

The Opinion of Parents of Autistic Young people on the Influence of Health on Professional Career Choices, promoting Sustained Competitive Advantage

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Abstract. Young autistic people are one of the most sensitive social groups as they experience discrimination because of stereotypes about disability and segregation in job market and education system. Social stigma and its impact on the life opportunities and emotional well-being of people with intellectual disabilities (IDs) are a subject of both practical and theoretical importance. Increasing numbers of individuals with Autism Spectrum Disorder (ASD) are entering postsecondary education; however, many report feeling lonely and isolated. It is recognized by international organizations who work in the fields of human rights protection and disability, this problem is mentioned in the legal documents protecting the rights of disabled people and is prevalent in the works of Lithuanian and foreign researchers. Autism disorder is considered one of the most complicated child development disorders that affects not only child's intellectual and social capabilities but also their own and their family members' professional career. The object of the research is the narratives reflecting parents' attitudes toward the future of their autistic children. The aim – to indicate the possibilities of parents of autistic young people to receive timely medical diagnostics of health disorders that has influence on person's health and career. The theoretical part of the article deals with theoretical aspects of autism, health diagnostics and career opportunities. After the completion of qualitative narrative research the attitude of parents of autistic children on the medical diagnostic and health services provided to their children was identified and there was determined the influence of these components on the education and career. Practical conclusions in the form of recommendations: The need for applied ASD research, emphasizing the competences that ensure career aspirations, is actual in the reality of education. Contemporary social networks and information technology provide the possibility to integrate interdisciplinary connections. On this basis all stakeholders (health and education professionals, researchers in ASD) have the possibilities to participate in development of research instruments and in carrying out research. The mechanism of effective assurance of the supervision of the law acts is also recommended in political self-government institutions of each region.

Keywords: *autism, healthcare education, social sustainability, social networks, stigma research & intervention strategies, strategies of sustainable development, sustained competitive advantage, sustainable development goals.*

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Introduction

The World Health Organization in its report on Disability accentuates education and employment as one of the biggest obstacles that are faced and says that the inclusion of the disabled into meaningful activities that are adequate to their state positively affects their health, makes them improve and integrate into society (WHO, World report on Disability, 2011). The relationship between disability variety integration and social sustainability has been paid much attention in academia.

Relevance is based on the fact that with the adoption and ratification of the United Nations Convention on the Rights of Persons with Disabilities in 2006, Lithuania assumed responsibility to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Article 24 states that countries, Parties of the following Convention, shall ensure the right of persons to appropriate education at all levels and lifelong learning directed to the full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity; development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential; enabling persons with disabilities to participate effectively in a free society.

The theoretical part of the article examines disabilities, conceptual basics of autism. Autism spectrum disorder (ASD) is a complex developmental disability; signs typically appear during early childhood and affect person's ability to communicate, and interact with others. ASD is defined by a certain set of behaviors and is a "spectrum condition" that affects individuals differently and to varying degrees. There is no known single cause of autism, but increased awareness and early diagnosis / intervention and access to appropriate services / support lead to significantly improved outcomes. Some of the behaviors associated with autism include delayed learning of language; difficulty making eyecontact or holding a conversation; difficulty with executive functioning, which relates to reasoning and planning; narrow, intense interests; poor motor skills' and sensory sensitivities. Again, a person on the spectrum might follow many of these behaviors or just a few, or many other ones. The diagnosis of autism spectrum disorder is applied based on analysis of all behaviors and their severity. The American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition (DSM-5) provides standardized criteria to help diagnose ASD.

Despite the scientific research being carried out, political decisions that guarantee the integration and the implementation of human rights and publicity in social media, the phenomena of stigmatisation disability, especially related to intellectual disorders, remains in the society.

It is also relevant in the scientific discourse. Paying attention to the diagnosis of autism, Broady, Stoyles, & Morse (2014) stress that despite a growing evidence base regarding autism spectrum disorders and their increasing prevalence, children on the autism spectrum and their families continue to perceive stigmatisation from various sources throughout the community. These perceptions of stigma can profoundly impact the quality of life of these children and their carers alike. Stigma is prominent in the lives of autistic individuals and their families and contributes significantly to the challenges faced by families raising an autistic child. Parents and carers can feel blamed for their child's behaviour, feel socially excluded and isolated and suffer from low self-esteem and poor psychological well-being (Lodder, Papadopoulos, & Randhawa, 2019). A relatively new concept in the autism stigma literature is that of 'self-stigma' among parents and family carers. Self-stigma among parents/carers has been defined as the phenomenon by which the public's negative stereotypes towards both autistic people and, crucially, their family carers, subsequently becomes accepted by parents/carers and incorporated within their own psychological identity. Scientists that carry out

stigma research stress that the scientific analysis of this phenomenon is important because the evidence may also be used to help shape future local and national (and potentially international) autism policy so that the importance of stigma in relation to caregivers' psychological well-being and their caregiving role is emphasised. Jahoda & Markova (2004) in general notes that social stigma and its impact on the life opportunities and emotional well-being of people with intellectual disabilities (IDs) are a subject of both practical and theoretical importance. The disability movement and evolving theories of self, now point to individuals' ability to develop positive identities and to challenge stigmatizing views and social norms.

Materials and Methods

The object of the research is the narratives reflecting parents' attitudes toward the future of their autistic children. The purpose is to reveal the parents' attitude towards the future of their autistic children in narrative stories. The justification of the research methodology – narrative analysis – is presented. The study involves demographic characteristics of fourth people – parents (male sex), circumstances of research data collection, the role of the researcher is revealed. Data processing is carried out in accordance with the methodological requirements of the dialogical narrative analysis.

In order to reveal the parents' subjective experience, a qualitative narrative research was chosen. The article uses this narrative theory: Narrative means “to account” and is derived from the term *gno*, meaning to know. Theoral storytelling traditions of earliest man were narrative inquiries that sought to address questions of meaning and knowing. From the beginning, narrative embodied multiple ways of knowing. For the Greeks, there were both *episteme*, knowledge of the practical or everyday (also termed logical-rational thought), and *gnosis* or *poesis* (also termed mytho-poetic), knowledge related to the larger questions of meaning (Hendry, 2010). Narrative analysis in the human sciences refers to a group of approaches to diverse kinds of texts, which have in common a storied form. As nations and governments preferred narratives about history, so do social movements, organisations, scientists, other professionals, ethnic / racial groups, and individuals in stories of experience. Narrative approaches are not appropriate for studies of large numbers of nameless and faceless subjects. Some models of analysis are slow and painstaking, requiring attention to subtlety: nuances of speech, the organisation of a response, relations between researcher and the subject, social and historical contexts – cultural narratives that make “personal” stories possible (Riessman, 2008).

The participants of interviews were chosen by the convenient and criterial selection, meaning that these participants were met during participation in the activities of associations that unite parents who raise young people affected by autism. Out of the populations available to the researchers, six participants were chosen according to set criteria: from married families (the child is being raised / the young person lives with both of the parents), the young person was diagnosed with moderate or severe disability, mild intellectual disorder, their age is below 29 years. This age criteria is based on the definition found in terms of The Situation of Work with the Youth Implementation in Lithuania Analysis (2015) carried out by the Department of Youth Affairs under the Ministry of Social Security and Labour of the Republic of Lithuania, that defines that a young person is a person from 14 to 29 years old. While preparing the “Participant Consent” form it is mentioned that the exact participant is being invited for the interview because in this stage of the research the information about the experiences of parents who raise young people affected by autism is being gathered and it is stressed that specifically their experiences are very significant, just as other information provided by them. There is also presented the information that the data received from the interview will be significant for achieving the aim of the

research – to analyse the life stories of people with autism spectrum disorder according to the existing sociocultural conditions and the conditions of provision of medical services.

The interview characteristics. Direct interview is being carried out as the participant is aware of the aim of the research. It is provided that it is an in-depth interview because while reaching for the aims of the research and applying the narrative methodology it is needed to communicate with the participant for a long time and also, the experiences that are being talked about are attributed to sensitive topics, so empathy, while keeping the guidelines of the researcher's task, is important, as well as attentiveness to the participant, it is also important to keep in mind that autism is a diagnosis that is quite complicatedly accepted by parents because of its attribution to the group of intellectual disorders and mental illnesses.

The interview type – free, non-structured conversation, there are no planned questions, list of topics or the time limit for answering. The researchers give absolute freedom to the participants, the conversation guidelines are related to topics familiar to the both participants of the conversation, the participation of the researcher is minimal – to fill in pauses, possible moments of tension, ask questions that would help indicate hidden moments or clarify information and develop the conversation. It is also important that the questions would be constructed in a way that would allow the participant to provide a story that would be as comprehensive as possible. It is provided that it might be needed to carry out more than one interview when trying to analyse the life context of the participants, important social events and characteristics.

Results

While carrying out the research the material gathered during the interviews firstly naturally divided itself into categories of time intervals: of the past and of the current situation. This experience of the researchers shapes the assumption that during the conversations parents, who raise children with disability, try to reveal their experience gained after many years. The provision of medical services, receiving of them and being an active participant of this system reveals interesting and meaningful experiences of parents. In general they reveal the possible tendencies. Therefore, while analyzing the stories of parents, the reflections about medical services and indications in the past are very important as well. When comparing the past and the current situation, parents directly feel the evolution and changing of their child's (currently a young person) relationship with medical employees and can compare and evaluate the progress and foresee complications. While comparing the stories of the participants of the research, the interconnected components that compose the narrative of the parents' attitude to their child's health condition while pursuing career in the context of sustained competitive advantage stood out:

Positive emotions about current employment → The importance of the guarantees of the Labour Law to the career of autistic young people → Anxiety about the future, related to the changing health condition → "The hottest spots" in the projections of future

Positive emotions about current employment are revealed in the stories of parents:

A: "... I couldn't believe that my son would be accepted to that job. We expected that we will have to calm him down, comfort him and encourage him. But the new were that he is fit to work... (pause, deep sigh) It is indescribable... We were proud."

B: "What was I feeling? Joy. I can't remember another day when I felt this happy (...)."

C: "I was proud, even if I was afraid. For another person it would probably seem like any other experience or feeling. But for us, our family, it was a victory (...)."

D: "...I felt like crying. But it was such a good feeling that my child too finally grew up, became an adult and that now in his life there is something that is in the lives of other people."

The importance of the guarantees of the Labour Law to the career of autistic young people

C: "The head of the personnel department introduced us to exemptions that are indicated in the Lithuanian Labour Law and ensured that they will be implemented. Company X, that employed my son is holding the opinion that socially responsible business is inseparable from the integration of disabled people. Acting in accordance with these laws is the internal value of their organization."

E. "No, the employer did not introduce us to the legal acts. But in our association (authors' note: parents are members of an association that unites parents of autistic children) parents shared this relevant information and the information prepared by lawyers, that is relevant and that we should be familiar with."

A. "We got to know about the legal acts that protect the disabled workers' rights on the special websites on the internet. Then we inquired about their implementation at the workplace. When signing the employment contract we were already informed about a paragraph that indicates the possibility to do a part of work distantly."

During the analysis of the conversations, the most quantitative expression of information was provided about this component of the narrative: **Anxiety about future**, related to the changing health condition. In this stage the associations with the past experience, that was reflectively conveyed and evaluated from the temporal perspective by the parents stood out. Very influential for that was the gained experience, which was very various: positive, neutral, negative.

A. "Our family doctor doesn't think that autism is a disease and thinks that it more likely is the difficulties of upbringing and that the arising problems will be solved the best by time. Well, autism itself is not a disease, but doctors shouldn't not mind this diagnosis. Because when a child catches a cold or feels some kind of ache our doctor is an irreplaceable specialist, all of her treating methods are effective, very rarely we have to use antibiotics or experience complications. But when it comes to autism, her position is very peculiar (...). But she fills all the necessary documents, writes prescriptions, but doesn't hide her sceptic attitude towards rehabilitations and other therapies. The doctor is more concerned about the cardiological problems of our son, she insists on constantly checking it, because heartbeat disorders are an adjacent diagnosis already since teenage years. When organizing the medical documents, the so-called medical commission, that is needed to be done and presented to the workplace, the doctor noted that a certain amount of work, related to the adjacent diagnosis, is limited. We ourselves are very worried that the heart problems might make the path to getting a job even more difficult. It would be huge shock to our son (...).

B. Ever since teenage years we are visiting the same neurologist in the children's hospital of the city. We came there because of the movement delay, because our son didn't walk for a long time, would lose his orientation and would fall. (...) And now every six months we go to the neurologist for a consultation, I don't know how we would have lived further and what we would have expected if not this doctor. Exactly his doctor started organizing the disability documents of our and arranged visits to many specialists. We had to talk to psychiatrists. They just consulted us. Of course it is probably the doctor we were afraid of visiting and didn't want to see the most. That's why it is very important what kind of a person that doctor is, so that he would understand that his diagnosis will affect

the entire life of the child. So I'm mostly worried about my son's possible depression and anxiety, its consequences in the daily and especially in the work environment.

C: The most anxiety is caused by the fact that besides autism there's the diagnosis of epilepsy. Currently the episodes are mild, medication treatment is being applied. But this disease is very insidious. There's also a very big fear of possible injuries. Because with his diagnoses the treatment would be very complicated. And if any surgery and long treatment would be needed, the autism and epilepsy episodes would get worse. I really hope that it won't happen.

D. My son is short-sighted and has eyesight problems. And he does his work on a computer. Therefore he himself and I are afraid that it will become an obstacle at work. Also because of his constant sedentary work, his free-time at the computer and him being overweight (he doesn't like to move, feels too insecure to exercise) his spine is curved. So if we want to stay in the job market we'll also have to take care of his weight problems, so there wouldn't be any complications with his spine.

“The hottest spots” in the projections of future

I've been working as a bagger in a local grocery shop. Sometimes it gets very difficult for me to stay focused on my task, because I tend to lose my touch with the customers surrounding me: I struggle reading non verbal expressions (usually I just focus too much on their emotions, thinking about if they accept me or not), which makes me very anxious, because it makes me feel like I did something wrong, perhaps a small mistake like forgetting to put some groceries into the bag or missing a small pack of gum, even though I might have not done anything like that and everything is fine. Another issue is that if I don't concentrate on my customers, I might get confused by small gestures, such as customer saying 'hello' or asking me a question. This attracts my attention to them, which forces me to forget what I was doing before, as I have to think for a bit what exactly did that person want from me. Unfortunately, a lot of the customers don't really know what ASD is, so they just give me weird looks and that does not help my case either – it makes me even more self conscious about my inability to immediately accept their gesture. Some people even tend to make fun of me straight in front my face, but usually it is youngsters. I try to think that they don't really want to hurt me – they just don't have enough knowledge about ASD and are not used to seeing such people, but it still becomes hard at times to soak it all up like some sort of a sponge and this makes me forget to trust people in general, even though it is just a small minority of people that are acting in such a way.

I also fear that I don't really have a career path. Sure, everyone has to start from somewhere at every workplace, but because of my disorder, I feel like people can't trust me with more complex tasks, even though I know I'm completely capable of doing that. My upper management tries to understand me and my disorder, but it ends up feeling as if I'm being downplayed in a way – they try too hard to protect me and that just ends with me not getting enough experience in something that I could perfectly do by myself after getting some practice. I'm glad I have a job at all, because it took me a while to find a place that would accept me as I am, but I wish I had a broader choice.

Discussion

This study is of particular importance not only for parents raising children with disabilities but also for professionals working in education, health, and social care. By analysing parents' narratives, the research provides valuable insights into the expectations, concerns, and perceived challenges sur-

rounding the future of children on the autism spectrum. These findings lay the groundwork for the active involvement of multiple stakeholders, including education and health professionals, social workers, and researchers specializing in autism spectrum disorder, in the design of research instruments and the implementation of subsequent studies. Moreover, the results highlight the need to develop effective mechanisms that ensure consistent oversight of legal and policy frameworks at the regional level within self-government institutions. Strengthening collaboration and dialogue among parents, practitioners, researchers, and policymakers is therefore crucial to ensure that support systems are comprehensive, evidence-based, and responsive to the real needs of families.

Conclusion

The spreading of autism on a global scale, affecting more and more people without any restrictions on gender, race, social layer or other human identifications, creates new theories and promotes the scientific research of the spreading of autism. Autism is an interdisciplinary challenge that requires a wide range of research.

Reconstructing the narrative of parents who raise children with autism does not contradict the factors found in scientific literature, they are expanded by individual experiences. Parents' stories revealed the interrelated components that make up the narrative of the parental attitudes towards the child's future: Positive emotions about current employment, The importance of the guarantees of the Labour Law to the career of autistic young people, Anxiety about the future, related to the changing health condition.

After the completion of qualitative narrative research the attitude of parents of autistic children on the medical diagnostic and health services provided to their children was identified and there was determined the influence of these components on the education and career. Practical conclusions in the form of recommendations: The need for applied ASD research, emphasizing the competences that ensure career aspirations, is actual in the reality of education. Contemporary social networks and information technology provide the possibility to integrate interdisciplinary connections.

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Jaunuolių, turinčių autizmo spektro sutrikimų, tėvų nuomonė apie sveikatos poveikį profesinės karjeros pasirinkimui, skatinant ilgalaikį konkurencinį pranašumą

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Santrauka

Jauni žmonės, turintys autizmo spektro sutrikimą, priklauso vienai jautriausių socialinių grupių, nes dažnai susiduria su diskriminacija, stereotipais, segregacija darbo rinkoje ir švietimo sistemoje. Autizmo spektro sutrikimas laikomas vienu sudėtingiausių raidos sutrikimų, turinčiu įtakos ne tik vaiko intelektiniams bei socialiniams gebėjimams, bet ir jo šeimos narių profesinei bei socialinei raidai. Tyrimo objektas – tėvų naratyvai, atspindintys jų požiūrį į vaikų, turinčių autizmo spektro sutrikimą, ateitį. Tyrimo tikslas – atskleisti tėvų galimybes laiku gauti kokybišką medicininę diagnostiką ir sveikatos priežiūros paslaugas, darančias įtaką vaikų išsilavinimui bei karjeros perspektyvoms. Teorinėje dalyje analizuojami autizmo, sveikatos diagnostikos ir karjeros galimybių aspektai. Atlikus kokybinį naratyvinį tyrimą nustatyta, kad tėvai teigiamai vertina dabartines užimtumo galimybes ir teisinius darbo garantijų aspektus, tačiau jaučia nerimą dėl vaikų ateities, ypač dėl sveikatos būklės pokyčių. Tėvų pasakojimai papildė mokslinę literatūrą individualia patirtimi, atskleidė sveikatos, švietimo ir socialinių veiksmų sąsajas. Išvados pabrėžia tarpdisciplininių tyrimų būtinybę, praktinių kompetencijų ugdymo svarbą karjeros siekiam ir veiksmingo teisės aktų priežiūros mechanizmo reikalingumą regioninėse savivaldos institucijose. Taip pat akcentuojama, kad socialiniai tinklai ir informacinės technologijos gali būti naudojamos tarpdisciplininiam bendradarbiavimui, įtraukiant sveikatos bei švietimo specialistus ir autizmo spektro sutrikimų tyrėjus į tyrimų priemonių kūrimą bei jų įgyvendinimą.

Reikšminiai žodžiai: *autizmas, sveikatos priežiūros švietimas, socialinis tvarumas, socialiniai tinklai, stigmos tyrimai ir intervencijos strategijos, tvaraus vystymosi strategijos, tvarus konkurencinis pranašumas, tvaraus vystymosi tikslai.*