“A responsibility of families, a responsibility of everyone.”

Family Advocacy for Disability Inclusion in Latin America, North America and Europe/Eurasia

2023 Social Connectedness Fellowship Program
in Partnership with Special Olympics International

By Paula Camino & Margaret Turley
Social Connectedness Fellow, 2023 / Special Olympics Athlete

Special Olympics

SAMUEL CENTRE
FOR SOCIAL
CONNECTEDNESS

TABLE OF CONTENTS

EXECUTIVE SUMMARY

This report explores family advocacy for inclusive education of children with disabilities. The study centered around three research questions exploring the landscape of family advocacy, the experiences of families involved in such advocacy, and the wider implications of community and belonging in this context.

The project adopted an inclusive research methodology, through the close collaboration of a researcher with a disability and a researcher without a disability. The project also adopted a mixed methods approach, combining literature review with a survey and four semi-structured interviews.

Initial findings spotlight that families conduct individual advocacy to bridge the gaps between the right to inclusive education and the realities they face. Their advocacy isn't a one-time affair, but rather relies on building relationships with schools, learning support assistants and other parents. This helps them overcome a series of systemic barriers in their advocacy. Initial findings show that advocacy can have positive outcomes, as it leads not only to better education for children with disabilities, but also a stronger sense of belonging to the disability community.

The research provides a series of recommendations to encourage further research, such as conducting focused inter-sectional research. It also provides actionable steps for organizations interested in fostering family advocacy for inclusive education, such as supporting existing advocacy programs and fostering parent-athlete networks.

GLOSSARY

Convention on the Rights of People with Disabilities (CRPD): A United Nations treaty ratified by 177 countries, which came into force in 2006. The CRPD lays out State's obligations to recognize and realize the rights of people with disabilities.

Easy-to-Read: A form of communication designed to include people with intellectual disabilities. It uses simple phrases in active voice, combined with large scale text and images to convey clear messages.

Inclusive education: Education that allows persons with disabilities to receive quality education in the general education system, including the provision of reasonable accommodations.

Neurodiversity: The different ways in which people's brain's work. In this context, we use the word to distinguish neurodiverse people from "neurotypical" people – those whose brains have average functioning.

Person with disabilities: "Those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (CRPD Article 1).

Reasonable accommodation: "Necessary and appropriate modification and accommodations not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms" (CRPD Article 2)

Universal design: "The design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed." (CRPD Article 2)

Special Olympics International (SOI): "Special Olympics is a global movement of people creating a new world of inclusion and community, where every single person is accepted and welcomed, regardless of ability or disability" (Special Olympics International website)

Samuel Centre for Social Connectedness (SCSC): "The Samuel Centre for Social Connectedness (SCSC) is a 'think-and-do tank' that supports individuals and communities around the world in overcoming social isolation and realizing the right to belong." (Samuel Centre for Social Connectedness website)

1. INTRODUCTION

Families have long been central to ensuring the rights of people with disabilities are respected and promoted. Special Olympics International (SOI) recognizes the significance of family engagement. Building on successful initiatives like the Family Support Network, sibling engagement,[1] and the Global Leadership Coalition,[2] SOI is developing a global strategy to empower family members as advocates for inclusive sports and education.

This research serves as the starting point for this strategy, providing SOI with insights into family advocacy's current landscape, impact, outcomes, and best practices. Note that this study is preliminary and will be followed by a more comprehensive project with an institutional partner.

1.1. A Note on Inclusive Research

A standout element of this project is SOI and the Samuel Centre for Social Connectedness' (SCSC) commitment to participatory research, as evidenced in the participation of a non-disabled researcher and a researcher with a disability in every iteration of this Fellowship program,[3] as well the requirement for Fellows to conduct a Community Engagement Initiative.[4]

---

[1] Special Olympics, "Resources. Sibling Engagement," https://resources.specialolympics.org/community-building/families/sibling-engagement

[2] Special Olympics, "Global Leadership Coalition," https://www.specialolympics.org/special-olympics-global-leadership-coalition-for-inclusion

[3] See for example: Olivia Najdovski, *Intellectual Disability and Sibling Relationships: Perspectives of Individuals with ID* (n.p., Samuel Centre for Social Connectedness, 2020); Adriana Vanos, *Social Connectedness, Self-Determination & Health at Home: An Examination of Special Olympics Athletes and Their Families' Experiences During the COVID-19 Pandemic* (n.p., Samuel Centre for Social Connectedness, 2021); Aida Mohajeri, *Supporting Families of Special Olympics Athletes during COVID-19: An Inclusive Research Project* (n.p., Samuel Centre for Social Connectedness, 2021).

[4] "Community Engagement Initiatives. Fellows are also tasked with conducting community engagement initiatives, where they engage creatively with the communities their research is designed to serve." Samuel Centre for Social Connectedness. Fellowship program. Summer 2021.

This research was carried out by co-researchers Paula Camino, a Samuel Centre Research Fellow, and Margaret Turley, a Special Olympics athlete and researcher. Because Margaret is a high-level athlete, she was set to compete at the SOI World Games in Berlin in June 2023, and joined the project in early July.

Participatory research prioritizes the involvement of the researched groups in the research process.[5] There are multiple approaches to it,[6] which can be thought of as a continuum:[7]

In this project's context, inclusive research (and not methods further along the continuum), was chosen due to time, financial constraints, and researcher expertise. It mandates substantial participation throughout all stages of the research process: design, collection, analysis, and output creation.[8]

See examples here: https://www.socialconnectedness.org/wp-content/uploads/2021/09/CEIs-2021.pdf

[5] Tom Shakespeare, *Disability: The Basics* (Milton: Routledge, 2018), 159; 1. Janice Ollerton, “IPAR, an Inclusive Disability Research Methodology with Accessible Analytical Tools,” *International Practice Development Journal* 2, no. 2 (November 2012), 4-5. https://doi.org/https://www.fons.org/library/journal/volume2-issue2/article3; Iva Strnadová and Jan Walmsley. “Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice?” *J Appl Res Intellect Disabil* 31 (2017): 133-4.

[6] For a detailed exploration of the complexities of collaborative research with persons with disabilities, see: Harriet L Radermacher, *Participatory action research with people with disabilities: Exploring experiences of participation.* PhD diss. (Victoria University, 2006)

[7] Adapted from multiple sources, including Harriet L Radermacher, *Participatory action research* and conversations with professors Renata Bregaglio and Andrea Wakeham.

[8] Shakespeare, *Disability*, 161; Ollerton, “IPAR”, 7; Strnadová & Walmsley, “Peer-reviewed articles”, 133; Melanie Nind. "The practical wisdom of inclusive research" *Qualitative Research*, 17 (2017): 278-9; Iva Strnadová, Leanne Dowse and Benjamin García-Lee, *Doing Research Inclusively: Co-Production in Action* (Sydney: University of New South Wales Disability Innovation Institute, 2022), 11, 19-21, 23-4; Chicago Beyond, “Why am I always being researched? A guidebook for community organizations, researchers and funders to help us get from insufficient understanding to more authentic truth,” (Chicago: Chicago Beyond, 2019), https://chicagobeyond.org/researchequity/.

Inclusive research recognizes the subjects (people with disabilities) as active contributors;[9] not as people with intellectual limitations that prevent them from engaging with research.[10] This aligns with the founding tenet of the social model of disability and the Convention on the Rights of Persons with Disabilities (CRPD): “Nothing about us without us.”[11]

Inclusive research is especially important in a project such as this one with potential programmatic implications. CRPD Articles 4.3[12] and 29[13] enshrine the right of people with disabilities to be consulted and involved in the decisions that affect them. SOI's research projects and Global Leadership Coalition reflect this practice.[14]

It would be an oversight not to mention that inclusive research has inherent access and power problems. It’s important to recognize that there are power relations in any team of co-researchers, which are exacerbated by the presence of a perceived ‘expert’ without a disability.[15]

---

[9] Colin Barnes and Geof Mercer, eds., *Doing Disability Research* (Leeds: Disability Press, 1997), 5.

[10] Jan Walmsley, “Involving Users with Learning Difficulties in Health Improvement: Lessons from Inclusive Learning Disability Research,” *Nursing Inquiry* 11, no. 1 (March 2004): 54–64, https://doi.org/10.1111/j.1440-1800.2004.00197.x., 54; Ollerton, “IPAR”, 7.

[11] Barnes and Mercer, *Doing Disability Research,* 5.

[12] *“Article 4 – General obligations*
(...) 3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.”

[13] *“Article 29 – Participation in political and public life*
States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake:
a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia,
(...) b) To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs.”

[14] Special Olympics. Global Leadership Coalition.

[15] Michelle Brooks and Stephanie Davies, “Pathways to Participatory Research in Developing a Tool to Measure Feelings,” *British Journal of Learning Disabilities* 36, no. 2 (October 17, 2007): 128–33; Walmsley, “Involving users”, 54.

In this case, Margaret's perception of my experience and information access might have positioned me as the project leader. To counteract this, we established measures. Personal Zoom calls fostered open communication. We reshaped roles, underscoring equality. Crucially, we extensively discussed research as praxis, sharing experiences and thinking about accessibility.

In those discussions, we agreed on three fundamental points that have been the guiding principles of this project: (i) Research instruments need to be accessible, (ii) research practices need to be adaptable to optimize autonomy, and (iii) outputs need to balance academic integrity and accessibility.

Our strategies align with those proposed by other authors to make research projects genuinely inclusive, as opposed to merely tokenistic.[16] To fulfill our principles, we made sure that:

(i) Our survey, interview guide and informed consent form were written in easy read format.

(ii) Each researcher pursued independent tasks, fostering collaborative findings through weekly meetings. Margaret's preference for oral communication shaped our interactions, ensuring her input was accurately captured.

(iii) Our research output takes an unconventional form–easy-to-read PowerPoint presentations–because a traditional report has barriers to access for people with disabilities. While sacrificing some nuance, this approach widens our audience, encompassing SOI and SCSC staff, athletes, and family members.

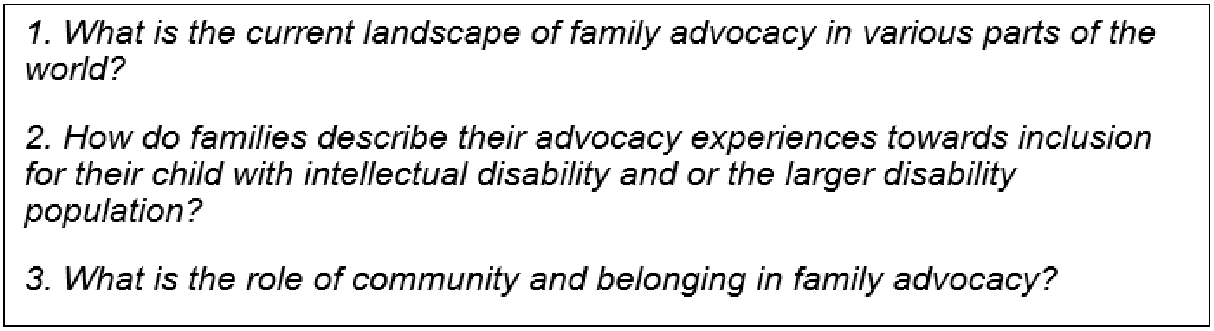
---

[16] Ollerton, "IPAR", 7; Strnadová & Walmsley, "Peer-reviewed articles"; Strnadová et. al, *Doing Research Inclusively*; Chicago Beyond, *Why am I always being researched?;* Brooks and Davies, "Pathways"; Barnes and Geoff, *Doing Disability Research;* Christine Bigby, Patsie Frawley, and Paul Ramcharan, "Conceptualizing Inclusive Research with People with Intellectual Disability," *Journal of Applied Research in Intellectual Disabilities* 27, no. 1 (December 4, 2013): 3–12, https://doi.org/10.1111/jar.12083.

Given our time and abilities, we felt this was the best compromise to ensure an accessible output.

1.2. Methodology

The methodology of this project was collaboratively designed by the co-researchers and SOI. SOI initially posed three overarching research questions:



1. What is the current landscape of family advocacy in various parts of the world?

2. How do families describe their advocacy experiences towards inclusion for their child with intellectual disability and or the larger disability population?

3. What is the role of community and belonging in family advocacy?

Based on the above questions, Paula created a mixed methods research plan with three key elements: literature review, qualitative inquiry, and quantitative inquiry. This method allowed a balancing act between inclusive research and the real limitation that the co-researcher would join the project at the halfway point.

In the project's initial two months, Paula immersed herself in the SOI landscape, conducted a literature review on family advocacy in education, and specifically focused on reports that are readily accessible. This preparation occurred before Margaret joined, aiming to bridge the accessibility gap in academic literature. Notably, we only found two reports in easy-to-read format addressing advocacy for inclusive education.[17] We thus included other easy to read documents around each area to complement the research.[18]

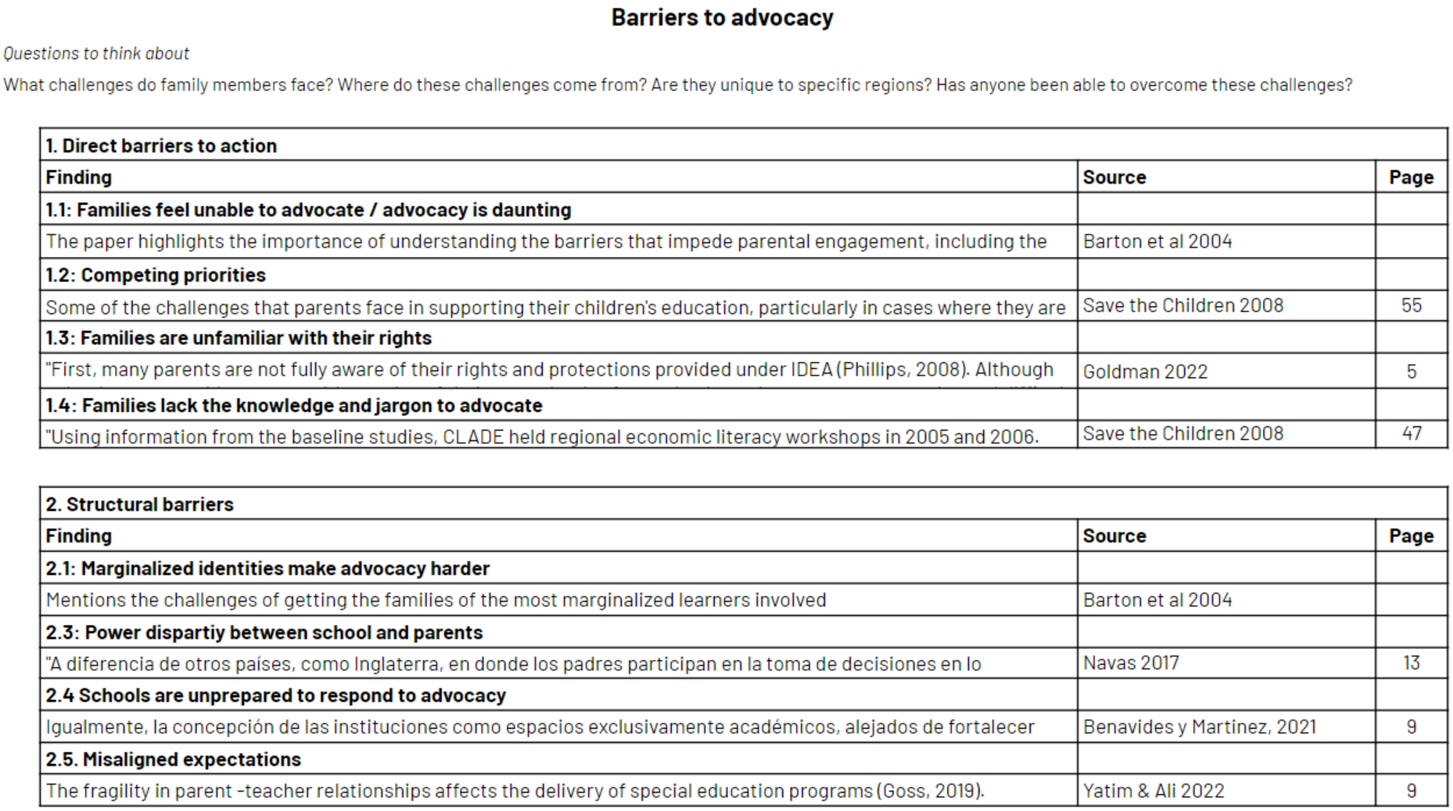
---

[17] Inclusion Europe, *Why we care about education. Inclusion Europe position paper on inclusive education*, (n.p, Inclusion Europe: 2021); Karen Fisher and Sandra Gendera, *Study about Family Advocacy*. (Sydney, UNSW Social Policy Research Centre: 2022).

[18] Inclusion Ireland. *Guide to Advocacy*. (Dublin, Inclusion Ireland: 2011); United Nations Committee on the Rights of People with Disabilities. *General Comment 7: How to work together with organisations of persons with disabilities. Easy Read*. (Geneva, United Nations: 2018); Disabled Persons Assembly, Imagine Better, Waikato University. *Spaces of Belonging. A report about disabled people's experiences of*

Paula employed an exploratory approach for the literature review, sourcing English and Spanish papers from 2006 onward through academic databases, Google Scholar, and EBSCO host.[19] To enrich the database, artificial intelligence tools like Connected Papers and Scite were employed. Since valuable disability advocacy knowledge resides in NGO reports, a conventional Google search was also conducted.

Roughly 100 texts were gathered, annotated, and filtered, with key quotes consolidated into six matrices covering diverse aspects. The structure of the matrices is included in the Appendix to this document. A sample matrix looks like this:



Barriers to advocacy

Questions to think about

What challenges do family members face? Where do these challenges come from? Are they unique to specific regions? Has anyone been able to overcome these challenges?

1. Direct barriers to action		
Finding	**Source**	**Page**
1.1: Families feel unable to advocate / advocacy is daunting		
The paper highlights the importance of understanding the barriers that impede parental engagement, including the	Barton et al 2004	
1.2: Competing priorities		
Some of the challenges that parents face in supporting their children's education, particularly in cases where they are	Save the Children 2008	55
1.3: Families are unfamiliar with their rights		
"First, many parents are not fully aware of their rights and protections provided under IDEA (Phillips, 2008). Although	Goldman 2022	5
1.4: Families lack the knowledge and jargon to advocate		
"Using information from the baseline studies, CLADE held regional economic literacy workshops in 2005 and 2006.	Save the Children 2008	47

2. Structural barriers		
Finding	**Source**	**Page**
2.1: Marginalized identities make advocacy harder		
Mentions the challenges of getting the families of the most marginalized learners involved	Barton et al 2004	
2.3: Power dispartiy between school and parents		
"A diferencia de otros países, como Inglaterra, en donde los padres participan en la toma de decisiones en lo	Navas 2017	13
2.4 Schools are unprepared to respond to advocacy		
Igualmente, la concepción de las instituciones como espacios exclusivamente académicos, alejados de fortalecer	Benavides y Martinez, 2021	9
2.5. Misaligned expectations		
The fragility in parent -teacher relationships affects the delivery of special education programs (Goss, 2019).	Yatim & Ali 2022	9

---

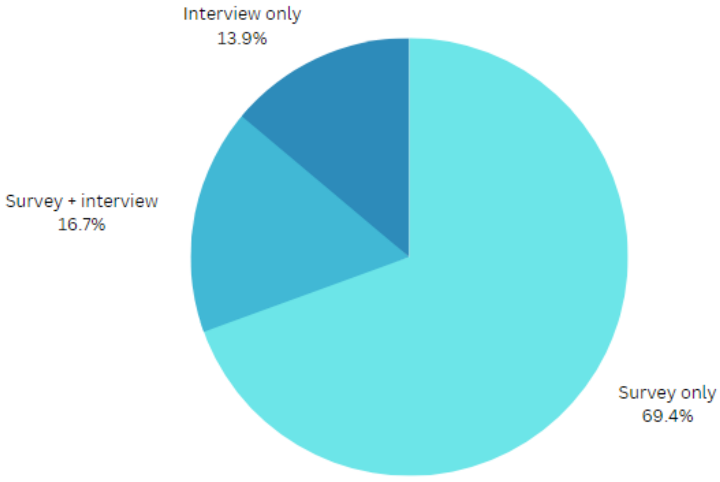
belonging, place and community. (n.p., Imagine Better, Waikato University and Disabled Persons Assembly: 2019); Disabled People Partnership for Inclusive Education. *Advocacy and Training Toolkit* (n.p, Disabled People Partnership for Inclusive Education: 2011).

[19] 2006 is used as a cut-off date for literature review as this was the year the CRPD was ratified. This ensures that the papers reviewed respond to the social model of disability enshrined in the CRPD, as well as the specific definition of inclusive education used in the CRPD. Prior to CRPD, there was no consensus on what "inclusive education" meant.
Some texts written prior to 2006 have been included, as they provide useful information on the work NGOs have done to further inclusive education. Where that is the case, it will be appropriately noted.

Though the literature review extended beyond its initial timeline due to text volume, the subsequent collaboration with Margaret led to a mixed methods strategy. This strategy contrasted literature findings with real experiences of SOI families across three regions.

For both quantitative and qualitative approaches, a survey and a semi-structured interview guide were developed. Margaret's lived experience with inclusive education refined these tools. The survey comprised 18 questions, with pathways depending on respondents' experiences. The semi-structured interview guide contained 17 questions, further exploring survey topics.

Survey dissemination occurred via Google Form and call-to-action posters were sent to SOI Regional Coordinators in North America, South America, and Europe/Eurasia region. Respondents were able to choose to respond to the survey and/or participate in a video. Responses totaled 36, with 17 parents and 1 niece from Latin America responding, as well as 18 people from Europe and North America.



Due to the lack of responses from North America, interviews focused on Latin America and Europe. The inclusion criteria for interviewees were that they were family members to a person with a disability, based out of the target regions of the study, had previous experience with advocacy for education, and were familiar with Zoom. We selected five interviewees on a first come, first served basis. One person did not show up to the designated interview time and did not reply to our attempts to reschedule the interview. We provided an interview stipend of 40 CAD per interviewee in recognition of their time, effort and any potential barriers to participation like internet usage, childcare, etc. Interestingly, some interviewees asked that this be donated to a charitable organization.

1.3. Limitations

Four main limitations are evident in this study: time constraints, research team composition, quantitative inquiry design, and literature gaps. While efforts have been made to mitigate these limitations, it's essential to acknowledge that this is an initial exploratory report, and these issues can be addressed in future research:

(i) **Time:** This research was carried out over a period of 3.5 months. Due to the wide scope of the research questions, the study cannot fully respond to these.

(ii) **Co-researchers:** Inclusivity was compromised due to a co-researcher's late inclusion, leading to an initial design crafted solely by individuals without disabilities. Geographic limitations restricted our research to three regions, one of which is not included in the initial stages of the family leadership program.[20]

---

[20] "The goals of the overall family engagement strategy for Special Olympics is to mobilize and train family members to advocate to governments and global development organizations on the importance of inclusive education. Targeted areas for this work include the following regions and countries: Africa, Asia Pacific, East Asia, Europe Eurasia, Middle East North Africa, North America". Samuel Centre for Social Connectedness Fellowship Program. Project proposal: Family Advocacy for Disability Inclusion.

(iii) **Quantitative inquiry design:** The survey failed to recollect socio-demographic data from participants. Given that previous research has identified differences in advocacy based on socio-economic status and race,[21] it would have been useful to include this.

(iv) **Literature gaps:** There is scarce academic literature on family-led advocacy for inclusive education,[22] with an overwhelming majority of research being from the United States.[23] Further details are explored in section 2.3.1.

1.4. Outputs

The project's outputs are tailored to meet the needs of two distinct audiences: (1) SCSC and SOI require a comprehensive research report on family advocacy that can be used for program design, and (2) Family members and athletes, in line with inclusive design principles, need easily understandable key findings.

To address these needs, we will present our research via PowerPoint presentations housed on a Google Site. This platform ensures accessibility for diverse audiences, accommodating disabilities with features like high contrast text and larger

---

[21] This has been registered mostly in the US. For further detail see: Meghan M. Burke, Kristina Rios, Marlene Garcia, and Sandra Magaña. “Examining Differences in Empowerment, Special Education Knowledge, and Family–School Partnerships among Latino and White Families of Children with Autism Spectrum Disorder.” *International Journal of Developmental Disabilities* 67, 1, 2020: 75–81; Goldman, Samantha E; “Special Education Advocacy for Families of Students with Intellectual and Developmental Disabilities: Current Trends and Future Directions.” *International Review of Research in Developmental Disabilities*, 58 (2020):1–50; Meghan M. Burke, Kristina Rios, Chung eun Lee. “Exploring the Special Education Advocacy Process According to Families and Advocates”, *The Jl of Special Education,* 53, 3 (2018): 131-141; Trainor, Audrey A. “Diverse Approaches to Parent Advocacy during Special Education Home—School Interactions.” *Remedial and Special Education* 31, no. 1 (October 9, 2008): 34–47. https://doi.org/10.1177/0741932508324401.

[22] By “academic literature on family-led advocacy” we mean articles published in journals, books or chapters in books that address family advocacy directly and specifically in relation to inclusive education of people with disabilities. Of course, much has been written about inclusive education and advocacy separately.

[23] Of 20 journal articles reviewed, for example, 11 were written by US based authors and analysed local experiences. 6 of those articles shared co-authors. This in opposition to 6 articles produced out of different Latin American countries, 1 from the UK, 1 from Kenya and 1 from Singapore.

fonts. The amalgamation of images and text aids comprehension. This approach maximizes the impact of our findings and supports program development.

1.5. Positionality Statements

Positionality refers to the ways in which a researcher's identity categories create inherent biases in their approach to research.[24] Paula is a female lawyer from Lima, Perú, specialized in human rights law. My perspective is shaped by a rights-based approach and the social model of disability ingrained in my training. While I have family members with disabilities, I lack firsthand experience of disablement. Additionally, my socio-economic status has set my family experiences apart from those of the wider population.[25]

Margaret is an Irish Special Olympics Athlete and researcher with an intellectual disability. She was trained in research through Inclusion Ireland by professors from the Dublin Institute of Technology. She approaches disability from an understanding that everyone has the right to be involved in decisions. Margaret wasn't able to stay in mainstream school because of her disability. So, she does this research with the hope

---

[24] Mark Fathi Massoud, "The Price of Positionality: Assessing the Benefits and Burdens of Self-identification in Research Methods," *Journal of Law and Society* 49, no. S1 (July 26, 2022): S64-86, https://doi.org/10.1111/jols.12372.; Oral Robinson & Alexander Wilson, *Practicing and Presenting Social Research* (Vancouver: University of British Columbia, 2022), 6; Darwin Holmes, Andrew Gary. "Researcher Positionality - A Consideration of Its Influence and Place in Qualitative Research - A New Researcher Guide." *Shanlax International Journal of Education* 8, no. 4 (September 2020): 1–10. https://doi.org/10.34293/education.v8i4.3232.

[25] The World Bank estimates that people with disabilities make up 20% of the world's poorest people. Based on this, Inclusion International's Global Report on Poverty and Exclusion estimates that 26 million people with disabilities live on under 1 USD a day [Inclusion International, *Global Report on Poverty and Exclusion* (London, Inclusion International: 2006)].

While there is no one clear statistic that illustrates the relationship between disability and socio-economic status, various studies have pointed towards the reinforcing disability-poverty cycle. See for example: ILO. *Breaking the vicious circle of disability and extreme poverty.* (n.p, ILO: 2014); Department for International Development. *Disability, poverty and development* (London, DFID: 2014).

that in the future, people have the chance to choose between mainstream or special education. This might affect the way she looks at the results of our research.

2. ISSUE, EVIDENCE AND KEY FINDINGS

2.1. The Right to Inclusive Education and the Need for Stronger Advocacy

To understand this research in the context of SOI's approach, it is important to situate ourselves within a specific model of understanding disability. This research follows the social model of disability. This is the model recognized in Article 1 CRPD, the legal instrument that informs the standard global approach to disability.[26]

The social model implies recognizing that disability is not an inherent condition, but rather a situation that arises from the interaction of a physical, mental or sensory impairment and a legal, social or physical barrier. It is when these barriers, compounded with an impairment, prevent the full participation of a person in society, that a person finds themselves to have a disability.[27]

Through the lens of social connectedness, the social model is one that prioritizes belonging.[28] It argues – unlike previous approaches to disability – that people with

---

[26] *"Article 1 - Purpose*
The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.
Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

[27] Article 1 CRPD; United Nations Committee on the Rights of Persons with Disabilities. *General Comment No. 6 on equality and non-discrimination.* CRPD/C/GC/6 (Geneva, United Nations: 2018), parr. 9; Agustina Palacios. *El modelo social de discapacidad. Orígenes, caracterización y plasmación en la Convención Internacional sobre los Derechos de las Personas con Discapacidad (Madrid, Cinca: 2008),* 14-15; Michael Oliver and Colin Barnes, *The New Politics of Disablement* (New York, Palgrave Macmillan: 2012),164-165; Agustina Palacios y Francisco Bariffi, *La discapacidad como una cuestión de derechos humanos. Una aproximación a la Convención Internacional sobre los Derechos de la Personas con Discapacidad* (Madrid, Cinca: 2014), 19.

[28] See more: Kim Samuel. *On Belonging*. (New York, Abrams Press: 2022).

disabilities should not be ostracised from the rest of society.[29] Where previous models had focused on the social isolation of people with disabilities unless they met certain conditions, the social model fosters connection through the focus on lifting barriers for people with disabilities.[30]

Analysing an issue through the lens of the social model thus means placing the emphasis on the barriers that people with disabilities and their family members face when interacting with the world, as opposed to their impairments. For example, in this research, we were focused on advocacy strategies. With this in mind, we did not ask participants what type of disability their family member has, as it is not relevant to our understanding of their advocacy strategies.

The current understanding of inclusive education is aligned with the social model. Under the social model, everybody has the right to be included in society. In education, the onus of lifting the barriers that would prevent a student with an intellectual disability from participating in a "regular" school lies on the school and not the student; because those barriers are ingrained in the educational system, not because of the student's neurodiversity.

This also aligns with the language of social connectedness. Social connectedness posits that everyone should have equal opportunity to belong (exercise agency and basic human rights), regardless of personal characteristics, through reciprocal relationships with people, power, place and purpose.[31] This acts as a counterpart to social isolation – a situation where people are denied the opportunity to

---

[29] We refer here to the moral/religious model and the medical model of disability. See more in: Palacios. *El modelo social.*

[30] "In our work, we defined social isolation as the "inadequate quality and quantity of social relations with other people at the different levels where human interaction takes place, at the individual, group, and community, and within the wider social environment"" (Samuel, *On Belonging*, p. 27)

[31] Samuel, *On Belonging,* 18.

engage with others, through explicit or implicit barriers. Indeed, inclusive education aligns with the tenets of the social connectedness model, in creating a situation where all students are given ample opportunity to build community together. On the contrary, segregated education perpetuates social isolation and exclusion through legal and physical barriers, as it reinforces the message that people with disabilities are “others” in our society.

Article 24 of the CRPD recognizes every person with a disability’s right to inclusive education.[32] The article covers a comprehensive series of conditions necessary to realize inclusive education, of which I will highlight a few. Article 24, and the scholarship associated with it,[33] is clear in stating that education for individuals with

---

[32] *“Article 24 - Education*

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

a. The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;

b. The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;

c. Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

c) Reasonable accommodation of the individual's requirements is provided;

d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.”

[33] UNESCO. Global Education Monitoring Report 2020. Inclusion and Education: All means all (New York, UNESCO: 2020), 11-14, 31-32; UNESCO. *Temario abierto sobre educación inclusiva: materiales de apoyo para responsables de políticas educativas* (Santiago, UNESCO: 2004), 14-15; Álvaro Darío Dorado Martínez, y John Lesber Benavides Benavides, “Inclusión Educativa De Adolescentes Con Discapacidad En El Nivel De Secundaria En Instituciones Educativas De América Latina: Revisión sistemática,” *Informes Psicológicos,* 23, 1 (2013): 12-28; Vernor Muñoz, *The right to education of persons with disabilities. Report of the Special Rapporteur on the right to education. A/HRC/4/29* (Geneva, United Nations: 2007), para. 9; Sightsavers. *Making inclusive education a reality*, (n.p, Sightsavers: 2011); Ulises Sánchez Delgado et. al, "Inclusión Educativa en América Latina, una mirada más allá de la educación especial", *Revista ConCiencia EPG*, 1, 1 (2016): 95-106.

disabilities aims both to develop their abilities and foster inclusion. Inclusive education serves not only the individual, but also benefits society.[34]

The precise definition of inclusive education has been widely debated.[35] Here, we will follow the approach taken by the Committee on the Rights of Persons with Disabilities (CRPD), an UN treaty body that supervises CRPD compliance. The CRPD Committee differentiates between distinct educational models, categorizing them as exclusionary, segregationist, mainstream inclusion, and genuine inclusion.[36] If we go back to our social connectedness framework, exclusionary and segregationist education again perpetuates social isolation. The Committee argues along those lines – these types of education perpetuate the narrative that people with disabilities should remain separated from mainstream society.

Importantly, the Committee argues that mere enrollment in mainstream classes without corresponding structural accommodations does not align with authentic inclusion.[37] For authentic inclusion to happen, countries must adopt a systemic approach that prepares the educational system to respond to the needs of all learners. Curriculums, organizational structures, and pedagogy need to be adapted.[38] This will require governments to provide additional support and training to school staff, ensuring that they are able to deliver high quality education.[39]

---

[34] Jacqueline Jodl and Maya Bian, "Global State of Inclusion in Education: A review of the literature," Policy Brief 108, (Special Olympics Global Center for Inclusion in Education: January 2023), 7; Inclusion International and INICO. *Better Education for All: A Global Report*, (Salamanca, INICO: 2009), 23-25.

[35] Inclusion International, *Better Education for all*, 32; Save the Children, *Making Inclusive*, 2.

[36] United Nations (Committee on the Rights of Persons with Disabilities). *General comment No. 4 (2016) on the right to inclusive education, CRPD/C/GC/4* (Geneva, UN: 2016), parra. 11.

[37] UN CRPD Committee, CRPD/C/GC/4, parra. 11.

[38] UN CRPD Committee, CRPD/C/GC/4, parra. 12; UNESCO, "Temario abierto", 25-28.

[39] UNESCO, "Temario abierto"*,* 27, 35; Jo Walker. *Equal Right, Equal Opportunity. Inclusive Education for Children with Disabilities.* (n.p, Handicap International and Global Campaign for Education: 2013), 5-6.

These adaptations often take the form of reasonable accommodations.[40] Reasonable accommodations are necessary and appropriate changes made to ensure equal enjoyment of human rights, without placing undue burden on institutions.[41] These measures are case-specific, tailored post hoc,[42] and should be provided free of cost.[43] An unjustified denial of reasonable accommodation is considered an act of discrimination.[44] In the context of education, reasonable accommodations usually appear as:[45]

Accommodation	Example
Adaptations to the built environment	Changing the location of a class to a different room
Curriculum adaptations	Replacing an item in the curriculum for a more accessible alternative or removing certain items.
Pedagogical adaptations	Providing class handouts in easy-to-read format Allowing students extended time to complete assignments
Learning support assistance	Providing learning support assistants in class Providing reinforcement lessons after school hours

Advocacy is especially important when we think about reasonable accommodations. Reasonable accommodations should not be unilaterally imposed on people with disabilities. Rather, they must respond to the person's will and preferences. These are articulated in meetings with schools, which is where this and other studies will find that most parents conduct their advocacy.[46]

---

[40] UN CRPD Committee, *CRPD/C/GC/4*, parra. 12c.

[41] Article 2 CRPD; UN CRPD Committee, *CRPD/C/GC/4*, parra. 28.

[42] UN CRPD Committee, *CRPD/C/GC/6*, parra 23-27; UN CRPD Committee, *CRPD/C/GC/4*, parra. 28.

[43] UN CRPD Committee, *CRPD/C/GC/4*, parra. 17.

[44] Article 4 CRPD; UN CRPD Committee *CRPD/C/GC/6,* parra 17; UN CRPD Committee, *CRPD/C/GC/4*, parra. 31.

[45] UN CRPD Committee, *CRPD/C/GC/4*, parra. 30.

[46] UN CRPD Committee, *CRPD/C/GC/4*, parra. 30.

Globally, inclusive education is far from a reality. There is not an exact figure on how many children with disabilities are out of school, due to difficulties inherent to measuring disability globally.[47] Despite this, UNICEF estimates that compared to children without disabilities, children with disabilities are 49% more likely to have never attended school, and 43% more likely to be out of school by upper secondary if they have more than one disability.[48] The likelihood of having attended school is also tied to socioeconomic status.[49] At the same time, not all countries legislate for inclusive education. In fact, a 2020 UNESCO Monitoring Report found that globally, only 17% of countries expressly legislate inclusive education for children with disabilities, whilst 25% continue to legislate for segregated education.[50]

It is important to note that this disparity does not show up in our survey. Twenty nine out of 31 respondents shared that their family members did have access to education. Sixteen of these people accessed inclusive education, 6 accessed special education and 4 had attended both. Based on Margaret's knowledge of Special Olympics and the types of education experiences that people described, we suspect that the survey may have reached a group with high socio-economic status living in more developed countries. In the future, we would recommend that surveys control socioeconomic status and location.

---

[47] Washington Group. About the Washington Group on Disability (Website); UNICEF. *Seen, Counted, Included. Using data to shed light on the well-being of children with disabilities*. (New York, UNICEF: 2021), 10-15; UNESCO. Global Education Monitoring Report, 12; UNESCO Institute for Statistics. *Information Paper No. 49, Education and Disability: Analysis of Data from 49 Countries* (New York, UNESCO: 2018), 7-9.

[48] UNICEF, *Seen, Counted, Included*, 152.

[49] UNICEF, *Seen, Counted, Included,* 94.

[50] UNESCO, *Global Education Monitoring Report,* 36.

2.2. Defining Advocacy

In the context of global exclusion of people with disabilities from mainstream school services, advocacy becomes a necessity. There is no universal definition of advocacy, and the word is quite elusive outside of technical circles. When we asked survey respondents if they were familiar with the term advocacy, 47% said they were. They defined advocacy in varied ways, which we have grouped into four primary categories: (i) Influencing other people, (ii) Fighting for a person's interest, (iii) Fighting for a group's interest, and (iv) Setting an example.[51]

We chose to share a definition created by the Butler County Board of Developmental Disabilities with our survey respondents to ensure that they answered questions about advocacy coming from a common point. We chose this definition due to its ease of communication and alignment with broader definitions:

> *"Advocacy is acting to support a person, cause or policy. People can advocate for themselves, others or both. Advocacy may mean different things to different people and may change depending on the situation."*[52]

Of course, advocacy is a far more complex concept. It can be understood as "a planned and organized process by which citizens seek to influence the processes of adoption and implementation of public policies by various state actors or other public actors (such as international organizations) (Promundo, UNFPA, MenEngage, 2010)."[53] These citizen-led processes can be local, regional, national, or international, and can be

---

[51] Further detail of answers is provided in the creative output of this project.

[52] Butler County Board of Developmental Disabilities. *An Advocacy Guidebook for People with Developmental Disabilities* (Butler, Adult Advocacy Centers: 2021), p. 5.

[53] Renata Bregaglio, María Susana Barrenechea, Paula Camino and María Alejandra Espino. *Guía Regional para la incidencia política basada en evidencia y jurisprudencia para la protección de los derechos humanos de las personas LGBTI* (Lima, Promsex: 2020), 16.

carried out through different activities aimed at influencing decision makers in the public sphere.[54]

Advocacy, then, seeks to respond to multiple potential scenarios. Sense International, for example, identifies four potential scenarios that can trigger an advocacy process: (i) Absence of policies to solve an issue that affects a specific group; (ii) Existence of policies that directly harm a specific group; (iii) Non-compliance with the first type of policies; (iv) Lack or misuse of public resources to fulfill a law of policy.[55]

Advocacy can be broadly categorized into four types: systemic advocacy, individual advocacy, self-advocacy, and legal advocacy.[56] Our survey respondents intuitively identified systemic advocacy (fighting for group interests) and individual advocacy (fighting for a person's interest). Individual advocacy, the most relevant to our research, focuses on supporting specific people with disabilities in accessing their rights, whether that is through accessing support, resolving conflicts, or managing relationships.[57] It can be formal or informal, and is most often carried out because of personal connections, although it can be carried out by professionals.[58]

---

[54] UNESCO. *Promoting Inclusive Teacher Education Advocacy Guides* (Bangkok, UNESCO Bangkok Office: 2014), 8; Africa Disability Alliance*. Advocacy Toolkit for Disability Mainstreaming* (n.p, African Disability Alliance: 2019), 10; CARE. *The CARE International Advocacy Handbook* (Geneva: CARE, 2014), 1-2; Save the Children. *Making Inclusive Education a Reality: How can happen. Save the Children's experience. Save the Children's Experience.* (London, Save the Children: 2008), 45; Renata Bregaglio et. al, *Guía Regional*, 16-18; Scott Kupferman and Robert Hand, *Toolkit. Systemic Advocacy for People with Disabilities.* (Community Development Authority, Dubai: 2017), 3-5; EENET, *Enabling Education Review. Special Issue: Inclusive Education Advocacy.* (Hollingworth, EENET: 2015), 3.

[55] Sheila Verena Jacay Munguia, *Manual de Incidencia Política: Nuestra experiencia en Sordoceguera* (Lima, Sense Internacional Perú: 2014), 14-15.

[56] NCOSS. *Report on disability advocacy, representative and information organisations.* (New South Wales, NCOSS: 2019), 8; West Virginia University Center for Excellence in Disabilities. *Types of Advocacy* (Website)

[57] Kupferman and Hand, *Toolkit,* 4.

[58] Disability Australia Hub, Disability A-Z (Website); West Virginia University Center for Excellence in Disabilities. *Types of Advocacy* (Website)

Historically, this has been the type of advocacy carried out by family members to ensure the enjoyment of rights of their family members with disabilities.[59] In fact, once presented with our definition of advocacy, 75% of our survey respondents indicated that they had advocated in the past. They have advocated for education (17 respondents), healthcare (12 respondents), independent living (10 respondents), sports inclusion (18 respondents), supported decision making (12 respondents) and other rights (5 respondents).

In the context of inclusive education, we can argue that parents carry out individual advocacy to ensure the compliance with inclusive education policies and laws, as well as the correct use of resources to ensure a quality education for their children. Indeed, in many countries, legislation and policies create the need for parents to be actively involved in monitoring and promoting quality education.[60] In some cases, parents have even been able to drive legislation.[61] The literature also identifies that parents advocate for their children seeking an improved learning environment, supporting the adaptation of existing learning strategies.[62]

---

[59] Scifres 2012, Wright & Taylor, 2014 in Audrey A. Trainor, *Diverse approaches,* 35; Campaña Latinoamericana por el Derecho a la Educación, *El Derecho a la educación de las personas con discapacidad: ¿Cómo estamos en América Latina y el Caribe?* (Sao Paulo, CLADE: s.f.); Sara Cofiell, *Giving a Voice to the Parent/Guardians/Caregivers of Students with Special Needs: Advocacy for Services*, Masters Diss (Dominican University, 2015); Meghan M. Burke and Samantha E. Goldman, "Documenting the Experiences of Special Education Advocates," *The Journal of Special Education* 51, no. 1 (April 15, 2016): 3–13; UNESCO, "Temario abierto"*,* 32; Inclusion International, *Better Education for All*, 105.

[60] Miriam Navas, "Las familias de estudiantes con discapacidad en la escuela, sus necesidades y demandas. Caso Ecuador", *Familia y Educación en el siglo XXI: Formación parental para los nuevos retos sociales,* 12, 1 (2017): 20-31, 2; Ministerio de Educación. *Orientaciones generales para fomentar la participación familiar en la educación* inclusiva (Bogotá, Ministerio de Educación: 2019), 23, 32; Goldman, "Special education advocacy", 3; Burke & Goldman, "Documenting the experiences", 3; Cofiell, "Giving a Voice", 19.

[61] Audrey A. Trainor, "Diverse approaches"*,* 34; Monica Cortes et. al., *Families as Leaders in the Journey to Inclusive Schooling. Keys to achieving transformational change* (n.p., Centre for Inclusive Futures: 2018), 10.

[62] UNESCO. Guidelines for inclusion: Ensuring access to education for all (Paris, UNESCO: 2009), 19; Sandra Alper, Patrick J. Schloss, and Cynthia N. Schloss, "Families of Children with Disabilities in Elementary and Middle School: Advocacy Models and Strategies", *Exceptional Children,* 62, 3, (1995):

In the United States, Trainor identifies four archetypes that family advocates fall into, depending on their goals and knowledge of disability.[63] She identifies intuitive advocates (those who are intimately familiar with their children), disability experts (those who have a lot of knowledge about disability), strategists (parents who combine knowledge of disability and systems to advocate for their child) and change agents (parents who advocate for systemic change). Most of our interviewees fell into the category of strategists, as they were intimately familiar with school systems and used their knowledge of their children to get them the best possible education.

In fact, 23 of our survey respondents had advocated for inclusive education. Our interviewees, who we had screened previously for experiences of advocacy, shared that they carry out their advocacy within school settings, working directly with teachers, principals, learning support assistants and sometimes district officials.

2.3. Understanding Parent Advocacy for Inclusive Education

Because parent advocacy for inclusive education is highly personal, it can be difficult to systematize and analyze information across regions. Considering that initial limitation, we have chosen to organize this section of our report into four parts : (i) Gaps in research, which will provide an understanding of the sources used, (ii) Strategies employed by family members, (iii) Barriers to advocacy and (iv) Outcomes of advocacy.

2.3.1. Gaps in Research

261–270, 262; Amanda R. Musolino-Olson. *Parent Advocacy in Special Education: Critical Principles and Action Steps*. Master's thesis; Goldman "Special education advocacy", 3.

[63] Trainor, "Diverse approaches", 40 – 43.

An important limitation for this project is the scarcity of academic literature on family-led advocacy for inclusive education.[64] When we looked at academic journals that specifically explore the role of family members in inclusive education, the overwhelming majority of research on the topic has been published in the United States (11 texts), with few examples from Latin America (6 texts), Europe (2 texts), Asia (1 text) and Africa (1 text). Interestingly, of the 11 texts from the US, 6 share one or more co-author affiliated to a university.[65] There is further literature from this set of co-authors that was not reviewed due to the temporal limitations of this project, but further research should review these documents and engage with the authors.

Grey literature was more relevant to this project. While we compiled 27 texts, only 5 specifically address parental advocacy for inclusive education.[66] The remainder made references to parent involvement in the broader context of inclusive education. As such, it is difficult to have precise information on the strategies and barriers family members encounter. It was especially difficult to track the outcomes of advocacy efforts undertaken by family members.

In the academic context, this may be caused by the fact that parent advocacy for students with disabilities is a relatively niche subject, going through a process of organic growth. In grey literature, this may be caused by a lack of funding from organizations to

---

[64] Articles in journals and academic books.

[65] Burke et. al., “Exploring the Special Education”; Burke et. al, “Examining Differences”*;* Samantha Goldman, *Special Education Advocacy*; Samantha E. Goldman, Meghan M. Burke, Maria P. Mello, “The Perceptions and Goals of Special Education Advocacy Trainees”, *Journal of Developmental and Physical Disabilities*, 31 (2019): 377-397; Chung eun Lee, Meghan M Burke, Leann Smith DaWalt, Chak Li and Julie Lounds Taylor, “The Role of Parental Advocacy in Addressing Service Disparities for Transition-aged Youth on the Autism Spectrum”, *Autism,* 26 (2022): 1001-1006; Zach Rossetti et. al, “Parent Perceptions of the Advocacy Expectation in Special Education”, *Exceptional Children*, 87 (2021): 434-457.

[66] Including manuals, reports, policy papers and toolkits

conduct research,[67] as well as by the competing priorities that family members face,[68] which act as a barrier for their participation in long term research projects.

2.3.2. Strategies Used by Family Members

Different authors identify different types of family advocates and advocacy strategies.[69] Some authorship identifies strategies relevant to specific contexts – authors based out of the United States like Alper, Schloss & Schloss and Burke et. al, for example, outline the strategies of family advocates who focus on participation in IEP meetings held based on IDEA legislation in the United States.

Regardless, we have compiled certain strategies that are common to both academic and grey literature, to provide an overview of strategies a family member might use to advocate for inclusive education. These are explained in further detail and exemplified in the creative output of this research:

1) **Establishing a clear goal:** Parents focus their advocacy on securing access to inclusive education. This occurs, according to our survey and interviews, by meeting with school headmasters and regional offices. Once that is secured, they focus on ensuring their children have access to reasonable accommodations to receive a quality education.[70] This is an ongoing advocacy effort that usually

---

[67] In 2019, CANDID's Advancing Human Rights report found that only 3% of the global share of foundation human rights funding goes to organizations working on the rights of people with disabilities. Of these funding, only 13% goes towards research. Citation: CANDID, "Helping You Understand Human Rights Grantmaking," Advancing Human Rights | The State of Global Foundation Grantmaking, 2019, https://humanrightsfunding.org/.

[68] Save the Children, *Making Inclusive Education*, 55; Samantha E. Goldman, *Special Education Advocacy,* 5; Zach Rossetti et. al, *Parent perceptions*, 10.

[69] Sandra Alper et. al, "Families of Children", 266-267; Meghan Burke et. al, *Exploring the Special Education*; Audrey A. Trainor, *Diverse approaches,* 40-43; Sandra Gendera and Karen R Fisher, *Family Advocacy Model Research* (Sydney, Social Policy Research Centre UNSW: 2022), 3-6.

[70] 1. Meghan M. Burke and Samantha E. Goldman, "Documenting the Experiences of Special Education Advocates," *The Journal of Special Education* 51, no. 1 (April 15, 2016): 3–13, https://doi.org/10.1177/0022466916643714; Trainor, "Diverse approaches", 35: Nurul Azhana Mohd Yatim

occurs in constant communication with learning support services and teachers. Whilst the literature based out of the United States refers to this type of advocacy occurring in IEP meetings, our interviewees shared that communication (and thus advocacy) was ongoing, often through informal channels.[71] Contrary to our expectations, our survey showed that 80% of family members ranked their communication with their supports as “good” or “very good”. The same was true for students.

2) **Being reactive:** Parental advocacy isn't solely about setting predefined goals; it's also about cultivating the ability to respond effectively to dynamic situations within the educational landscape. Rather than relying solely on a rigid plan, successful advocacy hinges on equipping parents with the tools to address diverse scenarios that may arise, such as instances of classroom exclusion, bullying, or inadequate teaching. This adaptive approach empowers parents to advocate for immediate concerns and work collaboratively with support systems.

3) **Community building and collective action:** Across countries, relationships between parents appear as an important source of support, social capital, and knowledge.[72] Faced with an asymmetry of power between individual parents and the education system, acting together provides parents with social capital to bridge that gap.[73] Similarly, it creates opportunities to bridge knowledge gaps

---

and Manisah Mohd Ali, “Parental Advocacy for Students with Special Needs: A Systematic Review Study”, *Intl Jl of Academic Research in Progressive Education and Development,* 11, 2 (2022), 8.

[71] Burke et. al, “Exploring the Special Education”; Burke et. al, “Examining Differences”*;* Goldman, “Special Education Advocacy”; Goldman et. al, “The Perceptions and Goals”; Rossetti et. al, “Parent Perceptions”, Trainor, “Diverse approaches”, 35.

[72] Save the Children, *Making Schools Inclusive*, 55; Navas, “Las familias”, 3; Trainor, “Diverse approaches”, 45; UNICEF, *Participación de los padres,* 16-17; Family Advocacy. *All students learning together. Taking action on education* (New South Wales, Family Advocacy: 2016), 7.

[73] Trainor, “Diverse approaches”, 465-6; Navas, “Las familias”, 3.

between parents who are familiar with legislation and those who are new to advocacy.

In this process, passing down experiences of advocacy becomes especially important, as interviewees S3, S4 and E15 shared with us.[74] In doing so, parents build community over the shared purpose of seeking out better education for their children, connecting with each other within a system that tends towards disconnection[75].

4) **Building relationships with schools:** Since the brunt of advocacy occurs in the relationship between parents and designated support services, they adopt a series of flexible strategies to ensure a positive relationship with school staff.[76] These include ensuring swift communication,[77] collaborating in building out accommodations,[78] supporting extracurricular activities,[79] and even supporting schools with teaching materials.[80] This requires that each party have clarity on their roles in a child's education.[81]

   Our interviewees especially emphasized communication and collaboration, sharing that they often found themselves problem-solving with teachers and support services to ensure their child's needs were met. One interviewee

---

[74] Trainor, "Diverse approaches", 42; Yatim & Ali, "Parental Advocacy", 10.

[75] Samuel, *On Belonging,* p. 191.

[76] Family Advocacy, *All students,* 13; Norma Graciela López-Márquez. "Funcionalidad familiar y participación escolar de las familias de niños con discapacidad", *IE Revista de Investigación Educativa de la REDIECH,* 8, 14, (2017): 111-128, 121-2.

[77] Navas, "Las familias", 3; Francis et al 2016 in *Musolino-Olson. Parent Advocacy*, 29; Trainor, "Diverse approaches", 43; Family Advocacy, *All students,* 13-16.

[78] Navas, "Las familias", 3; Love et al 2017 in *Musolino-Olson. Parent Advocacy*, 31; UNESCO, *Temario abierto*, 90-91; UNICEF. *Participación de los padres,* 13.

[79] Burke et al, "Exploring the Special Education"; Rosetti et al 2018; Love et al 2017 in *Musolino-Olson. Parent Advocacy*, 31.

[80] Mrotier & Arias 2020 in Yatim & Ali, "Parental Advocacy", 9.

[81] UNICEF, *Participación de los padres*, 21.

reported constant communication via WhatsApp, whilst another reported daily check-ins with support teachers. Here, parents capitalize on empathy and reciprocal cycles of belonging to build community with school staff.

5) **Capacity building:** A cornerstone of parental advocacy is the need for capacity building, which has been institutionalized to varying degrees. Parent training has been shown to have a "considerable impact" on children.[82] Capacity building occurs through formal channels, such as training programs,[83] or informal connections between parents.[84] Our interviews showed evidence only of informal connections between parents, always forged through membership to Special Olympics.

6) **Professional advocacy:** The literature in the United States registers that parents often work with professional advocates or former teachers to accompany them in meetings with schools. These are trained, specialized individuals who provide different forms of support to family members.[85] While we have not found evidence of this occurring elsewhere, interviewees from Israel and Costa Rica shared experiences of hiring former teachers as learning support assistants. Other reports have also proposed the involvement of local NGOs as partners to families advocating for inclusive education[86].

---

[82] Beaudoin, Sébire, & Couture, 2014; Lee, Niew, Yang, Chen, & Lin, 2012; Wade, Llewellyn, & Matthews, 2008 in Çitil 2022, 4.

[83] Goldman, "Special education advocacy", 9; Goldman et al, "The Perceptions", 4; 1. Mahmut Çitil, "Informative Parent Training on Parental Advocacy and Legal Rights for Families with Children with Special Educational Needs," *International Journal of Psychology and Educational Studies* 7, no. 3 (September 2020): 178–93, 180; Cofiell, "Giving a Voice", 2.

[84] Hess et al 2006 in *Musolino-Olson. Parent Advocacy*; Trainor, "Diverse approaches".

[85] Burke et. al, "Documenting the experiences", 3-4; Goldman, "Special education advocacy", 8; Cofiell, "Giving a voice", 12.

[86] UNESCO, *Temario abierto,* 39.

2.3.3. Barriers to Advocacy

A constant across the literature and our interviews is the complex nature of advocacy. The following section compiles some of the most common barriers family members face in their advocacy, covering both personal (emotions and priorities) and structural (information and power disparities).

1) **Advocacy feels daunting:** Starting to advocate appears daunting to families, as it requires them to face technical discussions with perceived authority figures. Families are intimidated by the lack of available information and opportunities to collaborate, difficulty understanding jargon, as well as the stigma and emotional toll attached to advocacy.[87] Our 4 survey respondents indeed shared that they had not advocated because they lacked skills or information or were unfamiliar with advocacy.

2) **Competing priorities:** The daily struggle for survival often limits parent's ability to advocate.[88] Under the current care model, parents need to juggle financial demands, time poverty, and home care obligations.[89] This leaves little to no time to both learn about advocacy and advocate themselves. Interestingly, while our interviewees reported spending a significant amount of time on advocacy, they did not share feelings of exhaustion. This may be because interviewees had the support of family members - in fact, interview E1 consisted of a set of parents.

---

[87] Burke et al, "Documenting the experiences", 3; Goldman et al., "The perceptions", 3; Yatim & Ali, "Parental advocacy", 4; UNESCO, "Temario abierto", 94.

[88] Save the Children, "Making Schools Inclusive", 55; Navas, "Las familias".

[89] Ministerio de Educación, "Orientaciones generales", 33; Rossetti et. al in *Musolino-Olson. Parent Advocacy*, Alper, Schloss & Schloss, "Families of children", 263.

While the remaining interviewees where individuals, they did mention the importance of the support of family and friends in their advocacy.

3) **Lack of accessible knowledge:** Families often grapple with a lack of information on their rights and avenues to demand them.[90] When they do seek out information, it is exceedingly technical and thus excludes parents who do not have high levels of education or an intimate knowledge of education systems and disability legislation.[91] This excludes a significant number of parents from accessing information. That, in turn, means that family members do not have the correct tools to navigate advocacy conversations, limiting their ability to succeed in these.[92] While our interviewees did not speak to their knowledge of rights, they all agreed that they were self-taught in adapted pedagogies.

4) **Existing power dynamics:** Structural barriers and power dynamics significantly shape the landscape of family advocacy. Literature in the United States has documented how marginalized identities compound the barriers described above, especially when parents have cultural or linguistic differences.[93] This did not show up in our own research since our survey did not control for socio-demographic characteristics, and our interviewees identified as White/Caucasian, city-dwellers and all spoke the native language of the countries they live in.

---

[90] Zuckerman et al. 2014 in Citil, “Informative parent training”, 2; Goldman et al “The perceptions”, 5; Yatim & Ali, “Parental advocacy”, 4-9; Inclusion International, *Better Education for All,* 132.

[91] Mandic, Rudd, Hehir, & Acevedo-Garcia 2010 in Goldman, “Special education advocacy”, 3; Fitzgerald and Watkins, 2006; Lian and Fontánez-Phelan 2001 in Trainor, “Diverse approaches”, 35.

[92] Cofiell, “Giving a voice”, 2.

[93] Burke et. al, “Examining Differences”, 75-6; Goldman, “Special Education Advocacy”, 5; Trainor, “Diverse approaches”, 36-45: UNESCO, “Temario abierto”, 93-94.

On the other hand, the power differential between schools and parents emerges as an attitudinal barrier, reducing the legitimacy of parent perspectives and authority within the education ecosystem.[94] In the language of belonging, parents (and students) are usually isolated from decision-making structures within schools, which stops them from meaningfully determining the way education is delivered[95]. In their advocacy, they work to overcome this power differential.

5) **Tensions with schools:** Our interviewees pointed to two additional elements that were not present in the literature. Some interviewees who had had access to learning support assistants shared that those assistants faced a constant tension between the needs of the child and the willingness of the school apparatus to accommodate them. Part of their advocacy, then, was helping assistants navigate those tensions. All interviewees, as well as some survey respondents, shared that teachers constantly told them that they did not know how to adapt their teaching methodologies. In response, parents opted for a very human approach, inviting teachers to learn alongside them, as shared by S3 and S4. In this way, they seem to intuitively know that building belonging between them, teachers and support services can be successful in improving education outcomes.

6) **Prejudice against people with disabilities:** When asked about barriers, our interviewees were unanimous in saying that the biggest barrier they face in their advocacy is the stigma surrounding people with disabilities, called ableism. This

---

[94] Goldman, “Special Education Advocacy”, 5; Burke & Goldman, “Documenting the experiences”.
[95] Samuel, On Belonging, 19, 191.

has been corroborated by other researchers.[96] Our interviewees shared that ableism extends, naturally, beyond the school setting. them, this structural barrier appears to underlie problems in accessing inclusive education, making their advocacy even harder.

2.3.4. Outcomes of Advocacy

Research on outcomes, particularly systemic ones, remain somewhat elusive within the context of parental advocacy. This scarcity can be attributed to the limitations in research we have mentioned, and the difficulty of tracking individual action. Despite this gap, we can glean some insights into outcomes from texts that describe the advocacy process and our own surveys and interviews.

1) **Access to education:** In some regions, the most immediate outcome of advocacy is the opportunity for children to study in inclusive schools. This showed up in our Spanish survey results, in which 4 respondents shared that they had difficulty matriculating their children in schools. They escalated the situation to regional offices, through which they were able to secure access.

2) **Improved learning outcomes:** Advocacy does fulfill its purpose of improving learning outcomes for students. When family members become involved in education, their children receive better services, improved experiences, report greater progress and higher satisfaction with their education.[97]

---

[96] Jo Walker. *Equal Right,* 26-27; George Odongo, “Barriers to Parental/Family Participation in the Education of a Child with Disabilities in Kenya”, *Intl Jl of Spec Education*, 33, 1 (2018): 21-33, 24-25.

[97] Save the Children, “Making Schools Inclusive”, 19-28; UNESCO, “Guidelines”, 23; Goldman, “Special education advocacy”, 37; Yatim & Ali, “Parental Advocacy”, 10; UNESCO, “Temario abierto”, 89.

3) **Skill building for parents:** Because capacity building is one of many advocacy strategies, parents build new skills in the process. Advocacy has been shown to increase inclusive education knowledge, understanding of services and interventions and communication skills.[98] This, in turn, allows parents to make more informed decisions.[99] Whilst our interviewees did not directly mention this, they related how they became progressively more skilled advocates over their child's schooling.

4) **Stronger relationships with schools:** Because parents are constantly interacting with support services and school staff, this leads to communication, collaboration through empathy, and shared decision-making between parents and educators; advocacy builds more effective school-parent partnerships.[100] These partnerships then allow for improved learning outcomes. Since teachers' work becomes rooted in understanding and empathizing with families, they are more responsive to student needs.[101] Interviewees E1, for example, shared that they felt they had a great relationship with their son's current school after working closely with them in his first year.

5) **Stronger relationships within the disability community:** One study by Goldman reports that with more advocacy comes a stronger sense of involvement in the disability community more broadly.[102] This is reflected in our

---

[98] Goldman, "Special education advocacy", 37, Yatim & Ali, "Parental Advocacy", 10.
[99] Yatim & Ali, "Parental Advocacy", 10.
[100] UNESCO, "Guidelines", 21; European Agency for Development in Special Needs Education, *Key Principles for Promoting Quality in Inclusive Education – Recommendations for Practice* (Denmark, European Agency for Development in Special Needs Education; 2011), 13.
[101] Save the Children, "Making Schools Inclusive", 19-20; Burke et. al, "Documenting the experiences", 4.
[102] Goldman, "Special education advocacy", 28

interviews. All 4 people interviewed, shared how upon realizing they were successful advocates, they had begun to connect with other parents through Special Olympics and schools. This has provided them with a sense of community and a support system, where they no longer feel alone in their fight. This shows how a shared sense of purpose - advocating for inclusive education - has built belonging amongst parents, who are collectively able to act on their feelings of purpose.

3. RECOMMENDATIONS & IMPACT

As stated, this report is merely an initial exploratory approach to parental advocacy for inclusive education. It will be useful as a tool for both SCSC and SOI to conduct further research on the topic, and the final creative output can serve as a starting point for families or people interested in gaining a basic understanding of family advocacy.

Based on the literature reviewed and the Community Engagement Initiative conducted, we can recommend the following:

3.1. Recommendations for Further Research

- **Investigate systemic outcomes:** There is a large missing piece of this research that relates to systemic advocacy that might be either carried or initiated by family members. Although we conducted extensive research of approximately 100 texts, we only found two concrete examples of parents affecting legislation, in

Romania[103] and the UK[104]. Further inquiry might uncover more examples, but we were limited by the time constraints of this fellowship.

- **Conduct longitudinal studies:** Undertake longitudinal studies to track the long-term impact of parental advocacy on children's educational trajectories, including academic progress, self-esteem, and post-education outcomes.
- **Assess advocacy training:** Evaluate the effectiveness of different advocacy training programs and interventions in building parents' skills and confidence and examine how these interventions contribute to improved outcomes for children. An initial study has been carried out by Samantha Goldman in the United States, which contrasts the outcomes of five different advocacy programs. Similar studies should be carried out globally.
- **Adopt an intersectional analysis:** This research is incomplete because it did not control for sociodemographic factors in its engagement with the community. Future studies should make sure to account for factors such socioeconomic status, cultural background, and geographic location to better understand parental advocacy differences.
- **Areas for further inquiry:** Relationship with other family members, understanding if athletes share the same impression, tracking ad hoc family support systems.

---

[103] Cortes et. al, *Families as leaders,* p. 10.

[104] UNICEF. Participación de los padres y madres, la familia y la comunidad en la educación inclusiva. (Nueva York, UNICEF: 2014), 23; Richard Rieser. *Implementing Inclusive Education: A Commonwealth Guide to Implementing Article 24 of the UN Convention on the Rights of Persons with Disabilities*. 2nd Ed. (London, Commonwealth Secretariat: 2012), 129-130.

3.2. Recommendations for Program Design

- **Identify a family advocacy model:** Several models and strategies were reviewed in this project. SOI should identify more models and select an existing one as a framework. For example, Gendara and Fisher's research on New South Wales based organization "Family Advocacy" has identified a model that works on three levels, and may be applicable to an organization like SOI:[105]
    - **Individual and family level advocacy:** The organization supports family members in conducting ongoing advocacy and safeguarding for their children.
    - **Family leadership development:** The organization identifies and trains families to advocate in school settings, at the same time driving change in their communities and networks through their actions.
    - **Systemic advocacy:** Family advocacy carries out activities to foster the promotion and protection of the rights of people with disabilities at the systems level, with the input of family members.
- **Support existing family advocacy programs:** All family members interviewed stated that they are already teaching other Special Olympics parents how to conduct individual advocacy in school settings. An interviewee from Malta shared that their local office has an informal support system set up, with referral procedures and ties to local government officials. These existing networks should be empowered and can be used as pilots.

---

[105] Karen Fisher and Sandra Gendera. *Family advocacy model research. Prepared for Family Advocacy NSW* (Sydney, University of New South Wales: 2022), 3-6.

- **Establish parent-athlete networks and support groups:** Create platforms where parents and athletes can connect, share experiences, and support one another. Facilitate support groups and online connections that allow families to exchange insights, strategies, and resources, fostering a sense of community and solidarity.

- **Develop comprehensive training programs:** Create accessible and comprehensive training programs that empower parents with the knowledge and skills needed to effectively advocate for their children with disabilities. The focus should be on competencies such as: Rights-based knowledge, strategy design, non-violent communication, and curriculum adaptations.

- **Work with schools to prepare better responses:** Schools continue to be unprepared for inclusive education, as they deal with lack of training and resources. Organizations should work with schools at the same time as they work with parents, to ensure that any advocacy efforts can have a successful outcome.

CONCLUSIONS

Our research addressed three fundamental questions concerning family advocacy in education. First, we explored the current landscape of family advocacy. Second, we looked at the experiences of families engaged in advocacy. Third, we investigated the significance of community and belonging within advocacy. The conclusions in this section are organized in response to these three questions.

Research Question 1: Current Landscape of Family Advocacy

- Inclusive education remains a distant goal in most regions, necessitating advocacy efforts.
- Advocacy takes various forms, with parental advocacy largely being individual and interpersonal.
- Advocacy complexity varies regionally, presenting diverse challenges and approaches.
- Key barriers to advocacy mirror existing social structures: lack of information, power disparities with the school system, and designing accommodations without formal training.

Research Question 2: Family Advocacy Experiences

- Advocacy doesn't conclude upon getting a child into school; it's an ongoing process.
- Effective communication with learning support assistants (LSAs) is crucial in ensuring quality education.
- Parent-to-parent support fosters successful advocacy.
- Stigma and societal information gaps hinder advocacy for inclusive education.
- There is an emotional toll associated with advocacy. Despite this and other barriers, parents continue to advocate for their child's education. In fact, our survey and interviews show that it is possible to create positive education experiences, especially relationships with supports.

Research Question 3: Community and Belonging in Advocacy

- Advocacy outcomes include improved access and permanence in educational settings, fostering a sense of community.
- Successful advocacy contributes to a stronger connection between peers, educators, and students.
- Longitudinal studies are recommended to comprehensively assess the impact of family advocacy.
- An intersectional approach from research design onwards is crucial for a holistic understanding.

About the research methodology:

- Inclusive research requires time and effort to tailor methods and outputs for everyone.
- Embracing emancipatory research principles can minimize non-disabled researchers' protagonism.
- A focused approach in research design, delving into one advocacy paradigm within SOI families, would have yielded depth over breadth.

In conclusion, our research underscores the importance of family advocacy in the realm of inclusive education. It reveals the diverse and often challenging nature of advocacy, with families serving as pivotal advocates. These families face emotional and structural obstacles, yet our survey and interviews indicate that positive educational experiences, particularly through supportive relationships, are attainable. Moving forward, we suggest that this research be continued with a more focused research design, prioritizing depth over breadth, to gain profound insights into specific advocacy paradigms.

ACKNOWLEDGMENTS

My most important acknowledgement is to Margaret Turley, Special Olympics Athlete who joined the project at the halfway point. It is not easy to join a research project once it has begun, with limited ownership of the design and strategies. Much less so when the traditional scaffolding of research has not been built for people with disabilities. Margaret went above and beyond to be an equal partner on this project.

This research would not have been possible without the financial and academic support of the Samuel Centre for Social Connectedness. Olivia Smith Rodrigues, Fellowship Program Manager, has been instrumental in supporting the analysis and organization of this research with acute comments.

At the same time, it would not have been possible without the work and disposition of Special Olympics International's Research and Family Engagement teams. Hannah Helton and Ashlyn Smith have been fundamental in workshopping ideas and providing unlimited access to family members in the SOI system.

Lastly, the research would not be possible without the relentless work of Special Olympics family members and athletes around the world. Without their constant effort to build a more inclusive world, this research would be unthinkable. Without their openness to share their stories, it would be incomplete.

BIBLIOGRAPHY

Africa Disability Alliance. “Advocacy Toolkit for Disability Mainstreaming.” (n.p, African Disability Alliance: 2019) https://www.cbm.org/fileadmin/user_upload/Publications/Disability_Mainstreaming_Toolkit.pdf.

Alper, Sandra, Patrick J. Schloss, and Cynthia N. Schloss. “Families of Children with Disabilities in Elementary and Middle School: Advocacy Models and Strategies.” *Exceptional Children*, 62, 3, (1995): 261–270. https://doi.org/10.1177/001440299606200307

Barnes, Colin, and Geof Mercer, eds. *Doing Disability Research*. Leeds: Disability Press, 1997.

Bigby, Christine, Patsie Frawley, and Paul Ramcharan. “Conceptualizing Inclusive Research with People with Intellectual Disability.” *Journal of Applied Research in Intellectual Disabilities* 27, no. 1 (December 4, 2013): 3–12. https://doi.org/10.1111/jar.12083.

Bregaglio, Renata, María Susana Barrenechea, Paula Camino y María Alejandra Espino. “Guía Regional para la incidencia política basada en evidencia y jurisprudencia para la protección de los derechos humanos de las personas LGBTI.” (Lima, Promsex: 2020), https://promsex.org/wp-content/uploads/2021/12/GuiaRegionalParaLaIncidenciaPoliticaAdelante.pdf

Brooks, Michelle, and Stephanie Davies. “Pathways to Participatory Research in Developing a Tool to Measure Feelings.” *British Journal of Learning Disabilities* 36, no. 2 (October 17, 2007): 128–33. https://doi.org/10.1111/j.1468-3156.2007.00476.x.

Burke, Meghan M., Kristina Rios, and Chung eun Lee. “Exploring the Special Education Advocacy Process According to Families and Advocates.” *The Journal of Special Education* 53, no. 3 (November 28, 2018): 131–41. https://doi.org/10.1177/0022466918810204.

Burke, Meghan M., Kristina Rios, Marlene Garcia, and Sandra Magaña. “Examining Differences in Empowerment, Special Education Knowledge, and Family–School Partnerships among Latino and White Families of Children with Autism Spectrum Disorder.” *International Journal of Developmental Disabilities* 66, no. 1 (December 25, 2018): 75–81. https://doi.org/10.1080/20473869.2018.1487502.

Burke, Meghan M., and Samantha E. Goldman. “Documenting the Experiences of Special Education Advocates.” *The Journal of Special Education* 51, no. 1 (April 15, 2016): 3–13. https://doi.org/10.1177/0022466916643714.

Campaña Latinoamericana por el Derecho a la Educación, El Derecho a la educación de las personas con discapacidad: ¿Cómo estamos en América Latina y el Caribe?, (Sao Paulo, CLADE: s.f.) https://redclade.org/wp-content/uploads/CLADE_InformeDiscapacidad.pdf

CANDID. "Helping You Understand Human Rights Grantmaking." Advancing Human Rights | The State of Global Foundation Grantmaking, 2019. https://humanrightsfunding.org/.

CARE. "The CARE International Advocacy Handbook." (Geneva: CARE, 2014) https://www.care-international.org/files/files/Care%20International%20Advocacy%20Handbook.pdf

Çitil, Mahmut. "Informative Parent Training on Parental Advocacy and Legal Rights for Families with Children with Special Educational Needs." *International Journal of Psychology and Educational Studies* 7, no. 3 (September 2020): 178–93. https://doi.org/10.17220/ijpes.2020.03.016.

Chicago Beyond. "Why am I always being researched? A guidebook for community organizations, researchers and funders to help us get from insufficient understanding to more authentic truth." (Chicago: Chicago Beyond, 2019). https://chicagobeyond.org/researchequity/.

Cofiell, Sara. "Giving a Voice to the Parent/Guardians/Caregivers of Students with Special Needs: Advocacy for Services." *Masters Diss* (Dominican University: 2015) https://cardinalscholar.bsu.edu/bitstreams/b701c3fb-8614-475e-bf58-260a8a067427/download

Cortes, Monica et. al., "Families as Leaders in the Journey to Inclusive Schooling. Keys to achieving transformational change." (n.p., Centre for Inclusive Futures: 2018) https://inclusiveeducation.ca/wp-content/uploads/sites/3/2018/04/Families-as-Leaders-Pamphlet-Final-2018.pdf

Crenshaw, Kimberle. "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics." *University of Chicago Legal Forum*, 1989, 139–67. https://doi.org/10.4324/9780429500480-5.

Department for International Development. "Disability, poverty and development." (London, DFID: 2014) https://hpod.law.harvard.edu/pdf/Disability-poverty-and-development.pdf

Disabled People Partnership for Inclusive Education. "Advocacy and Training Toolkit." (n.p, Disabled People Partnership for Inclusive Education: 2011). https://www.allfie.org.uk/inclusion-resources/1220/

Disabled Persons Assembly, Imagine Better, Waikato University. “Spaces of Belonging. A report about disabled people’s experiences of belonging, place and community.” (n.p., Imagine Better, Waikato University and Disabled Persons Assembly: 2019) https://inclusionireland.ie/wp-content/uploads/2020/11/Spaces-of-Belonging-ETR-New-Zealand.docx

EENET, Enabling Education Review. Special Issue: Inclusive Education Advocacy. (Hollingworth, EENET: 2015) https://www.eenet.org.uk/resources/docs/EER%20advocacy.pdf

European Agency for Development in Special Needs Education, Key Principles for Promoting Quality in Inclusive Education – Recommendations for Practice (Denmark, European Agency for Development in Special Needs Education; 2011) https://www.eenet.org.uk/resources/docs/key-principles-EN.pdf

Family Advocacy. “All students learning together. Taking action on education.” (New South Wales, Family Advocacy: 2016) https://www.family-advocacy.com/assets/ce93bc49e3/all-students-learning-together-booklet.pdf

Fisher, Karen and Sandra Gendera. “Family advocacy model research.” Prepared for Family Advocacy NSW. (Sydney, University of New South Wales: 2022). https://www.unsw.edu.au/research/sprc/our-projects/family-advocacy-research.

Fisher, Karen and Sandra Gendera. “Study about Family Advocacy.” Easy Read. (Sydney, UNSW Social Policy Research Centre: 2022). https://www.unsw.edu.au/content/dam/pdfs/unsw-adobe-websites/arts-design-architecture/2023-03-fam-easy-read_final/2023-03-fam-easy-read_final.pdf.

Francis, G. L., Blue-Banning, M., Haines, S. J., Turnbull, A. P., & Gross, J. M. S. (2016). Building “our school”: Parental perspectives for building trusting family-professional partnerships. *Preventing School Failure*, 60(4), 329-336. https://doi.org/10.1080/1045988X.2016.1164115

Gallegos Navas, Miriam Mariana. “Las Familias de Estudiantes Con Discapacidad En La Escuela, Sus Necesidades y Demandas. Caso Ecuador.” *Familia y Educación en el siglo XXI: Formación parental para los nuevos retos sociales* 12, no. 1 (January 1, 2017): 20–31. https://doi.org/10.17163/alt.v12n1.2017.02.

Goldman, Samantha E., Meghan M. Burke, Maria P. Mello. “The Perceptions and Goals of Special Education Advocacy Trainees.” *Journal of Developmental and Physical Disabilities*, 31 (2019): 377-397. http://dx.doi.org/10.1007/s10882-018-9649-2

Goldman, Samantha E. “Special Education Advocacy for Families of Students with Intellectual and Developmental Disabilities: Current Trends and Future

Directions." *International Review of Research in Developmental Disabilities*, 2020, 1–50. https://doi.org/10.1016/bs.irrdd.2020.07.001.

Hess, Robyn S., Amy M. Molina, and Elizabeth B. Kozleski. "Until Somebody Hears Me: Parent Voice and Advocacy in Special Educational Decision Making." *British Journal of Special Education* 33, no. 3 (August 24, 2006): 148–57. https://doi.org/10.1111/j.1467-8578.2006.00430.x.

Holmes, Andrew. "Researcher Positionality - A Consideration of Its Influence and Place in Qualitative Research - A New Researcher Guide." *Shanlax International Journal of Education* 8, no. 4 (September 2020): 1–10. https://doi.org/10.34293/education.v8i4.3232.

ILO. "Breaking the vicious circle of disability and extreme poverty." (n.p, ILO: 2014) https://www.ilo.org/wcmsp5/groups/public/---africa/---ro-abidjan/---ilo-lusaka/documents/publication/wcms_313672.pdf

Inclusion Europe. "Why we care about education." Inclusion Europe position paper on inclusive education. (n.p, Inclusion Europe: 2021). https://www.inclusion-europe.eu/why-we-care-about-education-new-position-paper/

Inclusion International and INICO. "Better Education for All: A Global Report." (Salamanca, INICO: 2009) https://www.inclusion-europe.eu/wp-content/uploads/2019/01/Education_Global_Report.pdf

Inclusion International. "Global Report on Poverty and Exclusion." (London, Inclusion International: 2006) https://s38312.pcdn.co/wp-content/uploads/Hear-our-Voices-Global-Report-on-Poverty-and-Exclusion.pdf

Inclusion Ireland. "Guide to Advocacy." (Dublin, Inclusion Ireland: 2011). https://inclusionireland.ie/wp-content/uploads/2020/10/guidetoadvocacy20112.pdf

Jacay Munguia, Sheila Verena. "Manual de Incidencia Política: Nuestra experiencia en Sordoceguera." (Lima, Sense Internacional Perú: 2014) https://deafblindness.info/wp-content/uploads/2021/10/Manual-de-Incidencia-Politica-2014.pdf.

Jodl, Jacqueline and Maya Bian. "Global State of Inclusion in Education: A review of the literature." Policy Brief 108. (Special Olympics Global Center for Inclusion in Education: January 2023). https://www.inclusive-education-initiative.org/sites/iei/files/2023-01/108_Global%20State%20of%20Inclusion_Policy%20Brief_V21.pdf

Kupferman, Scott, and Robert Hand. Toolkit. "Systemic Advocacy for People with Disabilities." (Community Development Authority, Dubai: 2017) https://www.cda.gov.ae/ar/HumanRights/Documents/Advocacy_Toolkit-%20EN-8Sept2020.pdf

Lee, Chung eun, Meghan M. Burke, Leann Smith DaWalt, Chak Li, and Julie Lounds Taylor. “The Role of Parental Advocacy in Addressing Service Disparities for Transition-Aged Youth on the Autism Spectrum.” *Autism* 26, no. 4 (November 29, 2021): 1001–6. https://doi.org/10.1177/13623613211057660.

López-Márquez, Norma Graciela. “Funcionalidad familiar y participación escolar de las familias de niños con discapacidad”, *IE Revista de Investigación Educativa de la REDIECH*, 8, 14, (2017): 111-128 https://www.scielo.org.mx/scielo.php?script=sci_arttext&pid=S2448-85502017000100111

Martínez, Darío Dorado, Álvaro, y John Lesber Benavides Benavides. “Inclusión Educativa De Adolescentes Con Discapacidad En El Nivel De Secundaria En Instituciones Educativas De América Latina: Revisión sistemática.” *Informes Psicológicos*, 23, 1 (2013): 12-28. https://doi.org/10.18566/infpsic.v23n1a01.

Massoud, Mark Fathi. “The Price of Positionality: Assessing the Benefits and Burdens of Self-Identification in Research Methods.” *Journal of Law and Society* 49, no. S1 (July 26, 2022): S64-86. https://doi.org/10.1111/jols.12372.

Ministerio de Educación. Orientaciones generales para fomentar la participación familiar en la educación inclusiva (Bogotá, Ministerio de Educación: 2019) https://colombiaaprende.edu.co/sites/default/files/files_public/2020-12/Orientaciones%20Participacio%CC%81n%20Familias.pdf

Mohd Yatim, Nurul Azhana, and Manisah Mohd Ali. “Parental Advocacy for Students with Special Needs: A Systematic Review Study.” *International Journal of Academic Research in Progressive Education and Development* 11, no. 2 (April 9, 2022): 62–73. https://doi.org/10.6007/ijarped/v11-i2/13065.

Muñoz, Vernor. “The right to education of persons with disabilities.” Report of the Special Rapporteur on the right to education. A/HRC/4/29 (Geneva, United Nations: 2007 https://documents-dds-ny.un.org/doc/UNDOC/GEN/G07/108/92/PDF/G0710892.pdf?OpenElement

NCOSS. “Report on disability advocacy, representative and information organisations.” (New South Wales, NCOSS: 2019) https://www.ncoss.org.au/wp-content/uploads/2019/12/Report-on-disability-advocacy-representative-and-information-organisations-October-2019.pdf

Odongo, George. “Barriers to Parental/Family Participation in the Education of a Child with Disabilities in Kenya.” *International Journal of Special Education* 33, 1 (2018): 21-33. https://files.eric.ed.gov/fulltext/EJ1184076.pdf

Oliver, Michael and Colin Barnes. *The New Politics of Disablement.* New York, Palgrave Macmillan: 2012.

Ollerton, Janice. “IPAR, an Inclusive Disability Research Methodology with Accessible Analytical Tools.” *International Practice Development Journal* 2, no. 2 (November 2012). https://www.fons.org/library/journal/volume2-issue2/article3.

R. Musolino-Olson, Amanda. “Parent Advocacy in Special Education: Critical Principles and Action Steps.” Master’s thesis. https://spark.bethel.edu/etd/836.

Robinson, Oral & Alexander Wilson. *Practicing and Presenting Social Research*. Vancouver: University of British Columbia, 2022.

Palacios, Agustina.” El modelo social de discapacidad. Orígenes, caracterización y plasmación en la Convención Internacional sobre los Derechos de las Personas con Discapacidad.” (Madrid, Cinca: 2008).

Palacios, Agustina y Francisco Bariffi. “La discapacidad como una cuestión de derechos humanos. Una aproximación a la Convención Internacional sobre los Derechos de la Personas con Discapacidad” (Madrid, Cinca: 2014), https://bit.ly/2A16qKT

Rieser, Richard. *Implementing inclusive education: A commonwealth guide to implementing Article 24 of the UN Convention on the Rights of Persons with Disabilities*. London: Commonwealth Secretariat, 2012.

Rossetti, Zach et. al, “Parent Perceptions of the Advocacy Expectation in Special Education”, *Exceptional Children*, 87 (2021): 434-457 https://doi.org/10.1177/0014402921994095.

Samuel, Kim. *On Belonging.* New York, Abrams Press: 2022.

Save the Children. “Making Inclusive Education a Reality: How change can happen. Save the Children’s Experience.” (London, Save the Children: 2008) https://dylbw5db8047o.cloudfront.net/uploads/1590.pdf

Sightsavers. “Making inclusive education a reality.” (n.p, Sightsavers: 2011) https://www.eenet.org.uk/resources/docs/16079_Sightsavers%20IE%20Policy%20Paper%202011%20-%20FINAL.pdf

Strnadová, Iva, and Jan Walmsley. “Peer-Reviewed Articles on Inclusive Research: Do Co-Researchers with Intellectual Disabilities Have a Voice?” *Journal of Applied Research in Intellectual Disabilities* 31, no. 1 (June 22, 2017): 132–41. https://doi.org/10.1111/jar.12378.

Strnadová, Iva, Leanne Dowse and Benjamin García-Lee. *Doing Research Inclusively: Co-Production in Action.* (Sydney: University of New South Wales Disability Innovation Institute, 2022).

Shakespeare, Tom. *Disability: The Basics*. Milton: Routledge, 2018.

Trainor, Audrey A. “Diverse Approaches to Parent Advocacy during Special Education Home—School Interactions.” *Remedial and Special Education* 31, no. 1 (October 9, 2008): 34–47. https://doi.org/10.1177/0741932508324401.

Ulises Sánchez Delgado et. al, "Inclusión Educativa en América Latina, una mirada más allá de la educación especial", Revista ConCiencia EPG, 1, 1 (2016): 95-106 https://doi.org/10.32654/CONCIENCIAEPG.1-1.10

UNESCO Institute for Statistics. Information Paper No. 49. “Education and Disability: Analysis of Data from 49 Countries.” (New York, UNESCO: 2018) https://uis.unesco.org/sites/default/files/documents/ip49-education-disability-2018-en.pdf

UNESCO. “Global Education Monitoring Report 2020. Inclusion and Education: All means all.” (New York, UNESCO: 2020) https://unesdoc.unesco.org/ark:/48223/pf0000373718/PDF/373718eng.pdf.multi

UNESCO. “Guidelines for inclusion: Ensuring access to education for all.” (Paris, UNESCO: 2009) https://www.ibe.unesco.org/sites/default/files/Guidelines_for_Inclusion_UNESCO_2006.pdf

UNESCO. “Promoting Inclusive Teacher Education Advocacy Guides.” (Bangkok, UNESCO Bangkok Office: 2014) https://bangkok.unesco.org/sites/default/files/assets/article/Education/doc/20_Dec_ADVOCACY_combine.pdf

UNESCO. “Temario abierto sobre educación inclusiva: materiales de apoyo para responsables de políticas educativas.” (Santiago, UNESCO: 2004), https://unesdoc.unesco.org/ark:/48223/pf0000125237_spa

UNICEF. “Participación de los padres y madres, la familia y la comunidad en la educación inclusiva.” (Nueva York, UNICEF: 2014) https://www.unicef.org/eca/sites/unicef.org.eca/files/2019-05/Cuadernillo%2013.pdf

UNICEF. “Seen, Counted, Included. Using data to shed light on the well-being of children with disabilities.” (New York, UNICEF: 2021) https://data.unicef.org/resources/children-with-disabilities-report-2021/

United Nations Committee on the Rights of People with Disabilities. “General Comment 7: How to work together with organisations of persons with disabilities.” Easy Read. (Geneva, United Nations: 2018) https://www.ohchr.org/Documents/HRBodies/CRPD/CRPD_C_GC_7_8757_EasytoRead.docx

United Nations Committee on the Rights of Persons with Disabilities. “General Comment No. 6 on equality and non-discrimination.” CRPD/C/GC/6 (Geneva, United Nations: 2018) https://documents-dds-ny.un.org/doc/UNDOC/GEN/G18/119/05/PDF/G1811905.pdf?OpenElement

Walker, Jo. Equal Right, “Equal Opportunity. Inclusive Education for Children with Disabilities.” (n.p, Handicap International and Global Campaign for Education: 2013) https://docs.campaignforeducation.org/reports/Equal%20Right,%20Equal%20Opportunity_WEB.pdf

Walmsley, Jan. “Involving Users with Learning Difficulties in Health Improvement: Lessons from Inclusive Learning Disability Research.” *Nursing Inquiry* 11, no. 1 (March 2004): 54–64. https://doi.org/10.1111/j.1440-1800.2004.00197.x.

Washington Group. “About the Washington Group on Disability.” https://www.washingtongroup-disability.com/about/about-the-wg/

West Virginia University Center for Excellence in Disabilities. “Types of Advocacy.” https://cedwvu.org/resources/types-of-advocacy/