AIR-P Presents:

Systems Approaches in Autism Services Research
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Co-Director Academic Autism Spectrum Partnership in Research & Education
INTRODUCTION

• Research faculty Regional Research Institute for Human Services / School of Social Work; alumni PSU’s Systems Science program
• Founding Co-Director Academic Autism Spectrum Partnership in Research and Education (AASPIRE); initially from the community side
• Community-engaged research & practice, systems thinking, measurement, dynamics at the intersection of science, society, and technology
• Improving employment outcomes / extending anti-ableist & neurodiversity practices
• Science for social change!
AGENDA

• Systems Concepts
• Systems Methods
• Leverage and Intervention
• Wrap-up and Q&A
WHAT IS A SYSTEM?

Simple answer:
• A set of parts
• That inter/relate with each other
• Such that they create a whole
• Which exists in relation to an environment (with either an open or closed boundary)
WHAT IS A COMPLEX SYSTEM?

Systems with such complicated interrelationships between parts that it’s not possible to effectively predict their behavior or to understand them by examining the parts.

- Non-linearity and feedback
- Irreversibility
- Emergence and self-organization
- Adaptation
- Tipping points
SOME CHALLENGES INTERVENING IN COMPLEX SYSTEMS

• If you can’t predict the behavior of the whole by examining its parts or their individual relationships
  • How can you understand it?
  • How can you change its behavior?

• Need a holistic (i.e., non-reductionist) approach to problem-solving

• Need to think systemically—in whole-systems—even if it means giving up (due to the massive complexity) the goal of control

• (note this is distinct from thinking systematically…which may also be useful, but…)
“We can't impose our will upon a system. We can listen to what the system tells us, and discover how its properties and our values can work together to bring forth something much better than could ever be produced by our will alone.

We can't control systems or figure them out. But we can dance with them!”

-- Donella Meadows, *Dancing with Systems*,
https://donellameadows.org/archives/dancing-with-systems/
ISSUES OF COMPLEXITY IN AUTISM EMPLOYMENT INTERVENTION RESEARCH

• Messy, real-world setting
• Heterogeneity of autism, autistic people, workplace cultures, fields, jobs, etc.
• Interrelatedness of employees, employers, and supports/services, etc.
• Influence of public perception, public policy, attitudes toward autism, etc.
• Intersections between autism and other marginalized identities
• Unpredictability of the lives and contexts of employees and employers
• Unpredictability of the broader economic environment
ISSUES WITH REDUCTIONIST APPROACHES

• Reductionist (traditional) approaches tend to try to simplify, for example
  • Limiting to narrow demographics, job types, job settings, autism characteristics, etc.
  • Focusing on the autistic person as the intervention recipient
  • Limiting outcomes to those that can be measured more easily/cleanly/quickly
  • Assuming a stable environment / context
  • Ignoring real-world application and dynamics over time like…

• Will teaching someone how to behave in a neurotypical manner in a certain kind of HR interview have any positive impact and/or no negative impact on their ability to be successful in the job or in the future?

• In other words, is a typical HR interview a point of leverage?
LEVERAGE POINTS: PLACES TO INTERVENE IN A SYSTEM

“…places within a complex system…where a small shift in one thing can produce big changes in everything.”  –Meadows

Understanding how the structure of a system generates behavior gives clues as to how we can change the structure to change the behavior = more effective and acceptable interventions for less effort ..and a better understanding of what outcomes to target in the first place!
SYSTEMS METHODS
(A VERY SMALL SUBSET!)
APPROACH: SYSTEMS THINKING

• Holistic / non-reductionist approach to inquiry
• Focuses on the relationships of parts and the feedback between them over (sometimes long) time instead of looking at component parts in isolation
• Includes consideration of the environment
• Is inherently transdisciplinary
• Many potential solutions to complex problems

From Checkland Soft Systems Methodology in Action p.A11
MULTIPLE PERSPECTIVES / THINKING IN LAYERS

• Perspectives: stakeholders/disciplines/world-views/priorities/etc.

• System layers:
  • Supra-system – Why?
  • System – What?
  • Sub-system – How?

Checkland, SSM in Action, p.A24
GENERATIVE CAUSALITY

• The usual way we think about causation: Does X lead to Y?
• Generative causation: What about X leads to Y?
• Centers the dynamics / structure
• Correlation and association lose their typical importance
• Why do we care?
  • If structure generates behavior
  • Then understanding the structure
  • Teaches us something about how to modify the behavior
  • In other words, leverage
TOOL: CAUSAL LOOP DIAGRAMS

• A means to identify and map causal structures
• Can provide insight into behavior
• Can provide insight into leverage - including if it fits a known pattern
• Can help communicate and articulate complex situations
• Process has been adapted for use with stakeholders who have no formal systems training using Group Model Building
• (comes from system dynamics)
CLD LANGUAGE

• **Variables** (text) – the parts of the system that change

• **Causal links** (connecting lines) – the relationship between variables
  • Have direction (arrowhead)
  • Have polarity (reinforcing +, balancing –)
  • Join variables

• **Delays** (broken links or boxes) – indication that the influence is not immediate

• **Loop identifiers** (synthesis of causal loop) – what is this loop about?
  • Name (text)
  • Loop direction (arrow)
  • Polarity (R/B; snowball/seesaw)
EXAMPLE: AUTISTIC BURNOUT

- AASPIRE’s autistic burnout study
- 19 individual interviews, 19 internet sources, team expertise
- Playing with CLDs at one point…

- Leads to a “growth and collapse” type behavior
- System grows faster than available resources can keep up

![Diagram showing the cycle of runaway pressure, masking of autistic traits, expectations, social/financial rewards, exhaustion, resource drain, and energy.](image-url)
APPROACH: ACTION RESEARCH

• Approach to inquiry Lewin 1940s; expanded greatly today along many branches
  • Subjects of research are also the co-researchers – places the subjects of intervention inside the system of inquiry
  • Research for the purpose of making (wanted, positive) change; that is, research for the purpose of action
• A means to include stakeholder perspectives that might otherwise be marginalized (esp. emancipatory branches designed to shift power)
DON’T DO SYSTEMS WORK ALONE!

Multiple perspectives are required for holistic problem-solving / systems thinking!

Consider knowledge/power feedbacks

- What research questions are asked
- How the research is designed
- Whose knowledge is legitimized
- Who the research participants are and whose data is captured
- How the findings are interpreted
- How the findings are framed during dissemination
CONTINUUMS OF ENGAGEMENT

**Depth of engagement**
- Community advises
- Community collaborates
- Community takes leadership

**Frequency of engagement**
- One-time or short engagements
- Regular meetings
- Community in all work

**Leadership engagement**
- Academic directed
- Both academic and community directed
- Community directed

**Team engagement**
- Single community advisor; many academics
- Equal numbers of community and academic members
- Many community collaborators; one academic
EXAMPLE: COMMUNITY BASED PARTICIPATORY RESEARCH & AASPIRE

- Emancipatory approach developed in public health; has formalized principles
- Community members co-researchers in every phase
- Lived experience / community knowledge valued on same level as academic expertise
- Community-directed research priorities

16 YEARS RUNNING!

- Team made up of academic researchers, autistic individuals, family members, healthcare providers, disability services professionals.
- In partnership with PSU, OHSU, Autistic Self Advocacy Network, Autism Society of Oregon, Multnomah County DD Services, Syracuse U, Vanderbilt, U of WA, UCSD, and members of the Autistic community at large.
TOOL: CRITICAL SYSTEMS HEURISTICS

• A set of questions for stakeholder groups to use in order to think critically about what they are doing, why, and who has the power
• Stakeholders answer from their own perspective
• Good at exposing things that might have otherwise been marginalized
• Good at revealing and examining the world-views of the people involved in the project
• Do the potential recipients of a proposed intervention feel the same way about it as the scientists who designed it???
BOUNDARY ISSUES

• **Motivation** – what is the impetus and where’s it come from?
• **Power** – who controls it and how?
• **Knowledge** – what expertise/experience feeds into it?
• **Legitimacy** – where’s this centered?
BOUNDARY CATEGORIES

- **Stakeholder** – client, decision-maker, professional, witness
- **Concern** – purpose, resources, expertise, emancipation
- **Difficulty** – measure of improvement, decision environment, guarantee, world view
- **[Key - Motivation / Power / Knowledge / Legitimacy]**
TOOL: CRITICAL SYSTEMS HEURISTICS

(see Werner Ulrich & https://www.betterevaluation.org/en/plan/approach/critical_system_heuristics )
INTERVENTION AND LEVERAGE
LEVERAGE POINTS: PLACES TO INTERVENE IN A SYSTEM

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Understanding how the structure of a system generates behavior gives clues as to how we can change the structure to change the behavior = more effective and acceptable interventions for less effort

…and a better understanding of what outcomes to target in the first place!
Donella Meadows’ leverage points (Source: based on Meadows, 1999; credit: UNDP/Carlotta Cataldi)
IDENTIFYING POSSIBLE LEVERAGE FOR INTERVENTION AT THE PHYSICAL EVENTS LEVEL (BURNOUT)
LEVERAGE AT THE PHYSICAL EVENTS LEVEL (BUFFER)
LEVERAGE AT THE PHYSICAL EVENTS LEVEL (BUFFER)

<table>
<thead>
<tr>
<th>Reduced Load</th>
<th>On a basic level, allowing periods of withdrawal, or decompression time at the end of the day, or even throughout the day can make a big difference.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time off / breaks</td>
<td>Take a spiritual retreat [laughs] like that's not a definite way of curing it but that's the only way I came up with is give yourself a break, withdraw into your own world and give yourself a break</td>
</tr>
<tr>
<td>Social withdrawal</td>
<td>The biggest thing of all you can give yourself, or your loved one, is time.</td>
</tr>
<tr>
<td>Reduced activity</td>
<td>I have gone through a few distinct periods of burnout and have successfully managed them by withdrawing from the world as best I could.</td>
</tr>
<tr>
<td></td>
<td>Pulling back from activities, tweaking how much you do of different activities...all are important</td>
</tr>
</tbody>
</table>

LEVERAGE AT THE SOCIAL/SYSTEMS STRUCTURE LEVEL (RULES OF THE SYSTEM)
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<table>
<thead>
<tr>
<th>Being Autistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attending to autistic needs</td>
</tr>
<tr>
<td>Unmasking</td>
</tr>
<tr>
<td>Using autistic strengths</td>
</tr>
</tbody>
</table>

IDENTIFYING POSSIBLE LEVERAGE FOR INTERVENTION (EMPLOYMENT)

IDENTIFYING POSSIBLE LEVERAGE FOR INTERVENTION (EMPLOYMENT)

LEVERAGE AT THE SOCIAL/SYSTEMS STRUCTURE LEVEL (GOALS OF THE SYSTEM)

Instead of the goal being to behave in a neurotypical manner in a certain kind of HR interview (which increases the masking variable in the burnout system...) what if it was--

• Having more flexible / unconventional HR hiring practices?
• Increasing the number of supervisors and hiring managers who understand autism?
• Creating neurodiversity-friendly workplace climates?
IDENTIFYING LEVERAGE AT THE CONSCIOUSNESS / MENTAL MODELS LEVEL (SCIENCE)

IDENTIFYING LEVERAGE AT THE CONSCIOUSNESS / MENTAL MODELS LEVEL (SCIENCE)

LEVERAGE AT THE CONSCIOUSNESS/MENTAL MODELS LEVEL (NEURODIVERSITY PARADIGM SHIFT)

• Policy change toward anti-ableist language in major autism journals & in academic literature (https://doi.org/10.1089/aut.2020.0014)

• New areas of research / research focus (e.g., masking)

• Increased representation in research and policy (IACC, INSAR’s ARC, AIA)

• Inclusive research…just AASPIRE in 2006 now dozens internationally!

• Autism acceptance (not awareness)

• AIR-P! 😊
WRAP-UP AND Q&A
TAKE-AWAY POINTS

• Complex systems (like autism services) are difficult or impossible to understand, predict, or control, particularly using traditional reductionist approaches.

• Systems thinking is a holistic (non-reductionist) approach to inquiry that can help to understand the structure, behavior, and intervention points of complex systems—and comes with useful frameworks, methods, and tools.

• Including for inclusion of stakeholders within the system of inquiry itself.

• The closer you get to paradigm shift, the more leverage you’ll have 😊.
THANK YOU!

• Thank you to the AASPIRE team, and to all our research participants and who shared their wisdom and experience with us
• Autism in Adulthood journal – consider submitting
• Contact me! draymake@pdx.edu | http://doraraymaker.com
• Newsletter at doraraymaker.com (includes updates on AASPIRE’s research, study findings, study recruitment, publications, etc.)
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Website  
airpnetwork.ucla.edu
Thank you for attending!
A link to view the recording will be emailed to all registrants.
We hope to see you next month!

Aug 16, 2022
4:00 p.m. - 5:00 p.m. ET

AIR-P Presents — Involving Community Partners in Autism Research
By Lisa Croen, PhD and Maria Massolo, PhD

In affiliation with Kaiser Permanente

- Community Based Participatory Research (CBPR) benefits community participants, health care providers and researchers alike
- Resulting research reveals a deeper understanding of the uniqueness of the communities studied, and a more accurate framework for testing and adapting healthcare interventions to community needs.