



B.Sc. in Psychology

Department of Psychology

Parents perspective on the quality of life for their disabled
adolescents

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Foreword

Submitted in partial fulfillment of the requirements of the BSc Psychology degree, Reykjavik University, this thesis is presented in the style of an article for submission to a peer-reviewed journal.

This thesis was completed in the Spring of 2022 and may therefore have been significantly impacted by the COVID-19 pandemic. The thesis and its findings should be viewed in light of that.

Abstract

The main goal of this study was to see if parents of disabled adolescents feel like their child's quality of life is impaired. This was a qualitative study where the perspective of the participants was evaluated. The purpose of this qualitative study was to determine whether disabled adolescents get the help they need, if they feel like the community treats them differently and if their quality of life is good. All five of the participants had disabled adolescents that had little community and social skills and needed everyday assistance with daily activities. Each participant was interviewed in a non-standardized manner and their responses were examined. The results showed that all of the participants agreed that their children's quality of life should and could be increased/improved. That includes more funding, more personalized assistance and more social activity.

Keywords: Disability, parents, adolescents, quality of life

Útdráttur

Meginmarkmið rannsóknarinnar var að sjá hvort foreldrar sem eiga fatlaða unglunga finnst eins og lífsgæði barna sinna séu skert. Þetta var eigindleg rannsókn þar sem sjónarhorn þátttakanda var metið. Tilgangur þessarar eigindlegu rannsóknar var að kanna/athuga hvort fatlaðir unglingar fái þá aðstoð sem þeir þurfa, hvort þeir fái þá þjónustu sem þeir þurfa, ef samfélagið kemur öðruvísi fram við þá og hvort lífsgæði þeirra séu góð. Allir fimm þátttakendurnir eiga fatlaða unglunga sem hafa litla samfélags- og félagsfærni og þurfa aðstoð við dagleg verk. Tekin voru viðtöl við hvern þátttakanda með óstöðluðum hætti og voru svörin síðan skoðuð eftir þeim og séð hvað var sameiginlegt meðal þátttakanda. Niðurstöðurnar sýndu að allir þátttakendur voru sammála um að lífsgæði barna sinni ættu og mættu vera betri, en það felur meðal annars í sér aukið fjármagn, persónulegri aðstoð og meiri félagslegri virkni.

Lykilorð: Fötlun, foreldrar, unglingar, lífsgæði

Parents perspective on the quality of life for their disabled adolescents

According to WHO (World Health Organization, 2021) approximately 15% of all the people in the world have some sort of disability, with 2 – 4% of those individuals experiencing considerable difficulty in their daily life. That's more than one billion people in the world (World Health Organization, 2021). Disability needs more attention today than it did before, as disabled people are living longer than they used to (Lee et al., 2020). Disabled children are up to four times more likely to act badly, compared to their non-disabled peers. They are more likely to show bad behavior because of their cognitive impairment. Those behaviors can be hard to control, anti-social, distressing, and/or get in the way of family routines and activities. People often have problems into later childhood and adolescence because they get harder to manage. Children's safety and well-being could be at risk because of bad behavior. They could be at risk because as they get older they are harder to supervise and become stronger. They might not be able to participate in school, community, and social activities because of their cognitive impairment (Stuttard et al., 2014).

Attitudes toward disabled people

Since the 1970s, global attitudes on the inclusion of people with Intellectual and Developmental Disabilities (IDD) in ordinary public life have shifted dramatically. Rather than separating people with IDD from non-disabled people there has been growing support in recent years for giving services to them at home and in educational settings (Al-Kandari, 2015). Disabled adolescents are not as likely to attend school as adolescents without any disability. It has been linked to that there are not enough schools for disabled adolescents. Those disabled teenagers who are in school have reported that their educational experience has not been good (Maxey & Beckert, 2017).

Nosenko-Stein (2017) studies' purpose was to look into the many perceptions and misconceptions around disabilities. Interviews were conducted with 11 men and 16 women

with disabilities, and six experts were also interviewed. Both of the interviews were in-depth interviews. According to Nosenko-Stein results, the stigmatization of disability and disabled individuals has resulted in discriminatory views. In a perspective of a “normal” person, individuals with disabilities are still considered as “others” and their problems are solved by “normal” people.

There is a lot of data on what siblings think about disabilities and prenatal testing. Friedman and Owen, (2016) researched how disabled people’s siblings are affected by prenatal genetic testing. In the research they used prenatal genetic testing to find out more about how the siblings of people with disabilities think about prenatal genetic testing and what disability means in society. They studied how siblings' decisions reflected their views on disability. The findings of this study were that siblings have both personal and broad stakes in their siblings’ experiences with disabilities, which affects how they see things.

In the study that Tervo & Palmer, (2004) did, it turned out that in comparison to “Scale of Attitudes toward Disabled Persons” (SADP) norms, negative views against disabled persons were more common among nursing undergraduate students. Work experience is important if you want to feel at ease during a hard rehabilitation process. For more positive attitudes, you need specific educational experiences.

Geçkil et al., (2017) investigated the impact of empathy for nursing students towards disabled people, and the ATDP scale was used, “Attitudes Towards Disabled Person scale.” As a result, the student’s attitudes towards disabled people changed and lasted at least six months due to disability empathy exercises with first-grade nursing students. Positive attitudes toward disabled persons can help improve the quality of nursing care they receive. Nurses must be sufficiently qualified to provide quality services to disabled persons. Therefore, it is vital to experiment with various ways to develop nursing students’ positive

attitudes about impaired individuals. Empathy exercises, which are recognized as the most effective way for the objective, can be preferred.

Another study by McKenney (2018) aimed to look at how 10 participants' attitudes toward individuals with disabilities changed after taking part in disability simulation activities as a part of a study program. The mood in the participants changed when they started to not only respond out of sympathy but became more empathetic and eventually wanted to help people who were disabled.

Parent of a disabled child

Being a parent of a disabled child or a child with special needs, such as an intellectual or developmental disability, is virtually always a life-changing experience, transforming parenting into something more unexpected and difficult (Blake et al., 2019). There is a common misconception that having a disabled child or a child with special needs will have a detrimental influence on the family, however, there is compelling evidence that this is not the case. Personal growth and attitudinal shifts to disability and family resilience are revealed in research concentrating on the transformative benefits of having a disabled child.

Despite these potential benefits, many parents of disabled children experience financial hardships, adversity, and obstacles due to their child's unique demands. When official or informal support resources are lacking or unavailable, such as caregivers, parents are forced to battle institutions that do not always meet their children's needs (Blake et al., 2019).

Work industry for disabled people

In a study by Ayman et al., (2018) they talked about how organizations and foundations serve an important part in improving and making life better for disabled people. Disabled persons are an economically and socially disadvantaged population. Non-profit organizations in Northern Cyprus, a developing country, are using new media in their studies to help disabled individuals (Ayman et al., 2018). Social responsibility projects that aim to

improve the quality of life for people with disabilities can be hard for non-profit groups like associations and organizations that rely on donations to stay alive. In order to make people with disabilities' lives better, these groups are having trouble with their businesses. The social media presence of foundations was better than that of associations.

A study by Barnes & Mercer, (2005) focused on the disabled people's exclusion from the British labor market. The exclusion of disabled people from the workforce is discussed in relation to mainstream sociological conceptions of work, unemployment and underemployment. This has clearly been a major role in the isolation of disabled persons during the previous two centuries. It will continue to be a major issue in the campaigns of both parties of disabled people and non-disabled people.

Jalba et al., (2017) did a research on disabled people who struggled to keep up with the work industry since there were many robots today to cover every work for the society. Automation is becoming more common in all aspects of everyday life and work industry which is replacing the workforce of disabled people. To help people with disabilities integrate into the workforce in Germany, sheltered workshops have been set up, in which disabled individuals and industrial robots can work together to create sophisticated goods using industrial image processing. In a sheltered workshop, disabled people assembled high-pressure hydraulic pumps using industrial robots. After assembly, the pumps are fully automated and tested for leaks at extremely high pressures. If skilled professionals are more likely to be used for job preparation and supervision of impaired workers, rather than for boring and dangerous activities, the investment may be beneficial. Intelligent robot protection equipment can also be used to allow robots to collaborate with disabled workers.

Takeuchi et al., (2020) came up with the idea of "avatar work," which allows people with disabilities to do physical tasks like customer service through telework. They wanted to make sure everyone could do anything if they had a free mind, even if they were bedridden.

Disabled people can use avatar work to do physical work from home by controlling a robot called "OriHime-D" with a mouse or by looking at it, depending on their abilities. A two-week limited avatar robot cafe was set up to see how people with disabilities could work from home using OriHime-D. Ten disabled people took part in this study, and the results were that they could build an avatar job that contributes to mental fulfillment. It has also been shown that the experimental cafe's work content is suitable for people with disabilities seeking social interaction. Legal difficulties have been identified as a potential future issue for the societal implementation of this research.

The main goal of this research was to see if parents of disabled adolescents feel like their children's quality of life is impaired. This was a qualitative study to gain a deeper knowledge of the subject. The research question for this study was: Do parents of disabled adolescents feel like their quality of life is impaired?

Method

Participants

The participants in this study were recruited using a snowball sampling method. The selection criteria for participants were that their children were disabled adolescents in 8th – 10th grade in Klettaskóli. Klettaskóli is a school for children/adolescents with special needs and disabilities. All of the participants' children have little language skills and none of them are in a wheelchair. The gender or age of the people who took part in this study did not play a role in which people were chosen for the study. The age of participants ranged from 37 – 54 (M=48) and the gender proportion was almost equal with three females and two male participants. Five out of the six participants had boys and only one participant had a girl. The age of the adolescents in this study ranged from 14 – 16 (M=15). They all live in the greater Reykjavík area. The participants names who took part in this study were changed so that they could stay anonymous. The participants were the following:

Petra Sigurðardóttir: 54 year old woman who has a 14 year old disabled son

Ólöf Jóhannsdóttir: 52 year old woman who has a 16 year old disabled daughter

Ingunn Pálsdóttir: 49 year old woman who has a 14 year old disabled son

Arnar Leifsson: 37 year old man who has a 16 year old disabled son

Bjarki Ómarsson: 47 years old man who has a 15 year old disabled son

Materials

An unstandardized frame of questions in a qualitative interview was used in this study (see appendix A). Because the interview's format was not standardized, some questions may not have been asked, and others may have been added during the interviews based on the participant's narrative. There were nine questions in the questionnaire, the researcher had the questionnaire with consideration to when asking the questions in the interview. In the beginning of each interview the researcher introduced himself and began by asking the participants name and how it is to have a child with special needs. Questions that were asked were the parent's view of their children's quality of life, that included questions about their social life, prejudices and safety. The questions in the questionnaire were composed in January 2022, but were adapted until the interviews took place.

Research design

This was a qualitative study. Because the interviews were done in an unstandardized manner and the outcomes were subjective, variables could not be numerically specified. The major goal of this study was to learn more about if parents of adolescents with disability feel like their adolescents have the best quality of life they could have. Also, if the parents experienced any prejudices regarding their children's disability, and if the parents feel there should be better accessibility for adolescents with disability.

Procedure

All of the interviews were conducted in March 2022. The snowball sampling method was used to get participants, at the end of the interviews, each participant was asked if they could recommend someone else to participate in this study. As the interview began the researcher asked the participants if they wanted to take part in this study and each participant said yes, which was the informed consent. The participants were informed that they could quit this research whenever they wanted to. All of the participants were asked if they wanted to meet in person or do an online video interview. All of the interviewers wanted to conduct the interview online and the participants chose the date and time that suited them the best. The interviews were recorded with a voice recorder on a mobile phone which was collecting the data. The shortest interview was 9:30 minutes and the longest was 16:02 minutes (M = 13:47 minutes). After the interview, the participant's narrative was written down straight afterwards and was transcribed and documented. The notes from the documented interviews were 19 pages in total. After each interview had been written down, a pattern of what the interviews had in common began to emerge and the researcher began to write down similar themes. While the interview took place, the researcher marked down important points that the participants talked about.

Data analysis

The data was conducted via a voice recorder in all of the interviews. During the data collection process, relevant and significant findings were highlighted and noted. As the interviews progressed, there were clear signs of what was similar between these interviews. Those similarities were four themes: getting help from others; community treating them differently; quality of life and accessibility. With these concepts, the research's main goal was fulfilled, to see if parents of disabled adolescents feel like their children's quality of life is impaired. These themes were then analyzed later.

Results

Getting help from others. All of the participants mentioned that they accepted help from caregivers, took advantage of short-term accommodation, made their children attend social centers and attend Reykjadalur, which is a summer camp for disabled children and adolescents.

If parents need assistance from caregivers, they need to assign it themselves. They have to make sure that the caregivers are qualified enough and meet their standards. Disabled adolescents get a certain amount of hours of help assigned to them depending of the severity of their disability. This is assigned to each disabled adolescent from their municipality. For example, Petra's 14 year old son has the right of more hours with caregivers, compared to other adolescents, and she has 8 caregivers helping her out. Arnar only has one caregiver helping him out because his 16 year old son is less disabled than Petra's son. Petra stated in her interview, *"I have asked for over 2 years for more assistance at home since my son is getting bigger and stronger, but the system has failed me relentlessly"*. Even though Petra has eight caregivers and the right to more hours with caregivers than most parents with disabled children, she still struggles and requires more assistance with her son. Ólöf also mentioned that if she herself does not reach out to get assistance for her 16 year old daughter, the system benefits from it because she is not taking advantage of the time she is entitled to. The system benefits from it because they assign a certain amount of hours to each parent who has disabled adolescents and if they do not take advantage of it the system gets to keep the profit which is supposed to go to the caregivers. Ólöf also noted, *"She has sometimes had a support family but they have all given up on her because taking care of a disabled adolescent is a hard job"*. So Ólöf is therefore mostly alone with her daughter. Arnar stated in his interview that his sons grandparents are his support family and also that his son went for the first time to Reykjadalur this year. He has always denied going but didn't really have a choice last year and he absolutely loved it and wants to go again this year.

Based on these results, the system doesn't encourage parents with disabled adolescents to reach out for help because the system benefits from it. It is also obvious that it is difficult to get support families and that Arnar is fortunate to have parents who provide support while Ólöf does not have such a good support network. She therefore needs to rely more on herself and the system.

Community treating you differently. Nearly all of the participants talked about that they felt like the community treated them differently because of their child's disability. Arnar was the only one who didn't feel that way and said, *"He's always shown more respect and almost all people see right away that he is disabled"*. Petra and Ólöf talked about how some people show tolerance and others do not. Petra stated, *"There are a lot of places that I never go with him to because it doesn't suit us"*. Ólöf said, *"I went with my daughter to a concert last night and there were two ladies sitting next to us that were very frustrated with her behavior"*. Arnar doesn't feel like the community treats him differently because Arnar thinks that people can realize immediately by looking at his son that he is disabled. He definitely notices when people look at him and his son differently when they go swimming because he is willing to walk around naked because he does not sense what is normal.

The prejudices usually come unconsciously from other people. Many people are unaccustomed to seeing disabled adolescents and do not know how to behave around them. Like Ólöf stated in her interview, *"I never let myself be angry or disappointed when I see someone being frustrated with my daughter because I have to, of course, respect that they might have never seen a disabled person in their life"*. Because it's something that some people are afraid of and unfamiliar with, the prejudices that the parents experience are abnormal. Like Ingunn who has a 14 year old son stated in her interview, *"If I speak on behalf of parents who have disabled adolescents, we ourselves step aside a little bit to make some situations easier for us and other people"*.

Quality of life. The participants all thought that social participation is very limited for disabled adolescents and that it could be better. Late night social center begins for the kids in Klettaskóli in 8th grade and that is once a week for two hours. Ingunn's son has a twin brother that is not disabled and she noted in her interview that she thinks it's really sad to watch his brother grow up with a lot of freedom of what he can do and has been in social center since 5th grade. She stated that there are a lot of things that her disabled son will never experience in comparison to his twin brother because there is not enough funding to finance that. Bjarki, father of a 15 year old disabled son, had the same thoughts about this and noted in his interview: *"It really makes you wonder, shouldn't the disabled adolescents get more options rather than non-disabled adolescents who have no problem making friends. I find this really peculiar."* Arnar talked about how very limited the work his son can do when he finishes high school. Remedies should be encouraged for more job opportunities for disabled adolescents.

Disabled adolescents have a certain inhibition, that is just a fact that can't be changed, and of course the society should accommodate such adolescents. There should be more awareness raising for better quality of life for disabled adolescents. Ólöf noted in her interview that they should be seen and that they should be allowed to participate on their own terms in the society. Many times they are put in situations they may not want to be in, but they have no choice, what so ever. It is really important to respect their decisions on what they want to do. Everyone should of course be a part of our society and take part in it.

Accessibility. There are so many different types of disability that the quote "one implies to all" does not count. Ólöf's child started going in a public school to an open/mixed class. This school for everyone can sometimes be a little violent towards disabled children since they cannot handle being in a normal class. Ólöf stated in her interview, *"When I first took my daughter to public school they were kind of inventing the wheel, hiring a*

developmental therapists, creating facility for her and so on, but with Klettaskóli the teachers there have specially trained themselves to work with disabled children". Nearly all of the participants talked about how there should be a special department for disabled students in the biggest schools in Iceland. There has been a really long wait and great attendance for parents to get their child into Klettaskóli, because the biggest schools do not have a special department.

When parents go to the swimming pool with their adolescents it can sometimes be a bit challenging to be with them in the dressing room. Arnar talked about in his interview that there should be more special rooms in the swimming pool's dressing room. It's not easy to be with a disabled adolescent in a normal dressing room and keeping your eyes on them at all times because many disabled adolescents do not have the sense for it that it is not socially right to be naked in the swimming pool.

Discussion

The goal of this qualitative research was to discover whether or not parents of disabled adolescents believe that their child's quality of life has been affected in any way by their disability. Also to find out if the community treats disabled adolescents differently and if they have a good quality of life. The results showed that all participants believed that improving their children's lives was desirable. That means more funding, more help, and more social interaction.

With this in mind, the themes of this study became: getting help from others, community treating you differently, quality of life and accessibility.

Based on the first theme, getting help from others, the system should nurture better to caregivers. The system could provide them with courses so they are more prepared to deal with disabled adolescents and not give up on them. Like Ólöf talked about lack of consistency with support families and caregivers, and too many of them have abandoned her

daughter, which has made her get to know so many new support families. This situation has also made things harder for the whole family because they do not get the help they so desperately need. This is not acceptable for families with disabled members, in the long run people get exhausted from all the hard work they have to give to keep things together. Most often there are other family members that need attention; there is work that needs to be done, marriage to work on, social life, etc. If people go on with their lives for years and years with limited support, there are more chances of a “burn out” for the parents, which costs society much more in the long run. More people should definitely consider being caregivers for disabled people because according to study by Geçkil and collages (2017) the nurses were qualified to provide quality services to disabled persons and they had a positive view on working with them. In many cases people want to work with disabled people, but are afraid of doing so because they think it is very stressful and do not know how to behave around disabled people. However, it actually has a very positive and rewarding effect on people.

Based on the second theme, community treating them differently, a study by Al-Kandari (2015), Nosenko-Stein (2017) and McKenney (2018) researched that community treats disabled people differently. In a study that Al-Kandari (2015) did, it was said that disabled adolescents are not as likely as adolescents without any disability to attend to school because the educational experience for disabled adolescents has not been good and they do not get as good education as the adolescents without any disability. The school system treats them differently, just like Ólöf stated in her interview that her 16 year old daughter didn't get the education she needed when she attended “normal” school. In a study that Nosenko-Stein (2017) did, people with disabilities are considered as “others” by people without any disabilities, which is a huge problem in the society that their problems are solved without their consent. Disabled adolescents often have no choice about what they are about to do. In the study that McKenney (2018) did, the attitude towards disabled people changed after the

participants took part in a study that focused on how the community treats disabled people and actually wanted to help disabled people more. There should definitely be an awareness of how they are treated so more people would have more empathy and want to help them more. Based on the interviews in the current study, society is not accepting disabled adolescents as any others. They are treated differently with the way people view them and by lack of social interaction they are provided with.

Based on the third theme, quality of life, according to the results of Barnes and Mercer (2005), the labor market needs to be open to employing disabled people; many places have the technology to do some work for them which would be ideal for disabled people to do. Something that is not too difficult but could be a perfect first time job for disabled individuals, as Arnar stated in his interview that he wants more job opportunities for his son after he graduates from high school. When the researcher asked the participants about an example of how the quality of life could be better for their children, they agreed that there should be more activity available for those children.

According to WHO (2021) around 15% of the world's population has some sort of disability so there should definitely be more accessibility for them. Based on the fourth theme, accessibility, there should be more options for disabled adolescents to choose from. As the situation is today they only get 2 hours a week a night opening in their social center and can go to Reykjadalur once in the summertime. Petra also talked about that her 14 year old son has few options to choose from to go to a playground that suits him because of his disability.

Finally, there should be more awareness in the society that disabled adolescents feel more seen. Disabled adolescents need a strong spokesperson to fight for their existence and fight for them to be acknowledged as any other member of society. In the past, the gay community was hidden and mocked but with strong spokespeople who fought for their

recognition; they no longer have to be ashamed of who they are and are considered a part of our society. This should be the case for disabled adolescents as well, starting now.

If these four main solutions that were mentioned by the participants; getting help from others, community treating them differently, quality of life and accessibility would improve as they should then life of disabled adolescents could be much better. One advantage of conducting these kinds of studies is that the society gains an understanding of what it's like to live as a disabled person in the society. The same results may not be obtained through the use of standardized questionnaires and data analysis. These types of studies offer critical information that is critical for future growth and advancement.

The first limitation of this study was that there were only five participants; perhaps the results would have been more accurate and more extensive if there had been more participants. The second limitation in this study was that only one participant had a girl and the other four had a boy. The results may have turned out differently if the gender ratio had been more equal. The third limitation is that the interviews were conducted with the children's parents; perhaps the results would have been different if the interview had been conducted with the adolescents themselves and they could have told their own perspective about their quality of life. The strengths in this study were that this was a qualitative research which was very important because the researcher was researching a specific group in the society. What qualitative research has above quantitative research is the ability qualitative research has to explain better what the target group, participants, has to say while quantitative research has pre-determined questions that can often only be answered yes/no or strongly disagree/neutral/strongly agree. In qualitative research, participants are given the opportunity to present their knowledge and experience, while in quantitative research, the researcher needs to capture people's attitudes. Most people would consider this research worthwhile if it resulted in a good society for everyone in some way.

It would be fascinating to compare the results of a quantitative study similar to this one. As a result, it is hoped that future generations would do further research on the subject, with relevant advancements as a result. In future researches it could be interesting to interview the adolescents themselves and compare the results with them, which could be difficult. There are some disabled adolescents which this could be a possibility to do with, but some have no community skills, like the adolescents in this study. It could also be possible to interview the staff who provide services for disabled people.

The general conclusion was that the quality of life of disabled adolescents could be considerably better. This applies to both monetary contributions and conditions offered by the government or municipalities. Parents experience prejudice, increased stress and isolation as a result.

Appendices

Appendix A: Interview questions

1. Hvað heitir þú og getur þú sagt mér frá hvernig er að vera foreldri barns sem er með sérþarfir? (Hvers konar fötlun er barnið með?)
2. Nýtur barnið þitt sér þá þjónustu sem er í boði; dæmi: liðveislu, skammtímvistun, félagsmiðstöð, Reykjadalur, sumarhúðir.
3. Finnst þér samfélagið taka öðruvísi á móti þér vegna þess að þú átt barn með sérþarfir? / Finnst þér samfélagið taka öðruvísi á móti barni þínu vegna sérþarfa sinna?
4. Finnur þú fyrir fordómum vegna sérþarfa barn þíns?
5. Hvernig er með (samgöngur, afþreyingu..) dæmi: Fara í strætó, fara í bíó? (Ef erfitt/auðvelt, hvers vegna þá?)
6. Hvernig finnst þér að það mætti bæta aðgengi fyrir krakka með sérþarfir í samfélaginu okkar? (Ef svo hvernig þá?)
7. Finnst þér barnið þitt vera fá nægt öryggi vegna sérþarfa sinna?
8. Finnst þér að samfélagið gæti bætt lífsgæði krakka með sérþarfir? Hvernig þá?
9. Er eitthvað sem þú vilt bæta við í lokin?

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