



LUCI

Community-Based Participatory Research

Feasible solutions to real world problems require intense, often messy, engagement with the people and problems that lie at the heart of these projects.

Enter CBPR

Three basic principles:

- collaborative enterprise between researchers and community members
- validates multiple sources of knowledge and promotes multiple methods
- goal is social action/change → enhancing social justice

Action Research

“comparative research on the conditions and effects of various forms of social action and research leading to social action” that uses “a spiral of steps, each of which is composed of a circle of planning, action, and fact-finding about the result of the action.”

LEWIN, K. 1946. Action research and minority problems. *Journal of Social Issues* 2(4): 34-46.

LEWIN, K. 1948. *Resolving social conflicts*. New York: Harper.

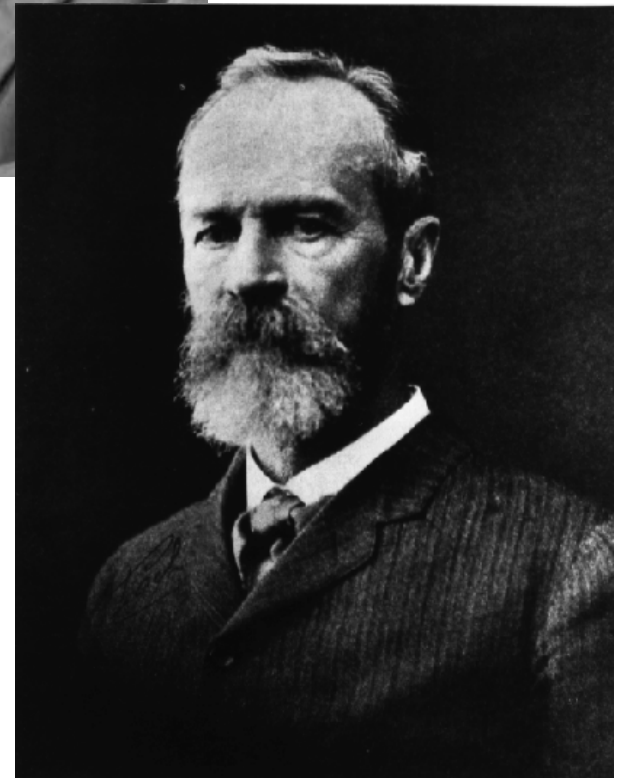
Pragmatism

science is complex,
humanly
meaningful, and
available to
everyone



DEWEY, J. 1976. *Essays on logical theory.* 1902-1903. (A. Boydston, ed.) Carbondale: Southern Illinois University Press.

JAMES, W. 1948. *Essays in pragmatism.* New York: Hafner.



“There is nothing so practical as a good theory.” – Kurt Lewin



Holistic and humanistic approach to research

Approach to work and ideals of research that became action research

AR differs in its ontological,
epistemological, and
methodological commitments:

the researcher is in *partnership*
with the research participants in
evolving research.

AR as Scientific Inquiry

Action is a means for developing knowledge.

Influence by researchers is an inevitable part of the social construction of scientific knowledge – not a “bias” or “contaminant.”

Local contexts and local solutions are privileged over generalizable results.

An example...

Innovative Technologies for Autism

Autism

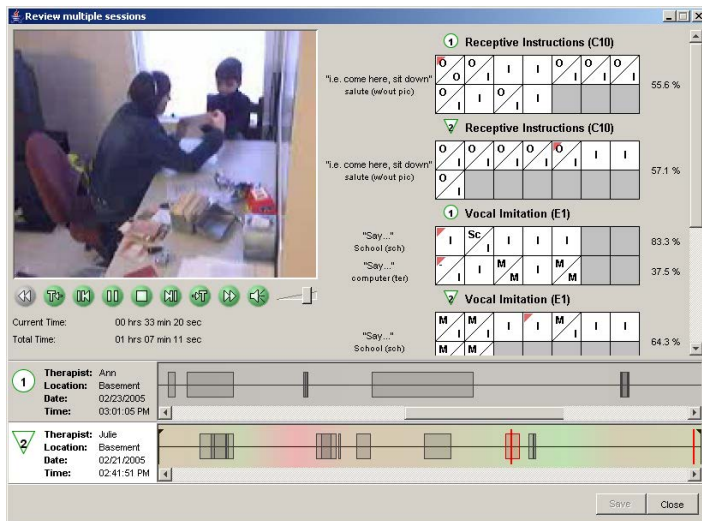
A developmental disability impacting language, socialization and behavior

Typically diagnosed in first 3 years of life, often after typical development

Prevalence estimated at 1 in 110



Early Work: Technologies for Treatment and Monitoring of Autism



Abaris

Hayes *et al.* Ubicomp 2004
Kientz *et al.* Ubicomp 2005
Kientz *et al.* CSCW 2006



CareLog

Hayes *et al.* CHI 2006
Hayes *et al.* CHI 2008

Visual Schedules



can help build

- security and trust
- motivation
- independence
- self-esteem



but they are hard to create, use, and manage

HODGDON, L. A. *Visual strategies for improving visual communication: Volume 1: Practical support for school and home*. Quirk Roberts Publishing, 1999.

MESIBOV G.B., BROWDER, D.M., and KIRKLAND, C. Using Individualized Schedules as a Component of Positive Behavioral Support for Students with Developmental Disabilities. *Journal of Positive Behavior Interventions*, 4(2): 73-79. 2002.

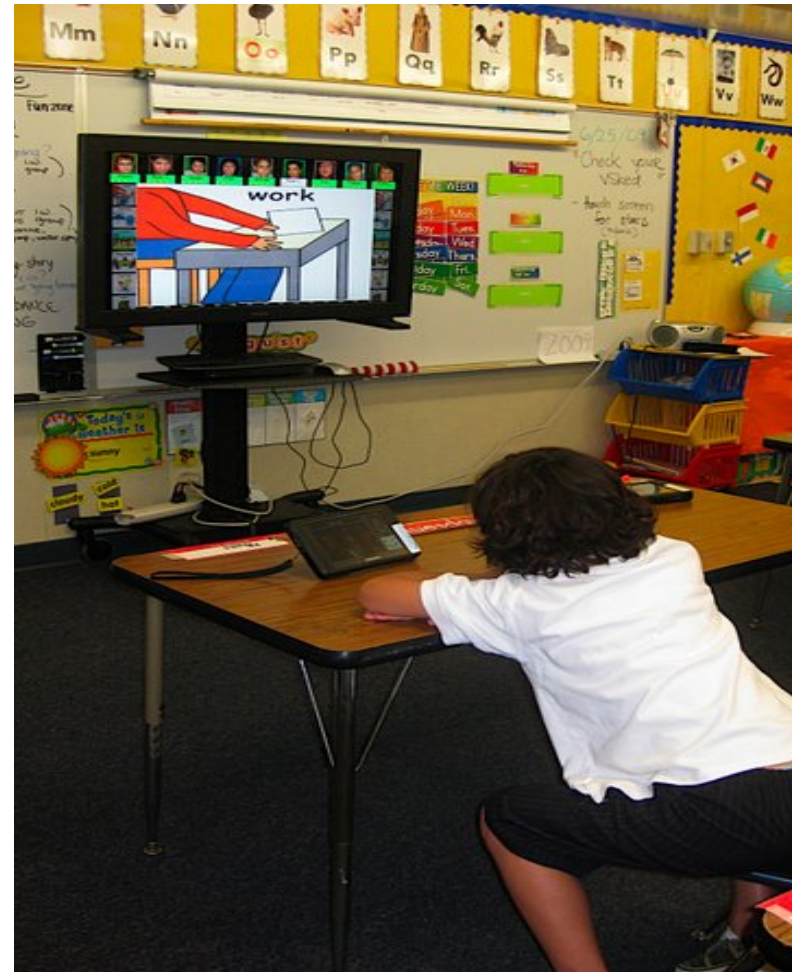
vSked: Interactive Visual Schedules

*with Lou Anne Boyd, Meg Cramer, Sen Hirano, Monica Tentori, Michael Yeganyan
and at various times Gabriela Marcu, Mohamad Monibi, and David Nguyen*

faster, easier
interactions

progressive
skill scaffolding

embedded
natural
record-keeping





vsked Teacher's View

Home | Students | Tasks | Graphs | Log Issues | Preferences

Your Tools: [Add Student](#) [Add Picture To System](#)

Your Class:

<p>Richard C DOB: 2000-01-02</p> <p>Notes:</p> <p>Delete Student / Edit Student / Change Picture</p>	<p>Frank L DOB: 2000-01-03</p> <p>Notes:</p> <p>Delete Student / Edit Student / Change Picture</p>	<p>Irene Y DOB: 2000-01-03</p> <p>Notes: Likes Swinging</p> <p>Delete Student / Edit Student / Change Picture</p>
<p>Romeo S DOB: 2000-01-04</p> <p>Notes:</p> <p>Delete Student / Edit Student / Change Picture</p>	<p>Alice B DOB: 2000-01-05</p> <p>Notes:</p> <p>Delete Student / Edit Student / Change Picture</p>	<p>Adam N DOB: 2000-01-06</p> <p>Notes:</p> <p>Delete Student / Edit Student / Change Picture</p>

Welcome to vSked

Irene

What month is it?

vsked Teacher's View

Home | Students | Tasks | Graphs | Log Issues | Preferences

Number of attempts per task over time.

Select a task:

Select a student:

[Refresh](#)

- Task Name: Calendar
- Student Name: Frank
- Description: This graph shows the number of attempts the student made on a particular task for each day they performed that task.

Days	Number of Attempts
2010-05-26	30
2010-05-27	10
2010-05-28	10
2010-06-02	10
2010-06-03	5
2010-06-04	5

vSke



Challenges to Community Participation in vSked

Changing design

Changing evaluation strategies, methods,
and goals

... but it's worth it!

We liked it so much, we went
back for more

The Social Compass

with Monica Tentori and Lou Anne Boyd

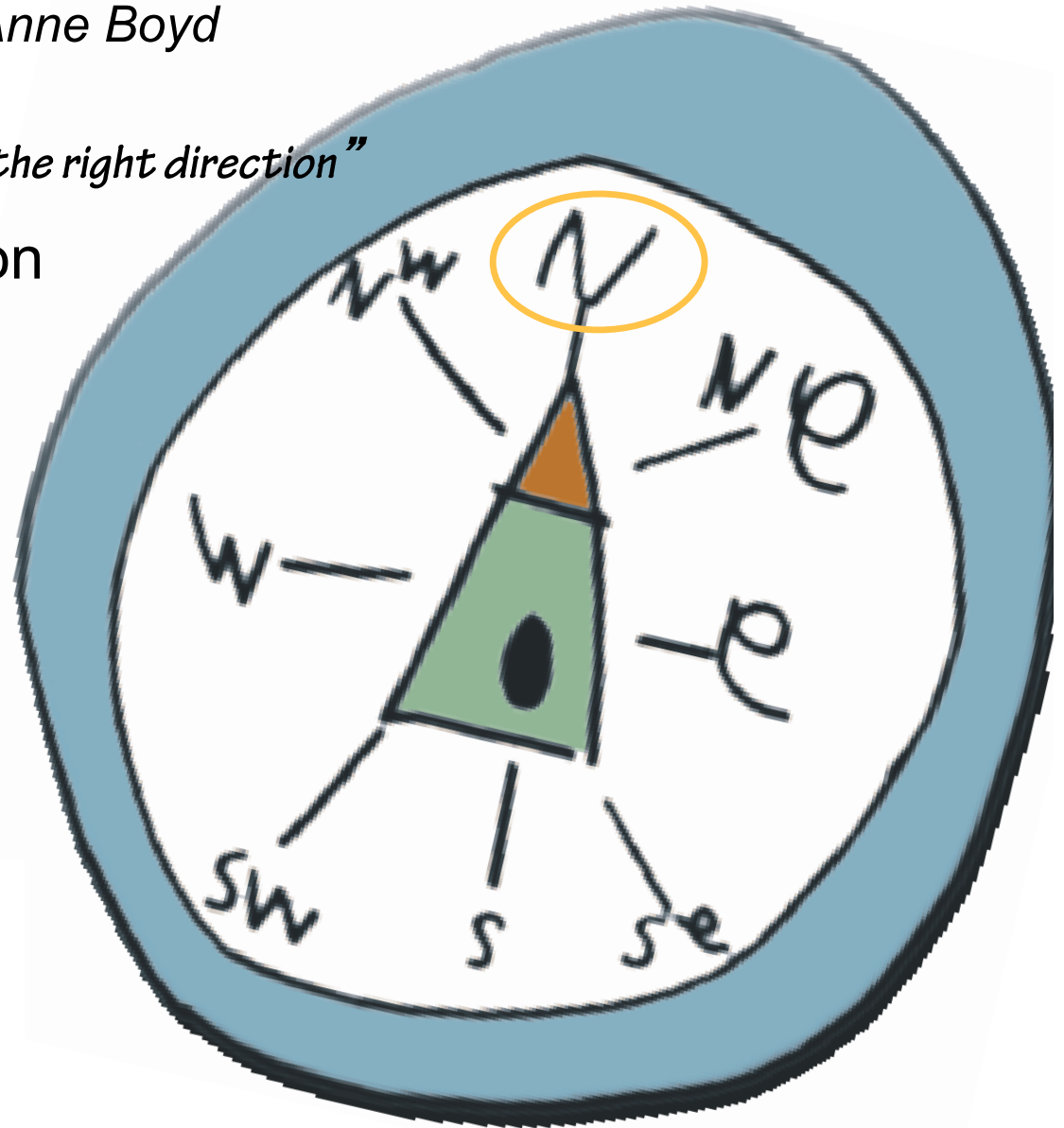
“steer the child in the right direction”

Nonverbal Communication

Emotion

“We” Skills

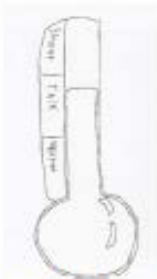
Social Problem Solving



1a. Body Language Binoculars



1b. Proximity Compass



1c. Voice -o-meter



1d. Glance Gauge

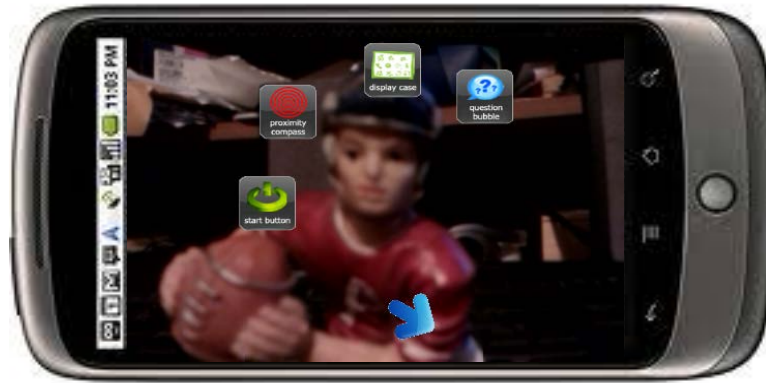
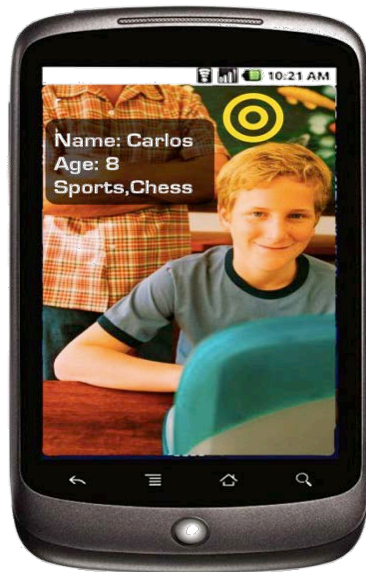
Understanding Social Skills Development of Children with ASD

Monica became trained in the Social Compass curriculum

For five weeks our team shadowed fourteen children during recess and lunch



Worked closely with community partners to evaluate the impact of the curriculum and design technological support for it



An interactive and mobile social compass

An augmented reality system to help children

- identify potential interaction partners
- augment stories with visual cues
- provide awareness of social missteps and
- tag memories

These are just slivers of the kinds of issues in schools and for autism

Working *with* children and adults with ASD not just *for* them

Looking at schools and classrooms more holistically in their approaches to technology
(see Meg Cramer...)

Doing CBPR & AR

with some colorful anecdotes from my own (research) life

- Developing research questions and problem statements
- Action and Intervention
- Evaluation
- Writing
- Moments of Celebration
- Leaving the Site
- Ethics

Research Questions and Problem Statements

Collaboratively constructed with research
partners,

especially when
you think
you know
best



Action and Intervention

Technological and organizational design
are “inseparable elements of the same
web of relationships”

GREENWOOD, D.J. AND LEVIN, M. 2007. *Introduction to Action Research*
2e. Thousand Oaks, CA: Sage Publications.

Solutions must be designed and
implemented democratically and
inclusively

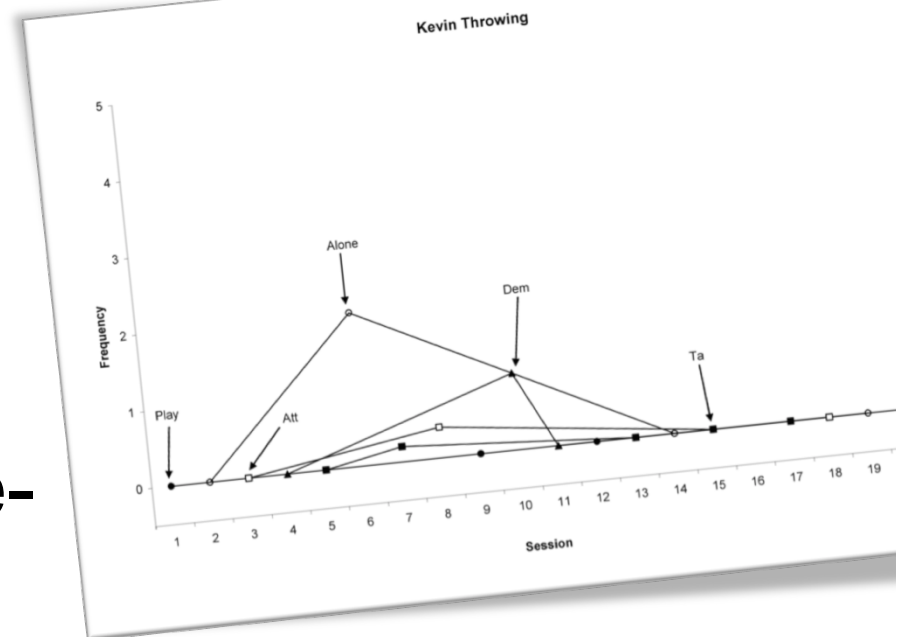
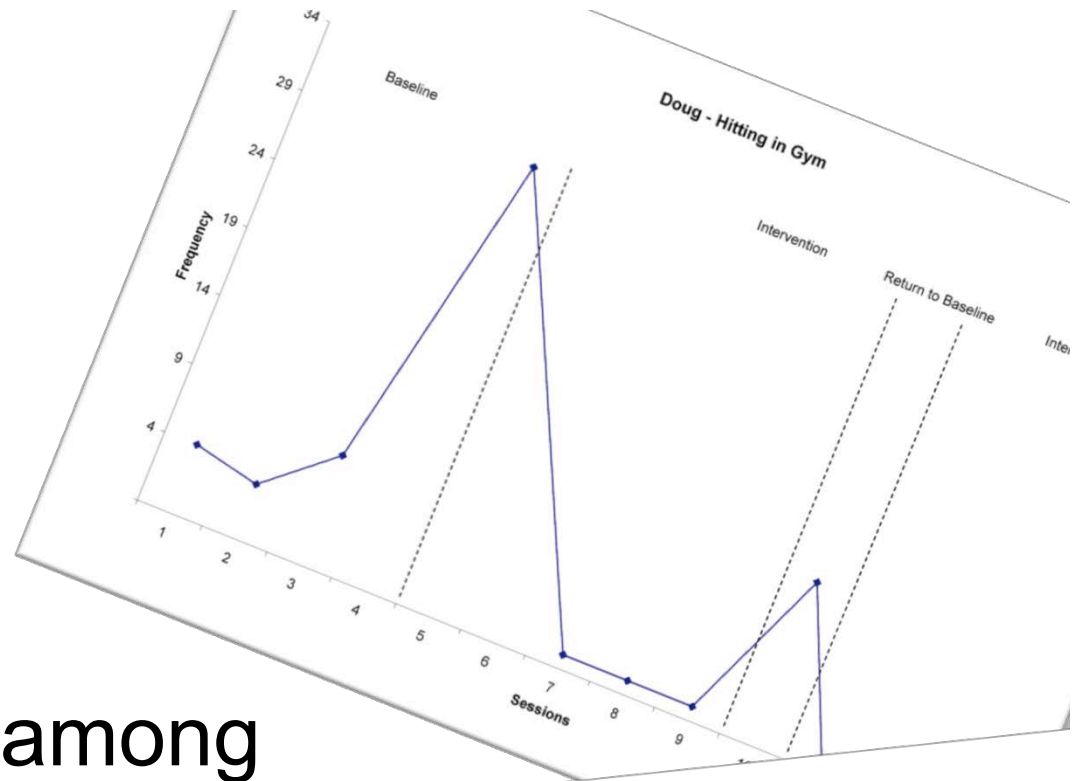
Learn *through* action; research over
design

Evaluation

Value-laden

Joint construction among all stakeholders

Seek ends that are acceptable to stakeholders, not pre-defined fixed metrics



Writing

Requires inclusion of community partners

Often includes creation of “non-academic” works

May necessitate working outside your comfort zone

Moments of Celebration

Long-term engagement is exhausting (for all involved)

With no clear end, intermediate goals should be marked



Leaving the Site

Sustainable Change

Can be very different from project to project and site to site

Ethics

Requires “standard” ethics

plus

Development of balanced power
relationships

Consideration of what action to undertake

Closing thoughts...

CBPR and AR require there to be a **research** element and that **change** be the central focus.

These approaches require long-term, meaningful, collaborative engagement with community **partners**.

It can be very hard, but well worth it.

Questions?

Upcoming:

Thursday – Start Final Presentations

Shameless Plug:

Come get free food and see what cool stuff
we are doing in autism and technology on
December 8:

[http://www.ics.uci.edu/community/events/
autismtechshowcase/](http://www.ics.uci.edu/community/events/autismtechshowcase/)

Your final paper...

Leaders as change agents

- Describe the concept of servant leadership using your own research and the readings.
- Using Paul Farmer and examples from your service site, describe some key characteristics of good leaders (and whether you see them as servant leaders).
- Reflect on your own views on servant leadership as a viable path to change.
- Use your other readings to talk about things Paul Farmer does well (or needs to improve) and that you and the leaders at your service sites do well (or need to improve). Examples of issues you could address include:
 - Using and gathering social capital
 - Cultural competency
 - Political action
 - Advocacy and protests

Pragmatics of your final papers

- Approximately 5-10 pages, double-spaced, 10-12 point font (Arial or Times New Roman)
- Professionally written (at a minimum, running it through grammarly should generate no major errors)
- Well cited (use references from your readings as well as things you dig up on your own).
- Due to TurnItIn.com by Friday Dec 14 at 5PM (I will send a link)

Grading Criteria

1. Do you clearly define servant leadership? Do you cover all of the characteristics of servant leadership?
2. Do you clearly relate other issues from your readings and research?
3. Do you state a compelling thesis? Do all the points in the essay relate to this thesis? Do you use reasoning and evidence to support your main points?
4. Do you engage in detailed analysis of your experience? Do you point to specific instances of your experiences in the field?
5. Is your paper clearly organized? Do topic sentences signal new ideas and does material in each paragraph relate clearly to that topic? Are ideas presented in logical order?
6. Do you use the English language appropriately and effectively? Are there errors of grammar, spelling, mechanics, or format? Do you find a consistent style and voice that clearly articulates your thoughts?