



# **Designing for Autism: Empowerment, Awareness, and Acceptance**

I649 Capstone / Research for Design / Final Report

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# OVERVIEW



In a society designed around the needs of neurotypical people, individuals with autism almost always struggle to fit in. What can designers do to improve the community experience for children with autism, so that they have more chance to learn and grow? How can we promote autism awareness and acceptance in the community?

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# CONTEXT



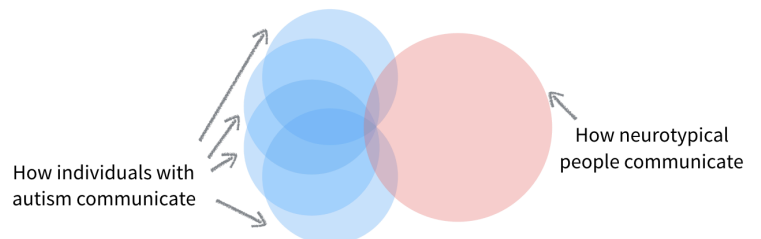
## What Is Autism?

Autism is a group of neurodevelopmental conditions. It starts in the womb and continues to affect the individuals throughout the lifespan.

Due to the **atypical neurological development**, individuals with autism have distinctively atypical ways of sensorimotor processing, thinking, and interacting. The autistic mind tends to register more information, resulting in **a sensory experience that is more intense and chaotic**.

*“One analogy that has often been made is that autistic individuals have a different neurological “operating system” than non-autistic individuals.”*  
—Nick Walker from [neurocosmopolitanism.com](http://neurocosmopolitanism.com)

The ongoing task of integrating and navigating this intense experience requires lots of attention and energy, and leaves autistic individuals with less than enough attention to focus on social interaction. One common misconception about autism is that it is a set of “social and communication deficits.” Many people don’t realize that **the social challenges** are merely a by-product of their atypical sensory processing.



Autism is not a disease. It is not a disorder. It is simply part of the spectrum of **human biodiversity**, just like the diversity in ethnicity. This diversity needs to be recognized and designed for.

*“In the context of a society designed around the sensory, cognitive, developmental, and social needs of non-autistic individuals, autistic individuals are almost always disabled to some degree.”*

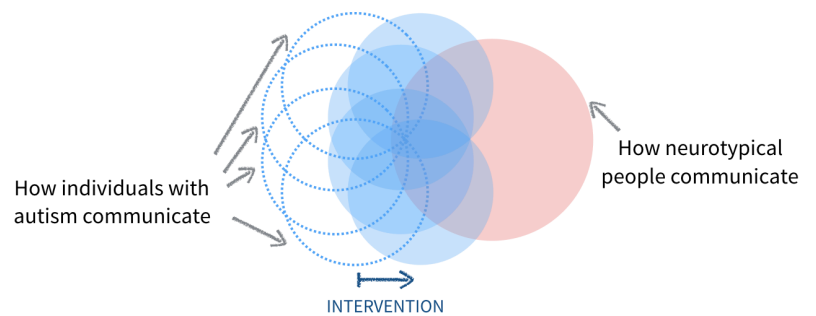
—Nick Walker

## Autism and Design Efforts

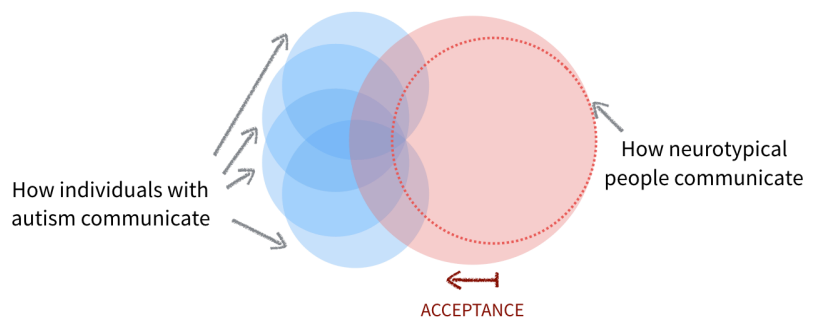
What have designers done so far for autistic children? What can we do to break down the misconception about autism, to facilitate the communication between autistic and non-autistic individuals, or to improve their quality of life?

After reviewing 50 designs that are dedicated to helping autistic children, facilitating communication, or combating stereotypes, I found most of them on a spectrum of Intervention—Acceptance.

Toward the Intervention end of the spectrum, designs are focused on facilitating their sensory development, teaching them communication and social skills, and helping them to cope with social-related anxiety. Intervention empowers autistic children by changing how they communicate and interact, in a way that is more acceptable by non-autistic individuals.



Toward the Acceptance end, designs are focused on raising awareness of autism, educating people about autism, and creating an environment for autistic and neurotypical children to play and learn together. Acceptance helps autistic children by changing how non-autistic individuals think about autism and how they communicate and interact.



## Focus of This Project

Along the spectrum of Intervention—Acceptance, **this design research project is focused on the Acceptance half**, based on the following predispositions or reasons.

1. Autism is part of the human biodiversity that needs to be accepted, and not a disease that needs to be cured. Non-autistic people should know what autism is. The social environment should be more inclusive.
2. For a better communication/interaction between autistic and non-autistic people, both sides need to do their part. Autistic individuals have been learning about how neurotypical people interact with others. Neurotypical people should do the same—being the majority is not an excuse.

The core of the project is to **understand how autistic individuals interact with people and the world** and to seek ways of **promoting such understanding and acceptance among neurotypical people**.

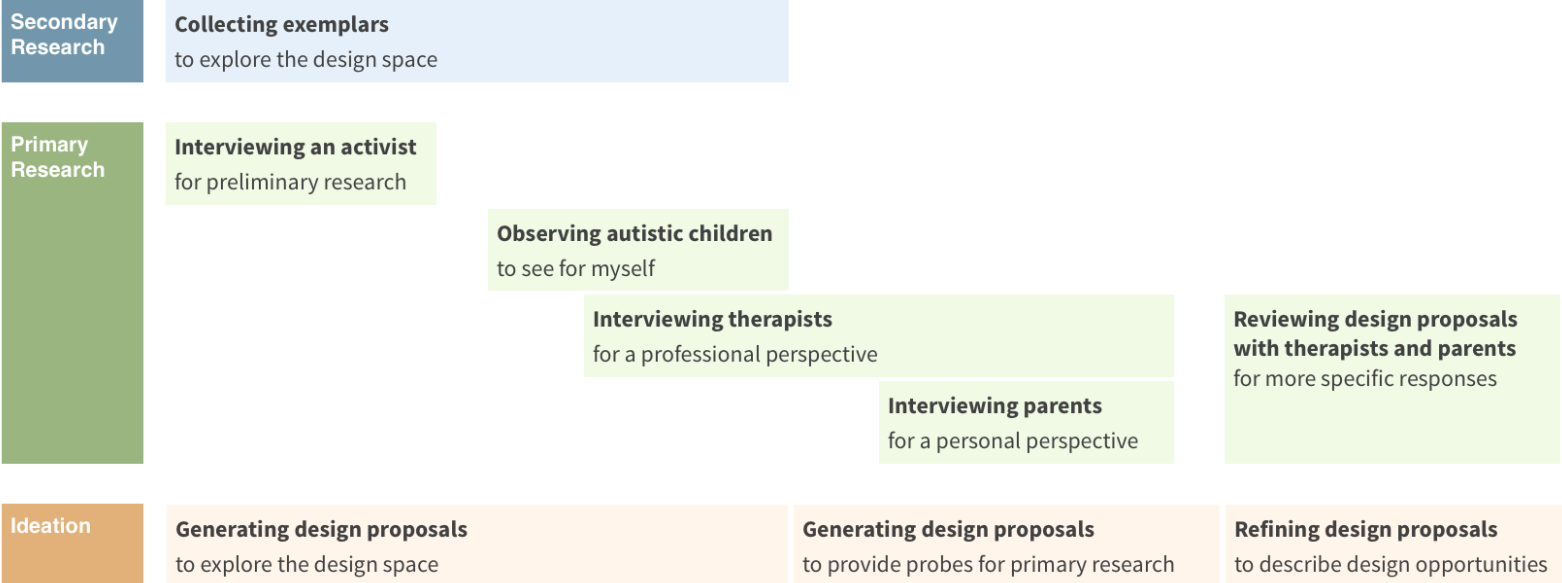


# RESEARCH



## METHODS AND RESULTS

The main objective is to understand the various ways that autistic children communicate with their parents, teachers, caregivers, peers, and other adults. The plan is to understand what communication methods have worked well for autistic children when they are with someone they know well, and see how some of these methods can be adapted to situations where autistic children would interact with people they do not know.



## Interviewing An Activist

At the early stage of the project, I reached out to people working in organizations that provide support for families impacted by autism, wanting to seek their opinions on what design can do for autistic children.

I interviewed **Andrew Lambert, the president of Monroe County Autism Foundation (MCAF)**. MCAF connects families impacted by autism with the services and resources that they need. MCAF also organizes several community events every year to raise awareness of autism in Bloomington.



### Desired Learns

- How to reduce the stigma or stereotype related to autism?
- Every autistic child is different. How to design for a group of people with such various needs?
- Where should we stop trying to improve how autistic children behave and just accept the way they are?

*See Appendix A for the complete script.*

### Top-line Learnings

#### Two stereotypes of autism

- **Bad parenting.** Sometimes people blame the parents for their autistic children not behaving well in public, especially when the children are older. “Why can’t they grow up and behave normally?” The fact is there’re too many things in the environment that the parents don’t have control over.
- **They can’t do more.** Andrew knows a cashier at Target who is autistic. He said to Andrew once, “*People don’t think I can do more because I don’t seem like a normal person, but I love my job. I can’t drive because I have spatial awareness problem, but I can take a bus to this job.*”

**Effective ways to break down stereotypes**

- **Repeated messages.** “For messages like flyers, posters, and campaigns, there’s some effectiveness there, but you have to have repeated messages, which can be very expensive.”
- **Let them interact and mingle.** Andrew organizes community events for autism community and believes in the power of infotainment. “When you laugh with someone, you find the connection with that person. Why don’t we try to do events for people where they can just be silly and have fun? And at that moment we’re all together in this.”

**Balancing intervention and acceptance**

- **Some interventions are about survivor skills.** Applied Behavioral Analysis programs teach children to eat safely, use bathroom, or look at people. These are necessary for their survival.
- **There isn’t a general rule for what is or is not a necessary change.**

**Next Steps**

- Andrew introduced me to Little Star Center for further research opportunities with autistic children, therapists, and their families.



## Observing Autistic Children and Interviewing Therapists

**Little Star Center** is a non-profit facility that provides applied behavior analysis (ABA) programs for children affected by autism in Indiana. **Two families** consented to participate in the research project.

With each family, I first started with observing the child interacting with his therapists within the center for 3 hours, and interviewing one of his therapists for 2 hours.



### Desired Learns

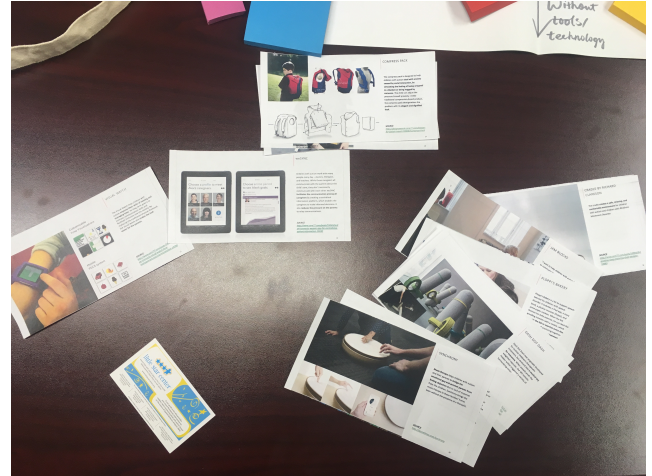
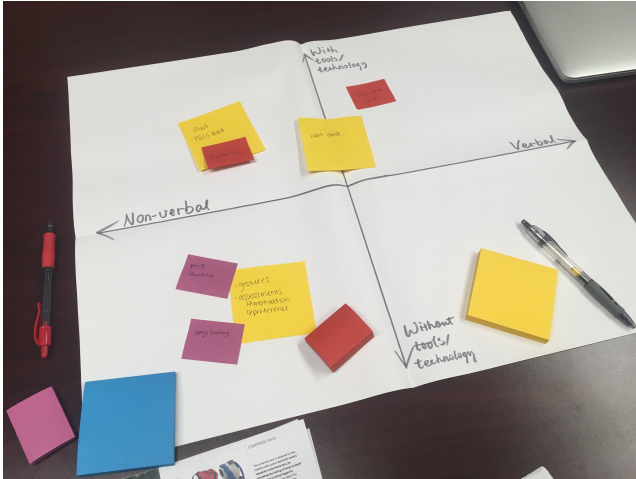
- How do children with autism interact with their therapists at the therapy center?
- How do children with autism interact with people in the community?
- What can be done to improve the interaction between these children and people in the community?
- How are these children and their families affected by stereotypes?

### Research Methods

- **Fly-on-the-wall observation.** During the first hour of the observations, I stayed back as much as possible, did not interfere with what the therapists and the child were doing, and took notes of my observations and questions.
- **Contextual inquiry.** Later on in the observations, when one of the therapist had time to talk to me, I asked questions about why they do what they do with the children.
- **Narrative inquiry.** In the interviews, I asked lots of questions about the specifics, so that it would be more likely for the interviewees to recall something relevant from their previous experience and tell me a story about these recollection.



- **Mapping toolkit.** In the interview, I asked the interviewees to write out the communication methods that they use and map it onto two axes, verbal—nonverbal and tools—no-tools. The axes per se are not that important, because they are more of a way to to facilitate the conversations visually and get the interviewee involved.



- **Photo probes.** I selected 18 designs that are crafted with autism in mind and asked the interviewees for feedbacks. How do they feel about these designs? How do they relate their past experience to the designs? Do they think the designs will help?

See Appendix B for the complete script, and Appendix D for the set of photo probes.

## Top-line Learnings

### How therapists interact with children with autism?

- What is Applied Behavioral Analysis (ABA)? What do ABA therapists do?
  - ABA is a scientifically proved method to systematically analyze and alter children's behaviors for the better. It is basically **a two-step process: assessment—acceleration/deceleration.**
  - In the first step assessment, the therapist evaluates a child's skills level and takes notes of his unwanted behaviors.
  - For the skills that the child needs to learn, the therapist writes an acceleration program to reinforce each skill.
  - For the unwanted behaviors, the therapist writes deceleration programs to decrease or replace them.
  - Assessing a child's behaviors is **an ongoing process**, so that it informs how well the acceleration and deceleration programs are working.

- A very important aspect of ABA is to **not reinforce unwanted behaviors**.
  - When a child throws a tantrum because he wants your attention, you will be reinforcing this unwanted behavior if you try to comfort him, because you are giving him exactly what he wants—your attention. The correct thing to do is to ignore him, as bad as it sounds, and only pay attention to him when he stops the unwanted behavior.
  - **Identifying the function of a behavior** is important for not reinforcing it.
    - Is it for attention?
    - Is it to gain access to something (e.g., toy and food)?
    - Is it to escape doing something (e.g., putting on socks)?
  - Identifying the function of behaviors is difficult even for trained professionals, let alone novel people.
- **ABA therapists think intervention is more important than promoting acceptance.**
  - They want the kids to be as independent as possible, because they live in a world where not everyone knows about autism.
  - For the special needs of these kids, the therapists tend to push them a little bit to see if they can build up a tolerance, and only provide accommodation when it's a necessary stepping stone. (Being independent means not needing accommodations.)
- No two kids with autism is the same. **Lots of time and patience** is how ABA therapists get to know the children that they work with.
  - When a therapist first begins to work with a kid, he/she needs to spend two hours observing and playing with the kid, in order to gain his/her own perspective on the kid.
  - When therapists spend lots of time with a kid, they start to see patterns in what the kid likes or dislike and why the kid shows certain behaviors.
- Generalizing what the children have learned in the therapy center to other environment is both important and difficult.
  - For them to be truly independent, they need to be able to do the same skills for anyone at the therapy center, home, school, and any other places.

### **Experience in the community**

- Taking a child with autism out to the community can be challenging because...
  - There're **too many sensory stimuli** for the children and they could be easily distracted from what they are supposed to do.
  - When a kid has **a meltdown in a public space**, people usually don't know what to do and thus stare at the kid and his family a lot. This attention usually



reinforces the kid's bad behaviors and causes lots of emotional stress on his parents or the adults that look after him.

- People talk to the kid as if he's younger than he actually is, but the kid can pick on many cues if **people think less of him or talk poorly of him.**
- How therapists deal with the challenges they face in the community?
  - When therapists take the kid to a grocery store to work on some skills, the therapists will talk to the manager at the store in advance and explain who they are, what they do, and what might happen there.
  - When a kid has a meltdown and people nearby start staring or being uncomfortable, the therapists will show them a "community card", which explain that they've just encountered a kid with autism. [picture of the card]
- What can be done to improve these children's experience in the community?
  - Letting them be in the community and be with all kinds of people is the best way to improve the dynamics. It helps the children to get used to being around people that they're not close to. It also helps other people in the community to know what autism is and how to act around individuals with autism.
  - Children with autism don't need toys that are specially designed for them. They need toys that they can play together with any other kids.

### **Stereotypes of autism**

- A kid has to have a **diagnose of autism** to receive services that are covered by insurance. The diagnose helps them in a way, but also contributes to the stereotypes at the same time by putting a label on them.
- "**Special toys** for special kids with special needs" is very stereotypical.
- When people have **misconception about what a kid will be able to do or what he is interested in doing**, they don't try to branch out with that kid and thus limit the kid's development.
- **Stereotypes in the workplace** can make employees with autism seem less employable, when they're just as qualified.
- Some basics things that everyone should know about autism:
  - **No two kids with autism are the same.** Autism is a spectrum, and individuals with autism can have very different skills, interests, habits, and personalities. Just like how every neurotypical individual is so different.
  - **Accept that you may not always know why someone is doing what he's doing.** Don't just assume something and pass on the judgement.
    - Don't be afraid to ask the accompanying adults questions, if you are concerned with what you are seeing and not sure what to do.

- **Treat them like you would any kids.** Don't talk to them in baby language. Don't talk poorly of them in front of them. Always be respectful.
- **Keep accommodation to a reasonable level.** It might feel wrong to not provide accommodation sometimes, but the children need the space to grow and learn.

### **Wildcards**

- **The communication between parents and various service providers** is an opportunity area. Service providers can do their jobs better when they're on the same page. Parents also benefit from more efficient communication a lot.
- **Finance is a big factor** for most families impacted by autism and non-for-profit organizations with limited budget. They can only afford what is absolutely needed.

## Interviewing Parents

With **the same two families** that receive services from Little Star Center and has consented to participate in the research, I interviewed **one parent from each family**. The interviews lasted 1.5 hours each.

### Desired Learns

- How do children with autism interact with their parents and siblings?
- How do the children and their families interact with people in the community?
- What can be done to improve the interaction between these children and people in the community?



### Research Methods

- **Narrative inquiry.** In the interviews, I asked lots of questions about the specifics, so that it would be more likely for the interviewees to recall something relevant from their previous experience and tell me a story about these recollection.
- **Photo probes.** I selected 18 designs that are crafted with autism in mind and asked the interviewees for feedbacks. How do they feel about these designs? How do they relate their past experience to the designs? Do they think the designs will help?

*See Appendix C for the complete script, and Appendix D for the set of photo probes.*

### Top-line Learnings

#### **Parents and therapists share similar opinions on most subjects:**

- They also want the kids to be as independent as possible, because they won't outlive their children and take care of them forever.
- By spending lots of time with the child, the parents gradually develop an understanding of the child's personality—what he likes, what he dislikes, what he really connects with.



- Going out to the community can be very challenging, because too many sensory stimuli can cause the kid to have a meltdown, and then people start staring and make the situation worse.
- Finance is definitely a big thing for most families. The kids usually see multiple service providers and doctors, and the families need to keep up with the costs, especially when insurance won't help.

### **The challenges of spending family time in the community:**

- In the community, other adults and children aren't necessarily excluding them, but they don't know how to act around individuals with autism.
- Often times, people make assumptions about what they see.
  - When the kid with autism doesn't talk back to them, they don't realize that he has autism, assume that he might have a hearing problem, and start talking to him in a loud voice that the kid can't stand.
  - When the kid has bruises on his face that are caused by his self-injuring behaviors, people might look at his six-foot-tall father and assume that he is hurting the kid.
- Knowing that people might have all these assumptions causes great emotional stress on the parents.
- Many families avoid going to restaurants together, because their kids still can't handle waiting for food very well, and they don't want to cause a scene in the public.

### **Intervention versus acceptance or accommodation**

- While parents want their kids to be more independent through therapies and training, they tend to have a more positive view of providing accommodations to the kids than therapists.
- Dealing with challenges in their day-to-day life with few accommodation is very overwhelming for the parents. They might not always push their kids a little bit to learn, like the therapists would.

# RESEARCH



## INSIGHTS

To bring insights together from all previous research activities, this section will cover the following topics:

- Why is social interaction so challenging for children with autism?
- How does Intervention and Awareness help with their social interaction?
- What is autism awareness and acceptance, exactly?
- How can we design for autism awareness and acceptance?

**Important note:**

Both therapists that I interviewed have worked with both low- and high-functioning children, but both children who participated in the project are on the low-functioning end of the spectrum. I tried to avoid over-generalization as much as I could, but discussions about specific situations are inevitably biased toward low-functioning children, as I collected more information about them.

## Why is social interaction so challenging for children with autism?

Both genetics and social factors are contributing to the challenges that children with autism are facing. In a four-step process, **the genetics and the social factors interact with each other and form a vicious cycle** that continue to hinder the social development of children with autism.

### Step 0 — Atypical neural development causes atypical sensory processing.

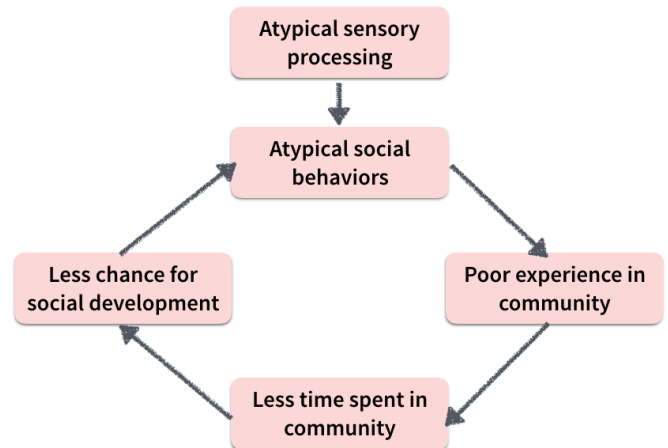
Most individuals with autism have a very intense and chaotic sensory experience. Sounds, colors, sunlight, textures, movement—stimuli that neurotypical people don't even pay attention to, can sometimes stress them out.

**Step 1 — Atypical sensory processing causes atypical social behaviors.** It takes autistic individuals lots of energy to make sense of their sensory experience and keep it cohesive, which leaves them with little cognitive resource for social interaction and regulating social behaviors. E.g., A child with autism might be overwhelmed by some noises in a grocery store and start crying.

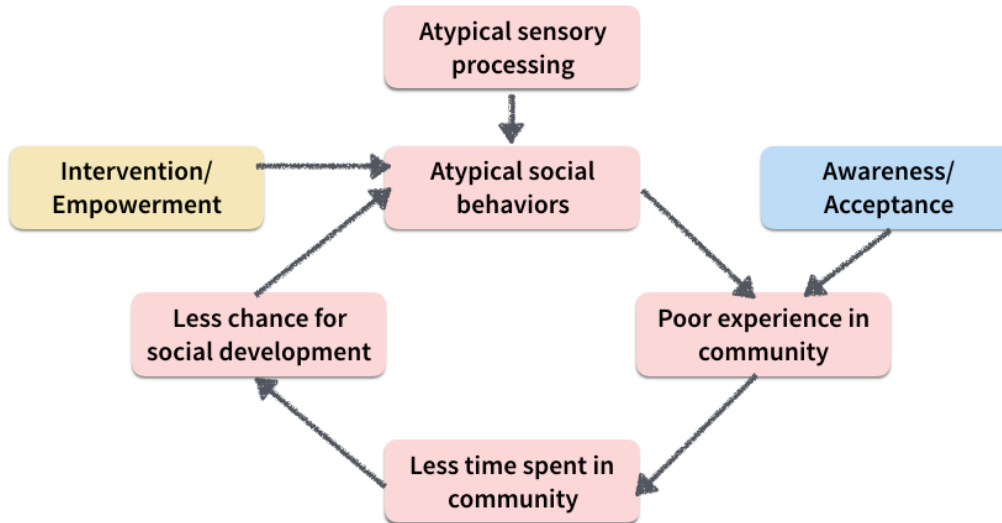
**Step 2 — The atypical social behaviors lead to a poor experience in the community for the children and their families.** When people don't know how to act around children with autism, they tend to stare or pay excessive attention to these families, which almost always make the parents feel embarrassed, pressured, or judged.

**Step 3 — Families avoid taking their kids out to avoid the poor experience in community.** When the pressure of taking the children out to grocery stores, restaurants, or libraries becomes too much, parents have no choice but avoid these community outings.

**Step 4 — Children with autism don't have enough chance to develop their social skills in a community setting,** which causes them to continue to fall behind on their social development and leads us **back to Step 1.**



## How does Intervention and Awareness help with their social interaction?



### Intervention and Awareness breaks the vicious cycle at two different points.

Intervention/Empowerment focuses on changing these children’s behaviors, teaching them to cope with sensory difficulties, and teaching them communication and social skills. When the children reach a higher skills level, they will have a better experience in the community.

Awareness/Acceptance focuses on improving the community experience for the children, no matter what their skills levels are. It often involves changing how neurotypical people think about them and act around them. With a better community experience, these children get more time in the community and more chance to learn.

**Both Intervention and Awareness are a necessary link to keep the vicious cycle from coming back.** Awareness ensures that these children have the chance to practice what they’ve learned from therapists in various real-life environments. Empowerment ensures that these children continue to learn, so that they’ll need less and less accommodation.

## What is autism awareness and acceptance, exactly?

### **Understand that autism is a spectrum. No two kids with autism are the same, just like no two neurotypical kids are the same.**

It's very attempting for us to simplify things based on labels—"He has autism, so he doesn't look at people", or "She likes puzzles because she has autism." While autism describes some of the challenges they might be facing, it doesn't describe who they are, what they like, or what they're capable of. If we can look past the label, we will see that they are just as diverse as all neurotypical kids.

### **Treat them like you would any other kids.**

This can mean two different things.

One, never talk to them as if they were less than you; don't use baby talk; don't talk poorly of them in front of them. While some of them are not verbal yet, they understand a lot and will be hurt if treated poorly.

Two, keep the accommodation to a reasonable level. Although most accommodation is offered out of kindness, it might unintentionally limit the space for them to learn and grow.

### **Be patient as they learn to function in the community.**

Their behaviors in the community might be inappropriate and puzzling to many of us, and our instinct is to look and try to figure out what's going on.

*"There's a lot of kids there, so they have to wait in line. This one learner, he would just fall to the floor and lay there crying, and we were just letting him do it, because we can't make the line go any faster. There were some moms and they were looking and staring at us like 'I wanna pick that kid up but I can't and I'm not supposed to.'"—Kaitlin*

A big part of autism acceptance is accepting that you may not always know why they do what they do. Don't stare. Don't judge. Ask if you can help, when you feel compelled to do something about it.

## How can we design for autism awareness?

### What are some difficult situations that these families need to deal with?

When the therapists and the parents talked about their experience **being in the community with the children**, three kinds of “problematic” situations came up frequently. These situations can occur in **grocery stores, supermarkets, restaurants, libraries, museums, theaters, schools, playground, and family gathering.**

#### 1 — There are too much sensory stimuli that could cause a meltdown.

*“When he was little, I used to take him grocery shopping. We would go by the seafood counter, and he would just have a fit, because of the smell. I never realized it until later. Now we just don’t go to that part.” —Amber*

*“We were at the library once. He saw another kid’s candy, immediately wanted it, couldn’t have it, got mad, and started being aggressive towards me because I was blocking him from getting the candy.” —Kaitlin*

#### 2 — When the child has a meltdown, bystanders’ attention often reinforces the child’s bad behaviors and makes the parents feel judged.

*“I know people don’t understand, but sometimes it’s so hard to deal with it emotionally, to see your child doing that, to have to wonder what people are thinking anyway.” —Amber*

#### 3 — Sometimes people assume that these children aren’t capable of doing more.

*“Her teacher one day told me ‘she loves to do puzzle, and it’s because of her autism.’ But no, it’s not. She likes to do puzzle, but have you tried this, this, and this? Because she likes to do those things too.” —Kaitlin*

*“He’s like 9-year-old and he doesn’t talk, so I talked to him like he was a baby. That was a huge mistake on my part...Like you’ll forget how old they are, just because they are not neurotypical.” —Grace*

# DESIGN PROPOSALS



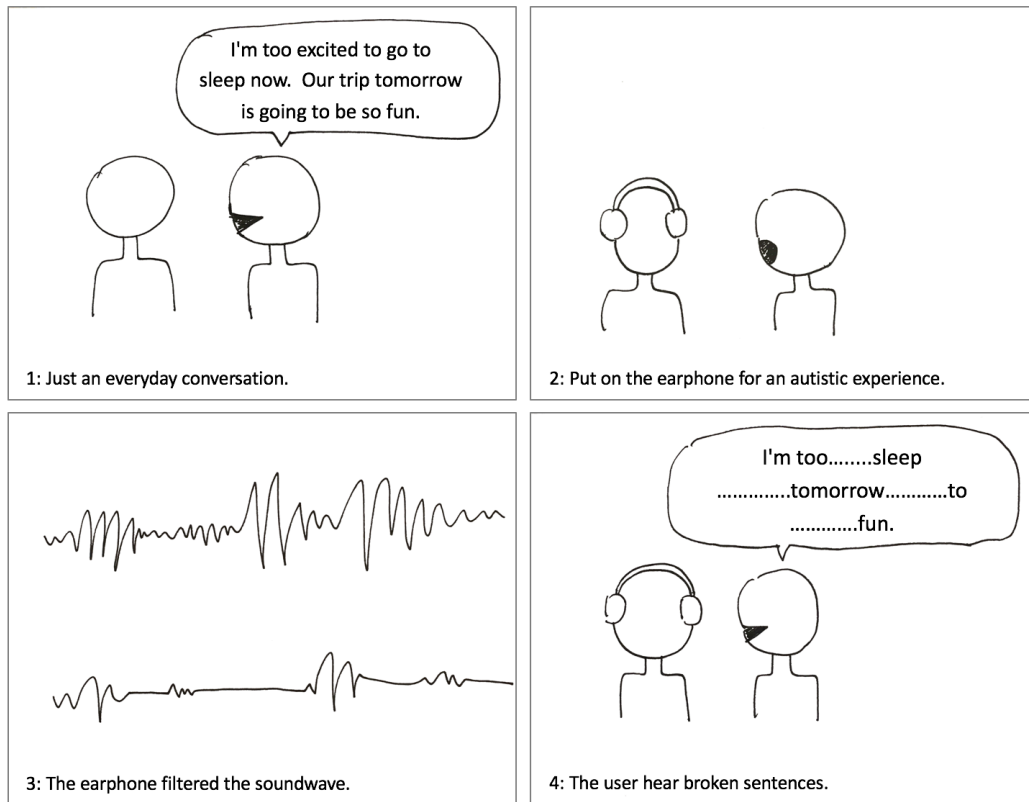
To apply these insights to design scenarios, I came up with 10 design proposals in the form of storyboards. Based on the feedback from the therapists and the parents, I reached some new conclusions about how design may promote autism awareness.



# {1} An Autistic Experience

## Design Context

Most people don't know how to act around individuals with autism, because they've never met someone with autism. How might we simulate the chaotic sensory experience of children with autism for neurotypical people, so that they can sympathize with what they're going through?



## Therapists say...

- What research do you have for what an autistic experience is like?
- Keep in mind that the experience of every person with autism is different.

## Parents say...

- Kids with autism can be very sensitive to other things than sounds, such as direct sunlight and the texture of clothes.

## Design Implications

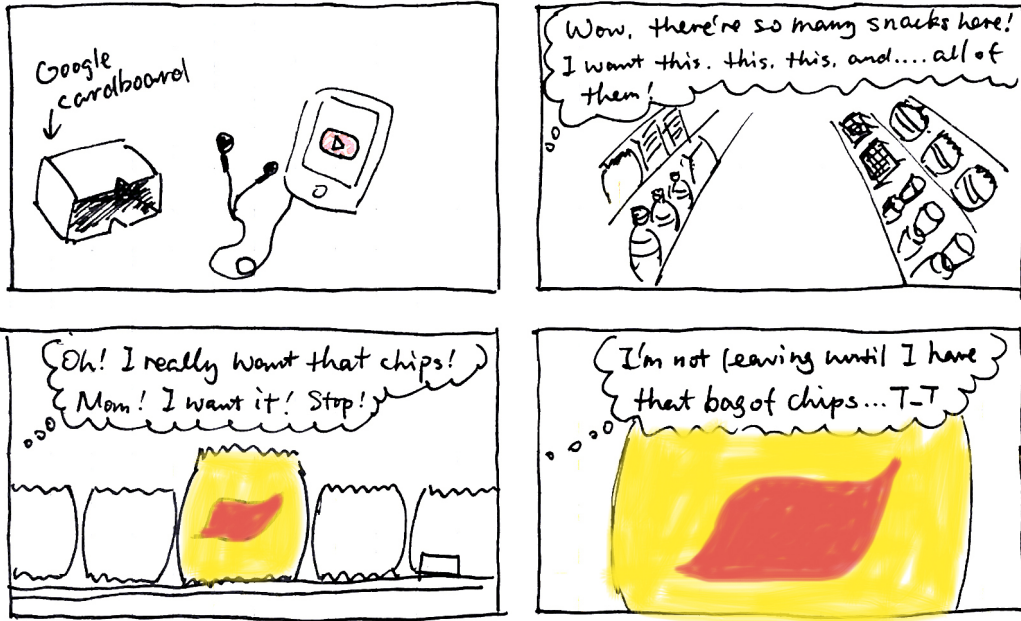
1. We can talk to autistic individuals who can communicate verbally to learn about their sensory experience.
2. While the simulation is not completely accurate and can't cover every aspect of living with autism, it can still evoke sympathy by showing how chaotic and frustrating the experience is.



## {2} An Autistic Experience V.2

### Design Context

How might we simulate the chaotic sensory experience of children with autism for neurotypical people, so that they can sympathize with what they're going through?



### Therapists say...

- A college student on the spectrum developed a simulation game that achieve the similar purpose. <https://tromlui.itch.io/asd>

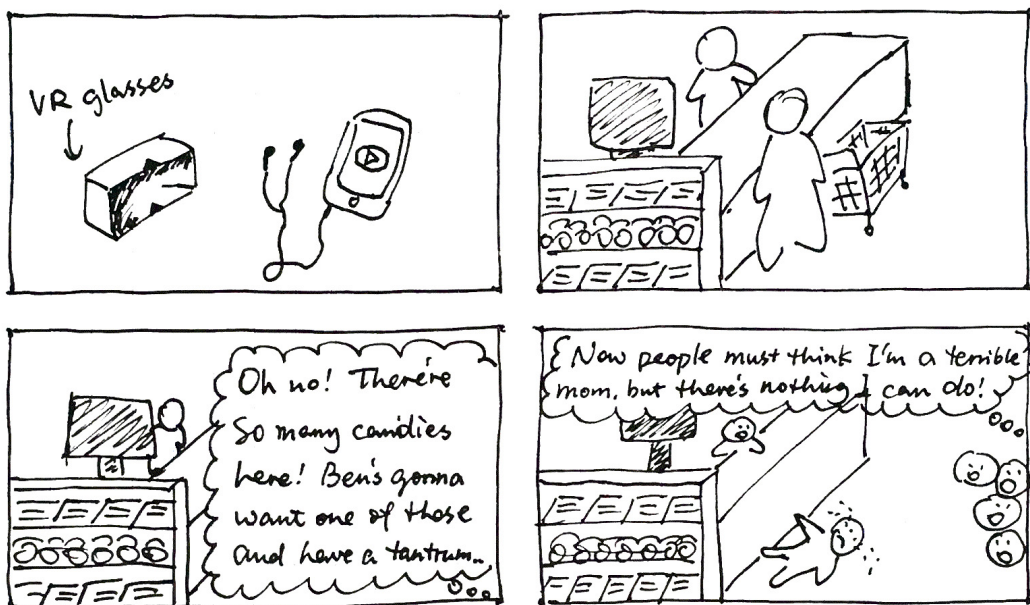
### Parents say...

- I like that this one uses more sensory channels than just sounds.

## {3} Parenting Someone on the Spectrum

### Design Context

When a kid has a meltdown at a public space, the staring and perceived judgement from surrounding people often causes great emotional stress for the parents. How might we simulate the experience of taking care of a child with autism people in the community, so that they will be more understanding of what these parents are going through every day?



### Therapists say...

- I really like this one because you can have concrete data from parents on what their experience is like.
- Consider showing some positive experience too. Being parents to a kid with autism is not always gloomy.

### Parents say...

- I really like this because it shows something that we need to deal with everyday.
- It will be helpful if you can show people how a typically fun experience, like going to a zoo, can present multiple problems to a family like us.

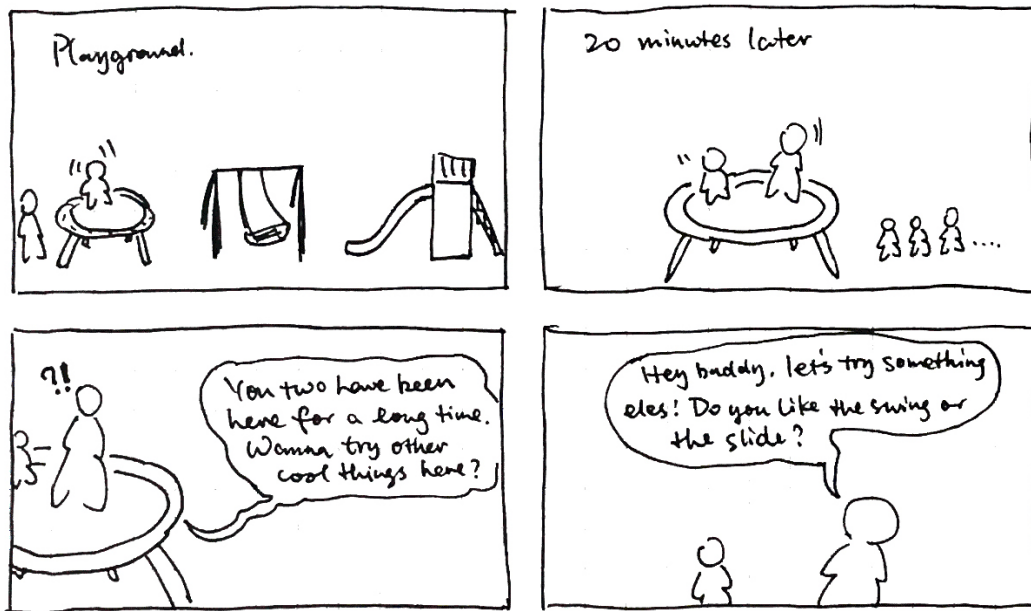
### Design Implications

3. It might be easier for neurotypical people to sympathize with the parents than with kids on the spectrum. Parents in general have a lot in common—they feel stressed and embarrassed when the kids make a scene in public; but, they still love talking about their kids all the time; they always want the best for their kids no matter what.

## {4} A Talking Playground

### Design Context

Many adults assume that children with autism have limited interests and thus don't try to branch out with them. How might we ensure that when adults are always trying different things with these children to facilitate their development?



### Therapists say...

- It's a good idea bringing attention to kids with autism having various interests.
- Consider providing video modeling to adults about how they can help these children play and learn.

### Parents say...

- Children will need a good variety of choices, since not everyone will be interested in jumping on a trampoline.

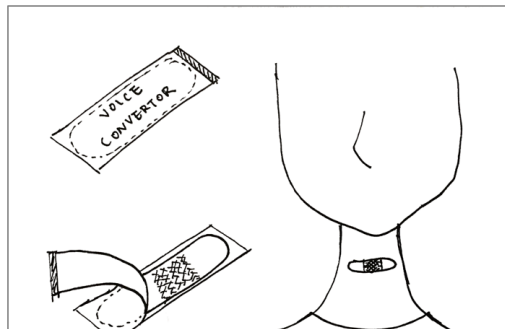
## {5} The Voice Convertor

### Design Context

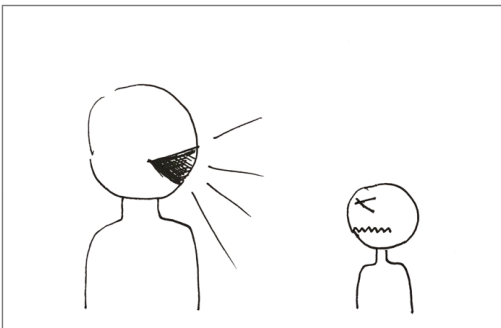
Many children on the spectrum are very sensitive to loud sounds. How might we gently remind people in the community to keep their voice low and manner soft when they're interacting with a child with autism?



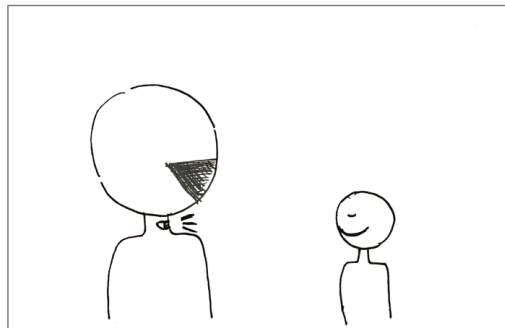
1: Voice convertors are available for people with little experience of interacting with autistic children.



2: It looks just like a Band-Aid, for your throat.



3: Without the voice convertor, you might scare an autistic child if you get carried away and speak too loud.



4: The voice convertor senses the presence of any autistic children and make your voice soft and kind for them.

### Therapists say...

- I like the idea but not the device itself. With Behavioral Skills Training, it is possible to teach adults to keep their voice low without using such a device.

### Parents say...

- I can see us using these in a family party. I can just pass these out to everyone before the party starts. It is not specific for anyone, so it won't hurt anyone's feeling.

### Design Implications

4. It's important to also consider how the design will make the neurotypical people feel. Will the design make them feel uncomfortable? Will they be offended by being told what to do?
5. One limitation of this research project is lack of input from neurotypical people who don't have much experience with kids with autism.

## {6} Baby-Talk Detector

### Design Context

For children with autism who are also non-verbal, being talked to as if they were younger often hurts their feeling, because they are able to understand a lot. How might we gently remind people in the community to use age-appropriate language with non-verbal children?



### Therapists say...

- This can be very useful, since even professionals who have experience with kids on the spectrum still do that sometimes.
- When telling adults not to use baby talk, you need to do it immediately after they have used baby talk. Otherwise, it's very likely that they won't remember when they did it and why it's considered inappropriate.

### Parents say...

- This can also be used to remind people that they don't have a hearing impairment.

### Design Implications

6. Reminding people of how they should act around children with autism needs—it needs to be done *continually* and *within the contexts*. People are so used to how they should interact with neurotypical people, that it's almost going against their instinct to act differently around children with autism.

## {7} Autism Advocate on Shopping Carts

### Design Context

When a child with autism has a meltdown in a grocery store, shoppers' unnecessary attention and judgmental stares often cause lots of emotional stress on the parents. How might we prevent other shoppers from staring and making the situation worse?



### Therapists say...

- This is very similar to the community cards that we use.
- Consider advertising this to parents, and give them a chance to opt in or out.
- Be careful about including diagnose information in the message. You need to get consent from the families to release that information.

### Parents say...

- This can be very helpful to us. It's very hard to attend to the child and explain to fellow shoppers at the same time.
- Ability to customize messages would be great.

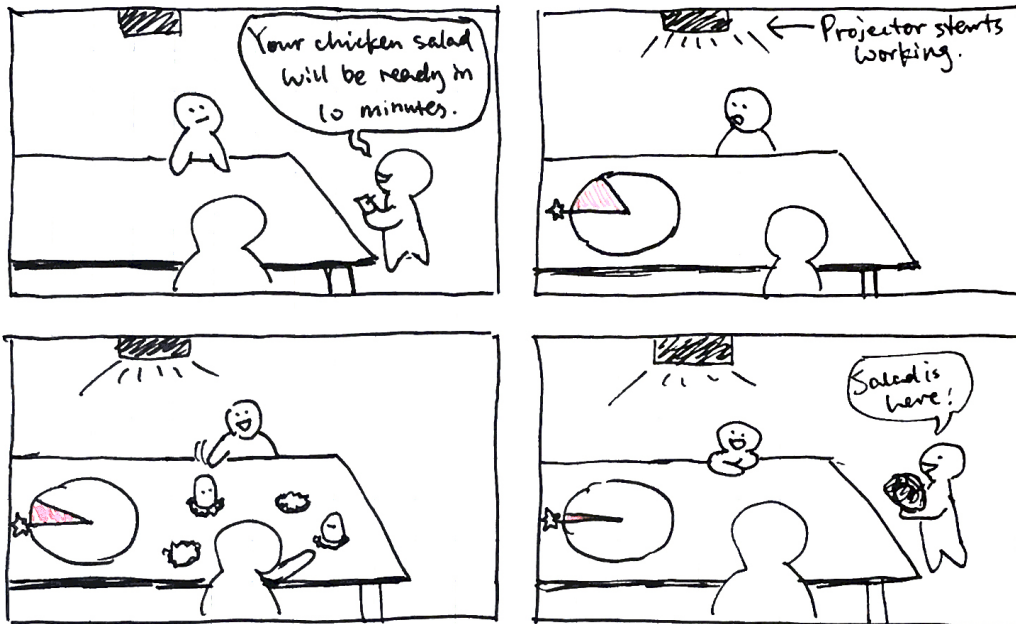
### Design Implications

7. When it comes to releasing sensitive information, always give the family control over what will be released and what won't.

## {8} A Better Waiting Experience

### Design Context

Many families avoid taking children out to restaurants, because they have difficulties waiting for food. How might we make waiting easier for children with autism, so that parents can afford to take them out more often?



### Therapists say...

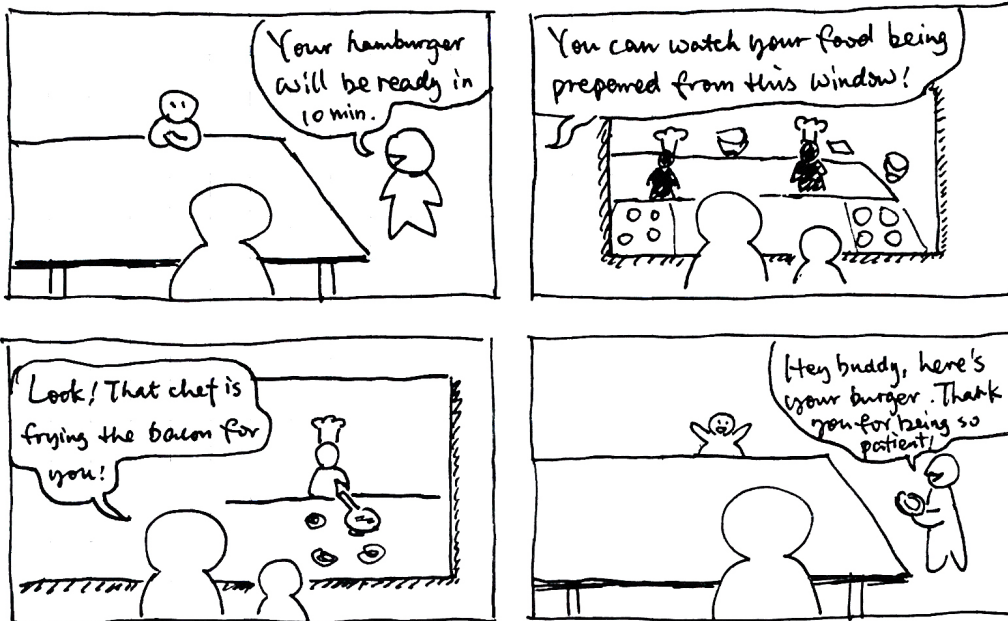
- Not every child knows how to wait with a timer, but it works for those who were trained to do so.
- Something tangible that a kid can hold in his hand may be better than projected images on the table.
- As far as distraction is concerned, kids move on from one thing to another really fast. Consider taking data on what kinds of distraction these children like.



## {9} A Better Waiting Experience V.2

### Design Context

How might we make waiting for food at restaurants easier for children with autism, so that parents can afford to take them out more often?



### Therapists say...

- I like that you're reinforcing the kid by saying "thank you for being so patient!"
- It will work for some kids but not everyone.

### Parents say...

- My kids really like to watch hand-on things. This would be great for them.
- They sometimes pretend to make food with toy kitchen kits. You can add that to this scenario too.

### Design Implications

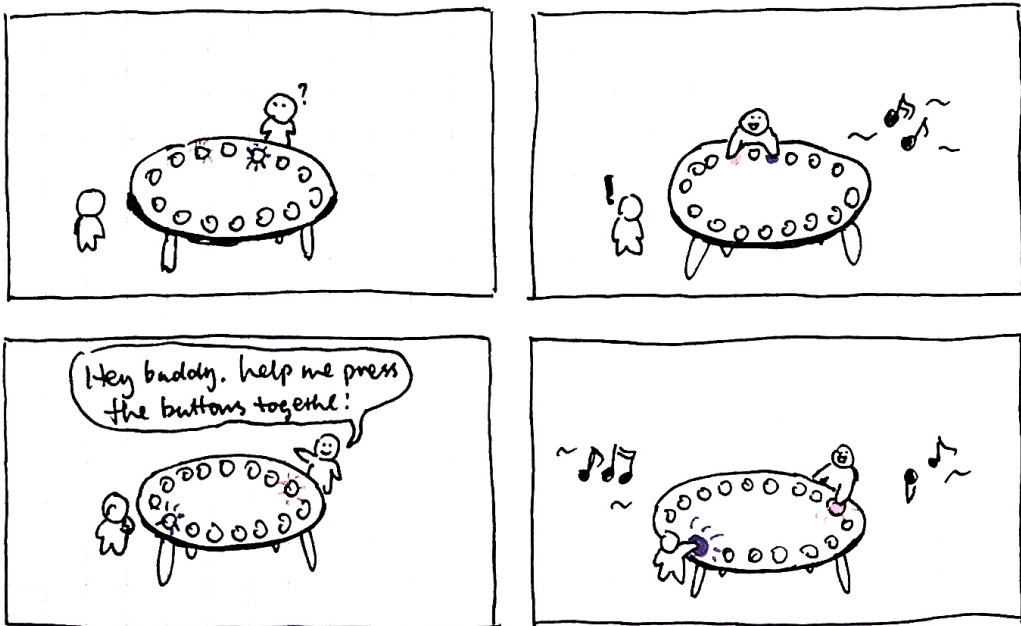
8. This seems to be a recurring theme—every kid is different. They have different skills levels, preferences for rewards, and interests in activities. We might need to accept that most designs that we come up with will not work for every kid with autism. The best we can do is to offer various kinds of designs for the kids and families to choose from.



## {10} Collaborative Play

### Design Context

Playing with peers is an important for children with autism, but many of them play by themselves more often. How might we create a game, activity, or environment for children with autism and neurotypical children to actually play together?



### Therapists say...

- This could be marketed to teach neurotypical kids to play cooperatively. This isn't just for children with autism. This is good for kids in general.
- Children with autism can learn to respond to their peers' requests first, and be the one requesting later.

### Parents say...

- I like that there is a goal to the game [so that they can achieve something together].
- It'll be nice to have some pep talk for the neurotypical children, so that they know my kid may play differently.

### Design Implications

9. Inclusive activities/games/toys are good for removing the stereotype of "special toy for special kids".

### Design Implications

10. There're more to be discovered about what makes a good cooperative game. Two potential strategies: one, setting a goal for the kids to accomplish together; two, prepare the neurotypical kids for repeatedly initiating request to play together.

# RESEARCH



## MORE INSIGHTS FROM DESIGN

Throughout the process of coming up with ten proposals, gathering feedbacks, and deriving design implications from the feedbacks, I kept reflecting on how we can design for autism awareness. In this section, you'll find:

- What are some design strategies for promoting autism awareness and acceptance?
- What are some constraints/pitfalls to look out for?



## How can we design for autism awareness?

### What are some design strategies for promoting autism awareness and acceptance?

Generally, the best ways to promote autism awareness are to create more opportunities for them—neurotypical people and individuals with autism—to be around each other. Just like you get to know someone by hanging out with him.

#### **Evoke empathy with children with autism or their parents.**

People don't know how to act around someone with autism largely because they've never met someone with autism. What if we create a way for them to experience what these children and their parents have to go through every day?

#### **Guide neurotypical people to act properly around these children.**

“Acting properly” can mean many different things—talking gently, using age-appropriate language, not judging them, being patient when they learn, trying different things with them. What if we can prompt people to do the right things in the right contexts?

#### **Alter the environments to provide reasonable accommodations in the public.**

Accommodation is not meant to be a permanent aid for these children; it's more like a scaffolding that enables them to be in the community to learn, so that one day they won't need the accommodation any more. What if we can provide some necessary accommodations outside home and school?

#### **Create opportunities for kids in general to play together.**

Interacting with their neurotypical peers is an important opportunity for children with autism to pick up social skills, but we tend to see more parallel play than cooperative play when these children are together. What if we can create a game for them to play more cooperatively?

## How can we design for autism awareness?

### What are some constrains/pitfalls to look out for?

**Every kid is different. You can't design for all of them at once.**

If we try to come up with a persona for a child with autism, we will probably end up with a dozen and these still won't cover everyone. We need to accept that we can't design for all of them at once, but we can still offer different solutions for children with different needs.

**Design for the whole community, not just for the children with autism.**

Throughout the project, I immersed myself in these children's world to learn what they need, but I realize that I missed a link by not getting feedback from those who have no experience with autistic children. When a parent said "I like this design because it won't embarrass my grandma", I realized that we need to design something that the whole community can receive well and benefit from.

# APPENDIX

A | Script for Interviewing Andrew Lambert

B | Script for Interviewing Therapists

C | Script for Interviewing Parents

D | Photo Probes Used in Interviews with Therapists and Parents

**A | Script for Interviewing Andrew Lambert**

- Tell me a little bit about yourself
  - What do you do at IRCA/MCAF?
  - What kinds of interactions do you have with autistic children and their family?
- About reducing stigma and discrimination
  - What kinds of stigma do people hold against Autistic?
  - What kinds of negative impact does stigma have on Autistic?
  - When I search “reducing stigma” on Google, most of the search results are campaigns, posters, info-graphics, and other materials that aim at raising awareness among the general public. How effective do you believe these efforts are?
  - What do you believe are the most effective ways to reduce stigma, stereotype, and discrimination?
- About every autistic individual being different
  - I saw a poster saying “If you know one autistic children, you know ONE.” Although their diagnosis all include the same word “autism”, that doesn’t mean that their conditions are the same, and we shouldn’t see the diagnosis as a label. This is very different from most other medical and mental conditions, where a diagnosis clearly informs the doctors of what to expect and what to do for the patient. How do you deal with this, in your experience of working with autistic children and their family? What are something that you must pay special attention to on a case-by-case basis? What are something common that you know you can do for every children?
- About empowering the autistic and increasing social interaction
  - Many efforts to help the autistic, such as reducing stigma, empowering the autistic, and increasing social interaction, are often interrelated. You can’t really do one of them without involving another.
  - Many programs (such as ABA therapy) are devoted to increase social interaction by “improving” autistic children’s behaviors. On the other hand, there’s a notion that autism can’t be cured; it needs to be accepted. How do you view these two conflicting notions or approaches? How much effort should be made by both parties to increase social interaction?

## B | Script for Interviewing Therapists

### Introduction (5')

- Turn on audio recording
- Confirm timing: 90 minutes
- Explain who I am and why we are doing this.
- There are no wrong answers. Any input is good input.

### The basics (5')

- What do you do here everyday as a therapist/BCBA?
- How many children do you currently work with?
- What activities do you do together with Connor? With other children?
- How did you become a therapist? What makes you want to work with autistic children?

### Communication with the therapist (20')

- How do you and these children communicate? Could you map out your ways of communication on this poster? (Use the mapping toolkit and sticky notes)
  - Ask about specific stories when they're learning or playing
  - With tools: What are some difficulties that you guys have had with the tools?
- How much of these methods can be adapted to improve the communication between autistic children and other people? What needs to be changed?
  - How well does PECS work when used by non-professionals? What're some things that can be improved?
- How do you therapists come up with these tools and techniques?
- In terms of communicating with others, is Connor different from other children that you work with? How?
  - How did you come to realize these differences? As far as communicating is concerned, how do you find out what works and what doesn't work for a kid?

### Communication with others (20')

- When you and the children that you work with go out to the community, what are the interaction between the children and other people like?
  - *[look out for when they were affected by stereotypes]*
  - *[look out for positive experience]*
- How would you explain to someone who has never met any autistic child about what he should do when interacting with the child?
- What are some basic things about autism that you think everyone should know?
- What are some mistakes that people often make when they interact with an autistic child?
- What are some things that people can do to improve the communication with autistic children? What are some things that the society as a whole can do?

**Stereotype and stigma (15')**

- As far as you're aware of, what kinds of stereotype do people have against autistic children and/or their families?
- How are autistic children and their families affected by these stereotypes?
- What are some things that people or the society can do better to reduce the negative effects?

**Reactions to concepts (15')**

- I collected some designs that are dedicated to helping autistic children.
  - Pick out two designs that you think autistic children will benefit from the most. Why?
  - Please pick out two designs that surprise you. Why?
  - What are some issues that these designs haven't addressed, but you wish they have?
- I collected some designs that are dedicated to combating stigmas.
  - Pick out three designs that you think are the most effective in combating stigmas. Why?

**Interacting with the family (10')**

- What should I know about interacting with autistic children's family (and Connor's family in particular)?
- What are some mistakes to look out for in my language/expressions and manners?

**Exploring the specifics**

- You mentioned ... previously. Is this always the same, or does it change? Why do you do it this way?
- Have there been any special circumstances where you've done it differently? Why? How was that?
- Has anything about the way you do this change over time? How? Why?

**Wrap up**

- Did I miss anything? Is there anything you want to tell me?
- Is there anything you want to ask me?
- Tentative next steps

\* I revised this script four times, usually after I learned new information from previous observations and interviews.



## C | Script for Interviewing Parents

### Introduction (5')

- Turn on audio recording
- Confirm timing: 90 minutes
- Explain who I am and why we are doing this
- There are no wrong answers. Any input is good input.

### The basics (10')

- Tell me a little bit about yourself.
  - What do you do?
  - What's your day-to-day like?
- Could you tell me a little bit about Jack?
  - When and how was he diagnosed?
  - What's his day-to-day like?

### Communication between child and parent (15')

- When you and Jack spend time together, what do you guys do?
  - What about when Jack spend time with other family members?
  - *[See if they spend time in the community -> prepare for the next section]*
- Jack is non-verbal. How do you communicate with him?
  - How much can Jack understand when you talk to him?
  - How do you find out about what he wants or needs?
  - What are his ways of telling you what he wants or how he feels?
- *[Exploring the specifics]* You mentioned ... (a way of communication) ... previously.
  - Is this always the same, or does it change? Why do you do it this way?
  - Have there been any special circumstances where you've done it differently? Why? How was that?
  - Has anything about the way you do this change over time? How? Why?
- *[Mapping toolkit]* We've talked about how Could you map out your ways of communication on this poster?
  - Any tools that you use? How do you come up with these tools/protocols?
  - Ask about specific stories
- Since autistic children are on a spectrum and everyone is different, a way of communication that works for one kid might not work for another. How do you find out what works and what doesn't work for Jack?
  - Ask about specific stories

**Communication with others / experience within the community (15')**

- Do you and Jack spend time in the community (like parks, grocery stores, or other public spaces)?
  - Where do you guys go? What is that experience like?
  - Do you and/or Jack have any interaction with people in the community? What is it like?
  - *[look out for situations where they are affected by stereotypes]*
  - *[look out for positive experience]*
- How would you explain to someone about how he should interact with Jack?
- What are some things that you want people to do differently when they interact with Jack?

**Stereotype and stigma (5')**

- What are some things about Jack that you want people around him to know about?
- What are some basic things about autistic children that you think everyone should know?

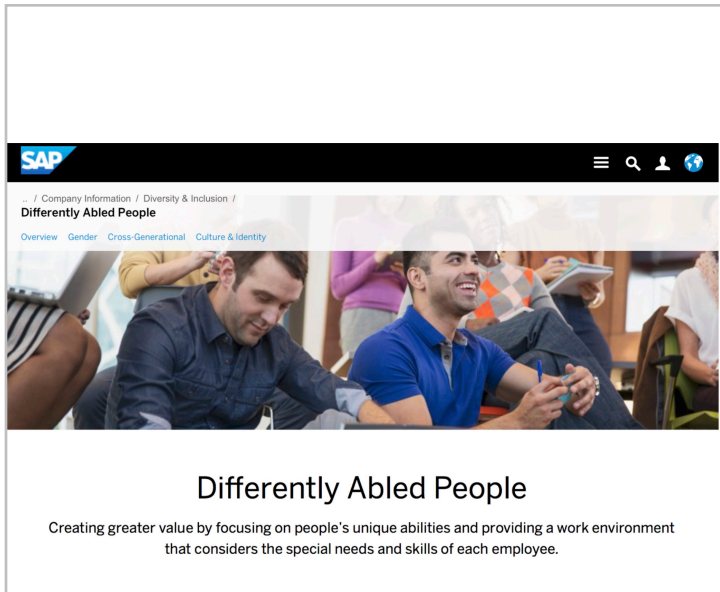
**Reactions to concepts (10')**

- Here are some designs that are dedicated to helping autistic children.
  - Please pick out two designs that you think autistic children will benefit from the most. Why?
  - Please pick out two designs that surprise you. Why?
  - What are some issues that these designs haven't addressed, but you wish they have?
- Here are some designs that are dedicated to combating stigmas.
  - Please pick out three designs that you think are the most effective in combating stigmas. Why?

**Wrap up**

- Did I miss anything? Is there anything you want to tell me?
- Is there anything you want to ask me?
- Tentative next steps
- Thank you.

D | Photo Probes Used in Interviews with Therapists and Parents



**SAP: AUTISM AT WORK**

SAP's autism work program has onboarded 100 employees with autism in 16 roles by 2015. They see people with autism as "differently abled people" who have unique abilities, rather than people with limitations.

*SOURCE*  
<http://www.sap.com/corporate/en/company/diversity/differently-abled.html>

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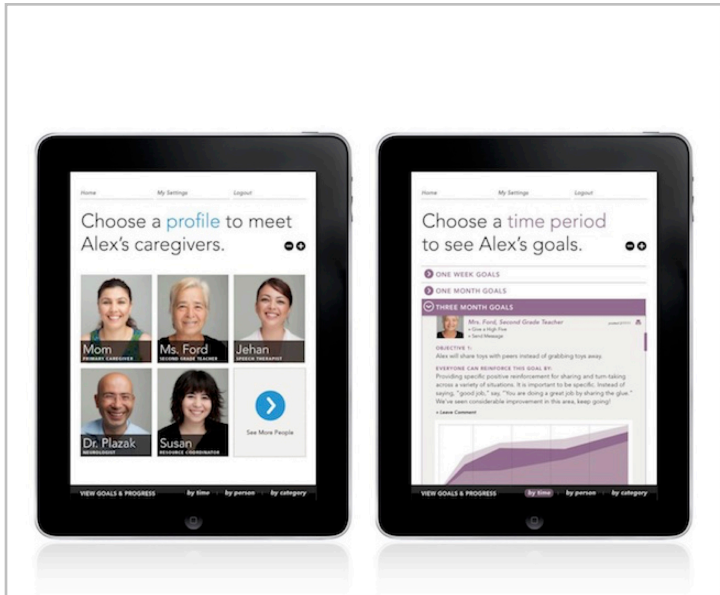


**GOBUG**

Gobug is an interactive toy that facilitates social learning for children with autism, but individuals of all ages and abilities can join the game. Gobug is activated when at least two participants each hold a controller. They need to collaborate to make gobug move faster or go in a certain direction. Many skills are involved in the gaming experience – social interaction, verbal communication, visual tracking, motor planning, etc.

*SOURCE*  
<http://www.core77.com/posts/19262/autism-connects-gobug-interactive-toy-19262>

19



weSYNC

Children with autism work with many people every day – doctors, therapist, and teachers. While these caregivers all communicate with the parents about the child's care, they don't necessarily communicate with each other. **weSYNC facilitates the communication among all caregivers** by creating a centralized information platform, which enables the caregivers to make informed decisions. It also **reduces the pressure on the parents** to relay communications.

SOURCE  
<http://www.core77.com/posts/19240/autism-connects-wesync-app-for-centralizing-patient-information-19240>

20



Customizable Time Visualizations



Mobile PECS system

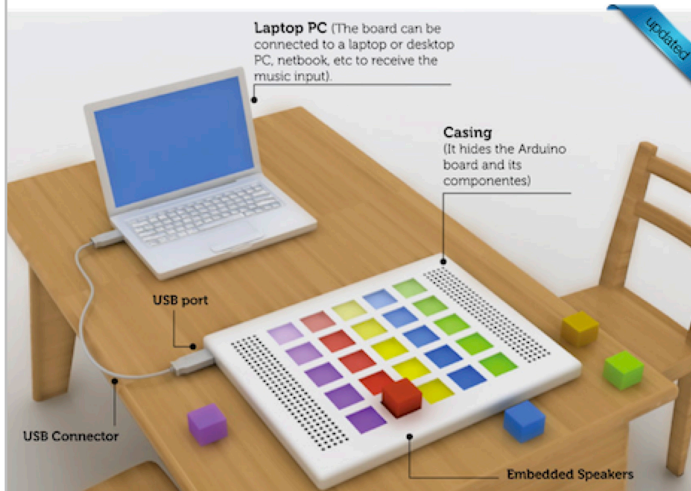


VISUAL WATCH

The Visual Watch help children with autism **improve their skills of sensing and managing time**. Its long-term goal is to increase communication skills and facilitate inclusion into the society. By replacing the traditional physical flashcard, the visual watch also **makes the task easier for the parents**.

SOURCE  
<http://www.core77.com/posts/19260/autism-connects-visual-watch-time-management-and-communication-19260>

21



COMMUNICATING THROUGH MUSIC

This game board is designed to be used by a child with autism and an adult (his or her caregiver, teacher, or parent). The game board produces sounds of various tones and instruments when cubes are placed at certain slots by the child or the adult. This is supposed to **facilitate the communication** between two players. The sounds are also **customable to accommodate each kid's specific needs**.

SOURCE  
<http://www.core77.com/posts/19276/autism-connects-communicating-through-music-19276>

22





LINE UP

"Line up" is a game designed to teach children with autism to **recognize facial expressions**, by using their interesting in lining up objects.

The designer did a good job in introducing positive behaviors to children with autism, through activities that they're naturally comfortable doing.

SOURCE  
<http://www.core77.com/posts/19294/autism-connects-line-up-a-facial-recognition-game-19294>

23



BEARHUG

"BearHug is a tool for providing effective Deep Pressure to the torso. It promotes the child to gain independence because they can control the amount of pressure they need themselves. As **some children with ASD have a hard time communicating their needs**, this tool can give them the power to be in control to help their sensory systems self-regulate, thus easing their anxiety and helping them function better. "

SOURCE  
<http://www.core77.com/posts/19295/autism-connects-bear-hug-wearable-deep-pressure-therapy-19295>

24



JAM BLOCKS

"I want to help children with autism learn to communicate using music."

The designer did so by facilitating the **social interaction between children and parents**, and specifically focusing on **eye contact, turn-taking, and joint attention**.

SOURCE  
<http://designwards.core77.com/interaction/46613/Jam-Blocks>

25

POOKI



"Pooki is a toy designed for all children, but is particularly attractive to Autistic children."

Pooki is designed with **customization** in mind, since every child with autism is unique and is sensitive to different triggers.

Pooki is also designed to **remove the stigma** of "special toy for special children", as all children can play with Pooki.

SOURCE  
<http://designawards.core77.com/Strateay-Research/48324/Pooki-A-Toy-for-All-Children>

26

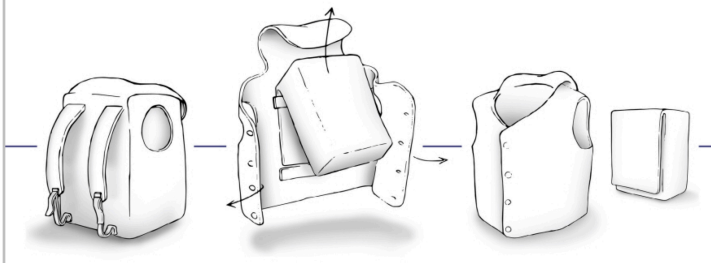
COMPRESS PACK



The compress pack is designed to help children with autism **deal with anxiety caused by social interaction**, by **simulating the feeling of being wrapped in a blanket or being hugged by someone**. The child can adjust the pressure himself privately. Unlike traditional compression-based product, the compress pack destigmatizes the problem with its **elegant and dignified look**.

SOURCE  
<http://designawards.core77.com/Design-for-Social-Impact/49608/Compress-Pack>

27



SYNCHRONY



**Music therapy** helps children with autism and their parents to **bridge the emotional gap and prevent parents from feeling dejection** due to lack of response from the children. Synchrony brings the music therapy to these families' home, even without the presence of a therapist.



SOURCE  
<http://kennethay.com/synchrony>

28



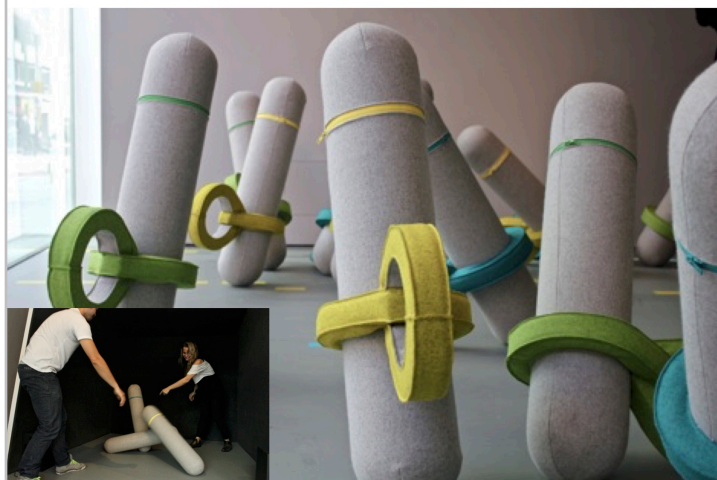


SENSEABLES

Senseables are outdoor and footwear designed to enhance autistic children's touch sensibility, **increase peer acceptance**, and facilitate learning independence.

SOURCE  
<http://www.core77.com/posts/20306/Core77-Design-Award-2011-Senseables-Student-Winner-for-StrategyResearch>

30



DASH DOT DASH

Dash Dot Dash was originally developed for autistic children's therapeutic treatment, but evolved into a **musical toy for everyone**. When people push the weighted capsules, the Wii remote hidden within triggered a variety of harmonizing notes.

SOURCE  
<http://www.core77.com/posts/20572/London-Design-Festival-2011-Inside-Playful-Minds-by-Physical-Pixels-at-University-of-Arts-London>

33



BUDDY

Buddy is an interactive toy that teachers and parents can use to teach autistic children the concept of **joint attention**. The flexibility to **customize** the toy enable children and family to create their own experience, and also allows the **generalization of the learned social skill**.

SOURCE  
<http://designwards.core77.com/Design-for-Social-Impact/29801/BUDDY>

31



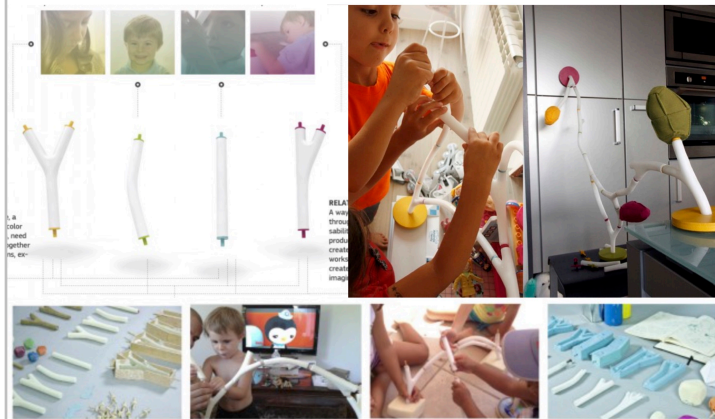


CRADLE BY RICHARD CLARKSON

The cradle creates a safe, relaxing, and comfortable environment for children with autism and children with Rhythmic Movement Disorder.

SOURCE  
<http://www.core77.com/posts/19983/flat-spotting-sleep-inducing-chair-designs-19983>

34



Y·L·L·Y

Y-L-L-Y is a construction game designed to help autistic children communicate, collaborate, and create. The irregular forms of the building pieces are intentionally designed so to encourage autistic children avoid using the product ritually and thus build structures more creatively.

SOURCE  
<http://www.core77.com/posts/25395/Cor-e77-Design-Awards-2013-Honorees-Strategy-n-Research>

35

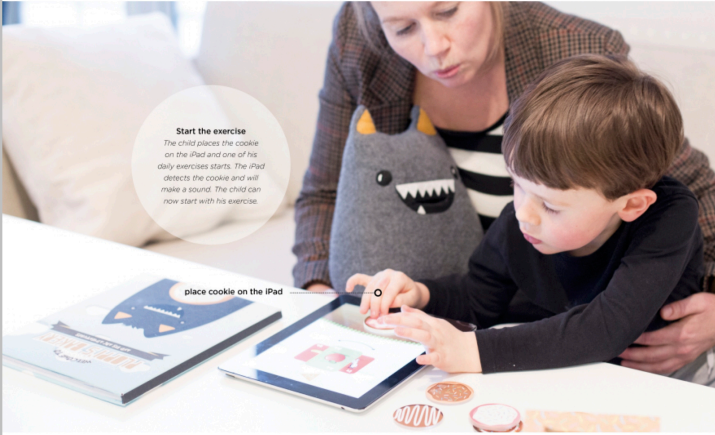


REACH & MATCH

Reach & Match helps visually-impaired and autistic children develop touch sense, social skills, and literacy (braille). It promotes the notion of "inclusive play" and creates a bridge between children with and without special need.

SOURCE  
<http://www.core77.com/posts/27965/www.facebook.com/reachandmatch>

36



**Start the exercise**  
The child places the cookie on the iPad and one of his daily exercises starts. The iPad detects the cookie and will make a sound. The child can now start with his exercise.

place cookie on the iPad

### PLOPPI'S BAKERY

Ploppi's Bakery is a kit to support speech exercise for children with speech disorder. It includes a iPad app, a story book, a plushie monster (Poppi), and some paper cookies. When the kid finishes his daily exercise, he can feed the growling monster with a cookie, which **motivate the kid to exercise every day**. The experience of practicing together also **facilitate the bonding between parents and children**.

**SOURCE**  
<http://designawards.core77.com/Interaction/48225/Ploppi-s-Bakery>

# ACKNOWLEDGEMENTS



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