Designing for inseparable Conjoined twins: Interaction Design Approach (Craniopagus Case Study)

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Abstract:

Conjoined twins are two babies who are born physically connected to each other. For some of these conjoined twins the separation process is possible, but for some others is not. Therefore, it is important to design special products to support them in their daily activities and mental and physical development without health and psychological problems. As well as helping parents to care for their children in their work as parents of children with problems in dealing with their needs and dealing with those around them.

Research Importance:

The research presents a case study "Menna and Mai". They are two identical twin girls of the type attached to the head (Craniopagus). And the focus to solve the problem of walking and mobility as one of the problems faced by each of the twins and deal with each other with parents and deal with this problem in the case of the pre-separation or non-separation. The researchers explored and discussed the related needs, the limitations and conditions in order to suggest a suitable design for this specific case, applying interaction design technics to decrease the complexity of the using process for both parents and kids, and in the same time ensure kids ability to develop their own identity, skills as normal as possible.

Research Objectives

Focusing on one need, which is walking, as a basic need to develop the rest of child's skills easily and naturally, that moving kid is a learning kid. Helping the two girls to walk freely and response for each of them to give the opportunity to walk and help each other.

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Keywords:

Craniopagus; Conjoined Twins; Interaction Design; Skills development.

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Introduction

Conjoined twins are two babies who are born physically connected to each other. They are identical twins who develop with a single placenta from a single fertilized ovum. (Mayo Clinic Staff). For some of these conjoined twins the separation process is possible, but for others it is not. And from here emerges the crucial need for very special design to fulfill the growing physical and psychological needs for every specific case according to their physical situation, in addition to the needs of their parents, to help them raising and assisting their kids in everyday activities.

The research works on a specific case (Menna & Mai) as an example. Focusing on the process of walking and transportation in general as one of the major problems in everyday life for any conjoined twins, at least until they get separated when it becomes possible, or for lifetime if they are inseparable.

So, the researchers will explore and discuss the related needs, limitations and conditions in order to suggest a suitable design for this specific case, applying interaction design technics to decrease the complexity of the using process for both parents and kids, and in the same time ensure the kids ability to develop their own identity and skills to feel as normal as possible.

1. Conjoined Twins (physically and psychologically)

As mentioned before, conjoined twins are two identical children physically connected to each other with one placenta from one fertilized egg. Some twins can be separated and the type and success of the surgery depends on the position of their cohesion. The birth of conjoined twins is very difficult, they usually die in the womb of their mothers or die immediately after birth, about 40-60% are born stillborn. Another 35% live for one day. The overall survival rate varies between 5% and 25%. It is a rare case; it is estimated to range from 1 to 50,000 births to 1 to 2,000,000 births.

1.1 types of Conjoined twins:

Conjoined twins are usually classified by the point at which they are joined. And there are 3 main separate types identified in the last century, as the following:

- Conjunction never involving heart or umbilicus.

Craniopagus, Pygopagus

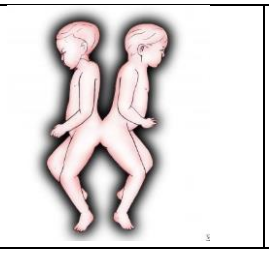	• Pygopagus twins are commonly joined back to back at the base of the spine and the buttocks. • Incidence is about 19% of all conjoined twins. • Separation is possible. The survival rate is high.

Table No.1 – a description of Pygopagus

- Conjunctions always involves the Umbilicus (Midline Conjunctions).

Thoracopagus, Omphalopagu, Ischopagus, Parapagus, Cephalopagus,

	**Chest :** Thoracopagus • Twins are joined face to face at the chest. They often have a shared heart and may also share one liver and upper intestine. This is one of the most common sites of conjoined twins. • Approximately 35 -40 % • Separation surgery depends on cardiac anatomy.
	**Abdomen:** Omphalopagus • Twins are joined near the belly button. Many omphalopagus twins share the liver, and some share the lower part of the small intestine (ileum) and colon. They generally do not share a heart. • This is the second most common representing 30-35%. • Highest rate of separation survival.
	**Pelvis:** Ischiopagus • Twins are joined at the pelvis, either face to face or end to end. Many ischiopagus twins share the lower gastrointestinal tract, as well as the liver and genital and urinary tract organs. • About 6% of all conjoined twins. • Separation is physically possible.
	**Trunk:** Parapagus • Twins are joined side to side at the pelvis and part or all of the abdomen and chest, but with separate heads. The twins can have two, three or four arms and two or three legs.

Table No.2 - Midline Conjunctions cases

- Rare forms of conjoined twins, having different patterns.

The twins may be asymmetrically conjoined, with one twin smaller and less fully formed than the other.

	**Length of spine:** Rachipagus, also called rachiopagus • Twins are joined back to back along the length of the spine. This type is very rare.
	**Head and chest: Cephalopagus** • Twins are joined at the face and upper body. The faces are on opposite sides of a single shared head, and they share a brain. • These twins rarely survive

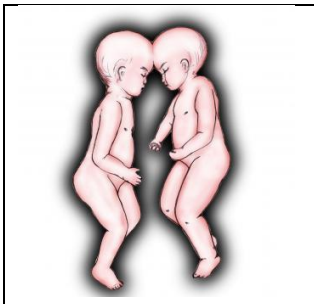	**Head: Craniopagus** • Twins are joined at the back, top or side of the head, but not the face. Craniopagus twins share a portion of the skull. But their brains are usually separate, though they may share some. • It has an incidence of about 2% of all conjoined twins. • Various forms and orientations of fusion may be seen, with both neural and major vascular connections.

Table No.3 – examples for rare cases

Separation barriers therefore differ in each species. The twins may share the late organs or other parts of their bodies, for example:

• Two arms: dibrachius	• Three arms: tribrachius	• Four arms: tertrabrachius
• Two legs: bipus	• Three legs: tripus	• Four legs: tetrapus

From the above it is concluded that each case of the remaining separated conjoined twins has its own physical conditions.

1.2 Conjoined Twins & developing skills:

For cases that are difficult to be separated for multiple reasons or being inseparable, there are number of problems that make nearly no chance for them or their parents to live an easy normal life, or to be capable of developing their skills and personalities as young, growing children as they actually are.

For example, in case of Craniopagus twins that are being joined at the side of the head, but not the face. Walking as a basic skill will be delayed to be gained or even could be neglected totally, especially with a condition like opposite face direction (faces toward outside). Also as an initial activity according to both Gill Connell, Cheryl McCarthy may affect the process of developing the personality and other related skills, like coordination of one of the twins at least as they said "*A Moving Child Is a Learning Child*" that all learning begins with the body. That movement itself is considered as a building unit for sensory perceptions, it helps the brain to reach its full potential. Walking also as an activity may cause the deformation of body parts as a result of wrong positioning in trying to make a balanced walk.

In the following discussion, the researchers will try to focus on some psychological issues relate to walking as an activity for developing the skills.

1.2.1 Taking Control: parents side

The baby usually takes his/her first steps before completing his/her first year, it is known that the baby's walking develops about 6 months after taking the first steps and becomes more mature, until it moves in a way that resembles regular walking.

The baby will begin to feel more confident after walking for two months, moving, picking up, carrying things, pulling them behind him, and climbing stairs. By the middle of the second

year, the child tries to throw and kick the ball and learn to run. By the age of two, the child may jump in place. That's what supposed to happen somehow with conjoined twins, but when it happens? It takes much longer time, much harder efforts with some unpleasant consequences according to their type.

In the same time it is not an easy task for the parents to handle and control the movement of their children inside and outside home. For example: The father of the main case in this research (Menna & Mai) – which will be discussed in details later - said" When my wife needs to do housework, she can't. So I bought a swing for playing. And we give them path together. After caring about them and trying to help them to stand up and walk ".

It is impossible to go with them anywhere or let them go however they like independently, not forgetting the effort that it takes to transport them from one place to another. In the same time, the problems grow by time as they gain weight and become harder to control, as the more the brain is conscious and motivated for any reason, the more movement is expected.

1.2.2 Taking Control: Child side

Observing a normal toddler trying to walk around, recognizing how it is too hard for parents to control his/her movement or. Some questions raised inside the researcher`s mind, considering those inseparable Conjoined twins, such as:

- **How will they learn to walk?**

According to each case conditions, learning how to walk will not be an easy task at all. However, the twins may develop their own way to walk somehow, this could be later than it is supposed to happen. Which in turn will slow down or affect negatively the process of developing their skills.

- **Who will take the lead?**

Although they are a conjoined Twins, but they still have 2 separate brains. Which means, that they are 2 separate personalities, with different thoughts, feelings and attitudes. And as a result of these differences, one of them may force his/her twin to follow and obey, which could create negative consequences on the follower personalities.

- **In which way will they move? And How to avoid the physical deformation that could happen as a result of this abnormal way of walking?**

One of the twins will pull the other to his/her direction as in case of (Rachipagus, Pygopagus, Thoracopagus, and Omphalopages), in a way that requires continues physical therapy to rehabilitate the emerging deformation time by time. That what has been confirmed by questioning the father in this research case, when he said that" One of his daughters pulls the other one, who has a different direction so the other's eye is pulled. Their movement increase every day. They gain high flexibility for crawling towards the back. So, according to the advice of the medical team they need a walker to support psychological & physical therapy for the growth of the mind".

These questions do not stop at this point, where there are some more issues that need to be considered. Respecting all the previous trials, which have tried to provide solutions for such cases. The researchers claim that there is deeper impact that could emerge as an unintended result for different aspects of such cases.

1.2.2.1 The impact on Personality:

Thinking as an inseparable Conjoined twins, there will be two approaches to follow:

- **Physically**: there is only one of us with two minds.
- **Psychologically**: there are two of us here sharing one life.

Each one of the twins cannot claim that he/her is the only person in the body which he/her has received as the other one`s mind-supporting some parts of the brain. Psychological theories claim that each of them could lose almost all of their bodies, except the parts of their own brains which are responsible for his/her psychology. While biological theories claim that they could lose all of their psychology.

All cannot be right. Each would still be around, though nothing is left of our mind-endowed human organisms. In cases of conjoined twins in which there are two independent minds, psychological and biological theories of their identity will disagree about whether there is one or two human beings in existence. So any unusual situation as with the conjoined twins will affect the natural Psychological growth of at least one of them, if not both of them.

Therefore, a careful thinking need to be applied, when designers try to develop supporting products for such cases. It is not a matter of just making life easier for both the conjoined twins and their parents, or in other words making the inseparable Conjoined twins livable as they get to do somehow the basic day life activities. Where design as a sophisticated profession aims toward making human life not just easier and pleasurable in general, but also ensures the equity and equality as well.

2 Designing for conjoined twins:

According to Norman & Draper, the design with a child-centered approach focuses on children's needs and use. As a user, adults design most products for children without often knowing how they treat technology and what they need.

One of the first aspects to consider when designing for children is the cognitive development of children.

Their cognitive development allows them to use information from their past experiences for future planning. When designing a product, not only the development of the child and the potential risks are needed to be known, but the children themselves need to be involved somehow as design partners.

2.1 children role in design process:

Druin (2001) identified the different roles that children can play during the design process: users, labs, informants and design partners, they vary according to the degree of contribution and stage of design in their intervention. While the roles of users and testers are to evaluate products, the roles of informants and designers are primarily related to the design phase.

2.1.1 Children as users:

The involvement of children as users often occurs at the beginning or at the end of the design process, increasing the chances of developing a technology that does not meet children's needs. Ethnography can occur when children participate as users. At the beginning of the design process, children's interests, current activities, and technology are currently assessed.

At the end of the design process, the impact of handling and learning improved technology on children's lives is understood.
The main disadvantage of this approach is that children do not directly affect the design of technology because they are already designed.

2.1.2 Children as Testers:
In order to make the technology competitive, designers make children test prototypes, completed products and competitive products to extract feedback about the designed product.
This helps to overcome design problems such as improving the used technology and reducing costs.

2.1.3 Children as Informants:
In this role, children share ideas and opinions with the design team, which works as consultants on key points in the development and design process. It enables children to contribute their ideas to the design process through interviews, questionnaires, focus groups and similar activities.

2.1.4 Children as Design Partners:
In Druin's classification, the highest level of participation of children in the design process is through their work as design partners. The idea of this role is to have children as equal partners in the design team. Where design ideas come from the process of collaborating adults and children.

2.2 Age Groups:
Predicting the behavior of the user child is difficult because of different age groups and how they grow. To create an experience for a child we must create something fun and educational; game is kind of education. Most children use apps, services and products for entertainment.
In "Genetic Knowledge Theory", Piaget (1952) studied how to develop knowledge in humans through four stages. Selected by age categories:
• Up to two years: sensory stage; Intelligence in the form of motor movement.
• To the age of 7 years: Intelligence becomes intuitive in the pre-operating phase.
• From 8 to 11 years old: it is a concrete operational structure, and logical intelligence begins.
• From 12 to 15 years old: it is the official operational structure, where thinking is involved.
Read more (Design with Children: Reflections on Active Participation of Children in the Interaction Design Process, Understanding Children in Design P38, by JP Hourcade - 2008).
In terms of motor skills, the first and second stages will be sufficient for this research. Understanding these phases can help designers move forward with the design process. Imagine a closer scenario of what might actually happen while children use the proposed design, identify and analyze undeclared reactions by children. Do not forget that in the case of conjoined twins, these stages may differ from normal stages.
Ordinary young children (ages 3 to 5) spend most of the day playing with friends and sharing their experiences. They are able to walk and run, but have no motor skills. They have vivid imagination, but lack patience for tasks. They want to learn and understand identities. Creating easy tasks to complete is a successful design for children at this stage.

The product contains a kind of interactive mechanics (orsum) simple and fun to attract the child. Children at this age category love to repeat the same tasks over and over again because repetition is part of the learning and playing processes.
With (ages 6-8) children begin to develop special identities. Realize the concept of winning, losing and fun challenge. They develop motor skills, and most of them have limited experience in technology.

2.3 Baby Walkers for conjoined twins:

(Baby Walkers) is a very common product, with a basic scenario, as the following:

- Children usually lean forward and walk, exercising the child's muscles. Encourage bone to grow correctly. Baby walkers helps children move before they are ready to walk by themselves and teach them to develop a balance and to use postural muscles to walk. They develop forward -leaning postural rather than upright and centered walking for children.
- As car seats, strollers, cribs, bassinets, baby carries, portable baby chairs, bouncy seats. Baby walker acts as a child Containers, limit children's movements when needed to keep children safe or for any other reason.
- Walkers with wheels provides the ability to give the child freedom to move, and be more mobile. But it exposes them to new risks, like falling down stairs or hitting some objects in their way. Caregivers may not be able to respond quickly due to the speed of child's mobility.

For conjoined twins in general, there are some products, but for temporary use. And the researchers claim that it fulfilled the necessary requirements to some extent. In many cases, it did not consider the differences in the measurements ergonomically, neither motor considerations nor child identity were considered. As will be shown in the following examples:

- For early ages, there are products used to train them to stand (Pic.1) but they do not urge them to start walking.

Pic.1 standing conjoined twins' holder

- A kind of customized stroller just to get out of the house (Pic.2).

Pic. 2 conjoined twins' stroller

- Helping the twins to walk freely somehow, a kind of baby walker (Pic.3) was specially designed. But did consider the spatial space to move inside the house and the difference in personalities and attitudes.

Pic. 5 conjoined twins' baby walker

But when it comes to Craniopagus twins, no product has been found except for the previous stroller (Pic. 2). It is important to notice that the variables in measurements, face direction and angle is quite different for each case, making no chance for mass production for such type of conjoined twins as with most types of conjoined twins. Customization or special design will be always the only way to fulfill each case needs and requirements individually.

3 Designing for "Menna & Mai"

The Egyptian twins "Menna & Mai" are conjoined at the side of the head, but not the face. In other words Craniopagus case (Pic. 6). They share a portion of the skull, but their brains are not totally separate. Mai is the one on the right side and Menna on the left side. Their heads are heavy for their bodies. Mai sleeps on her back, but Menna sleeps on her right side. They have 2 heads with oblique angle (Pic. 7).

At the time of preparing this research (Feb. 2019), their age was around 4 years. Their separation is possible, but not affordable, that the operation will cost around 4 million US dollars. So they have to live and grow as they are, until it become possible to do it.

Mai suffers from tension in the skull, which makes her always feel uncomfortable and suffer from pain and bleeding because of the uncomfortable position of the skull, she suffers from bloody vomiting, and the condition of continuous deterioration. She is a nervous girl opposite to the other one.

The parents do physical therapy exercises for the legs of the two girls, in a trial to keep their muscles in an acceptable condition, regarding that they did not learn how to walk yet. Mai also has a problem in the heart that is preventing any heavy effort.

Pic.6 to the left - face directions for both (Menna & Mai)
Pic.7 to the right – (Menna & Mai) sleeping position

Due to such poor health and physical care, the two children have weak legs due to immobility. Therefore, they need a kind of baby walker that can provide the ability of developing walking skill for both girls, and in the same time easy for the parents to control alternately.

3.1 Design considerations:

Walking freely, it is necessary to make sure that learning and practicing to walk require the ability to walk free, without any tightens. Regarding face direction for both of them (Fig. 1), it will be difficult to let them walk in the same time. As the walking direction of the two girls is nearly the opposite.

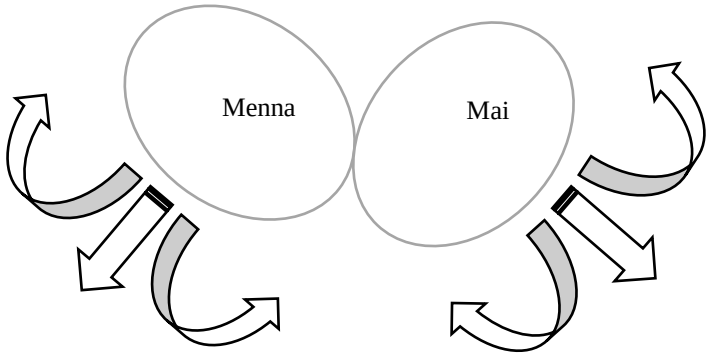

Fig. 1- Movement Directions (Heads with Oblique Angle)

The design of regular baby walker supposed to offer the chance to walk freely, and this cannot be achieved with the regular way. Especially with the existence of another person that could pull in the opposite direction or even slowdown the movement. Therefore, it is necessary to think about:

A. Educating the twins to do walking with achieving motor compatibility for both of them or to exchange turns. And this will be so difficult at the beginning, regarding the nature of their age.

B. Preventing any movement of one of them, while the other practice walking. And this could cause negative psychological impact on the prevented one, if the design did not respect their individual needs and provides equal chances to lead.

C. Controlling their movement by third party like the parents, when it is needed.

So, the researchers propose the solution as a robotic based unit. Where there will be a chance to offer help and support whenever needed, increasing the pleasure using baby walker which may encourage the girls to learn how to walk faster and better. With many other options such as Parental control, tracking, health monitoring … etc.

3.2 The proposed solution:

Searching for a proper solution for (Menna & Mai), offering them the chance to walk freely without any restrictions. The main problem was that it cannot be done without holding one of them to make the other one capable to walk. And this was totally refused to avoid any negative sequences on their personalities.

An idea just emerged into the mind, let them practice walking without actually walk "Walk without Walk". An electrical walking treadmill (Fig. 2) is just what was needed to achieve such idea. Let them both walk freely at the same time, by adding two of customized walking treadmill within a new design for the baby walker.

But the motive to walk, or in another way keeping this motive was the next problem, regarding practicing regular walk on a treadmill in position, will not be that pleasurable activity to do for a long time of their lives. To solve this problem, the idea has been developed to use only one treadmill at a time to drive a robotic baby walker. With additional option, which is the capability to exchange the roles in controlling the baby walker. In this way, the researchers claim that this development will keep the motive to walk.

The third problem was how to organize the process of exchanging roles in driving the unit. There was three possibilities:

I. By time, that each one of them has a scheduled time to lead and drive. What requires a kind of training for the twins, and an indicator that let them know who is leading. The indicator could be led light similar to traffic signs (green means it`s your turn to drive, red means it`s not your turn, or yellow when both stop walking for preset time what means you have the choice to take control and drive).

II. Parental Control, through remote control parents can decide who can drive according to what they observe and know about their girls' needs. As the two girls have two reverse characters, Mai is very nervous, but Menna is apathetic, quiet, and not interactive. So, Mai has higher power. And this should be regulated.

Also, they can take the control of the baby walker or disable the baby walker totally for any reason.

III. By the development of skills and experience, the girls can sensibly exchange the leadership. The one who needs it, has to ask the other one to approve through controllers. But she cannot take it by herself until the unit is totally stopped for a preset time.

Fig. 2 – Walking Treadmill

In which way the baby walker should go, is the fourth problem to deal with. Where the direction of both treadmill is fixed, some solutions is required to control the direction of moving smoothly and rationally. Some of these suggested solution will be discussed in the following points:

I. **Eye tracking,** where the process of measuring eye activity, either by measuring the point of gaze (where one is looking) or the motion of an eye relative to the head, could be used to convert this movement into direction to drive the baby walker. It is possible to install a front camera with gauges to monitor the eyes of children or let them wear glasses to follow the movement of their eye.

So the leading girl will walk on treadmill to activate the baby walker, and by her eye movement she controls the direction of driving.

However the solution seems to be possible technically, but it also seems complicated using many devices. In the same time, such technic does not help mimicking the natural way of walking. Also conflicts with the nature of walking scenarios, where it is not necessary to look in the direction you walk all the time. So using eye tracking technic may limit the behavior of exploring the surroundings especially in the early stage of their age.

II. **Joystick,** seems to be magical, easy to learn and a low cost device to use for controlling the baby walker. But it remains like eye tracking technic does not mimic the natural way of walking. In addition to keeping one busy hand holding the joystick, decreasing the chance to engage easily in any handy activity, because it requires an advanced coordination between the controlling hand and the activity engaging hand.

III. **Weight sensor,** as a result of observing and studying child walking behavior, the researchers found that child usually lean with his body towards the direction he/she wants to take (Pic. 8). Therefore, it will be suitable and more effective mimicking child`s natural walking behavior to distribute sensors on the inner frame of the baby walker (Fig. 3), to capture the direction that the girl wants to take, by sensing her body weight.

Pic.8 - baby lean toward the intended walking direction

That means, whatever the exact side the leader girl lean towards while walking on the treadmill, will be translated into the direction she will go with. With almost no need for any coordination with any other part of her body, the same way the regular baby walks (Fig. 4).

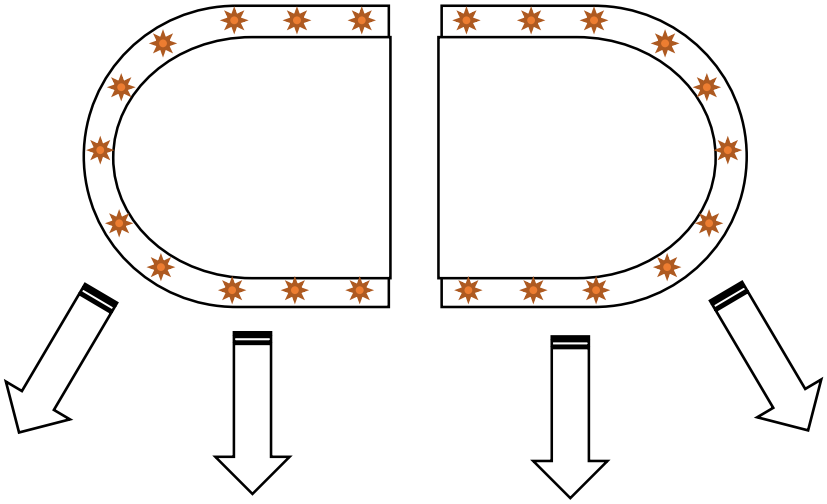

Fig. 3 - Sensors distribution on the inner frame of the baby walker

Of course, there is number of optional additions that could be applied to enhance the baby walker`s features and capabilities, such as:

- **GPS,** to outline a safe zone, pre-defined by the parents to move in. To avoid misplaying or going elsewhere, however it was indoor or outdoor. GPS also could help tracing the girls' activity, in order to measure their development, and the differences between both of them.
- **Proximity sensors,** to detect the presence of any objects or obstacle in their way and avoid crashing it. By stopping the baby walker and preventing it to go any further in the direction of the detected object. The safe distance could be modified according to the available space and types of surrounding objects.

- **LED Screen with Cam,** to let them see each other while talking, or to make each one of them able to see what the other one sees. Additional application could be installed as gaming or learning Apps.
- **Augmented reality glasses,** as an alternate solution for the LED screens.

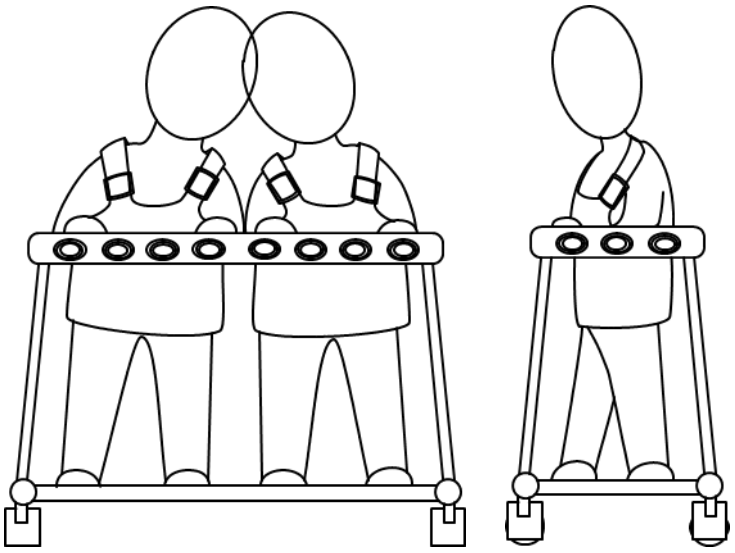

Fig. 4 - Final concept

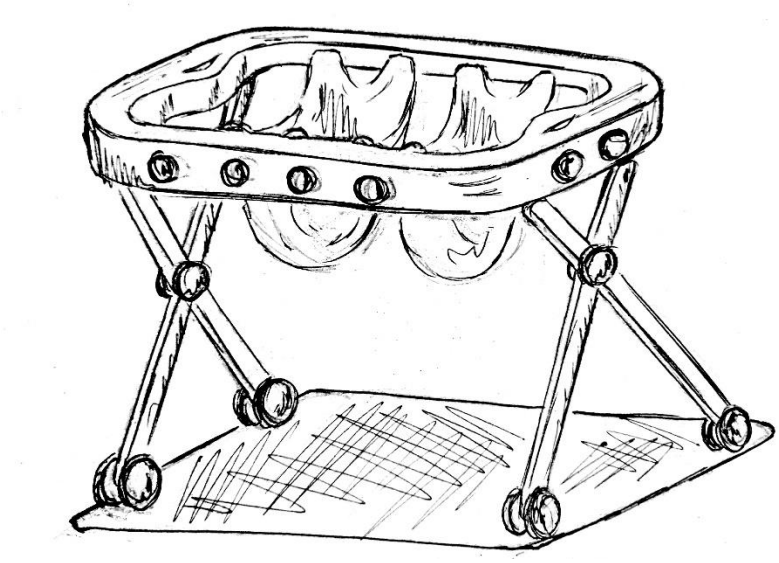

Fig. 5 - Final concept (sketch)

Results

- Design provides an opportunity for children to walk freely by teaching them to walk while achieving the compatibility of each of them.
- Encourage girls to learn how to walk faster and better.
- Control their movement by a third party such as parents, when needed.
- Easy parental control, tracking and health monitoring.

Recommendations:

- The availability of design ideas and products that are suited to such cases because they face life problems, not just walking.
- Develop age-appropriate designs for this case.

- Design ideas suitable for various cases.

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