

Leisure time of families with children suffering from Asperger syndrome

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Abstract. Asperger's syndrome is one of the pervasive developmental disorders according to the International Classification of Diseases (tenth revision). Problems of this type of disability are found in many areas, for example – the system of care, diagnosis, education, the number of organizations that deal with this condition and provide these services. Recent research has shown an increase in autism spectrum disorders (every hundredth child is born with this diagnosis). Children with Asperger syndrome are intrinsically “blind” in public and seem rude, and these situations are not easy for their parents. The most difficult area for parents is free time. Children cannot organize their leisure time, plus the ability to meaningfully spend their time is very limited. Incidence of organizations offering leisure activities for people with autism is usually larger in big cities, because the concentration of these children is greater. The aim of this paper is to characterize the basic theoretical background and find out what leisure time possibilities exist for a family having a child with Asperger's syndrome. How can a family with a child with Asperger's syndrome spend leisure time?

Introduction

Asperger syndrome (henceforth AS) is a pervasive developmental disorder according to the International Classification of Diseases (10th revision). Etiology of the syndrome is unclear; however, factors causing brain anomalies resulting in this handicap are reported. Autism was first described by Leo Kanner in the 1940s. He was the first to describe its symptoms and define the criteria. Simultaneously, Hans Asperger described the effects of Asperger syndrome. The two syndromes were afterwards separated and mistaken for childhood schizophrenia [2]. Issues connected with the disorder are found in numerous spheres, such as care system, diagnostics, education or the number of organisations providing services for people with AS. The number of organisations themselves is not the only problem; there is also the number of experts including personal assistants and assistants for pedagogues, who are lacking. The choice of this particular topic is partly due to the rising number of children with AS in our society. The latest surveys revealed an increase in autism spectrum disorders (one child out of 100 is born with the diagnosis). Other reasons for the choice include insufficient enlightenment and invisibility of the disorder, which is characteristic of the diagnosis. It is not obvious as e.g. poliomyelitis. Children with Asperger syndrome are internally “blind” and seemingly misbehave in public, which is usually a difficult situation for their parents.

Autism spectrum disorders (ASD) represent very serious developmental disorders. The deficiencies of ASD affect three areas (social interaction, communication and imagination). ASD is often accompanied by other disorders or even intellectual disability. Asperger syndrome, however, is the only autism spectrum disorder which can never be accompanied by intellectual disability; the minimal IQ of an individual with this diagnosis has to

be 80 or more. The disorder may have a significant impact on the quality of life, regardless of the impossibility to diagnose intellectual disability in people with AS. This always depends on the degree of impairment in the individual areas; the general handicap is influenced by accompanying variable and non-specific features, which may aggravate problem behaviour. The syndrome may be classified as high-functioning, medium-functioning or low-functioning. The lower is the functional degree the worse is the quality of life of the individual and his/her family.

As far as parents are concerned, the most demanding area is leisure time. Children are unable to organise their free time, moreover, their possibility to spend it in a meaningful way is highly limited. The number of organisations providing leisure time activities for autistic children is greater in big cities since there is a higher concentration of children with the disorder. There are some possibilities of spending free time in smaller towns as well, nevertheless, the clubs or events are designed for mixed groups of children with AS and children with other mental disorders. It is very difficult to fill the free time of autistic children, teach them to play spontaneously and find the right activity which they could enjoy, letting their parents relax. The history of autism in the Czech Republic is short, in comparison with other countries, everything is only beginning to develop, which is a serious problem. The situation is best in the case of parents and children who live near APLA – Association helping people with autism or similar organisations.

Dealing with leisure time of children with AS is very demanding and exhausting. Leisure time should be used for relaxation and activities which gratify the individual, giving him strength and vitality. Families of children with AS cannot freely choose any activity, moreover, they have to face certain specific features related with the diagnosis. Similarly to everything else, spending of leisure time depends on the degree of impairment. The higher the degree, the greater the lack of acquired skills and the longer the time needed to learn them. A child with AS does not have imagination, which results in the inability to find an activity independently, as well as to initiate and develop games. S/he has stereotyped behaviour and clinging interests, in which the child is absorbed and which restrict the choice of activities. The child may cling to his/her interest so firmly that the family has to conform to his/her wishes. Otherwise, another activity might lead to frustration, inner tension and uncertainty. The behaviour is further characterized by compulsive and repetitive actions and ritual behaviour. The child seeks routine in activities, since it gives him/her certainty, security and predictability. Missing routine may provoke problem behaviour or deep anxiety. Thus, the family has to employ effective strategies of soothing the child or prevent all trouble in the first place. The extent to which the family may engage in their favourite activities depends on how serious the diagnosis is. Some children need to have their free time structured and visualised. These assumptions served as the basis of the definition of the main research objective in the empirical part, which is also the main research question, and specific objectives.

Empirical research

1. Research question

The aim of the article is to explain the theoretical bases and present results of an empirical survey intended to describe the possibilities of families having a child with AS to spend free time. Two specific objectives were set:

PO1: Find out how a family having a child with AS spends free time. (The area of the specifics of free time of families having a child with AS).

PO2: Find out whether a family having a child with AS may spend free time in their home region. (The area of the influence of local environment on leisure time activities).

Based on the defined specific objectives, partial research questions were formulated and divided into two areas: the area of the specifics of free time of families having a child with AS and the area of the influence of local environment on leisure time activities.

1.1 The area of the specifics of free time of families having a child with AS

RQ1: What are the activities accessible to a family having a child with AS and a healthy brother or sister?

There are various effects of the disorder which may restrict leisure time activities of the family. Schopler [4] explains that strong compulsive behaviour forces the individual to repeatedly engage in one activity in the exact same way. Children are often unable to give their activities up, which causes big problems and interferes with the functioning of the household. Furthermore, compulsive and ritual behaviour in public makes parents nervous and may limit the family's participation at social events. Stereotyped behaviour has curious manifestations, such as flapping one's hands or shaking one's fingers, which sometimes occur in connection with interest in a particular object. Moreover, children require constancy, i.e. they tend to repeat an action in the exact same way or desperately cling to familiar objects. A change in the usual course of actions greatly upsets them. This is very limiting to the life of the family. Families prefer to stay at home to going out, because the children lack skills which they might use during their free time. Thorová [5] states that the individual may be absorbed in his/her interest to the extent of disturbing the life of the family. It is probable that all the aspects influence and limit the family's choice of activities as well as free time in general.

RQ2: Do children with Asperger syndrome have problems with toys and playing?

Children cannot play, imitate and pretend, they have no sense of victor and loss, and they may seem indifferent or even hostile if they play with different toys or peers. They are often excluded from the game or laughed at because of their peculiar behaviour, imperfect social behaviour and ability to cooperate. These children let the toy enchant or tease them unless the activity is organised by an adult. They often play repeatedly with one toy only, although there are many other interesting toys [4]. Moreover, they often play with the toy in a non-standard way and are seldom interested in a new toy and a new activity [5]. We expected different problems with games and toys in children with Asperger syndrome.

RQ3: Does the child with Asperger syndrome manifest an unusually strong preference for his/her favourite activity in his/her free time?

Children with Asperger syndrome cling to their interests. The more stressed they feel, the stronger the clinging and desire of routine. As Čadilová, Žampachová [1] explain, the choice of activities is governed by a specific interest, they often cling to specific activities and are not easily persuaded to give them up as the activities make them feel successful and help them to live in a unpredictable world. Therefore it is probable that the children will strongly prefer leisure time activities in their free time and cling to them.

1.2 The area of the influence of local environment on leisure time activities

RQ4: Is there an organisation offering leisure time activities for children with Asperger syndrome in the region where the family lives?

There is a general lack of organisations offering leisure time activities for children and families having a child with Asperger syndrome. According to Čadilová, Žampachová [1] the situation improved after 1989, when the association Autistik was formed in 1990. In 2000, the association in cooperation with the Ministry of Education, Youth and Sports ran the training programme TEACCH founded by Miroslava Jelínková. Also in 2000, the associations

RainMan and APLA appeared, followed by APLA jižní Morava (“South Moravia”) and APLA Praha (“Prague”). There are currently six APLA associations reacting to the needs of their regions. Regardless of this improvement, it remains probable that some families do not live in a region having an offer of leisure time activities provided by a non-profit organisation.

RQ5: Do the families make use of the offer of personal assistance in leisure time of their children (in the vicinity of their homes)?

Personal assistance in the case of clients with AS, as mentioned by Vosmik a Bělohávková [7], is focused on the arrangement of contact with social environment. A personal assistant for children with Asperger syndrome typically accompanies them on the way to/from school or to events outside school. Uzlové [6] states that the extent and forms of care are always determined by the parents. The care by the personal assistant is beneficial for the whole family. Families probably will make use of the offer of personal assistance in leisure time of children (accompanying to leisure time activities or on the way home).

2. Research methods

The principal method of data collection was a direct one – structured interview. The second method supplementing the first one and enabling comparison and understanding of differences in opinions was the documentary method (personal case study based not only on the analysis of accessible documents) focused on the past, contextual factors and attitudes preceding certain event [3]. The analysis dealt with various causes, determinants, factors, processes and experience related to the fact in question.

3. Research sample

The object of the research was ten families having a child with Asperger syndrome. There was a healthy sibling in each family who was involved in data collection with the exception of one infant aged six months. Five families, specifically five mothers having children with AS aged 8 to 12 were contacted through email. Contacts of three mothers were provided by the director of a leisure time centre providing help for families having children with ASD, who was also interviewed and participated at the writing of case studies. The two remaining mothers were approached based on personal acquaintance. All mothers were granted anonymity and willingly gave the structured interview as well as material and information needed for the case studies, which they often helped to write and let us see the necessary documents. The topic, main objective and research questions were made known to the mothers in advance. The dates of the interviews were arranged via email. The interviews took place in domestic environment and one interview in a café, all were realised at the turn of January and February 2014 and lasted one to two hours. Asperger syndrome was diagnosed in all the children; however, the degrees of functionality differed. All children are integrated at primary schools, three live in Prague, two in a middle-sized city (70 thousand inhabitants approx.), two in a town (15 thousand inhabitants approx.) and three in smaller municipalities (5 thousand and less) in the vicinity of cities. Data collection was based on two sub-samples. The first one comprised ten respondents (mothers of children with AS), the second “healthy” siblings of children with AS (70% were boys). The mothers were aged from 34 to 45 years. The youngest sibling was 7 years, while the eldest was 22. Most of the mothers had university education. One of them was on parental leave, the others worked in pedagogical or social sphere.

Results and discussion

The realised interviews and analysis of the individual case studies suggest the following:

RQ1: What are the activities accessible to a family having a child with AS and a healthy brother or sister?

The families have their favourite activities accessible to all members. They select them together but some base their choice on the needs and interests of the child. Two families only are limited by the child's clinging to specific activities and have to conform to his/her wishes. Leisure time activities of the families are also influenced by other manifestations of problem behaviour of the child, e.g. verbal aggression. There are obstacles in the form of clinging but also other accompanying impairments interfering with the activities. If there is nobody else to look after the children they can do hardly anything, partners are dependent on each other, which is usually limiting. The results are tiredness and frustration, which is a consequence of the lack of self-realisation in leisure time. The siblings gave answers mostly identical to their mothers'. The families may engage in a restricted number of activities, however, they conform to the child with AS and are limited by him/her to a certain extent.

RQ2: Do children with Asperger syndrome have problems with toys and playing?

The children are interested in games and toys, they have their favourite ones and are able to play with them and entertain themselves. Some of the do not use the toy every day, preferring to engage in their favourite game, which is a computer game. A toy is used for favourite game by two children only and its use is functional. A non-functional use is to be found in one boy. The children do not join in game activities, nor they initiate them, not even a boy with high-functional Asperger syndrome. They accept the rules of games, however, in some cases it is advantageous if the game is entertaining for the child. The children do not have friends, they prefer to address younger children, in which they succeed more easily. Only some of the children are able to assume social roles. The relationships with brothers and sisters are slightly better, they sometimes play together because they know each other. The siblings sometimes conform to the children with AS and if they are unwilling to accept the proposed activity, each child engages in his/her own interest.

RQ3: Does the child with Asperger syndrome manifest an unusually strong preference for his/her favourite activity in his/her free time?

The choice of a leisure time activity is partly affected by the clinging interests, some of the children are able to choose a different activity, contrarily, two of them are almost completely unable to do so and it is very difficult to dissuade them from their preferred activity. Leisure time activities are in some cases accompanied by stereotyped behaviour. If they spend their leisure time in an unfamiliar environment, it is more suitable to visualise the time schedule and selection of activities and structure it using pictures, while verbal structure is sufficient with some of the children.

RQ4: Is there an organisation offering leisure time activities for children with Asperger syndrome in the region where the family lives?

Most of the respondents agree that there are offers of leisure time activities in their region except for two (living in a village and a small town), who stated that there were no activities for children with AS in their region, they miss them but the right organisations are too distant. There exist different organisations APLA, ZAJÍC, Stanice techniků (Technicians' station) or tourism clubs providing leisure time activities for children and parents. An association in the vicinity of the family living in the small town offers activities for children with intellectual impairment, however, they are not satisfactory for the boy with AS. Nevertheless, he was offered the possibility to participate on trips with APLA, although he is not from Prague. All families spend part of their time outside their region and two respondents mention obstacles

within their locality. One of the two families stated that there were no suitable activities offered in their region. In order to compensate for this, they spend some time outside their region with APLA in Prague, where their son goes on trips or stays.

RQ5: Do the families make use of the offer to personal assistance in leisure time of their children in the vicinity of their homes?

Personal assistance is accessible to all families, since there are organisations offering this service in their vicinity. Two of the families do not use the possibility at all. Personal assistants usually accompany the children to clubs or other activities or on the way home. The families are helped by their own family members, such as grandmothers, grandfathers or elder siblings. One family only have to rely entirely on themselves, there is no one to look after the children, they have few friends and the respondent did not mention help from a personal assistant nor a family member. Some of the families use the services of personal assistant, others combine them with the help from grandparents.

Conclusion

Specific objective 1 – the area of the specifics of leisure time of families having children with Asperger syndrome:

Families having a child with Asperger syndrome engage in their favourite common activities such as trips, going to swimming pools, holidays, camps etc. They select the activities together however; they more or less conform to the needs and interests of the child. Spending free time together is possible; however, there are some limitations and unusual elements. Some of the families are limited by the clinging interest of the child and if it is absent, there are still other obstacles to their spending of free time such as specific problem behaviour – verbal aggression and other associated disorders. The children have their favourite toys and games in which they find an entertainment however their general ability to engage in games is limited. Difficulties occur mainly in the case of collective games with other children since children with AS have insufficient gaming skills. The children are able to entertain themselves using a toy if it is used for their favourite game. Non-functional manipulation and ordering were identified in one boy, the other children do not frequently have problems with toys. The quality of their game does not interfere with the leisure time of the family. Children with AS partly prefer one leisure time activity, which is predominantly influenced by the clinging interest, some may choose different activities. On the other hand, two of them never opt for another activity and it is difficult to dissuade them from their favourite one. The extent to which the selection of family leisure time activities is limited, both in the case of parents and children, always depends on the severity of the deficiencies in the child with AS.

Partial objective 2 – the area of the influence of environment on leisure time activities:

We may summarize that the environment in which the families live determines the possibilities of offering leisure time activities. Organisations providing leisure time activities are too distant for two of the families (living in small towns); there is no offer of suitable activities in their region. There are some organisations offering activities, however, those are not suitable for children with Asperger syndrome. The situation of these families is more difficult because of the place where they live, the reason might be the fact that they live in a small town or in a village. One of the families compensates for this going on trips and stays with APLA. Three of the families mention no major problems with leisure time in their region, which might be a result of their living in a big city. All families spend a part of their free time outside their region. The service of personal assistance is accessible to all families but not all use it. All families except for one can really on the help of others, which

they use for the children's leisure time, on the way to clubs or home. Some affirmed that the problem lies in the diagnosis of their child rather than the surroundings. Eight families face no difficulties in their region, while the remaining two lack the offer of suitable activities in their region. The situation is better in the case of personal assistance, which exists in the vicinity of all families, i.e. in their region. The accessibility of personal assistance in the region is good but this is not the case of organisations providing suitable activities for families with children. Families living in smaller municipalities feel the limitations of the offer of leisure time activities, missing organisations which would provide them in their region. Families living in bigger towns face no problems with the offer of activities in their vicinity [8]. The situation is best in Prague and central Bohemia. The case of personal assistance is different. A personal assistant helps the family accompany the child to clubs or home. Personal assistance is to be found in every region.

The results of the present research study may open a space for questions asking about what should be done to improve the quality of leisure time in the local environment of the families. The possibilities should not be dependent on the place where the family is, the important fact being that there are few organisations and a rising number of children with Asperger syndrome. Further mapping of the situation should involve asking about the families' propositions of improvements of the current situations.

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