



Designing for Autism: Empowerment, Awareness, and Acceptance

1694 Capstone
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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?

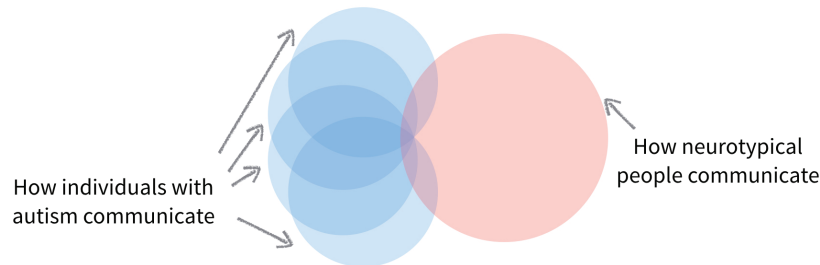
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CONTEXT

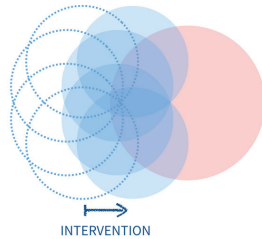
What is autism?

Autism is a group of neurodevelopmental conditions. 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. 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.

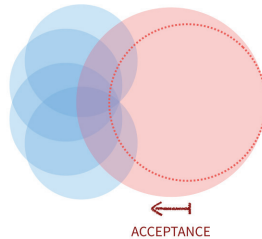


Autism and design efforts

After reviewing 50 designs that are dedicated to helping autistic children, 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.

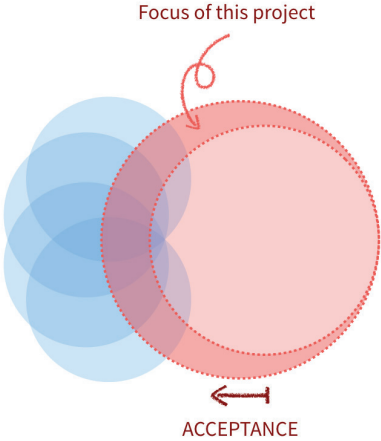


Toward the Acceptance end, designs are focused on raising awareness of autism, educating people about autism, and creating an environment for autistic and neurotypical children to play and learn together. **Acceptance helps autistic children by changing how non-autistic individuals think about autism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

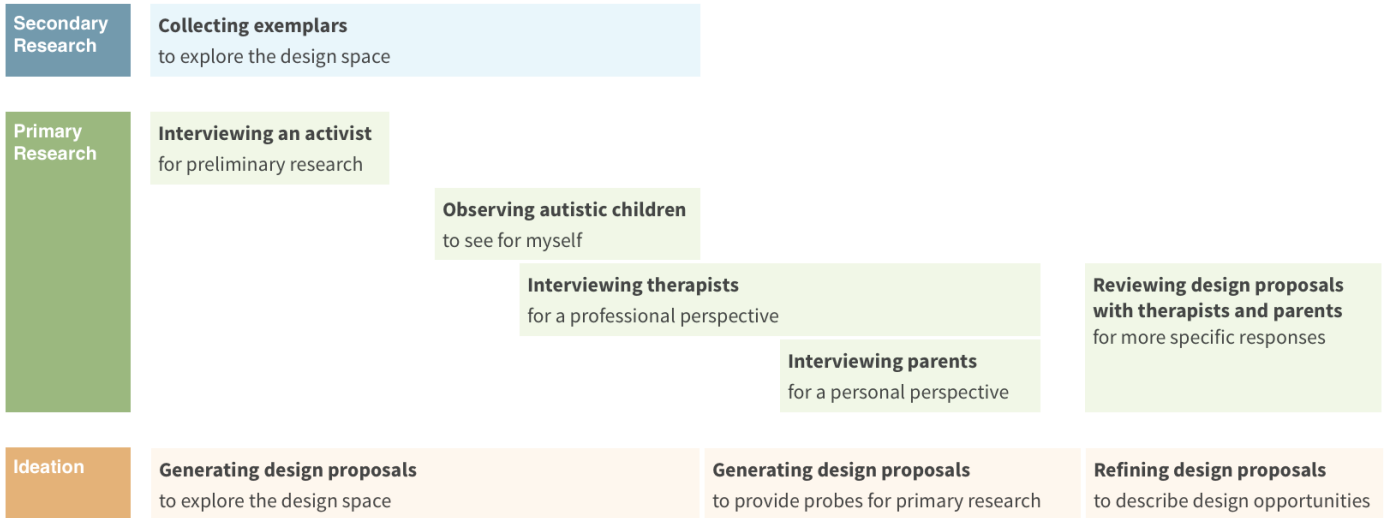
Focus of this project

Along the spectrum of Intervention—Acceptance, this design research project is focused on the Acceptance half, because autism is part of the human biodiversity that needs to be accepted, and not a disease that needs to be cured.

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

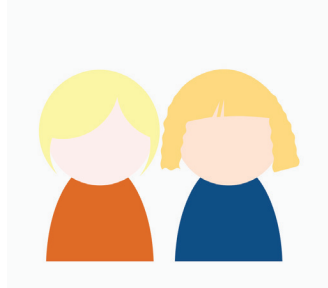


Participants



An activist for autism

I interviewed Andrew Lambert, the president of Monroe County Autism Foundation (MCAF), to learn about his experience of advocating for people with autism and their families.



Two children with autism

Both children are on the low-functioning of the spectrum. I spent 3+ hours with each of them observing how they interact with people in the therapy center.



Their therapists

Both children received applied behavioral therapy from Little Star Center. I talked to two of their therapists to find out how these children learn to communicate there.



Their parents

For each child, I talked to one of their parents to learn about how their families spend time together, and what their experience is like in the community.

Research methods



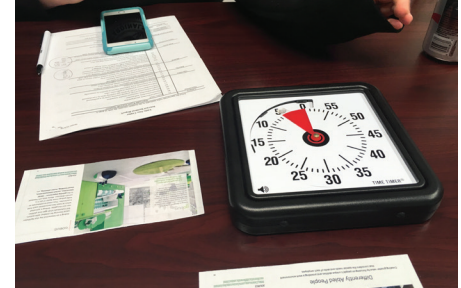
Fly-on-the-wall observation

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.

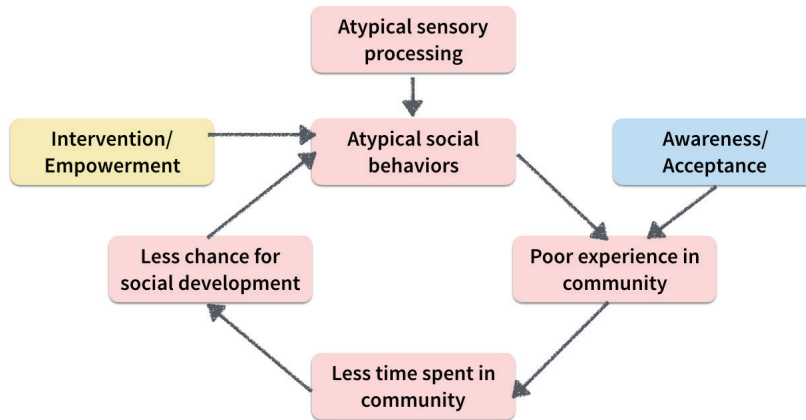


Photo probes

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?

INSIGHTS

How does Awareness help with the social learning of children with autism?



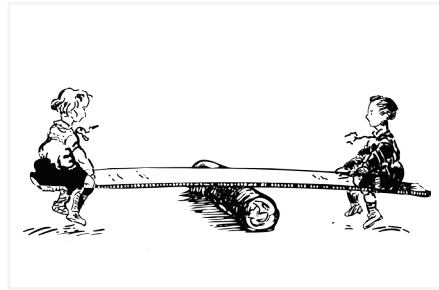
Both genetics and social factors are contributing to the challenges that children with autism are facing. In a four-step process, they interact with each other and form a vicious cycle that continues to hinder the social development of children with autism.

Intervention and Awareness breaks the vicious cycle at two different points. **Awareness/Acceptance improves the community experience for these children, so that they get to spend more time in the community to learn.** Awareness is a necessary link to keep the vicious cycle from coming back.

How does Awareness help with the social learning of children with autism?



Understand that autism is a spectrum. No two kids with autism are the same, just like no two neurotypical kids are the same. The diagnose “autism” doesn’t describe who they are, what they like, or what they’re capable of.



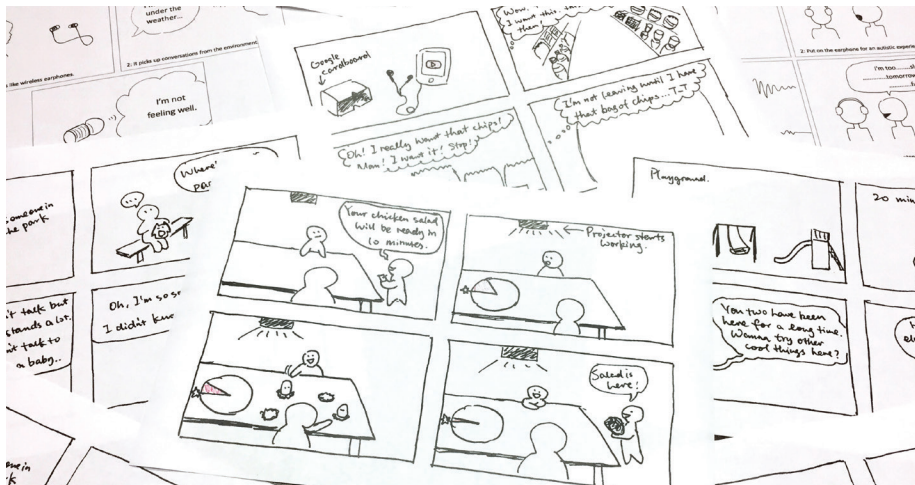
Treat them like you would any other kids. One, never talk to them as if they were less than you; don’t use baby talk; don’t talk poorly of them in front of them. Two, keep the accommodation to a reasonable level to give them space to grow.



Be patient as they learn to function in the community. Their behaviors in the community might be inappropriate and puzzling to many of us. Accept that you may not always know why they do what they do. Don’t stare. Don’t judge. Ask if you can help.

DESIGN PROPOSALS

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



{1} Parenting someone on the spectrum



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 for people in the community to evoke empathy?

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.

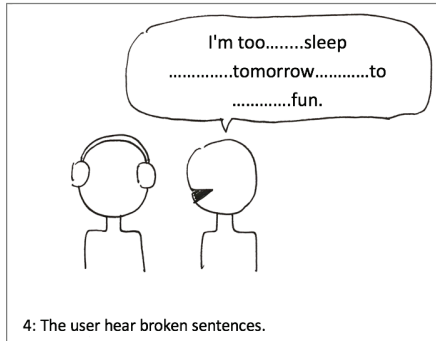
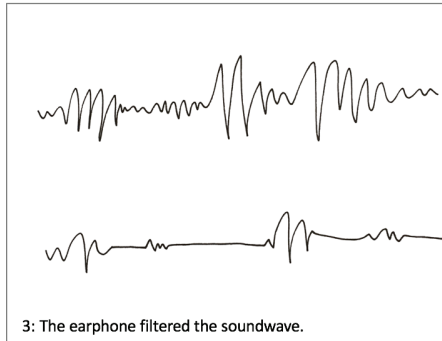
Parents say...

- 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 implication

1. 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.

{2} The Voice Convertor



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?

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.

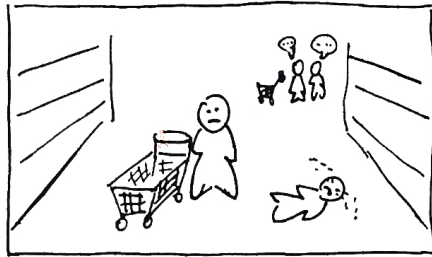
Parents say...

- 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.

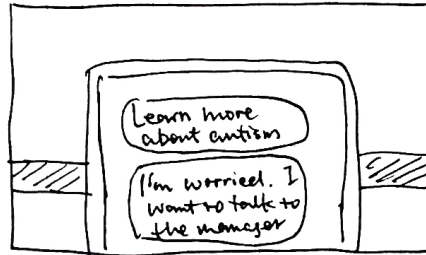
Design implication

2. 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?
3. One limitation of this research project is lack of input from neurotypical people who don't have much experience with kids with autism.

{3} Autism Advocate on Shopping Carts



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.

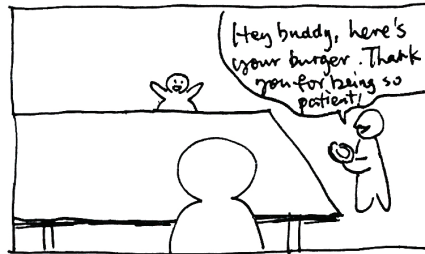
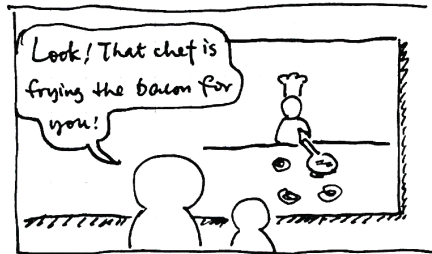
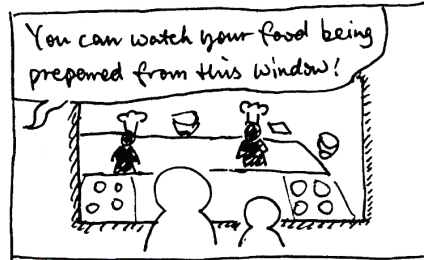
Parents say...

- 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 implication

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

{4} A Better Waiting Experience



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.

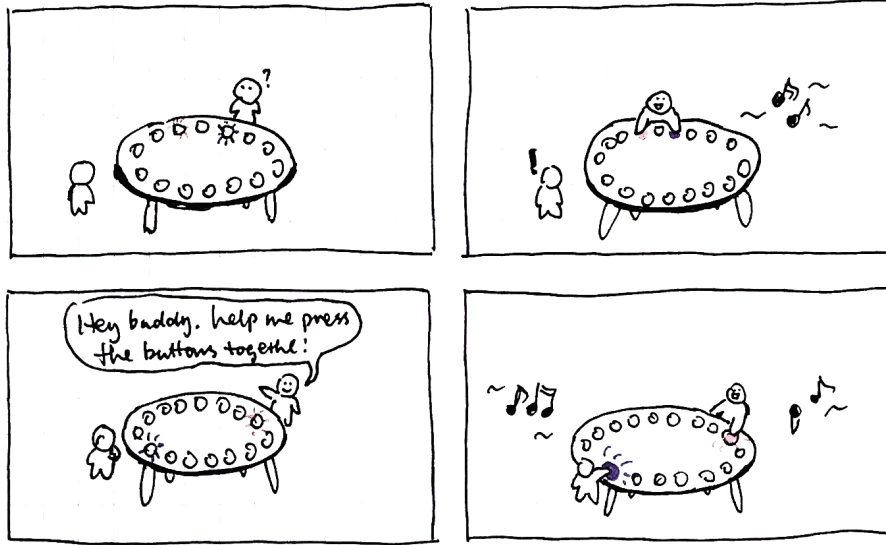
Parents say...

- 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 implication

5. 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.

{5} Collaborative Play



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 implication

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

Design implication

7. 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.

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