

This paper has been accepted for publication in British Journal of Visual Impairment.
This is the accepted version of the paper.

The role of habilitation services in the lives of children and adolescents with visual impairments

Ifigeneia Manitsa

Kingston University London

Dr. Fiona Barlow-Brown

Kingston University London

Corresponding author: Ifigeneia Manitsa, Psychology Department Kingston University
London, Penrhyn Road, Kingston-upon-Thames, KT1 2EE

K1738620@kingston.ac.uk

ORCID iD

Ifigeneia Manitsa <https://orcid.org/0000-0002-0239-3579>

Abstract

Previous research suggests that children and adolescents with visual impairment may face several challenges in their academic learning and socio-emotional development due to restricted mobility, feelings of loneliness and dependency on others. Habilitation services attempt to provide support with respect to many of these challenges that may positively impact on well-being and mental health, such as enabling independence in daily tasks, participation in social activities and developing self-confidence. Literature also shows that individuals who have received educational and vocational rehabilitation support report higher quality of life and more positive self-esteem. Therefore, the primary focus of this study was on the rehabilitation, recreational opportunities and educational resources provided by vision habilitation services for children and adolescents with visual impairments. The role that these services may play in school and daily life, as well as in the socioemotional development of children and adolescents with visual impairments was also examined. This research covers the perspectives of professional staff, parents, children, and adolescents and considers both the immediate and potential long-term benefits of these services. The findings of the study highlighted the positive impact that this support has on children and adolescents' independence, personal-safety, and self-confidence. The findings also indicated the positive impact of this support on the mental health of their families and benefits of providing continued support and expanding these habilitation and recreation services.

Key words: habilitation services, visual impairment, childhood, adolescence, family

The role of habilitation services in the lives of children and adolescents with visual impairments

Literature suggests that some individuals with blindness or low vision may experience difficulties in completing everyday tasks, such as travelling independently (Low et al., 2020), finding employment (Southwell, 2012) and participating in social activities (Jessup et al., 2017). The literature also shows that children and adolescents with visual impairments may also present with more emotional and behavioural difficulties than their sighted peers (Pinquart & Pfeiffer, 2014) due to restricted mobility, feelings of loneliness and dependency on others (Augestad, 2017). Although students with visual impairments usually reflect on the positive impact of adaptive technology on their academic performance (Thurston, 2014) and the importance of developing an inclusive curriculum (Datta & Palmer, 2015), research shows that challenges often arise in academic learning due to a lack of a written policy and the limited number of learning materials that have been adapted to individual needs (Bodaghi et al., 2016). Therefore, to promote the overall wellbeing and quality of life in the field of visual impairment, past research suggests a need to provide more tailored support.

With respect to providing support for potential challenges faced by individuals with visual impairments, habilitation and rehabilitationⁱ services address several life areas that may contribute positively to mental health and well-being, such as enabling independence in daily tasks, participation in social activities and the development of self-confidence (Cimarolli et al., 2006). Research on the role of rehabilitation services in the transition from school to employment for young people with blindness or low vision has indicated that participants in vocational training programmes had the opportunity to further develop daily living, problem-

solving and social skills (Crudden, 2012). Despite the limited empirical data on the impact of habilitation support on the academic learning and socioemotional development of children and adolescents with visual impairments, research shows that individuals with SEND who have received support from rehabilitation services report high quality of life and positive self-esteem (Bogart, 2014). Therefore, considering the potential challenges that may arise in academic learning and socio-emotional development (see Celeste, 2006; Khadka et al., 2012, De Verdier, 2016; Worth, 2013), it could be expected that the provision of habilitation support may have a positive impact.

Whilst providing specialist services can appear very costly due to the increasing demands on health and social care (Rabiee et al., 2016), investing in professional services and ensuring specialist support is available in the field of visual impairment may enable children and adolescents to overcome any challenges arising in academic learning and socio-emotional development and thereby avoid future costs to both health and social care budgets. Consequently, the focus of this current research is on the role of habilitation support in independent life skills, recreational opportunities and educational resources that are provided by specialist services to children and adolescents with vision impairments and the role that this support may play in school and daily life, as well as socio-emotional development. In particular, this study examined:

1. The role of the professional staff in providing children and adolescents who have vision impairments with the appropriate daily living, academic and social skills to live independent lives.

2. Parents' perceptions regarding the benefits that are brought by the provision of habilitation services, recreational opportunities and educational resources in their children's daily life, academic learning and socio-emotional development.
3. Children and young adolescents' perceptions regarding the benefits that are brought by the provision of habilitation services, recreational opportunities and educational resources in their daily life, academic learning and socio-emotional development.

Method

Design

An interpretivist case study approach that allows researchers to conduct a detailed exploration of complex issues, such as the outcomes of the provision of specialist services to vulnerable groups (Crowe et al., 2011), has been used in this study. This epistemological approach has been extensively used in the disciplines of social sciences and it promotes the understanding of key concepts as perceived from different individuals who belong to specific social groups (Crowe et al., 2011; Stake, 1995).

The main focus of this case study was on a UK charity offering habilitation skills training and socio-emotional support, through the provision of individual habilitation skills training lessons and group recreational activities, for children and adolescents with sensory impairments, as well as offering additional support to their families.

Materials

A semi-structured interview was used to enable participants to reflect on their own experiences, thoughts, and specific points of interest. Contradictions that participants held might have been revealed through the semi-structured interview where they had the chance to reflect on their own beliefs and morals. This technique also allowed researchers the flexibility to refine the interview schedule according to participants' stories and to explore motives which had not been investigated before (Horton et al., 2004).

Four interview schedules were developed to examine the impact of habilitation services on the academic and social lives of children and adolescents with vision impairments and their parents. Each interview lasted approximately 20-30 minutes (one interview lasted 55 minutes). All interviews were conducted remotely via Zoom and were audio recorded.

The research received a favorable ethical opinion from the Research Ethics Committee of the (Name of the Faculty and University). In addition, online information sheets and consent forms were distributed to participants, who were asked to provide their written consent before the interview. However, children aged 8-11 years gave their oral consent and parental written consent was additionally given for all the children and adolescents who participated in this study.

Participants

Thirty-six semi-structured in-depth qualitative interviews were conducted with 11 children and adolescents with visual impairments (nine students were registered as severely sight impaired and two as sight impaired) aged 9-17 years (seven female and four male), 16 parents (12 female and four male) of children and/or adolescents with visual impairments who were receiving habilitation support from this specific charity at the time of the interview and 11 professional staff members (all female) from the “Children & Young People” team of the service (three habilitation specialists, four recreational workers, two administrators, one family support worker and the Head of the service) between April and December 2020. One child and three of the adolescents who participated in the study also had additional needs, such as hearing impairment, autism spectrum disorder (ASD), health issues and mobility problems. Only those aged eight years and above were interviewed because evidence indicates that self-evaluation starts in middle childhood (Harter, 2012), therefore, children younger than 8 years may have been unable to successfully evaluate the impact of the service provider on their personal academic and socio-emotional development.

Participants were recruited via social media (e.g., Twitter) and newsletter advertisement. Participants were required to have been receiving habilitation support from this particular charity at the time of the interview and to be able to participate in a remote online interview. Three £20 vouchers were given to students and their parents as prize draw incentives for participation.

Data analysis

The data was analysed by conducting thematic analysis which focuses on the identification of patterns of meaning across a dataset and it is one of the most frequent types of analysis in qualitative research. Thematic analysis was also selected for its flexibility, as it is a research tool that can be applied across a range of theoretical and epistemological approaches (Braun & Clark, 2006). Thematic analysis consists of the following six phases: (1) familiarization with the data, which refers to the reading of the data and the identification of repeated patterns in the dataset, (2) initial coding, which focuses on the extraction of the most fundamental information and the emergence of important features from the dataset, (3) searching for themes, which involves the formation of themes and sub-themes based on the initial codes, (4) reviewing themes, which refers to the re-evaluation of the themes against the dataset and the confirmation that they create a coherent story, (5) defining and naming themes, which includes the detailed analysis of each particular theme and its sub-themes and the allocation of a name to each theme/sub-theme and (6) producing the report, which involves the write-up of the data (Braun & Clarke, 2006).

The first author of the study analyzed the data independently following the steps above. When the analysis was complete, the second author of the study checked the analysis and discussed any points of difference until a consensus was reached. The themes and patterns that were identified in the data, as well as their interpretation, are presented in the following section.

Findings

Two main themes emerged from the analysis: (1) supporting independence and (2) providing multifaceted socio-emotional support. Several sub-themes have been also developed and are further analysed below.

Supporting independence

This theme refers to the actions that the professional staff take to promote accessibility in schools, the home and in the community. It also focuses on the positive effect of this person-centred provision on children and adolescents' confidence and their self-advocacy skills.

Accessibility issues

Parents described the support they received from the service which mainly focused on the preparation of EHCP plans, school transport and staff liaising with schools.

...they helped with EHCP in getting that right and disputes about the EHCP and that took a long time and like I said meetings at school. They helped with, even down to things like helping me write the application for college transport to help me write letters and giving me supporting letters as... (female parent no.4)

Like parents, the professional staff also explained that they work closely with the children and adolescents' schools and especially with their QTVIs. In particular, they mentioned that they

Speak with QTVIs on a regular basis because they want to ensure that children's needs are addressed both from an educational and habilitation/ independence perspective. They also thoroughly described the procedures they follow to create a program that best meets individuals' needs.

Yes, so I do speak with the QTVIs on a regular basis, so as soon as we get our referrals in, our referrals tend to come from the QTVIs, I contact them and I just say I picked up this particular child, they may know them so they will give us feedback on that child, and then we might work with them, we might go to the school together, so that is the work that can be done together... (habilitation specialist no. 2)

Other than the support received regarding their children's learning experience, some parents also mentioned that the service provider initiated some modifications in their home, such as kitchen adaptations: *"We were given lots of tips about putting her equipment in a box where she could easily find it and so it didn't get mixed up with our things. Just things like that that as sighted people, we didn't ever consider"* (female parent no.7).

Finally, both parents and adolescents referred to all the actions that the organization had undertaken to promote full accessibility in recreational opportunities. The following is a direct example of where the actions of the organisation in terms of promoting accessibility led to a significantly enhanced experience.

The show that I had seen was the Lion King and it was one of my favorites and it helped blind children and people to understand the story and they do a touch tour so they can feel their props and feel the cat's costumes and the house for them, and descriptions and they could understand what they are doing on the stage. (female adolescent no.6).

Promoting confidence

In this sub-theme, parents highlighted the positive impact of receiving habilitation and educational support in their children's school lives. Specifically, they described the effect that this support had on their children's self-confidence, especially when starting a new school, and the importance of taking into consideration students' needs when providing support.

She couldn't have gone to a normal school without them having come in and given her some support before she went in and shown her how to find things like just finding where the toilets are and things. They made sure that she had a visit to the school before her first day there. Someone has thought, what would a child who can't see very well need to know on her first day... (female parent no.3).

Some parents also pointed out that their children's safety is always secured in all the recreational events organised by this specific charity. According to parents, this means that they don't feel the need to accompany their children which thus promotes independence. *"I have never been to any event since 2012 that has not been well organised and been safe and taking care of these kids... if I have to drive to a (name of the organization) event and I have*

got to stay there for the whole thing, that to me is defeating the object because the objective is, I want her to go these things because I want her to have independence.” (male parent no.4)

It was also emphasised that children’s participation in these activities had a positive impact on their school life. Parents reported that their children were able to first engage in some recreational activities with the organisation before then repeating them with their classmates, therefore, through this process, they felt safer and more confident: *“It was nice for him to be able to go first with us and (name of the organization), he felt really really comfortable knowing then that when he came back with school in a few weeks’ time, after the summer holidays, he knew where everything was. (female parent no.12)*

It was apparent from professional staff that their service promotes a person-centred approach to each child’s independence, importantly focusing both on their specific abilities and on their families’ needs. The view that working in a flexible child-centered way rather than being prescriptive in the service delivery might be the key to their service’s success: *“I think it is about being person-centred looking at what those children need and what those families need”*. (Head of the service).

Having a voice

There were distinct dialogues across many of the participants about the influence of this support on their self-advocacy skills. Parents highlighted how important is for their children to seek assistance whenever they feel that they need it and advocate for themselves: *“It did last year*

because they advised her on—you went in and spoke to everybody in all the tutor groups and that was through advice from (name of the organization). There was a lot of things she did last year at year 11 that helped her, and it also helped her to tell her peers what was happening to her.” (female parent no.1). Like this mother, other parents suggested that staff members from this service had advised their children to explain their lack of vision to their teachers and classmates to make them aware of their particular needs.

The professional staff indicated the importance of working closely with children and adolescents with visual impairments in order to develop their self-advocacy skills. In particular, they shared some strategies they use to achieve this, such as designing habilitation sessions that help them increase their daily living skills and independence: *“...I have done quite a lot of work where I made teenagers go into a shop and ask the customers’ support for asking them to find something, so that they have the practice and the skills and it means the next time they go in, they know that they can do it themselves...”* (habilitation specialist no.2)

Three staff members also explained that adolescents are involved in the decisions made about the organisation of recreational events so that they can have their own impact on the development of these activities. Particularly, they explained that they usually ask their 11UP group (social group for individuals aged 11-18 years) what activities they would like to participate in (e.g., trying a quiz or experimenting with other types of remote activities over zoom during lockdown) and highlighted the fact that this process may promote these individuals’ independence, who may be able to acknowledge their own voice and its impact. *“...particularly the eleven-up group, we like them to choose what activities they want to do,*

and we try to make it as mainstream as possible and get the mainstream adapted...” (Head of the service).

Providing multifaceted socio-emotional support

In this theme, participants described the development of their children’s sense of belonging through their participation in recreational opportunities. Parents also referred to the emotional support that their families receive from this organisation.

A place to shine

In this sub-theme, parents expressed their concerns about their children’s visual impairment that may limit their social interactions with their peers and stressed the importance of actively participating in recreational activities: *“She has experienced lots of, when she first started secondary, she struggled socially, and she got quite isolated... I think that means as well that she is, has the practice of relating with her own peer group rather than just being surrounded by adults all the time, which is sort of a danger, really with children with special needs often as an adult and they miss out on that peer group interaction.”* (female parent no. 7).

Other than parents who referred to the positive impact of recreational activities on their children’s reduction of self-isolation, adolescents also highlighted the importance of participating in these activities in order to develop their own sense of belonging: *“...it makes*

me feel like accepted in like in the society because when you are a disabled person in society, you can often feel like you are a bit secluded from the main group. Now, I feel like, when I go to the events, I feel like I am very much included into the activities which are so nice.” (female adolescent no.7).

The professional staff also thoroughly described some of the recreational opportunities that they had organized and the positive impact they had on the well-being of children and adolescents. Staff members also explained that these activities are always adapted to these individuals' needs and sponsored by the charity, therefore parents do not have to be concerned about their children's safety or the financial cost of the activities.

So, I think in that respect we give them the experiences that other people in their age would get, but we just do it in a safe environment for them, so they get to experience the same sort of things, but many times they experience a lot more than their friends, you know indoor skydiving and rock climbing and jumping... (recreational worker no. 4)

Emotional support for families

Parents reported the development of their children's resilience, as well as the promotion of social interactions with their sighted peers: *“...we have all been worried about her self-esteem and how she copes or has coped with losing her eyesight because it happened quite quickly. So much so that her educational psychologist advised us that they were waiting for her to break*

down, which she has never done. I think part of that is because she has always had somebody else to go to.” (female parent no. 1).

The emotional support that parents have received from the service has been also accentuated. The examples that parents and professional staff members shared with us focused mainly on parents' initial reaction to their children's diagnosis or their emotional response to other people's reactions to their children's impairment: *“In the beginning, when he was first diagnosed... then obviously me and mum were a little bit down. As time went on, what was the future for (name of the child) we were thinking, you know. And then with the other additional needs. They were amazing. Absolutely amazing.”* (male parent no. 2)

Some parents also reported the organisation of some events where they had the opportunity to meet other parents of children with visual impairments and share their experiences. Parents highlighted the detailed planning of these events and the unique information they had access to during these sessions: *“There was so much useful information that was given regarding lots of things that sighted people take for granted such as technology, self-care, cooking etc. This was not just information on the day, but it was followed up with an email that had follow up information based on questions that parents had asked at the meeting”* (female parent no. 12).

In addition, parents described specific cases when no one else supported them and their children, except for this particular service. This support could relate to the completion of paperwork, the provision of practical assistance and emotional support, encouraging safety and independence and the fact that this service advocates for their children's rights of education and equal treatment. This is illustrated by the quotes below:

“We have been working on different paperwork and so things like his social care assessment, carer’s assessment for myself and also, particularly over these last few weeks, chasing the Transport Department because (name of the child) didn’t receive any transport for the first three weeks at college. She was helping us to chase that problem.” (female parent no. 11)

“How to use a white cane. No-one could have taught her that that I know of. How to navigate around an unfamiliar environment. Lots of things. How to find something that you have dropped on the floor, if you are blind or how to tie your shoelaces. That was really good. There is a lot of things.” (female parent no. 7)

Some parents also described in detail the support they received during the COVID-19 lockdown, when the majority of all the other services were suspended: *“Help during the lockdown, actually, when a lot of other people and other services weren’t continuing and that was something that sort of continued throughout and they came up with this brilliant idea of still being able to do the cooking sessions through Zoom...”* (female parent no. 4).

Discussion

In general, past research has suggested that a lack of vision may negatively affect the completion of everyday tasks related to hygiene practice, mobility, and academic performance (see Elsman et al., 2019). Children and young people with visual impairments may face

numerous challenges in socio-emotional development and inclusion (Rosenblum, 2000; Worth, 2013) which may derive from a lack of vision (Green et al., 2004; Peterson et al., 2000) and/or the lack of the appropriate auditory stimulus (Bartoli, 2019; Brambring & Asbrock, 2010; Pijnacker, 2012).

Despite there being limited research focusing on the role of habilitation services in the lives of children and young people with visual impairments; the positive effect of habilitation services has been previously highlighted in the literature, which reports a positive impact of habilitation support in academic learning and mental health of individuals with visual impairments (see Bogart, 2014; Cimarolli et al., 2006; Crudden, 2012). Like previous literature, the findings of this research project have highlighted the positive impact of habilitation services on the daily lives and socio-emotional development of children and adolescents with visual impairments. In particular, the actions that this specific service undertakes to promote full accessibility and inclusion of children and adolescents with visual impairments in their school and social environment have been discussed in this study. The person-centered approach of this service was deemed central to the experiences and development of the service users. Our findings have also shown that habilitation services may closely work with young people with visual impairments supporting the development of essential life skills, such as mobility, cleaning, and cooking, and developing lifelong self-advocacy skills. The children and adolescents who participated in this project also referred to feelings of belonging and acceptance that they developed through the socio-emotional support received and especially through their participation in recreational activities tailored to their specific needs. It should be highlighted that all the parents that participated in this project described specific situations where this was the only service that continuously supported them by promoting their families' positive well-being.

Although this study provides useful insights into the role of habilitation services in the lives of children and adolescents with visual impairments, there are some limitations that need to be discussed further. Previous research shows that the format of children and adolescent mental health measures may significantly affect participants' performance (Patalay et al., 2015), therefore a similar situation may also apply to the children and adolescents that participated in this study. This means that although some children and adolescents might have felt more comfortable in disclosing personal information through our online interviews, others might have needed more time to build rapport with the main researcher of this study and share their thoughts. In addition, participation in the study required participants to access Zoom, therefore this could potentially mean that families with limited access to technology would not be able to participate. Finally, the current study only focused on a specific service provider in the UK, therefore similar outcomes may not be found in habilitation service providers across the country. Recent research by Guide Dogs and the Thomas Pocklington Trust showed that only a small number of children and young people with visual impairments are currently supported by local authorities in the UK and also highlighted the lack of a holistic approach towards the needs of students with visual impairments and their families (Messenger & Palmer, 2021). However, we hope that the findings of this research project will encourage areas of the country without habilitation services to invest in specialist services to promote the independent living of individuals with visual impairments.

Whilst providing specialist services can appear very costly, especially in these times of austerity, both the current research reported here and existing research also discussed, demonstrate that the provision of this support, as age appropriate, may promote independent

living, emotional resilience, and future employment with the ability to care for themselves and their families. Indeed, the WHO global disability action plan (2014-2021) has also clearly stated the value of habilitation services and the importance of extending and strengthening the provision of this support in the areas of health, education, employment, and social life. Specifically, the WHO guidelines have accentuated the importance of investing more in the provision of habilitation support that encourages individuals' independence and personal safety in the educational and social environment, as well as their families' welfare. It seems, therefore, that the importance of providing habilitation support has been widely recognised in the literature, thus future research and practice should focus on the development of more person-centered approaches that will ensure the independent living of individuals with visual impairments and the prosperity of their families.

Declaration of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by (name of the charity) and the National Lottery Community Fund [grant number 0010316453].

Acknowledgements

We are particularly thankful to all the families and staff members who participated in this research project and responded to our call for participants.

References

- Augestad, L. B. (2017). Mental health among children and young adults with visual impairments: A systematic review. *Journal of visual impairment & blindness*, 111(5), 411- 425. <https://doi.org/10.1177%2F0145482X1711100503>
- Bartoli, G., Bulgarelli, D. & Molina, P. (2019). Theory of Mind development in children with visual impairment: The contribution of the adapted comprehensive test ToM storybooks. *Journal of Autism and Developmental Disorders*, 49(9), 3494-3503. <https://doi.org/10.1007/s10803-019-04064-3>
- Bodaghi, N. B., Cheong, L. S. & Zainab, A. N. (2016). Librarians empathy: Visually impaired students' experiences towards inclusion and sense of belonging in an academic library. *The Journal of Academic Librarianship*, 42, 87-96. <https://doi-org.ezproxy.kingston.ac.uk/10.1016/j.acalib.2015.11.003>
- Bogart, K. R. (2014). The role of disability self-concept in adaptation to congenital or acquired disability. *Rehabilitation Psychology*, 59(1), 107-115. <https://psycnet.apa.org/doi/10.1037/a0035800>

- Brambring, M., & Asbrock, D. (2010). Validity of false belief tasks in blind children. *Journal of Autism and Developmental Disorders*, 40(12), 1471–1484. <https://doi.org/10.1007/s10803-010-1002-2>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-201.
- Celeste, M. (2006). Play behaviors and social interactions of a child who is blind: In theory and practice. *Journal of Visual Impairment and Blindness*, 100(2), 75- 90. <https://doi.org/10.1177%2F0145482X0610000203>
- Cimarolli, V. R., Boerner, K. & Wang, S. (2006). Life goals in vision rehabilitation: Are they addressed and how? *Journal of Visual Impairment & Blindness*, 100(6), 343-352. <https://doi.org/10.1177%2F0145482X0610000605>
- Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A. & Sheikh, A. (2011). The case study approach. *BMC Medical Research Methodology volume*, 11(100). <https://doi.org/10.1186/1471-2288-11-100>
- Crudden, A. (2012). Transition to employment for students with visual impairments: components for success. *Journal of Visual Impairment & Blindness*, 106(7), 389-399. <https://doi.org/10.1177%2F0145482X1210600702>
- Datta, P., & Palmer, C. (2015). Insights into the support services for students with vision impairment. *Australasian Journal of Special Education*, 39(2), 143-158. <https://doi.org/10.1017/jse.2015.8>
- De Verdier, K. (2016). Inclusion in and out of the classroom: A longitudinal study with visual impairments in inclusive education. *British Journal of Visual Impairment*, 34(2), 130-140. <https://doi.org/10.1177%2F026461961562542>

- Elsman, E. B. M., Al Baaj, M., Van Rens, G. H. M. B., Sijbrandi, W., Van den Broek, E. G. C., Van der Aa, H. P. A., Schakel, W., Heymans, M. W., de Vries, R., Vervloed, M. P. J., Steenbergen, B. & Van Nispen, R. M. A. (2019). Interventions to improve functioning, participation, and quality of life in children with visual impairment: A systematic review. *Survey of Ophthalmology*, 64(4), 512-557. <https://doi.org/10.1016/j.survophthal.2019.01.010>
- Green, S., Pring, L., Swettenham, J. (2004). An investigation of first-order false belief understanding of children with congenital profound visual impairment. *British Journal of Developmental Psychology*, 22(1), 1-17. <https://doi.org/10.1348/026151004772901087>
- Harter, S. (2012). *Self-perception profile for adolescents: Manual and questionnaires*. Denver, CO: Department of Developmental Psychology, University of Denver. <https://portfolio.du.edu/SusanHarter/page/44210>
- Horton, J., Macve, R. and Struyven, G. (2004). Qualitative research: Experiences in using semi-Structured interviews. *The Real Life Guide to Accounting Research*, 339–357. <https://doi-org/10.1016/B978-008043972-3/50022-0>
- Jessup, G. Bundy, A. C., Broom, A. & Hancock, N. (2017). The social experiences of high school students with visual impairments. *Journal of Visual Impairment & Blindness*, 111(1), 5- 19. <https://doi.org/10.1177%2F0145482X1711100102>
- Khadka, J. R. B., Margrain, T. H., Woodhouse, M. J. & Davies, N. (2012). Listening to voices of children with a visual impairment: A focus group study. *British Journal of Visual Impairment*, 30(3), 182- 196. <https://doi.org/10.1177%2F0264619612453105>

- Low, W. Y., Cao M., De Vos, J. & Hickman, R. (2020). The journey experience of visually impaired people on public transport in London. *Transport Policy*, 97, 137-148. <https://doi-org.ezproxy.kingston.ac.uk/10.1016/j.tranpol.2020.07.018>
- Messenger, C. & Palmer, R. (2021, July/August). Visual impairment – habilitation study. *SEN*, 113, 68-69. <https://issuu.com/senmagazine/docs/sen113>
- Patalay, P., Deighton, J., Fonagy, P., & Wolpert, M. (2015). Equivalence of paper and computer formats of a child self-report mental health measure. *European Journal of Psychological Assessment*, 31(1), 54–61. <https://doi.org/10.1027/1015-5759/a000206>
- Patalay, P., Deighton, J., Fonagy, P., & Wolpert, M. (2015). Equivalence of paper and computer formats of a child self-report mental health measure. *European Journal of Psychological Assessment*, 31(1), 54–61. <https://doi.org/10.1027/1015-5759/a000206>
- Percy-Smith, L., Tønning, T. L., Josvassen, J. L., Mikkelsen, J. H., Nissen, L., Dieleman, E., Hallstrøm, M. & Cayé-Thomasen, P. (2017). Auditory verbal habilitation is associated with improved outcome for children with cochlear implant, *Cochlear Implants International*, 19(1), 1-8. <https://doi.org/10.1080/14670100.2017.1389020>
- Peterson, C. C. & Peterson, J. L., Webb, J. (2000). Factors influencing the development of a theory of mind in blind children. *British Journal of Developmental Psychology*, 18(3), 431-447. <https://doi.org/10.1348/026151000165788>
- Pijnacker, J., Vervloed, M., P., J. & Steenbergen, B., (2012). Pragmatic Abilities in Children with Congenital Visual Impairment: An Exploration of Non-Literal Language and Advanced Theory of Mind Understanding. *Journal of Autism and Developmental Disorders*, 42(11), 2440-2449. <https://doi.org/10.1007/s10803-012-1500-5>

- Pinquart, M. & Pfeiffer, J. P. (2014). Change in psychological problems of adolescents with and without visual impairment. *European Child & Adolescent Psychiatry*, 23(7), 571-578. <https://doi.org/10.1007/s00787-013-0482-y>
- Rabeee, P., Bernard, S., Baxter, K. & Parker, G. (2016). Community-based vision rehabilitation provision in England. *British Journal of Visual Impairment*, 34(3), 248-261. <https://doi.org/10.1177%2F0264619616658313>
- Rosenblum, L. P. (2000). Perceptions of the impact of visual impairment on the lives of adolescents. *Journal of Visual Impairment & Blindness*, 94(7), 434-445. <https://doi.org/10.1177%2F0145482X0009400703>
- Southwell, P. (2012). The psycho-social challenge of adapting to visual impairment. *British Journal of Visual Impairment*, 30(2), 108-114. <https://doi.org/10.1177%2F0264619612441766>
- Stake, R. (1995). *The art of case study research*. London: Sage Publications Ltd.
- Thurston, M. (2014). “They Think They Know What’s Best for Me”: An Interpretative Phenomenological Analysis of the Experience of Inclusion and Support in High School for Vision-impaired Students with Albinism. *International Journal of Disability, Development & Education*, 61(2), 108-118. <https://doi.org/10.1080/1034912X.2014.905054>
- WHO. (2014). *WHO global disability action plan 2014-2021: Better health for all people with disability*. WHO. <https://www.who.int/disabilities/actionplan/en/>
- Worth, N. (2013). Making friends and fitting in: A social relational understanding of disability at school. *Social & Cultural Geography*, 14(1), 103- 123. <https://doi.org/10.1080/14649365.2012.735693>

Interview Schedule for children

1. How much do you feel that your life has been affected by (name of the charity)?

1 – not at all

2 – a little

3 – somewhat

4 – quite a lot

5 – a lot

2. What is the best thing about (name of the charity) and what they do for you?

3. What is your name?

4. What is your gender?

5. How old are you?

6. Are you severely sight impaired (blind) or sight impaired (partially sighted)?

7. Do you have any other additional special educational needs? If yes, what additional special educational needs do you have?

8. How many years have you been receiving help and support from (name of the charity)?

9. Can you describe the help and support that you are receiving from (name of the charity)?

10. How many times per week/month do you receiving support from them (refer to each type of support separately)?

11. How does the support you receive affect your school life?

a) How does the support you receive affect your school grades? Can you give me some examples?

b) How does the support you receive affect your participation in classroom activities? Can you give me some examples?

c) How does the support you receive affect your ability to complete school tasks alone, without receiving any help from a teacher or teaching assistant, in the classroom?

d) How does the support you receive affect your ability to move alone in the school environment, without receiving help from a teacher or teaching assistant? Can you give me some examples?

e) How does the support you receive affect your participation in activities which take place during play time or lunch time in school? Can you give me some examples?

f) Is there any activity that you have accomplished in school and (name of the charity) has helped you with it? Can you, please, explain this?

12. How does the support you receive affect your home life?

a) How does the support you receive affect your ability to complete home tasks alone, for instance making your bed or setting the table, without receiving any help from your parents?

b) How does the support you receive affect your ability to move alone in your house, without receiving help from your parents or other family members (for example, siblings)? Can you give me some examples?

c) Is there any particular activity that you have accomplished at home and (name of the charity) has helped you with it? Can you, please, explain this? – relationships with family members?

13. How does the support you receive affect your daily life in general?

a) How does the support you receive affect your ability to move alone outside your house without receiving help from your parents, teachers or other adults? Can you give me some examples?

b) How does the support you receive affect your participation in the same activities with your friends (for instance going to the park, playing sports, eating together)? Can you give me some examples?

c) Is there any particular activity that you have accomplished and (name of the charity) has helped you with it? Can you please explain this?

d) How does the support you receive make you feel in general? Can you give me some examples?

14. Would you like to continue receiving support from them? Why or why not?

15. If yes, what type of support would you like to continue receiving from (name of the charity) and why?

16. Is there anything that (name of the charity) has taught you or helped you with that other people haven't?

17. Do you have any suggestions for improvement on their services? If yes, can you explain these further?

Interview Schedule for adolescents

1. How much do you feel that your life has been affected by the services and support that you receive from (name of the charity)?

1 – not at all

2 – a little

3 – somewhat

4 – quite a lot

5 – a lot

2. What is the best thing about (name of the charity) and what they do for you?

3. What is your name?

4. What is your gender?

5. How would you describe your ethnic origins?

6. How old are you?

7. Are you sight impaired (partially sighted) or severely sight impaired (blind)?

8. Do you have any other additional special educational needs? If yes, what additional special educational needs do you have?

9. How many years have you been receiving support from (name of the charity)?

10. What type of support do you receive from them (rehabilitation services, recreational opportunities, educational resources and employment programme)? Can you describe the support that you receive from (name of the charity)?

11. How many times per week/month do you receive support from them (refer to each type of support separately)?

12. How does the support you receive affect your school life?

a) How does the support you receive affect your school grades? Can you give me some examples?

b) How does the support you receive affect your classroom participation? Can you give me some examples?

c) How does the support you receive affect your relationships with your classmates? Can you give me some examples?

d) How does the support you receive affect your relationships with your teachers/teaching assistants? Can you give me some examples?

e) How does the support you receive affect your independence? Can you give me some examples?

f) How does the support you receive affect your personal safety? Can you give me some examples?

13. How does the support you receive affect your home life?

a) How does the support you receive affect your relationships with your close family (parents and siblings)? Can you give me some examples?

b) How does the support you receive affect your relationships with other family members? Can you give me some examples?

c) How does the support you receive affect your independence? Can you give me some examples?

d) How the support you receive affect your personal safety? Can you give me some examples?

14. How does the support you receive affect your daily life in general?

a) How does the support you receive affect your relationships with your friends who do not go to the same school as you? Can you give me some examples?

b) How does the support you receive affect your independence in general? Can you give me some examples which show that this support has helped you achieve better independence in both long and short term?

c) How does the support you receive affect your personal safety in general? Can you give me some examples?

d) How does the support you receive make you feel in general? Can you give me some examples?

15. Would you like to continue receiving support from (name of the charity)? Why or why not?

16. If yes, what type of support would you like to continue receiving from (name of the charity) and why?

17. Is there anything that (name of the charity) has taught you or helped you with that other people haven't?

18. Do you have any suggestions for improvement on their services? If yes, can you explain these further?

Interview Schedule for parents

1. How much do you feel that your lives have been affected by the services and support that you and your child receive from (name of the charity)?

1 – not at all

2 – a little

3 – somewhat

4 – quite a lot

5 – a lot

2. What is the best thing about (name of the charity) and what they do for you?

3. What is your child's name?

4. What is your child's gender?

5. How old is your child?

6. Is your child sight impaired (partially sighted) or severely sight impaired (blind)?

7. Does your child have any other additional special educational needs? If yes, what additional special educational needs does your child have?

8. How many years is your child receiving support from (name of the charity)?

9. What type of support does your child receive from them (rehabilitation services, recreational opportunities, educational resources and employment programme)?

a) Does your child have access to rehabilitation services? Can you describe these rehabilitation services?

b) Does your child have access to recreational opportunities? Can you describe these recreational opportunities?

c) Does your child have access to educational resources? Can you describe these educational resources?

10. How many times per week/month does your child receive support from them (refer to each type of support separately)?

a) How many times per week/month does your child have access to rehabilitation services?

b) How many times per week/month does your child have access to recreational opportunities?

c) How many times per week/month does your child have access to educational resources?

11. How does the support you receive affect your child's school life?

- a) How does the support your child receives affect their school grades? Can you give me some examples?
- b) How does the support your child receives affect their classroom participation? Can you give me some examples?
- c) How does the support your child receives affect their relationships with their classmates? Can you give me some examples?
- d) How does the support your child receives affect their relationships with their teachers/teaching assistants? Can you give me some examples?
- e) How does the support your child receives affect their independence? Can you give me some examples?
- f) How does the support your child receives affect their personal safety? Can you give me some examples?

12. How does the support you receive affect their home life?

- a) How does the support your child receives affect their relationships with you and other close family members (siblings)? Can you give me some examples?
- b) How does the support your child receives affect their relationships with other family members? Can you give me some examples?
- c) How does the support your child receives affect their independence? Can you give me some examples?

d) How does the support your child receives affect their personal safety? Can you give me some examples?

13. How does the support you receive affect their daily life in general?

a) How does the support your child receives affect their relationships with their friends who do not go to the same school as them? Can you give me some examples?

b) How does the support your child receives affect their independence in general? Can you give me some examples which show that this support has helped children and adolescents with visual impairments achieve better independence in both long and short term?

c) How does the support your child receives affect their personal safety in general? Can you give me some examples?

d) How does the support your child receives affect their self-esteem and well-being in general? Can you give me some examples?

14. Do you, as a parent of a child with visual impairment, receive support from (name of the charity)? What type of support do you receive?

a) Are they teaching you any academic and daily life skills in order to better support your child? Can you give me some examples?

b) Are they providing you with emotional support? Can you give me some examples?

c) Are they providing you with any other type of support which has not been mentioned? Can you give me some examples?

15. Would you and your child like to continue receiving support from (name of the charity)?

Why or why not?

16. If yes, what type of support would you like to continue receiving from (name of the charity)

and why?

17. Is there anything that (name of the charity) has taught you or helped you and/or your child

with that other people haven't?

18. Do you have any suggestions for improvement on their services? If yes, can you explain

these further?

Interview Schedule for the professional staff

1. What is your name?

2. What is your gender?

3. What is your job title?

4. How many days/hours are you working per week?

5. By the end of this year (2020), how many years will you have been working for (name of the charity) in total? If that is less than a year, please indicate the time in months.

6. By the end of this year (2020), how many years in total will you have been working with individuals (children, adolescents and adults) with visual impairments? If that is less than a year, please indicate the time in months.

7. By the end of this year (2020), how many years in total will you have been working with children and adolescents with visual impairments? If that is less than a year, please indicate the time in months.

8. How many children and adolescents with visual impairments are you currently supporting?

9. What type of support do you provide to children with visual impairments? Can you give me some examples?

a) Are you giving them access to rehabilitation services in order to teach daily life skills? Can you give me some examples?

b) Are you giving them access to recreational opportunities? Can you give me some examples?

c) Are you giving them access to educational resources? Can you give me some examples?

10. What type of support do you provide to adolescents with visual impairments? Can you give me some examples?

a) Are you giving them access to rehabilitation services in order to teach daily life skills? Can you give me some examples?

b) Are you giving them access to recreational opportunities? Can you give me some examples?

c) Are you giving them access to educational resources? Can you give me some examples?

11. What type of support do you provide to parents who have children with visual impairments? Can you give me some examples?

a) Are you teaching them academic and daily life skills in order to better support their children? Can you give me some examples?

b) Are you providing them with emotional support? Can you give me some examples?

a) Are you providing parents with any other type of support which has not been mentioned? Can you give me some examples?

12. How does the support you provide affect children and adolescents' school life?

a) How does this support affect their school grades? Can you give me some examples?

b) How does this support affect their classroom participation? Can you give me some examples?

c) How does this support affect their relationships with their classmates? Can you give me some examples?

d) How does this support affect their relationships with their teachers/teaching assistants? Can you give me some examples?

e) How does this support affect their independence? Can you give me some examples?

f) How does this support affect their personal safety? Can you give me some examples?

13. How does the support you provide affects children and adolescents' home life?

a) How does this support affect their relationships with their close family members (parents and siblings)? Can you give me some examples?

b) How does this support affect their relationships with other family members? Can you give me some examples?

c) How does this support affect their independence? Can you give me some examples?

d) How does this support affect their personal safety? Can you give me some examples?

14. How does the support you provide affects children and adolescents' daily life in general?

a) How does this support affect their relationships with their friends who do not go to the same school as them? Can you give me some examples?

b) How does this support affect their independence in general? Can you give me some examples which show that your support has helped children and adolescents with visual impairments achieve better independence in both long and short term?

c) How does this support affect their personal safety in general? Can you give me some examples?

d) How does this support affect their self-esteem in general (school and daily life)? Can you give me some examples?

15. Would you like to share any particular good practice that you are using in your work and has a positive impact on children and adolescents with visual impairments lives (daily, academic and social)? Could you give me some examples?

16. Do you have any suggestions for improvement on (name of the charity) services? If yes, can you explain these further?

ⁱ Although these two terms have been used interchangeably, habilitation services mainly address the needs of children and adolescents born without vision or who have lost their vision before they had the opportunity to gain a clear understanding of the sighted world (Percy-Smith et al., 2017), whereas rehabilitation services address the needs of adults who have lost their vision once they have gained the appropriate knowledge about different concepts of the sighted world (e.g., orientation and mobility; Rabiee et al., 2016).