

Engaging Cerebral Palsy Adults

PROJECT REPORT

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IDC School of Design
अभिकल्प विद्यालय

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Communication Design Project II (P-II)

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1

Introduction

Cerebral palsy is a motor function disorder arising from damage to part(s) of the brain before, during or soon after birth. In layperson words, CP affects movement of the limbs, posture, ability to control physical movements, and even speech. The condition arises from neurological centres that control the body's muscles. The extent of the disability caused by this varies widely- one person with CP will be able to move about and take care of oneself completely and another would be a fully dependent person who cannot even chew food. CP may or may not be accompanied by other neurological disorders.

This project is based on CP adults who remain dependent on their caregiver.

What do we do to pass free time? How do we entertain ourselves? We watch TV, read books, play games, go out, meet friends and family. But with the limitations of a person with cerebral palsy (CP), these modes of entertainment also become limited. And the free time they have day to day may be more. So, what do they do in their free time?

The aim of my project is to engage and entertain a grown-up CP person in their free time, independent of assistance and efforts of the caregiver. This activity should function as a companion and additionally, also be therapeutic.



Mira's paintings

Motivation

Eight years ago, I started conducting art classes for a 29-year-old girl, Mira, living with cerebral palsy. Since then, I have built a close connection with her and her parents and have observed the kind of activities she indulges in (mostly motivated by her parents). Most of these activities are to maintain her state of body and mind. For example, art class, music class, physiotherapy, yoga class and other such activities.

Because of the COVID lockdown in 2020, a lot of the classes were not happening for her. The tutors could not come to her house for sessions and hence she lost the activities she was doing on a daily basis and lost all the external interaction/socialization enabled by them. This resulted in her simply sitting doing nothing. She could not be moved even by her parents to try doing something on her own. It could also be said that some depression had hit her.

This situation made home in my mind and here I am.

I noted down more observations and thoughts- some from reading about CP people and mostly based on Mira's life:

- The care-giving days of a CP adult's guardian have no end- from taking care of their daily natural physical routines to keeping them engaged in between these. But with time, guardians develop their own natural limitations tied to their age. So, what if a CP person is able to engage himself/herself independent of assistance or independent of the mental and physical efforts of the guardian?
- Most content for CP people is based on learning for kids. Therapies are an important part of their learning years. But after their major learning age, constant and regular efforts need to be made in maintaining effects of these therapies and learning in a grown up.

2

The Study

2.1 Secondary Study

First, I needed to understand CP better- what is already out there and also, what are the challenges faced by CP people and their care givers, to get a better perspective for my topic.

CP refers to a group of movement and posture disorders caused by damage to part of the brain before, during or immediately after birth. The condition is categorized into Hemiplegia, Diplegia and Quadriplegia depending on the affected body part. There is another categorization based on the type of movement affected- Spastic, Athetoid, Ataxic. CP affects every 1.5-2.5 per one thousand births in India. And about 40-45% are non-ambulatory (cannot walk). A large percentage of the CP births are also associated with neurological problems. (Source for the statistics: www.rehabcouncil.nic.in)

CP is not an uncommon condition in India. But most easily available resources online are U.S. based- Centres for Disease Control and Prevention (www.cdc.gov), Cerebral Palsy Research Network (www.cprn.org), CerebralPalsy.org (www.cerebralpalsy.org) and more. There are resources for and about CP adults and their caregivers available on these. Stories available of real CP adults are about those who eventually lead life independently. But they do illustrate the lack of resources available for CP adults.

“It feels like you are just cut loose when you are 18 and told to “have a good life!”” - writes Heather Hancock, a CP adult, in CP Stories on cprn.org.

In the same set of stories on the above link, Dr. Unni Narayanan, a Paediatric Orthopaedic Surgeon, says, “there is so much more society can do to allow people with disabilities to live fuller lives without needing to fix them.”

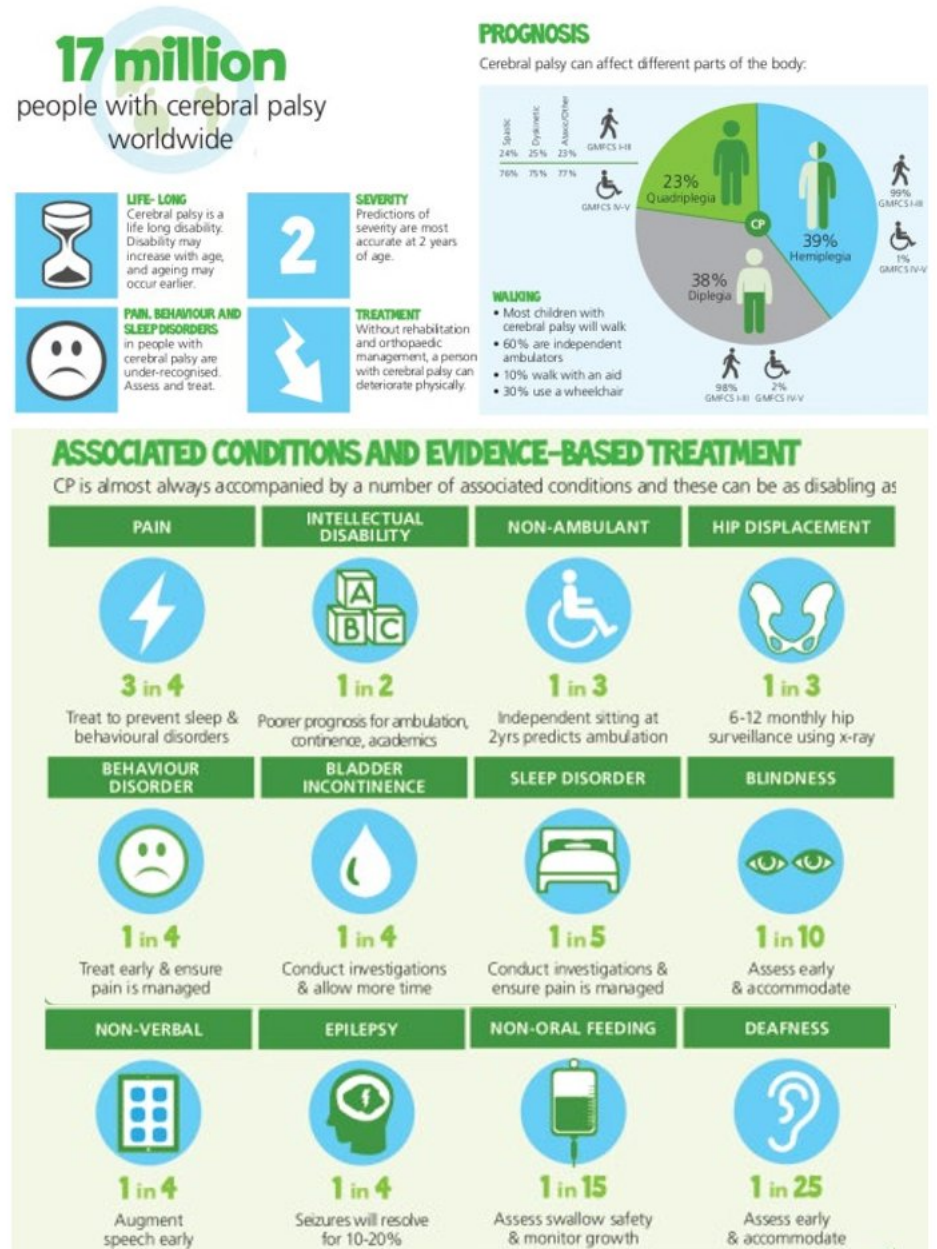
Additionally, challenges of caregivers of CP adults, also cannot be ignored. Parents have to re-adjust their life completely after discovering their child's condition. They have to give more time for making their child do routine things which normal kids would be able to do in no time. Behavioral changes are a major concern with CP people as they are trying to comprehend and accept their own disabilities. Hence both mental and physical states need constant monitoring and treatment. Even the parent takes time to get hold of the fact and all that it accompanies upon discovery of the condition.

A wellbeing guide for parents and caregiver by Dr. Elise Davis of University of Melbourne, available on cprn.org, says that care givers are trapped in responsibilities and forget looking after themselves in trying to do the best for their child. They might even forget what it really is to feel happy only because they might not have felt so since long.

"You can't pour from an empty cup" - Unknown

Apart from hunting for resources outside, I looked at work done in a related area at IDC- Jellow. In one of the presentations on D'source, was mentioned "...feeling of dependency, disability, which leads to isolation." This insight backs the problem on which my topic is based.

Having gathered such information, which includes almost nothing about CP adults who are dependent on their caregivers, I move to my primary research.



Part of CP Infographic, Source: www.reachingforthestars.org

2.2 Primary User Study

This is a subject that can be best understood with first-hand conversations and observations. I needed to understand things from the perspective of both parent and child and needed some expert inputs as well for a broader view of things. I started by talking to the source of my motivation- Mira's mother. From her, I got the contact of a physiotherapist, Dr. Spoorthy Prabhu who works with C.P. kids in Vadodara, Gujarat. I also got in touch with Ms. Amena Latif, founder of Jyotirmay, a vocational and academic training centre for disabled adults. She has also been a long-standing member of ADAPT (formerly Spastics Society of India), Bandra. Jyotirmay, based in Vile Parle, Mumbai, has about forty CP adults enrolled. From Ms. Latif, I got contacts of parents of ten CP adults, of which I could talk to seven before the Stage 1 of the project. She also kindly allowed me to shadow online sessions conducted by Jyotirmay for a few days. All their sessions were being conducted online due to COVID. In these sessions I could observe some of the adults whose parents I talked to which helped me get an independent perspective of the traits of that adult as compared to the parent's descriptions of them.

From all these conversations I tried to find answers to the following:

- The validity of my topic and its basis that dependent adults with cerebral palsy lack things to do independently in their free time owing to their lack of resources and interactions due to their lack of ability.
- What are the range of abilities and disabilities, natural and acquired, of such people?
- How do they spend their time now?
- What are their likes and interests and the commonalities and variety in them?
- What they should do and what they can do.
- What and how much is the parents' involvement in all that they do.

2.2.a. *Validity of the topic*

The basis of my topic stands valid from the following insights in addition to my initial motivation of Mira's lockdown experience:

- Dr. Prabhu mentioned, from observations made in her patients, that most parents of such kids give up on making additional efforts on the child by the age of 10-12 yrs. They take care of the child's bare minimum requirements and include them in their own activities within the limits of their convenient capacity. Meaning there is almost no additional effort made at engaging them in between essential routine activities. A parent shared that it is difficult for parents to accept and comprehend their child's condition. Also, of all the eight parents I talked to, I could gather the varying degrees of understanding of their child in all aspects- their likes, dislikes, their personalities, emotions, experiences.
- Ms. Latif started her centre for CP adults as a result of ADAPT, Bandra shutting down its services and activities for these adults. All the adults from the Bandra centre are ones that Ms. Latif's centre, Jyotirmay, takes care of. This move in itself is testimony for the need to keep dependent CP adults engaged.
- Ms. Latif mentioned a CP adult boy's case where he was left alone in his house during the lockdown after his father, his only dedicated caregiver, passed away. The mother and sister were not as dedicated caregivers.
- Resources on D'Source about Jellow present the fact that CP kids' disability and dependency lead to isolation which in turn leads to boredom. This will only magnify as life progress in age but no other aspect.

2.2.b. *The range of abilities*

Next, from the eight parents of CP adults I talked to and the online sessions I observed, there was a broad variation in the range of their gross motor functions (ranging in extremes over the five GMFCS levels).

I can broadly classify their physical abilities in three categories:

1. Ones who can walk, but either not perfectly or with some support. Also, their hands function in limited capacities. (Probably Hemiplegic)*
2. Ones who cannot walk but can use their hands, though in limited capacity. (Probably Diplegic)*
3. Ones who cannot use any limbs and are completely dependent for any physical movement. (Probably Quadriplegic)*

**I am making probability guesses about the medical terms because all parents did not know this medical term for the child's motor functions and others are who I only observed in the online sessions.*

Most of them also do not speak as normally and clearly. Some speak with difficulty, their effort physically visible as they move their entire face to say something. They have required speech therapy in their early years, without which they could not have learnt speaking. And some of them (mostly they would be Quadriplegic) can only make sounds that do not involve the tongue's movement. These sounds are like "ma," "pa," "mumma," "pappa," "baba," "o," "om."

Of the eight whose parents I talked to, six use mobile phones independently, again, in varying degrees. But only two of all use a computer. Their activities on the phone could be simply navigating to a game and playing it, searching for and watching videos and music videos on YouTube. But only two of them can chat on WhatsApp and place calls.

A few of them can independently operate a TV remote and surf through channels to put on the right one.

Despite all that they can independently manage to do on the phone, it is intriguing that most of them cannot read or write, due to the lack of hand-eye coordination and other difficulties which also disabled them

from receiving any conventional education. Only two of them managed normal education till secondary or high school. These two are also the ones who manage to independently operate a computer too and can also read and write to some extent.

2.2.c. How they spend their time and their likes and dislikes

These eight CP adults are between ages 22 and 36. Five of these are over 29 years old. So, I got a decent perspective of how life gets as they get older. In the ones I observed in the online sessions, participants were as old as 45 years of age- all engaging together, equally in the same activity as the 22-year-old. The development seems to lie in their emotional maturity- they understand things better and have a better grip of their emotions and moods than when they were younger. It was just one case, where the 32-year-old with Quadriplegic CP, seems to be fed up with her disability, refused to engage in any routine activities and throws more tantrums instead- this is what the mother is guessing from her recent behaviour and responses. Mothers of the younger ones, those below 25, complained of the stubbornness, and attitudes.

Almost invariably, all of them love to talk to people. Whether introvert or extrovert, any interaction other than with their parents makes them happy and they look forward to it. Whether they put it as having a peer group or meeting or talking to friends, it was mentioned by all parents. I observed this in the online sessions too- even though they might not be very participative, they would attend all sessions each day and sit through them. I make this point because they could simply choose to not attend these sessions if they cannot participate as there are some who chose to do so from the eight I talked to. These, who do not attend are not motivated enough to engage in online interactions because they can neither do anything physically nor speak much. They prefer offline interactions where they just enjoy looking at others doing things.

Another common activity most of them like and also “love” doing is listening to music. There was just one parent who did not emphasize on this interest in the child. Listening to music was also an option for an activity for a “Fun time” online session.

A majority of them want things to be fun or “majja” and “entertainment” as a couple of parents put it. From the parents’ descriptions, “fun” means when things are light-hearted, and no effort has to be made- like watching TV programs and movies or going out.

All of them need support to do things and most of them even want it more than they need it. Like the ones who are physically more able, can help around in house chores like folding clothes. But they will do it only if their mother accompanies them. And there are no compulsive dislikes in the vocational activities as long as they are done in company.

All eight are slow at everything they do. For example, if they eat on their own or get dressed on their own or even drink a glass of water, they take much more time than a fully able person.

2.2.d. What they should and can do

The activities I observed being conducted in the online sessions of Jyotirmay makes my list of activities that can be done by such adults on a regular basis. These include:

- Learning singing. This helps with the speech.
- Listening to and comprehending stories with morals. This is to help them understand real life concepts like values and morals.
- Learning language and grammar (English) with activities like making sentences using the given word, understanding “Opposites” and similar concepts.
- Learning drawing, colouring and crafts. This is for their hand-eye coordination. A few of the eight explicitly mentioned they like

colouring. It is a fun activity for them as opposed to drawing which requires more skill, care and precision. I have observed this over the years with Mira too.

- Learning simple cooking which includes mostly cold items like bhel, sandwich or something simple and staple like tea.
- Drama sessions which did not really include acting but understanding things like different shades of a colour, different expressions for emotions and recited short poems and playing Simon says.
- Learning the concept of money and billing. This involved doing simple calculations limited to addition and subtraction.
- “Fun time” activities could be solving easy puzzles like spot the difference and other puzzle games. It could also be listening to music, or just chit chatting

These activities conducted are in the form of interactive games with simple questions and answers. The tone of voice is always appreciative and fun. Nobody is forced to participate or speak though they are prompted and encouraged.

An interesting occurrence in these sessions was that the participants randomly called out each other in the middle of the session and to make casual conversation. Like, one would suddenly notice a friend in all the Zoom tiles and call out to ask, “How are you?” or “Did you have fun during Ganpati?”

2.2.e. Involvement of caretaker

All the parents I talked to are too occupied with taking care of their child. Some expressed their fatigue which increases with age and desire for a break of at least few hours a day. Some also expressed that they are needed by the child all the time, but they are taken for granted in the presence of an outsider.

The schedules of both the parent and child are completely interdependent. The parent themselves take primary care of all routine tasks and there may or may not be a hired help to assist through them. Some have clearly defined a schedule for their day in relation to their child's care whereas others go through their day flexibly.

Some or the other family member was present by each CP adult in all online sessions. While the CP adult appeared to be doing the tasks in the foreground, they received all assistance required from the family member present in the background.

2.2.f. Other insights

A dependent CP adult's exposure to things is limited to what their caregiver exposes them to. So, what a CP person can or cannot do, not only depends on their condition but also on the caregiver's knowledge and understanding of CP and their background and lifestyle choices. Some parents knew the details of their child's condition while others did not. Among ones with a similar condition, some were tried to be schooled normally while the others were enrolled in a special school from the start. It probably also depends on the medical consultation they receive on how to go about dealing with their child's condition and growth. Comparing two Diplegic and one Quadriplegic* adult from the eight I studied- one of the diplegics can use a phone and even a tab and a laptop independently. Whereas the other diplegic boy could not use a mobile in the slightest independent capacity. On the other hand, the quadriplegic girl could use a mobile phone independently in some capacity (she will be lying down on the bed and can navigate to an app and operate it). So may be if the diplegic boy is encouraged to use a phone he will manage to use it to some extent at least.

**Quadriplegic CP disables all physical movement and as a result the person remains cent percent dependent. Diplegic has both lower limbs affected and only one hand may function to a decent extent to carry out tasks like holding objects with little to none fine-motor-skills.*

All the adults I learnt about love to interact with others. Whether they like to or can do an activity did not seem like the primary factor for them to attend the online sessions at Jyotirmay, nor is it what stops Mira from signing up for any class. They come to these sessions to look at others, see others do things, do things with others and interact. There were CP attendees in the online sessions who did not really participate, but only observed. Randomly in the middle of these sessions, one CP adult would notice another and call out to greet them. So, their attention to who is in the class overpowers the attention to what is being done. Even Mira's lockdown experience was due to the loss of such external interaction which had been arranged by her parents in the form of classes. It was not the lack of things to do. There is something or the other that they all can do. TV is the simplest thing that can keep them independently entertained. Mira can draw and paint on her own and even surf on her phone and laptop. Hence, isolation is the problem. There is the drive in her to do something only when another person engages in that activity with her. When this company is missing, the drive also vanishes. So, there is not a lack of things to do as much as there is a lack of company. This finding deviates in essence from the initial basis for my topic which was the lack of things to do for a dependent CP adult.

These adults usually may not seem as mature as any other person of their age in the way they act and respond to things. Most of their IQs are low but their maturity may not necessarily be tied to any intellectual impairments but to the limitations that their physical disability binds them in. They are not able to explore the environment as any other person would both as a child and as a grown up. Parents also naturally remain more protective and would not want to expose their child to face any possible negativity. Whereas we learn from our many experiences as we grow and mature.

3

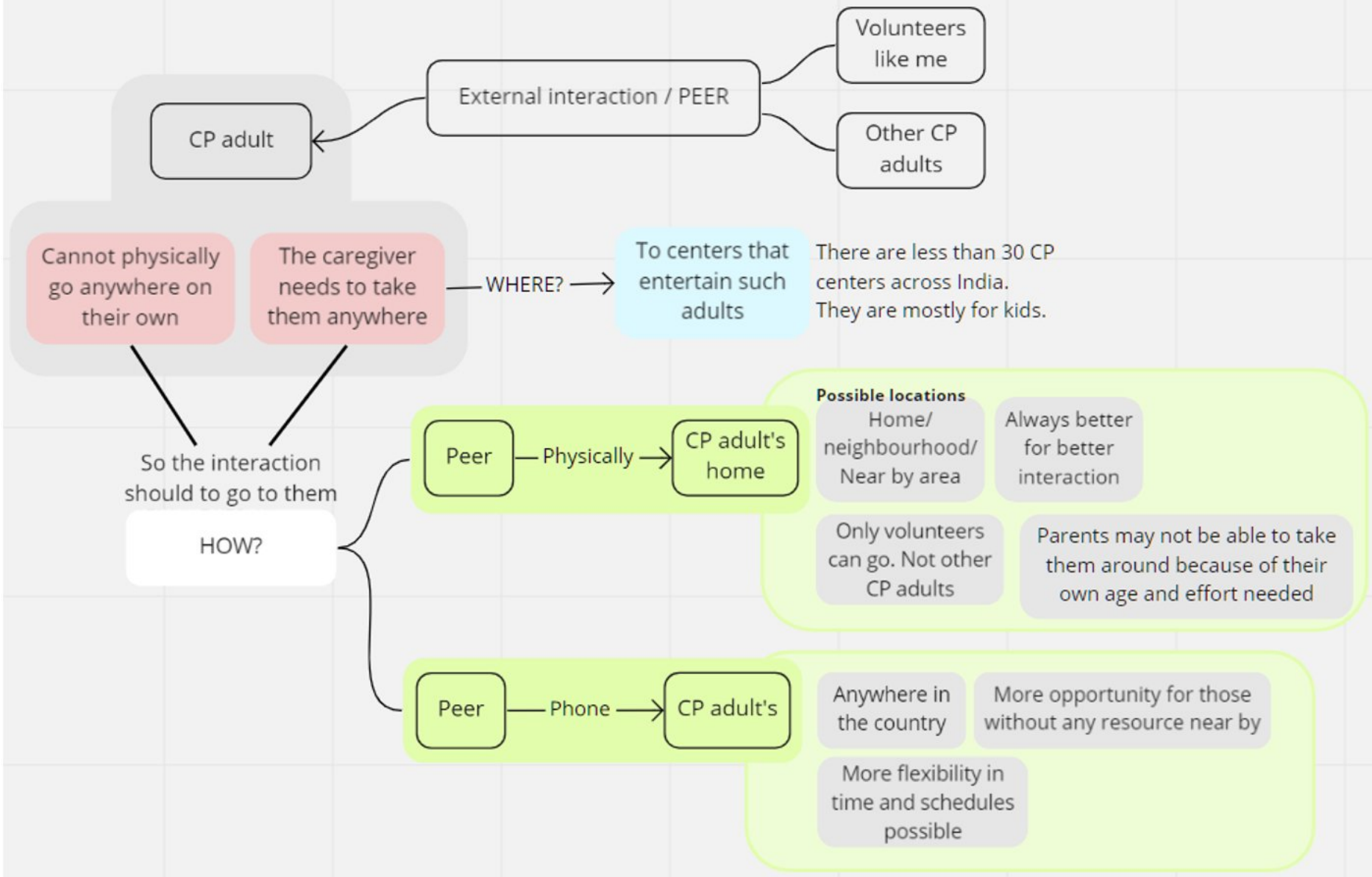
Conceptualization

Feedback from Professors on my user study, inferences and direction, urged some repositioning of my perspective on the problem I was trying to solve and of my method of studying it. The first shift, as discussed in the last section, was in what part of the problem I was prioritizing and focusing on. The problem is not as much the lack of things to do but the lack of people to do things with. So, the goal would be to give that interaction or create possibility for external interaction for CP adults. The second shift, for the scope of this project, was that I started focusing more on my wealth of experience with Mira to produce quality output though it would be only for a few like her. To design for more variations in condition would require studying much larger sample sizes for each condition.

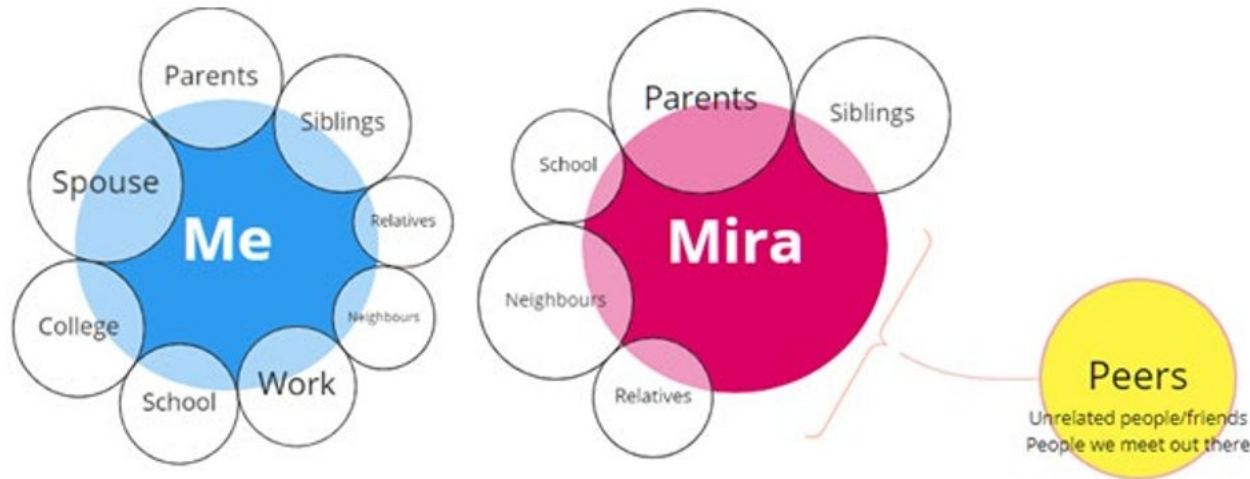
Though I focus on my experience with Mira, my target group is those like her but are not facilitated with the means to interact with outsiders to make and have friends. And I also do not leave out findings from other interactions and observations from the user study.

Since the problem is based on interaction and socialization now, a rough comparison between what any person's social network would look like to that of a dependent CP adult, helped in estimating the extent of interaction missing.

Iterated goal: To create possibility of external interaction for CP adults.



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We generally acquire peers or friends in our life through time spent at school, in college and at work. We are able to carry forward friends from here further ahead in life. We also make more friends directly or indirectly through these friends. We run into a variety of experiences outside home, outside the protection of our parents, which nourish us to mature as adults. At some point in life we also find a partner, a companion. Our parents do not remain our major companion and source of interaction. Whereas a CP adult would have little to none of such exposure and interaction. Parents will naturally remain protective and subconsciously monitor all interaction for the extent of vulnerability and even simply their constant presence.

3.1 A mobile-based solution

A mobile based solution seems suitable for this project for the following reasons:

- My target group is dependent. They cannot physically go somewhere- a limitation which is at the heart of the problem.
- From the user study, mobile is the one easily available resource that can connect them to others.
- It is not easy for parents to find and call people to come and engage with their grown-up child.
- Parents may not be actively thinking about any external engagement. This could be for many reasons- it doesn't occur to the parent, they may be embarrassed to bring the kid in front of others, they may not know where to look, they take care of the basic needs and are unable to think beyond that or don't know what to do beyond that.
- Mobile will facilitate the primary connection. Both parties can further decide to physically meet at their own discretion.

Storytelling my way to an idea

3.2 The personas

The goal is to connect a dependent CP adult to possible peers. So, the first stakeholder is a CP adult and another stakeholder can be any person who will be willing to spend their time as a friend with a CP adult. I chalked out characters/personas of a CP adult and a possible peer (a fully able adult or another CP adult). I do not stick to Mira's and my own persona because there will be people like her but not as equipped or well-supported and to be able to imagine beyond our personalities and beyond the equation that exists between us.

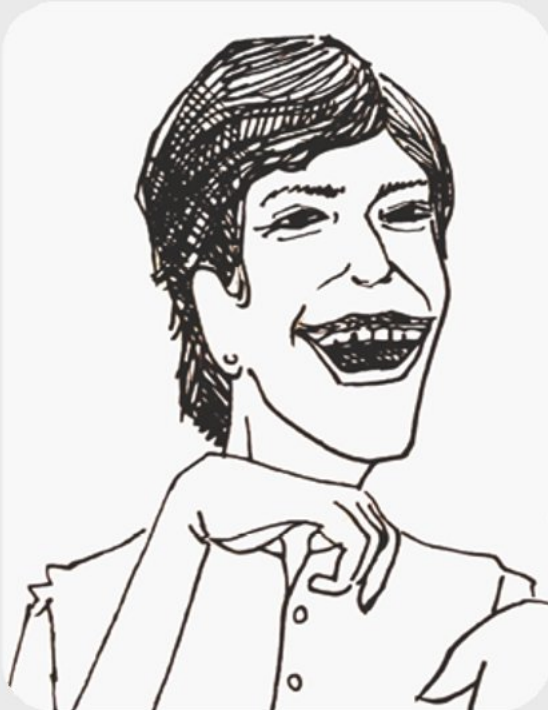


Abhi (Volunteer)

27 yrs old | Lives in Ahmedabad

Abhi is an animator, working with a studio in Ahmedabad. He is a graduate from a Fine Arts college and has been working since graduation. He lives independently in a shared flat right now. His typical day involves his office hours where the work environment is very upbeat and active to keep minds creative. He goes back home and sometime hangs out with friends he made from small cafe events he attended, sometimes with flatmates and at other times he stays alone, watching movies, learning new things, practicing and experimenting with his skills.

He also has a couple of friends studying psychology who are currently interning at a training center for disabled adults. From conversations with them he comes to know about such adults and wonders how life would be to remain dependent even as an adult. He hasn't really participated in any philanthropy activities before this and has little awareness about challenges that a disabled person might be facing. He wishes he could help or do some good. But doesn't know how.



Priya (CP Adult)

35 yrs old | Diplegic | Lives in Vadodara

Priya wakes up in the morning at around 8. Her mom gets her up between 8:30-9 and takes her to the toilet, brushes her teeth and gives her a bath. After this she is seated at the dining table and given breakfast and milk. This routine gets over by 11.15/11.30. After this Priya watches TV while her mom is finishing up house chores. Priya operates the remote on her own. She has an older sister who is married. Priya's father is retired and keeps himself busy with his routine and social circle.

After 1/1.5 hrs of watching TV, she has to go to the toilet. Her mother takes her and cleans her when done. After some time, Priya is served lunch which takes 30-45 minutes to finish. She sits at the table for another 30 mins while her mom watches something of her choice on the TV. Then Priya is laid down on the bed at around 3. She doesn't really sleep then but fiddles around on her phone playing some game or watching youtube videos or simply lying down doing nothing.

She gets up at 5, is taken to the loo and has tea and some snacks. Then she gets ready and is taken to her physiotherapist at 6. Here she sees CP kids with their parents. The regulars greet Priya and her mom and parents have casual talks before their turn with the doctor.

They come back home by 7.30. Before mom gets to cooking, Priya is freshened, her clothes changed and is stationed in the drawing room. She watches TV again until dinner. Dinner is between 8.30-9 when her parents switch to a channel of their choice. By 9.30, everything is wrapped up and everybody just sits watching TV. Sometimes they might call up some relative to catch up and then mom, dad and Priya would talk about them later.

Priya is then taken to the loo and put to bed by 11-11.30. She doesn't sleep then though. She again fiddles on her phone, playing some game or watching some video or listening to songs. She really sleeps at around 1.30-2.



Mayuri (CP adult volunteer)

29 yrs old | Lives in Anand

Mayuri is a very lively girl. She loves talking to people- the maximum interaction she gets is from her couple of neighbors

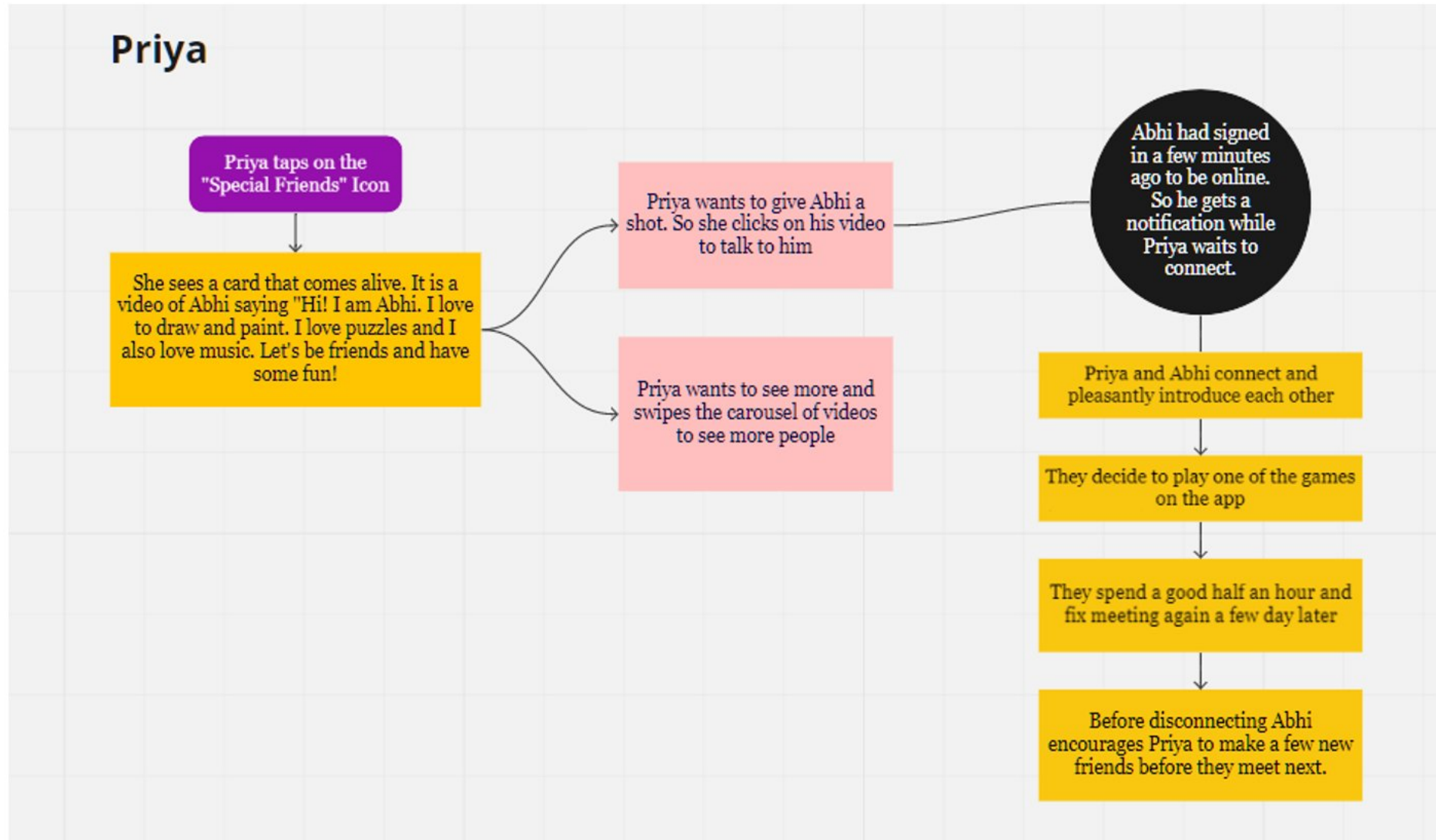
She gets up in the morning around 9 and finishes her morning routine largely on her own. She can manage to do some things on her own like brushing the teeth, going to the bathroom, bathing, eating and even walking but with some support. Only she is very slow at everything. For example, it will take her 15-20 minutes to dress up. She also has some learning disorders and a low IQ.

She is mostly doing nothing much between her morning routine and lunch when she might try help her mother with some house chores like folding clothes or in the kitchen. But she can't do much which can be of help. She Between lunch and dinner, she will watch TV and sit outside the house in the evening to watch kids playing and look for opportunities to chat with a passing neighbour.

Dinner is with family at the table after her father gets back from work. Her father watches news after dinner which she is not interested in. She sits for a bit in the drawing room and then retires to her bed. She fiddles around in the phone looking at Youtube videos or playing games. She sleeps late by 1 or 2

The personas enact a concept

3.3 Their task flows



Mayuri

Mayuri's doctor tells her and her mother about the Special friends app in her tri-weekly physiotherapy sessions. He suggests she could befriend other CP and guide those who need guidance.

She installs and opens the app

With her mother's help she registers on the app using the invite the doctor gave

She creates her video to put up as her introduction, again with the help of her mother

She goes online

She browses videos of others- both volunteers and CP adults

She chooses to chat with a CP adult

Abhi

Abhi is free for a bit and decides to be available on Spl. Friends.

He opens the app

He switches his status to online

His pre-uploaded video is now visible to others who come online.

He browses other volunteers and also CP people online

He keeps the phone aside and does his work

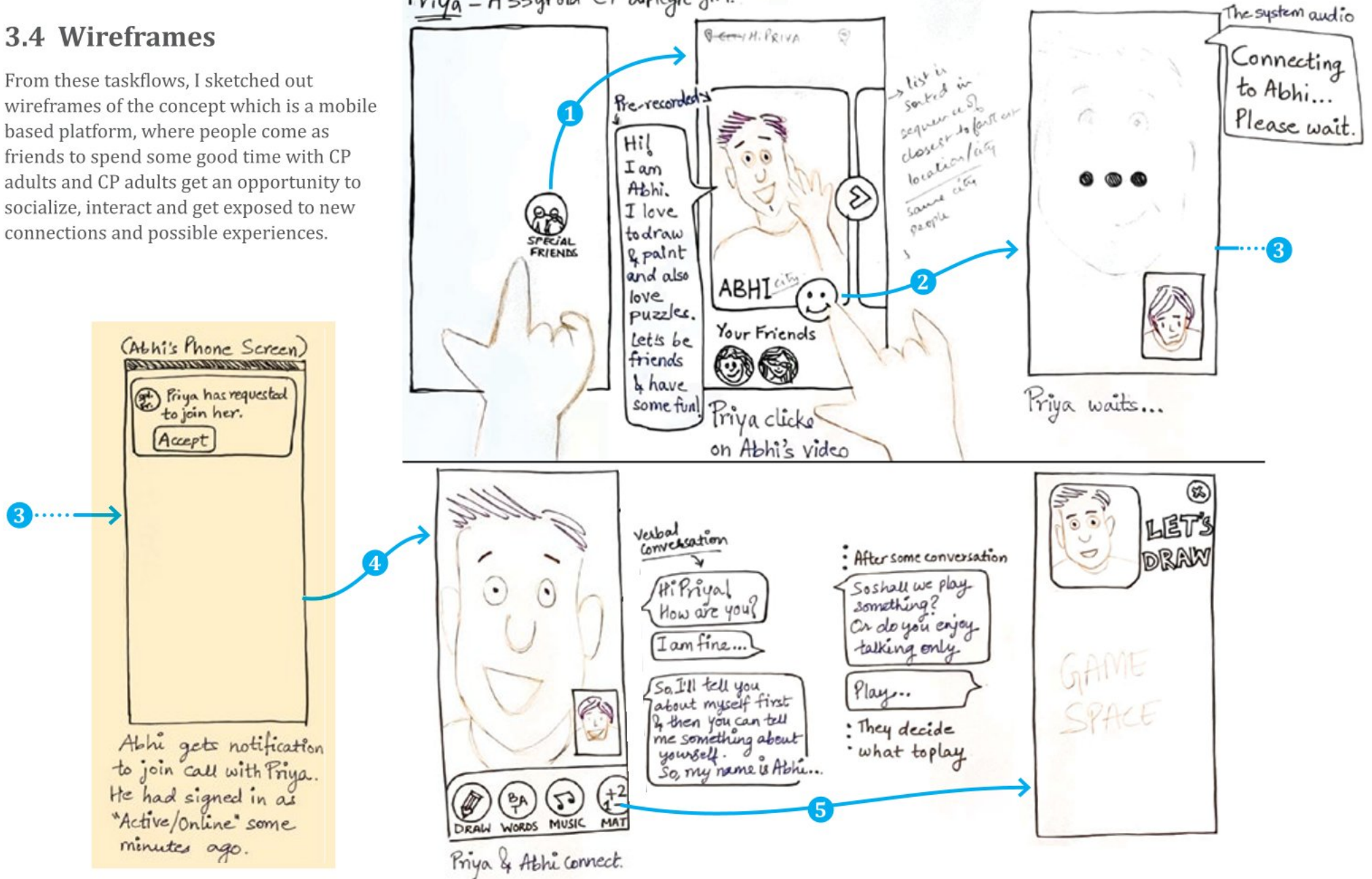
He receives a notification that Priya is requesting him to join

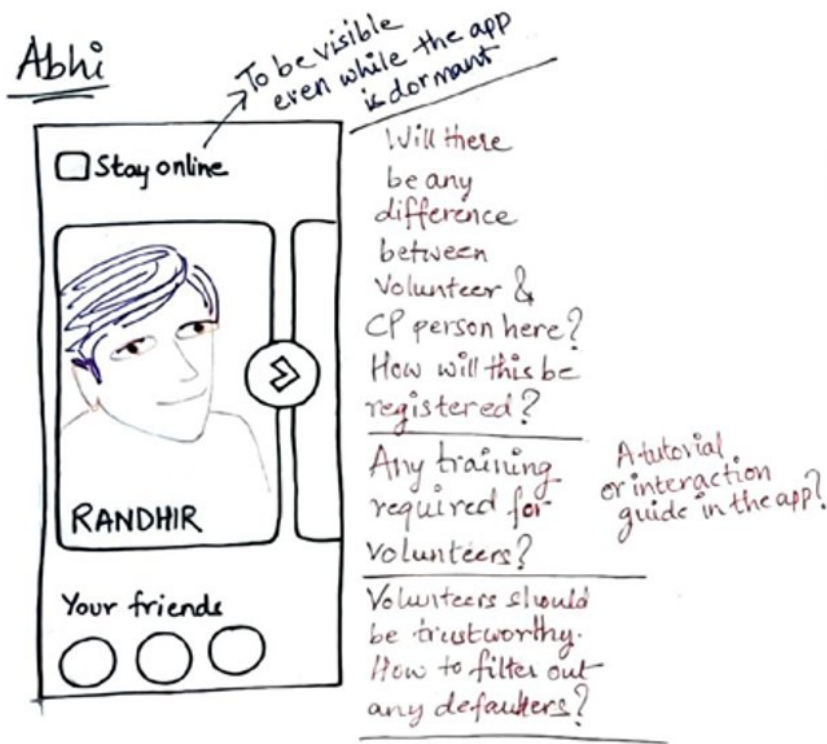
He accepts it and talks to Priya

3.4 Wireframes

From these taskflows, I sketched out wireframes of the concept which is a mobile based platform, where people come as friends to spend some good time with CP adults and CP adults get an opportunity to socialize, interact and get exposed to new connections and possible experiences.

Priya - A 35yold CP diplegic girl.





Video call based: Now, our CP adults operate a phone in limited capacities in terms of the fine motor skill of their fingers to interact with the interface and in terms of reading and typing. So interaction on this platform will entirely be based on video calling. Also, the purpose is to make possible interaction between parties that may not physically be able to discover each other.

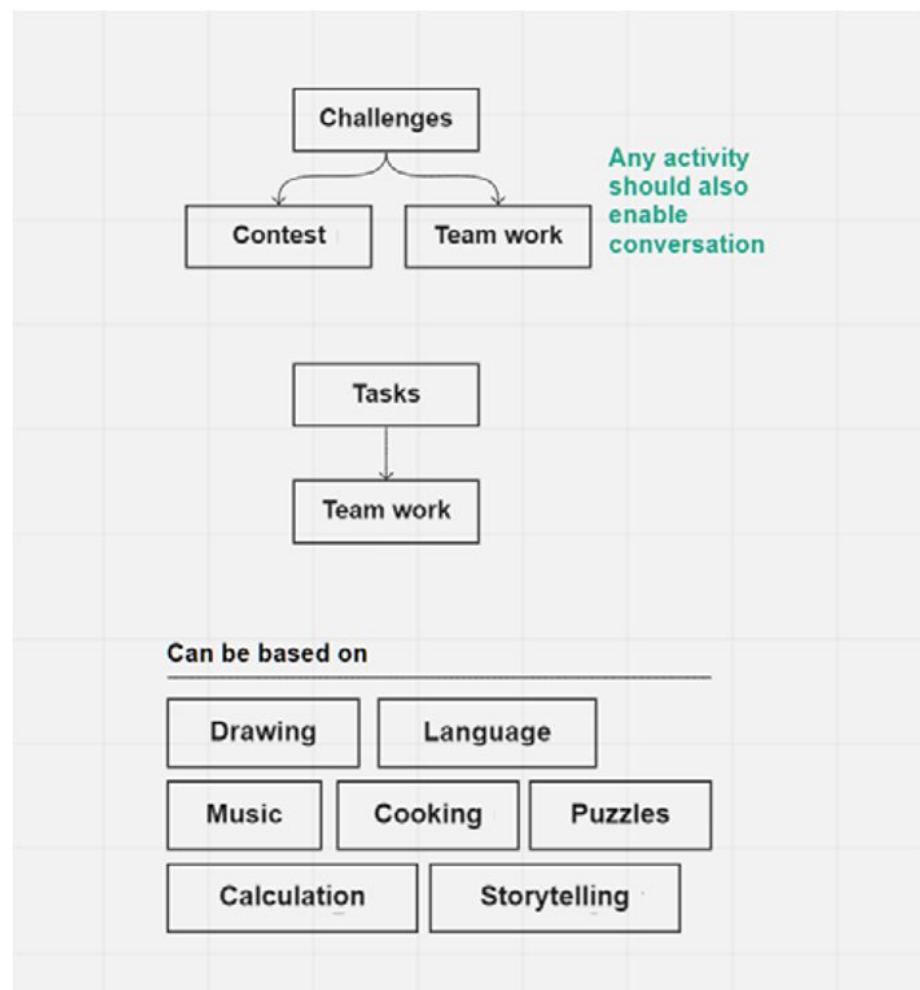
The video call component of this concept poses concerns about risks involved. Should such a vulnerable population be exposed to random strangers? How should the trustworthiness of any volunteer be ensured? And how should the platform register and differentiate between the profiles of a CP adult and a volunteer. At this stage I only note them and address it further ahead after the first iteration of the entire idea.

I'd like to note a thought here that we grow and mature as adults through the many random people we meet and our experiences with them. And our primary stakeholders here are also adults.

Facilitating conversation: Consider the scenario when Abhi and Priya (my personas) get in touch on this platform and are active on their first video call right now. What will their conversation be? Both will introduce themselves- name, place, what they do currently, what might be on their minds right now. And? What more? Abhi will try to be careful and cautious and will not be able to get as casual and open as he may get with any other new friend. Priya has not been so randomly exposed to new people before, and she understands that there is a difference in her and the other person. So what will she talk? So, the platform should provide opportunities to break the ice and create a bond. This can be achieved through activities that that can be done together, as has been in the case of my relationship with Mira and also in the case of engaging CP adults at the center. These activities can be simple games, but chosen and designed to enable conversation and create moments together. Games that involve discovery, surprise, newness, fun, discussion, guess work, commentary, scope for error and making jokes.

3.5 The games

Categories of games: Observing the online sessions of Jyotirmay gave me an idea of the range of possible activities these adults can engage in. Also, in direct conversation with some of the CP adults, I found out the kinds of games that they are interested in.



Brainstorming game ideas:

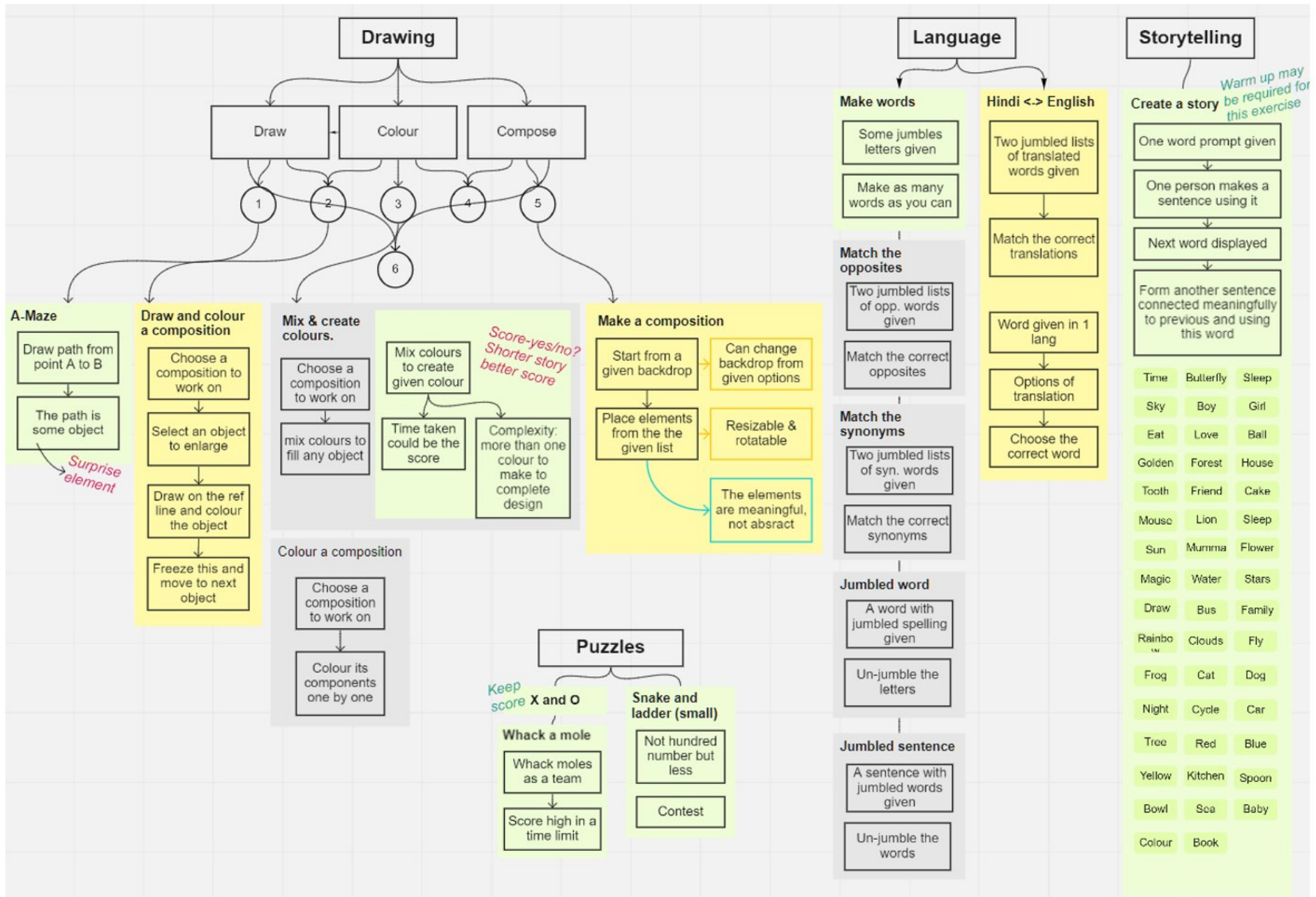
From these categories, I branched out to specific game ideas. The games focus on teamwork i.e. doing something together to facilitate building companionship. Also, if the CP person in a particular session is not able to carry out a task in the game, the other person can complete it for them. This in no way has been taken as an intrusion and interference by any CP adult in my observations upto now. Infact they feel a sense of having done the activity even though their helper/company would have carried it out in the most part.

There could also be games with very simple interactions with the screen that can be played as a contest between the two parties instead of team work.

The games can be picked from what exists such that the participants feel familiar with it and there is little to no learning curve required. Or they should be very simple to understand. This shall be to eliminate the risk of disinterest from confusion and to keep the focus on using the game as a tool to break the ice and facilitate bonding.

The overall mechanics of the games shall be borrowed from physical/ offline game play where no system restricts exactly how the game will be played by which player. Instead, the game is only defined by declaring a set of rules and resources and it is at the discretion of the players to play it as they like.

I also tested a few games with both types of stakeholders on the platform. The results of these test rounds are elaborate with the game's description in the following section. I'll stick to the names of the personas, Abhi and Priya, to refer to the participants of these test rounds.



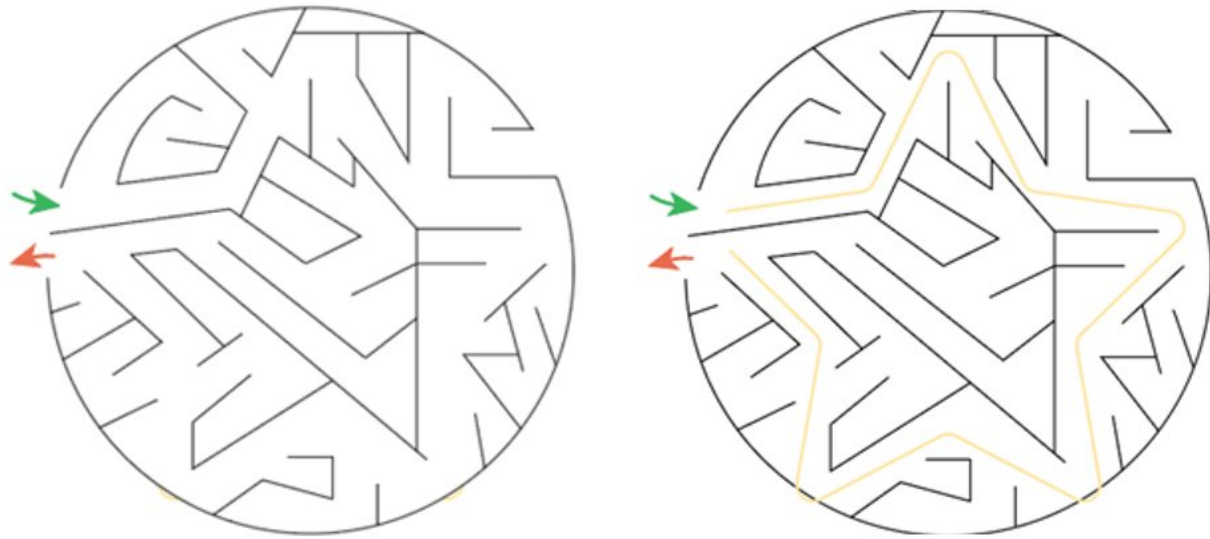
Game 1

A-MAZE

Category: Drawing + Puzzle

Objective:

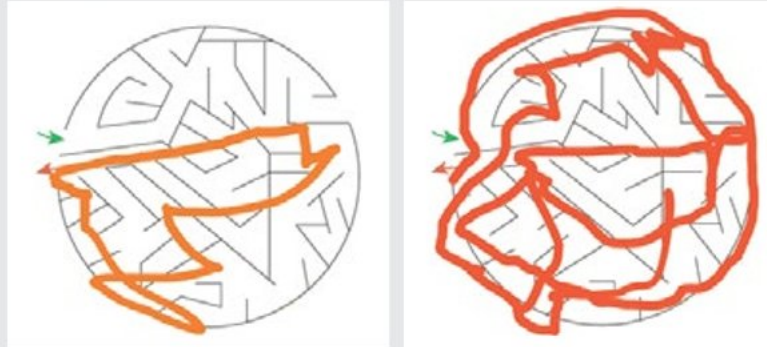
Drawing is an activity which is difficult for those with fine motor skill disabilities. Which is why it is also not a favourite among such a group. Though, colouring, which always follows drawing, is a dear activity to those interested. A-Maze makes the act of drawing interesting- it carries the goal of solving a puzzle rather than drawing something. The solution reveals that the player has drawn something. The game is exactly like what we have played in newspapers and magazines as children and enjoy it even as grown ups. It is a maze where the player has to find their way starting from an entry point A to an exit point B. Only, in A-Maze, the pathway from A to B is a meaningful image.



Testing this with a fully able adult using WhatsApp's marker tool (when sending an image)



Testing this with a CP adult using the same tool (two attempts)



Result: The testing with the CP adult did not reach the revelatory part of the game since the participant was doing it independently. But it did point out that the maze should be wider for easier navigation of a finger through it.

Game 2

DRAW & COLOUR

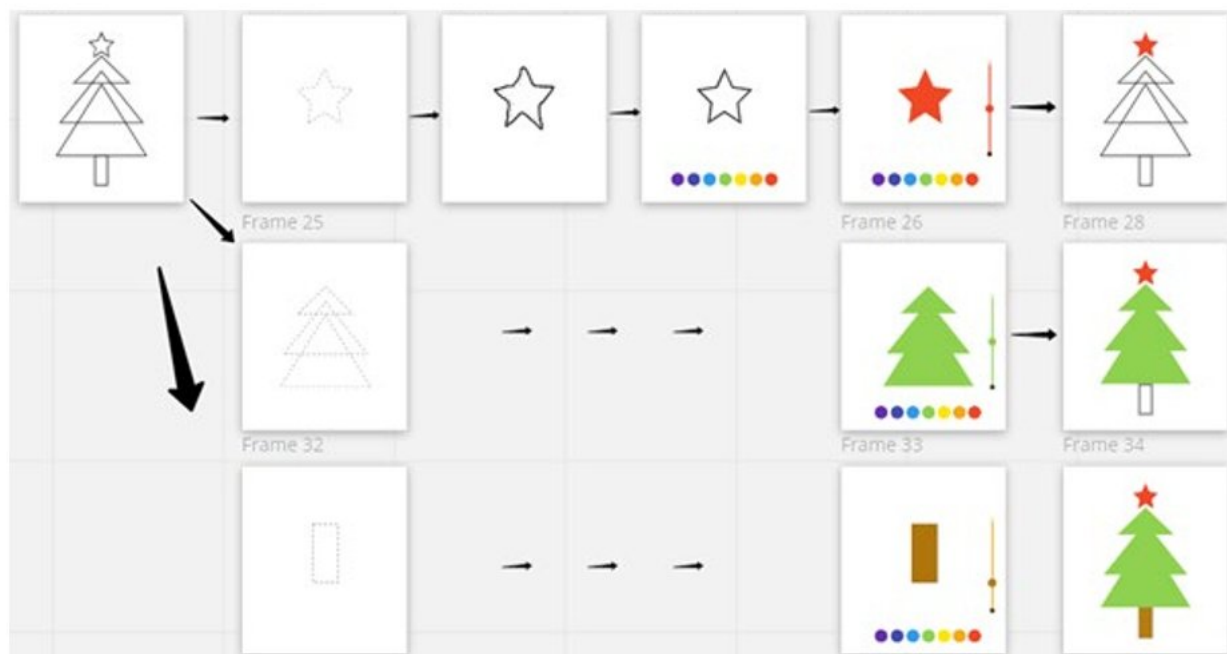
Category: Drawing and Colouring

Objective: To create a coloured composition.

A bunch of un-coloured compositions is given to choose from- imagine colouring book illustrations. Both players work together to complete the chosen composition.

Each element of the composition can be selected and isolated to work on. In isolation the outline of this element is a dotted line, which any player has to trace on to make the drawing. Once drawn, they move to colouring it. Once they mark this element as done, they are directed back to the composition with the updated status of the element worked on. In this way, both players work together or take turns to draw and colour each element to finish the composition. In the end, the CP adult and the volunteer will have a shared creation in their record.

Opportunities of interaction: Both players decide through conversation which composition they want to work on. The elements of the compositions in this decision-making can reveal likes and dislikes of both parties which can be accompanied with stories of reason for that choice. The parties talk to decide how they carry out the task- whether they take turns and do it any other way. Choosing colours for each element again requires shared decision making and promotes some conversation and reveal choices and thought process.



Game 3

COMPOSE

Category: Composition

Objective: To create a composition with the given elements.

A bunch of backgrounds are given to choose from to start creating. After this step, more elements are revealed which can be added to the composition. Any number of these can be added and each can be resized, rotated and freely moved around. The background and the elements given are meaningful. They are not abstract. This activity is intended to be freely carried out as a team. The players can decide when to stop and freeze a composition.

Opportunities of interaction: Since it involves freely choosing and putting together meaningful elements, the outcomes can easily turn out bizarre. The process of choosing an element and possibility of placing it in any position in any manner naturally makes way for discussion, consultation, commentary and jokes.

(Reference from Care for Our World by Sunbreak Games)

Game 4

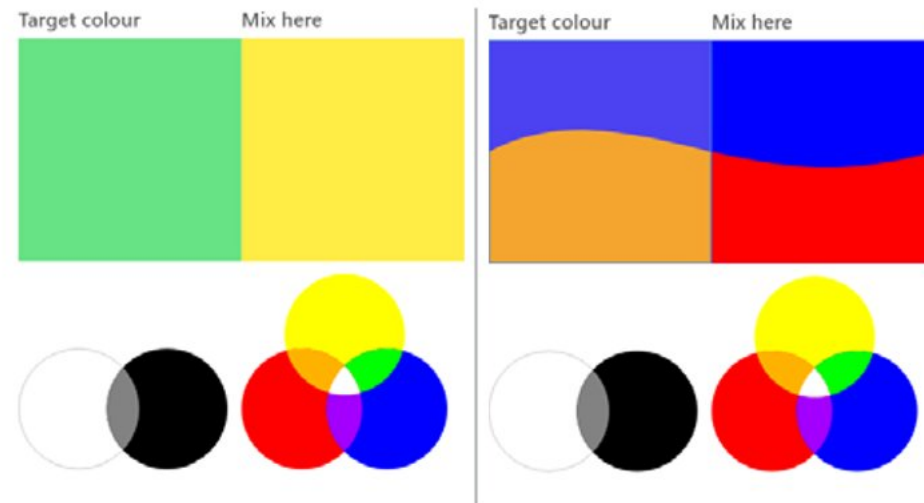
MAKE THE COLOUR

Category: Colour

Objective: To mix primary colours to make the given target colour.

Two blocks of colours are given- one with a target colour and another is to mix and make a colour. The players have to use swatches of the primary colours given separately to mix and create a colour in the mixing block that matches the target colour in the other block. There is no time limit in this game. The game ends when, either the target colour is achieved or the players decide to pass and try another target colour.

Opportunities of interaction: For this activity, both parties would be trying to figure things out together. So they'll discuss what they understand and discover to move the activity forward. There will be guess work and scope for mistakes with decision making.



Game 5

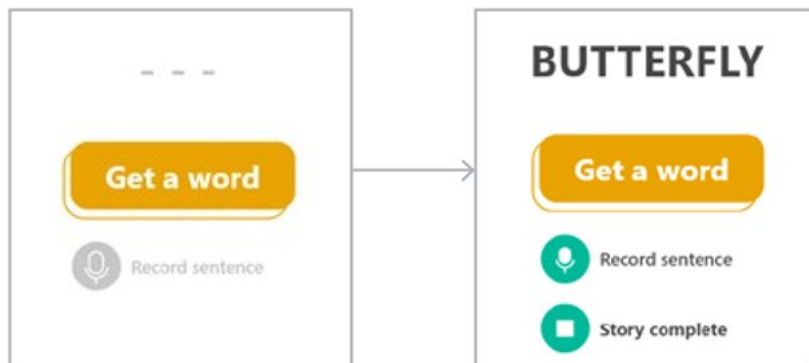
STORYTELL

Category: Storytelling

Objective: To create a story

Both players have to work together to create a story sentence by sentence using random words generated. The game starts when the first random word is given to the players. They have to create a sentence as part of a story using this word at least once. This sentence is recorded by the players. Another word is generated which they use in a new sentence which should be in continuation of the previous as developing a story. Each sentence is recorded each time. The game rules mention taking turns to create sentences but there is no monitoring. There is no time or word or sentence limit. The players decide when to end the story and start a new one. At the end of the story they can review the entire recorded story at once.

Opportunities of interaction: This is an entirely dialogue based game. The players have to think out loud and create and continue towards an uncertain outcome. This will involve discussion, consultation, bizarre ideas and connections because of the element of randomness and uncertainty and hence jokes.



Game 6

WORDS

Category: Language

Objective: To create words from the given alphabets

Both players have to work together to create as many words as they can from the given set of alphabets within a time limit. There are two possible variations for this part:

Variation 1: The given is a set of alphabets. Words have to be created using only these alphabets.

Variation 2: The given is a pair of alphabets. Words have to be created starting with this pair.

The time limit will be comfortable and not too short. Each word they create will have to be typed out by any of the players. Each typed word adds to that round's list of words. The game ends when the timer runs out. The number of words created is the score for that round.

Opportunities of interaction: This is again a dialogue based game. The players have to think out loud of words that come to mind. There is constant brainstorming and commentary about the time.

I tested both the Storytell and the Words games with participants fitting both my personas. This testing was done through Whatsapp video call and paper chits as the game resource. They played two to three rounds of each game in a span of 45 minutes. Both participants remained engaged and interested.



Screenshots from the Storytell and Words game testing

Game 7

X & O

Category: Puzzle

Objective: To make a row, column or diagonal of three Xs or Os

This will be a contest between the two players and it is the regular X & O game which we play with pen on paper, chalk on board, with sticks in sand, scratches on walls and other surfaces. Though this will be on separate mobile devices of the players, the interface acts as a shared device like a piece of paper would act between two players of this game. Both players can make the marks for each other too. The game ends when one player achieves the goal. The next round starts when the players are done analyzing this round and choose to move to the next.

Opportunities of interaction: This game involves simple strategies and working against each other in a light hearted spirit. It encourages commentary and scope for mistakes that can be pointed out later.

Game 8

WHACK A MOLE

Category: Fun

Objective: To whack as many moles that appear each time they appear.

This game is the common whack a mole game. There will be several holes on the screen. Things will come out of any random hole at any time and the player should tap on it to whack it each time. Both players play this together as a team. The score is the number of mole they have whacked in that round. There will be a time limit for each round.

Opportunities of interaction: This game let's one go crazy. The possibility to go crazy together gives the opportunity to connect. And there is a straight-forward but not an overwhelming sense of a shared achievement.

Game 9:

SNAKES & LADDERS

Category: Puzzle

Objective: To reach the end of the grid first.

This game will replicate the offline version in most part. The difference will be that it will have a smaller grid and not a grid of 100 numbers, for ease of interaction. The players can choose to replace the dice with another mini game. The mini game is that the player will have to answer a question. The answer results in a number which will be the number of steps the player takes. The question could be to list names of birds with a cap on the number. The number of list items will be the number of steps for the player to move.

Opportunities of interaction: The game play and rules itself result in the players experiencing expectation, achievement and setbacks. These give rise to commentary. The mini game involves guess work, record keeping and discussion.

3.6 Language and tone of the platform

When interacting with such a disabled person, our tone of voice naturally becomes sympathetic and we talk like we may talk to a child. But unless we treat an adult like an adult, a friend like a friend, that role and designation only remains limited to its nomenclature. That we have to treat such an adult as a child is our unconscious assumption. But, as explained earlier, any naivety we see in a CP adult may not necessarily come from a lack of intellect but the dirth of exposure. (The movie Margerita with a Straw and the documentary Crip Camp show how these adults are really adults in every sense but people around them fail to acknowledge it.) This argument does not rule out the care that may be needed in such interactions.

The language of the platform shall reinforce the idea of coming here as friends. Starting from the name, which for now is “Special Friends”. Any call to actions shall also follow the same theme.

The call to actions and feedbacks on the platform shall be image and audio heavy. Text shall be avoided as far as possible because more often than not the limitation of reading will be present in the CP adults.

4 The Design Prototype

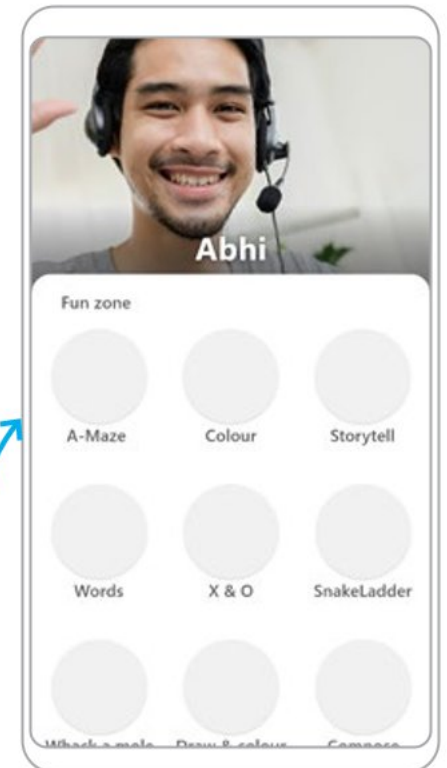
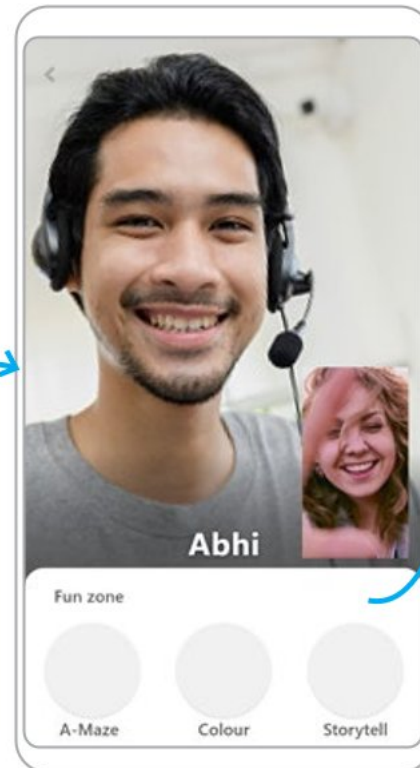
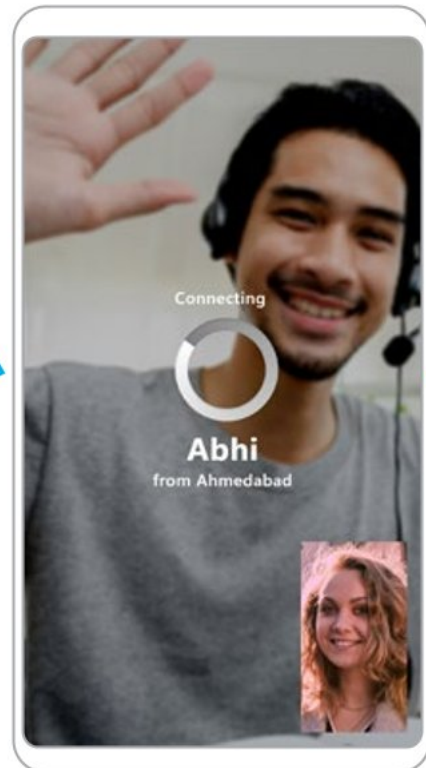
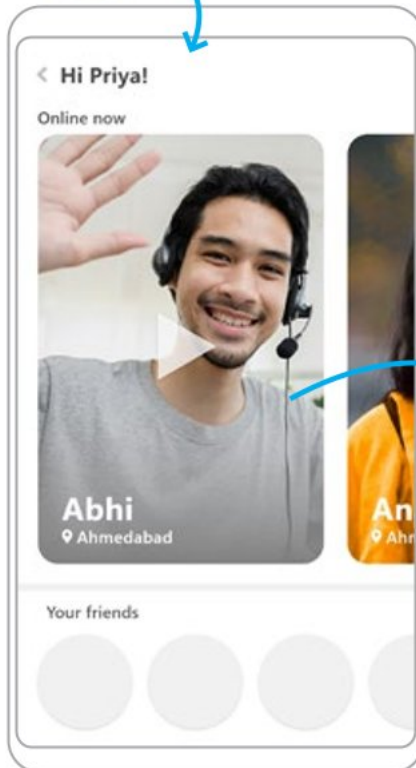
To be able to present the concept elaborated in the last section and get feedback, I developed a demo level prototype from mid fidelity wireframes. This prototype is of the CP adult's side.

Please interact with the prototype [here](#).

Or scan the QR code.



Special FRIENDS



5

Feedback

I shared the prototype with our professors at IDC and with teachers of CP adults at Jyotirmay and gathered their feedback. The idea was well received by our IDC Professors. The variety of games provided and the fact that their basic idea is taken from what exists as common knowledge seemed to work well. The purpose of these games is primarily providing a fun engagement and there is an element of usefulness attached where possible was also acknowledged. Like the A-Maze game attempts to work on the hand-eye coordination skill.

While the teachers at Jyotirmay were majorly concerned about the video call heavy model. The concern was only around the sexual exploitation of an innocent and gullible CP adult. They shared specific examples of romantic feelings and relationships of these adults gone wrong. Their concern was parent-like where they are simply being very protective because they know the other person will always have an upper hand over their child. From more discussion with them some ideas

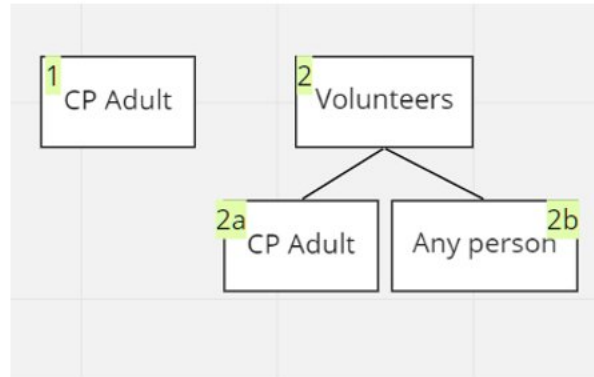
came across that can be considered- the video call could be between a group of people and not just one on one. All that is said and done in a group will naturally be censored and thought over twice and there will always be witnesses. CP to CP interaction can be focused on which can also eliminate most of the risk.

The concerns expressed by these teachers are not theirs alone. A little more analysis of the concern brings out points that may help navigate to a solution. First, the purpose of this platform is to provide peers. A one-on-one interaction will always help build a better connection. Or a group interaction can introduce one to possible connections followed up by reaching out individually. The concern of sexual exploitation arises when both parties are of opposite genders. So, the list of people online could be filtered by the system to match the gender of the user. Some filtration system could be applied for any volunteer to sign up in the first place.

6

Thinking about the system

Types of participants on the platform

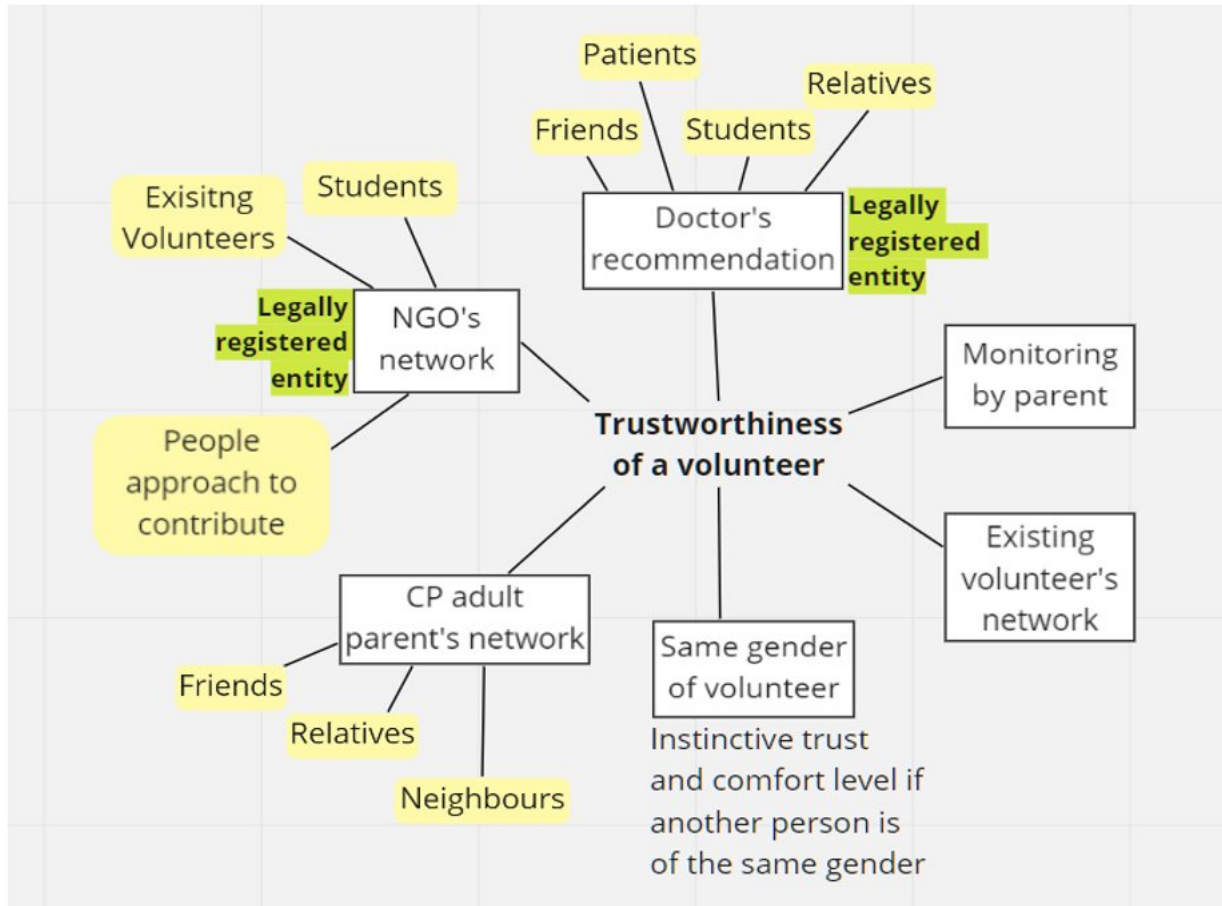


The scenario

- Volunteers will come on the platform
- They may or may not be well-meaning and trustworthy
- CP adults who are dependent are quite gullible and may not assess a stranger's trustworthiness correctly
- Parents usually come to know about resources for their CP kid from a doctor
- NGOs may have/can attract a relevant network of people
- The major fear for the system is of sexual exploitation of the gullible CP adult. There is specific concern about safety in interaction between opposite genders. Though there is possibility of a mishap between same gender interaction too, the tendency is to trust more in a same gender interaction.
- Another fear is sharing of sensitive information- the CP adult may provide such info naively.
- The parent can monitor or approve of volunteer before or during a video call
- The challenge is to ensure that well-meaning volunteers signup
- If a person comes from a trusted network, their trustworthiness can be established better.

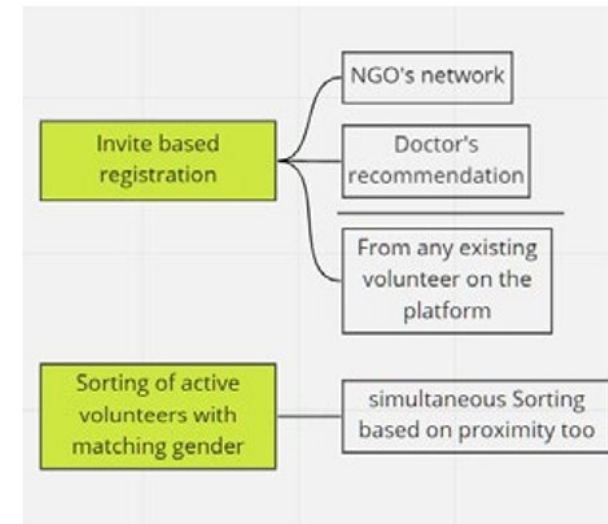
Ensuring well-meaning volunteers signup

Factors that can establish trustworthiness of a volunteer:



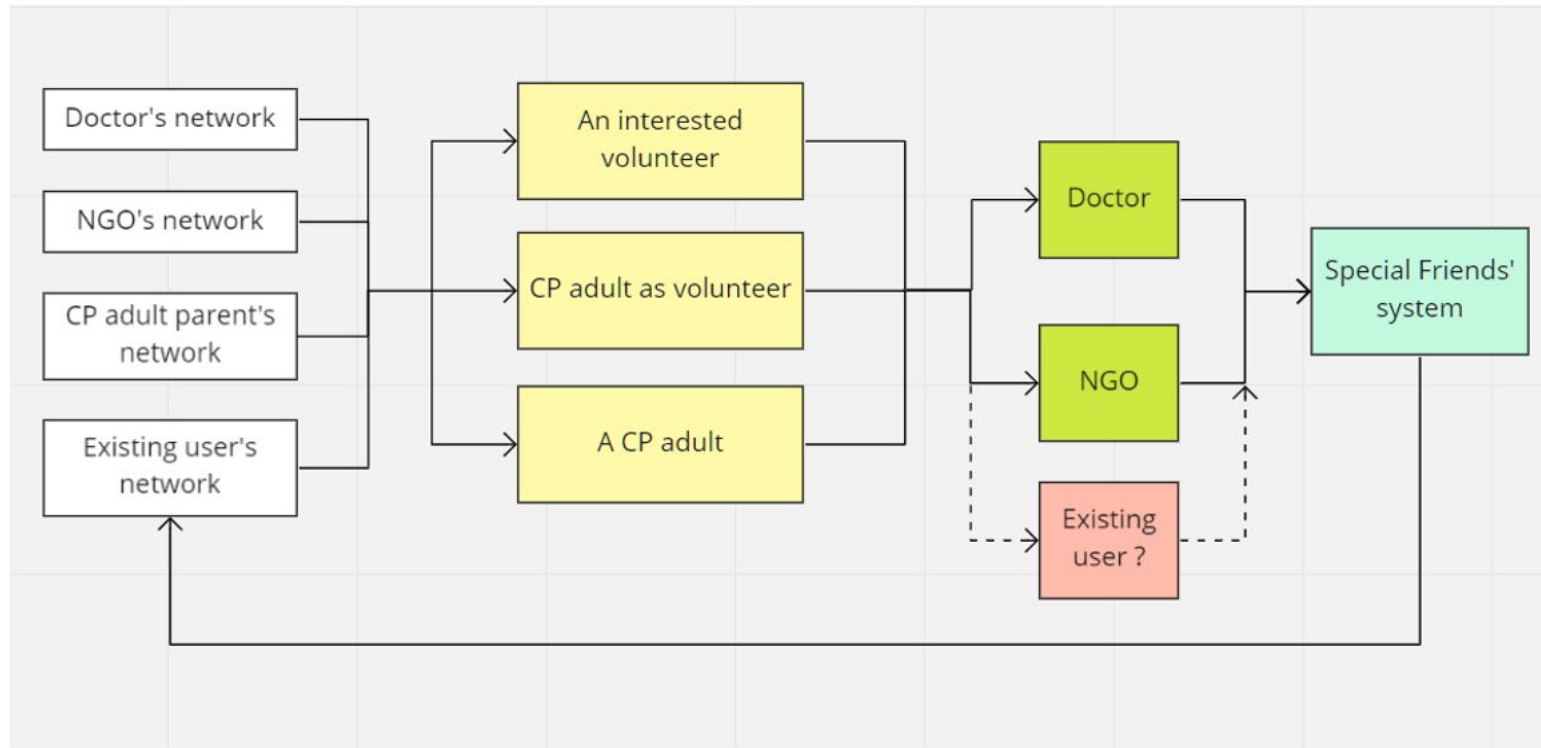
So, if people can sign up only using an invite from:

- A doctor (paediatrician, physiotherapist, neurologist, therapist) who consult about CP
- An NGO working in this space
- An existing volunteer on the platform

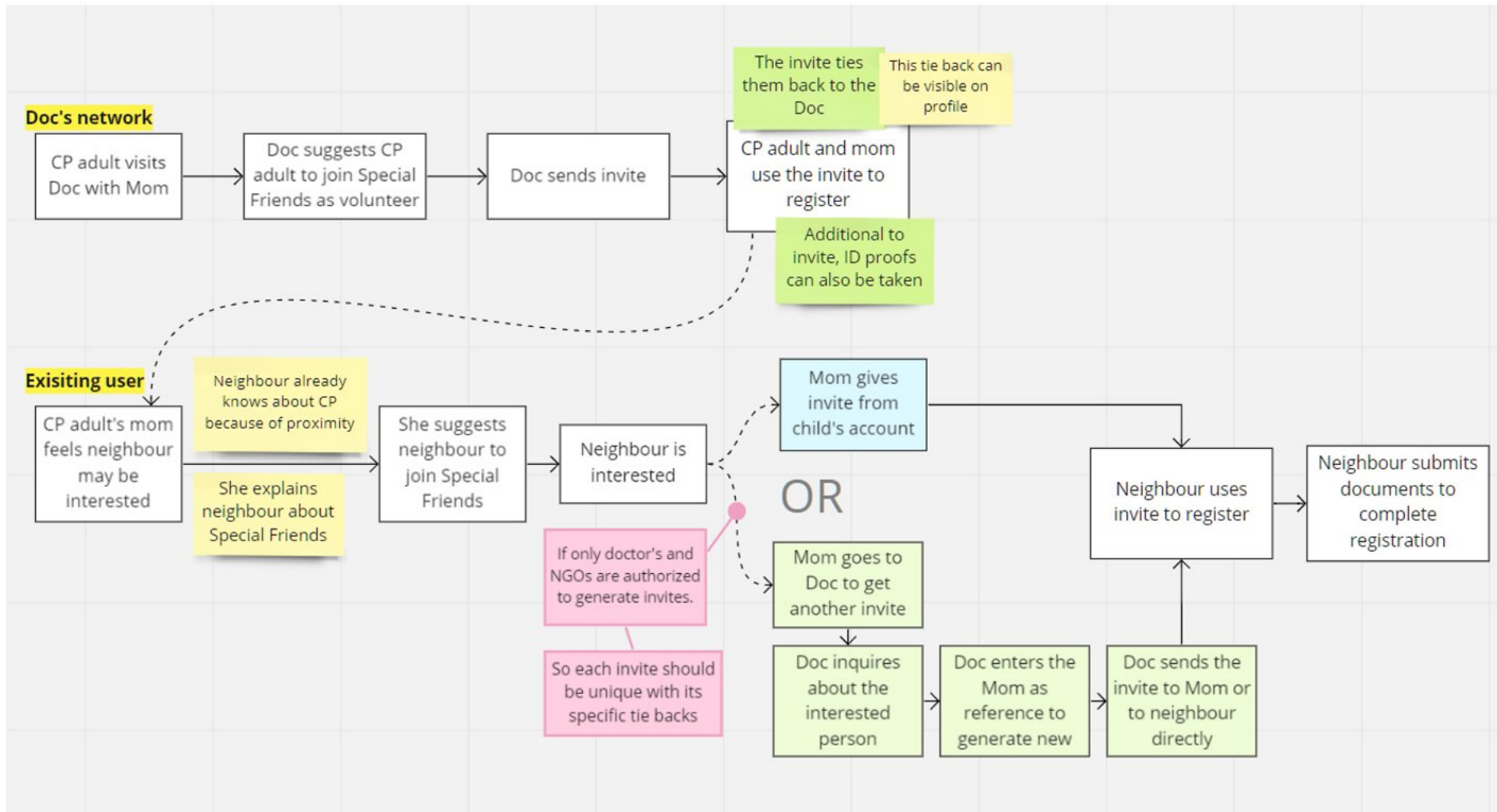


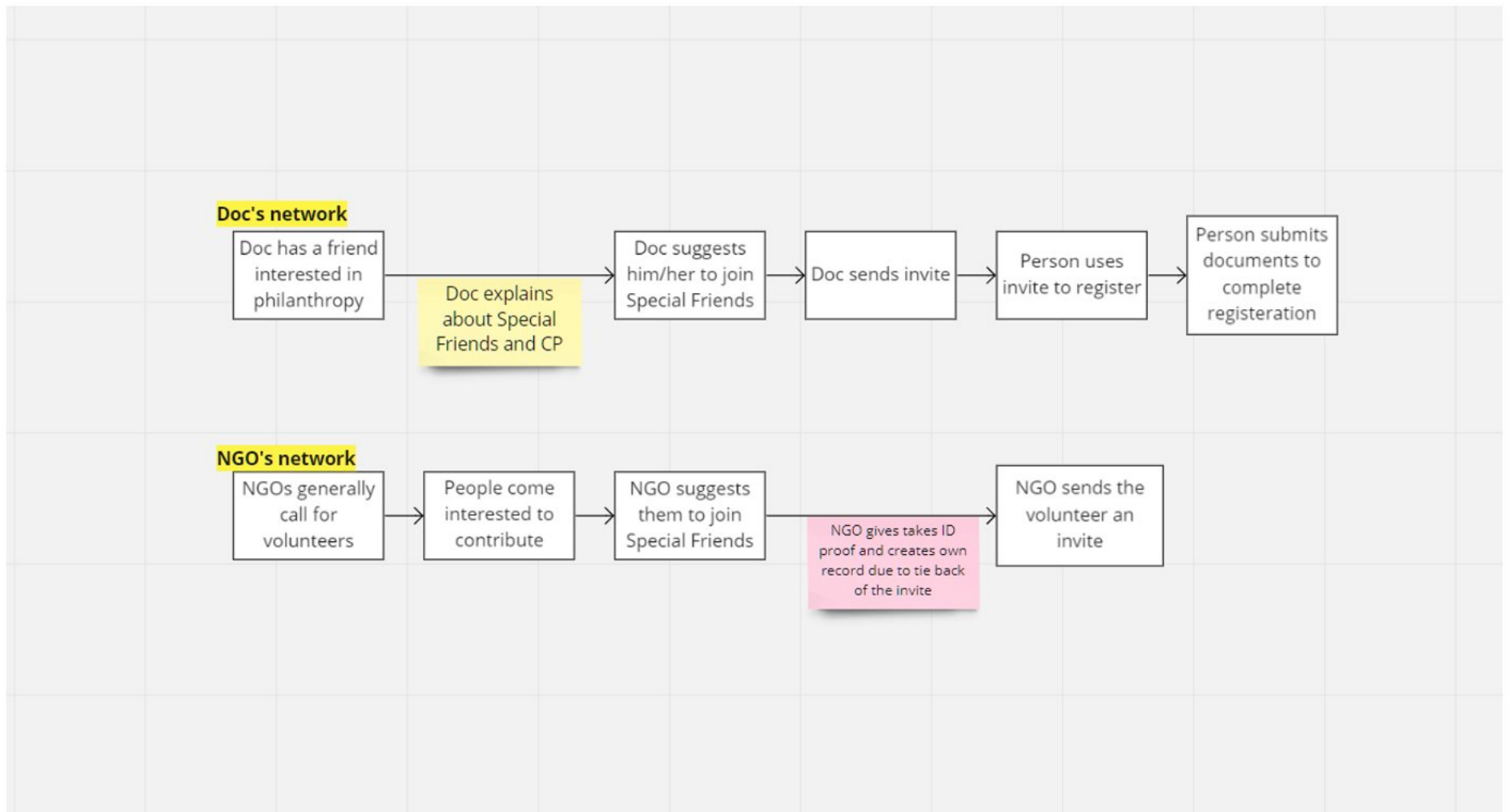
Leveraging the network

The process of filtering through the network can be made a requirement to be part of the platform. Only invites from authorized entities can get one to register.



Possible scenarios





In addition to the invite, ID proof of the participant can be collected during registration for a stronger record in the system to tie back in case of any mishap and to lay down the tone for a no-nonsense space.

7

Conclusion

The result of this project is the concept of a platform for CP adults to find friends. The platform is live video based facilitating one on one interaction since the CP adults will mostly not be able to read or write and they long to see and hear another person to interact. The participants of this system will be CP adults looking for interaction, a CP adults as a volunteers and any others as volunteers.

To break the ice between the two parties when they meet first and to give more reason to come back and meet, the platform provides interaction enablers i.e., the activities and games. These activities and games are derived from a list of categories which I observed in what is actually done at centers for such adults and from my own experience with Mira. The primary aim of these activities is to be fun and enable conversation and the secondary aim is also to be useful.

Lastly, to ensure that only well-meaning and trustworthy participants join the platform, I propose an invite-based registration system. The chain starts from Doctors and NGOs who deal with the CP population. It can be extended to existing participants on the platform who will be able to generate their own invites to give to others. The invites used to register will tie the participants back to the node. In addition to the invite, an ID proof can be taken during registration to enforce the platform as a no-nonsense space.

This project concludes at the first design iteration ready to be developed into a prototype to assess and iterate further. Further work to be done includes making the interface friendly for its participants and thinking about more activities and games to suit a wider range of abilities, interests and interactions.

8

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