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Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV

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ISSN 1689-9903

Publisher
Wydawnictwo Naukowe UP
PL 30–084 Kraków, ul. Podchorążych 2
tel./fax 12 662–63–83, tel. 12 662–67–56
e-mail: wydawnictwo@up.krakow.pl
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Print
Zespół Poligraficzny UP, zam. 72/11

Introduction

The presented issue is devoted to psychological problems of disability in the context of school as well as cultural inclusion. The papers are based on different international experiences, which should be very interesting for Readers and can enable a comparison of both similarities and differences in the political and cultural backgrounds. Authors from different European as well Asian and American Universities were invited to present their research results and theoretical outcomes. These are professionals working in the field of exceptional persons psychology and education from the Autonomous University of Barcelona, Sichuan Normal University, Palacký University of Olomouc, University Hradec Králové, University of Birmingham, the Autism Research Centre of the Autism Society of Washington in the USA and ELTE University in Budapest.

The education of children and pupils with disabilities increasingly approaches the boundaries of the fields of special education and psychology. This situation is caused by the current level of knowledge in these fields. Special Education, as the original and scientifically equipped area, is gradually orienting away from a solely medically-oriented cooperation toward psychology as another scientific partner. The authors of the contributions included in this volume show very close proximity to both special education and exceptional psychology. It is not only a reflection of the situation in Europe, as some authors present work that is carried out outside of Europe. Diagnosis, treatment, education – these are key words that are common to the contributions. On the one hand, there is an apparent high degree of specialization of individual authors, and on the other hand, it is this specialization that calls for an inclusion of psychology with a special focus on working with people with disabilities. The authors' contributions represent the current state of knowledge in their respective fields. The aim of publishing all contributions is not only to make the professional public familiar with the latest research results, but also to provoke discussion and offer topics for further research activities, thereby pushing the boundaries of knowledge.

The issue is composed of three main parts. The first part describes **the psychological aspects of sensory and motor impairments.** Most of the papers are related to hearing impairments, however, there are also articles in the field of cerebral palsy as well as blindness.

The first paper by Joanna Kossewska discusses “Theory of Mind in deaf children in the context of inclusive education”. The paper concentrates on a comparison of the educational environment. Findings show that education in a Total Communication classroom, where sign is used along with speech, neither enhance nor detract from ToM development, relative to mainstream schooling. Deaf studies consistently suggest that deaf children from hearing families, educated in either oral or sign language, are delayed in developing mentalizing skills compared to their native--signing and hearing age-matched peers. The results of some studies point to the importance of participation in everyday conversations with family members and friends, which in one way or another facilitate the understanding of others as mental agents. Consequently, if language and early family conversation are critical factors for ToM development, orally educated deaf children with hearing aids are expected to be delayed in mastering concepts of false belief.

Kika Hadjikakou presents “Deaf identity construction: a case study”. The paper presents inside information on different routes to identity construction within the deaf population. The exemplification of identity construction is a case study carried out with a Deaf Cypriot adult whose family and educational background does not match those of the general deaf population. The findings indicate that his family experiences, initial contacts with the Deaf and the Cypriot Sign Language (CSL), as well as the academic and social experiences shared at school between the participant and his classmates and teachers played a crucial role in his identity development. The findings of this study entail implications for the provision of effective support services and deaf awareness courses within general schools, as well as for oral deaf children’s contacts with Deaf adults in order to develop ‘healthy’ identities.

Liu Shenglin and Miloň Potměšil present the paper “Chinese families’ adaptation to childhood deafness: implications for psychoeducational support for families with deaf children in China” which presents mixed approaches of quantitative and qualitative research to examine how Chinese families adapt to the challenge of having a deaf child in the family. The results showed that in general Chinese families adapt positively to childhood deafness while experiencing strong and long-term grief. The positive adaptation can be contributed to the characteristics of the Chinese family, positive changes in family beliefs, and concrete steps toward the child’s future, etc. The sorrowful experience is due to lack of adequate social support and an array of difficulties related to childhood deafness itself. Finally, implications for psychoeducational support for families with deaf children in China are discussed.

Mariana Fuentes describes “Equal opportunities in mathematics: what does research on how young deaf children learn teaches us?“ The Author reviews research on teaching/learning mathematics in young deaf children. Research proves that deaf children show a delay in learning mathematics but reveals that the developmental process is probably very similar in deaf and hearing children. Difficulties in learning mathematics are linked to difficulties in obtaining information in an incidental way from the environment in young children that are both deaf and hearing. Deafness is not a causal factor but a risk factor for difficulties in learning mathematics. The paper discusses adapting teaching strategies to deaf children’s learning features based on spatial processing, which is better in deaf children.

Petra Bendová presents the paper titled “Socio-psychological aspects of the application of alternative and augmentative communication (AAC) in pupils with cerebral palsy”. The text draws on the use of partial aspects of alternative and augmentative communication (AAC) in children/pupils with a cerebral palsy diagnosis, acquaints with the practical experiences of the author as well as the outcomes of research investigations carried out in the given area. It also defines the means most often used and specifies view points which lead to the choice of these systems. The developmental effect of the AAC system on expressive speech, cognitive ability, and social competences of patients is described. Finally, the practical significance of AAC exploitation from a psychological and socialization point of view (especially concerning educational and integration) is outlined.

Kamila Růžičková and Ivan Růžička in the paper “Development of social competences in youths with a visual impairment” analyze the transition to a self-sufficient lifestyle in visually impaired individuals. This process is not always smooth and easy for blind adolescents. The article deals with the role of the family and institutions in the development of social competencies of blind adolescents, which improves the quality of transition to a self-sufficient lifestyle.

The second part is devoted to **disability in the context of inclusion and culture** and is opened by Miloň Potměšil who presents “The sentiments, attitudes and concerns of educators when working under the conditions of inclusion”. The author presents a part of the international research project SACIE (Sentiments, Attitudes & Concerns about Inclusive Education) focused on sentiments, attitudes and concerns of educators working with disabled people. This study aims at discovering whether the above stated parameters change after achieving a qualification in special needs education. The results of the research encompass a period of three years aimed at describing a group of 794 educators from the point of view of the development of their attitudes, opinions and concerns focused on the process of inclusion. The research is divided into two phases – the 1st phase before commencement of a university (Bachelor’s) specialized study of special needs education, and the 2nd phase conducted a month before the termination of this three-year study programme.

Ge Chen presents “Narrative research on the identity of disabled people in Tibetan culture” The paper is based on a long-term anthropological investigation that identifies that disabled people have a very positive identity in Tibetan culture. The article describes the stories of two disabled Tibetan individuals using the narrative method. According to these cases, the religious background is analyzed as one of the important factors that influence the identity of severely disabled Tibetan people.

The problem of “The adaptive behaviour of children with an intellectual disability in China” is presented by Xie Yuhan. The article summarizes existing research on the adaptive behaviour of children with an intellectual disability in China in an effort to assess current research findings. It discusses the concepts, assessment methods, characteristics of development and factors influencing adaptive behaviour in children with an intellectual disability in China. Based on the reviewed literature, the article concludes with a discussion on the topics that need to be addressed in future studies, such as developing assessment instruments fit for Chinese individuals, exploring more in-depth influential factors and internal mechanisms, strengthening the research on intervention, and integrating different study methods.

Yan Peng presents the topic “The attitudes of mainstream primary school teachers toward inclusive education: A perspective from the People’s Republic of China”. Although the practice of inclusive education in China started in the middle of the 1980s, inclusive education is still facing lots of developmental challenges. The paper presents a study aimed at first identifying the mainstream primary school teachers’ attitudes toward inclusion of students with special educational needs, second, examining the teachers’ perception of their ability to implement inclusive education in their regular classes, and third, identifying the support they need the most to help them carry out inclusive education in practice. The results show that teachers have negative but contractive attitudes toward inclusive education and feel that they are not capable of implementing inclusive education in their regular classrooms. Most of the tested teachers reflected they really needed support from the government, school administrators, and parents of children with SEN, and so on (e.g., financial support and professional training opportunities) to help them carry out practical inclusive education in regular classrooms. The study ended with research-based recommendations for future practice.

A very important social problem concerning nicotine addiction in Chinese teenagers is presented by Lei Yong, and Wu Yuxuan in the article titled “Smoking behaviours in teenagers – companion and relationship influence mediated by the self-control effect”. It discusses the distinct differential influence of companion’s smoking on gender and grade as well as self-control. A positive relation was found between companion’s smoking and the teenager’s smoking behaviour while self-control and smoking behaviour were negatively related. Behavioural self--control is a significant negative predictive factor of smoking behaviour in teenage students. Emotional self-control and mental (cognitive) self-control have a negative mediating effect on the relation between smoking behaviour of the companion and the behaviour of the teenager. Behavioural self-control and mental (cognitive) self-control have a negative mediating effect on the relation between availability of smoking opportunities on the part of the companion and the teenager’s smoking behaviour. The research has very important practical implications for protecting teenagers from a smoking addiction.

The third part is related to **Autism Spectrum Disorder.**

The paper by Miklós Györi is again about Theory of Mind, which seems to be the topic that staples the whole Issue in an appropriate way. The paper presents a study aimed at individual differences and the precise nature of ToM impairment in autism. The author relates to three issues: (1) the relationship between solving Theory of Mind tasks and the real existence of Theory of Mind abilities, (2) the relationship between Theory of Mind abilities and social-communicative symptoms in autism, and (3) the fluctuation vs. stability of Theory of Mind competence. The findings show that Theory of Mind abilities show a striking variation in high functioning autistic individuals, from a deep impairment to a relatively complex understanding of minds, including in some cases compensatory strategies. Language and Theory of Mind have a very specific relationship in autism, and existing Theory of Mind abilities show remarkable stability in some subjects while others are more unstable in this sense.

Olga Bogdashina analysis “Sensory perceptual issues in autism: why we should listen to those who experience them”. The recognition of sensory perceptual differences (both strengths and weaknesses) is still quite a new field and, unfortunately, many professionals are unaware of these issues, how to recognize them, and what to do about them. The paper presents a detailed description of perceptual impairments which constitute the autistic world and make their experiences very specific. The qualitative nature of sensory experience should be taken into account in terms of therapy as well as education of ASD patients.

Agnieszka Rynkiewicz presents a detailed analysis of “The use of computer technology and the internet in teaching and therapy of individuals with Autism Spectrum Disorders (ASD)”. Use of computer programs and software in teaching and therapy of individuals with ASD is a relatively new field of research but shows very promising results. Virtual reality is also gaining traction as a form of psychotherapy at some academic medical centres. Many individuals with ASD have unique talents and are skilled in responding to visual cues, such as pictures and animations. Computers not only unlock many unique talents that individuals with ASD possess, but also facilitate the development of social skills that are crucial to functioning in society. In addition to selected computer programs and software, the article also presents some important facts about the diagnosis and sensory profile in ASD and connects these facts with a discussion about computer-mediated-communication, CMC, which is used by individuals with ASD. The article is primary focused on individuals with Asperger syndrome and high-functioning autism.

David Preece presents “Respite care for families with children with Autism Spectrum Disorders: how services in northamptonshire UK are working to meet the challenge”. This paper identifies the importance of respite care services for many families with children with autism spectrum disorder (ASD) but also some of the obstacles that may prevent families from accessing such services. It describes how Northamptonshire County Council, a local authority in the United Kingdom (UK), is working to meet the challenge of providing ‘autism-friendly’ respite services. As well as outlining the major characteristics of these services, and how they seek to meet the needs of families with children with ASD, the paper describes the limitations of these services and the challenges and issues that remain.

Offering the publication to our Readers, the Authors as well as the Editors hope that they will find the presented studies in the field of exceptional psychology and education interesting. We hope that reading these articles enhances their personal reflections, proves helpful in solving various theoretical and practical problems or becomes useful for educators, psychologists, sociologists and students of these disciplines. If our Readers find the issue satisfying their intellectual as well as practical needs related to supporting exceptional persons, the Authors shall feel gratified.

Editors
Joanna Kossewska, Miloň Potměšil

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Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

PSYCHOLOGICAL ASPECTS OF SENSORY AND MOTOR IMPAIRMENTS

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Theory of Mind in deaf children in the context of inclusive education

Introduction

Deciding on a particular school setting in which to place a deaf child or adolescent is of great importance, as research indicates different social outcomes of mainstream schools as opposed to residential schools.

The specific decision depends on the questions the parents ask themselves at the very beginning, "Does my child want to be in a school with similar peers or with hearing ones?", "What particular method is best for my child?", "Will my deaf child benefit more from being surrounded by hearing peers and consequently lack communication skills which could result in its isolation from the Deaf culture or will he/she benefit more from being surrounded by deaf peers?" The parents have to make an assumption as well as a prediction of the outcomes of what will be better for the child: to function in the hearing world with lip reading abilities, talking and listening for sounds almost as a hearing person does, or to be proud to be Deaf, to be a part of the Deaf community and sign fluently, or finally to be proud of functioning in both worlds (Harvey, 1989). However, there are consequences to either decision that have long-term effects on the child's personal and career goals as well as academic achievements (Marschark, 1997). These consequences may be related to the development of Theory of Mind – the fundamental human ability of understanding the mental life of other people, which implies understanding and predicting their behaviour.

Inclusive education for the deaf

Integrative education is a form of education in which the teaching and learning process is adjusted to the individual developmental needs and educational capabilities of a deaf student. As a result, the child can go to school locally, and the learning conditions are adjusted to their individual capabilities and limitations through an individual curriculum, appropriate for their developmental rate and learning speed, special methods and forms of teaching, support of an assistant teacher, specialist help, appropriate facilities and equipment, and finally, special forms of testing. Integrative education should be considered a transitory form, and modern educational policy towards disabled students should be aimed at promoting **inclusive education**. Inclusion does not mean that children should be placed in mainstream schools. Instead, it means changing schools so that they better serve the different needs of children and provide appropriate support. The school as a whole must change so that it offers access to the full scope of educational services and enables full social integration of all students.

According to Mittler (2000), integration is based on preparing the child for the move from a special school to a mainstream one. It is, therefore, deeply rooted in the so called "deficit model" (convergent with the medical rehabilitation model), based on the assumption that it is mostly the child's deficits that require correction, while the school does not necessarily have to change in any way to meet the individual needs of the child. The "deficit model" assumes that learning difficulties originate in the mind of the child.

Inclusion, on the other hand, does not involve placing children in mainstream schools. It means changing schools so that they better serve the children's needs, which involves helping teachers assume responsibility for teaching all children in their original schools, and preparing teachers to teach those children who are at the moment excluded from their original schools, regardless of the reason for the exclusion. It concerns all children who do not benefit from being at school, not just those deemed to have "special educational needs". Inclusion is based on the "social model", which assumes that society and its institutions are oppressive, discriminating and impairing. As a result, emphasis is put on eliminating the barriers that prevent disabled people from participating in social life. Eliminating these barriers can be expressed as changing the institutions, laws and social attitudes that contribute to the creation and maintenance of exclusion mechanisms. The social model is, therefore, based mostly on changing the teaching environment.

The differences between inclusion and integration may be summarized as presented in Table 1.

INTEGRATION	INCLUSION
Emphasizes the needs of 'Special Students'	Emphasizes rights of all students
Changes or remedies the subject	Changes the school
Benefits of integration for the special needs student	Benefits of inclusion for all students
Presence of professionals, specialist expertise and formal support	Presence of informal support and the expertise of mainstream teachers
	Quality teaching for all

Tab. 1. The differences between inclusion and integration (Thomas et al. 1997)

One of the major arguments for the inclusive education of deaf students has been the expected great benefits for them. In the inclusion setting they are able to learn how to interact with hearing peers using common ways of communication. The question is: what are those common ways of communication? Is it oral language, Total Communication or sign language? This social interaction provides the deaf students with a context in which to develop social skills that are necessary for functioning in the hearing world (Mertens, 1989). It seems very important to stimulate the competences related to functioning in a bicultural context. Advocates of inclusion placements believe that placing deaf students in classrooms with hearing peers will enhance their social integration (Stinson and Lang, 1994). Inclusion placements also break down the stigma, isolation and social exclusion associated with attending a residential school, as well as the lack of verbal languages competencies used in many everyday life situations (Kauffman, 1993). Participating in classes with hearing peers provides regular contact with societal norms and this contact is assumed to be the primary step in the development of friendship and social acceptance (Gregory and Bishop, 1988); it might also stimulate moral development and the hierarchization of values.

Inclusion is a very positive idea, although it requires providing all the aforementioned necessary support. The support services offered within an inclusion setting have an impact on the self-concept and social adjustment of students. Students in inclusion classes who received support from itinerant teachers for the deaf , who tutored the deaf students and consulted with their regular classroom teachers, exhibited stronger self-concepts than students without any support (Reich, Hambleton, and Houldin, 1977).

Mainstreaming does not always provide self-identity or emotional security. In contrast to the previously cited research on residential/inclusion comparisons, Stinson and Lang (1994) reported that deaf students who were placed in inclusion settings described their social experiences as lonely, rejected, and socially isolated. If deaf students are mainstreamed, they will face many frustrations due to their inability to fit into either world. It has also been shown that students who attended residential schools reported more positive social experiences than those placed in inclusion settings (Mertens, 1989) and had higher levels of self-esteem, greater maturity, and more positive social and emotional adjustments compared to students in inclusion programs (Farrugia and Austin, 1980).

According to Marschark (1997), in order to decide which school is the best for a specific child, we need to look at the development of deaf student's social skills in the context of a hearing social environment versus one that is deaf. Such differences can be found when investigating deaf student's developmental abilities and self-identity. Marschark (1997) concluded that when giving equal exposure to both mainstreamed and residential settings, social interaction with deaf peers in partial mainstreaming is much better than total mainstreaming. He emphasizes that mainstreamed settings do not increase the amount of emotional security in deaf students. On the contrary, deaf students in residential schools reported that they had more friends, felt emotionally secure, and had higher self-esteem, were accepted by their peers, and could communicate very well in sign language.

Some problems related to mainstream schools were described in detail by Ramsey (1997). The most important problems for deaf children are: isolation, lack of a language development model, secondhand information gathered through interpreters, and hearing children distancing themselves from the deaf. Teachers also had poor attitudes, such as paternalism, which deeply affect deaf children's development. The teachers expressed these attitudes by refraining from asking deaf students to respond, by showing a lack of understanding about Deaf culture, and by having poor signing competences (about twenty words). The teacher can also misunderstand the deaf student's behaviour when he/she looks away from either the teacher or the interpreter.

The study by Obrzut, et al. (1999) presented evidence suggesting that deaf and hard of hearing children in residential schools have higher self-concepts than their peers in regular public school classes. Usually deaf adolescents from mainstream schools suffer from social isolation and have lower self-esteem than hearing adolescents because of communication difficulties (Higgins and Nash, 1987). This significant difference might also depend on the means of communication used within the family. Deaf and hard of hearing children of deaf parents appear to have better self-concepts than deaf and hard of hearing children of hearing parents (Obrzut, et al., 1999). Perhaps the reason for this outcome is due to successful academic and communication skills within the family.

Even if inclusive education might lead to positive experiences for deaf children, negative effects can show up later in life. According to Marchark (1997), inclusion is not only about becoming sociable, but also about one's academic skills, over-all mental ability, and success with the vocation of choice. Inclusion is not only related to the education system but is a life-long process with reference to different conditions and outcomes.

Deaf education in Poland

Deaf education in Poland usually takes place in phonic schools or with the use of a system based on spoken and sign languages as supporting tools. Language is the basic social communication tool. The command and use of a particular language enables and facilitates acquisition and exchange of knowledge and information. Language is not a mere expression of freedom, because it goes beyond the personal sphere and becomes a necessary tool which enables a person to function in society.

In Poland, there are four forms of education available for people with hearing impairments. A particular form is selected on the basis of the child's communication abilities and their command of Polish. Each of these four forms has its advantages and disadvantages, and each is addressed to a relatively narrow group of recipients. In theory, each of these four forms of education offers a similar curriculum, but in practice, considerable differences may occur. The first form is mainstream schools, usually attended by hard of hearing students who know the structures of the Polish language to a level that enables them to communicate freely. They are often students who, for various reasons, lost their hearing during the post-lingual period (after they have acquired the structures of speech). In a mainstream school, a deaf student is an equal member of the class, but is often treated as an addition to the class of hearing children. Such a student, however, has the same rights and responsibilities, which affect the learning process, whose scope is usually typical for that particular type of school. Deaf students in mainstream schools cover the standard primary, junior secondary, and senior secondary school curriculum without any special exemptions, apart from being exempt from learning a second foreign language – which they usually choose not to learn.

Another form of schooling, which is gaining increasing popularity, is integrative classes in mainstream schools. Assistant teachers in integrative classes may know sign language or its elements (although they are not required to), thanks to which the teaching process is more effective even in the case of completely deaf students. Hearing impaired students benefit from the presence of an assistant teacher, but the curriculum remains the same as for all mainstream school students.

The third form of education is schools for the hard of hearing. Such schools are rarely separate units; they usually constitute a part of a training and educational centre, which often requires boarding. Students are often unable to use such a special centre for economic and social reasons and attend mainstream schools regardless of their command of the spoken language.

The fourth and last form of education is schools for the deaf (training and educational centres with boarding facilities). Teachers in such schools use sign language, sometimes also phonogestures, which eliminates communication barriers and enables effective learning.

Schools for the hard of hearing and deaf offer a slightly modified curriculum. Due to the differences in teaching methods and curricula, their graduates have a lower level of general knowledge than students finishing mainstream schools.

Over the years 2003–2006 the number of deaf children in mainstream schools has dropped, while the number of hard of hearing children in such schools has increased (Table 2).

	2003/04	2004/05	2005/06	2006/07	2007/08
Blind	144	69	81	108	82
Visually impaired	950	1089	1318	1546	1529
Deaf	233	225	248	244	209
Hard of hearing	1074	1503	1683	1831	1870
Mild mental handicap	3104	4047	4543	4912	5209
Moderate and severe mental handicap	1024	1472	1638	1790	1787

Tab. 2. Number of children by type of disability in the years 2003/04–2007/08 (source: Czajkowska-Kisil, 2010)

According to Czajkowska-Kisil (2010), schools may offer actual education, as well as apparent education – when disabled students are taken care of by special needs educators and in their absence are left unsupported with no help from their teacher or peers. Inclusive education is much more beneficial than integrative education, because disabled students are dispersed in different classes, which prevents re-creating environments based on segregation.

Theory of Mind in deaf children

Human beings have a deeply-rooted mental competence for being fascinated with other people, both significant others as well as strangers, and for predicting and explaining their behaviour. The process of explaining other people's behaviour is based on understanding their mental states – their beliefs, desires and intentions.

Individuals understand the behaviour of others in terms of their beliefs about the world. The ability of attempting to understand the mental life of other people is called Theory of Mind (ToM) and was coined by David Premack and Guy Woodruff (1978), who first tested a chimpanzee's ability to predict a person's behaviour by means of mental state attribution.

ToM appears to play a very important role in human social behaviour. The history of ToM research is rather long and various theories on the nature of ToM development have been produced. One of them is a neurological theory that explains the neural mechanisms underlying ToM development, whose neural correlates have been identified in the following regions: bilaterally in the temporal poles, in the left superior temporal gyrus, temporo-parietal junction, and the posterior cingulate cortex, based on significant increases in cerebral blood flow in the aforementioned areas (Fletcher et al., 1995, Saxe and Kanwisher (2003). A second theory posits that false-belief understanding develops out of other capacities that mature during infancy. For example, pretend play (Leslie, 1987) and shared attention (Baron-Cohen et al., 1996) may be skills that precede ToM abilities. There are some specific prerequisites to Theory of Mind. First, a child must understand that individuals can have desires –this can be assessed by joint attention and protodeclarative pointing. Second, they use pretend play skills and meta-representation. Third, they begin to use mental state terms such as “think,” “know,” “want,” and “remember”.

The third theory postulates that the development of ToM is influenced by exposure to conversation about mental states (Jenkins and Astington, 1996; Perner, Ruffman, and Leekman, 1994) and verbal ability in normally developing children (Białecka-Pikul, 2002). However, communication difficulties may prevent some children from being able to successfully converse with others. De Villiers and de Villiers (2000) have emphasized that performance in false belief tasks depends on understanding complex language and that individual differences may reflect differences in language ability.

On the basis of many observations and the above-mentioned theories, it can be stated that deaf children suffer from impairments in ToM development. The first study in the field of Theory of Mind in the deaf conducted by Peterson and Siegal (1995) revealed that 65% of profoundly deaf Australian children, aged 8–13 and using Auslan (Australian Sign Language), failed the false belief test, while only 35% of them passed a version of the classic „Sally-Anne” task. The level of performance shown by deaf children did not differ significantly from that reported for autistic children of a comparable (nonverbal) mental age. These results were replicated in a later comparison of deaf and autistic children across a wider age range and using a broader range of tests (Peterson and Siegal, 1997, 1999, 2000).

Several studies have shown that deaf children of hearing parents who learn sign language as school-aged children (non-native late signers) and do not use sign language as their first language, tend to perform at a lower level on false-belief tasks than their hearing mental-age-matched peers (Courtin, 2000; de Villiers and de Villiers, 2000; Peterson, 2004; Peterson and Siegal, 1999, 2000; Russell et al., 1998; Woolfe et al., 2002).

The developmental delay is very significant – research showed that 60% of deaf late signers between the ages of 13 and 16 passed false-belief tasks. However, native signing deaf children (deaf children of deaf parents) do not lag behind hearing children in Theory of Mind development (Russell et al. 1998). Theory of Mind tasks are typically administered verbally, which raises the question of whether the linguistic demands of these tasks mask some deaf children's conceptual competences. However, it is worth noticing that according to some researchers, deaf children of hearing parents show difficulties in ToM development even if the task instruction is almost nonverbal. Figueras-Costa and Harris (2001) found that oral deaf children (i.e. those using spoken-language) performed significantly better on a nonverbal false belief task than on a verbal false belief task, suggesting that verbal Theory of Mind tasks may underestimate the understanding of some deaf children. The deaf children in the Figueras-Costa and Harris study all had hearing parents, used spoken Catalan or Spanish, as well as hearing aids. However, even on the nonverbal false belief task, the deaf children's tested performance was delayed by about 4 years relative to hearing norms. Other studies have also found that deaf children of hearing parents, both signing and oral, perform poorly for their age on Theory of Mind tasks even when verbal demands are reduced (Schick et al., 2007; Woolfe et al., 2002). Woolfe et al. (2002) used "thought pictures" in their study. However, in the study by Falkman and Hjelmquist (2007), the difference between native signing and late signing deaf children in mentalizing skills remained significant even though the Theory of Mind task was made more comprehensible by using minimal verbal instructions.

Theory of Mind of deaf children in the context of education

Theory of Mind development might also be related to the **educational system.** The school environment also seems to be an important factor in ToM development in deaf children. They usually attend one of three types of schools: segregated, mainstream or regular schools for the hearing. These types differ not only in terms of the impact of social and cognitive integration but, what is more significant, in the mode of communication. Schools vary in the level of oral vs. sing language that is used. Children educated by means of total communication, bilingual communication and oral language, were compared for differences in ToM development (Courtin, 2000, Peterson, Siegal 1999).

Interestingly, research demonstrates that profoundly and pre-lingually deaf children of hearing parents who are taught in the oral language mode are also delayed in developing insights into the minds of others (Courtin, 2000; de Villiers and de Villiers, 2000; Peterson, 2004). An orally-taught deaf child is not exposed to sign language; in consequence his/her speech, vocabulary and syntax are limited and the level typically present at 4 years of age is insufficient to support elaborate mind-talk, especially in reference to others' beliefs (de Villiers and de Villiers (1999). Language and early family conversation are critical factors for ToM development so orally educated deaf children with hearing aids should be delayed in mastering concepts of false belief.

Research on ToM in deaf children has been carried out in different countries, with different views on deaf education and with children being exposed to different sign languages. Although deaf children are exposed to various forms of language in education, they are delayed in ToM development – a consistent finding across various studies. In the majority of deaf studies from the UK and Australia, children are recruited from schools which follow the philosophy of Total Communication, where spoken language is usually combined with signed English (English is translated in a word-by-word way according to English syntax), supplemented by lip reading, finger spelling and British/Auslan Sign Language (Peterson, 2004; Peterson and Siegal, 1999; Russell et al., 1998). In other studies deaf children are recruited from mainstream schools with sign language provision or special schools with bilingual communication using both spoken English and British Sign Language (Woolfe et al., 2002), are orally taught (de Villiers and de Villiers, 2000) or educated primarily in sign language (Falkman, 2005).

Courtin (2000) conducted an analysis in order to determine any differences in ToM performance between children from institutional school settings versus hearing mainstream schools. Deaf children of hearing parents are delayed in the development of Theory of Mind no matter what communication pattern has been adopted in their education, which means that the delay is not specific or related to the teaching method at school. However, no significant differences were found that might point to differentiating aspects of the means of communication used in different school settings. Oral deaf education does not engage in the use of sign language, speech reading or Total Communication, but focuses on receptive (listening) and expressive (spoken) language. The child is usually treated behaviourally during the teaching procedure and creativity and plasticity decrease. Deaf children thus become over-controlled and there is less space for flexible and creative discussions.

Peterson and Siegal (1999) have found, however, that orally instructed deaf children performed better in comparison to native signing children. This result might either be confusing or understood as the glorification of oralism in deaf education. Nowadays however, there is rather week acceptance of oral treatment compared to bilingual education (Grosjean, 2001). This result should be interpreted very carefully. One reason for these conflicting results could be the different hearing status of children included in these studies. In Peterson and Siegal (1999), the children included in the oral deaf group had a moderate to severe hearing loss, whilst in Courtin (2002) and de Villiers and de Villiers (2000), only children with severe or profound hearing impairments were included. Thus, with the resulting differences in access to everyday conversation depending on the children's hearing level, these children could develop mentalizing skills at different ages. Some hearing parents of deaf children opt for a purely oral approach to family communication as well as for mainstream or regular oral-only schooling. Language development is generally delayed in orally educated, profoundly deaf children who use conventional hearing aids (Svirsky, Robbins, Iler-Kirk, Pisoni, and Miyamoto, 2000) so they would also be expected to have a delay in ToM. However, only about 25% of deaf children develop speech skills sufficient for full educational access. Language delays in oral settings are typical, even with intensive speech therapy. There is much less evidence supporting oral methods than is generally assumed (Marscharck, 1997). Along with delayed language, restrictions upon the oral deaf child's opportunities to exchange information about thoughts, feelings, or intentions with hearing parents, peers and siblings may curtail ToM development. An orally-taught deaf child who is not exposed to sign language, experiences a language development delay in reference to limited speech, vocabulary and syntax. In a typical developmental path for these children, language is so simple at age 4 that it is insufficient to support elaborate mind-talk, especially in reference to others' beliefs (de Villiers and de Villiers 1999). Consequently, if language and early family conversation are critical factors for ToM development, orally educated deaf children with hearing aids should be delayed in mastering concepts of false belief.

Findings show that education in a Total Communication classroom where sign is used along with speech, neither enhance nor detract from ToM development, relative to mainstream schooling (Peterson 2004).

In the context of the established finding that Theory of Mind growth is seriously delayed in late-signing deaf children, and some evidence of equivalent delays in those learning speech with conventional hearing aids, the study by Peterson (2004) explores ToM development in deaf children with cochlear implants. Implants can substantially boost auditory acuity and rates of language growth. Despite the implant, there are often problems in socializing with hearing peers and some difficulties with language, lending special theoretical interest to the present comparative design. No significant ToM differences emerged between deaf children with implants and those with hearing aids or between those in oral-only versus sign-plus-oral schools. Nor did the deaf children perform any better on ToM tasks than their age-matched autistic peers. Overall, it would seem that false belief performance by oral deaf children with implants or hearing aids closely parallels that of late-signing deaf children from hearing families (Peterson and Siegal, 2000).

Research on ToM development in deaf children thus suggests that, provided a child's hearing loss is severe to profound, and provided that there is no fluently signing family member, there is a delay of 3 to 5 years in comparison to hearing children.

This might be an argument in favour of bilingual education (Marscharck, 1997) which assumes that sign language is the primary basis of deaf children's development, both in cognitive and emotional-social aspects. It provides a good framework for the development of a second language, which for the deaf means the oral national language used by the hearing majority.

In American research it was found that there was no significant effect of the predominant language of school instruction, ASL versus oral English, on verbal ToM tasks. ToM performance of two groups of deaf children of hearing parents (oral deaf as well as ASL signers) were significantly worse than that of comparative groups: a control group with hearing children and deaf children of deaf parents using ASL (Schick, el al. 2007).

Cross-country comparisons of ToM in Estonian, Italian and Swedish deaf children were presented in interesting studies (Meristo, 2007; Meristo, Hjelnquist, 2009; Meristo, Falkman, 2007) on the important role of education conducted in a native language environment in order to maintain the expression of mind-reading skills through practice. Four groups of deaf children aged 7–16 years with different language backgrounds at home and at school, i.e. bilingually instructed native signers, orally-instructed native signers, and two groups of bilingually instructed late signers from Sweden and Estonia, respectively, were measured on ToM. The bilingually instructed native signers performed at a significantly higher level on the ToM measures than the other groups of deaf children.

The study confirmed that deaf children from hearing homes lag several years behind hearing children in developing mentalizing skills, and that it is an advantage for deaf children to have deaf parents when it comes to understanding the minds of others. However, it presented a very complex environment, with the language environment being the common thread. The Estonian and Italian studies were conducted in a group of deaf children with deaf parents, where the children did not use sign language at school, and it was found that the advantage of having deaf parents is not independent of other factors. Deaf native signing children from an oral school performed worse on Theory of Mind tasks than deaf native signing children from a bilingual school. These results provided strong evidence that bilingual education is a better background for ToM development than oral education, even for native early singers who have non-restrictive contact with a significant other who uses sign language in everyday communication. On the other hand, the Swedish health, rehabilitation and educational systems promote – in comparison to other countries – the idea of defending the rights of minorities to live and develop their own culture. Many procedures are adopted for this purpose, such as very early diagnosis of deafness and sign language instruction immediately offered to hearing parents if they expect to give birth to a deaf child, together with early sign language experience at preschool for deaf children. Results of a study conducted by Meristo (2007) showed that these practical interventions were generally very useful, but were, however not enough for the group of late signing children to be put on the same developmental track as deaf children of deaf parents and to develop ToM on the same level as native signers. It seems that there are some important differences in the early coordination of minds and introduction to the minds of others in the two communication environments and family backgrounds (deaf and hearing), because mentalizing is sensitive to specific kinds of early experiences. These differences, however, are yet to be found.

Conclusions

1. Summing up, deaf studies consistently suggest that deaf children from hearing families, educated in either oral or sign language, are delayed in developing mentalizing skills compared to their native-signing and hearing age-matched peers. The results of some studies point to the importance of participation in everyday conversations with family members and friends, which in one way or another facilitate the understanding of others as mental agents (Woolfe et al., 2002).
2. Secondly, it is possible that Theory of Mind skills are important for the development of social interaction skills, particularly those skills required at school. Astington and Pelletier (1998) argue that there may be a relation between children's level of Theory of Mind development and their ability to learn by instruction and collaboration. They suggest that Theory of Mind understanding is also linked to the development of scientific thinking and critical thinking.
3. Education requires children to talk about mutual understanding and misunderstanding, to reflect on their own beliefs as well as the beliefs of others, and to

shift perspectives when evidence suggests that another point of view is valid. All these require Theory of Mind skills.

4. There is also evidence that teachers of the deaf, as well as hearing teachers of hearing children, vary a great deal in how much they talk about the mind. Given that many deaf children often have a limited range of social partners who they can communicate fluently with, restricted input is a serious issue for many children.
5. The education of deaf children living in an integrated environment needs to look beyond functional communication and academic skills and ensure there is also a focus on more complex aspects of social and emotional understanding and development.

Acknowledgments
The author was supported by a scholarship from the Polish Ministry of Science and Higher Education.

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Theory of Mind in deaf children in the context of inclusive education

Abstract

Making decisions about particular school settings for deaf children or adolescents is of great importance due to the varied results of research that assess the social outcomes of mainstream schools versus residential schools.

However, there are consequences to either decision that have long-term effects on the child's personal and career goals as well as academic achievements. The consequences might be related to Theory of Mind development, the important human ability of understanding the mental life of other people, which implies understanding and predicting their behaviours. The paper presents a developmental pathway for Theory of Mind in deaf children in the context of education.

Teoria umysłu u dzieci głuchych w kontekście edukacji włączającej

Streszczenie

Podejmowanie decyzji o umieszczeniu głuchych dzieci lub nastolatków w określonej szkole jest bardzo ważne, gdyż istnieją zróżnicowane wyniki badań, porównujące szkoły integracyjne ze szkołami z internatem pod względem opanowanych przez uczniów kompetencji społecznych.

Każda z decyzji ma swoje konsekwencje oraz długotrwałe skutki wpływające na osobiste i zawodowe cele dzieci, jak również na osiągnięcia w nauce. Konsekwencje te mogą mieć związek z rozwojem teorii umysłu, która stanowi istotne umiejętności człowieka, pozwalające na nadawanie znaczenia życiu umysłowemu innych osób, co pociąga za sobą zrozumienie oraz przewidywanie ich zachowania. Niniejsza praca przedstawia drogę rozwoju teorii umysłu u dzieci głuchych w kontekście edukacji.

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FOLIA 98

Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

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Deaf identity construction: a case study

Introduction

Identity is a very complicated issue. Its development involves an interactive process, closely connected with each person's experiences, and originates from interpersonal processes as well as the language used to understand and reflect upon these experiences (Ohna, 2003).

For deaf people, the concept of identity is socially constructed and influenced by factors such as the individual's characteristics, as well as situational, social, and societal conditions (Foster and Kinuthia, 2003; Leigh, Marcus, Domosh and Allen, 1998; Parasnis, 1998). Kannapell (1994) suggests that the definition of cultural identity among deaf people should be based on how the deaf identify themselves in terms of language, personal, and social identity; and that these three major types of identity are strongly interrelated.

It is well established in the literature that deaf people mainly develop four kinds of identities. First, culturally Deaf people are those who are proud of being Deaf, identify with the Deaf culture, and primarily socialize with Deaf adults. Culturally Deaf people view Deaf Culture as encompassing companionship, language, folklore, art and common history. Then, there are those that identify with culturally hearing people and hearing culture and prefer to form close relationships with hearing adults. These deaf people speak in favour of speech and lip reading capabilities for a deaf person's success and generally view deafness from a medical perspective. Biculturally deaf people immerse themselves both in the Deaf and the hearing culture. Finally, deaf people may develop a marginal identity (including those that feel ambivalent about being deaf), search for a reference point (hearing or Deaf), and do not integrate within the hearing or the Deaf community (Bat-Chava, 2000; Foster and Kinuthia, 2003; Israelite, Ower and Goldstein, 2002; Kannapell, 1994; Leigh et al., 1998).

A number of factors, such as growing-up in certain family environments (deaf/hearing parents), an experience of acceptance in the family, the school-environment, past and present structures of communication, and participation in the Deaf Community influence the development of identity (Bat-Chava, 2000;

Maxwell-McCaw, 2001). Historically, research studies in the field of deaf identity indicate that the school environment and family background are the primary agents for children's eventual development of identity (Maxwell-McCaw, 2001; Padden and Humphries 1988).

As far as the effect of family background is concerned, research findings suggest that parents have a significant influence on identity, with the majority of deaf and hard of hearing children of hearing parents having a marginal or hearing identity. On the other hand, deaf children with Deaf parents are most likely to develop a culturally Deaf identity (Bat-Chava, 2000; Leigh et al., 1998; Maxwell-McCaw, 2001). However, taking under consideration that only 5–10% of deaf children are born in Deaf families (Shein, 1989), it is worth investigating how various school backgrounds impact the ultimate development of their identities. Bat-Chava (2000) found that deaf children attending deaf schools are most likely to have a culturally Deaf identity. Similarly, in a study carried out by Maxwell-McCaw (2001), participants with a hearing identity largely attended mainstream programmes, while those with a Deaf identity were more likely to have attended residential programmes.

However, there is not enough research on how deaf people whose characteristics do not match those of the general deaf population, cope with identity construction. Thus, the aim of this study is to provide inside information on different routes of identity construction within the deaf population.

Methodology

Method

A case study was carried out with an adult Cypriot Deaf individual. The pseudonym John will be used for the participant in order to protect his anonymity. John's story was deliberately chosen because his family (one oral deaf and one hearing parent) and educational background (his required education was not fulfilled) did not match the family and educational background of the majority of the deaf population.

Procedure

In-depth semi-structured interviews were conducted to gather data for this study (Borg and Gall, 1983). The general issues that were to be investigated were formulated as an interview guide. This interview guide was developed based on a current review of literature on the development of deaf identity (Hadjikakou and Nikolaraizi, 2007).

Three interviews were carried out, averaging two hours per interview. For the interviews, places were chosen where the respondent felt comfortable in expressing his thoughts (e.g. at his home, at his favourite cafe etc), as a non-threatening environment ensures and strengthens confidentiality (Oppenheim, 1997). The interview was carried out in Cypriot Sign Language (CSL), since the researcher is a fluent user of CSL. Each interview was videotaped to keep a record of the obtained information. Ethical issues regarding anonymity, confidentiality and access to the research findings were discussed with the participant, who gave informed consent prior to data collection.

A qualitative approach, which relies on direct quotations from the interviews, was applied to analyze the collected data (Knodel, 1993). Three steps were followed in the analysis of the interviews: a) text transcription – the first step in the analysis of the interviews was to arrange a transcription of the detailed notes and audio/video tapes of the interviews, b) code procedures – when a printed document of all interviews was produced the researchers studied the transcript and identified those sections that were relevant to the research questions of the study; the interview topics served as a general guide for developing code categories (Foster and Kinuthia, 2003; Hadjikakou and Nikolaraizi, 2007); a set of four primary code categories was created: family experiences, educational experiences, identity, and identity construction; and finally c) search procedures – once the code categories were assigned and noted in the margins of the interviews, the data was copied, cut and pasted, and sorted into separate code folders; a printout was produced, which was used as supporting material in an interpretative analysis.

Results

This paper briefly describes John's historical path and highlights in detail his family and educational experiences, as well as his identity construction. John is 48 years old and audiologically hard of hearing. He is happily married with a Deaf signing wife and has three hearing children. He works in the private sector and is an active member of the Deaf community[1].

Family experiences

John's family background consists of a deaf oral father and a hearing mother. However, this parental type is rare, since there is evidence that the Deaf community is inter-married – 80–92% of married Deaf people are married to another Deaf person (Kyle and Allsop, 1982; Schein and Delk, 1974). John does not have any other brothers or sisters.

> *My mother is hearing and my father is deaf. In the past, I used to communicate exclusively orally with my father because he is hard of hearing. My daddy did not know how to sign, because he is old and at that time, there was no School for the Deaf in Cyprus. Since there were no Deaf women, he found a hearing woman .... my mother and he got married to her. They communicated exclusively orally with no signs.*

John describes himself as being closer to his father, who is deaf, than to his hearing mother. He describes the communication difficulties his father encountered with hearing relatives and how he was often isolated and not in a position to follow their discussions.

> *My mum has a sister, uncles, aunts who used to pay us a visit. My mother was hearing and she could talk with them. My father couldn't hear and he mostly communicated with me. He couldn't understand what they were saying, so he mostly communicated with me. Thus, I feel closer to my father. Because he is deaf, we could communicate better.*

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[1] Note: In this paper, the lower case "d" is used to refer to those deaf people who do not sign, are oral, and do not belong to the Deaf community, whereas the upper "D" is used to refer to Deaf adults who belong to the Deaf community, are signing Deaf and are considered culturally Deaf. The term ''deaf'' also refers in general to the condition of not hearing (e.g. deaf-parented families).

Similarly, previous studies revealed that deaf people felt isolated from their wider hearing family environment mostly because of a lack of communication (Foster, 1988; Hadjikakou and Nikoloraizi, 2008), as happened with John's father. Participants in previous studies (Breivik, 2005; Hurwitz and Hurwitz, 1995) who were raised in families with other deaf members described the ease of communication between them, as well as the positive experiences they derived from it. Similarly, John emphasizes that he could communicate better with his deaf father.

Educational experiences

John attended a general school. Despite the fact that his parents took him to the school for the deaf, the headmaster did not accept him, because he had good speech.

> *I remember that when I was young my parents wanted me to attend the school for the Deaf in Morphou. I went there, but the headmaster said, 'He talks, and he should not stay at the School for the Deaf. He may lose his good speech. He has to go to the general school to learn how to speak and become stronger.' My parents accepted his suggestion.*

Someone could argue that things might have been different for John if he had attended the school for the deaf. He might have developed a Deaf identity from an early age, through contacts with other deaf children and through extracurricular activities at the residential school (Hadjikakou and Nikolaraizi, 2007). However, John's experiences at the general school were very negative. No support services were available at that time in general schools in Cyprus, and he struggled on his own in the classroom without learning anything throughout the years.

> *I attended the 'hearing schools.' The teachers didn't know how to sign. I watched the teachers talking and talking, but I could not hear. I was sitting and watching them, and I was wondering about what they were talking about. I didn't know, and I could not hear. I tried to be patient. I was watching and watching from the first till the final grade of primary school. Sometimes, the teacher came close to me and tried to help me with the lessons. I could not write. I was just drawing and she told me, 'Well done.' Throughout the classes, I learnt nothing, just the same. I was sitting alone and I was just drawing. Then my parents asked me if I wanted to go to the Gymnasium, and I told them, 'No,' because the same thing would continue. That would mean hearing people talking and me not understanding anything. I decided to get a job.*

In previous studies, the negative experiences of deaf people who had attended general schools were also reported (Hadjikakou and Nikoloraizi, 2007). Access to communication in general classrooms was extremely difficult because participants had to cope alone, with no support services, amongst the rest of their hearing classmates (Foster, 1988; Leigh et al., 1998; Nikolaraizi and Hadjikakou, 2006). John and other similar-aged deaf children were the first to be integrated in Cyprus' schools. In those times neither had sophisticated support services been developed nor were Cypriots' attitudes towards deaf people positive (Thoma, Hadjikakou, Petridou and Stylianou, 2004).

John mentioned that he used to play with hearing children during the breaks. He noted that they were mostly hanging around with him because they felt pity for him, as has been similarly suggested by other researchers (Nikoloraizi and Hadjikakou, 2006).

> *During the breaks I used to play with the hearing children. They were all together and they watched me be alone. They said, 'He is deaf ... pity,' and they would call me to play football with them. When we went for excursions they used to help me.*

Construction of deaf identity

When John was young, he did not have any contacts with Deaf people and would communicate exclusively orally with them. He also emphasized that when he was young (before he met the Deaf) he did not feel comfortable with his deafness. Similar feelings have been identified by deaf participants in previous studies (Israelite et al., 2002; Kent, 2003; Stinson and Liu, 1999).

> *When I was young, I felt very much ashamed for being deaf. I didn't know what to do.*

It was only when he was 17 years old that he accidentally met a Deaf person. It was then that he started wondering about the hearing/marginal identity that he had had developed at that time.

> *Before the age of 17 I was socializing and communicating exclusively orally with the hearing. It was only after the age of 17 that I met Deaf persons, and I asked my parents, 'Why haven't you told me anything about the Deaf? I should have met the Deaf before.' And they told me, 'But we took you to the School for the Deaf, but they did not accept you because you were hearing. You want to meet the Deaf again? Let it be so.'*

John also noted that after he had met the Deaf, he started feeling more comfortable with his Deaf identity.

> *When I was young, I felt very much ashamed for being deaf. I didn't know what to do. After I had met the Deaf (at seventeen), I felt OK; I didn't have any problem with this. I did not feel ashamed for my deafness. I have made slow progress.*

John also stressed that despite the fact that in the past he felt closer to the hearing, he now feels closer to the Deaf.

> *In the past [before the age of 17], I used to feel closer to the hearing. Now, I feel closer to the Deaf. I can communicate with the Deaf if I face a problem. I feel close to hearing people but closer to the Deaf.*

Participants in previous studies (Hadjikakou and Nikoloraizi, 2007), who attended general schools, also stressed that their first meetings with adult Deaf people, as well as the learning of CSL in their adolescence and in their early adulthood, were crucial for the development of their deaf or bicultural identity.

John's mother was a bit reluctant in the beginning to let him meet other Deaf people, and John made an effort to persuade her to allow him to do so. In the current literature, other deaf people expressed gratitude to their parents for not opposing learning CSL when they asked for it in adolescence (Hadjikakou and Nikoloraizi, 2007).

> *I told them, 'I am deaf and I was locked up at home all day.' Now I feel better that I have met all these people. My mother was a bit scared at the beginning. She asked me if I could communicate with the Deaf, and I told her, 'Yes I can!' Then I decided to invite home my Deaf friend one day so as to prove to my mother that I could communicate well. My mother was really moved when she saw me communicating in sign language. She told me, 'Well done that you can communicate so well! You can go to the Deaf clubs from now on.'*

Meeting adult Deaf signing people was crucial for the development of John's Deaf identity. He describes his first experiences with Deaf adults and Cypriot Sign Language (CSL).

> *I met adult Deaf persons when I was 17 years old. I went to the racecourse and I met accidentally 4–5 Deaf people signing with each other. I saw for the first time Deaf people signing with each other. I was wondering what that was. Until then I only spoke. I tried to do some signs and I asked them, 'Why do you sign?' I told them that I was deaf, but I spoke and I couldn't sign. They told me, 'If you are deaf you need to sign.' Then, one of those Deaf people helped me and taught me how to sign. The first time we had a sign language class, I felt rather dizzy. It was a completely different way of communicating for me. Slowly-slowly, I learned to sign. It took me about six months to learn to sign well. I liked the communication with the Deaf, so I wanted to learn quickly how to sign. I was a bit patient, and in six months I could sign well.*

John also described how his father slowly learned the signs and became a member of the Deaf community through his son's contacts. Thus, John was so thrilled with his contacts with Deaf people and with CSL that he introduced his father to the Deaf Community and to CSL when his father was rather old.

> *My father had only hearing friends. No Deaf friends. When I was seventeen I met the Deaf and I learned how to sign. I told my father, 'Why don't you come to the Deaf club? There are a lot of Deaf people there and it's really nice. You can communicate more easily with signs.' My father came and he liked it. And he used to come often to the Deaf club. I played football with the Deaf, and my father used to come and watch me play with the Deaf, and he liked it. Slowly-slowly he learned how to sign. Just before he died he lost his sight. He could only communicate with me through tactile signs.*

Identity

John considers himself as Deaf, despite being audiologically hard of hearing.

> *I am Deaf. I am not hard of hearing, because I do not wear a hearing aid. People who are hard of hearing communicate better than the Deaf. The Deaf cannot…. they sign and watch the speaker's lips.*

John can communicate both orally with hearing relatives and other hearing people and in CSL with his Deaf wife and friends.

> *With my wife who is Deaf, I communicate in CSL. I communicate with my Deaf friends in CSL. With the hearing I communicate orally. Sometimes, I use some signs with my speech so as to teach them. But they do not know how to sign. I can speak quite clearly. I lip read rather well. If a speaker speaks too fast, I can't follow the discussion. They have to speak*

> *slowly. (...) With my young children I try to speak because they are hearing. I try. Of course, I use both signs and speech. It's easier for me to communicate in CSL with my Deaf friends.*

Despite the fact that John communicates well with the hearing (through speech and lip reading), he acknowledges that communication with the Deaf in CSL is much easier. Deaf participants in previous studies with good oral skills also spoke in favour of CSL, stressing that it is a very relaxed mode of communication (Hadjikakou and Nikolaraizi, 2007).

> *With the hearing I can communicate well. Once, a hearing person asked me something because he thought that I was listening. I told him, 'Sorry, I cannot follow you, I am Deaf." He felt uncomfortable and he asked me, 'How am I supposed to communicate with you?' I told him, 'Don't worry and speak slowly and I will lip read.' Then he spoke fast, but I told him, 'Slowly-slowly so as to lip read.' I had a similar experience with another hearing person. I explain to them, and slowly-slowly we can communicate. It's easier to communicate in CSL. I like it. I realized ever since I was 17 that it's easier to have Deaf friends and to communicate with them. Communication with the hearing is difficult. If I am with the hearing, I just close my mouth and I don't understand anything. Whom am I supposed to speak with if I hang around only with hearing people? It's very difficult."*

Despite the fact that John socializes with the hearing, he feels closer to the Deaf than to the hearing.

> *I have some hearing friends, but most of them are Deaf. Because I speak, I can socialize with the hearing. Three to four times a weak, I meet the Deaf. Once a week I meet the hearing. These hearing people are not my relatives.*

He believes that the Deaf should not only speak but use CSL as well. Corresponding views were expressed by participants in similar studies (Hadjikakou and Nikolaraizi, 2007).

> *The Deaf should speak and also use CSL. If a deaf child faces difficulties in speaking, he/she should use signs. If he can speak, let him/her speak. Of course, CSL is better than the first language.*

John stressed that he chose a Deaf wife for various reasons, the main one being ease of communication compared to the difficulties faced when communicating with a hearing partner, as his father experienced with his hearing wife. In previous studies (Hadjikakou and Nikoloraizi, 2007; Nikolaraizi and Hadjikakou, 2006), both bicultural and Deaf participants stressed that they would only get married to Deaf spouses, mainly due to the ease of communication between them. They also emphasized their similarity with each other.

> *When I was young and I watched my deaf father with my hearing mother, I could see that they couldn't get along well, and that they faced various difficulties. Sometimes, my mum would speak on the phone, and my dad would ask her, 'Who are you talking with?' Sometimes, she wouldn't respond, and I realized that they faced a huge problem. In some other cases, two or three people would come home for a visit. These were my mum's friends. My father used to ask my mum, 'What are you talking about?' She used to say "Mind your*

> *own business!' I thought that if I got married with a hearing wife in the future, I would face similar difficulties. I thought that it would be better with a deaf girl, since we would be the same. I guessed that we wouldn't face any difficulties, since the communication would be better. That's why I got married to a Deaf wife."*

He also mentioned that sometimes he faces difficulties in his interaction with the hearing, probably due to communication difficulties.

> *There are some hearing people who behave well to me whilst some others who don't. For instance, I remember that once a hearing colleague asked me something about the job. I didn't understand and I made a mistake. He shouted at me. I tried to explain to him, but he got even angrier and I closed my mouth. I tried to be patient. Some Deaf envy me but most of them don't. Maybe they feel jealous of me because of my good job or because I sign well and I am smart. The rest of the Deaf don't sign well and they feel jealous of me.*

John is an active member of the Deaf community, elected on the board of one of the clubs.

> *The Deaf clubs must be in place. They are vital for the entertainment of the Deaf and for their communication as well. When I stay at home, I see the same things; I don't learn anything new. I think that it's better to go to the Deaf club, to meet my friends, to hang around, to discuss about my problems and family. We need to discuss with each other because the same things can happen to us. However, if we constantly stay at home, we are not informed about the news. We do not learn things. The Deaf clubs should thrive.*

In previous studies, it has been reported that Deaf clubs worldwide have a multidimensional role and many functions (Hadjikakou and Nikoloraizi, 2011; Hall, 1994; Romeo and Renery, 1994; Padden, 1996).

Discussion

This study reveals the route to identity construction followed by deaf persons who come from backgrounds that are different than those of other deaf people. Only 5% of signing Deaf or oral deaf people get married to hearing persons. Of those, only a few give birth to deaf children. John comes from such a family environment; he is deaf with a hearing mother and oral deaf father. He was raised in a hearing environment and had attended a general primary school. This study has shown that in early adulthood John developed a Deaf identity. Nowadays, he primarily communicates in CSL, identifies himself as Deaf, and socializes mostly with Deaf people.

Identity construction is a dynamic process, which emerges through present and past experiences, interactions between oneself and the surrounding social environment (Nikolaraizi and Hadjikakou, 2006). Certain factors were fundamental for the construction of John's Deaf identity, since he had had a hearing or marginal identity when he was young. The most crucial element was his first contact with Deaf signing adults in his adolescence (when he was 17). As similarly reported in previous studies (e.g., Hadjikakou and Nikolaraizi, 2007; Nikolaraizi and Hadjikakou, 2006) in which orally educated adolescents met Deaf signing adults for the first time, John initially experienced feelings of surprise, then joy and relief when he could finally communicate with people who were like him (Deaf) in a relaxed and accepting way (through sign language, i.e. CSL). Similarly, Breivik (2005:22) stresses "the sense of liberation when introduced to a signing community and experiencing the 'companionship' and 'sharing' that introduces a positive cultural flavour to the difference of deafness."

Another crucial factor in the development of John's Deaf identity was the family environment in which he grew up in, and more specifically, the communication difficulties he observed between his hearing mother and oral deaf father. As stressed by him, those difficulties made him choose a Deaf wife so as to communicate easily with her in CSL.

Another fundamental factor in the development of his Deaf identity, were his very negative educational experiences. When attending primary school, John spent most of his day alone without having learnt anything, due to the lack of support services and lack of deaf awareness among his teachers. At that time, he did not have any real friends, because of the communication difficulties he encountered with his hearing peers. Those who approached him were motivated by feelings of pity rather than real love. In his adult life, he chose to socialize mostly with Deaf people rather than with hearing people, since he could communicate easily with them in CSL. John is well accepted by the Deaf, is a member of the Deaf community, and has been elected on its different boards. In John's case, it is important to stress the way in which he introduced his oral deaf father to the Deaf community and gave him the opportunity to meet other Deaf people for the first time, as well as the chance to socialize with them in CSL.

In this study, other important issues have been raised as well. For instance, current functions of Deaf clubs have been described, as has been similarly done by previous studies (Hadjikakou and Nikoloraizi, 2011; Hall, 1994; Romeo and Renery, 1994; Padden, 1996). Specifically, Deaf clubs offer a place to meet, to discuss matters of mutual interest, and to provide recreation while using a relaxed mode of communication, i.e. sign language. Deaf clubs organize different social and sports events and offer the Deaf the opportunity to participate in them. Deaf clubs have also been described as information centres where Deaf participants can get informed about various issues, given that access to information is not easy for them. Finally, the role of Deaf clubs in Deaf people's lives, their unity, and future progress were stressed as well.

This study revealed communication difficulties that were present between deaf and hearing people, even for those deaf people who have obtained good oral and lip reading skills, as has been similarly reported elsewhere (Hadjikakou and Nikolaraizi, 2007). Sometimes, deaf people feel isolated and cut off from the hearing world because they are not in a position to follow their discussions (Hadjikakou and Nikolaraizi, 2008). In this study, John often referred to such feelings when describing communication difficulties he encountered with hearing peers at school, hearing adults at work or during everyday activities, as well as when recalling the communication barriers between his deaf father and his hearing mother and hearing relatives.

The above is also related to the fact that the Deaf community tends to be an inter-married one (Kyle and Allsop, 1982; Schein and Delk, 1974) – deaf people tend to get married with each other, mainly due to the ease of communication between them (Hadjikakou and Nikolaraizi, 2007). In this way, personal frustrations and intra-familial conflicts are prevented.

This study highlights different routes to identity construction and has implications for the provision of effective support services and deaf awareness courses within general schools where hearing teachers instruct deaf children. It also emphasizes the need for exposing oral deaf children (regardless of their family background) to Deaf adult role models, which may gradually lead to the construction of "healthy" deaf identities.

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Deaf identity construction: a case study

Abstract

The aim of the current study was to provide inside information on the different ways of constructing identities within the deaf population. To obtain relevant information, a case study was carried out with a Deaf Cypriot adult whose family and educational background did not match those of the general deaf population. The findings indicated that his family experiences, initial contacts with the Deaf and with Cypriot Sign Language (CSL), as well as academic and social experiences shared at school between the participant and his classmates and teachers played a crucial role in his identity development. The findings of this study entail implications for the provision of effective support services and deaf awareness courses within general schools, as well as for oral deaf children's contacts with Deaf adults in order to develop "healthy" identities.

Budowanie tożsamości u głuchych: analiza przypadku

Streszczenie

Celem prezentowanego badania była analiza introspektywnych danych dotyczących różnych sposobów budowania tożsamości w populacji osób głuchych. W celu uzyskania istotnych informacji, przeprowadzono analizę przypadku z udziałem dorosłej cypryjskiej osoby Głuchej, której środowisko rodzinne i społeczne nie pasowało do ogółu populacji głuchych. Wyniki pokazały, że doświadczenia rodzinne Johna, jego początkowe kontakty z cypryjskim językiem migowym (CSL), jak również doświadczenia akademickie i społeczne związane z udziałem kolegów z klasy oraz nauczycieli odegrały znaczącą rolę w rozwoju jego tożsamości. Wyniki badania pociągają za sobą sugestie dotyczące zapewnienia skutecznych metod wsparcia oraz kursów świadomości dla głuchych w szkołach masowych, jak również kontaktów oralnych głuchych dzieci z dorosłymi osobami Głuchymi w celu rozwoju „zdrowej" tożsamości.

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FOLIA 98

Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

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Chinese families' adaptation to childhood deafness: implications for psychoeducational support for families with deaf children in China

Introduction

It was the family, not the child that was in turmoil when a child was diagnosed with a disability (Gregory and Knight, 1998). For most parents, our children are everything to us: our hopes, our ambitions, our future (Department for Education and Skills, UK, 2003). For the overwhelming majority of families, the birth of a child with any disability can create severe stress, which parents find difficult to manage. Numerous studies have documented the impact of a childhood disability on family life. For example, Singer and Farkas (1989) used the Impact-on-Family Scales to examine the maternal perceptions of the impact of infant disability on various components of family life. The results showed that a high degree of maternal stress was related to caring for their young children with developmental disabilities. Thirty-two respondents reported that the child's disability affected all aspects of family life. Problems with family social interactions and with finances were cited by the majority of mothers in this sample. Other researchers proposed that the responses of parents to the diagnosis of a serious disability in their child had many parallels with reactions to bereavement. The main difference was that the child's disability was a permanent source of sorrow, whereas death marked a crisis point beyond which readjustment could begin (Hall and Hill, 1996). According to Barnett et al. (2003), some common parental reactions to a child's disability were as follows: (1) feeling devastated, overwhelmed, and traumatized by the news; (2) shock, denial, numbness, and disbelief; (3) a sense of loss for the "hoped for child"; (4) feelings of guilt, responsibility, and shame; (5) marital and other family relationships becoming severely strained, etc.

Childhood deafness, especially deafness beginning at birth and in early childhood, can constitute a disability with serious ramifications for the rest of the family, especially when the parents are hearing because of the significant developmental gap between hearing impaired children and hearing children. A number of studies have investigated the negative impacts of childhood deafness on family life. For example, Meadow-Orlans (1995) investigated the stress of hearing mothers and fathers of 20 deaf or hard of hearing (D/HH) and 20 hearing nine-month-old babies using the Parenting Stress Inventory and a questionnaire tapping the Stress of Life Events and found that mothers whose infants were D/HH reported greater life stress compared to mothers of hearing babies. Calderon et al. (1999) proposed that the stress and challenges of raising a deaf child were most often associated with the diagnosis of hearing loss, learning new communication methods, being more involved in educational decision making, increasing contact with professionals in a number of disciplines, and purchasing and using technological supports, as well as the everyday experience of having a child who is different and communicates in a different manner. Jackson et al. (2008) used a qualitative method to collect a detailed description of parents' experiences from nine parents of eight children who were deaf. The results showed that hearing mothers all expressed feelings of intense emotion such as shock, fear and uncertainty of the future, etc. when the child was diagnosed with deafness. Most of the hearing parents in the study emphasized their relationship with their children as influenced often by the child's deafness and communication difficulties.

However, childhood deafness is not a barrier that is insurmountable for every family. While many researchers draw attention to the impact of childhood deafness on families, other researchers shed light on how families adapt to this crisis. Calderon et al. (1999) recruited 36 families with deaf children to examine the factors affecting mother and child adjustment. Results indicated the following: (a) social support emerged as an important predicator of maternal adjustment as well as a buffer between current life stress and maternal adjustment, and (b) maternal problem--solving skills, such as finding someone to talk to, finding appropriate resources for the child and arranging the child's educational programme emerged as a significant predicator of a child's adjustment. Hintermair (2000) reported stressful experiences of parents with hearing-impaired children in Germany. The results suggested that parents who frequently met with other parents showed evidence of a warm, accepting, trusting relationship with their child. Also, the findings of this study demonstrated that parents who had many contacts with hearing-impaired adults showed evidence of a strong sense of competence in regard to their child's upbringing. Štěrbová (2007) studied the coping behaviour of families with hearing impaired children in the Czech Republic. As a result of this study, she was able to list a large amount of coping behaviours which were indicated by mothers as very beneficial and useful, such as having active contact with children, endeavouring to maintain family stability, guiding children with a health disability to greater independence, maintaining calm and balance, speaking with doctors and specialists about matters relating to the child's health disability, and building a closer relationship with one's partner (2007, p. 129).

Nonetheless, disability, especially deafness, is a term that is culturally, historically, and philosophically relative in its interpretation. According to the World Health Organization (2001), a person's functioning and disability is conceived as a dynamic interaction between health conditions (e.g., disease, disorders, injuries, traumas, etc.) and contextual factors. Contextual factors represent the complete background of an individual's life and living conditions. Among them the environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. These factors are external to individuals and can have a positive and negative influence on the individual's performance as a member of society, on the individual's capacity to execute actions or tasks, or on the individual's body function or structure (WHO, 2001, p.16). As for childhood deafness, there are three models of deafness: the medical model, the social model and the linguistic model, and each looks at deafness differently. As a result, the impact of childhood deafness on a family and the family's adaptation is complex and contextual and depends on factors such as social attitudes toward deafness and social support for deaf children and their families.

Further, despite the numerous studies that had been conducted to investigate the impact of childhood deafness on family adaptation, those studies primarily used white, middle-class families in western countries as samples. Less attention has been given to families with diversified cultures and social contexts, such as China. China is a large developing country with a social and cultural background that is unique from other countries across the world. It is a country with a population of more than 1.3 billion, nearly one-fifth of the world's population and, consequently, a country of rigorous competition for education and employment. Additionally, China has a large population of disabled people – 82,960,000, and among them 3,890,000 are disabled children under the age of 14 years according to the statistics of the Second National Disabled Persons Sample Survey conducted in China in 2006 (National Bureau of Statistics of China, 2007). These children are the most vulnerable when competition for education and work is concerned. At the same time, China is deep rooted in Confucianism, which stresses the importance of offspring and the importance of a child's education. As a result, Chinese families show strong passion and motivation for providing a better education for their children (Lee et al., 2009). However, it is well-documented in the field of deaf education that the majority of deaf children achieve lower educational attainment than their same-age hearing peers (Marschark, 1993). Without a doubt, having a deaf child will violate every Chinese parents' deep-rooted expectations associated with having a completely healthy and promising child and will have far-reaching effects on the Chinese family's life. In these circumstances, it is important to evaluate how Chinese families adapt to the stress of having a deaf child in the family. This question is critical to researchers in the fields of disability and intervention research across the world.

Theoretically, the family as a functional unit adapts to stressful conditions through the process of restoring balance between their capabilities and demands while still facing their challenges (Patterson, 2002). During the past decades, several conceptual frameworks had been developed to explain the process of family stress adaptation, namely Hill's ABC-X model (1958), Patterson's FAAR model (1983), McCubbin and McCubbin's Resilience Model of family stress, adjustment, and adaptation (1989) (Weber, 2010). This study adopted the ABC-X model, one of the earliest theoretical explanations of how families vary in their responses to stress, as its theoretical framework due to the fact that it had been widely used as a useful tool for identifying the components that determine how successfully a family manages stressful events (Wilmoth and Smyer, 2009). The ABC-X framework involves the following: Factor A is the stressor event that has the potential to change the family system; Factor B is the family's resources that assist the family in solving the problem mainly stemming from the individual members, the collective family, and the community; Factor C is the meaning a family assigns to an event; Factor X is outcomes that occur on a continuum from maladaptation to bonadaptation[1] depending on the interaction of the event, the family's resources, and the meaning the family ascribes to the event (Wilmoth and Smyer, 2009). With ABC-X as the conceptual framework, this study sharpened its focuses on the following specific questions: 1) What are the impacts of childhood deafness on Chinese families? 2) How do Chinese families perceive childhood deafness? 3) What resources do Chinese families use to buffer the impact of childhood deafness? And 4) what are the general outcomes of how Chinese families adapt to childhood deafness?

Method

Questionnaire

To investigate the questions mentioned above, a questionnaire consisting of four parts was developed. The first part concerned information about the informant's background, including the relationship between the informant and the participant child, residence, educational level, and the duration of taking care of the participant child. The second part collected background information about the participant child, including the child's age, gender, if the child's parents were married, if the parents were hearing, the family's social economic level, the number of children in the family , the degree of the child's hearing loss, the diagnosis time of hearing loss, the onset of hearing loss, the amount of time the child wore hearing aids, who paid for the hearing aids, the time the child had been using cochlear implants, the payer of the cochlear implants, the child's communication mode, the types of therapy the child received, the payer of the therapy, the child's educational placement, and the payer of the special education. The third part was the main body of the questionnaire, which consisted of 29 items. These items were designed to examine the impact of childhood deafness on family life, the family's perception of childhood deafness, family collective resources, and community resources to buffer the impact of both childhood deafness and the level of family adaptation, the parent's subjective appraisal of parenting a deaf child, and other themes relevant to family adaptation. These items were marked on a five-point Likert scale. Every sentence contained only one complete thought with five possible responses as follows: not true at all (1), rarely true (2), sometimes true (3), often true (4), and true nearly all of the time (5). The fourth part of the questionnaire involved three open-ended questions to examine any difficulties the family encountered in parenting, the main way in which the family communicated with the child, and the most effective help the family received in parenting.

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[1] Bonadaptation is defined as „meeting the needs of the individual family member to enable them to achieve their maximum potential and also the functioning of the family system and its transactions with the community (work place, school, health care system)" (McCubbin, M.A. (1993). Family Stress Theory and the Development of Nursing Knowledge About Family Adaptation. [In:] S. L. Feetham; S. B. Meister; J. M. Bell & C. L. Gillis (Eds.) *The Nursing of Families*. New Bury Park: Sage, 46–58, p. 50).

Participants

One hundred and seven main caregivers of deaf children between the ages of 31 and 220 months, with severe or profound hearing loss from three special schools and the Chengdu Disabled Children's Early Rehabilitation Centre in Sichuan province, a western and relatively underdeveloped area in China, were invited to participate in the questionnaire survey. Considering the diverse family systems and the fact that the parents were not always the persons who knew the child best and were not always the main caregiver of the deaf child, the main caregivers for this study were defined as those caregivers who had been with a child more than one year and consequently knew the child best. In some cases, this was a parent, and in others it was not. This caregiver was invited to represent the family of the deaf child and present their responses on behalf of the whole family. Among the participants, the overwhelming majority of caregivers were parents and both had normal hearing. Other participants were grandparents or other relatives. More families lived in rural areas rather than urban areas; more families were from a lower income group than a middle income group, while no family was with a higher economic status; and the majority were married. Generally, these families can be viewed as representative of typical Chinese families with deaf children. Detailed data regarding the participants are listed in Table 1.

Given that child-related factors and relevant intervention services were often regarded as significant important factors which affected family adaptation to childhood deafness (Calderon et al., 1999), this study also collected information concerning the children's demographics, hearing-loss-related characteristics, and the nature

Variable	N (n=107)	%
Main caregiver		
Father	20	18.69%
Mother	62	57.94%
Grandparent or others	25	23.36%
Parental hearing		
Both hearing	100	93.46%
Both deaf	2	1.87%
Mixed	5	4.67%
Family residence		
Urban	35	32.71%
Rural	72	67.29%
Family income status		
Lower	61	57.01%
Middle	46	42.99%
Parental education		

Illiterate	2	1.87%
Primary education	16	14.95%
Secondary education	77	71.96%
Higher education	13	12.16%
Parental marriage		
Married	97	90.65%
Separated	6	5.61%
Divorced	4	3.74%

Tab. 1. Key characteristics of participant families

of intervention services the children received. One point that needs to be mentioned is that despite the national one-child policy that has been implemented in China since the 1980s, 41.12% of the participant children were not the only-child in the family. This phenomenon can probably be attributed to supplementary regulations of the one-child policy in China, which state that if the first child in the family has a certificated but not genetic disability, the family is entitled to give birth to a second child. As a whole, it was found that most of the Chinese deaf children didn't have access to adequate intervention services. Specifically, their hearing loss was diagnosed later than 24.5 months, a considerable number of the children did not use

Variable	Percentage
Gender	
Boy	61.68%
Girl	38.32%
Only-child	
Yes	58.88%
No	41.12%
Average age (months)	101.6
Age range (months)	31–220
Average age at diagnosis (months)	24.5
Rate of using Hearing aids	71.96%
Average age for using Hearing aids (months)	43.8
Rate of using Cochlear implants	14.95%
Average age for using Cochlear implants (months)	33.19
Receiving Sign language training	
Yes	74.77%

No	25.23%
Communication mode	
Natural gesture	12.15%
Sign language	31.78%
Spoken language	11.21%
Mixed approach	44.86%

Tab. 2. Key demographic and clinical characteristics of participant children

hearing aids or cochlear implants and if they did, they did not receive them early, and most did not receive sign language training. More detailed information about the participant children's characteristics are shown in Table 2.

Results and Discussion

A. The impact of childhood deafness on Chinese family life

As a stressor, childhood deafness considerably impacts Chinese family life**.** In this study the impact of childhood deafness was estimated from the items regarding the caregiver's communication with the deaf child, their feeling of fatigue, changes in the family economic situation, and the level of mutual communication between family members due to the child's deafness. On average, the participant families scored above 3 points – the boundary point between disagreement and agreement with the statements in Items 10, 11, 12 on the 5-point scale. It means that childhood deafness considerably impacts communication with the child, as well as feelings of fatigue and the family's economic condition.

Item	Mean score
Item 10: When parenting my child, I often feel difficulty in communicating with my child	3.48
Item 11: Parenting my child makes me have a feeling of great fatigue	3.50
Item 12: Because of the child's hearing loss, the economic status of our family has deteriorated	3.51
Item 22: The mutual communication of the family members has been affected by the child's hearing loss	2.29

Tab. 3. The impact of childhood deafness on family life

However, mutual communication between family members seemed not to be affected in the same way by childhood deafness, with a mean score of 2.29. The questions from the questionnaire and the mean scores are listed in Table 3.

Childhood deafness resulted in a series of family parenting difficulties. The data collected from the responses to one of the open-ended questions, "Please write about the biggest difficulty that you have experienced while parenting your deaf child," validated the influence of childhood deafness on Chinese family life. One hundred and four Chinese families responded to this question. Some families provided more than one response while others did not responded to this question. When there were multiple responses, only the first response was used to analyze the results. The caregivers' responses provided an array of difficulties, including increased financial demands, increased time demands, worry about the future, fear of their child being teased by others, a feeling of fatigue, difficulty in communicating with the child, not understanding the child and difficulty in being understood by the child, and difficulty in dealing with the child's behavioural problems. Sorting and categorizing all the responses, the study found that the five top difficulties Chinese families experience (demonstrated in Table 4) are: economic burdens, communication difficulties, educational problems, worrying about the child's future, and the impact of the child's deafness on normal work. The number of families that responded this way is presented in brackets, and specific descriptions of the difficulties from the most representative families are presented as an example.

The five top responses from Chinese families concerning parenting difficulties
• Financial burden (37) *e.g.: "We can not afford his cochlear implant and one parent has to stop working in order to accompany his study."* (A16)
• Difficulty in Communication (30) *e.g.: "The biggest problem is we can not understand her when she communicates with us by sign and she can not understand what we say when we speak to her in spoken language." (B23)*
• Educational puzzle (18) *e.g.: "Sometimes we do not know how to educate him as we lack professional knowledge about the hearing impairment." (D16)*
• Worrying about the child' future (5) *e.g.: "He can not speak and understand well, what would happen if both his parent and grandparent die?" (A14)*
• Normal work being delayed (4) *e.g.: "I feel tired and can not work normally because every day I need to send him for speech therapy and take him back after work." (C6)*

Tab. 4. The five top responses from Chinese families concerning parenting difficulties

B. Chinese families' perception of childhood deafness

A large quantity of Chinese families experienced the social stigma associated with childhood deafness. This study collected families' perception of childhood deafness with two items. According to the responses to Item 2 (My family has always been teased by other people because of my child's disability) and Item 3 (My child's deafness means the child will not have a bright future), listed in Table 5, it was found that 69.8% and 67% of Chinese families with deaf children scored 3 points and above on these two items respectively. This meant that most of them tend to agree that a deaf child does not have a bright future and the families feel teased by others due to the child's disability. To some degree, these families' perceptions of childhood deafness are reflections of the Chinese social attitude toward deaf people. Compared with the understanding of the deaf culture in other parts of world and the growing success of deaf individuals in every walk of life, this is not common in China. This reality is worthy of attention since a considerable number of deaf children and their families still live with severe social stigma associated with childhood deafness.

Statement	Degree of agreement (n=106)				
	1	2	3	4	5
Item 2: My family has always been teased by other people because of my child's disability.	10.4%	20.8%	40.6%	19.8%	8.5%
Item 3: My child's deafness means the child will not have a bright future.	17.0%	16.0%	39.6%	9.4%	17.9%

Tab. 5. Chinese family's perception of childhood deafness

C. Family Resources

Family collective resources

Chinese families with deaf children were assisted by strong resources stemming from the family itself. Regarding the family as a functional unit, this study examined the families' resources from items dealing with family cohesion, family open communication, and family belief changes with stressful demands via Items 6, 13, 4, 7, 8, and 9. Only Item 4 was scored adversely. The statistics listed in Table 6 indicate that Chinese families benefit most from their strong cohesion, and childhood deafness makes Chinese families more optimistic about the future, more tolerant toward differences and more altruistic to others rather than forcing them to believe in 'destiny'. Also, open communication, such as sharing emotions and opinions, is probably useful in helping Chinese families coordinate resources and efforts to cope with the negative impacts imposed on them by childhood deafness. These results are consistent with other research on Chinese culture. For example, Ju and Chu (1996) have argued that for thousands of years, close family relations had been a major cornerstone of traditional Chinese culture. According to Xu et al. (2007), an outstanding expert in the Chinese family, one of the salient features of the Chinese family is cohesive family support while facing challenges and stressful events.

Variable	Item	Mean score
Cohesion	*Item 6: My family is characterized by close relationships and mutual support.*	4.16
Communication	*Item 13: To educate the deaf child we often share emotions and opinions in my family*	3.62
Fatalism	*Item 4: Facing the child's deafness, my family tends to be fatalistic.*	2.82
Altruism	*Item 7: While parenting my child, the degree of my altruism has increased.*	3.98
Tolerance	*Item 8: While parenting my child, the degree of my tolerance toward differences has increased.*	3.94

Optimism	*Item 9: While parenting my child, my degree of life optimism has increased.*	3.71

Tab. 6. Chinese families' collective resources

Community resources

Chinese families received only limited resources from individuals, organizations, and government agencies. Community resources from outside the family unit were found to be one of the important significant factors which predicted the outcomes of positive family adaptations (Margalit and Kleitman, 2006). This study examined the help families received from the extended family, professionals, other parents, and the social welfare agency. In general, Chinese families got extremely limited support from professionals, parental groups, and community or social welfare agencies. The main source of support for them came from the extended family and relatives. The descriptive statistics of community resources for the Chinese families are listed in Table 7.

Item	Mean score
Item 13: The support from my extended family and other relatives often help me greatly.	3.34
Item 17: My family can often get necessary information from professionals.	2.69
Item 18: My child can choose to attend specialized preschool or regular preschool, age-appropriately and freely.	1.30
Item 19: My family has access to a self-help group of parents.	1.91
Item 23: The financial support from welfare is high enough to meet the special needs of the child.	2.52

Tab. 7. Chinese families' community resources

D. Outcome of families' adaptation in general

Generally, Chinese families positively adapted to childhood deafness, accompanied by strong stress-filled feelings. The process of adaptation was an ongoing process, so it was difficult to judge whether the outcome of adaptation was good or bad at any particular point in time. This study inferred the outcome of Chinese families' adaptation from the combination of the level of family adaptation and the family's appraisal of their emotional experience toward parenting a deaf child. As a result of this dynamic process, the level of family adaptation was examined by four criteria: 1) accepting the past, 2) functioning in the present, 3) expectations for the future, and 4) general emotional experiences with raising the deaf child. Specifically, the level of adaptation was assessed by Items 25, 14, 24, 28, 27, and 29 on the questionnaire and was listed in Table 8. Among the items, only Item 14 was scored reversely. Based on the fact that scores were higher than 3 points on all items, one result was apparent – Chinese families have a good level of adaptation with an increase of acceptance over time, function normally, and have good expectations for the future. However, this satisfactory adaptation was also accompanied by long-term stressful experiences as Chinese families, in general, agreed with the statement that parenting a deaf child is linked to chronic sorrow and grief. The detailed statistics are presented in Table 8. Theoretically, the result of positive adaptation accompanied by stressful experiences is not a new thing. Masten et al (1994, in Luthar 2000) distinguished three groups of good adaptation: (1) at-risk individuals or families that show better-than-expected outcomes, (2) positive adaptation maintained despite the occurrence of stressful experiences, and (3) good recovery from trauma. As with other handicaps, childhood deafness is irreversible and has no recovery, consequently, for most of the families, a stressful experience is inevitable and bound to appear recurrently despite the fact that most of the families have come to terms with their child's disability.

Item	Mean score
Acceptance	
Item 25: Compared with the early days after the diagnosis of the hearing impairment, there is more acceptance and peace in my family at present.	4.52
Present functioning	
Item 14: Because of my child's deafness, my marital relationship has deteriorated	3.20
Item 24: Best efforts have been made to promote the child's communication and learning in my family.	4.62
Item 28: My relationship with my family has become closer in the course of parenting the deaf child.	4.16
Expectations	
Item 27: My child will have a bright future and be a beneficial member to society in the future.	4.03
Item 29: My family has the ability to deal with the child's difficulties and problems in the future.	3.70
Present emotional experience	
Item 1: Parenting a deaf child has been linked with chronic sorrow and grief.	3.59

Tab. 8. Overall outcomes of Chinese families' adaptation to childhood deafness

Conclusion

The purpose of this study was to examine how Chinese families adapt to childhood deafness in such significantly different cultural and economic conditions. This study adopted Hill's ABC-X model as the theoretical framework and developed a questionnaire to examine the influence of childhood deafness as a stressor on family life, family perception of childhood deafness, family resources from inside and outside the family unit, and the overall outcome of family adaptation. The findings of this study suggest that Chinese families adapted positively to childhood deafness according to the increase of acceptance over time, good functioning and good expectations for the future, despite strong stressful experiences and feelings that accompanied the process of adaptation. Further, the level of positive adaptation can probably be contributed to the Chinese family's resources from inside the family, such as family cohesion, open family communication and changes in family beliefs, namely altruism, optimism and tolerance toward the child's disability. Also, Chinese families benefited from the limited community support that came from extended family members and relatives. The strong stressful experiences related to family parenting may be caused by the changing social stigma associated with childhood deafness, such as the notion that childhood deafness means a child can not have a bright future and the lack of adequate educational supports, such as professional services and parent advocacy groups. However, these conclusions need to be further replicated by more descriptive studies with samples from other parts of China.

Implications for psychoeducational support

Because of the close relationship between family well-being and a child's healthy development, professionals are recognizing that improving the family's emotional life can serve as a pivotal focus when providing intervention services to empower families with deaf children. While the Chinese government is attempting to provide more financial support for handicapped children and their families, it has encountered many financial limitations. It is imperative that more attention be placed on psychoeducational support for these families to reduce their feelings of grief. Based on previous studies and in response to the identified difficulties that families experienced in this study, psychoeducational support should mainly include emotional, cognitive, and educational aspects, as proposed by the following:

Normalizing family grief. Little in life prepares someone for raising a child with a disability like deafness. Grief is a normal reaction to having a deaf child in China, a country where the Deaf Culture is not popular. The grief that families feel often comes from the loss of the hoped for child and not being able to control or change the situation. Not only should families be prepared for the strong emotional reactions after the diagnosis is accepted, but they should also be informed that some feelings of grief may always reappear and persist. They should be prepared for feelings of grief that emerge as a result of environmental triggers, such as contact with others with children of the same age who are developing normally.

Positively making sense of childhood deafness. As a result of some common Chinese myths and social stigma associated with deafness, such as, "deaf people have lower IQs than people with normal hearing", "deaf people are all underachievers", it is reasonable that many Chinese families worry about their children's future and experience strong sorrowful feelings when raising a deaf child. However, childhood deafness does not necessarily lead to delays in the child's development or lags in cognitive, language, and social areas. The many successful, intelligent, and socially well-adjusted examples of individuals in China and all over the world indicate that having a deaf child is not primarily a story of gloom and doom. Families with deaf children should be informed of these successful stories and should be given the opportunity to interact with other deaf adults. This approach has been successful, as evidenced by the findings of previous studies (e.g. Hintermair, 2000). These findings demonstrate that parents who had many contacts with hearing-impaired adults showed a strong sense of competence in regard to their child's upbringing. This approach may be the best way to help families build new hopes and dreams for their children and themselves.

Developing or taking part in a self-help parent group to share experiences and knowledge. Self-help or advocacy groups are formed by members who share a similar condition and understand each other. As a social support system, these groups help participants cope with risky conditions through supportive relationships among members. For instance, in groups, members can help validate the feelings and emotions of other members, establishing the universality of grief. Group members also pool and share information with one another. Meanwhile, group members can make comparisons, recognize, and benefit from other member's knowledge and coping strategies. However, in this study a number of Chinese families reported that they have no access to self-help groups. Consequently, at present when the Chinese government is taking steps to develop intervention service systems and improve the quality of services for children with special needs and their families, developing and organizing self-help family groups should be one of the cost-effective intervention services considered for families in these strained financial times.

Providing comprehensive information to address families' educational problems. In this study, a large number of Chinese families with deaf children reported that they did not get necessary information from professionals, and many wrote about difficulties in communicating with their children and their general dilemma regarding educating their children. To help families gain control over childhood deafness, intervention programs must have a systematic body of information, including knowledge from multiple disciplines, to provide these families or other families with similar experiences to help them make informed decisions. Specifically, this should include information on: (1) hearing and hearing loss; (2) sensory devices and relevant auxiliary equipments; (3) how children grow and develop; (4) the unique characteristics of the development of deaf children; (5) skills to communicate with deaf children and strategies to deal with children's behavioural problems; and (6) what services and educational options are available locally for specific children. With informational support, families will be helped to recognize that childhood deafness is only a risk that challenges the family rather than a barrier which is insurmountable.

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Chinese families' adaptation to childhood deafness: implications for psychoeducational support for families with deaf children in China

Abstract

Childhood deafness not only impacts children's development, but also affects all aspects of family life. This study used a sample of 107 families with deaf children from China to examine how Chinese families adapted to the stress of having a deaf child in the family. A questionnaire was developed to assess the impact of childhood deafness on family life, the family's perception of childhood deafness, the family's resources, and the overall outcome of adaptation. The results showed that childhood deafness, as a stressor, impacted Chinese family life considerably, leading to a series of parenting difficulties, such as additional financial burdens, difficulty in communicating with the child, and so on. However, in general, the surveyed Chinese families adapted to childhood deafness positively despite experiencing strong and long-term grief. The positive adaptation could probably be contributed to Chinese families' collective resources, such as family cohesion and open communication. Finally, implications for psychoeducational support for families with deaf children in China are discussed.

Adaptacja chińskich rodzin do głuchoty dziecka: implikacje dla psychoedukacyjnego wsparcia dla rodzin dzieci głuchych w Chinach

Streszczenie

Głuchota dziecka wpływa nie tylko na jego rozwój, ale także na życie rodziny. Badania, w których uczestniczyło 107 rodzin głuchych dzieci z Chin, miały na celu zbadanie sposobu radzenia sobie ze stresem uwarunkowanym posiadaniem głuchego dziecka. Opracowano kwestionariusz oceniający wpływ głuchoty dziecka na życie rodziny, rodzinną percepcję głuchoty dziecka, rodzinne zasoby i rezultaty procesu adaptacji. Wyniki ujawniają, że głuchota dziecka jako stresor wpływa na życie chińskich rodzin i jest przyczyną poważnych trudności związanych z dodatkowym obciążeniem finansowym, a także w zakresie komunikacji z dzieckiem. Rodziny chińskie dobrze się jednak adaptują do głuchoty dziecka dzięki zasobom społecznym, takim jak spójność rodziny i otwarta komunikacja. Omawiane są także implikacje dla psychoedukacyjnego wsparcia dla rodzin z dzieckiem głuchym.

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FOLIA 98

Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

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Equal opportunities in mathematics: what does research on how young deaf children learn teach us?

Introduction

Nowadays, we face the challenge of preparing deaf children and youngsters to be as competent as their hearing peers in their adult life. To do this, deaf students should acquire new knowledge, learn new abilities, and solve new problems. It has been frequently pointed out that the society and economy of the XXI century will depend on workers competent in mathematics. In this context, educational aims should focus on helping deaf students become exceptional problem solvers, to reason, to make logical connections, to value this assignment and to earn confidence in their abilities to learn mathematics (National Council of Teachers of Mathematics, 1989, cited in Daniele, 1993). If deaf people are going to successfully participate in society, they should be provided with school experiences which adequately prepare them for such full participation. In more and more technologically advanced societies, which require increasing abilities on the part of its members, deaf people should be able to benefit from opportunities to develop problem solving strategies and abilities that are generalizable to employment and an independent life.

In this article a revision of research on mathematics in young deaf children will be made and will show what can be learned about some key considerations regarding teaching mathematics to deaf children, with the aim of achieving equal opportunities for deaf and hearing individuals.

The delay of deaf children in the area of mathematics

A substantial amount of research reported that deaf children are delayed by two or three years in learning mathematics with regard to their hearing peers (National Council of Teachers of the Deaf, 1957; Wollman, 1965, cited in Nunes and Moreno, 2002; Wood et al., 1983; Wood et al., 1984; Allen, 1995, cited in Pagliaro, 1998a; Traxler, 2000, cited in Pagliaro and Ansell, 2002).

Since the end of the fifties, researchers have reported failure in teaching mathematics to deaf children in the USA and Great Britain. In Spain, the situation may be worse due to its general context. A few years ago, a committee of national and foreign experts presented a report to Congress alerting about the low achievement of youngsters in sciences, especially mathematics, physics and chemistry. It pointed out that, “It is necessary that the teaching of these science subjects is reinforced, that the initial and permanent training of [school] teachers of these subjects is redesigned, that teaching time is augmented and that there is an overall increase in practical exercises in school laboratories, and that science is explored” (Jounal El País, 07/21/03). In the case of deaf people, Fernández-Viader points out that there are very few that have had success in their secondary studies and very few that have had access to the university level (MEC, 1996; Fernández-Viader, 1997c, 1999a, cited in Fernández-Viader, 2002). We can consider that in a basic school subject like mathematics, failure is not unusual for the deaf population.

Wood et al. (1983) studied if hearing loss as such was the cause of the delay but discarded this idea due to the fact that not every deaf child demonstrated more problems in solving standardized exams with regard to their peers. If deafness itself would be the cause of difficulties in mathematics, deaf children that have adequate achievement in mathematics considering their age level would not exist. However, approximately 15% of profoundly deaf pupils overachieve with regard to children in general.

In another study, Wood et al (1984) formulated the hypothesis that educational setting was the cause of difficulties in mathematics, due to the fact that special schools may prioritize teaching oral and written language over teaching this particular subject. They thought that mainstream schools with special units for deaf pupils received better attention regarding the teaching of mathematics. Nevertheless, from the obtained results, educational setting had to be discarded as a factor causing the detected difficulties. It was observed that deaf and hearing students did not differentiate in the type of errors committed and in the particular items they made mistakes on. Also, deaf children did not appear to be more impulsive than hearing children when solving the tasks.

Other researches have highlighted some factors that could contribute to deaf children’s poor performance in mathematics. The most remarkable disadvantage is due to the fact that deaf children have fewer opportunities for incidental learning (Furth, 1966; Marschark, 1993). They have difficulties learning from certain incidental situations, from which hearing children obtain knowledge.

On the other hand, there are factors that are directly related to the formal education of deaf children, as the curriculum is frequently centred round calculations and basic abilities (Pagliaro, 1998b). Some studies report a deficit in the preparation of deaf teachers for teaching mathematical contents in a beneficial way to deaf students (Pagliaro & Ansell, 2002). According to this research, teachers often rely on repetitive paper and pencil exercises or computer sequences of exercises. In a study carried out in the USA with kindergarten to primary school teachers investigating the use of story problems in teaching mathematics to deaf children, it was found that teachers used story problems relatively infrequently. Less than 20% of the teachers indicated that they used them daily. Those who used them less frequent were teachers of the lower grades, as if they were waiting to use story problems once children have acquired the ability to use operations and number facts to solve them. Findings regarding frequency and mode of presentation of story problems showed that teachers followed an instructional pattern in which story problems were used as opportunities for the students to practise knowledge that was *already* acquired (Hiebert et al., 1996, cited in Pagliaro and Ansell, 2002).

Other factors related to oral language competence that make understanding of given mathematical tasks problematic, such as story problems, may be related to the difficulties deaf children have with reading comprehension (Serrano, 1995) or the use of words that have different meanings inside and outside of the classroom, as well as the possibility of expressing the same idea in different ways. This can cause difficulties for the deaf students for whom oral language is not their first language (Kidd et al., 1993).

Considering deafness as a risk factor in learning mathematics

Nunes and Moreno (1998a) suggest that hearing loss should not be considered a cause of the difficulties that deaf children have in learning mathematics but a risk factor for difficulties in learning mathematics. First of all, as we have previously outlined, not all deaf students are delayed in regards to their hearing peers (Wood et al., 1983). Secondly, most of the conducted research has not found – or has found a weak – correlation (Nunes and Moreno, 1998a; Wood et al., 1983) between hearing loss level and achievement in mathematics. The statement, *"the more hearing loss the worse the achievement level"*, does not apply. Next, the development of counting (Secada, 1984), calculation abilities (Hitch et al., 1983), and problem solving abilities (Nunes and Moreno, 1997, cited in Nunes and Moreno, 2002) seem to follow the same pattern as that of hearing children but at a slower pace. On the other hand, an explanation of a delay in terms of reading comprehension cannot justify poor performance on tasks that do not involve reading, as for example, conservation tasks.

To sum up, there is no a clear explanation of the cause of the delay in deaf children and youngsters in the area of mathematics. This is due to the fact that hearing loss has always been thought of as the cause of the delay. A cause is intrinsic to the learning process and would affect it – deaf and hearing children would qualitatively differ in the development of mathematical concepts. Conversely, a risk factor is external to the learning process and so, the number development process would be very similar in deaf and hearing children. The foundation for learning mathematical concepts is not language but the schemas of action, and because of this fact, the learning processes of deaf children would not differ qualitatively from those of hearing children.

Also, considering deafness as a risk factor means that the difficulties deaf children have in learning mathematics may be overcome by adapting teaching strategies to the learning capabilities of deaf children. As we will present in the following section, educators may help prevent the delay by adapting their teaching to a preferred way of processing information by deaf children and adjusting it to both overcome disadvantages as well as profit from the advantages that deaf children have in learning mathematics, as has been shown by recent studies (Zafarty et al., 2004).

The development of mathematical concepts in deaf and hearing children

Young hearing children (5 or 6 year olds) are able to think about situations that involve numbers and are able to solve a variety of simple problems. The majority of these children are able to use counting to solve easy problems of addition, subtraction, multiplication and division if they are able to represent these situations with concrete objects – they have schemas of actions, i.e. generalized ways to organize their actions to solve problems.

Two key difficulties of learning mathematics for young children are related to 1) learning the number system and 2) coordinating their schemas of action with concepts of mathematical operations.

With regard to the first subject, learning the decimal number system implies grasping the concept of place value. For example, for the number 12, it is necessary to understand that the 1 at the leftmost side means 10 units and that the 2 means 2 units. Children able to count to 12 may not be able to combine a coin of 10 cents with two 1 cent coins to make 12 cents. To do this they need to be aware that every value up till 10 is included in only one representation – the comprehension of counting based only on linear one to one correspondence is not enough. The ability to combine coins of different values is an indication that children understand *additive composition*, which means that they are aware that every number can be seen as the sum of other numbers (Nunes and Bryant, 1996). Comprehension of additive composition is a better specific predictor of understanding place value in our number system and the concepts of addition and subtraction (as assessed through problem solving). Acquiring the concept of additive composition is often facilitated in hearing children by knowledge derived from counting money. Deaf children are shown to be significantly behind hearing children in counting money (Nunes and Moreno, 1998). Counting money, an activity frequently learnt in informal experiences outside school, provides children with experiences that are more cognitively advanced than counting objects.

With regard to the second issue of coordinating children's schemas of action with concepts of mathematical operations, there are some aspects that should be taken into account:

Firstly, there is correspondence between a situation posed in a problem and the arithmetic operation that should be used to solve it. In some problems, there is clear correspondence between the situation and the arithmetic operation while in others there is not. For example, in the following problem, "Mary had some sweets; her mother gave her 5 and now she has 9. How many sweets did she have before?" the situation involves addition of sweets, but the operation that leads to solving the problem is subtraction.

This means that the child has to build various types of connections between schemas of action and arithmetic operations – direct connections are not enough. The process that leads to the development of these connections is social because the conditions of the arithmetic operations, defined during the course of history, are cultural and conventional. As communication is involved in learning these cultural concepts, deaf children are at a risk. Nevertheless, as stated earlier, the foundation of this type of learning is not language but schemas of action, and therefore, the processes of deaf children should not differ qualitatively from those of hearing children. Once they know the conventional aspects, the organization of their concepts should be very similar to that of hearing children, and predictors of their performance should be the same for both groups.

Deaf children show both disadvantages and advantages for learning certain important mathematical concepts. For example, learning the counting chain is difficult for deaf children (Nunes and Moreno, 1998a). Hearing parents of deaf children seem to put less emphasis on teaching the counting chain to them, and conversely, hearing parents of hearing children, as well as deaf parents of deaf children, normally dedicate more time to practise the counting chain. Nevertheless, once they have learnt it, they can use it as efficiently as hearing children (Secada, 1984). Moreover, as has been studied with signing deaf children, sign language allows deaf children to develop object counting abilities at least as good as those developed by hearing children on the basis of oral language (Leybaert and Van Cutsem, 2002).

Another detected difficulty that deaf children have is making inferences involving time sequences. The results of an intervention study (Nunes and Moreno, 2002) dealing with this subject show that teaching concepts at school that hearing children seem to acquire informally and using drawings and diagrams to support communication about time sequences, enhances deaf children's mathematical learning.

Deaf children also show some advantages with regard to hearing children, for example, better spatial processing in number representation tasks (Zafarty et al, 2004). The conclusions of a study carried out with 85 deaf children between the 2nd and 5th grade of primary school indicate that enabling deaf children to solve problems using drawings and visual mathematical tools meaningfully enhances their ability to solve problems using action schemas, compared to using materials that are normally used at school (Nunes and Moreno, 2002). Results are also consistent with the hypothesis that both deaf and hearing children develop number comprehension through schemas of action, which should be connected, later on, with formal representations at school. Both deaf and hearing children showed the same difficulties with different problem types. Problems with an unknown result were easier than problems with an unknown transformation, which in turn were easier than problems with an unknown beginning – which were the most difficult to solve for both deaf and hearing children. This shows that development with respect to solving addition and subtraction problems did not differ between deaf and hearing children. Studies on solving strategies in addition and subtraction show that deaf children use the same strategies as hearing children, with the exception of those strategies that include the use of sign language (Frostad, 1999).

Conclusions

Research of the last decades coincides on the fact that deaf children show a delay in learning mathematics with regard to their hearing peers, although it seems that both deaf and hearing children have the same mathematical development. Further analysis show that the cause of this delay is not clear. This supports the idea that a key aspect is the design of instructions that will help both deaf and hearing children create strong links between their own action schemas and the mathematical concepts they learn at school, and this applies to additive as well as multiplicative reasoning (Nunes et al., 2009).

The idea of conceptualizing deafness as a risk factor for difficulties in learning mathematics (Nunes and Moreno, 1998) opens the door for educators and psychologists to design instruction activities that will overcome these difficulties by taking into account preferred ways of communicating and processing information by deaf persons.

With regard to communication, we think an important aspect is teaching deaf children in a language that they have complete access to, i.e. sign language. It should be, however, considered that it should not be the only language at school but the vehicular language of instruction since communication problems cause deaf students to be delayed not only in mathematics but in every area of instruction.

With regard to information processing abilities, an overall conclusion is that mathematical tasks should be designed to match deaf children's information processing preferences – teaching strategies should be adapted to a visual way of processing information. Deaf young children are better than hearing children in processing information presented in a spatial modality (Zafarty et al., 2004). The use of visual mathematical tools implemented in exercises, such as the number line, graphs, and tables enhances deaf children's mathematical learning, both in addition and subtraction as well as in multiplication and division. Conversely, their difficulties in processing time sequences may be overcome with the use of drawings and diagrams to support sequential information present in story problems (Nunes and Moreno, 2002).

Another important conclusion is that problem solving should be used as a privileged way to *teach* mathematical concepts and not as a way to *apply* knowledge already acquired, both with deaf and hearing children. It is important that children have frequent opportunities to interact with various types of story problems, taking profit of their intuition and experience.

Of the presented experiences, we can extract other didactical recommendations, such as the importance of explicitly teaching certain important concepts that hearing children learn partly outside of school (what is called incidental learning) as, for example, the concept of additive composition. Other strategies include teaching concepts focused on various perspectives, using graphical representations of the given information, emphasizing teaching how to count, and of course, using story problems for teaching basic mathematical concepts.

With regard to the importance of teaching in an explicit way certain concepts that hearing children learn outside of school, it is recommended to teach deaf children certain notions about the decimal number system that constitute the base of number knowledge (Fuentes, 1999). Hearing children possess knowledge about the number system before explicitly being taught it. This knowledge is not enough to immediately use as a tool for communicating cardinality but constitutes the foundation of the formal properties of the decimal number system (Tolchinsky, 2003). Number notations are, in a distinct way, part of the children's surroundings before they begin formal schooling, and in an indirect way, through comments adults make about them. In the case of deaf children of hearing parents, communication about notations may be affected in a certain way, so concepts about notational media, which hearing children obtain in an incidental way, should be explicitly taught to deaf children.

According to the research we have synthesized, communication and didactical aspects seem to have a substantial amount of responsibility in the mathematical achievement of deaf children. With regard to teaching aspects, trained teachers of the deaf who are competent in their knowledge of mathematical contents, pedagogical strategies and *cognition*, i.e. how students acquire and process the contents, are the foundation. Another possibility is to have mathematics teachers that work with an interpreter in the classroom.

We want to add that conducting research about the development of teaching methods that are able to help deaf children enhance their achievement in this area, may also enhance the performance of children that suffer from a delay in mathematics, being either deaf or hearing.

Considering the problems of communicating school contents, we support the idea that schools should adapt to deaf persons, mainly through programs of bilingual education, "It seems obvious that, for deaf persons, access to education and culture is achieved when the educational response adapts to their needs. This response should recognise and respect their specific differences. For the deaf students, the difference is only the channel of access to information, and, as a consequence, to the school syllabus" (Fernández-Viader, 2002). Schools should adapt to the needs of deaf students and not the reverse, and this is a prerequisite for achieving equal opportunities for deaf students.

Acknowledgements
The author wants to thank the Ministry of Science and Innovation (MICINN)-SPAIN-Ramón y Cajal Programme for its support for this work.

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Equal opportunities in mathematics: what does research on how young deaf children learn teach us?

Abstract

In this article we review research on teaching and learning mathematics by young deaf children. Research proves that deaf children show a delay in learning mathematics but reveals that the number development process should be very similar in deaf and hearing children. Previous and recent studies agree that the difficulties young children have in learning mathematics are linked to difficulties obtaining information in an incidental way from their environment. Considering deafness not as a cause but as a risk factor of difficulties in learning mathematics (Nunes and Moreno, 1998) opens a way of overcoming difficulties via adapting teaching strategies to the learning capabilities of deaf children. Research recommends taking advantage of deaf children's preferred ways of processing information and of their better spatial processing skills. The reviewed studies reveal a hopeful future regarding the achievement of equal opportunities for deaf and hearing persons in this important area of knowledge.

Równe szanse w matematyce: czego dowiadujemy się z badań dotyczących uczenia się dzieci głuchych?

Streszczenie

W niniejszym artykule dokonujemy przeglądu badań dotyczących nauczania–uczenia się matematyki młodszych dzieci głuchych. Badania dowodzą, że u dzieci głuchych widoczne jest opóźnienie w nauce matematyki, lecz proces rozwoju liczenia powinien być bardzo podobny u dzieci niesłyszących i słyszących. Analizowane badania zgodnie wskazują, że trudności w nauce matematyki związane są z trudnościami uzyskiwania przez małe dzieci informacji w sposób przypadkowy ze środowiska. Uznanie głuchoty nie za przyczynę, ale za czynnik ryzyka trudności w nauce matematyki (Nunes i Moreno, 1998) otwiera drogę do pokonania przeszkód poprzez dostosowanie strategii nauczania do możliwości uczenia się dzieci głuchych. Zaleca się wykorzystanie preferowanego przez dzieci głuche sposobu przetwarzania informacji oraz lepiej rozwiniętych umiejętności przetwarzania przestrzennego. Omówione badania ukazują jasną przyszłość w odniesieniu do wyrównania szans dla osób głuchych i słyszących w tej ważnej dziedzinie wiedzy.

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FOLIA 98

Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

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Social-psychological aspects of the application of alternative and augmentative communication (AAC) in pupils with cerebral palsy

Introduction

Communication represents one of man's most important needs in life. It plays a significant role in the development of human personality and has its substance and simultaneously even integral place in man's socialization and education.

Many times we meet people whose verbal communication ability is significantly impaired as a consequence of a severe health disability. It is important to realize and keep in mind that it is necessary to make it possible even for these persons to become active participants in communication. Augmentative and alternative systems of communication serve this purpose. Their role is to minimalize the communication deficit and compensate impaired communication ability; this means forming a new support or substitute communication canal, which enables these individuals to become equivalent communication partners (Šarounová, 2006).

Alternative and augmentative communication in the context of cerebral palsy

A characteristic group, in the sense that it should receive attention, is a group of children/pupils with a diagnosis of cerebral palsy. These are individuals who usually exhibit severe physical disabilities, impaired communication abilities and often damage of mental or sensory functions. The sort, type and level (degree) of the primary and even secondary deficit significantly influences the choice and possibility of using systems of augmentative and alternative communication in practice and including these individuals in society (Chomiak, 2005).

The author of this study has been interested in detail in the AAC problem since 2002. The presented information comes both from general conclusions from research (questionnaire) conducted in 2006 and further from the author's practical experiences which were obtained as a speech therapist working in school facilities meant for pupils with mental and combined disabilities.

It follows from the results of the conducted questionnaire survey that in the group of individuals with cerebral palsy (note that the sample was formed by 57 children/pupils with a polio diagnosis who simultaneously had severely damaged communication abilities), AAC is the measure that is maximally exploited, especially in individuals with a quadriplegic spastic form of cerebral palsy and even further in individuals with a dyskinetic cerebral palsy form.

The initiation of AAC use in individual users has taken place in the space of 3–16 years, which is certainly very closely connected with the historical application framework of AAC use in the territory of the Czech Republic. (Note: AAC systems have been more intensively applied since the end of the 20th century).

Approximately in half of the AAC users we met, the system was replaced with a different one. From the dialogue with practicing professionals it appears that changes in the utilization of the AAC system are most often caused by:

a) an unsuitable choice of the AAC system, caused by insufficient knowledge on the part of support staff, especially in the area of diagnosis, selection and practice in working with the AAC system;
b) progressive, but also regressive changes in the development of a child with cerebral palsy, which influences his/her communication competences as well as the optimality with which he/she utilizes the selected AAC system;
c) the negative attitude of the social environment of the AAC user for the selected communication system.

In the selection of a suitable AAC system for individuals with cerebral palsy, besides severe damage to the verbal aspect of speech, different degrees of damage to the coarse and fine motorics and mental disabilities often play a significant role. In another words, it can be said that the choice of an AAC system is considered to have communicative potential for an individual, to further his intellectual level and both motorics of the upper extremities and their coordination, and last but not least, to even the social competence of a potential AAC user with that of his environment (Laudová, 2003).

Concerning the representation of the exploitation of separate AAC systems in children/pupils with cerebral palsy, most often pictograms, then real objects, and finally their reduced-size pictures are used as compensation or support for communication. Letters and reading are used in methods of social reading, exchange communication systems, the communication system MAKATON, and finally the Bliss system and sign language (Kaul, 2003).

With regards to the consequences of severe health problems (i.e. motor and mental) in individuals with cerebral palsy, it often appears that they use more accessible communication means, respective AAC systems, for communication (i.e. approximately in 60% of the cases, although 36% use a framework of communication that combines the elements of two AAC systems, 13% use three AAC systems simultaneously, 7% have their commutative potential supported with four systems of AAC simultaneously, 2% have an active participation of five AAC systems, and 2% have even six AAC systems). (Note: We see a combination of two AAC systems especially in persons who use pictograms for communication. Their application into special pedagogical practice is successively connected with the application of the methods discussed next. These are the social reading method, and if need be, even the global reading method. With a lot of connections of AAC systems in the framework of communication with persons with a cerebral palsy diagnosis, we mostly meet individuals in whom it is possible, with regard to the quality of their motor functions, to have connected specificities of static and dynamic communication systems.

This is, however, also possible e.g. in individuals where it is necessary within the support framework of functional communication to apply a multisensory approach, which could be demonstrated as the connection between an object and symbol (e.g. snapshot, picture/relief of the picture or pictogram of given object), gestures (signs for given objects), and spoken word (Laudová, 2003)).

The choice of a certain type of system of alternative or augmentative communication in a given individual with cerebral palsy is also related to the ability of that individual to recognize and then identify objects and symbols (photos, pictures, pictograms, etc.), with the help of which he/she communicates. These especially include eye movements, facial mimics, gestures (also shown on symbols), words, as well as other means, e.g. showing the symbol, answering with the help of a communicator or in writing, usually with specially adopted computer hardware or software.

Concluding from the results of the research investigation, the identification of symbols in a given target group is most often done by eye movements, gestures, verbal notifications (in the sense of a confirmation of a yes / no choice), and in a limited measure, even by mimicking (a consequence of the elasticity of facial muscles).

Communication with persons with a cerebral palsy diagnosis (which is the basis of AAC), besides traditional nonverbal manifestations of the body of these individuals (e.g. mimicry, eye gaze and gestures), is often supported with further relief communication means of a technical and non-technical nature, such as communication tables, communicators and computers. Usually, these are commercially produced aids which are used in the framework of special pedagogical intervention for training communication and educational techniques that stem from the underlying ideas behind separate AAC systems. The aim of applying these aids in practice is to support and extend the communication potential of individuals with cerebral palsy, i.e. users of AAC, to ensure functionality of their communication with their surroundings, and to eliminate contingent origins of information and communication deficits in these persons (Alm, 1992).

Research has shown that most children/pupils with cerebral palsy use, as a means of support for communication on an AAC basis, commutative tables, next their own body (face-play, eye gaze, gestures), then computer technology, and finally communicators or other supporting communication means as e.g. a portfolio or set of photos (Šarounová, 2006).

AAC systems, without dispute, take part in developing the personalities of individuals with a cerebral palsy diagnosis, which can be demonstrated by a number of case studies. It is apparent that AAC systems work not only in a pure communication sphere, but also influence the mental condition and development of an individual with cerebral palsy (by decreasing frustration from unsatisfied communication needs, mental tension, anxiety, and by increasing self-esteem and self-confidence of the individuals) and obviously also take part in the upbringing and educational processes as well as integration into society of individuals with polio and with expressive speech impairment (Laudová, 2003).

Within this framework of research, it has been shown based on data collected from respondents (educational workers, speech therapists and workers of special pedagogical centres) that the extent to which AAC takes part in the development of factors, is a real predictor of successful communication, education and integration of children/pupils with cerebral palsy. In this sense, attention has been devoted to the evaluation of the expressive speech development of individual users of AAC systems, their cognitive ability and their social competences. From the respondents' answers it appears that from the above introduced factors, they assign AAC the greatest role in the area of development, next in the area of emphasis on social competences of AAC users, and finally they see its least significance in the area of cognitive abilities (see Table 1)

AAC's role in %	social competences	cognitive ability	expressive speech
0	1 (1.8%)	3 (5.3%)	12 (21.1%)
25	17(29.8%)	22(38.6%)	29(21.1%)
50	21 (36.8%)	10(17.5%)	8(14%)
75	16(28.1%)	21(36.8%)	7(12.2%)
100	2(3.5%)	1(1.8%)	1(1.8%)

Tab. 1. AAC role's in the development of partial areas of personality of an individual with cerebral palsy

It is evident that the principal significance of the application of AAC systems in children/pupils with cerebral palsy consists primarily of fulfilling the communication needs of these individuals and contributing to the development of their communication potential. Communication systems that function on an AAC systems basis could be generally considered a means of support in the education of individuals with cerebral palsy who simultaneously have an expressive speech impairment (and as such are an unavailable means of integration for these persons into common life) (Šarounová, 2006).

Part of the application of AAC systems in communication, education and integration of individuals with cerebral palsy is also mapped onto the framework of a given research investigation. From the results, it globally holds that practicing professionals give AAC the highest importance in the area of communication, next in education, and finally even in integration (Bandžuchová, 2002).

Concerning the significance of applying AAC in the area of communication development and support, based on 11 persons (i.e. 19.3%) with cerebral palsy, AAC has, according to the professional estimates of respondents, a maximal influence on the development of communication competences and realization of communication acts, an extraordinary effect according to 22 (i.e. 38.6%) respondent, an average effect according to12 (i.e. 21.1%), a substandard effect according to 8 (i.e.14%), and finally according to 4 (i.e. 7%) respondents, a minimal effect.

In support of educational processes of individuals with cerebral palsy, according to data obtained from the answers given by respondents, utilization of AAC systems is maximally demonstrated in 4 (i.e.7%) clients, extraordinarily in 19 (i.e. 33.4%), on average in 17 (i.e. 29.8%) users of AAC, on a substandard level in 10 (i.e.17.5%) and minimally in 7 out of 57 individuals in the research sample (i.e. in 12.3%).

AAC's part in the integration of persons with cerebral palsy who simultaneously have an expressive speech impairment is possible (based on obtained data) at a maximal level in 7 (i.e.14%) individuals with cerebral palsy in the research sample; in 11 (i.e.19.3%) the effect is extraordinary, in 20 (i.e. 31.1%) the effect is average, and in 10 (i.e. 17.5%) it's substandard. Finally, there were 12 respondents of the questionnaire (i.e. 21.1%) who leaned towards a minimal effect of AAC on the integration of these individuals.

Conclusion

It follows from the introduced information that AAC systems become an integral supportive part of the quality of life of individuals with cerebral palsy with a comorbid severe expressive speech impairment, provide support for the complete development of their personality, have an effect on their mental health, take part in the improvement of their education, and at the same time contribute to their integration into society. With regard to actual trends in the area of care for individuals with health problems and with regard to the effort of compensating opportunities in the area of education and minimalizing the consequences of health problems, further development in the future is expected with the support of the educational and social policy of the Czech Republic.

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Social-psychological aspects of the application of alternative and augmentative communication (AAC) in pupils with cerebral palsy

Abstract

The text outlines partial aspects of the utilization of alternative and augmentative communication in children/pupils with a cerebral palsy diagnosis and acquaints with the author's practical experience as well as the outcomes of research investigations carried out in the given domain. It further defines the means that are used most often in ACC and specifies view points that lead to the choice of these systems. Also the effect of alternative and augmentative communication systems is outlined in terms of the development of expressive speech, the cognitive abilities and social competences of its users, and the practical significance of the exploitation of alternative and augmentative communication from a psychological and socialization point of view (especially in reference to education and integration).

Społeczno-psychologiczne aspekty zastosowania komunikacji alternatywnej i wspomagającej (AAC) u uczniów z porażeniem mózgowym

Streszczenie

Tekst ten nakreśla aspekty wykorzystania komunikacji alternatywnej i wspomagającej u dzieci/uczniów ze zdiagnozowanym porażeniem mózgowym, zaznajamia z praktycznym doświadczeniem jego autora, a także z wynikami badań uzyskanymi w tym zakresie. Omawia najczęściej stosowane środki, wyszczególnia punkty widzenia, które prowadzą do wyboru tych systemów komunikacji. Przedstawia również wpływ systemu komunikacji alternatywnej i wspomagającej na rozwój ekspresyjnej mowy u jego użytkowników, ich zdolności poznawczych oraz kompetencji społecznych, a następnie nakreśla praktyczne znaczenie wykorzystania komunikacji alternatywnej i wspomagającej z psychologicznego i socjalizacyjnego punktu widzenia (zwłaszcza edukacyjnego i integracyjnego).

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Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

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Development of social competences in youths with a visual impairment

Introduction

Adolescents and youths with visual impairments have more opportunities to build a brighter future today than during any other historical period. There are many educational programmes and assistive or rehabilitative services that are available, as well as a wide variety of ways to help youths achieve their full potential. Effective laws supervise and protect their education and employment rights as well as grant open access to their communities. Worldwide, there are many vocational departments, foundations and agencies, which provide or support rehabilitative services and transition programmes. Most of them offer services associated with six major skill areas: adjustment to blindness, independent living skills, communication, orientation and mobility skills, support systems, and vocational development. This article deals with the options that are available for supporting and aiding the development of social competences in adolescents and youths with visual impairments during their transition to a self-sufficient lifestyle in the Czech Republic.

Theoretical basis

Social competences enable establishing, maintaining, and adequately terminating social contacts with other individuals, institutions and groups. “They can be divided into several groups: interactive skills, perceptive skills, communication skills, organisational skills and behavioral skills” (Galvas, 2001, p. 89). An independent lifestyle also includes, among many other practical skills, task solving and social interaction skills in different environments, such as work, free time, shopping or transportation. Elementary social roles include those of a parent and a subordinate or superior. Therefore, adult social competences are defined by the ability to successfully orientate oneself in various communicative or social situations and in roles that are characteristic for an adult.

For many youths, the time of transiting into being on their own means a growing awareness of the number of social situations to be dealt with and solved without outside help. As a result, they review their capabilities and realize how inexperienced they actually are[1]. This situation can be even more complicated in the case of youths with impairments, whose development and self-sufficiency is further limited.

If the individual has not acquired enough experience and sufficient practical skills to live an independent life, adolescence can bring about many conflicts which are a secondary cause of psychical stress and may eventually lead to attempts of postponing responsibility for one's own life and the actual process of becoming independent. Focused preparation for successful social interaction may ease this process and improve the situation, allowing for good quality socio-cultural participation in society. It should also be mentioned that the basis for successful social integration into "grown up" society (Lopúchová, 2006) lies in the optimal development of social competences at a young age.

According to Galvas (2001), improving communication and social competences allows for such quality of individual behaviour, communication, attitudes and self--perception, which would further enable visually impaired youths to feel a lower level of psychical stress during social contact, have more effective participation in society, be less dependant on the social environment and reach a higher level of life quality and success.

The contemporary situation in the Czech Republic

There have been major developments in the area of support aimed at the education and integration of persons with visual impairments in the recent decade in the Czech Republic. However, supporting social competence development in youths with visual impairments still remains rather outside the main scope of professional interests, which can be illustrated by comparing data on this support from the Czech Republic with data collected in other developed countries[2]. Based both on research carried out in the Czech Republic and on practical experience, we can assume that there is high potential for development in support of communicative and social skills (as shown, for example, in selected findings in the 2009[3] Ptáčková investigative survey).

> An investigative survey by Ptáčková (2009) shows that 5% of the respondents with low vision and 30% with blindness assess *their social skills level* with terms ranging from 'satisfactory' to 'highly unsatisfactory.' Boys tend to be less sure of their social behaviour (25%) than girls (10%); integrated education students tend to be less sure (20%) than special school students (15%). Up to 45% of students with visual impairments think that employing *assertive techniques* in their behaviour presents a problem for them. The level of *communication skills* was evaluated in a more concrete way. According to

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[1] Insufficient social skills are frequently palpably perceived in concrete situations when persons do not react in an appropriate way or are aware of the fact that they are not coping well with the situation (Jesenský, 2007).

[2] An example of this is The Texas Department of Assistive and Rehabilitative Services, a state agency that supports Vocational Rehabilitative Programs, and the Division for Blind Services Transition Programe.

[3] The survey dealt with estimating social and communicative skills in secondary school youth with visual impairments. It employed both an objective and subjective assessment (n=40) (Ptáčková 2009).

> the collected data, 20% of girls and 25% of boys with a visual impairment considered their level of communicative skills unsatisfactory to highly unsatisfactory. This group consisted of 5% of students with low vision and 40% of students who were blind, with special school students (30%) prevailing over integrated school students (15%). This can be further illustrated by the following facts:
>
> The ability to open communication with a stranger was seen as unsatisfactory by 10% of students with low vision and 50% of students who are blind (55% of these students were girls and 65% were boys).
>
> The ability to ask other people for help was seen as unsatisfactory by 30% of girls and 45% of boys, with special school students and students who are blind combined.
>
> Surprisingly, many students felt uneasy about explaining their disability to other people. This skill was perceived as unsatisfactory by 25% of girls and 30% of boys. Again, special school students prevailed (45%) over integrated school students (20%). Students with low vision (30%) perceived informing other people about their visual impairment more troublesome than students who were blind. The situation slightly improved during secondary school education, as these problems were reported by 35% of first year students and only by 15% of final year students.
>
> Another interesting fact became apparent when Ptáčková *investigated students' participation in these communicative activities*. Only 50% of girls and 25% of boys regularly participated in this type of activities; students who were blind (65%) prevailed over students who had low vision (15%).
>
> *Integrative free time activity participation* brought other surprising findings. 35% of girls and 70% of boys seldom participated or did not participate at all in activities, which would bring them together with their unimpaired peers. There were 70% of blind students and 30% of low vision students in this group; special school students (45%) perceived the social barrier here more palpably than integrated students (20%).
>
> The main outcomes of the survey were as follows: girls aged 14–22 perceived their social and communicative skills as more satisfactory than boys of the same age. Girls and boys who attended an integrated primary or secondary school (even for a limited time period) perceived their social and communicative skills as more satisfactory than special school graduates.

The next section of the article deals with the possibilities concerning special education and rehabilitation support for the development of social competence in adolescents and youths with visual impairments in the Czech Republic.

Social competence specifics throughout childhood and adolescence

Social learning starts at birth and continues throughout the lifespan. It is linked to mental development and is influenced by the quality of relationships and social experiences of an individual. Children learn about social interactions in the social environment they are surrounded by (Carver, Scheier, 1996).

The primary cause of uneven development is a visual impairment. Social learning is based mainly on imitation, though errors can be compensated for through verbal description. Better results can be obtained based on one's own experience or reflection training.

The secondary cause is lack of personal experience. A growing number of situations with limited perception in childhood causes communication problems and conflicts. School attendance increases demands on children's social skills without family support. In addition, peer relationships grow more complex. At this stage, it is very important what behaviour stereotypes the child acquires in communication. Therefore, development is *influenced by the child's social environment and by the amount and quality of their social experience*. Children with serious visual impairments are often unable to acquire optimal ways of socially acceptable behaviour only by imitation, although often they do not even have enough opportunities for that. Conflicts and their ill-handling give rise to undesirable social experiences and behavioural stereotypes, which further influence personal development. When children with visual impairments are concerned, Gűttnerová and Vítková (2002) speak of *the risk of acquiring ill-developed social skills* and the possibility of *developing behavioural abberancies*. Thus, school age is the best period for education in communicative and social skills and their practice. On the contrary, insufficient educational support in the given area leads to problems in self-acceptance and in relationships with the social environment. The family represents the basic platform for learning and practising social skills.

The fundamental role of family

The family holds the possibility for the intentional or unintentional development of an individual's special needs and for a development focused on certain areas of social competence. However, there are also factors that lower the efficiency of the above mentioned type of development or even make it impossible. Parents often do not realize how important their attitude towards the future independent life of a child with a visual impairment is. Their dotting care and fears complicate the process of social maturity (Tvoze, 1981).

The transfer of social skills within a family is realized mostly through imitation and incorrect stereotypes (found especially in low socio-economic status families) have a significant influence over a children's behaviour. Boarding school placement also shows a negative effect on the process, as the family struggles with providing low educational intensity and complexity of social skills. The troubled relationship between the parent and the child in pubescence can have a negative impact on the area of social learning. The family role here can be partly substituted with specialized institutional care or by another person.

The role of educational institutions

Clearly focused support of social competence in adolescents with visual impairments can be provided by special education centres in the Czech Republic. In order to aid individual, independent development, the curricula of special schools pay special attention to teaching orientation and mobility.

Given the right conditions, a class can represent a highly suitable environment for developing social competences. There are various situations and relationships that can be found here over a relatively long period of time. In order to use this educational potential effectively, school curricula should allow enough space for this issue. Unfortunately, the Czech educational system does not pay sufficient attention to this problem in the long run. The special educational needs of each individual with a serious visual impairment should be part of an individual education plan. Consistent social competence development adjusted to suit special educational needs should be included in an individualized education plan for every person.

Support through the concept of social learning at school age

Clearly focused support of children's social competences can also be provided through vocational institutions. These can include educational and rehabilitative organizations, so forms of support can vary from short teambuilding courses to integrative free time activities and individual psychological care. For example, the concept of "Social Learning" (Strittmatterová, 1999) represents a sophisticated system of social learning support in school-aged children with serious visual impairments. It is based on a three-platform model: *blocked interaction, intervention and integration*. Its impact on the child is complex, dealing both with physical and mental aspects. The concept aims at reaching a social level that would allow the pupil to blend with society while maintaining his or her complex personality. The main support areas include:

- acceptance of the child's individuality,
- improvement of the life conditions that can be influenced,
- coping with delayed development and eliminating problems,
- influencing possible negative dispositions and aberrations in behaviour.

Specifics of teaching social skills in adolescence

Education in adolescence should be carried out mainly by allowing youths to experience different situations. Individual issues should be combined with practising formal and informal social skills and broadening the youth's experience. The goals can be identified in the following areas:

- setting up a good, well-balanced mental state by strengthening, "This is me"– building up self-confidence and trust in one's abilities;
- increasing mental resistence by positive self-evaluation;
- learning behaviour strategies which will allow the individual to take part in the life of the society, have satisfactory performance and actively acquire new tasks, roles and responsibilities;
- development of the ability to create relationships (communication and cooperation skills, being able to criticize and compromize, being able to plan and organize);
- learning about the rules of social behaviour, practising social roles by dealing with both mock and real life situations (Gűttnerová, Vítková, 2002).

"Adolescents need social networks, social support, friendships, and intimate relationships to feel like they belong and have a strong sense of self-worth as they move into adulthood" (Gold, Shaw, Wolffe, 2010).

Supporting the development of social competence in young adults

The main aim should lie in the ability of a young person to acquire basic social roles and typical formal and informal situations relatively independently and without excessive mental stress (Baekhoff, Kamp, 1994). For people with visual impairments, this means acquiring especially the *skills of social interaction and behaviour* without major errors and without perceiving excess mental stress. Other factors include *specific abilitie*, which make dealing with certain situations easier (these situations, as a rule, have a major influence on the visual impairment). However, at this stage, transition programmes which would prepare young people for the transition from school to adult life, independence and employment, are not available in the Czech Republic. At the moment, most Czech institutions working in this area deal only marginally with developing social skills in youths. Tyfloservis (an institution offering social rehabilitation services) for this purpose uses the Course in Social Skills (Galvas, 2001). However, the demands of youths with visual impairments require further adjustments to the course in order to suit the special educational needs of this target group. For the next version of the programme for young adults, it would be suitable to make changes in the following issues:

1. Dropping the group form of the course, transforming its contents into a conceptual form, and including individual educational approaches and real life situation training.
2. Using the method of experience learning, which is well-received in the given target group and yields good results.
3. Running young adult groups separately from the older participants.

The so-called Goldstein method from the Netherlands for practising social skills for adults with a serious visual impairment is highly beneficial, but in the Czech Republic is, in fact, used very scarcely. This educational method uses roleplay for real life situations that participants find difficult to handle or works with those areas of social skills that they find troublesome. The basic element of the training is role playing using, for example, modelling techniques and practising various behaviour modes, including home preparation practice and subsequent feedback. The advantages of this method surely lie in its close link to reality, a deeper understanding of the practised skills and the variety of training situations. The training continues until its participants can observe a reasonable reduction of mental stress while solving a particular situation. Even introducing individual elements of the Goldstein method into social learning and into young adults' social skills training will undoubtedly prove beneficial.

Conclusion

Social interaction skills make the integration of a person with a visual impairment into society successful or unsuccessful. Special educational assistance in this area may help young people acquire a self-sufficient life style more easily, which can be considered as one of the indexes of the quality of life objective. However, the Czech special support system for children and adolescents still shows certain gaps that are waiting to be filled. Ranked among the most significant ones is the full acknowledgment of the need for special education and the importance of practising social skills during school attendance. Also, upon the completion of compulsory school attendance, it is necessary to provide subsequent and widely available systematic special support for young adults in the Czech Republic.

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Social competences development in youths with a visualimpairment

Abstract

The transition to a self-sufficient lifestyle is not always smooth and easy for adolescents and youths with visual impairments. The article deals with the role of the family as well as the possibilities of vocational support in the development of social competences of adolescents and youths that improve the quality of the transition to a self-sufficient lifestyle.

Rozwój kompetencji społecznych u młodzieży z uszkodzeniem wzroku

Streszczenie

Przejście w kierunku samodzielności i niezależności życiowej u nastolatków i młodzieży z uszkodzonym wzrokiem nie zawsze jest bezproblemowe i łatwe. Niniejszy artykuł traktuje o roli rodziny oraz możliwościach wsparcia zawodowego w rozwoju kompetencji społecznych u nastolatków i młodzieży, co podnosi jakość procesu przejścia ku samowystarczalnemu stylowi życia.

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Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

DISABILITY IN THE CONTEXT OF INCLUSION AND CULTURE

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The sentiments, attitudes and concerns of educators when working under the conditions of inclusion

Research background

In regards to the fact that our research is directed to the field of special needs education, which represents, in the context of pedagogy and education, a very good example of an inter-field approach, we shall first define the respective terminology. To begin, it is necessary to mention normalization, integration and inclusion. Probably the most fundamental statement in relation to upbringing and education was expressed in the Salamanca Statement (1994) by the representatives of 92 UNESCO member states. This declaration outlines the tendencies that lead to the elimination of discriminatory attitudes by establishing open inclusive schools and, subsequently, by creating social consciousness directed also towards the principle of inclusion. The main issue discussed therein was education and, as a result, the principal theme for the entire process was: "Education For All". A significant attribute was the notion of *normalization*, which is closely linked with the necessity of adjusting conditions ensuring a "normal" life for people with intellectual disabilities. It was first introduced by a Danish lawyer, Niels Erik Bank-Mikkelsen (1999). This concept was evolved further, especially in the northern European countries, and it was from there that it disseminated to other countries as a set of principles. These principles ensure the adjustment of the environment and the attitudes of society in such way that they comply with the needs of people with intellectual disabilities. Adjustment / normalization refers to common every-day activities and the involvement in every-day life of the society to an extent acceptable for each particular person. We are convinced that this concept then gave rise to a similar view on the process of education (Gilbert, C. and Hart, M. 1990) and socialization of people with other types of disadvantages.

One of the most frequent definitions in our target sphere is *integration*. A specification of this definition is found in a regulation (2001) given out by the Ministry of Education of Czech Republic in which individual and group integration is distinguished. *Individual integration* is described in terms of the conditions that are present in kindergarten, primary and secondary schools or college which are not separately designed for pupils with special educational requirements, but simultaneously provide corresponding educational conditions and necessary special pedagogical or psychological care. The second type of integration is, according to the stated material, the education of pupils with special needs in a class at a specific school, designed specially for pupils with other types or intensities of impairments.

Group integration is, in this article, characterized as the education of pupils in a special class or a specialized class formed under specific regulations. Pupils can join other pupils from the school for certain subjects and are, within their capacities, brought in on all extracurricular activities.

Another essential term for this study is *inclusion*. In Czech sources, the difference between integration and inclusion is, in some instances, not clear. E.g., Průcha (1998) defines inclusion in education as the result of a movement, which aims to create conditions for integrated education even for severely disabled individuals. The precise line between the two concepts is not always clearly specified. Written materials focusing on current educational issues usually apply both notions only in a limited extent (e.g. Průcha, 2002). The term inclusion is associated with a change in the special-needs-education paradigm (Forlin 2006). Let us remind you of the fact that the first pioneering steps in this field in our country are attributed to J. Jesenský (1998). This takes us back to the conference in Spanish Salamanca where inclusion became the key word. The final resolution calls for programmes focused on the education of pupils with disabilities in conditions that are available in general schools and highlights the principles of individualization, both in planning the contents and pace of education, as well as in the requirements necessary for adjustments to the educational environment. In regards to this, it is fundamental that the pre-school educational phase is included in the entire educational process and is considered an equal developmental phase. The concept of inclusion follows basic human rights, which – if they are to be abided by – cannot exclude a group of people with special needs (Meijer, 2001). From our point of view, it is also important that this does not represent only a phase of educational activities, as a rule fulfilled by intellectually disabled individuals at the age of twenty, but that it is envisaged as a life-long process – inclusive of finding a place for the individual in society and his/her involvement in working life. At present, the process of inclusion is, in the Czech Republic, reflected e.g. in the implementation of general principles in a social services law as well as in standards of social services applied to real life practices.

Inclusion thus, for our purposes, represents a set of conditions which, if they operate mutually/bilaterally, provide people with intellectual disabilities with an approach by the majority of society that focuses on developing their potentials in individual sectors. Furthermore, it supports their abilities so that they become fully functional tools in a maximally independent life within this society.

As stated earlier, this approach was reflected in the change of the special needs education paradigm, which has subsequently become a comprehensive pedagogical branch. In comparison with the preceding concept of being handicapped, understood mainly from the medical point of view, special needs education is envisaged today as a supportive line of education.

The objective is thus to prepare a disabled individual for his/her life in society so that his/her experience is of the highest possible quality and as close as possible to the life of the (unimpaired) majority of the population. With respect to the fact that the educational stage partakes in the quality of life to a great degree, we mention here *inclusive pedagogy* or *inclusive education*. Inclusive pedagogy represents, in our current conceptual view, an approach which treats diversity as a principal idea in educational process. It is possible to claim that the line of inclusive pedagogy is a successor of integrated pedagogy. The fundamental difference lies in the fact that pedagogy, in the event of inclusion, operates in connection with human rights. To simplify things, it may be stated that a school must be conformed to a child, not the child to the school (Groma, 2008).

For the purpose of our study, we summarize the fundamental difference between integration and inclusion, which lies in a diverse conceptualization of the child/pupil. The concept of integration respects the diversities that arise between a group of impaired children and a group of unimpaired children. The main effort is to include or join two different groups (different in health conditions or educational needs) within the educational process and provide necessary support to special needs education wherever required. Inclusive pedagogy views children or pupils from a position that does not distinguish among differences caused by the above-mentioned reasons, but works with a group where each individual has comparable needs (Milovanovitch, 2009).

The relation between integration and inclusion can be clearly defined according to Kocurová (2002) as follows:

Integration – focus on the needs of a disabled individual, the expertise of professionals, special intervention, contribution to the integrated pupil, a partial change of the environment, focus on the educated disabled pupil, special programmes for the disabled pupil, and evaluation of the pupil by a professional.

Inclusion – focus on the needs of all pupils, the expertise of common educators, substantial teaching for everybody, contribution to all pupils, an overall change of the school, focus on the group and school, a general strategy implemented by the teacher, teacher evaluation, and focus on educational factors. Education in this sense is not only meant to setup specific knowledge in accordance with a particular subject, but means upbringing as well. A description of different attitudes to upbringing methods and goals is made by Pospisil (2009).

The aims of the educational process are stipulated in a national, and later in the school, educational curriculum and, if need be, in an individualized plan serving as a tool that corresponds to specific needs. From the point of view of pedagogical policies and principles, there is no evident difference between inclusive and integrated education. Modern educational philosophy views, within the framework of general pedagogy, the current trend as comprehensive. In this respect, R. Barrow and R. Woods (2006) mention on pages 94 – 95 the requirements for educators and teachers who implement an educational process; they characterize this process as "rational". It is further explain from the perspective of the modern concept of pedagogy and the necessary competencies of teachers. The competencies of teachers towards disabled children and pupils are dealt with in a publication by A. W. Brue and L. Wilmshurst (2005) who list the competencies of educators that are essential for working with children and pupils with various types of impairments and special educational needs. With reference to the Rehabilitation Act of 1973, and especially section 504, there are specific requirements for teachers regarding strategies focusing, for example on process organization, manifestation of behaviour, adjustments of the environment and conditions, etc. Also a publication by K. Hull (2002) describes the characteristics of inclusion and inclusive education and sees the following assumptions as fundamental (p. 13):

- Disabled children may take part in the same educational programmes as their contemporaries.
- They can visit an environment which reflects their real age.
- They can, if need be, use an individual approach in the form of an individualized educational plan (IEP).
- They have the right to receive support from special needs education, according to their needs.

In a study, the same authors address the requirements imposed on educators working under the conditions of inclusion and, apart from practical competencies, try to refer to other presumptions which they claim essential for performing this specific work. For our purposes, we can state in line with the above-mentioned authors that the list of requirements and spectrum of pedagogical competencies are much more extensive in the case of inclusive education (as in integrated education). We take into consideration general educational work focused on children and pupils, both impaired and unimpaired, which naturally demands readiness and competencies of respective pedagogical personnel. Hájková (2005) as well as Blake, N., Smeyers, P., Smith, R., Standish, P. (2006) define professional competencies of a teacher as a set of prerequisites for performing teaching activities, and also as a capacity to act intelligently in situations, which are constantly new and unique with the aim of finding a suitable on-the-spot response. If a teacher possesses these abilities to evaluate and make decisions, he/she is apt to choose suited responses in situations which can be completely new and unexpected (more on this topic can be found in Lambe (2007)). With respect to the fact that our aim is not to present the specific competencies that are expected of teachers specialized in the education of disabled children (in terms of the type of disability), and taking into account the specificities of such a disability, we present only as an illustration the requirements of educating a child with impaired hearing. Apart from communication competencies in Czech and sign languages at the common user's level, in order for the educational process to be performed without any communication barrier as a limiting factor, we shall enumerate other fields where the teacher's awareness is assumed: emotional literacy – introduction to theory and practice of emotional life, definitions and descriptions of individual emotions and experiences; self-control – conscious behaviour motivated through a pre-set goal; social competencies – establishing and developing social skills adequate to the child's age, corresponding to the culture and environment in which the child is based; the development of positive relationships with his/her contemporaries – exercise and development of social skills in a group of his/her contemporaries; and finally, the skill to solve problems in inter-personal relationships. We are intentionally omitting the field of knowledge because we assume its definition in accordance with the national curriculum and success in the given subject if the following conditions are met: the educator's communication competencies, on the one hand, and intellect corresponding to the requirements for completion of primary education, on the other hand (Potměšil, 2007).

The research results of studies conducted by D. J. Bjarnason (2005) in Iceland indicated a close correlation between changes in conditions as part of the transformation of traditional approaches to the form of inclusive education and their reflection in the preparation of future educators. In regards to the monitored competencies and attitudes, the author clearly talks about "… [the] changed general educator's roles in the face of growing student diversity".

It's these requirements bestowed on the educator and his/her personality in the process of inclusive education that prompted us to cooperate on the above-stated research. Inclusive education in conditions present in the Czech Republic is more similar to integrated education. Terminology deduced from the notion of inclusion occurs, at present, in our pedagogical documents merely in three instances: the Bílá Kniha (White Book) – the 2nd revision uses this term in chapter 10, *"speciální vzdělávání (special needs education),"* parallel to the term integration and in relation to the elimination of segregated education. Furthermore, Directive No. 17/2005 Coll., dated 27th July 2005 concerning the further education of educators, the accreditation committee and career system for educators, as amended in the Directive No. 412/2006 Coll., dated 14th August 2006, mentions the term inclusion in relation to the requirements for the education of educators with reference to the scope of their competencies. The third document is the Methodological Guideline for the reimbursement of educators and other school employees, pre-school and school facilities and their ranking within the 16–wage-tariff catalogue of works, Ref. No.: 30 207/2003-2. Therein, *inclusion* is mentioned only once in relation to the required professional competencies for qualifying for the 11th wage tariff. The respective legislation (School Law Act, No. 61/2004 Coll., dated 24th September 2004 for pre-school, primary, secondary, college and other education (School Law) as amended (the latest amendment No. 49/2009 Coll., dated 28th January 2009) or the Methodological Guideline for integration of handicapped children and pupils into schools and school facilities in the course of the school year 1997/1998, MŠMT ČR (Ministry of Education, Youth and Sports), ref. No. 18996/97–22, Directive No. 73/2005 Coll., dated 9th February 2005 for education of children, pupils and students with special educational needs and for children, pupils and students of prodigious talent, as amended by regulation No. 62/2005 Coll., dated 19th March 2007) is being applied in real every-day education. We are convinced that there are many variants, forms and methods of work relating to the mentioned educational forms. We were, like our colleagues from abroad, mostly interested in the attitudes, feelings and concerns of educators, who can, in their every-day practical life, expect a situation when they might educate a disabled child and they should, naturally, succeed in their role as a teacher and fulfil their required educational objective. The target group was selected from educators who were just about to start a 3-year specialized study of special needs education for teachers who had completed their Master's degree with specialization in teaching the unimpaired population.

In order to be able to collaborate on the research, it was necessary to fill out the same questionnaire (Loreman et all. 2007) as our foreign colleagues, with the exception that it was in Czech (unaltered in respect to meaning and presentation of items from the English original).

Analysis of the acquired data

First, we processed the returned questionnaires in terms of the demographic information from the first and the second phases of the study.

The first phase included 563 and the second phase 231 informants from all over the Czech Republic. The first phase addressed 22.4% and the second 12.3% of males. Females who completed the entire questionnaire made up 77.6% of respondents in the first and 87.7% in the second phase. Statistically, the prevalence of women was confirmed at a significance level of p = 0.001.

Out of the total number of 563 informants, 13 were not working in the pedagogical field and 15 were for various reasons out of the working process at the moment.

The age of informants oscillated in the first phase at 32.8% (and 27.9% in the second phase respectively) for individuals up to the age of 29 years, at 37.8% (42% respectively) for informants between 30–39 years of age and at 29.4% (30.1% respectively) for those above the age of 40.

The education level of our informants was as follows: 59.5% of informants in the first phase and 59.8% in the second phase completed secondary schools education, 24.6% of informants in the first phase and 31.1% in the second phase completed their study with a Bachelor's degree, and 15.9% of informants in the first phase and 8.7% in the second phase completed a Master's degree. A mere 0.5% of the informants in the second phase had completed a doctorate programme (PhD).

Regular and frequent contact with people with intellectual disabilities was reported by 42.5% of informants in the first phase and 68% in the second phase. 57.5% of informants did not have any opportunity for such encounters in the first phase and 32% in the second phase.

The query about previous professional preparation for teaching practice specialized for people with intellectual disabilities was evaluated as follows: without preparation – first phase 50.5%, second phase 15.5%; preparation assessed as very insufficient – first phase 21.9%, second phase 15.1%; sufficient preparation (completion of a specialized course consisting of, at least, 40 hours of training) – first phase 28.1%, second phase 69.4%. Here, the increase in the educational level among the informants of the first and second phases is quite obviously reflected. The statistical significance of the difference in the monitored waves is proved at the level of p = 0.0001.

Awareness of the respective legislation and organization of education for people with intellectual disabilities was evaluated by 2.1% of our informants as very good in the first phase and by 4.6% of informants in the second phase and as good by 21.7% and 30.6% of informants, respectively. 32.1% of informants in the first phase assessed their awareness as average whereas in the second phase it was 52.5% of the monitored cohort. Insufficient awareness was reported by 22.9% of informants in the first phase and by 8.2% in the second phase. The last option, no awareness, was selected by 21.1% of informants in the first phase and 4.1% in the second phase. The difference in perceiving one's own awareness of the discussed issue was among the monitored waves confirmed at the level of significance of p = 0.001 for the benefit of the second phase.

Another item was the feeling of confidence when teaching disabled pupils. This perception was evaluated as very good by 7.3% of informants in the first phase and 6.5% in the second phase and as good by 25.7% of informants in the first phase and 43.3% in the second phase. The feeling was evaluated as average by 30.3% of informants in the first phase and 33.5% in the second phase. Evaluation as low was reported by 18.4% in the first phase and 8.8% in the second phase. A feeling of prevailing uncertainty was chosen by 18.4% of informants in the first phase and 7.9% in the second one. A feeling of certainty when teaching handicapped pupils increased relatively with the length of the study. We showed a statistically significant difference at the level of p = 0.001.

Insufficient experience with education of disabled pupils was perceived by 49.2% of informants in the first phase and 19.8% in the second phase. 26.4% of informants in the first phase and 30.4% in the second phase marked their experience as scarce, but still sufficient. The last option – sufficient (i.e. at least 30 days of training) – was selected by 24.4% of informants in the first phase and 49.8% in the second one. The issue of experience with education of disabled pupils proved to be dependent on the length of the study. At a significance level of p = 0.001, we confirmed a difference in the acquired experience among informants in the first and the second phases.

Our analysis focused also on another part of the questionnaire whose results are presented below as well as clarified in the discussion. An evaluation of the statements was as follows: definitely yes (AA), yes (A), no (N), definitely not (NN). These abbreviations will be used in the text below. The levels of significance are presented in the attached table (Table 1).

1. The statement "I don't mind the company of people with an intellectual disability" was evaluated with strong consent by 97% of informants in both waves (AA or A).
2. Furthermore, 94.9% of informants in both waves stated (NN or N) that they are not apprehensive of direct contact with people with an intellectual disability.
3. The statement that pupils and students suffering from problems with communication in spoken language can be included in classrooms of standard schools was marked as AA or A by 83% of informants.
4. Also, the statement that pupils and students requiring the presence of an assistant can be included in classrooms of standard schools was marked as AA or A by 89.6% of informants.
5. The statement that pupils and students with signs of aggressive behaviour can be included in classrooms of standard schools was marked as NN by 70.8% of informants in the first phase and 68.6% in the second phase. At the level of p = 0.01, there exists a significant difference between the evaluations of this statement as valid or invalid in the first and second phases.
6. The statement that pupils and students requiring an individualized educational plan can be included in classrooms of standard schools was marked as AA or A by 64.5% of informants in the first phase and 87.6% in the second phase. Also this item showed a statistically significant difference at the level of, at least, p = 0.001 between the evaluations of the statement as truthful in the first and second phases, compared with its negation in both waves.

7. In both waves of the research, informants were addressed with the statement that pupils and students who need special communication techniques in their education (Braille, sign language) belong to classrooms in standard schools. 45.4% of informants in the first phase and 59.9% in the second phase marked this statement as true. Statistical processing of the results obtained in both waves showed that the answers between the first and the second phases differ at the level of significance of p= 0.001 detrimental to the acceptance of pupils with specific communicational needs.
8. The statement that pupils and students with attention deficits belong to classrooms in standard schools was evaluated as true by 60.9% of informants in the first phase and as much as 77% in the second phase. The majority of informants in both waves expressed their consent to the presence of pupils with attention deficits in inclusive education, and the level of significance was, at least, p = 0.001.
9. Another statement to be evaluated was: “Pupils and students who systematically fall behind in their educational results belong to classrooms in standard schools.” In the first phase of the research, 58.9% of informants agreed with this statement and 46.5% in the second phase.
10. Informants were to evaluate the following statement: “I’m convinced that the presence of a disabled pupil or student shall significantly increase my work load.” 69.3% of informants in the first phase and 72% in the second phase evaluated this statement as truthful.
11. The statement: “I’m not convinced of the quality and effectiveness of support, which is provided when educating integrated disabled pupils and students on the part of professional workplaces” was evaluated as true by 58.3% of informants in the first phase and 58.8% in the second phase, comparable with findings by Valeo (2008).
12. The educators´ own competencies were to be characterized by the following statement: “I’m not convinced that my preparation for working with disabled pupils and students is sufficient for achieving the required results.” Accordant evaluation was expressed by 58.9% of informants in the first phase and 46.5% in the second phase. Statistical analysis showed that informants in both waves were worried about the sufficiency of their competencies for working in an inclusive educational environment.
13. The questionnaire also monitored the ideas of the informants about the organization of the educational process through the following statement: “I’m convinced of the fact that on my part it is not possible to pay necessary attention to an integrated pupil or student.” 36.4% of informants in the first phase and 31.2% in the second phase evaluated this statement as truthful.
14. Another statement presented to our informants was as follows: “I’m apprehensive that disabled pupils or students shall not be well accepted in a classroom of intact contemporaries.” 39.6% of informants expressed their consent with this statement in the first phase, and 41.7% in the second one.
15. Concerns about direct contact were expressed in the last statement: “I regard the presence of a disabled pupil or student in a classroom as a great source of

mental load for myself." It was evaluated as true by 27.7% of informants in the first phase and 29.6% in the second phase.

Questionnaire item	Mann-Whitney U	Wilcoxon W	Z	Asymp. Sig. (2-tailed)
Company	62597.5	218558.5	-0.54005	0.589
Concerns	57286	82711	-1.91715	0.055
Problems	58481	200792	-0.65738	0.511
Assistant	54719	77724	-1.09567	0.273
Aggressive	56274.5	82609.5	-2.54772	0.011
Individual plan	54108	79986	-3.52563	0.000
Spec. comm. Tech.	54550.5	80428.5	-3.19875	0.001
Attention 1	48306	71959	-4.0902	0.000
Falling behind	58855.5	84506.5	-1.67871	0.093
Load	61007	87113	-0.93893	0.348
Effective support	61519.5	209759.5	-0.19167	0.848
Preparation of spec. needs education	50748	190404	-3.58397	0.000
Attention 2	54990.5	200520.5	-1.86188	0.063
Acceptance	61977	88083	-0.53676	0.591
Psychical load	61154	86805	-0.62301	0.533

Tab. 1. Statistical significance of questionnaire items

In order to conduct further analysis, we divided the above-mentioned items into two groups:

1. Labour input and stress – items 1, 2, 10, 11, 12, 13 and 15.

If we consider the group of statements referring to labour input and stress when working with disabled pupils and students under conditions of integrated education, we can conclude the following from the acquired data:

- More than 90% of informants of both waves do not have a negative relationship towards people with intellectual disabilities.
- Approximately 70% of informants in both waves believe that the presence of a pupil with special educational needs in a classroom will increase their work load.
- 58% of informants in both waves expressed their misgivings about sufficient support for integrated education on the part of professional workplaces.
- The level of one's own competencies was regarded as insufficient by 58.9% of informants in the first phase and 46.5% in the second phase.
- More than 30% of informants (36.4%, respectively 31.2%) voiced their concerns that it is not possible to pay enough attention to a pupil with specific educational needs.

- The presence of a disabled pupil was regarded as a great source of stress by 27.7% of informants in the first phase and 29.6% in the second.

2. The Education Process and its management – items 3, 4, 5, 6, 7, 8, 9 and 14.

In this set of statements, we were looking for answers regarding the process of inclusive education and the opinions of educators about managing their tasks.

- Statements focusing on the presence of pupils with impaired communication competencies and the possible presence of an assistant were evaluated positively by over 90% of informants in both waves.
- Almost 70% of informants in both waves negated the possibility of incorporating pupils with aggressive behaviour into a standard classroom in the form of inclusive education.
- A shift in the evaluation of effectiveness and acceptability of work according to an individualized plan was demonstrated when comparing the results of the first phase, 64.5%, and the second phase, 87.6%.
- Concerns about the application of special communication techniques were expressed by 45.4% of informants in the first phase and by 59.9% in the second phase.
- 60 to 80% of informants did not show any concerns about working with pupils with ADHD disorders.
- The presence of pupils who are constantly unsuccessful at school was unthinkable for 58.9% of informants in the first phase and 46.5% in the second phase.
- Problems with acceptance of disabled pupils by unimpaired class mates were expected in both waves by approximately 40% of informants.

Conclusion

Conclusions relating to labour input and stress and the process of education and its management:

The informants of our research relate positively to people with intellectual disabilities, more than half of them are concerned about insufficient support for integrated education from professional workplaces, they realize the associated higher work load, but the implementation of inclusive education does not seem to bring about any increased levels of stress for them. Half of the informants sense a lack of competencies and, consequently, are also concerned about whether they will be able to pay sufficient attention to pupils with special needs.

Furthermore, our informants showed a willingness to accept a pupil with specific needs and possibly even cooperate with an assistant. Work based on an individualized plan is accepted by informants and is regarded as beneficial. They, however, refuse to work with students with behavioural disorders of aggression due to the constant lack of success, whereas working with pupils with attention disorders does not seem to cause any concerns. A proportion of informants (40%) expressed their concerns about the acceptance of pupils with specific needs into the society of an unimpaired group in the classroom.

If we are to search for answers concerning sentiments, attitudes and concerns of educators working in conditions of inclusion, then we can state that the sample of informants addressed in our research demonstrated conscious willingness to cooperate on projects of individual inclusion. They, however, feel concerned about key issues concerning the lack of professional competencies and support and the effectiveness of such educational work. Our research did not, contrary to our expectations, show any significant difference in the stated items, i.e. there was no expected shift towards better results, when comparing data before the commencement of the study and after its completion.

Acknowledgements
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Annex 1

Items of the questionnaire were selected and sequenced in the following way:

ATTITUDES AND CONCERNS OF EDUCATORS TOWARDS INCLUSIVE EDUCATION

1. I work in teaching:
   ☐ Pre-schools ☐ Primary schools ☐ Secondary schools ☐ spec. needs education
   ☐ others (state) …………

2. ☐ male ☐ female

3. Age: ☐ below 29 ☐ 30–39 ☐ above 40

4. My highest completed education is: ☐ secondary school ☐ Bc. ☐ Mgr. ☐ PhD

5. I have regular and frequent exposure to disabled children: ☐ yes ☐ no

6. I have completed professional preparation for work with people with an intellectual disability:
   ☐ 0 ☐ which I perceive as very insufficient ☐ sufficient (at least 40 hours of the course)

7. My awareness of the respective legislation and organization of education for people with an intellectual disability is:
   ☐ very good ☐ good ☐ average ☐ insufficient ☐ none

8. Perception of certainty when educating people with an intellectual disability:
   ☐ very good ☐ good ☐ average ☐ low ☐ rather uncertain

9. I find my experience in education of people with an intellectual disability:
   ☐ insufficient ☐ scarce but still sufficient ☐ sufficient (30 days, at least)

The table included the following statements, informants were asked to express their evaluation of the statement from strong consent to strong disagreement:

1. I don't mind the company of people with an intellectual disability
2. I'm apprehensive about direct contact with people with an intellectual disability
3. Pupils and students with problems in the field of communication through spoken language can be placed in classrooms of standard schools
4. Pupils and students requiring the presence of an assistant can be placed in classrooms of standard schools
5. Pupils and students with signs of aggressive behaviour belong in classrooms of standard schools
6. Pupils and students who require an individualized educational plan belong in classrooms of standard schools
7. Pupils and students who require special communication techniques (Braille, sign language) for their education belong in classrooms of standard schools
8. Pupils and students with attention deficits belong in classrooms of standard schools
9. Pupils and students who systematically fall behind with their school results belong in classrooms of standard schools
10. I'm convinced that the presence of a disabled pupil or student shall significantly increase my work load
11. I'm not convinced of the quality and effectiveness of support, which is provided when educating integrated disabled pupils and students on the part of professional workplaces
12. I'm not convinced that my preparation for working with disabled pupils and students is sufficient for achieving the required results
13. I'm convinced of the fact that on my part it is not possible to pay necessary attention to an integrated pupil or student
14. I'm apprehensive that disabled pupils or students shall not be well accepted in a classroom of intact contemporaries
15. I regard the presence of a disabled pupil or student in a classroom as a great source of psychical load for myself.

The sentiments, attitudes and concerns of educators when working under the conditions of inclusion

Abstract

This research is part of the international research project SACIE (Sentiments, Attitudes & Concerns about Inclusive Education). The international research team is formed of Dr. Ch. Forlin – Institute of Education Hong Kong, dr. T. Loreman and Dr. Ch. Earle – Concordia University College of Alberta, Canada, Dr. U. Sharma, Monash University, Victoria, Australia, and the author of this article.

The research was focused on the field of sentiments, attitudes and concerns of educators when working with people with intellectual disabilities. This study aimed at discovering whether the above stated parameters change after qualification was achieved in special education. The results of research, encompassing a period of three years, aimed at describing a group of 794 educators from a developmental perspective of their attitudes, opinions and concerns focused on the process of inclusion.

The research was divided into two phases – the 1st phase before commencement of the university (Bachelor's) specialized study of special needs education, and the 2nd phase conducted a month before termination of this three-year study programme.

Uczucia, postawy i obawy nauczycieli pracujących w warunkach inkluzji

Streszczenie

Prezentowane badania są częścią międzynarodowego projektu badawczego SACIE (Uczucia, postawy i obawy dotyczące edukacji włączającej). Międzynarodowy zespół badawczy tworzą: dr Ch. Forlin z Instytutu Edukacji w Hongkongu, dr T. Loreman i dr Ch. Earle z Concordia University College of Alberta w Kanadzie, dr U. Sharma z Monash University, Victoria, z Australii oraz autor tego artykułu.

Badania dotyczą uczuć, postaw i obaw nauczycieli pracujących z osobami z niepełnosprawnością intelektualną. Badania mają na celu określenie, w jaki sposób wyżej wymienione parametry zmieniają się po uzyskaniu przez nauczycieli kwalifikacji w zakresie pedagogiki specjalnej. Wyniki badań realizowanych w ciągu trzech lat w grupie 794 nauczycieli uwzględniły rozwojową perspektywę zmiany postaw, opinii i uczuć nauczycieli w związku z procesem integracji szkolnej. Badania zostały podzielone na dwa etapy – pierwszy przed rozpoczęciem (licencjackich) uniwersyteckich studiów specjalistycznych w zakresie pedagogiki specjalnej, a drugi na miesiąc przed zakończeniem trzyletniego programu studiów licencjackich. Artykuł przedstawia zaobserwowane zmiany.

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FOLIA 98

Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

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Narrative research on the identity of disabled people in Tibetan culture

Instruction

Disabled people are a special group in this society. Their lifestyles are different from the lifestyles of most other people; their psychological development is also different from that of others'. Although vulnerable groups in today's society, close attention isn't paid to the lives of disabled people. Furthermore, their psychological development doesn't receive the necessary importance and research interest as it should. According to an aboard study of disabled people's psychological development, there has been an increase in research concerning their education, development of socialization, and identity issues and acceptance, which have become a hot spot in this research domain. At present, there are less research achievements in this field in China compared to this type of research aboard. We obtained preliminary results after having analyzed the data from home and abroad and found that the identity of disabled individuals is usually negative as it is difficult for them to evaluate themselves in a positive way.

However, I have found different results in my long-term anthropological investigation – disabled people show a lot of positivity in their identity and the development of their socialization is relatively successful and cheerful. This result is different from most domestic and foreign research results. Therefore, in this article I will describe the special performance of the identity of disabled people in Tibetan culture and an analysis of the reasons behind it.

Defining the concepts[1]

Tibetan Culture

Tibetans form one of the minority groups that have a long history and advanced culture in the Chinese national family. Millions of Tibetan people are located mainly in the Qinghai-Tibet plateau where the average height above sea level is more than 4000 meters. A lot of authors, especially some western scholars, think

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[1] The related concepts are defined in order to clearly demarcate the meaning of concepts in this article.

that "Tibet" is equivalent to "Tibetan". It should be noted that the extension of the concept of "Tibetan" is much wider than the concept of "Tibet". Nowadays, "Tibet" is administratively "the Tibet Autonomous Region" which is one of the autonomous areas of the People's Republic of China with 95% of inhabitants being Tibetan. However, the main spread of Tibetan nationality not only includes Tibet, but also almost the entire Qinghai-Tibet plateau and its adjacent areas. These areas include several units: Tibet, Qinghai, Gannan[2], Chuanxi[3], Dianxi[4], and so on.

Tibetan culture is a kind of cultural form in the region of the Qinghai-Tibet plateau created by Tibetans. This kind of culture is deeply rooted in the local culture, but also influenced by other cultural factors. Because of this, the Tibetan culture has certain differences that are concretely expressed. For example, in terms of different dialects, the Tibetan culture includes Kangba Tibetan, Anduo Tibetan, and Weizang Tibetan. In addition, Tibetan is classified as a different area. In this article, Tibetan culture mainly refers to the area of Chuanxi[5] Tibetan culture.

Identity

The concept of identity is widely used in psychology and sociology. It means the extent of the person's approval for his/her status, namely the extent of this approval and the internalization of his/her status. The concept reflects individual differences and group attitudes. Xu (2010) interpreted the identity as status identity, which means a person's attitudes towards an understanding, recognition and acceptance of his/her own national culture, and the characteristics of his colour, gender. Identity is also a kind of psychological phenomena and a kind of psychological process, and at the same time identity is a context problem. Because one person may belong to more than one group, in a particular context he would choose an identity; namely he/she attributes to a certain group and the identity of the group becomes his/her main focus.

The disabled identity mentioned in this article refers to how disabled people understand and accept the identity of a disabled status which concerns the disabled person's expectations and value.

The reality of a disabled identity in Tibetan culture

Since 2004, my colleagues and I have been carrying out anthropological investigations into Tibetan culture and education in the Chuanxi Tibetan areas. To our surprise, during the process we found that the local lives of the disabled are comfortable – they show a more active attitude and positive identity towards themselves in primitive conditions of unspecialized education, rehabilitation and alleviation of poverty, which is different from the Han areas. Therefore, a narrative is used to report some of the Tibetans' stories.

The story of John

John is a young Tibetan man, 25 years old, born in a poor country in the Aba state in the western part of the Sichuan province.

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[2] It means the south of Gansu province in China.

[3] It means the west of Sichuan province in China.

[4] It means the western Yunnan province.

[5] The western Sichuan province.

John's parents work in X city, a more developed city than his hometown, which is why at the age of two he came to live in this city with his parents. During that time he had access to good education, starting from primary school through high school. When he was 18 years old, he enrolled in a provincial university after having passed a very difficult examination and became the pride of his family. Unfortunately, he caught a heavy cold after attending military training for new students. His abilities of looking after himself were poor and the distance from the university to his home was far, so he couldn't get timely treatment until he was unconscious and sent to hospital by his classmates. However, by then the common cold had turned into acute meningitis. His illness had worsened by the time his parents arrived at the hospital and his intelligence was seriously damaged. It was equivalent to that of a 10 year old child. When he awoke, he had lost most of his memory and basic abilities. It's important to note that this mental injury can't be reversed and he will never return to his normal life as a youth.

At present, his parents have gone on early retirement and set up a "happy farmhouse[6]" in their hometown in order to create more comfortable living conditions for him.

John's understanding of his differences

Now, John can't go to university and lives at the happy farmhouse set up by his parents. His mother teaches him elements of simple knowledge and he often helps his parents with doing certain things.

John's attitudes are very pure and simple towards his "differences" with other normal young men, *"I'm ill now, I can't remember former things and I can't go to school." For his living conditions at present, he doesn't show self-degradation and anxiety. During the interview, he said to me smiling, "I'm fine; I study everyday and help my parents do some things. (…) I lived in X city before, I didn't know friends in my hometown, I have made many new friends since I came back who are all friendly to me." Also towards his future, he showed surprising positivity, "My mother said that my illness is still difficult to cure. If I can be cured, I will go back to school. If not, I will do my job at home and I can help my parents with the happy farmhouse. "*

It is not scientific to judge John's attitude as positive and optimistic based on such an interview because John's intelligence is equal to the intelligence of a 10 year old child. But all in all, it is a good thing for John's future that he can lightly face his "differences" and his abilities.

Family and social support for John

It needs to be explained that the "social support" mentioned in this article isn't related to welfare policy. It mainly refers to support from the social and human environment, namely the surroundings of disabled people and the (social) group's attitude towards the disabled.

John's parents were very good state-owned enterprise employees and his father was a middle level leader. They had high income and their life was prosperous and happy. His parents retired early and went back to their hometown to build a house and set up a happy farmhouse after John became ill. But the status of the family is worse than before because the happy farmhouse business is not as good as they had

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[6] It's a kind of hotel for excursions to the farm, always set up by the local farmer.

hoped it would be. His father said that they didn't regret their choice, *"For my child, we went back home. My son is ill, the people*[7]*outside laughed at him and made him fear going outside. Our place*[8] *is pure, and my child feels more suitable [there] than outside." "When I was in X city, my former colleagues even said, 'His son has become a foolish youth, he has nothing in the future.'"*

During the interview, we truly found that John's father's description was correct. Tibetans who live in his hometown are friendly to his son, *"We can't laugh at him, the child is very pitiful, why would we laugh at [him]?" "The suffering is his fate. He will be OK if we help him past this difficulty."*

The story of Peter

Another person's story we should narrate is that of an old Tibetan man. He was born in the city of Ganzi in Danba County in the western part of the Sichuan province and he has lived in Danba his entire life – he is 58 years old now. He is a carpenter.

The old man is innately deaf. He has never gone to school and he can't read or write. He is, however, happy. He has a virtuous wife and two healthy children, a son and a daughter, who have already finished their education at the local school. The old man is an excellent carpenter and bricklayer in his country. He often helps people in the villages build houses and makes furniture in several counties. The local people feel respect for him because he is very kind and his craft is excellent. The old man finds his value in this ability.

Peter's understanding of his differences

Although the old deaf man is illiterate, he can't read or write, his life is valuable due to his own power. The old man told us with sign language, *"Although I can't hear and speak, I am actually not different from others, we are the same person. We drink beer together and we are so happy. "* His current life is satisfactory to this old man. He hopes that the future will be great, *"My children are very healthy, my son is working and my daughter is still a student, they are so kind to me."* We were very glad that he was always smiling happily and placidly in the interview.

Family and social support for Peter

His wife is a very virtuous farmwife. She is so dedicated because she not only does the farm work and feeds the cattle, but also takes care of the family every day. She was very shy when she talked about her marriage, *"I felt a bit anxious when I was preparing to marry him because this life isn't convenient. But I think it's very important that he is a kind man. We have been very happy since our marriage." We asked the daughter of the old man, "Did you feel embarrassed because of your deaf father?"* The daughter shook her head eagerly and said, *"No, no, I didn't feel [even] a bit embarrassed, and in my opinion, it isn't a thing of losing your face. When I was a child, I didn't know why my dad was different from the others, why he could not speak to me? But now, I understand and I love my dad dearly."*

The old man has received high praise from the friends and villagers around him. They said, *"He is the best carpenter in our village. (...) He is very kind, his skill is excellent and his wages are low." Regarding his disability, the villages show sympathy*

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[7] In this sentence "the outside people" means the people in X city; Han people are usually called "outside people" by Tibetans.

[8] "Our place" means the Tibetan region.

and compassion, "His family is better than before because his children have grown up; we hired him to do some easy things and gave him a lot of earnings several years ago. He knew that we were helping him, so he tried to do his best. (...) The deaf man is a pitiful sight. We often invite him to drink together. "

A brief summary of the stories

We recorded the two Tibetans' stories using the narrative method. Although their identities showed obvious individual characteristics, the identified statuses are changing. But overall, they accept their disabled status, have self-approval, and don't show an obvious feeling of isolation and self-despisal. They already find their value in their real lives.

"We can see the sun from a drop of water" – although we have only narrated the stories of two disabled individuals, we find that disabled people show a high level of identity in our long-term research in the Tibetan area. They not only can make sure of this identity themselves and through their cultural groups, but it also actively reflects their value in social life.

Religious sense of worth – important factors influencing the identity of the disabled in the Tibetan region

The factors influencing the identity of disabled people are complex. For example, some scholars study the factors influencing deaf identity from three aspects: the degree of hearing loss, the time that hearing became impaired, family factors and the educational mode.[9] Besides the regular factors, harsh natural conditions, a simple production form, less pressure, and so on influence the identity of the disabled in the Tibetan area. In addition, Tibetans are deeply influenced by the Tibetan culture, so one of the most important factors for the disabled Tibetans is their religion.

It is clear that religion is what can best represent culture on the level of ideas if we treat Tibetan culture in terms of material, conceptual and behavioural aspects. Tibetan people all have their own religion, which was formed during the process of fighting against the harshness of nature. The religion originally worshiped everything as a spirit on earth and later turned into totemism with a ceremony, generally called the "Benbo" religion ("Bon" religion for short). Buddhism was formally introduced into Tibet at the beginning of the 7th century. After fighting for a long time against the Bon religion, Buddhism and the Bon religion assimilated and integrated with each other forming Tibetan Buddhism – a religious culture with national and regional figures. Tibetan Buddhism is the main aspect of Tibetan religious culture.

The principle that "any form of evil cannot be done; every form of kindness should be done; every form of desire should be cleared by oneself," is the religious discipline of Tibetan Buddhism. It is also the orders of other types of Buddhism. The religious discipline forms the code of ethics, which develops generosity and insists on altruistic behaviour. The traditional sense of worth influenced by this religion becomes the important factor influencing the identity of the disabled in Tibet.

The Nirvana extrication realm of life

Tibetan's Buddhist outlook on life is what makes the different stratums of Tibetan believers have an entrustment in their own ultimate life, i.e. they pursue the ultimate

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[9] Hu Yamei, Research on the Deaf Identity of College Students [D], Liaoning Normal University, 2005.

value of the "future world" and the "Buddhism kingdom".[10] The pain of this life will be the sweets of the future. Everything they do is based on the principle of whether it is beneficial for the future and for becoming a Buddha. They have their own destination, fate. This kind of pursuit of an open soul and ultimate value makes their life rich, develops their personality, and clears up mental confusion and inner tension.

The disabled who have a Tibetan cultural background are influenced by these ultimate values, and naturally this makes their hearts quiet, calm, optimistic, and indifferent. It doesn't matter whether you are a disabled or an able-bodied guy, it is normal to be in pain for the "future world" and the "Buddhism kingdom". To solve the ultimate problem of life and values is to solve inferiority, worry and other emotional disorders in real life; then it is possible to have positive identities of your own.

Mercy and altruistic moral consciousness

Due to the influence of the Buddhist altruistic spirit, most Tibetan believers have a morality of compassion, kindness, equality and friendship. For the sake of interpersonal relationships, any moral subject tries their best to eliminate their selfishness and pursue the principle that everything is for everybody. This forms the modest and harmonious Tibetan spirit. This kind of moral consciousness enhances kinship between people, and is beneficial for remitting contradiction and tension between people and for building a harmonious life order.

This kind of mercy and altruistic moral consciousness creates the perfect survival condition for the disabled in Tibet. People around them treat them modestly, mercifully and with dedication, which gives great non-governmental social support and facilitates the villagers to be kind to John and Peter. It's a good example.

Intense passion for life

Tibetan Buddhism is full of the passion for life. This kind of religion pays attention to life. One with the highest life and a supreme good heart cares for all lives, even showing compassion to animals and plants, and advocates love towards them as well as their living environment.

People in the Tibetan region show their compassion for life including animals and plants, let alone human life. Even though the disabled have deformities on their bodies, they are still human live and need other people's respect and care. As disabled people, they respect and love their life; as healthy people, they respect and care for the life around them. The disabled people in Tibetan culture further strengthen their identity.

The principle of equality and independence in handling affairs

The sense of equality in Tibetan Buddhism states that people are born equal among each other as well as between human life and other forms of life. Meanwhile, Tibetan Buddhism affirms that people can overpass their own limitations to make the leap from a human to a Buddha by their own hard work. It means that our destiny is under our control and a better life is gained by our hard work in modern society.

The sense of equality of people in Tibet and the attitude in life that our destinies are under our control provide a harmonious atmosphere for people and a tenacious work will for the disabled in Tibet.

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[10] Lu Yang, On the Thoughts of Tibetan Buddhism Ethics [J], Beijing Instituted of Graphic Communication, 2010(2): 60–63.

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Narrative research on the identity of disabled people in Tibetan culture

Abstract

It's a common view in academia that most disabled people have a negative identity. However, presented long-term anthropological investigation, showed that disabled people had a very positive identity in Tibetan culture. This article describes the stories of two disabled Tibetan individuals using the narrative method. In reference to these cases, the local religion is analyzed, which is an important factor that deeply influences the identity of disabled Tibetans.

Badania narracyjne nad tożsamością osób niepełnosprawnych w kulturze tybetańskiej

Streszczenie

W środowisku akademickim powszechnie sądzi się, że większość osób niepełnosprawnych przejawia negatywną tożsamość. Jednak prezentowane właśnie długoterminowe badania antropologiczne pokazują, że osoby niepełnosprawne w kulturze tybetańskiej przejawiają bardzo pozytywną tożsamość. Niniejszy artykuł prezentuje biografie dwóch osób niepełnosprawnych, opracowane na podstawie metod narracyjnych. Odwołując się do tej analizy przypadków, uwzględniona została miejscowa religia, która jest jednym z ważniejszych czynników głęboko wpływających na tożsamość tybetańskich osób niepełnosprawnych.

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Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

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The adaptive behaviour of children with an intellectual disability in China

Introduction

The study of adaptive behaviour originated from a debate on the diagnostic criteria of an intellectual disability. For many years, adaptive behaviour was largely ignored in the assessment of special individuals, and an IQ score tested with an intelligence scale was the sole criterion of intellectual disability. Many problems in using an intelligence scale were exposed. A lot of researchers doubted and opposed IQ scores as a unique criterion of intellectual disability and augured that it should be diagnosed in different ways. In 1936, Edgar A. Doll first put forward the view that a person's social competence should be strongly considered as a diagnostic criterion for intellectual disability. From then on, more and more researchers focused on adaptive behaviour. In 1959, the American Association on Intellectual disability (AAMR) formally proposed the inclusion of adaptive behaviour as a diagnostic criterion for intellectual disability.

In China, the second countrywide disabilities investigation in 2006 reported that there were approximately 5.54 million people with an intellectual disability – 6.68 percent of all reported disabilities. Researchers found that there are many problems concerning adaptive behaviour, such as aggression, difficulty with communication, impairment of self-control, anxiety, withdrawal, impulsiveness, and so on (Sun and Ji, 2007; Zhang, 2004; Wei, 1997; Liu, 2009). Although developing the intellectual ability of children with intellectual disabilities is very difficult, it is easier to improve their adaptive ability. So, in order to facilitate independence and social responsibility in children with intellectual disabilities, it's very important to improve their adaptive competence for special education.

What characteristics of adaptive behaviour do children with intellectual disabilities in China have? What measurements are used to test their adaptive behaviour? What are the influencing factors? What should we do to improve the adaptive competences of children with intellectual disabilities? To answer these questions, this article summarizes the research carried out in recent years in China on the adaptive behaviour of children with intellectual disabilities and proposes topics that should be investigated in the future in order to provide suggestions for further studies in this area as well as ideas on education for children with intellectual disabilities in China.

The concept of adaptive behaviour

The concept of adaptive behaviour, which is also called social adaptive behaviour and social competence, is not always defined uniformly. AAMR (1981) defines adaptive behaviour as an individual's effectiveness in meeting the standards of maturation, learning, personal independence and social responsibility that are expected for his or her age level. Grossman (1983) views adaptive behaviour as an individual's competence in everyday activities that meets the demands of his/her personal life and of society or behaviour that meets the demands of the natural and social environment. AAMR (1992) describes ten basic social adaptive skills, including communication skills, self-care skills, family life skills, socialization skills, community life skills, self-direction skills, health and safety skills, study skills, entertainment skills, and work skills. AAMR (2002) further denotes adaptive behaviour as conceptual, social and practical skills. Conceptual skills include language, reading, writing, and concepts of money. Social skills include interpersonal skills, responsibility, self-esteem, gullibility, following rules, and obeying rules. Practical skills include daily-life skills (eating, dressing, toileting, housekeeping, transportation, etc), occupational skills and safety skills.

Chinese researchers have further views on the concept of adaptive behaviour. Luo and colleagues (1992) regard social adaptive competence as the ability of an individual to change his/her attitude and habit to adapt to the social environment and meet social demands. Wei (1999) categorizes adaptive behaviour from the perspective of the students' learning and development as an individual, social, and occupational adaptation. Individual and occupational adaptations are equivalent to practical skills described in the AAMR definition of intellectual disability, and similarly, social adaptation is equivalent to social skills. Wei thinks it incorrect to made adaptive behaviour equivalent to social adaptive competence. This is because adaptive behaviour includes adaptation to the natural and social environment, whereas social adaptive competence is related to social skills, such as interpersonal interaction skills whose key component is building and maintaining good social relationships. As a result, social adaptive competence is only a part of adaptive behaviour and not equivalent to adaptive behaviour (Wei and Wang, 2004). Shen and Zheng (2010) consider adaptive behaviour as an individual's basic skill, demanded by social culture, which is trained by adapting oneself and adapting to society. According to his view, adapting oneself is the ability to survive, such as manage self-care, cognition, emotion; adapting to society is participating in society, gaining social resources and having social responsibility.

Despite the differences in the detailed contents of various definitions, there are two consistent themes. One is that adaptive behaviour is related to personal independence and social responsibility in order to adapt to the natural or social environment. The other is that the diagnostic criteria for adaptive behaviour vary with age and culture.

The measurement of adaptive behaviour in children with an intellectual disability in China

Certain measurements of adaptive behaviour have been developed and used in Western countries, such as the Adaptive Behavior Inventory for Children (ABIC, Mercer and Lewis, 1978), the AAMD Adaptive Behavior Scale (ABS, Nihira, Foster, Shellhaas, and Lehand, 1974) and the Vineland Adaptive Behavior Scale (VABS, Sprrow, Bella, and Ciccehitte, 1984). Because of the differences between the Chinese and Western cultures, we shouldn't directly copy the Western scales of adaptive behaviour to test children with intellectual disabilities in China. As a result, certain scales have been revised and developed.

Adaptive Behaviour Assessment Scale for Children The scale was developed by Yao and Gong in 1984, includes 54 items, and assesses unimpaired or intellectually disabled children from 3 to 12 years of age. This measurement consists of eight sub-domains: sensorimotor development, self-help, language development, self-direction, social responsibility, concepts of time and space, occupational skills and economic activities. These skills are categorized into 3 dimensions: independence skills, cognitive skills and social/self-control skills. Independence skills include sensorimotor development, self-help, occupational skills and economic activities. Cognitive skills include language development and concepts of time and space. Social/self-control skills include self-direction and social responsibility. The internal consistency coefficient of the scale is more than 0.74; test-retest reliability is between 0.96 and 0.99; inter-rater reliability is more than 0.93; validity is between 0.80 and 0.90.

Social Life Competence Scale for Infant-Student in Junior Middle School This is the second version of the scale, originally created by Zuo and Zhang in 1994, and based on the "S-M Social Life Competence Inventory". The scale assesses unimpaired or intellectually disabled children from 6 months to 15 years of age. The six sub-scales are: self-help, locomotion, schoolwork, communication, participation in group activities, and self-control. The internal consistency coefficient is 0.98; criterion-related validity is 0.95. The measure is widespread in scientific research and clinical work.

Adaptive Behaviour Scale for Children This scale was created by Wei in 1996 based on the AAMD Adaptive Behavior Scale (school edition, 1981) and includes 79 items that assess unimpaired or intellectually disabled children from 3 to 15 years of age. The scale consists of two sub-scales. One was designed to evaluate adaptive behaviour and includes six sub-domains: motor development, language development, self-help skills, housework skills, self-management and socialization. The other was designed to evaluate maladaptive behaviour and includes twelve sub-domains: aggressive behaviour, antisocial behaviour, opposition behaviour, discreditable behaviour, withdrawal, rigid and self-hurt behaviour, inadequate interpersonal interaction styles, language impairment, feeing disorders, odd behaviour, hyperactivity, and emotional instability. The internal consistency coefficient is more than 0.98. Other detailed information about reliability and validity has not been reported.

Adaptive Behaviour Inventory for Children with an Intellectual Disability The inventory was developed by Shen and Zheng in 2010 and assesses intel-lectually disabled children who are 3 to 18 years old. It is designed to use a 5-point scale, ranging from never to almost always; high scores indicate a higher level of adaptive behaviour. The inventory includes 68 items representing 6 dimensions: sensory development, motor development, self-help, interpersonal relationships, self-management and social responsibility. The internal consistency coefficient is 0.98; the test-retest reliability is 0.95, validity coefficients are between 0.69 and 0.95.

Characteristics of adaptive behaviour in children with an intellectual disability in China

General characteristics

In China, researchers have adopted different scales to measure the adaptive behaviour of children with intellectual disabilities as compared to that of unimpaired children. The results are consistent, revealing that the level of adaptive behaviour in children with intellectual disabilities is significantly lower than that of unimpaired children, while maladaptive behaviour is significantly higher.

The development of adaptive behaviour in children with intellectual disabilities falls behind that of same-age unimpaired peers (Luo, 1992; Wei, etc., 1997; Zhang, 2002). With advancing age, the gap between the adaptive behaviour of children with intellectual disabilities and unimpaired children becomes wider and wider, especially concerning the level of cognitive competence (Zheng and Huang, 2005). Furthermore, a study indicated that the discrepancy between children with intellectual disabilities and unimpaired children was the greatest in language development and the least in motor development (Wei, 1997). Researchers reported that the main cause of late adaptive behaviour development was the disability of cognition and thinking, which was caused by delayed language development (Wei, 1997; Zhang, 2002).

In their study, Sun and Ji (2007) found that the scores on maladaptive behaviour in children with intellectual disabilities were higher than that of unimpaired children; problematic behaviour was also more serious than that of unimpaired children. The proportion of problematic behaviours in children with intellectual disabilities was 39.4%, two times that of unimpaired children. The main maladaptive behaviours are: aggressive behaviour, emotional instability, withdrawal, bad speaking habits, and inadequate interpersonal interaction styles (Wei, 1997; Liu, 2009).

Individual differences in adaptive behaviour

The gap in adaptive behaviour among intellectually disabled children is wider than for unimpaired children. The development of the adaptive behaviour of intellectually disabled children is more imbalanced than that of unimpaired children (Luo, 1992; Wei, 1997). The skills related to cognition and thought develop worse, while other skills develop better (Wei, 1997). Chen (2005) employed the Adaptive Behaviour Assessment Scale for Children to test 133 students with intellectual disabilities and analyzed the differences in their scores in independence, cognitive, and social/self-control skills. The results indicated that social/self-control skills develop best and that independence and cognitive skills develop worst. This is in line with the research results of Jia (2001) and Zhang (2002). They discuss the reasons behind these results and there was found a significant positive correlation between cognitive skills and intelligence. Because of an intellectual disability, cognitive skills develop worse than social/self-control skills and independence skills. The level of independence skills is lower than that of social/self-control skills. A potential reason for this is the comorbidity of an intellectual and physical disability in some children – these children's independence skills are affected by their physical disability.

Gender differences in adaptive behaviour

Are there gender differences in the adaptive behaviour of children with intellectual disabilities? The results from studies are not consistent. Wang and Wang (2004) adopted the School Social Behavior Scale (SSBS) by Kenneth and Merrell, to evaluate 887 mentally retarded students in Beijing. The study found that boys' scores were significantly higher than girls' on the antisocial behaviour subscale. Meanwhile, the girls' scores were significantly higher than that of boys' on the self--management skills subscale. Liu (2009) reported that boys' scores were significantly higher than girls' on rigid, self injury behaviours and bad speaking habits.

However, the same results did not appear in the research of Zheng (2005) who investigated 110 students with intellectual disabilities using the Child Assessment Scale of Adaptive Behavior and analyzed their scores in terms of gender differences in adaptive behaviour. The study demonstrated that the development of adaptive behaviour was not significantly different between mentally retarded students of different genders. These results were supported by Wang (2006), who studied the adaptive behaviour of children with a mild intellectual disability and found that there was no significant difference between girls' and boys' adaptive behaviour. The issue whether or not there are gender differences in children with intellectual disabilities should be investigated further.

Developmental tendencies of adaptive behaviour

Although the level of adaptive behaviour in children with intellectual disabilities is significantly lower than that of unimpaired children, their adaptive competence continues to develop. There is great developmental potential in the adaptive behaviour of children with intellectual disabilities (Wei, 1997). Jia (2001) reported that the adaptive behaviour of children with mild /moderate intellectual disabilities develops between 4–12 yeas of age. Concretely speaking, cognitive skills develop fast before 7–8 yeas of age and then gradually slow down. On the other hand, social and independence skills still continue to develop with age .These findings were confirmed by a study conducted by Jia and Zhang (2003) who adopted the Adaptive Behavior Scale for Children and carried out comparative research among unimpaired children and children with mild and moderate intellectual disabilities between the ages of 4 and 12 on the cognitive and social abilities and independence skills that are part of adaptive behaviour. The results indicated that the development of independence skills and social abilities accelerated with age, but that the cognitive ability of children with intellectual disabilities developed much slower than that of unimpaired children. Therefore, they propose that an intervention concerning adaptive skills should be early and that it may be more effective if these interventions are directed in preschool towards children with intellectual disabilities.

These results indicate that adaptive behaviour in mentally retarded children has great potential and that the gap in adaptive behaviour between mentally retarded children and unimpaired children can be narrowed by early and effective interventions.

Factors influencing adaptive behaviour in children with an intellectual disability in China

A. Intelligence

Adaptive behaviour is both different from intelligence and related to intelligence. Guo and Dai (2008) explored the relationship between IQ and adaptive behaviour and found a moderate correlation between the children's intelligence component and adaptive behaviour. Therefore, intelligence may be an important factor in the adaptive behaviour of mentally retarded children. This view is supported by Chen and colleagues (2005) who tested the intelligence and adaptive behaviour of 133 students with intellectual disabilities aged, between 7 and 17, in two special schools for the mentally retarded. Analyses revealed that students' scores on adaptive behaviour decreased according to their level of intellectual disability. A significant positive correlation was found between intelligence and adaptive behaviour. Zhang (2002) found that the level of development of adaptive behaviour in children with moderate and severe intellectual disabilities was lower than that of children with mild intellectual disabilities. Zheng (2005) analyzed the declining trends of the three factors of adaptive behaviour: cognitive ability, independence skills, and social ability, comparing different groups of children with intellectual disabilities (borderline, mild, moderate, severe, and profound). Along with the degree of intellectual deficiency in students, different factor capacities of adaptive behaviour had different declining trends – social ability declined according to the level of intellectual disability; independence ability declined significantly between the borderline group and the severe group but had no obvious decline from the severe group to the profound group. Cognitive ability declined significantly between the borderline group and the mild group and between the severe group and the profound group but didn't decline obviously from the mild group to the moderate group.

These studies demonstrate that being limited by intelligence, the development of social adaptive abilities in children with intellectual disabilities is also impeded. When training the adaptive capacity of children with intellectual disabilities, the degree of the intellectual disability should be considered and different training methods should be used accordingly (Wang and Yuan, 2007).

B. Parenting styles

Parenting styles play an important role in the adaptive behaviour of children with intellectual disabilities (Jiang, 2004; Zhao, 2006; Wang, 2006). A study by Zhao and Wang (2006), who employed a questionnaire to examined 268 unimpaired and mildly mentally retarded students aged from 12 to 15, explores the relationship between parenting style and the adaptive behaviour of mildly mentally retarded students. The results showed a significant difference in parenting style between these students and their unimpaired peers. In addition, parenting style had a significant influence on the students' adaptive behaviour. Parental warmth and understanding had a positive effect on the adaptive behaviour of children with mild intellectual disabilities, but parental punishment, rejection and denial had a negative effect. To further examine the relationship between parenting style and the adaptive behaviour of children with mild intellectual disabilities, a multivariate logistic regression analysis was conducted and found that parenting styles can predict the adaptive behaviour of these children, maternal styles being especially more effective than paternal styles. These results revealed that maternal warmth and understanding can positively predict the children's communication, socialization and self-help abilities. Maternal rejection and denial can negatively predict self-direction abilities. A study by Wang (2006) came to the same conclusion. The reason why mothers play a more important role in the development of their children's abilities is because most children are mostly taken care of by their mothers, especially children with intellectual disabilities in China. In comparison to fathers, mothers take more time to stay with their children and give them more care.

C. Peer relationships

Peer relationship effect the adaptive behaviour of children with intellectual disabilities also. Peer relationships may promote the level of cognition, socialization and social behaviour of children and contribute to their social adaptation development (Zhao and Zhou, 2003).Wang (2006) reports that acceptance by peers can positively predict the child's communication and socialization abilities. Fear and inferiority in communication can negatively predict locomotive and occupational abilities.

In China, the status of peer acceptance for children with intellectual disabilities is worse than for unimpaired children. Children with intellectual disabilities are more afraid and self-contemptuous in communication with others than unimpaired children (Zhang, 2006). Additionally, unimpaired students generally choose a negative attitude towards mentally retarded students (Wu, 2003). Hence, children with intellectual disabilities are not willing to actively communicate with peers, their peer relationships are not good, and consequently, their social adaptive ability is influenced.

D. Educational situation

In China, learning in special schools and learning in regular classes are the two main educational situations of children with intellectual disabilities. Are there any differences in adaptive behaviour between children with intellectual disabilities in special schools and those in regular classes?

Wang (2006) reported that students with intellectual disabilities who were taught in regular classes, showed a higher degree of adaptive behaviour than those in special schools. Hong (2006) thinks that children with intellectual disabilities in special schools have fewer friends, are more passive and lonelier than those in regular classes. It may be that students with intellectual disabilities who are taught in regular classes have better peer relationships than those in special schools and experience fewer negative parenting styles (Wang, 2006).

However, there is also a different viewpoint. Zhang and colleagues (2004) adopted the Mental Health Test to explore the mental health of children with a mild intellectual disability and found that those who were taught in regular classes had more conspicuous mental health problems. Their scores on anxiety, interpersonal anxiety, proneness to loneliness, physical symptoms, and proneness to fearfulness were obviously higher than those of children in special schools. They conclude that children with intellectual disabilities in regular classrooms may have more maladaptive behaviours than those in special schools. Therefore, the influence of the educational situation on adaptive behaviour in children with intellectual disabilities should be further discussed.

Intervention in adaptive behaviour in children with an intellectual disability in China

What should we do to improve the adaptive behaviour of children with intellectual disabilities? A number of researchers proposed certain suggestions. Wu (2010) points out that the main interventions for children with intellectual disabilities in China include musical therapy, sensorimotor integration therapy, language training, mental health education and peer help. Hu (2003) analyzes the case of training calligraphy for three months by three children with intellectual disabilities and concludes that calligraphy training might be an effective method to improve and raise mental abilities, to increase confidence, and to eliminate harmful habits and negative emotions. Xu and Xu (2003) attach importance to the family-education model for children with intellectual disabilities which includes changing the family environment, developing the family's potential and thinking highly of the child's own interaction with his/her daily living environment. Zhang and Zhang (2005) believe that the environment provides an important approach to fostering adaptive abilities; subject education and social practice are considered very significant training methods. Wang (2006) thinks that adaptive ability can be improved by environmental influence and educational intervention. An environmentally ecological curriculum is an ideal educational model for teaching the intellectually disabled and with mutual support from schools, families and communities, the adaptive ability of mild to severely intellectually disabled children could be improved.

Prospects for future research

Based on current research, some consistent conclusions can be gained. The development of adaptive behaviour in children with intellectual disabilities is lagging, but there is great developmental potential .The discrepancy in adaptive behaviour among children with intellectual disabilities is greater than among unimpaired children. Intelligence, parenting styles, peer relationships and educational situations affect the adaptive behaviour of children with intellectual disabilities. Overall, the findings reviewed here provide basic knowledge of adaptive behaviour in children with intellectual disabilities in China. However, research in this area is not sufficient, as several important issues have not been addressed in depth yet.

Firstly, the measurement instruments of adaptive behaviour in children with intellectual disabilities need to be developed. In China, the scales of adaptive behaviour in children with intellectual disabilities have some issues. First, most of the scales are revised based on Western scales and may not be very fit for Chinese individuals. Second, insufficient reliability and validity should be tested further. Third, the countrywide norm has not been created. Hence, measurement instruments of adaptive behaviour that are of good quality and that are fit for Chinese children with intellectual disabilities should be developed.

Secondly, research on factors influencing adaptive behaviour in children with intellectual disabilities has not been sufficiently in-depth. At present, research on these factors mainly focuses on intelligence, parenting styles, peer relationships and the educational situation. However, many other potential factors are not included, such as personality, cultural context, social support, and so on. Also the mechanisms – how these factors influence adaptive behaviour in children with intellectual disabilities – should be explored in the future in an attempt to better understand the adaptive behaviour of these children.

Additionally, research on adaptive behaviour interventions for children with intellectual disabilities is greatly deficient. There have been only a few articles related to education and intervention for adaptive behaviour and most of them are theoretical. Empirical information about interventions from a psychological viewpoint is lacking. Consequently, more research on interventions is needed and may be helpful in developing better support for this population. Effective ways and operational guidance for adaptive behaviour in children with intellectual disabilities is also badly needed.

Finally, the majority of studies rely on survey methodology and cross-sectional studies; other research techniques have not been used to explore adaptive behaviour in children with intellectual disabilities. In the future, besides using quantitative methods, qualitative study methods should also be used, such as open interviews, observations, case investigations, etc. Longitudinal studies are equally necessary to attempt to investigate the changes and development of adaptive behaviour in children with intellectual disabilities as they grow older.

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The adaptive behaviour of children with an intellectual disability in China

Abstract

This article summarizes existing research on adaptive behaviour in children with intellectual disabilities in China in an effort to assess current research findings. It includes the concept, measurement, characteristics of development and factors influencing adaptive behaviour in these children. Based on the literature, this article concludes with a discussion of several topics that need to be addressed in future studies, such as developing assessment instruments suitable for Chinese individuals, exploring more in depth the influential factors and internal mechanisms of adaptive behaviour, as well as strengthening the research on intervention and integrating different study methods.

Adaptacyjne zachowania u dzieci z niepełnosprawnością intelektualną w Chinach

Streszczenie

Artykuł przedstawia istniejące badania dotyczące zachowania adaptacyjnego dzieci z niepełnosprawnością intelektualną w Chinach. Analizuje pojęcie, metody oceny, rozwój i czynniki wpływające na zachowania adaptacyjne. Na podstawie literatury wskazuje kierunki dalszych badań, m.in konieczność opracowania narzędzi badawczych adekwatnych do warunków chińskich oraz pozwalających na uchwycenie czynników i wewnętrznych mechanizmów. Podkreśla także znaczenie interwencji i integracji różnych podejść.

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FOLIA 98

Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

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The attitudes of mainstream primary school teachers toward inclusive education: a perspective from the People's Republic of China

Introduction

„Inclusive – a word much more used in this century than in the last, it has to do with people and society valuing diversity and overcoming barriers" (Topping and Maloney, 2005, p.1). Inclusive education is one of the most important current trends in the theory and practice of education. China began to nationally initiate inclusive education under the name of *sui ban jiu du* (Learning in Regular Classroom, LRC) in response to global trends and domestic pragmatic requirements after the middle of the 1980s (Deng and Zhu, 2007a). LRC has become the key form of providing compulsory education to children with disabilities in China. Though China has shown rapid development in special education since the end of the 1970s, special educational resources are still limited for children with disabilities because of the huge population and the fact that people who have disabilities are dispersed very broadly. Nowadays, in China the population exceeds 1.3 billion, and according to the official statistics from the national statistics office, there were 82.96 million people with disabilities in China till the year 2006, i.e. 6.34% of the whole population (Leading Group of the Second China National Sample Survey on Disability and National Bureau of Statistics of the People's Republic of China, 2007, May 28). Although we had set up 1672 special schools for children with special educational needs (SEN), it still could not meet the needs of special education development – 63.19% of school-aged disabled children went to school, but at the same time there were still 227,000 school-aged disabled children in China who did not go to school until the end of 2008 (China Disabled Persons' Federation, 2009, April 23).

Inclusive education has great significance for most children with disabilities in China. Most of the time, the only alternative for school-aged children with SEN is to go to school to receive nine years of compulsory education. China has implemented inclusive education more than twenty years ago. On the one hand, the amount of children with SEN being taught in regular schools increased greatly, but on the other hand, the quality of inclusive education is still a problem; some children with SEN only 'sit' alone in the regular classrooms or their names are on the registry although they stay at home (Wei, Yuan and Liu, 2001; Chen, 2003; Meng, Liu and Liu, 2007).

Also, there are lots of problems that are waiting to be solved, one of them being the attitudes that mainstream teachers have toward inclusive education.

Research results in China are varied. Generally, three kinds of attitudes can be identified in recent studies. Firstly, partial investigations show that some regular education teachers in primary schools have negative attitudes toward inclusive education (e.g., Liu, Du and Yao, 2000; Wei, 2000). Secondly, there are other studies that show that most regular education teachers in primary schools have positive attitudes toward inclusive education (e.g., Zeng, 2007; Qian and Jiang, 2004). The third kind of surveyed attitude was the cautious attitude meaning that it 'depended on' other circumstances. Study results showed that there were lots of factors that could influence mainstream teachers' attitudes toward inclusive education, e.g. effective teacher training, the kind of disabilities the child with special needs had, and how severe the disability was (Peng, 2000, 2003).

These findings confirmed the importance of regular education teachers' attitudes toward inclusive education and revealed their various attitudes toward inclusive education from different points of view and from different experts in China. In addition, these findings were complicated and confused the author. In order to further realize the real status quo of regular education teachers' attitudes toward inclusive education, the following research questions were made the focus of this study:

1. What are the primary mainstream teachers' attitudes toward inclusive education in China?
2. Do they perceive that they are capable of implementing inclusive education?
3. What difficulties do they face when implementing inclusive education in their regular classrooms?

Method

A review was made of the relevant Western and Chinese literature describing target groups' (especially teachers', parents' and principals') perceptions of and attitudes toward inclusive education, mainly Deng's research findings (2004a), which revealed that teachers' attitudes toward inclusive education consisted of three principal components: the advantages and disadvantages of inclusive education and the advantages of a special school. According to the research questions of this study, one draft of the questionnaire was created, carefully worded, and formatted in Chinese by the author for mainstream primary school teachers involved in an inclusive program.

The researcher invited three special education experts and three frontline practitioners with at least 10 years experiences in implementing inclusive education in regular schools in China to review the draft and give suggestions. Minor changes in the wording and formatting of items were made following these critical reviews. The final questionnaire was field-tested by using 30 primary school mainstream teachers involved in an inclusive program.

This questionnaire is comprised of four parts. The first is an introductory statement to declare the purpose and significance of the research and an assurance of confidentiality. The second section has open-ended questions to elicit respondents' background information. The third section uses a 5-point Liker scale format (strongly disagree, mildly disagree, not sure, mildly agree, strongly agree) for items assessing respondents' attitudes toward inclusive education. The last section is designed as one open-ended question which asks respondents to list three difficulties they face when implementing inclusive education in their regular classrooms. In total there are 22 items.

Sampling

The Chinese respondents were regular education teachers from urban and rural mainstream primary schools in Sichuan Province, which is located in the southwest of China and has a population of 83,29 million (National Bureau of Statistics of China, 2001). Two sample sites, the Qingyang District of Chengdu City and the Xinjin County of Chengdu City, were selected for investigation. Mainstream primary schools that had students in classes with any of the three major disabilities, i.e. mental retardation or a hearing or visual disability, were chosen in the two sample sites from grade 1 to grade 5. As a result, 120 teachers from 36 mainstream primary schools were surveyed; among the returned questionnaires, 98 questionnaires proved useful for further analysis, including 66 urban questionnaires and 32 rural questionnaires.

The demographic information of the Chinese mainstream primary school teacher sample showed a high percentage of female respondents (85%). 40.8% of respondents were 30–39 years old. 57.1% of them had a bachelor education degree. 68.3% of them had less than five years of teaching experience with students with SEN in regular classrooms. 38.8% of them reported that they had never received any training in inclusive education. 44.9% of respondents reported they received less than one month of training. Finally, 58.2% of them had done some school-based research for inclusive education[1].

Procedures of investigation

Firstly, the author contacted the related local education departments to make an announcement to all participating schools, asking for cooperation. After that, the author personally conducted the formal survey on the spot, going from school to school.

Data analysis

Data were coded and entered into the Statistical Package for Social Sciences (SPSS) for Windows (15.0). Statistical analysis of the data was conducted using descriptive statistics and a one-way ANOVA.

Results

1. Results from closed questions of the questionnaire[2]

60.2% of all respondents agreed that all children should be educated in regular classes, but it seemed there were many disputes on this point (M=3.37, SD=1.271). 66.3% of them agreed that students with SEN could improve academically because of inclusive education. Also, 79.6% agreed that inclusive education could promote these students' social and emotional development and 78.6% of them reported that inclusive education promoted different students' mutual communication, understanding, and acceptance about individual diversity. The item, "There are

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[1] Corresponding data can be found in annex 1.

[2] Corresponding data can be found in annex 2, 3 and 4.

sufficient supportive resources and professionals to support inclusive education in regular schools," had a relatively low mean (M=2.83) with the highest standard deviation (SD=1.313), which reflected lower level agreement as well as the fact that there were many disputes on this point.

Respondents did not agree they had corresponding knowledge and skills to educate students with SEN, and responses were varied due to the relatively low mean (M=2.84) and high standard deviation (SD=1.097). 59.2% of respondents did not agree regular education teachers' instructional effectiveness would be enhanced by implementing inclusive education and it seemed there were many disputes on this point (M=3.00, SD=1.218). The opinion as to whether regular education teachers felt comfortable working with students with SEN and their parents, seemed to be controversial and responses were centred on "not sure" (M=3.19, SD=1.233).

It's interesting that at the same time, 78.6% of respondents agreed that special, separate settings could best serve the needs of students with SEN. The low mean score (M=1.62) and low standard deviation (SD=0.711) indicated that respondents mildly agreed that children with severe disabilities should be educated to a large extent in special, separate settings. The statistics showed that respondents mildly agreed that special education teachers were trained to use different teaching methods to teach students with SEN more effectively, and they also mildly agreed that children communicating in special ways should be educated to a large extent in special, separate settings. All the statistics of the items analyzed in this paragraph indicate that respondents had positive attitudes toward separate special education.

90.8% of respondents agreed that inclusive education sounded good in theory but to a large extent did not work well in practice (M=1.79, SD=0.759).

In addition, a one-way ANOVA for respondents' attitudes toward inclusive education as a whole showed that teachers with different genders, teaching years, educational backgrounds, training types, and training time did not demonstrate significant differences. However, there were significant differences between respondents who had different experiences with research, F (1, 96) =18.934, p<0.001.

As a whole, the average mean of the entire attitude was 2.73 with a relatively lower standard deviation of 0.633, indicating all responses of this section were centred to a large extent on "not sure"; that's to say, it seemed that respondents had relatively negative attitudes toward inclusive education. It is very interesting, however, that all statistics showed huge contradictions between teachers' attitudes toward inclusive education and special school education. On the one hand, they recognized the advantages of inclusive education, but on the other, they admitted that there were benefits connected to special school education also, and at the same time, they agreed that, "inclusive education sounds good in theory, but difficult to realize in practice".

2. Result from the open-ended question of the questionnaire

In the last part of the questionnaire, there was one open-ended question designed to ask the regular education teachers to write down three current difficulties they were facing when implementing inclusive education in their regular classrooms. About three fourths of all 98 respondents wrote down their opinions. On the whole, all difficulties were outlined as the following:

"We have too large teaching workloads for regular education in order to attend to students with SEN."

To be specific, this aspect included these concrete difficulties: the class size was too big, it was difficult to meet individual special educational needs; teachers had too much pressure from regular teaching tasks, they had to devoted most of their time and energy to finishing heavy regular teaching loads, so they had no time to take particular care of students with SEN and to tutor them in class or after class. Many teachers expressed that, "I am willing, yet unable".

"We lack knowledge and skills about special education, which caused us to feel difficulty in implementing inclusive teaching in regular classes."

Many teachers reported they had no knowledge and skills about how to teach students with SEN in regular classrooms because they lacked the corresponding training and experience. For example, lots of teachers said it was very difficult to grasp the instructional goal, contents, approaches and methods for teaching students with SEN, because these students were so different from typical students. Some teachers reported they had no idea how to adjust their teaching pace, methods and content to satisfy both students with and without SEN. The majority of teachers expressed their strong desires to have opportunities to get some training about special education and observe other teachers' practical inclusive teaching.

"We have some difficulties in communicating with students with SEN."

Many teachers reported they felt it was not easier to communicate with special education needs students, especially with students with hearing disabilities. They found that sometimes students with SEN liked to hide thoughts and feelings in their hearts and didn't like speaking about them to teachers, such as students with mental retardation. So, teachers did not know what these students really needed. And several teachers reported that communication difficulties among teachers, typical classmates, and students with SEN rose with age. Also, some teachers reported they observed that students with SEN became more inferior, sensitive and taciturn with age because they lacked in achievement and lagged behind other typical students, although teachers had no idea how to help them.

"We lack cooperation and support from parents' of children with SEN."

Teachers reported that some parents didn't want to accept and admit their children's exceptional needs, and they had a lot of resistance and violent reactions when teachers tried to tell them their children's exceptional actions and needs. Some parents had inappropriate expectations for their children's academic development, e.g. some of them had very low expectations and had even lost confidence in their exceptional children; they only cared about their eating and dressing but not about their learning and education. This is not to say that they educated their children at home; on the contrary, few parents had too high expectations for their exceptional children; they always hoped their exceptional children would develop as well as their typical peers. Some teachers reported parents were unable to implement family tutoring at home for their children with SEN, because they lacked patience or did not know at all how to do it.

"Our schools' support for inclusive teaching is not enough."

Some teachers reported that the leaders didn't attach importance to inclusive education in practice. Many teachers reported their school had no financial support for inclusive education and that they and their students with SEN could not get necessary teaching materials and equipment. Many teachers reported their school could not provide necessary support and services to students with SEN, such as specific textbooks, rehabilitation training, and equipment. Lots of teachers reported they could not get fair pay and good conditions though they devoted so much for inclusive education; their rewards were not always proportionate to their work. A few teachers reported that the teacher's assistant in their class lacked professional knowledge, and they could not offer appropriate services to students with SEN and help them integrate well into the regular class.

"There is still a small portion of typical students and parents of typical children that negatively support inclusive education."

Though teachers encouraged typical students to make friends with their disabled classmates, several teachers reported that a few of them did not like to do that. Some teachers reported there were some communication barriers between students with SEN and their typical classmates, especially for students with hearing disabilities. Also, several teachers reported that parents with typical children did not support having their children sit next to their classmates with SEN or becoming providers of peer-tutoring, because they worried that the special students would interfere with their children's 'normal' learning in the class.

"Current education system barriers are radical obstacles."

A few teachers reported that China's existing education system was knowledge-centred and exam-oriented, which made inclusive education in essence difficult to realize.

"The government does not have specific and effective policies to support inclusive education."

Several teachers realized that either the central government or local government should establish more tangible and pressing regulations and policies to support inclusive education. The existing policies could not guarantee that inclusive education would be implemented in real earnestness.

The results of the questionnaire showed that the respondents had negative but decrease attitudes toward inclusive education and felt they were not capable of implementing inclusive education in their regular classrooms. Most of them reflected they really needed support from the Government, school administrators, parents of children with SEN, and so on to help them carry out practical inclusive education in regular classrooms.

Discussion

The findings from the questionnaire mentioned above show that respondents were not consistent. However, these contradictions rightly reflect the characteristics of China's inclusive education.

Firstly, the author guesses that challenging social and cultural views of people with disabilities might influence respondents' attitudes toward inclusive education. Some adverse views come from the general public, such as "the existence of people with disabilities is worthless because they can not contribute to our society" (Xiao, 2005), meanwhile, "many people still believe that China will never be able to provide education for children with disabilities until all 'normal children' receive an education" (Chen, 1996). True equal treatment and respect for people with disabilities has not been developed well in China's current society. Wide acceptance and equal treatment for people with disabilities is not formed in the Confucian tradition, though most people have compassion for them.

Secondly, most regular education teachers do not have a good and deep understanding of inclusive education in the context of an adverse social atmosphere for people with disabilities, also because of the lack of professional training in inclusive education. In written responses to the open-ended question, some respondents said they did not clearly know what inclusive education was, so the most of them agreed that the benefits of inclusive education were just what these teachers thought – *"inclusive education should have these benefits"*.

Thirdly, until now, there has been a severe shortage of supportive resources for Chinese inclusive education. Mainstream schools still lack teaching materials and equipment, compensation training, counselling services, and qualified teachers to meet SEN education (Hua, 2003; Xiao, 2005). Compared with regular schools, special schools have a better equipped environment, more sufficient resources and professional services, and experienced special education teachers. So, if conditions permit, regular education teachers would like students with SEN to go to special schools.

Fourthly, China does not have enough special schools to offer special education to the majority of students with SEN, and most of the time, learning in regular classroom is the only alternative for students with SEN, and especially in extensive rural areas regular education teachers obviously realize this fact and have to accept students with SEN.

Finally, though teachers had an overload of teaching tasks and lacked knowledge and skills about special education, they did as much as they could for students with SEN and these students made some progress. So, they did think students with SEN could be integrated into regular classes in the existing condition, though many of these students could not get appropriate and sufficient support at regular schools.

Other researchers also showed similar findings about regular education teachers' attitudes toward inclusive education (e.g., Deng, 2008).

Conclusion and recommendations

In conclusion, because of an adverse social atmosphere and traditional notions about people with disabilities, there is a lack of an effective and systematic support system for inclusive education, and mainstream primary school teachers' attitudes toward inclusive education are still negative and contradictive. To improve this status quo, the following aspects can be considered:

1. Further intensifying and fostering positive social attitudes toward persons with disabilities via all kinds of approaches;
2. Accelerating the pace of legislation for special education, especially to establish a specific law for special education to mandate clear and flexible government financial support and systematic professional training;
3. Adjusting the development plan of the delivery of special education services. At the end of the1980s, a plan that "Special schools would constitute the 'backbone' of the system, and a large number of special classes and Learning in Regular Classrooms would serve as the 'body' (Deng and Guo, 2007b)," was advocated and has promoted the development of special education in China in the past two decades. However, it is not suited for the current development status of special education. The plan should be adjusted as, "a certain amount of special schools will serve as resource centres and a large amount of Learning in Regular Classrooms combined with resource room or itineration special education professionals will serve as the 'body' (Deng, 2004b)".
4. Accelerating the pace of the entire educational reform in China. Though China has carried out many educational reforms since the 1980s, current education is still knowledge-centred and exam-oriented, which basically hinders inclusive education's development. Only once quality-oriented education is advocated, mainstream teachers' attitudes toward inclusive education might begin to gradually change and inclusive education may really make great progress and be a possible in the future.

Limitations of this research

Our Chinese questionnaire sample was limited to mainstream primary school teachers in 36 regular primary schools in Chengdu City of Sichuan Province in China. It is unknown whether the characteristics of the respondents from these regions might be shared by samples from other regions.

Acknowledgements

This article is one of the outcomes of Research Project Supported by Scientific Research Fund of Sichuan Normal University for Young researchers; Project name: Research on the Chinese resource room's foundation and running in the context of inclusive education; Project Number: 10YBW11.

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Annex 1

	Variable	Frequency (n=98)	Percentage (%)
Gender	Male	13	13.3
	Female	85	86.7
Age	20–29 years	29	29.6
	30–39 years	40	40.8
	40–49 years	29	29.6
Educational Background	Secondary education	6	6.1
	College programs	30	30.6
	Bachelor programs	56	57.1
	Master or Ph.D. programs	6	6.1
Years of teaching students with SEN in a regular classroom	within 1 year	13	13.3
	1–3 years	30	30.6
	3–5 years	22	22.4
	5 years above	33	33.7
Grades that the teacher taught	1	11	11.2
	2	18	18.4
	3	16	16.3
	4	12	12.2
	5	41	41.8
Training types	None	38	38.8
	Pre-service	1	1.0
	Nonperiodic In-service	47	48.0
	Periodic In-service	8	8.2
	Pre-service + Nonperiodic In-service	4	4.1
Training time	Within one week	16	16.3
	1 week to 1 month	28	28.6
	1 month to 6 months	9	9.2
	above 6 months	7	7.1
	Missing	38	38.8
Research for inclusive education	Yes	57	58.2
	No	39	39.8
	Missing	2	2.0

Tab. 1. Demographic information of the sample (P.R.C)

Note: P.R.C is the abbreviation of the People’s Republic of China.

Annex 2

Items	Sd	Md	Ns	Ma	Sa	M/SD
All children should be educated in regular classes.	8.2%	25.2%	6.1%	41.8%	18.4%	3.37/1.271
Both students with and without SEN can academically improve because of IE.	8.2%	18.4%	7.1%	44.9%	21.4%	3.53/1.245
IE is likely to have a positive effect on the social and emotional development of students with SEN.	3.1%	10.2%	7.1%	54.1%	25.5%	3.89/1.004
IE programs provide different students with opportunities for mutual communication, thus promoting students to understand and accept individual diversity.	2.0%	11.2%	8.2%	55.1%	23.5%	3.87/0.970
There are sufficient supportive resources and professionals to support IE in regular schools.	16.3%	33.7%	17.3%	18.4%	14.3%	2.81/1.313
I have corresponding knowledge and skills to educate students with SEN.	7.1%	42.9%	12.2%	33.7%	4.1%	2.84/1.097
Regular education teachers' instructional effectiveness will be enhanced by having students with SEN in regular classes.	10.2%	31.6%	17.3%	29.6%	11.2%	3.00/1.218
I feel comfortable working with students with SEN and their parents.	10.2%	22.4%	18.4%	35.7%	13.3%	3.19/1.223

Tab. 2. Teachers' attitudes towards IE (P.R.C) – Advantages of IE

Note: Sd=Strongly disagree, Md= Mildly disagree, Ns=Not sure, Ma= Mildly agree, Sa=Strongly agree; Weights of "1", "2", "3", "4", "5" are correspondent to the categories "strongly disagree", "mildly disagree", "not sure", "mildly agree" and "strongly agree"; IE=Inclusive Education, SEN=Special Educational Needs. P.R.C = People's Republic of China. Items in Table 2 are mainly based on Deng (2004a).

Annex 3

Items	Sd	Md	Ns	Ma	Sa	M/SD
The needs of students with SEN can be best served in special, separate settings.^{x}	1.0%	11.2%	9.2%	40.8%	37.8%	1.97/1.009
Children with severe disabilities should be educated in special, separate settings..^{x}	1.0%	1.0%	4.1%	46.9%	46.9%	1.62/0.711
Special education teachers are trained to use different teaching methods to teach students with SEN more effectively. ^{x}		5.1%	5.1%	45.9%	43.9%	1.71/0.786
Children who communicate in special ways (e.g., sign language) should be educated in special, separate settings. ^{x}		11.2%	7.1%	44.9%	36.7%	1.93/0.944
IE sounds good in theory but does not work well in practice. ^{x}	1.0%	3.1%	5.1%	56.1%	34.7%	1.79/0.759

Tab. 3. Teachers' attitudes towards IE (P.R.C)—Disadvantages of IE

Note: Sd=Strongly disagree, Md= Mildly disagree, Ns=Not sure, Ma= Mildly agree, Sa=Strongly agree. Adverse weights of "5", "4", "3", "2", "1" are correspondent to the categories "strongly disagree", "mildly disagree", "not sure", "mildly agree" and "strongly agree" to all items with "x". IE=Inclusive Education, SEN=Special Educational Needs. P.R.C = People's Republic of China. Items in Table 3 are mainly based on Deng (2004a).

Annex 4

Items	Sd	Md	Ns	Ma	Sa	M/SD
All children should be educated in regular classes.	8.2%	25.2%	6.1%	41.8%	18.4%	3.37/1.271
Both students with and without SEN can academically improve because of IE.	8.2%	18.4%	7.1%	44.9%	21.4%	3.53/1.245
IE is likely to have a positive effect on the social and emotional development of students with SEN.	3.1%	10.2%	7.1%	54.1%	25.5%	3.89/1.004
IE programs provide different students with opportunities for mutual communication, thus promoting students to understand and accept individual diversity.	2.0%	11.2%	8.2%	55.1%	23.5%	3.87/0.970
There are sufficient supportive resources and professionals to support IE in regular school.	16.3%	33.7%	17.3%	18.4%	14.3%	2.81/1.313
I have corresponding knowledge and skills to educate students with SEN.	7.1%	42.9%	12.2%	33.7%	4.1%	2.84/1.097
Regular education teachers' instructional effectiveness will be enhanced by having students with SEN in regular classes.	10.2%	31.6%	17.3%	29.6%	11.2%	3.00/1.218
I feel comfortable working with students with SEN and their parents.	10.2%	22.4%	18.4%	35.7%	13.3%	3.19/1.223
The needs of students with SEN can be best served in special, separate settings.[x]	1.0%	11.2%	9.2%	40.8%	37.8%	1.97/1.009
Children with severe disabilities should be educated in special, separate settings.[x]	1.0%	1.0%	4.1%	46.9%	46.9%	1.62/0.711
Special education teachers are trained to use different teaching methods to teach students with SEN more effectively. [x]		5.1%	5.1%	45.9%	43.9%	1.71/0.786
Children who communicate in special ways (e.g., sign language) should be educated in special, separate settings. [x]		11.2%	7.1%	44.9%	36.7%	1.93/0.944
IE sounds good in theory but does not work well in practice.[x]	1.0%	3.1%	5.1%	56.1%	34.7%	1.79/0.759
Total	/	/	/	/	/	2.73/0.663

Tab. 4. Teachers' attitudes towards IE (P.R.C)--Total

Note: Sd=Strongly disagree, Md= Mildly disagree, Ns=Not sure, Ma= Mildly agree, Sa=Strongly agree; Weights of "1", "2", "3", "4", "5" are correspondent to the categories "strongly disagree", "mildly disagree", "not sure", "mildly agree" and "strongly agree"; adverse weights of "5", "4", "3", "2", "1" are correspondent to the categories "strongly disagree", "mildly disagree", "not sure", "mildly agree" and "strongly agree" to all items with "x"; IE=Inclusive Education, SEN=Special Educational Needs. P.R.C = People's Republic of China. Items in Table 4 are mainly based on Deng (2004a).

The attitudes of mainstream primary school teachers toward inclusive education: a perspective from the People's Republic of China

Abstract

Inclusive education is one of the most important current trends in the theory and practice of education. Though China has carried out many experiments on how to integrate children with special educational needs to learn in regular classrooms near their home since middle of the 1980s, inclusive education is still facing lots of developmental challenges.

The purpose of the study was to identify mainstream primary school teachers' attitudes toward inclusive education. The study was also designed to examine whether these teachers perceived themselves capable of implementing inclusive education in their regular classrooms, and what support they most needed to help them carry out inclusive education in practice.

One questionnaire was designed to obtain the needed data and was distributed to mainstream primary school teachers involved in inclusive programs and working in 36 public schools in China. An analysis of the collected data indicated that these teachers had negative but contractive attitudes toward inclusive education, and that they felt they were not capable of implementing inclusive education in their regular classrooms. The study ended with research-based recommendations for future practice.

Postawy nauczycieli masowych szkół podstawowych wobec edukacji włączającej: z perspektywy Chińskiej Republiki Ludowej

Streszczenie

Edukacja włączająca jest jednym z najważniejszych trendów w nowoczesnej teorii i praktyce edukacyjnej. Choć w Chinach już od połowy lat 80. prowadzi się wiele eksperymentów dotyczących włączenia dzieci ze specjalnymi potrzebami edukacyjnymi do masowej klasy w pobliżu miejsca zamieszkania, edukacja włączająca nadal pozostaje wyzwaniem rozwojowym.

Celem badania było określenie postaw nauczycieli masowych szkół podstawowych wobec edukacji włączającej. Badanie zostało również przeprowadzone, aby określić, czy nauczyciele spostrzegają siebie jako będących w stanie zrealizować edukację włączającą w klasach masowych, a także jakiego wsparcia oczekują, by móc realizować edukację włączającą w praktyce.

Specjalny kwestionariusz został zaprojektowany w celu uzyskania niezbędnych danych i został rozesłany do nauczycieli 36 masowych szkół podstawowych w Chinach. Analiza zebranych danych wskazuje, iż nauczyciele przejawiają negatywne postawy wobec edukacji włączającej oraz sądzą, iż nie są w stanie realizować edukacji włączającej w klasach masowych. Analiza zakończyła się wyprowadzeniem zaleceń dla przyszłych działań.

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Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

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Smoking behaviours in teenagers – companion and relationship influence mediated by the self-control effect

Introduction

Nowadays youths have become a huge consumer group in the cigarette consumption market. A report by China's Ministry of Public Health in 2008 on smoking control concluded that among 130,000,000 teenagers (13–18 years old), 15,000,000 are smokers, and what's more, those who have attempted to smoke count over 40,000,000.

According to Fang, Li and Dong's survey in 1996, in primary and middle school twenty percent of the students have learned to smoke. Teenagers' smoking behaviour is directly related to their adult smoking behaviour. According to a survey by China's Ministry of Public Health, 75% of adult smokers start between the ages of 14–24. Currently, researchers are focusing on the reasons, factors, approaches, and treatment strategies related to teenagers' smoking behaviour. Some studies analyze smoking behaviour from the perspective of the social environment, and the results show that companions' smoking is one of the most important and stable factors (Flay et al., 1983). Companions are inclined to smoke if one teenager is a smoker (Conrad et al, 1992). Adolescence is the transition phase from childhood to adulthood, and relationships with companions have a unique role which cannot be replaced by adults during the teenager's developmental process (Fang, 1997). Cheng and Sang (2002) state that a companion is a person with the same or similar social cognition as the individual with whom he/she lives or studies together with. A companion group is often classified in two ways: as a one-way selection or two-way selection. One-way selection has two main forms: in the first, individuals choose a companion group by themselves according to their own situation; in the second, individuals determine their companion group according to some criteria, such as interests, hobbies, personalities, abilities, etc (Fang et al., 2001). Two-way selection is when individuals make the choice according to the wishes of both sides, and includes two kinds of methods: social measurement and network technology (Feng, 2009).

Researchers generally believe that companions can influence young people's development and adaptation (Brendgen, Vitaro, and Bukowski, 2000). Berndt et al.

(1989) point out that companions' influence on teenagers can be positive, but it also can be negative depending on the characteristics of the group of friends. A friend that doesn't behave badly can prevent the teenager from getting involved in anti-social behaviour (Brown, Lohr, and McClenahan, 1986). However, if the contrary is true (i.e. the friend exhibits negative behaviour), this can lead to the existence and development of bad behaviour (Elliott, Huizinga, and Ageton, 1985). Interactions between individuals and companions increase in adolescence. Since most teenagers live with companions, this provides a natural background for them to discuss their life or learn from each other (Fang, 1997). Compared to parent-child relationships, equality and mutual benefits, a lot of mutual understanding, and similarly developing task and emotional experiences produce many common communication topics between teenagers and companions (Fang, 1997). Furthermore, companions are an important form of support for the development of social psychology, and can provide a kind of important security for exploring a new environment (Berndt and Keefe, 1995). There are similar goals and expectations among companions, in particular, close friends and same sex companions (Hallinan and Williams, 1990). Some research results show that having contact with 'bad companions' is a powerful predictor of adolescent problematic behaviour (Hawkins, Catalano, and Miller, 1992; Moffitt, 1993).

When smoking for the first time, most teenagers are in the presence of their companions. Good friends have a greater impact on smoking behaviour than other peers and groups. Fang's (1997) results illustrate that an important factor of teenagers' smoking attempts is the number of smokers who are good friends. Unger et al. (2002) point out that 55.8% of teenagers who smoke obtained their first cigarette from classmates or friends; the smoking rate of good friends is 53.32% for smokers but 12.5% for non-smokers. According to the national survey conducted in 70 secondary schools in China in 1996, 50.8% of young smokers are impacted by their companions. It is more likely that teenagers smoke if their companions are in favour of smoking; the more companions that smoke, the greater the likelihood that the given youth will smoke, and vice versa (Fang et al., 2001). Bauman and Fisher (1986) find that there is a significant correlation ($p<.001$) of adolescent smoking behaviour with both the perceived or actual smoking behaviour of their companions. Mosbach and Leventhal (1988) believe that the group teenagers want to join is in accordance with their attitude and behaviour – different groups have different smoking rates. There is an extremely significant relationship between adolescent smoking behaviour and smoking by the best friend. In adolescence, the smoking rate of the best friend is 44.8%, whereas the non-smoking rate of the best friend is only 6.5% – the proportion of smoking is 7 times that of non-smoking (Urberg, 1992).

Kopp et al. (1982) define self-control as an individual's self-regulatory behaviour that matches the individual's values and social expectations, can stop or lead to specific behaviour, and controls the impulse of violating ethnical standards. Posner and Rothbart (2000) propose the concept "effortful control" and consider it as a kind of ability – restraining a superior reaction and implementing an inferior reaction. Liu (1998) believes that children execute management and control on self-cognition, self-emotion, and self-behaviour, etc. according to social expectations and requirements. Wang and Chen (2004) define self-control as the ability to restrain and manage self-cognition, self-emotion, and self-behaviour according to social standards, and see it as a kind of will. Self-regulation is a complex system that has its own unique structure. It is an internal mechanism that lets individuals guide their goal orientation with time and environmental change (Carver and Scheier, 2000). Low self-control can explain the relationship between teenagers' bad behaviour and other factors. For instance, teenagers with low self-control tend to choose teenagers for companions with the same low self-control. Gottfredson et al. (1990) illustrate that individuals with low self-control easily behave badly in bad contexts; they think low self-control is a chief factor that leads to bad behaviour. Zheng and Zhang (2007) find that the lack of self-control not only induces criminal actions, but also brings with it social consequences, for instance, difficulties in establishing social connections, tendencies to come into contact with bad companions, dealing with a lot of pressure, and so on. In this article, we define self-control as one's own active control of psychology and behaviour. It is a conscious choice without external supervision and comprises adjusting and controlling behaviour appropriately, inhibiting impulses, resisting temptation, and postponing satisfaction to achieve objectives. Teenagers' smoking behaviours can be influenced by companionship. Thus, an attempt will be made to investigate the mediating effect of self-control in teenagers.

In reference to the abovementioned theoretical background, the presented research was conducted to verify the following hypotheses: H1. There will be a significant distinction in gender and grade on the influence of companions' smoking and self-control; H2. There will be a significant correlation between the influence of companions' smoking and smoking behaviour; H3. There will be a significant correlation between smoking behaviour and self-control; H4. Self-control will be a mediating effect on the relationship between companions' smoking and teenagers' smoking behaviour.

Method

Our study adopts Feng's (2005) questionnaire of companions' influence on teenage smoking behaviour. The questionnaire's factors include: knowledge of companions' smoking, companions' smoking behaviour, pressure exerted by the companions, and smoking opportunities afforded by companions. The questionnaire uses a five-point scoring system: full compliance, rather in line with, uncertain, not consistent, and totally inconsistent.

The study uses certain questionnaires, such as the "Smoking Questionnaire" from the U.S. National Institute on Drug Abuse, and the "Youth Smoking Survey" from Fang (1996). The study also adopts the "Youth Self-Control Questionnaire" from Wang and Lu (2003). The questionnaire includes three dimensions: emotional self-control, behavioural self-control, and mental self-control.

Sample and survey administration procedures

In this study, samples were obtained from four middle schools in Chengdu City, Si Chuan province, China. All students were divided into 3 different grades: grade 2 in junior high school and grade 1 and grade 2 in senior high school. The questionnaires were given to students between the ages of 14–17. In total, 700 questionnaires were obtained, all of which were recycled, maintaining the valid questionnaires after eliminating the invalid, with a recycling rate of 83.6%.

Results

In general, companions' smoking behaviour received the highest score and pressure exerted by companions got the lowest score (Table 1).

	knowledge of companion's smoking	companion's smoking behaviour	pressure exerted by companion	smoking opportunities afforded by companion	companion's influence
M	3.197	3.533	1.861	2.489	4.486
SD	1.005	1.103	.971	1.200	1.669

Tab. 1. Mean and standard deviation of companions' influence

To inspect gender and grade differences in companions' influence, an analysis of variance was conducted to examine interaction effects. The results are shown in Table 2.

	gender		grade		gender * grade	
	F	P	F	P	F	P
knowledge of companion's smoking	48.976	.000	3.367	.035	3.165	.043
companion's smoking behaviour	83.630	.000	8.249	.000	7.590	.001
pressure exerted by companion	40.362	.000	10.668	.000	2.120	.121
smoking opportunities afforded by companion	117.628	.000	21.332	.000	2.781	.063
companion's influence	107.311	.000	23.350	.000	4.530	.011

Tab. 2. Interaction of gender and grade on companions' influence

Gender differences in the influence teenagers' companions have are at an extremely striking level for the four factors. The differences in grades also stand out. The interaction of gender and grade is significant for the knowledge of companions' smoking, as well as companions' smoking behaviour and influence. However, pressure from a companion and the opportunity to smoke did not have a significant interaction.

The relationship between a companion's influence and smoking behaviour can be seen in Table 3. Four factors concerning companions' influence had a significant positive correlation with students' smoking behaviour.

	knowledge of companion's smoking	companion's smoking behaviour	pressure exerted by companion	smoking opportunities afforded by companion
smoking behaviour	.296**	.403**	.461**	.621**

** p<0.01

Tab. 3. Analysis of smoking behaviour and companions' influence

Multiple regressions were conducted to further explore the relationship between companions' influence and smoking behaviour.

	R	R2	Adjusted R2	F	standardized coefficient
smoking opportunities afforded by companion	.621	.386	.386	366.445***	.621***

*** p<0.001

Tab. 4. Multiple regression analysis of companions' influence and smoking behaviour

It can be seen from Table 4 that smoking opportunities afforded by a companion have the greatest influence – a positive prediction can be drawn from this.

Gender differences in self-control were found that were significant in three factors as well as in overall self-control (Table 5).

	gender		grade		gender * grade	
	F	P	F	P	F	P
emotional self-control	16.363	.000	1.418	.243	1.347	.261
behavioural self-control	21.146	.000	6.696	.001	.310	.734
mental self-control	4.067	.044	6.714	.001	.024	.976
overall self-control	18.374	.000	6.153	.002	.471	.624

Tab. 5. Interaction of self-control on gender and grade

As can be seen from Table 5, gender differences in self-control are significant in three factors and in overall self-control. Grade differences do not achieve a significant level in emotional self-control. Grade differences in self-control are significant for behavioural self-control, mental self-control, and overall self-control. An interaction of gender and grade does not achieve a significant level in three factors of self-control and overall self-control.

After the comparison of these three factors and overall self-control, the following is obvious:

- For behavioural self-control, junior grade 2 is significantly different from senior grade 1 and senior grade 2;
- For mental self-control, junior grade 2 is significantly different;
- For overall self-control, junior grade 2 is significantly different from senior grade 1 and senior grade 2;
- For emotional self-control, junior grade 2, senior grade 1, and senior grade 2 are not significantly different.

The study hypothesizes that teenagers will smoke due to their companions' influence. However, some students exhibit smoking behaviour, while others do not. Internal self-control might stop teenagers from being influenced by their companions' smoking behaviour.

Negative correlations were found between self-control and smoking behaviour (Table 6).

	emotional self-control	behavioural self-control	mental self-control
Smoking behaviour	-.239**	-.374**	-.230**

* ** p<0.01

Tab. 6. Analyses of smoking behaviour and self-control

Table 6 shows that emotional self-control, behavioural self-control, mental self--control, and smoking behaviour are negatively related.

A predictive function of behavioural self-control on smoking behaviour was found (Table 7).

	R	R2	Adjusted R2	F	net F	standardized coefficient
behavioural self-control	.374	.140	.140	95.061***	95.061	-.374***

***p<0.001

Tab. 7. Regression analyses of self-control and smoking behaviour

The analysis shows that behavioural self-control has the greatest influence on smoking behaviour and that it has a negative predictive function on the smoking behaviour of teenagers.

There is a relationship between companions' influence, self-control, and smoking behaviour.

In the same external environment, some youths exhibit smoking behaviour, while others do not. This indicates that the internal characteristics of teenagers should be taken into consideration when dealing with youths' smoking behaviour. This study assumes that self-control regulates the relationship between smoking behaviour and companions' influence.

A mediating effect of self-control on the relationship between companions' influence and smoking behaviour was found by exploring the relationship between companion's influence, self-control, and smoking behaviour (Table 8).

	emotional self-control	behavioural self-control	mental self-control	smoking behaviour
smoking behaviour	-.239**	-.374**	-.230**	1
knowledge of companion's smoking	-.111**	-.241**	-.150**	.296**
companion's smoking behaviour	-.191**	-.308**	-.195**	.403**
pressure exerted by companion	-.157**	-.342**	-.173**	.461**
smoking opportunities afforded by companion	-.278**	-.455**	-.299**	.621**

$p<0.01$, N=585

Tab. 8. Analyses of companions' influence, self-control and smoking behaviour

The results presented in Table 8 show that:

(1) Smoking behaviour and companions' influence in all factors has a significant positive correlation.

(2) Self-control and smoking behaviour are negatively correlated, and companions' influence and smoking behaviour are negatively correlated.

A mediating effect of self-control on the relationship between companions' influence and smoking behaviour was found. Mediating effects of the three self-control factors on the relationship between knowledge of companion's smoking and smoking behaviour were explored.

The results in Table 9 show that there are no mediating effects of self-control on knowledge of companion's smoking and smoking behaviour.

	Predictor variable	ΔR^2	F	B	t
First step: main effect	knowledge of companion's smoking				
	emotional self-control	.131	43.707***	-.208	-5.357***
	behavioural self-control	.185	66.174***	-.322	-8.348***
	mental self-control	.123	40.838***	-.190	-4.843***

Second step: mediating effect	knowledge of companion's smoking ^{x} emotional self-control	.131	29.103***	-.008	-.197
	knowledge of companion's smoking ^{x} behavioural self-control	.186	44.356***	.033	.878
	knowledge of companion's smoking ^{x} mental self-control	.123	27.199***	.009	-0.229

* p<0.05** p<0.01***p<0.001

Tab. 9. Mediating effect of self-control on knowledge of companion's smoking and smoking behaviour

However mediating effects of the three self-control factors on the relationship between companion's smoking behaviour and their own smoking behaviour were found.

The results presented in Table 10 show that emotional self-control and mental self-control have a mediating effect on companion's smoking behaviour and their own smoking behaviour.

	Predictor variable	ΔR²	F	B	t
First step: main effect	companion's smoking behaviour				
	emotional self-control	.190	68.130***	-.168	-4.408***
	behavioural self-control	.232	87.758***	-.276	-7.235***
	mental self-control	.186	66.686***	-.157	-4.130***
Second step: mediating effect	companion's smoking behaviour ^{x} emotional self-control	.196	47.201***	-.080	-2.136*
	companion's smoking behaviour ^{x} behavioural self-control	.234	59.053***	-.046	-1.222
	companion's smoking behaviour ^{x} mental self-control	.192	46.060***	-.077	-2.024*

* p=.05** p=.01*** p<.001

Tab. 10. Mediating effect of self-control on companion's smoking behaviour and their own smoking behaviour

There were no mediating effects of the three self-control factors on the pressure exerted by a companion and smoking behaviour. The results in Table 11 show that there is no mediating effect of self-control on pressure exerted by a companion and smoking behaviour.

	Predictor variable	ΔR²	F	B	t
First step: main effect	companion's pressure				
	emotional self-control	.241	92.303***	-.171	-4.662***
	behavioural self-control	.266	105.313***	-.246	-6.498***
	mental self-control	.236	89.797***	-.155	-4.218***

Second step: mediating effect	companion's pressure ^{x} emotional self-control	.243	62.075***	-.044	-1.212
	companion's pressure ^{x} behavioural self-control	.266	70.099***	-.006	-.160
	companion's pressure^{x} mental self-control	.239	60.667***	-.053	-1.441

*** p<0.001

Tab. 11. Mediating effect of self-control on pressure exerted by a companion and smoking behaviour

Mediating effects of the three self-control factors on the relationship between smoking opportunities afforded by a companion and smoking behaviour were positive (Table 12).

	Predictor variable	ΔR²	F	B	t
First step: main effect	smoking opportunities afforded by companion				
	emotional self-control	.391	186.552***	-.071	-2.116*
	behavioural self-control	.397	191.236***	-.116	-3.198**
	mental self-control	.388	184.593***	-.049	-1.439**
Second step: mediating effect	smoking opportunities ^{x} emotional self-control	.392	125.111***	.043	1.323
	smoking opportunities ^{x} behavioural self-control	.403	130.882***	.083	2.557*
	smoking opportunities ^{x} mental self-control	.393	125.594	.074	2.244*

* p<0.05** p<0.01*** p<0.001

Tab. 12. Mediating effect of self-control on smoking opportunities and smoking behaviour

It can be seen from Table 12 that behavioural self-control and mental self--control play a role in positively mediating the effect between smoking opportunities afforded by a companion and smoking behaviour.

Discussion

The main research aim was to investigate companions' influence and smoking behaviours in teenagers. Bandura's observed learning theory (1986) explains the relationship between companions' influence and smoking behaviour – there is very frequent contact among friends, who play an essential part in the life of teenagers. Therefore, companions' smoking behaviour, knowledge of smoking and smoking opportunities afforded by the companion, as well as inducing conduct for smoking set a learning example for smoking behaviour.

The means of pressure exerted by a companion are the lowest. Yang (2002) holds that when young people disobey social norms or social regulations, they tend to attribute it to external factors; they consider their own smoking behaviour to be subjected to companions' smoking behaviour or the opportunities for smoking afforded by their companions, never considering it as negative pressure exerted by their friends. An investigation among students who indulge in smoking shows that students believe that smoking together is a part of social interaction, and rejecting this means being unsocial. Compared with a lack of a 'sense of belonging' because of being excluded, they consider the pressure to be lighter than the bad emotional experience.

Gender differences in companions' influence are extremely significant between total scores and the four factors – boys are impacted by companions' influence more than girls. This conclusion is consistent with other research results (Griesbach et al., 2003). The possible reason for this is that according to traditional Chinese society, male smoking behaviour is considered normal behaviour, which facilitates social contact with each other, and is a very effective way of releasing tension. However, female smoking is unacceptable because it always involves a bad impression and habits.

In terms of facing pressure (that is not in favour of smoking), boys are naturally less likely than girls. The study finds that smoking behaviour of individuals is impacted by companions in junior grade 2 more sufficiently than in the other two grades. The underlying reason may be related to the critical transition period of the younger youths.

Correlation analysis showed that the four factors of companions' influence have a positive correlation with smoking behaviour. Fang's (2001) study shows that the smoking behaviour of companions impacts the smoking behaviours of teenagers more significantly. We believe that the reasons for this are that knowledge of smoking behaviour shows attitudes toward smoking, which are moral judgments from the internalization of external standards. Students are at a significant point in time when they go against external authority (such as teachers, parents) and shape their own moral standards. They begin to form so-called reasonable moral judgments according to their own cultural values.

There is a positive predictive function between smoking opportunities afforded by companions and smoking behaviour. Maybe the reason for this lies in the fact that students probably find it hard to say no to their companions' advice concerning smoking. They consider that a rejection will hurt their feelings, and if they can't get along well with others their status will drop among their friends in the group.

Gender differences in self-control achieve a significant level on the three factors and the overall score, and even at an extremely significant level on emotional and behavioural self-control. Girls score higher than boys on self-control. The behavioural self-control of boys has a significantly lower score than girls, but girls' score on emotional self-control is significantly lower than boys. Yang and Song's (2000) study also shows that gender differences are significant in the development of self-control. Moreover, all differences in girls are more significant than in boys. The reason may be that girls are more sensitive to facing external factors, whereas males often exhibit behavioural problems. In addition, the physical development of boys and girls is totally different. We know that girls step into the physiological developmental stage earlier than boys, which makes the girls perform more maturely in many aspects of self-control.

Grade differences in self-control achieve a significant level among behavioural self-control, mental self-control, and the overall score of self-control, but the factor of emotional self-control does not. Wei's (2009) study also suggests that the main effect of teenagers' self-control is manifested in two aspects – behavioural self-control and mental self-control, but does not show much in terms of emotional self-control. The reason may be that junior students are more susceptible to the influence of authority than senior students. They are also more willing to obey teachers and parents and constrain their behaviour by conforming to external social rules. However, the senior students' awareness of independence lets them not only depend on but also fight against authority.

Although there is no directly related research on self-control and youth smoking behaviour, research results on self-control and adolescent behavioural problems show that self-control factors have a universal influence on drug abuse in adolescents. The lower the self-control, the greater the chance of drug abuse, which supports the idea that low self-control causes youth drug abuse (Zheng and Zhang, 2007). Gifford (2002) considers that essentially, self-control is a selection process among behaviours of different values for individuals. Teenagers' smoking behaviour proves that they meet the characteristics of their group. According to Gifford's psychological mechanism of the self-control paradigm, students with lower self-control need to get compensation in a short time, which may be companions' appreciation, acceptance, or approval.

The results showed that behavioural self-control has a significant negatively predictive function for the smoking behaviour of teenage students. According to Gifford's theory, smoking behaviour of students is closely related to their low self-control behaviour. When their companions have actual smoking behaviour and persuade them to smoke, they will more likely choose smoking and be consistent with their companions' behaviour due to their own low self-control.

The higher the self-control scores, the less vulnerable an individual is to a friend's persuasion to smoke. Students with low self-control are more vulnerable to the companion's influence and select and develop smoking behaviour. The relationship between companions' smoking behaviour and teenagers' smoking behaviour will be weakened by enhancing students' emotional self-control and mental self-control. This means that if the companions are heavy smokers, their friends are more likely to smoke. But if students themselves have strong emotional and mental self-control, they will less likely be impacted.

Conclusions

The influence of companions' smoking is distinctly different according to gender and grade, and the same goes for self-control. There is a significant positive relation between the influence of companions' smoking and smoking behaviour, while self-control and smoking behaviour are negatively related. Behavioural self-control is a negatively predictive function for teenagers' smoking behaviour ($p<0.01$). Emotional self-control and mental self-control have a negative mediating effect on the relationship between companions' smoking behaviour and teenagers' smoking. Behavioural self-control and mental self-control have a negative mediating effect on smoking opportunities afforded by a companion and teenagers' smoking behaviour.

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Smoking behaviours in teenagers – companion and relationship influence mediated by the self-control effect

Abstract

Self-control can be defined as active control of one's own psychology and behaviour. It is a conscious choice without external supervision and comprises adjusting and controlling behaviour appropriately, inhibiting impulses, resisting temptation, and postponing satisfaction to achieve objectives. Teenagers' smoking behaviour can be influenced by companionship. 700 participants were randomly chosen from middle schools. The results sustain the hypothesis that self-control partially mediates the relationship between students' smoking behaviour and companions' influence.

The influence of companions' smoking is distinctly different according to gender and grade. There are significant positive relations between the influence of companions' smoking and smoking behaviour, while self-control and smoking behaviour are negatively related. Behavioural self-control is a negative predictor of smoking behaviour in teenagers (p<0.01). Emotional self-control and mental self-control have a negative mediating effect on companions' smoking and teenagers' smoking. Behavioural self-control and mental self-control have a negative mediating effect on the relationship between smoking opportunities afforded by companions and teenagers' smoking behaviour.

Palenie u młodzieży – wpływ relacji społecznych i towarzystwa zapośredniczony przez samokontrolę

Streszczenie

Samokontrola stanowi umiejętność aktywnego kontrolowania własnego zachowania. Polega na dokonywaniu świadomego, pozbawionego zewnętrznego przymusu, wyboru właściwego zachowania, hamowaniu impulsów, opieraniu się pokusie, odraczaniu zadowolenia związanego z osiąganiem celu. Grupa społeczna może wywierać wpływ na palenie papierosów u nastolatków. Przebadano 700 losowo wybranych uczniów ze szkół gimnazjalnych. Uzyskane wyniki potwierdzają hipotezę zakładającą, że samokontrola jest czynnikiem pośredniczącym w relacji pomiędzy paleniem przez uczniów a wpływem towarzystwa.

Wpływ palącego towarzysza jest wyraźnie zróżnicowany w zależności od płci i klasy szkolnej. Istnieje znaczący pozytywny związek pomiędzy wpływem palenia towarzysza a reakcją młodzieży, podczas gdy samokontrola i reakcja palenia są powiązane w sposób negatywny. Samokontrola behawioralna jest negatywnym predykatorem reakcji palenia u nastolatków (p<0.01). Samokontrola emocjonalna i samokontrola poznawcza stanowią negatywne czynniki pośredniczące w relacji pomiędzy paleniem grupy rówieśniczej a paleniem badanych nastolatków. Samokontrola behawioralna i samokontrola poznawcza mają negatywny pośredniczący wpływ na relację pomiędzy dostępnymi sytuacjami palenia w towarzystwie a reakcją palenia nastolatków.

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FOLIA 98

Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

AUTISM SPECTRUM DISORDER

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Theory of Mind in autism: more variations and more complexity than once believed

Introduction

The presented studies are aimed at a finer understanding of autism (autism spectrum disorders) at the cognitive level. As such, they are motivated by the conviction that a satisfying scientific understanding of autism is a multi-level interdisciplinary enterprise. As autism has genetic roots in most of the cases, even evolutionary issues arise about the persistence of its genetic background in the human genetic pool. It is a task for genetics, neuro-embryology and developmental neurology to explain how genetic and environmental factors interact in giving way to the atypical neural development as the biological foundation of this syndrome. The psychological/cognitive level is often seen as a conceptual link between brain and behaviour. By understanding autism on this level we hope to get a deeper insight into which psychological mechanisms work atypically in autism, due to the atypical organisation of the neural bases of these psychological/cognitive functions. On the other hand, understanding the cognitive background of autism offers us an explanation for the specific behavioural patterns seen in this disorder.

All this implies also that a relevant and valid psychological explanation of autism is necessarily very ‘sensitive’ to findings on the neural background of autism, as well as to the more and more refined descriptions of the symptoms and other behavioural characteristics. The research summarised below has been conducted with the intention to incorporate the relevant neural and behavioural findings when designing the studies and interpreting the results.

As the last introductory remark here, it should be emphasise that these works were inspired by the conviction that autism, though not entirely, but still essentially is a cognitive or, more precisely, a neuro-cognitive disorder. That is, although non-cognitive psychological and neuro-physiological mechanisms, such as arousal-regulation processes, emotional processes, motivational factors and low-level sensory processes do often function atypically in this syndrome, the core features arise from an atypical organisation of *cognitive* mechanisms. That is, efforts to reveal the cognitive basis of autism are, at the same time, efforts to understand the essence of this syndrome on the psychological level.

The 'Theory of Mind' hypothesis of autism as a single-factor explanation

It was clearly a breakthrough in the psychological understanding of autism when Baron-Cohen, Leslie and Frith (1985) suggested that 'Theory of Mind' ability may be impaired in autism, and this impairment may lead to the core triad of behavioural symptoms.

Theory of Mind ability, or, more precisely, naïve Theory of Mind ability (briefly: ToM), is widely defined as the human cognitive ability to attribute mental states to various agents, and to interpret, explain and predict their actions as causal consequences of the attributed mental states. It is widely held to be a crucial basis of human social intelligence and intentional communication, although many aspects of the cognitive organisation, neural basis, and developmental history of this ability are still unclear.

It was an important starting point for our studies to see that the original, early version of the ToM hypothesis was a very strong one, in at least five respects. Namely, it assumed that:

1. ToM impairment is universal in autism; it is present in all cases.
2. At the same time, it is specific to autism; no other (developmental) disorder involves such a deficit.
3. ToM impairment explains all core features of autism, that is, it causally determines the 'autistic triad'.
4. It is a primary deficit – there is no more elementary and earlier cognitive deficit that could give rise to it.
5. And, finally, at the very heart of the ToM impairment in autism there lies an inability to represent mental states, as the very essential cognitive deficit in autism.

This early, strong form of the ToM hypothesis of autism is represented – with more or less cautionary reservations – by, for example, Baron-Cohen et al. (1985), Baron-Cohen (1995), Happé (1994), or Leslie and Thaiss (1993).

Since 1985, hundreds of studies confirmed that a ToM impairment exists in autism, but, at the same time, a considerable bulk of evidence suggests that the original, strong variant of the ToM hypothesis cannot be maintained in all five respects. Now, I just shortly refer to a few kinds of findings that have lead to a necessary revision of the strong hypothesis – the points below are very far from an exhaustive review.

1) *The existence of passers*. It has been demonstrated convincingly in several studies that many individuals with autism do pass formal Theory of Mind tasks, including several forms of false belief tasks (for a review, see Györi, 2006). This fact, in the first approximation, goes against the claims that ToM is universally impaired in autism and that this impairment leads to the core symptoms.

2) *Missing/uncertain causal links*. Although the hypothesis that a deeply impaired ToM might lead to all the three core clusters of the 'autism triad' is undoubtedly plausible (see, e.g., Györi, 2006; Happé, 1994), surprisingly little evidence supports the existence of these causal links. There seems to be no such evidence at all concerning the third area of impairments, i.e. repetitive behaviours and restricted interests (see Russell, 1997). Available evidence on the causal links between ToM impairment and symptoms in reciprocal socializations and communication, on the other hand, are also considerably ambiguous (see, e.g., Frith and Happé, 1994; Frith et al., 1994; Happé, 1993; for a summary also Györi, 2006).

3) *Other documented cognitive deficits*. In the late 1980s and early 1990s several other cognitive impairments/characteristics of autism were documented. The most important among these seem to be impairments in executive functions and detail-focused processing (‘weak central coherence’), but various deficits in sensory processing, facial processing, attentional processes, memory functions, etc. have also been demonstrated.

4) *The unfolding complexity of the neural background*. Studies on the neural basis of autism show that the ‘autistic brain’ is different from the ‘neurotypical brain’ at several points and on various levels, and that the pattern of anomalies changes quite dynamically in the course of development (see, e.g., the volume edited by Zimmerman, 2008).

These and many other kinds of findings should make all researchers in the field at least cautious about maintaining a strong variant of the ToM hypothesis of autism – and about maintaining any single-factor explanation of this syndrome on the psychological level. But, on the other hand, one should be equally cautious about not rejecting ToM impairment as a part of the cognitive explanations of autism. As I emphasised above, a huge bulk of evidence shows that this impairment is present in this population, and supports that there is a causal link from this impairment to several symptoms. Instead of throwing away this important part of the mosaic, it is better to find its precise place in the complex image that is emerging.

A better understanding of the precise nature and role of ToM impairment in autism requires asking and answering a set of more specific questions, partly old, partly new ones. Our studies briefly presented below have been aimed at clarifying a few of these. I emphasise three of them here.

Heterogeneity? Does ToM impairment show heterogeneity in autism? Is it the case that ToM functioning/dysfunctioning shows highly variable patterns across individuals?

Is passers’ ToM ability based on genuine understanding of mental states? It is a key issue, for many reasons, if passers, or at least some of them, have a genuine ToM mechanism.

How is theory of mind related to other cognitive functions? As ToM impairment seems to be a part of a highly complex pattern of cognitive impairments, it appears important to understand the relationship between this ability and other relevant cognitive abilities in autism.

How stable/unstable is theory of mind ability in autism – if it exists? As I shall discuss in somewhat more detail below, little is known about the stability of cognitive functions in autism. It may prove important in the future to understand to what extent complex cognitive functions, such as ToM, are stable/unstable in autism.

Do passers have a genuine Theory of Mind ability?

Since the first empirical testing of the (strong) ToM hypothesis of autism, it has been an important question if those individuals with autism who pass Theory of Mind tasks in controlled, laboratory situations possess a genuine theory of mind ability, or not. This problem, often called ‘the problem of passers’, has inspired considerable empirical research as well as theorising. We do not yet have the final answer to this problem, and the proposed theoretical solutions range from the claim that ToM may be sound in passers (e.g., Ozonoff et al., 1991a, b), via the assumption that ToM development is significantly delayed (Baron-Cohen, 1989), to various claims about atypical, compensatory cognitive processing underlying passers' success in standard ToM tasks (see., e.g., Happé, 1994; Klin et al., 2000) – just to mention a few from the theoretical spectrum on passers (for a more detailed review, see again Györi, 2006).

In our view, solving the problem of passers requires evidence from various methodologies, such as findings from experimental psychology, neuroscience, developmental studies, and so on. These investigations should take into account the potential heterogeneity of the cognitive mechanisms behind ToM task success, too. In the studies I'm going to concisely present here, we applied an experimental methodology and, in order to handle potential cognitive heterogeneity, we amalgamated it with a single-case design. More detailed reports of these studies can be found in Chapter 6 of Györi (2006) and are in preparation in a revised and updated form (Györi et al., in preparation, a and b).

We used a paradigm adapted from experimental psycholinguistics (Gibbs, 1986) to investigate if high functioning individuals (adolescents and young adults) with autism (n = 22) are able to understand and interpret ironic versus literally meant utterances in context and to compare their performance to a matched control sample of individuals without autism (n = 21). The major methodological novelty of this study was the way of presentation – subjects read little stories in a sentence-by-sentence, self-paced way from a computer screen – and the way we combined the experimental design with a single case design was to allow conclusions on the cognitive processes underlying task success even on an individual level.

We used understanding irony as a test field of ToM ability, as both theoretical-conceptual theorising and some empirical evidence show that interpreting ironic utterances requires second-order understanding of intentions; see Sperber and Wilson (1988) and Happé (1993). Moreover, the specific paradigm we applied allowed us to take processing time measurements. We expected these data to open a window into the more specific processing patterns associated with task success. Below you see an example for an ironic story with the test and control questions:

> Kate and Eve are good friends.
> They often go out together.
> As they met today, it began to rain.
> So they went to a cinema.
> Kate said as they stood up at the end of the film:
>
> Now, it is time to go back to that nice weather!
>
> - Did Kate really mean that they are going back to nice weather?
> - When she said this, was she happy?
> - Why did she say this?
> - Was the weather indeed nice when Kate said this?

Our first study with 14 literally ending and 14 ironically ending stories as stimuli has brought some expected and some non-expected results (see Gyori et al., in preparation, *a*). As an expected result, non-autistic controls understood significantly more stories than the experimental group with autism. However, the difference between the two groups was less dramatic than we expected (the average success rate was 84.5% in the autism group, and 92.8% in controls), and the group with autism showed much better performance than expected in such a complex task requiring second-order understanding of intentions: 3 of the 22 subjects made no error at all, and only one of the 22 performed on a random level!

Also surprisingly, the analyses on the processing time *patterns* and error *patterns* did not reveal dramatic differences between the two groups: by and large, the same effects of story variables were found in the two groups on the group level, although there was a generally higher variability in the autism group and some differences were present in the individual-level effects we found.

In sum, though the autism group was weaker in the task as expected, both performance data and processing time data indicated a surprisingly high level of understanding of non-literal meaning, and, assumedly, a surprisingly high level of ToM functioning.

Although such findings are not alone in the literature as some studies have found success in relatively complex tasks of ToM in autism, such as Bowler (1992), or Happé (1993), it appeared that it would be worth remaining cautious about accepting too quickly a conclusion that complex ToM indeed functions in our sample.

Instead of accepting such a conclusion quickly, we wished to investigate the possibility that passers, or at least some of them, applied *some non-Theory-of-Mind-based compensatory strategy* to solve the simple irony task outlined above. We speculated that a hypothetical compensatory strategy we named 'Reality-Based Short-Cut Strategy' could in principle help our subjects solve the simple irony tasks without ToM. Figure 1 below shows the relatively simple algorithm of the hypothetical 'Reality-Based Short-Cut Strategy'.

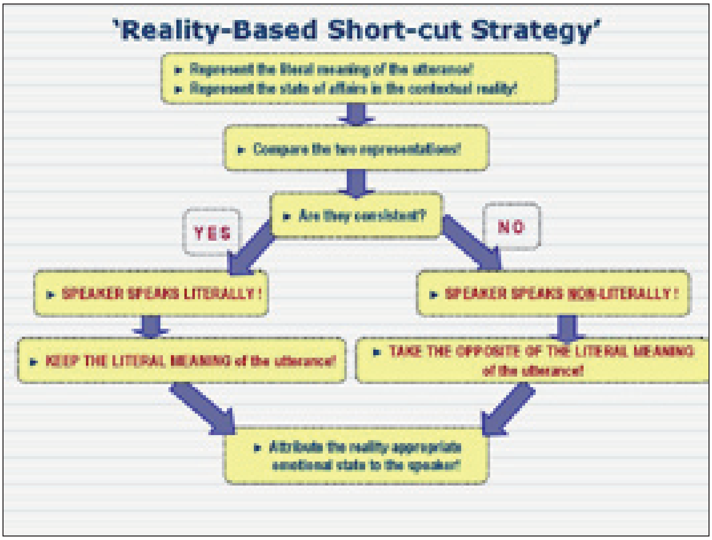


Fig. 1. Reality-Based Shart-Cut Strategy for solving irony tasks without ToM

Our question in the second study (see Györi et al, in preparation, *b*) was, naturally, if any of our subjects with autism indeed used this non-ToM compensatory strategy when solving a simple irony task – normally solved by attribution of an ironic intention requiring ToM ability. In order to answer this question we needed a task that would be able to tell apart those who did use ToM from those who used the 'Reality-Based Short-Cut Strategy'. We devised the *False Irony Task* to do this.

The False Irony Task can be seen as an amalgam of the Simple Irony Task and a false belief task, in the sense that the False Irony Task is centred on an utterance which *is meant ironically*, but – due to changes in the context unknown to the speaker – is, at the same time, *literally true*. A false ironic version of the above sample story is shown below here:

> Kate and Eve are good friends.
> They often go out together.
> As they met today, it began to rain.
> So they went to a cinema.
> Sitting in the cinema, they did not notice that the rain stopped outside, and now it was shining.
> Kate said as they stood up at the end of the film:
>
> *Now, it is time to go back to that nice weather!*
>
> - *Did Kate really mean that they are going back to nice weather?*
> - *When she said this, was she happy?*
> - *Why did she say this?*
> - *Was the weather indeed nice when Kate said this?*

The key feature of false ironic stories is that by relying on ToM ability, that is, by understanding the beliefs and intentions of the speaker they are interpreted as ironic (the utterance of the speaker is meant ironically), while using the 'Reality-Based Short-Cut Strategy' they are interpreted as literal (as if the utterance of the protagonist is meant literally). That is, false ironic stories are able to tell apart genuine mental state understanding (ToM) from a specific compensatory strategy.

In this second study, therefore, we presented simple ironic, simple literal, false ironic and false literal stories – these last being literal counterparts of false ironic stories – to 16 high functioning subjects with autism, 15 of whom took part previously in our first study as well.

Our goal was to categorise subjects in terms of ToM ability vs. compensation on the basis of their patterns of performance. As the False Irony Task is highly complex in terms of required ToM ability, we can assume with considerable certainty that those subjects who pass these tasks and all the simpler tasks do possess – a quite complex – ToM ability. Seven of our 16 subjects showed this pattern: performance at ceiling. One has good reason to conclude that these subjects have quite complex ToM ability – although this does not mean at all that their ToM ability is unimpaired.

Those subjects who *consequentially* fail in the False Irony Tasks and in the False Literal Tasks, while consequentially succeeding in simple ironic and simple literal stories, most probably apply the 'Reality-Based Short-Cut Strategy'. Two of our subjects in this study showed this pattern of performance.

And finally, 3 subjects showed another, relatively clear pattern of success and failure: they failed in the more complex tasks due to a failure to represent and remember the context of the stories. We may cautiously conclude that these subjects have a complexity limitation in representing and remembering the context for mental state attributions.

Our results, of course, do not represent a decisive, final word about the problem of passers but are informative on some aspects of the issue. They form strong evidence for considerable cognitive heterogeneity in terms of ToM ability in autism. Moreover, the errorless performance in a set of quite complex ToM-related tasks by a considerable proportion of our subjects strongly suggests that some high functioning individuals with autism do possess complex Theory of Mind ability. Besides, some subjects clearly showed a pattern that indicates the application of an algorithmically identified compensatory strategy – for the first time in the literature. Finally, a part of our findings suggests that in a third sub-group some kind of general cognitive complexity limitation may underlie ToM failure.

These findings, especially if verified by further studies, naturally raise a set of novel questions – questions about the stability of these sub-groups, the dependence of the variability of ToM performance and compensatory strategies on other cognitive characteristics (such as general intelligence and language), the actual developmental pathways these variations may be part of, and so on. I shall return to some of these issues later in this paper.

Does language have a specific role in understanding minds in autism?

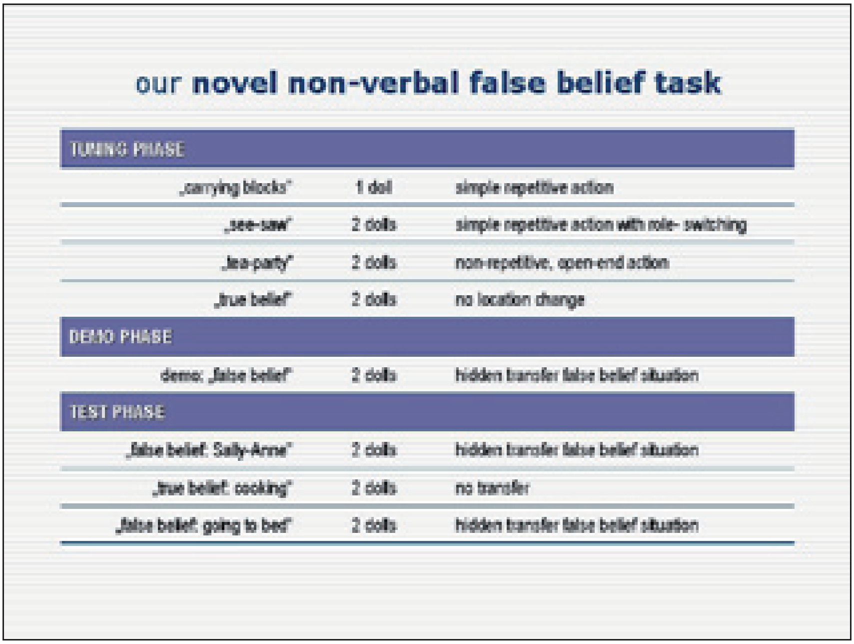
The relationship between ToM abilities and linguistic abilities is an important question both in typical development and in autism, for many reasons. From among these I now emphasise the issue of compensation. As we have just seen, language-based compensatory strategies may play an important role in substituting to some extent the missing ToM ability in some individuals with autism. From this conclusion, the question naturally follows if there is a specific developmental relationship between ToM and language in autism.

We investigated this issue by developing *a novel non-verbal false belief test method* to test ToM ability without relying on linguistic skills, and by designing a correlative study based on this novel tool. Preliminary findings from this study have been published in Hungarian (Györi et al., 2007), while a report in English on the 'final' findings is in preparation (Györi et al, in preparation, c).

As our review of the existing (published) non-verbal false belief tasks showed important disadvantages for each of these methods (such as a need for previous training and knowledge transfer, as in, for example, Call and Tomasello, 1999), we decided to design a novel non-verbal false belief test. Our aim was to create a procedure that (1) is fully non-verbal, (2) expects a complex, goal-directed action as a manifestation of ToM ability, (3) does not require previous training and knowledge transfer, (4) is developmentally adequate at the critical (mental) age of 3–6 years.

The basis of our procedure is to enact short scenes by puppets and pass over the control of the protagonist puppet to the child at a crucial moment. The way the child completes the scenes is indicative of her/his grasp of the mental states (beliefs) of the protagonist puppet.

The actual testing scenes are preceded by tuning scenes, where no mental state attribution is expected yet, but where the goal is to familiarise the child with the basic setup and, at the same time, to increase the complexity of the scenes gradually. The final version of our procedure, which also includes a demonstration phase (when the experimenter demonstrates a false belief-driven response), is shown below in Figure 2.



our **novel non-verbal false belief task**

TUNING PHASE		
„carrying blocks"	1 doll	simple repetitive action
„see-saw"	2 dolls	simple repetitive action with role- switching
„tea-party"	2 dolls	non-repetitive, open-end action
„true belief"	2 dolls	no location change
DEMO PHASE		
demo: „false belief"	2 dolls	hidden transfer false belief situation
TEST PHASE		
„false belief: Sally-Anne"	2 dolls	hidden transfer false belief situation
„true belief: cooking"	2 dolls	no transfer
„false belief: going to bed"	2 dolls	hidden transfer false belief situation

Fig. 2. Non-verbal false belief task

In order to reveal any specific relationship between langauge and ToM in autism, we applied this method in the context of a comparative correlational study.

Our subjects were 16 children with autism with an average verbal mental age of 97 months, 55 typically developing children with an average verbal mental age of 49 months, and 22 children with various developmental language disorders with an average non-verbal mental age of 68 months.

In the correlative study, four kinds of data were analysed for all groups: (1) data from standard, first-order, verbal false belief tasks; (2) data from our non-verbal false belief test; (3) data from a test of grammatical development (TROG-H – under Hungarian standardisation and adaptation, for the original TROG, see Bishop, 1983); (4) data from a test for lexical development (the Hungarian version of the Peabody Picture Vocabulary Test, Csányi, 1974)

In the autism group the adequate module of ADOS (Lord et al., 1999) was administered to each child to control the severity of symptoms.

Without going into detail in this paper, I will just shortly state that our non-verbal false belief test yielded the expected results in the neurotypical sample. Figure 3 below illustrates this by comparing findings from this method to those from standard verbal false belief tasks.

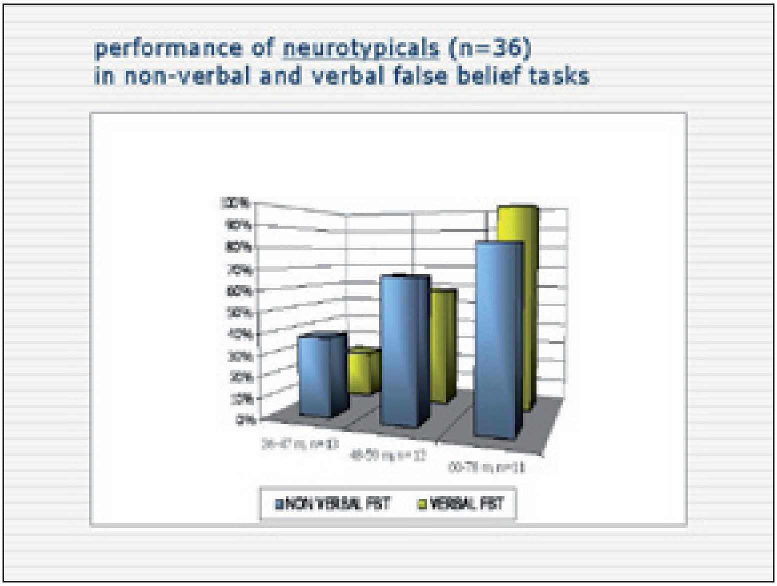


Fig. 3. The performance of verbal and non-verbal false belief tasks by neurotypicals (adapted from Györi et al., 2007)

The pattern of correlations was quite similar in the neurotypical and in the autism groups and fundamentally in line with previously published findings (see, e.g., Tager-Flusberg, 2000), also in the sense that the correlations between verbal false belief understanding and linguistic measures were even stronger in the autism group. The crucial finding for us here is that the severity of social-communicative symptoms in the autism group showed no correlation with verbal false belief task performance, while a significant negative correlation (r = - 0.44) was found between the severity of these symptoms and performance on our novel non-verbal false belief task! This, in other words, means that there is no relationship between social-communicative symptoms and the level of false belief understanding in verbal tasks, while the level of non-verbally measured false belief understanding indeed shows a relationship with social and communicative competence in everyday life. Yet in other words: the better the non-verbal ToM ability, the weaker the socio-communicative symptoms – while there's no such relationship between verbally measured ToM ability and these symptoms in our study.

These findings are in line with the assumption that language represents a compensatory route to apparent mental state understanding not only in the algorithmic way, as demonstrated in the studies reported first, but also in a developmental sense. A possible explanation of our findings is that linguistic measurement of ToM activates this compensatory mechanism, which is not indeed efficient in everyday life, while non-verbal testing of ToM activates an ability to attribute mental states spontaneously, without explicit verbal cues. This more 'genuine' ToM ability, although still impaired, is more efficient in guiding social behaviour in everyday life.

The stability of existing ToM competence

Our last issue to touch upon in this paper is that of the stability of the performance patterns shown in ToM-related tasks by individuals with autism. Without going into detail, it is worth emphasising how little is known about the stability of cognitive performance in autism. This is especially true of relatively *short-term stability in specific cognitive tasks* – as, of course, several studies targeted long-term (developmental) stability of such general abilities as IQ. In our conviction the issue of (short-term) stability/instability may prove important both from a clinical and a theoretical-explanatory point of view – if clarified by empirical data.

Below I report the first case-study-like findings from an ongoing study of ours that is aimed at gaining more insight about short term stability/instability of complex but specific cognitive abilities in high functioning autism normally linked to the prefrontal cortex.

In this study we use a relatively simple but requiring methodology: we measure ToM ability, executive functions, working memory functions, and source memory functions repeatedly and by various tasks. Our main question is whether high functioning subjects with autism show more instability in these cognitive functions than matched controls and developmental controls.

Here I report preliminary findings only from the first 5 subjects with high functioning autism and only from a version of the paradigm introduced in the first part of this paper – the False Irony Test.

This novel version of the False Irony Test contains 2 practicing and 12 target stories (tasks) presented on a computer in a written form in a self-paced sentence-by-sentence way. From among the 12 target stories, 3 are false ironic, 3 are false literal, 3 are simple ironic, while 3 are simple literal. The stories are presented in a randomised order.

The simplified design of these repeated measurements is shown below in Figure 4.

A summary of the findings from 5 subjects (all with a diagnosis of autism, with a normal IQ, and in the age range of 15 to 25 years) can be seen below in Table 1. This table shows the success/failure patterns of these subjects in the 12 tasks of each of the three False Irony Test measurements. It also shows two indices calculated to characterise their level of performance and stability of this performance across the three measurements. The *performance index* is simply the ratio of passed tasks from among a total of 36. The *stability index* was calculated in the following way: if the performance in the given task was the same across the three measurements, a score of 1 was given; if just two measurements gave the same result, the score was 0.5; if all three measurements in the given task gave different results, the score for the task was 0. The sum of scores could possibly range from 0 (total lack of stability) to 12 (total stability). The stability index was then calculated as the ratio of this sum to the total of 12 tasks. Its maximum value is 1 (total stability), the minimum is 0 (no stability at all).

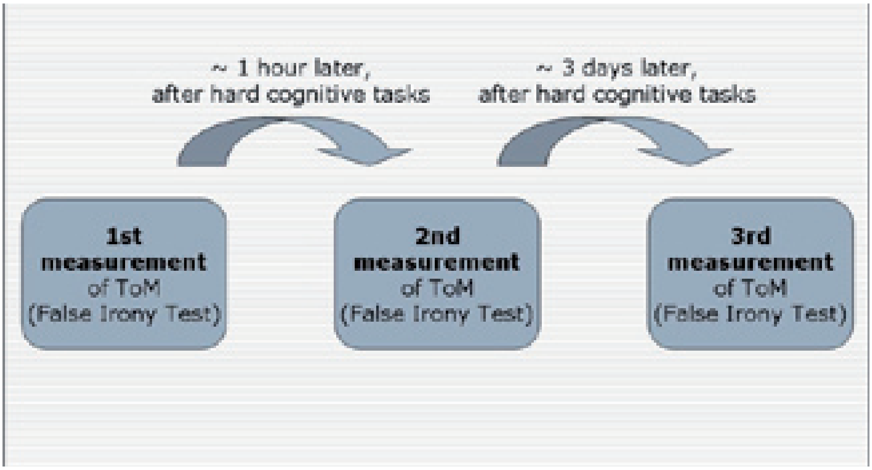


Fig. 4. The stability of ToM competences

		False Irony Tasks			False Literal Tasks			Simple Ironic Tasks			Simple Literal Tasks			performance index	stability index
subject	measurement	FI1	FI2	FI3	FL1	FL2	FL3	IR1	IR2	IR3	LI1	LI2	LI3		
nr 1 (male)	1	I	CF	CF	F	F	CF	F	P	P	I	P	P	0,47	0,708
	2	P	CF	CF	P	CF	CF	P	P	P	F	P	P		
	3	F	CF	CF	P	CF	CF	P	I	P	P	P	P		
nr 2 (female)	1	P	P	P	P	P	P	P	P	P	P	P	P	1	1
	2	P	P	P	P	P	P	P	P	P	P	P	P		
	3	P	P	P	P	P	P	P	P	P	P	P	P		
nr 3 (male)	1	P	P	P	P	P	P	P	P	P	P	P	P	0,92	0,91
	2	P	P	P	P	P	CF	P	I	P	P	P	P		
	3	P	P	P	P	P	CF	P	P	P	P	P	P		
nr 4 (male)	1	P	P	CF	CF	P	I	P	P	P	P	P	F	0,78	0,83
	2	P	P	P	CF	P	I	P	P	P	P	P	P		
	3	P	F	P	CF	P	P	P	P	P	P	P	P		
nr 5 (male)	1	CF	CF	CF	CF	I	I	I	I	I	I	P	P	0,22	0,96
	2	CF	CF	CF	CF	CF	I	I	I	I	I	P	P		
	3	CF	CF	CF	CF	CF	I	I	I	I	I	P	P		

Tab. 1. The performance of 5 subjects in three subsequent administrations of our False Irony Test. Abbreviations: P – passed; F – failed; CF – failure due to compensatory strategy; I – invalid response

The table 1 exemplifies interesting heterogeneity both in terms of ToM performance and ToM stability. In line with the results of the first studies summarised in this paper, we found subjects with quite high performance, that is, with quite complex ToM performance (subjects nr. 2 and 3), as well as a subject with quite low performance (subject nr 5). Very interestingly, however, we see remarkable stability of both high performance and erroneous performance: both subject 2 and subject 5 showed remarkable stability though they are at the two extremes in terms of ToM ability, as reflected in this study. Subject nr 1, however, whose performance is between these two extremes, showed a lower level of stability in his pattern of failure and success. An important next step in understanding these patterns as well as high functioning autism, as such, should be a clarification of what determines stability vs. instability, how stability/instability in ToM is related to stability/instability in other cognitive abilities, and, finally, how stability/instability is related to symptoms. We do trust that the continuation of this study may offer at least tentative answers to these questions.

Summary

Our findings – largely in line with some results in the literature – suggest that the issue of Theory of Mind ability and its impairment is a highly complex one. With the important reservation that some of our findings need further replication/confirmation, the following tentative general conclusions can be drawn:

- First of all, the population of high functioning autistics seems highly heterogeneous in terms of the level of complexity of their ToM abilities.
- Secondly, within this heterogeneity there exist individuals who have quite complex ToM abilities – even if this is manifested reliably in unnatural experimental settings. On the other hand, there also exist individuals who, at least for some tasks, use non-ToM-based compensatory strategies to solve tasks typically solved by mental state attribution.
- Thirdly, verbally mediated ToM ability seems non-efficient in controlling everyday social behaviours as it does not show a significant correlation with socio-communicative symptoms.
- Not verbally mediated ToM ability, on the other hand, seems to have such a causal significance.
- Finally, high functioning individuals with autism, as a group, seem to be heterogeneous also in terms of the stability of their ToM ability. While we find subjects with both quite high levels of ToM ability and subjects with quite low levels of ToM ability who show, at the same time, remarkable stability of the patterns of their success and failure, we see subjects whose performance is much less stable in repeated measurements. It is one of the interesting questions emerging here, how this neurocognitive instability – if further confirmed – contributes to the clinical picture of high functioning autism.

Acknowledgements

The research summarised in this paper have been funded to a varying extent by the Autism Foundation, Budapest; the Hungarian Scientific Research Fund (OTKA, grant nr. 61615);

the 7th Frame Programme of the European Commission (HANDS project, grant nr. 224216), and a Bolyai scholarship of the Hungarian Academy of Sciences. Special thanks go to those colleagues who contributed substantially to the research presented here and have been co-authors in publications; foremost, but not only, to Dr. Anna Balázs, Dr. Krisztina Stefanik, Barbara Batta, Ildikó Kanizsai-Nagy, Noémi Hahn, and Ágota Markovich.

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Theory of Mind in autism: more variations and more complexity than once believed

Abstract

The present paper is an overview of our research from the last few years, which was aimed at getting a finer image of Theory of Mind impairment and its consequences in autism. Theory of Mind is a crucial human cognitive ability to understand and predict others' behaviour by attributing mental states to them. This ability is, as it is well-known, developmentally impaired in autism, but relatively little is known about the individual varieties and the precise nature of this impairment.

The studies summarised in this paper were aimed at three issues: (1) if those individuals who are able to solve Theory of Mind problems indeed have a Theory of Mind ability, (2) how existing Theory of Mind abilities are related to linguistic abilities and to social-communicative symptoms in autism, and (3) if the existing Theory of Mind competence in autism is stable over time or shows atypical fluctuation.

In order to solve these issues we applied various methodologies of cognitive psychology, including experimental, psycholinguistic and psychometric methods. Our findings show that Theory of Mind ability shows a striking variation in high functioning autism, from deep impairment to relatively complex understanding of minds, including compensatory strategies in some cases. Also, we found that language and Theory of Mind show a very specific relationship in autism, and existing Theory of Mind ability shows remarkable stability in some subjects, while others are more unstable in this sense.

In sum, these findings indicate that the impairment of Theory of Mind ability in autism is a far more complex issue than once believed, and calls for further intensive research.

Teoria umysłu w autyzmie: większe zróżnicowanie i większa złożoność niż wcześniej sądzono

Streszczenie

Niniejsza praca stanowi przegląd naszych kilkuletnich badań, których celem było uzyskanie dokładniejszego obrazu zaburzenia teorii umysłu oraz jego konsekwencji w autyzmie. Teoria umysłu stanowi zasadniczą zdolność poznawczą człowieka, która pozwala rozumieć i przewidywać zachowanie innych poprzez przypisywanie im stanów umysłu. Jak doskonale wiadomo, zdolność ta jest rozwojowo zaburzona w autyzmie, jednakże stosunkowo niewiele wiadomo na temat poszczególnych odmian i dokładnego charakteru tego zaburzenia.

Celem badań opisanych w niniejszej pracy była analiza trzech zagadnień: (1) czy jednostki, które są w stanie rozwiązać problemy teorii umysłu, rzeczywiście posiadają zdolność w zakresie teorii umysłu, (2) w jaki sposób istniejąca zdolność w zakresie teorii umysłu związana jest z umiejętnościami językowymi oraz społeczno-komunikacyjnymi objawami w autyzmie, (3) czy istniejąca kompetencja w zakresie teorii umysłu w autyzmie jest trwała, czy przejawia nietypowe wahania.

W celu przeanalizowania tych zagadnień, zastosowaliśmy różnorodne metody psychologii poznawczej, łącznie z metodami eksperymentalnymi, psycholingwistycznymi oraz psychometrycznymi. Wyniki naszych badań pokazują, że zdolność w zakresie teorii umysłu wykazuje istotne różnice w autyzmie wysokofunkcjonującym, począwszy od poważnego zaburzenia do stosunkowo złożonego rozumienia stanów umysłu, włączając także strategie kompensacyjne w niektórych przypadkach. Ponadto, dowiedzieliśmy się, że w autyzmie pomiędzy językiem a teorią umysłu zachodzi specyficzna relacja, a teoria umysłu u niektórych osób przejawia niezwykłą stałość, podczas gdy u innych nie.

Podsumowując, niniejsze wyniki pokazują, że zaburzenie w zakresie teorii umysłu w autyzmie jest problemem o wiele bardziej złożonym niż wcześniej sądzono oraz wymaga dalszych intensywnych badań.

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FOLIA 98

Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

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Sensory perceptual issues in autism: why we should listen to those who experience them

Introduction

At present, the diagnosis of autism is based on behaviour. The behaviours that indicate autism are interpreted as impairments in social interaction, communication, rigidity of thoughts and activities. That is what we see. However, can we rely on the analysis of these behaviours when we develop programmes to help people with autism?

Let us take one example: A child enters the room and touches the walls, the furniture the objects, and then takes an object from the table and smells it. How shall we analyse this behaviour? Shall we count how many times this child smells things and people, taps objects, touches furniture, etc. and then create sophisticated graphs, tables and statistical charts to explain it? Or shall we find out why he does it? If we find out that this particular child is blind we would not need the statistics of his ‘bizarre behaviour’ in order to understand his problems (and his behaviours). That is exactly what is happening in the field of autism. We examine, analyse and measure ‘impairments of social interaction, communication and rigidity of thoughts and create theories to explain them. However, a breakthrough has come from personal accounts of people on the autistic spectrum. Their descriptions of experiences (though they may differ in some ways) have a potential to point researchers in the right direction. It is difficult to overemphasise the importance of *listening* to those who experience differences in their perception of the world. If we know what is going on, we can investigate what causes it (including brain structure and function studies, biochemistry, cognitive, linguistic, emotional and social development). To start with, instead of asking why they behave the way they do, we should ask: How do they perceive the world?

From the very beginning of the ‘official history’ of autism (Kanner, 1943), the syndrome of autism has been described from the outside, what it looks like, rather than how it feels from the inside. Now we can get a unique opportunity to learn what it is like to live with autism. Numerous personal accounts have been published and many autistic individuals are willing to talk at conferences and congresses about their experiences. The autistic authors feel they have to give their side of the story as hundreds of books on autism written by professionals and parents often 'get it wrong'. They want to clarify things and their views must be taken seriously. They want us to know what it is like to live with a nervous system that functions differently, what it is like to be different, what it is like to be misunderstood and mistreated.

Because autism is a spectrum disorder, it means that people are affected to different degrees, and autistic individuals have a wide range of social awareness, sensory perceptual differences, communicative skills and cognitive abilities. However, the spectral character of autism is seen differently by autistic individuals – not as described behaviours but rather as identified underlying problems. For example, in some people autism may cause difficulty with emotional information, while in other cases it may cause problems with language, sensory processing or a combination of these (Williams, 1996). Autism never manifests itself in the same way twice, as there are many types of it (O'Neill, 1999). Autistic individuals differ from each other as much as their non-autistic peers.

Donna Williams (2006), an adult with autism, describes autism spectrum not as single condition, but as a 'fruit salad' – a cluster of a whole range of often unrelated underlying conditions. If we take several people diagnosed with autism and focus on the behaviours known as the Triad of Impairments, each area of difficulty may have a completely different underlying cause or a combination of causes for each of these individuals (Williams, 2006). Donna does not see 'autism' (as a collection of symptoms) but rather compounding collections of autism-related problems and different adaptations and compensations to different types of autism-related problems, when any difficulty affecting one system of functioning will cause a weakening in another system as it tries to compensate (Williams, 1996). According to Donna Williams (2006), any (or a combination) of the following, can cause problems with communication, social interaction, imagination, learning or behaviour (i.e. autism):

> information-processing differences; social-emotional anxiety states; impulse-control and mood issues; personality and identity issues; environmental and boundaries issues (p.17).

The majority of cases of autism may actually be compositions of a combination of co-morbid conditions that block and severely disrupt development. The idea that someone who is severely autistic will grow up to be just as severely autistic may in many cases depend on whether these 'blocks' are recognised and addressed (Williams, undated, b).

Each person gives his or her *personal* perspective on autism which may not coincide with others. Nevertheless, in all the diversity of their descriptions one can find certain similarities that run through *all* the accounts. And surprise, surprise, they do not see autism as a triad of impairments but as information processing problems and cognitive and sensory perceptual differences. In short, autism is seen as a fundamentally different way of being – perceiving, interpreting and thinking. How does the triad of impairments fit into this construct? Unfortunately, the triad, while being useful for diagnosis and recognition of autism from the outside, has brought many misconceptions of the condition. Often "impairments of social interaction, communication and imagination" are interpreted as *inabilities* to interact, communicate and imagine. However, if we look at these 'impairments' from the point of view of "fundamentally different ways of being" we will see a different interpretation of the same behaviour:

Social interaction

People with autism do interact and form relationships but of a different nature. Many of them have a strong desire to be with other people, to express themselves and to be understood. Although some of them want friends desperately, they often find that the people with whom they interact consider their interests somewhat strange. Since their world is so different from that of non-autistic people, they often have a hard time in 'normal' social relationships that come from ideas learned in early childhood. These ideas are not necessarily logical for autistic people and are a sort of 'fantasy' which they do not understand well. Therefore, they may do and say many things that violate most people's social context without realising that there is something they are violating. The social isolation that results from this increases their loneliness and feelings of being different (Joan & Rich, 1999).

Social communication

Non-autistic people are often puzzled by the 'odd' communication expressed by individuals with autism. However, persons with autism may be equally puzzled by their non-autistic communicative partners. It is often not so much that an individual with autism has no regard for their rules, as that the person cannot keep up with so many rules for each specific situation (Williams, 1996). Sometimes they are not aware of social cues because of the same perceptual problems which affect their understanding of other aspects of the environment. For example, visual processing problems may prevent the person from learning to recognise and interpret facial expressions. They may have to develop a separate translation code for every person they meet. Even if they can tell what the cues mean (because they have learned them theoretically) they still may not know what to do about them (Sinclair, 1992).

Establishing communication and understanding between any two people with different experiences and perceptions involves developing a common language. As an autistic person's experience and vocabulary (verbal and non-verbal) may be idiosyncratic, a great deal of effort must be taken on both sides to develop this common language (Sinclair, 1989). Communication is a two-way process, and it takes two people to mess up a conversation. Not all the problems are caused by people with autism. Non-autistic people have a lot to learn about the art of communication with those who do not converse in the same way, whether it is verbal or non-verbal language (Bovee, undated). Thus, the impairments of communication in autism are better described as qualitatively different ways to interact, communicate and process information which do not coincide with conventional ones.

Imagination

Bearing in mind that autistic cognitive processes are qualitatively different relative to the cognitive processes of the non-autistic population, the creativity and imagination of a person with autism will be qualitatively (and contextually) different as well (Bogdashina, 2004). For example, visual thinking has enabled Temple Grandin[1] to build entire systems in her imagination (Grandin, 1996a). The extremely vivid imaginative powers and enormous creativity of people with autism are seen in poetry and prose, music and art (e.g., Kochmeister, 1995; Lawson, 1998; Williams, 2003).

On the other hand, there are behaviours, such as unusual responses to sensory stimuli, that have not been included into the diagnostic definition of autism but which are difficult to ignore. (In the past, these responses were described as 'abnormal' or 'bizarre'.) However, bearing in mind the differences in perception, cognitive processes and adaptive strategies that autistic people acquire, their so-called 'bizarre responses' are likely to be logical and functional. These behaviours "help ground the autistic person, provide rhythm and order, calm, and simply feel good!" (O'Neill, 1999, p. 33). Many individuals with autism describe their stereotyped ('bizarre') behaviours as compensatory strategies to regulate their systems and to cope with information overload. These self-stimulatory behaviours (or 'stims') may serve several purposes, and one and the same behaviour may have different underlying causes. Some examples of different functions of stimming are:

– *defensive*: in order to reduce the pain or discomfort caused by hypersensitivities (e.g., "This behaviour is an attempt to eliminate a sensory assault that interferes with functioning." (Shore, undated))
– *self-stimulator*y: to improve the input in the case of hyposensitivity (e.g., "You may observe the same autistic person rubbing sandpaper on his bare arm, or banging his knuckles sharply into a solid wooden dresser, then peering at them as if to say, 'Oh, hello, hand. So you do belong to me, then… A lot of self-stimulation, including rocking the body, swaying, flapping the hands, rubbing the skin, and countless others, are pleasurable, soothing connections with the senses." (O'Neill, 1999, p. 33))
– *compensatory*: to interpret the environment in the case of 'unreliable' sensory information (e.g., "I was coping in a world where other people effectively realised nothing of that. I reacted to all this bombardment and confusion with those physical movements, silence and strange sounds which are generally lumped together as 'autistic behaviours'." (Blackman, 2001, p. 19))
– *out of frustration*: (e.g., "Sometimes head banging and knuckle nibbling, tantrums, or outbursts happen as a way of letting someone know enough is enough!" (Lawson, 2001, p. 78))
– *just pleasurable experiences* that help to withdraw from a confusing environment: (e.g., "Rocking and spinning were other ways to shut out the world when I became overloaded with too much noise. Rocking made me feel calm. It was like taking an addictive drug. The more I did it, the more I wanted to do it." (Grandin, 1996a, pp. 44–45))

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[1] Temple Grandin (born August 29, 1947) is an American doctor of animal science and professor at Colorado State University, bestselling author, and consultant to the lifestock industry on animal behavior. As a person with high-functioning autism, Grandin is also widely noted for her work in autism advocacy and is the inventor of the squeeae machine designed to calm hypersensitive persons. (ed.)

Characteristics of autism defined as secondary in mainstream research literature seem to be primary for many people with autism. Such features, for example, as unusual responses to sensory stimuli are often seen as the core description of autism. Besides, from the 'autistic' perspective, these responses are 'normal' (not 'unusual' or 'bizarre') because they are caused by different sensory-perceptual processing. Many authors with ASD consider autism largely as a condition relating to sensory processing (e.g., Gerland, 1997; Grandin, 1996a; Hale, 1998; O'Neill, 1999) and suggest that the true deep-rooted cause of all social and communicative and emotional problems is of a sensory-perceptual nature (see, for example, VanDalen, 1995; Morris, 1999):

> Now I think that the use of speech and of other sensory activities that are normally lumped together as 'communication' are themselves a kind of sensory exploration. One's sense of self as a person is augmented and developed in the process. The spoken environment is a peculiarly human invention, and like all other environments is learned by experience, both as a receiver and as a speaker. But for me all was distorted and unpredictable (Blackman, 2001, p. 11).

They identify the problems they experience as differences/ disturbances in their sensory perception and information processing. Temple Grandin (1996a) puts forward a hypothesis that there is a continuum of sensory processing problems for most autistic people, which goes from fractured, disjointed images at one end to a slight abnormality at the other.

However, not all people with ASD make sensory-perceptual issues the cornerstone of autism. One of the reasons may be the different interpretation of sensory problems. The confusion may be caused by 'official descriptions' of sensory difficulties – limited to hypersensitivities (over-responsiveness) and hyposensitivities (under-responsiveness). In this case, the statement "autism is not about sensory difficulties" is absolutely correct. Autism is about sensory differences, which are far more complicated than, for example, 'tactile defensiveness'. Autism is about a different development of sensory perception that brings about a different development of cognitive mechanisms. Visual thinking, for instance, which is quite common in autism, is the product of this development, while hypersensitivities and defensiveness are by-products that should be addressed as soon as they have been detected.

However, there is a very important point to take into account – not all the differences in perception are dysfunctional, and sensory differences are not necessarily problems or difficulties. Some may be interpreted as strengths or even superabilities that can become 'dysfunctional' if not recognised by the outside world. Non-autistic people can not appreciate some perceptual abilities of autistic individuals because they do not know they exist! Imagine that you are unable to see the colour red, how could you appreciate the beauty of red roses? If the majority can not see it, the ability to enjoy the 'redness' becomes useless and dysfunctional (Bogdashina, 2005b).

The problem for many autistic individuals is that they do not realise that their sensory perceptual processing is different (e.g., Grandin, 1996ab; Lawson, 2001; McKean, 1994; O'Neill, 1999; Willey, 1999). Temple Grandin, for instance, thought that other people were better and stronger than she was because she could not tolerate scratchy clothes or loud noises (Grandin, 1996a). A typical thought they might have is:

> There is something wrong with me. I can't do things right. Everyone is mad at me. No matter how hard I try, something goes wrong. Other people can do things I can't. It must be my fault that I'm having so much trouble (Spicer, 1998).

It is no wonder that they are often unaware that they perceive the world differently from the other 99 per cent of the population, because they have nothing to compare their perception with (Morris, 1999). The first realisation of their differences usually comes in the late teens or even later (Lawson, 2001; Willey, 1999). It may come as a kind of revelation, as well as a blessed relief, when they learn that their sensory problems are not the result of their weakness or lack of character. However, the problem is that people around them are often unaware of their different perceptions, and do not make any effort to accommodate and adjust to these differences:

> Suppose you are color-blind, and cannot distinguish between red and green. You are in a room with other people, all of whom have normal vision. No one – not even you – knows that you are color-blind. Everyone is handed a list of instructions. They are printed in red against a green background. Everyone except you knows exactly what to do. They cannot understand why you just sit there. The paper looks blank to you, and you cannot understand how others know what to do. Think of how you would feel, especially if the others stared at you, or whispered, or laughed (Spicer, 1998).

Everything we know about the world and ourselves has come through our senses. All our knowledge therefore is the product of what we have seen, heard, smelt, etc. Differences in perception may radically change the course of cognitive, language, emotional and social development. The manifestations of sensory differences are likely to be different in different people (or in the same person at different ages), but it is possible to identify the common features and recognise compensatory strategies and adaptations children with autism have developed to cope with their problems, and construct hypothetical paths of sensory development in order to free the child from developmental blocks that hinder the unfolding of their abilities.

We can distinguish some features of 'autistic perception' of the world, based on the testimonies of high-functioning autistic individuals and close observations of autistic children. Below I will discuss the most commonly reported perceptual phenomena and their possible influence in other aspects of development.

An inability to distinguish between foreground and background information (Gestalt perception – Bogdashina, 2003)

Autistic people are bombarded with sensory stimuli. They are often unable to filter irrelevant details and, instead, perceive the whole scene as a single entity. They perceive everything without filtration and selection. This results in a paradoxical phenomenon: sensory information is received in infinite detail and holistically at the same time. It can be described as gestalt perception – perception of the whole scene as a single entity with all the details perceived (but not processed!) simultaneously (Bogdashina, 2003). This feature was described by Kanner (1943) as a universal feature of autism – the inability to experience wholes without full attention to the constituent parts:

> a situation, a performance, a sentence is not regarded as complete if it is not made up of exactly the same elements that were present at the time the child was confronted with it (Kanner, 1943, p.246).

In the past, Kanner's comments were interpreted as a characteristic that followed from a deficit in central coherence (Frith, 1989; Happe, 1994). However, with evidence from personal accounts and given research studies (see, for example, Ozonoff et al., 1994), we can conclude that at a perceptual level autistic children have a strong drive for coherence – 'gestalt perception'. If the slightest detail is changed, the whole scene (gestalt) is different, i.e. unfamiliar. For children with autism to recognise things, these things must be exactly the same as when they initially experienced them. Only then will they know what to do with them (Williams, 1996). The same is true about routines - if something goes differently, they do not know what to do. The gestalt of the situation is different. All of this results in fear, stress and frustration and may explain their dislike of changes and preference for routines (Bogdashina, 2003). They may react to all this bombardment and confusion with certain physical movements which are generally known as stereotypical 'autistic behaviours' (Blackman, 2001). These 'ritualistic behaviours' serve as reassurance and create some order in daily life (O'Neill, 1999). Individuals with ASD may experience gestalt perception in any sensory modality. A person who experiences visual gestalt perception has great difficulty in separating a single detail of the scene from the whole picture (without this detail the whole picture will be different). People with auditory gestalt perception seem to pick up all sounds with equal intensity. They often feel 'drowned' in the sea of background noise and can not isolate, for example, the words of the person they are talking to from other noises in the room (e.g., fans working, doors opening, somebody coughing).

On the conceptual level, gestalt perception leads to rigidity of thinking and difficulty in generalising. Autistic children can perform in exactly the same situations with exactly the same prompts but fail to apply the skill if anything in the environment, routine or prompt has been even slightly changed. Each and every situation is unique. They can learn what to do in one situation but be lost if the slightest detail is different. Children with autism might be baffled when things change or go differently. Even the slightest changes may confuse and upset them. Another confusing (and frightening) thing for children with autism may be when something emerges in the situation that does not belong to it, as it destroys the 'gestalt' of the situation. To feel safe, they create 'gestalt behaviours' – rituals and routines. These behaviours bring reassurance and order in daily life which is otherwise unpredictable and threatening. These rituals may seem long and complicated to outsiders. However, for an autistic person, it is one act of meaningful experience, and if any part of it is missing (for example, a person is prevented from completing a seemingly meaningless ritual) the whole experience becomes incomplete, unfamiliar and frightening (Bogdashina, 2004).

Gestalt perception may bring sensory overload that, in turn, may have different consequences, such as overloaded, fragmented perception, delayed processing, distorted perception and hypersensitivity.

Vulnerability to sensory overload

The vulnerability to information overload is one of the distinctive features of individuals with ASD, which often goes unnoticed by their non-autistic communicative partners. If they continue to process all the in-coming information, despite their inability to keep up with it, overload sets in. This eventually brings anxiety, confusion, frustration and stress, which, in turn, can lead to challenging behaviours (Bogdashina, 2005).

Fragmented perception

When too much information needs to be processed simultaneously, people with autism are very often not able to break down the whole picture into meaningful units and process only those bits which happen to get their attention (Bogdashina, 2003). It seems as though people with autism react to parts of the objects as being complete entities in themselves (VanDalen, 1995). As children with ASD perceive their surroundings and people they encounter in bits and pieces, they interpret and store in their memory their individual (and idiosyncratic – from the non-autistic point of view) impressions of their experiences. They use these unconventional definitions of places, things and people to function in their environment. As these definitions differ from non-autistic ones, the carers find the behaviour of their child incomprehensible. In contrast to the 'universal weak central coherence' explanation in autism, Ozonoff et al. (1994) hypothesize that individuals with autism do indeed focus on details at the expense of seeing the big picture, but do it at a conceptual level. That is, they may have no problem visually processing the whole picture; their difficulty may only be apparent when the individual elements are meaningful pieces of information that must be integrated to form a general idea or understanding at a higher-order conceptual level.

In the context of fragmentation, we can see the role of attention and how the attentional mechanism functions in autism. Differences in attentional functioning may be central to many social and cognitive deficits in persons with autism, as efficient attending is essential to the development of other aspects of functioning. Sensory issues and attentional issues become closely connected and are most likely to be both real and primary. In some cases, one may help cause the other. Both attentional and sensory problems may have developmental consequences which may lead to the full autistic syndrome (Blackburn, 1999). As there is too much information coming in, it is hard to know which stimuli to attend to. The inability to filter out the information (gestalt perception) and distinguish the relevant from the irrelevant, to distribute different amounts of attention across present stimuli depending on their significance, and to sustain attention results in increased distraction and overload and impairs cognitive functioning. Involuntary responses to irrelevant stimuli interfere with the processing of relevant information. Without efficient filtering and selectivity of attention, the child finds it difficult to make sense of the environment. Children with ASD are often unable to divide their attention between the object they want and the person from whom they are supposed to ask for it, because for many of them, shifting attention from one stimulus to the other is a relatively slow process. Being able to use divided attention enables an individual to assess a number of situations and to make choices about them far quicker than many people with autism (who use single focused attention) are able to. Therefore, many individuals with ASDs may have difficulty with executive functioning (e.g., organizing, planning, processing, decision making). Sometimes this leads to obsessive ordering, rituals, repetitive behaviour and/or a lack of organizational ability outside the attention tunnel (Lawson, 2003).

Another common attentional difficulty in autism is the failure to establish and maintain joint attention, i.e. the ability to attend to the same stimuli as another person. This leads to a failure to share experiences. In turn, this results in the failure to comprehend the meaning of the interaction and hinders social and cultural development (Bogdashina, 2005). However, overselectivity and narrow attentional focus may be seen not as a deficit but rather as an attentional difference (Lawson, 2001).

Delayed processing

As a consequence of fragmented perception, people with autism may experience delayed processing. Perception by parts requires more time and effort to interpret what is going on with or around them. It may appear as though they do not feel pain, do not want help, do not know what they are saying, do not listen or do not want to. However, by the time some of these sensations are processed and understood, they may be several minutes, one day, a week, a month, even a year away from the context in which the experiences happened (Williams, 1996).

Distorted perception

People with autism may experience all sorts of distortions in their perception, especially when they are in a state of nervous overarousal and/or information overload. No one can guess that their eyes, for example, pick up different signals from the light, shade, colour and movement (Blackman, 2001):

> My enchanted world of light and sudden gaps into which people and objects moved, affected the way that I processed my fellow human beings… I basically emphasised folds and depths… So I perceived people… as slightly distorted. This was not only in shape, but also in the composition of the components of their bodies in my visual imagination (p. 26).

Hypersensitivity

Hypersensitivities to sensory stimuli are very common in autism. Their senses may be too acute and be disturbed by stimuli that do not bother non-autistic individuals. For instance, certain things they touch may hurt their hands (McKean, 1999). They may dislike places with many different noises or lights (Grandin, 1996a; Lawson, 2001; Shore, Undated). The fear of certain sounds that hurt their ears may be the cause of many ‘challenging behaviours’ and tantrums. Many ‘bad behaviours’ are triggered due to anticipation of being subjected to a painful stimulus (Grandin, 1996a).

Hyposensitivity

Sometimes their senses may become dull to the point that they can not clearly see or hear the world around them, or even feel their own body (Hawthorne, 2002). This state may be either permanent or temporary. To stimulate their senses and to get at least some meaning of what is going on, they may wave their hands around or rock or make strange noises.

Inconsistency of perception

People with autism may be tossed in a sensory maelstrom, so that the sensations may be unbearable one minute and yet completely unfelt the next (Blackman, 2001). Fluctuation of the 'volume' of perception is quite common in autism. The inconsistency of perceiving information, when the sensations (hence, the interpretation of what is going on) are changing day to day, hour to hour, sometimes even minute to minute (McKean, 1999), does not help the learning of social and emotional cues from people.

These and other sensory-perceptual inconsistencies and differences bring sensory overload in situations that would not bother other people. Stephen Shore (a high-functioning person with autism) calls sensory problems in ASDs (when the senses are turned up too high or turned down too low) 'sensory violations'. Combined with distorted and unreliable sensory information, these sensory differences can make dealing with the environment in an intensive manner very difficult, especially when transitions are involved (it is easier to do what you already know) (Shore, 2003).

Adaptations and compensations

Consciously or unconsciously, autistic persons develop their own perceptual styles in order to cope with their unique perceptual issues. These styles may be seen as defensive strategies and voluntary and involuntary adaptations and compensations, which the person with autism acquires very early in life. Timing and personal and environmental differences bring further variables of development in each particular individual, influencing cognitive and language functioning, emotional and social development. Many children with autism who are considered 'low--functioning' could develop and lead more independent lives if their compensatory strategies were understood, fostered, developed and refined (Williams, 1996). They learn very early in life to control their environment. The most common adaptations and perceptual styles in autism are:

- System shutdown
- Mono-processing
- Peripheral perception
- Compensating for an unreliable sense with other senses.

System shutdown

Too much sensory overload may result in a system shutdown. When the person cannot cope with sensory information, s/he may shut down some or even all sensory channels. Many children with autism are suspected to be deaf as they do not react to any (even very loud) sounds. Their hearing, however, is often very acute, but they learn to 'switch it off' when they experience overload and can not cope with the rate of incoming information. In order to shutdown the painful channel(s), they may engage in stereotypic behaviours or deliberately distract themselves through other channels (for instance, touching objects to 'switch off' their vision or hearing), or to withdraw altogether. If this strategy is mastered early in life, they are often reluctant (in the fear of painful bombardment of unmodulated, unfiltered stimuli) and, with time, unable to 'switch the channels back on'. It leads to self-imposed sensory deprivation that, if not addressed, may lead to irreversible hindrance of development:

> Auditory and tactile input often overwhelmed me. Loud noise hurt my ears. When noise and sensory stimulation became too intense, I was able to shut off my hearing and retreat into my own world (Grandin, 1996b).
>
> When a baby is unable to keep up with the rate of incoming information, its threshold for involvement or attention is not great before aversion, diversion or retaliation responses step in, or plain and simple systems shutdown: nobody's home (Williams, 2003, p. 50).

Many individuals with ASD agree that perceptual problems such as feeling deaf, blind or dumb, are experienced as very real. They are caused by shutdowns of the sensory systems that may be, in turn, caused by stress, or brought on by an inability to cope with incoming information (Williams, 1999). In shutting down their sensory systems, they may not receive the stimulation that is required for normal development. Temple Grandin (1996b) hypothesizes that possibly there are secondary central nervous system abnormalities which happen as a result of the child's avoidance of input. The initial sensory processing abnormalities with which the child is born cause initial avoidance. However, the limbic system, which has abnormalities, is not mature until the child is about two years old. The possibility of secondary damage to the central nervous system (CNS) may account for why young children in early intervention education programmes have better prognosis than children who do not receive special treatment (Grandin, 1996b). To back up her argument, Grandin (1996b) cites animal and human studies that show that restriction of sensory input causes the CNS to become overly sensitive to stimulation. Animals placed in an environment that severely restricts sensory input also develop many autistic symptoms such as stereotyped behaviours, hyperactivity, and self-mutilation. The effects of early sensory restrictions are often long lasting, and the hypersensitivity caused by sensory deprivation seems to be relatively permanent. One possibility is that autism may be a type of developmental deprivation syndrome and disturbances of the attentional mechanism (in combination with sensory difficulties) may also contribute to the condition (Blackburn, 1999).

Mono-processing

To limit the amount of information and avoid overload and fragmentation, people with autism may use one sensory channel at a time, while the rest of the senses are on hold. It brings certain restrictions to their perception but helps to make sense of information in at least one sensory modality. Later, they learn to switch channels and, though not simultaneously through all the senses, they may still get some meaning of an object, event, or situation. For example, the child uses his vision and sees every minute detail, sees that the colours are vibrant and, perhaps radiantly brilliant, but loses track of s/his other senses and does not make much sense of sounds in the background, loses the feeling of touch or body awareness (O'Neill, 1999). People with autism may be unable to process information produced simultaneously on the outside and inside and, for instance, while touching something they may feel the texture of the object, but have no sense of the hand, and then switch channels and feel the hand but lose the sensation of what the hand is in contact with (Williams, 1998).

Peripheral perception

Another strategy to avoid overload and get meaning from the outside world is peripheral perception. Autistic persons can often understand things better if they attend to them indirectly, for instance, by looking out of the corner of their eyes (O'Neill, 1999) or listening peripherally. The same is true of other senses if they are hypersensitive – the indirect perceptions of smell, taste or touch are often defensive strategies to avoid overload and keep in touch with reality. In this case, it is a kind of indirectly confrontational approach in contrast to a 'normal' directly confrontational one (Williams, 1996).

Timing

If sensory problems start early in life and the child learns to shut the systems down (in order to protect himself from painful and scary experiences), he creates a self-imposed sensory deprivation that leads to the complete isolation of the child from the outside world. It prevents him/her from learning via imitation and social interaction. Those who acquire autism-specific perceptual styles (monoprocessing, peripheral perception) get different experiences from the same stimuli that can not be shared with non-autistic people whose perceptual styles are 'normal' (Bogdashina, 2005).

Most, if not all, autistic children may have auditory processing problems, but they vary in severity. Those with minor difficulties often end up hyperverbal and have above average intelligence, more in the Asperger syndrome pattern than in the classical autism pattern (Klein, 2002). There is a group of children with ASD (at the so-called low-functioning end of the spectrum) who experience very severe auditory processing problems. They are not only late speakers, but may not speak at all or spend their entire lives with 'dysfunctional' speech. Many of these people have significant problems getting even the literal meaning of receptive language in any consistent or ongoing way. They can be anywhere from completely functionally 'meaning-deaf' to, at best, getting the literal meaning of 50–70 per cent of incoming auditory information. Their ability to link auditory input to any mental images is missing – the words fall, meaningless (Williams, undated, a). If the capacity to perceive and interpret information is impaired, no verbal conceptualisation is achieved spontaneously. In this case, the transition from what Donna Williams calls 'sensing' to interpretation and verbal development may be delayed. The ability of a child to automatically learn language cannot proceed if the incoming information is perceived as a confusing jumble of noise, rather than coherent speech, when someone talks to him/her. Klein (2002) hypothesizes that the longer this auditory deficiency continues, the longer the neurons will continue to develop in a haphazard (and useless) manner, and the harder it will be to remediate the growing language difficulties. Developmental blocks (biochemical, metabolic, perceptual, cognitive, emotional, psychological) should be unblocked to free up development. This will bring the beginning of expression through social interaction and communication with others. A lot depends on how consistent and predictable sensory perception and information processing are and how rewarding and comprehensible the new experiences are (Williams, 1998). The timing of the advent of sensory problems may determine which type of autism develops:

> The exact timing of the sensory problems may determine whether a child has Kanner's syndrome [here: HFA] or is a nonverbal, low-functioning autistic. I hypothesize that oversensitivity to touch and auditory scrambling prior to the age of two may cause the rigidity of thinking and lack of emotional development found in Kanner-type autism. These children partially recover the ability to understand speech between the ages of two-and-a-half and three. [Those] who develop normally up to two years of age, may be more emotionally normal because emotional centres in the brain have had an opportunity to develop before the onset of sensory processing problems. It may be that a simple difference in timing determines which type of autism develops (Grandin, 1996a, p. 50).

Differences in perception lead to development of different abilities and thinking styles, which are often not taken into account by those who live/work with those with ASDs. As more educators, doctors and parents understand these differences, more children with autism will be helped from their isolation and misunderstanding (which is tantamount to mistreatment) at younger ages. It is possible to help a child develop his or her potential if the carers work with autism, not against it. Learning does not end in childhood. The autistic brain may develop at a much steeper rate than is otherwise expected, even to the point of almost catching up with its non--autistic counterpart (Hawthorne 2002). The environment may either speed up the development or hinder it. In order to help them, we need to know how the senses of each individual work and what (voluntary or involuntary) strategies each individual has acquired to function in the environment (Bogdashina, 2005b). The recognition of sensory-perceptual problems is a new field and, unfortunately, many professionals are unaware or unknowledgeable about these problems, how to recognize them or what to do about them (Williams, 1996). Isn't it time at last to listen to those who live with autism and consider the problems they identify as the primary ones, instead of going in the opposite direction?

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Sensory perceptual issues in autism: why we should listen to those who experience them

Abstract

The paper challenges the way we think about how we analyse and interpret the behaviours we see in Autism Spectrum Disorder (ASD). The focus is on sensory issues, with the main argument being that many of the behaviours we observe may be logical responses to sensory stimulation (e.g., overload, delayed processing, fragmentation) and not attributable to other factors.

Problemy natury sensorycznej i percepcyjnej w autyzmie: dlaczego powinniśmy słuchać tych, którzy ich doświadczają

Streszczenie

Niniejsza praca podaje w wątpliwość nasz sposób myślenia dotyczący tego, jak analizujemy i interpretujemy zachowania obserwowane w ASD (zaburzenie ze spektrum autyzmu). Centralnym punktem zainteresowania są kwestie sensoryczne, za którymi przemawia główny argument, iż wiele z obserwowanych zachowań może stanowić logiczną reakcję na stymulację sensoryczną (np. nadmierne obciążenie, opóźnione przetwarzanie, fragmentaryzacja), a nie wynikać z innych czynników.

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FOLIA 98

Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

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The use of computer technology and the internet in teaching and therapy of individuals with Autism Spectrum Disorders (ASD)[1]

> *Across the world there is a passionate love affair between children and computers…. and more than wanting it [computer technology], they seem to know that in a deep way it already belongs to them. They know they can master it more easily and naturally than their parents. They know they are the computer generation.*
>
> Seymour Papert
> *The Connected Family*, 1996.

Diagnosis and sensory profile in ASD in the contest of computer-mediated-communication (CMC)

Many individuals with autism spectrum disorders (ASD) have limited verbal skills but are extremely proficient in skills related to technology and written communication (Ward and Meyer, 1999). They have a 'natural' affinity with computers (Prior et al., 1998). According to Goldsmith and LeBlanc (2004), parents and clinicians regularly report that children with autism are drawn to technological devices, and researchers have noted the importance of devising treatments that take advantage of this fascination. Evidence-based multimedia programs demonstrate significant improvements in social and academic skills of ASD individuals (Bernard-Opitz et al., 1999; Bosseler and Masaro, 2003; Gray, Creighton, McMahon, and Cunningham, 1991; Heimann et al., 1995; Kinney et al., 2003; Hetzroni and Tannous, 2004; Mangan, 2008). Also recent studies using the computer as a vehicle for communication (Brownlow and O'Dell, 2006; Rejendran and Mitchell, 2000; Scott, 2008) prove that people who are on the autism spectrum communicate more easily using computer-mediated communication (CMC) such as: instant messages (IMs), emails, chat rooms, text messaging, virtual worlds or blogging. Brownlow and O'Dell (2006) have demonstrated that in chat rooms ASD individuals are finding a voice in an online environment and the Internet is a powerful tool in enabling this voice to be heard (p. 315). As described by Ward and Meyer (1999), many able individuals with ASD find a group identity in the Electronic Age (p. 136).

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[1] A Polish version of this text has been originally published in the book *Oblicza rehabilitacji* by Bargiel-Matusiewicz, Pisula and Walewska (Eds.), Warszawa: MediPage Publisher.

Currently, professionals think of autism as a ‘spectrum’ disorder, meaning a group of disorders with similar features. The spectrum ranges from a severely affected, mentally retarded individual who may need to be institutionalized, to a brilliant individual who is very well adjusted but exhibits barely visible autistic behaviours in social and communication areas. Publication of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in May 2013 will mark one of the most anticipated events in the field of mental health (APA, 2010). One of the reasons for this is that the American Psychiatric Association (APA) will recommend a new name for the category of autism spectrum disorder (ASD), which currently includes autistic disorder (commonly called as autism), Asperger’s disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS). According to APA’s work group, this single category (ASD) will better reflect the state of knowledge about its pathology and clinical presentation, as the previous criteria were equivalent to trying to “cleave meatloaf at the joints” (APA, 2010). Many individuals with Asperger’s syndrome are usually of average or above-average intelligence and are often able to mask or accommodate their differences. According to Mayor (2008), many of them make it well into middle age or live their whole lives without being formally diagnosed (p. 24). Diagnostic criteria in regards to high-functioning individuals on the autism spectrum, for example people with Asperger’s syndrome, are controversial and professionals are still in disagreement. According to Harvey and Latica (2002), Asperger’s syndrome is a neurological difference that has been socially constructed as a disorder (p. 659). Levin and Schlozman (2006) challenge the paradigm of how we distinguish between mental illness and the spectrum of normal behaviour in regards to Asperger’s syndrome and high functioning autism (p. 430). Baron-Cohen (2002) describes Asperger’s Syndrome not as a disability but simply as a different cognitive style (p. 186). Harvey and Latica (2002) state that Asperger’s syndrome is an inborn neurological difference accompanied by a range of behaviour patterns that would count as normal, though eccentric.

Individuals with autism spectrum disorders (ASD) share common deficits that may be present from early childhood, like social impairments, narrow interests and repetitive adherence for introducing routines. These people (ASD) sometimes have problems as a result of social constraints and stigma. Many tend to experience isolation and a lack of understanding in their everyday lives. Many are often misunderstood and rejected, often resulting in frustration, anger, depression and lack of self-esteem. They struggle to effectively communicate their needs, thoughts and emotions in face-to-face situations. What comes ‘naturally’ to most people does not come ‘naturally’ to ASD people and according to Rynkiewicz (2009), this social awkwardness of ASD individuals, although physically invisible, can be highly disabling (e.g., colour blindness) (p. 26). Cumine et al. (1998) states that children with Asperger’s syndrome do not pick up social skills incidentally; they need to be specifically taught (p. 39).

Individuals with ASD have a unique sensory profile that often causes a sensory overload. They have difficulties with multichannel receptivity and processing, and possess a range of abnormalities, including hyper- and hypo-sensitivity, sensory distortion of sound, vision, touch, taste, and smell (O’Neill and Jones, 1997). Typically

ASD people need longer time to process the information and respond to different sensations and situations. Thus, computers allow ASD individuals not only to work at their own speed, but they (computers) minimize competing sensational information in the environment that might cause distractions. They (computers) help reduce social anxiety experiences during face-to-face interactions and accommodate the autistic need for sameness, control and predictability. Computers provide a controlled, structured, and interactive environment. As Attwood (2007) states, the computers are logical, predictable and not prone to moods. According to Schultz et al. (2000) and Klin et al. (2002), problems with noticing and perceiving many nuances of social interactions in face-to-face situations may be due to reduced eye region fixation time that ASD individuals have. Schultz et al. (2000) and Klin et al. (2002) conducted experiments where ASD individuals viewed social scenes while eye-tracking technology simultaneously measured their visual fixations. The study revealed that people who were on the autism spectrum fixated more on mouths and objects, but not on eyes. 'Reading' speakers' facial expressions is crucial, as humans do not develop language skills solely by hearing spoken words. Some educational software such as *Mind Reading* (Baron-Cohen, Wheelwright, Hill, Raste and Plumb, 2001) or the children's animated series *The Transporters*, has been developed by professionals from the Autism Research Centre at the University of Cambridge to teach the skill of recognising emotion expressed on faces. More details about this software and animation series are included later in this paper.

The Internet could change the lives of average citizens as much as the telephone did in the early part of the 20th century and television in the 1950s and 1960s (Kraut et al., 1998, p.1017). Shields and Behrman (2000) have noted that, "Computer technology has transformed society in profound ways. For better or worse, the increasing pervasiveness of computer technology is a reality no one can ignore." (p. 4). Effective communication is critical. Like Shklovski, Kraut and Rainie (2004) noted, communication is the mechanism people use to develop and maintain the social relationships that are so valuable to their physical and mental health. The Internet leads to more and better social relationships by freeing people from the constraints of geography or isolation brought on by stigma, illness, or schedule (Kraut et al., 1998, p. 1017). ASD individuals struggle in face-to-face interactions. However as Brownlow and O'Dell (2006) noted, poor communication patterns of ASD individuals in face-to-face communication situations are not reflective of their communication abilities as a whole (p. 315). The Internet helps to rehabilitate or 'normalize' communication deficits in high functioning ASD individuals.

ASD people find the Internet very attractive as it offers computer-mediated-communication (CMC), such as email, blogging, instant messaging (IM), etc. Email is probably one of the most popular options of CMC (Burnett and Wilkinson, 2005; Lenhart, Rainie, and Lewis, 2001; Livingstone, 2003; Madell and Muncer, 2004; Quigley and Blashki, 2003; Sun et al., 2005). Bryant, Sanders-Jackson, and Smallwood (2006) noted that computer-mediated-communication (CMC) is more frequently used by socially isolated adolescents. Since many ASD people suffer from anxiety or even panic attacks during social encounters, CMC provides a safe mode of communication for them. It facilitates communication more easily in this population (Brownlow and O'Dell, 2006; Rajendran and Mitchell, 2000; 2006; Scott, 2008).

Our today's society is in a *digital revolution*, and the Internet facilitates communication in fundamentally different ways from other semiotic situations. According to Baron (2005), CMC provides young users the opportunity for social affinity and control over when and with whom to interact (p. 29). ASD people prefer CMC to conversing, as it is different from other forms of communication, such as face-to-face interaction, traditional writing, and phone conversation. ASD individuals struggle in face-to-face and phone conversations due to their weaknesses in auditory and verbal processing (Cohen and Sloan, 2007). They also process different stimuli and events with delay (Rynkiewicz, 2009). The phone conversation has all the immediacy of face-to-face communication and requires use of spoken language and the need to generate quick, novel responses, whereas emailing or phone texting requires graphic symbols and has a slower pace. A slower pace due to this delay in processing is something that ASD individuals need as an executive or temporal buffer. They (ASD individuals) need more time to sort out complicated social events and exchanges, organize thinking and connect the emotions to thoughts. The lack of nonverbal cues in emailing, text-messaging, or blogging etc. is actually an advantage for ASD writers as it allows them to plan, compose, edit, and deliver their written messages, something face-to-face or phone conversations do not allow. The gender difference in regards to the Internet usage by ASD people should be noted as well. ASD men are more likely than ASD women to use the Internet for purposes related to entertainment and leisure. ASD men more frequently play games or create their own websites, whereas females use the Internet primarily for interpersonal communication, emotional support and educational assistance. ASD females more frequently use chat rooms, emails, instant messaging, and join various discussion groups and clubs. Both sexes of the ASD population, however, are task-, information-, and content-oriented. They browse the Internet with passion for information related to their special interests.

Computer-mediated communication (CMC) has properties of both written and oral language and as Merchant (2003) noted, the medium of e-mail has plenty to offer to young writers (p. 110). Some ASD people can write beautifully, however the process of writing is typically slow and laborious (Rynkiewicz, 2009). A skilful teacher and mentor may use CMC to teach writing to ASD people. Online chats, emails and text-messaging give ASD individuals autonomy, creativity and a high level of interaction. According to Herring (2002), email allows users the time to carefully compose and edit their messages, which may be formal and linguistically complex. People with Asperger's syndrome and high functioning autism are afraid to make mistakes and misspellings. Unlike in traditional writing, however, misspellings online are taken as a sign of typing inaccuracy rather than lack of education (Scott, 2008). The Internet lexicon is the other reason why ASD people like CMC. It has various types of abbreviations, distinctive graphology, idiosyncratic spelling, and unique use of punctuation (Crystal, 2006). It allows ASD people to express their emotions and feelings during online conversations, something they struggle in during face-to-face interactions. They can capitalize a message, underscore, and italicize text, as well as place asterisks or brackets around words to add emphasis. They can use graphic symbols like emoticons too. ASD people have deficits in understanding complex emotions (Baron-Cohen, 1991), however, it is a myth that individuals from the autism spectrum do not experience complex feelings and emotions. Computer-mediated-communication rehabilitates this impairment as they (ASD people) can express feelings and emotions in writing, for example in email. ASD individuals also express complex emotions in other forms of computer art, like in drawing or music, and computers facilitate this. Engagement in computer activity, which is a special interest for ASD individuals, provides a calming effect, relaxation, as well as pleasure.

The emergence of new kinds of relationships between writers and readers where the interaction is heavily screen-based has pedagogical implications as it suggests new kinds of relationships between students and teachers. Nowadays, the out-of-school practices of students are increasingly screen-based, which is opposite to school literacy curriculum that is dominated by practices based on print-based text (Holloway and Valentine, 2003). Email opens new possibilities for ASD writers and enriches the curricular emphasis on genres and forms. It also expands the horizons of writers as they write for new online audiences. According to Scott (2008), users of the Internet explore new ways of expressing ideas as well as feelings towards their correspondents, and this new creativeness actually promotes the culturally valued practices of reading and writing. Educators might rethink what literacy means in the current era, dominated by computer technology, and ensure that schooling is not so focused on controlling literacy, but empowering the young to explore its full potential. According to Baron (2005), CMC is unlikely to play a significant role in altering writing standards – unless we as parents and educators let it (p. 31).

Peer relationships are important, especially to adolescents. As Tennant (2008) reflects, “Making the world a better place alone is an oxymoron, because no place of solitude is a better place for human beings” (p. 4). Problems like rejection and lack of close friends are among the strongest predictors of depression and low-self esteem. ASD people do prefer solitude, but this does not mean that people with high functioning autism or Asperger’s syndrome do not look for friendships and social interactions. Typically ASD individuals find friendship among people who share the same special interests, hobbies, and passions. The flexible and potentially anonymous Internet environment allows some shy and anxious ASD adolescents to explore their identity; as Heisler and Crabill (2006) stated, CMC allows concealing or constructing identities related to gender, race, class, and religious affiliations. To ASD people, instant messages (IMs), another form of CMC, are like “hanging out” face-to-face and talking on the phone. The *digital revolution* allows ASD individuals to be digital citizens’ net generation. They belong to a large ‘virtual community’. However as suggested by Scott (2008), Internet usage can undermine or foster the well-being of ASD individuals, depending on whether it supplants or expands opportunities for meaningful, daily contact with close peers.

ASD people can create truly meaningful, close relationships with their friends online. Online communication has become increasingly popular among individuals with autism for self-advocacy and for meeting other individuals with autism (Robertson and Ne’eman, 2008). Like Brownlow and O’Dell (2006) have stated, the Internet enables ASD individuals to be heard (p. 315). Formal organizations create online communities to support ASD people, like OASIS@MAAP, Autism Society (former Autism Society of America), Autism Society of Washington, etc., serving as the primary recourses to teach, inform and advocate. Informal online communities such as WrongPlanet.com serve primarily as a network to meet and chat online with the other individuals from the autism spectrum. Often older, well-educated and accomplished ASD individuals serve as the online mentors to younger ASD individuals. It presents a natural predilection of people with ASD to form more and stronger relationships with individuals who are much older or younger than themselves (Attwood, 2007; Bauminger and Kasari, 2000; Jones and Meldal, 2001; Rynkiewicz, 2009). According to Kraut et al. (1998), generally, strong personal ties are supported by physical proximity. However, this may not be true with ASD individuals because of their sensory profile, as many ASD people find both physical touch and eye contact uncomfortable. Computer technology, therefore, provides a comfortable social and physical distance for children and adults with ASD. It also provides visual support.

ASD individuals are relatively skilled in responding to visual cues, such as pictures and animations (Bernard-Opitz, Sriram and Nakhoda-Sapuan, 2001). The effective treatment for students with ASD should include 'visualized' procedures because children with ASD have 'strength' in visual thinking (Yamamoto, 2007). Also, individuals on the autism spectrum appear to favour visuospatial over linguistic mediation (Sahyoun et al., 2009). Vision dominates our perception of space, not because of any inherent physiological advantage of visual over other sensory connections in the brain, but because visual information tends to be more reliable than other sources of spatial information; and the central nervous system integrates information in a statistically optimal fashion (Witten, 2005, p. 489). Visual spatial information is exceptionally reliable and precise while the same information in other sensory systems can be easily distorted. For example, acoustic cues change gradually with stimulus location, compared with the resolution of optical signals, and the cues are easily distorted by echoes caused by objects in the environment or changes in the shapes of the ears (Witten, 2005, p. 490). Individuals with autism spectrum disorders (ASD) report a propensity for visual rather than verbal modes of thinking. Children with ASD use inner speech or visual imagery to support recall from short-term memory (Williams et al., 2008, p. 51). The study of Grinter et al. (2009) supports the superiority of visuospatial analysis in students that score high on the Autism-spectrum Quotient (AQ). These students are faster and more accurate on the Embedded Figures Test (EFT) and the Block Design subscale of the Wechsler Intelligence Scale III compared to those that score low on the AQ. Many students on the autism spectrum see in pictures. Like Dr. Grandin said, "My mind is similar to an Internet search engine that searches for photographs." (Grandin, 2009, p. 1437).

Berube (2007) argues that since autistic children possess special gifts in visual/spatial areas, we should support these abilities instead of "correcting" them into a more "normal" range (p. 5).

Selected computer programs and software used in teaching and therapy of individuals with ASD

TeachTown is a research-based computer-assisted therapy for children with autism spectrum disorders. The program uses practices from Applied Behaviour Analysis (ABA), education, speech and language, and developmental psychology.

Thanks to its online capacities, this computer program allows teachers, parents and clinicians to coordinate the child's education and therapy in multiply locations from where all the data is automatically synchronized via the Internet. A child can work on any computer that has the software installed and an Internet connection. The curriculum is designed for developmental ages two to seven. However, the creators of TeachTown are planning to design the curriculum for older children and teenagers in the near future (M. Vaupel, personal communication, November 20, 2009). TeachTown is a subscription service where the curriculum, lessons, reinforcers, and generalization activities for off computer learning are consistently updated. Off-computer generalization activities are written for non-experts so any family member can teach them to a child. This cost-effective tool is used to teach receptive language, cognitive/academic, social skills, and adaptive life skills (Whalen, 2009; Whalen, Moss, Ilan, Vaupel et al., 2010).

Transporters – is a 3D children's animation series created for both high--functioning ASD children who have developed age appropriate language and cognitive abilities and low-functioning ASD children who have significant learning difficulties. The animation has been designed to enhance understanding and recognition of emotions by children with autism spectrum disorders between the ages of three and eight. There are eight characters, vehicles with grafted real-life faces of actors who show emotions. The series consists of 15 five-minute episodes, each of which focuses on a key emotion or mental state. The 15 key emotions shown on the vehicles' faces are: happy, sad, angry, afraid, disgusted, surprised, excited, tired, unfriendly, kind, sorry, proud, jealous, joking and ashamed (Baron–Cohen, Golan, Chapman, Granader, 2007; Golan, Ashwin, Granader, et al., 2010).

The Virtual World is a therapeutic 3D program designed by researchers from The Virtual World Lab at the University of Texas in Dallas. The program uses a platform from Second Life, the popular virtual world (Mangan, 2008). The idea is that patients go to an "island" customized for therapeutic purposes to build social skills. Patients design their avatars which look nearly identical to themselves by choosing from programmed gestures, smiles, and shrugs. They can even express their reactions, like for example impatience, by tapping their feet. Patients experience encounters like in real life scenarios (e.g., in a restaurant, office, home, or park, etc.). These virtual encounters evoke responses and emotions. If behaviour during any encounter in the Virtual World is socially inappropriate, the Virtual World is put on pause and a clinician, together with the patient, discuss and consider how to better handle the situation. Patients with autism spectrum disorders who have been tested so far with this program have shown improvements in social skills. They are less likely, for instance, to make inappropriate jokes and they are better in reading people's body language (Mangan, 2008).

Mind Reading – *The Interactive Guide to Emotions* – is software created by researchers from the Autism Research Centre at Cambridge University to teach children and adults with Asperger's syndrome and high functioning autism to recognize emotions. It is an interactive guide to emotions and mental states. It is based on a taxonomic system of 412 emotions and mental states, grouped into 24 emotion groups and 6 developmental levels from age four to adulthood. There are three main sections: Emotions Library, Learning Centre and Game Zone. Emotion

Library presents different emotions as video clips with a definition and a story for each emotion. Learning Centre has lessons and quizzes about emotions while the Game Zone provides the games and informal, fun learning about emotions (Golan, Ashwin, Granader, et al., 2010; Golan and Baron-Cohen, 2006).

Bubble Dialogue – is a computer program for individuals with autism to help regulate interaction, such that the social impairment characteristics of Asperger's syndrome are less conspicuous. The program allows autistic individuals to analyze, repeat and finish a task at their own, typically slower speed. The program engages in role-play scenarios; participants can repeat a scene, analyze relevant cues many times without annoying or boring others. They (participants) report they can be relaxed, because they do not receive public criticism and there is also no heavy face-to-face interaction processing required while conversing (Gray, Creighton, McMahon, and Cunningham, 1991).

AViSSS – Animated Visual Supports for Social Skills program is an application designed by researchers from the University in Kansas. It is a three-dimensional (3D) virtual environment for children with Asperger's syndrome for teaching social skills. This 3D virtual environment has multiple scenarios with animations, characters and objects that present various situations and problems that a student needs to address. Each response that a student gives to AViSSS generates a result and explanation of their choice (Ehrlich and Miller, 2009).

The following two projects are worth mentioning in this article because of their potential for research in computer technology and ASD:

Collegium Futurum 21 (CF21) – is a middle and high school program in Poland where students use modern technology and multimedia tools. The program is designed to teach the general population of students, however, the educational environment is very well-suited for able students with Asperger's syndrome and high functioning autism. The program partners and is supported by the Autism Society of Washington. This educational program uses the essence of Web 2.0, blogs, webquests, YouTube, expert Internet portals, e-learning 2.0; it builds online communities for students' projects. The virtual campus has teachers and experts available online for students from Europe, Canada, and the USA as well. Students create online events, e-videos, market their own websites (banners, blogging, etc.), design projects using computer graphics, and learn about copyright laws and privacy policies. Modern teaching is offered, such as I-Search, Web Quest, RAFTT, etc. Classes are small, 5 to 10, students and each student has a mentor (Raczyńska, 2010).

MEDIATE – MultiSensory Environment Design for an Interface between Autistic and Typical Expressiveness. This is a European-funded project of full-body, non-invasive, interactive computer space that generates real-time stimuli (visual, aural and vibrotactile). The project is designed for low-functioning children with autism who have no verbal communication. It shows that children who need very rigid daily routines and who do not cope well with unknown places actually become curious enough to enter out of their own will and start to play (Parés et al., 2006).

Conclusion

The effectiveness of computers and the Internet in teaching and therapy of people with Autism Spectrum Disorders (ASD) has been demonstrated in a number of recent studies (Bernard-Opitz et al., 1999; Bernard-Opitz, Sriram, and Nakhoda-Sapuan, 2001; Bosseler and Masaro, 2003; Chen and Bernard-Opitz, 1993; Heimann et al., 1995; Hetzroni and Tannous, 2004; Kinney, Vedora,and Stromer, 2003; Lewis et al., 2005; Mangan, 2008; Moore and Calvert, 2000). Although more research is still needed, the results of studies that have been completed up to this point are highly promising and reveal that ASD individuals may benefit from a departure from traditional methodologies (Brownlow and O'Dell, 2006). Computer technology and the Internet unlock the potential and talents of ASD children and adults. As Cartwright stated, "Technology is what the gift of fire and light was to our forefathers." (N. C. Cartwright, personal communication, March 7, 2010).

Acknowledgments
The author was supported by a scholarship from The Rachel Royston Permanent Scholarship Foundation, Alpha Sigma State, Washington, Delta Kappa Gamma Society International, USA.
The author would like to thank:
Art Ellis, Ph.D. from Seattle Pacific University, USA for mentoring and support.
Nancy Cartwright, Ph.D. from West Texas A&M University, USA for mentoring and support.
Sharon Zima of the Autism Society of Washington and Rusloc localization company, for editing.

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Use of computer technology and the internet in teaching and therapy of individuals with Autism Spectrum Disorders (ASD)

Abstract

Use of computer programs and software in teaching and therapy of individuals with ASD is a relatively new field of research, but it shows very promising results. The use of computer technology and the Internet in ASD has demonstrated effectiveness in a number of recent studies. Virtual reality is also gaining traction as a form of psychotherapy at some academic medical centres. Many individuals with ASD have unique talents and are skilled in responding to visual cues, such as pictures and animations. Computers not only unlock many unique talents that individuals with ASD possess, but also facilitate the development of social skills that are crucial for functioning in society. In addition to selected computer programs and software, the article also presents some important facts about the diagnosis and sensory profile in ASD and connects these facts with the discussion about computer-mediated-communication, CMC, which is used by individuals with ASD. The article is primary focused on individuals with Asperger's syndrome and high-functioning autism.

Wykorzystanie techniki komputerowej i internetu w nauczaniu oraz terapii osób dorosłych z ASD

Streszczenie

Wykorzystanie programów i oprogramowania komputerowego w nauczaniu oraz terapii osób z ASD stanowi stosunkowo nową dziedzinę badawczą, aczkolwiek przedstawia bardzo obiecujące wyniki. W kilku najnowszych badaniach, stosowanie techniki komputerowej oraz internetu u osób z ASD okazało się efektywne. Rzeczywistość wirtualna jako forma psychoterapii zyskuje także szansę na realizację w niektórych akademickich ośrodkach medycznych. Wiele osób z ASD posiada unikalne zdolności i obdarzonych jest umiejętnością reagowania na bodźce wizualne, takie jak obrazki czy animacje. Komputery nie tylko wyzwalają wiele niezwykłych talentów, które posiadają osoby z ASD, lecz także ułatwiają rozwój umiejętności społecznych, niezbędnych dla funkcjonowania w społeczeństwie. Oprócz wybranych programów i oprogramowania komputerowego, artykuł ten przedstawia również pewne znaczące fakty dotyczące diagnozy i profilu sensorycznego w ASD oraz łączy te fakty z dyskusją na temat komunikacji zapośredniczonej komputerowo (ang. *computer-mediated-communication* – CMC), która jest stosowana przez osoby z ASD. Artykuł zasadniczo skupia się na osobach z zespołem Aspergera oraz autyzmem wysokofunkcjonującym.

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FOLIA 98

Annales Universitatis Paedagogicae Cracoviensis

Studia Psychologica IV (2011)

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Respite care for families with children with Autism Spectrum Disorders: how services in Northamptonshire UK are working to meet the challenge

Value and benefits of respite care for families with children with ASD

Respite care services for disabled children – or 'short breaks' as they are now named in the UK – are social care services that enable such children to spend short periods of time (from a few hours to a few days) away from their families. Such services have developed rapidly in the UK since the 1980s (Stalker, 1996) and have been shown to be of benefit to families, the disabled children, and to the state.

Benefits for families

Respite care has long been identified as important for families with children with ASD (Bristol and Schopler, 1983). Families with children with ASD can experience higher levels of stress than those whose children have other impairments (Koegel et al., 1992; White and Hastings, 2004). However, they often have limited social support from relatives, neighbours and friends (Boyd, 2004; Preece and Jordan, 2007a). Respite care can help reduce stress in families (Chan and Sigafoos, 2001), as well as provide them with the chance to have a break from caring and doing things that they cannot do while the child with ASD is at home (Preece, 2000; Tarleton and Macaulay, 2003).

Benefits for children with ASD

Appropriate respite care can also give children with ASD positive experiences (Preece and Jordan, 2007a; Tarleton and Macaulay, 2002). Such services can provide both social and educational opportunities, enabling the children to generalise existing skills and learn new ones, as well as taking steps towards greater independence and adulthood.

Benefits for the state

Effective respite care can also provide benefits to the state. Respite care can help families carry on caring for their child (Beresford, 1994) and can reduce expensive out-of-family placements (Abelson, 1999; Boyd, 2002) and the long term costs to the local government of intervention and support (PricewaterhouseCoopers, 2007). Also, when children with ASD remain living in their local communities, it is easier to plan and develop appropriate services to meet their needs as adults.

Obstacles for effective respite care

However, although respite care can be beneficial on many levels, there are a number of obstacles for families with children with ASD experiencing positive respite care support.

Inappropriate services

Considerable research and literature within the fields of education and psychology identifies that the impact of the characteristic impairments of ASD causes children with this condition to require specific, special types of intervention and education (Ozonoff et al., 2003; Simpson, 2005). Their educational and treatment needs are identified as being different from those of children with other disabilities. Approaches and settings that are appropriate for other children with special needs do not necessarily work for them (Jordan and Jones, 1997) and consequently many children with autism may need to attend a school or unit specific to autism (Jordan et al., 1998).

Research shows that specific, special types of intervention are also needed in social care supports for individuals with ASD and their families – and that generic respite care services for 'disabled' people can be inappropriate for those with ASD (Barson, 1998; Van Bourgondien and Elgar, 1990). Problems can occur for a number of reasons, including lack of staff understanding and expertise about ASD; ecological issues, such as noise, light, space, security and staffing levels within the environment; the types of activities on offer; and as a result of attempting to meet the needs of a wide range of children with differing needs and abilities within the same setting.

Inadequate levels of service availability

About a third of the families on waiting lists for short breaks in the UK have children with ASD (Tarleton and Macaulay, 2002), and many wait for years without ever receiving a service (Barson, 1998; Sargent, 1995). Even where services are available, the level of service available may be too little (Preece, 2000) and demand for services far exceeds availability. Brady (1998) found that 55% of families with children with ASD considered lack of short breaks as a problem.

Eligibility criteria

More able children with ASD – such as those with Asperger Syndrome (AS) – are less likely to access respite care services than those with ASD and additional learning disabilities (Preece and Jordan, 2007a) and may be considered too able to meet eligibility criteria for services (Oberheim, 1996). The behaviour presented by many children with ASD – such as self-injury or smearing faeces – can prevent them from being accepted by some services (Barson, 1998). Moreover, even when children with ASD initially meet eligibility criteria for respite care services, they are often subsequently excluded due to the impact of their behaviour on others (Sargent, 1995; Van Bourgondien and Elgar, 1990).

Understanding and attitudes of social workers

In the UK, families can only access social care services, such as respite care, as a result of referral by a social worker employed by the local authority. At the individual family level, the role of the social worker assessing their situation is crucial. Decisions about whether the family are eligible to receive a service, and what type and level of service should be sought, all depend upon the social worker's assessment.

However, social workers and parents may conceptualise short breaks differently, attaching different values to differing models of service. MacDonald and Callery (2004) suggest that social workers tend to perceive services that remove disabled children from their families (even for short breaks) negatively, and that they seek to provide services that do not remove the child from the family home. Nonetheless, parents still value services that provide them with overnight breaks (MacDonald and Callery 2004; Preece, 2000), while reactions to in-home services are mixed (Olson and Maslin-Prothero 2001).

Preece (2000, 2011) further identifies that parents of children with ASD consider short breaks, where the child leaves the family home to fulfil a number of different functions, including providing a break from caring, providing social opportunities both for the child with ASD and the rest of the family, and fulfilling a social educational role for the child. However, MacDonald and Callery (2004) find that often social workers considered this model of service as their least preferred option, suitable only in crises; and the gate-keeping of scarce services further means that access to short breaks is often restricted to those families whose circumstances are most difficult.

Furthermore, many social workers have an inaccurate understanding of ASD (Preece and Jordan 2007b). This can further militate against families receiving appropriate services, as social workers may underestimate the difficulties facing some families, or misjudge the type of support that they need. All of these factors can prevent families receiving appropriate services, as social workers may underestimate the difficulties facing some families, or misjudge the type of support that they need.

What is needed?

Considering the range of different functions that it may perform, Lindsay (1996) suggests that a spectrum of respite care services is required. These functions include

- *domiciliary* respite care (where support is provided in the family home)
- *holiday* respite care (to allow the disabled child and their family – either together or separately – to have a holiday)
- *emergency* respite care (to address unexpected or emergency situations)
- and, most importantly, *planned* respite care, to provide regular short breaks for the child and family.

Respite care services within Northamptonshire, UK

Respite care services have been developed to meet the full range of respite care needs (Preece, 2003). *Domiciliary* respite care is provided either by contracted agencies or through direct payments made to the families. *Holiday* respite care is provided through a range of methods. These range from signposting families to sources of grant funding to providing direct payments (either to pay for workers to accompany the child on a family holiday or to support the child at home while the rest of the family have a break). *Emergency* respite is provided either by the county's residential respite home (for up to 28 days maximum), with a 'contract carer' or through short-term fostering. Finally, and most crucially, *planned* respite care is provided by family-based and residential services.

Furthermore – and acknowledging the need of individuals with ASD for specialist, autism-specific approaches and services – these respite care services form part of a planned and integrated range of services for people with ASD and their families within Northamptonshire.

Northamptonshire

Northamptonshire is a mainly rural county in the centre of England, about sixty miles north of London. It has a population of about 650,000 – about a third of this population live in Northampton, the county's main town. The county has a school-age population (3 – 18 years) of about 100,000 – about 1,000 of these children have a diagnosis of ASD.

Since 1990, education, health and social care service providers and parents in Northamptonshire have worked together to develop a multi-disciplinary, integrated approach to providing services to people with ASD (Preece et al., 2000). A range of services has been established, including autism-specific educational, day care and work settings, advisory services for schools and families, job coaching for adults, and residential care for adults and children. Services in the county are grounded in the consistent use of the structured teaching strategies of the TEACCH approach (Mesibov et al., 2005). Key facets of this approach are:

- physical structure: clarifying the purpose of physical space, reducing distractions
- schedules: visually presenting information about what will happen and when
- work systems: providing organisational strategies to complete activities
- visual structure: helping with organisation, increasing clarity and providing instruction.

Services also utilise related interventions that complement the TEACCH approach, such as the Picture Exchange Communication System (PECS) (Frost and Bondy, 2002) and Social Stories™ (Gray and Garard, 1993).

Family-based respite care

Prewett (1999) identifies a nationwide shortage of family-based respite care placements for children with ASD in the UK. To address this, Northamptonshire County Council recruited and trained ASD-specific 'contract carers' across the county. Each carer is contracted for 208 days per year (including 24 days paid leave) and is required to provide 182 days of care per year, including 26 weekends, in their home. They look after one child, or sometimes two children, at a time, for which they receive a retaining salary and an additional payment for each overnight stay from the county council – the service is free to families.

The contract carers support up to eight families each and this service has been targeted particularly towards families with younger children, or those who find it hard to cope with group living. Whereas breakdowns are generally high in family-based respite care placements for children with ASD (Sargent, 1995), placement stability with the contract carers has been high (Preece, 2003).

Residential respite care

Residential respite care is provided at a six-bed residential home located in one of the county's towns. This home provides service to forty families with children aged between five and eighteen years, and is open 360 nights per year. Stays are pre-booked, with children staying a maximum of four nights at a time. Each family's package of support is individualised, dependent on factors such as their assessed level of need, the child's age, needs and wishes, and availability. Currently, packages of care vary from 12 to 96 nights per year, with an average of 30–40 nights. Again, services are provided free to families.

Photo 1. The residential respite care home

The professional staff team at the home comprises the registered manager, two senior residential care workers, and four residential care workers. They are supported by night staff, care assistants, a cleaner and a clerk. The staff- child ratio is at minimum 1 member of staff per 2 children. However, more staff will be deployed if this is identified as necessary. During the night, a member of night staff is on duty, with a member of the professional team sleeping-in at the home, and another on call. Each family has an identified 'key worker' from the professional team, who is their main point of contact with the service.

Northamptonshire's respite care services for children with ASD have been externally identified as effective (Social Services Inspectorate/Audit Commission, 1999) and exemplars of good practice (Carlin et al., 2004), and research has indicated a high level of parental satisfaction (Preece, 2002).

Making respite care effective for children with ASD

Making respite care work for families with children with ASD can be challenging, but such services are important tools not only for providing families with effective, dependable and regular breaks, but also to give children with ASD social opportunities and to help develop their independence. Interviews carried out with families who used these services (mothers, fathers, siblings, and the children with ASD themselves) identified a number of factors which the families associate positively with quality services (Preece, 2009). These factors are:

- the physical environment
- staff attributes, including their understanding of ASD
- consistency with other settings and use of ASD-appropriate approaches
- individualisation
- activities on offer
- grouping of children

These factors are discussed below. All quotes are from families using respite care services in Northamptonshire.

Physical environment

The nature and appropriateness of the environment – providing a structured yet homely setting – is of fundamental importance to families.

“I don’t know what I was expecting really… just something a bit clinical and institutional, really. And I was so pleased that it was a normal house... It looked like a normal house and that was really nice.” (Mother of a child with ASD)

Photo 2. A bedroom in the respite care home

The link carer’s homes are ‘normal’ homes in local communities. Residential respite care is provided at a seven-bedroom detached house in a small town. The physical environments across these settings have been modified to be ‘autism-friendly'. Walls are decorated in muted and pastel colours, and rooms are largely free of ornament and clutter to reduce confusion and over-stimulation. Clarity of physical structure is important to children with ASD (Mesibov et al., 2005) and so the different areas of the environments – bedrooms, bathroom, play areas, dining rooms – are clearly identified and labelled.

The residential respite care home has six bedrooms available for children and these are differentiated to address different needs – some have running water, while others do not; some have carpets, others have waterproof floor coverings. Where possible, children sleep in the same bedroom every time they stay at the home. The home has a transition area – where children's TEACCH schedules are located – and two separate gardens – a larger area with play equipment, and a smaller sensory area. The building is externally secure with external doors opened by electronic keypads, and window and door alarms. Other safety and security features of the building include built-in storage, alarms on bedroom doors, flush fitting lighting and toughened glass in all windows.

Photo 3. The home's transition area

Staff attributes, including their understanding of ASD

> The people… they really knew what they were talking about. They seemed to really understand autism… They seemed very willing to chat to you about everything, and would be willing to try anything that would be suitable for your child (Father of a child with ASD).

The skills, attributes and expertise of the workers involved are crucial in making respite care work. Peeters and Jordan (1999) identify a range of personal attributes they consider necessary for workers in the field of ASD – to be ‘bitten by the bug of autism’ and to have imaginative skills, the ability to adapt their natural style of communication and social interaction, the willingness to work as part of a team, adaptability and humility. Many of the workers in the services clearly have been ‘bitten by the bug’, and as a result staff turnover is low, which helps maintain consistency.

Training is also vital. Contract carers and residential care workers are all consistently trained within the TEACCH model. All workers receive initial induction training in ASD and in the use of structured approaches. Within the residential respite care service, all staff attend a 3-day TEACCH seminar; all of the home’s professional staff attend 5-day, intensive hands-on TEACCH workshops, as well as receiving training in Social Stories™ (Gray and Garard, 1993) and PECS (Frost and Bondy, 2002). Workers have also been supported to undertake higher education courses at the University of Northampton and the University of Birmingham.

Consistency of approach across environments

> It is important that there is consistency to keep the continuity between school, home and respite care. If everybody uses the same strategies, the children are less confused (Mother of a child with ASD).

Photo 4. Visual supports are used consistently across environments

Before any respite care stays, the residential staff or contract carers will visit the family home, and observe the child in school, to identify where positive routines have been developed, so that these can be replicated. TEACCH schedules and visual supports will be developed to be consistent with those used at school or in some cases these visual supports will be made more concrete to help the child cope with the new environment. The contract carer or the allocated key worker from the residential respite service will complete an autism-focused assessment with the family to identify the child's physical needs, self care skills, communication skills, social interaction, interests, likes, dislikes, routines and behaviours. Any sensory or perceptual issues that the child might have (Bogdashina, 2003) are also identified.

The contract carer or key worker liaises regularly with the child's family and school to ensure that the systems in place in the respite care setting remain current and appropriate, and that they take account both of the child's development and of any difficulties they may be having.

Individualisation

> They're all individuals, you know. If you have [a] room full of autistic children, they can be completely different from each other (Mother of a child with ASD).

All children using the respite care services are provided with individualised daily schedules (telling them the sequence of events), work systems (to help with tasks such as dressing, washing and toileting), and communication systems. These are differentiated to match each child's communicative level and can range from functional objects to written systems. Daily schedules are, where possible, developed so that the activities the children undertake are built around their strengths and interests.

> Andy, Annette's husband, was into all the cars and that. So he would just sit in garage with him. And she had a PlayStation and that, so he was happy (Sister of a child with ASD).

Within the residential respite home, this level of individualisation means that – at any given time – up to six children, all potentially using schedules and visual supports at different levels of abstraction (from objects to written words) – may be engaging in different activities. The role of the key worker is central to carrying out this individualisation effectively. Key workers are responsible for ensuring that appropriate structure and visual supports are in place, and ensuring that other staff are aware of each child's needs.

Activities are coordinated through the use of the children's individual daily schedules. This requires thorough timetabling and planning by the staff team. The day is divided into three shifts: morning (7 a.m. to 2.30 p.m.); afternoon (2.30 p.m. to 9.30 p.m.) and night (9.30 p.m. to 7 a.m.). Before the start of each shift, workers are identified to take responsibility for children allocated to them. These workers discuss and plan the activities the child will undertake during the shift. The shift is planned as a group, so that group activities are structured, and individual activities are synchronised to avoid clashes.

Photo 5. A work system enables a child to dress independently

Use of ASD-appropriate approaches

> Since…using TEACCH he has been able to finish things, accomplish basic tasks, get through the day, understand what's required of him, and his frustration has reduced. I've seen and been through what he's like without TEACCH…the behavioural problems are unbearable (Mother of a child with ASD).
>
> (Schedules are helpful)…'cos then I don't forget what I'm supposed to do (Teenager with ASD).

The use of ASD-appropriate approaches and tools is vital in making respite care work for these children and their families. The TEACCH approach uses structure at four levels – physical structure, daily schedules, work systems, and visual structure (Mesibov et al., 2005) – and these are integral in both contract carer's homes and at the residential respite service. Tools such as choice boards and PECS communication systems, and visual information (such as visual calendars and sleep charts) are vital to help children communicate their preferences and wishes, cope with waiting and sharing, and understand when preferred activities will occur.

Photo 6. A 'sleep chart' lets a child know when he will return home

Activities

> Annette took me to the cinema. Going to Annette's was fun! (8 year old with ASD).
> The best thing is that… if it's a nice day you get to go out (Teenager with ASD).

Accessing the community, and learning to undertake and enjoy outings and community activities, are important aspects of the respite care experience for children with ASD. Children attending respite care services engage in a wide range of activities, including trips to parks, nature reserves, swimming, museums, cinemas, shopping, restaurants and the seaside. As with other activities, the use of structured approaches and visual supports helps the children understand what is going on, helps reduce confusion and anxiety, and clarifies when activities will end (and what will happen next).

Grouping of children

> I get on really well with him… we just wind each other up and have a laugh (Teenager with ASD).

Generally children staying with contract carers are there alone or perhaps with one other compatible child. When planning respite care at the residential home, it is important to book children's respite care so that they are in the home with children whose behaviours they can tolerate, who share some common interests and skills (so that group activities can be undertaken).

Limitations and problems

Northamptonshire's multidisciplinary approach, and the consistent use of ASD-appropriate strategies, has enabled respite care services to be developed that meet with the approval of families, children with ASD and external assessors. However, significant limitations and difficulties remain.

Demand exceeding capacity

The county's respite care services are running at full capacity. Some families have to wait for several months between being identified as eligible for a service and beginning to access it.

The number of children with a diagnosis of ASD within the county rose from approximately 100 in the early 1990s to over 600 fifteen years later (Whitaker, 2007). The level of service available has not risen in line with this increase, and research (Preece and Jordan, 2007a) has shown significant levels of unmet need. Over half the families who participated in this study expressed a current need for respite care, and almost two thirds felt they would need it in the future – but such services were only being accessed by about a quarter of the families. Unmet need is particularly significant among families whose children with ASD are higher functioning, in mainstream schools or under eleven years old; and in families who do not have a social worker.

Need for different types of service

Families and children have also expressed the desire for a wider range of service models. These include services specifically for children with Asperger Syndrom (AS); services aimed at teenagers; workers who can provide care for all the family's children (not just the child with ASD); after-school clubs; support with children's preferred activities (such as trampolining); and support for siblings.

Availability of funding

While the population of children identified with ASD is growing, services are dependent on the availability of funding from local and central government, and upon the competing demands and pressures from other publicly funded services – the police, emergency services, schools, other areas of social care, and so on. This means that funding is always limited and that budgetary pressures are inevitable.

Conclusion

This paper discusses how one UK local authority has sought to address the issue of providing appropriate respite care to families with children with ASD, within the context of a multi-agency ASD strategy based upon the principles of the TEACCH approach. What has been appropriate in Northamptonshire may be inappropriate elsewhere – both within the UK and elsewhere in the world – and there are undoubtedly many other ways in which services could have been developed. Nonetheless, the "Northamptonshire approach" is offered as an example of what has been done, and it is hoped that this information may be helpful for others.

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Respite care for families with children with Autism Spectrum Disorders: how services in Northamptonshire UK are working to meet the challenge

Abstract

This paper identifies the importance of respite care services for many families with children with autism spectrum disorder (ASD) but also some of the obstacles that may prevent families accessing such services. It describes how Northamptonshire County Council, a local authority in the United Kingdom (UK), is working to meet the challenge of providing 'autism-friendly' respite services. The paper outlines factors that families have identified as being positively associated with quality in respite care for children with autism and their families. These are the physical environment, staff attributes and their understanding of ASD, consistency with other settings, the use of ASD-appropriate approaches, individualisation, the activities on offer, and the way that children are grouped. As well as outlining the major characteristics of these services, and how they seek to meet the needs of families with children with ASD, the paper describes the limitations of these services and the challenges and issues that remain.

Opieka zastępcza dla rodzin z dziećmi z zaburzeniami ze spektrum autyzmu: jak działają służby w Northamptonshire w Wielkiej Brytanii, aby sprostać temu wyzwaniu

Streszczenie

Niniejsza praca przedstawia znaczenie służb opieki zastępczej dla wielu rodzin dzieci z ASD, lecz także identyfikuje przeszkody, które uniemożliwiają rodzinom dostęp do takich usług. Opisuje ona, w jaki sposób rada hrabstwa Northamptonshire, władza samorządowa w Zjednoczonym Królestwie Wielkiej Brytanii i Irlandii Północnej, pracuje nad sprostaniem wyzwaniu zapewnienia „przyjaznych dla autyzmu" usług opieki zastępczej. Niniejsza praca przedstawia w zarysie czynniki, które zostały uznane przez rodziny za pozytywnie kojarzone z jakością opieki zastępczej dla dzieci z autyzmem oraz ich rodzin. Są nimi: środowisko fizyczne, cechy pracowników i ich wiedza o ASD, spójność z pozostałym ośrodkami, stosowanie odpowiedniego podejścia do ASD, indywidualizacja, oferowane zajęcia oraz sposób dzielenia dzieci na grupy. Oprócz zarysowania głównych cech tychże służb oraz tego, w jaki sposób usiłują one sprostać potrzebom rodzin dzieci z ASD, niniejsza praca opisuje także ograniczenia tych służb oraz wyzwania i problemy, przed którymi stoją.

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