

Theamatic Article

Students with Special Needs and Their Parents – Informal Participation of a Parent in the Education of an Adult Child

Katarzyna Kutek-Sladek¹, Monika Pyrczak Piega²

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Abstract

The article presents the issue of participation of adult students' parents in their academic life. There are many examples in the literature of how important is the support of students' with disabilities parents at the universities. This determines academic success. Disability (its depth, type, cause, limitations resulting from it) is a determining factor for independence, and consequently for the parent's participation in the student's academic life. The parent's attitude towards their own child's disability is also related to the parent's participation in the study. The main questions of presented research is: how do students, parents and university staff see the participation of parents in their adult children higher education? This study was qualitative in nature and the individual in-depth interviews were conducted in the course of the study. Two female students with disabilities and their mothers, as well as a member of staff from the one of Polish university's disability office, were invited to participate in the study. The results show that students, parents and university's staff can present different opinions about parental support. The fact is that parental participation cannot be permanent. Each time this type of support should be considered on an individual basis, with particular regard to the welfare of the the student. The results of the survey are relevant to the university's process of planning support for students with disabilities so as to work with parents with the students' consent.

Keywords: student with disability; parents; university; parental support

Introduction

The aim of this article is to show the participation of students' parents in their study proces. According to Katarzyna Skalska (2023), there are a number of factors that determine how a handicapped student will function and adapt at university: resilience to stress, social skills, attitude toward one's own disability, positive interpersonal relations with various members of the academic community, undertaking additional activities, the level of support adequate to the individual situation of the student with a disability. „Perceptions of disability are important constructs that influence not only the well-being of people with disabilities but also the moral compass of society. Negative attitudes toward disability can lead to social exclusion and isolation of people with disabilities, while positive attitudes promote social inclusion” (Saadun, et al., 2023). This is why parents of adult students can be frequent participants in their academic life. Their attitudes toward their own child's disability and the relationship between them can also be counted among the determinants of educational success (Mntambo, 2021).

The main question of the current research is: how do students, university staff, and the parents themselves see the participation of parents in the higher education of their adult children? The IDIs - individual in-depth interviews – were conducted throughout the study. The collected information was grouped and recorded in the form of a matrix, aimed at selected issues corresponding to the research questions.

¹ The Pontifical University of John Paul II in Krakow, Krakow, Poland; katarzyna.kutek_sladek@upjp2.edu.pl

² The Pontifical University of John Paul II in Krakow, Krakow, Poland; monika.piega@upjp2.edu.pl

The first part of the paper is the theoretical basis of the research. The next part shows research methodology and results, in three points: student, parent and university perspective. The conclusion presents a discussion of the research results and summary.

Theoretical basis

Currently in many countries of the European Union there are several definitions of disability used for various purposes, e.g. social rehabilitation, vocational rehabilitation and employment, medical care, education. Many definitions note the complexity of this concept, such as the World Health Organisation in the *World Report on Disability* (2011). It defines disability and its impact on human functioning. Also, it points out the complexity, dynamics, multidimensionality, and location of disability in various aspects of human life.

One of the most important factors in the effective development of a person to independence is knowledge and education. Knowledge is one of the most valuable assets that determines the development of the state, as well as of Man. It is knowledge that allows individuals and collectivities to compete effectively in not only domestic, but also international labor markets. People with high qualifications, who are creative, and possess a researcher's attitude are among the most desirable in the employment system and are also the best paid. The process of obtaining knowledge, competencies and qualifications is inextricably linked to the process of education, which today is one of the basic aspects of life and needs of Man. In general terms, education, leads to people becoming learned, enabling them to use the knowledge they have gathered throughout their private and workplace lives (Solarczyk-Ambrozik, 1995).

Obtaining a college degree provides a better start in life and more opportunities. People with disabilities, via a college degree, have ample opportunities to get an education and improve their skills. It prevents them from feeling isolated from their surroundings because of their disabilities. However, an important aspect here is to dispel the stereotype that a person with disability is not useful. By obtaining a diploma, one can ensure social acceptance (Solarczyk-Ambrozik, 1995) and even raise his/ her position in society – leaving the „not useful” stereotype behind to become an active and integral part of a community. A critical role in the process of instructing people with disabilities is played by the family (National Collaborative on Workforce and Disability for Youth, 2015). Okoń (1987, p. 45) states that a family is „(...) a small social group consisting of parents, their children and relatives. Parents are united by the parental bond, which is the basis of family upbringing, as well as the formal bond that defines the duties of parents and children to each other.” Family, from the moment of the child's birth, influences his all-round development, passing on certain habits, skills, values. The family is a place where phenomena of a different nature – biological, sociological, economic, psychological and pedagogical - are intertwined. As a result, the family can be defined as the universal environment of human life. Each family has certain goals towards its life and activities are aimed, tasks that it performs for each family member, e.g. – satisfying the needs of the members; these are called the functions of a family (Auleytner, Głabicka, 2001).

A study conducted by Pentor Research International S.A (2009), based on interviews with handicapped people, distinguished three types of caregiver attitudes: good support – an attitude in which caregivers show acceptance and understanding of the problems faced by the person with a disability; overprotectiveness – treating a person with a disability through the lens of his illness; lack of support, an attitude associated with a lack of acceptance and understanding of the problems and handicaps that result from disability.

According to a study by Daniel Kukla (2009) conducted among first-year students of the pedagogical faculty at the Jan Długosz Academy in Częstochowa, the main determinant of choosing a university was proximity to the family home (57%), 14% of the respondents revealed that the choice of the university was due to the example of other colleagues and classmates, and only 8.16% of the respondents chose the university because of its high level of instruction in their specialty. Nearly 41% of students chose this university because of its good reputation. Students also gave other reasons for applying for an index at this university: lack of places in their dream field of study, availability of a master's degree, and lack of money to study in another city were among them.

At the same time, it should be mentioned that the parents' level of education, as well as the family's material status, determine expectations for their children's educational future. Belonging to a certain socioeconomic group significantly affects the level of educational aspirations and actual access to education – especially higher education. According to a study by Hanna Żuraw (2014), people from families with at least a high school education were more likely to go to college. Thus, what counted was a family providing support and a kind of pattern of life path, in which education had an important place. The period of study is often associated

with a student moving out of the family home, and then, in addition to academic tasks, he or she also faces the problems of running his or her own household. For a student with a disability, this would be a bit easier when he or she can count on help from family and friends. Social interaction, which is in the nature of social support, involves overcoming a problem situation, and is accomplished through the exchange of emotions, information, and actions (Sowa, Wojciechowski, 2001).

In conclusion, the role of parents in helping their adult children navigate and function with a disability is very important, and is much appreciated by the disabled students themselves. Nevertheless, it is worth remembering that parents of higher education students with disabilities have to put a lot of effort not only into parenting, but also (and perhaps most importantly?) into learning independence and gaining experience so that the young person can and will be able to take care of himself eventually.

Research methodology and results

This study is qualitative in nature. The subject of this research is contained in the topic of studying people with disabilities, and its aim is to show the participation of students' parents in their study process. The theoretical and methodological intention of the article is to divide it into three perspectives: studential, university institutional, and parental. This division is dictated by the multidimensionality of the phenomenon in which these three parties participate.

In order to analyse the topic in depth, a research problem was posed, which was encapsulated in the following research questions:

I. The main research question: How do students, university staff, and parents, themselves, see the participation of parents in the higher education of their adult children?

II. The specific research questions:

1. Student perspective: How do students perceive the presence of their parents in their study process? Do they want or need their parents' presence? Does parental participation or lack thereof limit students' activity at the university?

2. Parent perspective: How does the parent see his/her presence in his/her child's study process? Is his/her presence needed and desired by the adult child? Does he/she support the adult child in being active at the university?

3. University perspective: How often and in what ways do parents of students participate in their adult children's study process? Is this welcomed by the university?

The raw data was transcribed and collated, analysed and interpreted in relation to the main and specific research questions. The structuring of the collected data started with their selection and segregation, according to the purpose of the study. The collected information was grouped and recorded in the form of a matrix oriented toward the issues corresponding to the research questions: assessing the legitimacy of, need for, limited activity due to, views on, regularity of and forms/activities of parental presence at the university.

Two female students with disabilities and their mothers, as well as a member of staff from the university's disability office, were invited to participate in the study. A separate set of questions was constructed for the students followed by the parents, and similarly for the university staff members. The essence of the interview was to obtain detailed information about the parent's involvement in their child's tertiary studies. The interviews were conducted during the months from July to September 2023.

The first student (ST1) is a 25 year old female, studying for an undergraduate degree, with a severe congenital disability, the cause of which is Childhood Cerebral Palsy. The other student (ST2) is 29 years old, studying for a master's degree, with a congenital severe disability and is visually impaired. The university employee (P1) is a person with 14 years of experience working with people with disabilities in the disability service at one of Krakow's universities (Poland).

First perspective: STUDENT

Students are adults and, according to Polish law, the university cannot provide parents with information about their children's study process without their participation and consent. It is not possible for the university to respect the views, opinions and decisions of a parent. Without the parent's involvement, he or she should deal with matters in administrative units on his or her own, contacting lecturers all by themselves regarding important matters. However, there are situations in which parents are intensively involved in their adult children's

academic life. Students with all kinds of profound limitations willingly involve their parents in their student affairs. Without parents, a student would not be able to cope with many situations.

The main research question was further detailed with the following specific questions in the student perspective: how do students perceive the presence of their parents in their study process? (analysis in relation to the areas: „views on parent’s presence”, „assessment of regularity of parent’s presence” and „forms of parent’s activity at the university” in matrix containing data from the interviews), do they want or need their parents’ presence? (analysis in relation to the areas: „assessment of legitimacy of parent’s presence” and „assessment of need for parent’s presence” in matrix containing data from the interviews), does the parent’s participation, or lack thereof, in the adult child’s study process limit the students activity at the university? (analysis in relation to the areas: „limitation of student’s activity/activity in perspective of parent’s presence” in matrix containing data from the interviews).

The students surveyed had different types of disabilities, which generated different needs in terms of adapting the learning process. ST1 was a person with a mobility disability. She required a lot of support with her own activities at university, mainly due to overcoming accessibility barriers. She reported that her mother is always present with her in class and also helps her to get to and from the university. ST2 was a person with a visual disability. Using the disability service support at the university, she did not see the need for a parent to participate in her study process. According to ST1, her mother did not undertake any activities at university.

ST1 was independent and did not need support with organisational matters. In the case of ST2, the mother did not undertake any activities in the university because she was not present in the study process.

ST1 reported problems in getting to the university and activities inside the university on a daily basis, related to accessibility barriers because she was a wheelchair user. ST2 coped with activities at the university on her own. The biggest difficulty she reported when she started university was the fear of lack of social acceptance of her disability among her peers. In terms of adapting the educational process, ST1 required conducting activities in accessibility accessible buildings. In contrast, ST2, due to her visual difficulties, reported mainly visual limitations. Parents’ approaches to the idea of their children starting university were similar. According to ST1 and ST2, parents reacted with apprehension and fear. Over the course of the study, their attitudes changed.

In summary, according to the students, the participation of parents in their study process depends on the type of disability and the needs they have at the university.

If these needs are at a high level and the student manifests many limitations due to the disability, the parent’s participation is considered necessary and legitimate by the student. As in the case of ST1.

Parents of students with disabilities may or may not be present in their study process. They may or may not undertake any activities at the university to support their children. Both respondents reported that parents’ attitudes towards their study plans were initially negative and apprehensive, but over time this attitude changed to a supportive one.

Second perspective: THE PARENT

The willingness to help one’s own child is inherent in the role of a parent. If the adult-child-parent relationship is right, there is no reason to reject a parent’s help while at university. However, if the parent presents an overprotective attitude, he or she limits the child’s autonomy. He or she watches every step the child makes, does not allow decisions to be made and bears the consequences in place of the student, this would be very hurtful to the student.

Also, the main research question was further detailed with the following specific questions in the parent perspective: how does the parent see his/her presence in his/her child’s study process? (analysis in relation to the areas: „assessment of regularity of parent’s presence”, „views on parent’s presence”, „forms of parent’s activity at the university” in matrix containing data from the interviews), is his/her presence needed and desired by the adult child? (analysis in relation to the areas: „assessment of legitimacy of parent’s presence”, „assessment of need for parent’s presence” in matrix containing data from the interviews), does he/she support the adult child to be active at the university? (analysis in relation to the areas: „limitation of student’s activity/activity in perspective of parent’s presence” in matrix containing data from the interviews).

The data collected during the interviews with the mothers indicate that, depending on the type of student’s disability, a parent’s participation in the educational process of a child with a disability is not obligatory. M1 indicated that assistance in fulfilling her university duties is legitimate because her daughter requires constant

support. She was dependent for mobility. Her mother helped her with organisational matters, with moving around the university, and oversaw her schedule. Although, ST1 assessed her mother's support differently and considered herself more independent than her mother reported. The mother was always present with ST1 at the university. M1 was supportive of her daughter's decision to go to university, but was full of concerns about whether her child would manage.

M2 was not present in her child's study process because her daughter's disability did not, in her opinion, require the support of a parent. She did not undertake any activities at the university and allowed her daughter to manage on her own. She reported that the support of a parent in the study process of a child with a disability is very important, but is dependent on the disability and what limitations the young person has. Before her daughter started university, she was concerned about whether her daughter would cope at university, far from the family home. She later considered these fears to be unfounded. M2 was convinced of her daughter's independence and believed that her presence at university was not needed, nor would her child want it.

M1 supported her daughter in her daily academic life. She was convinced that without her help her daughter would not have been able to cope with her studies primarily due to accessibility constraints. The mother tried to involve her daughter in various academic activities so that her daughter could progress, being fully convinced of the fact that her daughter wanted her help.

M2 was emotionally supportive of her daughter's activities at university, however, due to her lack of presence in her daily studies, she did not have a direct influence on the activities her child undertook.

A third perspective: THE UNIVERSITY

The staff in disability services at universities oversee the boundaries in cooperating with parents. Furthermore, the main research question was detailed with the following specific questions in the university perspective: how often and in what ways do parents of students participate in their adult children's study process? is this welcomed by the university?

The analysis was also based on the "assessment of legitimacy of parent's presence", "assessment of need for parent's presence", "limitation of student's activity/activity in perspective of parent's presence", "assessment of regularity of parent's presence", "views on parent's presence and forms of parental activity at the university" in matrix containing data from the interviews.

P1 reported that students with disabilities are overwhelmingly independent and do not require parental support. In general, university staff favour independent study, offering students with disabilities, a wide range of different forms of support that enable them to study without a parent and with autonomy. These forms include, for example, the assistance of teaching assistants who perform support activities, replacing parents. However, in spite of this, a small number of students with disabilities want parental assistance and fully accept it. There are also those who do not want to use parental assistance, manifesting this reluctance very strongly. The presence of a parent at the university can also be a sign of an overprotective attitude towards the student with a disability. The parent's involvement is then so high that it can inhibit the student's independence. Overprotective parents, defending their children with disabilities, can be demanding.

P1 reported that there are students who would not manage their studies without parental support. She also knew of those who find it more difficult to study in the presence of a parent. The decision to allow a parent into the study process is helped by indications that, this parental support is accepted by the student and the difficulties manifested in studying are such that the parent's help can be invaluable.

Discussion of the research results

The interviews conducted revealed the full complexity of the problem of parents' participation in their adult children's education. The research questions were posed from three perspectives. Students' perceptions of their parents' presence in the study process depend on students' concerns about barriers to their disability. If concerns are high and limitations are frequent the presence of a parent is desired by the student. ST1 reported that she was concerned about accessibility and logistical barriers to getting to the university, with her mother (M1) accompanying her to and from campus. In other matters at the university M1 does not participate as the student manages on her own. M1's presence does not limit her activities at the university. ST2 on the other hand, despite her fears, does not use her mother's help, she was independent in everything, however, she believed that the parent's participation is invaluable when the disability causes limitations to the student's autonomy. This was

also the view of her mother. Parental support for students with learning disabilities is a predictor of their academic success (Bartolo et al., 2023). However, students present different opinions about this support. Some of them do not want parental support, valuing autonomy and independence (Hees et al., 2018). Others involve parents in important organisational matters at the university (Bartolo et al., 2023) and appreciate their emotional support (Hees et al., 2018).

Both M1 and M2 believed that a parent should support their child with a disability at the university when the situation requires it, but only when necessary. They presented correct attitudes towards their children's disabilities. They reported, as do their daughters, that their support is or would be only when the children manifest a need and only to the smallest extent possible. M1 supported according to her daughter's expectations, ST2 did not need this type of support, which M2 fully respected. As mentioned above, research reports indicate that parental support at university should be based on the student's consent. There are those who consider such support to be unwanted (Duma and Shawa, 2019).

As the university perspective shows, parents of adult children with disabilities are exceptionally present in their children's academic life. Depending on their attitudes towards their child's disability, they support their child only to the limited extent needed, or show overly caring, demanding, overly demanding attitudes. The presence of a parent at the university is closely related to the severity of the disability and the limitations of the disability. It is only permissible if the student consents and if staff in the disability service consider their relationship to be appropriate and the parent's support to be essential. Parents at the university can be an invaluable support, but strong boundaries must be placed on this type of collaboration. The family, as the most important social group for human beings, is a source of support in many areas of functioning. therefore, the involvement of family members in the educational process of a person with disabilities strengthens his/her capabilities (Akanke, 2023). As considered by Kreider et al. (2015, p. 10) „Students relied on support from parents, romantic partners, roommates, good friends, caring class mates, caring instructors, and health practitioners in managing the multiple layers of complexity experienced as a university student with an invisible disability”. This demonstrates that parental support is an important factor for academic success, not only for people with severe disabilities that significantly impair their independence. However, college is a place where students learn self-reliance and self-sufficiency for future professional roles. Therefore, parental participation cannot be permanent (Mntambo et al., 2021).

Summary

Disability (its depth, type, cause, limitations resulting from it) is a determining factor in independence, and consequently for the parent's participation in the student's academic life. According to Mntambo (2021, p. 247) „the level of assistance required by students with disabilities is mostly determined by their type of disability.” If a student is confronted with many barriers, the parent naturally wants to help, to support him or her. The parent's attitude towards their own child's disability is also related to the parent's participation in the study. The more open-minded the attitude, healthy, allowing independence and autonomy in action, the less parental participation in the educational process. „College attendance continues to be a near-universal expectation of parents for their children in the United States” (Qian et al., 2020, p. 256). Making the decision to study and actively studying with the support of disability services can reduce or negate the need for parental support for the student. On the websites of many American universities one can find guides for parents of students with disabilities, containing the most important organisational information. This indicates that parents of students with disabilities are active participants in their children's academic life. The example is the American University in Washington DC, where the website's Information for Parents & Families section states explicitly that „prior to college, parents have often played a major role in advocating for their children's disability needs.” Respecting this fact, the university is creating an area accessible to parents.

In Mntambo et al. opinion (2021, p. 244) „parental participation in their children's academic lives has an impact on their general behavior and academic life, where many hurdles and variables may prevent successful parental participation. Parents' own feelings about their abilities to assist, as well as their lack of knowledge and awareness of the school system, influence their comfort level with being involved in their children's academic lives”. Parental participation in the education of students in higher education is an additional form of support for them and can ensure their success.

According to Kokhan & et al. (2003, p. 6) „the formation of an educational concept in the field of inclusion, often, is not a guarantee of effective education for a student with disabilities. Only the coordinated work of all

officials and services of the university, students, as well as the student's family, will allow us to hope for decent development, self-organization and integration into a full-fledged student life". Parental assistance is an important factor for successful study. Therefore, each time this type of support should be considered on an individual basis, with particular regard to the welfare of the student and the law. The education of people with disabilities at the tertiary level should be inclined to „...seek solutions that strengthen individuality, which is based on subjectivity and autonomy” (Skalska, 2023, p. 87).

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