

Small Group Sessions: Knowledge Translation and the Policy Process

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1. Introduction

We opened the session with a general orientation to knowledge translation and the policy process for children's health and development.

Knowledge translation can be defined simply as the use of research evidence in policy and practice. However, a more complete definition of knowledge translation is the reciprocal exchange of ideas among the different groups involved in the policy process, including researchers, service providers, families, advocates and policy-makers themselves.

The policy process is complex. Policy-making encompasses multiple levels (legislative, administrative and clinical), jurisdictions (national, provincial, regional and local) and sectors (health, education, children's services and community services). It is also important to consider the major influences on policy-making: managing *institutional* constraints (e.g., budget cuts), reconciling competing *interests* (e.g., public spending versus tax cuts), and advancing new *ideas* (e.g., investing in children).

When it comes to ideas about autism spectrum disorders (ASD), there are some longstanding differences between the various groups involved, resulting in ongoing court cases and public inquiries about intervention funding. We presented several scenarios to illustrate the problem of knowledge translation from the diverse perspectives of parents, researchers and policy-makers. We then asked participants to discuss their own perspective on knowledge translation and to identify priorities for improving the exchange of ideas in the field of ASD.

2. Participants' Perspectives on Knowledge Translation

- Participants in this session spoke as parents and family members of children and adults with ASD, as service providers and managers, as researchers in clinics and universities, and as policy-makers from various provinces.
- Many participants were comfortable speaking from multiple perspectives. For instance, some parents had returned to university once their children were older, in order to educate themselves about autism and to help other families — they've gone through the journey and now they're in a position to share. Several policy-makers had service backgrounds, while service providers often had some research training.
- Participants emphasized that ASD is a complex condition. No two children with ASD are exactly alike. When it comes to policy and services for children with autism, there are no "magic bullets" or "quick fixes."
- One of the biggest challenges for knowledge translation in ASD is that research rarely provides simple answers. Researchers work in specialized fields and published research is often uncertain or ambiguous. But there are many advocacy groups who are willing to give seemingly simple answers to families, to the media and to policy-makers.
- Service providers, in particular, felt that it was often challenging to reconcile research evidence with other information and ideas about ASD, in order to provide the best advice to families.
- Policy-makers also wondered how to identify good research. How do you know when research is reliable enough to take action? How do you make recommendations to senior policy-makers based on research that is always in progress and ever changing?
- Participants emphasized that knowledge translation was especially important during critical periods in the development of ASD. At the time of diagnosis, for instance, many parents are desperate to learn as much as they can about ASD and appropriate interventions. Service providers and policy-makers are also concerned about being able to provide reliable information to parents during this period.

3. Participants' Priorities for Knowledge Translation

- There was a general desire for more communication and collaboration between the various groups concerned with childhood ASD. Why are researchers, service providers and policy-makers still working in isolation? In a “fantasy world,” everyone would come together to ask questions and identify shared priorities.
- Many participants talked about the need for additional training and support for the people who see children with ASD every day — parents, service providers, teachers, support workers, physicians and pediatricians.
- Participants also identified a need for training in knowledge translation itself. In other words, how do you most effectively share your experiences and views with others? How do you influence the policy process for ASD? There is no agreed-upon way to do these things.
- In particular, many researchers and service providers felt that they needed more support to engage in knowledge translation. Universities could provide researchers with incentives to spend more of their time on knowledge translation activities; and service providers are often overwhelmed by the demand for interventions, so they don't always have the capacity for knowledge translation.
- Several participants felt that everyone should be more comfortable “working with shades of gray.” In other words, we need to accept a degree of uncertainty and ambiguity when it comes to ASD research.
- Others suggested that we should tell more positive stories about children with ASD, because there are too many “scare stories” in circulation. Family members can be very influential in the policy process, because their personal stories about ASD are particularly powerful.

Thank you to all our participants.