Co-Designing with Communities

Liz Sanders, Ph.D
The Ohio State University

•

Erika Braun
Collective Design Initiative

•

Sapna Singh
Collective Design Initiative

Community Engagement Conference | The Ohio State University | January 24, 2018
Aging
Autism
Diabetes
The Department of Design
MFA in Design Research and Development

AGING
Co-Design Studio 2015: Future Aging and Social Engagement
Co-Design Studio 2017: Future Aging and Social Engagement
MFA Thesis 2018: Adam Fromme

AUTISM
MFA Thesis 2016: Erika Braun
Grant 2017: Discovery and NCH Pilot Grant

DIABETES
Co-Design Studio 2016: Living with Type 2 Diabetes
What is Co-Design?
What is Co-Design?

Co-design is an approach to design that actively involves all stakeholders in the design process to help ensure that the result meets their needs and is usable.

Also referred to as participatory design, at the heart of this understanding is the notion that we should therefore not be designing for people, but rather, designing with them.
Co-Designing with the Aging Population

In collaboration with Ohio Living Westminster Thurber
The Co-Design Studio: Co-Designing with the Aging Population

- Invite graduate students from all over OSU via a poster
- Bring in expert speakers from OSU and the community
- Students generate topics and form teams
- Students team up with co-designers around the chosen topics
- The co-designing teams explore, prototype and iterate
- The topics usually change
- The teams continue toward a design concept or solution
- The co-designers present together
The graduate students’ disciplines:

- Arts Administration, Education and Policy
- Fisher College of Business
- Industrial and Systems Engineering
- Public Health
- Occupational Therapy
- Design
Co-Design Studio 2015: Future Aging and Social Engagement

**Shoe shopping:** Finding the perfect fit

**Co-designing capes:** Reciprocal generativity

**Deciding where to spend the rest of your life:** A decision-making tool for seniors and their families.
The Physical Mobility Team

Diary Entry #1:
What kind of work did you do before retiring?
What did you like about it?

Diary Entry #2:
When you want/need to go somewhere, how do you get there? What do you have to do to arrange travel?

Diary Entry #3:
What is an activity that you used to enjoy that you feel is limited by your current circumstances? What is that limitation?

Diary Entry #4:
Please describe a typical day in your life (from morning to bedtime).

Q&A: (please circle and/or fill in the answer)

Diary Entry #7:
What is your favorite thing to do these days?
Co-Design Studio 2015
Co-Design Studio 2015
Co-Design Studio 2015
Co-Design Studio 2015
Co-Design Studio 2015

Uncertainty / patterns / insights

Clarity / focus

Senior-Centered Decision Making

Apartment Usability / Layout

We Are Here

Research

Concept

Design Solution(s)
Ladies and Gentlemen, Boys and Girls, Children of all Ages!!

Over the past couple of weeks while the Student Team was out playing, the Senior Team was slaving over our joint project! Just another example of how easily kids can get distracted from the primary task!! We had two meetings and a really heavy homework schedule! But extreme dedication and pure perseverance paid off and we made modest progress without our sister team!

At the last meeting (last Tuesday) I was elected (coerced) to write an introduction and assemble all our collective efforts up to now into a single Word document. Once I agreed to that they let me up and everyone left me with little other guidance. So I feel free to do or write whatever I please.

Here is what I have decided to do: I am going to briefly summarize our work over the past two work sessions, assemble the products of our effort just as they were forwarded to me, and share some other information I stumbled on to which you might want to fold into your equation somewhere. There probably will not be much surprise in what you are getting since I think most of what is here, except for these summary
Co-Design Studio 2015
Co-Design Studio 2015
Co-Design Studio 2015

Prelude
Pathmaker for your retirement move.

Name this "scenario"
The 3rd Act

Your nickname:
Sue

Decision Maker
Spouse/Partner
Child
Friend
Relative
Co-Design Studio 2015

Logistics
Give us the specifics

Health
What ranks as important? Hold and drag each consideration

Results
Summary

Resources
Local info agency on aging

Case Study: Interview

How do you feel about moving?
Pick Three

Finances
How much do you know?

How confident are you in your financial retirement?
Co-Design Studio 2015
The graduate student disciplines:
- Arts Administration, Education and Policy
- Fisher College of Business
- Industrial and Systems Engineering
- Psychology
- Design

From eight countries:
- India
- China
- Indonesia
- Turkey
- Kuwait
- Australia
- USA
Co-Design Studio 2017

**Passport:** a program to help with new resident onboarding

**Event planning:** helping residents use the Ohio Living Westminster Thurber community

**Mentoring programming:** how to develop and implement a mentoring program for new residents to Ohio Living Westminster Thurber

**Senior and driving:** when is it time to give up the keys?

**New map:** for Ohio Living Westminster Thurber
The public space and physical ability team
Our Starting Point (week 1)

- Public space
- Memory
- Activity
- Fall prevention

- Hearing loss
- Mobility
- Daily activities
Co-Design Studio 2017
Our Direction

Our codesign sessions allowed us to dwell on these issues.

The recurring topic was driving.
How to start a conversation on driving, mobility and aging
How to start
a conversation on
driving, mobility
and aging

A tool for assessment of ability
Adam Fromme, Gretchen Alexander, Chris Allen, Maggie Moove,
Bob Roth, Jianxu Willard, Ardiyanto, and Trisha Shah

Table of Contents

So, what is this and how do I get started? .................................. 7
The Pretest ............................................................................ 17
Session 1 Vision ...................................................................... 21
Session 2 Hearing .................................................................... 43
Session 3 Physical mobility .................................................... 51
Session 4 Cognitive function .................................................. 66
Session 5 Support ................................................................... 82
Action .................................................................................... 96
Next Steps ............................................................................. 102
Did you know
In 2014, more than 236,000 were treated in emergency departments for motor vehicle crash injuries.

In the age group 80 years and over, one in three people have vision less than the legally required driving standard. It is projected that, by the year 2051, there will be at least double the number of elderly people and thereby an increase in the number of people with impaired vision.
**General vision information**

People over age 60 should have dilated eye exams yearly. During this exam, the eye care professional will put drops in your eyes to widen (dilate) your pupils so that he or she can look at the back of each eye.

This is the only way to find some common eye diseases that have no early signs or symptoms. If you wear glasses or contact lenses, your prescription should be checked, too.

See your doctor regularly to check for diseases like diabetes and high blood pressure. These diseases can cause eye problems if not controlled or treated.

If you or your loved one is over the age of 60, talk about these symptoms:
- a) Suddenly cannot see or everything looks blurry
- b) See flashes of light
- c) Have eye pain
- d) Experience double vision
- e) Have redness or swelling of your eye or eyelid

**Common eye problems**

**Glaucoma**

**How it affects your driving**

Glaucoma often comes from too much fluid pressure inside the eye. If not treated, it can lead to vision loss and blindness. People with glaucoma often have no early symptoms or pain. You can protect yourself by having dilated eye exams yearly.

**What can be done**

Glaucoma can be treated with prescription eye drops, lasers, or surgery.
Test 1
How To Test Your Eyes With This Amsler Grid

Hold this page at arm’s length and cup one eye.

---

Test 2
Ishihara Color Vision Test
Session 5 - Support

Why these 4 discussions?

We identified 4 types of support. Each type relates to driving in its own way, but together they will help inform you when decisions need to be made about your older adult in the Summary Section.

The four types of support are:

Financial
  What is the cost of ownership?
Caregiver
  Who can help?
Location
  What support is in your area?
Social
  How else can you meet your social needs?
Downloads of the PDF are available at

\[ \text{design.osu.edu/6400drivingbook} \]

The book will be distributed by the Ohio Department of Transportation in 2018.
An Age-friendly Evaluation Tool for Public Places
Adam Fromme MFA 2018

Co-designed with older adults
To be used by older adults
Now collaborating with Age-friendly Columbus to certify local businesses as age-friendly places.
Framing the Wicked Problem of Transitions for Adults with Autism

MFA Thesis

In collaboration with OSUWMC, Nationwide Children’s Hospital, Caregivers, and Adults with Autism
The project began with exploring the unmet needs and opportunities tied to OSUWMC’s CAST (Center for Autism Services and Transitions)

*but that’s not where we ended up...*
What we discovered was that in order to best serve our patients with autism during the transition process (from adolescent to adulthood), we need to develop service offerings, tools and processes that go beyond fixing physical ailments and the physical environment of the clinic,

to helping people living with autism reach their maximum potential outside the clinic.
“We have a lot of ideas. What we don’t have is cohesion and shared understanding across stakeholder groups to define unique opportunities that could be implemented to create an ideal transition and clinic experience.” - Chief Innovation Officer for OSUWMC’s Idea Studio
There were **many ideas but little convergence** around which ideas would have the greatest impact on stakeholders.

Individuals with autism did **not have a platform** to voice their needs and ideas.

There was **little communication** between NCH and CAST providers.

There were many **needs** of patients/families that had **not yet been fully addressed**.
**Initial Questions to be Explored**

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

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

How can we **vet and prioritize collective goals/ideas**?

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

9 Parents
With children on different ends of the spectrum

9 Adults with Autism
Who could consent for themselves

Caregivers (Parents)
Adults with Autism
OSUWMC Healthcare Administrators
Healthcare Providers (CAST)
Healthcare Providers (NCH Child Dev. Center)
Typical Design Approach

Discovery

Framing

Ideation

Evaluation

Prototyping

Launch
Instead of jumping into brainstorming ideas for the clinic, we broadened our scope and began at the discovery phase to collectively understand the context of the problem for reframing.
DISCOVERY
- Priming Homework (Prep and Reflect)
- Method Cards

Framing
- Understanding unique perspectives by looking at transitions through different lenses.
- F2F Interviews
- Focus Group
- Focus Group

Ideation
- Initial Ideas
- Needs / Wants & Concerns
- Presentation created by each stakeholder group to elicit empathy
- Problem Probing
- Cluster Mapping
- Opportunity Finding Workshop
- Analysis Prioritization of Wants/Needs
- Ideation Workshop
- Persona Profiles Futuring Scenarios Prototyping
Generates ANXIETY
Making it almost impossible to SOCIALLY INTERACT
Making it hard to CONCENTRATE
Causing OVERSTIMULATION
Heightening SENSORY SENSITIVITY to sounds, lights, and touch
Which causes STRESS
Fear of SOCIAL INTERACTION

Negative Feedback Loop (self-fulfilling prophecy)
Opportunity Finding Workshop

We co-design many ideas including:

- A Resource Platform
- Connected Care Team Model
- Social Gaming Platform

Ideation Workshop
The workshop with adults with autism and the Opportunity Finding Workshop with all stakeholders changed the direction of the project from focusing just on the clinical setting, to the broader needs of transitioning adults that extended beyond the environment of the clinic.
“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.
Outcomes

We can create true value in the new clinic and make it sustainable by:

- Understanding the patient’s **holistic needs** (not just medical)
- Bringing in **social workers** and other extenders/connectors to help patients and families navigate the transition process and care needs
- **Improving training and awareness** within/outside the clinic for a more patient-centered model and increased access to quality care
- Providing **resources** in the clinic that help to **connect** adult patients to **housing, socialization, and employment opportunities**
Intangible Outcomes

Pre and post assessments demonstrated increased empathy and understanding about transition challenges for different stakeholders, and the feeling of empowerment to make improvements to the system.

Hospital administrators, providers, and parents benefited from hearing the needs and wish fors of patients with autism, directly from patients with autism.

“Nothing about us, without us.” - Justin, an adult with autism

The adults with autism felt heard, their ideas and thoughts valued and equal to that of the other stakeholders collectively participating in the workshops.
Future Possibilities

**Product, environment and service concepts** were imagined. Many of the ideas touched on topics like: **Navigation and Care Coordination, Socialization, Long-term Planning, and Improved Access to Quality Care**, which could be carried out and further developed in future projects and research studies.

Next Steps

**As a continuation of the work done for the MFA Thesis**, we received a grant to explore key opportunities connected to many of the topics above, **in the context of healthcare transitions** from pediatric care (NCH) to CAST, and from CAST out to specialists and other General Practitioners.
Co-Designing Processes & Solutions for Healthcare Transition in Autism

Continuation • Sponsored • Discovery & NCH Pilot Grant

In collaboration with OSUWMC, Nationwide Children’s Hospital, Caregivers, and Adults with Autism
Research Questions

What is the current healthcare transition process from NCH to CAST?

What could/should a future, ideal transition process look like? What tool(s)/resources/services are needed?

With an rapidly growing patient population at CAST, how can we equip our patients with the ability to be able to get care anywhere?
Participants

- Patients with Autism
- Caregivers (Parents)
- OSUWMC (CAST)
- OSUWMC Physicians
- Nationwide Children’s Hospital

7 Parents
With children on different ends of the spectrum

- 2 Adults with Autism Who could consent for themselves
- 3 Internal Medicine GPs
- 2 Pediatric Psychologists (NCH)
- Medical Director (CAST)
- 2 Nurses (CAST)
- 2 Pediatric Psychologists (CAST)
- Program Coordinator (CAST)
- Administrative/Triage Associate (NCH)
- Lean Process Specialists (NCH)
- 3 Social Workers (NCH)
- Social Worker (CAST)
- 2 Adults with Autism
- Resident (NCH)
- Developmental Pediatric Physician (NCH)
- 1 Diabetes Transition Coordinator from NCH
- OSUWMC Physicians
**Approach**

**Multiple One-on-One Interviews & Co-design Workshop Sessions**
To understand stakeholder needs and together generate new solutions/ideas for a more ideal process.

**Iterative Prototyping**
To validate and refine ideas. Ideas were constructed on paper during the sessions and brought into the following sessions for feedback and iterative development.
What We Learned

The current single-path approach feels more like a **transfer** than a **transition**.
What We Learned

The ideal is a multi-path approach with options for different types of patients, with differing needs, which leverages the value of saturation and parallel care, with increased care coordination touch points.
What We Learned

Multiple Dimensions of Healthcare Transitions

1. **Patient-Centered Care** (y-axis)
2. **Education and Outreach** (z-axis)
3. **Level of Support/Independence** (x-axis)
Current insights and challenges mapped to the current journey

“How Might We” opportunities mapped to a future ideal journey
Outcomes

We developed a **standardized, yet customizable** process and set of tools for transitions that:

- **Assesses, measures and tracks** changes/patterns in patients overtime (pre, during, and post transitions)

- **Involves patients (and caregivers)** in shared decision-making, future planning, and goal setting to encourage/support self-advocacy and mastery of skills for individual success and the ability to get care anywhere
A **new process** (with increased care coordination touchpoints) and **system of tools** is currently being **prototyped and tested** at CAST to measure patient progress through transitions and their ability to get care anywhere post-transitions.
Healthcare Transition Toolset

- **Creates engagement** in the transition process through the integration of visual materials, starting with a visual guide of the process
- **Educates** patients and caregivers in the process of transitions
- **Facilitates** open discussion around goals/concerns and shared decision-making for long-term planning
Healthcare Transition Toolset

- **Encourages goal-setting and mastery** of skills necessary for transitioning into adult care, building self-advocacy, and getting care anywhere

- **Assesses current state, while also** providing patients, caregivers, and providers with a **plan of action**

- **Potential to generate revenue** for the clinic through the process and toolset
Intangible Outcomes

Captured the **tacit knowledge** about transition care held by various providers

Brought providers from **NCH and OSU** together to **collaboratively assess** the current processes, identify overlaps/misalignment, and explore future opportunities together

Involved caregivers and adults with autism in the process of not only expressing unmet needs but **co-designing solutions** for transitions
Next Steps

**Prototyping** the New Transition Process and Assessment Tool to determine changes (emotional, functional, etc.) in transitioning patients overtime.

Exploring capabilities of integrating the **assessment tool into MyChart** so progress and milestones can be shared across providers and care supporters.

Developing **Educational Resources And Outreach Programs** that facilitate continual learning and the creation of peer-to-peer networks for organic learning among patients, caregivers, and/or GPs.

Exploring capabilities of a **Gamified Responsive Website** to help individuals with autism practice self-advocacy and master skills (from assessment) needed for getting care anywhere.
Co-Designing Solutions for Diabetes Care

Interdisciplinary Co-Design Course

In collaboration with those living with Type 1 diabetes, parents, healthcare providers and medical device companies
This collaboration came about through Design 6500, a co-design studio course taught by Prof. Liz Sanders.

**Goals**

To bring young people living with Type 1 Diabetes (T1D), parents, healthcare providers and others directly into a co-design process with the students in order to:

- Understand the current experience of growing up with and living with T1D and
- Use co-design to imagine and express concepts for future experience that could improve the lives of those living with T1D.
DISCOVERY
- Learning from Experts
- Experiential Immersion
- F2F Interviews
- Focus Groups

FRAMING
- Identification of Themes
- Circles of Care
- Opportunity Framing

IDEATION
- Ideation Workshop
Guest Speakers

- Dr. Kathleen Wyne, MD PhD, Associate Professor, Endocrinologist from OSUWMC
- Katie Thivener, OSU Senior with T1D who is heading up the OSU chapter of the College Diabetes Network
- Marco De Polo, Anja Seybold and Keith Verner, Roche Diagnostics Operations, Inc. Diabetes Care
- Colleen Rinehart, Diabetes educator from OSUWMC who has T1D
- Dr. Elizabeth Buschur, T1DM Transitions Clinic from Nationwide Children’s Hospital
- Dr. Andrew Wapner, Director of the Center for Public Health Practice at OSU’s College of Public Health and pediatric expert
- T1D/T2D confusion
- Education
- Transitions
- Connections across the circles of care
- Building empathy for others in the circles of care
- Mental health
- Nutrition
- 24/7 management
- Support for the inner circle
Experiential Immersion

Students got first hand experience using diabetes monitoring devices provided by Roche.
Circles of Care

Interviews conducted for better understanding of the circles of care
<table>
<thead>
<tr>
<th>Inner Circle</th>
<th>Healthcare Providers</th>
<th>Communities</th>
<th>Business + Government</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zach, Besma, David,</td>
<td>Travis, Mae, Laura, Kathleen</td>
<td>Tally, Abel, Caroline, Darwin</td>
<td>Erika, Becca, Sapna, Anna</td>
</tr>
<tr>
<td>Josh</td>
<td>Physicians</td>
<td>Teachers</td>
<td>Medical device manufacturers</td>
</tr>
<tr>
<td>Moms</td>
<td>Nurses</td>
<td>Coaches</td>
<td>Suppliers</td>
</tr>
<tr>
<td>Dads</td>
<td>Social workers</td>
<td>School nurses</td>
<td>Pharmacy benefit managers</td>
</tr>
<tr>
<td>Significant others</td>
<td>Mental health practitioners</td>
<td>Other students</td>
<td>FDA</td>
</tr>
<tr>
<td>Siblings</td>
<td>Diabetes educators</td>
<td>Co-workers</td>
<td>Government</td>
</tr>
<tr>
<td>Close friends</td>
<td>Dietitians</td>
<td>Bosses</td>
<td>Insurance companies</td>
</tr>
<tr>
<td>Other close family</td>
<td>Pharmacists</td>
<td>Larger group of friends</td>
<td>Policy makers</td>
</tr>
<tr>
<td>members</td>
<td>Dentists</td>
<td>General public</td>
<td>Non-profit organizations</td>
</tr>
<tr>
<td></td>
<td>Health coaches</td>
<td></td>
<td>Advocacy groups</td>
</tr>
</tbody>
</table>
Co-Design Workshop

All four teams with 40+ workshop participants that included T1D patients, inner circle of care, community members, healthcare providers, medical device company representatives
Type 1 Diabetes and Inner Circle of Care

Co-Designing and Educational Insulin Pump Game:
The co-design team worked with Certified Diabetes Educator Eileen Faulds at OSUWMC to help bring her vision of a simulation game that can teach diabetics about pump use.

During the workshop, the team explored three different scenarios that would be part of the simulation game:

- Exercise
- Hypoglycemia
- Site occlusion / DKA

The co-design activities focused on the scenarios in the game and how the game is delivered.
Co-Designing an Educational Insulin Pump Game with Type 1 Diabetes

“Leaving the workshop that night, I had such a sense of empowerment and appreciation for the community where I live and work.”

- Eileen Faulds

“The experience gave me insights and ideas that I wouldn’t have been able to get from anyone else; from the language the students used to the scenarios we enacted.”

- Jeremy Patterson
Type 1 Diabetes Awareness in the Community
Envisioning the Future - Journey Map for a Type 1 Diabetic in Middle School

Guiding Principles

- Foster and build a culture where the message could influence the environment and vice-versa
- Create policies to improve the educational experience of T1D's
- Continue to use technology as a tool to spread information and increase T1D literacy

Type 1 Diabetic Journey

- **Stages**
  - Home
  - Bus
  - Classroom
  - Cafeteria
  - Classroom
  - Sports
  - Home

- **Caretaker**
  - Parents
  - Bus Driver
  - Teacher
  - Nurse
  - Coach
  - Parents

- **Technology**
  - Sync Data
  - Digital Bulletin Board

- **Experience**
  - Blood glucose levels is easily synced and shared between caretakers and doctors

- **Doing**
  - Checks blood glucose (BG) for continuous glucose monitor (CGM)
  - Takes insulin
  - Eats breakfast
  - Talks with parent about plans of the day
  - Have to be on top of my BG levels today or coach won't let me play
  - Excited to play in the soccer tournament later
  - I hope I didn't leave my biology homework at home!
  - Happy to see friends
  - Should I get the sweet potato or not?
  - Hungry
  - Tired

- **Think**
  - Checks CGM
  - Takes insulin
  - Checks school food app for nutritional information
  - Takes lunch
  - Checks CGM
  - Visit nurse's office, asks for snack recommendations for the game later
  - Talks to coach before game
  - Talks to the student their BG levels are good and they should be able to play
  - Eats before the game
  - I wonder if I'll score today
  - Tired

- **Feel**
  - Checks blood glucose (BG) for continuous glucose monitor (CGM)
  - Takes insulin
  - Eats dinner followed by a snack before bed
  - Talks to parents about game and maintaining BG levels

**Policy**

- New laws to the Family Medical Leave Act (FMLA) will give parent the opportunity to temporarily take care of their kids even if they haven’t been employed with their employer for 12 months
- All Bus Drivers are required by law to get T1D training when they take the Commercial Driving License (CDL) with the 5 (School) and P (Passenger) endorsement
- T1D education is integrated into school curriculum
- Each school in a district will be required to have a Licensed Practical Nurse (LPN)
- T1D should be incorporated in the Individualized Education Plan (IEP) of each student the student comes in contact with
- All Coaches will be required by law to have extensive T1D training in order to better understand the...
Type 1 Diabetes and Outer Circle of Care

The co-design team explored the ideal healthcare system for three critical transitions for T1D patients: Diagnosis, Going to College and Pregnancy
Type 1 Diabetes and Outer Circle of Care

The co-design team identified the need for a Medical Home that connects the T1D patients to all the required resources.
Next Steps
Next Steps & Future Possibilities

- Spring 2018 Co-Design Studio focused on the ICU
- Return to Ohio Living Westminster Thurber for Co-Design Studio 2019
- Developing products and services for implementation
- Future collaborations for other healthcare areas
Thank you!

Questions?

Liz Sanders | sanders.82@osu.edu

Erika Braun | erika@collectivedesign.us

Sapna Singh | sapna@collectivedesign.us