

The Quality of Life of Pupils with Autism Spectrum Disorders – Comparative Research on Mainstream Integrated Education and Special Education Institutions in Poland

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Abstract

The article attempts to analyse the issue of students with autism spectrum disorders who attend two types of educational institutions – integrated classes in mainstream state school and special education institutions with separate classes for students with autism. Popularity and availability more often than effectiveness affect the choice of an educational institution. Parents' decisions may also stem from lack of awareness of the scope of educational activities conducted in each institution. One of the measures of educational success is the evaluation of the quality of life in certain spheres of students' lives.

Keywords: autism spectrum disorders, quality of life, education system

1. Introduction – autism and the quality of life

The phenomenon of researching the quality of life was initiated by Martin E.P. Seligman, who started to change the approach to this problem. According to Seligman, it is important to create what is best rather than correcting the worst in life (Seligman, 2000, pp. 415–422). As suggested in a number of studies (e.g. Ching, Mei-Hui, Jeng-Yi, 2014), it is vital to take it into consideration in care and educational activities, as well as when checking the potential happiness as an ele-

ment of personal well-being. David Lykken pointed out that personal well-being is shaped by biological factors (genetics) but within broad limits an individual can make choices instead of letting genetics take over (Lykken, 1999; Broadbent, Galic, & Stokes, 2013).

These considerations are especially important for people with perception disorders entering the social environment or interaction. Autism spectrum disorder (autism earlier – classifications of the DSM 5, or infantile autism – ICD) is characterized mainly by communication difficulties (ranging from restrictions to complete impossibility), and entering social interaction. The main features of autism are empathic disorders (Golarai, Grill-Spector, Reissa, 2006, pp. 145–160; Uljarevic, Hamilton, 2012; Chowdhury, Benson, Hillier, 2010), perception disorders, problems with transferring emotions (Claude, Bertone, 2016, pp. 115; Schultz, 2005, pp. 125–141; Gillespie-Lynch, et al., 2012) and thus inadequate perception of the social situation. These specific symptoms, often referred to as the autism triad of impairments (e.g., Gould, Wing, 1979; Frith, 2014), are relevant for the perception of children diagnosed with autism spectrum disorders (according to the latest DSM 5 approach). Audrey F. Burgess and Steven E. Gutstein (2007, pp. 58–1040) have identified indicators that increase the QoL level of autistic people. Results of research conducted mainly on adult individuals showed that they experience a lower quality of life compared to others (van Heijst, Geurts, 2014, pp. 158–167). By conducting a deeper analysis of the functioning of people with autism spectrum disorders, it is important to consider their quality of life and the impact of the education system they were influenced by. In the case of education for people with disabilities, in most countries there is an eclectic, mixed-segregation system with a focus on social inclusion. The main factor influencing the development of social skills is the ability to imitate, which, depending on the adopted systemic solutions, takes place through modelling on the behaviour of peers and adults or is limited to the therapeutic effect system – the introduction of the family environment into the therapy system.

Research on the quality of life of children and adolescents with autism, which the author has been running for many years (Błeszyński, Orłowska, 2016a), initially encountered mistrust of the environment. This was mainly due to the approach of people with a diagnosis of autism spectrum disorders as degrading consciousness and self-determination. Comparative studies conducted in the group of students with intellectual disabilities of varying degrees (mild, moderate, severe) and then in the group of students with autism changed the view of the problem and social acceptance of these individuals (Błeszyński, Orłowska, 2016a; 2016b).

Based on the grant obtained by the author's home university – Nicolas Copernicus University in Toruń (WNP-169), an attempt was made to analyse the quality of life of students involved in integrated schools and special education institutions, assuming that the main distinguishing feature is the availability of peer contacts and thus increased self-determination in decisions about entering social interaction.

1. Theoretical assumptions

In this study, the author's research is based on R. Cummins' ecological theory (Cummins, Gullone, Lau, 2002). The research concerned the perception of the quality of life and was conducted in cooperation with Deakin University in Australia. In the design, the issue of the quality of life was recognized subjectively and objectively, which allowed for making wider analyses and comparisons. The analyses included variables related to occurring and co-occurring disorders and recordings of statements of the surveyed subjects. Extensive material allowed for presenting some of the most representative or specific results against a larger group, which is the value of the research and the subsequent analysis.

The research used 7 questions (Personal Wellbeing Index – Intellectual Disability 3rd Edition – Cummins, Lau, 2005) on the main spheres influencing the quality of life measured by respondents alone, with support or alternative communication, using symbols (emoticons, Makaton or Bliss System). In some cases, transcripts of the statements that were given during the survey was made additionally or instead of marking the chosen answers.

The study took into account the prevalence of disability in children as well as the age and level of development. With the consent of the University of Deakin in Australia and after obtaining the right to conduct research in Poland (the author's study was qualified as coordinating research), the researcher translated and adapted the test to the Polish environment.

2. Methods

2.1. Subjects

The study included students from two mainstream state schools and two educational institutions (where students with a type of disability are placed with parental consent) with an option of boarding for pupils diagnosed with autism spectrum

disorders, randomly selected in northern Poland. The chosen institutions are education and care centres, working according to the Polish education system, with the same core curriculum but organised in different manner and working at different levels of intensity. In mainstream state schools (in which most classes are organized with/for children diagnosed with autism spectrum disorders), groups were composed of children with different development disorders (on average in a class there were about 8 students) and various working methods were used. However, in the educational institutions attended by children with autism, work was often carried out in the model: three children and a therapist – but there were also team activities (groups were mainly composed of the wards of the resort) and the dominant method of work was cognitive behaviourism.

In total, 58 students (9 girls and 49 boys) were surveyed and they completed questionnaires and 23 students (2 girls and 21 boys) were interviewed. The students had not been diagnosed with multiple disorders. The study group ranged in age from 8 to 26 years. The students attended elementary, middle and vocational schools.

2.2. Ethical considerations

The research was carried out under the grant of the Faculty of Education of Nicolas Copernicus University in Toruń (WNP-169). The first step was to obtain the consent of legal guardians for the participation of their children and adolescents in the study. Subsequently, the respondents were informed about the purpose of the research, the degree of communicativeness and the extent of knowingly giving answers (that was the first question) were determined, then the research was conducted.

2.3. Measures and organization of the research

The study was conducted on a one-off basis, depending on communication possibilities, by presenting a list of questions, reading questions or using an alternative communication system. The study included 2 state schools with integrated classes and 2 educational centres with classes for children with autism spectrum disorders (in which classes were held only with the children with diagnosed autism).

The study was conducted in May and June 2017 as an integral study of perceptions of the quality of life of people with disabilities. The examination of each student lasted an average of 10–20 minutes.

3. Research results

3.1 The quality of life of (as chosen by) students with autism spectrum disorders

After setting appointments with the school head teachers, the study was conducted according to the schedule. In the case of 23 students, it was necessary to conduct qualitative research in the form of an interview, which further enriched the research results. In the case of the overall evaluation of the quality of life, regardless of sex and school, the highest results were (in order) in the evaluation of the sense of security and financial satisfaction and the prospects for future life. The lowest results were obtained in assessing the possibilities for interaction and satisfaction with the activities performed outside the home.

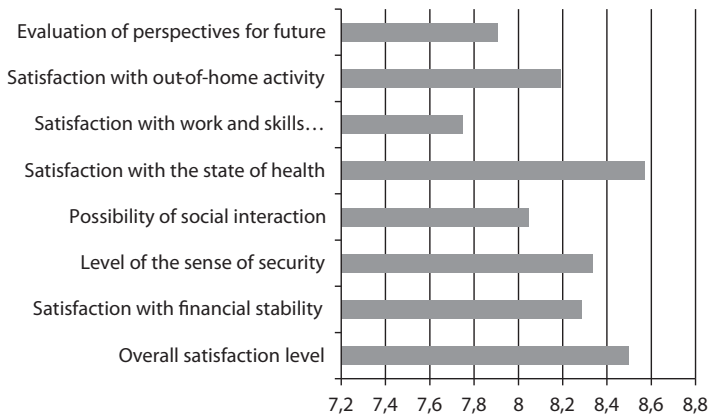


Figure 1. The quality of life of (as chosen by) pupils with autism spectrum disorders.

Source: own research

It can be said that the stages of education are an important element of the introduction to society as well as the acquisition of interpersonal skills, shaping a positive perspective on the further acquisition of social skills, above all, being and performing various social roles.

It should be noted that all the participants' responses indicated a high degree of satisfaction (above 7.5), which suggests that the percentage value of satisfaction with the quality of life of the students with autism spectrum disorders indicates their satisfaction with life.

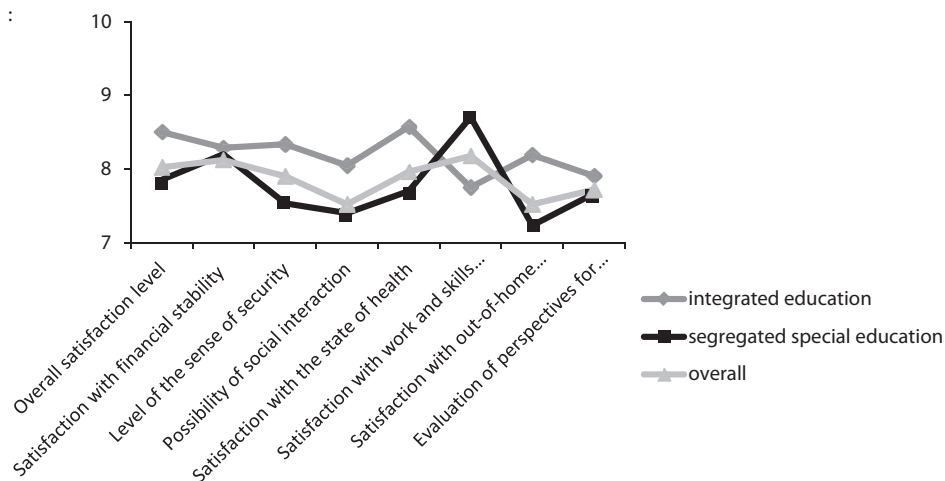


Figure 2. The quality of life of (as chosen by) students with autism spectrum disorders- overall results [N=57]
Source: own research.

Another element of the presented analyses was the diversification of the obtained average results by the education system, and above all the verification if being among peers while learning in state mainstream schools has its values presented in the obtained results of the survey of the quality of life.

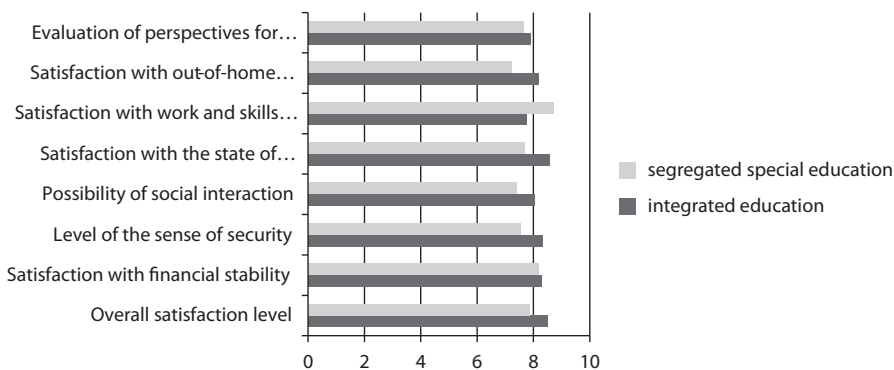


Figure 3. The quality of life of (as chosen by) students with autism spectrum disorders learning in special educational institutions (segregation) [N=37] and in state mainstream schools with integrated classes (integration) [N=21]
Source: own research.

The results obtained indicate that changes must be made to the outlook on needs and actions in the education systems. The most similar results in both groups are (average results and differences are shown in brackets):

- satisfaction with the material level (S = 8.2 and I = 8.3 – difference 0.1);
- evaluation of future perspectives (S = 7.7 and I = 7.9 – difference -0.2).

The biggest differences related to:

- satisfaction with out-of-home activity (S = 8.2 and I = 7.2 – difference 1.0);
- satisfaction with work and skills acquired (S = 8.6 and I = 7.7 – difference of 0.9);
- satisfaction with the state of health (S = 8.3 and I = 7.5 – difference of 0.8);
- overall satisfaction level (S = 8.5 and I = 7.9 – difference of 0.6);
- possibility of social interaction (S = 8 and I = 7.4 – difference of 0.6);

and in the opposite correlation:

- sense of security (S = 7.8 and I = 8.7 – difference -0.9);

After analyzing the results obtained, it can be stated that integrated education, in addition to the sense of security, in all the examined areas indicates a higher level of satisfaction with the quality of life of the ASD students.

3.2. Quality of life at different stages of education

Average results in the timetable are interesting when presented at different educational stages.

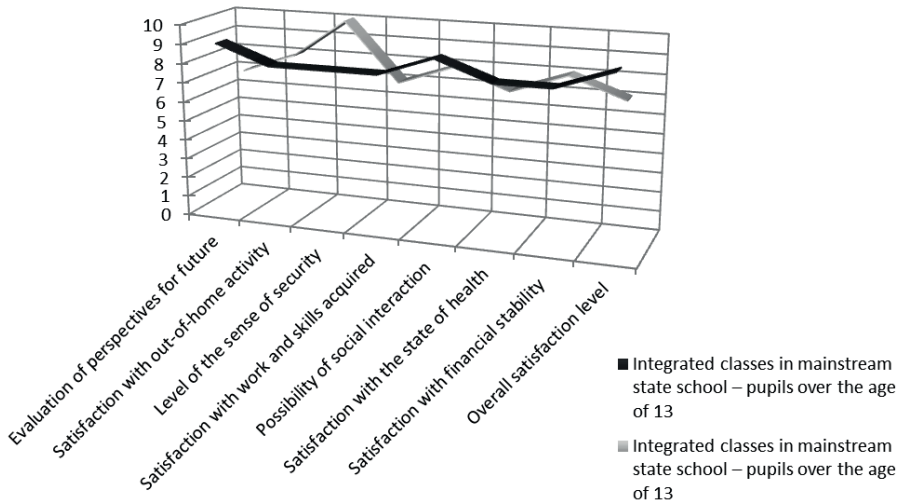


Figure 4. Results at different stages of education – state mainstream schools with integrated classes [N=21]

Source: own research.

In the case of the presented studies, it can be concluded that in integrated education there is an increase in the results relating to health state assessment connected with age, but less satisfaction of the respondents with their work, skills and their perspectives.

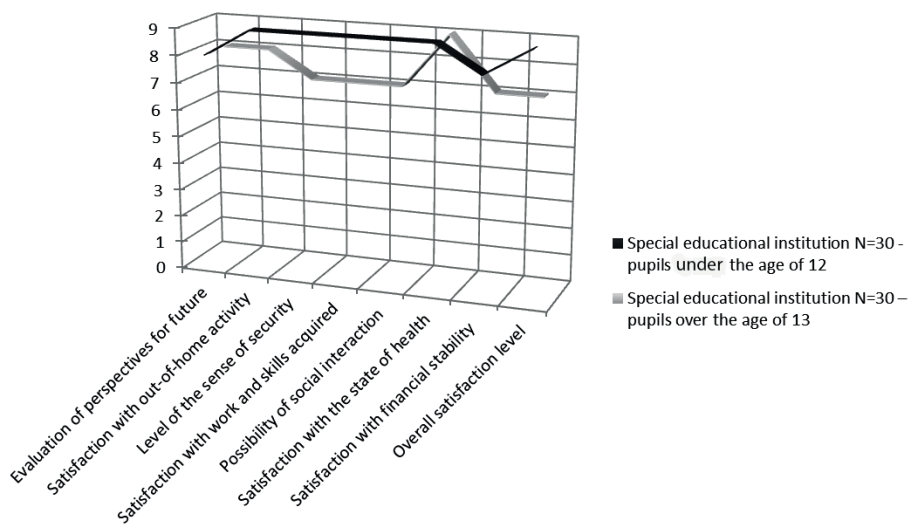


Figure 5. Results at different stages of education – special educational and care institutions [N=37]

Source: own research.

In the case of segregated education, the quality of life (financial satisfaction, satisfaction with the state of health, with the possibility of interaction, with work and skills acquired, evaluation of future perspectives) are lowered with age, and the level of satisfaction with safety is increased. The level of satisfaction with out-of-home activities remains unchanged.

Although the results of the data obtained are high (above 7 in 10 points), there are differences that are undoubtedly visible due to access to extended social interactions, which may be the consequence of the place of residence (because of the zoning of integration education, which is not the case with special education).

4. Discussion and conclusions

The study was conducted on a small number of subjects ($N = 58$). However, the study group consisted only of ASD students without multiple disabilities. The possibility to conduct the research as well as obtain the required consent to carry it out (especially diagnosis and interviewing) was a serious constraint, but the author was not refused either by the tutors or the teachers.

In this study, the students gave answers very objectively and appropriately to the questions asked. Quite frequent inquisitiveness and perspective drew the attention of the researchers.

In response to the last question about the prospect of further life, the younger students talked about their specific professional dreams and the near future (e.g., "I will be a firefighter. I will go to Croatia for holidays, I will be with my parents, we will go to the sea-side, I will have to study and work hard. I do not know what I will do in the future"). The older students' statements were characterized by more general assertions and awareness of support (e.g., "It will be good, after lower secondary school, I will go to vocational school, I may become a mechanic, I'd like to be a shop assistant"). There were also responses full of uncertainty (e.g., "This is in question, I would like to be a driver of an ambulance" – which often resulted from the respondents' recent personal experience), or awareness of constraints influencing the ASD individuals' functioning in society (e.g., "I'm afraid that I will not have a good job as I have a problem with contact with other people – it is necessary in life; in the future it will also be bad"), focusing on positive look to the future (e.g., "I know I must be optimistic").

Significant, though seemingly imaginary, responses were the ones in which high-status professions were indicated ("I would like to become a surgeon and be with my family in the future, and I have always wanted to be a professor of history, but I haven't decided yet"). These choices are related to the specifics of the profession (there is no need to enter into a closer interpersonal relationships) and the level of skills and intellectual abilities is typical of people with ASD. There are also interpersonal responses, such as "I have not thought about what I will do in the future; I have no idea who I'd like to be in future and what I'd like to do; Maybe I'll have a wife". The statement about the desire to start a family appeared in responses three times and was associated with the better functioning ASD individuals. This points to the observation of the environment and modelling on it.

By making a comparative analysis of integrated and segregated education on the basis of the results obtained, it is important to notice that special education institutions are centres for students with different degrees of intellectual disability not

only for ASD pupils. This can be an important factor in raising the awareness of the quality of life, providing a sense of security. However, it limits the acquisition of social interaction (acquisition of appropriate behaviour patterns), as students are often confined to the school environment (as mentioned earlier, the important factor is zoning, which does not apply to special education institutions).

It should be noted that the results obtained in the research are high on the list, which can prove the adaptation of the ASD students to the environment and social determinants. Nevertheless, there are differences that result from the quality (not just quantity) of social interactions students are able to enter. A lesser sense of security in the case of integrated classes may also result from higher requirements for students, which should facilitate the transition to adult, independent life with different situations and possible social roles. However, it would be a mistake to show the superiority of integrated education over segregated education because of the number of people surveyed. In this sphere, an individual's predispositions and the family environment in which the child is raised and introduced to society (social inclusion) are vital.

5. Implications and recommendations

This study approach to the problem of the quality of life allows for presenting the thesis that it is necessary to conduct research which should not analyse levels and but the dimensions of the sense of quality of life in relation not to the type of disability, but to other determinants, often resulting from the environment, individual predispositions and the system in which the inclusion takes place. Expanding research into the education system (with the same requirements – the core curriculum), gender, the educational stage will allow for a broader look at the quality of life issue, as suggested in this type of research (Barnes, Mercer, 2003; Speck, 2016). Nevertheless, the inclusion of personalized statements of the surveyed students showed a fuller aspect of the perception of the quality of life. Finally, the author stipulates that it is advisable to link quantitative and qualitative research, with particular regard to the analyses conducted, with the results obtained with regard to the specificity of the researched group and the situation.

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