

Small Group Sessions: Treatment

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Discussion focused on ASD treatment research priorities, prefaced by a brief overview of existing research on both the efficacy and effectiveness (as implemented in communities) of treatment/intervention in ASD. Existing findings, derived largely from studies conducted in highly controlled university settings, have established the efficacy of several approaches, particularly those that employ behavioural/ABA techniques and focus on specific targets (e.g., language/communication, social and other adaptive skills; see, e.g., report of the “National Autism Centre” in the United States, 2009, for review of several treatment/ intervention approaches rated as “established”). We know relatively little about the effectiveness of community-based treatment programs, and even less about the relative effectiveness of different treatments or service delivery models. Within our groups, there was wide recognition of the paucity of research in Canada on effective treatments/interventions or service delivery models for ASD, in part due to the lack of available services. The major exceptions are community-based early intervention programs, implemented across the country, but, except for a few studies, there are no data on their effectiveness. Among the questions raised are: Do we have evidence that treatment delivered in a given province/community is effective? Or, do we even know that the treatment is being implemented properly? In this context, it was emphasized that care needs to be taken in drawing any conclusions about a given treatment in the absence of appropriate quality control. Community-based early intervention programs in Canada are being delivered by paraprofessionals, but little is known about the quality of programming or supervision. Moreover, virtually nothing is known about treatment models that span into adulthood and the senior years. What would a viable, cost-effective lifespan service delivery look like? Finally, concern was expressed about the untenable quality of life experienced by families living with a family member with severe behaviour problems, many of whom are severely disabled without a functional communication system.

Major themes explored include the need for:

- A clear sense of the over-arching goals of treatment research, notably to support and enable children and adults with ASD so that they can function more effectively (e.g., vs. striving to change them into “neurotypicals”, at the risk of losing their personal identity) and experience a better quality of life; related goals are to:
 - facilitate access to regular social, recreational and spiritual opportunities, as appropriate;
 - enhance understanding of the diversity and cultures among those with ASD;
 - be careful not to over-medicalize ASD, risking the emotional and social well-being of individuals, while recognizing the need for appropriate medical care; and
 - seek ongoing input from individuals with ASD and other key stakeholders.
- Development and evaluation of lifespan supports and interventions/treatments in communities, with a particular focus on older children and adults, and individuals with severe behaviour problems, some with limited, if any, speech, and including support for parents.
- Major research efforts aimed at establishing the effectiveness of various forms of intervention/treatment (across disciplines), with a focus on those that are most promising, feasible, sustainable and cost-effective, and including information on:
 - the relative effectiveness of different treatments and service models
 - which treatments are most effective for particular children and adults
 - “acceptable” minimal interventions (vs. “all or none”, although some viewed this as potentially discriminatory vs. standard practices with other disorders)
 - critical family variables and readiness for treatment
 - the specifics of what treatment was delivered
 - possible confounding variables (e.g., co-existing medical problems or treatments, or parental stress, that might account, even partially, for the effects of the treatment under study)
 - treatment fidelity

- whether behavioural/ABA treatment makes a difference with older children
 - more socially valid, quality of life outcome measures
 - sex differences
 - the characteristics of non-responders
 - both short-term and long-term outcomes
 - biomedical treatments that have best evidence for effectiveness, recognizing that we need more understanding of the biology of ASD before we can propose appropriate biomedical treatments
- Research aimed at ensuring more timely access to appropriate intervention/treatment, recognizing all of the above and that:
 - timely access to diagnostic assessments is critical (e.g., otherwise the early “window of opportunity” is lost and parents can lose hope)
 - treatment needs to be individualized, and, where appropriate, focused on language/communication
 - sensory issues may need to be considered (and may reflect a physical condition, or a particular learning history, thus underscoring the need for care in deciding what treatment is most appropriate)
 - good standard medical care is essential (notably, physical problems might interfere with learning/progress; several examples provided of everyday medical conditions, which, when treated, led to huge improvement)
 - Research on effective parent training programs (e.g., parents often are unsure about what to do, and have limited or no resources, or are overwhelmed by the masses of information, some of which is contradictory; need training sessions and education on basics of ABA and other evidence-based teaching strategies, and opportunities to talk to other parents and to individuals with ASD in order to see the positive qualities of people with ASD).
 - Research on effective training programs for direct service providers in the community; and, more generally, research on effective ways of educating physicians and other clinicians, teachers and other school personnel, and community care providers about ASD.
 - Research aimed at fostering a culture that respects research, with a better understanding of funding constraints and a commitment to follow through with studies so that we can learn as much as possible.
 - Effective knowledge transfer of advances in treatment research, including:
 - success stories about older individuals with positive outcomes
 - information on how to manage the message (e.g., strong claims from untrained people, and a lot of people are trying to push some interventions, diets for example, as if they are good for everyone, while others are trying to scare everyone away from some interventions)
 - Effective knowledge transfer aimed at informing funders that:
 - the priority for families is research on treatment and support
 - a variety of methods are warranted and have merits, depending on the status of evidence and the context (e.g., RCTs may neither be possible in community contexts, nor necessarily warranted until there are positive findings using other methods, and other experimental methods have distinct strengths)
 - Greater transparency regarding how public funds are being spent, both in research and service.
 - Enhanced shared (common) knowledge regarding efficacious/effective treatments/intervention (e.g., via a website); general recognition that families need to be informed to make good decisions; suggestion that CAIRN might do this.

Consider the relative merits of establishing a national standards report for the support and treatment /intervention of children and adults with ASD.