

Physical and leisure time activities – factor of inclusion of families with deaf-blind child.

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Abstract

In Czech Republic the rights of deafblind people are represented by NGOs VIA, LORM or Zablesk. This is the organization of parents and friends of deafblind children, which organizes international family conferences. The last one (5/2006) was aimed to the importance of physical and leisure time activities for the families. We strongly believe that families of deafblind children play crucial role in their early development and social inclusion. Our task is to study the ways to use physical activities in help for families with deafblind children. Participation in physical activities can increase the likelihood of independence and improve the quality of life of deafblind children (Lieberman & Taule, 1998). At the same time leisure time physical activity can be practiced by whole family and can also serve as an effective coping mechanism - further the possibility of using coping behavior "to do the activities together with my children".

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Introduction

Deaf-blindness (DB) is distinct disability, which is caused by the combination of hearing and visual impairment. Carter, Van Andel and Robb (2003) define persons who deaf-blind as those having dual impairments resulting in limited social opportunities important to fulfilling well-being needs. Some DB people are totally blind and deaf while others have some remaining use of one or both senses. Some people are born deaf-blind while others acquire this disability by disease or other long-term health problem. Leisure time activities plays crucial role on lives of individuals who are deaf-blind as they have high unemployment rates and at the same time quality of leisure time activities significantly contributes to quality of life. While most authors focus on the opportunities and participation of DB persons in

leisure-time activities we have decided to focus on families (as cohesive unit) of DB persons as families serves as primarily source of leisure time habits.

Families of deaf-blind children play crucial role in their early development and social inclusion. Sobotkova (2001) brings attention to the importance of adaptability, which she defines as the amount of flexibility of family system to change its structure of power, roles and rules of relationships based on the developmental and situational stress or in other words the ability to adapt to the changing requirements and challenges of life. The developmental stress is defined as transitional crisis in the developmental cycle of family (transitions) such as the birth of a child, starting of school. Situational stress can be for example severe disability of family member or other unexpected burden which affects whole family. The birth of deaf-blind child brings about major challenges to family and the challenges arise repeatedly during the life cycles of families. Coping with stress becomes a process that facilitates the achievement or maintenance of the stability and unity of the family system and it supports individual growth and development. The general coping style of a family depends on various factors such as the circumstances, the extent to which the threat becomes incorporated into family relations and tasks, available family resources, previous experience of the family. Families of children who are deaf-blind can serve as great support and earliest teachers of their children (Van Dijck, 1998).

Motor skills is considered to be prerequisite to the development of any form of formal communication (Van Dijck, 1998) and participation in physical activities can increase the likelihood of independence and improve the quality of life of deaf-blind children (Lieberman & Taule, 1998). At the same time leisure time physical activity can be practiced by whole family and can also serve as an effective coping mechanism.

Lieberman and Stuart (2002) argue that DB persons have special leisure time needs resulting from common unemployment. According to Priest (1999) leisure experience is defined by two criteria: a) is entered voluntarily and of free choice; and b) is intrinsically motivating in and of its own merit. Carter, Van Andel and Robb (2003) highlight the importance of leisure time experiences as one of major goal of therapeutic recreation, because it significantly contributes to individual's quality of life. Therapists within leisure education should facilitate following aspects: a) sense of freedom; b) satisfaction; and c) joy. Zabriskie and Heyne (2003) and Scholl, McAvoy, Rynders, and Smith (2003) that leisure time activities of families of persons with disabilities needs to be taken in accounts of research as family serves as primarily

source of leisure time habits and in turn quality of life of persons with disabilities. Leisure time activities can also serve as vital coping strategy for whole family and thus these opportunities need to be explored. School et al. (2003) suggested that research on family recreation is still in its infancy, but can potentially lead to enhancement of life by explaining psychosocial benefits of leisure time activities to families of persons with disabilities and by understanding barriers and hindrances in family leisure activities. Recreational activities can fulfill great variety of needs of persons who are deaf-blind. Lieberman and Stuart (2002) suggest that recreation facilitates communication among individuals who are deaf-blind. Recently Lieberman and Stuart (2002) studied current involvement of individuals who are deaf-blind in recreational activities, their preferences, barriers for participation and possible solutions to these barriers. There are numerous activities that persons who are deaf-blind could take part in, but they must have choices and know how to access them. It has been reported that persons who are deaf-blind experience the great amount of social isolation (McInness, 1999; Petroff, 1999), which can make their participation in recreational activities more difficult. Furthermore Lieberman and Stuart (2002) reported following barriers that hinder participation of deaf-blind: transportation, lack of others to participate with, lack of adequate programs, lack of time, negative attitudes of those offering the activity, and lack of communication.

So far no studies have been done about the current state of recreational activities for persons who are deaf-blind in Czech Republic. The aim of this study was to explore family related recreation of families with child who is deaf-blind and the benefits that recreational activities can bring to families with child who is deaf-blind.

Methods

Participants

Participants of this study were five families of children with deaf-blindness (DB) described in detail below. We have selected families of children with congenital DB, who are currently in time of transition of children from school to home communities. The families were selected from pool of available families – members of NGO Zablesk. Criteria for selection of families were: a) children with congenital deaf-blindness; b) age of DB children from 15 to 21yrs; c) children were currently in time of transition from school to home communities; and d) willingness of families to take part in this study. Leisure time/ sport activities can help these families to cope

with the transition processes. These families are coping with transitional crisis related to the adolescence of their child as well as the middle age crisis of parents.

Questionnaire

We have used self made questionnaire to obtain basic information about the current state of leisure time physical activities (LT/PA) of families of children who are deaf-blind. The questionnaire was validated and approved by panel three independent experts, who met following criteria: a) University teacher from adapted physical education or special education; or b) Special education teacher with experience with DB children; or c) Psychologist (counselor) with experience with DB children. Afterwards the pilot study was conducted with two families of DB child. In current study following questions were used: a) How important are leisure time physical activities in family? b) Is family taking part in organized leisure time physical activities? c) Which activities can be done with child who is DB? d) Are there sufficient options of leisure time physical activities?

Interview

Interviews with parent(s) of children who are deaf-blind were administered with the aim to learn in depth and detailed information about lives of families of children with DB. Only part of interview was focused exclusively to leisure time physical activities. The aim of this part was to explore their experience, beliefs and concerns related to adapted physical activities. Length of interview was approximately 120-180 minutes. Interviews took place at home of families in presence of parents (both if applicable) of children with DB. Families knew principal investigator from previous programs for families of deaf-blind children (family camps), where she also provided service as counselor (psychologist) and personal assistant.

Method of Analysis

Data analysis was open to emergent themes, which occur concurrently with data collection when using naturalistic paradigm (Erlandson, Harris, Skipper, & Allen, 1993). We have followed suggestions of Creswell (1998) who suggested that researcher engages in process of analysis of data in spiral fashion starting with data collection, managing the data, reflection with domain analysis (Spradley, 1980)

memoing, comparing, describing, interpreting. Therefore the interview structure developed over the time. We have prepared semi-structured interviews based on previous studies of families of children with hearing impairments. Interviews were audio taped, transcribed and sent to participants to check for accuracy. Then we have proceed with open and axial coding (Strauss & Corbin, 1990) in order to define, conceptualize and classify key themes, events and beliefs.

Results

None of the families was included in any specific program of adapted physical activities. Data are presented according to statements of participants and based on their experiences. Parents were not offered any choices of specific APA intervention; the intent of the study was to map the current state of families. Physical activities of family members were studied separately in relation to all members and at the same time we also kept the focus on whole family as functioning system. In all families we have encountered kind of amazement related to questions about barriers to participation. Parents were often unable to identify exactly concrete barriers and limited their comments to “disability of child being the barrier”. This is one of the examples of their lack of information as APA for children who are deaf-blind is almost nonexistent.

Form the analysis of interviews with parents emerged following perceived needs of children and parents. Children have number of needs, some of them are general needs and some are specific for children who are def-blind.

Physical activities (PA) and leisure time activities (LTA) can facilitate structure of daily (weekly) schedule very much needed for children who (with limited visual and audio stimuli) have difficult time to distinguish between day and night.

....for example we go swimming twice a week. We do this for our child.... it is the regularity, which we try to follow for her....

....So I must make up some program for him, as he likes to do things, I for example, would screw something and he would unscrew it. Any we do this maybe three hours /note. Son has this activity connected with the travel from-to school/.

Children have the need to take part in activities and if activities are not provided to them or their participation is not facilitated they might take part in activities, which are not desirable.

....She is sitting and is looking for something to do....so for example she throws out trashcan, or she finds something to do. For example she has found string (belt) in pants she can pull out and play with....

..He needs to be entertained, somehow fill out leisure time. I must make up some program for him, entertain him, teach him. He can play little by himself, but only for short time...

For parents it is important that their children are healthy and have desirable physical appearance. This need can serve as great source of motivation to take part in physical activities.

.... We go swimming, so we would not get so fat. She has the tendency to gain weight, so we try to do exercise...

....This bicycle, I have modified so if I push him his pedals will move....So I am pushing and he is not pedaling, but still it moves his legs, yah...

Participation in PA or LTA and successful completion of something can bring child happiness and joy, which bring parents the sense of satisfaction.

....she is happy when we say we go to trip, she gets frolic and that is good to see...

....When we go by train, he loves it, on the train he likes to communicate using sign language, which he did not want before. Yep so it is so laid back....

....She likes to butter baking plate with brush, so I let her do it ..or even cut things. I know she is careful....

Discussion

Deaf-blindness recently became more discussed disability in Czech Republic. Big part in this is due to the establishment of three organizations devoted to improve lives of people who are DB. The main aim of these organizations is to inform society and professional about specific needs of these persons. Based on our findings we can conclude that appropriate leisure time physical activities can help to reduce personal and family stress and facilitate appropriate coping. Unfortunately currently there is lack of opportunities in Czech Republic. Leisure time activities can serve as factor

supporting communication and organization within family. In LT/PA every member of family is participating as him(her) self. Therefore he(she) can reach certain aims and feel independently and still be a part of family activity. These mechanisms can support family coherence and unity (Sobotkova, 2001). During LT/PA in natural environment (e.g. bowling, sledging) family is in common contact with surrounding and can therefore use social support. This brings us to final point, where we argue that family being able to participate in LT/PA as others, can perceive itself on the same level as others, which in turn might help them to cope with stress.

Our findings are in agreement with Smith (1994) who claims that reasons for participation in recreational activities vary and for persons with disabilities these reasons might include: fun, exercise, meeting others, entertainment, challenge, occupying the mind, or a change of environment. Parents told us about their feelings of fulfillment of child's needs. Significant finding is also that parents have similar needs and reasons for participation in LT/PA, which we consider to be important coping mechanism, form of individual coping. Therefore, if we want to offer appropriate LT/PA we must keep in mind to assure conditions specific for: a) general need of persons with deaf-blindness; b) concrete specific needs of given individual based on his(her) skills and abilities; and c) specific needs and requirements of given family. We could not agree more with Lieberman and Stuart (2002) who stated that there are numerous activities that persons who are deaf-blind could take part in, but they must have choices and know how to access them.

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