Case Study Title: A common ground for autism

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1. What is/was the context and key challenge(s) in your K* case study?
   a. When, where and how long did this initiative occur, or is it ongoing?

The social value and public relevance of biomedical research is often challenged. Major investments go into this research every year, in the hope that these investments will yield knowledge capable of transforming people’s health and wellbeing. For life-long conditions like autism, the promise of biological markers, treatments, or even cures is yet to be fulfilled. Increasingly, we are recognizing the scientific challenges we need to overcome as we resolve complex questions including what causes autism, why it impacts people differently, and how to reduce its disabling consequences.

Less recognized is that the accumulating body of research knowledge in autism has profound utility in how families, practitioners, and the wider public view, understand, and respond to individuals affected by the condition. The value of this research is concealed when we expect scientists to provide medical pills, treatment recipes, or even gadgets to repair the “broken” brains of young children. The power of this knowledge rests on creating a space for meaningful dialogue, where different perspectives and needs meet and overlap in a common ground.

In such a space, we are able to dispel myths, and advance both research and practice. Historical examples of problems solved in this way include the debunking of the idea that autism is caused by so-called “refrigerator mothers” who do not show affection toward their children. Today, we have learned that autism emerges as a function of genetic and non-genetic factors that interact in complex and probabilistic ways. The condition fundamentally changes how a child’s brain develops and functions, which results in both individual strengths and challenges. Importantly, within this common ground, we learned that an effective method to overcome the challenges resulting from autism is to enable parents to act as their child’s primary interventionist and advocate.

Within the umbrella of a Canadian Network of Centres of Excellence (NeuroDevNet), we have been supporting knowledge translation and exchange in the broader area of brain development and developmental disorder, using multiple strategies. The first is a “push” strategy, where we enhance engagement and understanding of biomedical research in the community. The second is a “pull” strategy, reaching out to the community to identify facilitators and barriers to knowledge access and uptake. Examples of activities include surveys, focus groups, and interactive workshops. Many researchers have been already involved in similar activities in diverse communities, including in under-resourced settings. Our goal over the next two years is to create a sustainable toolkit supporting the design, delivery, and evaluation of such activities.
2. Who are/were the players and why did/do they need to come together?
   a. What was/is the reach of the initiative? See above

3. How did/does K* play a role in the story, i.e. tools/techniques/approaches.
   Sharing scientific developments, hypotheses, and findings requires scientists to abandon their silos in favor of a common ground. For example, interactive workshops are conducive to supporting dialogue and exchange between researchers and “front-line” community health workers. This method is adaptable to specific contexts, such as high- or low-income settings. In designing and delivering these workshops across diverse settings, we have noticed striking parallels. The commonality in manifestations of autism across geographical boundaries means that the experience of practitioners overlaps significantly. Much of the scientific knowledge concerned with the biology of autism we would consider to be “without borders.” Moreover, communities converge as they strive to promote independence, dignity, and self-determination among those affected by autism, and their efforts to combat the resulting stigma and discrimination. As such, scientific knowledge is not only supportive of practice but also of advocacy, reaffirming that biological difference is not equivalent to inferiority.

   On the receiving end, we have found that scientists realize that what they can offer to individuals affected and their families is only narrowly defined by the current state of the science. More important than recent study results are holistic and critical frameworks for how autism affects an individual across the lifespan, and how its impact extends to the whole community. This common ground approach encourages scientists to become advocates for rigorous, innovative, and equitable research priorities. An example of progress in this area is a special collection of research articles appearing in the journal Autism Research, featuring research studies and perspectives from low- and middle-income countries, rarely found in the mainstream scientific literature. The extent to which this translation occurs -- the flow between scientific knowledge and the lived experience of those affected wherever they may be -- is a key indicator of its success.

4. What was/is the intended impact/contribution of K* and, if you can, tell us whether K* had an impact and how.
   : To date, we have measured the impact pilot activities qualitatively through feedback from participants, but we do not have follow-up measures to verify longer-term impact. We have found that factors indicative of success include participants’ commitment to the utility of scientific knowledge, and ways in which it can support their personal and professional experience. Often, scientists are working in competition with misleading popular ideas and fads. Combatting myths can be very challenging, and distract them from more valuable priorities. Like most other knowledge translation approaches, it is both time and resource-intensive, making sustainability major challenge. Finally, the evidence base for effectiveness of knowledge translation is still emerging.

5. What are the lessons from this example that others should know about/could be transferred, in general and particularly in a resource-limited context?
   A long-term challenge will be to transform the role of individuals affected by autism, their families, and the wider community from passive consumers of knowledge received from scientists, to active participants in dialogue taking place in the common ground. While this is already taking place to some extent, this aim cannot be fully realized without valid and sustainable frameworks in which this exchange can take place. We need to rethink the boundaries separating researchers from the public and reinforcing cycles of blame, and instead engage everyone in a common ground.

6. Any other observations..: