

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

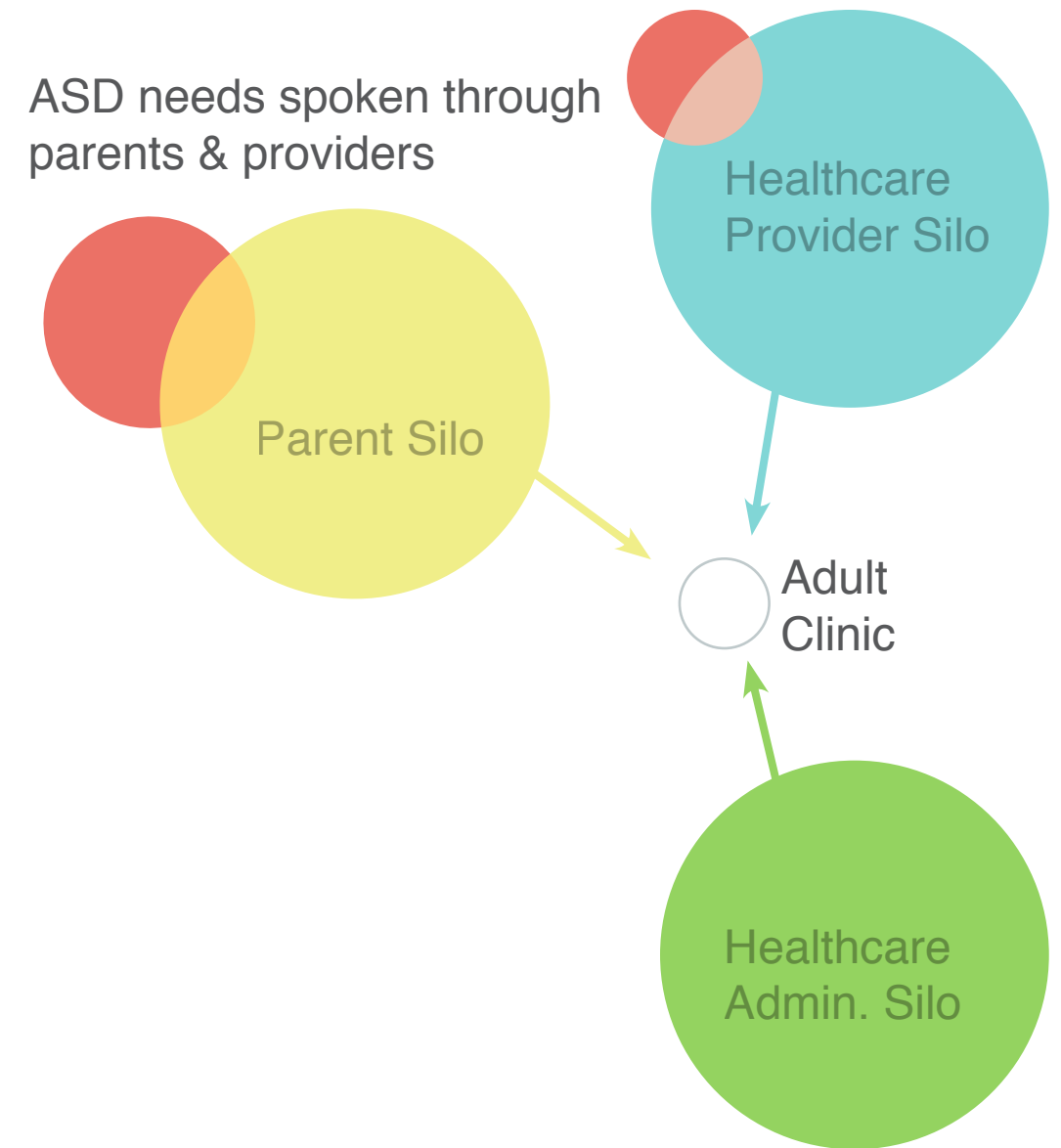
Before our co-design project:

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?

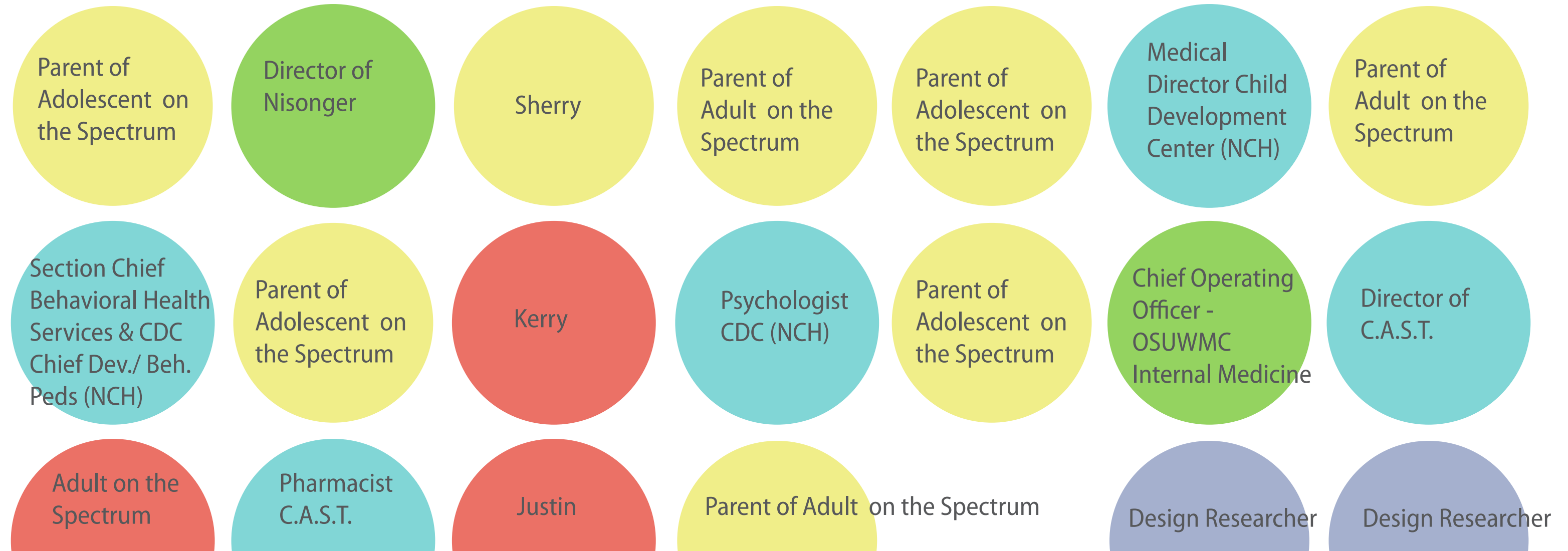
How do we **create true value** in the new clinic and make it sustainable?

- 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?**

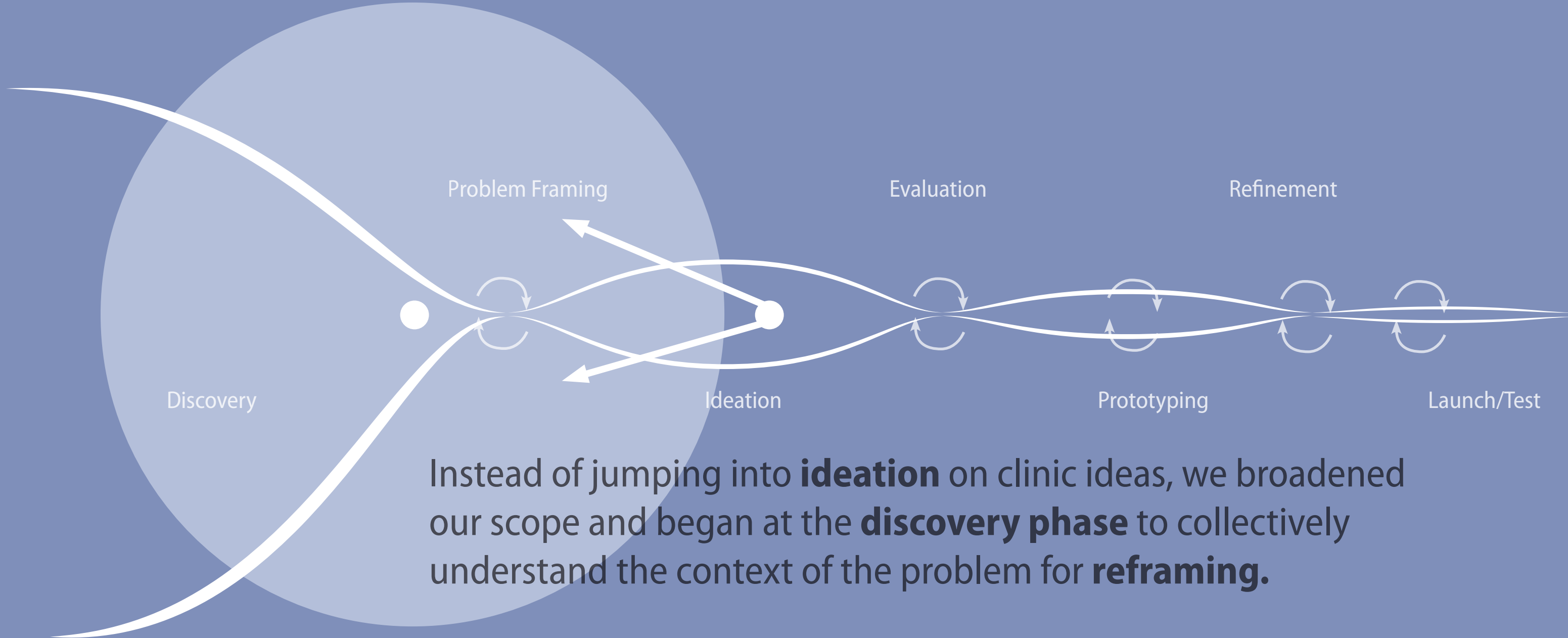
● Healthcare Providers
 ● Parents
 ● Adults on the Spectrum
 ● Healthcare Administrators
 ● Design Researchers

The stakeholders involved throughout this co-design project.

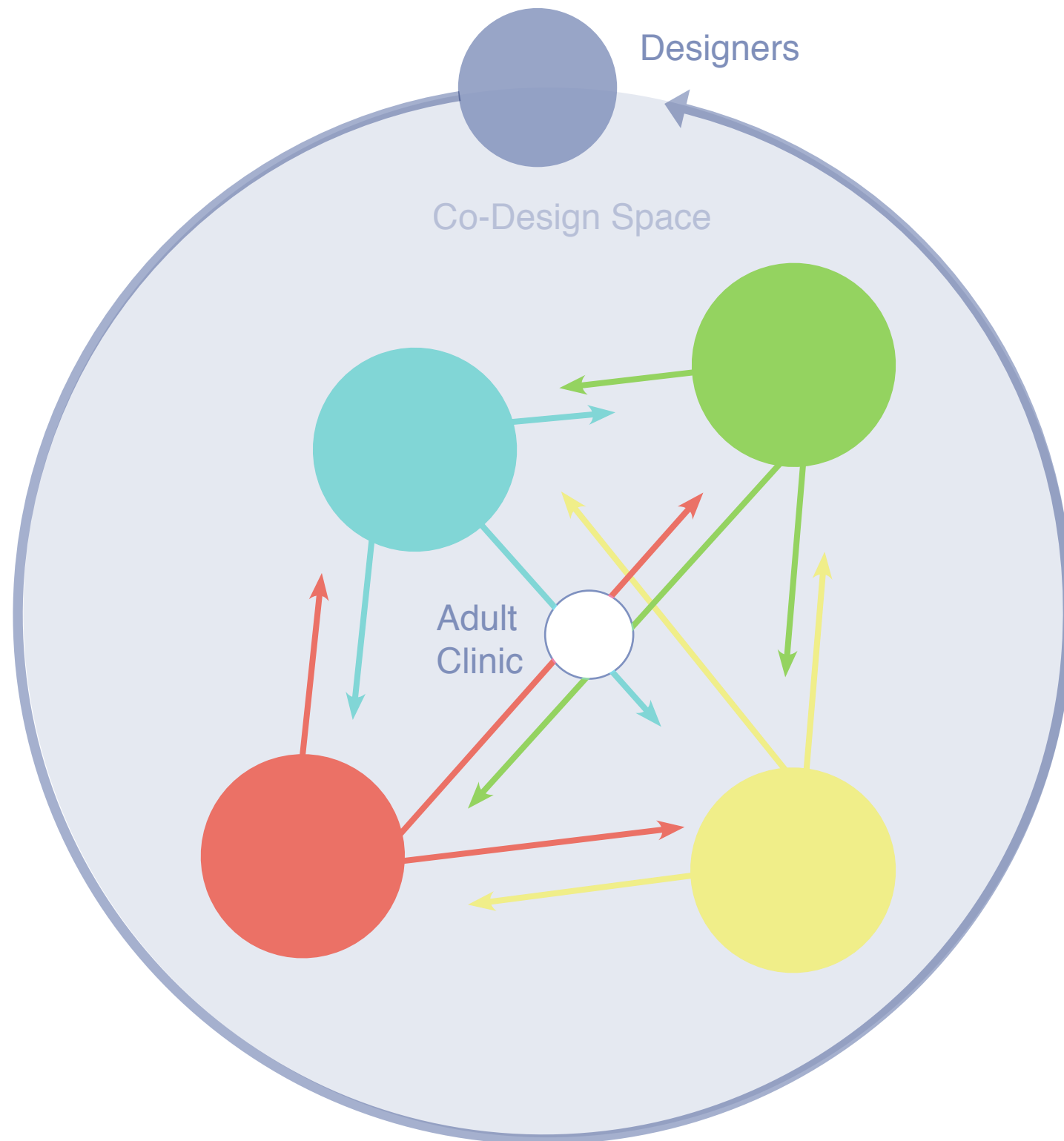


“When we are given an infinite creative space to work within, it can be every bit as paralyzing as the most confining restrictions. A defined space helps us direct our creative energies in a more articulate fashion. We must be more willing to accept at least some small degree of definition of our respective 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.**

Designers took on a more central, facilitator role.

Adult Clinic



The aim of the sessions was to:

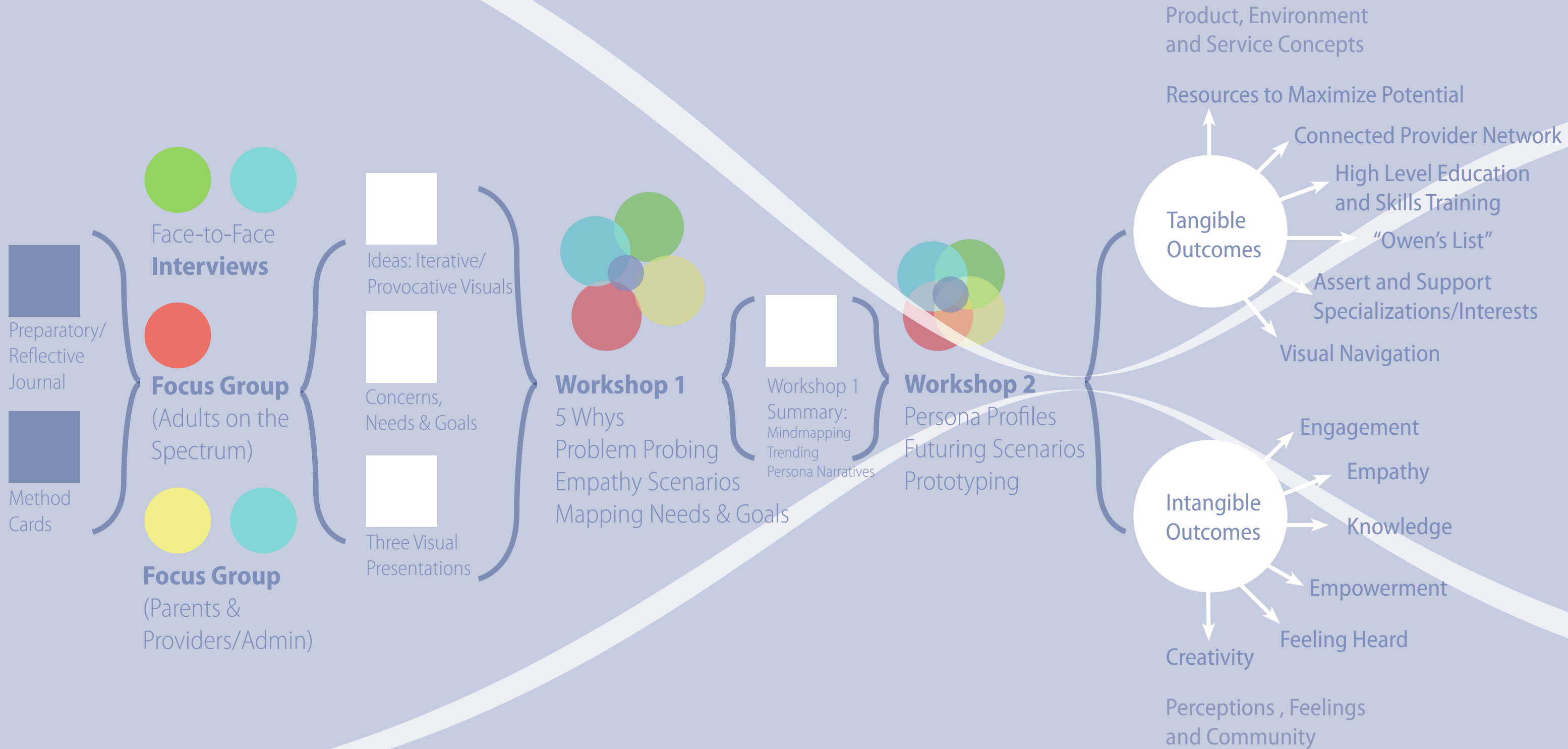
Reframe the problem around opportunities that could have a greater impact

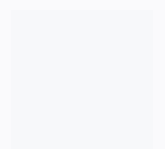
Draw out **new insights**

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





Method



Method



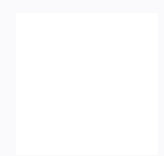
Facedirect
Interviews



Focus Group
(Adults on the
spectrum)



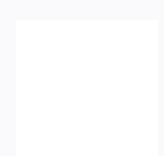
Focus Group
(Parents &
Providers/Admin)



Identifying
Provisional Goals



Concern
Narratives

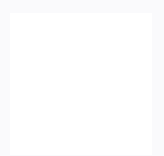


Thematic
Descriptions



Workshop 1

5 Whys
Problem Probing
Empathy Scenarios
Mapping Needs & Goals

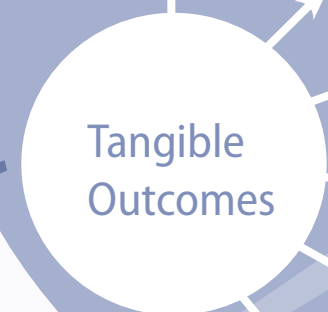


Workshop 1
Summary
Narratives
Personal Narratives



Workshop 2

Persona Profiles
Future 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

Creativity

Product, Environ.
& Service Concepts

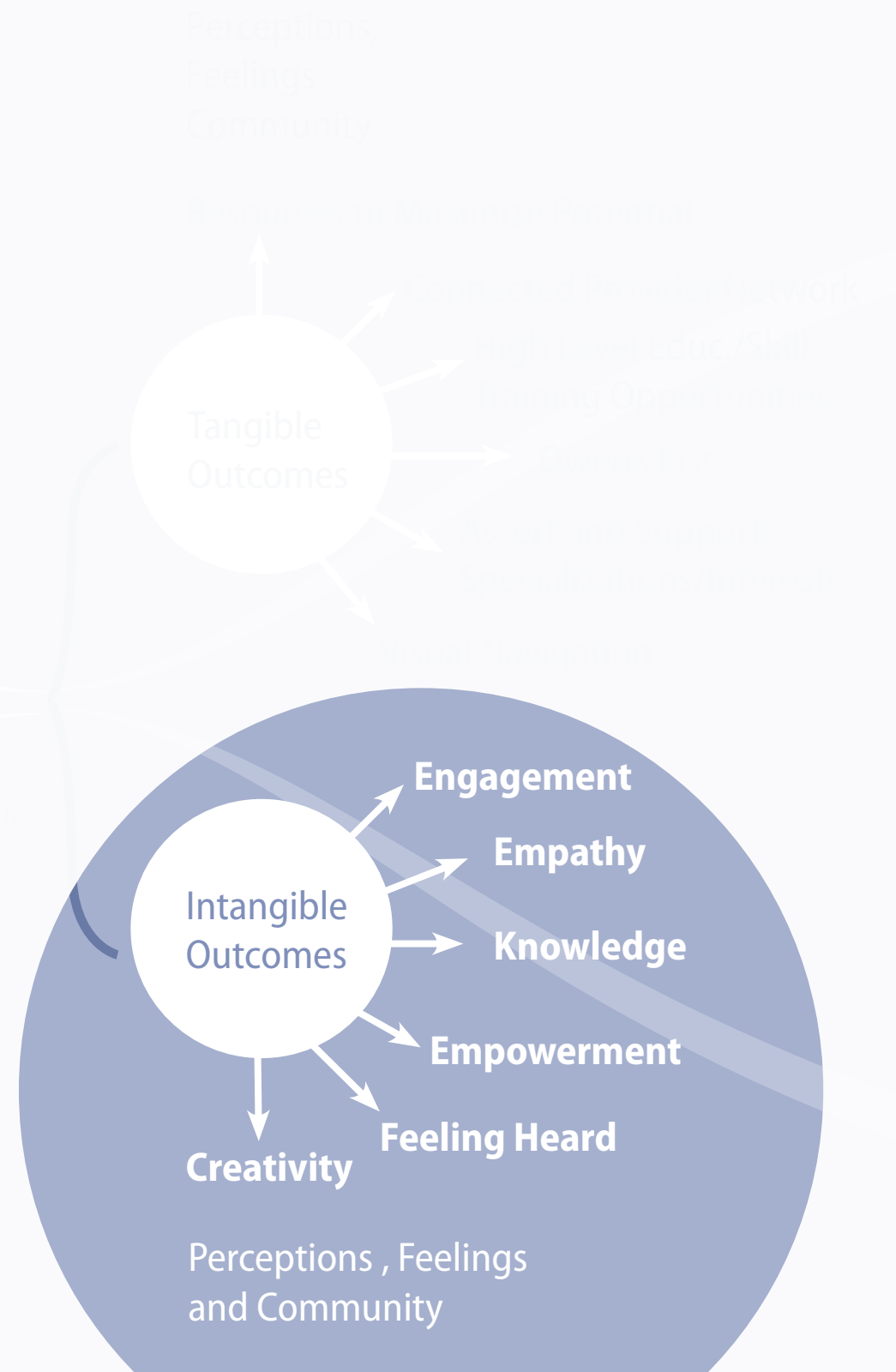
Engagement

Empathy

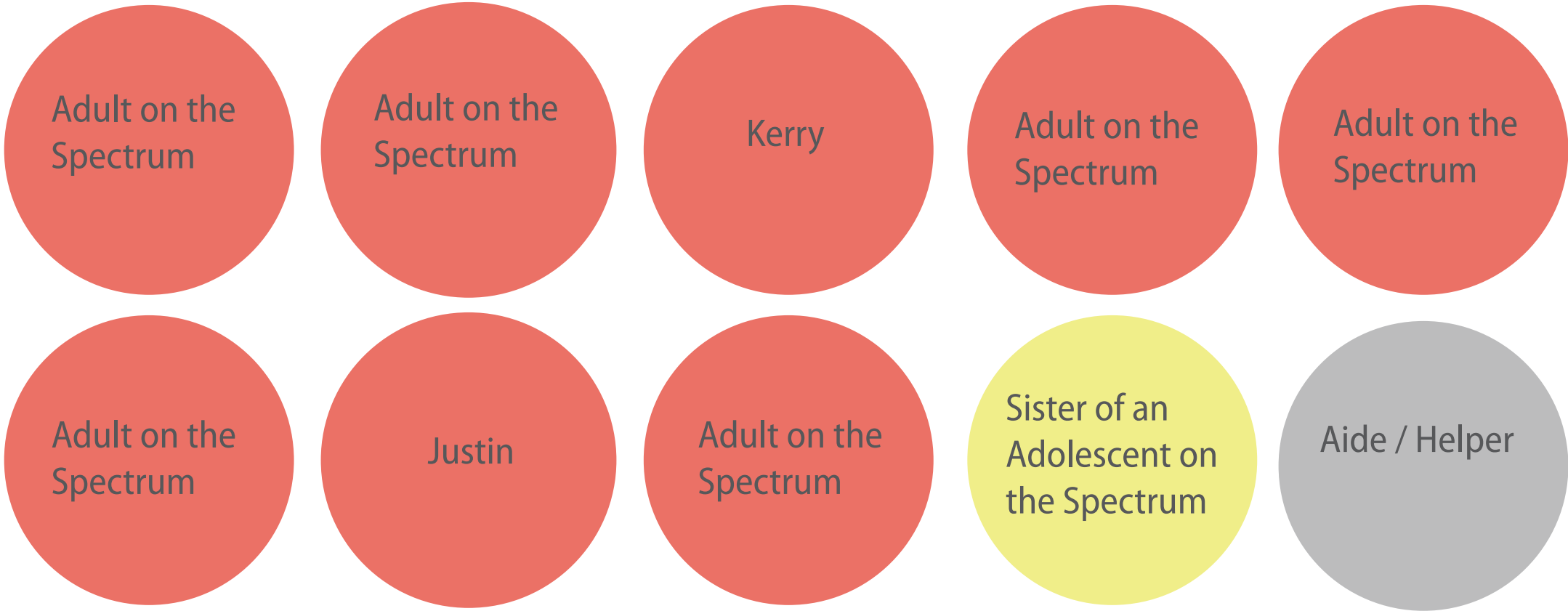
Knowledge

Empowerment

Feeling Heard

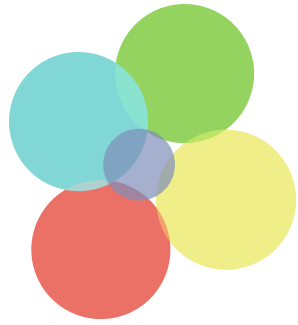


Focus group session (with *mostly* adults on the spectrum) around clinic improvements



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

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

Accessibility & Continuous Care/Support

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

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 & 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
- "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 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 AND parent
- Establish stronger ties with Nationwide & other providers.
- Establish more integrated communication channels between providers/extenders and programs

Social Interaction Opportunities

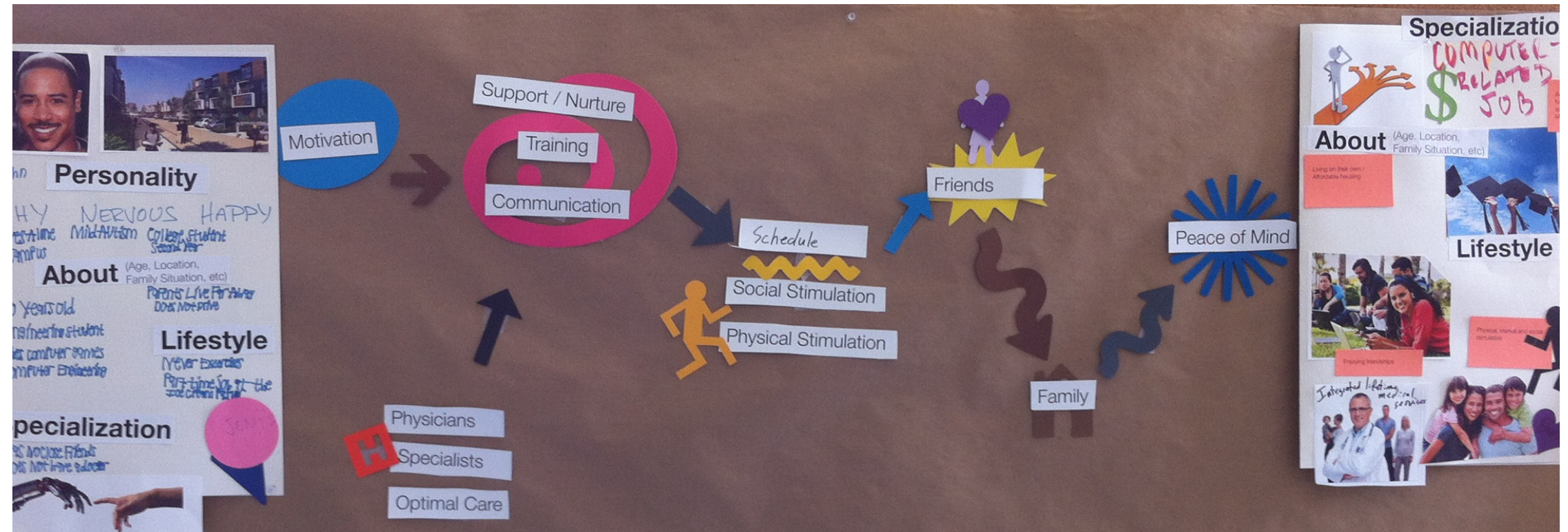
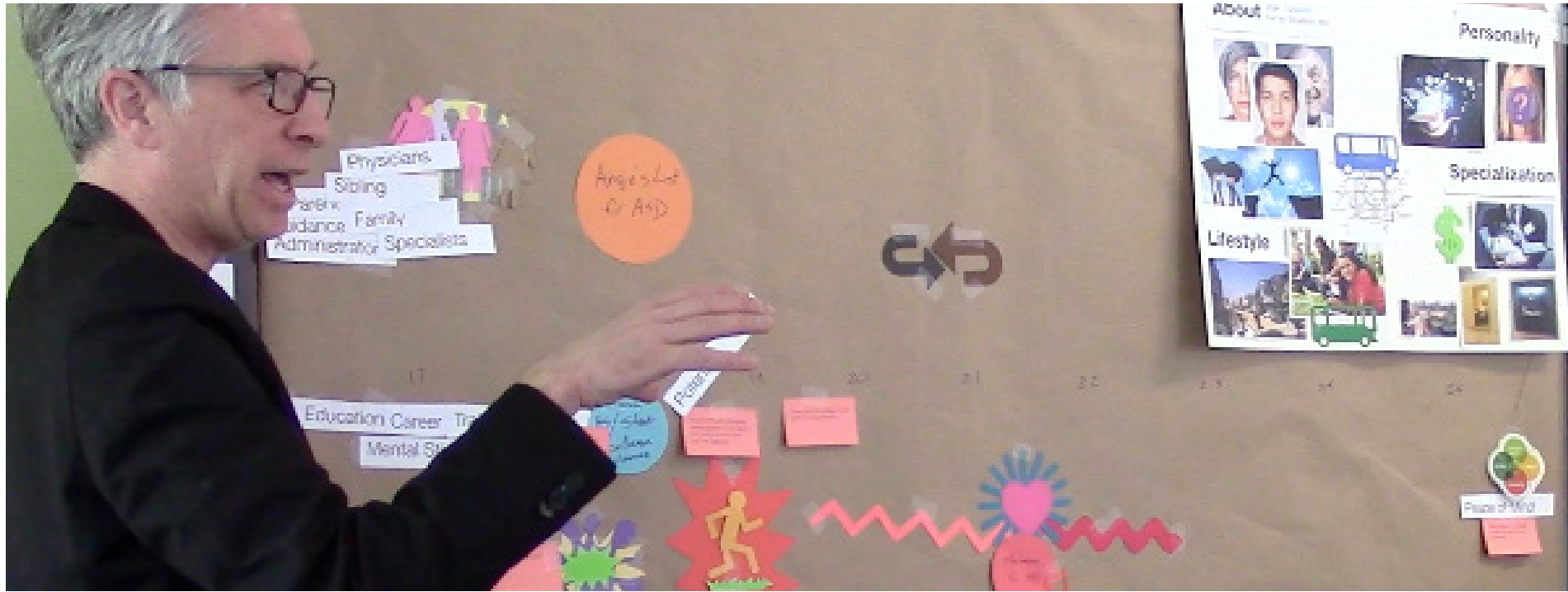
- Open/flexible communication modes inside and outside the clinic
- Infographics
- Text to speech programs on iPad tablets
- Integrated social, physical, and mental stimulation programs (safe and accessible recreation centers)

- 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/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 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?
- Univesal 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

- 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
- Tools and channels to help parents send out a 'cohesive message' while also recognizing that each child/adult on the spectrum is unique and has individual needs.
- Mainstream + special needs higher education (similar to Oakstone model): specialized spaces and learning opportunities & specialized services and expectations (beyond their graduates stocking shelves)



Photo(s) from workshop 2

OWEN'S LIST

Career/vocational

results: 1-6 of 12

- computer programmer, Tenn
- app developer, microsoft
- data entry
- library cataloger

search:

- level of education
- interests/abilities
- type of supervision
- supported/independent
- behavior support
- transportation

OWEN'S LIST

profile (create an account)

- Enrichment
- Education
- Housing
- Recreational
- Social
- Career/vocational
- Medical Care
- Respite
- Caregivers
- Crisis intervention

- zip code
- age
- funding
- sex
- behavior support
- comments level



OWEN'S LIST

Housing

Vugar Inn www.vugar.inn.com

Photo(s) from workshop 2

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.

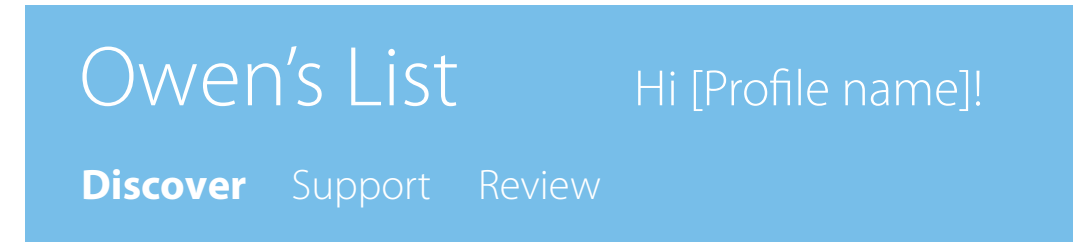
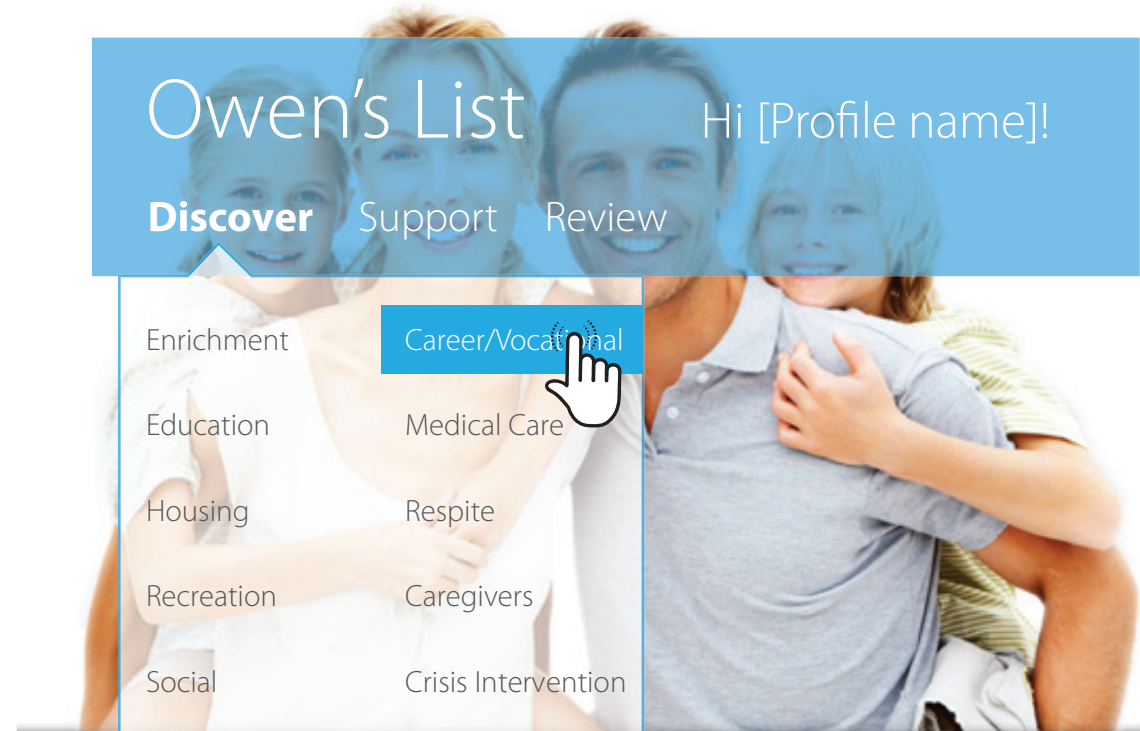
Next Steps

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.



NEAR

Long-Term Planning

- Tools to help providers & parents discover & reinforce child's specialized 'focus' & potential
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- More programs to help avoid or prepare for "The Cliff" after a child on the spectrum graduates from high school
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LONG

Improved Navigation

- Software & social program/directory
- Increase 'buy-in' from outside physicians requires:
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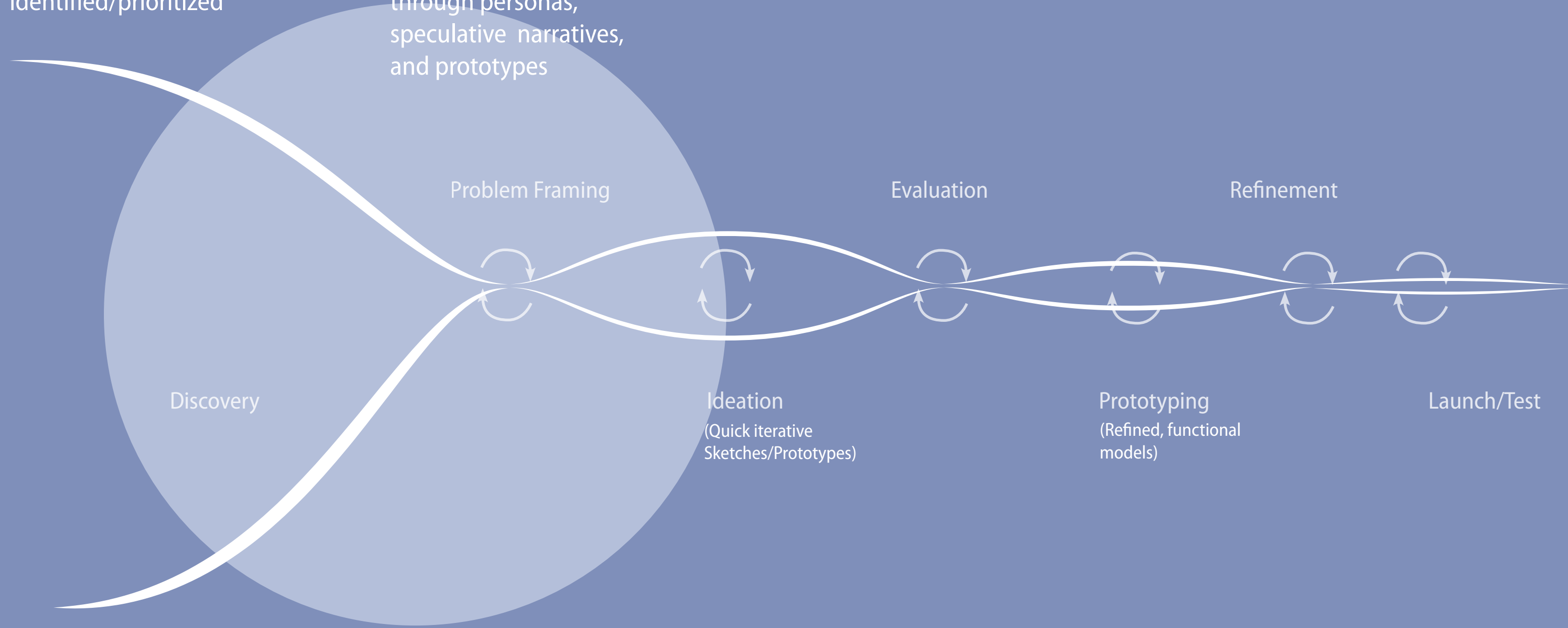
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Phase 1

Needs, opportunities and gaps identified/prioritized

Phase 2

Opportunities explored through personas, speculative narratives, and prototypes



Phase 1

Needs, opportunities and gaps identified/prioritized

Phase 2

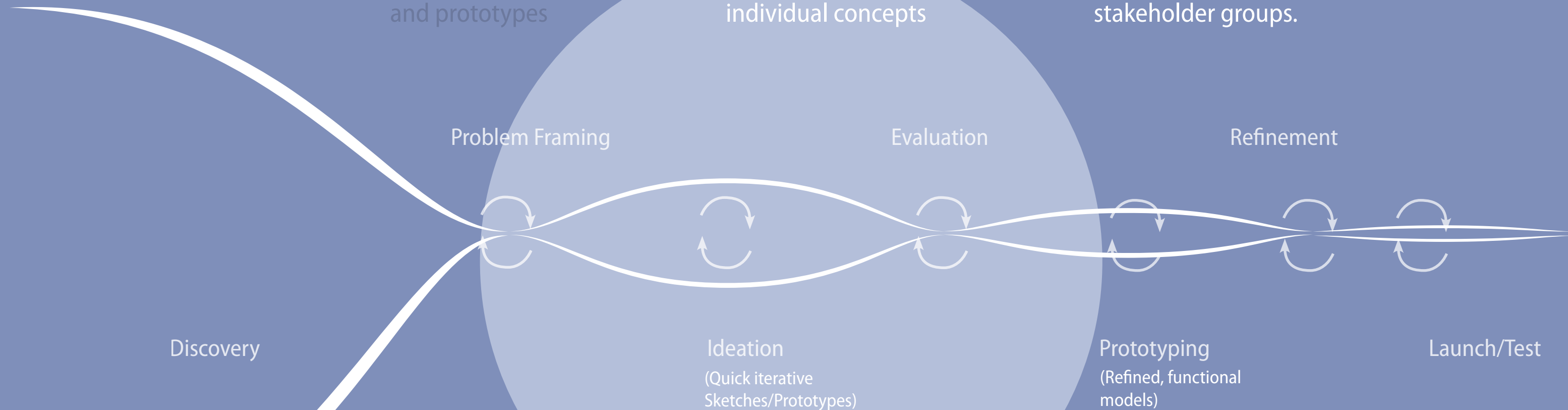
Opportunities explored through personas, speculative narratives, and prototypes

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.

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

erikabraun@gmail.com | braun.132@osu.edu

