Involvement of Mothers as a Precondition for the Inclusion Process of Children with Complex Communication Difficulties

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HOW TO CITE:
Doroszuk, J. (2024). Involvement of mothers as a precondition for the inclusion process of children with complex communication difficulties. *International Journal of Special Education, 39*(1), 113-123.

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DOI:
https://doi.org/10.52291/ijse.2024.39.11

ABSTRACT:

Involving families is crucial in the multifaceted inclusion process of children with complex disabilities and communication challenges, particularly in developing communication skills. The main objective of this research project was to determine the significance given by mothers to the inclusion of children with complex disabilities. A qualitative, constructivist study was conducted, in which data was collected through semi-structured group interviews. The study involved mothers in an association, focusing on inclusion and the role of parental involvement in developing tailored communication systems and supportive environments for their children. The parent's voice as a supportive element in creating a communication environment may result from structural determinants and a reaction to systemic deficiencies in the area of childhood developmental support.

Keywords: Family; AAC User; Inclusion, Mothers Engagement.

INTRODUCTION

This article explores the role of parental involvement in the inclusion of children with complex disabilities and communication challenges who rely on augmentative and alternative communication methods. It emphasizes that educational and social inclusion are interlinked, particularly for school-aged children; one cannot exist without the other. The article argues that the success of inclusion depends not only on the child's needs and developmental characteristics but also on the family's involvement and removing barriers to inclusion (Mezzanotte, 2022; Reichle et al., 2002).

The article discusses the crucial role of parental involvement in the inclusion of children with complex disabilities and communication challenges, emphasizing parents as primary communication partners and often co-creators of their children's communication systems. It highlights the necessity of parents acting as intermediaries between their children and the social environment, underlining that such engagement is essential for the child's successful inclusion (Baldassarri et al., 2014; Batorowicz et al., 2006). Further details on this inseparability will be explored later in the text.

Considerations on inclusion most often focus on the practical dimension of the social model of disability (Thomas, 2004; Barton, 2023), inclusive school culture (Harris et al., 2020; Zamkowska, 2018), democratic conditions of the educational community (Davis et al., 2020), universal design for learning as the basis for constructing an inclusive educational setting (Pausateri, 2022; Fovet, 2020; Meyer et al., 2014).

There are an increasing number of studies and articles on the specificity of inclusion of a specific group. In the case of students with complex communication difficulties, researchers focus mainly on teachers' attitude toward students' use of AAC methods (Aldabas, 2019; Mukhopadhyay & Nwaogu, 2009; Patel & Khamis-Dakwar, 2005). Another example of research in this field is the efficacy of AAC user inclusion in relation to the effectiveness of the strategies employed or consumer satisfaction. (Lund &Light, 2009; Beukelman & Mirenda, 1990). Research focused on AAC user inclusion barriers also plays a critical role (Johnson et al., 2006; McNaughton & Bryen, 2007; Higginbotham et al., 2007). Aldabas (2019), based on the conducted research, points out the importance of barriers in the communication environment - school and family in particular. He concludes that these are more important than the difficulties on the part of the AAC user. Parents are also indicated as helpful in overcoming barriers related to the use of high-tech equipment (De Bortoli et al., 2014).

This article explores a less researched area: the role of environmental resources in the inclusion of AAC users with complex communication difficulties. It emphasizes the need for both the AAC user to be prepared for social engagement and for the social environment to adapt to interacting with verbally non-communicative children with intellectual disabilities. Family involvement is highlighted as crucial for individuals with complex disabilities. Education is identified as a key area for inclusion, with experiences from Australia showing how viewing human diversity as a resource can foster inclusive social groups in schools. Inclusive education, moving beyond segregation and enhancing integration, is increasingly adopted. Parental involvement is underscored as essential for successful inclusion in both educational and social contexts (Rafferty et al., 2001; Palmer et al., 1998).

Huer (1997) pointed out that in the case of communication support for children with disabilities, the user of AAC is not an individual but a family (e.g., due to the family's communication code and its impact on the choice of communication modality). Due to the development of mobile technologies, both the process of selecting communication aids and the creation of AAC software applications more and more often involves AAC users themselves and supportive stakeholders, usually family members (Baldassarri et al., 2014). In the case of the AAC user being a child, as well as when the child is not independent in terms of communication, the parent's actions are not only limited to introducing and operating the communication aid. McNaughton et al. (2008), based on a study conducted with parents of children with cerebral palsy and AAC users, distinguished additional roles of parents: loving caregivers, teachers, playmates, technical support personnel, and advocates. Their respondents also indicated the importance of activities motivating the child to communicate with an unprepared communication partner. However, the actions of the family members most often indicated in the literature are mere involvement in the act of communication and the use of tools for AAC. Researchers suggest that being an active communication partner by parents is also associated with a high sense of responsibility and emotional burden. (Jones et al., 1998; Parette et al., 2000; Goldbart &Marshall, 2004).

The effectiveness of inclusion for children with complex disabilities significantly relies on the preparedness of communication partners and optimal communication conditions. Parental support is crucial, they understand their child's communication needs and provide security. The parents' role extends to shaping the educational environment and influencing teacher competencies. A study by De Polo et al. (2009) in South-Eastern Italy highlighted challenges in cooperation among families, schools, and students, referencing the "Silos effect" from management sciences, which denotes a lack of collaboration. This issue is particularly critical for children with complex communication needs, where the quality of cooperation between environments is vital. The study underscores the importance of inclusion for children using AAC, emphasizing that the quality of parent-school cooperation significantly impacts the inclusion process. This area forms the core of the research I have developed and conducted. Parental involvement plays a crucial role in the success of inclusion and the quality of cooperation with educational environments for children with complex disabilities and communication difficulties. Existing research does not adequately cover the dimensions of this involvement. This study aims to address this gap mothers' experiences by focusing on the experiences of mothers in Poland who are involved in their children's inclusion process.

METHODS

Participants and recruitment

The study selectively sampled mothers of children with complex disabilities and communication difficulties, specifically those active in a community of parents with similar challenges. The extent of parental involvement in supporting AAC users became apparent during analysis rather than sample selection. The sample comprised eight women, most with one child with complex disabilities and one with two. Three years ago, these women formed an association to offer mutual support, enhance skills relevant to their children's development and other areas, and access group psychological support. Their regular weekly meetings foster trust and support. Participant and child characteristics, such as disability type, communication methods, and educational settings, are detailed in Figure 1.

Research Design

The main category the research had been constructed for was the inclusion process of children with complex disabilities. The approach used was qualitative research design and the main research issue was extended to the following specific issues: How do mothers of children with complex disabilities understand social inclusion? How do mothers of children with complex disabilities understand educational inclusion? How do mothers of children with complex disabilities describe the processes of including their children in a social and educational environment? What difficulties do mothers of children with complex disabilities describe in the inclusion process of their children?

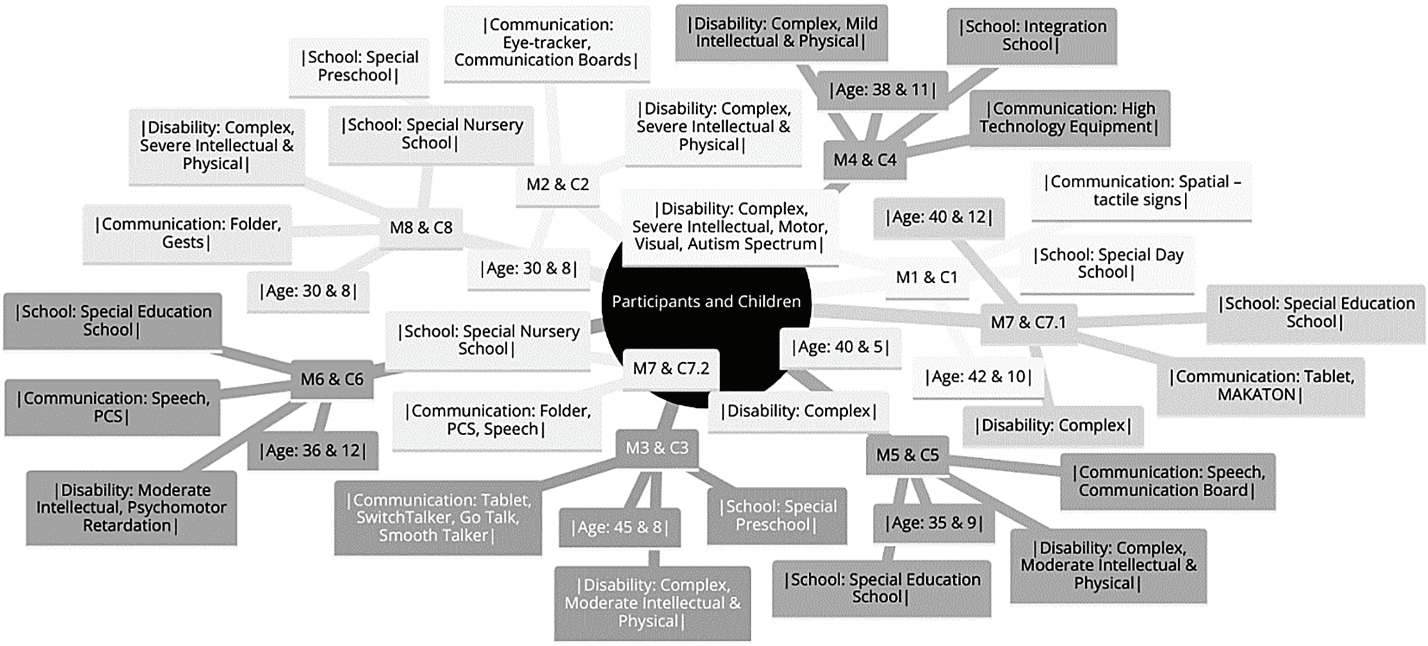

Figure 1. Participant and Their Children's Characteristics, Including Disability Type and Etiology, Communication Methods, and Child's Educational Institution.
Source: Own elaboration.

The research method applied was a semi-structured group interview, which in the constructivist paradigm allows, in the process of analysis, insight into developing meanings and attributing sense to given experiences (Holstein & Gubrium, 1997). Due to the research's focus on quality and its ethical dimension, it was important for the researcher to properly conduct the interview ensure while at the same time ensuring that respondents knew each other and felt safe enough to comfortably share their thoughts on personal matters (Flick, 2011).

The research's main objective was to learn how the inclusion process is perceived and defined by mothers of children with multiple disabilities. Supervising the child's optimal development in the sphere of communication and application of AAC methods constituted a prevailing aspect in statements given by the respondents. The research indicated thus that the category of engagement in supporting the development of the child's individual communication system (ICS) by their mother was brought to light as the prevailing factor supporting their inclusion. The actions of the researched mothers are critical for raising quality of their children's social functioning.

Respondents were informed about the purpose and procedure of the study, and they received the appropriate consent forms, which all participants duly signed. The The Research Ethics Committee at the University of Gdansk, Poland accepted the research design regarding application No. 2/24.10.2022.

Procedures

The interview was preceded by a message exchange with the president of the selected mother-child association, wherein the purpose of the study was presented. The interview was conducted during one of the association's regular meeting sessions. This began with the researcher introducing herself (although she was indirectly known to some of the respondents due to her professional activities), presenting the purpose of the study and assuring them of the ethical standards that guide the researcher and signing off consent forms.

During the interview, the researcher directed questions to the group, to which the interviewees answered voluntarily. The researcher inquired if any issues required clarification. When posing questions, the researcher used interview guidelines created on the basis of the research problems. The interview was centered around the issue of inclusion, particularly the areas of inclusion and exclusion of children with complex disabilities, parental involvement, difficulties, and perspectives in the process of educational inclusion.

Data analysis

The next step for the researcher was to transcribe the recording. Performing this independently allowed the researcher to become still more familiar with the research material.

The survey was analyzed in the constructivist trend; it had a thematic character and consisted of analyzing and identifying patterns in the data collected, using MAQDA software (Braun & Clarke, 2006). In the context of the research problems, this thematic analysis led to the emergence of five main categories. These categories encapsulated the core patterns and themes identified within the data, providing a comprehensive framework for understanding the research findings. Each category represents a significant aspect of the data, offering insights into the underlying issues and contributing to the overall narrative of the research.

RESULTS

Analysis of the research material according to the research problems posed made it possible to identify four main categories: barriers, exclusion, parental involvement, and the role of the mother-as-stakeholders, which are related to 4 following conclusions: environmental barriers facing persons with disabilities as barrier in the process of their inclusion; counteracting exclusion as the prevailing pro-inclusion measures; the parent's engagement in supporting the child's communication skills as a condition of their inclusion; the role of the mother-as-stakeholders of their child's inclusion process.

The research conducted started with a question concerning the definition of inclusion. This issue – what is the process of inclusion of persons with disability for the respondents – leads us into the presentation of the analysis, as the significance respondents attributed here brings us to their struggle against social exclusion, as well as difficulties experienced by the mothers studied and their children in a social environment.

In statements given by mothers, inclusion may be summarized as a process on the path to equality.

Inclusion that is facilitation, that is perceiving us as equals, identical, irrespective of disability, but looking solely at a human as they are. (M1)

What seems to be characteristic in this statement, is the reference to the normative and social paradigms of disability, as well as identifying the social situation of the disabled child and their family.

Inclusion may also be summarized as counteracting discrimination and isolation of persons with disability, as in the following example.

What is painful for me is that we are even discussing inclusion, since because we are talking about inclusion, it means that exclusion has occurred. This fact itself gives us pause for thought; how is it possible that we have been excluded for us now to be included? For me, the question is, what causes our exclusion? Children are excluded. And how can we eliminate exclusion so that there is no need for inclusion? (M5)

Inclusion in this context seems to be a corrective action, yet, at the same time it is equally a confirmation of the process of exclusion and discrimination. Therefore, as a result, it also raises negative emotions. Moreover, it seems significant that in this definition, the process of inclusion, as well as the directly related exclusion, does not affect the child itself but the entire family entity. Later on in their statement, the respondent was convinced:

First, their mothers are excluded, then their fathers, then their families, and finally, the children are excluded. I am of the opinion that firstly, a mother with a diagnosis feels excluded, then the family is excluded, and then, everyone excludes themselves starting with friends, then exclusion from using stairs, not to mention schools, education, swimming pools, planes, transport. (M5)

In the context of this statement, areas of exclusions are disclosed - personal, environmental, educational or situational, which concern both the child with the disability and their family. However, dimensions of the social exclusion process would seem to imply the scope of inclusive measures which should counteract the former.

The respondents also understand inclusions as assigning responsibility for supporting the child's development to parents.

Inclusion in the process of our children's education consists of us as parents being able to benefit from various webinars, training sessions, workshops on the same level as therapists and, I would say that this inclusion of parents is often related to placing the responsibility for educating our children firmly on the parents' shoulders. (M2)

This definition was mainly connected to the topic of educational inclusion. It was also extended by the statement concerning teachers' lack of relevant skills, particularly in the area of working with a child with multiple disabilities and communication difficulties. In this context, increasing the role a parent plays in their child's education and therapy seems to come within an inch of assigning parents with full responsibility and diminishing the engagement of pedagogues, teachers, and therapists.

Inclusions are also defined by respondents as a theoretical intention, which is only starting to evolve in practice as illustrated in the following quote.

This topic is only just beginning to come to the fore due to a generational shift. (M4)

In this understanding, inclusive measures are only just surfacing in environments of those with disabilities in the Polish social space, therefore making them difficult to assess. In other respondents' statements, it was the parents who were pinpointed as the pressure force that influences counteracting the discrimination and isolation of this social group.

Inclusion is also referred to a process rendered impossible, as in the quote that follows.

Children are getting more overweight. For example, I notice that we do less walking now, simply because it is more difficult. Also, C3 being an older child, and with the weight that he carries, it is difficult for him to establish any kind of social relations. It is not possible at all. (M3)

Inclusion as a process hindered or rendered impossible by lack of accessibility in the environment faced by children with specific needs was a common theme in statements given by respondents.

The subject matter that respondents felt most strongly about was that of educational inclusion. Points raised here included experiences related to inclusive education and educational "exclusion" of their children, mainly regarding education in special schools, attended by the majority of their children, with only one respondent's daughter being at a regular integrated school.

Definitions made by respondents, with emphasis placed on social participation and the feeling of exclusion, determine their involvement in supporting the development and functioning of their children. A large part of the measures undertaken by respondents is related to the sphere of communication. Awareness of difficulties and barriers encountered by respondents is key to guiding their activity. Obstacles to their children's inclusion, or event exclusion factors, listed by respondents can be divided into three groups.

- Schools failing to cater for the needs of children with multiple disabilities and complex difficulties in communication, the inability provide a student with holistic support.

Even if this is a special school, there is no ideal school that would be appropriate for every disabled child. There is no such school that would be able to take care of this child and provide them with everything they need. If the physiotherapy is good, the communication is poor. If the social environment is good, there is a problem with something else. I think that this is the problem. (M1)

Responses showed disappointment and even anger at how ill-adapted educational facilities they deal with are to the needs of a non-verbal child, as they require a non-standard and individualized process to support their development in communication skills. This dissatisfaction also concerns a lack of holistic support – i.e. the satisfaction of all developmental needs of a child in one educational and therapeutic facility. Negative emotions felt by respondents are not, however, of a destructive nature; instead, they drive them to act and search for other ways in which they can support and improve their children's functioning and development.

- A lack of social awareness, implying situations in which it is difficult for a child with disabilities (and difficulties in communication) to join in various activities alongside their peers.

If our children cannot join in with fun in a given way, they are also excluded or omitted. (M3)

In this area, it was difficult to select short fragments from the interview. However, the statements given by respondents unequivocally implied care for the social activities of their children connected to unawareness, unpreparedness, and a lack of willingness and openness of communication partners - both children and adults. Also, in this aspect, the respondents found an area for their activity, as teachers, guides for interlocutors of their children.

- Inaccessibility of public spaces to the needs of persons with disabilities:

If we cannot change our child's diaper in a public place because there are no facilities provided, how can we even discuss human rights? If we have to put a mat on a urine-soaked floor because there is no seat in the toilet, then it is scandalous, it is below human dignity, and everything else pales in comparison... (M2)

We don't go anywhere with the boys, especially C7.1, because of the problem with changing. (…) There are so many things we have been forced to give up because of the toilet issue. We don't visit friends anymore because it's just embarrassing. (M7)

Adapting public spaces to the needs of those with disabilities is a long-term process. It also has a direct impact on inclusion by creating conditions, or not as the case may be, for groups to take part in various social activities. These barriers make respondents even more determined to find ways to deal with difficult situations, yet also are a reason for withdrawal and lower activity in certain areas.

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The characteristics of a school do not accept the possibility that a child that does not have the use of their hands, but only sight can be intelligent enough to provide them with education in the form of reading and writing. Another issue is how to teach and adjust educational materials to a child who, in addition to this, is nonverbal. (M2)

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2. Inaccessibility of public spaces to the needs of persons with disabilities:

It is difficult to talk about any comfort of education at school, even at an special school, if basic things are missing - there's no ramp, no adapted toilet, or nobody who can change them. How can we even talk about inclusion? (M7)

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The activities respondents chose minimize the consequences of the indicated obstacles. Awareness regarding the importance of developing communication skills and using augmentative and alternative communication methods is also worth pointing out, as expressed in activities undertaken and, in the case of the majority of respondents seems to be the priority of their activity. Respondents' activities concern all areas of supporting the development of the child's communication skills. A description of activities and their significance is laid out in the Table 1.

The category greatly emphasized in respondents' statements was the urge to engage in supporting the child's functioning in the realm of communication. Respondents are aware of the difficulties experienced by their offspring and a lack of suitable support the system provides. The significance attributed to their activities can be seen in the following testimonies.

They have to know that they cannot exclude my daughter by not giving her the opportunity to learn with this method [AAC], because this is a school for children with disabilities, and I demand it. (M1)

Table 1. **Parental Actions in the Area of Supporting the Development of Children's Communication Competencies and their Significance.**

Activity	Example	Significance
Developing an individual communication system for a child	*C1 is in AAC since kindergarten; because she has a cortical visual impairment and severe intellectual disability, her communication is hindered, but what we have worked out and have been doing are tactile strategies, start stop strategies and later on, she was more involved so we also learned, I started looking for external aid. For some time – I think for 3 years – we were going to an AAC therapist, with whom, with the assistance of the supervision, we developed a strategy of communicating with C1 on spatial – tactile symbols*. (M1)	- Adjusting activities to the child's needs; - Monitoring specialists' activities; - Coordinating knowledge among specialists; - Standardizing techniques across environments; - Coherent activities
Developing communication aids	*Right now, C1's communication consists of myself making each symbol for her. It works best on books, poems, I modify books I am reading to her in the participant reading strategy, we have a plan of the day. Each activity is presented on a spatial-tactile symbol. I also made the same symbols at the school, because AAC for children with multiple disabilities is, unfortunately, not popular at the C1's school, I am very sorry about this, so I put together a plan of the day where I presented her lessons with a consideration of breakfasts, lunches and classes in which she participates. How is it used by them? I am afraid that not in a manner I would like them to.* (M1)	- Customizing aids to child's needs; - Control over aids; - Standardizing aids across environments; - Stimulating communication activity of the child.
Stimulating communication activity of the child – creating communication situations and contextual aids for communication	*Wherever possible we take communication tools with us. A toolkit, that is, 2 images choice or eye-tracker, because these are the most convenient. The communication book is designed for C2 to be able to ask questions and participate in a conversation as an active, and not passive, person. It allows her to lead and ask questions, because it is difficult for a child to answer random questions made up by an adult on an ongoing basis, so we are trying to reverse this role of an asker for C2. (M2)* *I am also preparing contextual boards for places, where I am not convinced that they will be adjusted to her needs e.g. a contextual board for communication at a dentist or other specialised doctors so that C2 can ask about the procedure, will it hurt, what are you going to do to me, how long will it last, or for her to be able to comment what was nice and what was not. These are screen boards or contextual boards in which we are modelling*. (M2)	- A possibility of a child's communication activity in various situations; - Taking care of the child's subjectivity, their possibility to express themselves in various situations; - Improving the quality of services offered by other entities.

Stimulating communication activity of the child – creating communication situations and contextual aids for communication	*We are participating in various cultural events, where C3 has the possibility to participate in social life. If possible, I organise an opportunity for C3 to actively participate in what is happening by using his communicator. At a store C3 pays for shopping with a card. In a café he chooses a dessert. I am making visual presentations for C3 for him to be able to talk about where he was and what he was doing*. (M3)	- A possibility of a child's communication activity in various situations; - Taking care of the child's subjectivity, their possibility to express themselves in various situations; - Improving the quality of services offered by other entities.
Preparing the environment and building a community of properly prepared and willing communication partners	*We are trying to teach the environment, in which C2 functions, because it is not easy for somebody to independently come up with a way to communicate with C2, so we are preparing a group of people with whom we are meeting, so that they can communicate with her, how to ask questions, and the rest is left to the interlocutor, if they are flexible and willing enough and, primarily, if they believe that this child is aware of the surrounding world, because you do not have to have great skills, sincere desire to communicate is enough.* (M2) *We are striving for communication in this form [with the use of high technology equipment] and we are also preparing interlocutors for it. The process requires patience and takes a bit more time, but we believe that we are on the right path.* (M4)	- The activity directly supporting social inclusion of children - Improving social awareness; - Facilitating communication both for the child and their communication partner.

The truth is that children who communicate, who have the freedom of movement, have a lot more options even in an integrated school. And in the case of highly dysfunctional children it is something that requires a huge amount of work on behalf of their parents and teachers who are willing to do so. (M4)

Activities done by the respondents, their awareness and also engagement imply that they fulfill a new social role – that of the mother-as-stakeholder. Due to the thematic and quantitative scope of these considerations as well as the need to ground this category theoretically, this will be a topic for a separate publication.

DISCUSSION

The interview primarily aimed to understand the importance mothers place on their child's inclusion process. However, most discussions centered on supporting the child's communication development, crucial for children with functional difficulties to participate in social activities. These topics, while distinct, are closely related.

The research highlights the critical role of supporting communication development, establishing individual communication systems, and creating effective communication conditions in the social environment for children with complex disabilities. Utilizing augmentative and alternative communication methods and parental involvement are essential for the child's inclusion, reflecting the inseparable link between a child and their family in therapy, education, and social participation. The study reveals that parental engagement extends beyond specific activities to encompass all stages of developing effective communication skills, including normalizing these processes and preparing social and communication partners. This comprehensive approach to fostering communication directly addresses the main research question about inclusion, suggesting that systemic barriers necessitate community-driven efforts. For the respondents, supporting their children's communication emerges as a fundamental aspect of advocating for and achieving inclusion.

Research highlights the importance of developing family-centered therapies, where families seek partnerships with professionals to improve outcomes (Parette et al., 2000). Studies, such as those by Johnson et al. (2009) in Australia, underscore the role of speech-language pathologists in promoting social inclusion through enhancing positive attitudes and communication skills among community partners. Further research points to the significance of supporting various communication methods for children's inclusion, emphasizing the roles of therapists and peer communities as key elements of the social system (Calculator, 2009; Downing, 2005; Johnson et al., 2009).

Research participants, namely mothers of children with disabilities, adopt the role of stakeholders, steering towards the empowerment of such parents. While accepting support, they actively coordinate and influence their children's therapeutic interventions, particularly in communication, acting as coordinators for various entities involved. This approach mirrors roles seen in parents of children with cerebral palsy as noted by McNaughton et al. (2008), but extends further into empowering mothers as proactive agents in their child's inclusion process. This empowerment responds to the specific needs and challenges of including children with complex disabilities in Poland, highlighting a crucial link between effective inclusion and national social policy.

IMPLICATIONS

The voice of the parent, an informed and active communication partner, which resounds in the material analyzed can be seen as both a consequence of a systemic change in the approach to the family already in early development support and also an implication for changes in the area of communication partners' awareness. Preparing the communication environment for a partner requiring non-standard solutions is an activity necessitating change on both a local and a global scale. Enabling effective communication for a person with complex difficulties in this area is one of the main conditions for their social inclusion, particularly when a person's functional difficulties also involve the motor sphere since a person's level of autonomy and agency depends on their communication skills. In turn, these are constructed precisely in the family and local environment. In this context, the importance of theoretical considerations and practical actions aimed at supporting the family system increases still further.

In the area of theoretical considerations, it is worth highlighting the importance of placing activities aimed at building an enabling communication environment in the normalization and emancipation paradigm of special pedagogy, as well as in the perspective of social and educational inclusion. It is also necessary to analyze and describe parents' actions with regard to supporting their children's ability to communicate as descriptions of good practices, as well as confirming the importance of the actions of the family environment. Furthermore, it is essential to look at the relationship between the phenomenon of social exclusion and communication barriers faced by people with complex disabilities.

Whereas in the context of practice, the following may be identified as key areas such as strengthening transdisciplinarity while unifying interactions in the area of communication with a child with complex disabilities. Additionally, during AAC intervention, interactions are increased aimed at the communication medium, including preparing communication partners for specific, often structured acts of communication. Supporting parents in building their skill sets as primary communication partners and "liaisons" between different environments in which a child with disabilities resides and could communicate is crucial for the communication process.

The study focused on a purposefully selected group of mothers, employing a single research method. The exclusive participation of mothers might suggest a bias in depicting parental involvement, yet in Polish society, women often spearhead activist efforts for their children. Their active participation in supportive group activities contributed to a high level of mutual support and security, fostering openness and providing rich research material. This selection emphasized parental empowerment, reflecting the tendency of mothers to undertake child development support activities predominantly.

Analyzing research realities helps highlight critical issues and identifies areas for further exploration. From a broader perspective, this study suggests potential directions for quantitative and qualitative research. Quantitatively, assessing the impact of parental involvement on the inclusion of children with complex communication needs or multiple disabilities in various communities could be valuable. Qualitatively, exploring the perspectives of AAC users and their parents' involvement in the inclusion process presents an interesting avenue. Additionally, the topic of social inclusion for individuals with profound intellectual or complex disabilities, considering their needs and resources, warrants further theoretical and empirical investigation. Within these discussions, the crucial role of family involvement as a potentially sole avenue for social participation is underscored.

CONCLUSION

It is not possible to summarize the considerations made based on the analyzed study without setting it in the Polish reality, i.e. the fact that the inclusion process is still at the developmental stage. External barriers are found in various areas of life, from infrastructure to the lack of knowledge among the Polish people about specific needs and ways of communication of children with complex disabilities for users of AAC, which contrasts with the growing awareness of the communities involved. Grassroots activities in Polish society are significant for systemic change in the face of an underdeveloped public sector concerning children with disabilities and the need for the deinstitutionalization of the care. Therefore, emphasizing the importance of parental actions in the area of building a child's ICS and an informed communication environment is important both from the perspective of the social perception of the parent's role and the inclusion of an AAC user. On the other hand, from the perspective of international considerations, the actions of the communities involved embedded in concrete realities can promote discussion and optimization of implemented practices.

Both in the micro- and macro-systemic perspective, it is important to combine considerations on inclusion with the issue of minimizing communication barriers as well as with the analysis of the potential of family involvement. The article presents a certain fragment of the mother's involvement, which is important for the situation of children, but also for the local environment in which these mothers are active. However, in the context of reflection on the meaning of participants' actions can be an inspiration to the development of local strategies of deinstitutionalizing those with disabilities through further engagement of the family environment in the form of partnership and minimizing communication barriers based on the experience of mothers-as-stakeholders.

ACKNOWLEDGEMENTS

I would like to express sincere thanks to the Association of Mothers of Children with Disabilities for their support and inspiration during the preparation of this article.

DISCLOSURE STATEMENT

No potential conflict of interest was reported by the author.

FUNDING

None

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