PARTNERS IN RESEARCH SERIES

NATIONAL AUTISM INDICATORS REPORT:

Establishing a National Autistic-led Research Agenda

JANUARY 2025

AUTISM RESEARCH FOR US

ASAN AUTISTIC SELF ADVOCACY NETWORK

PAC POLICY, ANALYTICS, & COMMUNITY Research Program

THE POLICY IMPACT PROJECT

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About the Autism Research for Us Symposium

Background

In the past, autism research has mostly been conducted by non-autistic people, and researchers have described autism as something bad that should be fixed. Describing autism in this way has negative effects on how society views and treats autistic people and may even negatively affect how autistic people view themselves. A collective of autistic self-advocates, autistic researchers, and like-minded allies wanted to fix this.

In September 2023, the Autistic Self-Advocacy Network (ASAN) and the Policy and Analytics Center (PAC), based at the A.J. Drexel Autism Institute, located within the Dornsife School of Public Health at Drexel University, held a **symposium** about autism research. A symposium is a meeting that brings people together to talk about an idea or problem.

The symposium was held over four half-day sessions with more than 150 participants, including speakers. We invited autistic self-advocates, autistic researchers, non-autistic researchers and other key collaborators to the symposium.

The planning team prioritized autistic attendees as experts. Autistic people expressed what they wanted and needed from future research.

Together, autistic self-advocates and researchers, both autistic and allies, set out to create a plan for research. Autistic people led the plan in collaboration with PAC team members. The symposium included discussion of topics that needed additional research and thoughts on how to go about doing this research.

Participatory research was a common topic of discussion at the symposium. Participatory research, in this specific instance, is when the autistic community and researchers work together to design, carry out, and share research.

The symposium also centered research led by autistic people and autistic participants who belonged to more than one community that experiences marginalization, including:

- Autistic people of color (such as Black, Hispanic/Latine, Asian, Indigenous)
- Autistic people who do not communicate through speech, either all of the time or some of the time (also called “non-speaking” or “partially speaking” autistic people)
- Autistic people who are LGBTQ+. LGBTQ+ stands for lesbian, gay, bisexual, transgender, queer, and other marginalized sexual orientations and gender identities.
- Autistic people with intellectual disabilities
- Autistic people with mental health disabilities

Words To Know

Throughout this report there will be several acronyms and words that may be unfamiliar but are important to understanding the report. Below is a list of key words to know.

- **CBPR:** CBPR stands for **Community Based Participatory Research**. This is a way of doing research where researchers and community members serve as equal partners throughout the entire research process. CBPR often has goals like educating people, improving how research is done, or changing society. CBPR looks at the differences in how much power researchers have versus how much power community members have. CBPR is especially helpful when working with marginalized groups (like autistic people). CBPR can help build better relationships between researchers and marginalized groups. CBPR can help make sure the way knowledge is shared between researchers and marginalized groups is more fair. .
- **Focus group:** When a group of people come together to talk about a specific topic with a moderator. A moderator is a person who leads the focus group.
- **Symposium:** A meeting that brings people together to talk about an idea or problem.
- **Research:** The process of trying to answer a question or find the solution to a problem.
- **Participatory research:** A way of doing research where the researcher or researchers, and community members who are most impacted by the research, work together throughout the research process. When we talk about research, we use "most impacted" to mean the group or groups that the research affects the most. For example, autistic people are the most impacted group in autism research.
- **Research studies:** Research projects that people do to learn new information or to answer a question. Research studies are designed to make sure the information they get is correct.
- **Multiply marginalized:** Marginalization is when people are unfairly left out of society or groups because of more than one part of their identity, such as their:
    - race
    - gender identity
    - sexual orientation
    - age
    - disability
    - immigration status.

    For example, Jacob is a Black, gay man with an intellectual disability. Different parts of society treat Jacob badly because of his identities. Because Jacob is treated poorly based on more than one identity, he is multiply marginalized.

- **Neurology:** In relation to autism, neurology looks at how the brain and nervous system work for autistic people. It can help explain sensory experiences, unique ways of communicating, and how someone processes information.
- **Research agenda:** An agenda is a plan that focuses on issues in a specific area. A research agenda focuses on issues within specific kinds of research. This research plan will focus on autism research.
- **Reparative research**: Research that acknowledges harms that have been done by research in the past and seeks to do more equitable and ethical research.
- **Ethical consideration:** Things to think about within research to make sure the people who participate in the research are not harmed by the research.
- **Support needs:** Things people need help to do.

Partnering and Planning for the Symposium

ASAN and PAC partnered to plan the symposium. We wanted to create a research agenda that represented the priorities of the autistic community, rather than the priorities of non-autistic researchers.

ASAN is a nonprofit by and for the autistic community. ASAN believes that all autistic people have the right to equal access, rights, and opportunities and works to make this belief a reality. ASAN works to give power to autistic people across the world to take control of their own lives and the future of their common community. ASAN seeks to organize the autistic community to ensure their collective perspectives are heard when people talk about autism and autistic people.

The Policy and Analytics Center (PAC) is based at A.J. Drexel Autism Institute in the Dornsife School of Public Health at Drexel University. PAC is a group of researchers from many different backgrounds and types of research. PAC does research that helps people develop social and health policy in different places across the U.S.

Staff from ASAN and PAC worked together for over a year to plan; outline the mission, goals, and the vision for the symposium; and to identify key speakers and invited participants.

Focus Groups

Before the symposium, ASAN held six **focus groups**. The goal was to center autistic people who have been most often left out of research in the past.

Focus groups included autistic adults from around the world, but specifically focused on including people from marginalized identities who have been under-represented in research such as:

- Autistic people with intellectual disabilities

- Autistic people who do not communicate through speech, either all of the time or some of the time (also called “non-speaking” or “partially speaking” autistic people)
- Autistic people with higher **support needs**
- Autistic people of color (Black, Hispanic/Latine, Asian, Indigenous and other communities)

Focus groups helped the team identify the priorities of the autistic community to decide what to talk about at the symposium.

Structure of the Symposium

The symposium was held virtually in real time. This was done to increase the number of people who could attend, and in response to the concerns of the ongoing COVID-19 pandemic. The format consisted of presentations and discussions about current and future research. The planning team identified four main tracks of discussion, informed by the focus groups.

The four tracks at the symposium were:

- **Biology and Neurology.** Topics in this track included etiology (where autism comes from), biology, genetics, neuroscience, and psychology (not including mental health care).
- **Health Care.** Topics in this track included mental health, co-occurring conditions (other illnesses or disabilities that can happen alongside autism), health care outcomes, health care supports, and cultural competency (making sure professionals have the skills to give good health care to autistic people from many different cultures).
- **Services and Supports.** Topics in this track included augmentative/alternative communication (AAC) and communication strategies, Medicaid home and community-based services (HCBS), education, plus therapies and interventions besides mental health services for all ages.
- **Adulthood and Aging.** Topics in this track included transitions into adulthood, employment, parenting, adult diagnosis, trajectories (how things change) over the lifespan, and aging.

Participants in each track discussed:

- the future of research
- how research should be done
- how autistic people can lead and guide research
- gaps in research
- ethical research

Goals of the Symposium

The goals of the symposium were to answer the following questions regarding topics, methods, and dissemination strategies:

Topics

- What are the gaps or weaknesses in current autism research?
- What research questions do autistic people prioritize going forward?
- What are the most urgent priorities for autism research right now?

Methods

- What strategies should be required for research that is respectful and centers those with lived experience?
- How can partnerships between researchers and the autistic community shape the future of autism research?
- What are **ethical considerations** for conducting research that respects, values, and prioritizes lived experiences?
- How do we set up research that will work for the future, as we learn more?

Dissemination Strategies

- How can autism research best reach the people who need or want to use it?

After the Symposium

This report details the contents of the discussion from each track.

This can be used to guide autism research and the policy that governs how funding is allocated to this research. In the U.S., the Interagency Autism Coordinating Committee (IACC) gives advice about government funding for autism research. The IACC is a federal committee that makes suggestions about what kinds of autism research the government should fund. You can read more about the IACC in ASAN's guide about the IACC. Members of the IACC could use the information in this report to understand topics that a group of autistic people said were important to research, along with priorities for how this research should be conducted.

Autism research should match the priorities of the autistic community. Autistic people should get to decide what autism researchers study. When non-autistic people decide what autism researchers will study, without the input of autistic people, the research may not actually be helpful to autistic people.

ASAN's motto is *Nothing About Us Without Us*. ASAN believes that autism research should not be done without seeking input and guidance from the autistic community. The team at PAC affirms this motto.

Resources and Partners

To learn more about the work that ASAN and PAC are doing:

- **www.autisticadvocacy.org/Research**
- **https://airpnetwork.ucla.edu/about/arrb**
- **www.policyimpactproject.org**

For more information please contact:

The Autistic Self Advocacy Network: info@autisticadvocacy.org

The Policy Impact Project: Policyimpact@drexel.edu

About the Information in This Report

The findings in this report are based on an analysis of symposium session transcripts. These transcripts captured the discussions, perspectives, and insights shared by invited speakers and participants. Staff from ASAN and PAC systematically analyzed the transcripts to identify key themes. To ensure accuracy, ASAN and PAC staff then reviewed and refined these themes.

General Summary

This section summarizes cross-cutting topics. These are topics that apply to all autism research no matter what the topic is.

Below are cross-cutting topics that we heard across session. These topics were repeatedly nominated by participants for further research exploration, reflecting key areas of interest and importance.

Issues with Current Research and Research Methods

Research that is not driven by community priorities

- Genetic research and research searching for a cure for autism (or causation) continues to be heavily funded despite community concerns (e.g., about eugenic implications).
- Research funding is disproportionately higher for genetics research than for topics like lifespan issues, quality of life, services and supports.
- Over time, autism research has been influenced by the priorities of funders, non-autistic researchers, and parent advocates, but usually not by autistic people themselves.

Stigmatizing/stereotyping in research

- Autism researchers have a large impact on how autistic people are viewed in society.
- Research that sees autism as inherently negative leads to a focus on screening and prevention, rather than changing society to support autistic people.
- Research on autistic people's communication and perception often focuses on supposed deficits or weaknesses, instead of trying to understand how these processes work differently for autistic and non-autistic people.
- Some research furthers common stereotypes about autistic people (e.g., They must have useful "superpowers" to be accepted; they are all neurologically the same; they do not have a sexuality).
- The wide range of presentations and support needs among autistic people is sometimes used to divide the autistic community.

Issues with research practices

- Research often fails to respect the consent and perspectives of autistic children.
- Consent forms and other participant-facing materials are usually not written in plain language. Plain language is a specific style and format of writing that makes information clear and easy to understand.
- Research institutions are not addressing the past and present harmful practices that cause many autistic people to distrust researchers.

- Progress in **community-based participatory research (CBPR)** has been limited to areas of research where it is "easiest" to recruit participants and conduct the research.

Exclusion of multiply marginalized autistic people in research

- Autism research has typically focused on white, upper middle class, cisgender boys. We need more research regarding autistic people with intersecting marginalized identities (e.g., autistic women of varying economic backgrounds). Autistic people who are marginalized based on their race, ethnicity, age, gender, sexuality, support needs, and other identities are left out.
- Inaccessibility, prejudice, and even study protocols (e.g., disqualifying autistic people with co-occurring disabilities) can create barriers to inclusion.
- Researchers often ignore the multiple intersecting identities and cultural contexts of autistic people, both in their recruitment and data collection.
- Multiply marginalized autistic people are often excluded from roles that make decisions about research funding, ethics, and study design. This reinforces problems, like the ones listed here, because there is little motivation for people who are not impacted by these problems to change research practices.

Exclusion of autistic researchers

- Many autistic researchers and autistic academics are pushed out of their fields by prejudice, discrimination, and a lack of accommodations.
- Many autistic researchers are unable to be openly autistic due to stigma.
- Autistic researchers are sometimes excluded or dismissed from autism research because they are seen as being biased.
- Autistic people are often limited to roles as advisory board members, not as funding decision-makers, institutional review board members, full members of study teams, and principal investigators.

Directions for Research Methods

Autistic-led and participatory research approaches

- Research on autism needs to include, center, and be led by autistic people with a variety of skills, support needs, identities, experiences, and ages.
- Autistic people should be involved in research at all stages and in all roles (e.g, members of research teams, advisory committees, Institutional Review Boards.).
- Autistic community priorities should drive decisions about which topics to study and which research to fund.

- All fields of autism research should use community based participatory research, participatory action research, and/or other partnerships with autistic communities.
    - Researchers should study ways to implement community participation in research and study the impacts of community participation on research outcomes.

Centering multiply marginalized autistic people in research

- Multiply marginalized autistic people need to be included as collaborators from the beginning of the research process, centered in leadership, and supported in research spaces.
    - In autism research, "centering" autistic people means placing a focus or emphasis on them, making the expressed needs of the community a priority. It involves framing the research, questions, or analysis around their experiences and viewing things through an autistic lens without projecting neurotypical expectations onto the work.
- Researchers need to center their research processes around the accessibility needs of multiply marginalized people in the autistic communities they study.
- Research should promote cultural responsiveness through training, protocols, and community representation on the research team.

Intersectionality and Diversity of Participants/Populations

Research the experiences of…

- Autistic adults in general and autistic older adults specifically.
- Autistic people who are not from “WEIRD” (Western, Educated, Industrialized, Rich, and Democratic) backgrounds.
- Other multiply-marginalized autistic people as described above

Accessibility for research participants

- Language
    - Use plain language in participant-facing materials.
    - Invest in linguistically and culturally accurate translations of study materials into other languages.
    - Be mindful of pace and clarity when speaking.
- Financial. Ensure equitable compensation for research participants and community collaborators.
- Location. Offer multiple virtual and in-person options, and transportation assistance.
- Time. Offer flexible scheduling, non-traditional hours, and caregiving support.
- Process:

- Offer multiple modes of participation
- Provide flexible accommodations for all disabilities by asking ALL participants about their access needs, not just those with apparent disabilities
- Develop ways of including autistic children's self-reports

Accessibility in dissemination

- Prioritize open-access publishing.
- Use accessible language in published material (e.g., plain language and Easy Read versions, lay summaries). Note that using accessible language does not mean leaving out details or information you would include in a formal language document; it means communicating those same details in an accessible way.
- Share research beyond academic journals and databases (e.g., through social media, public presentations and discussions).
- Use multiple communication formats (e.g., visuals/pictures, videos, audio).
- Communicate key takeaways and action items directly to self-advocates, clinicians, and service providers.

Transparency and ethics

- Be transparent with participants about how data will be collected and used.
- Avoid misleading participants (e.g., when trying to control response bias).
- Disclose conflicts of interests when there are financial ties to treatment research.
- Disclose all potential harms caused by treatment research.
- Consider the involvement of minors in research.
- Share information about risks that come with having one's name attached to research projects as a collaborator (e.g., harmful responses to research).

Transforming the Field

Support autistic researchers inside and outside of academia.

- Increase inclusion in higher education through accommodations, peer support, and mentorship programs.
- Recognize the skills and expertise of autistic researchers and advocates outside of academia.
- Use existing tools that connect researchers to autistic collaborators with relevant lived experiences and expertise (e.g. INSAR Community Collaborator Request).

- Ensure training, mentorship, and professional development opportunities for non-academic autistic researchers. Models exist but are not widely used.
- Ensure supportive working conditions for autistic researchers including accommodations, respect for access needs, equitable pay, remote job options, and job security.

Codify inclusive research practices.

- Create guidelines for funders, ethics committees, and researchers on including people with intellectual and developmental disabilities in the full research process.
    - Practice neurodiversity-affirming values, not just language.
- Institutional Review Boards should accept accessible alternatives to currently inaccessible training programs.
- Institutional Review Board procedures should protect research participants without creating undue barriers to research with multiply-marginalized autistic people. For example, the process of giving consent to participate in research should be accessible; for example, expressed in plain language.

Self-advocacy and allyship

- Activists and allies need to work with the diversity of the autistic community. There is no one perfect approach to language, research, and activism.
- It is important to consider the experiences and needs of those in the community who cannot speak for themselves (e.g. young children).
- Autistic people can educate and involve the people around them in advocacy, but should not be tokenized as the only people doing so. Collaborators should not assume that every autistic person has the capacity to educate them about autism in addition to performing other responsibilities in a research setting.
- Non-autistic allies should support autistic people who speak up about harmful research practices, rather than becoming defensive.

The Need for Community-Based Participatory Research

Research approach: CBPR

- Community-based participatory research design, like the Academic Autism Spectrum Partnership in Research and Education (AASPIRE), should guide research with autistic people.
    - The ways to meaningfully include autistic people in research are applicable across research topics, even when the research has nothing to do with autism.
- When researchers survey diverse autistic communities, research topics are re-centered around autistic people's priorities, needs, and autonomy as the primary stakeholders. Overall, autistic

people say there is a need to shift away from a focus on “curing” or preventing autism and a need to shift toward community priorities.

- Autistic people, especially those who are marginalized in multiple ways, should shape research from the very beginning (i.e., deciding what to research).
    - People with lived experience relevant to the research question(s) at hand should be involved in planning research questions, methods, and outcome measures.
    - Need to include autistic people at every step of research, from formulating topics to designing and carrying out studies to accessing/using research products.
    - Invitations for participatory research should be advertised within the community.
- Autistic people should have the training, education, communication support, and mentorship needed to fully participate in research.
- Participatory research should be accessible for all autistic people by including accommodations and multiple ways to participate.
    - Increase accessibility of research participation for autistic people with a variety of support needs.
- Current funding structures, which at times prioritize specific scientific research, make it difficult to conduct community-based participatory research.
- Need to include and advocate for autistic researchers within autism research.
- Funding incentives could help increase CBPR.

The Need for Better Dissemination of Research Findings

- Communicate with all stakeholders, including self-advocacy organizations, service providers, service recipients, caregivers, and policymakers.
- Create plain language and easy-read translations of research.
- Work with publishers that offer open-access publishing or encourage sharing.
- Use non-academic communication formats to reach community members, including social media, videos, online community forums.
- Communicate with service providers through targeted materials (e.g., accessible tip sheets for implementation).

Dissemination with community

- Use accessible language in the findings of original publications.

- Plain language versions of findings should be longer (due to the language and formatting standards for plain language) and include just as much detail as the original publications.
- Findings and relevant implications should be accessible through “short and loud” public communication formats (e.g., bus posters) and shareable online materials.
- Stakeholders (including autistic community members, research networks, advisory panels) should not simply be informed of the research findings; there should be a two-way dialogue to see what findings make sense or do not make sense to them.

Use within community

- Research findings should be translated into educational materials, and researchers should give people the resources to educate others in their communities.
- Disseminate more plain-language, accessible materials in general.

Dissemination to community

- Disseminate research findings in a more accessible way.
    - More plain-language products
    - Disseminate products such as photos or visual

Biology and Neurology

Research Topics

It is important to remember that neurological differences aren't characteristics to be cured. They are just part of the diversity of how people's brains work. It is important to understand that autism is a valid way of being, and neurology should just be one piece of understanding it. Autistic people's own perspectives and experiences are key to this understanding.

More Words to Know

- **Apraxia:** A movement difference where someone has trouble making purposeful movements, even though their muscles work fine. For example, a person with apraxia might know what they want to do, like wave or speak, but their brain has barriers in sending the right signals to make it happen.
- **Dyspraxia:** A motor challenge that makes it hard for someone to plan and coordinate physical movements. People with dyspraxia may have trouble with activities like writing, tying shoes, or catching a ball. It's not due to how the brain processes movement.
- **Ehlers-Danlos syndrome (EDS):** A group of conditions that affect the connective tissues, like skin, joints, and blood vessels. People with EDS may have very flexible joints that can be easily injured, stretchy skin, and may bruise easily. There are different types of EDS, and symptoms can vary.
- **Mast cell activation syndrome (MCAS):** A condition where certain cells in your body, called mast cells, release too many chemicals that cause allergy-like symptoms. People with MCAS might have reactions like itching, swelling, stomach problems, and trouble breathing, even without a clear trigger.
- **Postural orthostatic tachycardia syndrome (POTS):** A condition that affects blood flow. When people with POTS stand up, their heart rate increases, which can cause dizziness, fainting, and feeling tired. It happens because their body has trouble adjusting to standing upright.
- **Sensory differences:** Autistic people may experience sensory differences. They may be hyper-sensitive or under-sensitive to specific sights, sounds, smells, or textures. This can be a positive thing but can also cause distress or discomfort.

Biology

Etiology

- What are autistic peoples' perspectives on biological autism research, especially genetic autism research?
- Autistic people are often divided into broad subgroups based on subjective behavioral observations. What are useful subgroups based on objective, specific measurements of biological/physiological factors (e.g., movements, stress hormones)?
- Connections between biological and neurological mechanisms of autism (e.g. What are the hormonal mechanisms behind emotional dysregulation for autistic people?)

Co-occurring conditions

- Genetic and other biomedical research into commonly co-occurring conditions could lead to a better understanding and identify ways to manage symptoms that can cause stress.
- What sort of long-term health conditions are more prevalent among autistic people, and why?
    - Especially need more research on **Ehlers-Danlos syndrome (EDS), mast cell activation syndrome (MCAS),** and **postural orthostatic tachycardia syndrome (POTS).**
- Prevalence and experiences of gastrointestinal (GI) conditions among autistic people.
- Biological connections between autism and **dyspraxia** and/or **apraxia**.
- Connections between autism, central sensitization syndromes, and chronic pain.
    - Exploration of potential psychological, social, and biological factors that could influence associations.
- Efficacy of existing medications (including interactions and combinations) for chronic health conditions that autistic people experience.
- Understanding diagnostic overshadowing, or when health problems of autistic people are dismissed as being part of autism.

*Somatic / **sensory** experiences*

- Autistic experiences of puberty, menstruation, and menopause.
- How peri-personal space (PPS) experiences of autistic people relate to differences and difficulties with movement, speech, and social interaction.
- What are different sensory profiles (i.e., shared sensory sensitivity experiences) of autistic people?

- Impact of sensory environment on autistic people; how to make spaces more accessible for autistic people with different sensory profiles.
- Eating-related behaviors and experiences in autistic adults, e.g., avoidant/restrictive food intake disorder (ARFID), or misophonia (emotional or physiological responses triggered by specific sounds).
- What sleep issues are unique to autistic people vs present in the general population?
- What factors negatively and positively impact sleep in autistic people, and how? (e.g., sensory issues, social and environmental factors)
- How can we help autistic people struggling with sleep? (e.g., developing medication- and behavior-based interventions, accommodations at school or work, helping autistic people explain sleep concerns to doctors)

Neurology and Neuroscience

Etiology and assessment - neurological differences

- Which neurological outcome measures are meaningful for services research?
- Research into the validity of neurological measurement scales developed with allistic people for autistic people.
- Research on the reasons behind differences between autistic and non-autistic brains in brain imaging findings.
- Beyond basic features of perception, what other basic neurological features are different for autistic vs. allistic people?
- Presentations of autism and dyspraxia can overlap. What are the neurological differences between these diagnoses?
- Neurobiological research into sources of apraxia, dyspraxia, and other sensory movement differences among autistic people, with a focus on therapeutic implications.
- Understanding the sensory, movement, and memory encoding issues of nonspeaking autistic people - neurobiological connections between apraxia/dyspraxia and communication difficulties.
- Understanding of the neurobiology of autism, apraxia, and dyspraxia to develop objective/physiological metrics for diagnosing and distinguishing each.

Co-occurring neurological conditions

- Need interdisciplinary research between medical and psychological fields regarding neuropsychiatric conditions in autistic people.

    - Particularly in relation to the rise in neuropsychiatric conditions in people who have "Long COVID."
- Seizures in autistic people and effectiveness of current treatments.
- More research on the intersection of autism and dementia and other neurodegenerative conditions - including prevalence/risks, mechanisms, and lived experiences.
- How cumulative lifetime experiences of social, physical, and educational engagement opportunities affect risks for cognitive decline among autistic people.
    - How specific needs around social interaction and sensory stimulation relate to cognitive health and risks for neurodegenerative conditions.
    - How overstimulation or other negative experiences might relate to risks for neurodegenerative conditions through stress processes.
- How autistic people can engage in their communities in ways that do not contribute to chronic stress.

Supports and systems

- How are neurodegenerative conditions identified in autistic people? Validity of diagnostic tools for autistic people, especially nonspeaking autistic people.
- Challenges to recognizing neurodegenerative conditions in autistic people (e.g., discontinuity of care, diagnostic overshadowing).
- Applications of technologies that use non-verbal data to understand mental processes.
- How to incorporate monitoring decline into existing care models, specifically using evidence-based tools, practices, systems that work for autistic people.
- How systems of care can meet needs related to autism and Alzheimer's or dementia simultaneously, and how autistic people navigate these systems.

Technology and Communication

Technology

- How people with dyspraxia/apraxia develop motor control skills to use AAC.
- Development of non-invasive brain computer interface technologies that help in communication.
- How mechanisms of current technologies may or may not be useful for autistic people with different neurological conditions.

Assessments for communication

- Evaluate the effectiveness of assessments, supports, and services for communication using single-subject research design with outcome measures chosen by people being assessed.
- Developing tools and practices for individualized approaches to communication assessment.

Supports and systems

- How can AAC users with higher support needs direct their lives and access reliable support? How can we facilitate their full participation?
- What kinds of supports and services can help people with dyspraxia/apraxia?
- Understanding the lived experiences of autistic people with dyspraxia, apraxia, and communication difficulties.
- Who is most at risk for barriers to supports and treatments?
- External barriers to accessing supports, treatments, services, etc. for autistic people with executive functioning challenges.

Research Methods

Research Approach

Formulation and conceptualization

- Mindset guiding all research must shift *from* curing autism *to* valuing (neuro)diversity.
- Need interdisciplinary research that combines medical and psychological perspectives.
- Need a balance of medical and social models of disability, with respect to recognizing specific support needs of autistic people (including broader access to healthcare).
- Balance of strengths-based opportunities and challenge-based solutions
    - Strengths-based opportunities: Ensuring belonging/participation of autistic people through communication support, education and employment opportunities, accommodations.
    - Challenges-based solutions: Brain-biology, biomed, technology, precision pharma, supports.

Research Design

Intersectionality and diversity of participants/populations:

Research the experiences of:

- Autistic people who have been historically excluded because of their support needs, including:
    - Those who do not speak, including those who use AAC or other communication supports
    - Autistic people with intellectual disabilities
    - Autistic people with apraxia/dyspraxia
- Autistic people who have not accessed a formal diagnosis

Outcomes and measurement

- Autistic people should be asked about their own experiences, especially through accessible qualitative studies.
- Move beyond behavioral observations alone; studies should use combinations of objective measures (i.e., directly capturing biological/physiological data) and subjective measures (especially self-report).
- Longitudinal studies and studies that measure long-term outcomes are needed across all topics; need to move beyond correlational approaches alone.
- Single-subject research designs should be used to capture individual change over time.

Inclusive/accessible data collection

- Take steps to minimize sensory overwhelm and supply options for self-regulation in the data collection environment.
- Communicate reasons for unavoidable study procedures that may activate sensory issues (e.g., having to wear certain clothing or monitors).
- Maintain consistent access to alternative communication tools/communication partners for participants who need it.
- When possible, consider alternative study settings (e.g., participant's home vs. lab) and space out study appointments or activities.
- Devise research tasks and measures that do not rely on fine motor skills, the ability to sit perfectly still, fluent communication, and fast reaction times.
- Ensure the durability and accessibility of research equipment.
- Share protocols across labs and learn about protocols in other diverse populations.

Research Applications: Biology

- Neurological and psychological research can be used to educate teens about their disabilities/executive function profiles and help them advocate for their needs.
- Research on autism and technology (e.g., brain computer interface (BCI)) should be used to develop assistive devices rather than punitive behavioral interventions.

Research Funding and Data Advocacy

Funding priorities

- Research into movement differences in people with disabilities needs funding.
- Stakeholders – especially autistic people – should have their priorities taken into consideration in funding decisions. Autistic community members have concerns about causation/prevention research in genetics, which is heavily funded.

Research advocacy/policies

- Requiring public accessibility and public presentations as part of funding awards would ensure key stakeholders are kept well-informed.
- More advocacy is needed to combat ableism in scientific research and increase inclusion of all autistic researchers, including those who do not speak.
- The National Institutes of Health (NIH) requires researchers to add the collected data to public repositories to receive public funds.
    - Participants are not given the option to only consent to their data being used for the study they are participating in without it being added to public repositories.
    - Policy changes are needed to give participants options to consent and revoke consent to secondary uses of their data.

Research Ethics

Consent and transparency

- Informed consent should be accessible/comprehensible across a range of support needs.
- Nonverbal signs of distress, or requests to stop, from participants (including kids whose parents consent) should be taken seriously as acts of dissent.
- People should be well-informed in detail of the consequences of genetic data collection before they can consent to it - including how data will be used and who can access it.

Individual benefits and risks

- Need to seriously consider the burdens placed on individual participants in autism research (e.g., energy, extensive testing).
- Importance of fairly and tangibly compensating autistic research participants while still considering concerns about pressures on economically-disadvantaged participants, such as compensation that could cause someone to go over the monthly earnings threshold for social security benefits.

Community benefits and risks to consider

- Genetics research may be useful for understanding health conditions or distressing symptoms that autistic people experience and may help families prepare to welcome/support their autistic children.
- However, "cure," causation, screening, and prevention research can pose eugenic implications, and policies are needed to prevent autism research from being misappropriated for harmful purposes.
- Genetic research focusing on the causes of autism can also increase pathologizing, stigma, discrimination, and exposure to harmful interventions.

Avoiding stigmatizing/ableist research

- Avoid conflating genetic variances associated with autism with being "autistic" in animal research.
- Avoid assuming that all differences are pathological; instead, address common health issues that impact autistic people (e.g. epilepsy and gastrointestinal issues).
- Avoid broad generalizations, categories, and labels that obscure the heterogeneity of challenges and strengths among autistic individuals.
    - E.g., conflating spoken communication with IQ, using arbitrary labels of "high-" vs "low-functioning" and "profound autism." These generalizations can unnecessarily divide the autistic community and exclude individuals from both opportunities and additional supports.

Sessions That Informed the Discussion of Biology/Neurology

Introductions and Discussions of Current Research. This first session included general discussion of the current state of research regarding biology/neurology, which included ethical concerns, how research includes autistic participation, what areas are under researched and where we should go from here.

Beyond Causation and Prevention: Making Biological Research Work for Autistic People. The bulk of biological and genetic research focuses on causation and in some cases, prevention of autism. This runs counter to autistic community priorities. This session was a time to reflect on how this approach to autism research does a disservice to our community and to identify new approaches. We discussed

research avenues that benefitted the autistic community and how we can incorporate community-based participatory research approaches.

Autism and Neurodegenerative Conditions. Neurodegenerative conditions occur when cells in the central nervous system (CNS; i.e., brain/spinal cord) are progressively breaking down or getting worse, usually in an irreversible way. Common examples are Alzheimer's and Parkinsons. This research presentation, followed by discussion, on neurodegenerative conditions discussed the higher rates of these conditions in the autistic community and how we can better support autistic people with neurodegenerative conditions.

Autism and Sleep Deep Dive: What Do We Need To Know? Autistic people of all ages are more likely to have poorer sleep quality and sleep disorders, but most research is done on children. We discussed current gaps in existing research and what autistic people prioritized for the direction of sleep research.

Autism and Chronic Physical Illness: What We Don't Know. Autistic people are more likely to have physical chronic health issues, such as Ehlers-Danlos, migraines, and gastrointestinal issues, but there are many things that we still don't know about why and what that means for our community. We heard from researchers looking into these subjects and discussed what it means for our community and what research would be helpful to autistic people with these conditions.

Ask A Bio-Neuro Researcher. This was a town hall for autistic folks to ask questions to bio-neuro researchers. We invited all autistic attendees to discuss topics such as: what research on a topic already exists, how research should be done, ethical concerns, and the importance of including autistic people meaningfully in leading research. This session helped participants flesh out unfamiliar concepts or confusing issues in the biology and neurology track and prepared them to engage in self-advocacy in the research field, but also in medical contexts.

Autism, Apraxia and Dyspraxia: What Self Advocates Want to Know. Self-advocates led a discussion about the connections between apraxia, dyspraxia, and autism. Much of the research on this topic does not include autistic people with apraxia and dyspraxia and does not consider community priorities. Self-advocates discussed what they want to see from research on this topic.

Services and Supports

Research Topics

More Words to Know:

Augmentative and Alternative Communication (AAC): AAC refers to all the ways that someone communicates besides talking. People of all ages can use AAC if they need ways to communicate other than through spoken language. Augmentative means to add to someone's speech. Alternative means to be used instead of speech. Some people use AAC throughout their life. Others may use AAC only for a short time.

Home and Community-Based Services (HCBS): HCBS are services that allow Medicaid beneficiaries to receive care in their homes or communities instead of in institutions. HCBS can help people preserve their independence and connections to family and friends.

Augmentative and Alternative Communication (AAC) and Communication Strategies

Overall, research should:

- Focus on how people can access supports that help them communicate and advocate for their goals and wants.
- Reflect existing conversations within the AAC community.
- Avoid reinforcing negative assumptions about AAC users and their methods of communicating (e.g., assumptions that AAC is not valid communication).

AAC technology and features

- Improve accessibility of AAC by incorporating joysticks, switches, and eye-gaze technology
- Make AAC more portable
- Use AAC to sing, make jokes, make changes in tones, speak diverse dialects, and make full sentences quickly on the go.
- Develop AAC vocab that teens and adults find useful (e.g., sex, gender, relationships; menu-based options for high school and college-level classes; religion; day programs).
- Make AAC with full sets of multilingual vocabulary that users can quickly switch between or use simultaneously.
- Include Indigenous languages in AAC devices

- Develop user-friendly augmentative and alternative communication (AAC) options for autistic people. What are autistic people's priorities for features and ease of navigation?

Research AAC user experiences.

- Experiences of autistic teens with ID who use AAC - what they want to learn, how they learn, what their goals are.
- What is AAC acquisition like for older users?
- What are the best ways for AAC users to have control over their own communication system?
- How do adult AAC users navigate supports, services, and self-advocacy?
- What are the assumptions that people make towards AAC users? How does this impact their participation, including within research?

Medicaid Home and Community-Based Services (HCBS)

Eligibility/finding services

- What supports and services do autistic people need that are currently non-existent or inaccessible through state HCBS?
- Understanding population-level inequities in accessing HCBS (i.e., who is and isn't accessing services through various systems?)
- How many people apply for HCBS and get turned away? Why?
- Assessing and addressing the impact of known barriers to services:
    - Availability and accessibility of information
    - State variability in eligibility for HCBS waivers
    - Income limits and asset limits
    - Policies that limit eligibility for HCBS to "all or nothing"; how this impacts people's abilities have their specific service needs met by HCBS
    - Workforce shortages and representation within the service workforce
    - Stigmatization and discrimination as a barrier to seeking services

Service direction

- Do people who self-direct their HCBS have better outcomes/greater satisfaction than those who receive traditional HCBS?
- How many people receiving self-directed services are making decisions about their own services in practice (versus a family member or guardian)?

- How can self-directed HCBS services be made more accessible to people with varying support needs?
- How do paid family caregiving arrangements impact autonomy and transition to adulthood?
- How can peer supports supplement HCBS?

Assessing HCBS quality and outcomes

- More pilot programs and long-term program evaluation for supports and services, led by autistic people.
- Assess adverse events experienced by service users.
- Efficacy of HCBS Settings Rule and similar policies to improve services: Are people having their rights to privacy, visitors, self-determined schedules, employment options, etc. respected?
    - How can researchers evaluate policy implementation and service quality across different states, providers, and types of services?
- How do people who receive HCBS define good outcomes for HCBS? How well are their services aligning with those self-determined standards?
- How do HCBS users define quality of life? How do people make big choices about their lives, and how does access to these choices affect quality of life?

Transitions and Employment

Pre-transition and transition services

- How to address limited collaboration between school and adult systems and support parents in navigating this transition.
- How to help parents/educators presume competence around employment.
- Experiences of transition into adulthood for Black autistic youth, in particular.
- Why people do or do not transition into the workforce after high school.
- Early work experiences for autistic high schoolers

Assessing employment services

- Develop and utilize better measures of the supports that people need to access employment.
- How are employment services working and not working for autistic people?
- Examine transition/employment service use patterns, effectiveness of services, and entry/exit into workforce data over time.
- Who is not accessing services, or is excluded from services, and why?

- How and why do some states perform better than others in employment services?

Developing and implementing employment services

- Develop transition leadership and training opportunities for direct support professionals and employers.
- What keeps direct support professionals and employers from implementing best practices?
- Strength-based ways to support autistic people at work
- How to match autistic people with careers aligned with their interests/knowledge, not just short-term, entry-level work.
- How can we best provide education about employment through peer mentoring and support for people with IDD?
- Translating positive outcomes from employment services for people with other kinds of disabilities to autistic people/people with IDD.

Independent Living

Guardianship

- What are alternatives to guardianship?
    - What models would work for people across various situations, marginalized identities, and cultural backgrounds?
- Benefits of guardianship alternatives:
    - How disabled people enrich their communities when they have agency over their lives
    - Cost-effectiveness of alternatives
- What happens in cases where guardianships are limited or abolished through policy action?

Aspects of independent living

Independent living does not necessarily mean receiving no support or living alone. It means the person decides what supports they want and where they want support from.

- Need research on how to implement factors known to promote independent living:
    - Service models that support different individual situations and cultural backgrounds
    - Accessible, affordable housing units within the community
    - Transportation support options

    - Support and understanding from peers, guardians, roommates, professionals, etc.
- Developing practical resources to support autistic people in different independent living situations, such as with roommates and family members in the community.

Therapies/Interventions (Non-Mental Health)

Centering autistic perspectives within therapies/interventions

- Using strength-based practices to accommodate different ways of processing and focusing
- Shifting therapies to focus on autonomy, not compliance, from a young age
- Understanding and addressing the health impacts of stressful environments, a lack of appropriate supports, autism stigma, discrimination, bullying, and other harmful experiences.
- Understanding and addressing the impacts of masking, camouflage, and communication difficulties in interactions between autistic and non-autistic people.
- How do behavioral interventions impact quality of life from an autistic perspective?

Developing and implementing therapies/interventions

- Ensuring true person-centered planning within therapies/interventions
- Ensuring culturally/linguistically responsive services.
- Structure service delivery to promote quality of life and maintain this over time, rather than only providing acute support in crisis/severe situations.
- Develop further resources for autistic people experiencing homelessness, trauma, abuse, and other adverse situations.

Research Methods

Research Approach:

Conceptualization/frameworks

- Follow practices of presuming competence and affirming neurodiversity, as defined by autistic people themselves.
- Define the aim of services as meeting autistic people's individual, dynamic needs and goals for both support and independence.
- Instead of only focusing on fixing "problem behaviors," understand and address how autistic people's environments and larger social systems impact their experiences.

- Avoid broad labels that obscure nuances in autistic experiences (e.g., “low” vs. “high” functioning, “mild” vs. “severe”).

Community-based participatory research

- Research to develop and evaluate services should be done with people who receive services, their family members and/or other caregivers, and people who provide services.

Research design

Intersectionality and diversity of participants/populations:

- AAC users should be included in all autism research, not just AAC-specific research.
- More research should focus on and include autistic people with intellectual disabilities and other disabilities in addition to autism.
- Need efforts to include autistic people with multiple marginalized identities, especially racially and ethnically marginalized autistic people.
- Expand participatory research specifically focusing on intersectionality

Accessible/inclusive research procedures:

- Academic environments need to improve education about accessible research methods for researchers.
    - Data collection tools and procedures can be modified to the needs of the population and the individual (e.g., conducting assessments via text, sending questions ahead of time, allowing as much time as needed to answer).
    - Research instructions should be cognitively accessible (e.g., written in plain language).
    - Provide accommodations and supports to research participants (e.g., incorporate participants’ support persons or communication partners, include communication specialists on research teams, offer communication and sensory regulation tools).
- Communicate clearly about potential impacts of compensation on benefits, find alternative forms of compensation if necessary.

Outcomes and measurement

- Use qualitative designs to identify the supports, services, and outcomes that are important to autistic people themselves.
- Use self-report over parent/caregiver proxy measures whenever possible.
- Assess impacts of services using long-term outcomes and longitudinal data.

- Use person-centered and accessible tools to measure quality of life with all autistic people (e.g., Personal Outcome Measures from the Council on Quality and Leadership, National Core Indicators).
- When evaluating services, use measures that capture quality and impact, not just quantities and frequencies of use.

Research dissemination and application: Services and supports

Research Applications

Data on the quality of services and supports can be used for:

- Person-centered planning (devising supports *with* the service recipient, not *for* them)
- Discovering disparities in service access and quality
- Identifying factors that affect the quality of people's lives
- Looking at the quality of individual providers and/or state provider infrastructure

Research Funding and Advocacy

Funding priorities and practices

- Funders need to prioritize qualitative inquiry, community/participatory research
- Need funding for translating findings for publications about research and services
- Inclusion of HCBS participants in research (as participants, researchers, and collaborators) should be tied to funding to ensure inclusion.
- To ensure higher-quality data collection, funding should be attached to high-quality data collection by states and providers.
- More funding is needed for research intended to improve services, supports, and assistive technologies for autistic people, beyond behavioral interventions.

Research advocacy/needs

- Increase collaboration to address the separation and inconsistency in data collection practices across service systems and states.
- Address biases within research-related agencies (e.g., IRBs not believing that researchers with IDD can be fully contributing, paid members of the study team)
- Improve the accessibility and transparency of datasets from federal agencies

- Increase training and funding to help researchers and community partners create and share plain-language findings.

Suggestions for Policy and Practice

- Fund self-advocacy efforts to educate HCBS recipients on their rights and what to do if their providers are not meeting requirements.
- Reform HCBS policy to allow people to receive the services they need without living in poverty and without giving up choice over employment.
- Address long HCBS waitlists and staff turnover as well as discrimination within the direct support professional workforce.
- Support access to multiple services by increasing Medicaid coverage and integration across systems (e.g., mental health services, services for older adults, disability services).
- Expand implementation of practices known to be effective, including person-centered planning and individualized placement and support.
- Help people maintain access to employment-related supports after they are hired.
- Allow access to Applied Behavioral Analysis (ABA) alternatives through insurance, state, and school policies.
- Ban behaviorist practices proven to harmful, such as the use of aversives (i.e., painful stimuli meant to stop a behavior)

Sessions That Informed the Discussion of Services and Supports

Introductions and Discussions of Current Research. Our first session included discussion of the current state of research regarding services and supports, which included ethical concerns, how research includes autistic participation, what areas are under researched and where we should go from here.

HCBS and Waiver Services: How Research Can Support Policy Recommendations

Our panel discussed how we could better identify best practices and disparities and access to services and supports. Research must be used to formulate policy recommendations and create policy change. We discussed systems fragmentation, the many weaknesses of our current systems to provide these services, and how we could use research to advocate for change.

Alternative and Augmentative Communication (AAC) Access

A panel of autistic people who use AAC discussed their priorities for autism research and the need for community-based participatory research approaches for research into AAC. We discussed the current and future directions of research on these topics. We also discussed issues with access to AAC.

Employment Services

This session was a panel where panelists spoke on employment services, and how research can be used to create better systems for competitive integrated employment. We discussed barriers and racial disparities in current services. We also had a discussion where self-advocates discussed what they wanted to see from research.

Beyond Behaviorism Ages 0-22: What does the future of services research look like for autistic youth?

Current autism services are focused primarily on a behaviorist approach, which many people in the autistic self-advocate community condemn. We discussed how we can create an education and services system for autistic youth that matches the priorities of the autistic community.

What We Want to See from Research on Independent Living

Speakers and attendees discussed barriers to independent living and how community-based participatory research can create innovative programs that match our priorities. We discussed supported decision making, access to service, and how we can move toward self-directed services.

Positive Behavior Supports and Measures of Quality of Life

Current autism services and research do not always consider our measures for quality of life, and usually define these measures in more restrictive ways than our communities do. This session discussed services quality measures as defined by people with I/DD as well as barriers to access current supports and services.

Adulthood and Aging

Research Topics

Below are topics nominated by participants for further research exploration, reflecting key areas of interest and importance: independence, transitions, and relationships.

Independence, Transitions, and Relationships

Higher education

- Implementing supports for disabled college students:
    - Accessibility of recruitment and application processes
    - Accommodations and accessibility once in college
    - Faculty training/knowledge about accommodations and disability
    - Peer interactions/inclusive climate
    - Career preparation services

Employment

- Unemployment, underemployment, undesired employment, and unfairly compensated employment.
- Defining and measuring employment satisfaction for autistic people
- Improving employment services, programs, and policies (systems-level)
- Understanding and implementing strategies for obtaining/keeping employment (accommodations, accessible and inclusive work environment, on-site supports).
- Understanding and addressing barriers to obtaining/keeping employment

Autonomy, self-determination, and community living

- Supporting financial literacy and agency
- Resources for those who do not complete high school
- Development and evaluation of tools, models, and programs to support self-determination.
- Opportunities for engagement and fulfillment beyond work.

Relationships and family supports

- Romantic relationships and friendships
- Support for autistic caregivers and parents
- Support for caregivers and parents of autistic people

Systems Interactions and Trajectories

Diagnosis and intervention experiences

- Disparities in diagnosis; late diagnosis
- Impact on identity and wellbeing
- Experiences with interventions (ABA, other interventions)
- How can diagnostic systems focus on identifying individuals' specific needs, rather than broad labels?
- Develop diagnostic assessments with input from autistic people, with attributes that matter to autistic people.

Institutional interactions

- Experiences with institutionalization, guardianship, and incarceration
    - How access to diagnosis and special education systems impact these experiences.
    - Alternatives to these systems

Research Methods

Research Design:

Participants/populations:

- More research should focus on the experiences of autistic people who face intersecting forms of marginalization, including:
    - Autistic older adults
    - Racially and ethnically marginalized autistic people
    - LGBTQIA+ autistic people
    - Autistic women

- Studies should include and specifically focus on autistic people with higher support needs:
    - Autistic people who do not speak and autistic people who use AAC or need other communication support.
    - Autistic people with intellectual disabilities
- Comparing outcomes for autistic adults who receive Medicaid/Medicare versus those who don't.

Methodology

- Need for more qualitative studies that center autistic perspectives and experiences.

Outcomes

- Long-term outcomes and longitudinal designs are needed to examine impacts of policies/programs.

Research Funding and Advocacy

Funding needs

- Funding agencies should prioritize research at the intersection of sexuality/sex education and disability
- Need more funding for research about accessing higher education

Data advocacy

- Advocate for large-scale, population-level datasets with valid measures of autism AND gender, sex, and sexual orientation.

Research applications: Autism and Aging

Dissemination to community

- Make research products accessible for older adults, both in content and delivery methods.
- Share accessible resources about puberty/aging experiences, college, adulthood transitions, family planning, choosing social connections, collaborating with caregivers, and parenting.

Bridging gaps between research and policy/practice

- Researchers should partner with high schools and colleges to apply findings about college transitions and accessibility needs of autistic students and students with IDD.
- Need for government agencies to take up research findings

- Broadening definition of “activities of daily living” to include important areas like parenting, relationships, sexuality.
- Listening to autistic people’s needs around fair employment

Sessions That Informed the Discussion of Adulthood and Aging

Introductions and Discussions of Current Research

Our first session included discussion of the current state of research regarding autism and aging, which included ethical concerns, how research includes autistic participation, what areas are under researched and where we should go from here.

Accessing Higher Education

Panelists discussed barriers to higher education, focusing on student-defined success, as well as discussing the various postsecondary education options autistic people have, while also pointing out the limitations of existing services.

We All Grow Up: Supporting Puberty, Reproductive Health, and Sexual Education for Autistic Youth and Adults

Panelists discussed the ways in which people with I/DD often are not given access to sex education and information about reproductive health. Topics touched on included consent education, equitable access to sexual education, LGBTQ+ competency, and other reproductive and sexual health issues that affect folks at different stages of their lives.

Aging and Supports for Older Adults

This session discussed aging and autism and the need for research and attention to the consequences of aging. This included ensuring that autistic people can age in place and handling when caregivers age or pass on.

Understanding Parental Rights & Resources for People with Intellectual & Developmental Disabilities

Speakers discussed discrimination against parents with intellectual and developmental disabilities as well as the lack of research about autistic parents who raise autistic children. Panelists discussed equitable access to reproductive care before, during, and after pregnancy, go over legal rights that people with I/DD have, and discussed contributions that parents with disabilities can bring to research.

Transition Services

This session, speakers discussed transition services and innovative practices within social and community integration. Speakers touched on good goal setting as well as preparation for employment and/or higher education. After mini presentations, there was time for attendees to ask questions.

Employment Across the lifespan

This session discussed what employment can look like for autistic people across one's entire lifespan. Speakers provided insight on options for support, such as acquiring accommodations, pushing back against discrimination, and navigating raises, promotions, and retirement.

Health Care

Research Topics

Below are topics nominated by participants for further research exploration, reflecting key areas of interest and importance: adult health priorities.

Adult Health Priorities

Adult healthcare

- Access to care and health services
- Service utilization
- Access to emergency services
- Barriers to care

Sexual and reproductive health

- Autism-affirming, LGBTQIA+-inclusive, sex-positive sex education
- Reproductive decision-making
- Pregnancy experiences and outcomes

Mental and emotional health

- Especially prioritize this for people with higher support needs
- Autistic burnout
- Social isolation with aging

Aging-specific / developmental experiences

- Puberty
- Menopause
- Cognitive health in older adulthood

Physical health

- Dental care
- Gastrointestinal conditions
- Neurologic conditions
- Chronic conditions

- Long-term health outcomes

Mortality

- Causes of mortality
- Preventing early mortality

Experiences with healthcare

- Prioritize healthcare experiences for people of color, especially Black children and adults.

Child Health

Service access

- Preventive services

Systems Interactions and Trajectories

System navigation

- Prioritize making it easier for autistic people to navigate and understand Medicaid, Medicare, and social security.
- Increasing awareness of system benefits

Research Methods

Research Design

Participants/populations:

- Need for intersectional approaches to autistic health that encapsulate all aspects of autism (mental health, physical symptoms, sensory issues, etc.) as well as social and environmental factors (e.g., intersecting forms of marginalization).
- More health research should focus on the experiences of autistic people who face intersecting forms of marginalization, including:
    - Racially and ethnically marginalized autistic people.
    - LGBTQIA+ autistic people

- Health studies should include and specifically focus on autistic people with diverse support needs:
    - Autistic people who do not speak and autistic people who use AAC and/or have higher support needs.

Methodology

- Need more qualitative studies that center autistic perspectives and experiences in health care, using qualitative methods such as Photovoice or visual arts.

Outcomes

- Long-term outcomes and longitudinal designs are needed to examine impacts of policies/programs.

Research Funding and Advocacy

Data advocacy

- Need data to better understand those diagnosed later in life
- Advocate for large-scale, population-level datasets with valid measures of autism

Sessions That Informed the Discussion of Health Care

Introductions and Discussions of Current Research
Our first session included discussion of the current state of research regarding health care, which included ethical concerns, how research includes autistic participation, what areas are under researched and where we should go from here.

Receiving Health Care as an Autistic Person

In this session, speakers and attendees discussed the changes that need to be made to our health care system to create one that works to support autistic people in all areas of health care. We talked about current research on this topic and discussed gaps in the research. We also discussed how to collaboratively implement increased accessibility to medical professionals to improve healthcare outcomes in the future, as well as make policy changes based on research.

Autism Diagnosis Across the Lifespan: Prevalence and Practices

Participants in this session discussed topics related to autism diagnosis, including prevalence rates, diagnostic disparities, self-advocate led autism diagnostic criteria, and late diagnosis. We had speakers and then time for discussion.

Accessible Health Communication

It is crucial that autistic people receive clear, accessible communication on health-related topics. We discussed how to improve access to care and provide resources for our community in different areas, such as preventative care. ASAN staff discussed lessons from the ongoing COVID-19 pandemic on the need for Plain Language and Easy Read translation and outreach to self-advocates on these topics.

Medicaid, Medicare and Health Outcomes

Speakers discussed access to healthcare for autistic people on Medicaid and Medicare, especially disparities in care and how policy and process changes can better serve autistic people. We also discussed access and funding for home-and-community based services and related topics to improve health outcomes for autistic people using these services.

Racial Disparities in Autism Diagnosis and Health

This session specifically addressed the intersectional experiences of autistics of color and the medical industrial complex (MIC) which is disproportionately harmful and inaccessible for people of color. We discussed the continued impact of racial disparities in diagnosis on communities of color, and how this relates to the school-to-prison pipeline. We talked about the need for research that identifies this impact as well as the need for solutions.

Current and Future Directions of Physical Health Research

This session discussed how physical health research can better include autistic people in meaningful ways. We heard from researchers and autistic people working on participatory research and discussed how other researchers could implement these approaches.