Co-Designing for the Future

Erika
Co-Designer/Design Researcher

Sherry
Co-Designer/Parent

Justin
Co-Designer/Adult on the Spectrum

Kerry
Co-Designer/Adult on the Spectrum
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.

- Healthcare Providers
- Parents
- Adults on the Spectrum
- Healthcare Administrators
- Design Researchers

- Parent of Adolescent on the Spectrum: Kerry
- Director of Nisonger: Sherry
- Adult on the Spectrum: Justin
- Parent of Adult on the Spectrum: Parent of Adult on the Spectrum
- Section Chief Behavioral Health Services & CDC Chief Dev./ Beh. Peds (NCH): Parent of Adolescent on the Spectrum
- Parent of Adolescent on the Spectrum: Parent of Adolescent on the Spectrum
- Medical Director Child Development Center (NCH): Parent of Adult on the Spectrum
- Adult on the Spectrum: Parent of Adolescent on the Spectrum
- Pharmacist C.A.S.T.: Parent of Adult on the Spectrum
- Design Researcher: Design Researcher
- Design Researcher: Design Researcher
- Psychologist CDC (NCH): Parent of Adolescent on the Spectrum
- Parent of Adolescent on the Spectrum: Parent of Adolescent on the Spectrum
- Chief Operating Officer - OSUWMC Internal Medicine: Design Researcher
- Director of C.A.S.T.: Design Researcher
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
Resources to Maximize Potential
Connected Provider Network
High Level Education
and Skills Training
“Owen’s List”
Assert and Support
Specializations/Interests
Visual Navigation

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

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Workshop 2
Persona Prototypes
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Trending Persona Narratives

Product, Environment & Service Concepts

Tangible Outcomes

Resources to Maximize Potential
Connected Provider Network
High Level Education and Skills Training
“Owen’s List”
Assert and Support Specializations/Interests
Visual Navigation

Intangible Outcomes

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High Level Educ./Skills Training Opportunities
Assert and Support Specializations/Interests
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Resources to Maximize Potential
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Feeling Heard
Intangible Outcomes
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)
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 & vocation/occupation resources (job placement)
- Vision Planning (AASPIRE Toolkit) with IMAGES
- Pharmacy & other extenders brought sooner into 'sensitive' transition process
- Life-skills training, modeling & social stories
- ‘Interface’ 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 & clearignhouse 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 w/Nationwide & other providers
- Transparent & accessible communication channels between healthcare institutions

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
  - Give them control in the space
  - Dark, calm music, no clashing stimuli
- Stress reducers to increase health and functional abilities of child & parent
- Establish stronger ties with Nationwide & other providers.
- Establish more integrated communication channels between providers/extenders and programs

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)

- 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 ‘silo’ education/training (up to PhD) for specialized interests
- Provide means to spread resources and responsibilities: between C.A.S.T. and other healthcare institutions/specilists, etc and between parents and young adults (interface roles and responsibilities)
- Siri & Apps to help people on the spectrum become more independent/dependent
- 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.
OWEN'S LIST

CAREER/VOCATIONAL

Skills:
- High school/graduated
- Employment/Unemployment
- Voluntary work
- Family involvement

Needs:
- Education
- Housing
- Recreation
- Social
- Health/Wellness
- Income
- Housing
- Transportation
- Employment/training

OWEN'S LIST

Protagonist:
- Enrichment
- Education
- Housing
- Recreation
- Social
- Coram
- Medical care
- Reproductive
- Caregivers
- Crisis/activation

OWEN'S LIST

Profile (circle one):
- Adult
- Child
- Teen

OWEN'S LIST

Housing
Vuga Inn
www.vuga.in
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.
Long-Term Planning

- Tools to help providers & parents discover & reinforce child’s specialized ‘focus’ & potential
- Vision Planning (AASPIRE Toolkit) with IMAGES
- Owen’s List of ‘sensitive’ transition process
- Owen’s List of Life-skills training & social stories
- Owen’s List of Housing/employment opportunities/networks
- Owen’s List of Affordable, high efficiency homes (materials & layouts)
- Owen’s List of ‘interfacer’ roles & responsibilities
- Owen’s List of Mainstream + special needs higher education (similar to Oakstone model): specialized spaces and learning opportunities to help avoid or prepare for ‘The Cliff’ after a child on the spectrum graduates from high school

Improved Navigation

- Owen’s List of Integrated network based on neurodiversity directory
- Owen’s List of Sensory support/ ‘Expectation’ guides for parents/patients & providers
- Owen’s List of Ubiqitous Sensing Technology
- Owen’s List of Sensor devices for outside physicians: changing the ‘spectrum
- Owen’s List of Contextualized navigation, ability for parents/patients & providers to know what to expect & have an understanding of the ‘spectrum
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Accessibility & Continuous Care/Support

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Integrated network based on neurodiversity directory

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Phase 1
Needs, opportunities and gaps identified/prioritized

Phase 2
Opportunities explored through personas, speculative narratives, and prototypes
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Needs, opportunities and gaps identified/prioritized

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

Phase 2B
Determine project teams
Co-Design with project teams to prototype individual concepts

Phase 3
Design team refines and further develops co-design concepts. Present refined concepts to stakeholder groups.

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.
Are there any questions?