

References & Image Descriptions for Family and Disability Activism

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Cover

Image Descriptions

Page # : Cover

Alt text : Portrait of a cyborg infant in a green that also features curious birds, a growth chart, flower pictures and a dream catcher.

Long description: A completed painting depicting a cyborg infant in a green bassinet. Birds have entered the room through an open window. They have toppled a potted plant which lies beside the cradle. A yellow canary stands on the floor below a child's growth chart. It appears to be looking into a closet in which an empty cradleboard is just visible in the shadows. Three pictures of flowers decorate the wall above the cradle. A dream catcher hangs from a curtain rod above the cradle from which is also draped a white lace curtain. One of the birds, a brown headed cowbird pulls on the wires attached to the infant's arm.

Chapter: Introduction

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Chapter 3: Tàcharan: An "Autie"-Ethnographic Examination of the Biopolitics of Changelings and Cyborgs

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Chapter 4: Empathy Deficits among Neurotypicals

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Chapter 5: Black Deaf Ordinary Who Deliberately Signs

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Chapter 6: Intersections of Deafness, Blindness, Deafblindness, and Gender: The Deaf Community, Blindness, and Deafblind Activism in Families

Image Descriptions

Table 6.1

Page # : 93

Alt text : Table 6.1 lists the memoirs of five books written by women who are Deafblind: Helen Keller, Ruth Silver, Rebecca Alexander, Haben Girma, Elsa Sjunneson.

Long description: Table 6.1 lists the memoirs written by women who are Deafblind. The first book listed is “The Story of My Life,” by Helen Keller and it was published in 1902. The second book, “Invisible: My Journey through Vision and Hearing Loss,” is written by Ruth Silver and was published in 2012. The third book, “Not Fade Away: A Memoir of Senses Lost and Found,” is written by Rebecca Alexander and was published in 2014. The fourth book entitled, “Haben: The Deafblind Woman Who Conquered Harvard Law,” was written by Haben Girma and published in 2019. The last book is entitled, “Being Seen: One Deafblind Woman’s Fight to End Ableism.” It is written by Elsa Sjunneson and was published in 2021.

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Chapter 7: Aging Out of Children's Hospitals: People with Complex Medical Conditions and Their Families in the Twentieth and Twenty-First Centuries

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Chapter 8: Survive and Thrive: How Little Lobbyists Empowers Families to Fight for Disability Justice

Image Descriptions

Figure 8.1

Page # : 135

Alt text : LL logo in red, white and blue, with a child holding a star and a heart with an EKG line

Long description: LL logo in red, white and blue, with a child holding a star and a heart with an EKG line. Text reads: Little Lobbyists, a family-led group advocating for children with complex medical needs and disabilities

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27. 27. Elena Hung interview, 11:53:57 to 11:55:24.
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29. 29. Today, Little Lobbyists' board and staff are diverse, and it is led by a disabled woman of color (Elena Hung identifies as a disabled person); however, our organization still relies on families with time and resources to volunteer long, unpaid hours. These families are skewed white and higher income. Promoting diversity, equity, and inclusion remains a challenge.
30. 30. While disabled adults are free to make their own decisions to risk their health and safety, parents of disabled children in the U.S. can be held legally responsible for such decisions by child protective services. Children can even be removed from the care of parents whose actions are deemed unsafe, whether or not the parent was following the wishes of the child to begin with.
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Chapter 9: How to Do Limitless Lifelong Self-Determination

Image Descriptions

Figure 9.1

Page # : 150

Alt text: 3 boxes labelled Autonomy, Competence & Relatedness. 2 stick figures (one in a wheelchair) on a box labelled Self-Determination

Long description: Three boxes are lined up horizontally, each saying, “Autonomy,” “Competence,” and “Relatedness.” A stick figure character standing and another stick figure in a wheel chair rest on a text box that says “Self-Determination.”

Figure 9.2

Page # : 159

Alt text: A Pie Chart that shows that the 13% of students with disabilities endured 80% of the physical restraints in schools.

Figure 9.3

Page # : 165

Alt text: examines how the level of restrictive guardianship is influenced by Student Self-Determination and influences on the parent

Long description: This figure examines how the level of restrictive guardianship is influenced by Student Self-Determination and influences on the parent. Examples include the student’s acceptance of disability pride, exposure to trauma, and decision-making support. Examples of parent influences include attitude toward Dignity of Risk, child’s level of support needs, and attitudes encountered in the medical and school systems.

Table 9.1

Page # : 152

Alt text: This table lists ways that caregivers can help build self-determination in infants aged 0-3.

Long description: This table lists ways that caregivers can help build self-determination in the areas of autonomy, competence and relatedness for infants aged 0-3. Examples include developing decision-making to build autonomy; recognizing competence in sleeping and eating; and building relatedness in caregivers, medical professionals, and therapists. Strategies include giving babies age-appropriate choices and respecting those choices and respecting all abilities in areas of key development like walking and talking. The author says, “Just because people can’t walk, doesn’t mean they can’t have movement—just like the Civil Rights Movement. Walking is limited, but Movement is limitless.”

Table 9.2

Page # : 153

Alt text: This table lists ways that caregivers and educators can help build self-determination in elementary school students

Long description: This table lists ways that caregivers and educators can help build self-determination in elementary school students. Examples include learning to speak up and speak out and developing disability pride for autonomy; working with students to understand how they learn best and using that information to teach other subjects like reading and writing for competence; and providing opportunities to work together, teaching cooperation not compliance, and creating peer to peer relationships so that friends are included for relatedness. Strategies include not limiting self-advocacy skills to just asking for help, instead recognizing that self-advocacy can change the world, and also using assistive tech to help students succeed.

Table 9.3

Page # : 154

Alt text: This table lists ways that caregivers can help build self-determination in elementary school students.

Long description: This table lists ways that caregivers and educators can help build self-determination in elementary school students. Examples include learning to speak up and speak out and developing disability pride for autonomy; working with students to understand how they learn best and using that information to teach other subjects like reading and writing for competence; and providing opportunities to work together, teaching cooperation not compliance, and creating peer to peer relationships so that friends are included for relatedness. Strategies include not limiting self-advocacy skills to just asking for help, instead recognizing that self-advocacy can change the world, and also using assistive tech to help students succeed.

Table 9.4

Page # : 158

Alt text: This table lists the types of restraints, number of incidents, and incidents involving students with disabilities

Long description: This table lists the types of restraints, number of incidents, and incidents involving students with disabilities. For example out of the 101,990 cases of seclusion and restraints, 79,676 were used on students with disabilities.

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