

media



at Stanford University

**Working Towards a Co-Pilot Model:
Opportunities to Bridge Gaps in the Support
Ecosystem for Autistic Children**

**January 2022 Workshop Series
Summary**

BACKGROUND

Neurodiverse children benefit from assistance and support from various people, including teachers, aides, behavior technicians, occupational therapists, and most especially, their parents or immediate caregivers. Providing learning opportunities for a disabled child requires an ecosystem of support, with each participant understanding the interactions and goals of their counterparts and serving as agents for the child.

Just as many airplanes fly with two pilots, jointly coordinating the information streams and demands of flight navigation, effective care for disabled individuals requires a team of professionals addressing different elements of wellness - including healthcare, communication, education, and behavior. The current structure of the autism care ecosystem places service providers in silos with little cross-communication. Organizations and professionals inside this ecosystem might have the best intentions yet not receive the cooperation or information needed to make their work more successful. In addition, these various service providers and groups have independent incentives that may not align. Discovering options and managing communication between the parties generally falls to parents and caregivers, while simultaneously caring for their child.



What We Set Out To Do:

In a series of three consecutive meetings, this workshop series, inspired and resourced by members of mediaX, addressed the question:

How might workshop participants conceptualize an ecosystem of support for disabled children, particularly those on the autism spectrum, to make changes that will close the gaps of a broken ecosystem?

To understand opportunities to create a more effective ecosystem, including shaping the capabilities and mindsets of ecosystem participants, mediaX invited exploration into the following areas:

- Infrastructure and interaction to incentivize better communication and cooperation with other support personnel.
- Training and professional development for teachers and medical professionals working with children with disabilities, particularly autism.

Recognizing that systems depend upon the actions and opportunities of individuals within the existing network, the workshop focused efforts on surfacing perspectives from participants inside the current care ecosystem, thus informing opportunities for broader change.



What We Set Out To Do:

Thought leaders' insights and participants' viewpoints explored starting points, roadblocks, and pathways to solutions. Each day of the series highlighted specific areas of exploration:

January 12th, Building Together: At Home and in the Community

The workshop explored opportunities and challenges that bridge multiple contexts, including game-based therapeutics that can be used at home, how schools might serve as wellness centers, and conceptions of neurodiversity in schools, universities, and the workplace.

January 19th, Growing Together: Training and Professional Development

The workshop explored how training and professional learning might impact the mindset and perceived opportunities of teachers, therapists, clinicians, and other ecosystem players.

January 26th, Informing Each Other: Information, Data, and Processes

The workshop explored barriers and opportunities for more seamless sharing of information and processes between players in the ecosystem, thereby enhancing opportunities for holistic care.

Participant Perspectives:

Participants represented a wide variety of backgrounds and perspectives.
Expertise present included:

- State & Country Disability Policy
- Autism Technology Growth
- Pediatric Autism Research
- School Administration (High School Principal)
- Inclusive Education & Special Needs Teaching
- Classroom Inclusion Specialization
- Occupational Therapy
- Clinical Psychology
- Pediatric Nursing
- BCBA & Parent Training
- Autism & Play Culture
- Lived Experience (Autistic Individual)
- Employment for Disabled People
- Intersection of Disability, Race, & Criminalization
- Parents of Autistic or Disabled Child
- Disability Advocacy
- Early Support for Families with Autistic Child
- Data & Privacy



What We Learned:

There are many opportunities for improvement to systemically support neurodiverse and autistic people, including children. This includes ways to serve unmet need and enhance the functional collaboration of existing services. It is important to note that the autistic population is broader than those with an official diagnosis. Many people do not yet have a diagnosis but would still benefit from supportive services. **The current ecosystem is interconnected**, including players in education, medicine, policy, technology, and parents and children. **However, the interactions between players are under-funded, under-structured and the system is understaffed. The challenges to mediate these gaps are rooted in both logistics and in interactions between people.** With the lens of opportunity-identification, a view of these issues follows in the “What If…” section.

Operating from an “abundant mindset” or “growth mindset” opens pathways for inclusion and support focused on every person’s unique experiences and contributions, including people considered neurodiverse. This philosophy is recommended instead of a “deficit mindset,” which positions neurodiverse individuals, such as autistic children, as having something wrong that needs to be fixed.

It is essential to begin with the needs of autistic individuals. Understanding their needs must include hearing autistic people’s perspectives, voices, and lived experiences and needs in discovering and strategizing services. Existing conversations inside the autistic community in the United States recommend including autistic individuals in planning services to be delivered. As a next step, participants of this workshop series suggested bringing ideas developed in this

What We Learned:

workshop into a conversation led by autistic individuals, rather than inviting someone from the autistic community to act as a representative minority.

There are differing perspectives on the language used when referencing people on the autism spectrum. This topic of terminology is laden with strong emotional opinions, as language choice carries connotations and assumptions, even if unintentional. Two of the most used methods are “autistic children” (identity-first language) or “children with autism” (person-first language). Current research recommends identity first-language as preferred. Much of contemporary language referencing autism or other neurodiversity is rooted in medical terms, which can create bias or negative framings of disability as something to be fixed. Individuals within the autistic community, and their families, often have a strong preference for language choice. An opportunity exists to align language conventions in a way that is supportive and affirming rather than exclusionary and derogatory.

Most of the participants in this conversation were American; hence the explorations into neurodiversity, autism, and healthcare and education systems were primarily situated within the context of the United States of America. Interestingly, the international views represented (England and the Netherlands) did reveal dramatically different approaches, policies, terminology, classification, and cultural influences. **An important implication is that tools or processes developed in one culture will require cultural adaptation when applied in another.**

What We Learned:

The conversational exchanges of the workshop series wove in and out of challenges and opportunities, embracing a variety of participant perspectives contributed during dialogues. Below, critical points of these dialogues are broken into five sections: **Thinking About Disability, Thinking About Learning Difference, Changes to Professional Development and Organizational Culture, Pressing Needs, and Potential Solutions.**



What We Learned:

Thinking About Disability:

Earlier diagnosis can enable earlier and more effective intervention. However, wait lines and not knowing where service openings exist both present a challenge. The diagnosis itself is a privilege and can be influenced by socioeconomic status. Many individuals on the autism spectrum face challenges in receiving support because they have not yet received an official diagnosis.

Gender and culture play prominent roles in parental advocacy and diagnostic and intervention processes. Marginalized populations are disproportionately underserved and criminalized.

The framing of interventions has lasting effects and is often influenced by race. The existing power structure defines disability with nuances that suggest some disabilities appear more “acceptable” than others. Operating from an abundance mindset enables a more appreciative approach to diverse individuals’ skills and perspectives. Integrating this approach into public discourse and everyday life would create more inclusive environments. The inclusion and mainstream exposure of disabled voices as experts are essential for research, media campaigns, developing apps to work with families, or running outreach organizations.

What We Learned:

Thinking About Learning Differences:

Addressing learning differences holistically benefits all students, especially through socialization in the classroom. Learning based on concepts of both disability and ability must include the whole person, including race, class, and gender. The Universal Design for Learning (UDL) framework provides principles to improve and optimize teaching and learning by removing barriers to learning. UDL benefits all students while being specifically supportive of those with disabilities.

Competency-based education and work-based learning experiences support accessible learning. Creating more inclusive opportunities for neurodiverse children will require redistributing quality educational opportunities, creating spaces for families and students to participate in the decisions that affect students' learning trajectories, and recognizing and valuing all students' differences.

Advocacy tools are available. Individualized Education Plans (IEP) are tools that can be used strategically due to IEP's designated institutional and legal power. The IEP's role as a legal document establishes the school's accountability under California and federal laws. This means that the child's school is required by law to provide the services, support, and resources included in the IEP.

What We Learned:

Thinking About Learning Differences (Continued):

Socialization models, such as the Integrated Playgroups model, bring neurotypical and neurodivergent children together in small groups to form a play culture, enhance socialization and communication, and encourage creative expression.

Communicative competence is essential for social acceptance and functionality; all people must have the ability to express themselves and demonstrate what they do or do not know. Meeting this standard is also necessary to achieve inclusion for those with disabilities. Although California is a right-to-work state, for many disabled or neurodiverse people, illiteracy in written and spoken communication undermines that right. Communication challenges can also impede assessing needs, inhibiting obtaining services or support tools and putting additional burdens on both families and service providers.

What We Learned:

Changes to Professional Development and Organizational Culture:

To ensure that curriculum and training for professionals working with neurodiverse individuals meet actual needs, professional preparation must include experience with the people to be served. This mandate for inclusion includes incorporating autistic voices throughout the design and the dissemination of curriculum and creating opportunities for autistic individuals to enter the professions serving their peers.

Clinical mentorship empowers younger colleagues with experiential learning in service values and thinking skills to enable future change across practice areas. For Occupational Therapists, for example, this can be an effective way to ensure that OT-child relationships occur within a framing of collaboration with the child's family.

Corporations welcoming of neurodiverse people are demonstrating the advantage of diversity to innovation and business competition. As organizations, schools follow fundamental organizational dynamics and behaviors. An opportunity exists to facilitate change by encouraging school administrations to promote inclusive attitudes and practices in their management.

What We Learned:

Changes to Professional Development and Organizational Culture (Continued):

Two life goals for the neurodiverse population are often employment and self-support. The pathway for preparedness to accomplish these goals maps backward all the way to preschool. In employment contexts, concepts of teamwork and leadership often have an assumed “ableist bias” and seldom consider neurodiversity. This bias is particularly important as autistic people interview for jobs, undertake advanced schooling, or work towards career advancement.



What We Learned:

Pressing Needs:

Professionals and parents want to improve life experiences for neurodiverse individuals. Removing the barriers to collaborative care is a first step. These obstacles include lack of resources and staff, difficulty in sharing information or reports, a dichotomy between special education and general education, poor pay for professionals who have engaged in significant training, teacher burnout, and the need for policy and funding to support initiatives.

Workshop participants described a shortage of specialists in all tracks of the autism care ecosystem, including but not limited to child psychiatrists or psychologists, registered behavior technicians, occupational therapists, speech pathologists, teachers, and aides trained in neurodiverse education. Insufficient staffing for current service needs begs investments to create an entire pipeline of services to address mental health, including neurodiversity and autism.

Parents and advocates bear heavy burdens to navigate multiple systems and providers that are not aware of the competition or collaboration among services and often do not share information or data. Parents request integrative, communicative systems that respect privacy and dignity. One positive example of care coordination is the practice of designating schools as wellness providers, enabling the receipt of state and federal funding by schools providing support services.

What We Learned:

Pressing Needs (Continued):

Accomplishing change requires shifts in the policy environment to create new learning environments that will require new school organizational and financial structures, new words to describe ability, and an expanded range of assessment methods.

The current language used by professionals is insufficient to describe a continuum of ability. Generating new terminologies, with agreement across service providers, will enable a more accurate discussion of the full range of abilities and accommodations. For example, the Autism Collective brings people together to create awareness of pathology-related language and to refine the concepts of autism in a positive neuro-diversity framing.

Additionally, there is a need to create pathways for medical and educational goals, diagnoses, and plans to connect services rather than compete. Opportunities for professionals from each field to exchange information, learn about each other's perspectives and goals, and build relationships could make a significant difference in the continuity and effectiveness of service. The suggestion was made to hold an annual symposium for professionals, policymakers, parents, and neurodiverse people to learn from each other and network; it would be essential for this symposium to have buy-in from the boards across various fields of expertise (Education, Medicine, Social Work, etc.).

What We Learned:

Setting Up Solutions:

Community networks and positive socio-emotional climates support human capacity-building. Measures and metrics of school features that demonstrate a coherent ability to welcome difference are needed to assess and incentivize schools on those qualities. These metrics are needed now, as California is investing \$3Billion in community schools of all levels.

Cognoa is in the early stage of running a survey of families with an autistic child to understand needs, particularly regarding communication between the medical and educational pathways. A better understanding of the current state can inform strategic pathways for improvement.

Technology can provide an objective means of assessment and identification. In developing countries with little infrastructure and few systems to identify and assist autistic individuals, technology tools have demonstrated several successful methods for early identification and therapy. Technology can be a tool for empowerment if used to provide context to professionals in the autism care ecosystem, such as sharing progress development across different specialty services. In addition, technologies such as machine learning can enable the processing of large amounts of data to explore opportunities to increase the number of children receiving care.

What We Learned:

Setting Up Solutions (Continued):

Mobile games and other technology tools can enable parents to work with their children to build specific skill development while waiting to receive therapy; this home support can bridge gaps in treatment, including transience of staff and variability of quality.

Getting buy-in from the multiple stakeholders in the system, including insurance companies and pediatricians, is essential to pursue new opportunities and systemic change. An open challenge exists to identify and implement incentives to build a functional ecosystem of person-centered services. This goal is a considerable challenge; nevertheless, several examples illustrate the feasibility of addressing it.

Communities of Practice build support and knowledge through a bottom-up approach for the multiple players involved in a child's care. Communities of Practice have a shared vision, are agile and collaborative, and are ready to respond to change. The Communities often include general and special education teachers, psychologists, occupational therapists, physical therapists, parents, and administrators. People in the group learn from each other over time; together, the team members produce a shared repertoire of routines, sensibilities, artifacts, and teaching and learning styles.

What We Learned:

Setting Up Solutions (Continued):

Schools can act as a hub for communication but may need additional scaffolding to bridge silos. An example of facilitating this conversation is the creation of a Wellness Center at Irvington High School in Fremont, CA. Another multi-sector approach is visible through Sacramento County's development of an integrated care system. By installing a mental health professional in every school, the county designates schools as medical primary care sites. Sacramento county then ensures that schools don't have to worry about paying for mental health services, and the schools and the county can access Medicare and MediCal funding.



What If...

While it is difficult to enact change, either on an individual or on a systemic level, many of the challenges in the current system can be viewed as opportunities for improvement. A wide variety of pathways would generate a positive impact either for individuals within the system or for the system itself. The questions below offer bold visions and starting points for creating a system that more fully meets the needs of neurodiverse individuals.

Challenge: Change requires buy-in from multiple stakeholders.

What if.... A coalition of mission-focused, goal-oriented professionals could develop, including medical and education professionals, policymakers, and insurance providers?

Challenge: Schools are assessed based on graduation rates, student scores, and other measures that often encourage a mentality of “sorting” students.

What if... Features of schools demonstrating the coherent capacity to welcome difference could be used to develop new measures and metrics to assess schools? Funding could then be tied to this new model.

What If...

Challenge: Parents of children with autism must navigate the communication and priorities of multiple systems without shared data. This is a heavy burden.

What if.... A novel system could verify identity and provide the necessary permissions to exchange documents and information? The system should be easily accessible for both parents and providers.

How: Respect the privacy of the child. Be aware that different organizations (school vs. medical vs. law enforcement) will have differing views on what factors are important and on what data is sensitive. Be cautious in sharing information as it might have later repercussions for the child.

How: Resolve the issues of securing and having confidence in the identity of the people using the data and their roles. Every user, not just the student, will have to agree on the threshold for identification. Permission must be granted in both directions for each exchange of information, then apps or plug-ins can be built on top of this framework. Permission should offer variations that align with parents' and child's rights and personal choices.

Challenge: Students often only receive help once something is wrong.

What if... School environments supported students holistically? Educators could create, embrace, and prioritize opportunities to understand and connect with students from different perspectives.

What If...

Challenge: Many teachers are reluctant to engage with higher-need children in their general education classes. Teachers suffer from burnout and don't feel equipped to help students with disabilities.

What if... Smaller class sizes enabled more personal instruction?

What if... General education teachers felt prepared to work with the needs of all students? This could be achieved through pre-service training or professional development. General and special education teachers could work in teams to build and support inclusive practices.

What if... Universal Design for Learning (UDL) threaded throughout teacher training or professional development workshops? This practice emphasizes that there is no “average” learner - variability is the norm. There are different ways to represent the content and multiple ways to act and express knowledge. Support for students with and without disabilities is embedded in the context of the learning environment itself. The learning environment is then beneficial for all students.

How: One example of a training approach is visible in STEP, Stanford Teacher Education Program. All STEP elementary teacher-training candidates are required to take a course “Dis/ability and Access in the Elementary Classroom,” which includes learning the practice of UDL.

How: By creating a team atmosphere, the appearance of competition between General Education and Special Education could be reduced.

What if... Education and training programs instruct about and encourage self-care strategies to help prevent burnout for people working with neurodiverse individuals?

What If...

Challenge: Many teachers are reluctant to engage with higher-need children in their general education classes. Teachers suffer from burnout and don't feel equipped to help students with disabilities.

What if... Communities of Practice brought support teams together around children needing support? Communities of Practice enable clear exchange of information and coordination of care.

How: Creating a “Wellness Center” at a school can create a specific location and focal point for conversations about students in need.

How: Designating a school as a medical provider, such as by installing a healthcare professional at the school, can allow medical funds that support student wellbeing to be allocated to a school.

Challenge: Concepts of teamwork and leadership often have an assumed “ableist bias” and seldom consider neurodiversity.

What if... Secondary schools teach communicative competence and deconstruct conceptions of teamwork? The traditional structure of learning, classrooms, and school time could be leveraged.

How: Guide teachers on alternative ways to provide students better access to classroom activities and organize classroom activities. New activities can challenge typical notions and open spaces that allow students to engage with a different culture. One resource is the book *Competency-based Education*.

How: Create more opportunities for workforce-based learning.

What If...

Challenge: Early intervention can create better outcomes for children, but late access to services due to long-wait lines and full clinics can make a diagnosis difficult to obtain.

What if... Technological tools could expedite the assessment and therapy processes while children are on waitlists?

What if... Inclusive play practices could provide opportunities for neurodiverse and neurotypical children to learn from and with each other. [Integrated Playgroups](#) are one example of this approach.

What if... Early-learning programs (pre-school and kindergarten) could incorporate supportive environments that prevent children from being moved into special needs tracking?

Challenge: Educational and Medical systems sometimes act as competitors or barriers to each other.

What if... An annual symposium offered professionals in education and medicine an opportunity to learn from each other and network? Buy-in from the Boards of Education and Medicine across various fields of expertise could establish professional development requirements.

What If...

Challenge: Many autistic people have co-occurring features and diagnoses. These individuals may go to the hospital for these other reasons, which disrupts school and any therapeutic treatments, setting the child's progress back and incurring costs to the healthcare system.

What if... Developing integrated payment models could enable joint management and payment for multiple related conditions rather than individually. If integrated payment is done systematically, it could positively impact both the individual in care and healthcare systems.

Challenge: Care for an autistic individual generally only supports the costs covered for the patient, not for the support around them – for family or caregivers, for example. This narrow vision can inhibit the coordination of care if costs are not linked.

What if... Language about coordination of care was to be included in insurance documentation? This added language could increase the likelihood of the coordination occurring, as it would be tied to the receipt of funding.

Challenge: Current language about autism creates bias because it is pathology-focused and deficit-based.

What if... Developing new terminology could describe the full range of ability, with agreement across service providers?

What If...

Challenge: There are not enough workers in the ecosystem. In addition, service providers do not necessarily match geographically with the children who need the services.

What if... Incentives encouraged more entrants into the workforce pipeline?

What if... Developing new technical platforms could match children in need with providers? [Elemetry](#) is an excellent example of a company working to do this. In addition, telehealth services could reach students who need support.

What if... Clinical mentorship could provide healthcare workers with support and instruction early in their careers?

Challenge: Race, gender, and social status are interconnected with disability, disability access, and public perception of the disabled person.

What if... Disability is consistently framed as an intersectional issue?

What if... Pathways existed for people with cultural capital and know-how to share their knowledge with less informed or more burdened caregivers? This route embraces a mentality where “a rising tide lifts all boats.”

What if... Service providers transitioned from assumptions that non-normative actions are maladaptive or criminal to a more holistic approach that explores the root cause of behaviors?

Challenge: Many professionals in the special needs ecosystem receive low pay compared to the amount of school and training necessary. This discrepancy increases stress and drives people to leave the field.

What if... More opportunities existed for career growth?

What If...

Challenge: With such a complicated system, it can feel difficult for any one individual, such as a teacher or a service provider, to make an impact, even if that person desires change.

What if... Every person took ownership of an individual lever that he or she could pull to enact change, even if small? By exploring one's role in the ecosystem, including interactions with other participants or information exchanged, it may be possible to find new opportunities to engage in advocacy or support.

How: For teachers, their lever is content. Teachers can design content around students' interests using what they know about their students. Education training programs can teach, model, promote, and coach these actions.



Resources:

Below is a list of resources that were shared during the workshop series. Suggestive rather than comprehensive, the list opportunities for exploration.

gapmap.stanford.edu

<https://www.mdpi.com/1660-4601/18/9/4696/htm>

[Culturally Responsive Teaching and the Brain](#) by Zaretta L. Hammond

<http://www.bigpicture.org>

[Brooklyn Lab Charter School](#)

<https://actionaly.com>

<https://serr.disabilityrightsca.org>

<https://med.stanford.edu/espa/coordinator.html>

<https://www.ocali.org/>

An advocate-created video on YouTube which can be helpful for parents who learn better via video:

[https://www.youtube.com/watch?v=5ey7vYGNTZU&t=.](https://www.youtube.com/watch?v=5ey7vYGNTZU&t=)

Organizations:

- CASE - Community Alliance for Special Education
- PHP - Parents helping Parents
- Support for Families of Children with Disabilities - *workshops focused on IEP navigation*