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CONSUMER AWARENESS ON NON-MEDICAL INTERVENTIONS FOR AUTISTIC CHILDREN AND ADULTS IN UKRAINE

ОБІЗНАНІСТЬ СПОЖИВАЧІВ ЩОДО НЕМЕДИЧНИХ ВТРУЧАНЬ ДЛЯ ДІТЕЙ ТА ДОРОСЛИХ З АУТИЗМОМ В УКРАЇНІ

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Abstract

The conducted study implicates broadening the choice of educational therapy services by means of diversifying them with new world-common reliable approaches by picking only the most effective and humane ones with the lowest number of negative social and mental health consequences, which on one hand, will help Ukrainian society to defeat environmental determinism.

This paper is written from consumers' point of view and is based on analysis of different interventions used for autistic children and adults. The special attention is paid to educational therapies: such as Incidental Teaching, Milieu Therapy, Pivotal Response Treatment, Self-Management, Time Delay Cognitive Behavioral Therapy, JASPER and other widely used all over the world. The research proves that from the listed variety of methods, only 4 of them are commonly used in Ukraine. Among those methods are: ABA therapy, DIR (Floortime) therapy, Sensory regulation therapy and the TEACH therapy.

One of the reasons was lack of accessibility of information on any other methods of educational therapy, aside from the ones being already commonly used in Ukraine. Whenever you search for any methods of autistic individuals treatment using Google search engine, it represents you nothing but ABA therapy (which does not even always meant the therapy mentioned in the description in some of search engine results was in fact the ABA therapy, sometimes they misstitle TEACH for ABA, for example).

Also there was no statistics on autistic children and adults education centers being accessible in Google search engine results after using both Russian and Ukrainian language, which also proves the low level of current type of information accessibility, which effects customers' awareness level on this topic.

Low level of customers' awareness on non-medical, especially educational therapies for autistic children and adults, was also identified after analyzing 51 of their anonymous forum feedbacks from Ukrainian forums for parents. This analysis has shown that consumers are not being fluent in any other methods of

Key words:

autism, consumer awareness, determinism, educational therapy.

Ключові слова:

аутизм, обізнаність споживача, детермінізм, навчальні інтервенції.

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education therapies for autistic children and adults, except ABA therapy, which represents low level of their awareness on the diversity of methods of educational therapies for autistic individuals available all over the world, as well as of their effectiveness, humanism lower quantity of negative consequences on autistic individuals' learning abilities, social independence and quality of life, as a result, and their validity for long-term educational and developmental goals.

A range of recommendations was developed to diversify range of educational services for autistic children and adults and to increase level of their parents' and legal guardians' awareness on this field for them to have a choice.

Анотація

Ця стаття на основі аналізу закордонних досліджень щодо ефективності різних видів немедичних втручань для дорослих та дітей з аутизмом, порівнянням навчальних програм та технік, пропонує огляд найбільш поширених з них. Встановлено, що в Україні найчастіше використовують АВА-терапію, хоча дослідники звертають увагу на її слабкі місця та обмеження. Водночас інші різновиди інтервенцій, зокрема, поведінково-когнітивних, не надто відомі в Україні і не представлені на ринку соціальних та освітніх послуг. Про це свідчить пошуковий комп'ютерний аналіз у Google та аналіз коментарів на спеціалізованих форумах в Інтернеті.

Визначено, що низький рівень обізнаності споживачів щодо немедичних втручань та наявних послуг може свідчити про відсутність свободи вибору або детермінізм, що, у свою чергу, пов'язано з низьким рівнем доступу подібного роду інформації, і ставить питання щодо надійності методів навчання осіб з аутизмом в Україні. Запропоновано низку рекомендацій стосовно підвищення рівня обізнаності споживачів, що могли б стимулювати попит на ефективні інтервенції для дорослих та дітей з аутизмом.

Introduction

Autistic individuals constitute a significant part of human society and the population of them is likely growing (1 of 68 in 2014 versus 1 of 150 in 2000) (Christensen et al., 2016). There is also the evidence, that around 44% of autistic children and adults have either average or above average intellectual abilities (Christensen et al., 2016), despite autism is still associated with learning disabilities, which means individuals with autism can be taught but need different teaching approach than neurotypical individuals. As autism is known as «developmental disorder characterized by impairments in social interaction and communication, often accompanied by stereotypical or repetitive behaviors» (Liu, King & Bearman, 2010) and also a disorder which cannot be cured or «overgrown», and individuals on autistic spectrum need to learn to live with it by developing adaptation traits and sensory integration. So the main goal of autistic individuals education must be social interaction and verbal/non verbal communication skills development aimed at social autonomy, development of peer relationships (Bauminger-Zviely, 2013) and other social skills (White et al., 2007). Therefore children and adults with Autism spectrum disorder (ASD) need to be encouraged for social interaction, and not be demotivated by methods used on them.

In Ukraine, the number of autistic individuals is claimed to increase by 30% every year (Kurylo, 2015). However, social work with them is not well developed, a limited scope of non-medical interventions are available for those who have mental health problems and other social problems (Semigina & Boyko, 2014).

This paper looks on the range of non-medical interventions for people with ASD that are well-known in the international practices and identifies Ukrainian consumers' level of awareness about interventions. The study objectives are to review key reasons and consequences of low level of customers' awareness on those interventions, and to suggest certain range of solutions for increasing their level of awareness, which means to decrease the level of its negative consequences, and their influence on social situation in Ukraine.

Theoretical Framework

The paper looks on the most common approaches to non-medical autism interventions (mostly educational and auxiliary therapies) their conformity to the clinical picture of autisms and to the main goals of autistic individual education, as well as their accessibility, breadth of choice and choice options in Ukraine, and the problems individuals face during appropriate method selection, and negative social and health consequences of the limits this social category is put into. The conducted review implicates broadening the choice of educational therapy services by means of diversifying them with new world-common reliable approaches by picking only the most affective and humane ones with the lowest number of negative social and mental health consequences, which on one hand, will help Ukrainian society to defeat environmental determinism, which causes negative mental consequences itself, for this social category, and on the other hand, to adapt and promote more actual up-to-date methods which correspond autistic individual goals (which are communication development, social development, cognitive development and «social responsibility and independent performance of activities» (Machiodi & Grenshaw, 2014) «to improve social communication and other language impairments and modify behaviors to improve an individual's quality of life and increase social acceptance» (American Speech-Language-Hearing Association, 2016), based on self-management and maximum of social integration and social autonomy as a result) better.

This research substantiates repetition based methods that were criticized by Rea (2015), covering the mains reason of their negative influence on autistic individuals learning abilities and social integration.

This research is based on the concepts of «free will» as the ability to choose between different possible courses of action (Omoregie, 2015) and «lack of free will» (McLeod, 2013) which is associated with low level of current type of services customers awareness (that can be seen in their feedbacks on current type of services, which is in its turn associated with low level of specific information accessibility. Lack of free will may lead to developing more of mental issues, especially when it comes to people with developmental and/or mental disorders, if taken into consideration reverse process being also common to happen (McLeod, 2015). Lack of free will is often defined by researchers as one of social injustices, as free will or a possibility of being able to choose is a necessary part of functioning, and its lack may lead to developing more of mental issues, especially when it comes to people with developmental and/or mental disorders (McLeod, 2015).

It also appeals to environmental determinism conception (McLeod, 2013) by showing how this phenomenon affects certain social category (autistic individuals, their families and/or legal guardians) in Ukraine exposing the main reason of this social issue spreading. Research of this phenomenon is impossible without defining the main sources of individuals' autism awareness and without «anecdotic evidence» as the most common sources of this kind of awareness being taken into consideration (Liu, King & Bearman, 2010).

Methodical Approach

The desk review was used for identification of non-medical intervention for ASD. The special focus was made on educational therapy as kind of therapy that is used with individuals who have learning disabilities, differences and challenges. Such interventions offer a range of intensive individualized integration designed to help address learning problems. The other type of interventions was auxiliary or supportive, therapy to overcome problems resulting from the disease process» (National Advisory Cancer Council, 1969). In case of ASD it helps to overcome problems accompanying illnesses sensory processing disorder, movement disorders etc.

In the current study, a computer search initially yielded around 100 articles, and the subsequent screening and evaluation process found around 20 studies to meet methodological criteria on ASD-intervention models that target both the social and cognitive-academic domains. From this set of research studies, 7 focused intervention practices were selected and described.

In order to assess awareness on the non-medical interventions the modeling of a social situation to the availability and accessibility of the information from the point of view of the customer was employed. Firstly, the thematically-based search on Google was undertaken. Secondly, we chose anonymous forum feedback as

a rapid appraisal tool (Engel & Schutt, 2014) to uncover customers' attitude to the situation in Ukrainian market of educational therapy services for autistic children and adults to identify the level of their awareness on the range of educational services for autistic children and adult in the world and in Ukraine, their contents, effectiveness and validity for short-term and long term educational goals. Overall, 51 anonymous feedbacks on autistic children teaching approach in Ukraine were analyzed on three forums: Forummam, 2012 (12 feedbacks); Littleone forum, 2012 (15 feedbacks); Uaua, 2010 (23 feedbacks). These forums were not either created or moderated by educational centers' for autistic individuals .

Key Findings

Non-medical interventions for people with ASD

The desk review allows configuring a list of the most used techniques and cognitive-behavioral-ecological interventions used for non-medical support to people with ASD (Adams, 2012; Boyd et al., 2014; Moes & Frea, 2002), as well as positive and negative characteristics associated with different interventions (Kasner, Reid & MacDonald, 2012; Kavale & Spaulding, 2011; Warber, 2016).

One of the most commonly used interventions is the **Applied Behavior Analysis (ABA)**. The ABA teacher observes the behavior of a person with autism and then provides instructions on any necessary missing skills. The teachers teach by providing a concise instruction and reward a correct response, thus encouraging the positive behavior. This intervention is based on reward system (in Ukraine often reward and punishing system) for following instructions, which often develops fear of not following instruction because of not getting any reward and/or be punished for that, which may lead to no motivation for performing any actions beyond the instructions and for thinking independently. It basically «improves» children's behavior by making them more submissive. This intervention is the most popular method for Ukraine.

One more intervention is called **TEACCH**. It is a structured teaching method that provides an organized school environment with a strict schedule, visual teaching methods and short, clear instructions. These programmes can easily be personalized. TEACCH is based on strict schedule, which repeats again and again every day. So it's, first of all, based on repetitions and aims to develop certain daily habits. As a result autistic individuals become dependent on their daily schedule stability, and tend to get stressed in a case of the necessity of changing their daily routine, often if even they are warned in advance about certain changes going to happen. Schedule changes often lead to autistic meltdowns. As a result individuals start being schedule dependent for a long period of time, sometimes even lifetime. So in some cases, we can speak about life-term consequences.

Sensory Integration Therapy is an auxiliary therapy aimed to adjust autistic children's or adults' behavior by means of satisfying individual's sensory needs according to the type of sensory processing disorder they have. Sensory integration's positive influence level mainly depends on primal therapy type and friendly environment (American Speech-Language-Hearing Association, 2016).

These interventions have significant disadvantages and «side effects», which provide high risk of negative consequences on autistic individuals learning abilities and social integration.

One more intervention has an abbreviation DIR (the full name is **Developmental, Individual Difference Floortime**). It uses play to teach autistic children emotional engagement, how to connect ideas and focus attention as well as problem solving and self-expression (Warber, 2016). DIR aims to improve children's development by teaching them self-regulation and social problem solving, but it's only suitable for the age of 0 to 2 years old, and many children are diagnosed with autism when they are older. Which means if the child is diagnosed later, they will the most likely start with ABA in Ukraine, the main disadvantages of which are mentioned above.

The undertaken analysis proves that other interventions are considered as the most effective for the people with ASD by researchers (Dababnah & Parish, 2016; Odom et al., 2010; Palmer, Didden & Lang, 2012; Wong et al., 2015), but they are not popular in Ukraine:

- **Incidental Teaching** – a teaching technique that utilizes behavioral procedures; naturally occurring teaching opportunities are provided, based on the child's interests. Following the child's lead, attempts to

communicate are reinforced as these attempts get closer to the desired communication behavior (Patterson, Smith & Mirenda, 2012).

- **Milieu Therapy** – a range of methods (including incidental teaching) that are integrated into a child's natural environment. It includes training in everyday environments and during activities that take place throughout the day, rather than only at "therapy time" (Warren, 2011).

- **Pivotal Response Treatment (PRT)** – a play-based, child-initiated behavioral treatment. Formerly referred to as Natural Language Paradigm, PRT has as its goals to teach language, decrease disruptive behaviors, and increase social, communication, and academic skills. PRT targets pivotal areas of development (response to multiple cues, motivation, self-regulation, and initiation of social interactions) that are central to – and result in improvements across – a wide range of skills (Koegel & Koegel, 2006). PRT emphasizes natural reinforcement (e.g., the child is rewarded with an item when a meaningful attempt is made to request that item).

- **Self-Management** – an approach that involves interventions aimed at helping individuals learn to independently regulate their behaviors and behave appropriately in a variety of contexts. Individuals learn to tell the difference between appropriate and inappropriate behaviors, monitor and record their behaviors, and reward themselves for using appropriate behaviors. Self-management interventions can be used across a wide range of ages from early childhood through adulthood.

- **Time Delay** – a behavioral method of teaching that fades the use of prompts during instruction. For example, the time delay between initial instruction and any additional instruction or prompting is gradually increased as the individual becomes more proficient at the skill being taught. Time delay can be used with individuals regardless of cognitive level or expressive communication abilities.

- **Cognitive Behavioral Therapy (CBT)** – approach that combines cognitive and behavioral learning principles to shape and encourage desired behaviors. CBT is used primarily to help individuals with ASD improve behavior by learning to regulate emotions and control impulses. Examples of programs/approaches that incorporate CBT principles include the following (American Speech-Language-Hearing association, 2016).

- **JASPER (Joint Attention Symbolic Play Engagement Regulation)** – an approach that combines developmental and behavioral principles. This approach targets the foundations of social communication (joint attention, imitation, play) and uses naturalistic strategies to increase the rate and complexity of social communication. The approach incorporates parents and teachers into implementation of intervention to promote generalization across settings and activities and to ensure maintenance over time (Kasari et al., 2008).

Results of Google search

The search with key words «quantity of educational institution for children with developmental disorders in Ukraine», «quantity of educational institution for children with autism in Ukraine» and «quantity of ABA-centers in Ukraine» using «Google» in both Ukrainian and Russian languages ended up with zero results. There was no file containing any statistics on this topic found. Which means, there is no accessible source of such kind of information able to be easily found by customers. One of the reasons for this phenomenon is that such institutions are opening and closing nearly every day, often in private apartments, and sometimes without being certified.

We also made a request like «nonmedical therapy for autistic» and all the results were either about ABA-therapy or Floor-time or generally about «behavior correction», and «helping children with developmental disorders, using both Ukrainian and Russian language. By this we can assume, there is a low level of accessibility of the information on other methods of educational therapy in Ukraine.

Analysis of consumers' feedback

Though we analyzed 51 feedbacks from the consumers' current type of services, and the contents of those comments can also be considered as a proof of low level of their educational therapy methods awareness. Though the authors of those feedbacks are not aware of the existence of any other educational therapy approach, aside from ABA-therapy, they often operate two polar statements, like «with ABA» and «without any therapy» (Littleone forum, 2012), without seeing any other choices. But, in fact, sometimes they are talking about TEACCH mistitling it for «ABA» or giving it no title only describing it as «strict schedule» or «home regimen» (Littleone forum,

2012). By which we can assume, the consumers are not aware even what titles of education methods for autistic individuals are.

Among those 51 feedbacks there were 32 positives feedbacks (Forummam, 2012 (6), Littleone (11), Uaua, 2010 (10) and 19 negatives ones (Forummam, 2012 (6), Littleone (4), Uaua, 2010 (9)). By positive feedbacks we mean feedbacks, in which certain level of customers' satisfaction with the services provided was mentioned. Which does not necessary mean high level of their awareness on this field, but often is determined by the lack of their awareness on others methods and techniques, as it often included current form of contradiction: «ABA vs nothing» (Uaua, 2010). By negative feedbacks we mean the feedbacks which contain different kind of criticism or doubt in educational methods for autistic children and adults provided in Ukraine.

All the positive feedbacks were written in a very emotional style, did not contain any kind of criticism at all, and were based on one of those 2 standard formulas:

«Thank you [name of the therapist or institution] !!! You make miracles !!! Thanks to you my child is going to public school now!» (Forummam, 2012);

«How can anyone not understand that ABA is universally recognized worlds the most affective and the most humane method? It has been proved 10000000 times, why don't you still want to believe it?!» (Forummam, 2012)

Among the positive feedbacks we analyzed there were four of inhumane ones, with the contents, like: «I'd rather want a child to be trained (like animal training type – AN) than ungovernable» (Uaua, 2010) or «he started to speak in memorized phrases (which doesn't coincide the definition of «Speech», and speech is not being a cognitive process for him as a result - AN), but still he talks» (Littleone forum, 2012), which basically means, the consumers are unaware of any other result of education for autistic individuals, and do not know about educational therapies with lower amount of negative consequences on human development of autistic individuals.

Speaking of negative feedbacks, we must admit, they all had different contents and different type of hesitation and level and object of criticism. Some of the customers were only making generalizations, for example: «Quantity of ABA therapy in Ukraine differs much to the worse from the quality of the one abroad» (Uaua, 2010). Some were criticizing its contents, like: «Many people are against it (ABA – AN), it looks like animal training, rewards+punishments without any comprehension» (Uaua, 2010).

Some customers were speaking of its possible negative consequences:

«If you have an unexperienced therapist, they can harm much» (Uaua, 2010);

«The slightest (therapist's – AN) mistake can lead to serious problems» (Uaua, 2010);

«People (therapists – AN) without a proper preparation can have negative influence on your child ...the child may start to ask for rewards for doing the simplest job and to expect all his actions to be planned by the adults, and not to do what is necessary without adult's order. A person with deficient initiative cannot be socialized normally» (Uaua, 2010).

In some of those feedbacks lack of free will was literary mentioned, and it was said «parents have nothing left to do, but to choose ABA» (Uaua, 2010). Which means, they doubt the effectiveness of therapies provided in Ukraine, but still do not see any alternative to them.

Discussions

Recent researches prove, methods not based on repetition (Rea, 2015) as well as methods which combine various approaches at the same time (American Speech-Language-Hearing association, 2016; Dababnah & Parish, 2016; Odom, et al., 2010; Palmer, Didden & Lang, 2012; Wong et al., 2015) are considered as more effective for cognitive processes and social skills development, and methods based on encouragement instead of reward system and on self-management and self-control instead of following instruction enforcement are claimed to be «safer», which basically means having less negative consequences on ASD individuals social life and self-attitude.

Despite there are other method which are considered to be more effective and less traumatic ABA and TEACCH remain the most commonly used in Ukraine. The other problem is they are usually used solitary instead

of being used with other methods, because a number of researches show using a range of approaches (Bauminger-Zviely, 2013; Kavale & Spaulding, 2011) is more effective in communicating and other social skills development.

As «anecdotal evidence» (Liu, King & Bearman, 2010) remains so far the main source of information about autism in Ukraine, investigating search engine results and anonymous customers' feedbacks gave us an opportunity to see customers' awareness level and the way they influence each other's opinions. We can assume, there is a low demand on other educational therapies not only because of low supply, but also due to lack of customers' awareness about other methods existing. We can also make an assumption, which in its turn requires further research, that low level of customers' awareness can affect level of supply in this industry or can be one of its sources. But to prove it further investigations are required.

We also must take into consideration specialists' intervention to those kinds of forums, and them trying to affect feedbacks on repetition-based non-medical therapies methods for autistic individuals. If some consumer was unsatisfied with the services provided before, from time to time they received therapists' replies of current contents: *«I am very sorry, you didn't like it! You just need to pick up another specialist/institution to try this therapy again»* and giving their contact details below. And sometimes they managed to change consumer's opinion this way.

As this paper is written from consumers' point of view, it is necessary to emphasize the main issue as those more effective methods as being hard to find not only because of the complexity and confusion of searching process (because of being entitled in the wrong or confusing way), but as well because of being used by tutors and therapists in rare cases. Ukrainian therapists prefer to use methods, which are already common and «by ear» as «anecdotal evidence» (Liu, King & Bearman, 2010).

Ukrainian education market offers the variety of education services associated with teaching neurotypical children, and very narrow range of the same type of services for autistic children), often associated with therapists imposing their own view to the customers. For example, many parents of autistic children have been told «there is no other way for your child to be taught» when talking to ABA-therapists in Ukraine, which is inapplicable because there are more than 30 non-medical autism interventions (American Speech-Language-Hearing association, 2016), excluding the ones implying Early Intervention Practices (Warren et al, 2011). Doing this therapists only strengthen their own empowerment aggravating the situation for their autistic clients by making them more dependent. We also agree that lack of free will (McLeod, 2013) may lead to developing more of mental issues, especially when it comes to people with developmental and/or mental disorders.

To overcome the challenge of «lack of free will» it will be valuable to organize in Ukraine the targeted awareness campaign devoted to educational therapy methods for autistic children and adults to increase the level of people's awareness of them, for them not to be that easily misled and to be able to make a wider range of inquiries and requests when it comes to nonmedical interventions for autistic individuals.

Further recommendations include:

- to encourage public and private educational institutions to adopt new educational methods for autistic individuals' training, and to organize certified staff training by foreign specialists who are able to teach them to practice new more humane and less risky educational methods and to combine them affectively for further achieving of long-term goals;
- to arrange marketing research of non-medical services for autistic children and adults to be carried out to see the picture of the market situation in this industry, and for further its analysis to figure out its main problems for their further solution.

Final considerations

In this paper, the problem of environmental determinism autistic individuals face when searching for educational or any other kind of non-medical intervention is uncovered. This social issue is represented by low supply despite of high demand, which implies not only the lack of necessary educational or social institutions, but also a very narrow range of services offered and provided by them. If current Ukrainian institutions want to show they apply for and offer some innovations they usually focus on auxiliary therapies instead of trying new

educational methods or combinations of methods. They usually offer a very narrow, even limited range of the most common methods, such as ABA, TEACH, DIR. Those methods are popular because of being the most known and the most talked about, and because of being able to fulfill short-term goals relatively quickly, although they are seen as the ones which have various negative consequences for long-term goals, such as social intervention and social autonomy.

Moreover, individuals with ASD and their parents and legal guardians are often misinformed and misled because the title of the method some educational institutions provide does not always coincide with its contents. Misinformation also takes place when therapists try to convince their students/patience or their families or legal guardians in «absence» or «non-effectiveness» of other educational therapies, aside from the ones they practice.

This basically leads to this social category to be defined determined or obliged to choose between a narrow range of questionably affective methods and deal with negative consequences of being taught by them.

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