thus, line 31 is a comment, line 38 is a request, while line 45 can be interpreted as either a request or an agreement.

While [Excerpt 1](#) provides only a glimpse into our daily lives, it illustrates the complexity and richness of my son's communicative repertoire that includes gaze, vocalizations, pointing gestures, facial expressions, images, and interactions with digital devices. Overall, it can be seen how AAC modeling facilitates epistemic contributions (Hedman et al., 2024) from both communicative partners, allowing them to co-construct meaning (Canagarajah, 2023). In the absence of formal support, we build a community of two that operates on shared rhythm, glances, and mutual trust. While AAC manufacturers like AssistiveWare (n.d.) are vocal promoters of presuming competence of autistic communication partners, Crip Linguistics reminds us that uncritical and overly romanticized view of competence can risk reintroducing normative pressures. Beals (2022) argues that the best community partners "do not presume anything, but assess first and then calibrate language and instruction accordingly (p. 73)". This approach is not about presuming incompetence, but a more critical redefinition of what competence might look like. Crip Linguistics encourages us to ask not whether someone is competent according to normative benchmarks, but how competence can be

achieved through access, patience, adjustments, and care.

This excerpt also showcases how long it can take to navigate to a certain word while using AAC. Luckily, AAC modeling involves almost no displacement of time and place, as it is linked with the persons' present. Moreover, in the AAC communication, multiple frames of interactions are at play. For example, my son and I are engaged in watching a cartoon, while I am simultaneously working on his skills like turn-taking and shared attention. Thus, not only is alternative communication layered, but so are participants' identities. In this transcript, I am a caregiver, an educator, a communicative partner, and a facilitator of my son's independence. All these roles are layered in every use of the AAC device. This aspect should be taken into account, as it might take an uneven amount of time for every communication partner to get to "play" each role.

It is not easy to approximate how long it will take for me or my son to become versatile in all the communicative roles and reach high proficiency in AAC, and whether it will happen at all, especially since we do not have access to our first language on AAC and receive no individual training from our community partners. Both these issues form barriers in promotion of epistemic access (Kerfoot & Bello-Nonjengele, 2023) to more AAC users, especially since research into the difficulties faced by hearing parents in learning sign language (Lieberman et al., 2024) shows that learning alternative communication is attainable, and should be promoted by all the community partners. Unfortunately, unequal and non-consistent access to AAC or AAC training is still a major challenge for many community partners, both in Russia and Sweden. Similar to parents in the study by Moorcroft et al. (2020), I was just given a link to the generic educational resources created by the app manufacturer. In comparison, when I was trying to introduce key word signs in Swedish, I was invited to a series of in-person workshops at the rehabilitation center. This shows how a communication method that is supported by private companies is also gatekept from the families: these companies offer access to the technological "solution" (app, device, symbol library), but not the embodied, relational, and pedagogical support needed to learn how to use it meaningfully. On doing so, they participate in a neoliberal model of access, where communication is treated as a product to be purchased, rather than a practice that needs to be nurtured. Unlike free and community-based training workshops, such as the one for key word signs I attended, commercial AAC systems offload the burden of training and implementation on families, expecting them to be self-learning, self-funding, and self-responsibilizing while navigating complex communicative needs. Similar workshops could become a life changer for parents of autistic children who decide to use low or high-tech AAC, especially since a lack of adequate training and support in AAC is one of the main reasons for AAC abandonment (Moorcroft et al., 2020). Meanwhile, the specialists are not checking our progress frequently enough (about

Excerpt 1. My son (S) and I (M) are negotiating what to watch on TV

01 M: щас минутку= (0.6)	Wait a minute
02 M: т::ак что тебе =====поста[вить]?	<u>Well, what do you want to watch?</u>
03 S points to the cartoon multiple times (0.6)	
04 M: это да?	<u>This one, yeah?</u>
05 S paces near the TV (0.5)	
06 M: ну дава::й↑ (0.5)	<u>Ok, let's do it</u>
07 S jumps	
08 M: о↑й какой ((in a smiling voice)) ты радостный	<u>Look at you</u> <u>You're happy</u>
09 M: ты <радостный>	<u>You're happy</u>
10 M takes the AAC device and starts searching for the word "happy"	
11 M: д::а::	<u>Yeah</u>
12 S continues to jump happily off-camera (0.26)	
13 S leaves the room	
14 M: куда ты поше::л? (0.16)	<u>Where did you go?</u>
15 M: придешь? (0.10)	<u>Are you coming?</u>
16 S approaches M and hugs her	
17 M: д::а:: ((in a smiling voice while still browsing the AAC))	<u>Yeah</u>
18 M: ой.ой.ой.	<u>Oh. Oh. Oh.</u>
19 S leaves the room	
20 M: °ща::с ((browsing on AAC)) (0.32)	<u>Wait</u>
21 M: [имя] ты где? (0.7)	<u>[name], where are you?</u>
22 M calls S by his nickname (0.7)	
23 M calls S by his nickname (0.3)	
24 M: идем посмотрим вместе↑((in a smiling voice)) (0.8)	<u>Come, let's watch it together</u>
25 M calls S by his full name (0.5)	
26 S returns to the room	
27 M: ой↑ ты в туалете был	<u>Oh, you were in the bathroom</u>
28 M: мхм(.) какой ты? (.)	<u>Mhm. How are you?</u>
29 ((pushes the button "happy" on the AAC device))	
30 M: [радостный]↑ да?	<u>Happy, yeah?</u>
31 M(AAC): [happy	
32 S: (((vocalizes while hugging M))	
33 M: [да:: ой(.) обнима::шки ((in a smiling voice))<обнима↑шки>	<u>Yeah, huggie, huggie</u>
34 S: (((vocalizes while hugging M too hard))	

01 M: щас минутку= (0.6)	Wait a minute
35 M: [ой.ой. сильно↑ СИЛЬНО очень. [имя].[имя]↑	Oh.Oh. <u>That's too hard. Too hard.</u> [name]. [name].
36 M: [имя], сильно. Перестань так	[name]. That's too hard. Stop it.
37 M: (((pushes the word "stop" on AAC))	
38 M(AAC): Stop	
39 S stops hugging	
40 M: тебя обнять?	<u>Do you want a hug?</u>
41 Хорошо ((searches for a word "hug" on the AAC)) (0.9)	<u>Good.</u>
42 M: тебя обнять еще, [уменьшительно-ласкательное имя]?	<u>Do you want another hug, [diminutive name]?</u>
43 M: еще обнять? Давай еще [разок	<u>Do you want another hug? Let's</u> <u>do one more</u>
44 (((points to the word "hug" on the AAC))	
45 S(AAC): hug	
46 M hugs S	

three times per year on average), and when they do—it is primarily focused on the language conflict: us using AAC in English at home vs school using it in Swedish and trying to persuade us to switch to Swedish only.

Even as concepts like presuming competence gain visibility in AAC discourse, families are often left to interpret and implement these ideas on their own, with minimal to no guidance from professionals or access to peer-reviewed publications. The distance between what is promoted in theory and what is supported in practice often creates a vacuum that can be quickly filled through online communities, social media, and pseudoscience. This self-responsibilization of families and autistic individuals is another symptom of education and healthcare under neoliberalism, with its transformation of public services into market-driven ones (Braedley & Luxton, 2010).

As a result, while Moorcroft et al. (2020) believe that family-centered practices such as listening to parents and finding compromises could be a potential solution to issues such as AAC abandonment, we must also be very careful with what we understand as a family-centered practice, as many solutions under this undoubtedly good intention risk ending with “the family should decide and be responsible for everything” scenario, similar to ours. Such a delegation of all the tasks to the families contradicts the politics of access and the framework of interdependence (Hamraie & Fritsch, 2019) that advocates for the mutual reliance and support systems among all the community partners surrounding an autistic person. Moreover, it contradicts the ethics of care by continuous exposure to epistemic harms, instead of a multimodal episteme (Kerfoot & Bello-Nonjengele, 2023) that recognizes that people think, learn, and communicate not only through speech and writing.

This autoethnographic study attempted to trace how communicative agency is shaped and often constrained

by the layered presence of micro, meso, and macro community partners (Collins, 2011, p. 415) in the life of one transnational family with an autistic child in Sweden. At the time of writing, my family faces the possibility of deportation due to the constantly moving goalposts in Sweden's migration rules. Thus, our FLP will likely change again. Adjust, adapt, and accept, or be forced to. I do not know what the future holds, or what decisions we will have or will be forced to make when it comes to my son's communication. At times, it feels that not only is he denied communicative agency, but also, we are, as decisions on both macro and meso levels leave us with almost no choice.

In conclusion, I want to highlight that leaving a non-speaking autistic child without access to communication in their first language or providing them with only a limited set of cards to communicate with is the opposite of care work. This approach is akin to placing someone in a foreign country with restricted means of communication, offering them only a limited phrasebook for the rest of their life. While this may sound too dramatic, it reflects the consequences of a society that is governed not only by modality chauvinism, but also language policies privileging one language. I do not believe that this is a challenge unique to Sweden; a similar story could be shared and witnessed anywhere in the World. Although we are a transnational family, the barriers and challenges we encounter are not unique to migrants. The withholding of multilingual AAC support and the delegation of linguistic care work to parents are trademarks of neoliberal governance that leaves everyone a vulnerable observer, or at best, a commentator with no power to intervene.

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Conflict of Interest Statement

The author declares that there is no conflict of interest related to the content of this article.

Positionality Statement

I am a Russian PhD student living in Sweden since 2019. As a neurodivergent woman and a parent of an

autistic child, I approach this research from both personal and analytical perspectives. My experiences navigating language, healthcare, education, and cultural differences as an immigrant deepen my understanding of communication across diverse contexts. These intersecting identities inform my awareness of privilege, marginalization, and access to language, disability, and migration, which are central to my research.



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Appendix

Transcription conventions (based on Jafferson [2004])

. : falling intonation

? : rising intonation

, : slightly rising intonation

↑ : rising pitch in the following segment

↓ : falling pitch in the following segment

:: : lengthened speech

= : latched speech

- : cut off word

CAPITALS : louder volume

(()) : vocal effect accompanying speech or transcriber's notes

[: beginning of overlap of speech or nonverbal actions

> < : sped up speech

< > : slowed down speech

(number) : duration of silence in seconds

(.) : a pause of roughly one-tenth of a second

: nonverbal actions occurring without speech or at around the same time as the speech in the line immediately above.

 : translation

(AAC) : AAC produced turn