

# **A Story of Unspoken Efforts of Elaine Drover**

Designing Hi-Tech Augmentative & Alternative Communication Systems with  
Individuals with Cerebral Palsy

By

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## ABSTRACT

This paper explores the communication challenges and opportunities associated with Augmentative and Alternative Communication (AAC) systems through the lens of Elaine Drover, a woman in her 60s with cerebral palsy (CP) from Newfoundland, Canada. Employing a 'with' rather than 'for' philosophy, this design research project utilizes a three-dimensional framework of inclusive design, which includes recognizing and respecting human uniqueness and variability, using open and transparent processes, and co-designing with those who find current designs challenging. This approach addresses the necessity of designing within complex adaptive systems and highlights the significance of co-design methodologies. By integrating personal narratives and collaborative design, the study investigates the specific needs of individuals with cerebral palsy, aiming to dismantle communication barriers and foster a more inclusive society. The findings emphasize the importance of understanding user needs, goals, and contexts, particularly when developing essential tools that require substantial personal investment. This research not only provides insights into enhancing current AAC systems but also proposes a foundation for future technological innovations in assistive communication, advocating for a shift towards more empathetic and inclusive design practices.

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## INTRODUCTION

I am a communication assistant to Ms. Elaine Drover. Elaine grew up with cerebral palsy in Baie Verte, Newfoundland, Canada. At the age of 7, she left her family home to live in an institution. She has lived in many homes and today, she resides in a care home in Toronto. At the age of 14, she began learning Blissymbolics, a decades-old generative semantic language, to acquire literacy. She learned to communicate and eventually began expressing complex thoughts once she fully attained literacy.

Despite her struggles, she has cherished communication with others, often saying, 'Hello, how are you? Just joking, and Thanks for coming!' even if it takes her a little bit more time to say it than others. Her writing style and tone differ, which can only be understood through spending enough time with her. She has contributed to demonstrating communication through Blissymbolics and has lived away from family, communicating with strangers, some of whom became her most cherished friends.

Elaine possesses a wealth of knowledge regarding communication challenges and opportunities. She lives within numerous adaptive systems around her that have shaped her experiences and often created barriers for her. She has transitioned from using a low-tech AAC system, a Bliss board – a display with symbols arranged in a grid for the user to point at – to a hi-tech AAC system to communicate with others. Thus, her experience is important to highlight and understand to design and develop a communication system that adapts to the changing and variable needs of Elaine. She is an expert in her field that consists of communication struggles, augmentative and alternative

communication systems, and individuals with cerebral palsy. She, like many others, lives on the boundaries of our society.

This paper is based on her experiences, highlighting her struggles and opportunities in communicating through technology. This paper does not aim to solve communication struggles, provide a checklist, or establish testable criteria. Instead, it serves as an entry point to considerations necessary for designing future Augmentative and Alternative Communication (AAC) systems, advocating for design 'with' individuals with cerebral palsy rather than 'for' them. We followed a 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, recognizing that we are always designing within a complex adaptive system. This paper aims to address gaps within the complex adaptive system that Elaine is a part of, shedding light on her life experiences to guide our design decisions. By leveraging her journey, we can develop a design concept that resonates with her needs and aspirations. Additionally, the paper outlines essential design considerations necessary for crafting a solution that aligns with user requirements and fosters inclusivity.

## CONTEXTUALIZATION

In this section, we talk about Elaine and her experience with communication from early years in her life till now. This will provide context to our design decisions and help situate our participant.

Technology should not only prioritize aesthetics and creativity but also demonstrate a profound understanding of all users, their unique abilities, and the complexities of their situations (Treviranus, 2018). Designing responsibly becomes particularly challenging when it involves essential items for individuals or items that users must make significant investments in.

Technology has played a pivotal role in Elaine's life, forming a deeply personal relationship with her from acquiring the right equipment to setting it up, receiving training, and adapting to it. When Shirley McNaughton, one of Elaine's oldest friends, first introduced me to her, Elaine initially refused to have a communication assistant. She had meticulously crafted her technological ecosystem and had adapted to it, fearing the loss of agency she had cultivated over the years. We assured her that my role was solely to assist her in gaining more control, and since then, our relationship has only grown

## **ELAINE'S EARLY LIFE AND INTRODUCTION TO BLISS**

Elaine, one of ten siblings, was born in Baie Verte in the 1960s with cerebral palsy. At the age of 7, she moved to an institution in St. John. Until she turned 10 years old, Elaine could neither speak nor walk. However, at the age of 10, she made a friend slightly older than her who could understand what she was trying to communicate.

Elaine began learning Blissymbolics at the age of 14 at a school named the Virginia Waters School, in their special education classrooms. She developed a fondness for her teachers, with her favorite being Jane Green. Ms. Green learned about Blissymbolics in Toronto and brought back her knowledge to teach her students.

*Figure 1: Elaine and Jane Green are sharing a joyful moment on a park swing.*



*Taken from Elaine's writings.*

*"Bliss and Jane Green*

*My life begins with Bliss. Jane Green introduced Bliss to me.*

*Mrs. Green was the principle at Virginia Waters School in St. John's Newfoundland. She came from England.*

*Mrs. Green was in the classroom when I entered the room. She taught spelling and math. I was 12 years old when I started at Virginia Waters School. Mrs. Green had two students who couldn't communicate one of them was me. She had the opportunity to go Toronto and learned about Bliss she came back and showed us about Bliss. She showed us how Bliss worked, I kind of liked and we watch the film about Mr. Bliss. God I must have saw it 100 times.*

*I grew up with Bliss and I still use it.*

*Bliss opened many doors. I could communicate my needs through Bliss.*

*Jane was someone special to me, she came in my life throughout the years. I loved car trips with Jane many of them to McDonalds.*

*Now those times V.O.C.A. (Voice Output Communication Aids) wasn't in my world. Jane always took the time to stop and talked. I was out of Mount Pearl by then Jane knew I didn't like it.*

*I learn Mrs. Jane Green die"*

Blissymbolics, applied to Augmentative and Alternative Communication (AAC), was a collaborative effort involving professionals from various disciplines such as speech pathology, psychology, occupational therapy, engineering, and education. It was pioneering work that resulted in the development of effective communication strategies for students with complex communication needs and users of AAC systems. It provided them with the opportunity to develop language, cognitive and literacy skills.

The history of Blissymbols traces back to Charles K. Bliss, a Jewish individual born in 1897, who, following his release from a Nazi concentration camp in 1939, traversed various countries. It was during his time in Shanghai, China, that he was captivated by Chinese ideograms, spurring his invention of a novel, intuitive and universal writing system in 1949, first self-published in its entirety in 1965.

Driven by a desire to bridge gaps between people from disparate backgrounds and promote peace, Bliss, as a visionary who had endured violence and segregation, envisioned his creation as a means of connection. Despite numerous endeavors over the years, his utopian vision largely went unnoticed. These symbols, devoid of phonetics, consisted of fundamental symbols representing ideas, offering a multitude of combinations to form new characters.

Decades later, Shirley McNaughton, a special educator at Canada's Centre for children with complex communication needs (CCN), encountered Semantography (Blissymbolics) in a book titled "Signs and Symbols Around the World". Recognizing its potential, she viewed the system as an avenue to enhance communication with children affected by cerebral palsy – a language that had all the capabilities of a language, but in



a semantic form.

In 1971, McNaughton, alongside a team of interdisciplinary clinicians, initiated an assessment project at the Ontario Crippled Children's Centre (now Holland Bloorview Kids Rehabilitation Hospital), integrating Blissymbols into the educational curriculum for preschool to grade one child. Utilizing Bliss as an augmentative and alternative communication method, she began communicating with her students. One notable instance involved a student utilizing Blissymbols to express a desire to dress up as a vampire for Halloween by using the symbols showcasing the efficacy of AAC in facilitating functional expression (*Symbols – AAC Community*, n.d.).

This experience, as narrated by Arika Okrent (2009), prompted McNaughton's realization of the significance of Blissymbolics. Contrary to individuals like Stephen Hawking, who had acquired language before losing their ability to speak, children with cerebral palsy faced distinct challenges. While Hawking could rely on text-to-speech technology, children with cerebral palsy lacked the ability to read, posing a significant obstacle to their communication and educational development.

McNaughton explained her experience interacting with children with cerebral palsy before introducing Bliss to the group. They had little boards with pictures on them — a picture of a toilet, a picture of some food, all needs-based pictures — I went through a year just asking them yes-or-no questions: “Would you like to do this? Would you like to do that?” But they couldn't initiate anything themselves. They seemed to understand what was said to them, and, more important, they seemed to have something to say. “You could just tell with the twinkle in their eye or something.” (Okrent, 2009, p. 270)

McNaughton's journey with Blissymbols sparked profound excitement as children quickly embraced the system, leading to emotional moments captured in the documentary film, "Mr. Symbol Man". It was released in 1974. For the first time, children with complex speech needs could express themselves, nurturing creativity and independence. McNaughton and her team made slight adaptations to the language to suit the children's needs.

## **GROWTH AND APPLICATION OF BLISS**

McNaughton and her team designed classrooms for group teaching, consulting both students and parents in developing the language and exploring new teaching methods. The significant progress made at the Centre required formal organization and led to the establishment of Blissymbolics Communication International in 1975 in Canada. Through their work, beginning in Toronto, Canada, and reaching people worldwide, Blissymbolics has been applied to augmentative and alternative communication (AAC), a term adopted in the eighties. The use of Blissymbolics spread from Canada to over 30 countries in the following years. Presenters were trained in many countries, and they provided workshops to teachers, speech language pathologists and occupational therapists in their respective countries. Numerous meetings were held internationally to develop vocabulary and share knowledge of the language as it was being used in AAC.

For over 50 years BCI has worked with individuals with cerebral palsy, aiding them in improving their communication and literacy skills, while also providing leadership in the global application of Bliss. In 2012, the international role and responsibilities were transferred to Sweden, and BCI (in Canada) was renamed Blissymbolics Communication Institute - Canada (BCIC). The Canadian focus shifted to providing resources to supporting Bliss users and alumni, providing resources for the Bliss community in Ontario, and participating as a member in the work of Blissymbolics Communication International. Elaine currently serves as the Vice President on the board of BCIC.

To provide context as to why to include Bliss as an important factor in this paper is because Elaine learnt literacy through it and because this semantic language is different from picture sets and line drawings. Blissymbols function through approximately

1400 basic Bliss-characters, derived from Semantography-Blissymbolics, with over 6,500 Bliss-words contained in the BCI Authorized Vocabulary. Unlike the Latin alphabet, each Bliss character represents an abstract or concrete concept, allowing for multiple combinations and interpretations. These symbols are constructed within a matrix, with indicators used to modify grammatical or semantic elements, thereby enhancing expressiveness and versatility. In accordance with standard rules, the conceptual semantic nature of Blissymbols permits unique adaptations to suit different linguistic contexts, as exemplified in Hungary and Israel.

The symbols will always be accompanied by words for those who are unfamiliar with the system. The symbols themselves are simple but they are part of a communication system with broad and unique capabilities. By learning Bliss, students have a personal and flexible communication system when their early language and literacy skills are developing. If they have difficulty learning traditional orthographical print, they can continue in Bliss taking advantage of its many language capabilities. Blissymbols allow students to gain a deeper understanding of language concepts and the world about them. These symbols can be used at a pre-reading level, but are sophisticated enough to allow expression of thoughts, ideas and feelings at an advanced level. Just like any language, Bliss has a syntax that is followed based on the country or community it is being used or spoken.

Figure 2: Displays Blissymbols categorized by their types—arbitrary, ideographic, pictographic, and composite—demonstrating the systematic approach to visual language representation in Blissymbolics.

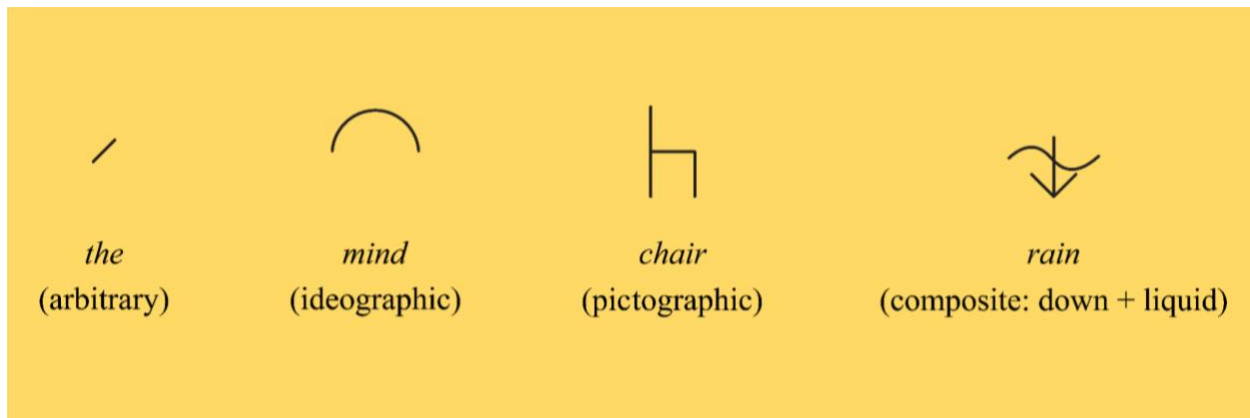
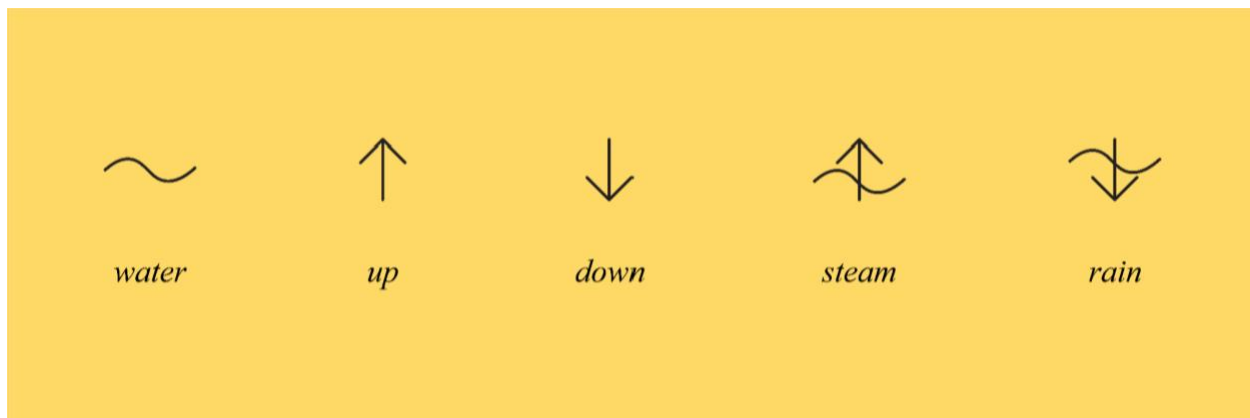


Figure 3: Examples of Blissymbols representing characters, showcasing the simplicity and effectiveness of Blissymbols in conveying abstract concepts through clear visual symbols.



The component parts (Bliss-characters) of each Blissymbol are sequenced to form a Bliss-word and several Bliss-words are sequenced to form a sentence. Blissymbols can help to understand abstract concepts which lead to the development of students' intellectual, social and emotional development. Many AAC users can benefit from a system with broader capabilities than pictures when they are developing language and approaching literacy. Students can relate some of their own experiences to pictures and it makes pictures easier to learn at first, but students can gain a deeper understanding of concepts through the language capabilities of Blissymbolics, and they can learn to

decode Blissymbols, a process that parallels reading.

While speaking children can rely on phonetics to decode written words, this approach is not accessible to non-speaking children. Blissymbols offer an alternative method that doesn't require learning sound-letter relationships. For non-speaking students, Blissymbols can be taught based on the shape of the symbol itself. For instance, a circle could represent an eye, simplifying the learning process and enhancing accessibility for all learners. There is a logic to how the symbols are sequenced on Bliss displays. The sheets of paper with symbols were included in plastic folders used for menus at restaurants and cafes. The child would memorize over time where each symbol is located. Skilled Bliss users could construct their own symbols and expand the vocabulary on their displays to an infinite level. Elaine made her display bigger with her teacher, Anne Martin. She included names of her teachers, her friends, her family and even added a section for just letters to spell words once she could understand English words and letters.

McNaughton and her team initially implemented standard displays for all students. However, they quickly recognized the need for more personalized communication tools and transitioned to providing blank grids and Bliss-stamps (like postage stamps). Bliss users like Elaine could decide where each Bliss-stamp would be placed on the grid and select only those stamps that were useful to meet their personal needs. During her design sessions with her teacher, Elaine utilized these stamps to create her display. The grids were available for different sized vocabularies and for different sized stamps. Students could select their personal vocabulary and arrange their vocabulary as they saw fit.

McNaughton and her team had realized that the tailoring of designs to individual students and their abilities was necessary. This realization prompted them to delve into experimenting with technology to further personalize the AAC system. While Elaine was not part of these experiments as they primarily took place in Toronto, it shows how Bliss progressed through the incorporation of technology.

*Figure 4: A young child in a wheelchair using a Blissymbol communication device, illustrating the device's role in supporting language development and emotional expression in young users.*

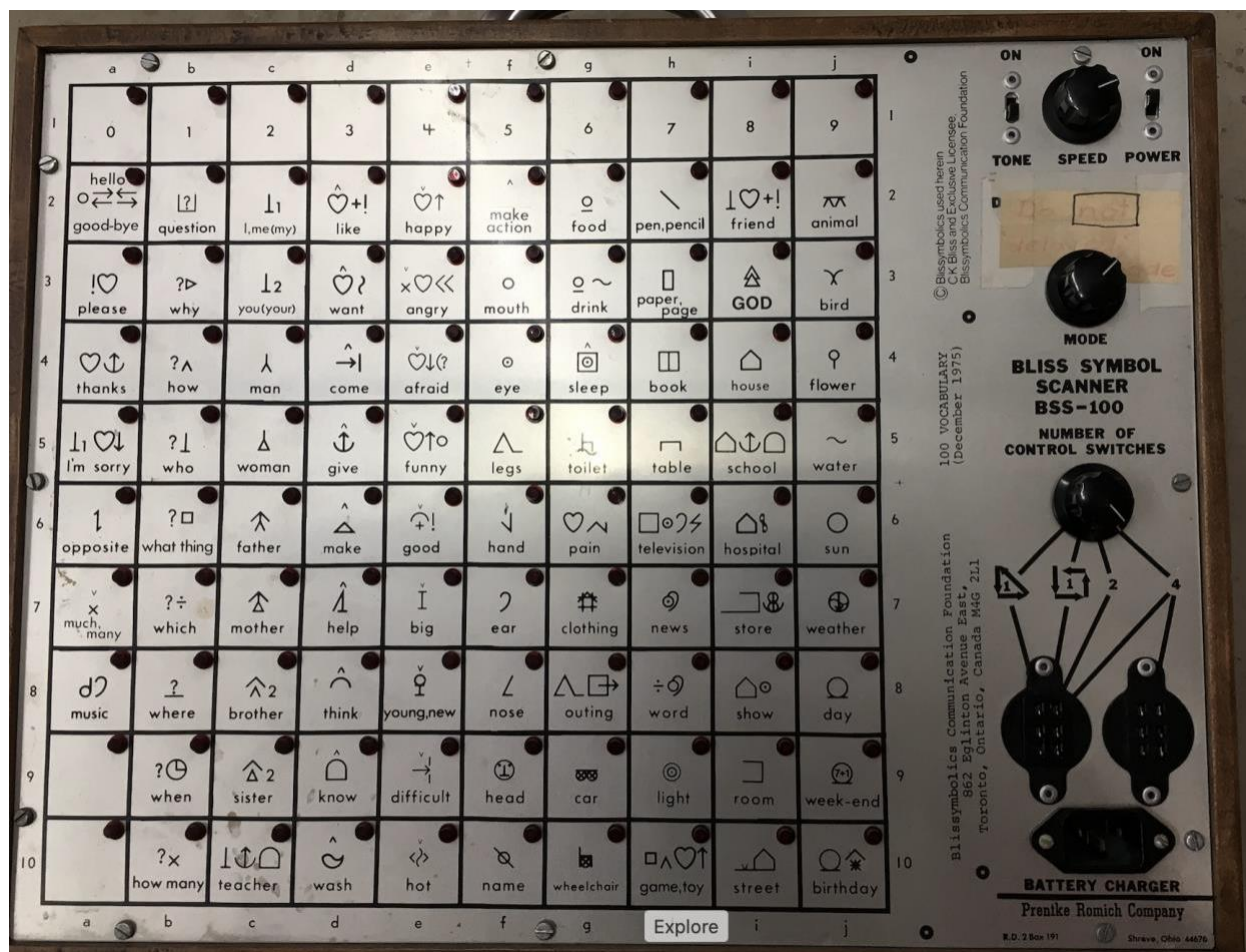


*Figure 5: The early prototypes utilized light-emitting diodes (LEDs), allowing students to control the scanning of lights over the display. However, when taken outside into sunlight, the device failed to function properly because it was difficult to discern the*





Figure 6: Bliss display manufactured by Prentke Romich in 1975. An augmentative and alternative communication (AAC) device equipped with Blissymbols overlaid by descriptions, integrated with control switches, and a battery charger for dynamic user interaction.



This also entailed the development of a scanner for 100 Blissymbols, which users could control using a joystick or a similar device, scanning the lights on the display. Additionally, certain experiments were designed to be controlled by the user's feet, for those children who could only use their legs.

McNaughton leadership role in the design of the Blissymbolics Minspeak Word Strategy (BMW). In the late 1980s, the BMW was developed through collaboration with Sue Odell and Lee Mehrlich, both proficient Bliss users, and Annalu Waller, at the onset of her career in Assistive Technology. It combined the strengths of Blissymbolics, the Minspeak

strategy developed by Bruce Baker, and the Word Strategy by Bruce Baker. The "M" in the BMW, Minspeak, relied on associated meanings to arrive at the final meaning. For instance, an Apple icon could represent not only an apple but also redness, all colors, fruit, and all fruits, depending on the other symbols incorporated into the code. The BMW was structured based on the QWERTY keyboard, making it accessible to users who had some knowledge of print. It incorporated Blissymbols within the code sequences. However, it also incorporated Blissymbols within the code sequences. Additionally, it could utilize the pre-associations of Minspeak to generate codes for vocabulary acquisition.

Figure 7: BMW featuring an organized grid of Blissymbols, each corresponding to specific grammatical categories such as nouns, verbs, and adjectives, enabling complex language construction for AAC users.

1	1. Q <sub>AAC</sub> Shift Once	2. Q <sub>AAC</sub> Shift Off	Dem / /	Conj   +	Adv. vΛ	Prep > □	Adj v	Adj+er x	Adj+est x	Noun □	Noun Pl □	N Psn ↓	Pl Psn Pl ↓	Abs Trn e ⊕ ⊖	Enter ↵	Store ⌘
2	Obj ↓Λ	Poss ±	Verb Λ	Verb+s Λs	Verb-ing Λ→	Verb-ed Λ)	Verb-en ΛV	To-Verb Λ	What ?	Interj ⊙!	Minspeak x ⊕ ⊙	Force ⊕	Number #	Poem ⊕ ⊖ ⊙	Spk Mark ⊕ ⊕	Spk Mod ⊕ ⊕
3	I+ ↓1	We+ ↓1	Help Λ	Give ⊕	Comm ⊕ ⊕	Tool ⊕	Cntry ⊕	Lim thre ⊕	Year ⊕	Month ⊕	Day ⊕	Many x	Part ÷	Relation <	Spk Dsply ⊕ ⊕	Spk Sel ⊕ ⊕
4	You+ ↓2	They+ ↓3	Receive ⊕	Write ⊕	Eye ⊕	Repeat 	Water ~	Weight ⊕	Put ⊕	Food ⊕	Without -	Also +	Equal =	Opposite ↕	Del Char ⊕ ⊕	Del Syst ⊕ ⊕
5	He+ Λs	Prvrb Λ	Quiet -2	Want ⊕	Electric ⊕	Religion ⊕	Think ⊕	Young ⊕	Umbrella ⊕	If ⊕	Without ⊕	Past )	Present ) (	Future (	Del Word ⊕ ⊕	Del Select ⊕ ⊕
6	She+ ↓3	Prvrb-s Λs	Am/Be ⊕	Stop ⊕	Directn ⊕	Forgive ⊕	Go ⊕	Have ⊕	Journey ⊕	King ⊕	Love ⊕	House ⊕	Return ⊕	Legsfeet ⊕	Rev Ver ⊕ ⊕	Spch Op ⊕ ⊕
7	It+ ↓1	No -#	Dress ⊕	Zebra ⊕	Exclaim !	Can ⊕	Value ⊕	But ⊕	Near ⊕	Maybe ⊕	Money ⊕	Furnitur ⊕	Yes +##	Say ?	Exc Star ⊕ ⊕	Spch Off ⊕ ⊕
8	Air Z	Open ⊕	Not -!	Finish ⊕	Cause ⊕	Birth ⊕	Sexual ⊕	Lang ⊕	No Thre ⊕	1 svr thr ⊕	2 svr thr ⊕	sp msk ⊕	txt msk ⊕	txt t5 sp ⊕	Clr Dsply ⊕ ⊕	Clear ⊕ ⊕
	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P

These communication technologies were used to facilitate the communication needs of children and adults and underwent continuous refinement, guided by experimentation and user abilities. Blissymbolics stands out for its versatility and accessibility across different technology levels. In no-tech environments, symbols can be manually drawn on surfaces such as sand, paper, or blackboards. In low-tech settings, the Bliss board or display—a grid of symbols—enables users to point, gesture and effectively convey thoughts. In hi-tech scenarios, some modern Information and Communication Technology (ICT) platforms support Blissymbols, including integration with digital AAC systems like Voice Output Communication Aids, as demonstrated by a Bliss Alumni, Pete Zein.

## **TRANSITION TO HIGH-TECH AAC SYSTEMS**

After Elaine moved out of her home at the institution, she went to live with a couple. She got enrolled in a program where she learned various life skills such as cooking and handling money, and she co-authored a cookbook in Blissymbols with the couple she was living with. Elaine quickly became one of the fastest students in pointing to symbols to craft her messages for her listeners. She carried her Bliss board with her everywhere she went. At the time, that was her communication companion.

In the summer of 1986 while living in St. John, Elaine showcased the new "Talking Bliss Apple" developed by the Trace Centre in Sudbury, which never became commercially available. An article from Blissymbolics Communication International's (BCI) magazine, *Communicating Together*, described Elaine captivating visitors by demonstrating Blissymbolics and showcasing the software program called 'Bliss apple'. Her engagement with the Bliss board made a lasting impression, with the article likening Elaine's interactions to a tennis match, where she volleyed Blissymbolics questions, surprising her conversational partners.

"Elaine Drover plays her Blissymbol board the way some people play tennis: trading volleys from the baseline until she sees her chance. 'What do you know about Blissymbolics?' she asks, catching the other party off guard. 'Well,' he replies, very seriously, 'I'm familiar with the outline, but not the details.' Now Elaine moves to the net and goes to her backhand. 'Smart cookie!' she exclaims. Game and set."  
(Henderson,1986)

*Figure 8: A black and white photograph of young Elaine interacting with a Blissymbolics board communicating her message to Ian Henderson.*





Figure 9: A black and white photograph of young Elaine interacting with a Blissymbolics board smiling while looking in the camera.



After completing her studies, Elaine relocated from St. John's to Parry Sound around 2004-2005. Her permanent residence became "Friends" in Parry Sound, and she spent summers at the Bliss Learning Centre (BLC) in Bala, Muskoka, a summer residential Blissymbolics instructional program. The BLC's Program Director was Shirley McNaughton. Elaine told me, "*I went to help my friend Shirley!*" The program offered an annual 5-day residential, social, and learning experience for 40 Bliss users and alumni,

focusing on Bliss instruction. The Director of Friends was also a member of the BLC's Board of Directors, and she had initially met Elaine when Elaine worked at the Bliss Learning Centre.

By 2011 there had been a decline in the use of Blissymbols in Canada, a trend that had begun in the eighties and accelerated in the nineties as picture sets and line drawings became more prevalent, overshadowing Bliss. This shift was primarily due to the education system transitioning towards integrated education. Children were now placed in integrated classrooms, encountering different teachers each year and interacting with peers who had various abilities and communication styles. For non-speaking children with cerebral palsy, this change often resulted in withdrawal and isolation, as they struggled to receive the specialized instruction they required. Teachers, finding line drawings and picture sets easier to teach, opted for these methods to facilitate communication for such children.

Transitioning from low-tech to hi-tech AAC systems is seen as a significant milestone for most Blissymbolics users like Elaine. After gaining literacy, many users move on to digital AAC systems like Voice Output Communication Aids (VOCAs) for face-to-face communication and computers for written communication. The pressure of using phonetic-based devices becomes important after gaining literacy. Apart from some, most Bliss Alumni have eagerly shifted to using these devices, and they mostly prefer it now, leaving Bliss behind. Elaine is one of a few that remain, however, strong advocates for the use of Blissymbols for young children as they approach literacy.

*Figure 10: Elaine in her own apartment utilizing adaptive technology with two computer screens and specialized input devices to maintain her productivity and independence.*



Around 2014, Elaine became a member of the Ontario Federation of Cerebral Palsy (OFCP). She began living independently at the OFCP apartments, describing it as the most independent she had ever felt. She had her ideal setup and had transitioned to hi-tech Augmentative and Alternative Communication (AAC) systems. Transitioning from low-tech to hi-tech AAC systems is a significant milestone for most Blissymbolics users. After gaining literacy, many users progress to digital AAC systems like Voice Output



Communication Aids (VOCAs) for face-to-face communication and computers for written communication.

Elaine followed a similar path, using a speech-generating device for crafting messages and a laptop for communication with friends and family. While she still cherished her personally designed Bliss board for nostalgic purposes, her primary mode of communication had evolved through years of learning Blissymbolics. Not only could she express herself through spoken output, but she was also functional in reading and writing.

Elaine's journey with her hi-tech AAC system began about ten years ago. She received her device through the AAC clinic at Hennick Bridgepoint Hospital, under Ontario's Ministry of Health's Assistive Device Program (ADP). While Ontario boasts around 26 AAC clinics primarily serving children, Hennick Bridgepoint Hospital caters to individuals over 18 years old. Ontario's ADP is more advanced with technology than others in the country. While Elaine was in Parry Sound, Shirley got her enrolled in the ADP clinic in Toronto which she had to travel to for training and other routine checkups. Despite the efforts of the ADP, awareness about these services remains lacking, leaving a gap in accessibility for many individuals due to the high cost of these devices.

For her to get a device, Elaine went through a thorough assessment by speech-language pathologists and occupational therapists to determine which device best suited her and her unique capabilities. Elaine can still use her right hand to type. She can say a few words which you can understand after spending some time with her. She can use her left hand but only if she absolutely needs to. She cannot write but can hold a pencil, pen or remote with the help of her other hand.

Individuals can lease or purchase the devices from the ADP clinics. The cycle for a new assessment is every five years. Elaine mostly goes by herself, as she prefers it. The ADP covers 75% of the cost for most equipment and supplies, while 25% is expected to be paid by the user. Currently, there are 1600 individuals with speech and writing needs under the ADP in Ontario. The process to determine if a new device should be included as part of the list is determined by the clinicians and manufacturers. It does not include those who will eventually interact with it, either directly or indirectly. These devices can be very expensive. Even after covering 75%, the remaining amount can be too much for individuals who are unemployed and do not have an income of their own apart from what they receive as disability benefits from the government and organizations they are part of. The OFCP assists with payments for individuals with cerebral palsy, and they also provide housing if needed.

## **CHALLENGES & ACHIEVEMENTS IN INDEPENDENCE**

Elaine lived in an independent apartment for several years but not without worries of her own. True independence means something different for everyone. One can feel overwhelmed when trying to live independently, especially with a disability that restricts mobility. This includes needing help with daily chores such as grocery shopping, laundry, cleaning, etc. It also includes taking care of one's physical and mental health. Elaine worked on all these things by herself, with some help from her family and friends, but ultimately made decisions on her own. At one point, Elaine had a volunteer with her who would help her write letters to her family. They would also play a puzzle game which Elaine enjoys a lot. Elaine is a puzzle herself – a complex adaptive human.

After a few years of digestive problems, Elaine learned that she could not eat by mouth and started tube feeding. Her health has deteriorated since then and her schedule is filled with checkups and medications. She had to give up her apartment and move to a care home where most of her needs are taken care of. However, Elaine misses her independence as she has lived on her own for many years. Elaine's journey reflects the challenges faced by individuals with complex communication needs. Despite advancements, accessibility and affordability remain key issues in ensuring true independence for individuals like Elaine. All these experiences will be invaluable in informing our design decisions and considerations as we collaborate with Elaine to develop an enhanced system.

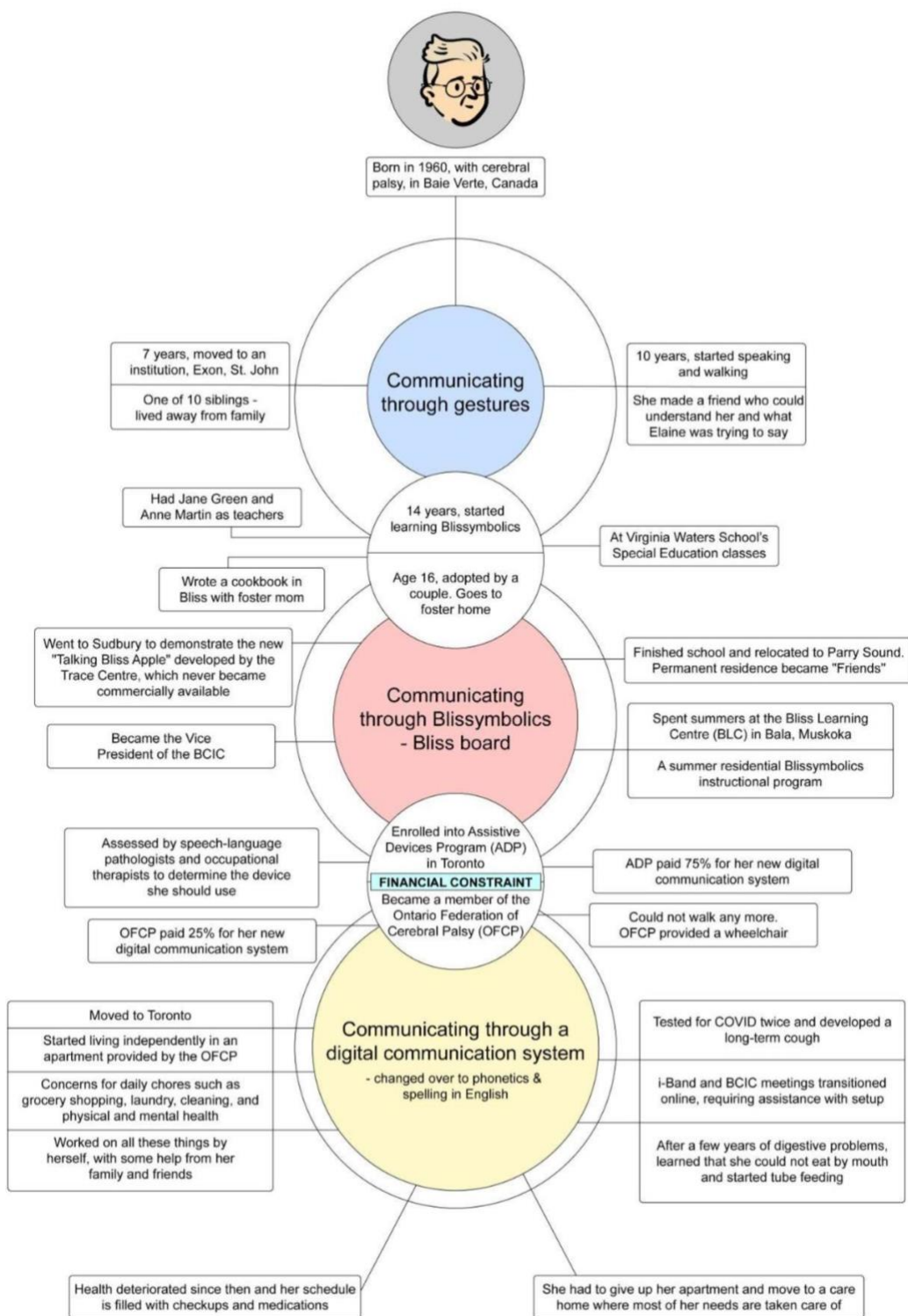
## **DESIGN**

In this section, we have integrated both primary research with the participant and secondary research. The secondary research serves to provide additional support for the design, while the primary research offers context for the design decisions. Essentially, we will leverage Elaine's context and situation while exploring advancements in AAC systems within the industry to enhance her communication system based on her specific needs and requirements.

## **PROJECT OVERVIEW**

This comprehensive circular system map illustrates the major life events and transitions of Elaine, a woman born with cerebral palsy in 1960 in Baie Verte, Canada. It highlights her communication development from gestures to Blissymbols and digital systems, her educational background, her personal and medical challenges, and her support systems.

Figure 11: Figure 11: Elaine's Life Journey System Map



## **OBJECTIVE & RESEARCH QUESTIONS**

The objective of this project was to co-design an AAC system that integrates Blissymbolics as a communication language and investigate methods to reduce communication time and increase effectiveness for individuals with cerebral palsy (CP).

Our research questions for this project were:

- I. What strategies can decrease the time and effort gap between AAC and non-AAC users?
- II. How might we design or create more opportunities for language development and language growth?
- III. How can we promote Bliss as a minority language and its importance in the process?

## **PRIMARY RESEARCH**

In our primary research, our focus was on understanding the design process through the lens of our participant, Elaine, who relies on an Augmentative and Alternative Communication (AAC) system due to her physical limitations. We examined various aspects of Elaine's communication experiences, including the diverse conversational scenarios she encounters in her daily life.

The "Who" aspect of our research centered on Elaine, highlighting her as the primary user of the AAC system. We delved into her communication needs across different contexts, from formal discussions with healthcare practitioners to casual conversations with friends and interactions with shop assistants at a mall.

The "Why" aspect underscored the importance of understanding the nuances of Elaine's interactions for designing an effective AAC system. By recognizing the complexities of different conversation types and listeners, we aimed to tailor the system to enhance Elaine's ability to communicate efficiently in various scenarios.

The "What" aspect involved developing contextual predictions and a communication palette (keyboard) that adapts to different conversation types and listeners. This entailed considering both familiar and unfamiliar listeners and incorporating features that facilitate effective communication across diverse contexts.

The "How" aspect of our research was driven by a storytelling and co-design approach. We engaged in a collaborative journey with Elaine to explore and understand her communication experiences. Co-design, as defined by CO-CREATION SKILLS & TRAINING (2019), fosters a collaborative learning process between users and designers,



enabling the expansion of knowledge and insights for all involved parties. Through this approach, we gained firsthand experiential knowledge about Elaine's unique needs and preferences, while also exposing her to potential options she may not have considered before.

Throughout our research, storytelling emerged as a powerful tool for connecting with Elaine on a profound level. By delving into the depths of her lived experiences, we were able to bridge the gaps between our perspectives and gain a deeper understanding of her communication challenges and aspirations. This holistic approach facilitated a more nuanced and empathetic design process, ultimately leading to the development of a more tailored and effective AAC system for Elaine.

## SECONDARY RESEARCH

The secondary research consisted of the following to support the design decisions made later in the paper.

- I. **Integration of LLMs in AAC Systems:** LLMs like GPT-4 have revolutionized text generation, offering human-like responses that can greatly reduce the effort required by AAC users. According to Valencia et al. (2023), integrating LLMs could potentially decrease user keystrokes by 75%, making communication faster and more efficient for individuals with speech and language impairments.
- II. **Enhancing Predictions through Contextual AI and RAG:** Contextual AI leverages the context in which communication occurs to provide more accurate predictions of what the user might want to say next. Retrieval Augmented Generation (RAG) takes this a step further by pulling in information from external sources to enhance the quality of the predictions, making the AAC system more intelligent and responsive.
- III. **Strategies for User Agency, Privacy, and Autonomy:** Empowering users with agency and autonomy is crucial. This involves developing strategies that ensure user privacy and allow for personalization and customization. By doing so, AAC systems can be tailored to the unique communication styles and preferences of each user, thereby enhancing the overall user experience.
- IV. **From Static Grid Displays to Dynamic Ones:** The evolution from static grid displays to dynamic ones is another leap forward. Dynamic displays can adapt to the user's communication patterns over time, presenting options that are more likely to be used based on previous interactions. This adaptive approach can

streamline communication, making it quicker and more intuitive.

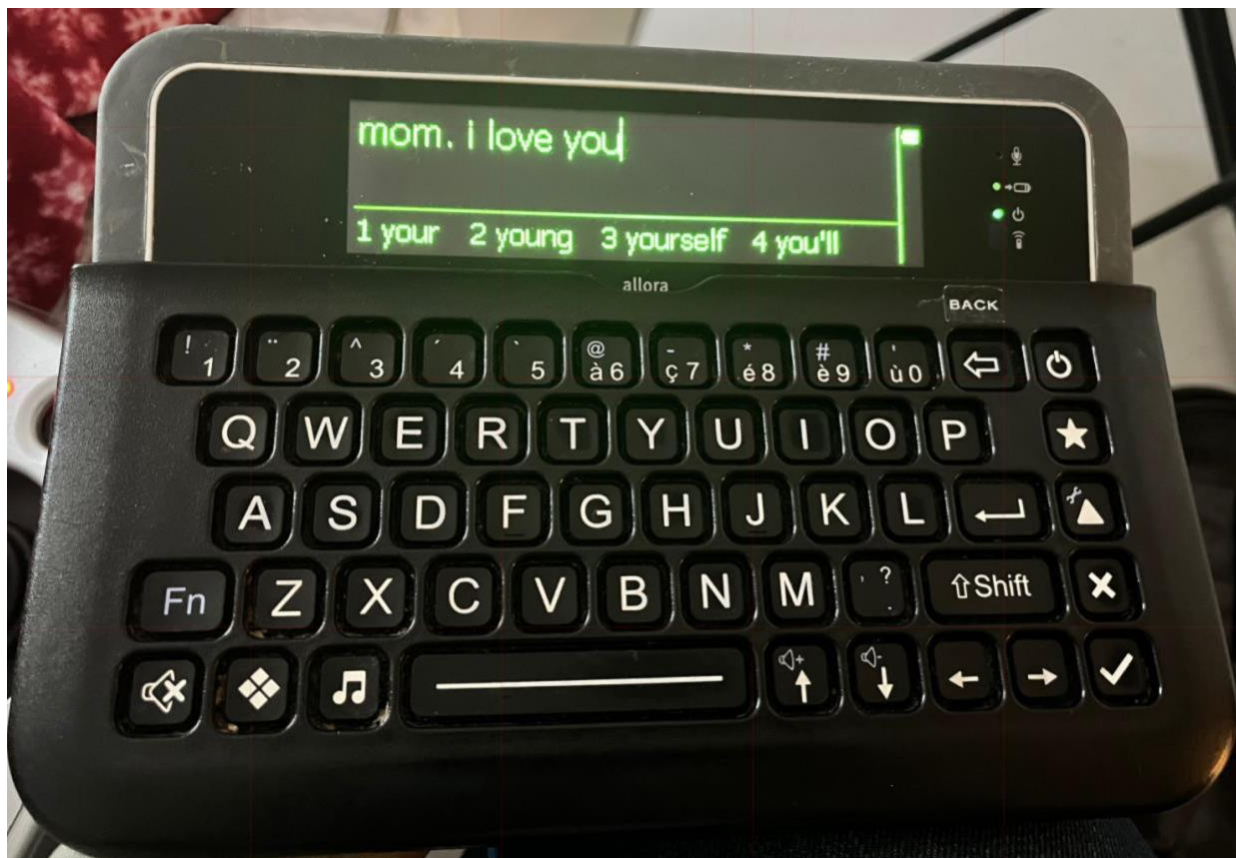
## **ETHICAL CONSIDERATIONS**

Necessary permissions from the Research Ethics Board (REB) and consent from Elaine were obtained and approved for co-design research to determine the palette layout, vocabulary, palette groupings, and navigation among palettes. We received her consent by reading out the consent forms and clearly stating what the project entailed. We also took her written consent through her signature.

Our process in taking consent was to read out the content to Elaine. We printed out all the forms for her and asked her for her signature for approval. She had a hard time writing her signature. Recommendation for the REB to create different formats to obtain consent from participants, especially for individuals with cerebral palsy who are not able to provide verbal and written consent.

## PROCESS

Figure 12: Elaine's current device that she uses for communication.



Elaine utilizes a device manufactured by Jablasoft, known as the Allora 2. Acquiring her device a decade ago, she has become accustomed to its functionality over time. However, a crucial component of the device, the screen used for viewing typed content on the reverse side of the device is no longer functional. The listener needs to be beside her to see what she is typing if she is in a crowded space. The manufacturer has discontinued this model. Nevertheless, an online manual detailing the device's functionalities remains accessible for reference.

## Affordances

This device features a phonetic QWERTY keyboard designed to facilitate Elaine's writing of words and sentences. Elaine predominantly spells out her words manually. Notably, the device lacks spelling and grammar check functionalities, necessitating Elaine's manual correction of her spellings. However, it offers a list of word suggestions that appear horizontally on the screen. These suggestions can be accessed using the number keys at the top of the keyboard, requiring the user to press each key twice for selection. Initially, Elaine struggled with this feature, often entering the number and then deleting it to retype the word. We recently discovered this, and she now attempts to utilize it regularly in her writing. Previously, when attempting to select words, the device would display random options. We have since customized it to display the words Elaine commonly uses, enhancing her user experience.

Furthermore, during interactions with Elaine, I often anticipate her intended words before she completes them, potentially hindering the system's ability to learn her preferred vocabulary. The device limits Elaine to typing out only two lines of text at a time. It includes essential functions such as a spacebar, a button to enable message playback, arrow keys for navigating messages, and buttons for deleting individual letters or entire sentences. Additionally, it features a power key for turning the device on and off, and a function key that, when pressed in combination with other keys, provides access to settings. However, Elaine finds it challenging to use this function key as she primarily relies on her right hand and struggles with her left hand. While Elaine demonstrates the ability to manipulate two fingers on her right hand, it remains uncertain whether this capability extends beyond a mere demonstration or if she employs alternative

techniques when alone. Moreover, observations reveal that Elaine rarely utilizes certain keys on her communication device. Similarly, on her keyboard (she uses a separate keyboard for her laptop), she encounters challenges where inadvertent keystrokes occur due to the proximity of symbols to the delete button. This often results in unintended typing, as she mistakenly presses adjacent keys while aiming for deletion, repeating the action multiple times before achieving the desired outcome. These insights underscore the need for a user-friendly interface that mitigates such challenges and enhances Elaine's interaction experience.

### Understanding Challenges

In the following sections, we will discuss the observations and findings gathered through interviews and explorations. This will encompass the challenges Elaine faces and explore how advancements in technology can enhance her communication, making it more effective and efficient. These inform our design decisions, which we will discuss in the following sections.

### *Initial Observations and Conversations*

In contrast to conventional approaches reliant on sketches or written proposals, our design process embarked on a different trajectory. We initiated comprehensive discussions centered around agency and control, specifically delving into their implications for Elaine. Immersed in Elaine's world through extensive interaction, we gained profound insights into her cherished activities and unwavering determination in overcoming challenges. For example, Elaine finds immense joy in personalizing Christmas cards, investing effort to craft messages. Additionally, her unwavering social

commitment to friends and family is evident in her active participation in significant events, such as attending her friend's mother's funeral. Despite facing logistical hurdles, Elaine adeptly arranges transportation via email and meticulously plans her schedule. Her engagement in the i-Band, where she eagerly anticipates playing alongside her Bliss Alumni peers, further underscores her enthusiasm for meaningful interaction. The Bliss i-Band comprises Bliss Alumni adults with physical disabilities who gather weekly to play music together using virtual instrument apps found on their iPads.

Our discussions emphasized the necessity for technology that could adapt to Elaine's unique requirements. However, upon introducing her to a new iPad, we encountered initial challenges, particularly with touchscreen interaction. Understanding the significance of addressing her specific needs, such as preventing inadvertent keystrokes, we embarked on a series of iterative experiments. Through these efforts, we gained valuable insights into Elaine's interaction preferences, identifying areas where touchscreen functionality proved cumbersome. Challenges arose when tasks like typing a passcode or swiping to unlock the iPad proved difficult for her. Additionally, setting up chords herself posed considerable obstacles. These findings underscored the importance of designing a solution that alleviated these challenges and empowered Elaine to engage with technology more effectively.

### *Exploration of User Interaction and Preferences*

During our sessions, Elaine and I engaged in dialogues facilitated by her laptop, where she would save typed notes for reference. Initially, when approaching the topic of enhancing her AAC system, Elaine expressed apprehension, citing her comfort with the

current setup. This marked a significant turning point in our design process. Recognizing Elaine's initial apprehension about altering her AAC system, we decided to pause and reevaluate our strategy. During this period of reflection, we shifted our focus to consider the broader implications of our concept design, particularly its potential to aid children in learning Blissymbolics and communication based on Elaine's experience learning the Blissymbolics language in the 80s and her communication aspirations. We reflected on questions on learning what limitations existed then and how we can use technology now to empower more users.

### *Data Transfer Dilemma*

Upon acquiring a new laptop, Elaine faces challenges of her old data not being transferred, resulting in the loss of her written blogs and other valuable information. Despite my efforts to retrieve her writings, I was unable to locate them. In response to this predicament, I devised an online version to ensure the preservation of her data. However, upon reflection, I realized that this solution might not be optimal, as it existed separately from her communication system. Recognizing the need for a more cohesive approach, I engaged Elaine in a discussion regarding the integration of her writings into her communication system. Striving to remain impartial and mindful of bias, sought Elaine's opinion on the matter. After thorough deliberation, Elaine agreed that incorporating her writings directly into her communication system would be beneficial.

### *Context-based Suggestions / Predictions*

AAC users typically communicate at a slower pace than non-AAC users, with an approximate gap of 80 words per minute (Valencia et al., 2023). Our most significant



discussion revolved around the time Elaine spends crafting a message. Given her extensive interactions, which include using Zoom chat during i-Band sessions to connect with friends and greet everyone, Elaine invests considerable time in spelling out each word. However, interruptions occur when a pop-up appears on the screen covering the chat feature, indicating poor sound quality from Elaine's side. She then uses her joystick to dismiss the popup, which takes her a few seconds. Subsequently, as she resumes typing, the pop-up reappears, causing further delays. To mitigate this, I often mute me when attending meetings. Additionally, when someone shares their screen on Zoom, the screen switches to full screen mode, and the chat becomes a separate box covering some part of the screen. This setup poses challenges for individuals solely relying on chat for communication. Therefore, when communicating remotely with Elaine, I unshare my screen and wait for her response via typing. However, this is not a solid solution.

I downloaded Spotify for her, a digital musical service app. Elaine found it difficult to understand, but she uses Discord, although I have yet to witness her using it. She regularly utilizes Facebook and Gmail. However, navigating scrollbars poses a challenge for her as she uses a joystick. Often, the joystick inadvertently selects items, and Elaine struggles to deselect them, resulting in the selected icon following her as she navigates other tasks. These observations underscore the need for patience and understanding in the design process to create a device that is both effective and efficient. The interactions should be designed with her, understanding her day-to-day frustrations such as these.

As previously mentioned, she relies less on proffered predictions, as they often lack relevance to her. While enhancing functionality and accessibility is essential, ensuring the usefulness of the suggestions presented is equally critical. In our deliberations, we

explored strategies to streamline the message crafting process for Elaine. How might we train the system to understand context and offer suggestions tailored to Elaine's needs, thus expediting the message creation process? To address this challenge, we turned to Large Language Models (LLMs). Unlike conventional machine learning models, LLMs are uniquely designed to comprehend the complexities of human language. This encompasses discerning the nuanced meanings of words and grasping the intricate connections between them (What Exactly Are LLMs in the Artificial Intelligence Space and How Can They Be Utilized? 2024). Conceptually, they could decrease a user's keystrokes by 75% (Valencia et al., 2023). We started experimenting with LLMs. I introduced her to ChatGPT where we wrote her a poem with only one line of text. She was surprised and didn't know about ChatGPT.

I introduced Elaine to ChatGPT. Taken from ChatGPT.

“Title: Elaine’s Poetic Tribute (March 13, 2024) **Gulay**: Write me a poem for Elaine

Drover. **ChatGPT**: *In fields where whispers softly sigh,*

*Where dreams like dandelions fly,*

*There walks Elaine, a gentle rover, In every step, a grace, a cover.*

*Beneath the moon's soft silver glow, She wanders where the wild winds blow, With eyes*

*that hold the stars above,*

*And a heart that beats with endless love...”*

After seeing this, she became more interested in the project and started thinking of ways that I could make the system better and use something like ChatGPT to help with writing full sentences. Valencia et al. (2023), in their paper, “The less I type, the better”: How AI Language Models can Enhance or Impede Communication for AAC Users, talk about their co-design sessions with participants using the feature of ‘extending replies’. The participants appreciated the ease provided by a macro that could extend short inputs into complete phrases, highlighting its potential to minimize the physical and mental effort involved in typing, especially when energy and motivation are low. One participant noted how this function could facilitate social interactions by allowing for quicker and less taxing communication. This feature was deemed particularly useful for those who sometimes avoid initiating conversations due to the effort required.

Additionally, the macro offered different responses to choose from, based on the context and mood of the user. For instance, it could suggest both “I’m hungry” and “I’m not hungry” as potential replies to an invitation to eat pizza, allowing users to express themselves accurately according to the situation and the relationship with the person they are communicating with.

However, the appropriateness of the phrase suggestions from the macro was called into question by participants, who pointed out the need for more contextual information to determine the suitability of the response. Factors like the device being used, the relationship with the conversation partner, and the user’s current mood were considered crucial for the relevance of the suggested phrases. When picturing conversations with friends, participants showed a preference for casual and friendly phrases over the more

direct and possibly impersonal options. (Valencia et al., 2023)

I also collaborated with the Inclusive Design Research Centre (IDRC) who are working on a similar project called the Baby Bliss Bot. At the time, Elaine suggested she use her Bliss board as it was faster for her to communicate. During the session we realized she was spelling the words more and that she is now very used to using English words and letters to communicate.

One of the LLMs exhibited several strengths. It demonstrated a generally high level of accuracy in its outputs, which was commendable for a language model. However, notable drawbacks detracted from its overall performance. For instance, the same LLM encountered an error when processing the phrase "Roy, nephew," inaccurately transforming it into "Roy and nephew" instead of the intended "my nephew Roy." This error highlighted a limitation in its understanding of context and sentence structure. Moreover, it displayed inconsistency in its responses across different sessions for identical inputs, indicating potential reliability issues. Despite instructions to provide responses in full sentences without additional words, it persisted in prepending "Elaine:" to each reply, deviating from the specified format.

One other thing to consider is understanding her style of writing and tone. If someone is not accustomed to the way she writes, it will be difficult to decipher what she writes. So, for the session, the prompt given to the LLMs was:

"Elaine is an AAC user who expresses herself telegraphically. She is now in a meeting with (person's name). Below is the conversation in the meeting. Please help to convert what Elaine said to first-person sentences. Only respond with converted sentences."

The example below will provide an example of Elaine's communication on Zoom when she addresses her colleagues and friends in Town Halls as the Vice President of the BCIC.

Taken from Blissymbolics Communication Institute of Canada's (BCIC) website.

- April 23, 2023, by Shirley



At our first Bliss Town Hall, held on April 17, 2023, everything went well except for one missing link! Our zoom host, Elaine Drover did not have an experienced support person with her and neither Elaine nor her new helper, Munna had been taught the difference between "private" and "everyone" zoom chat messages. Nor did Munna have the experience to help when Elaine's voca failed to repeat her entire message. (See \*\*\*) After her opening message, all of Elaine's messages went privately to Shirley and not to the full group! The group members took action and volunteered their messages, without prompting. So the meeting proceeded. However, Elaine did not know her messages were not being received and the group did not know Elaine was messaging!

Here is what Elaine had prepared in advance to open the meeting:

\*\*\* WELCOME TO OUR COMMUNICATE MEETING.,  
 WE CAN TALK THROUGH VOCA AND LETTERS BOARDS.. WE CAN SHARE IDEAS  
 WITH EACH OTHER.  
 WE ALSO UNDERSTAND WHEN PEOPLE TALK TO US,  
 WE ARE SMART TOO. WE KNOW WHAT WE THINK AND FEEL. WE ALSO PLAY MUSIC  
 WITH IPADS.~  
 WE HAVE FUN.

I trust people.

I had good friend ALAN became a counsellor- WHERE I LIVED AND WE TALKED A LOT MRS.  
 MARTIN WAS MY TEACHER. WE DEVELOP A RELATIONSHIP LOVE AND HATE RELATE  
 I KNEW THIS BEAUTIFUL LADY WHO USED BLISS. SHE LOVED LIFE. SUE  
 SHOWED ME HOW IMPORTANT LISTEN TO ANOTHER PERSON HERE TODAY  
 WE SHARED AND SHARING EVERYDAY.

OUR FRIEND PAUL WORKED HARD. I HAVE BEEN IN THEIR COMPANY. In  
 the world we bring  
 something to the table how you, feel or just need a little heart MUSIC WITH IPAD IS  
 BEAUTIFUL WE ENJOY EVERY WEEK. WE ARE LUCKY THOSE PEOPLE CARE TO  
 HAPPEN COMMUNICATE IN VERY IMPORTANT.

Both the paper and session conclude that there is a need for more context that needs to be given to the system for it to provide better suggestions for the individual. Thus, after a few more conversations with the IDRC, I looked at two possible solutions that can work. Let's consider Elaine visiting the doctor. She mentioned that these trips can be quite taxing for her, and she would prefer someone to help her communicate effectively.

### *I. Context and Schedule Provision*

Elaine would grant access to track her location, while her communication partner could input information about her schedule. They could input the date and time of her appointment. When she heads to the doctor's, the system will track her location, offering contextual feedback. This will enable her to seamlessly switch between her helper and the doctor, with the system providing context-based suggestions based on her whereabouts. Considering the limitations of this approach, it may involve significant manual effort and necessitate the presence of a communication assistant, undermining user autonomy and agency. Thus, we looked at the second approach.

### *II. Retrieval-augmented generation (RAG)*

An innovative approach to enhancing generative AI (GenAI) by integrating external sources of information into the response process. While LLMs excel at understanding and constructing sentences based on generalized patterns in human language, they often struggle when tasked with exploring current or specialized topics.

The RAG process, thus, empowers LLMs to fetch facts and data from external repositories to provide more accurate, authoritative responses that are backed by credible



sources, akin to citing precedents in legal cases. This not only enhances the depth of the answers but also increases user trust by offering verifiable sources, mitigating the issue of AI models making incorrect or fabricated ('hallucinated') statements. (Merritt, 2023)

Furthermore, ease of implementation is one of RAG's significant advantages; it can be incorporated into systems with minimal coding, making it less costly and faster than retraining models with new datasets. Furthermore, it allows for the dynamic introduction of new data sources without the need for extensive model overhauls. However, while RAG can significantly improve the relevance and freshness of AI outputs, it also introduces privacy concerns that need to be carefully considered.

According to recent research, while RAG can mitigate the leakage of training data from large language models (LLMs), it also poses a risk of leaking private information from the retrieval databases<sup>1</sup>. This is because RAG systems can potentially expose the data they access during the retrieval process. The privacy implications are under-explored, and new attack methods have demonstrated the vulnerability of RAG systems to such privacy breaches. To address these concerns, it's essential for builders of RAG systems and LLMs to implement robust privacy protection measures. This includes designing systems that minimize the risk of data leakage and using techniques that safeguard the privacy of the information being retrieved and generated. (Zeng et al., 2024)

RAG opens numerous practical applications by enabling conversations between users and data repositories. The potential of RAG has captured the attention of major tech companies like AWS, IBM, Glean, Google, Microsoft, NVIDIA, Oracle, and Pinecone, all of which are integrating RAG into their services to harness the power of GenAI in tandem

with specialized, up-to-date information from external data sources. (Merritt, 2023) This would prove a ground-breaking integration in AAC systems.

If this feature is added to the system, it would be able to extract relevant information from Elaine's computer and other sources like emails, to provide it to the doctor when Elaine requests it. It will be easier for her to communicate effectively and efficiently at times when it is a high-pressure situation for her, and she is unable to express it based on the environment she is in or thinking of the right words.

### *III. Speech-To-Text (STT) Technology*

Another thing to keep in mind is that there might be times when she doesn't understand the technical jargon used by the doctor, which could make communication more challenging. Elaine has expressed her concerns about this issue as well. By integrating speech-to-text (STT) technology with RAG, we could potentially generate responses that Elaine can better understand and choose from, allowing her to participate more actively in discussions about her health and make decisions with greater agency. However, this might require more discussions with Elaine and some experimentation to determine if it truly benefits her or not.

### *Weight & Portability*

In our consultations with Elaine, we delved into concerns regarding the optimal access points for our system. Elaine's challenges with touch screens were particularly emphasized. While there are ongoing efforts to design additional attachments for phones and tablets, concerns persist. Presently, Elaine's system, though portable, is heavy, demanding considerable strength to maneuver when not within arm's reach, especially

when she's using her laptop. However, it is easily portable on her lap. Given her reliance on a wheelchair and the absence of device mounting, she is unaccustomed to attachments. My aim is to minimize disruption to her established routines and comfort. By taking these factors into account, we may provide her with a switch (for use outside her wheelchair), a flexible stylus for easier tapping, and a tablet, offering a comprehensive solution for seamless adoption of the new system.

### Affordability and Support Programs

Moreover, the cost of creatively designed technologies found online can be prohibitive, with many not covered by ADP. For instance, ImaginAble Solutions, dedicated to enhancing the lives of people with disabilities, offers Guided Hands, a \$629.00 USD assistive device tailored to individuals with limited hand mobility. This pricing is exorbitant for those reliant on government disability programs without employment opportunities due to their disabilities.

The Government of Canada offers several financial support programs for individuals with disabilities, including CPP Disability Benefits, Child Disability Benefit, Registered Disability Savings Plan, Federal Excise Gasoline Tax Refund Program, and the upcoming Canada Disability Benefit. Notably, if one receives both a CPP survivor's pension and a disability benefit, they are combined into a single monthly payment capped at \$1,613.54 in January 2024. Furthermore, if someone is already receiving both retirement and survivor pensions and later qualifies for a post-retirement disability benefit, they will receive the higher of the survivor or post-retirement disability benefit flat rate.

It's essential to acknowledge that while this information sheds light on the existing support

system, it prompts critical questions. Will the devices we design be affordable for individuals relying on these programs? Moreover, why are individuals with disabilities disproportionately dependent on government support without adequate opportunities for employment? Our devices should facilitate greater independence and participation in the workforce. We'll explore these questions further in subsequent sections.

Currently, the system lacks flexibility. While ADP assists in funding various devices, there remains a gap. Decision-makers are manufacturers and clinicians, and they often fail to consider the needs of end-users directly or indirectly impacted by these devices, highlighting the need for systemic improvements.

### From Static to Dynamic Displays

As we delved deeper into the design process, we were keen on enhancing the new system to prioritize adaptability, and customization. In our previous discussion, we explored Elaine's familiarity with spelling, even utilizing her Bliss Board frequently. We also discovered her enjoyment of two games, puzzles, and Solitaire, both at the care home and on her laptop. This prompted me to consider gamification elements that could enhance her experiences and reflect on her interface interaction—both her current perspective and what she'll encounter when engaging with the system.

She demonstrated an eagerness to learn, having a dedicated section on her device for learning new words, potentially in multiple languages like French. While recognizing this readiness, it may fluctuate from day to day, influenced by factors such as her location or health status. We suggest introducing different modes for the communication device, possibly incorporating gamification to facilitate vocabulary expansion. She desires a

feature to track her progress and maintain a personal dictionary. We also explored the integration of a lookup tool and a dedicated section for learning new words, featuring a 'word of the day' with its corresponding meaning. This concept strongly resonated with Elaine's current practice of manually storing words in a notebook, highlighting the significance of seamlessly integrating new functionalities into her established workflow.

Furthermore, after a few discussions, Elaine expressed interest in incorporating the word "agency" into her vocabulary as her first word. Introducing definitions alongside new words could enhance her understanding and aid her in remembering how to use each word, thus reducing cognitive load. Although direct testing of such concepts with Elaine was not feasible due to time constraints, we explored the idea of gamifying the learning process. This involved rewarding Elaine as she learned new words, creating a sense of accomplishment and progress. The proposed gamification strategy aims to motivate Elaine to actively engage with her communication device, encouraging her to expand her vocabulary and deepen her understanding of words and their meanings.

We also revisited the idea of the stamps Shirley had used with her team to customize display boards. Creating a digital version of the concept provides us with the affordance to customize or adapt the palette. Elaine will be able to interact with her palette or keyboard by setting it up, and customizing each key to make it how she wants it to look in the end. There's a possibility that even though she doesn't change her keyboard often, it could evolve based on her experiences in a year or five years. We reflect on her upbringing and how her preferences might have changed over the years based on her experiences and the words she wants to use now rather than in the past. We considered that she should be able to customize her display based on her experiences, the listener,

and the context she is in.

During my conversation with the IDRC team, an intriguing research question emerged regarding the integration of dynamic displays into communication devices and how this shift may impact users' familiarity and usage patterns. It is crucial to consider the spatial metaphor of a known territory, such as one's home, that can be employed to illustrate the concept of familiarity and comfort with static communication boards. The introduction of dynamic displays introduces a new dimension of complexity, potentially resulting in feelings of disorientation or confusion among users. Consequently, this new system will necessitate some training for the user. Further discussion on this topic is included in the design considerations section.

Nevertheless, it creates a perspective for one to think about the extent to which gamification can be incorporated into communication devices to facilitate users' adaptation to dynamic displays. We should explore how elements of gamification, such as rewards or achievements, can encourage users to master the customization possibilities of the board, mostly those who are interested in playing games. Additionally, understanding users' reactions and reception to these changes is crucial, considering the potential frustrations or challenges they may encounter in navigating the dynamic interface. As we have discussed before, contextual considerations play a significant role for users who may need to adapt their communication strategies based on their surroundings, whether they are in a coffee shop, classroom, or shopping mall. Mastering the customization possibilities of dynamic displays become essential in these diverse contexts.

Additionally, we need to consider assessing communication effectiveness and user intent within dynamic chat systems, particularly in the context of AAC users. Users can delve into the parallels between gaming strategies and communication processes, reflecting on strategic decision-making and the impact of word choices on communication outcomes.

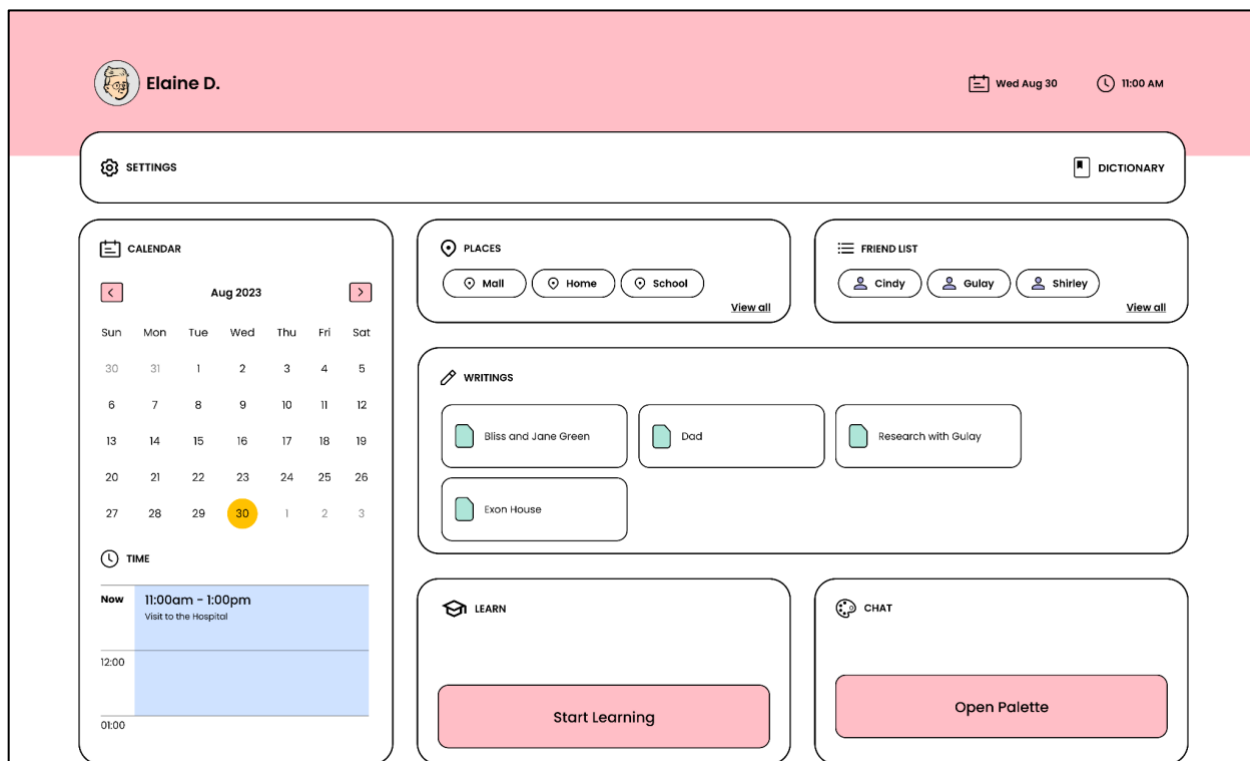
There are two levels of communication effectiveness that can be highlighted: firstly, the alignment of user input with intended choices generated by the system, and secondly, the overall effectiveness of the communication in conveying the intended message to the partner. This distinction underscores the complexity of evaluating communication success in dynamic chat environments. This will lead to user learning and improvement over time, reflecting on the iterative nature of communication and the desire for continual refinement in expression.

There is a dynamic interplay between user intent, system responsiveness, and communication outcomes. It highlights the need for comprehensive evaluation methodologies that account for both technical performance and user satisfaction in dynamic chat systems. By exploring these dimensions of effectiveness, we aim to enhance the usability and accessibility of AAC devices.

## DESIGN CONCEPT

This represents an initial concept crafted from our discussions thus far. We collaborated with Elaine to design this screen according to her needs and preferences. This design will continue to develop through further conversations and testing.

Figure 13: Digital Communication Interface



The image showcases an intuitive user interface designed for Elaine's communication partner. This is the proposed system that Elaine will encounter upon opening it. Below is a detailed description of its sections and the design intentions behind them:

### Profile and Settings

**Profile Display:** This personalization helps users identify their account easily and enhances the user experience by making the interface feel more personalized and secure. **Settings Icon:** Allows quick access to configuration options, providing users the



opportunity to customize the app according to their preferences and needs. This includes font size, screen display for night mode if required, language selection, and other settings as needed.

### **Contextual Interaction Buttons**

**Calendar Display:** This will help Elaine quickly see the current date and upcoming days, which is essential for planning and tracking daily activities. Currently both her calendars in her room are further away and she relies on me to let her know the date.

**Daily Schedule:** Directly below the calendar, there's a timeline for "Visit to the Hospital" between 11:00 AM and 1:00 PM, providing a clear, time-specific view of planned activities for efficient time management. Elaine often forgets her appointments and then must email those in charge to confirm. This system will help her keep track of all her appointments and visits. The system will track all her appointments and suggest appropriate predictions to Elaine when she is crafting her messages, tailored to the time and place.

**Places:** Lists common places such as Mall, Home, and School, along with a "View all" option. This feature is designed to quickly view or log visits to frequently visited locations. This will provide context regarding her location and tailor suggestions based on where she is.

**Writings:** Displays links like "Bliss and Jane Green," "Dad," "Research with Gulay," and "Exon House." This area serves as a quick-access point for managing personal documents or notes, facilitating easy retrieval and organization of written content. As

discussed before, Elaine has trouble finding her writings and when she goes from one laptop to the other, she loses her data. This system will save all her writings in one place so that it is easy for her to retrieve them. The system can employ retrieval-augmented generation (RAG) to enhance the generation of suggestions by retrieving relevant information about Elaine and integrating it into the suggestions provided.

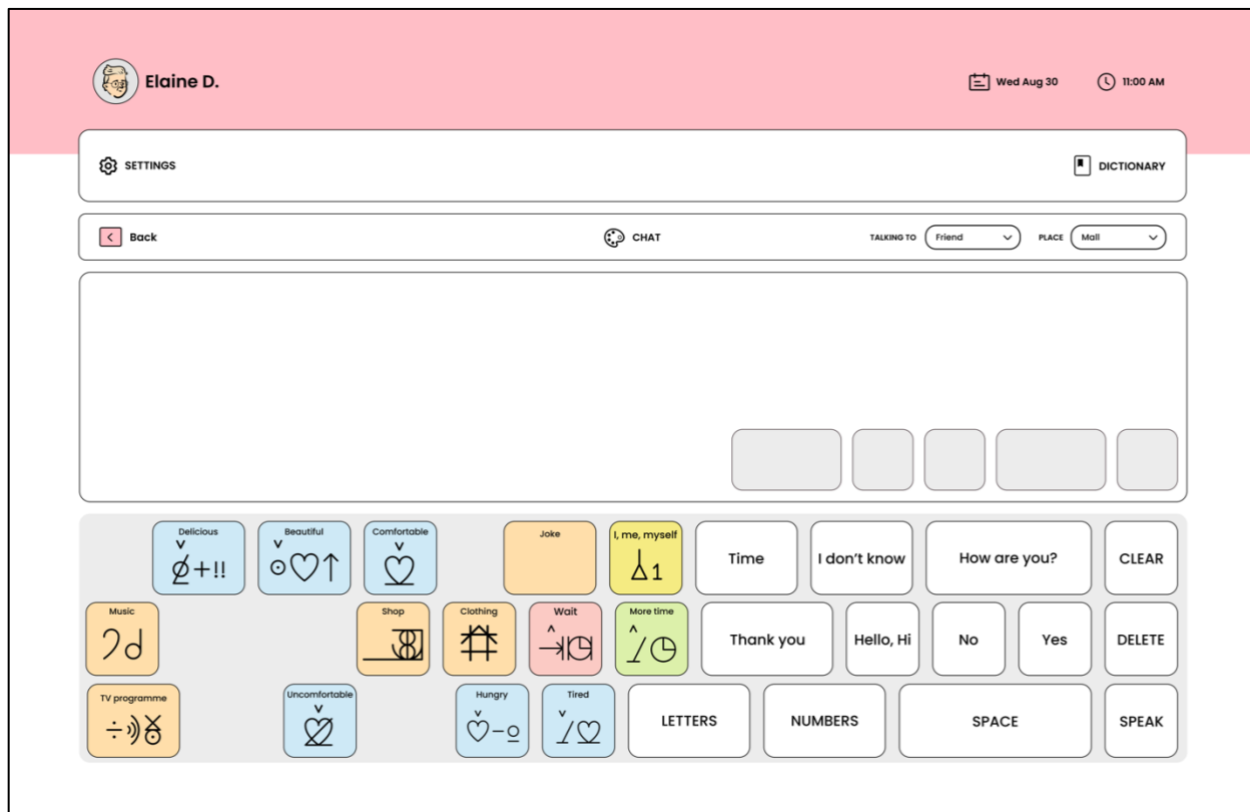
Friend List: Displays a list of friends, including Cindy, Gulay, and Shirley, with a 'View all' option to show more friends. This functionality enables easy maintenance and access to a list of people Elaine knows, allowing her to include additional individuals as she communicates with them. Moreover, this feature will be utilized to customize predictions based on Elaine's relationship with each friend or family member.

### **Learning and Communication**

Dictionary: The dictionary icon in the top right suggests a feature for quick word lookup, which is beneficial for educational purposes or enhancing language skills. "Start Learning" will activate a learning module or educational content, encouraging continuous personal development.

Chat Button: "Open Palette" will open a messaging tool or creative space, fostering communication or artistic expression. The design created with Elaine is shown below.

Figure 14: Digital Communication Interface: Chat Layout



### Profile and Settings

Profile Display: Repeated here for consistency. Settings Icon: Repeated here for consistency.

### Navigation and Tools

Back Button: Located just below the profile area will enable easy navigation back to previously accessed screens.

Dictionary: Repeated here for consistency and for easy look up.

### Chat Interface

**Quick Response Buttons:** These buttons are strategically placed to facilitate rapid communication. They include phrases like "I don't know," "How are you?" and other common responses, which help users communicate effectively and efficiently without the need to type.

**Action Buttons:** "Clear," "Delete," and "Speak" offer practical utilities for managing conversations, such as starting over, removing unwanted text, or using text-to-speech for auditory communication.

**Toggle Buttons for Letters and Numbers:** These will allow users like Elaine to switch between alphabetic and numeric input, providing flexibility depending on the communication needs.

### **Contextual Interaction Buttons**

**Emotive and Functional Buttons:** Labels like "Joke," "TV programme," "Hungry," and "Tired" are included to express emotions or actions quickly. These are especially useful in conventional text input, for communicating moods, needs, or activities with a single tap.

**Contextual Filters ("Talking to" and "Place"):** These dropdowns will let Elaine adjust the context of their communication, such as changing responses based on the person they are talking to or their location. This feature is crucial for providing relevant communication options that are appropriate to the setting or the interlocutor.

### **Rationale**

The screens were designed to reflect my discussions with Elaine. The first screen

incorporates all the features she requested, positioned for easy access with her righthand, which she primarily uses for typing and navigation. The palette displays symbols on the left, while commands such as 'delete' and 'clear', along with common phrases like "hi, how are you?" are on the right for quick access. These symbols dynamically change based on context. The color scheme of the keys aligns with the original Canadian version of Blissymbols, while commands are consistently in black and white. Customization options are available to accommodate Elaine's preferences and aid her functionality. The palette design is flexible; if Elaine desires a different keyboard style, we will collaborate on a new design. Key placement on the palette or keyboard prioritizes Elaine's most-used functions closer to the right and less-used options further away, ensuring ease of access.

The second screen is intended for her conversations and remains conceptual. It has only been shown to her and has not yet been tested in a live session, so it may be subject to other preferences. The design revolves around adaptability based on the conversation partner and environment, illustrated by Elaine at the mall with her friend. As Elaine crafts her messages, the system will provide suggestions based on the words she uses and will continue to learn from her choice of words. Elaine suggested using a dropdown or list format for ease of choosing whom she is talking to and where she is. The location can update automatically by the system. If she is talking to multiple people, the system will ask her to specify the intended recipient, and if she means both, it will generalize to a category like 'friend' or 'family'.

## **DESIGN CONSIDERATIONS**

Developing assistive communication technologies, especially for individuals with disabilities like Cerebral Palsy, requires a holistic and thoughtful approach. This section draws upon insights from Treviranus (1994), who emphasizes the need for flexibility, optimal configuration, continuous support, tailored training, and comprehensive evaluation in the design of alternative computer access systems.

### **I. Flexibility to Accommodate Skill Acquisition**

To be effective, AAC systems must be highly flexible to support users at various stages of skill acquisition. Designers should configure interfaces that are intuitive for novices, offering clear, self-evident steps, while ensuring that the system remains consistent and coherent as the user's proficiency grows. This adaptability allows the AAC system to evolve alongside the user's developing needs and abilities, ensuring long-term usability.

### **II. Optimal Configuration for All Users**

The configuration of AAC systems must cater to both novice and experienced users. Systems intended for beginners might feature external prompts and robust help functions to ease the learning process. Conversely, configurations for more skilled users like Elaine, should focus on internalized feedback mechanisms and streamlined interfaces, which facilitate a smoother, more efficient user experience. Balancing simplicity with functionality is crucial, allowing them to access more complex features as they master the basic ones.

### **III. Continuous Support and System Compatibility**

Continuity in system support and compatibility is crucial for maintaining user growth without interruptions. Developers and manufacturers must ensure that system updates and upgrades do not compromise the existing functionalities, thereby preventing any setbacks in the user's skill development. This ongoing support is essential, especially as market forces may not always prioritize the needs of the more adept users.

#### **IV. Tailored Training Strategies**

Training strategies should be customized to meet the unique needs and abilities of each user. Effective training might involve a blend of task simplification, skill decomposition, and contextual learning, all aimed at enhancing skill acquisition and retention. By varying the training tasks and contexts, designers can help users solidify their skills and better transfer them to real-world applications.

#### **V. Comprehensive Evaluation Beyond Conventional Metrics**

Evaluating user performance should extend beyond traditional measures like speed and accuracy. It is important to identify and address any factors that might hinder the user's ability to achieve automaticity, such as device inconsistencies or suboptimal user strategies. Evaluators should also consider the user's conceptual understanding of the system and any misconceptions that could negatively impact their skill development.

By integrating these design considerations, AAC systems can be more effectively tailored to meet the evolving needs of users, facilitating not just communication but genuine mastery and independence.

## LIMITATIONS

Understanding the limitations of this study is crucial for grasping its scope and implications. These limitations are essentially based on the specific research questions posed and point towards areas that require further investigation.

Firstly, there remain facets of Elaine's life that warrant further exploration. This project was developed based on the limited time I've spent with her over the past few months. Building a deep level of trust with an individual like Elaine requires time and commitment, especially in the context of conducting effective inclusive co-design research.

Secondly, this study primarily delves into the physical design aspects pertinent to language expansion and development among individuals with cerebral palsy, focusing on those residing in Canada. While this focus enables a detailed examination of specific design considerations, it may overlook the intricate interplay between users, technology, and broader environmental factors. Expanding future research to encompass a more comprehensive understanding of the ecological dynamics surrounding language acquisition by individuals with cerebral palsy could offer valuable insights into optimizing language development strategies.

Lastly, while this study endeavors to advocate for Blissymbolics as a minority language and underscores its foundational language abilities through Elaine's case study, it merely scratches the surface of Blissymbolics' potential. Exploring Blissymbolics' role in facilitating communication and language development across diverse populations offers valuable insights into independent language systems.



## **CONTRIBUTIONS**

This research makes contributions to the field of inclusive design, with a particular focus on augmentative and alternative communication (AAC) systems that incorporate Blissymbolics. By adopting a co-design approach, this work ensures that users with complex communication needs, especially those living with cerebral palsy, are active participants in the design process. This approach not only empowers users but also leads to more effective and personalized AAC solutions.

### **Enhancing Communication through Blissymbolics**

The study provides compelling evidence that Blissymbolics can improve communication efficiency. By incorporating Blissymbolics to AAC devices, prospective Bliss students and Alumni can express themselves more efficiently and effectively.

### **Addressing Systemic Gaps and Considerations for Canadian Users**

The paper highlights the gaps in government funding for assistive devices and underscores the importance of supporting independent living for individuals with cerebral palsy in Canada.

### **Ethical and Research Implications**

Furthermore, this work touches upon the ethical considerations of developing AAC systems. It raises awareness about issues such as user privacy and autonomy. The research also contributes to the broader discourse on inclusive design.

### **Creating Employment Opportunities**

The proposed design holds promise for integrating users into the workforce by facilitating communication in professional settings. By accommodating individuals with cerebral palsy and others with complex communication needs, it will foster inclusivity and open doors to employment opportunities.

It's important to note that this study centered specifically on Elaine Drover. While everyone is unique and their experiences are valuable, focusing on Elaine provided valuable insights. Despite the single participant, this research illustrates the benefits of tailoring designs to meet Elaine's distinct needs and preferences. Consequently, this paper offers a methodological contribution that can serve as a model for fellow researchers. Generalization in this context lies not in the specific features chosen, but rather in the approach utilized.

## **FUTURE SCOPE**

In the realm of augmentative and alternative communication (AAC) systems for individuals with cerebral palsy, there exists a wide array of avenues for future exploration and development. Here are some key areas that needs attention:

### **Advanced Interface Design**

This project went beyond standard user-centered design and attempted to find an average representative user. The research aimed at individualized design that does not attempt to generalize findings or conclusions, which then causes a compromise of design choices for the individual user. There is a need to delve into the development of more inclusive and adaptable interfaces for AAC systems. These interfaces should cater to the diverse needs and abilities of individuals with cerebral palsy, enhancing accessibility and usability.

### **Longitudinal Studies**

Conducting long-term studies is essential to understand the sustained impact of AAC systems utilizing Blissymbolics on the quality of life and communication abilities of individuals with cerebral palsy. By tracking changes and developments over an extended period, researchers can gain deeper insights into the efficacy and effectiveness of these systems, informing future design iterations and interventions.

### **Cross-Cultural Research**

Expanding research endeavors to encompass a diverse range of participants from various cultural backgrounds will be crucial for understanding, as it will inform the design

and incorporate a diverse spectrum of needs. This approach will allow for the exploration of inclusive co-design strategies and AAC system applicability across different cultural contexts. Moreover, investigating how cultural differences, legal frameworks, and support systems influence the communication experiences of individuals with disabilities will lead to more inclusive and culturally sensitive design solutions.

### **Exploration of Gamification**

Researching into integrating gamification elements into Augmentative and Alternative Communication (AAC) systems shows promise. Tailored gamification strategies can enhance user engagement, motivation, and learning outcomes.

Further investigation into the long-term effects of gamification on communication and learning skills development can provide valuable insights into optimizing AAC interventions for individuals with cerebral palsy. Specifically, gamification holds potential for enhancing learning and language exploration within AAC systems.

By focusing on these areas of future research, we can advance the field of AAC systems for individuals with cerebral palsy, fostering innovation and improving outcomes in communication and quality of life.

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