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Welcome to Club SODA: Ways of Welcoming a Hearing Sibling into the Deaf Community to Create Feelings of Acceptance, Belonging, and Lifelong Allyship

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Welcome to Club SODA: Ways of Welcoming a Hearing Sibling into the Deaf Community to Create Feelings of Acceptance, Belonging, and Lifelong Allyship

By

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Figure 1. Hand opening the Club SODA Activity Book. Picture by Elizabeth Lamark.

Abstract:

Children who have a sibling with one or more disabilities are more likely to take on caregiver roles, the role of the elucidator, as well as exhibit externalized aggressive behaviors and/or internalized depression and anxiety than their peers.[1,2] Causes of this vary but can include the differential impact of parents/caregivers, feelings of a "loss of childhood", communication challenges, and social stigma.[3,4] Acceptance and Commitment Therapy (ACT) is a therapeutic methodology in which a person works towards well-being by accepting and embracing current realities.[5] S.O.D.A. is the acronym for a Sibling of a Deaf Adult/child and this paper explores how welcoming a SODA through an ACT inspired activity book could introduce a child to the asset-framed cultural aspect of Deafness while still making space for the range of possible emotions. This proposed activity book is an attempt to encourage resiliency and

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[1] Warner-Czyz, Wiseman, and Nelson, "Quantitative and Qualitative Perspectives of Siblings of Children With Cochlear Implants."

[2] Tattersall and Young, "Exploring the Impact on Hearing Children of Having a Deaf Sibling."

[3] Tattersall and Young.

[4] Breslau and Prabucki, "Siblings of Disabled Children."

[5] "Acceptance and Commitment Therapy | Psychology Today."

belonging for those who could be considered periphery members of the Deaf community and to help solidify a healthy family system during a time of transition.

Acknowledgement

Introduction

During the time that a child is identified as Deaf, a family can go through a grieving process and feel overwhelmed with information, choices, and decisions to be made.[6] This can be exasperated by how the medical descriptors of Deafness center the physical deficit (i.e. "failing" a newborn hearing screening test, "hearing loss") rather than asset-framing or even including information about the Deaf community.[7] Additionally, doctors and medical professionals are primary points of contact for parents rather than Deaf adults or other forms of mentorship.

Sibling relationships can be a powerful and important role for a person over the course of a lifetime, and healthy connections can offer empathy, love, and support. A S.O.D.A. is the acronym for a Sibling of a Deaf Adult/Child. In considering family systems, children who have a sibling with one or more disabilities are more likely to take on caregiver roles, and the role of the elucidator, experience feelings of ambivalence towards their sibling, as well as exhibit externalized aggressive behaviors and/or internalized depression and anxiety than their peers.[8,9] Because there is no formal or informal way in

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[6] Sloman, Springer, and Vachon, "Disordered Communication and Grieving in Deaf Member Families."
[7] Chapman, "Representation and Resistance."
[8] Warner-Czyz, Wiseman, and Nelson, "Quantitative and Qualitative Perspectives of Siblings of Children With Cochlear Implants."
[9] Tattersall and Young, "Exploring the Impact on Hearing Children of Having a Deaf Sibling."

which these finding are presented to parents or caregivers, it's possible people go their whole lives without directly addressing these challenges.

Acceptance and Commitment Therapy (ACT) is a therapeutic methodology in which a person works towards well-being by accepting and embracing current realities.[10] While ACT was developed for adults and scholarship is still emerging on its benefits with children, adolescents who had depression have exhibited improved resilience by learning to accept challenging emotions rather than avoiding them.[11]

Asset-framing is the practice developed by Trabian Shorters and Benjamin Evans by which people or groups of people are defined by their assets and hopes before their challenges and deficits.[12] Originated for the Black community to center aspirational language, this framework is synergetic with the Deaf-Rights movement. Born in the 1980s, the Deaf-rights movement claimed Deafness with a capitol D and rejected that it was a medical condition in need of being fixed.[13]

By combining asset-framing with ACT methodology, a welcoming activity book could be a way to introduce a family to the Deaf community as well promote a siblings well-being during a time of family transition.

Problem Statement

How can families of Deaf children be supported in ways that encourage a healthy family system of care and communication?

Project

Despite ample research that points to the positive effects of community, families with Deaf children often only engage with the medical aspects of deafness. This can result in efforts to "fix" what is seen as a physical "deficit." For this project, I wanted to explore the tension of the cultural vs the medicalization of deafness and how reframing that tension could result in better well-being for the entire family, including the Deaf child.

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[10] "Acceptance and Commitment Therapy | Psychology Today."
[11] Parmar et al., "Acceptance and Commitment Therapy for Children with Special Health Care Needs and Their Parents."
[12] "Understanding Asset-Framing: Guidelines for CHCF Authors."
[13] Chapman, "Representation and Resistance."

After identifying the problem statement I had a series of expert interviews to determine the viability of the project. Following that validation, I began a broad design process starting with ideation. I presented 30 divergent ideas in the form of sketches for review. The ideas were categorized into "threshold and community," "language and communication" and "toys and tools."
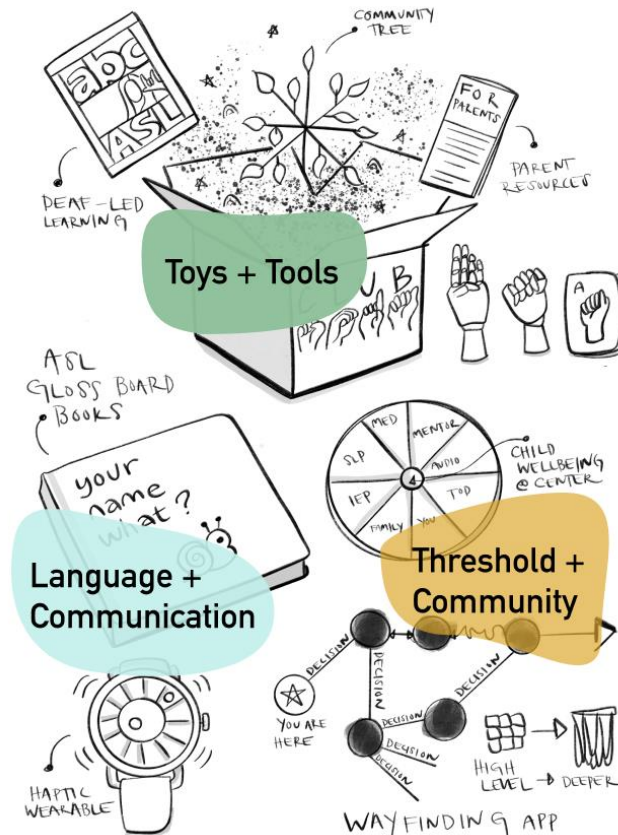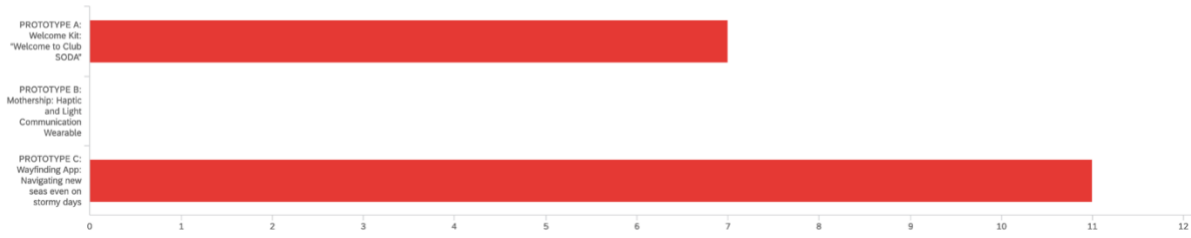

Figure 2. Shows some of the 30 divergent sketches presented during the early ideation process.

These ideas were narrowed down to three possible paths: A wayfinding information app, a welcome kit for SODAs, and a wearable communication device. From there I surveyed 20 people for their feedback on what project could best support the problem statement and which prototype was their favorite.
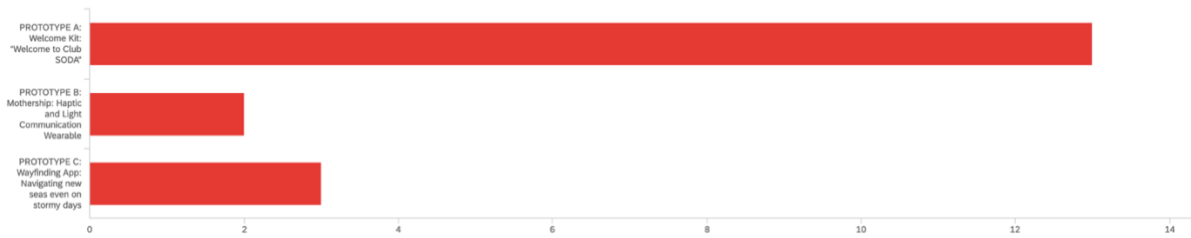
Figure 3. Results from initial prototype survey.

The results showed that while some more people supported the wayfinding app, the vast majority preferred the Club SODA welcome kit. This information told me that if the welcome kit could be robust, then that prototype could be very impactful. The feedback quote below was motivating as well:

> *"As a teacher of the Deaf at [this Deaf School], so many families are often unsure how to interact with their Deaf and hearing children- simply because parents often are learning ASL and forgot to teach their hearing children ASL to communicate with their Deaf sibling. Siblings are often a child's first friend, if a sibling learns ASL to communicate, Deaf child will feel involved in family matters, not just with parents but with siblings. I strongly believe this tool would be benefit [this Deaf School]!"*

To establish an effective welcome kit, root issues needed to be examined as well as effective ways of treating them. Acceptance and Commitment Therapy has been studied with families with children with

disabilities, showing positive outcomes.[14] I explored and identified 4 areas of pain points, or areas of concern or difficulty, with greater opportunity of acceptance/connection.

4 Paint Point Areas around Connection/Acceptance:

Parents/Grownups: Bidirectional impact/Differential parenting: not enough time or energy. Scheduled time/focus, understanding via pamphlet.

Deaf Sibling: Emotional ambivalence, struggle to communicate: ASL resources, love, respect, communication, play.

Environment/Social: stigma, out of balance responsibilities (feelings of co-dependence)

Myself: Positive self-talk, mental health, "There are lots of things about me, Club SODA Workbook" and in person SODA group.

I presented these 4 categories to a select group of experts and potential users and interviewed them about their thoughts. Through this I determined that an Activity Book that focused on the "myself" aspect could also include the other areas of connection, and be a viable option for families.

Using my list of pain points and an interpretation of Acceptance and Commitment therapy workbooks, I crafted 8 pages. Again, I surveyed my user group on the relevance and effectiveness of each page as well as ranking the pages.

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[14] Parmar et al., "Acceptance and Commitment Therapy for Children with Special Health Care Needs and Their Parents."
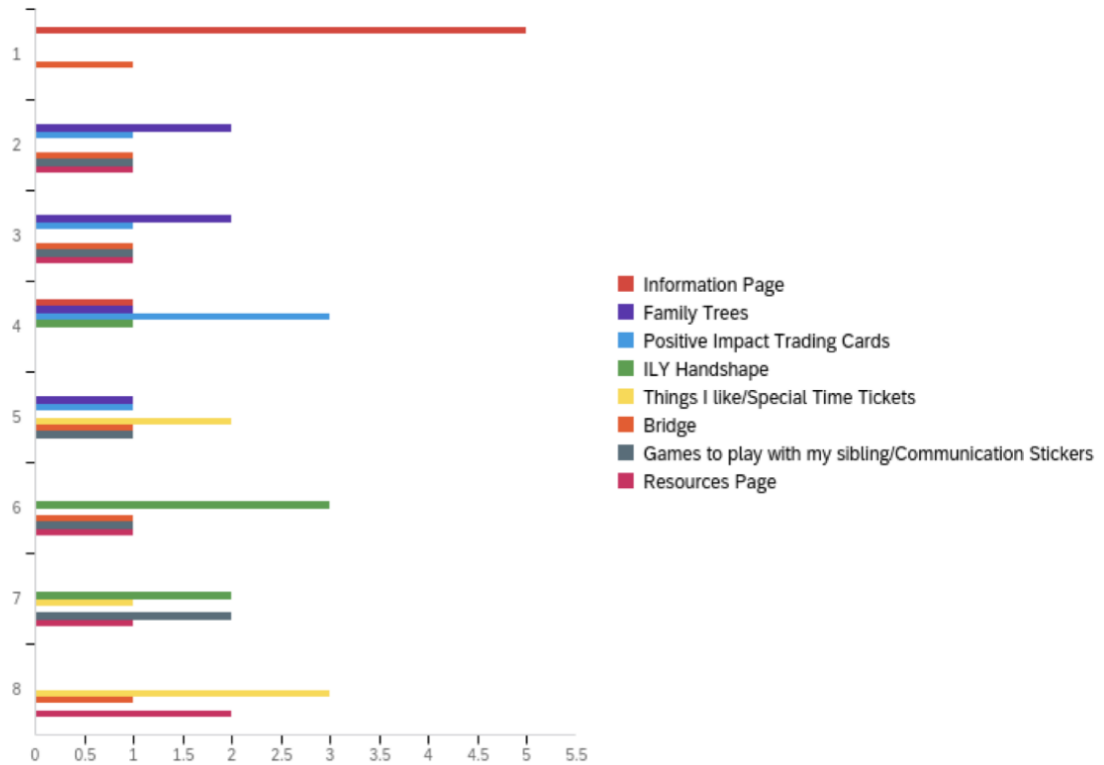
Figure 4. Survey page ranking.

Concept Refinement

The survey results helped to establish the validity of the activity book as well as indicate what pages needed reframing or eliminated. I was now back into a generative part of the process, designing and creating the content of the pages, the narrative structure and as well as the graphic design and visual language. I decided to create a kind of "call and response" narrative, where the SODA plays an active voice in the story. These alternating voices are illustrated through the use of distinct fonts and colorful backgrounds.

Figure 5. Screenshot of Activity book illustrating the two distinct voices in the narrative.

I reworked the title which helped to refine the project as a whole: "Club SODA: Ways of Welcoming A Hearing Sibling into the Deaf Community to Encourage Feelings of Acceptance, Belonging, and Lifelong Allyship." I now had the focal points of acceptance, belonging, and lifelong allyship.

For **acceptance**, I leaned more heavily around ACT and methodology. I added in points of reflections and mindfulness, as well as other workbook tools such as the ACT Matrix[15] which I modified to better suit the application of communication around the directional impact of caregivers.

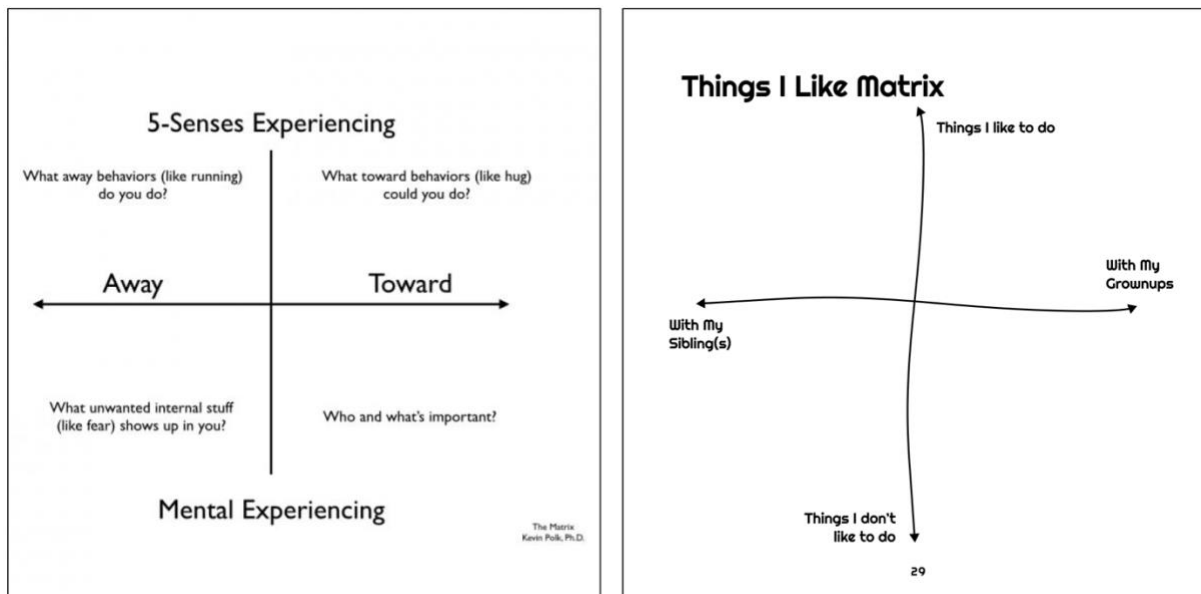[15] "The ACT Matrix | Association for Contextual Behavioral Science."

Figure 6. ACT "Mental Experience" matrix on the left and Club SODA's "Things I like" Matrix on the right.

For **belonging**, my survey revealed that it was widely agreed that a Club SODA pin would benefit the project. Based on my feedback about the diversity within the family unit, I pivoted away from the idea of a vertical (genetic) and a horizontal (community) tree and moved into the idea of a "community web." The prompt states "One of the ways people think about their family is through a family tree. In this book, we're going to think about a community like a web between the branches of that tree. With your grown-up, chat about some of the trusted adults and loving friends in your life. Fill in some names on the Community Web on the next page, and know that it is always growing!"
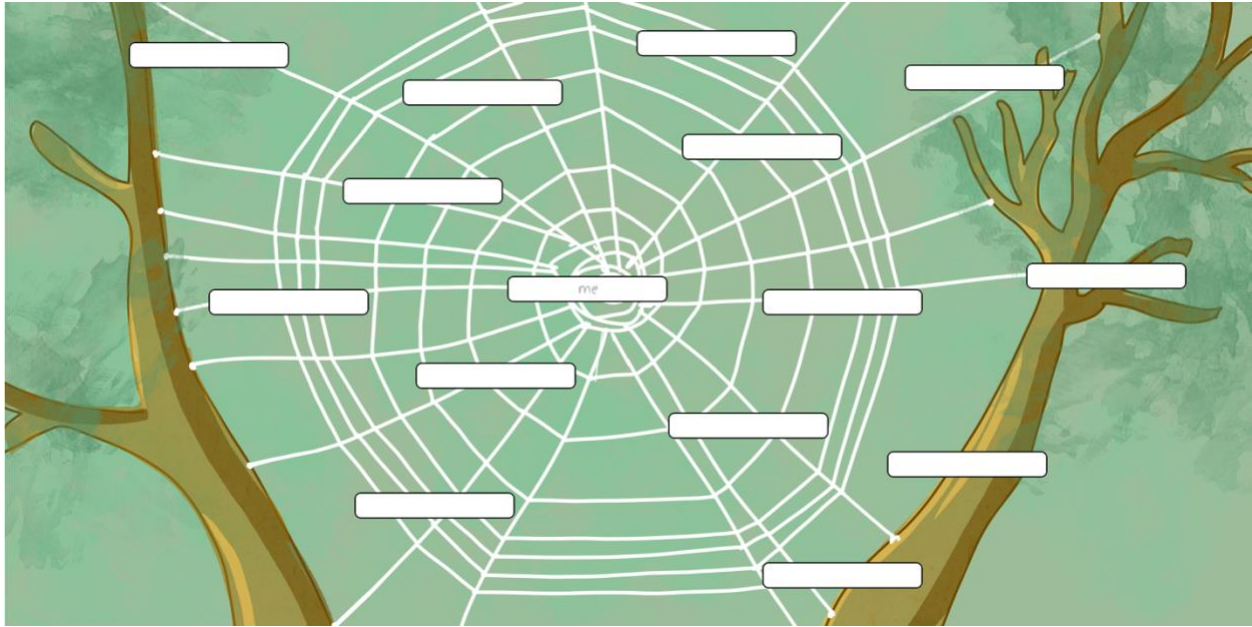
Figure 7. Community Web graphic

For **lifelong allyship**, my research has shown that one of the more effective ways that children process new concepts and emotion in through pretend play. In "Pretend Play, Creativity, and Emotion Regulation in Children", in one study is summarized to illustrate that "preschool children were assessed for emotion regulation and observed engaged in pretend play with their parents. Results indicated that children who engaged in pretend play with their parents more often were found to have higher ratings of emotion regulation."[16] Because of this I decided an open play block toy and the end of the book could be a useful addition to some of the more difficult concepts to digest. Additionally, one of my expert interviews with a Deaf Social Worker, gave this suggestion:

> *"If you are looking to expand this, a related activity could be interview questions or sentence starters for the readers to answer/ask each other questions. Could be just a few questions to get the siblings to understand and connect a bit deeper. Questions along those lines can connect to the consideration of "lifelong allyship"."*

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[16] Hoffmann and Russ, "Pretend Play, Creativity, and Emotion Regulation in Children."

Figure 8. Three children play with the bridge building toy. Picture by Elizabeth Lamark.

Final Interviews

After the narrative of the book was complete, and the visual language was relatively established, it was a good time to conduct final interviews with this prototype. I interviewed an adult SODA, a Visual Artist who is Deaf, the Principal at a Deaf Residential School, and a childhood Social Worker who is Deaf. The purpose of these interviews was to reestablish validity and to get any final feedback for improvement to the prototype. Overall, the feedback was very strong and provided me with final notes to consider. Quotes from three different interviewees are:

> *"This is a fabulous and much-needed resource for families navigating their worlds with deaf children and hearing siblings… I love that you included some mindfulness and reflection activities for siblings to do together. It is easy to read and very hands-on."*
>
> - Child Social Worker

"I think that the book does a really nice job inviting parents and kids to have a conversation (and I think sometimes parents and kids don't necessarily know how to start that conversation)… about deafness and Deaf culture. And I think that that's something that parents and kids really need... I'm thinking especially about, like naming and validating that being in the Deaf community might feel like favoring a kid over another kid. Just saying that's normal, and how can we balance that by giving you time that you need and some of the activities here are easy to use and allow for both parent and kid to explore what that looks and feels like for them?"

- S.O.D.A

"I believe this is a resource I would share in our welcome bag that we provide to families. I believe these tools would not only be useful for SODAs but it is a nicely broken down, easy to follow, and not overwhelming book to share with families in general. I could see versions for a grandparent/aunt/friend."

- Teach of the Deaf

Conclusions and Future Considerations

The value and format of a mental health activity book is becoming prevalent. While Club SODA could be considered niche, and as design continues to move towards customized experiences, my hope is this project does have a place in the broader mental health and inclusion landscape.

This project would be enhanced with the collaboration of a Deaf Culture expert and/or historian to ensure that all cultural sensitives are being considered. Further research is needed to better determine if the Club SODA Activity Book is effectively improving well-being and communication in the family unit. This could be done under the supervision of a child psychologist and through the use of surveys designed to quantify acceptance and belonging before and after doing the activities in the book.

Inclusive activity books could be scalable, generating a series that could be designed to include C/KODAs, as well as aunts, uncles, cousins, grandparents, and the extended family with the hope of creating a more expansive and inclusive family space for Deaf children.

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