ISSN 2579-2881

ARMENIAN JOURNAL OF SPECIAL EDUCATION

Scientific Methodological Journal

Second Issue of the Second Volume

Yerevan, 2020

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Welcome to the Armenian Journal of Special Education (AJSE). This journal is a peer reviewed journal in English for the enhancement of research in different areas of special, inclusive education and rehabilitation. The aim of the AJSE is to give a highly readable and valuable addition to the special education literature which will contribute to the decisive reference tool for years to come. Key to our aim is a vow to enlightening international authors, readers, and reviewers to become highly qualified and skilled writers, criticizers, and users of special and inclusive education research on international level, as well as advanced researching practices.

We are delighted to publish AJSE in English to reflect different issues of international and national special, inclusive education and rehabilitation fields that are relevant for up-to-date dispute. We are more than pleased to receive contributions for our next issue from special educators, rehabilitation field specialists, researchers, scholars and practitioners to ensure the reliability and the success of the Journal.

We highly appreciate any comments, feedback and suggestions that would help us to advance the objectives of the Journal. Always keeping in mind that education without innovative research and expansion is pointless for the community, we are keeping the track to interwove universally and contribute to global knowledge as much as it is possible.

Sincerely,

RUBEN MIRZAKHANYAN

CONTENT

Doi: 10.24234/se.2020.2.2.230

MODELING OF SPEECH THERAPY ASSESSMENT IN REGIONAL PEDAGOGICAL AND PSYCHOLOGICAL SUPPORT CENTERS

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ABSTRACT

Scientific indication chains with practical knowledge to prepare professionals to work effectively with children with speech disorders and their families. The importance of scientific evidence from around the world on speech disorders, assessment, analysis, diagnosis and intervention and its implication with practical knowledge to prepare speech therapists to work with children and their families is obvious and crucial.

The significance of this issue becomes more valuable when changes and reforms are taking place within the educational system in the country - something that has happened in Armenia and still requires research and adjustments in the field. The following study is guided by the contemporary framework that directs the successful assessment of speech disorders in children: World Helth Organization's International Classification of Functioning Disability and Health - Children and Youth (ICF-CY) (2007).

The article provides comprehensive, legislative, practical and clinical information for modeling speech therapy assessment within the scope of new reforms taken place in the country.

Key words: speech therapy, assessment, children with speech disorders, International classification of function, support center, pedagogical and psychological support.

INTRODUCTION

Children with disabilities or children with special educational needs and their families are among the most vulnerable groups in the Armenian society (UNICEF, 2012). They can be in special schools, inclusive schools, orphanages or completely out of education, and very often don’t have access to community based rehabilitation and early intervention services, having limited participation in different outdoor, art or cultural activities. According to the United Nations Convention of the Rights of Persons with Disabilities (2006), the Armenian government has ratified the commitment to “ensure and promote the full realization of all human rights and fundamental freedom for all persons with disabilities” (Article 1).

Like any reforms, educational reforms taken place in each period, unquestionably, cannot be supposed to be the reform of organization and implementation of education, as the implementation of such a comprehensive reform first of all implies adoption of relevant educational policies by upholding certain problematic issues in addition to the positive changes, cause certain problematic issues. All these issues certainly need to be examined, because the innovations in the educational field refer not only to the school learners, the teachers and parents but also penetrate into the life of the entire society and become the most effective means to combat discriminatory attitude; they develop and create favorable conditions and build an inclusive community to ensure the educational process of all learners (Harutyunyan, Hovyan, Saratikyan, Azatyan, Tanajyan & Muradyan, 2019 p.4).

REVIEW OF THE LITERATURE

In Armenia, like in many countries of the world, there are a lot of data gaps regarding persons with disabilities, hindering the possibility to make informed policy choices in fulfilling their rights (Harutyunyan & Hovyan, 2013). Only first steps toward including these persons into society, such as changing education policy and accepting inclusive education for children with special needs are done by different non-state organizations and governmental structures. Success with inclusion of children with special educational needs often depends on the perspectives of the teachers implementing the inclusion and specialists (speech therapist, special educators, psychologists, occupational therapists, social workers) working with these children and their families (Harutyunyan, Hovyan, Saratikyan, Azatyan, Tanajyan & Muradyan, 2019 p.6).

Speech disorders are quite frequent in early childhood, the most common type of which is a phonological impairment (Dodd, 2014). Children with speech disorders might have difficulty learning writing, reading, the whole phonological system of the ambient language, which results in pattern-based speech errors affecting entire classes or features of sounds. These children face an increased risk of literacy difficulties, poor educational outcomes and low self-esteem compared to their typically developing peers (McCormack, Harrison, McLeod, & McAllister, 2011). From this perspective, early speech therapy intervention is very much required for this group of children in school.

Only through broad assessment and analysis of the needs of children with special educational needs (conducted by different specialists) it is possible to realize and ensure the involvement of each child in the educational process to develop their communication, integration and learning abilities (McLeod & Baker, 2017).

At the same time, according to Protocol decision of the Government of Armenia as of 18.02.2016 the plan and timetable of implementation of universal inclusive education in Republic of Armenia was regulated. According to this decision, the following structural changes have been done in all Armenian regions since 2016 to 2022:

- regional pedagogical-psychological support centers (through transferring special schools into support centers) are founded;
- staff of new formulated regional pedagogical-psychological support centers is trained;
- children from special schools are allocated to inclusive schools;
- raised scale of funding for children with special educational needs in accordance with child needs is implemented, etc.

Guided by Law of the Republic of Armenia on General Education (2014) (Article 17 Part 7 “The procedure for providing pedagogical-psychological support services for the organization of education") the pedagogical-psychological support services for the organization of student education is provided at three levels:

1) school level;

2) regional level;

3) republican level.

School-level services are provided to learners who have been evaluated and recognized as being in need of special education. School level services are provided by service of pedagogical and psychological assistance of general education institution (teacher's assistant, special educator, psychologist, social pedagogue and nurse).

Regional services are provided by the regional center of pedagogical and psychological support based on the application of the directorate of the general education institution or the child's legal representative. Regional center specialists visit schools and provide support to the school's assistant team for developing student support services. In case of a child who is not attending a school/kindergarten, the assistance is provided in the regional pedagogical and psychological support center (Order N 370-N of the Minister of Education and Science of the Republic of Armenia of April 13, 2017).

After the approval of the student's individual learning plan, the regional support center and school directors jointly sign and validate the load, schedule of the services provided to the school (learner, teacher, parent) by territorial center and the attendance schedule of the territorial center's specialists. In addition, when designing the schedule, it is advisable to plan a specialist's visit to the school at least once a week. The schedule is attached to the IIP. The regional support center provides the necessary consulting and professional assistance on learners educational process to the learner's parent, the members of the school's pedagogical-psychological team and teachers to ensure permanent relationship between parents, specialists, and teachers in the form of mutual visits, telecommunication and online consultation (Order N 370-N of the Minister of Education and Science of the Republic of Armenia of April 13, 2017). If the analysis of the results of a child's school-level assessment indicates the probability of a child's any disorder, the institution, with the parent's consent, applies to the regional support center to carry out a regional assessment. Regional assesment can also be carried out directly on the parent's request. According to the order of the principal of the regional support center, a group of multidisciplinary team specialists implementing regional assessment is formed which comprises at least 3 specialists of the regional center: a special educator, a speech therapist and a psychologist. This assessment lasts at least a week after which the child assessment report and conclusion is compiled and submitted (Harutyunyan, Hovyan, Saratikyan, Azatyan, Tanajyan & Muradyan, 2019; Order N 370-N of the Minister of Education and Science of the Republic of Armenia of April 13, 2017).

At the same time Order N 370-N of the Minister of Education and Science of the Republic of Armenia of April 13, 2017 on approves the procedure for providing pedagogical-psychological support services for the organization of education and regulates the issues related to the provision of the above mentioned services. Revision and detailed analyses show that the procedure of child development peculiarities assessment need to be revised. The developmental difficulty assessment system is not free from insufficiencies. The scale of assessment provided by local governments to the specialists, where the child's developmental specificities are inserted and the need assessment is calculated, result in a distorted image, which, according to specialists, is often far from the real picture of child development and overcoming the difficulties (Harutyunyan, Hovyan, Saratikyan, Azatyan, Tanajyan & Muradyan, 2019).

In order to implement the policy of universal inclusive education in the Republic of Armenia, in accordance with Article 17.1 of the Law of the Republic of Armenia on General Education, the criteria of pedagogical-psychological assessment of speech and special educational needs of children are currently applied to children were adopted and based on International classification of functioning, disability and health: children and youth developed by World Health Organization (WHO, ICF- CY, 2007). Despite the fact that WHO ICF based assessment might require more administrative resources, it still enables to have more comprehensive information about a child and to better understand his environment, which may promote or hinder his social inclusion, as well as to establish more targeted services for the rehabilitation and social inclusion of people with disabilities (Harutyunyan, 2017).

These criteria have been developed in accordance with the requirements of the Law of the Republic of Armenia on General Education. The current Law stipulates that in order to increase the accessibility, quality and efficiency of educational services, the educational institution provides pedagogical and psychological support services for the organization of education defined by the authorized state body (Article 12, point 3, part 7). It provides the application of effective measures for individual support to children with special educational needs in those places where the educational process is parallel with the reforms. At the same time, it helps to contribute to the educational and social development of children with special educational needs, including children with speech disorders and their inclusion in society. However, within the framework of these educational reforms, in terms of regional level assessment, certain problems arise in the process of speech therapy (diagnosis), as such an assessment process is currently based on five main functional disorders: voice and speech, hearing, vison, intellectual (mental) (Order N 370-N of the Minister of Education and Science of the Republic of Armenia of April 13, 2017, Form 4). From this perspective, it is possible that the classification based on dysfunction cannot be a basis for determining the type, period, duration and scope of pedagogical and psychological support services, as function assessment is itself a medical process that requires narrow professional intervention.

In order to determine the type and degree of speech disorder, as well as other questions related to the child's speech problems, the child first of all should be assessed by a speech therapist comprehensively (Levina, 2015). Within this frame, the following article has the aim to discuss the modeling of speech therapy assessment in regional pedagogical-psychological centers within the scope of recently taken reforms in Armenia. Examination of speech disorders is a key precondition for organizing speech therapy intervention and the effectiveness of speech therapy work depends on the proper organization of this process.

METHOD

In order to understand the state of the art of speech therapy assessment within the frame of regional pedagogical and psychological support centers in regards with policy and practical implementation changes and reforms, the existing legislative documents were investigated. Qualitative content analysis was conducted to reveal the spectrum of new legislative innovations and to describe lawmakers’ evolving view of speech therapy assessment peculiarities. Qualitative content analysis is not a new approach to textual analysis. This method borrowed from the social and health sciences is used to analyze legal documents (Hall & Wright, 2008). Thus, applying proven methods from the health sciences and communication studies can support large-scale analysis of legal transcripts (Hall & Steiner, 2020).

This paper, based on the qualitative content analysis method, seeks to describe the approaches used to speech therapy assessment highlighted in the existing policy and its practical implication while organizing pedagogical and psychological support.

DISCUSSION OF THE RESULTS

According to the existing policy, the pedagogical-psychological assessment criteria for identification of the need for special education are used to organize the education of children with special educational needs in order to determine the increased amount of funding. According to the international and local legal acts regulating the education sector, inclusive education should be affordable, of a high quality and free; elementary and secondary education should be organized on an equal basis with other community members.

The importance of ensuring the necessary support for children with special educational needs in a well-established and well-defined full education system should have provided with a range of pedagogical conditions to ensure effective learning and inclusion in the educational process, which still remains unresolved (Harutyunyan, Hovyan, Saratikyan, Azatyan, Tanajyan & Muradyan, 2019 p.10). Yet, according to N 6 Protocol Decision of RA Government on 18.02.2016 on the approval of Action Plan and schedule of introduction to Full Inclusive Education system, the number of pedagogical and psychological assistance services in schools implementing inclusive education has been reduced by the average annual number of students in need of special education. This is a serious obstacle for a child with physical and mental development problems to remain out of education system, as most of them, in fact, can’t use pedagogical and psychological, rehabilitation and early interference services and has limited participation in community life. Thus, a key precondition for efficient assessment based on the WHO ICF-CY approach is the implementing specialists’ objective, compassionate and professional attitude. Each specialist must bear responsibility for objective assessment and provided information (Harutyunyan, 2017b).

Existing scientific studies aimed at organizing speech assessment according to the peculiarities of functional assessment are not completely sufficient for the diagnosis of speech disorders in Armenian-speaking children, and then for the organization of speech therapy intervention planned on the basis of that assessment (Alekseyeva, 2017; McLeod & Baker, 2017; Walther-Thomas, Korinek, McLaughlin & Williams, 2000). It means that this field requires multilevel and large-scale research. The need for the above-mentioned studies is urgent in the sense for the following reason: the model used in the speech therapy assessment process in regional pedagogical-psychological centers is going to be scientifically substantiated in Armenia for the first time. The new model of speech therapy assessment, based on WHO ICF-CY (2007) will provide an opportunity for functional assessment of the speech disorders on the one hand; on the other hand, to conduct intervention in order to overcome the speech problems of children with speech disorders in educational settings. Thus, WHO ICF-CY as a model provides a conceptual framework for a range of information that can be used to provide educational, social and rehabilitative care to a person, including assessment, intervention, prevention, health promotion, increased participation, elimination or reduction of barriers and promotion of public support, as well as the provision of supporting factors (Harutyunyan, 2017a).

In order to solve the problem, we consider it necessary first to analyze the current system of education of children with special educational needs in order to determine the increased amount of funding and then apply the criteria of pedagogical-psychological assessment of the need for the children who require special education (Order N 370-N of the Minister of Education and Science of the Republic of Armenia of April 13, 2017).

In order to provide speech therapy support at the proper level, professionals in the field must first be able to assess the child’s speech problems according to the general criteria based on the classification of speech disorders accepted in modern speech therapy. Unfortunately, in most cases, the above regularities of evaluation are not taken into account in regional pedagogical and psychological support centers. In this regards, while assessing the legislative documents and getting acquainted with the practical work of speech therapists from support centers, the following issues become more than urgent.

First of all, it is necessary to conduct review and analyses of existing dysfunctions and reflect to the type, period, duration and content of pedagogical and psychological support. At the same time review of filed related modern scientific literature is highly required. Exploring the work of speech therapists working in pedagogical and psychological support centers in the process of speech therapy assessment has very significant value. Understanding of targeted support methods not only in pedagogical and psychological support centers, but also in school while learning process is quite informative in regards of organization speech therapy assessment and future intervention. Based on the existing policies, it is essential to unify cooperative-consulting activities for the effective organization of the educational process of a child with a speech disorder within the framework of the services provided to teachers, in order to develop more favorable, effective ways of working with such children. And finally, the review of existing speech assessment tools, anamnestic data, and speech assessment cards is also important.

The importance of modeling speech therapy assessment in the current education system has been identified and substantiated by us. New model based on WHO ICF-CY (2007) is developed. This model will offer possibilities for an effective speech therapy assessment through a detailed methodological guidance which will enhance speech therapy assessment process in pedagogical and psychological support centers.

The functional assessment new model developed through the WHO ICF-CY (2007) must be aimed at the study and analysis of children's speech, voice, temporal rhythmic structure, general speech impairment, alalia, aphasia, oral and written language developmental levels, compliance with native language assessments. Degree of skills according to the relevant qualifications are described as light, moderate, severe and profound.

RECOMMENDATION

Review of the existing policies and qualitative content analysis that was conducted to reveal the spectrum of new legislative innovations in the field of speech therapy assessment provided by regional pedagogical and psychological support centers allowed us to come up with some concrete suggestions. First of all, it is proposed to elaborate methodological guidance “Speech disorders’ assessment and implementation of speech therapy intervention in support centers” which will be developed by our research team precisely for speech therapists working in pedagogical and psychological support centers and speech therapists working in inclusive schools. This methodological guidance will help to improve work performance of speech therapists, increase the efficiency of inclusive education within the framework of educational reforms, as well as choose the main ways of collaborative teamwork with children with special educational needs and their families, and indicate even more effective ways of organizing pedagogical and psychological work within the frame of inclusiveness.

Helping speech therapist to overcome their daily difficulties connected with assessment and speech therapy intervention we aim to acquaint them with the increase of professional knowledge and learning new practical skills of pedagogical-psychological assessment in terms of innovations in the field, and mastery of modern approaches.

Summarizing the invaluable role of speech function in the process of child development and analyzing a number of patterns related to developmental problems: speech, level of mental and personal development, which are not considered only in the context of teaching and upbringing, it is important to mention that speech therapists should be as professional as possible in carrying out the complex process of assessing speech disorders while working with children with special educational needs. Every specialist should be able to create peaceful, safe, trusting atmosphere, make the assessment process more interesting, fun, enjoyable, provide appropriate support, promoting the teaching of alternative methods of communication to the children as individually as well as in the group. Only using these approaches, it is possible to organize and coordinate the learning process of students with speech disorders, determining the positive outcome of psychological, pedagogical and rehabilitative intervention.

As the activities of the multidisciplinary team in the pedagogical and psychological support centers are mostly aimed at supporting not only children, but teachers from the given institution, it is very important to collaborate closely with them and provide necessary consultation regarding the issues they rise.

CONCLUSION

Based on the recommendation provided above, the following conclusion might be expected with its findings:

- Speech disorder assessment based on the criteria suggested by WHO ICF-CY (2007) allow to justify real existing problems that child is experiencing and find better ways of therapeutic intervention;
- Existence of methodological guidance allows to elaborate a new model of theoretically and scientifically based speech assessment system which will enable the implementation of effective speech therapy assessment in regional pedagogical and psychological support centers;
- The modeling of speech therapy in regional pedagogical-psychological support centers should be aimed at covering the general theoretical issues of speech therapy, classification of speech disorders, content of speech therapy assessment and methods of implementation, development of practical skills for organization of pedagogical and psychological assessment, as well as organization of pedagogical and psychological activities with children with special educational needs.
- The practical significance of the new assessment model will be determined by the means and methods of organizing speech therapy intervention, the complete development of children's speech and effective social adaptation.

Taking into consideration the fact that the research was carried out on the basis of the analysis of the existing legislation and problems, omissions, professional needs in the practical field of speech therapy, we believe that the modeling of speech therapy assessment is very timely in the sense that the existing reforms in the field of education in Armenia, connected with the shift to full inclusion, require a sufficient level of professional knowledge and skills, which will allow to improve professional activity and perform accordingly.

Regarding the availability of professional theoretical and practical materials proposed within the framework of pedagogical and psychological support, we believe, that the revised, supplemented training materials and analyzed results of outlined criteria will make the practical direction of the evaluation process effective. At the same time, it will enable the employees of the field to improve their professional activity with rich content-oriented materials.

Only after this implication will it be possible to reflect the weak points of existing legislation in the field and require purposeful actual changes.

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Doi: 10.24234/se.2020.2.2.231

PSYCHOLOGICAL BARRIERS OF INCLUSIVE INTERACTION

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ABSTRACT

The “inclusive” populations contain a great difference in sensory, cognitive and physical user capabilities, particularly when non-age-related impairments are taken into account. While this population is growing, the most productive research and strategy sector is unavoidably shrinking in part to that growth.

The article presents an analysis of the psychological barriers that arise in the process of inclusive interaction. The mechanisms of barriers’ genesis are substantiated: objective barriers determined by the presence of health limitations (biosensor disturbances) and subjective ones caused by the intrapersonal characteristics of the partners in the interaction.

Keywords: interaction, inclusive interaction, psycho-cognitive, emotional, communicative barriers, interdisciplinary approach.

INTRODUCTION

At present, the problem of interaction is interdisciplinary and is of interest to specialists from various scientific fields such as philosophy, psychology and pedagogy.

In the philosophical dictionary, interaction is interpreted as a process of mutual influence, any connection and relationship between material objects and phenomena (Suvorov, 2018).

The pedagogical science says that the interaction of a person with other people is a special type of communication, a relationship that involves mutual affections of the participants, cross-influences and changes. In the pedagogical plan, “interaction” determines the very existence of teaching and educational processes, it is associated with goals and content, methods and forms of pedagogical activity, motives of behavior and driving forces of the pedagogical process (Kan- Kalik,1981; Markova, 1993).

In psychology communication, which is used to characterize the whole diversity of natural and social phenomena, is often considered as a synonym for interaction. Communication is a complex multidimensional process of establishing and developing contacts between people, generated by the needs for co-operation and including the exchange of information, the development of a unified strategy for interaction, perception and understanding of a partner. Interaction is presented as a process of direct impact of objects (subjects) on each other, generating their mutual conditionalism (dependence) and connection (Lomov, 1981; Suvorov, 2018).

Since in the process of communication various kinds of interactions are realized and various relationships are formed, it can be represented as a subject - subject relations, where each participant of communication is active. Activity is measured by the initiative a person influences a partner while communicating, how participants in communication interact with each other and how the opposite side perceives the partner’s actions.

Activity involves the use of different means of communication and the willingness of an interaction partner to build behavioral strategies in accordance with the reaction of the partner.

But how to act in cases where there are objective obstacles to communication, associated with the presence of a person's health limitations and, as a result, limited communication opportunities (in the presence of sensory, biosensor, mental, etc. disturbances). In this case, we are talking about inclusive interaction - the full-scale entry in equal relations of persons with conditionally normative evolvement and persons with disabilities.

The purpose of this article is to systematize the idea of an inclusive interaction barriers (people with biosensor disturbances (deaf-blind adults) and sighted and hearing volunteers included in the guiding process of deaf-blind).

The problem of interaction between persons with biosensor disturbances (simultaneous hearing and vision impairments) was studied by native and foreign scientists (Suvorov, 2018; Sirotkin, 2006; Salomatina, 2005). As Sirotkin (2006) notes, the peculiarity of people with double sensory impairment is not only the complex of visual and hearing defects, but in many cases – problems with speech. Because of these barriers which are difficult to define in the interaction, caused by the unsuitability of traditional means of transmitting information (oral speech, listening to it, interpreting expressive signs based on vision - gestures, facial expressions, body language).

While arguing this point Suvorov writes: "... I have formulated the thesis that I (like so many other deaf-blind - probably, and not only deaf-blind), in many cases have the mechanisms of communication impaired, but they simply have not been established, have not been formed during the whole life. The point is not that we once knew how to communicate normally, but then for some reason we “forgot how”, but that we were never able to or were able to in a limited sphere, outside of which normal mechanisms had never formed so either an abnormal, pathological mechanism works, or neither works, we are just in complete abashment” (Suvorov, 2018 p.57).

Analysis of studies undertook by Basilova (2003), Yermakova (2013), Sirotkina (2006) and Suvorova (2018) made it possible to classify the barriers of deaf-blind and sighted and hearing interaction due to the following reasons which are introduced in Table 1:

Table 1.

Barriers of deaf-blind and hearing interaction presented in groups

The first group	**Psycho-cognitive barrier** - the inability to transfer the existing knowledge about the psychological characteristics of deaf-blind people in the practical aspect of interaction with them, and a barrier of incompetence associated with ignorance of means of information transmission to a deaf-blind partner (daktiology and sign language inefficiency)
The second group	**Emotional barriers** - the barrier of disbelief in their own strength; barrier of mental tension (anxiety, inability to initiate contact with a deaf and blind interlocutor); barrier of fear; barrier of shame and guilt arising from the awkwardness of oneself we had assigned.
The third group	**Communication barriers**, which exist as: ▪ a semantic barrier - occurs as a result of misunderstanding of the situation of interaction: a deaf -blind person may not understand the sense of the conversation, a joke, which may lead to a violation of behavior strategies;

	▪ a linguistic barrier: difficulties in communication depend not only on the language proficiency (verbal, gestural or diactological), but also on the specifics of this language. Using the sign language implies a different way of thinking, which often complicates understanding; ▪ a phonetic barrier - speech disturbance, incorrect grammar usage, etc, nuances of deaf-blind person`s speech make the perception for sighted-hearing difficult; ▪ a logical barrier- disability to express one's own thoughts to a deaf-blind person or, knowing dactylology, to get a message through without twisting the logic of the statement, etc.

It should be noted that this group of barriers is equally pronounced in both deaf-blind and interlocutors without any impairments.

More often deaf-blind person has this phenomena appearing as the barrier of personal self-conception, which expresses itself in the fear blaming, fear of being misunderstood, feeling of uneasiness, uselessness, their own importunity. According to Suvorov, in the vast majority of cases when there is a snag in communication, it is difficult to get out softly from a clearly bad situation, which author called a game, and therefore, talking nonsense, which is bitterly regretted by him for a very long time (Suvorov, 2018, p.58).

These sighted-hearing volunteers have shown these barriers to a greater extent as a barrier to disbelief in themselves, a barrier of fear and communication with deaf-blind people, a barrier of shame and guilt arising from embarrassment for oneself or another. Citing one of the volunteers participating in activities with deaf-blind children for several years, it is important to show that interaction is not an easy one to build and work on: *"I am so ashamed that after working for many years with children with health limitations, I still do not know how to interact with them."*

Thus, barriers may occur on the individual (subjective barriers caused by the peculiarities of interacting subjects) and functional (objective barriers caused by the complex structure of developmental disorder) levels. They can be both of objective (at the level of architectural, informational accessibility) and subjective (psychological unwillingness of participants in educational relations to interact, emotional barriers of fear and embarrassment, etc.) nature.

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Doi: 10.24234/se.2020.2.2.232

HIGHLIGHTS OF PRINCIPLES USED FOR AUGMENTATIVE AND ALTERNATIVE COMMUNICATION ASSESSMENT IN PATIENTS WITH CENTRAL NERVOUS SYSTEM DISORDERS

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ABSTRACT

Different technologies are used, including Augmentative and Alternative Communication (AAC), which can improve communication competences and life participation in patients with neurological conditions and communication deficits. The assessment of patients for the AAC need is a complex procedure encompassing not only speech and language assessment but also evaluation of cognitive, motor, visual, auditory, perceptive, and a variety of other general factors that influence the process of AAC method selection. Different standardized linguistic tools are used in the assessment process. Reassessments are an indisputable part of the AAC intervention process. Training of patients, caregivers, and other primary communication partners is imperative to ensure the successful use of communication technologies. The patients must take part in assessor controlled device trials to reveal the most appropriate AAC technology. Whenever needed, the AAC training ensures the permanent use of the technologies, providing ongoing support to the families once the skilled intervention is discontinued.

Keywords: Augmentative and Alternative Communication, assessment, intervention, neurological conditions, training, assessment tools.

INTRODUCTION

The process of decision-making for augmentative and alternative communication (AAC) assessment is based on a range of strategies and technologies that apply a variety of modalities, including no technology (no tech), low technology (low tech), and high technology (high tech) methods. The types of AAC methods that are effectively used in practice for patients with neurological conditions (cerebral palsy, traumatic brain injury, stroke, and other syndromes) are usually selected depending on the severity and size of the brain lesion and on the stage of recovery/rehabilitation process that patients are involved. In the majority of cases, it is a common practice for AAC intervention to be initiated with delay, and speech therapists usually apply AAC strategies only after the patient's recovery and associated communication disorders are stabilized (Fager, 2005). Different models of AAC intervention that are currently used in practice require methods which change and develop throughout the rehabilitation process to meet the altered/improved needs of the person, particularly for people with communication deficit related to neurological conditions (Fager, Doyle & Karantounis, 2007; Campbell, Baladin, & Togher, 2002; Deruyter & Donaghue, 1989). The primary goal of the AAC intervention is to facilitate a patient's ability to express their basic needs, to ensure their participation in decision-making about their care, and actively take part in therapy. Therefore, the AAC interventions ideally are initiated in the acute stages of rehabilitation. The speech therapists are forced to changes the AAC methods used in the course of recovery. These changes are anticipated throughout the rehabilitation program, and the expectation of change affects the decision of specialists about modes of interventions selected at different stages of recovery. Based on these approaches, the temporary use of no-tech strategies and low tech methods are usually applied in the initial phase of recovery, especially when the therapist can predict the positive outcome and register ongoing improvements. This strategy envisages the gradual improvement of AAC technology being used and the selection of high tech systems. As a rule, the high tech technologies are costlier, require a much longer period for training, and greater cognitive capacity is needed to control them effectively.

The development or change of the AAC device/method should be conducted with observations concentrated on the changing needs of the patient. In the early stages of neurorehabilitation, the patients with neurological deficit associated with altered communication may need the use of an AAC method, but the selection of the AAC strategy is influenced by a variety of factors, such as changes in the degree of alertness, the stability of general medical condition, type of pharmacotherapy, secondary complications, pain syndrome, and endurance. The AAC intervention usually applies the strategy of multimodal stimulation based on the involvement of different verbal and nonverbal tools to improve communicative competencies and intervention efficacy. In the majority of neurological patients' effectiveness of AAC use aiming to support communication skills required to satisfy the basic needs of a person using the simplest response categories (the maximum shortest response, e.g. yes/no), could be achieved by applying simple, low tech strategies (picture exchange, symbols or alphabet boards) (Light, 1988). In the second or middle stage of rehabilitation, the patients are adapted and more skilled in the use of low tech interventions, which depends on the time they have spent with the AAC method and experience/training of the communication partner. The second phase of neurorehabilitation has certain specific determinants. Patients with neurological deficits have improved cognitive skills, improved or recovered memory, and a higher level of alertness. All these factors contribute to the improvement in communicative skills. The individuals, therefore, can use more improved forms of alternative communication. In the last third stage of neurorehabilitation, the patients are less dependent on communication partners and possess better motor and communication skills to use high tech strategies. The third or late stage is conducted not in clinical settings, and the patients can receive AAC services in different community settings (support centers, offices of a speech therapist, outpatient clinics).

The selection of the AAC method greatly depends on the type of the neurological condition, and the type of communication disorder associated with the neurological condition. Patients with aphasia may experience a whole range of specific problems in using AAC strategies when compared to individuals with a different type of motor speech problems. Individuals with aphasia have limited ability to independently select and if necessary combine AAC methods and to control the selected communication systems. This limited ability is due to different degrees of the linguistic deficit. When selecting an AAC mode for this category of patients, who are considered partner-dependent because of aphasia, special training and instructions are needed for the patient and the communication partner (Lasker, Garrett & Fox, 2007). The speech therapist has to provide the patient with aphasia with a range of AAC methods and to help and support the patient in the selection process. The therapist has to ensure that proper selection is made which can facilitate and improve the communication skills of the patient and help him to become a less dependent communicator (Garrett & Lasker, 2005).

BACKGROUND FOR THE ASSESSMENT PROCESS

The communication process integrates different functional competencies: physical, mental, emotional, and behavioral. The interaction of these abilities provides proper communication skills. Assessment and interventional strategies in patients with communication disorders require a team approach, involving specialists who are competent enough to assess and restore the altered function. The AAC team must include not only the speech therapist, AAC specialist, ergo therapists, physical therapist, psychologist, and special educator, but also the caregivers. When planning for the assessment process the team members have to focus on the peculiarities of communication deficit, and priorities mentioned by the family members or caregivers of the individual with communicative dysfunction.

Patients with congenital or acquired neurological conditions may manifest different communication problems. A category of patients with cortical lesions in the brain may have aphasia when they lose the ability to use the language or understand it. Aphasia leads to receptive and expressive speech dysfunction, including the loss of not only verbal skills. Writing, typing, reading skills are lost together with speech and comprehension. The category of patients with neurological and communication deficit experiences also problems in social communication when trying to use pragmatic language skills (eye contact, turn-taking, initiation of conversation, etc.). The main type of motor dysfunction is usually dysarthria when speech disturbance is due to changes in articulatory muscle strength and tone. Speech apraxia is manifested by the increased level of efforts to produce speech, and lack of coordination in articulatory muscle contractions and oral movements, vocal changes (quality of voice and pitch) induced by not proper breath support, and dysfluency. Comprehension of patients is affected also by the lack of cognitive skills (Tobii, 2010).

Different linguistic competence measurement tools are used to evaluate the communication abilities of patients when considering different AAC options (Kertesz, et al 2007). The linguistic competence assessment tools (Kertesz, 2007; Dunn & Dunn, 2007; Semel, Wiig & Secord, 2003) and their brief descriptions are presented in table 1.

Table 1.
Tools used for the linguistic assessment

Western Aphasia Battery Revised	The Western Aphasia Battery was designed to provide the means of evaluating major clinical aspects of language function: content, fluency, auditory comprehension, repetition, and naming plus reading, writing, and calculation (Kertesz, 2007).
Clinical Evaluation of Language Fundamentals -Fourth Edition	CELF-IV is used to identify, diagnose, and perform a follow-up evaluation of language skill deficits in children, adolescents, and young adults (from 6 years to 21 years). It was designed to identify individuals lacking the basic foundations of content and form that characterize the language use: word meanings (semantics), word and sentence structure (morphology and syntax), as well as the recall and retrieval of spoken language (memory) (Semel, Wiig & Secord, 2003).
Peabody Picture Vocabulary Test, Fourth Edition	The Peabody Picture Vocabulary Test, revised edition (PPVT-R) measures an individual's receptive vocabulary and provides, at the same time, a quick estimate of verbal ability or scholastic aptitude (Dunn & Dunn, 2007).

The linguistic assessment helps to gather information about a patient's level of letter/symbol recognition (e.g. the patient tries to match pictures to words, etc.) and their written skills when trying to type answers to questions. Such an assessment contributes to the decision-making, helps to determine the symbols and language structure a patient might be able to use with selected AAC methods. Other than linguistic data the assessor can gather information from not structured observations studying the ways a patient communicates with partners and family members, as well as the strategies used by the patients, in cases when they are trying to augment speech verbalization using gestures or explicit facial expression.

The above-discussed tests are not able to determine whether a patient is appropriate for the AAC, or what type of AAC could be effective, but they explicitly reveal the areas or domains that should be targeted and a thorough analysis of the patient's weaknesses is a strong predicting factor in determining what type of AAC may provide with successful compensation.

A somewhat different approach is necessary when assessing children with communication deficits. In this stratum of patients, the assessment process requires a developmental approach when not only the language competencies of the patient are assessed, but also the stage of development. In older children and adolescents an ecological approach is used instead of the developmental assessment method. The ecological approach assesses the different functions of the patient concerning the environment and activities in which the patient participates. The ecological method and tools applied for this assessment method were developed by Brown et al in 1979. These tools are a helpful measure guiding the analysis of the environment and meaningful activities a patient is involved in (Brown. et al 1979). The difference between ecological and functional communication assessment is that the later includes standardized protocols such as the Communication Activities of Daily Living (Holland, Frattali & Fromm, 1999), or questionnaires for caregivers - ASHA FACS (Frattali, Thompson, Holland, Wohl & Ferketic, 1995). The functional assessment tools are useful when assessing adult patients to reveal a regularity of how a patient's communication deficit affects their functions and participation in real-life activities. Special efforts and time is required to reveal the patient's values and priorities; and by targeting them facilitate the selective integration or targeting of outcomes that are essential and are considered as a priority for the patient and caregivers. Special assessment tools like the Communication Needs Assessment (Fager, Doyle & Karantounis, 2007) or The Aphasia Needs Assessment (Garrett & Lasker, 2005) are proper methods to obtain information about the patient's communication skills and competences which are used in settings where the patient communicates most often and can reveal the priorities in communication methods (e.g., email, reading, writing, etc.).

The therapist must include the patient with caregivers in the assessment process, in cases when the patient is not an adult. The involvement of the patient is very important, as this promotes their self-determination and acceptance of the selected AAC method. On the other hand, the caregivers (who usually are individuals who use the AAC with the patient) can provide information about settings in which functional communication is most needed and can influence the acceptance of the AAC method. Another category of people that can assist the therapist in the assessment process is the medical staff or patient's care providers. These people from the patient's environment can supplement information about the communication needs of the patient, as these individuals are taking part in daily functions with the patient and caregivers.

All these issues discussed do not complete the scope of factors that impact the communication of neurological patients and their ability to use AAC technologies. This scope includes also the cognitive functions (e.g. attention, memory, inhibitory control, etc.) that can directly influence the communicative competences of patients and may also impact the ability to use AAC strategies. According to previously published research reports (Rowland & Schweigert, 2003), there are a variety of aspects related to cognition that can predetermine the patient's ability to use AAC methods. These aspects include memory, ability to understand relationships between people and objects, understanding of concrete and abstract symbolic representation, communicative intent, awareness, and metacognitive learning strategies. For the assessment process, the information representing the cognitive functions of patients is collected using neuropsychological assessment tools. The cognitive assessment is not always possible as the patients have speech or language impairment. The researchers and assessors are forced to use observational and descriptive data presenting the patient's performance during functional tasks or their test-taking behaviors. Multiple examples could be given describing the observational information (e.g., observations about initiation, attempts to make corrections, and patterns of visual search).

The use of different AAC methods, both the low and high tech methods, requires a certain level of motor skills. Motor skills are directly related to speech and some of them take part or influence the articulatory process. Motor skill assessment is required in patients with dysarthria, speech apraxia, and voice problems. These assessments are important to estimate the functional intelligibility of the patient, tested by various methods (cell phone, iPad, etc.) and in various settings (at school, at home, etc.). The use of AAC extremely depends on the use of an upper extremity. Different associated neurological conditions (paralysis, paresis, motor apraxia in patients with cerebral palsy, brain injury, or other conditions) hamper the person's ability to use a wide range of AAC tools. The input or access method in AAC technologies greatly depends on the upper extremity function (for example, to press a switch). Patients with apraxia who manifest with impaired motor planning and disturbed coordination may be confused when they have to select the target switch or push alternately several other switches. AAC specialists have to consider the medication that patients use to treat spasticity. Drug therapy may impact motor control and lead to reduced cognitive alertness, and/or articulatory musculature weakness. The reduced speech intelligibility is in some cases due to the side effects of pharmacotherapy. The mobility status of patients can affect the AAC method selection as well. A person who is walking needs a lighter device (e.g. Speech Generating Device (SGD), and those patients who are in a wheelchair can use heavier devices fixed to the wheelchair.

Auditory function and vision may influence the capacity to use different AAC methods, as a majority of high and even low tech methods rely on sight for symbols and words. However, neurological patients with severely impaired vision can use some AAC technologies. Information about a patient’s perceptual skills is essential in the assessment process, assisting the therapist with the method or device selection. Visual and tactile perception generates feedback for the AAC input when the patients have an auditory deficit.

There are other general factors, which have the potential to affect the ability of patients to use AAC. Medical instability, issues with behavior, decreased endurance, perceptual hypersensitivity, lack of financial resources, and psychological problems related to the acceptance of the acquired disability or need for AAC use.

A well-designed intervention plan is based entirely on a properly conducted assessment process. The assessment process of all functions should be followed by assessor-initiated device-trials, trying to determine the most appropriate device/method. The intervention plan must include reassessment sessions to evaluate the continued success of the selected AAC method and to reveal additional communication needs of the patient. Reassessments are a necessary part of intervention strategy as the patient’s communication recovers and the social environment continuously changes within the intervention process.

CONCLUSIONS

The assessment of patients for the AAC need is a complex procedure encompassing not only speech and language assessment but also evaluation of cognitive, motor, visual, auditory, perceptive, and a variety of other general factors that influence the process of AAC method selection. Reassessments are an indisputable part of the AAC intervention process.

Training of patients, caregivers, and other primary communication partners is imperative to ensure the successful use of communication technologies. The patients must take part in assessor controlled device trials to reveal the most appropriate AAC technology. Training of patients and communication partners must include the elaboration of prompts, selecting cues that require the least amount of effort. The prompts are essential when a patient is in pain or has other exacerbated conditions. Whenever needed AAC training ensures the permanent use of the technologies, providing ongoing support to the families once the skilled intervention is discontinued.

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Doi: 10.24234/se.2020.2.2.233

PARENTS VIEW ON IN-HOME OCCUPATIONAL THERAPY SERVICE

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ABSTRACT

Home is a significant environment for any child with or without special needs and one of the important environments where occupational therapy is aimed to bring improvement if necessary in terms of quality of life. The current descriptive qualitative study was designed to find out parental perceptions about occupational therapies provided in their own environments with their children with special needs.

The participants of the study were five parents whose children with different special needs were getting private in-house occupational therapy services provided by the researcher at the moment of the study. The data for this study was collected through semi-structured interviews. Interviews were designed to understand how parents perceive in-house Occupational Therapy Services.

The findings of the study suggest significant improvements in the quality of life of their children with special needs, thus no one could specifically differ occupational therapy interventions in-home and in other professional settings. It is obvious because of the lack of settings in Armenia with Occupational Therapies and lack of information about the profession in general. Future research is recommended to be conducted between two different groups with Occupational Therapies in-home and other settings, with a larger group and more specific issues. Findings revealed that in-home services are convenient in many different aspects for parents of children with special needs and it should be considered for future practices.

Keywords: Occupational therapy, in-house service, parents, children with special needs, early intervention, interview.

INTRODUCTION

Unfortunately, special needs are a growing problem all over the world as well as in Armenia. Subsequently, the need for rehabilitative services is growing. There are different possibilities of services in Armenia including private in-home services, which are provided by different professionals including Occupational Therapists. In this quite young field of rehabilitation in Armenia Occupational Therapy is still developing and there is a need for further exploration and research.

Each family, in general, is unique and has its own experience, families with children with special needs differ even more. The impact of disability is shaping parents and their life perceptions in a lot of ways. As there is a lack of information, it is important to discover, describe, and interpret each experience in order to build knowledge of parental issues concerning Occupational Therapy in Armenia.

The Occupational Therapist, the author of this thesis works only in the field of pediatrics at children's homes. During the years of providing exclusively in-home service, it was noticed that time spent with parents after therapies on the list equals to half of the therapy sessions itself, on some occasions even exceeding it. Usually, parents have a lot of questions, concerns, issues connected with children, they would like to discuss or be informed about. Hence, the question about the benefits of in-home Occupational Therapy services arose.

The primary environment for children is their homes and families where they spend the majority of their time. This study was designed to investigate the view on Occupational Therapy at home through parents' perception.

LITERATURE REVIEW

According to the Statistical Committee of the Republic of Armenia, there are 7525 registered children with disabilities in Armenia (Armstat, 2018). According to the Law of the Republic of Armenia, all disabled people have access to free health and rehabilitation care including children with disabilities (Law of social protection of persons with disabilities of RA, 1993). It includes treatment in hospitals and outpatient facilities that are operating in governmental order. However, there are two ways to get rehabilitation services in Armenia. According to disability policy, the first option is free in some rehabilitation centers that are working within the governmental order once or twice a year according to a disability type, physical or mental. The second option includes paid services at the same centers. Unfortunately, today the first option is very restricted because of very limited numbers of rehabilitation centers in Armenia. Very often, children need to register and be on the waiting list for several months or even years and then receive a restricted number of rehabilitation therapies enlisted in the government policies of free treatments. The waiting time has its negative impact on a child's development as early and intensive rehabilitation can decrease the number of disabilities and help children grow independently enabling their participation in daily life activities. According to Stephens and Tauber (2001) "early intervention refers to the most critical period of a child's development between birth and three years of age. Intervention refers to program implementation designed to maintain or enhance the child's development in natural environments and as a member of a family" (Stephens & Tauber, 2001 p. 708). Numerous studies have identified the importance of early intervention and various benefits have been reported (Farel, Meyer, Hicken & Edmonds, 2003; Guralnick 1997; Ayres 1979).

Despite the understanding of the importance of early intervention in Armenia as in a lot of other countries, there is significant shortness of rehabilitation services. According to UNICEF's mapping project (2017-18), there are about 30 rehabilitation centers and non-governmental organizations for disabled children all over Armenia. The majority of these centers are located in Yerevan - the capital of Armenia. They can be divided into three categories. The first category includes centers that are working dominantly within the governmental order. The oldest and biggest of them are Child Republican Rehabilitation Center and ArBeS Day Care Center which are providing both free and paid services. They are the largest facilities giving treatment to all kinds of disabled children either physically or mentally, with multidisciplinary teams and a large number of therapists. The second category includes big and small centers that are working within international funds or as non-governmental organizations with grants or private donations, such as “My Way” NGO, “Hay Mayrer” NGO, “Luse” NGO, etc. The diversity of therapies and the number of therapists depend on the size of the center and finances. Their services are mostly free but some of them also provide paid treatments. The third group includes small private centers run by professionals that only offer paid treatments and have limited options for treatments and professional staff.

The biggest rehabilitation center in Armenia is the Child Republican Rehabilitation Center and it yearly serves 800 children with different disabilities. ArBeS Day Care Center treats around 500 children with both physical and mental disabilities. All other centers accept a much smaller number of children from 20 in private centers to 300-400 in well-developed NGO centers such as “My Way” or “Luse”. All those services are done in both unpaid and paid ways. As discussed in the aforementioned paragraph, it’s obvious that there are long waiting lists in each center regardless of its size and working style. Because of that problem some centers limited their service to children below 7 years old, others accepted the same child once a year, some shortened the number of treatments one can obtain in the center. These all are done to allow a larger number of disabled children to get rehabilitation. However, the problem remains of a current interest as child rehabilitation and early intervention programs that combine a child and parent focus are reported to have a greater impact on the developmental outcomes of the child (Lekskulchai & Cole 2001). Children are considered eligible for early intervention services if they are delayed in one or more of the following areas: physical, cognitive, language and speech, psychosocial and self-help, or if they have a diagnosis of a physical or mental condition which will result in a developmental delay (Pelchat, Lefebvre, Proulx & Reidy, 2004).

In-home rehabilitation

The paradigm-change in health-care started in the mid-1980s in the Western world. It shifted from health-centered care to family-centered care, so the aim of treatment shifted from illness curing onto patients’ experiences with illnesses and/or disabilities (MacKean, Thurston & Scott, 2005). Child health-care embraced that change especially because of the increase in the number of children with chronic illnesses and disabilities. A family-centered approach considers the client, the child patient, and their family, rather than just the patient (MacKean, Thurston, Scott & 2005). That shift led to changes in the medical services as well as in parents’ view on the health -care their children get. In this model, family is seen as a central and crucial part of a child’s life. It is seen as a primary and strong source of support to overcome or fight health issues. The family-centered model points to the uniqueness of children and families and the existing diversity of people, their values, and their cultural beliefs. The family-centered model acknowledges parental expertise on a child’s and family’s life and their knowledge of the strengths and needs of children and family as a system. It is more competence enhancing rather than weakness focused (MacKean, Thurston & Scott, 2005) that help to overcome impairments in the way of achieving outcomes that reflect clients’ enhanced capacity to participate in their communities (MacKean, Thurston & Scott, 2005).

Occupational therapy is a client-centered practice and it is expected to embrace the ideals of the family-centered approach, although enacting these ideals can be challenging (Graham, Rodger & Ziviani, 2013). Thus, a successful intervention requires sensitivity to the perspectives of families (Cohn, Miller & Tickle-Degnen, 1999). Occupational Therapists need to focus on the outcomes outlined by parents as they are front liners living with children 24/7. The impact of the life-long disability on the whole family’s life and routine should be also considered. Attention should be paid to the surroundingu of the therapies within the means of family members and their expectations and not only to the process of intervention through action and gaining of performance components needed for it. Interventions with children with special needs can be effective only when they are sustainably integrated into routines of the family (Gallimore et al, 1989). Parental expectations from therapies are laying in contexts where their children live, learn, and play (Cohn et al, 1999). It is known that raising the child with a special need has a profound impact on the family system, including maternal mental health (Hauser-Cram, 2001), family routine (Marquenie, 2011), and financial status (Emerson, 2003). It is hard to overrate the need to expand Occupational Therapy intervention to a large circle of the whole family and its routine rather than provide direct sessions to the child. It should be aimed toward inclusion of parents as well as involve them in decision making, goal setting, and outcomes evaluation processes. Some will argue that parents are not experts in Occupational Therapy and will be right, but mutual work with a therapist who can enlighten a child’s needs and limitations will bring to more fruitful results. Due to collaborative work, parents can be trained to better care, child routine management, and advocacy. Mutual goal attainment can lead to an increase in parental understanding of child's independence in everyday life. Shared responsibilities for goal achievements usually bring more insight into the therapist's work and serve to implement changes into a child's as well as a family's life. The results of different research show that the parents who want to work collaboratively with health-care providers, care about their child, make decisions and implement a dynamic care plan proved to record the best results for their children and family (MacKean, Thurston & Scott, 2005).

The abovementioned shifting on health-care provision from health-centeredness to family -centeredness leads to a shift in care provision from professional facilities to consumers' homes. Because the model places the needs of the child and its family in the center of care in comparison that paradigm shift is further ahead in child health-care (MacKean, Thurston & Scott, 2005). That process in child-care started even in the 1980s (Hinojosa, Anderson & Strauch, 1998; Hinojosa, Kramer & Royeen, 2017) and in-home child rehabilitation treatment was growing in all areas because both home environment, as well as early intervention, are considered to be a critical variable in the effectiveness of treatment (Hinojosa, Anderson & Strauch, 1998). Home treatment can be referred to in different fields of rehabilitation such as Occupational Therapy, Physical Therapy, Speech and Language pathologist, educators, etc. Referral reasons vary on the needs of a child as well as families. Some families have difficulties using center programs but are open to accepting in-home treatment for children. Some parents have difficulties accepting that their child needs intervention especially in a medical setting, but they are open to home visits, and even over time they can recognize the need for continuing rehabilitation and get to use clinic services (Cohn, 2000). Parents can avoid centers due to transportation difficulties because clinics could be in a far distance from home. Also, if a child uses complex technical support, for example, a breathing machine or complicated wheel-chair, etc. it can be a reason for parents' unwillingness to take their child to the clinic. Parents' concerns about a child's safety in terms of health conditions such as catching flu or viruses are also one of the reasons to avoid centers. Employment and familial responsibilities such as taking care of others in the family can be an obstacle for visiting centers. Parents can prefer home treatment because of convenience (Hinojosa, Anderson & Strauch, 1998).

In-home rehabilitation in Armenia

In many countries of the western world (The Netherlands, Austria, Belgium, Germany) home-based rehabilitation treatment is well developed now and includes in it an early intervention. Children with special needs get their treatment at home for several years depending on the country and its disability policy. However, in Armenia, the situation with in-home treatment is a bit different. Armenians ethnically and culturally are a child-centered society in terms of adoring, spoiling, nourishing their children. It's especially exaggerated with the first-borns. Nowadays the quantity of children in Armenian families is decreased as well as in all civil world, there are 1-3 children in families. There are different reasons for that but most people mention the economical reason as the primary one.

Even though rehabilitation is a quite young discipline in Armenia, it started in the early '90s after a devastating earthquake in 1988 in Spitak, there always were limitations to get rehabilitation because of the abovementioned shortness of facilities as well as access to free treatment. Because of those limitations, in-home rehabilitation practice had started to develop in Armenia. It is started with Physical Therapy as at that period it was the only rehabilitative profession practiced in adult and child treatment in newly opened rehab centers. Then other related professionals such as Speech Therapists and later Occupational Therapists (OT) got involved due to their development in the field. Occupational Therapy started in Armenia in the 2000s when in-home treatment practice was well developed in its values and curricula. Even being students, Occupational Therapists used to do home visits to clients and have some interventions there. But it had occasional and learning character in the first years of development of the profession in Armenia. Several years ago, when the profession become more or less known in the rehabilitation world of Armenia OT's started to work in in-home rehabilitation with children with different types of disabilities.

The demand for having in-home rehabilitation treatment emerged from parents of children with special needs as they understood the need for early intervention, intensity, and permanency of therapies. It became obvious that during the pause in between treatment rounds in centers by a governmental order, children lose some skills and abilities due to different reasons such as an absence of professional control, laziness of child or care-takers, pity towards the child, or natural child growth, etc. So, care-takers started to seek for professionals who will provide therapies at their homes. Even all abovementioned referral reasons such as difficulties using centers programs, acceptance of their child's need of intervention, transportation difficulties, child's safety in terms of health conditions are true for Armenia as well, but mostly referral reason is long waiting time for institutional services and parents prefer to get to private services. In comparison with the western world in Armenia, the biggest restriction in in-home services is payment. In-home services in Armenia are paid by parents, because there are no agencies in Armenia, such as governmental or insurance companies who will pay professionals who provide in-home rehabilitation. This situation leads to the restriction of getting in-home treatment for the majority but the financially able ones. Even so, it doesn't diminish the need to investigate parents' attitudes toward Occupational Therapy in different settings.

The aim of this research is to find out **parental perception on having Occupational Therapy treatment with their children particularly the in-home environment**. Based on the study the research question is: ***are there benefits of having Occupational Therapy in-home, not at the centers?***

METHOD

To understand the parent's perception of having Occupational Therapy services provided in their homes in this study qualitative research frame was used. Since "qualitative research is about authentic engagement with the context within which one is situated, to advance understanding in the topic of interest" (Nayar & Stanly, 2016). Specifically, a descriptive qualitative approach was used because it gives the possibility to "seek the view or perspective of a sample group" (Nayar & Stanly, 2016), and help to describe a phenomenon in details and different aspects of the phenomenon can be recorded. This approach is useful in particular for evaluating participants' views on services or topics, findings can be used to improve the quality of services. Qualitative descriptive research results are easily conveyed to other professionals or clients without the need of knowing the theoretical orientation (Nayar & Stanly, 2016). Houses of the children with special needs served as substantive settings for this research. Semi-structured in-depth interviews were conducted with participants to assess their perceptions about in-home Occupational Therapy services.

Participants

The target population was the parents with children with special needs, regardless of specificity. Choosing criteria for participation were:

a) currently having an in-home Occupational Therapy service,

b) in-home service must be provided at least for six months. Gender, age, and relation to the child were not relevant but the person should be a primary caretaker and decision-maker for a child.

All participants were the clients of the researcher. They were informed about the aim of the study and informed consent was confirmed. All participants were from middle to high-economical home environment. Detailed data about the participants are represented in Table 1.

Five primary caretakers of children with special needs were chosen to be the participants of current research.

Table 1.

Participants of the study

	Age	**Gender**	**Education**	**Relation to the child**	**Child's age**	**Diagnosis of children**
Participant 1	34	female	University	Mother	6	Dysgenesis of corpus colosseum
Participant 2	70	female	School	Grandmother	7	Autism
Participant 3	45	female	University	Mother	15	Cerebral Palsy
Participant 4	32	female	University	Mother	7	Cerebral Palsy
Participant 5	28	female	University	Mother	2	Williams Syndrome

Ethical considerations

Since there was no research ethics committee in Armenia, gaining an official ethical license for the research was not possible. The research plan was approved and verified with the research supervisors at first; secondly, permission was gained from the parents and caregivers of the children. Additionally, participants were given the written information on the research aim, their rights, and the ethical obligations of the researcher. Also, informed consent was introduced to the participants. The names of the participants were kept anonymous and not used in the study.

Data collection

A semi-structured interview was designed for the data collection within the frame of this study (Adams, 2010; 2015). Semi-structured in-depth interviews often used by professionals, Occupational Therapists were included to get knowledge about the client's condition and complaints. During the in-depth semi-structured interviews "open, direct, verbal questions are used to elicit detailed narratives and stories" (Whiting, 2008). This kind of interviewing is used in a situation where a little is known about the topic of interest. It is one of the best tools to dig deeper. The semi-structured interviews are conducted conversationally and are the combination of closed- and open-ended questions, accompanied by why or how questions that lead to getting more variabilities of answers (Adams, 2010; 2015). A questionnaire with 4 questions containing sub-questions was designed to collect data about parents' perception of the topic.

Data analysis

Thematic analysis method was used to analyze the collected data. This method helps to search, analyze, identify, and report themes within data (Braun & Clarke, 2006). The thematic analysis is a search for themes that emerge as being important to the description of the phenomenon (Daly, Kellehear & Gliksman, 1997). The process involved the identification of themes through "careful reading and re-reading of the data" (Rice & Ezzy, 1999, p.258)

All interviews were recorded and transcribed verbatim to produce the data. Emerged themes were taken out using the transcripts from all interviews. When interviews were analyzed, themes emerged regarding parents' perceptions about Occupational Therapy in-home services and special needs as a whole. Themes were outlined if two or more parents stated similar concerns, thoughts, responses, or opinions. Supporting quotes were identified and documented during the data analysis.

RESULTS

The results of the study were derived from the interviews and four themes were developed from the analysis of the data. The citations to the themes were presented to prove the reliability and validity of the developed themes.

Tragic perception of "disability"

While reflecting this theme, caretakers mentioned that it was "*quite a shock to know about that, and standard questions came "why me, what for the end so on", "immediate hopelessness, but still deep inside there was still some little hope"*, "*when I knew about that I didn't deeply understand what is it, later when I explored it…surely it was shocking*" *(Participant 2)*. Generally, people all over the world as well as Armenians expect their children to be born "normal". Under the term "normal" they mean healthy and "ordinary, not different". Three of the children were diagnosed long after they were born, at the age of one, three, and even 12 years. Two others have been reported of some problems just after they have been born, which were proved with following medical examinations. Family life is drastically changing when a child is born or gets at some point in its life a disability. Usually, a disability strikes the lives of people out of the blue. One of those mentioned *"even though, we were informed at the hospital about the child's condition and monthly check-up, understanding of the problem came later, when she couldn't sit herself, then we started to worry" (Participant 4).* But even so, all parents mention that at some point they came to the decision making of "what to do?". Acceptance of having a "problem" with their child is quite a difficult process for all parents. Some of them don't accept it for the rest of their lives, they can cope with it, live with it, struggle even work toward overcoming it but still never accept it. Some never understand that there is a problem, they neglect it and prefer to blame the child, people around, family members, mostly mothers in spoiling the child, and fulfilling all the wishes. At that point, they all mentioned that it is not like a shock, as well as tragic perception is gone, but the necessity to help the child is becoming more important. So, they mentioned that *"All your questions vanish when you put them up and understand that you have to make a normal life for this child", "you just get over yourself and accept that there is no other choice", "That little hope inside pushes you to act, to do something for him", "you want to accept what you have" (Participant 5).* However, one mother mentioned that *"I am still not putting it up, even after all these years" (Participant 2)* whose child is already 15 years old.

Early intervention

The first basic theme outlined by all participants was the possibility of early intervention. That was a crucial part of getting in-home services for Armenian parents. After accepting the fact their child is different as well as other related information, parents learned that treatment could be in different ways free of charge in some rehabilitation centers, paid in the same ones or others and private at home. But they need to have it as soon as possible because every minute is important. *"It was difficult to find the right place and the right specialist, there are limited rehabilitation centers in the city, almost every center is overloaded, and we need to wait in the queue, but can the child wait, no he loses every day, in this sense in-home service was the only alternative…" (Participant 1).* So the treatments in centers are delayed due to the lack of the centers and a large number of children. None of the parents wanted to waste time anymore so they started to explore possibilities. Finally, through private contacts, all of the responders found the possibility to get in-home services provided by Physical or Occupational Therapists privately.

Personal convenience to have in-home service

Shock coping periods and measures are different to all people. It depends on personal characteristics and social networks around. Some coping aids in the current research were mentioned as "my family", meaning in one case the current family of husband and in-laws, in another case their own parents. One mother said, *"I don't know how convenient it will be here but my faith helped me to deal with this problem"*. Wish to do *"all of possible to help my daughter to get her a good life…yeah a normal life" (Participant 3).* Wish to *"Make his sisters' future life easier, because they will take care of him in the future".* At the moment of interviewing all responders mentioned that rehabilitative works positive results help to keep hope.

As it is mentioned above at some point, all parents concluded that the child needs some help. These conclusions were driven by different reasons. Some mentioned that the child was *"physically delayed in comparison with my niece who is the same age as her", "when I compare her with others on the playground it was discomforting".* One mother mentioned that *"searching for any help was like hanging on straws for me, another way to keep hope" (Participant 2).* Those who used the Internet started to search for information about a child's disability and where to refer for help. Others started to ask friends and relatives here and there to get to someone with similar problems. Mostly, in the end, all found some doctors or hospitals where they were given some information about treatments their children should get. Two out of five recipients in referral got a clear reference to get Occupational Therapy, that referrals were from medical doctors, one from Germany, one from Armenia. Two were referred by a Physical therapist who worked with those children, and one through another child's parents who already got Occupational therapy. Among other information parents learned that treatment could be in different ways free of charge in some rehabilitation centers, paid in the same ones or others and private at home. As it is mentioned above treatments in centers are delayed due to the lack of centers and a large number of children. None of the parents wanted to waste time anymore so they started to explore possibilities. Finally, through private contacts, all of the responders found the possibility to get in-home services provided by Physical or Occupational therapists privately.

Although all parents were given clear names of therapy they have to take, Occupational Therapy, among others, none of them had any understanding of what it is, why it is, and some of them where to get it. Even some of them were directed by doctors, others searched on the Internet, none of them knew what Occupational therapy is, and which are the benefits of it for their children. *"I did not know at all until you came to us and explained", "I got some idea from the Internet, but you made it more or less clear when came to us", "we didn't know but our friend told us that it's what our child needs", "physical therapist tried to explain why we need it" (Participant 4).*

All parents found current Occupational Therapists through personal acquaintance of therapists with referees. Trusting the professionals who advised the parents to get in contact with the current researcher. One of the reasons to contact the therapist was that therapies will be provided at home. During the research, it became clear that convenience is the strongest reason for getting in-home therapy. Parents mentioned that for them it is *"convenient, you know time-saving for me, I am at home, no rush and running", "give heaps of time to converse with a therapist about my child, before and after session, ask questions about her development", "comfortable for me, I am not worried where the child is what he is doing, how they get the therapy because he would come with grandmother in that case", "I can't get out from home because of my physical condition, so it is very helpful that you come to us, and I can see at any moment what you are doing" (Participant 3).* For children parents mentioned that *"You know long distance is hard for her and getting into the car and back, all this is tiring for her", "she is more concentrated at home because* *there is no noise and cries of other children and therapists around", "less disturbing environment, because it's her home and she is used to it", "for my daughter is easy to learn something, to focus, to get acquainted in a known environment because she is very curious and eager to explore and look all around in other places" (Participant 2).* One of the parents has noticed that *"it is safe for him, no need to get out …. how to tell…it is not convenient and useful" (Participant 5).* Another response reflects another point: *"I am afraid that she will copy wrong attitudes from other children because she is quick to do that, at least I was at that time…so it is good that it is at home" (Participant 2).* One mentioned *"Do you remember she had then big difficulties with traveling in a car, she couldn't sit or lie still and she panicked in the car, we rarely took her anywhere, it was a bliss to have therapies at home" (Participant 3).* All parents in different words noticed that *"you know home is home, it is cozier and I feel more secure for her/him" (Participant 1, 2, 3, 4, 5).*

Occupational Therapy in-home benefits exist

All responders' children were getting Occupational Therapy for a long period, from one year to three. But mostly they couldn't specify the difference between in-home and center services. All mentioned that their child has learned a lot of everyday life skills and that it makes their lives easier. *"Now he can go for shopping, yeah… with a list of goods and how much he will spend but at least alone, even cross the road watching to traffic lights" (Participant 1), "he can use certain numbers of mini buses to come home from school and go to "Tumo center" by himself" (Participant 2), "he uses the toilet, we don't use deeper anymore, he goes himself, switches on the lights, puts off the clothes and pees, then flushes the water and washes his hands" (Participant 4), "you know she started to notice with voice and shows with hand that she needs the toilet" (Participant 5), "she is writing, drawing, cutting, you know children with Cerebral Palsy like her mostly can't*" *(Participant 3).* There are even more things their children can do now parents couldn't differ whether it is due to the benefits from in-home Occupational Therapy service or Occupational Therapy itself. As parents said *"oh, you puzzled me... I have nothing to compare, we never get Occupational Therapy anywhere but at home", "I don't know if they can do in the center what you do at home", "there are no Occupational Therapists in the center we go for Physical therapy" (Participant 2).*

DISCUSSION

The results of this study provided an insightful understanding of the perceptions of the parents whose children have in-home Occupational Therapy services. The results of this study showed that the perception of disability striking out of the blue in Armenian parents does not differ from others all over the world. And that profound impact on the wider family system in terms of maternal mental health (Hauser-Cram, 2001), family routine (Marquenie, 2011), and financial status (Emerson, 2003) are common for Armenia as well. Coping mechanisms are developed during the time of processing “tragedy” but the impact is lifelong lasting.

Based on the results of this study, the strongest reason to get an in-home Occupational therapy is the convenience. Hinojosa, Anderson, and Strauch (1988) stated that as one of the reasons for home treatment. All of the parents mentioned that as the main reason for having therapies at home. In a broad term of convenience, various difficulties were outlined such as long waiting lists in governmental facilities, long distances to centers, mobility difficulties of child, safety issues for health conditions. All those are well-known reasons for in-home child rehabilitation care. However, all abovementioned have a personal character.

Parents in this study did not mention having an Occupational Therapy at home as their first choice. All mentioned that decision was made out of lack of the services at centers and in no other choice in private practices. Moreover, none of them was familiar or informed about the existence of such type of therapy and its field of interest. Other practitioners, such as doctors and physical therapists, and service consumers’ familiarity with the special needs field played a crucial role in service seeking. Being educated in rehabilitation care or getting it, they could recognize the need for and refer to Occupational Therapy. Three out of five parents did an additional web search for further information about therapy and its probable benefits. That gave some insight but very a broad and vague understanding. All participants mentioned that they grasped the meaning of Occupational Therapy during the time of getting service little by little.

Complimentary to the family-centered approach, all participants mentioned home and family environment during the therapies as one of the most positive sides of in-home treatment. That is echoing with paradigm-shifting from health-centered to family-centered (MacKean, Thurston & Scott, 2005). All parents pointed out that they could be a part of therapies and decision making.

However, the benefits of Occupational Therapies during in-home treatment weren't specified because all of the participants' children didn't get Occupational Therapy in other places such as centers. The progress in children's development in areas specific to Occupational Therapy such as different activities of daily living, grooming, dressing, toileting, eating, writing, etc., is obvious. But parents couldn't separate whether those benefits are of therapy itself or those are because the therapy environment is home.

CONCLUSION

The number of disabled people, including children, is rising all over the world (WHO, 2018) which is also true for Armenia. Lack of facilities for rehabilitation in Armenia leads to the development of in-home services in all related rehabilitation field professions.

Armenian parents, like all parents, want their children to have all possible opportunities for therapies as soon as the need is obvious, in-home services included. None of the parents wants to waste time on waiting lists of specialized service providers, so if they see a possibility to get services earlier, they take the opportunity. Moreover, parents like that situation of "open doors" to therapies, because it lets them see and somehow "monitor" the situation. The fact that they can talk to therapists before and/or after sessions as long and as detailed as they need, can't be overestimated. That serves to build rapport and mutually solve problems and challenges rising during the child's development. While reflecting children with special needs and their development, not in the general course, parents have a lot of questions and no professional counselor or service is often available with enough time to answer.

Convenience seems to be the basic reason for in-home treatments within this study. Based on that, we conclude that even after 12 years of existence, the awareness about Occupational Therapy in Armenia is very low. Yet that core imperatives of Occupational therapy of enablement of occupation in everyday contexts (Law, Baum & Baptiste, 2002) is being practiced in Armenia too, but even related professionals couldn't explain to the parents the specificities of Occupational therapy. Parents grasp some notion about it during therapy time in several months within every time explanation from the therapist.

The limitation of this study includes the shortness of the number of participants which was connected to the number of current clients of the researcher. At the moment of the study, no other Occupational Therapist was providing only in-home pediatric Occupational Therapy services which also cut the possibility to recruit parents from other therapists.

Given the insights from this research, it is highly recommended for Occupational Therapy practitioners on different levels to expand information about the profession in general and unique traits in particular. That will help parents to understand issues and areas that are crucial for the Occupational Therapy. Therapists should spread information about the profession in all possible means in all related institutions using parents' language with parents and clinical language with professionals. Education can be a critical way in which parents are provided the knowledge to advocate for their children and help them reach their therapeutic goals. It is known that educated parents better help their children.

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Doi: 10.24234/se.2020.2.2.234

MODERN ISSUES OF OVERCOMING STUTTERING IN SPEECH THERAPY

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ABSTRACT

Despite the fact that the phenomenon of "stuttering" is quite a mature and comprehensively studied issue in speech therapy, still many ambiguous sides of this problem remain unresolved. Most modern researchers would agree that multiple factors, including those associated with linguistic, motor, sensory, and emotional processes, are likely involved in its development and preservation.

According to the conceptual analysis of the problem of speech therapy, the need for a comprehensive application of speech therapy methods in the process of overcoming stuttering, as well as the need to introduce them in social micro-macro environments, is indisputable. The "maps" outlining the guidelines and the action plan, which would support the effective implementation of the latter.

A qualitative framework was used in order to obtain the review and experience that specialists have had during their practices while working with stuttering person and his/her family.

Key words: stuttering, speech therapy, micro environment, macro environment, speech therapy intervention, family centered speech therapy.

INTRODUCTION

It is well known that stuttering, as an anthropological issue, is in focus of such scientific fields like psychology, medicine, special pedagogy, speech therapy, and pedagogy. This is evidenced by the theoretical facts in many social, psychological, pedagogical, medical and other sources that raise the health, psychological, pedagogical and social issues of stutterers. This kind of studies often reflect the fact that stuttering restricts a person's free socialization and affects his or her mental health (Lokhov & Fesenko, 2000; Karpovan, 2003; Karpova, 2011).

The examined literature shows that stuttering is one of the most difficult speech disorders in human history, and still some issues related to overcoming this speech disorder and organization of speech therapy intervention and support have not yet been addressed properly. For example, theoretical research shows that there have been a lot of discussions in recent times about the need for verbal behavior management and family counseling for stutterers, but a complete functioning system has not yet been developed. The need for a comprehensive and in-depth study of these issues related with the requirements of modern speech therapy.

We believe that the latter can be the theoretical basis for developing new and effective approaches within the frame of family and speech therapy support.

LITERATURE REVIEW

From the analysis of the many existing views on speech therapy support, it has become clear that the issue under consideration is more relevant from the point of view of practical implementation of speech therapy assistance provided to stutterers and the creation of tools for its effective organization. In these processes, it is especially important to develop effective ways to organize speech therapy intervention and support for these individuals within the family, which, according to us, still need in-depth and extensive research. We think that in the process of overcoming stuttering those are issues that act as a serious challenge to modern speech therapy (Daniels & Gabel, 2004; Yaruss & Quesal, 2004; Huges, Gabel, Goberman & Huges, 2011; Missulovin, 2012; Maniadaki, 2017).

Modern speech therapy supports the fact that more than ever, much attention has been paid to family involvement. This is evidenced by the fact that speech therapy support in many cases could be closely combined with family psychotherapy. It is a psychotherapeutic process organized with families through group work aimed at developing the ability of stutterers to participate in public speeches and development, as well as overcoming sociophobia (Drapkin, 2001).The view that it is not possible to regulate the speech of people with speech disorders, especially those who stutter during individual work, without the active participation of the social environment and the family, is shared by Harutyunyan (1993), Missulovin (2012), Hovhannisyan (2001), Nekrasova (2001), Paylozyan (2017) and others. According to this approach, the work of regulating the speech of these people can be overcome by the use of complex methods and speech set by a speech therapist in different social environments. In other words, it is about the regulated speech live and spontaneous use (Andronova, 1986; Paylozyan, 2010; 2017). At the same time, the success of this complex work is based on the need for direct participation of families where person with speech disorder lives. The methods of family cooperation with speech therapists, development of tools, arming families with the necessary speech therapy tools, accompanying the stuttering process according to speech therapy guidelines are important factors in the process of treatment (Belyakova & Dyakova, 2001).

From this point of view, the problem under study is certainly very relevant according to Daniles & Gabel (2004) and Maniadaki (2017) that still requires very comprehensive solutions.

Based on the all mentioned above and given the urgency of the issue, we have set the following goals of this research:

1. to study the theoretical position of the speech therapy support provided to stutterers and their families;
2. to raise the issues in the domestic (Armenian) speech therapy from the point of view of the examined problem.

METHODOLOGY

Within the frame of this qualitative study as the main method of research the review and analysis of professional, scientific-pedagogical literature and researcher’s own experience was selected. In this qualitative research, the researcher is considered to be the most important research tool. Here the researcher uses her experience to get as close to the research phenomenon as possible, which makes it a very demanding technique. On the one hand, the technique requires discipline, analytic reflectivity and methodological experience. On the other hand, a researcher must be open-minded, she must observe herself well, note all the situations, thoughts and actions that happen to her during her practice (Byczkowska-Owczarek, 2014). Consideration of prior, relevant literature is essential for all research disciplines. When reading an article, independent of discipline, the author begins by describing previous research to map and assess the research area to motivate the aim of the study and justify the research question and hypotheses. This is generally referred to as the "literature review," "theoretical framework," or "research background" (Snyder, 2019 p.334). Based on the purpose of the review, the researcher used a number of strategies, standards, and guidelines developed especially for conducting a literature review within the frame of current study related to main issues of speech therapy while overcoming problems connected with stuttering.

The following tasks were posed to the researcher based on the main purpose of the research work:

1. to study the statement of work with stuttering person in speech therapy, psychological and pedagogical literature;
2. to make comparative analyzes between the approaches, means, methods and methodologies proposed for overcoming stuttering;
3. to study the position of speech therapy support for families of stutterers in both global and domestic speech therapy;
4. to analyze the speech therapy programs of stutterers from the point of view of the subject under study;
5. to study the experience of advanced speech therapists in terms of work with families of stutterers from theoretical point of view and identify the challenges and difficulties which influence speech therapy intervention process;
6. to identify and theoretically substantiate the need to introduce psychopedagogical and speech therapy conditions for speech therapy pedagogical support in families of stutterers;
7. to analyze the statements that create the practical need for family support for stutterers.

PROCEDURE AND RESULTS

In order to explain the theoretical implications of speech therapy intervention and support, we have particularly highlighted issues related to the application of methods used to overcome stuttering in the family environment and the difficult task of assisting the family in these matters. The data of the conceptual analysis of the problem show that there are many methods and methodologies aimed at regulating the speech of stutterers (Abramova & Gorkova, 2016; Hovhannisyan, 2001; Harutyunyan, 1993; Missulovin, 1988). At the same time research has proven that family based speech therapy intervention with stutters is organized with great enthusiasm and fervor.

Scientific analysis of the research problem has shown that many authors value the role of functional training with stutterers. The latter allows the appropriate verbal behavior to be formed and use of word as communication mean in different social environment (Anderson & Ofoe, 2019; Missulovin, 1988). According to authors these interventions must first be organized at home, but in many cases families are not aware about the methods and tools that can be used while organizing this intervention in practice. Krapivina (2003) presents a rather rich methodological consultation for pre-preschoolers in regards of organization and structuring speech therapy intervention. But still clear speech therapy approaches are not available here and author doesn’t reflect those (Belyakova & Dyakova, 2003). Theoretical data analysis shows that they are intended for speech therapists, not families. It should be noted that in speech therapy literature there are also many programs developed for children with speech disorders of pre-school compensatory groups. Mostly these programs are developed for children with phonological problems, those with general underdevelopment of speech, stuttering children and those with mother tongue mastery difficulties. However, in our opinion, all this programs can be considered as tools to support the organization and intervention of overcoming stuttering. Though, it is fair to say that they lack clearly developed work plans, intervention strategies, relevant methodological literature and technologies related to family centered speech therapy (Filicheva, Chirkina, Tumanova, Mironova & Lagutina, 2008). The authors cover the content of speech disorders and speech therapy intervention peculiarities in details including intervention conducted with stuttering children. They emphasize the content of the general and verbal behavior regulation of stuttering preschoolers. They believe that children should be able to control their behavior, control their emotional reactions and express adequate emotions (learn to keep calm in their new environment, listen carefully to the speaker; do not interrupt adults and friends, etc.). Within the framework of this program, the authors consider the creation of an appropriate social environment as a precondition for correcting stuttering. At the same time, it first of all understands the issues of parent-parent, child-parent relationship, the need to regulate the attitude towards the child's problem, the need for early intervention and overcoming of stuttering, the need to meet the general requirements of kindergarten and family (Filicheva, Chirkina, Tumanova, Mironova & Lagutina, 2008).

The study of the position of speech therapy intervention with the family showed that the main types of work with parents are parent meetings, individual and group counseling conversations (once a month, on the initiative of a speech therapist), open speech therapy classes provided to parents (once a week from the second academic year), parents' corners, which reflect the children's verbal cues, speech therapy tips and instructions.

At the same time, theoretical analysis of review literature shows that the systematic and generalized speech therapy guidelines developed for the purpose of resolving these issues, which should be given to other professionals working with children and all other family members, are almost non-existent. Rau (1964) finds that stuttering needs to be corrected when the first signs of speech disorder appear. According to him, the stuttering of children at the age of 2-5 is easier to overcome than at the age of 5-7. Still, speech therapy experience shows that very often the family, unfortunately, strengthens rather than prevents the first signs. The reason for this is that very often the family tries to help the child "with their own methods", but they are not useful at all or vice versa, not realizing that the child has a serious problem, considering it another childish evil, they force the child "so not to do it", and sometimes, overprotecting the child too much, they abuse his words, etc (Saratikyan, 2014; 2008).

Rau (1964) highlighting the role of the adult and the family in overcoming stubbornness suggests exemplary exercises for speech therapy intervention. These exercises according to our point of view, despite the fact that are quite old, can serve as a basis for developing a family support manual. It is known that Harutyunyan (1993) within the framework of the method of stable regulation of speech of stutterers prioritizes the need for the participation of the whole family and find it very important and crucial. And the methodology developed by her contains many instructions for families. However, it is not possible to consider it as a complete tool of speech therapy support provided to the family, because it requires very professional knowledge in terms of its applicability. We think that it is necessary to separate from these "similar methodologies" and develop such a methodological toolkit for the support of family speech therapy intervention and support that any family will be able to use. In our opinion, the development of such a methodological toolkit is necessary for the support of speech therapy for families of stutterers.

Based on the above mentioned, we can say that there are few scientific and methodological papers in the explored literature, which are dedicated to support and consultation to families of stutterers in speech therapy.

Still, based on personal experience in speech therapy intervention corrective action to regulate verbal behavior is also very important and requires individual approach to families of stutterers. In order to prevent stuttering, the works with parents and families, in which specialist clarifies the reasons for stuttering, the creation of a psycho-pedagogical environment necessary for overcoming the latter, the prevention of a number of wrong approaches by parents, and the therapeutic approach to regulating the child's verbal behavior seems to be significant.

According to Western experts, the matter of regulating verbal behavior should also be emphasized in the issues of correcting and overcoming stuttering. By the way, one of the main reasons for speech disorder is the peculiarities of family upbringing. Maniadaki (2017) makes an interesting argument - stuttering therapists often try to help stuttering persons. But this view is categorically rejected by Harutyunyan (1993), confirming that it is impossible to cure and get treatment by stuttering. In fact, during all the healing ceremonies, she pays special attention to the words of the family members and insists that they should be treated, because the stuttering family member is “a bad memory ring for the healer” (Andronova, 1986).

The analysis of the behavior and empathy characteristics of the relatives towards the speech of the stuttering children showed that the manifestation of alarming behavior often occupies a big room in their empathy: before the child's speech, *“the parent stutters with his whole attitude”; “I'm tense instead of him”, “When he can't say, I'm staring”, “I'm holding my breath until he says something”,* those are quotes we often hear from parents. Such behavior pushes the child to stutter in a reflective way, or in other words, reminds him of the stuttering (Saratikyan, 2014; 2009; Andronova, 1986).

As for the Armenian speech therapy literature, there is almost no work on stuttering issues. Author of this paper addressed the issue of stuttering in several of her articles (Saratikyan, 2014; 2009). In the theoretical analysis of the Western experience of speech therapy, many researchers believe that stuttering is more than a disorder of speech rate, rhythm and smoothness.

(Riper, 1982). It should be noted that in the context of the International Classification of Functions developed by the World Health Organization, clear explanations are given on how environmental factors, such as support and relationships, affect the quality of life of stutterers (Yaruss & Quesal, 2004).By the way, experience shows that the environment from which the first negative manifestations are received by the stutterer is often the family environment (Daniels & Gabel, 2004;Riper, 1982). Yairi (1997) conducted research to show how the family environment affects the person who stutters. Results of the study indicate that the role of the family environment has always been important and thus at the center of interest in many studies (Huges, Gabel, Goberman & Huges, 2011).

DISCUSSION

Based on our long-term experience working with stutterers, we have presented theoretical and practical analyses of the situation in several articles where we have been reflecting mostly number of issues related to stuttering counseling, early stuttering prevention, correction and overcoming. We are saddened by the fact that the reason for the deepening of stuttering may be professional error or incomplete consultation. According to research, and personal experience parents often say that professionals calm down unnecessarily and advise not to worry, assuring that stuttering is overcome automatically during life span. Some say that the speech therapist advised to speak slowly (but did not substantiate or explain why or how to do it), repeat exercises, ready-made texts, which did not help to overcome the problem, on the contrary, they bored and discouraged the child, etc. (Saratikyan, 2009).

Parents sometimes expect the squeaks to be overcome without any outside intervention, as many have heard that it is improved throughout life, and others do so for fear of deepening stuttering. From conversations with parents, it became clear that the vast majority of parents try to help the child with their own methods. During the research, there were families where they think that the child, if he wants, “can do it” in such a way that he does not stutter. Such approaches show that parents are not aware of the child's psychological difficulties, which is due to the ignorance of the psychological mechanisms of stuttering (Saratikyan, 2014).

A study of the family upbringing of the stuttering children, which shows that mistakes are made in order to help a child, often requires the family to repeat the word or phrase, to breathe, then to speak, to rest, to speak, etc., while such approaches have not been proven as they stifle the child. Attention concentration of self-speech exacerbates a child's neuroticism and negatively affects his or her speech process (expressive speech) (Anderson & Ofoe, 2019; Saratikyan, 2014;

2008; Andronova, 1986). There are more demanding parents who punish a child for stuttering, and some promise to reward.

During the literature review, we also encountered educational approaches when the child was compared to his well-spoken sister, brother, neighbor or other person, forcing him to copy his/her the words and speak like them. As it is known, such “support” is also not an effective way, as in that case the cramps often lead to a stable pathological condition and cause serious psychological problems (Andronova, 1986).

Thus, theoretical analyzes conducted based on literature review and personal experience investigation show that many of the works in the professional literature do not offer a solid speech therapy intervention methodological system in terms of practical support for the organization of family centered speech therapy intervention with stuttering children.

In the last twenty years, unlike in the Soviet era, families of people with speech disorders have been more likely to turn to speech therapists. This is due to the fact that along with the development of the profession, the information about the development of speech, its disorders and overcoming prospects, and the provision of visible results have increased among the public(Abramova & Gorkova, 2016).At the same time, it should be noted that according to the data of health care providers providing speech therapy services, stutterers and their families have started to apply to speech therapists less in recent years, which is explained by the poverty of 40% of the population and unfavorable social conditions (Missulovin, 2012 p.78). From this perspective we believe that this phenomenon is not only related to the socio-economic conditions of the population, but also to the quality of speech therapy services, the incompatibility of the expected and the obtained results. Speech therapy experience shows that experts, unfortunately, do not have enough knowledge to treat stuttering, working with a stuttering person and their family, that is why they often make the wrong indication, and sometimes, without rejecting the family, work, but the support provided is full of mistakes, shortcomings, and occasionally even completely inappropriate. In addition, speech therapists often avoid correcting this particular speech disorder due to lack of basic conditions needed for their work. For example, more than one specialist works in a speech therapist's room at the same time, the room is in a noisy place, the time is not enough, and so on. As for families, they often have incorrect information about the methods and means of stuttering treatment, as well as about the limits of coping, or after numerous therapeutic attempts have completely lost faith or simply are not aware of many issues related to this problem.

CONCLUSION

Thus, summing up the results of the present issues of stuttering overcoming theoretical analysis, we would like to highlight a number of key issues that, in our opinion are current problems in stuttering reduction and mostly refer to the families' full inclusion in speech therapy intervention and use of speech therapy methods in social life. For this reason, we find important the strategies related to:

- developement of speech therapy effective methods, methodics and techniques,
- developement of approaches for using abovementioned methods and techniques in social environment,
- rethink the necessary psychological, pedagogical and speech therapy approaches for the full involvement of families in the process of intervention,
- organization of structured speech therapy support, monitoring of the process, mobilization of technical means required for permanent cooperation in families, stimulation of the demand for families to use them, and training of methods.

We believe that the scientific research based facts presented in this study will act as a serious impetus for giving more in-depth solutions to the issue of speech therapy support for stutterers and will open a place for more researches in the field.

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Doi: 10.24234/se.2020.2.2.235

TEACHING BRAILLE LITERACY TO BLIND PRIMARY SCHOOLCHILDREN AND THOSE WITH RESIDUAL VISION

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ABSTRACT

Nowadays one of the main issues of pedagogy is teaching to primary school children who are blind and those with residual vision. Among those schoolchildren writing disorders are quite common and have a negative effect on their learning progress. The quality and acquisition of school curriculum slows down, and in general negatively affects the learning process of these children. The relevance of the study depends on the fact that sufficient methods, approaches related to teaching Braille literacy have not yet been thoroughly studied and developed.There are insufficient typhlotechnical, typhographic techniques to help promote literacy through the Braille system.

The study of the above-mentioned and other similar issues will help to fully implement the Braille system thus improving the writing abilities of children with visual impairments.

Key words: primary school blind children, primary schoolchildren with residual vision, Braille system, writing abilities, difficulties, assessment, assessment form.

INTRODUCTION

Braille is a tactile writing system used by people who are visually impaired. It is traditionally written with embossed paper. Braille users can read computer screens and other electronic supports using refreshable braille displays. They can write braille with the original slate and stylus or type it on a braille writer, such as a portable braille notetaker or computer that prints with a braille embosser (Damon, 2012). Braille literacy is a social-justice issue. Early Braille education is crucial to literacy, education and employment among the blind (American Foundation for the Blind, 2018)

Teaching writing in Braille requires special, purposeful approaches (Hudson, 2012). The first and at the same time the most difficult task to begin the process of learning literacy is to master the technical side of the learning process (Hermida & Rodríguez, 1996). Based on the analysis of the results of a number of studies in the related field, it is possible to state that while the absence of visual perception the technical side of the Braille writing learning process can be represented by the following actions:

- tactile perception of convex-dot letters;
- recognition of the latter and recognition;
- reproduction of the phonetic image of the word;
- perception of the word and letters(Seim, Quigley& Starner, 2014; Avramidis& Norwich, 2010; Bardin & Lewis, 2008).

It is worth mentioning that the fact that this problem is theoretically and practically insufficiently elaborated and developed complicates the issues of teaching means, approaches, pedagogical work of the reading and writing process through the Braille system among blind primary school children(Seim, Quigley& Starner, 2014).Therefore, we believe that the study of selection and coordination of special tools for the development of reading and writing skills of children with visual impairments will contribute to the favorable development of this work.

It’s obvious that the loss of vision negatively affects the perception of the outside world from all perspectives. Vision or eyesight is a true gift from nature. Due to it, it is possible to perceive the outside world with all its colors. More than 80 % information people get through eyes (Bardin & Lewis, 2008; Avramidis& Norwich, 2010).

While reflecting to writing it is very important to state that it is the hardest type of verbal activity. It requires special and targeted learning in order to acquire and master it. And for children with visual impairments it becomes more difficult to take up the writing (Seim, Quigley, &Starner, 2014). Among children with visual impairment and schoolchildren poorly performing at schools there is a group that has sustained difficulties in acquiring literacy even if they possess ordinary abilities. They are either not literate at all or read and write with typical mistakes. Visual impairments cause such personal characteristics as loneliness, selfishness, distrust of their own power and so on. These children experience difficulties in micro environment (Andjelkovic, 2017).

The analysis of the abovementioned methodological literature on the problem related to the statement of the current study shows that the problem of teaching the writing to visually impaired children with Braille system is considered pedagogically important. Solving many of issues related to this quite complicated process will help the growing generation become more literate and educated. The significance of this problem is mainly viewed in two aspects:

- the use of teaching with Braille system methods in N. Tigranyan special school for children with visual impairments in Yerevan;
- pedagogical difficulties that are faced during the educational activities among young blind schoolchildren and those with residual visual in school.

Therefore multiple analysis of this issue, its approaches, teaching with braille methods, selection, coordination of pedagogical methods, relevant typhlotechnical measures and conditions are considered important grounds for solving this problem.

The study of comprehensive approaches to learn writing with the braille system among young blind schoolchildren and those with residual vision, the analysis of theoretical approaches, the clarification of theoretical approaches and pedagogical conditions showed that in scientific-methodical literature it is viewed from different angles (Davtyan, 2018; Seim, Quigley, &Starner, 2014;Andjelkovic, 2017).

The first point is viewed as a purpose of studying unfavorable conditions where teaching the writing and developing writing skills to visually impaired children with Braille system happen. First of all it is the insufficient quantity of equipment, typewriters, books and so on. The next point is viewed as an insufficient development of schoolchildren fine motor skills, which stands as a barrier for organizing teaching of the writing (Davtyan, 2018). And because of this proper selection and application of appropriate methods and measures during the teaching process with Braille system writing becomes significant.

Taking into account the above mentioned, the main aim of the current study is to choose and coordinate some practical measures of schoolchildren with visual impairment poorly performing at school.

First of all it was planned to:

- study the difficulties of the writing with Braille system in N. Tigranyan special school for children with visual impairments in Yerevan;
- develop a portfolio for each child in order to study the learning abilities of the writing with Braille system.

Within this scope the following problems of the study are highlighted:

1. To study the relevance of the problem in modern scientific literature.
2. To examine the abilities of the blind preliminary schoolchildren and those with residual vision while teaching the writing with Braille system in school.
3. To coordinate some measures and their usage that support the development of the abilities of blind preliminary schoolchildren and those with residual vision during the use of Braille system and identify the special conditions for applying them.

METHOD AND PROCEDURE

In order to study the features of the writing with Braille system of blind primary schoolchildren and those with residual vision, the practical usage of the writing with Braille system was first investigated. 10 teachers from N. Tigranyan special school for children with visual impairments in Yerevan (capital of Armenia) participated in this research. The average age of the respondents was 33 to 55 years, and the work experience with children with visual disorders was 10 to 25 years.

The open-ended questionnaire was developed in order to understand the following aspects of the problem. The questionnaire included a number of questions, which were grouped in the following directions:

- The views and experiences of teachers about the current issue were extremely important within the scope of this study. They give importance to the necessity of using special methods and conditions for supporting the writing with Braille system of children who are blind and have residual vision. They consider the difficulties they meet during the learning process, whether they use appropriate tyflotechnical means.

- Reflection on Braille system for teaching primary school blind children or those with residual vision (what methods and tools are used in learning Braille, what problems they encounter in organizing the learning process, etc.).

During questioning the teachers, we tried to find out the stages of learning the writing.

RESULTS AND DISCUSSION

While analyzing the results of the data, it was obvious that the teachers mentioned the methods and measures they use to teach the writing with Braille methods that support to form the writing process. We also have tried to find out the difficulties they met while organizing the writing process with Braille system.

There were different answers like “the shortage of Braille textbooks and writing equipment”, “the level of physical readiness” and so on. So, the answers to our questions show that the majority of teachers think there is no corresponding scientific-methodical literature for Armenian children, that is the reason they can’t use objective methods such as exercises, games. So they use their own methods.

Thus, it became clear from the study that the majority of teachers point out the necessity of teaching writing to visually impaired children with Braille system. It is important to implement while they are primary schoolchildren. However, on the other hand the measures and methods can’t be used in practice because of the lack of relevant scientific-methodical literature. So there is a need to form and develop, to choose and coordinate the writing with Braille system.

Based on the above mentioned it is necessary to study the teaching process itself in the primary school where Braille system is used during the lessons. At the same time, it was very crucial for us to understand how much ready the children were to perceive and imitate this quite complicated system.

In order to explore deeply the abilities of teaching and learning to the primary schoolchildren who are blind and have residual vision with Braille system the assessment form was elaborated to measure the study preparedness among these children (Table 1).

Primary school children who are blind or have residual vision were selected for the participation based on the following two criteria: primary school age and already available knowledge in Braille system (2 girls and 4 boys). While using this form we have an aim to find out the following abilities children have and difficulties they experience while studying with Braille system:

- orientation abilities in micro area (in exercise book, in typewriter and its gaps);
- the abilities to use stylus;
- the right placement of typewriter to the Braille exercise book;
- to write point combination (letters, numbers, punctuation marks);
- the abilities to copy out (with one hand, with two hands);
- the abilities to find mistakes and correct them.

The assessment has been conducted in N. Tigranyan special school for children with visual impairments in Yerevan during 4 months (every day 1 lesson with the duration of 40 minutes).

Table1. Study preparedness assessment form for blind primary school children or those with residual vision

Study preparedeness assessment form for primary school children who are blind and have residual vision		
Child's First Name, Family Name and Name of father_______________________________________		
Tests	**1-5 points**	**Notes**
Readiness to use Tiflotechnical (vision related techniques) measures		
1. Vertical position near the seat		
2.Ability to use Braille typwriter correctly		
3. Proper installation to typewriter braille		
Motor skills		
1. Point combinations (letters, numbers, punctuation marks)		
2.Copying abilities (with both hands)		
3.Ability to find mistakes and correct them		
Ability to master writing skills		
1. Letter omission		
2. Words omission		

3.Gap and letters omission		
4.Understanding lines		
5. Understanding gaps and points		
6. Understanding the beginning of a word		

The use of the following form gave us an opportunity to find out the features, difficulties, readiness of using tyflotechnical measures, the development level of fine motor skills of primary schoolchildren who are blind or have residual vision while learning to write using Braille system.

The results indicate how well preliminary schoolchildren who are blind or have residual vision understand the writing with Braille system. As it can be seen in the “Study preparedness assessment form for preliminary school children who are blind and have residual vision” mastering the writing with Braille system, as well as level of the abilities was rated from 1 to 5 points. "5 points" are given to children with no mistakes, "4 points" in case of occasional mistakes, "3 points" in case of multiple mistakes (points, lines, cells, point composition of combinations and other confusions). In case of incomplete work or work done with support and assistance only “2 points" are given. When child refuses to participate in any kind of work than "1 point" is given.

We have taken an individual approach in assessing the children within the framework of this study. The age of children (6-7years old), individual abilities, features of motor skills, degree of visual acuity, secondary disorders are taken into account.

During the study it became clear that primary schoolchildren who are blind and have residual vision while using Braille system make various mistakes, faults, omissions. These schoolchildren who are blind and have residual vision have difficulties connected with the space orientation and quality of educational activities. This was also stated by Davtyan (2018) and Andjelkovic (2017). The following features are typical for those children:

- a low level of appreciation for the overall picture;
- condition of complete and partial perception of plot images;
- inability to differentiate the primary from the secondary;
- a low level of objects recognition;
- a low level of eye-hand coordination;
- unable to recall the letters;
- inability to distinguish numbers, letters and their elements;

- insufficient visual imagery;
- inability to distinguish elements of similar objects.

From our study it was clear that primary schoolchildren are interested in studying the writing with Braille method, however there were several difficulties with spatial orientation especially with micro spatial orientation, fine motor skills and tangible, visual perception. They had difficulties in finding educational stuff on the table, differentiating some terms like right, left, up, down. Those difficulties were among the works of blind children (making omissions, adding extra punctuation points, leaving gaps, confusing lines and so on).

Two of the children participating in the study, had difficulties in placing the typewriter to Braille exercise book, using stylus correctly. Blind children were also characterized by abnormal posture. It is important also to state, that primary schoolchildren who are blind and have residual vision have difficulties in mobility, balancing, coordination, space orientation, also touching inability, incomplete perception of characters. These things reduce the pace of acquiring the writing with Braille system and act as negative factors in learning process of the child. During the study only one of the schoolchildren didn’t make serious omissions, however, it is obvious that the assessment work needs to be continued to be able to state more validated and trustworthy results (Seim, Quigley, &Starner, 2014).

It’s necessary to mention that at school while educational process a lot of work is being done to design the writing of these children. While organizing the writing with Braille system a great attention is paid to the above mentioned problems. Especially the attention of schoolchildren who are blind and have residual vision is still involuntary and not focused so they find it difficult to concentrate their attention on one thing, they quickly get tired and deviated. For this purpose, different developmental activities are done, tyflotechnical measures are taken to improve the writing difficulties with Braille system. The organization of the writing for preliminary schoolchildren who are blind and have residual vision with Braille system is carried out on the basis of hearing and touching, so it’s very important to develop fine motor skills and tactile perception because it’s impossible to feel the examined items without them (Davtyan, 2018).

Along with writing with Braille system, some work is carried out to improve children’s’ fine motor skills and micro spatial orientation.

It should be noted that during daily school activities, substantial work is being done to improve the writing skills of these children. While organizing teaching Braille, great attention was paid to the above-mentioned issues. And the majority of teachers have emphasized the effectiveness of using a “Study preparedness assessment form for preliminary school children who are blind and have residual vision”.

CONCLUSION

The results of the study showed that teaching Braille literacy to schoolchildren who are blind or have residual vision during educational process is important because the base of educational process is the writing and an integral part of implementing it, is to do it correctly and objectively. However, in this regard appropriate methods and measures need to be completed. It is also explained by the absence of relevant scientific and methodological literature.

The studies show that teaching the writing to children with visual impairments during educational process needs to be replenished. It is the result of less mobility and activity, lack of interest, defective development of fine motor skills, lack of relevant books, and equipment. Our studies showed that teaching the writing plays an important role. That’s why some measures and methods are taken and developing games are organized. This is explained by the lack of the necessary literature dedicated to the study problem, targeted work, and didactic materials for the transmission of visual knowledge. However, to carry out this work successfully there is a need to replenish research and cooperate.

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Doi: 10.24234/se.2020.2.2.236

CHILDREN WITH INTELLECTUAL DISABILITIES: CHALLENGES IN EDUCATION

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ABSTRACT

Educational policies aimed at school inclusion have led to increased enrollment of students with special education needs in mainstream schools. As a result, there is an increase in problems and challenges that children face while studying at school.

The article aims to highlight some of the difficulties and challenges that elementary school children with intellectual disorder face while studying in a mainstream school. In this study, we have conducted a literature review that examines the level of development of higher mental functions in children with intellectual development problems: attention, perception, thinking, memory, speech.

Keywords: intellectual disabilities, mental retardation, development, age, intelligence, language, perception, attention, thinking, memory.

INTRODUCTION

The odd potential of intellectual disabilities in young children worldwide is a major concern. Realistic estimates suggest that approximately 780 million children may be affected between birth and five years' age (Olness, 2003). The number of young children likely to be affected by intellectual disability worldwide is eclipsed only by the diversity and complexity of the developmental patterns (Guralnick, 2005).

Reviewed evidence indicates that a substantial majority of children with intellectual delays exhibit special problems in studying as well as in forming peer relationships is school (Guralnick, 2006) which might be related to the development of higher mental functions. The highest and most complex level of human cognitive activity is thinking. Unlike other mental processes, thinking allows a person to operate with abstract concepts, make inferences and solve certain problems without interacting directly with an object, that is, thinking allows a person to go beyond the framework of sensory cognition. And such thinking processes like analysis, synthesis, comparison, abstraction, generalization, concretization help to acquire new knowledge (Schalock et al., 2010). Thinking is a generalized reflection of reality by a person, based on practical activity and sensual knowledge of the world, mediated by speech and acquired knowledge.

Intellectual disability, sometimes called cognitive disability, formerly referred to as mental retardation, is described as a disability characterized by significant deficits both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills that occur before the age of 18 in which needs for supports become imperative (Schalock et al., 2010; Tassé, et. al, 2012). As Schalock et al. (2010) pointed out, intellectual disability results in impaired cognitive abilities and adaptive skills and the need for extraordinary supports for a person to participate in activities involved with typical human functioning. Intellectual disability is, therefore, not only an inherent trait of any individual, but also is characterized by a combination of deficits in both cognitive functioning and adaptive behavior in which systems of support become imperative.

The World Health Organization's International Classification of Functioning, Disability and Health (WHO, ICF 2007) defines disability within a bio-psychosocial model, which integrates both factors of the individual and his/her environment in defining disability. Within the WHO ICF framework, disability is viewed as impairment in body function or structure; limitation in activity; and restriction in participation (UNICEF & University of Wisconsin, 2008). Therefore, the construct of disability has changed from focusing on a disorder within the person to a socio-ecological person-environment fit conception that focuses on understanding human functioning and disability based on the interactions between personal and environmental characteristics (Buntinx & Schalock, 2010).

According to Schalock et al. (2010) and Tassé et al. (2012), the condition of intellectual disability is described and defined in terms of three major components: the deficits in intellectual functioning, adaptive behavior, as well as the needs of systems of support. However, there are no universal biomarkers associated with intellectual disability, hence, a determination of intellectual disability is made relying on a robust clinical evaluation of child functioning (Tassé et al, 2012).

AIM AND METHOD

Our research aims at pointing out the difficulties that elementary school children with the intellectual disorder face while studying in a mainstream school. The literature review method helps us to examine the peculiarities of these children, school difficulties in combination with the level of development of higher mental functions of children with intellectual development problems: attention, perception, thinking, memory, speech. An effective and well-conducted review as a research method creates a firm foundation for advancing knowledge and facilitating theory development (Webster & Watson, 2002). Through integrating findings and perspectives from many empirical findings, a literature review can address research questions with a power that no single study has (Snyder, 2019).

For children with intellectual disabilities, thinking takes a special place. The development of this mental process plays an important role for educating the child, as well as for obtaining "life competencies", in order to prevent the child from "falling out" of society.

According to Vygotsky (1963), the thinking of children with learning disabilities develops according to the same laws and principles as the thinking of children without developmental disorders. But the disorder itself or the consequences of any disorder create conditions under which the child develops differently, his or her development follows a different path.

First of all, the thinking of children with learning disabilities is characterized by stereotyping, stiffness, and insufficient flexibility of thinking processes. That is why the implementation of new tasks among these children causes certain difficulties.

When dividing an object into parts, children with intellectual disabilities often emit fewer parts of the subject than typically developing children. They easily isolate sharp and protruding parts of the object, but do not highlight those details that do not have sharp outlines. Children hardly distinguish parts of an object that are similar in color or other properties of their surface. Thus, for children in this category it is characterized by unsystematic analysis, the absence of sequentially complicated division of objects (Vygotsky, 1963).

When identifying the properties of objects, children most often indicate permanent signs common to all objects of this kind. Features and idiosyncrasies do not stand out. Also, due to speech impairment and a relatively small vocabulary, children cannot give a verbal description of the parts and properties of the subject, which interferes with the comprehension of the object being studied. Considerable difficulties for schoolchildren with intellectual impairment are comparing objects. The main disadvantage of this process is that children often correlate inappropriate signs of objects.

The book "Peculiarities of the Mental Development of Pupils of a Secondary School" by Shiff (1965) provides a large amount of experimental data that characterize the inferiority of mental operations of children with impaired intelligence. So, for example, Zvereva and Lipkina (1953) concluded that when comparing objects, such children most often reveal differences in the objects they offer, but establishing similarities causes them certain difficulties, and sometimes children cannot establish similarities at all between items.

For children with intellectual disabilities, the development of perception is uneven, the acquired standards are often unstable, vague, there is no transfer of the learned mode of action from one situation to another. The relationships between the perception of a property, the ability to act with this property in mind, and the ability to make simple generalizations are quite complex. Children who successfully distinguish properties during classes cannot pick up paired items at the request of the teacher. They do not select them at all in everyday life, in independent activity, when you need to find a certain object in the room.

In the learning process, children learn the rules and general concepts with difficulty. Often, children with mental retardation memorize the rules by heart, but at the same time they do not understand the meaning or meaning of the learned rules. Therefore, the study of subjects requiring a clear understanding of the rules, such as the rules of grammar or arithmetic, presents the greatest difficulty for children with mental retardation.

Pinsky (1999) revealed that children with intellectual disabilities have an impairment of the structure and motivation of activity. So, he notes an impairment of the relationship between the goal and the action, as a result of which the process of performing actions becomes formal, not designed to obtain really significant results.

Often, children with intellectual disabilities replace or simplify the goal, guided by their task. As a rule, schoolchildren with impaired intelligence perform the task without preliminary orientation in it, without proper analysis of the data and requirements contained in it.

Perova (2001), Pinsky (1999), and Shiff (1965) noted the ease of the approach of schoolchildren with intellectual disabilities to the task. Having accepted the task and having shown great activity and a desire to carry it out, students at the same time show a carefree attitude towards the mode of action leading to the desired goal. In some cases, they, having all the necessary knowledge and skills to solve the problem, are not able to solve since this knowledge and skills are not updated at the right time. Some of the students are not able to plan their activities.

According to Zvereva and Lipkina (1953), the most accessible form of thinking for elementary school children with intellectual disabilities is visual thinking. However, the children experience some difficulties when completing tasks. So, it’s difficult for them to fold a simple cut picture or to correctly fill in the Segen board. Students have insufficiently developed practical actions. This is primarily due to the inferiority of sensory cognition and impaired motor sphere. At primary school age, child’s actions with objects are often impulsive in nature, they are not associated with a mental task and have no cognitive value.

Vygotsky (1978) revealed that great difficulties for students with learning disabilities cause tasks involving the use of visual-figurative thinking. But tasks that require from children verbal-logical thinking are particularly difficult. So, for example, when considering a color plot picture, a child cannot always establish the cause-effect relationships reflected on it. Most often, children see and perceive individual parts of the picture, but do not understand the plot as a whole. It is difficult for them to understand texts containing temporary, causal or other relationships. Children reproduce the material in a simplified manner, omitting many, sometimes the most significant parts of it. They can change the sequence of semantic links of the text and not establish the necessary relationships between them.

Apart from learning difficulties, children with mental retardation may face many behavior disorders as well. Behaviour disorders are particularly important for children with mental retardation, since in addition to the subjective distress they cause the individual; they restrict opportunities to engage in many normal activities. McDougle and others (1997) found that children with mental disorders who had behaviour problems have reduced freedom of movement, social and self-help skills, have fewer leisure activities at home and fewer friends at school than those without such problems.

Mentally retarded children show behaviours that are considered as problematic because of the harm or inconvenience they cause others, or to the child himself. The presence of behaviour problems in mentally retarded children puts great strain on teachers. Besides, they may interfere with learning in the school/classroom settings (Venkatesan, 2004). The author emphasized that when a child with mental retardation calls out things, shouts or stamps its feet, people attribute these behaviour problems to his primary condition of mental retardation. This, is however, not true. Behaviour problems may be viewed as learned patterns of behaviour or as a function of the contingencies or rewards received by the children in their respective environment (Venkatesan, 2004).

Holden and Gitlesen (2006) reviewed the various studies which indicated that 10%–15% of people with mental retardation show challenging behaviour, like attacking others (aggression), self-injurious behaviour, destruction, disruptive or socially unacceptable acts. He indicated that the challenging behavior is more common among elementary school children, among males, and increases with lack of communication skills and severity of mental retardation.

Bogdanova (2005) investigated the role of needful-motivational, emotional-volitional and communicative spheres in the regulation of the behavior of students with mental retardation in the learning process. It was found that one of the most problematic abilities of students with mental retardation was motivational regulation of behavior.

Bogdanova (2005) notes that behavioral disorders in students with intellectual disabilities may be due to teacher activity mistakes. In this regard, the so-called situational behavioral disorders that were identified as a response to the lack of a correct approach on the part of the teacher were identified. Such violations were attributed to: situationally-demonstrative, situationally-aggressive, situationally-insecure, situationally hyperactive behavior.

The development of ordinary and full-fledged, as far as possible, thinking in children with mental retardation is difficult, but an often solvable task. Achievement of the solution to this problem is possible through specially developed special pedagogy teaching methods and techniques used in the early stages of child development.

CONCLUSION

The literature review shows that elementary school children with mental disabilities face many obstacles and difficulties while at school. From the outcome of our investigation it is possible to conclude that the main challenges and difficulties are the following:

- stiffness and insufficient flexibility of thinking processes;
- unsystematic analysis, the absence of sequentially complicated division of objects;
- speech impairment and a relatively small vocabulary prevent children from giving a verbal description of the parts and properties of the subject, which interferes with the comprehension of the object being studied;
- difficulties in establishing similarities between items;
- generalization of subjects;
- memorizing the rules by heart without understanding the meaning of the learned rules;
- lack of motivation;
- task completion without proper analysis of the data and requirements contained in it;
- activity planning;
- seeing and perceiving individual parts of the picture without understanding it as a whole;
- challenging behavior.

Within this scope, it is essential to be able to address the needs of children and their families as soon as it is possible. It means that early intervention here is highly required. It is also important to focus on issues that support the adaptations that are and will be necessary to strengthen those families, as well as enable and facilitate child development. The education of children with mental disabilities took on a greater impetus from the second decade of the last century and several methods have been developed since then. Newer and more innovative methods are constantly evolving, which augurs well for the future. It is hoped that new elaborated and developed methods will soon solve at least some of the problems and difficulties that children with mental disabilities face while at school.

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Doi: 10.24234/se.2020.2.2.237

FINNISH POLICIES AND PRACTICES FOR SUPPORTING DIFFERENT LEARNERS

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ABSTRACT

Nowadays the inclusive practices allow all pupils to attend the school they would attend if they did not have a disability, and no pupil can be deprived of placement, because of a disability unless they are a danger to themselves or other students. Pupils with special educational needs are included in the school population and served in the general education classes alongside students without disabilities. Unlike traditional education practices, inclusive education strives to provide intervention, remediation, and support within the general education classroom. Inclusive education is based on the principle according to which education should be delivered at different levels using multiple methods to meet the needs of all pupils. Anyway, some authors discuss the risk of inclusion, which only involves moving special education practices into the mainstream classes. From this perspective, inclusion comes to mean nothing more than integrating children with special educational needs into regular classrooms and the process of ordinary teaching leaves unchanged. Based on this it is very important to investigate and analyze "the inclusive education" provided in the schools from the teachers' points of view in order to find out the real picture about the inclusiveness from a very broad perspective.

From this perspective, the review of Finish policies and practices shows that inclusion itself and by its nature is the favored approach to education for pupils with special educational needs, whenever possible.

Key words: inclusion, inclusive education, children with special educational needs, Finnish policy of inclusive education, mainstreaming, segregation.

INTRODUCTION

Inclusion includes every individual's right to be treated equally, and to be accorded the same services and opportunities as everyone else. In a school setting, full inclusion involves educating all children in regular classrooms all of the time, regardless of the degree or severity of a disability. Effective inclusion programs take place in conjunction with a planned system of training and supports. Such programs usually involve the collaboration of a multidisciplinary team, which includes regular and special educators (or other personnel) as well as family members and peers (Inclusion and Parent Advocacy: A Resource Guide Disability Resources, 1996). Although there has been a recent push for schools to educate pupils with disabilities in the general education classroom; however, in past years, the integration of pupils with disabilities with their typically developing peers was known as mainstreaming, which is different from inclusion in several ways. Mainstreaming is typically limited to putting a person with a disability next to typical people in the usually quite vague and unspecific hope that each will adapt to and learn about the other (Ainscow, Booth, & Dyson, 2006; Dyson, Farell, Polat & Hutchenson, 2004). This refers to the practice of educating students with special educational needs in classes with non-disabled students during specific time periods based on their skills. Students with special needs are segregated in separate classes exclusively for students with special needs for the rest of the school day (Zittleman & Sadker, 2006). Segregation in a separate classroom or special school exclusively for students with special educational needs is seen when students with special educational needs spend no time in classes with non-disabled students. Segregated students may attend the same school where regular classes are provided, but spend all instructional time exclusively in a separate classroom for students with special needs (Febo, 2016). In the case when the special class is located in a mainstream school, children with special educational needs may be provided with the opportunities for social interaction, integration outside of their classroom, for example in canteen, playground etc. (Hicks, 2011).

A policy of inclusion is generally understood around the world as part of a human rights agenda that demands access to, and equity in, education (Florian, 2008, p.202). Approaches to schooling of students with disabilities and other special needs have occurred interactively with civil and human rights movements. The move is always from segregated models of learning and towards schools designed to educate all children together (Peterson & Hittie, 2003).

The recent tendency in Europe is also to develop a policy towards the inclusion of students with special educational needs into mainstream schools, providing teachers with varying degrees of support in terms of supplementary staff, materials, in-service training, and equipment (European Agency for Development in Special Needs Education, 2003).

In many ways the Finnish school system is inclusive by nature (UNESCO, 2007). Development towards the school for everyone has begun years ago. Legislation that directs the Finnish education system is based on equality, justice of learning and on the principle of inclusion. The most important goal of education is to support growth and development of unique personality in all possible ways (UNESCO, 2007).

Finland's exceptional education system has long been a role model for the international community (OECD, 2014a; OECD, 2014b; OECD, 2014c; OECD, 2013).

LITERATURE REVIEW

The movement to integrate special education students into normal school classes started to develop in Finland in the 1960s (Moberg & Zumberg , 1994) and today in many ways the Finnish school system is inclusive by nature (Jarvinen, 2007). As it was already mentioned, the most important goal of education in Finland is supporting growth and development of unique personality in all possible ways. Schooling is provided first and foremost in context with mainstream education (UNESCO, 2007). Also the main goal of education is to guarantee the best possible learning to everyone. Every child is important and all the decisions are made from the children point of view (UNESCO, 2007; Jarvinen, 2007).

Nowadays the Finnish Parliament decides on educational legislation and the general principles of education policy and the government, the Ministry of Education, and the Finnish National Board of Education are responsible for the implementation of this policy at the central administration level (UNESCO, 2007). The government participates in the costs of schools by paying the so-called statutory government transfer to the education provider. The role of the Ministry is to prepare strategic policy guidelines for education, to prepare and share budget and to prepare educational laws. The main responsibility of NBE is to prepare and decide about the National Core Curriculum for schools and development of the Finnish education system (UNESCO, 2007; Jarvinen, 2007).

In history the dialogue on inclusion in Finland has commonly focused on pragmatic issues, especially on what comprises the best learning environment for learners with various learning needs, and on the consequences of integrating a learner with a disability into a mainstream classroom (Engelbrecht, Savolainen, Nel & Malinen, 2013). Due to this emphasis, the commitment to inclusion in Finland has traditionally tended to focus on the unique organizational traits and right actions mainstream schools require to provide support for learners with special education needs, preferably in separate settings in mainstream schools. Teacher education for inclusion has, consequently, focused on a separate program for those who intend to provide support for learners with special education needs in mainstream schools. As a result, comprehensive schools in Finland have retained some aspects of differentiation despite the fact that the reform adopted in the 1970s aimed to increase sociocultural, geographical and gender equity (Savolainen, Engelbrecht, Nal & Malinen, 2012). Special education support in mainstream schools has continued to grow, and largely relies on a pull-out as well as separate classroom models of instruction and support, based on a deficit approach to learners with disabilities and other special educational needs. In order to develop a more inclusive approach within mainstream classrooms, there has been systematic reform in recent years to move Finnish schools away from separate special needs programs within mainstream schools towards a more inclusive direction through a new Special Education Strategy (Finnish Ministry of Education 2007 - www.minedu.fi), the Revised Act on Basic Education (Finnish Law 642/2010 - www.finlex.fi) and the updated National Curriculum Guidelines (Finnish National Board of Education 2010 - www.oph.fi). Based on to the Revised Act on Basic Education, schools are now required to show evidence of adequate learning support in mainstream classrooms before any learner can be given more intensive separate learning support, and the decision about a learner’s needs are now principally based on a review by the teacher. These recommendations have been seen as radical in some circles, and the Trade Union of Education in Finland has expressed their concern that teachers’ workload will increase, and that they do not have sufficient professional skills related to disabilities, mainly because traditionally specially trained special education teachers have been responsible for the support of learners with special educational needs (Malinen, Vaisanen, & Savolainen, 2012).

Education for all in one school is the leading principle nowadays in Finland (Takala, Haussttatter, Ahl, & Head, 2012). And there is an individualized understanding of special education with a strong focus on different kinds of learning problems, methodological solutions and individual development and evaluations in Finnish educational system. Here the provision of special education, including segregated provision, is seen as part of inclusive education, especially the so-called part-time special education which does not demand an individual educational plan developed for children with special educational needs (Takala, Pirttimaa, & Törmänen 2009).

After getting acquainted more convincingly with the theoretical background of inclusive education in Finland we will shift to practical experience that every reader will find fascinating and worthy to know. Visiting a Finnish school leaves you amazed at first. It is a habit to swop your shoes for a pair of cozy slippers when entering the building, the children feel like they are at home and relaxed. All students call their teachers by their first names and no any tense and formal relationship exists. Above all the concept of including students with learning difficulties is deeply embedded in the system. Academically strong and weak students, as well as students with disabilities, are actually being taught in the same classroom (http://www.education-worldwide.de/Education-in-Finland-7023_e.html). It means putting in place a whole suite of provisions, including individualized curriculum, individualized teaching methods, modified assessment techniques and accessibility arrangements, all of which require support for the educator at the classroom level (Mitchell, 2008).

POLICY PUSHES

Amendments to the National Core Curricula for pre-primary and basic education happened in Finland in 2016. It reflects to organization of the support in inclusive schools. The main point of this is the possible earliest support in order to prevent the development and progression of the existing problems. Basic education is the same for all (European Agency for Special Needs and Inclusive Education,2020). There is no streaming, but children are supported individually so that they can successfully complete their basic education (European Agency for Special Needs and Inclusive Education,2020; Finnish National Board of Education, 2016). Based on this education providers, municipalities and private education providers, draw up local curricula and annual plans on the basis of the national core curriculum. The local curricula complement the objectives, core contents and other aspects related to instruction with local emphases. The needs of the pupils, local specificities as well as results from self-evaluation and development work are taken into account (Finnish National Board of Education, 2016). The essential aims of the new curriculum, are to develop the school culture and to promote instruction with an integrative approach. The aim is that all pupils, despite the fact or having or not special educational needs, will:

- understand the relationship and interdependencies between different learning contents;
- be able to combine the knowledge and skills provided by different subjects to form meaningful wholes;
- be able to adopt and use these in collaborative learning (Finnish National Board of Education, 2016).

According to PORI (Special education in Finland and Myötätuulen koulu) the support for growth, learning and school attendance is shaped into three main categories in Finland which is presented in table 1:

Table 1.

Three main categories of support students in school.

General support	Everyone has rights to general support.
Intensified and special supports are based on careful assessment and long-span planning i multi-professional teams and on individual learning plans for pupils.	
Intensified support	For a pupil who needs regular support in his/her schoolwork or several types of support simultaneously (Support for learning and schoolgoing, City of Helsinki). Pedagogical assessment is needed for planning the intensified support handled in the pupil welfare group of the school. Following this a learning plan is drawn up for the pupil (EACEA National Policies Platform, Eurydice, 2019).
Special support	If intensified support isn't enough, pedagogical statements shall be done into the pupil's overall situation and the type of support to be provided for the pupil. If necessary, the statement is complemented by specialists.

	Based on this information, the education provider makes an official decision concerning special support (EACEA National Policies Platform, Eurydice, 2019). Based on the subsequent decision, an individual learning plan is required to be developed.

PRACTICAL IMPLICATIONS

To guarantee the success of learning, teachers seek to give pupils personal goals and learning methods. In school practice, while working with children with different abilities it means:

- Individualized curriculum
- Individualized assessment
- Individualized teaching
- Acceptance
- Access, and
- Support.

Let’s reflect too each of these concepts shortly.

Individualized curriculum - making modifications to the curriculum is central to inclusive education; probably the biggest challenge educators face in creating inclusive classroom settings. It is a single curriculum that is, as far as possibly, accessible to all learners, including those with special needs. It includes activities that are age-appropriate, but are pitched at a developmentally appropriate level (Mitchell, 2015). To make the curriculum accessible, consider *modification, substitution, omission and compensation* in relation to content, teaching materials, and the responses expected from the learners.

Individualized assessment - when assessment is used for selection or ranking it is inevitable that learners with special education needs will fare the worst, thus stigmatizing them as failures and de-motivating them. It should assist you to adapt the curriculum and your teaching methods to all learners. So it allows you to diagnose why something occurred and then re-design learning opportunities. It should provide feedback to learners and parents. It should have focused on identifying what has not been achieved in rather than putting learners in some kind of order of merit. The adapted assessment should take account of leaners ‘particular needs of support. Assessment should result in individual learning plan. An Individual learning plan does not require a learner be given individual teaching. Rather that means a larger awareness of individual needs.

Individualized teaching - teachers should have a wide repertoire of pedagogical and professional skills. Their focus should be managing learning rather than managing learner´s behavior. Teachers require learners to complete their tasks and same time create positive self-beliefs in their students. Teachers always reflect their teaching and classroom outcomes. They fully consider learner´s cultural and language backgrounds in planning and delivering teaching. They are authoritative not authoritarians! And humor is always present in teaching. Teachers themselves can choose the teaching methods they use in order to achieve the objectives stated in the curriculum and pupils' individual education plans. The national core curriculum includes the guidelines for choosing the methods. In addition to the traditional and still common method led by the teacher, there are more and more teaching methods that focus on pupils.

Acceptance - inclusive education relies on educators, learners and their parents and all the society accepting the right of learners with special educational needs to be educated in general education classrooms and receive equitable resourcing (Mitchell, 2015).

Access - Physical environment: For learners with physical disabilities to be included, adequate access to classroom must be provided. This can mean ramps, lifts, adapted toilets, wide doorways, adequate space for wheelchairs in the classroom**.** Mental ethos/atmosphere: The joint values of teachers behind teaching practices (e.g. understanding of inclusion, ethics of care) sense of belonging and being heard is essential. Social interaction: Principal of equality, preventing bullying, meaning of teacher-student relationships, importance of peer group (teaming up a teaching group).

Support - usually **i**nclusive schools are served by multiple-skill student health care teams. The teams can include the principal, a school nurse and school doctor, a school social worker, a school psychologist, a special needs teacher and guidance counselor. The student welfare team works to promote the wellbeing of the school community and seeks solutions to assist pupils in need for support (Family Support, Helsinki, 2018). A pupil could have multi-professional support: assistant teachers, occupational, speech or physic therapists, psychologists, learning assistants. Teacher in inclusive setting should have good teamwork and leadership skills.

While reflecting to practical implication of existing policies in Finland it is very important to pay special attention on resources. Obviously inclusive education requires high levels of resourcing.

At the same time, the inclusive education might be more economically viable, given the expense involved in transporting and accommodating learners in special school, especially in rural areas.

To bring all of the before mentioned elements together, leadership is required at all levels: government, national education departments and ministries, district departments, school principals and classroom teachers. Within this scope Finnish educational system gives an opportunity to all parties concerned to be flexible and create all possible placements for children with different needs in mainstream school. Placement here is understood as an age-appropriate classroom in the learner´s neighborhood school despite the fact of child’s educational needs. It is important that learners with special educational needs are not then placed in ability-based groups for all their activities.

CONCLUSION

Conducted literature review regarding policy and practice in Finish school to support all learners we can state that Finnish school culture makes concrete values. Finnish functions as a learning community that takes care of the safety and wellbeing of each and every member of the community, systematically promotes versatile working approaches as well as cooperation and interaction. Thus Finnish school promotes equity and equality in practice and takes responsibility for the environment and focuses on a maintainable future.

Special attention is paid to the fact that mainstream schools offer opportunities for individual and shared learning for all its members (Finnish National Board of Education, 2016). All members take each other into account through a dialogic interaction, striving to adapt their own actions to the activities of each learner and the whole school community.

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Doi: 10.24234/se.2020.2.2.238

INTERDISCIPLINARY MEDICAL AND DENTAL DESENSITIZATION FOR PEOPLE WITH AUTISM

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ABSTRACT

Premier HealthCare, a member of the YAI Network, specializes in outpatient healthcare services (such as primary care, dentistry, psychiatry, rehabilitation, psychotherapy, psychological testing, and nutrition) for people with intellectual and developmental disabilities in New York City. This is one of the most in need, yet underserved, groups of medical and dental patients. Many people with autism spectrum disorder (ASD) have difficulty understanding the significance of healthcare procedures and become overwhelmed by the unfamiliar environment and sensory input of medical and dental practices. They may also have difficulty with communication and socialization, which can exacerbate anxiety and challenging behaviors such as self-stimulation, self-injury, aggression, and tantrums. Additionally, this heightened level of stress can potentially translate into disruptive behaviors or physical reactions to avoid treatment. These challenges combined with a lack of healthcare professionals trained and experienced in working with people with ASD can result in ineffective preventative care and high-cost procedures.

At Premier HealthCare, a desensitization program was initiated to increase functional participation in medical and dental exams and decrease use of physical restraints or general anesthesia for people with ASD. An interdisciplinary team of occupational therapists, behavior analysts, doctors, nurses, and dentists collaborate to address how to make medical and dental procedures more tolerable for patients with special needs using a protocol comprising of four main stages: evaluation, treatment, generalization, and maintenance. They work with caregivers to provide person-centered individualized care, ultimately leading to decreased anxiety, fear, and aggressive behaviors; increased participation; and better health outcomes for people with autism.

Keywords: Occupational therapy; disability; pediatrics; primary care; intellectual disability; developmental disability; desensitization; interdisciplinary; autism; dental desensitization; medical desensitization.

INTRODUCTION

The YAI network is a nonprofit organization that provides innovative services for people with intellectual and developmental disorders (I/DD). The organization promotes a “total life adjustment approach, emphasizing personal growth, social responsibility, employment goals, and the development of independence for the individual” (YAI, n.d.). Premier HealthCare is a member agency of the YAI network. It consists of a group of outpatient clinics that provide medical, dental, psychiatry, rehabilitation, mental health, and nutrition services primarily for the I/DD community throughout New York City. It is recognized as a Patient-Centered Medical Home by the National Committee on Quality Assurance (YAI, n.d.).

A desensitization program at Premier, funded by a grant from the New York State Office for People with Developmental Disabilities (OPWDD) was initiated to enhance functional participation during medical and dental exams. Desensitization is a type of behavioral therapy used by trained professionals to help people overcome fears, phobias and other anxiety disorders. It teaches relaxation and stress management techniques, while gradually exposing people to distressing situations, so the person can eventually face the situation without fear or anxiety (Davit, Hundley, Bacic & Hanson, 2011). At Premier, occupational therapists, behavioral analysts, nurses, doctors, dentists, and dental/medical assistants collaborate to address the anxiety, fears, and aggressive behaviors that can disrupt routine health management.

The American Occupation Therapy Association recognizes health care management as an instrumental activity of daily living (IADL) that supports daily life within the home and community. It involves developing, managing, and maintaining routines for health and wellness promotion (AOTA, 2014). Neuro typical individuals can struggle with this IADL due to fear, anxiety, lack of access to healthcare, and/or a decreased understanding of the importance of health maintenance and wellbeing. Individuals with disabilities are at an even greater disadvantage to participate in health care management due to developmental deficits, co-morbidities, and systemic barriers.

Research shows that people with autism spectrum disorder (ASD) are less likely to utilize preventative services, have more frequent visits to emergency departments, and have an increased number of unmet health needs compared to non-autistic adults (Nicolaidis, et al., 2015; Schell, Gillen & Scaffa, 2014). ASD is also associated with increased prevalence of several medical conditions such as immune conditions, gastrointestinal disorders, sleep disorders, seizure, obesity, dyslipidemia, hypertension, and diabetes contributing to an increased mortality risk (Croen et al. 2015; Hirvikoski et al. 2016). As a result, adults with ASD have poorer health and decreased life-expectancy than the general adult population (Mouridsen, Brønnum-Hansen, Rich & Isager, 2008). Thus, health care management is a crucial and life-saving activity for this population.

LITERATURE REVIEW

As specified in the diagnosis name, people with ASD present with a wide range of symptoms, skills, and levels of disability. Within this diversity there are several common features of ASD that can become barriers to participating in health care services such as social impairment, communication difficulties, and difficulty adapting to changes in routine.

Cognitive and communication differences can complicate identification and management of illnesses unrelated to the disability (Nicolaidis, Kripke & Raymaker, 2014). Many individuals with autism are unable to identify and communicate health changes to their caregivers. Research highlights the possibility that people with autism may not express physical discomfort in the same way as a neurotypical individual. This may lead caregivers and clinicians to interpret this as pain insensitivity or incorrectly lead them to believe that there is no pain - further complicating the assessment of their health status (Allely, 2013). Communication differences can also impair their ability to describe symptoms, follow directions, and understand the purpose of the doctors' actions causing anxiety and resulting in disruptive behaviors to avoid health management.

Several studies have shown that individuals with autism present with significantly greater levels of anxiety and anxiety disorders when compared to age-matched peers (Kim, Szatmar, Bryson, Streiner & Wilson, 2000; Ferrugia & Hudson, 2006; Evans, Canavera, Kleinpeter, Maccubbin & Taga, 2005). Fear and anxiety present as an obstacle to health care management in several ways. Firstly, individuals who fear medical and dental procedures are much more likely to delay or avoid exams and procedures, as well as regularly cancel or fail to keep appointments (Armfield, 2012). Secondly, fearful patients may prove difficult to treat, require more time, and present with behavioral problems resulting in a stressful experience for both patient and practitioner. A study conducted by Brahm, Lundgren, Carlsson, Nilsson, Corbeil and Hagglin (2012) indicates that caring for patients with dental fear is a source of considerable stress for many dentists and is associated with hard work, poor revenues, and little appreciation by employers. Finally, due to avoidance of preventative care, fearful patients often have poorer dental health. Those who delay dental care for a prolonged time might have extensive problems that require more complex and involved treatment (Armfield & Heaton, 2013).

Many people with I/DD have difficulty understanding and anticipating the social situations and contexts that occur in medical and dental procedures. Medical clinics and hospitals are dynamic environments where unexpected changes and uncertainty are common. This can be challenging for an individual who struggles with flexibility and deviations from routine. Within the appointments themselves, medical professionals use instruments and tools that may seem menacing, and the procedures can appear frightening or painful ultimately provoking a fight-or-flight response (Hawkins, 1991).

Sensory processing deficits emerge at a young age and are so commonly seen in people with autism that it can be considered universal feature of ASD and a potential diagnostic criterion (Thye, Bednarz, Herringshaw, Sartin & Kana, 2017; Tomchek & Dunn, 2007). Sensory processing is defined as the effective registration and accurate interpretation of sensory input from the environment. Sensory modulation is defined as the capacity to regulate and organize the information in order to remain at an appropriate level of alertness to adapt to challenges in daily life. Many people with ASD demonstrate difficulty filtering and developing an adaptive response to sensory stimuli (Tomchek & Dunn, 2007). The volume of environmental and novel/unfamiliar stimuli experienced in a medical setting can be overwhelming for individuals with sensory processing disorders. In an effort to regulate their systems individual may attempt to escape to an area with less stimulation or engage in self-stimulatory or self-injurious behaviors.

These challenging responses, coupled with a lack of health care professionals trained and experienced in working with this population, result in insufficient access to care and poor health. Most primary care providers lack the necessary training to care for patients with autism (Zerbo, Massolo, Qian & Croen, 2015). Medical and dental providers may not know how to interpret some of their patients' behaviors and make incorrect assumptions about their abilities and needs (Nicolaidis et. al., 2015). Providers may not be able to adapt to the situation appropriately and as a result opt to have patients physically restrained (strapped or held down) or sedated for routine procedures. Parents have expressed a fear or discomfort with these physical and chemical restraints as these can cause lasting negative associations and responses. These negative experiences may cause emotional distress and aversion to participation in future unrelated health appointments.

In addition, anesthesia and physical restraints can negatively impact the body. Procedural sedation side effects may have deleterious effects on the patient’s physical and emotional wellbeing. Possible side effects are change in heart rate and blood pressure, decreased rate of breathing, headache, inhalation of stomach contents into the lungs, nausea and vomiting, disorientation, and confusion (Johns Hopkins Medicine, n.d.).

Physical restraint can be dangerous as it involves physical struggle, discomfort, and it may put pressure on the chest or interrupt breathing. In addition, it has been postulated that potentially fatal cardiac arrhythmia can result from the combination of certain medications and the adrenaline produced by an individual’s agitation during restraint procedures (Putallaz, Rubins & Schwartz, 1999). The patient is not the only one at risk during physical restraint as health care workers may also be injured while attempting to restrict a struggling patient’s movements. Participating in routine medical and dental procedures without the use of a restraint is beneficial not only to the patient and family but also to the health care professionals involved.

Desensitization programs aim to increase the voluntary participation in routine medical procedures by reducing patient anxiety surrounding medical and dental procedures. This is done by empowering the patient with knowledge of what to expect through gradual exposure to the aspects of the procedure that cause anxiety. Research shows that desensitization techniques can increase compliance with dental and medical procedures in people with autism (Nelson, Chim, Sheller, McKinney & Scott, 2017; Kuhaneck, & Chisholm, 2012; Primeau, Gershon & Talbot, 2016; Davit, Hundley, Bacic & Hanson, 2011).

With a collaborative approach involving sensory integration, neuromuscular re-education, therapeutic exercises, behavior analysis, environmental modification, and co-treatment the desensitization program at Premier aims to address the challenges faced by patients with ASD and caregivers during routine medical and dental examinations. This team strives to decrease the use of physical restraints and general anesthesia, help promote health management, and ultimately enhance wellbeing for individuals with autism.

METHODOLOGY

The Team

What makes the desensitization program at Premier HealthCare unique is the collaborative co-treatment approach designed to foster dialogue between diverse disciplines and promote the development of an integrated health care model. Members of the team include the patient, their family/support system, the occupational therapist (OT), behavior analyst, as well as the dental, medical, and nursing staff.

Participants in the grant must meet the following criteria:

- OPWDD eligibility (disability meets the requirements specified in New York State) (OPWDD, n.d.)
- Autism spectrum disorder diagnosis
- Live with family
- Live in Queens or Brooklyn regions of New York City
- Have displayed challenging behaviors in previous attempts at dental or medical treatment (i.e. refusing to enter the dental/medical room, crying, screaming, rocking, and acting aggressively towards self and/or others)
- Due to the extent of these behaviors, more extreme measures may have previously been necessary (stabilization devices or general anesthesia) to administer critical medical and/or dental care.

The desensitization intervention is patient-centered and inclusive of the person's family or caregiver support system. It is important to talk to the patient and their family about their likes, dislikes, and interests to build rapport and for carryover of skills learned. Often, the therapists will provide tools or model strategies that the family can continue to practice at home in order to promote regular simulations of sensations and events that can take place during a routine exam (i.e. plastic tools to familiarize with the process, tactile input to decrease hypersensitivity, etc.).

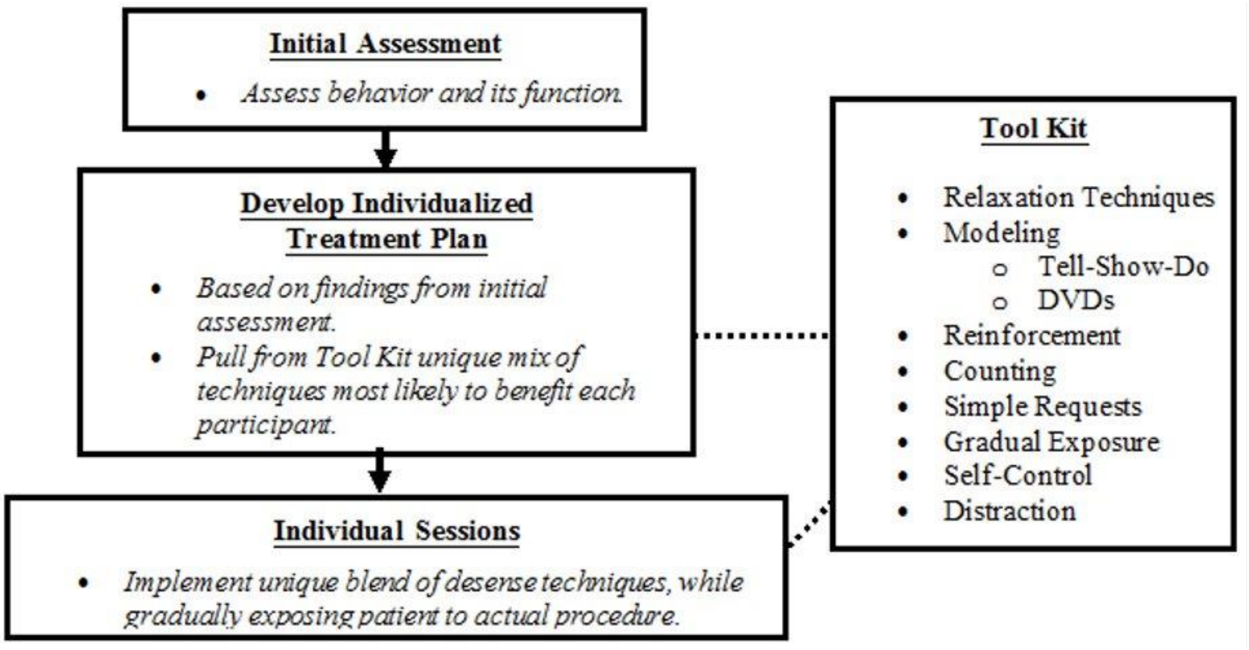
Occupational therapy practitioners utilize a holistic model by assessing sensory processing, as well as the impact of the environment and procedures on the individual. OT helps individuals across the lifespan participate in the activities they want and need to do through the therapeutic use of everyday activities. In this program, the highlighted activity is participating in routine medical and dental exams, or health care management. With their knowledge of sensory integration, ergonomics, and environmental impacts, the OT works with the team to identify accommodations or modifications to the environment and procedures. In addition, the OT serves as a liaison between the patient, caregiver, and the rest of the desensitization team.

The board-certified behavior analyst plays an important role in helping patients learn the skills needed for success by systematically measuring changes in behavior in relation to events that come before (antecedent) and after (consequence) the behavior of interest (completing medical/dental procedure). Some of the principles underlying human behavior include reinforcement (functional relationship between two events that increase behavior) and punishment (functional relationship between two events that decrease behavior). Individuals who are fearful of medical and dental procedures often have negative associations from previous experiences. The behavior analyst works with the patient and caregiver to identify meaningful rewards in order to positively reinforce participation in appointments and reshape the patient’s view of medical and dental procedures. Additionally, their ability to analyze the context in which behaviors present is vital in making modifications and accommodations to the environment and procedure.

Of course, the central part of this program and the ultimate goal is for patients to complete their regular health care visits with the medical, nursing, and dental staff. The relationship between doctor and patient is key to the success of desensitization program. Trust in specific doctors and nurses allows the patient to have positive associations with medical/dental procedures and furthers the process toward generalization.

The Process

The desensitization program has 4 major stages: evaluation, intervention, generalization, and maintenance.



The purpose of the evaluation phase is to identify the target behavior for intervention, determine the function of the behavior, and establish a baseline. The occupational therapist and behavior analyst assess the patient's skills, challenges, behaviors, and their functions. The OT assesses skills including cognition, visual perception, sensory processing, sensation, motor coordination, endurance, tone, functional balance, self-care, etc. The behavior analyst's evaluation includes a daily activity log, communication profile, behavioral language assessment, preference assessment, life activities checklist, and functional behavioral assessment. Information is gathered to assess the person's past experiences with medical/dental services, aspects that provoke the most anxiety, degree of fear surrounding different components of the exam, and if any calming techniques were developed from previously stressful situations.

Based on these results, an individualized treatment plan is developed including the target behavior, goals for intervention, and desensitization techniques that would likely meet the unique needs of the patient to reduce their anxiety. Below are some examples of occupational therapy and behavioral goals:

- **Occupational Therapy Goal:** Joe will demonstrate improved sensory processing/modulation of oral-tactile, vestibular, and proprioceptive input as evidenced by tolerating simulated teeth cleaning with prophy and hand scaling for 20 minutes with moderate verbal cues for direction-following to increase performance in dental health management.
- **Behavioral Goal:** Joe will display his ability to comfortably complete the prerequisite skills (i.e., communicate his needs, follow directives) as needed to successfully engage in medical/dental procedures; without excessive avoidant behavior (i.e. persistent vocal/verbal/physical resistance, escape).

OTs can incorporate sensory strategies to help patients stay calm and self-regulate in order to participate in their sessions. Most people are not aware of the volume of sensory stimuli present during health care appointments and there are many aspects of a medical/dental visit that may cause sensory overload for people with autism. People with tactile (touch) defensiveness may be sensitive to the feeling of probing hands, needles, bandages, thermometers, dental tools, vibrations in the mouth, and blood pressure cuffs. Those with olfactory and oral deficits may experience aversion to strong smells and/or tastes such as prophy paste, rinses, alcohol swabs, and cleaning solutions. Auditory system deficits may produce difficulty tolerating sounds of motorized dental tools and crowded waiting areas. Those with visual hypersensitivity can be distressed by bright lights (dental light, fluorescent lights in the clinic, and ophthalmoscopes for eye exams).

Touch, smell, taste, and sound are the more obvious stimuli in a medical clinic, however those with difficulty processing movement and pressure can also experience challenges during these appointments. Individuals with a disrupted vestibular system may dislike ordinary physical movements and experience motion sickness from riding in cars, elevators, or escalators making transportation to and from appointments difficult. In the case of gravitational insecurity, individuals may experience anxiety when their feet leave the ground, fear falling off on a high exam tables and dental chairs, or have poor tolerance of reclined exam chairs. In contrast, those who seek intense movement may have trouble sitting in a waiting room or remaining still for an exam (this is particularly important during blood draws, blood pressure readings, and dental work) and may attempt to elope. Lastly, proprioceptive system deficits may present as self-injurious behavior such as hitting or biting themselves and chewing or mouthing tools. The occupational therapist may incorporate sensory strategies during simulated medical visits which include using a weighted lap pad for calming deep pressure (the dental x-ray vest is a good alternative), headphones to muffle sounds, fidget objects to squeeze, oral motor chew toys, etc.

Outside of sensory processing issues, there are other challenges that may make healthcare participation difficult. Individuals with ASD often have low muscle tone or generalized weakness which results in difficulty maintaining open mouth position during dental procedures or inability to remain in certain positions necessary for medical procedures such as sitting unsupported during chest exam or during blood pressure readings. Therefore, the OT may also address muscle strength during intervention or utilize adaptive equipment for positioning in order to enhance participation during routine medical and dental visits.

Behavioral strategies may include modeling (the demonstration of a behavior), shaping (use of differential reinforcement to teach/learn new behavior), fading (the temporary use of a prompt or cue, errorless learning/teaching, and questions about the observed excessive response (a patient demonstrating excessive echolalia may be asked “Are you talking about something that happened in school?”). The stimuli that triggers or eases a patient’s excessive response and what was shown to be effective and/or ineffective in each session is analyzed.

The OT is trained by the medical and dental staff on accurate procedure and tool use, which allows for simulations during intervention. The OT and behavior analyst utilize co-treatment desensitization techniques, sensory integration, and behavioral strategies during simulated procedures. These simulations occur in the exam rooms with the actual tools used by the dental providers (i.e. dental mirror, explorer, air water syringe, saliva ejector, prophy handpiece, etc.) and medical providers (i.e. thermometer, sphygmomanometers, tourniquet, syringe, etc.).

The patient is gradually taken through the steps in the procedural sequence with individualized interventions. The patient is never forced to complete a step as it is counterproductive to the process. Every opportunity is given to provide choices (i.e. which exam room, which arm, etc.), explanations of tools/procedures, time to calm with sensory strategies as needed if agitated, and positive reinforcement throughout the session. The therapist makes every attempt to make sessions enjoyable for the patient and will end each session on a good note. It is important to know that the speed of the process is directed by the patient and may take many months or years. The team uses a gradual approach to achieve a “just right” challenge.

The primary area of concern for medical visits with these patients is their fear of needles. Treatment may first address simply getting a patient comfortable sitting in the exam room while engaged in a preferred activity, such as playing games, for a positive association. Once comfortable, preparatory steps to the procedure can be introduced (i.e. rolling up their sleeve, tying the tourniquet, wiping the area with an alcohol pad). This can be done with demonstration or even role reversal (patient acting as the medical provider while the therapist acts as the patient) in order to decrease the fear associated with these procedures. Eventually a capped needle may be introduced touching it on their fingertips, then gradually moving up their arm, and so on, until the procedure is tolerated.

A similar approach can be used for dental visits by first acclimating patients to the dental room environment, including remaining seated in the exam chair. The next step may be demonstration of how the dental tools look and sound like before applying tools distally (i.e. fingertips) and gradually moving up towards the lips/mouth. Colorful plastic tools may be used first and can be less intimidating than the metal tools that are primarily used.

Modifications can also be made to the environment or activity in order to adapt to the needs of each patient. Environmental modifications can include decreased visual stimuli (i.e. dimming the lights of the room, using sunglasses), decreased auditory stimuli (i.e. using noise-canceling headphones, playing calming music), and removal of triggers (i.e. provider not wearing the white coats as this may be intimidating). Activity modifications can include use of a visual schedule or social story to outline anticipated steps, incorporation of sensory strategies and breaks as needed, use of a token board or reinforcers as a reward system, and the therapist joining the patient in their actual medical/dental appointment for additional support and facilitation of strategies with the provider.

Caregivers should be educated on strategies and tools to help carryover the skills learned and to apply to their real medical and dental appointments (especially if they are outside of Premier). They can be given typical items used in medical and dental procedures to role-play going to the dentist/doctor at home (e.g. face masks, gloves, non-invasive tools such as the plastic tools, simulations). Social stories using photos or videos (real-life, animated, or of the patients/staff themselves) can be reviewed to explain the steps involved in their specific appointment.

In the generalization phase, the patients apply these strategies and skills to their real medical and dental appointments. This happens when the patient is ready to transfer their acquired skills to work with unfamiliar health care providers. In maintenance, patients have periodic therapy sessions to ensure they continue to have success in their appointments. The patient is seen on an as-needed basis in order to ensure preservation of learned skills and prevention of regression. While not all patients will complete every aspect of their medical and dental visits, this team strives for success by having patients be able to tolerate more than they could before without use of restraints and with a more positive overall experience.

Data Collection

Data is obtained for each session through progress note narratives and the Procedural Resistance Scale (PRS), the outcome measure form developed by Premier's desensitization team at the inception of the program. The PRS includes basic information about the type of visit or procedures done, a breakdown of the steps of the medical or dental visit, a scale to indicate level of resistance observed during each step, behaviors exhibited by the patient, interventions used, a Likert scale to assess level of improvement from previous sessions, and a comment section for any additional pertinent information. It must be noted that this is not a standardized assessment tool, but a form of documentation that was created specifically for this program.

DISCUSSION

Coordination of care is essential when utilizing various health care services for the individual to have the highest benefit. Effective teams are characterized by communication and collaboration. There are various models of interdisciplinary teamwork within healthcare: multidisciplinary, interdisciplinary, transdisciplinary. *Multidisciplinary* teams are characterized by various disciplines working together under one roof, each completing their own responsibilities with the patient at the epicenter. This best describes Premier HealthCare as a whole- providing various services to patients, each with distinctive patient-centered goals and treatment plans (Schell, Gillen & Scaffa, 2014).

Contrarily, *interdisciplinary* teams work together with the client to determine goals, how each team member will contribute, and create a collaborative plan. This team best describes the desensitization grant, as some interventions may be jointly carried out and the client is involved in the decision-making process. There can be issues that arise from an interdisciplinary team, however, if there is an uneven distribution of responsibility between team members. One team member may take the lead, pushing their own agenda further than another team member. For this reason, communication and trust are essential for the desensitization program to be a success (Schell, Gillen & Scaffa, 2014).

Transdisciplinary teams have interchangeable roles; expertise and responsibilities are shared. This is evident in the occupational therapist's approach as they incorporate aspects of behavior management, dental/medical intervention, and their own occupational therapy strategies throughout the desensitization process. It is important to note that frequent consultation with other disciplines is necessary to ensure accurate implementation of strategies not common to one's field. For example, in the desensitization program occupational therapists are trained by the dental and medical staff to properly utilize the tools and simulate procedures as accurately as possible. All three models are utilized in Premier. Each approach varies depending on the patient's needs and some models may be more effective than others. Clinicians should communicate earnestly about their capabilities and concerns, and the client's needs must be central to all decisions (Schell, Gillen & Scaffa, 2014).

Coordination of care is also essential when discussing discharge. In this program, discharge is not necessarily when a patient has "graduated" and reached the maintenance stage. Discharge can also be when a patient reaches maximum potential. Identifying a person's maximum potential requires clinical experience and judgement. This assessment requires consultation with all team members and can be a difficult topic to address with other clinicians and the caregiver. Therefore, education and consistent communication is key throughout the intervention process. Effective strategies and triggers that may escalate behavior should be reviewed with the entire team for use during future medical and dental appointments to be able to achieve the highest level of participation as possible. It is also important to note that participation and subsequent discharge from the program does not preclude a patient for joining the program again. Should circumstances change, a patient can be referred back to the desensitization program for evaluation and appropriate intervention.

Implications for Practice and Future Research

Research suggests significant autism-related health disparities, which may be additionally amplified for those individuals also who belong to disadvantaged groups, lead to more adverse physical health outcomes later in the life. This indicates that clinicians need to better understand the factors that promote physical health and develop interventions that maximize health and increase quality of life for people with ASD (Bishop-Fitzpatrick & Kind, 2017).

The desensitization program has had many successful outcomes in helping patients with ASD to demonstrate less resistive behaviors and take more steps toward successfully completing medical and dental visits. The consistent collaboration, coordination, and communication amongst the patient, caregivers, therapists, and providers exemplify a standard of care that can show success, not only with the autism population, but for overall quality healthcare. Further research is needed on desensitization with this population in order to measure efficacy and develop formal training modules to expand its use. This can include more robust use of new technology, such as virtual reality, to allow practice for situations that resemble real life as accurately as possible. Technology can also help in bridging the accessibility gap regarding communication and socialization that often impedes the ability of a person with ASD to successfully participate in their daily routine.

While Premier specializes in working with patients with I/DD, and consequently its staff are better equipped to work and adapt to the unique needs that this population has, not all patients with ASD have access or use these specialty clinics and not all primary care clinics have access to behavior analysts or occupational therapists. However occupational therapists have the training to develop, test, and implement health management interventions to improve overall well-being for individuals with autism (Schwartz et al., 2019). An interdisciplinary team can help design desensitization techniques to meet the needs of health care facilities that cater to the general population but may have some patients with ASD. These can include creating a sensory friendly environment, use of additional visual supports to prepare patients for procedures, and consistent collaboration with all members of the patient’s health care team. These strategies can be beneficial not only to patients with ASD, but to patients of all abilities who experience some level of anxiety during medical or dental appointments, as up to 20% of the U.S. population experience "white coat syndrome” during health care visits (Sine, 2008).

The current COVID-19 pandemic, while having a huge impact on a global scale and in its infiltration into daily life, has also highlighted the unique challenges of people with ASD. Face coverings are now the norm, but sensory tactile defensiveness can make it impossible to implement. Without the ability to tolerate wearing a face covering, people with ASD may not be able to access their community without risking their health and safety. Difficulty understanding the standards set forth by health officials, such as proper hand hygiene and compliance with face coverings, can negatively impact their ability to safely engage in infection control. Challenges in understanding social cues and appropriate social interactions can make the new concept of social distancing difficult to practice and therefore increase their risk of contracting the disease. Desensitization interventions such as social stories, sensory techniques, behavioral strategies, and simulations can help people with ASD implement the latest recommendations to combat COVID-19.

CONCLUSION

While the most unique aspect of this program is its collaborative approach, it can prove challenging to implement. Education and staff training for the medical and dental providers is crucial for understanding and acceptance in collaboration with the patient, caregivers, and therapists. At the same time, therapists need to be trained and educated on the nuances of all the medical/dental tools and procedures in order to accurately simulate and train patients/caregivers in preparation for their real health care appointments. It also becomes challenging to appropriately generalize these skills if the patient receives medical or dental care outside of Premier or undergoes procedures outside the scope of primary care (i.e. hospitalizations, surgeries, specialty care).

The process of building trust between the patient and desensitization team may be a time intensive process but is a vital element for success of the program. The patient may become accustomed to individual clinicians and experience regression if that clinician is no longer available to work with the patient before they reach the generalization stage. This may affect the desensitization program’s ability to be implemented in clinics with high turnover rates of staff or where long-term relationships between patient and clinicians are not possible.

Limitations to this study include the participant requirements of the grant. While people from all regions of New York City come to Premier HealthCare for services, only a limited number are eligible for the grant and can receive this co-treatment intervention. This limits the participant pool both for data collection and the number of beneficiaries of these services. In New York state, it is estimated that 3.8 million people have a disability, and only 7.9% of this population are able to go to the doctor alone (CDC, 2019). Ongoing needs assessments, data collection, and training is needed in order to expand services to all who may benefit from it. In addition, while the grant has a structured sequence, the implementation varies from patient to patient due to the unique characteristics of autism and individual patient needs. Although this allows the program and team to provide a patient-centered plan of care, it makes it challenging to development and implement standardized protocols and therefore its expansion to other settings and populations.

In conclusion, a desensitization program at Premier HealthCare, funded by a grant from the New York State Office for People with Developmental Disabilities (OPWDD), was initiated to help people with intellectual and developmental disabilities who were currently unable to tolerate routine medical and dental procedures without the use of stabilization devices or general anesthesia. The goals of the desensitization program are to reduce patient fear and anxiety related to dental and medical procedures; help patients build the coping skills needed to successfully complete dental/medical procedures; assist patients in receiving the primary care and participate in health maintenance activities; and reduce stress within families related to traumatic health care appointments. Over the past 10 years of the program, there have been a number of successes and this team continues to advocate for quality healthcare for individuals of all needs.

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