### **EMPOWERING WITH Co-DESIGN**

From Music-making to Achieving a Sense of Agency

By

Saee Sanjeev Tipnis

Submitted to OCAD University in partial fulfilment of the requirements for the degree of Master of Design in Inclusive Design

Toronto, Ontario, Canada, 2024

#### **Copyright Notice**

This work is licensed under the Creative Commons Attribution: Non-Commercial 4.0 International License.

To view a copy of this licence, visit http://creativecommons.org/ licences/by-nc/4.0/.

You are free to:

Share — copy and redistribute the material in any medium or format.

Adapt — remix, transform, and build upon the material.

Under the following terms:

Attribution — You must give appropriate credit, provide a link to the licence, and indicate if changes were made. You may do so in any reasonable manner, but not in any way that suggests the licensor endorses you or your use.

Non-commercial — You may not use the material for commercial purposes.

#### Notices:

You do not have to comply with the licence for elements of the material in the public domain or where your use is permitted by an applicable exception or limitation.

No warranties are given. The licence may not give you all the permissions necessary for your intended use. For example, other rights such as publicity, privacy, or moral rights may limit how you use the material.

#### Abstract

Music is a source of self-expression. Concerning adults with Cerebral Palsy (CP), active music-making brings multiple benefits. This paper explores strategies to empower Christine Jimenez musically. She is a 51-year-old individual with cerebral palsy and a member of the Bliss i-Band, a music community that gathers weekly as an ensemble. This design-based project investigates lived experiences and challenges associated with technology and communication within the Bliss i-Band and proposes design concepts to overcome systemic gaps. With an Inclusive Design approach, the project utilizes a community-led co-design practice by involving i-Band members, their music companions, and facilitators as collaborators. The three-dimensional inclusive design framework lays the foundation of this collaboration of designing within a complex adaptive system. By integrating every co-designer's narrative, we emphasize the importance of understanding user needs, goals, and contexts. This co-design intervention provides insights into the current system and proposes a foundation for future innovations within the Bliss i-Band and similar community frameworks.

#### Author's Declaration

I hereby declare that I am the sole author of this MRP (Major Research Project). This is a true copy of the MRP,

Including any required final revisions, as accepted by my examiners.

I authorise OCAD University to lend this MRP to other institutions or individuals for the purpose of scholarly research.

I understand that my MRP may be made electronically available to the public.

I further authorise OCAD University to reproduce this MRP by other means, in total or in part, at the request of other institutions or individuals for the purpose of scholarly research.

Saee Sanjeev Tipnis

#### Acknowledgements

My heart is overflowing with gratitude as I write this paper. Since I came across the Inclusive Design program at OCAD University, I have wanted to be a part of this institution. I feel fortunate that my well-wishers acknowledged my dream and supported me to achieve it! I want to extend my deepest gratitude towards the cornerstones of my life. I am deeply grateful to my Baba, my father, for his unwavering support, boundless care, and unconditional love. At this moment, I yearn for the presence of my dearest mom and grandparents. I know you are watching over me. My dearest Sudhanshu, my partner in everything! I couldn't have embarked on this journey without you, and I value your presence through every high and low. To my family, I am indebted for their financial support. Your belief in me and your perseverance in keeping my dream alive when it seemed insurmountable, I am forever grateful for.

Words fail to express my gratitude for the Toronto FAM: Advaith, Gulay, Harsh and Asmita. To my OCAD University Support, a special thank you to my Principal Advisor, Jutta Treviranus, for your invaluable guidance in the inclusive world. Thank you to all instructors for pushing my learning boundaries and instilling the principles of inclusive practice in me.

Shirley, Rebecca, Christine, and the Bliss i-Band --- your community has brought out the best in me! I am at a loss for words to express my gratitude for the space you have given me to grow and thrive. Your support and encouragement have been instrumental in my personal and professional growth.

#### Dedication

To:

Christine Jimenez:

You are a ray of sunshine,

Keep dreaming and keep smiling!

Bliss i-Band:

I hope you continue,

Celebrating life as it comes.

Blissful wishes to you.

Baba:

My dad, my everything,

I am because you are.

All that I do is for you!

#### Table of Contents

COPYRIGHT NOTICE	2
ABSTRACT	
AUTHOR'S DECLARATION	4
ACKNOWLEDGEMENTS	5
DEDICATION	
TABLE OF CONTENTS	7
LIST OF FIGURES	11
INTRODUCTION	15
THE PROJECT	
INTRODUCTION TO THE CO-DESIGNERS	
Saee S. Tipnis	
Christine Jimenez	
Shirley McNaughton	
Rebecca Chan	
BACKGROUND	
BLISSYMBOLICS COMMUNICATION INSTITUTE CANADA (BCIC)	
BLISSYMBOLICS	
CHARLES K. BLISS	
BLISS I-BAND	

PURPOSE OF THE BLISS I-BAND	
MUSICAL GOALS OF THE BAND	
CO-DESIGN 1.0	
ETHICAL CONSIDERATIONS	
OBJECTIVE AND RESEARCH QUESTIONS	
Our Approach	
3Ds of Inclusive Design	
Co-design	41
Contributors of this Project	42
CHALLENGES THAT STILL EXIST	44
REFLECTING ON THE WEEKLY I-BAND SESSIONS	47
Use of Technology & Accessibility Check	49
GarageBand	49
Chordify	52
Signing Sheet	53
IDENTIFYING GAPS FROM A COMPANION'S PERSPECTIVE	55
RESEARCH	61
SECONDARY RESEARCH	62
Cerebral Palsy	62
Music and Cerebral Palsy	63
PRIMARY RESEARCH	65
Christine's Lived Experiences	

1. Key findings from 1st Interview with Shirley McNaughton	67
Set-1: Prompting Questions	75
2. Key findings from 2nd Interview with Shirley McNaughton	76
Set-2: Prompting Questions	78
3. Key findings from interviews with Rebecca Chan	78
4. Key findings from Interview with a Companion	81
Set-4: Prompting Questions	83
DESIGN DECISIONS	84
DESIGN & DEVELOPMENT	86
Features of the Guide	87
Ideation	90
User Testing	98
DESIGNING ICONOGRAPHY	99
Shirley's Feedback	102
CHOICE OF COLOUR PALETTE	109
CO-DESIGN 2.0	112
Αςτινιτγ 1	113
ACTIVITY 2.	114
Астіvіту 3.	115
Астіvіту 4.	116
Christine's Response from the Co-design Activities:	117
LIMITATIONS	118

CONTRIBUTIONS TO AN INCLUSIVE WORLD	119
FUTURE SCOPE	120
REFERENCES	122

#### List of Figures

 Figure 1: Blissymbolics Communication Institute Canada (BCIC) logo on its website

 banner.
 24

Figure 2: Examples of Blissymbols representing characters, showcasing the effectiveness of Blissymbols in conveying abstract concepts through clear visual symbols.

Figure 3: Examples of Blissymbols representing "knowledge" and its integration with other symbols to form words like, "teacher" - Knowledge provider and "student" -Figure 8: Musical Goals of the i-Band written in Blissymbolics with their English 

Figure	12: GarageBand Logo 4	9
Figure	<b>13:</b> Screenshot of the GarageBand software application	0
Figure	14: GarageBand interface with chord settings, used to play while using Chordify	1.
	5	1
Figure	<b>15:</b> Chordify Logo5	2
Figure	<b>16:</b> Screenshot of the Chordify interface5	2
Figure	17: Chord Signing Sheet5	4
Figure	<b>18:</b> Christine's VOCA5	6
Figure	<b>19:</b> Christine operating her VOCA with a single switch next to her head5	6
Figure	<b>20:</b> Christine's acrylic desk with stickers of "YES" and "NO"5	7
Figure	<b>21:</b> Christine's musical set-up in her room5	9
Figure	<b>22:</b> Diagram of the Cone of Vision6	0
Figure	<b>23:</b> Christine's Cone of Vision limited to her iPad6	0
Figure	24: Manual signs used in Kodaly Approach of teaching music	0
Figure	<b>25:</b> Accessible music-set up co-designed at the Bliss i-Band	0
Figure	<b>26:</b> Infographic Formats in Print and Digital versions	6

Figure 27: User interactions of the i-Band members with the infographic guide
Figure 28: Placement of a QR Code on Christine's wheelchair
Figure 29: Simplification of setting up a "Grand Piano" on GarageBand into 5 easy steps.
Figure 30: Sketches of GarageBand interface for the infographic guide
Figure 31: STEP 1: Make a "Music Project" in GarageBand
Figure 32: STEP 2: Selecting Grand Piano in the virtual musical instrument gallery 93
Figure 33: STEP 3: Interface shows a virtual Grand Piano with black and white keys. 94
Figure 34: STEP 4: Locate 'scale' on function bar to set the Major Pentatonic Scale 94
Figure 35: Step 5: The virtual Grand Piano set for musical improvisations
Figure 36: Prototype in process highlighting important features of the guide
Figure 37: Accessible Features added to the Infographic guide
Figure 38: Internationally recognised icon for Accessibility
Figure 39: Icon representing persons with Cerebral Palsy
Figure 40: Various musical notes 101
Figure 41: Hand-drawn sketches while brainstorming iconography set

Figure 42: Blissymbol for 'Home' 10
Figure 43: Blissymbols for words, 'teacher', 'student' and 'helper'
Figure 44: 1st Digital iteration for the icon of a Bliss i-Band member
Figure 45: 1st Digital iteration for the icon of a supporter
Figure 46: Digital Sketches representing iterations to the icon set
Figure 47: A complete digital version for Bliss i-Band iconography 10
Figure 48: Digital changes made to the icons to achieve visual accessibility 10
Figure 49: Colour Palette co-designed with Christine for the Infographic
Figure 50: Final Icon set with colour usage to represent Bliss i-Band members 11
Figure 51: Application of Iconography on the prototype of a printed infographic 11
Figure 52: Placards set-up used for co-design activity 3

## Introduction

Welcome to the 'introduction'. This section will present you to a detailed overview of the project, our aims, and goals. In addition to this, you will be familiarised to all the co-designers of this Major Research Project.

#### The Project

Active music-making truly engages the entire brain. This creates the most potential for distraction, pain reduction, cognition, fine and gross motor development, and expression (Kubicek, 2022). Listening to music and reciprocating sounds is very normal to us, however, for individuals with cerebral palsy, participating in active music-making comes with multiple challenges.

Playing a musical instrument demands the coordination of hand movements with integrated auditory, visual, and tactile feedback, in a process that recruits multiple brain regions. Cerebral palsy affects the movement and coordination of the body and mind. Although CP is a spectrum disorder, the most common symptoms are stiff muscles, exaggerated reflexes (spasticity), lack of balance & muscle coordination (ataxia) and jerky movements that cannot be controlled. (*Cerebral Palsy - Symptoms and Causes*, 2023)

Bliss i-Band is a community of members with cerebral palsy who participate in active music-making by adapting this process to their abilities. The techniques and facilitating styles are such that makes music-making an enjoyable activity. However, certain gaps still exist. Every i-Band member has unique potentials, music styles & set-ups, and ways to communicate. Each i-Band member is assisted by a music companion.

I have been associated with the Bliss i-Band for more than 6 months as a music companion to Christine Jimenez. I have witnessed several mismatches relating to technology, infrastructure and communication that hamper Christine's agency over her music. The Bliss i-Band, although a small community is an entire complex adaptive

system. Each member can be considered as a complex part, having unique abilities which either enhance their experiences or create barriers. Designing for inclusion starts with recognizing exclusion. (Holmes, 2018) So, based on my empirical knowledge of being Christine's companion, I realised that these existing gaps not only affect Christine's musical experiences but more importantly hamper her agency. It is very important to involve Christine and understand her lived experiences if we aim to design a more accessible environment for her. My acquaintance with Christine Jimenez, Shirley McNaughton (Founder of the Bliss i-Band), and Rebecca Chan (Technology Coordinator) and our shared experiences motivated me to propose the idea of conducting a co-design with the Bliss i-Band.

This paper is based on every co-designer's experience, primarily Christine's. This paper does not aim to solve technological or communication struggles or provide any checklist of solutions. Instead, it serves as an entry point to considerations necessary for designing a training guideline to help future companions support Christine in a way that she feels empowered. Taking a step further, the project also displays a concept prototype of an infographic guide which has been collaboratively designed.

We aim to focus on the three-dimensional framework of inclusive design: recognizing, respecting, and designing with human uniqueness and variability, employing inclusive, open, and transparent processes, and co-designing with individuals who cannot use or have difficulty using current designs, recognising that we are always designing within a complex adaptive system. This paper aims to address gaps within the complex adaptive system that we all are a part of, shedding light on our experiences at the i-Band to guide

our design decisions. By leveraging our journeys, we can collectively support Christine and the Bliss i-Band in the fulfilment of its goals and purposes.

#### Introduction to the Co-designers

#### Saee S. Tipnis

I am Saee Sanjeev Tipnis, the author of this project. Born and raised in the culturally rich and diverse country of India, I have always admired art, craft, and literature. I am a graphic designer and Illustrator by profession. Along with music, sketching, and painting, I am involved in sports, reading, and learning different languages.

I have faced several incidences of exclusion in different social circles. The feeling of being ostracised led me to think about the impact of exclusion on the lives of people with disabilities. Right from a young age, I was inclined to interact and work with individuals who have stood up against all odds and made their contributions towards social inclusion. This got me to a phase of my life that I celebrate the most --- volunteering work.

I have always loved to participate in fieldwork and volunteering camps, right from beach cleaning, COVID - testing camps, to visiting old-age homes. I am passionate about sharing my time and effort towards a good cause. When I first read about the Inclusive Design program at OCAD University, I knew I would get a chance to display my skills as well as learn about the inclusive world! This Major Research Project is extremely close to

my heart as it is my first project as a co-designer, and I am delighted to share it with you all!

#### Christine Jimenez

I met Christine in September of 2023. Christine is originally from Burlington, Canada, and resides in a group home in Toronto. Her nature is charming and kind. She is the eldest of her siblings and is very close to her family. Christine is 51 years old and has lived her life with cerebral palsy. She experiences limited movement in her limbs and neck and relies on a wheelchair for mobility. Christine is non-speaking and uses a VOCA (Voice Output Communication Aid) to communicate and express herself.

As a child, she was outgoing, creative and enthusiastic. Christine was greatly supported by her family, especially her mother, who was also her primary caregiver. All the furniture in Christine's home was designed to suit her abilities. Christine was fond of literature, music, and art. As reported by Barbara Rush, Bliss instructor since 1971 and the First teacher to introduce Bliss to the Hamilton School Board: "Christine attended my classroom in the Cerebral Palsy Centre (CPC) located on the grounds of Chedoke Hospital. We were administratively attached to Holbrook School, which was a block away. I believe she was in our CPC kindergarten for a year and my primary class for two years before moving on."

Back to the present, Miss. Jimenez loves to watch television dramas, listen to music, and go on trips. She carries a very loving, caring, and joyous personality, just like her mother.

Apart from being an active member of the Bliss i-Band, she keeps herself occupied by participating in various social clubs. The staff at the group home supports Christine well. She is always delighted to have conversations, share her dreams, and play music!

#### Shirley McNaughton

I was introduced to the Bliss i-Band by Shirley McNaughton. Shirley, C.M., Ph.D., is a special educator teaching children and adults with cerebral palsy since 1968. In 1971, as a member of an interdisciplinary team, she discovered and applied the language of Blissymbolics to the communication programs of nonspeaking children. The program was emulated worldwide, and Shirley led the work that resulted in the founding of Blissymbolics Communication International in 1975.

She served as the first president of the International Society for Augmentative and Alternative Communication from 1983 to 1986. She was awarded the Order of Canada in 1989 in recognition of her efforts on behalf of people with disabilities. After leaving her position as Executive Director of Blissymbolics Communication International in 1989, she has continued to assist individuals who are still Bliss users or who are now Bliss alumni (All those who have progressed to literacy through gaining their language and communication foundation in Blissymbolics) in improving their communication skills through volunteer work. Music has played a vital role throughout Shirley's life. Taking her experience in special education and music, Shirley founded the Bliss i-Band in 2014.

#### Rebecca Chan

A dedicated team of facilitators assists Shirley, and one of its members is Rebecca Chan. Rebecca is Bliss i-Band's Technology Coordinator and has been involved with the group as a facilitator since the beginning of 2014. Rebecca has played and enjoyed music to a reasonable degree, even though she would not be so kind as to call herself a musician. She was raised with four other siblings and picked up the organ when her father obtained one and arranged for his daughters to take lessons. She adores the 1960s and 1970s folk music, especially the protest songs. She also dreams of being able to play classical music, show tunes, ragtime, and more while entertaining a crowd at the piano! She has resumed her piano practice recently and is enjoying rekindling that dream! Speaking Chinese, Rebecca is also fascinated by language, especially regarding the relationship between Blissymbolics and the characters from China that serve as its inspiration.

Our co-designer group is diverse in age, experiences, abilities, cultures, and more. One factor that holds us all together is the mutual feeling of Sharing—sharing our love, knowledge, and efforts and contributing towards an inclusive space.

#### Background

I moved to Toronto in October 2022. Being an international student, I knew I had to get a part-time job. Within the next three months, I started working at a restaurant. I had only started to be more cognizant of maintaining a work-life balance when a significant financial crunch jolted me.

My project advisor, Jutta Treviranus, was kind enough to listen to my troubles. Later, she referred me to Shirley McNaughton for a volunteering job. I was on cloud nine when I received Shirley's email. This was a means to financially support my education and a chance to commence my volunteering dream in a different nation.

I got stimulated to meet like-minded people, co-work, and acquire valuable skills. The first remote meeting with Shirley was vital as she introduced the Bliss i-Band, its history, Blissymbolics, and Music!

Music has been a very close part of my life. Coming from a diverse country like India, I have always greatly appreciated Indian classical Music. It was an opportunity to learn music from another part of the world. This was also the time when I came to know about Christine Jimenez and her condition. Having no previous experience of caregiving or even being around a person with cerebral palsy, I eagerly waited to meet Christine and interact with her.

## The Context

This section touches briefly on Blissymbolics Communication Institute Canada (BCIC), Blissymbolics language and its history. This background is essential to understanding the origin of Bliss i-Band, its purposes, and the musical goals of its formation.

#### Blissymbolics Communication Institute Canada (BCIC)

Blissymbolics Communication Institute Canada (BCIC) is the Canadian division of Blissymbolics Communication International (BCI). BCIC is a worldwide association of educators and professionals who work with Augmentative and Alternative Communication (AAC), with roots in Canada. The ground-breaking work of a clinical team in Ontario in the early 1970s has benefited non-speaking people worldwide. BCIC has been assisting individuals with cerebral palsy to develop their literacy and communication abilities for over 40 years. (*Blissymbolics Communication Institute Canada*) As part of this endeavour, leadership was provided for the global implementation of Bliss. Blissymbolics Communication Institute Canada's current priorities include serving Bliss users and alumni, offering resources to the Bliss community in Ontario and participating in Blissymbolics Communication International's work as a member.



Figure 1: Blissymbolics Communication Institute Canada (BCIC) logo on its website banner.

#### Blissymbolics

Blissymbolics communication system for worldwide communication was created by Charles K. Bliss (1897–1985). In 1971, an interdisciplinary team under the direction of Shirley McNaughton at the Ontario Crippled Children's Centre (now the Holland Bloorview Kids Rehabilitation Hospital) used it for the first time to help children with physical limitations communicate.

There are more than 5,000 graphic symbols in the Blissymbolics language. Each Blissword or symbol is made up of one or more Bliss-characters, which can be mixed and matched in countless ways to form brand-new combinations. (About, *Blissymbolics*) Bliss words are grammatically versatile and can be arranged to convey a wide range of sentence structures. Bliss has simple, elegant, based rules that make it ideal as a nonphonetically based language.

**Figure 2:** Examples of Blissymbols representing characters, showcasing the effectiveness of Blissymbols in conveying abstract concepts through clear visual symbols.



An example of word construction in Blissymbolics:

**Figure 3:** Examples of Blissymbols representing "knowledge" and its integration with other symbols to form words like, "teacher" - Knowledge provider and "student" - knowledge recipient.



Bliss words are brief and straightforward to use at a pre-reading level. However, they are sophisticated enough to express ideas, feelings, and thoughts and can be developed as proficiency increases. Blissymbolics can be applied to toddlers and adults and are suitable for people with a wide variety of intellectual skills since they use simple forms to make the symbols quick and easy to draw and express.

All the members of the Bliss i-Band are Bliss alumni. Many of them have become literate in English through Blissymbolics.

#### Charles K. Bliss

(September 5, 1897 – July 13, 1985) Mr. Bliss was an Austrian-Australian chemical engineer and semiotician, best known as the inventor of Blissymbols, an ideographic writing system. He was born in Austria-Hungary but was forced to flee to Australia during the Second World War as a Jewish refugee fleeing the Nazis.

Figure 4: Charles K. Bliss teaching the method to a child with disabilities.



Mr. Bliss was inspired to work on a language derived from signs and symbols while he was in Shanghai, China. The Chinese characters and their unique structures intrigued him. With over thirty-five years of dedication and hard work, Mr. Bliss developed a language that could enable users to form complete grammatical sentences with few

symbols. Blissymbolics is a scientifically supported symbol writing that can help overcome language barriers worldwide. He coined the term, "Semantography", which is a system of words to supplement speech. Blissymbols were first used by the teachers at Ontario Crippled Children's Centre (now known as the Holland Bloorview Kids Rehabilitation Hospital) to teach communication pictographically or symbolically to children with cerebral palsy. The children started with 10 symbols and within three years, they learnt 500 Blissymbols. They were able to communicate their emotions very efficiently and people engaged with them in longer conversations.



Figure 5: Shirley McNaughton with a student communicating with a Bliss-board.

# "EVERY SUCCESS OF AN IDEA DEPENDS UPON 2% INSPIRATION AND 98% PERSPIRATION"

**Charles K. Bliss** 

#### Bliss i-Band

The Bliss i-Band is a group of adults with physical disabilities who get together weekly to explore the possibilities of actively making music together with virtual instruments apps found in their Apple iPad. A decade old journey of the Bliss i-Band has shown advantages that come with group music-making for persons with physical limitations. Many of whom are non-speaking and use Augmentative and Alternative Communication (AAC) devices. The i-Band members are Bliss alumni.

Figure 6: The word is "Bliss i-Band" written in Blissymbolics.



The Bliss i-Band is a community-based group that relies on funding from private foundations, government councils and individual donors. The founding and current sponsor is the Lillian Meighen and Don Wright Foundation. The i-Band is also supported by The Ontario Arts Council, the Canada Council for the Arts, and Toronto Arts Council.

The band was started by Audrey King, (psychologist) and Shirley McNaughton, (educator) in 2014. Shirley also served as the first Music Director, bringing to the role her experiences in teaching Carl Orff Music for Children and iPad music with seniors.



Figure 7: A picture of the Bliss i-Band members in its early days.

They were ably assisted by Andy Stark, technology specialist, who continued to train and assist the group for the first three years of operation. After the first year of activity, Shirley and the group invited Aaron Lightstone to become Music Director. Aaron continues to bring his expertise as a professional musician, music teacher and music therapist.

Bliss i-Band's unique feature is that it invites professional musicians and singers to cocreate music. The funding received by Ontario Arts Council is dependent on this feature. This activity initiates interaction and creates awareness with respect to the abilities of these individuals. (*Biss i-Band*)

#### The Bliss i-Band recognises itself as a "Social Music Group" and not Music Therapy.

The Bliss i-Band is not considered Music Therapy but a platform for socializing with music. The i-Band members might not have the happiest of associations with therapy. It is not where members come to 'cure' or 'alleviate' their problems. However, being in this space reduces stress and gives them a blissful experience - like Music Therapy. If at all the music director uses his therapy knowledge to give someone a musical exercise, the purpose is not to remediate something. It is to help them participate better in the i-Band.

#### Purpose of the Bliss i-Band

I. To **provide learning experiences** for Bliss users/alumni and their supporters through a musical program that uses virtual instrument technology (iPad) to play ensemble arrangements of familiar songs, along with solo and dyad improvisation.

II. To **facilitate social interaction through ensemble playing** and attending musical events together.

III. To increase community awareness with respect to the abilities of individuals who are non-speaking through demonstrating their musical accomplishments.

(Biss i-Band)

#### Musical Goals of the Band

Figure 8: Musical Goals of the i-Band written in Blissymbolics with their English translations.



The musical goals help facilitators at the Bliss i-Band monitor the growth of every member and as a group. Blissymbols used in the above image were provided by Shirley McNaughton.

## Co-Design 1.0

In this section, we have integrated primary research with secondary research. The secondary research provides additional support for the design, while the primary research offers context for the design decisions.

#### **Ethical Considerations**

Necessary permissions from the Research Ethics Board (REB) and consent from Christine Jimenez, Shirley McNaughton, and Rebecca Chan were obtained and approved for co-design activities and personal interviews.

Shirley and Rebecca were sent a digital copy of the Invitation and Consent forms to obtain their digital signatures. Christine's consent was received by reading the consent form and clearly stating what the project entailed. I video-recorded Christine, giving her consent by typing her responses on her VOCA (Voice Output Communication Aid) and eye gestures. I read the forms to her as they were in a digital format.

The recommendation for the REB is to create different formats to obtain consent from participants, especially for individuals with mobility/ locomotion disabilities who cannot provide verbal and written consent.

#### **Objective and Research Questions**

This project aimed to co-design an Infographic Tutorial for Christine's future companions, guiding them to support Christine while giving her control of the music-making process. The extended part of this project, co-design 2.0, was focused on conducting one-on-one co-design activities with Christine to rekindle within her the importance of having a Sense of Agency. Our research questions for this project were:

1. What factors/gaps in the current complex system hamper Christine's control?

2. What features of the infographic guide can train Christine's future companions to support her with enhanced adaptability?

3. Which design decisions can help us make the guide more accessible, considering that Christine might receive support from multiple individuals?

4. Does having an accessible training guide open possibilities for the i-Band to expand its reach in the near future?
## Our Approach

As a team of valued collaborators, we are embarked on a journey to analyse our codesign process, which involved active participation from all stakeholders, from an inclusive lens and reflection on our methodology of Community-led co-design.

**Users:** We consider Christine as our primary user, followed by me as her companion. The i-Band facilitators, Shirley and Rebecca, play a crucial role in guiding the co-design process and ensuring the needs of the i-Band members are met.

**Use Case:** Christine receives the right help from her companion, which empowers and enhances her music experience. For Shirley and Rebecca: Having experience in collaboratively designing tutorials for present/ future music companions, inviting more volunteers with easily accessible training material.

**Why:** Understanding the varied scenarios we all encounter as a part of this system is essential. Especially when it comes to Christine, who is not only our primary user but also a key contributor to the project. It is also crucial to recognize the nuances of Christine's interactions with her musical device set-up and software used to enhance her ability to gain musical agency.

**What:** We aim to enable Christine to fulfil her intentions of making active music-making as accessible as possible. To achieve this, we are planning to co-design an infographic guide for her future companions, a tool that will be instrumental in this empowerment journey.

**How:** We are undertaking on a community-led co-design approach for our project, a journey that we are deeply grateful to be taking with Christine. Together, we will explore and understand her musical experiences across different scenarios, acknowledging the invaluable insights she brings to our collective understanding.

As collaborators, we aim to dive deeper into our experiences with the Bliss i-Band, from its early days till the present. Shirley and Rebecca, with their unique storytelling aspect, have enriched this process by narrating their journeys of being associated with the band. Through their narratives, we also ventured into the depths of Christine's lived experiences. As a newcomer to the i-Band, this framework has provided me with a unique opportunity to connect with my collaborators on a profound level. It has fostered a deeper understanding of our shared challenges and hopes, sparking a sense of excitement and inspiration for the journey ahead.

## 3Ds of Inclusive Design

#### (Treviranus, 2018)

The three dimensions of Inclusive Design by Jutta Treviranus lay the foundation of our project:

#### 1. Recognize, respect, and design with human uniqueness and variability:

We aspire to participate collaboratively and recognize the unique abilities of each collaborator. We also acknowledge the fact that "disability" is a potential state we all might find ourselves in the future. So, being mindful and respecting each other's variability is imperative while designing because if we reject the complexities of individuals who are a part of this system, we reject our future selves.

2. Use inclusive, open & transparent processes, and co-design with people who have a diversity of perspectives, including people who can't use or have difficulty using the current designs:

We consider our diversity of thoughts as a gift of our distinctive abilities, backgrounds, and goals. It is important to remember that our diversity can either simplify or even complicate this process. Therefore, keeping the co-design as transparent as possible is a must. We understand that each participant is providing inputs and feedback and helping to bring a shift in the current design of the complex adaptive system. This makes our design journey a collaborative process. We don't want to restrict this project to the given timeline because inclusive design grows from small successes and employs organic, nonlinear models of growth that engage as many perspectives as possible. For us, small milestones are of great importance as they are an output of a truly collective and transparent process.

#### 3. Realise that you are designing a complex adaptive system:

As a group, we realise that there might be many considerations beyond what we are designing now. There is the Bliss i-Band, which is a complex adaptive system --- with several intricate parts. There are different kinds of interactions taking place, for example, Christine's interaction with her VOCA is very distinct from her interaction with the GarageBand (Music software) on her iPad. The constraints of the living situation versus the online situation. The list is never-ending. So, it is indeed a very complex system and each one of them influences the design decisions that will be made. These decisions may support or hamper the accessibility and we need to take all of those into consideration. It is necessary to keep in mind that systems too have certain behaviours, just as diverse as individuals, and can react in very unexpected ways.

## Co-design

"Co-design is a process of designing with, rather than designing for". (Introduction to Community-Led Co-Design)

The Bliss i-Band is a community in itself!

Community-led co-design is an approach in which the co-design process, not just the outcome, is developed in collaboration with community members who will be directly impacted by the design. It engages existing leadership within those communities, by identifying and collaborating with members who will take on the role of facilitation of the co-design sessions. (*Introduction to Community-Led Co-Design*)

Community-led co-design occurs in a setting where individuals already know one another, within the community. One of the main benefits of the community-led co-design approach is that it frees up co-designers to concentrate on the design process itself, rather than having to worry about adjusting to a new location and people. Sharing our narratives has connected us to deeper levels.

## Contributors of this Project

Figure 9: Collaborators of the project and their requirements.



#### Figure 10: Collective ambition of the collaborators.



"Inclusive design begins with no predetermined end point and no generalised success criteria but arrives at greater innovation, flexibility, and general usability".

Jutta Treviranus

## Challenges that still Exist.

Shirley, Rebecca, and Christine have been a part of the i-Band since the time of its inception. As a newcomer, I aimed at brainstorming about the initial days and challenges at the i-Band with them. Moreover, it was necessary to understand what challenges continue to exist in this adaptive system.

The early days at the Bliss i-Band were not without their share of hardships. However, the facilitators, with their unwavering resilience, overcame these challenges, setting a strong foundation for the community.

#### A. Familiarizing with Music

All i-Band members were inexperienced in music. Imparting basic knowledge of musical notes was the first step to familiarise them with active music-making. To make the process of learning more enjoyable, Shirley used the Orff and Kodaly approaches to include playfulness in the learning. Orff and Kodaly approaches are playful methods of teaching music to children. Both methods are explained further in this paper.

#### **B. Extending Technological Help**

The facilitators, understanding the diverse needs of the i-Band members, extended their support to those who had no access to iPads. Through trial-and-error, they developed personalised musical set-ups, ensuring that all member's musical requirements were met. This inclusive approach to session facilitation was a testament to the community's spirit of unity and support.

#### **C.** Facilitators as Music Assistants

Most of the members were accompanied by their close friends or family to assist them with technology. Facilitators took turns to guide those without any support. Training every assistant was laborious for the facilitators. With every passing year, volunteers used to change, and the facilitators had to repeat the same training process, all over again. To make things easier, some of the instructions were stored in the form of videos which would be sent to the new volunteers as reference material.

#### **D.** Losing Members

2014, was the year when i-Band had most of its members. The band lost many of its remarkable members to death in the past few years. This resulted in a significant reduction in our community. After the 2020 pandemic, the i-Band transferred from weekly in-person sessions to Zoom meetings.

#### E. Shift to a Virtual Platform

In the beginning, the many technical complications of transmitting music in a Zoom meeting seemed overwhelming, but they managed to find ways to adjust the Zoom settings and take turns, select an instrument, and allow one member to play with Aaron at a time. The focus turned from playing music in the same room and hearing a collective sound to practising (on mute) while one member had a solo accompanied by Aaron. Everyone took turns.

The transition to online sessions has had a profound and ongoing impact on the band's musical goals. The way they create, collaborate, and perform has been fundamentally altered, and they continue to grapple with these changes.

#### I. Feeling the music -

Meeting in person versus online are very contrasting experiences. The aim of 'feeling the music' is lost to continuous disturbances in the quality of music, changing connectivity, and filtering of the original sound.

**II. Playing music with each other -** The i-Band members take turns playing their parts. By doing this, the facilitators and Aaron can focus on their music. This is very contrary to the practice when they used to meet in person. With two or multiple members playing at the same time, it becomes difficult to hear and identify sounds on the online platform.

**III. Listening to others play music -** While one member is playing music, generally all other members practise their part on a mute mode. This is also because everyone wants to play as much as they can in those two hours. Due to this behaviour, members concentrate more on their playing rather than listening to others play music.

**IV. Initiate Communication -** Connecting virtually does not give enough time for the members to interact with each other. The facilitators try to initiate a conversation at the beginning, but it is short-lived as everyone is eager to play music. Sometimes it is the opposite - while some members get into lengthy conversations, others are left with less time to execute their musical skills.

## Reflecting on the Weekly i-Band Sessions



Figure 11: Simplified infographic depicting Bliss i-Band weekly sessions.

Bliss i-Band meets every Wednesday at 1pm. We've chosen to use the Zoom video conferencing platform for our virtual meetings due to its advanced accessibility features, which we believe, makes our meetings more convenient and enjoyable for everyone. The 'Original sound for musicians' and 'Live performance audio' profiles in Zoom allow for greater preservation of audio received from microphones without using Zoom's echo cancellation and audio filters, ensuring the best possible sound quality for our music.

The facilitator shares the meet link at 12:45 pm. All the members join in the meeting with the help of their companions. We take the first fifteen minutes to discuss life updates followed by a quick round of 'Sound Check'. This process enables us to check whether the music being played on GarageBand is clearly audible on Zoom to everyone. This is done by simply switching on the "Original sound for musicians" in Zoom settings. Once every device's sound is checked, we decide on our songs to practise. Apart from Zoom, we use two more softwares: GarageBand and Chordify. Their functions and features are explained in the next section, "Use of Technology at the i-Band".

Bliss i-Band sessions are divided into two types:

**1. Music Improvisation Sessions:** Songs played in music improvisation sessions are pre-selected by facilitators and the music director. Every song has a 'Signature Key', which is set by companions on GarageBand and the i-Band members take turns to improvise in between different verses of the song.

2. Chordify Sessions: These sessions, held every alternate week or as per the availability of our music director, offer a unique opportunity for individual expression. We use the Chordify website along with GarageBand on the iPads. Chordify converts songs into chords, and each i-Band member is free to select the chord they wish to play. Before making this choice, they are shown a video of the songs along with the Chordify website to get an idea of the pace of the song.

Every i-Band session, filled with creativity and musical exploration, lasts for a fulfilling 2 hours.

## Use of Technology & Accessibility Check

Aim: To study interface and interactions of different technologies and devices.

## GarageBand

GarageBand is a fully equipped music creation studio with a complete sound library that includes instruments, pre-sets for guitar and voice, and an incredible selection of session drummers and percussionists. With an intuitive, modern design, it's easy to learn, play, record, create and share music projects worldwide. This software application was originally released for macOS in 2004 and brought to iOS in 2011. (*GarageBand for Mac*)

## Figure 12: GarageBand Logo



#### Affordances:

GarageBand for iOS takes advantage of a touch sensitive screen which does not require force or pressure to operate. However, it requires the use of a bare finger or conductive device. Since **Christine uses her knuckles to play the virtual keyboard**, this feature supports her ability. The Software does not use any flashing or blinking text, objects, or other elements having a flash or blink frequency greater than 2 Hz and lower than 55 Hz. Christine is sensitive to loud sounds and flashy lights. This quality of GarageBand allows Christine to play without worrying. The most important feature is that it connects its users to a virtual library of musical instruments.

## Challenges:

GarageBand does not permit a user to adjust colour and contrast settings. It has features to partially support individuals using Assistive Technology, but it is difficult to modify individual musical notes with Voice-over. Users with motor or other disabilities that prevent them from having direct skin contact with the touchscreen may be able to use Assistive Touch to connect an accessory to control iOS and GarageBand or employ the use of a conductive stylus to aid in usage. (*VPAT*<sup>TM</sup> for Apple GarageBand for iOS V1.2)



9:08 AM	Mon 18 Ma	r									হ 68% 💷
	0_0		\$ <b>†</b> \$			- 🥚	$\bigcirc$	)	<u>æ</u>	Q	€ €
	P										+
/								_			
					K	ł					
					Grand	* Piano					
		97									
<	0	>	Suste	in 🔒	Gliss	ando	. لا	Major Lentato	nic 🛄	~	
									- 1		
									- 1		
									- 8		
									- 8		
C2					C3					C4	



Figure 14: GarageBand interface with chord settings, used to play while using Chordify.

## Chordify

Purpose: Chordify turns any music or song into chords.

Figure 15: Chordify Logo.

# **chor**dify

Functionality: Any song can be searched on Chordify and converted into a set of chords. The image provided below displays a Chordify interface on a laptop screen. The black box is an indicator which moves across the screen as per the pace of the song, letting the viewers know which chord to play.

<b>chor</b> dify		S	Search any song				၇ ာ Upload	d song Discove	r Create account	🌐 EN 🛛 Sign up   Log in			
Spring m	nelodies a	re in the air! L	et your cr	eativity b	lossom 🕯	View of	ffer						(4.8 🖈 ) on Trustpilot
You	<b>Are My</b> grams	Sunshine Overview	<b>(Lullab</b> Edit	y Versi	i <b>on)   T</b> v all edits	he Hou	nd + Tl	he Fox Chord	ds 🕖 8.3	< :	Share G	Simplify Chords	You Are My Sunshin
14	•		3) 2, 1	الله المعالم (المعالم) Volume		Loop		100%  Tempo	Capo	Transpose	Midi	Print	Lullaby Version
\$ D	A	Bm		D G		D		D	D G	G		A	► YouTube Song Details RATING 8.3 / 10 (3) CHORDS D G Bm A KEY D MDM 6.9 Show more ▼
		G			А	D	А	Bm		D		A	Similar to You Are My Sunshine (Lullaby
D G				D				G		D	A/C#	Bm	233K jam sessions - chords OFFICIAL Somewhere ove 423K jam sessions - chords: F Pink Floyd - Wish You Wer
		D		А		D							249K jam sessions - chords:         Ben E. King - Stand P         239K jam sessions - chords:

Figure 16: Screenshot of the Chordify interface.

#### Affordances:

Chordify enables facilitators to convert songs into chords and apply the Kodaly approach of teaching music with signing notes. This helps the i-Band members to identify chord progression and chord changes.

#### Challenges:

The Chordify website is placed on the laptop screen of the facilitator in a way which makes it illegible for the i-Band members and sometimes for the companions to identify chords. It also happens that the black box moves very fast and makes it difficult for the members to keep a track of chord changes.

## Signing Sheet

Every song has a separate signing sheet.

#### Affordances

This sheet contains all the chords played in the song. This is where the Kodaly approach comes into the picture. At i-Band, companions and facilitators use hand gestures to sign chords and let i-Band members know of the chord changes. The chord signing goes hand in hand with the Chordify website. (*Detailed explanation of Kodaly Approach on page number: 69*)

#### Challenges:

With the use of GarageBand, Chordify, and the Signing Sheet at once, as a companion, it becomes challenging to take control of the entire set-up. This in turn affects Christine's music. When the chord sheet is shared on the screen by the facilitator it appears very small. Due to our complex music set-up and positioning, Christine cannot see me signing chords to her.





## Identifying Gaps from a Companion's Perspective

## Early Days with Christine

At our first meeting, Christine welcomed me with her bright smile. I had very limited knowledge of her ways of communication so at first it was hard to initiate a conversation. I was told that Christine was into literature and art, so I arranged for a few activities, involving reading from her favourite book to some digital painting. Christine thoroughly enjoyed her time reviving her hobbies. After overcoming one challenge at a time, we got more comfortable in each other's presence and my role changed from being an assistant to her companion.

#### **1.**Communication Barriers

Christine has a unique way of communicating. She uses a VOCA (Voice Output Communication Aid) to write down sentences. She uses the Tobii Dynavox I-15+ model that enables effective communication with its 15-inch touch screen, keyboard, switch, and flexibility of use. The VOCA is mounted on her wheelchair and operated by a switch which she operates with her head, since Christine has strong control of her neck movements.

In addition to this, Christine communicates with eye gestures. She answers questions in YES or NO, by pointing at the "YES" and/or "NO" stickers on her wheelchair. People she is more comfortable with, she just blinks her eyes when her response is a "YES".

## Figure 18: Christine's VOCA



Figure 19: Christine operating her VOCA with a single switch next to her head.



Figure 20: Christine's acrylic desk with stickers of "YES" and "NO".



As I reflect on my early training days, I recall the challenges I faced in understanding Christine's sentences. Her exaggerated movements often led me to believe she was in pain or discomfort, when in reality, it was just a sigh or yawn. I still grapple with interpreting her YES's and NO's. Formulating questions that Christine can respond to easily is sometimes a challenge, and there are instances when my questions only serve to confuse her further.

## 2. Observations of the Bliss i-Band sessions

The music improvisation sessions generally contain a significant amount of music information. Some of which are too technical and difficult for Christine and a few other members to comprehend. At times, Christine finds it tiring to sit through the session with barely playing any music.

Generally, individuals with cerebral palsy have higher levels of fatigue, especially physical, because they must exert more energy to perform tasks (2022). This might be affecting her ability to have a longer attention span and actively participate in the session. I have observed that Christine feels lethargic after a while, leading to a decrease in her engagement with the music.

#### 3. Handling Emotions

It's important to note that Christine's time to play music is limited to just two hours a week, making each session incredibly valuable to her. Therefore, when the facilitators engage in lengthy conversations, Christine's impatience is understandable as she eagerly awaits her turn to play.

#### 4. Christine's Musical Set-up

Christine's music set-up is space-restricted and crowded. We don't have a dedicated space to position ourselves and the devices we use. I have made a digital sketch to explain our positioning, which I have attached to this report for your reference.

Christine sits in her wheelchair, right in front of her is the VOCA. It is mounted onto the wheelchair, so I keep the laptop diagonally to her (on the edge of her bed). The laptop screen has the Chordify sheet and the signing sheet on it. I sit right beside her, signing the chords. The iPad is kept on an acrylic desk attached to her wheelchair. This set-up limits us in utilising the devices available to us. Being surrounded by so many devices make it difficult for me to sign and operate the devices.

Figure 21: Christine's musical set-up in her room.



## 5. Restricted Vision

Cone of Vision: The cone of vision is defined as the scope of what the observer can see clearly when looking into a scene.

Figure 22: Diagram of the Cone of Vision.



Christine's cone of vision is restricted only to her iPad screen. I have to place the iPad at a certain angle to Christine because she uses her knuckles to play music. Christine cannot see anything apart from the iPad screen while playing music.

Figure 23: Christine's Cone of Vision limited to her iPad.



## Research

This section is a collection of all key findings from the Secondary and Primary Research Data. List of "Prompting Questions" follows every key finding from personal interviews.

## Secondary Research

## **Cerebral Palsy**

Cerebral Palsy (CP) is a group of disorders that affects an individual's movement, posture, and balance. The clinical findings, which are due to an injury to the developing brain, are permanent and nonprogressive, but they can change over time. Cerebral palsy has multiple etiologies that can affect different parts of the brain, thus contributing to the broad range of clinical findings. Approximately 92% of cases of cerebral palsy are traced to the perinatal period. (VITRIKAS et al., 2024)

The diagnosis of cerebral palsy is clinical, based on the identification of the defining features. The diagnosis can be further classified based on the nature of the movement disorder: stiff muscles (spasticity), uncontrollable movements (dyskinesia), poor coordination (ataxia), or other/ mixed. (VITRIKAS et al., 2024)

Depending on the individual symptoms, persons with cerebral palsy receive different treatments. In all circumstances, though, it's crucial to have a conversation about expectations with families to help them set reasonable goals. It is imperative to engage a multidisciplinary team to address the numerous facets of care and customise the treatment plan to meet the specific needs of each patient. (VITRIKAS et al., 2024)

Formal physical and occupational therapies have been the cornerstones of treatment for movement and balance problems in children and adults with cerebral palsy. There are many different modalities and approaches to therapy, including stretching; massage; strengthening, weight-bearing, and balance exercises; electrical stimulation; treadmill use; and endurance training. (VITRIKAS et al., 2024)

## Music and Cerebral Palsy

Studies showed that people with CP due to difficulties in physical and mental function, social support, and other features have difficulty with rhythmic perception, rhythmic performance of movement, and responsiveness to rhythmic auditory stimuli. (The Effect of a Music and Movement Program on Gait, Balance and Psychological Parameters of Adults with Cerebral Palsy, 2016) The difficulty of understanding rhythmic sounds restricts the efficiency of movement and creates psychological distress, with consistent tendency for isolation and negative emotions toward the familiar environment and self (Manuel, Naughton, Balkrishnan, Paterson Smith, & Koman, 2003; Shields, Murdoch, Loy, Dodd, & Taylor, 2006). In intervention studies involving persons with mobility limitation, it was observed that the use of music and rhythm programs activated the motor and auditory system and consistently, improved balance, walking and mental health conditions. Moreover, it seemed to be of significant benefit as regards to coordination of movements and at the same time, improvement of gross and fine motor skills, enhancement of tactile sensation, and improvement of emotional and social development, especially in the case of individuals with CP participated in music and motor activities designed on the theory of

rhythmic auditory stimulation (RAS). (*The Effect of a Music and Movement Program on Gait, Balance and Psychological Parameters of Adults with Cerebral Palsy*, 2016)

Music and rhythm programs, through the use of rhythmic, harmonic, and melodic sounds in improvisations, musical compositions, sound reproduction, and other techniques, offer a comprehensive approach to addressing the challenges of cerebral palsy. These interventions not only improve communication, expression, organisation, learning, and mobilisation but also provide a rehabilitative effect. This versatility underscores the potential of music and rhythm programs to positively impact multiple aspects of individuals' lives, making them a valuable tool in the care of people with cerebral palsy. (Vinolo, 29th September 2021)

## **Primary Research**

Conducted through observations, personal experiences and one on one interviews.

## Christine's Lived Experiences

In contrast to conventional approaches reliant on sketches or written proposals, our design process embarked on a different trajectory. We initiated comprehensive discussions centred around communication, agency, and control, specifically delving into their implications for Christine.

Christine's enthusiasm for the Biss i-Band is palpable. She relishes the opportunity to play music with her peers, finding the experience of meeting in person and playing as an ensemble to be truly euphoric.

From the outset, Christine has been fortunate to have a strong support system. Her sister and later her music companions have been instrumental in assisting her with technology, ensuring that she never faced any significant challenges.

Christine finds it challenging to concentrate on the changing chords on Chordify while playing music on the iPad. She even thinks that signing musical chords is not helpful at times and the verbal cues help her better. When I say verbal cues, I generally pair signing with words. I say "Pause" when it's time to pause and "Play" when Christine is supposed to play the chord. Christine finds this more helpful than looking at the signing.

# "DON'T WORRY,

# **BE HAPPY**"

**Christine Jimenez** 

## 1. Key findings from 1st Interview with Shirley McNaughton

This interview was structured with an intention to understand the detailed history of Bliss i-Band and its journey through ten years.

#### 1.1. Introducing iPads to the Band

Shirley, a music enthusiast living in a retirement community, discovered a band in North Carolina that used iPad as musical instruments. Intrigued by this innovative approach, Shirley and Audry King (Co-founders of the Bliss i-Band) envisioned extending the use of iPad in music to adults. They brainstormed various ways in which an iPad could enhance the musical abilities of every i-Band member. For instance, Audry, who had polio since childhood and had limited arm mobility, found that she could still play music by using her fingers on the iPad. Shirley also found joy in playing music on the iPad alongside her.

## **1.2. Learning Together**

None of the members had previous education or any kind of experience in music. They had never been in a band and/or played as an ensemble. A lot of the members enjoyed playing music but had never created melodies. Acknowledging every i-Band member's unique ability and limitation, posed challenges to get them introduced to the basics of music. To begin this process, all i-Band members were first given time to interact with each other.

## 1.3. "The Chaos"

The biggest challenge in teaching music was to make every member feel the beat. With an inclusive approach, the i-Band facilitated a plan and took smaller steps, to achieve their goals, rather than setting a timeline for learning. Throughout the first year, all Shirley did was make them feel all the music.

#### Why was this the greatest challenge?

This is because music does not come naturally to people who have restricted mobility. It is difficult for people who have never felt the rhythm, to produce melodies. Their bodies cannot respond to music the way they want it to happen. Generally, individuals with cerebral palsy have higher levels of fatigue, especially physically, because they have to exert more energy to perform tasks. (Denslow, 2022) So, Shirley used a strategy:

She selected a song called, "Grand Old Duke".

It had very strong beats at different times. Every member was supposed to show some mobility on these strong beats. For example, "UP" or "DOWN". This was very frustrating for the i-Band members at first, because their bodies would not move in a certain way. With practice, they were able to make actions on every beat of the song.

#### 1.4. Inclusive Teaching Approach

Orff and Kodaly's approaches have influenced Shirley's way of teaching music. Numerous studies have shown the effectiveness of these methods in enhancing musical understanding, creativity, and collaboration among students.

Orff Approach: The Orff method, a product of the 1920s and 1930s, was crafted by Carl Orff – a German composer and educator. His philosophy was simple yet profound: children should be allowed to immerse themselves in music, experiencing it at their own pace and understanding, rather than being confined to theories and strict lesson plans. This approach brings a sense of freedom and joy to the learning process, making it a unique and intriguing method.

The Orff method includes multiple learning elements such as singing, dancing, acting, and using various percussion instruments. The main aspects of this approach include rhythm, melody, and improvisation.

Kodaly Method: The Kodaly Method, also known as the Kodaly concept, is an approach to music education that emerged in Hungary during the mid-twentieth century, thanks to the visionary Zoltán Kodaly. This method uses signing as a tool to teach music, with the aim of helping children sing the pitch accurately. **More than just a teaching method, the Kodaly approach is a celebration of music as a social and cultural experience.** It advocates for group music classes as the ideal platform to teach musical principles, creativity, and collaboration, especially to young children, emphasizing the importance of music as a shared experience. (Masterclass, 2021)



Figure 24: Manual signs used in Kodaly Approach of teaching music.

## 1.5. Altering the Kodaly Method

Shirley adapted the Kodaly Method to work for the Bliss i-Band members. She began *using these signs to give names to the chords.* This was designed with the intention of educating the Bliss i-Band members about different chords and chord changes.

## 1.6. Adapting the iPad to the User

Shirley's primary approach to using the Orff method was like her experiences as a special educator. Every i-Band member was helped in getting comfortable with their iPad's interface at their own pace. She mentioned in her interview,

"You adapt to their way of learning & not come at them with a set curriculum".

## 1.7. Downfall

The mixed group of people with acquired and congenital disabilities did not work as their learning spans were different. Individuals with acquired disabilities learned music much faster and lacked the patience to wait for individuals with congenital disabilities to catch up with them. As a result, many members left the group, one by one. The band was nearly closed.

## 1.9. Dependency on Funding

The Lillian Meighen and Don Wright Foundation funded the i-Band for its 1st year and continues to do so. *The Bliss i-Band depends on funding*. It continues to receive yearly funding from different institutions. To continue with that, it is very important to show gradual progress and growth. Even though the band has made some great accomplishments in the past couple of years, we have lost many members to death, some left the group as they shifted to a virtual set-up OR did not have assistants to support them. We are currently functioning with a small group, and this poses a challenge to our chances of getting future funding.

#### 1.10. Music device Set-up

Shirley mentioned that one of the **Bliss i-Band members improved her music skills** and the primary reason was her **music set-up**. The set-up, which was developed over the span of a few years, allowed her to concentrate on her music as well as the chordsigning. An accessible music set-up (physical and digital) proves to be a key factor in giving agency to the i-Band member.

## 1.11. Lack of Companions

Conducting i-Band sessions remotely has expanded our reach. There are many individuals situated in different parts of Canada and even in other countries who are willing to join. Unfortunately, this is not possible now because one of the predominant requirements of being an i-Band member is to have a music companion. This could be a friend, family or a volunteer. Moreover, the facilitators and technology coordinators are not well equipped with a systematic training guide to help them best guide future music companions.

## 1.12. Hope for the i-Band!

#### I. Inculcating a Balance

Shirley hopes that every i-Band member grows musically. According to her, there will always be a scope for each member to learn and play music. She feels fortunate that
learning is always integrated with playing music and hopes to inculcate this balance within our complex adaptive systems.

#### II. Better Training for Companions

The companions and facilitators are still learning ways on the internet, it is challenging for them to solve technical difficulties effectively. Sometimes, addressing a minute technical difficulty takes away a major chunk of our music time. We hope to expand how we support the training of the companions.

#### III. Expanding Globally

Shirley's dream for the band is to **extend it Globally**! She would love to include people from different countries, irrespective of their spoken languages. She says, "We would be making music and transcending languages".

# **IV. Get More Funding**

The primary aim for the i-Band is to get funding for making a complete set of training videos for its future volunteers. A more robust way of training people is to have accessible & consistent training videos.

# "EACH PERSON RESPONDS DIFFERENTLY, AND WE HAVE TO BE AWARE OF THAT"

Shirley McNaughton

# Set-1: Prompting Questions

Reflecting upon our interview, I jotted down some questions:

1. In what ways can the knowledge of music be extended to companions along with the i-Band members?

2. How can companions be introduced to more accessible ways of solving software related technical difficulties?

3. What are the possibilities of expanding the band with the use of a sophisticated training guide?

4. What adaptations in Christine's musical set up would give her more control over her musical journey? Can this be included in the guide?

5. How helpful are the strategies introduced by Shirley (e.g. Kodaly method) to Christine if her set up is very limiting?

To co-design with Christine, it was necessary to understand her history, So, we began with interviewing Shirley as she has been an integral part of Christine's education.

# 2. Key findings from 2nd Interview with Shirley McNaughton

About Christine and her life, before and after Bliss

#### 2.1. Learning with Blissymbolics

Shirley met Christine somewhere between the mid-80's to early 90's. Shirley was called by the Superintendent of special education to meet Christine and her teacher. Shirley began visiting Christine's home in Burlington. Christine and Shirley would practise new technologies in Blissymbolics. This personalized approach not only gave Shirley a deeper understanding of Christine's limitations and abilities, but also underscored the importance of tailored support in Christine's journey.

#### 2.2. Receiving a "lot more" help

In 2014, Christine joined the Bliss i-Band, and her younger sister would accompany her as her music support. At first, she had to hold Christine's hand and play music. Shirley knew that this was taking away Christine's agency over her playing and she was very aware of her strengths. To help Christine with better support and encourage her skills, Shirley got volunteers. Even after this, there were instances where Christine's hand was held and directed to play a certain way. This continued to bring hindrance to her agency. However, Christine, with her remarkable resilience and determination, never complained about anything. Once, she expressed her dissatisfaction by restricting her while playing on GarageBand. All she wanted was to play according to her will, a testament to her unwavering spirit.

#### 2.3. Physical & Musical Advancement

Now that Christine plays independently, she expresses herself through music. She has gained confidence and musicianship. She knows when to pause, and when to continue while doing music improvisation. The challenge is to guide Christine when it comes to Chordify sessions as the current device set-up limits her from having complete access to the chord sheet and signing. There is an improvement seen in Christine's sitting posture. She tries to sit upright. There is a striking difference between the photographs taken in 2011 and now. Christine can hold her head upright.

#### 2.4. Mindful Work

"Some people think about themselves and there are people who think about whom they are with" This is a primary quality which the i-Band looks for when hiring new volunteers. Being a part of an adaptive complex system, there are multiple levels at which companions must be trained. Companionship is not restricted to musical help; it is to truly understand the needs and requirements of a person. One important symptom commonly witnessed in people with cerebral palsy is that ageing comes faster. We must be very mindful while working with them. They should not stress their mind and body as they tend to use every bit of energy to fulfil a task.

# Set-2: Prompting Questions

1. By what means can essential values, such as empathy, patience, and respect, be inculcated in the future companions to support Christine in a way that gives her a complete sense of agency over her music?

2. How Can the training guide for volunteers be designed to not only equip them with necessary skills, but also foster stronger relationships between the i-Band member and their companions, making them feel more connected and collaborative?

3. Given that CP is a spectrum disability, every member has very different abilities. How can we emphasize the functional abilities available to the individual, like voluntary movements and other capacities, to give a better idea and personalise a music experience that caters to their specific needs and requirements, making them feel understood and catered to?

# 3. Key findings from interviews with Rebecca Chan

Rebecca joined Bliss i-Band from its inception, which was in the year 2014.

#### 3.1. Role of Technology

Rebecca mentioned, "Most of the support of i-Band members is dependent on technology. Technical adaptations enable them to do what they do and in the way they want to do it. And sometimes also disrupts the process."

#### 3.2. Starting Together

In the first meeting of the Bliss i-Band, everyone formed a circle and shared their musical background. At that time, none of them had a musical background or any experience of playing music except Shirley McNaughton. For Rebecca, the idea of being in a group and collaboratively playing music was very welcoming. There was a clear distinction in the band from its first year to second year after Aaron (Music Director) joined in. Shirley took leadership of the group in its first year and started with teaching signing and it furthered the knowledge of chord changes. Shirley also tried to impart knowledge on various musical scales. After Aaron joined, the members were introduced to different playing styles. Not going too much into the technical details but more into musicality. To give an experience of conducting an ensemble, members were assigned to play one note of a virtual bell. The member in charge conducted the session in a way that everyone played the bell on a selected chord. This was an attempt to make them more cognizant of the chord /note changes and its progression.

#### 3.3. Co-designing Accessible Music Set-ups for Everyone

Every i-Band member has a unique musical set-up. In the initial days, to get the band members comfortable with GarageBand, many collaborative strategies were used. It happened through a lot of exploration and trial & error methods. Step 1 was to find out the abilities of each member. One of the member's father was an engineer. He designed a headgear with a bracket, so it could be attached to a stylus. He also designed a structure to mount an iPad.



Figure 25: Accessible music-set up co-designed at the Bliss i-Band.

Rebecca and Shirley helped to set up music stations for members who did not have any family members to support in the early days. Some members would sit on the floor and play music. Everyone had a preference, and it was very much respected in the i-Band. The i-Band has also helped its members to get iPads and make accessibility changes.

# 4. Key findings from Interview with a Companion

Most of the i-Band members get technological help from their family and friends, except for Christine and one other member. Working with non-familiar individuals can be challenging at times, especially with language barriers. My interview with Gulay Sayeda, a music companion, gave me more insights into her experiences of being associated with the Bliss i-Band.

#### 4.1. Learning Experience

Bliss i-Band is not only about music but also about developing new skills. According to her, interacting with non-speaking people was challenging at first but was indeed a very remarkable journey. Being a Ui-Ux designer herself, she was intrigued by the technology used in making music, interaction with the VOCA, and learning the basics of music.

#### 4.2. Training for Companions

Gulay was introduced to the i-Band member in person and given brief training on the use of GarageBand, Chordify, and ways to record music. But when it came to recording a song and saving it, Gulay faced difficulty. Neither did she remember the process nor had any sort of a guide to refer to. An accessible information guide on the basics of software used in the process of music-making would be of help to Gulay.

#### 4.3. Challenges in Multitasking

It has been six months of Gulay supporting the i-Band member and yet she finds it challenging to work with their music setup. She is still figuring out ways to best support technologically along with chord signing and tracking Chordify and GarageBand. Managing everything at once is a task for her.

#### 4.4 Gaining Knowledge

Gulay and the support-seeker have very limited music knowledge. Even though the i-Band members play music using a scale that generally harmonious, knowing its special features could help the i-Band members elevate their music learning and playing experiences. Moreover, having the knowledge of some foundational concepts, companions can engage in this process more mindfully.

#### 4.5. Introducing Blissymbolics

Bliss i-Band is inspired by Blissymbolics, and all its members are Bliss alumni. In this entire process, Gulay observed that Blissymbolics is missing. Although the i-Band members have learned and communicated in Bliss, very few of them remember it now. *"Is there a way to revive Blissymbolics in the Bliss i-Band?"* – asks Gulay Sayeda.

#### 4.6. Feeling of being Left Out

The process of music-making is too technical. There have been times when Gulay was not able to meet the i-Band member she was supporting, and this made them feel left out while being in the virtual meeting. No one else could help them because of a lack of immediate access to any guidance on the software used.

# Set-4: Prompting Questions

1. Can the existing technology / devices be adapted to the comfort of the companions to help them assist better?

2. What impact will the inclusion of Blissymbolics have on the learning and participation of the i-Band members?

3. Will the training guide extend possibilities for individuals without any previous knowledge of the software, to extend immediate help to the members?

#### **Design Decisions**

Based on the key findings, we collectively made these design decisions:

#### Focusing on Communication Gaps:

Challenges observed can be categorised into Technological, Structural, and Communicative. To begin this co-design, we focused on the communication challenges because technology and structural-related issues will demand the involvement of respective professionals. This can be worked on in the future. Moreover, targeting communication gaps can help us achieve our immediate goal of customising Christine's music experience.

#### Formalising the Guiding Process:

Formulating a formal training process for future volunteers can avoid confusions that arise later in the process. To familiarise the companions with key concepts of software, adding Christine's user profile can reduce the chances of interaction errors. Introducing formal training can enhance confidence in companions and prepare them to face future uncertainties. With the support of a well-designed training system, the i-Band can invite more volunteers to assist.

#### Introducing Accessible Guidance:

We aspire that our future volunteers will have training readily available at any given time or situation. We think that a sophisticated infographic guide will serve this purpose. It will be an immediate source of information designed with Christine's accessibility requirements. Extending the use of this guide for someone without any volunteering experience.

#### Personalization of Support:

Christine would like to be assisted in a way she finds comfortable. Accommodating her requirements into our design decisions will allow us to co-create a customised support framework for Christine with the feature of altering any information as per future requirements. Realising human and systematic variability, we are open to future customisations in this guide.

# Design & Development

This segment provides insights on the design decisions and their influence on the features of this Infographic Communication Guide.

Figure 26: Infographic Formats in Print and Digital versions.



**The Aim:** To provide future companions with the basics of Chord Signing, GarageBand, and Chordify. Give ways in which they can best support Christine to augment her control over their music.

# Features of the Guide

These features will serve in creating an accessible and User-friendly guide for users:

Figure 27: User interactions of the i-Band members with the infographic guide.



#### 1. User Profile

Christine would like to have a section dedicated to her. It would introduce Christine, her musical choices, and ways of communicating. Based on Christine's user profile, future volunteers will have a holistic understanding of her preferences and assist her effectively. Being mindful of the variability of human behaviours and choices, the information provided by Christine could be altered at any point in time.

#### 2. Stepwise Simplification:

Since we are dealing with three different interfaces, Rebecca, our technical coordinator recommended keeping three different sections for GarageBand, Chordify, and the Signing Sheet. These individual sections will be provided with stepwise explanations of

every tutorial. The processes will be simplified and supported with illustrative infographics. Considering uncertain instances, Christine might be assisted by someone non-familiar to the Bliss i-Band on a temporary basis. (e.g. someone from the group home) In situations like these, simpler explanations will be more welcoming. *(Reference to the interview: 4.2)* 

#### 3. Accessible Formats

To have the infographic guide easily available, we will be working on two formats:

A. Printed Version:

The printed infographic will be placed inside the pocket of Christine's wheelchair. We don't want to make any assumptions about the preferences of our future companions, so we will keep an alternative source available. This could be helpful in uncertain cases where there is no online support.

#### B. Digital version:

This will be available as a PDF on digital devices. A QR Code can be attached to Christine's wheelchair for anyone to have access to it. Here is a sketch which demonstrates the placement:



Figure 28: Placement of a QR Code on Christine's wheelchair.

#### 4. Incorporating Reminders:

When dealing with complex devices, it's crucial to review minute details. We understand that small errors in digital musical settings can lead to inconveniences while actively making music. To provide companions with a sense of reassurance and minimise occurrences of technical errors, we propose incorporating recurring reminders in the guide. These reminders will serve as a recall value, ensuring that you're always on top of your device settings.

#### 5. Music Dictionary:

A notable feature of this guide will be to add a dictionary, an "i-Band Dictionary".

This guide will feature an inclusive 'i-Band Dictionary ', containing all the music terms frequently used at the i-Band, along with their explanations. This is a direct response to the challenges faced by companions who have limited knowledge about music. We Want to ensure that everyone, regardless of their musical background, feels considered and included in the i-Band community. *(Reference to interview: 4.4)* 

Our proposal for this guide is in line with Shirley's inspiring vision for the i-Band, which she aptly describes as 'Inculcating a Balance' in playing music and learning. We Aim to empower users and companions with knowledge, enhancing their musical experience and fostering a deeper appreciation for music. (*Reference to the interview: point 1.12 -I.*)

## Ideation

Since this was our first time participating in a collaborative design project, we commenced with design ideation by selecting one process that could be added to the infographic guide in the future. This was a 'pilot design phase' to see if we were taking the necessary steps towards inclusion. We asked Christine what she would like to work on. Her favourite virtual musical instrument to play is the "Grand Piano" on GarageBand. So, we chose to -

"Simplify the process of setting up the "Grand Piano" on GarageBand for music improvisation sessions and designing an infographic guide".

Here is a simplification of the steps required to set up this virtual musical instrument:

Figure 29: Simplification of setting up a "Grand Piano" on GarageBand into 5 easy steps.



Setting up the Grand Piano begins with locating the '+' add symbol, which initiates the creation of a new music project. This action will open GarageBand's music instrument gallery, where the grand piano can be found. To prepare for music improvisation, users need to modify the instrument's original scale. Specifically, they should change it to a "Major Pentatonic Scale". This adjustment is a key step in enabling efficient music improvisation.

**The Major Pentatonic scale**, a musical scale composed of 5 notes, is a true delight. Music created on this scale is always a harmonious treat for the ears, sparking inspiration and excitement in your music improvisation journey. **Concept Sketches:** I utilized my sketching skills to make detailed sketches of the GarageBand interface using a grid on the digital tool - Procreate. The image below contains 4 screens, each depicting one step involved in the process of selecting a "Grand Piano".



Figure 30: Sketches of GarageBand interface for the infographic guide.

After approving the sketches, the next step was to digitally create each infographic.

**Figure 31:** STEP 1: Make a "Music Project" in GarageBand.

Figure 32: STEP 2: Selecting Grand Piano in the virtual musical instrument gallery.





Figure 33: STEP 3: Interface shows a virtual Grand Piano with black and white keys.

Figure 34: STEP 4: Locate 'scale' on function bar to set the Major Pentatonic Scale

		• • •
	Grand Piano	
	• •	
		Off
		Major Pentatonic
		Major Blues Mixolydian



Figure 35: Step 5: The virtual Grand Piano set for musical improvisations.

#### Next Step:

We made significant strides in creating a high-fidelity prototype for a digital interface. In the future, we plan to design the guide in a printed format along with a digital version. But, considering accessibility, having an infographic guide available on mobile phones seemed a possible idea. This collaborative approach could also give us time to test our design by easily sharing it with our participants and people from outside the band, ensuring that everyone's input is considered.

As a graphic designer, I've been leading the digital iterations of our guide. These iterations have been shared with my co-designers, who have provided valuable insights and suggestions. Here are some screenshots of the guide and its features, which reflect our collaborative efforts and the progress we made.

Figure 36: Prototype in process highlighting important features of the guide.

Back	Ξ	Features of the Digital Guide
GarageBand Tutorial 1.		
Christine loves to play the 'Grand Piano' ! Here is a tutorial on setting up the Grand Piano for improvisation sessions.	1.—	Communication Style
		inforgrahic adds a playful tone to the conversation.
STEP 1		
Search for GarageBand logo on the app scre of your iPad. Once you find this icon - Click or		
Welcome to GarageBand!		
What you see now, is the home screen, to ope a new music project :	n	
Click on the plus sign $'+'$ on the top.	2.—	Simplified Infographics
Recents +		Key features involved in every step are illustrated in orange colour to give prominence.
Things to keep in mind :		
Make sure that you are in the 'Recents' folder.	3.	Help in communicating necessary details to avoid complexity.

Figure 37: Accessible Features added to the Infographic guide.



# **User Testing**

We deemed it crucial to evaluate the design prototype by Christine through a face-to-face meeting, recognizing the value of direct interaction in this evaluation process.

Here is what she had to say: "The design and format looks simple and is easy to understand. Each step has been explained concisely. The colours are very pleasing to my eyes, and I like the feature of having an i-Band Dictionary."

Shirley's Feedback: She was not just delighted, but truly impressed by the output. The prototype, with its well-incorporated features, elevated her experience and introduced a perfect balance of learning and music-making.

**Reflecting on Strengths and Weaknesses:** The infographic guide, with its simplified infographics, is a testament to Christine's efforts in making the GarageBand interface easily navigable. The soothing colour palette adds a playful touch to the guide, making it a joy to view. The guide instils confidence with its timely reminders, Bliss Dictionary, and explanations for Ui-Ux related jargon, aiding users in getting accustomed to the various processes.

The infographic was designed to suit one simple process, but it's important to note that complications might arise when dealing with more intricate functions. As we delve into further details, it's possible that one lengthy process will need to be divided into smaller ones. Managing a digital file with multiple tutorials can also pose challenges. Therefore, the overall design, starting from the basic grid structure, might need to be re-organized.

One potential area for improvement could be to provide ease in switching between tutorials in the design, especially when referring to more than one tutorial at a time.

# Designing Iconography

To introduce an element of the visual language in the Bliss i-Band, we collectively explored ways to include icons that would represent members. The icons can have greater application as we further the training of the guide and other deliverables. To begin with this, we started our search by studying some existing designs, functionality and applications of icons found in the society at large.

#### The Symbol of Accessibility

The wheelchair symbol is only used to indicate access for individuals with limited mobility, including wheelchair users. For example, the symbol is used to indicate an accessible entrance, bathroom or that a phone is lowered for wheelchair users. It consists of a usually blue square overlaid in white (or in contrasting colours) with a stylized image of a person in a wheelchair. It is maintained as an international standard, ISO 7001 image of the International Commission on Technology and Accessibility (ICTA), a committee of Rehabilitation International (RI). (Stanford University)

Figure 38: Internationally recognised icon for Accessibility.



Figure 39: Icon representing persons with Cerebral Palsy.



Engaging in a dialogue with Christine, we came up with an exciting idea to introduce a playful aspect to our music group's iconography. By drawing inspiration from musical notes, we proposed a new set of dedicated icons. These changes will not only bring order to our complex system but also enhance our efficiency. To implement this, we've categorized the i-band into three groups - 1. i-Band members, 2. Companions and 3. Facilitators. Our ideation process is driven by our shared inspiration from Musical Notes.

Figure 40: Various musical notes.



Sketches: I utilized my sketching skills to brainstorm on different possibilities of using the notes as our iconography base.

ICODOGRAPHY	alex concern but, its for
	C. monents what committee
FOR Band	
	iBand member
	1 2 1 3 · · · · · · · · · · · · · · · · · ·
	5.2 00 marship
	TO NOT I DEG
~ 233	
iband Facilitators	State Active and
the second se	13 months commenter and
00	0.7
00	$\rightarrow 2^2 5$
the sector for any the sector of the	Volunteer
	2
Eighth Note	2 iband member - playmusics
- sixteenth Note	2 supporters 3
dd - Beamed Eighth	Note 2 Factification J.
	circle represents the person
	I musical Note
0	[wheel chair]

Figure 41: Hand-drawn sketches while brainstorming iconography set.

# Shirley's Feedback

As a team of co-designers, we strived to keep this process as transparent as possible and involve everyone's perspectives at every stage of our progress. I reached out to Shirley and Rebecca, recognizing their expertise in music notes and Blissymbolics, for their invaluable feedback on the use of music notes, its consistency, and most importantly - functionality. Here is what Shirley and Rebecca, our esteemed co-designers, had to say:

They were able to decipher the meaning behind the sketches and understand that each role was represented by a dedicated icon. However, they noted a lack of uniformity across the icon set, which we can focus on improving.

They found the depiction of the wheelchair icon confusing, particularly the open circle at its base. They felt it didn't accurately represent a wheelchair, but rather resembled a trolley used for heavy objects.

**Recommendation:** To represent the note with a solid round to keep its character intact.

I drew inspiration to sketch the icon for an i-Band member referencing the "half note" in music and for the icons of companions and facilitators, I took reference from the 1/8 th and 1/6 th note. This was difficult for Shirley to comprehend. Associating a half note with 1/8 th and 1/6 th notes was musically troublesome for her.

**Recommendation:** We were committed to improve the design. We kept the idea of depicting i-Band members with musical notes but using one note instead of 3 different notes. This helped in bringing consistency to the icon set and making it easy for all members to visually remember it. Making use of a similar shape can bring a recall value each time the icon is viewed.

Considering that we have our roots embedded in the language of Blissymbolics which is based on symbols, we also explored areas to include Blissymbols. This also fits in well with point number 4.5 (Introducing Blissymbolics) from the interview with Gulay Sayeda where she mentioned that introducing Blissymbols to the infographic guide can open possibilities for reviving this language.

Shirley being the Blissymbolics expert shared her ideation: She said,

"I have to confess to you that **within Blissymbolics**, there are "pictographic" symbols that can be used as icons for your infographic, and they make a good distinction between any language that is to be included in the training guide". Here is an example:

Figure 42: Blissymbol for 'Home'.

HOME

Building (house) for which you have "feeling".

She shared the Blissymbols for your "facilitator" (or **teacher** who exchanges knowledge with the student), learner (**student** who benefits from the knowledge "received"), **helper** (person who provides support to the person).

Figure 43: Blissymbols for words, 'teacher', 'student' and 'helper'.



"It would be interesting to see if the above might be used to identify when information is being provided". Shirley added another dimension to this design process:

#### Demonstrating two ways of communicating for different purposes -

- 1. Icons to easily identify the different roles through illustration and Blissymbols to identify information points.
- 2. Representing the two ways in which members contribute:

Harmony with their assistant (could represent "assistant") "blue assistant" providing support for "pink member" to produce harmony.

Figure 44: 1st Digital iteration for the icon of a Bliss i-Band member.



Figure 45: 1st Digital iteration for the icon of a supporter.

# 

Limitations: The idea of involving Blissymbols intrigued all of us. However, the process would have demanded more time from us, and we were bound by a time limit for this project. We also viewed it through the lens of variability in the group. For new members coming in, it will be easy to comprehend musical notes at first glance. We made this decision with the inclusivity of our team in mind, ensuring that everyone, including new members, could easily understand and contribute to the project. For these reasons we decided to continue with the idea of musical notes and to incorporate all the feedback mentioned in our collective discussions.

# Sketches:



Figure 46: Digital Sketches representing iterations to the icon set.

Musical notes drawn in orange colour (extreme right) group as the final icon-set.

Figure 47: A complete digital version for Bliss i-Band iconography.



Figure 48: Digital changes made to the icons to achieve visual accessibility.

Considering inclusion and Structural modifications:

We decided to avoid placing the icon at an oblique angle concerning to its base. Keeping it exactly perpendicular to the base was keeping its musical characteristics intact. It was also observed that the "tail" of the musical notes (the tail is marked with a red circle on the R.H.S image) was very small and would be illegible to people with poor vision. We elongated the tail and checked by resizing the icons whether they were legible or not.

**Recommendation:** Adding colours to the icons. Adding more colours would allow us to add more functionality and an element of playfulness in the icon set.
## Choice of Colour Palette

Individuals with Cerebral Palsy may be more sensitive to different colours. This is because they have increased sensory responses, stronger visual processing abilities and differentiated cognition pathways. (Sanabria, 2022) Green, blue, grey and violet promote calm and a feeling of well-being. Blue reduces appetite and lowers body temperature. Blue is also the preferred colour for those with a visual impairment. Green helps to relax the nervous system and lessens feelings of stress. It seems to help with communication and developing speech skills. Cool colours may be a good choice for individuals where reducing stimulation is a high priority, such as those with ADHD or the hypersensitive variation of autism. (*Colours Vs. Special Needs Individuals: What You Need to Know*, 2019)

Christine and I designed a colour palette which was very pleasing to her eyes. Christine loves bright, fresh colours. Hence, we tried to incorporate those in the infographic.



Figure 49: Colour Palette co-designed with Christine for the Infographic.

An example of iconography with colours:



Figure 50: Final Icon set with colour usage to represent Bliss i-Band members.

Figure 51: Application of Iconography on the prototype of a printed infographic.



Application of Iconography in the Guide:

The image above shows a tentative placement of Christine's icon on a printed version of the infographic guide. The icon makes it straightforward to indicate that this is a guide, specially designed for Christine. Just like the guide, the usage of iconography can be extended to many other deliverables like badges, Bliss i-Band merch, individual music stationery, stickers, and many more!

# Co-Design 2.0

This is an extended version of co-design 1.0 and it consists of a series of small co-design activities conducted only with Christine. The section will take you through some of them along with its results.

**AIM of co-design 2.0:** Cultivating the importance of having a sense of agency in Christine by involving her in a series of co-design activities.

**Location:** Activities were conducted in Christine's room, a place she is very comfortable in. It was important to explore how this space can be adapted to fit into Christine's requirements.

**Designing Activities:** Based on the key findings obtained from Co-design 1.0, we formed a list of activities. Shirley and Rebecca shared some of the attempts made by previous assistants to help Christine with music. Taking those into consideration along with the reasons for their collapse and success, we designed activities.

**Time:** There was no definite time frame. The entire choice of participation and nature of facilitation was given to Christine. Not to be overburden with multiple jobs, we tried to conduct the co-design activities as a part of our weekly i-Band sessions. This also helped us in getting feedback from our extended community of Bliss i-Band.

# Activity 1.

**Deconstructing the Schedule:** Christine follows a timely schedule daily. She is given medication and other specific assistance at definite time intervals. To our observation, the majority consisted of activities that her caregivers set. The first activity was for Christine

to realize that she could add the activities she wished to do to this schedule. Schedules can be accommodated for her wants and changed at any time. On meeting Christine, I asked her one fundamental question, "What do **you** want to do today?". Christine utilized her VOCA to communicate her wishes to me, which I would list down. **The list of activities also made us realize the variability of human choices** because we never wholly followed a list. Our interactions with each other would change the course of activities several times. Sometimes we watched television for a couple of hours at a stretch and did not even bother playing music. A small example of this schedule made us think of the several complexities underlining a complex system such as the Bliss i-Band. There were times when we were required to adapt ourselves to our surrounding situation. With this understanding, we hope to build an inclusive mindset in our daily lives.

## Activity 2.

**Gaining Knowledge:** I was told by a teacher that one way of gaining independence or confidence is to gain Knowledge. Taking this perspective, we designed our second activity for Christine in which I intentionally set the incorrect chords on GarageBand. Before beginning her music practice, I asked her to check if the chords were correct. It took some time for me to locate the chords for Christine, considering the contrast issues on GarageBand.

Christine could identify the incorrect chords. By doing this, we hoped to inculcate the value of being cognizant of the system we are a part of and its essential aspects. As a result, Christine, who was initially utterly dependent on me to set the chords and signature keys, started checking them before playing music.

## Activity 3.

Adapting to the available technology inclusively: The title sounds very contrasting to the principles of Inclusive design, which suggest that design systems should adapt to the needs and requirements of individuals.

All members of the Bliss i-Band have been using this system of devices and technology for a decade. Although there are technological gaps, they find comfort in using this system because they are familiar with its interface.

We attempted to modify Christine's experience by adding the available material to the existing set of devices. We were mindful of not complicating this process for her and making sure that it did not affect anything else.

For example, Christine needed support reading the chords on GarageBand, which is difficult due to the lack of colour contrast. As an activity, we used more oversized placards to identify chords by placing them on the top half of the screen.

This was helpful especially when Christine was playing two cards at a time. Presently there is no colour separation to identity the difference of chords. Christine is prepared to move her hand accordingly.



Figure 52: Placards set-up used for co-design activity 3.

# Activity 4.

**Experimenting with the Musical Set-up:** The previous design setup was limiting both of us. As a part of activity 4, we changed our music set-up. We brought Christine forward,

keeping her in focus we changed the placement of all devices with respect to Christine's position.

**Many advantages derived from this:** We found comfort in dealing with the new set-up, and I could assist better while signing the chords. Christine could focus better on the screen as well as the meeting. We received feedback from our group stating that Christine looked more optimistic, that she was at the centre of the frame, and that they could clearly see her playing music on the iPad. She could interact better and without getting distracted.

# Christine's Response from the Co-design Activities:

With every co-design conducted with Christine, she felt more confident. There was considerable increase in her conversations with the Bliss i-Band members. She shared her weekly updates with other members, leading to long conversations. Christine insisted on playing and learning other virtual musical instruments on GarageBand. She was intrigued to see the variety of instruments available to her. Christine smiles more and is now inclined to have one-on-one meetings with the i-Band community members. She feels more confident and comfortable while playing music. She has even shown interest in participating in various cultural groups and dreams of teaching music to children!

#### Limitations

Acknowledging this project's limits allowed me to demonstrate that we have critically thought about the research problem, grasped the relevant literature published, and appropriately assessed the methodologies used to explore the problem. A crucial goal of the research process is to find new knowledge and challenge preconceptions and investigate what we do not know.

The design decisions and recommendations for the infographic guide are based on our co-design process over a brief period. Since the study is not a longitudinal one, many points might have been missed. This leads us to a future scope of investing more time to apprehend the underlying complexities better.

As Christine's current companion, the guide is predominantly designed based on our ease of interactions. It allows me to support her abilities to the fullest. However, Christine will be assisted by different individuals in the future, so the infographic guide must be redesigned according to their interaction choices. Dedicating more time to further studying our proposed recommendations will allow us to assess the adaptability of the current design.

The Bliss i-Band is a net woven with multiple complexities. This paper has focused on communication concerns while briefly discussing technological and infrastructural gaps. We realise that this is just the tip of the iceberg. To introduce a sophisticated training guideline for the i-Band, a comprehensive knowledge of all three facets and their interplay

is necessary. Expanding this to other members of the Bliss i-Band can give us more insights into creating that.

#### Contributions to an Inclusive World

Listed below are the reasons why this design-based research project contributes to the ever-growing world of Inclusive Design:

**An ideal Example:** This project adds another representative of community-led co-design work. I understand that every co-design process is different. However, this project illustrates some prominent principles of inclusive design and can be of use to inclusive design students as reference material.

**Encourage Designers:** This community-based project has great potential to encourage designers and other professionals to co-design with communities.

**Create Awareness:** The idea of 'Bliss i-Band' or even imagining a music band of people with cerebral palsy can be astonishing in many parts of the world. Highlighting their unique abilities and skills can create awareness and encourage community formation.

**Inculcating an Inclusive Mindset:** The paper highlights the positives of analysing our surroundings with an inclusive approach. It is necessary to understand that we all belong to a variable world --- one that we live in and the other that lives within us.

**Empowering Communities:** The paper highlights inclusive ways of empowering individuals on the edges of our society. Supporting these individuals and creating awareness for their abilities can empower communities. The project shows real work by integrating real users and sets an example that individuals who otherwise face exclusion in the existing system can lead society into sustainability.

#### **Future Scope**

**Extending the Co-Design:** This project took shape with the contributions of four collaborators from the i-Band. The same practice of community-based co-design can be conducted by involving all other community members to study future challenges.

**Continuous Study of the System:** Like each member, the band is a variable system. To enable the band to support its members efficiently, a continuous or longitudinal study of the design decisions and their impacts on its members can be arranged. This study can involve intricate parts like digital interactions, structural and technical adaptations, and volunteer guiding.

**Investigating for Accessible interfaces:** The music devices currently used at the i-Band cannot adapt to everyone's variabilities. A detailed investigation of more user-friendly musical software can be conducted collaboratively to check the features, affordability, and accessibility.

**Extending Relations to Communities:** Getting in touch with other communities, which may include designers, researchers, specialists, or even music enthusiasts, will broaden the horizons for inter-community knowledge exchange and collaboration in the future. (Cross-pollination of ideas)

**Expand Global Reach:** The concept of having a music band with persons who have cerebral palsy is unique. We can search for possibilities of extending this structure to other parts of the globe. This paper or any future study conducted within the i-Band community, can be used as a foundation. It will add to another future scope of translating the study material into multiple languages.

## References

About Blissymbolics. (n.d.). Blissymbolics Communication International. https://www.blissymbolics.org/index.php/about-blissymbolics

Biss i-Band. (n.d.). The BLISS i-BAND. https://www.blissiband.com/about.html

Blissymbolics Communication Institute Canada. (n.d.). Blissymbolics Communication Institute Canada: BCIC. <u>https://blissymbolics.ca/w532/</u>

Cerebral palsy - Symptoms and causes. (2023, September 28). Mayo Clinic. https://www.mayoclinic.org/diseases-conditions/cerebral-palsy/symptomscauses/syc-20353999

Colours vs. Special Needs Individuals: What You Need to Know. (2019, July 18). Disabled Living. <u>https://www.disabledliving.co.uk/blog/colours-vs-people-with-special-needs/</u>

Denslow, E. (2022, January 26). *Cerebral Palsy and Fatigue: Why It Happens & How to Cope*. Flint Rehab. <u>https://www.flintrehab.com/cerebral-palsy-and-fatigue/</u>

The effect of a music and movement program on gait, balance and psychological parameters of adults with cerebral palsy. (2016, December 28). https://www.efsupit.ro/images/stories/nr4.2016/art217.pdf

GarageBand for Mac. (n.d.). Apple. https://www.apple.com/ca/mac/garageband/

Holmes, K. (2018). *Mismatch: How Inclusion Shapes Design*. The MIT Press. *Introduction to community-led co-design*. (n.d.).

Community-Led Co-design Kit. https://co-design.inclusivedesign.ca/introduction/

- Kubicek, L. (2022, July 25). *Can music improve our health and quality of life?* Harvard Health. <u>https://www.health.harvard.edu/blog/can-music-improve-our-health-and-</u> quality-of-life-202207252786
- MasterClass. (2021, June 7). *Kodály Method Guide: 5 Principles of the Kodály Method 2024*. MasterClass. https://www.masterclass.com/articles/kodaly-method-guide
- Sanabria, L. (2022, June 8). *What is Color Psychology?* Accessibility.com. <u>https://www.accessibility.com/blog/what-is-color-psychology</u>
- Stanford University. (n.d.). *Disability Access Symbols* | Office of Accessible Education. OAE, Stanford. <u>https://oae.stanford.edu/students/disability-access-symbols</u>
- Treviranus, J. (2018, March 29). *The Three Dimensions of Inclusive Design, Part One*. Inclusive Design Research Centre. <u>https://idrc.ocadu.ca/ideas/the-three-</u> <u>dimensions-of-inclusive-design-part-one/</u>
- Vinolo, M. J. (29th September 2021). Effects of the Combination of Music Therapy and Physiotherapy in the Improvement of Motor Function in Cerebral Palsy: A Challenge for Research. MDPI. <u>https://www.mdpi.com/2227-9067/8/10/868</u>

VITRIKAS, K., DALTON, H., & BREISH, D. (2024, March 5). *Cerebral Palsy: An Overview*. <u>https://www.aafp.org/pubs/afp/issues/2020/0215/p213.html</u>

VPAT<sup>™</sup> for Apple GarageBand for iOS v1.2. (n.d.). www.apple.com. https://www.apple.com/accessibility/pdf/GarageBand\_iOS\_VPAT.pdf