Co-Designing for the Future

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Co-Design Case Study
The C.A.S.T. Clinic for Adults with Special Needs
(C.A.S.T., Center for Autism Services and Transition)

Autism is a wicked problem, even this small slice (the clinic) is wicked...
Presentation Overview

**Overview of Our Co-Design Process**
Stages of the Project
Erika

**Discussion about Co-Design**
Contributions and Discoveries, Benefits of Co-Design, Future Opportunities
Justin
Kerry
Sherry

**Outcomes of Our Co-Design Project**
Tangible and Intangible
Erika
C.A.S.T. was where we started...

it is not where we ended up,

because this is a wicked problem.
How is C.A.S.T. a wicked problem?

- Multiple stakeholders with different needs, opinions and perspectives involved
- Incomplete or contradictory information
- Intertwined micro problems wrapped into a larger web or macro system of problems
- There is no idealized end state - propose iterative ways to improve the situation rather than solve it
Before our co-design project:

There was limited communication. Every stakeholder had their own view of the problem, but limited understanding of the shared system or the needs of other stakeholders connected to the clinic.

**Persons on the spectrum did not have an opportunity to voice their needs or ideas. They were spoken for on behalf of parents and healthcare providers.**

There were many ideas, but little attention was paid to prioritizing and identifying patterns/relationships among the needs and goals of the collective stakeholder groups.

There were some needs that had not yet been fully addressed, even after opening the clinic.
The questions yet to be addressed were:

How do we **reshape the physical environment of the clinic** to meet the needs of the patients?

What are the **gaps/missed opportunities** in the current clinic and ASD network in Columbus?

How do we **create true value** in the new clinic and make it sustainable?

- Understanding the patient’s **holistic needs** (not just medical)
- Bringing in social workers and other **extenders/connectors** to work with patients and providers
- Improving **training and awareness** for a more **patient centered** (individualistic care) model

How can we vet and **prioritize collective goals/ideas**?
The stakeholders involved throughout this co-design project.
“When we are given an infinite creative space to work within, it can be every bit as paralyzing as the most confining restrictions. A defined space helps us direct our creative energies in a more articulate fashion. We must be more willing to accept at least some small degree of definition of our respective creative spaces before we can effectively learn to define the space by (and for) ourselves.” -Justin Rooney, an adult on the spectrum
Our **Co-Design** approach for C.A.S.T.

Instead of jumping into **ideation** on clinic ideas, we broadened our scope and began at the **discovery phase** to collectively understand the context of the problem for **reframing**.
During our co-design project:
The focus was on the **front end** of the design process.

Designers created a co-design space through which each stakeholder group had an opportunity to **voice their concerns, needs, goals, and ideas** with the collective group.

**Design thinking methods and visualization tools** guided stakeholders in gaining an awareness of:

- The **needs/goals of multiple stakeholders** within the **clinic system**

- A broader understanding of how the **needs within the autism system impacted the clinic’s goals.**
The aim of the sessions was to:

- Reframe the problem around opportunities that could have a greater impact
- Draw out new insights
- Bring about more shared understanding & personal connections
- Engender more critical, creative & collective thinking

“The conversation was much more wide-ranging than I expected. The making/designing of space was part of a much larger discussion.” - Parent
Face-to-Face Interviews
Focus Group (Parents & Providers/Admin)
Focus Group (Adults on the Spectrum)

Ideas: Iterative/Provocative Visuals
Concerns, Needs & Goals
Three Visual Presentations

Workshop 1
5 Whys
Problem Probing
Empathy Scenarios
Mapping Needs & Goals

Workshop 1 Summary:
Mindmapping
Trending
Persona Narratives

Workshop 2
Persona Profiles
Futuring Scenarios
Prototyping

Tangible Outcomes
Product, Environment and Service Concepts
Perceptions, Feelings and Community
Tangible Outcomes
Visual Navigation
“Owen’s List”
High Level Education and Skills Training
Connected Provider Network
Resources to Maximize Potential

Intangible Outcomes
Creativity
Engagement
Empathy
Knowledge
Empowerment
Feeling Heard
Perceptions, Feelings and Community

Preparatory/Reflective Journal
Method Cards
Face-to-Face Interviews

Focus Group (Parents & Providers/Admin)

Focus Group (Adults on the Spectrum)

Ideas: Iterative/Provocative Visuals

Preparatory/Reflective Journal Method

Cards

Three Visual Presentations

Concerns, Needs & Goals

Workshop 1

5 Whys

Problem Probing

Empathy Scenarios

Mapping Needs & Goals

Workshop 2

Persona Profiles

Futuring Scenarios

Prototyping

Summary:

Mindmapping

Trending

Persona Narratives

Product, Environment & Service Concepts

Resources to Maximize Potential

Connected Provider Network

High Level Education and Skills Training

“Owen’s List”

Assert and Support Specializations/Interests

Visual Navigation

Tangible Outcomes

Product, Environment & Service Concepts

Intangible Outcomes

Empathy

Knowledge

Empowerment

Creativity

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Intangible Outcomes

Product, Environment & Service Concepts
Connected Provider Network

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Workshop 1: 5 Whys

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Workshop 2: Persona Profiles

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Workshop 1: Summary:

Mindmapping

Trending Persona Narratives

Workshop 2: Resources to Maximize Potential

Engagement

Knowledge

Empowerment

Creativity

Feeling Heard

Perceptions, Feelings, and Community

Tangible Outcomes

Visual Navigation

Owen's List

High Level Educ./Skills Training Opportunities

Assert and Support Specializations/Interests

Perceptions, Feelings, and Community

Intangible Outcomes

Engagement

Empathy

Knowledge

Empowerment

Creativity

Feeling Heard

Perceptions, Feelings, and Community
Focus group session (with mostly adults on the spectrum) around clinic improvements

Discussion Topics:
(included but not limited to)
- Physical environment
- Patient/doctor relationships
- Navigation at the clinic
- Barriers along the clinic journey
  (from home to check-out)
Quotes from the healthcare providers and administrators after attending Workshop 1:

“It was very helpful to attend and hear the issues of the patients, parents and providers... I think I can be most helpful in trying to move those priorities forward.”  -Chief Operating Officer - OSUWMC Internal Medicine

“I quickly realized that **C.A.S.T. was not the biggest need, but just a small part of a bigger, broader need.** This occurred in the session where we grouped things together with the circles on the board.”  -Director of C.A.S.T
Open Discussion with Sherry, Kerry, and Justin.

What did you learn or take away from the co-design process?
How did your unique perspective contribute to this process?
When should co-design be applied?
What did you learn or take away from the co-design process?

Tangible and Intangible Outcomes

“Engagement, awareness, encouragement, and a sense of community came out of the sessions. There was a realization that there’s a broader community than we thought and that we can work together to solve this complex problem.” -Sherry
How did your unique perspective contribute to this process?

“Nothing about us, without us.” -Justin
When should co-design be applied?

Who should be a co-designer?

“New ways of thinking arose. New connections were made. These connections can lead to future collaborations.” - Sherry
“We can’t succeed in medical care unless people are succeeding in other areas of their lives - those go hand in hand.” -Director of C.A.S.T.

Biggest Discovery

The **biggest** opportunity was not to fix the physical environment of the clinic but to help people on the spectrum and their families reach their **maximum potential** through:

- Awareness
- Navigation
- Socialization
- Training
- Patient-centered services
Key areas of focus: maximizing potential, self-advocacy and peace of mind

Long-Term Planning
Affordable assisted/indep. housing
Celebrating & recognizing specializations
Careers & meaningful work
Transitions planning & reduced barriers
Expectations / road maps day-to-day and long-term care/support
Sustaining C.A.S.T. Clinic (with limited resources) for rapidly growing adult ASD population

Accessibility & Continuous Care/Support
-Universal care
-Connected care 'extenders'
-Stable funding in transitions
-Transparent/accessible funding
-Accessible & responsive communication

Improved Navigation
Streamlined & transparent funding networks
Accessible providers/resources (local)
Education/training admin. & outside specialists
Integration & streamlined communication
Expectations / road maps
Day of clinic visit

Social Interaction
Accessible social networks
Social training /tolerance & awareness
Social, physical, mental stimulation
Information sharing (clearinghouse)

Photo(s) from workshop 1
**Long-Term Planning**

- Tools to help providers & parents discover & reinforce child’s specialized focus & potential
- The C.A.S.T. network extends to life coaches & vocational/occupation resources (job placement)
- Vision Planning (AASPRIRE Toolkit) with IMAGES
- Pharmacy & other extenders brought sooner into ‘sensitive’ transition process
- Life-skills training, modeling & social stories
  - “Interfacer” tools for young adults on the spectrum (alleviate parents’ stress & increase self-advocacy)
- On-going training & support programs for outside medical specialist (beyond primary care physicians)
- On-going healthcare and therapy support for parents (at C.A.S.T) - Family Centered Care
- Road maps & clearinghouse with information for:
  - New ASD parents
  - Transitions
  - Housing/employment opportunities/networks

**Improved Navigation**

- Specialist outreach program/directory
  - Increase ‘buy-in’ from outside physicians requires:
    - Increasing navigation fluidity for parents/patients
  - Helping child on the spectrum know what to expect (decrease anxiety & increase self-advocacy)
  - Visual/iconic step-by-step clinic guides
  - Visual time expectation cues
  - Helping child know what to expect helps minimize harmful behaviors which come from confusion & not being able to communicate.
- Portable records (provide key info - long & short versions of medical record)
- Methods and tools to better engage w ppl. on the spectrum to uncover indiv. coping needs
  - Iconic ‘passports’ with ‘key’ medical info. for a ‘good visit’
  - Establish stronger ties with Nationwide & other providers.
  - Establish more integrated communication channels between providers/extenders and programs

**Accessibility & Continuous Care/Support**

- Calming/meditation area for parents and staff
- Open/flexible communication modes
- Infographics
  - Text to speech programs on iPad tablets
  - Sensory sensitivity & awareness
  - Themed ‘quiet focus rooms’
  - Sensory friendly spaces, environments, & activities
  - Stress reducers to increase health and functional abilities of child AND parent
  - Establish stronger ties with Nationwide & other providers.
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**Social Interaction Opportunities**

- Open/flexible communication modes inside and outside the clinic
- Infographics
- Text to speech programs on iPad tablets
- Integrated social, physical, and mental stimulation programs (safe and accessible recreation centers)

**Long Term Planning**

- Tools to make school counselors more aware of post-secondary opportunities for ASD persons
- Affordable, high efficiency homes (materials & layouts)
- Life-skills & social training + housing ‘dorms’
- Innovative funding models (ex. micro-enterprises)
- Careers in technology, futuring, data intelligence, etc
- Post-secondary ‘solo’ education/training (up to PhD) for specialized interests
- Provide means to spread resources and responsibilities: between C.A.S.T. and other healthcare institutions/specialists, etc and between parents and young adults (interfacer roles and responsibilities)
- Siri & Apps to help people on the spectrum become more interdependent/independent
- Maps, tools & programs to help avoid or prepare for “The Cliff” after a child on the spectrum graduates from high school
- Programs and housing to support adults on the spectrum after their parents pass-away.

**Integrated Navigation**

- Integrated network trained prov., extenders, & specialists
  - Cancer Care-Team model – ASD
  - Care coordination mapping: understanding roles for greater impact and a smoother run system
  - Care consolidation (clearinghouse) for parents and adults on the spectrum to easily access and contribute
- Effective, varied, and efficient communication channels between: Peds & adult care, Parents/patients & providers
  - Virtual/online/communication vs. face-to-face
  - MyChart, TeleMed … what else?
- Universal care-coord. mapping, navigation tools and clinic ‘expectation’ guides (day-of and long-term)
- Apps for parents, patients, and providers/extenders to track medical histories, treatments (and outcomes), and behavior/sensory sensitivities.
- Navigation app to find specialists (like Yelp): narrow search results by location, child’s specific needs, etc

**Ubiquitous Sensing Technology**

- Sensors to track physiological patterns, changes, and disruptions to: help caregivers better anticipate and manage ‘incidents’, and communicate signs for change behavior to new providers, caregivers, and aides.
- Sensors linked to provider tablet and MyChart so provider can see patterns (meaningfully detecting patterns) & know what to expect before the clinic visit
- Sensors and app reminders to manage a child or adult’s care & give them more interdependence (as child ages)
- Stress reducers to increase health and functional abilities of child AND parent
- Universal care solution communication ideas, destressor environ. designs, navigation tools, & clinic ‘expectation’ guides (day-of and long-term)
- Formulate sustainable supports and collaborative networks between providers and specialists

**Social Interaction Opportunities**

- Online video game community (commun. & education)
- Create safe spaces (digital and non-digital spaces) where ppl. feel they can be heard
- Life-skills & social training + housing ‘dorms’
- Open-source problem solving/innovative thinking community for people on the spectrum
- Innovative & accessible commun. channels among: parents, people on the spectrum, & mainstream

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Owen’s List
A description of the concept and how it originated during the workshops, by Sherry Fisher (Parent)

**Unmet needs:**
The parents talked about having to find all their children’s services by accident - there is no central resource for autism-related services. We primarily learn about service providers from other parents so finding services is a totally random process dependent upon whom you know and whom you happen to ask for info or referrals.

Providers operate in silos and they don’t know each other so they are not a resource.

**Inspirations and Concept Development:**
The Columbus Autism Parents Facebook group (which is a private parents-only group to allow for open sharing about school issues and providers), has a continuous flow of newly diagnosed families so I often see the same questions asked repeatedly (e.g., for a special needs dentist that takes Medicaid or a speech therapist, OT, etc.).

On a new site that we called Owen’s List parents could search for services whenever they need to and for wherever they are in their child’s lifespan. Similar to sites like Angie’s List and Travelocity, service providers could be rated, resources could be found by region, zip code, or search criteria, and search details could increase as you dig deeper.

The website would show the full spectrum of services and the pathway of what to consider at each age/stage of development. I’ve come across so many families who have no idea that they should apply to the DD system or SSDI for services for their child. They think their child is getting all their services through school but there is much more they might be eligible for. And if they miss the window for applying (under 22), their child may never be qualified for the services they need as an adult.

Owen’s List would be designed to connect parents with each other and resources, as well as connecting adults on the spectrum with one another and potential job resources.
**Next Steps**
Select a near or long-term idea (like Owen’s List)

Determine the project team (Experts brought in to further develop the idea into a tangible product or service)

Co-Design the idea further (in more depth) with the project team

Develop more refined visual prototypes of the concept.
### Improved Navigation
- Navigation tools to help providers and parents navigate and discover resources.
- Integrated network trained providers and specialists to help them understand the roles for greater long-term navigation.
- Care coordination mapping to help parents and adults on the spectrum to easily access and contribute.
- Care consolidation (clearinghouse) for parents and adults on the spectrum.
- Care coordination mapping to help caregivers better anticipate and manage incidents.
- Open-source problem solving/innovative thinking community for people on the spectrum.
- Mainstream + special needs higher education (similar to Oakstone model).

### Accessibility & Continuous Care/Support
- Calming/meditation area for parents and staff.
- Open/transparent communication modes.
- Infographics.
- Text to speech programs on iPad tablets.
- Sensory sensitivity & awareness.
- Themed quiet focus rooms.
- Give them control in the space.
- Dark, calming music, no clashing stimuli.
- Stress reducers to increase health and functional abilities.
- Establish stronger ties with Nationwide & other providers.

### Social Interaction Opportunities
- Online video game community.
- Create safe spaces (digital and non-digital spaces).
- Mainstream + special needs higher education (similar to Oakstone model).
- Open-source problem solving/innovative thinking community for people on the spectrum.
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### Tools
- Owen’s List directory
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Phase 1
Needs, opportunities and gaps identified/prioritized

Phase 2
Opportunities explored through personas, speculative narratives, and prototypes

Problem Framing                       Evaluation       Refinement

Discovery                   Ideation          Prototyping     Launch/Test

Problem Framing

Discovery

Ideation (Quick iterative Sketches/Prototypes)

Evaluation

Prototyping (Refined, functional models)

Launch/Test
Both near and far term concepts require various ‘experts’ and resources. If we have all of the right people involved, the connections and actions that need to be achieved at different levels of opportunities (near and long-term) become clearer.
What we learned from our co-design process.

1. **Design can do more than generate ideas.**
   Through the process of co-design, designers can help divergent stakeholders converge, empathize, and reframe a wicked problem in order for the collective group to identify and co-create key innovation resolutions.

2. **Everyone should have a voice.**
   Young and old, typical and a-typical, verbal and non-verbal, their needs, visions, and ideas of the future need to be heard.

3. **Wicked problems require input from a wide range of experts.**
   Co-designing with a collective group of varying stakeholders allows input and accommodation from many perspectives. Therefore, it is critical to provide a space/platform through which shared understanding of the systems and its parts can be achieved.

4. **Co-design outcomes extend beyond ‘tangible’ solutions.**
   The value gained by involving stakeholders in the beginning phase of the design process extends beyond helping designers arrive at tangible design opportunities (innovative products, service, and environment solutions), but also provides a sense of engagement, inclusivity, social wellbeing, feeling valued and heard (self-advocacy), and empathy in the collective group.
Thank you for listening.

If you have any questions or would like more information about the project and the outcomes feel free to contact me at:

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