Reimagining Assistive Devices to help Children with Cerebral Palsy (CP) to Communicate

GATE #01

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INDS-4006-002 ID Major Design Project 1
22 October 2020

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The ability to **communicate thoughts**, **feelings** and **information** is **essential** to the well-being of a child and their family. Many children with CP have **challenges communicating with speech** and too often it is **assumed** that a child who does not speak is **unable** to connect with or **understand** the **world** around them.

With appropriate **materials** and **focused activities** (interventions) the child with CP can become more able to communicate **thoughts and feelings** and eventually learn how to better **process** these **emotions** in a safe and non-stressful environment. One major problem facing families and therapists is that the children with CP have **unique** sets of abilities and **challenges** which **limits** their ability to **function** in general.

Why ?

I want to work in health care, especially with children who have physical disabilities.

I believe that if I can change one aspect of their daily lives it will assist them and their care-givers and allow them to move forward in other areas. **Small steps** will **lead** to **bigger** and **better** results overall. I see **dependency** as a major **psychological** concern in the **disabled community** and I want to counter this **feeling** of **helplessness**. I have worked with disabled kids at Beverly school and I was affected by the seemingly inanimate expressions on many of the children. It seems to me that they felt like **outliers**, perhaps even as lesser humans.

In addition I have a **21** year old **niece** who has an extreme case of quadriplegic Cerebral Palsy.

I wonder if there may have been **better** methods and **therapies** that might have helped her and her **family** deal with her **disability.**

Signals

STEEPV: Influence of Assistive Devices and Inclusive Desing processes for people with DD

Social	Technological	Economic	Environmental	Political	Values
AD enhance social inclusion for people with intellectual disabilities. [21] ADs play both central and peripheral roles in social interactions.[21] ADs in a school setting can encourage independent activity and improve productivity and can encourage expression of feelings. [21] Incentives to help families to get teens and young adults involved in learning about and selecting assistive technology.[22] There is a need to consolidate evidence on the interaction between ID, AT, community living and social inclusion.[19] One's proximal social environment has positive effects on both mental health and wellbeing.[23] Difficulties during medical examinations because of communication problems or behaviour problems. [16] Functional impairments can limit a child's ability to participate in the experiences of childhood.[9] A proactive approach should be taken to ensure that current and future ATs respond to the needs and challenges of society.[7] Designers often have too little insight into the life of patients leading to deficient design requirements which is a main cause for dissatisfaction and non-use. [10] Efficient mobility is a prerequisite to carrying out many daily activities and social roles (social participation). [20] Including people with disabilities and providing them with access to health and rehabilitation services is vital for their developmental and social inclusion needs. [26]	Greater digital access can improve the quality of life, particularly for the most vulnerable.[1] Factors affecting accessibility change according to user, task, and environment. [8] Technology alone is not enough. It should be combined with social and regulatory action that does not exclusively focus on individuals with disabilities. [8] Some manufacturers of proprietary technology do not make their devices aesthetically appealing to children with disabilities. [21] ATs differ from the mainstream status quo in quality of access and function. [21] Some ATs are relatively low-tech and very familiar, such as reading glasses, crutches and hearing aids.[8] Effective use of current technologies and regulations is necessary, combined with social action against discrimination and stigma. [8] A recent wave of widely publicized scandals around data privacy and security has made people mistrustful of big tech companies. [1] Breakthroughs in computing, sensors, mobile connectivity, artificial intelligence, robotics, 3D printing, and advanced materials are transforming manufacturing and production systems.[8]	There are around 1 billion people with disability in the world. They are often the poorest of the poor.[25] About 80% of people with disabilities live in low-income countries where poverty further limits their access to basic health services, including rehabilitation services.[26] Research on AT has focused on socioeconomic impacts such as education, employment and access to healthcare by people with ID.[1] Technological innovations in healthcare are changing the face of the industry.[1] Lack of appropriate training of healthcare professionals.[15] People with disabilities are often denied school or work opportunities which create barriers for their prosperity and well being. [26] Existing AD design is mainly focused on customized case studies. The economically disadvantaged and disabled face a heavier burden in accessing customized ADs. [24] Designing for disability can fuel innovation in many ways and offer multiple opportunities for technological investment.[7] There is general public misunderstanding of the regulations in place to protect consumer rights and to inform about digital health products and services.[1] The design process must involve people who know disabled users such as experts, therapists and parents. [17]	The ecological pathway reviews and informs disability and social inclusion as products of sophisticated interactions between environmental factors, capability and opportunities available to the individual.[15] Interventions to address inaccessibility can identify and prioritize according to security, accessibility and comfort in all environments.[15] Consider the people involved in developing the product; what type of DDs do they have? What type of support are they getting? Who are the stakeholders? [17] Assessment tools used in the rehabilitation field can often be reused and adapted by designers to make ADs that are relevant for other designers in the disability field.[17] Understanding how the physical and social dimensions of the home and school environment are associated with the use of ADs is critical.[3] As disabled children grow older the mechanisms of the home environment present challenges to independent functioning and require design interventions. [3] Accessibility, usability and universal design work together to enhance person-environment relationships. [14] The design and delivery of devices and services create unnecessary barriers if the particular needs of people in different age groups are not recognized. [8]	The need to improve systems of medical care delivery in special schools, community nursing, and clinical centers. [13] The value of patient data is increasing which will necessitate new technologies and government intervention to improve cybersecurity and deter cybercrime. [15] Lack of awareness by healthcare professionals on specific health issues results in poor healthcare coordination and reduced quality of care for patients with DDs.[15] There exists communication and information transmission issues between hospital staff, families and supported residential accommodations. [15] Adequate responses to discrimination and stigma will require broad attitudinal and organisational change in society.[7] How to implement financing and procurement policies that ensure assistive products are available to everyone who needs them. [26] ICF offers three perspectives to analyze the identity, the interests of key stakeholders or social actors, and the underlying societal ideals. [26] Increasing access to high-quality affordable assistive products as an integral component of universal health coverage. [26] Front line professions in the public service need better training how to use ATs effectively and communicate this info to stakeholders. [7]	Ethnic or racial discrimination may exist as a basis for not investing in or delivering technology and related services to specific populations. [8] Barriers exist related to socioeconomic status, education level and literacy, special needs or disabilities, or language ability. [8] People with disabilities feel empowered when using their devices, while also aware of misperceptions others have about ATs. [8] Design for disability should move beyond binary thinking to focus on maximum access.[8] Empathy is critical to the design process. Understanding how that differs from sympathy is even more powerful. Explore how this develops into participatory, insightful design.[4] Understanding disability as a human rights issue rather than an issue of medicine, charity or dependency. [9] There is no consensus about what design method is the most efficient when designing for the disabled or what factors need to be taken into account when choosing the best design method. [18] Development of universal design, in which the idea is to design products and environments to be accessible and usable by everyone rather than as special accommodations for people with impairments.[17] Rehabilitative interventions that address disability may reduce depressive symptomatology over time. [10] A 'one size fits all' approach to promoting ATs may be inappropriate, as individuals have different needs, desires and preferences, and live in different social, economic and infrastructural contexts. [7]

AD = Assistive Devices **AT = Assistive Technology** **DD = Developmental Disability** **ID = Intellectual Disability** **ICF = International Classification of Functioning for Disabled**

Signals

STEEPV Distilled Down to These Highlited Key Elements

Social	Technological	Economic	Environmental	Political	Values
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Demographics

“The term **developmental disabilities** can be defined as: a group of abilities and characteristics that vary from the norm in terms of the limits they impose on an individual's **independent participation** and **acceptance in society**, and are generally considered a life-long condition such as delays, disorders, or impairments in the areas of **gross motor skills**, **communication**, **cognitive**, or **social abilities** that exist during the human developmental period.” These disabilities can be observed in children with autism, **cerebral palsy**, downs syndrome, fragile x syndrome and fetal alcohol spectrum disorders (Appendix A).

More specifically in reference to children, recent UK research noted that children with developmental disabilities were significantly more likely to fall into the following categories:

- Be boys;
- Have been exposed to a greater variety of adverse life events (e.g., abuse, serious accidents, bereavement, domestic violence);
- Be brought up by a single parent (nearly always a single mother);
- Live in poverty;
- Live in a poorly functioning family (e.g., one that is characterized by disharmony);
- Have a mother who is in poorer health;
- Have a mother who has mental health needs;
- Live in a family with lower educational attainments and higher rates of unemployment;
- Have fewer friends.

These are some of the conditions:

- Cognition
- Communication
- Mobility/Gross Motor Skills
- Fine Motor Skills
- Self-Help Skills
- Social/Emotional Skills
- Adaptive Behavior
- Hearing Impairment
- Visual Impairment

Demographics

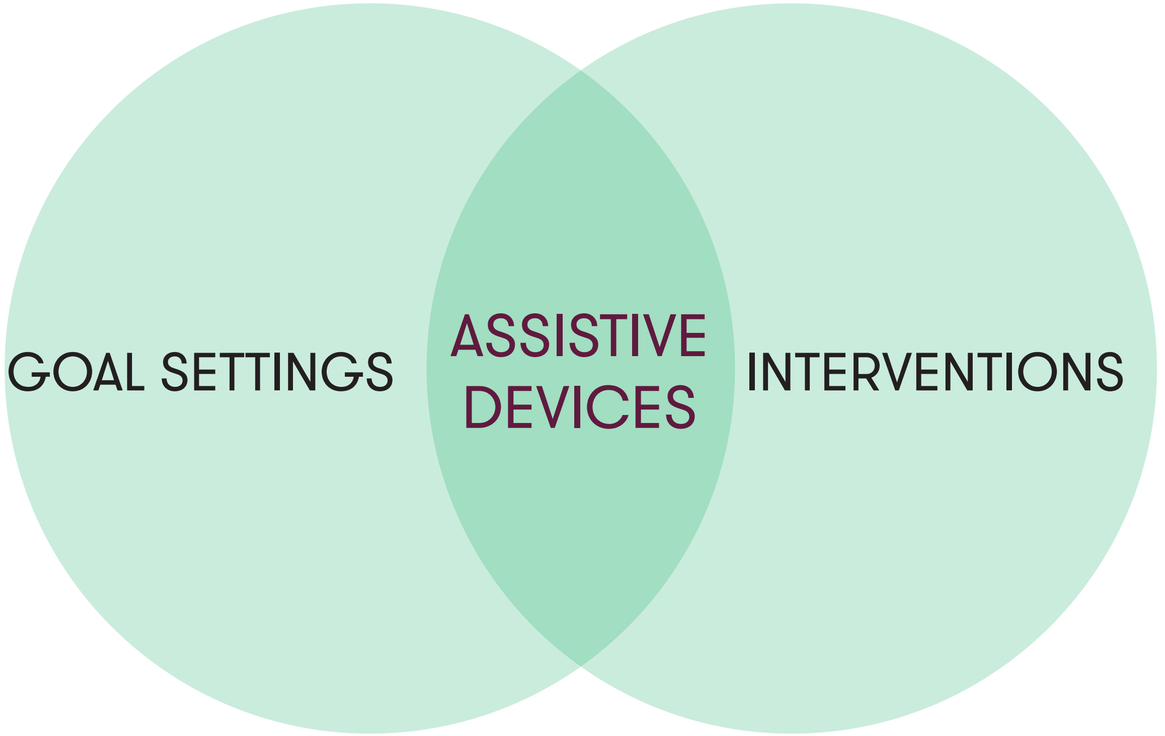
My Focus is Children with Cerebral Palsy (CP)?

CP is an umbrella term for a group of disorders that affects a person's ability to move.

CP is due to **damage** to the **developing brain** before, **during or after birth**.

CP affects people in different ways.
It can affect body movement,
Muscle control,
Muscle coordination,
Muscle tone,
Reflex,
Posture andBalance.

Focus



GOAL SETTINGS

INDEPENDENCE
WORKING
COMMUNICATION
ACTIVITY OF DAILY LIVING
MOBILITY

ASSISTIVE DEVICES

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC)
devices, systems, strategies and tools that replace or support natural speech for person who has difficulties communicating using speech (Appendix B).

INTERVENTIONS

PHYSIOTHERAPY
SPEECH THERAPY
OCCUPATIONAL THERAPY
MUSIC THERAPY
ART THERAPY
HIPPOTHERAPY
(Appendix C)

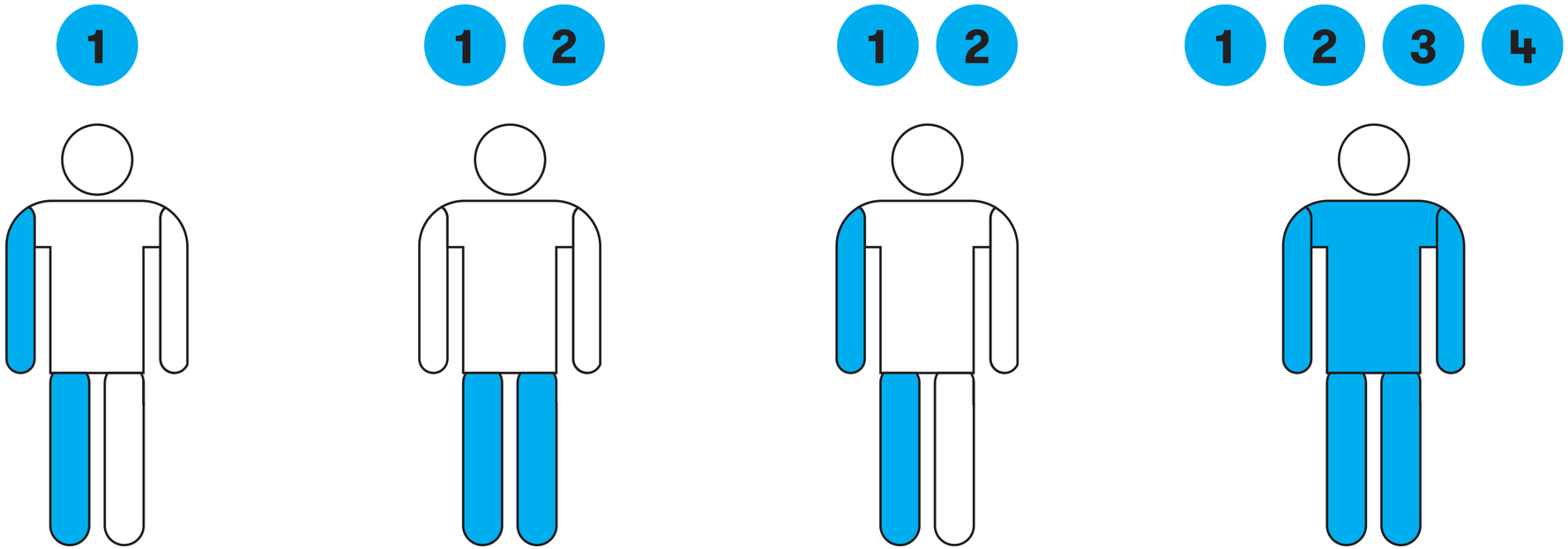
most importantly more participation in any activity

A ‘one size fits all’ approach to promoting ATs may be inappropriate, as individuals have different needs, desires and preferences, and live in different social, economic and infrastructural contexts.

www.trainual.com

PARTS of the BODY

About 75%-85% children with CP have spasticity (i.e. tightness of, or inability to control muscles).



MONOPLEGIA

one arm or leg affected

DIPLEGIA

both legs affected

HEMIPLEGIA

one side of the body affected

QUADRIPLEGIA

entire body affected

cerebral palsy can affect different parts of the body

ASSOCIATED IMPAIRMENTS

CP is a permanent life-long condition, **not progressive**, some of these signs of cerebral palsy can improve or worsen over time.

1 in 4
is unable to walk

1 in 4
is unable to talk

3 in 4
experience pain

1 in 4
has epilepsy

1 in 4
has a behaviour problem

1 in 2
has an intellectual disability

1 in 10
has severe vision impairment

1 in 4
has bladder control problems

1 in 5
has a sleep disorder

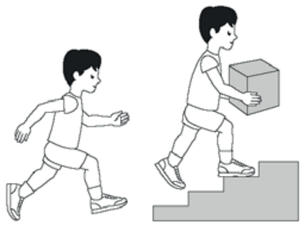
1 in 4
has saliva control problems

children with CP may also have a range of physical and cognitive impairments

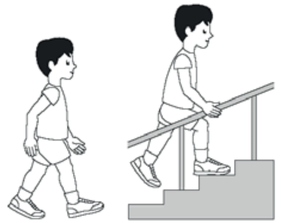
THE FIVE LEVELS OF CLASSIFICATION SYSTEMS

	GMFCS Gross Motor Function Classification System
I	Walks without limitations
II	Walks with limitations
III	Walks using a hand-held mobility device
IV	Self-mobility with limitations; may use powered mobility
V	Transported in a manual wheelchair

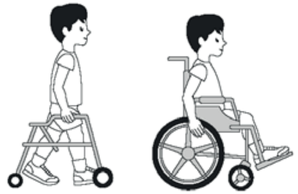
I



II



III

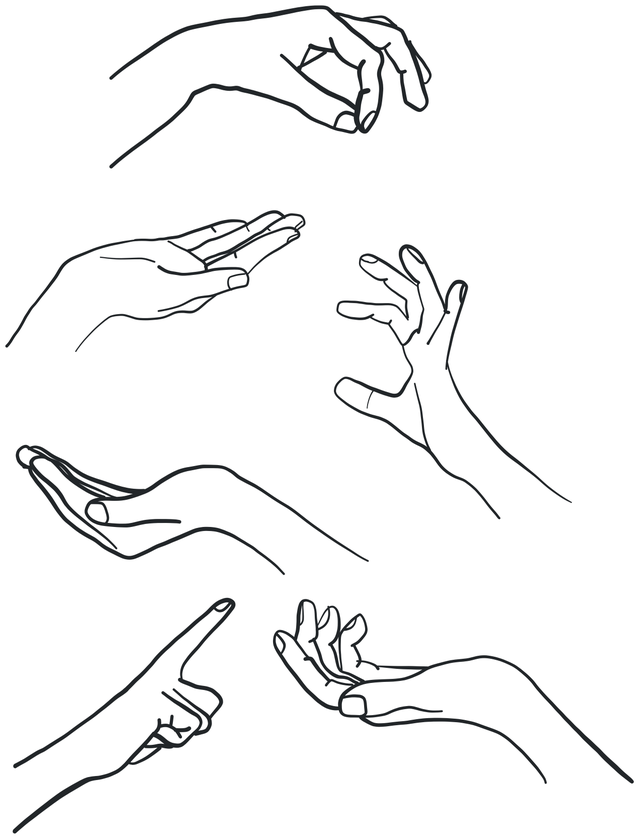


IV

V

THE FIVE LEVELS OF CLASSIFICATION SYSTEMS

	GMFCS Gross Motor Function Classification System	MACS Manual Ability Classification System
I	Walks without limitations	Handles objects easily and successfully
II	Walks with limitations	Handles most objects but with somewhat reduced quality and/or speed of achievement
III	Walks using a hand-held mobility device	Handles objects with difficulty; needs help to prepare and/or modify activities
IV	Self-mobility with limitations; may use powered mobility	Handles a limited selection of easily managed objects in adapted situations
V	Transported in a manual wheelchair	Does not handle objects and has severely limited ability to perform even simple actions



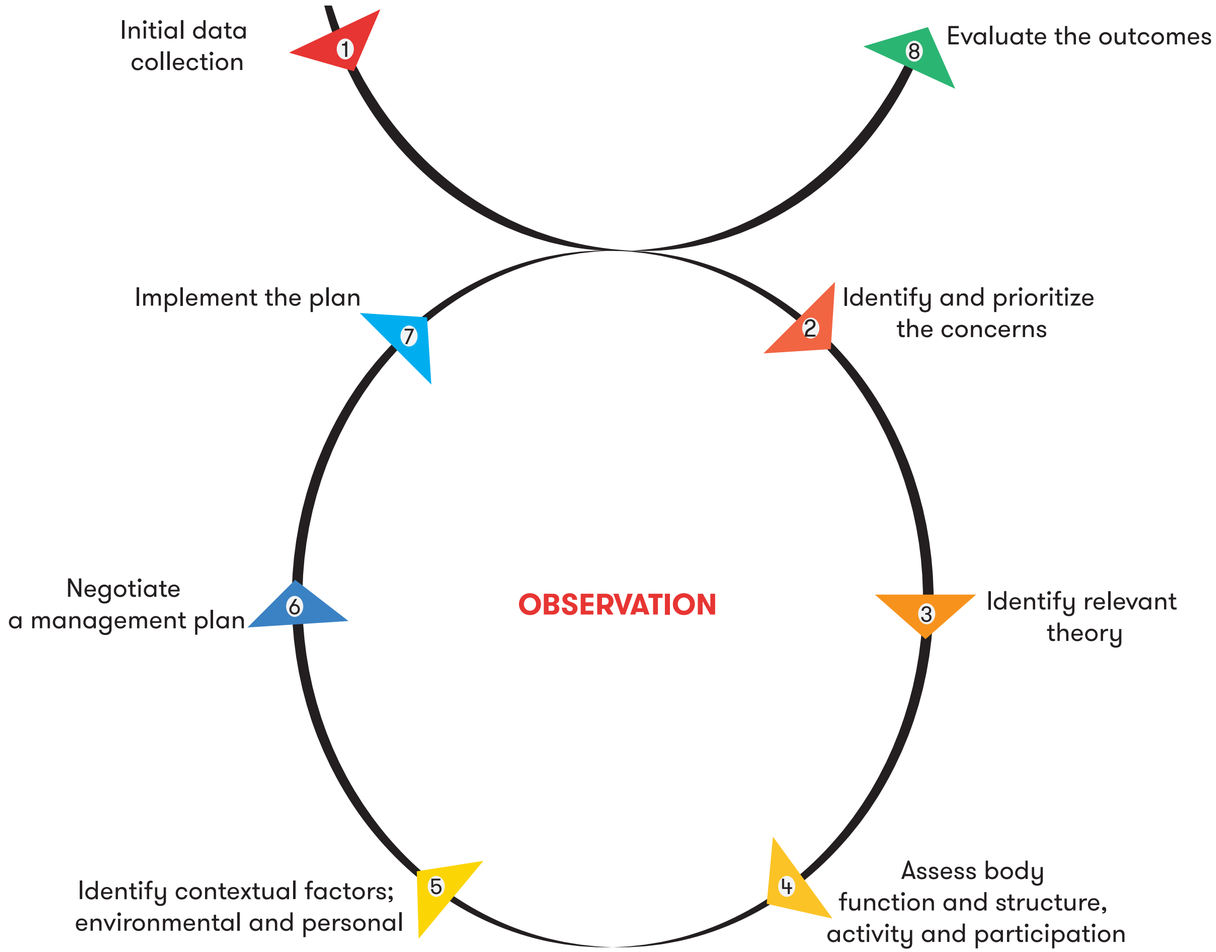
THE FIVE LEVELS OF CLASSIFICATION SYSTEMS

	GMFCS Gross Motor Function Classification System	MACS Manual Ability Classification System	CFCS Communication Function Classification System
I	Walks without limitations	Handles objects easily and successfully	Sends and receives with familiar and unfamiliar partners effectively and efficiently
II	Walks with limitations	Handles most objects but with somewhat reduced quality and/or speed of achievement	Sends and receives with familiar and unfamiliar partners but may need extra time
III	Walks using a hand-held mobility device	Handles objects with difficulty; needs help to prepare and/or modify activities	Sends and receives with familiar partners effectively, but not with unfamiliar partners
IV	Self-mobility with limitations; may use powered mobility	Handles a limited selection of easily managed objects in adapted situations	Inconsistently sends and/or receives even with familiar partners
V	Transported in a manual wheelchair	Does not handle objects and has severely limited ability to perform even simple actions	Seldom effectively sends and receives, even with familiar partners

Design Considerations

Children Age 4 - 16
CS Category Level IV & V

The users of the product must include not only the children who will use it for rehabilitation purposes, but also the **stakeholders** who will play an important role in facilitating the child's use of the product.



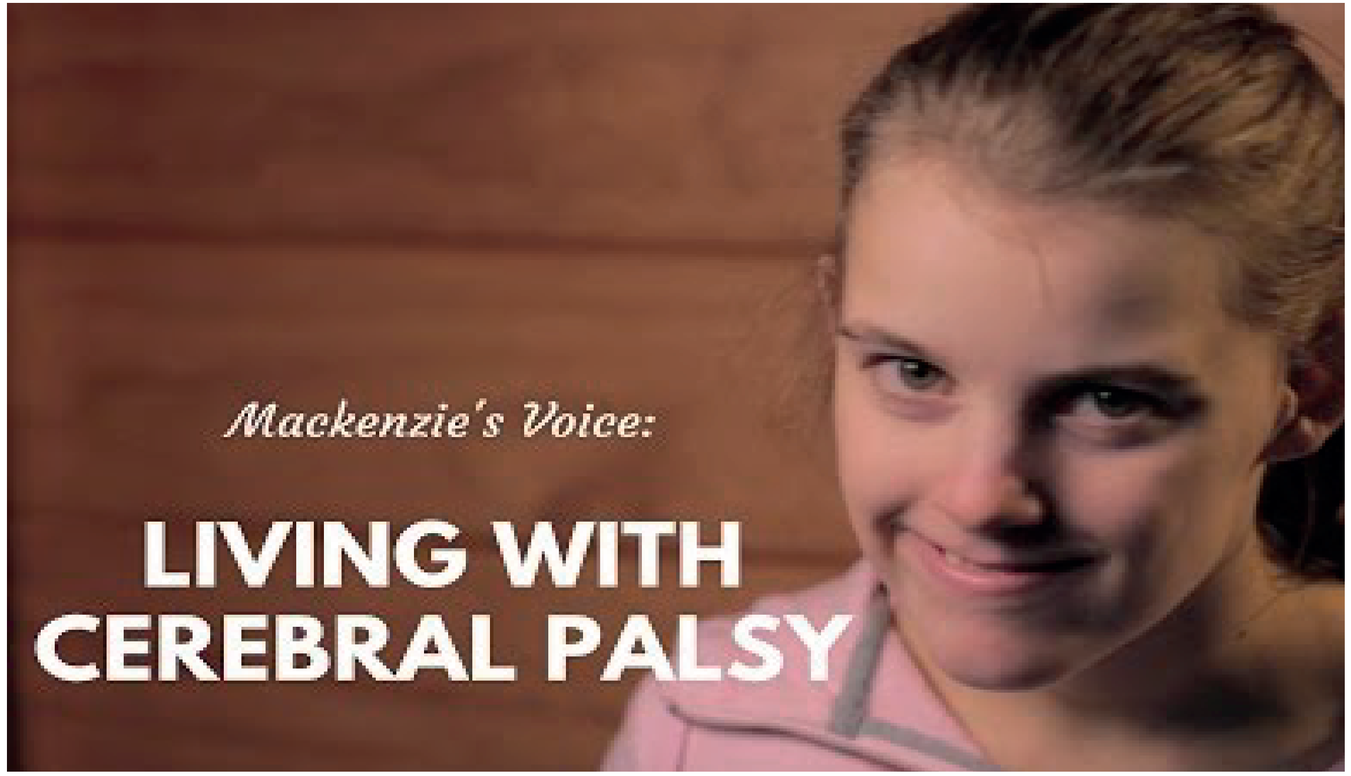
The intervention process:
Model adapted from the Canadian Occupational Performance Process Model (CAOT, 2002).

the product must be intuitive to use and universally adaptable from child to child


INTUITIVE AND ADAPTABLE

People with disabilities feel empowered when using their devices, but also are aware of misperceptions others have about ATs.

www.friendshipcircle.org



https://www.youtube.com/watch?v=u4gvcS9_F-Y

I see myself as
being normal
because,
I have been different
all my life…

Mackenzie, age 16

www.friendshipcircle.org

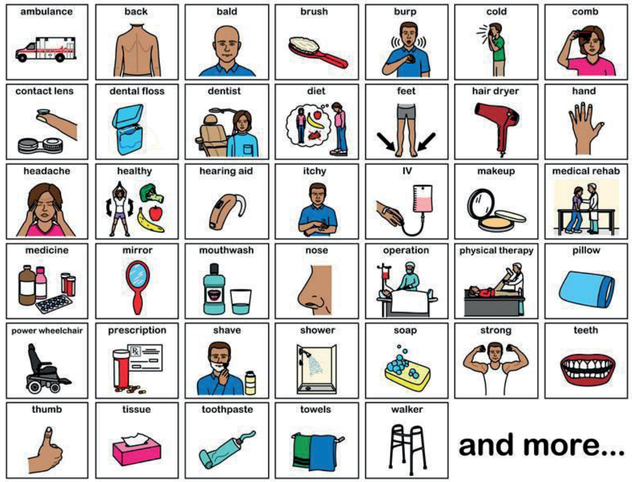
There are around 1 billion people with disabilities in the world. They are often the poorest of the poor.

www.balicaringcommunity.org

Design Considerations

Dynavox **$5000 +**

32 Message Communicator
$399



PCS™ ThinLine: Set 1
$150 (PC/MAC not included)

4 Plate Communicator Say It Play It
$165

iPad Speech only Case
(software and ipad are not included)
$500

many AAC devices are not mass produced and are often very expensive


AFFORDABLE

Design Considerations

A recent wave of widely publicized scandals around data privacy and security has made people mistrustful of big tech companies.

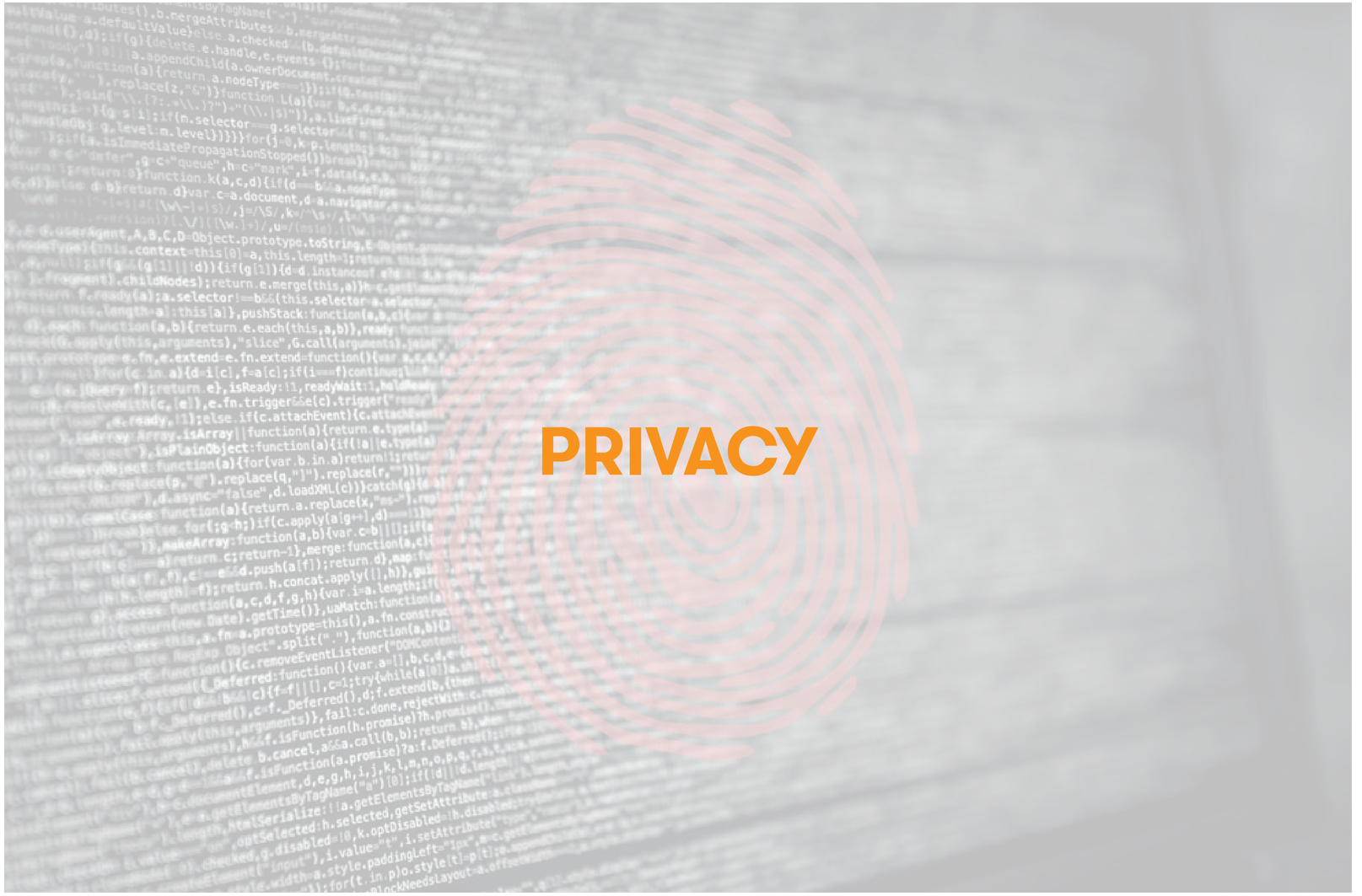
www.p2pfoundation.net

Design Considerations

How to protect the privacy of people with disabilities who rely on smart technologies to improve the quality of daily life?

Applications such as voice control, smart home devices, predictive text, and voice guided mobility maps etc. originate from large multi-national corporations and the data collected from these devices can be used as a commodity without the knowledge or permission of the user.

can low-tech or no-tech communication ADs provide the same level of assistance without compromising personal privacy


PRIVACY

Design Considerations

Understanding how the physical and social dimensions of the home and school environment are associated with the use of ADs is critical.

www.cerebralpalsy.org.au

Design Considerations

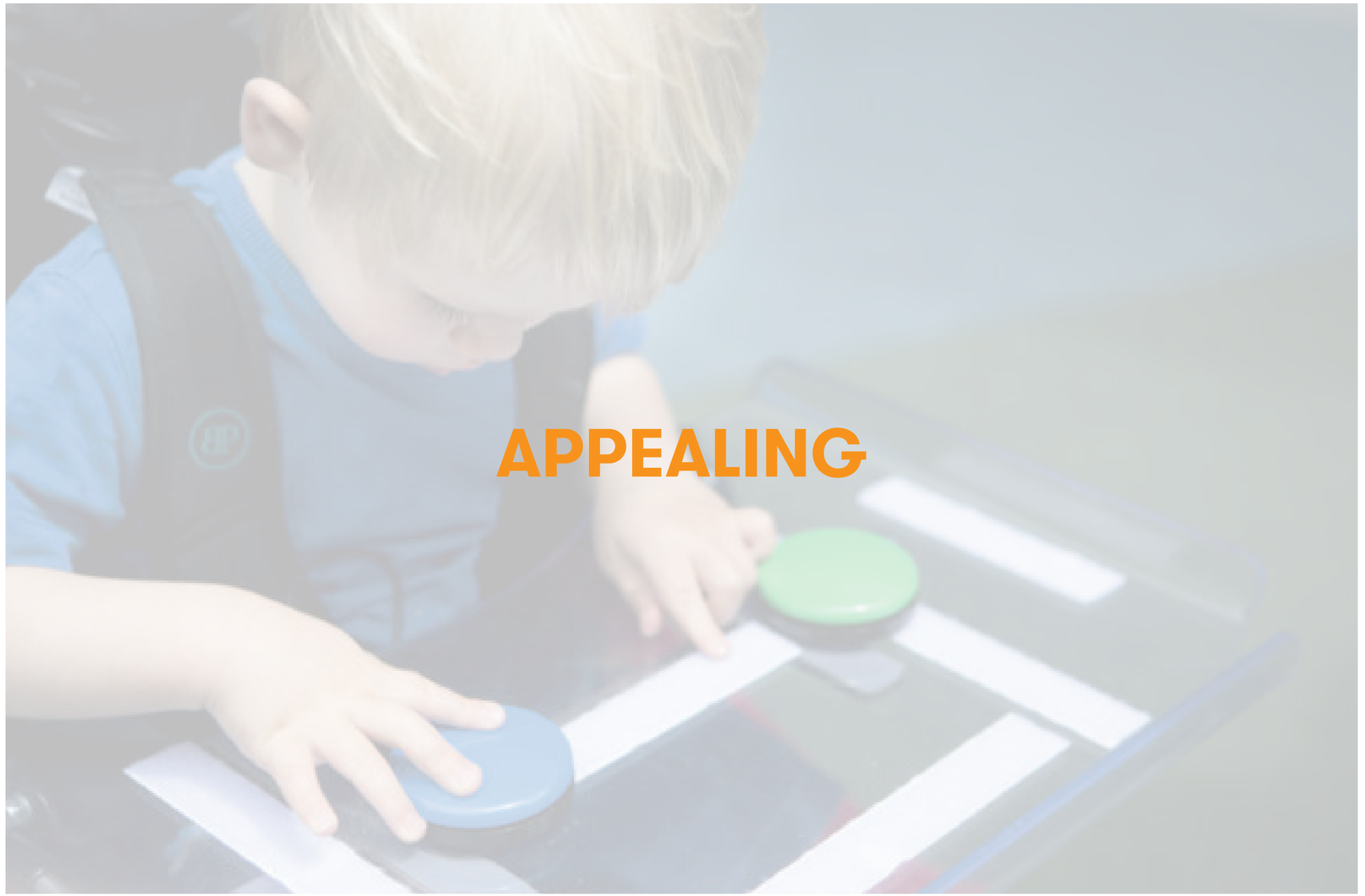
AAC (Augmentative and Alternative Communications) in a **school** and **home** setting can encourage **independent activity,** improve **productivity** and can **encourage** expression of **feelings**.

It has to **appeal** to the child **senses**.

Fun **Colourful** **Intruiging** **Attractive**

www.goodfon.com

the product must appeal to the child


APPEALING

Understanding disability as a human rights issue rather than an issue of medicine, charity or dependency.

www.wfmj.com

Standards & Policies

Built environment
Information environment
Communication environment
Policy environment
Attitudinal environment (Institute for Human Centered Design,2011).

Ontario
ACCESSIBILITY FOR ONTARIANS WITH DISABILITIES ACT 2005 (AODA)

Americans with Disabilities Act (ADA)

According to the Institute for Human Centered Design (2015b, para. 1), “Universal Design Principles” is a framework for the design of places, things, information, communication and policy to be usable by the widest range of people operating in the widest range of situations without special or separate design. (Appendix D)

apply Univerlsal Design Principles and Inclusive Desing techniques to serve more diverse audience


UNIVERSAL

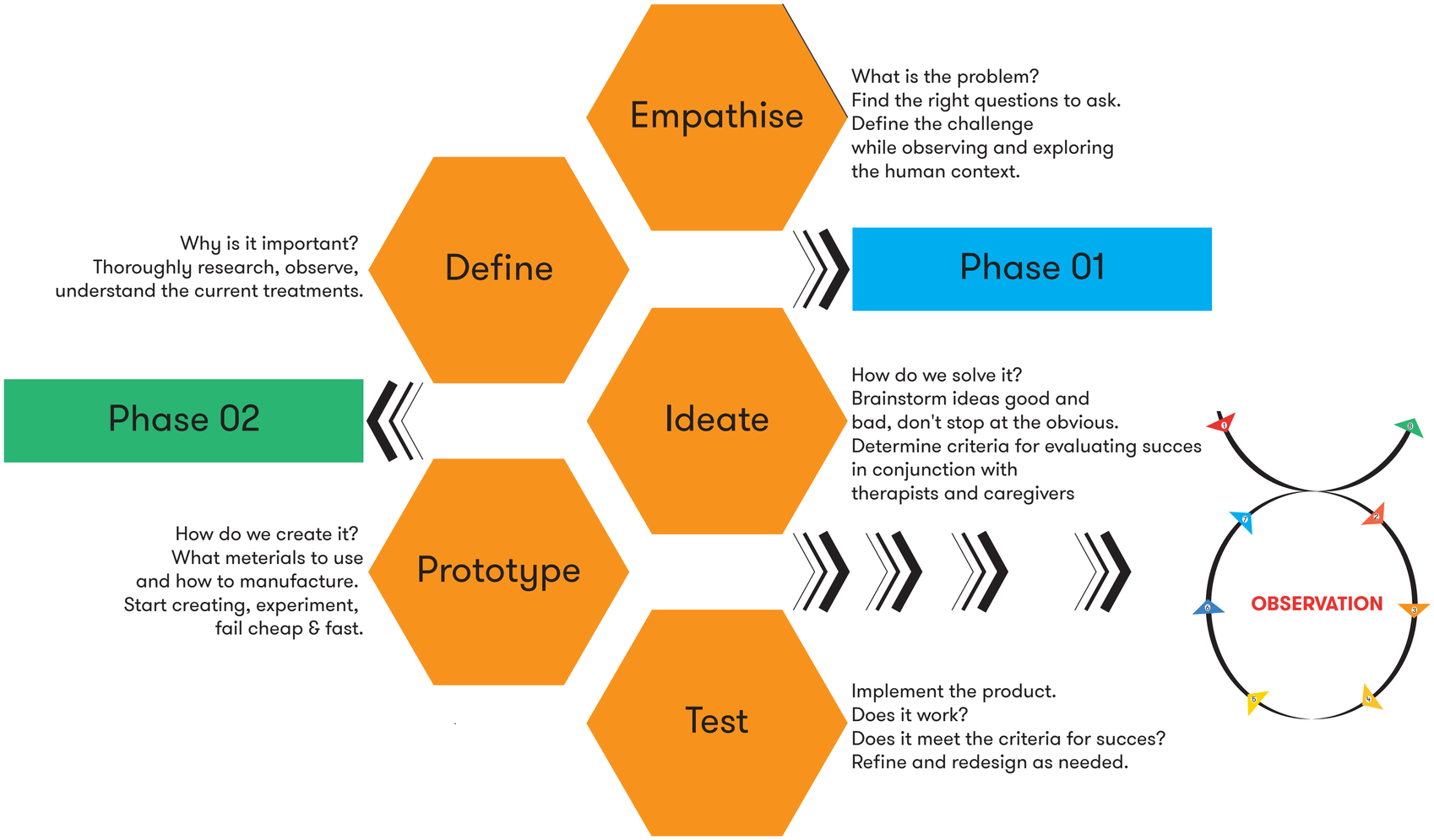
Design Considerations for Augmentative And Alternative Communication (AAC) Devices for Children with CP

- **INTUITIVE AND ADAPTABLE**
- **STIGMA FREE**
- **AFFORDABLE**
- **PRIVACY**
- **APPEALING**
- **UNIVERSAL**

most importantly to help non-Verbal children with CP to communicate and participate

Method

METHOD



the next step (PHASE 01) is to understand how non-verbal children communicate in everyday life

Give Them the Smile They Deserve

www.paciticmedicallaw.ca

Thank You

CITATION

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