

An Expert Discussion on Knowledge Translation in Autism in Adulthood Research

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THE JOURNAL *AUTISM IN ADULTHOOD* was launched in 2019 as a hub for research on autism in adulthood. One of the primary goals of the journal is to publish research that is important to autistic adults.¹ While generating new knowledge in areas important to autistic adults is a significant development, the penultimate goal is that new knowledge results in positive impacts on people's lives. This expert discussion is housed within an issue on the state of the science in autism in adulthood research. As research on autism in adulthood grows, it is critical that researchers are not merely expanding knowledge, but consciously and proactively attending to how that research can and should be integrated into policies and practices that improve the lives of autistic adults.

There are several terms used to describe the processes for connecting new evidence and practice or policy changes (e.g., translational research, dissemination, diffusion, and knowledge translation, knowledge exchange).² For this expert discussion, we use "knowledge translation" as a broadly encompassing term for the process of bridging research and practice.

Knowledge translation is a complex, iterative process of integrating research evidence into new policies and practices to improve lives.³ It can take years, even decades, for new knowledge to be integrated into practice—moreover, only a small portion of research is ever translated into practice.⁴ Knowledge translation can be aided by implementation science, the study of ways to promote the adoption of empirical findings into routine practice.⁵ To promote knowledge to action, knowledge translation should not be left unattended to or as an afterthought in scientific investigations.

In this expert discussion, we examine the current state of knowledge translation for autism in adulthood research,

critical issues for researchers to attend to, and recommendations to make progress on knowledge translation in our growing field.

Dr. Anne V. Kirby: *We have brought together a group of seven experts, including autistic leaders, funding and advocacy organization leaders, clinicians, and researchers, from multiple backgrounds (including psychology, public health, education, and social work), to explore knowledge translation and research on autism in adulthood. Let's start by introducing ourselves.*

Dr. Anne V. Kirby: I am the co-moderator for this round table discussion. I am an occupational therapist and assistant professor at the University of Utah (USA). My research focuses on the transition to adulthood for autistic youth, as well as autistic mental health.

Dr. Katherine E. McDonald: I am also here as a co-moderator. I am a professor of Public Health and the Acting Associate Dean of Research for Falk College at Syracuse University (USA). I conduct participatory research with adults with disabilities on social determinants of health, ethical, legal and social issues, and health outcomes. I am a member of the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE).

Dr. James Cusack: I am the Chief Executive of Autistica. Before that, I was our Director of Science. We are an autism research charity (an NGO) based in the UK. A big part of what we do is to ensure that research ultimately makes a difference for autistic people and their families, and we work in policy and information as well. I am also autistic.

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Dr. Brenna Maddox: I am an Assistant Professor and Clinical Psychologist at the University of North Carolina at Chapel Hill (USA) in the Department of Psychiatry. I am the Implementation Scientist for the TEACCH Autism program. My research focuses on how we can bridge the gap between research and routine practice to improve community services for autistic people across the lifespan, with a particular focus on improving mental health services for autistic adults.

Ms. Cheryl Mangan: I am the Manager, Research Translation for the Cooperative Research Centre for Living with Autism (Autism CRC)—the world’s first national cooperative research effort focused on autism across the lifespan. Together with our 56 participant organizations, and other partners around Australia and internationally, we seek to build capacity and support for neurodiverse environments, so every individual has the opportunity to reach their full potential. I lead the knowledge translation strategy, working through and with our network of research, government, and industry partners, to develop business cases, strategic partnerships, and action plans to translate research into policy, programs and digital products—real world solutions.

Ms. Lisa Morgan: I am an autistic adult with lived experience around suicide loss and the ensuing socially difficult aftermath. I have a business where I train professionals about how to support autistic adults in crisis situations. I use research findings to develop the autism-specific resources to use in my trainings. I am also the author of three books about supporting autistic people.⁶⁻⁸

Ms. Anne Roux: I am a health services researcher at the A.J. Drexel Autism Institute at Drexel University (USA), and I work in the Life Course Outcomes research program. We produce population-based statistics for stakeholders who need data to inform their decisions and programs and policies. I became interested in implementation and dissemination science when I was participating in state advocacy efforts around systems reform, and noticed that many decisions about programs were not based on science, and information about services was not being communicated to people in a way that they could understand and use. My research interests are grounded by my experiences as a family member to people on the autism spectrum.

Dr. Nidhi Singhal: I am a clinical psychologist and an autism researcher. I have been associated with Action For Autism for the past 20 years. We are a national, non-governmental organization based in New Delhi, India. Since 1991, we have been actively delivering lifespan services. We also train parents and professionals and have facilitated startup of other autism organizations in India and south Asia. Through our research, awareness, and advocacy activities and our work with the government we have also impacted policy and legislation. I work in the capacity of Director for Research and Trainings. In my role as a clinician, I rely on scientific evidence to inform my work, and my research is in turn influenced by my clinical experience.

Ms. Dori Zener: I am a clinician, and also a community partner in qualitative research projects in Toronto, Canada. I am a social worker by training, and am an Individual,

Couple, and Family therapist specializing in autism. I work with individuals aged preteen and up and focus on girls and women on the spectrum. I run a private mental health agency called Dori Zener & Associates where we offer counselling services and autistic-led peer support groups for young adults and adults on the spectrum, as well as counseling services. Our motto is “Embracing Neurodiversity” and 50% of our team identifies as neurodivergent.

Dr. Kirby: *Welcome everyone. We are thrilled to have you here. Let’s begin with: why is knowledge translation important?*

Dr. Maddox: There is a huge gap between doing research and actually having the findings of research get into community practice. It is widely reported that evidence-based practices take on average 17 years to be incorporated into routine health care.⁴ Knowledge translation is seeking to speed up this process. Perhaps a less-known fact is that the 17-year estimate is for how long it takes 14% of original research findings to actually reach routine practice.⁴ Only a minority of research findings are ever translated into routine practice.

Dr. Cusack: Knowledge translation is important because it is complicated, and it should not be taken for granted. I think we assume when research is published that there is a set of policymakers or service providers who are in a position to just implement that evidence. But the theory of change does not really work if you just assume that research is published in a journal and then people implement the findings. It requires resources.

Dr. Singhal: As most low- and middle-income countries, we struggle with limited resources for a very large population. It is therefore important for us to plan applied research and share findings in ways that go beyond an academic exercise. It needs to be able to make a wider impact—develop better services and improve skill sets of those involved, generate better awareness, dispel misinformation and misconceptions, and influence policies in ways that truly matter in the lives of autistic people.

Ms. Mangan: Knowledge translation is critical because the creation of knowledge does not, of itself, lead to implementation and positive impact. It must be translated into changes in practice, policy and behavior for the benefits to flow on to the community. Effective research translation cannot happen without the input of autistic people. Their perspectives and involvement are absolutely critical in every stage of the translation process from the development of priorities and problem exploration, through stages of solution development and delivery.

Ms. Zener: I think now more than ever we need to speed up knowledge translation because we are getting to a tipping point in autism research where autistic advocates’ voices are finally being heard and are influencing research directions. That is the kind of programming and services that we want to see moving forward. We want research to support programs and services that target autistic-defined quality of life and do no harm.

Ms. Morgan: In my experience, professionals who work with autistic adults do not have the right information. They need the right information so there is no unintentional harm done. Autistic adults who reach out for help are often harmed by well-meaning professionals who have that wrong information. To reiterate what others have said, it is important for autistic people to be involved through the whole process, from research priorities to the practical use of research findings. The information has got to be applicable to the “challenge” that autistic adults face in their daily lives. Autistic people are the only ones who know what it is really like to live with autism.

Ms. Roux: I think that not only is it important to think about dissemination and implementation of our science, but it is unethical not to do so. Adults with autism have been marginalized for a long time, and researchers—likely unintentionally—have not considered their perspectives. It is critical that we include people actively and meaningfully in our research processes both before, during and after we produce work, and there should be representation from everyone who is a potential user of the information or who is affected by the decisions that are made with the data and the science that we are producing.

Dr. Maddox: One piece that I appreciate about knowledge translation is that it involves researchers being humble. It is coming to the table knowing that I have certain expertise as a researcher, but it is the community stakeholders, the autistic adults, the clinicians who are the experts about what does and does not work in the community and learning from them. That is such a fun and productive part of the knowledge translation process. Another important part of implementation research is multidisciplinary teams. Oftentimes, members who are not routinely part of clinical trials—such as behavioral economists, organizational scientists, and health administrators—are involved in knowledge translation work. A variety of expertise is necessary to bridge the gap between research and practice.

Dr. Kirby: *What are some successful or promising examples of knowledge translation relevant to autism in adulthood? What are key things that work in these examples?*

Dr. Cusack: When I joined Autistica one of the things which we focused on was premature mortality in autistic adults, and the health inequalities for autistic adults. Based on research in the U.S. and Australia,^{9,10} we recommended that we should trial the use of health checks (health advice based on physical assessment, lifestyle questions, and medications review) in autistic adults. We held a workshop with researchers, autistic people, policymakers, and clinicians to design a health check which would work within the UK context and to determine how we could undertake a clinical trial on its efficacy, as well as to understand things like its uptake. That trial is now underway with funding from Autistica and National Health Service England (NHS).

We also had funding for resources dedicated towards policy. That meant that we had representatives from NHS England engaged in the process. When the NHS released their 10-year plan a year later, they made autism and learning disability a clinical priority, and they said that if the health

check is proven to be an effective method, they would be committed to implementing it.

Although we sometimes think about knowledge exchange as a sequential process, these things can actually be happening in parallel. You can be working with the government and lining it up and saying, “We have a potential solution here.” Our relationships with NHS have gone broader now—our Head of Policy and Head of Research spend half their time with NHS to focus on implementation.

Ms. Roux: I agree that we often view the “research to practice” process too linearly. Instead of waiting until you have findings to disseminate, and then reaching out to the community, you can be engaging in building community advisory boards and identifying what the needs are in the community right from the start. This is a strategy we employ when determining what topics to discuss in our National Autism Indicator Report series.¹¹ Our advisors tell us what is important for us to investigate, help us communicate findings in a way people can understand, and help us disseminate what we have learned.

We do have room to learn about effective dissemination of information related to autism in adulthood that is tailored to specific audiences. I think we have a lot to learn from other fields like cancer communication and HIV prevention that are better at reaching underserved communities.

Dr. Maddox: There is implementation science with children on the spectrum that we can learn a great deal from. For example, Drs. Brookman-Frazee and Stahmer have a study focused on testing implementation strategies to improve services for children on the spectrum.¹²

I have also learned some helpful things in my work on improving clinician knowledge, attitudes, and self-efficacy towards working with autistic adults in community mental health settings. A key recommendation is to include autistic adults in the development and delivery of clinical training programs.¹³

I also want to highlight Project ECHO (Extension for Community Healthcare Outcomes). It is a widely used model where community clinicians are paired with an interdisciplinary team of experts. They meet virtually regularly, and the idea is to move that knowledge from the minds of the experts into the hands of community clinicians. Drs. Malow and Mazurek are extending Project ECHO for health care with autistic adults. They include autistic adults as experts on the team to support and mentor primary care physicians in enhancing health care for autistic adults.

Ms. Morgan: As Co-Chair of the Autism and Suicide Committee of the American Association of Suicidology, I authored an autism-specific resource—the Crisis Support for the Autism Community toolkit.¹⁴ It was designed to be used by crisis center workers in real time while helping an autistic person in crisis on a call or text line. I developed it going straight from research findings to the information in the toolkit. It helps professionals identify autistic people who might be on the call or text line, understand how to communicate with them, and effectively support them in a crisis situation. The feedback has been really positive. People want to know that information. The key things that worked with the toolkit are: it was relevant, it filled a need, and it was easy to

use. It was also made available for anybody who needed to use it as a free downloadable file. We are using this approach to develop additional resources as well.

Ms. Mangan: One knowledge translation project I have had the absolute joy to co-lead with Associate Professor Marina Ciccarelli from Curtin University, is myWAY Employability, a smart web application to help autistic young people plan and prepare for their working life.¹⁵ myWAY Employability guides young people through a series of questions to help them identify strengths, interests, communication, and environmental preferences, and matches that to career and employment pathways. myWAY Employability was developed through collaboration with autistic young people and the adults who support them. It is built on the foundation of 6 years of research, trials and evaluation related to the Better Outcomes and Successful Transitions for Autism (BOOST-A) program, so it was important to maintain research fidelity. Adopting a human-centered design approach, we worked with over a hundred autistic young people to understand their needs and preferences, explore potential solutions, and ultimately co-design, test, and refine myWAY Employability. The website content was coproduced with a talented young autistic writer. We also established a neurodiverse youth advisory group, and paid them market rates, to come behind the curtain and provide honest critical feedback at key points throughout development. Engaging autistic people at every step of the process, and in coproduction, gave us confidence that we could deliver a product that would be relevant, engaging and useful for young people and their supporters.

Ms. Zener: One example of collaborative and creative knowledge translation is a research project that we did in partnership with the Centre for Addiction and Mental Health (CAMH) here in Toronto with Drs. Lai and Lunskey. With input from our Asperferme Toronto members, we examined the key ingredients of peer support services. It has been a really meaningful project. Our team consisted of autistic and non-autistic investigators and the knowledge translation was built right into the study design. To share our findings, we created a video bringing to life the experiences of the study participants.¹⁶ Our autistic team members led the creative video project and were compensated for their time. One difficulty is the dissemination. It is so important to raise awareness about the elevated mental health risks that autistic women face, and to demonstrate that something so simple as participating in a peer support group can have a positive impact on mental health. This is the kind of information that could and should really inform policy and practice.

Dr. Singhal: I feel we are way behind, and I know that I speak for not just India, but most low- and middle-income countries, especially South Asian countries. We are learning from the models available internationally while we develop indigenous resources.

In India, for a long time, no one put a lot of thought into autistic children growing up to become adults. This awareness has set in only in the last decade or so. We carried out one of the first studies on 54 autistic adults in New Delhi.¹⁷ In addition to the parents, many autistic people shared their own experiences. For us this was an important milestone for several reasons.

The study highlighted the limited educational, vocational and employment related opportunities for adults and the need to generate more services. It also opened the possibility of having speaking and non-speaking autistic people be active participants. Being part of a scientific research somehow “legitimized” what autistic adults said. People felt heard and respected, it helped reduce the stigma associated with autism, making it possible for many more adults to come forward and share. Just as significantly it sort of set the wheels in motion. Talking to autistic adults and their families, listening to what they wanted, it provided us direction. Things we had been thinking about, we now knew how to prioritize, and how to put it in action. In many ways it has impacted our initiatives around education, employment, self-advocacy, and our independent living programs as well as our awareness and advocacy activities.

Dr. Kirby: *What recommendations do you have for researchers and policymakers to improve the research-to-practice gap for autism in adulthood?*

Ms. Roux: Researchers and people in the community may feel a bit overwhelmed when we start to talk about dissemination and implementation of our programs and practices. A resource that was really helpful to me is Melanie Barwick’s knowledge translation planning tools.¹⁸

Dr. Maddox: I think we need more researchers who are doing knowledge translation work specific to autistic adults, including training the next generation, mentoring students and trainees and getting them excited about this.

We can also be learning from outside the autism field, including from implementation science-specific journals and conferences.^{19–22}

Another recommendation I have for researchers is to think long-term when planning a study: *What is going to happen in this community agency, school or clinic when the study is over? What supports will be left, and are the efforts sustainable?*

Dr. Cusack: I think a big thing in terms of how researchers engage with policymakers is to come with solutions. It is often not helpful for policymakers when people are constantly telling them there is a problem and nothing else. If you are able to come with a solution that is quite powerful.

I think partnering is also key. We increasingly have researchers come partner with us to think about the implementation of research findings and how we can use our mutual skills to work on that. When I think about research, my big questions are: *does it translate?, is it implementable?, and ultimately, does it make a difference for some autistic people?*

Diversity is something that we have not really talked about yet. I am proud of the fact that a third of our staff at Autistica are autistic, including myself, and we pay for and engage with autistic people in the activities we do. But there is work to do to ensure that we are broadly representative of all autistic people across the spectrum, particularly in the context of race and socioeconomic status.

Ms. Zener: Autistic individuals tend to go online for information and support. Identity affirming autistic influencers on

social media can raise awareness of the lived experience of being autistic and can help people feel a part of a community. I think it would be a good idea to collaborate with autistic influencers with large networks to disseminate information directly to autistic individuals and their loved ones. Then they can advocate for positive change with their service providers and policymakers.

Ms. Morgan: The research needs to be relevant and pertinent to the daily lives of autistic people and the way that they perceive, understand and experience the world. When I was writing the toolkit, I came across a lot of research that I was not able to use. When I did find research that I could use, I made sure how I described it was succinct. I used common, literal language, gave examples, was concise and put it into an easily readable format, which I think really helps the people that are using it to be able to help autistic people.

I made a bulleted, one-page reference sheet to use in real-time, so the crisis center worker would have that sheet right in front of them. The information came basically right from research to the crisis center workers, so they can use it in real-time to help autistic people.

Dr. Singhal: I think gaps exist at every step. One of the primary difficulties, at least in India, is that there are two different sets of people in the equation. One who conduct the research and the other who have the experience—lived experience or via their interactions with autistic adults and their families. Although we all recognize the importance of this collaboration, it seldom happens. And that leaves a gaping hole in knowledge translation.

We are beginning to recognize the importance of including people with autism in research projects—to conceptualize the project and also as participants. However, there are not enough research tools that have been developed that effectively capture their thoughts and opinions. The few available ones do not necessarily work outside of the U.S. or other developed countries. Thereafter, researchers because of their limited practical experience, may not know how to facilitate the communication process, especially across the spectrum—not just for those who use spoken language to communicate, but non-speaking individuals, including their voices, too.

And finally, while a scientific publication is very important, it is accessed only by those in academia and not necessarily by the significant non-academic others. So unfortunately, the gap continues to increase. We need to build bridges at many different levels.

Ms. Mangan: One of the most important things for researchers and for policymakers is to start by having conversations and allowing the time and space to allow people to speak about their experiences. It is also about valuing everyone's input on equal terms and giving people a choice around how they might want to contribute, and in what format.

Another thing to keep in mind is that research leadership does not necessarily have to be led by researchers. The Autism CRC has embraced the idea of co-leadership (e.g., by someone on the spectrum, an autism organization, or a service provider). This means that not only is the research grounded in community and service needs, the path to translation and commitment to implementation is baked into

the project from the beginning. And that is where the greatest impact happens, when you can actually just take research straight from a trial into everyday service delivery and refine the approach from there.

Dr. Kirby: *This has been such an informative discussion. Is there anything we did not talk about that you think is important?*

Ms. Roux: Funding is something that we have not talked about a lot.

First, many of our community partner organizations are struggling to run their services given the economic impacts of COVID. Asking people to implement science that was not designed to be implemented in under-resourced environments is challenging.

Second, funding for research is critical. We know that what gets researched is influenced by the funding mechanisms that are available. We need more thoughtful ways of funding dissemination and implementation. Oftentimes the research itself is funded, but then people have to come up with resources for dissemination. This presents an opportunity for advocacy to help the organizations who fund research to value and understand the importance of dissemination and implementation of those findings to increase the chance that the findings will actually help people.

Dr. Maddox: Knowledge translation can be hard, time-consuming work—although also incredibly rewarding! For people who are new to knowledge translation, it can be easy to get discouraged, especially if you are used to working in a field where you get quick progress.

I also want to highlight de-implementation. De-implementation is taking something out of practice—something that is inappropriate, that may not be evidence-based or may actually be harmful, or that may not be resource-efficient. There is an assumption that de-implementation is the reverse process of implementation, and that therefore the models of implementation transfer cleanly. But we are learning that there are unique aspects of de-implementation, and we need more research in the autism in adulthood field to understand that process.

Dr. Cusack: I am also thinking about reverse translation. There are a lot of research questions which are generated from practice that can be interesting and hugely impactful for researchers. I also think there is work to be done to synthesize the research that is out there—each study on its own does not need an implementation plan, but we can pull bodies of work together to connect to policy and practice.

Ms. Zener: I wanted to touch on something that Lisa was saying that relates to one of the challenges with engaging autistic adults in knowledge translation. I attended an autism research conference with a friend who is an autistic self-advocate. Beyond the fact that it was a complete information- and sensory-overload, the hardest part was sitting through lecture after lecture and poster after poster about how they are broken and needed to be changed or cured. It was emotionally draining and difficult for those people to attend the autism research symposium only to be told that who they are is not good enough, and there is something wrong with them.

Researchers need to be careful about their language as well as their focus.

I have also been told of several instances where autistic people were invited to sit on a research advisory panel but did not feel they were meaningfully included. The participants felt cut out of the process. They were not contacted by the researchers to review the study results or to contribute to the knowledge translation. The participants described feeling used and discarded, when many of them were very interested in maintaining involvement in the project and in ongoing research.

Dr. Singhal: I agree, I also feel information overload—it is confusing to know what research to listen to and to translate into practice and policy.

Ms. Morgan: Making research accessible to the public is also important, such as through open-access publications.

Ms. Mangan: I think one of the takeaways is that translation should be a humbling experience. Roper and colleagues²³ said co-production is about shifting mindsets and establishing a culture that embraces exploration and learning that genuinely values consumer knowledge and expertise, particularly from those most impacted by the problem.

It is very easy to think that sometimes when we have done research we have the solution—we must always engage the autistic community. Translation is hard work, it's important to accept that we are going to make mistakes, and there will always be situations where we could have done better. We are always going to have limited resources and other constraints upon us.

It is about continually reflecting on what has gone well, what could be different and challenging ourselves to learn and do better. It is only by sharing those learnings and experiences that we can collectively move towards that culture change.

Dr. McDonald: *Thank you everyone for your contributions. I have been hearing several themes in the discussion, hitting on essential issues that impact how research on autism in adulthood can be used to improve the lives of autistic adults. These include:*

- Designing research to enhance knowledge translation. Some promising strategies include involving stakeholders via coproduction of knowledge, attending to community priorities, needs, and resources, removing ableism from research foci, building multi-disciplinary teams, learning from fields that have made advances in knowledge translation, identifying solutions to problems or needs, and addressing knowledge generation and translation simultaneously rather than successively;
- Training future researchers in knowledge translation so they have increased capacity to design and carry out research poised for knowledge translation. Over time, these researchers can help reduce the knowledge-to-practice gap and ensure more research is translated. The inclusion of autistic researchers is critical to this goal;
- Regularly synthesizing research to summarize the quality of evidence available to inform changes in practice and policy;

- Making research accessible to non-scientists including fostering access to original research via “open access” as well as enhancing science communications by creating dissemination communications tailored to different audiences; and
- Maintaining funding for knowledge translation in standalone funding opportunities as well as requiring and supporting translation efforts as integral activities in research grants.

Collectively, these innovations can accelerate the ways that scientific advances directly benefit autistic adults and improve connections between science and autistic adults.

Dr. Kirby: *Thank you for that helpful summary. And thank you to everyone for joining us today. I am so enthusiastic about the positive impact that this discussion about knowledge translation can have in moving our field forward and ensuring that research in our field ultimately makes a difference in the community.*

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