Bridging the Research to Practice Gap in Autism Spectrum Disorder Treatment

by

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ABSTRACT

Autism spectrum disorder (ASD) impacts at least 1 in 68 individuals (Centres for Disease Control and Prevention, 2016) and though there are many treatments that can positively impact the condition, the adoption of evidence-based practices in community settings is slow (Dingfelder & Mandell, 2011). In partnership with a community-based service provider, this dissertation addresses three goals: 1) to critically evaluate measurement tools commonly used in community-based evaluation, identify strengths and shortcomings; 2) to evaluate a community implementation of Pivotal Response Treatment (Koegel, et al., 1989) using a new measurement technology - the Language Environmental Analysis System (LENA Research Foundation, 2016) as an applied example of improving measurement at the local level; and 3) demonstrate how the adoption of evidence-based practices is not just an empirical process, but a social one, that requires significant stakeholder involvement and engagement to encourage innovation diffusion and provider adoption. In combination, the studies that comprise the dissertation demonstrate how researchers can contribute to narrowing the research to practice gap in the context of community-based autism treatment.

PREFACE

This research was supported in part by grants or contributions-in-kind from the Autism Society of Edmonton and Area, Autism Research Centre, the Centre for Autism Services Alberta, and the Canadian Institute of Health Research Strategic Training Initiative in Health Research (CIHR - STIHR) Autism Research Training (ART) program.

This thesis is an original work by Michael Stolte. The research components of this thesis received ethics approval from the University of Alberta Ethics Board. The first study, "Pilot Study for Evaluating a Home-Based Parent Training Program for Autism Spectrum Disorder, Pro000378185 was approved on April 23, 2013. The second study, "Evaluating the Effectiveness of a PRT Community-based Autism Parent Education Program", Pro00044131 was approved on February 29, 2016.

This dissertation includes an introductory chapter that provides background research information and the scope of the dissertation (Chapter 1-2), three manuscripts (Chapters 3- 5), and a concluding chapter that integrates the findings (Chapter 6) across the manuscripts. An earlier version of Chapter 3 was orally presented at the 2014 International Meeting for Autism Research (IMFAR) in Atlanta, Georgia. The full review was published in the peer-reviewed journal *Research in Autism Spectrum Disorders* in January 2016. The Chapter 4 manuscript was presented locally at the Autism Research Rounds (Sept. 9, 2014, Glenrose Rehabilitation Hospital) and at the 2015 International Meeting for Autism Research in Baltimore, Maryland. The Chapter 5 manuscript has been submitted for presentation at the 2017 International Meeting for Autism Research in San Francisco, California. For all chapters, I, Michael D. Stolte, was responsible for conceiving the work, conducting the literature reviews, researching and designing the methodologies, completing the data collection, supervising and training the research assistants, liaising with community partners, analysing and interpreting the data, and writing the chapters.

All components of this manuscript were collaborative in nature and are in various processes of publication. The contribution of the co-author, Dr. Veronica Smith, was made on all three manuscripts, including the introductory and concluding chapters, through supervision, editing, and providing guidance on development of the methods and design, ethics application preparation, data interpretation, and intellectual and editorial support. Dr. Veronica Smith was the supervisory author and was involved with concept formation and manuscript composition throughout. The contribution of the co-author, Dr. Sandra Hodgetts, on the first manuscript, provided data analytic and research interpretation support, as well as input on earlier versions of the test review manuscript. Ms. Chantal Labonte, co-author on the third manuscript, provided support assistance in the data collection and served as one of the primary coders of the data.

DEDICATION

This thesis is dedicated to all the individual and families impacted by autism spectrum disorder, their resilience, and the unique challenges and opportunities this condition represents. You are all an inspiration to me and I thank you for everything you have taught me over the years.

This academic work is also dedicated to the memory of my mom, Geraldine Stolte (nee Nyland, Oct 15, 1941 - May 11, 1994) who taught me to be curious in all activities in life and modeled compassion and respect for all those that crossed her path.

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In particular, I want to thank Veronica Smith for her on-going support and professional mentorship. You have been an inspiration to me on how to bridge research and practice, how to be a rigorous scholar, how to be analytic yet compassionate, and you have mentored me into understanding the much broader context for why we do what we do. You have challenged, shaped and encouraged me into being a better clinician-scientist and for that I deeply thank you. Dr. Isabel Smith – you also have encouraged me to better understand PRT, as well as demonstrated the importance of using scholarly practice to inform clinical work. You have also shown me how to “scale up” models of support in community settings, without compromising the integrity of those models. Your passion for improving the practice for all is an inspiration. Dr. Hodgetts - you have been a friend, colleague and a mentor to me, working as colleagues at FLFA, then with initial offers to submit posters together long before the PhD program became a reality, and now as a member of my supervisory committee. You have modeled how to balance the demands of academic work with the realities of family life and have been a constant source

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In particular, I would like to highlight special thanks to Deborah and Sally. Deb – without your initial support to take a leave and pursue the PhD most of this work would not have been possible. So I thank you deeply not only for supporting me, but also for continuing to provide leadership in the autism service provision field. Your leadership and contributions are invaluable. Sally – also without your support and active participation, a significant portion of this dissertation may not have come to fruition. Your passion for increasing your skills and providing evidence-based practice to highly impacted families is an inspiration for all clinician-scientists. So thank-you!

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Finally, I’d like to personally thank the families that participated in this research and created time in their busy schedules to accommodate the additional demands of completing questionnaires, allowing me in your home, and a willingness to be video and audio-taped as you learned new skills on how to interact with your child. Due to privacy regulations, I can’t name you but you know who you are, and your contributions to future generations of individuals impacted by autism are acknowledged and appreciated. So thank you!

In closing, there are so many more people that have played a role in the journey thus far including academic mentors (Don Kuiken, Marvin McDonald, Paul Wong, and Harry VanBelle), family members, and other friends that are too many too list. If I missed you I apologize. I deeply appreciate all the support you have provided over the years and thank you from the bottom of my heart.

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Chapter 1: Introduction

As autism spectrum disorder (ASD) prevalence rates are now estimated to be 1 in 68 (Centres for Disease Control and Prevention, 2016) there is increased pressure to disseminate evidence-based intervention practices into community settings in an efficient and effective manner as it is in these settings that the vast majority of children with ASD receive their primary care. Unfortunately, despite significant government investment, the gap between practices established in research settings and those conducted in community settings continue to be large (Smith, Scahill, Dawson, Guthrie, Lord, Odom, et al., 2007; Wood, McLeod, Klebanoff, & Brookman-Frazee, 2014). In order to bridge this gap, there is a need for researchers to partner with local service providers to better assess how programs are delivered in community settings, and to create feedback systems that will not only add to the research evidence, but will also increase the quality of services that children and youth with ASD receive (Dingfelder & Mandell, 2011; Kasari & Smith, 2013; Stahmer, 2007).

At the heart of this dissertation were three main goals. The first goal was to critically evaluate measurement tools that are used in community-based evaluation. Key objectives were to include identification of tool use, shortcomings and strengths, and to explore whether new measurement technologies could be used as a means of embedding process oriented tools into community settings in a feasible, ecologically valid, and effective manner.

The second goal, in partnership with an accredited ASD early intervention service provider in Alberta, Canada was to evaluate whether one model of efficacious practice, Pivotal Response Treatment [PRT] (Koegel, Schriebman, Good, Cerniglia, Murphy, Koegel, 1989) when delivered in a community setting can be implemented as intended by the program developers and continue to demonstrate effectiveness in terms of child outcomes. Key objectives within this goal were to provide a comprehensive description of the PRT program within this practice setting, to evaluate fidelity of implementation and teaching, and to determine if PRT improves parent-child communication patterns as a result of program participation. A secondary objective was to utilize a new technology, the Language Environmental Analysis System [LENA] (Lena Research Foundation, 2016) to explore whether this digital language processor and its accompanying analytic software, has potential as an efficient, reliable, and valid measurement of program effectiveness.

A third goal was to frame solutions for bridging the research to practice gap within the broader theory of diffusion of innovation (Rogers, 2003). Within this theoretical model closing the gap must be viewed as not only an empirical process, but also a social one, that takes into account regional practice considerations such as local values, training needs, supervisor availability, administrative priorities, policy priorities, relative advantage of the program in question, costs, staffing, and other considerations that are not typically a central focus in traditional empirical research (Dingfelder & Mandell, 2011). Paying attention to social context enhances traditional models of implementation science which often begin with tightly controlled efficacy studies of new interventions in highly controlled settings and are only phased into community at the end stage of the process, after significant manualization, protocol development, and ideally randomized controlled trials in multiple settings (e.g., Smith et al., 2007). Unfortunately, this traditional approach to research dissemination has been criticized as uptake of evidence-based practices by community has been poor (Gyani, Shafran, Myles, & Rose, 2014). The community partnership model embedded throughout all aspects of this project and the policy paper attached in the appendix are examples of how researchers can engage with decision makers to influence the adoption of evidence-based practice.

These overarching goals will be addressed in a short literature review that covers a number of foundational topics related to ASD and community-based treatment. The first topic includes a brief review of the ASD treatment literature, describing the recommended practices for ASD and how those practices are being implemented, particularly in regard to the role parents play in these treatment programs, and the strengths and limitations of this evidence base. This is followed by an introduction to some theoretical frameworks for describing the process of implementing evidence-based practices into community settings, and some of the common challenges and pitfalls, as well as opportunities that these processes bring. Next, measurement and how it relates to ASD treatment is explored, particularly in its historical context with this field of literature, will be reviewed in regard to how well these tools are working, as they relate to intended treatment outcomes. Out of these measurement challenges, one possible solution for increasing efficacious practice is offered, and that is the use of the Language Environmental Analysis System [LENA] (Lena Research Foundation, 2016) a digital language processor that automatically analyzes communication patterns between a child and key adult, and has been used successfully in other settings with children diagnosed with ASD (Warlaumount, Richards, Gilkerson, & Oller, 2014; Warren, Gilkerson, Richards, Oller, Xu, Yapanel, & Gray, 2010). Finally, the three studies that in combination make up the dissertation are summarized; each study designed to answer specific questions that arise from this review, and that contribute to the knowledge base of closing the research to practice gap in community-based ASD treatment. The findings from these studies are then linked to the broader topic of bridging science and practice within the discipline of psychology. A fourth paper, that is not a formal part of the dissertation but included for background reference, is included in the appendix as a non-traditional means of influencing policy and autism supports in the context of Alberta.

Chapter 2: Foundations - The context for ASD treatment in Canada

ASD is a neurodevelopmental disorder of unknown origin that is typically diagnosed in childhood based on qualitative social communication and social interaction impairments across multiple contexts, as well as the presence of restricted, repetitive patterns of behaviour, interests or activities that interfere with daily functioning (American Psychiatric Association, 2013). Estimated prevalence rates in the general population are estimated to range from 1 in 68 (Centres for Disease Control and Prevention, 2016) to 1 in 143 (Fombonne, Quirke, & Hagan, 2011). Diagnostic rates of ASD in Canada have increased in overall frequency paired with decreasing average age of diagnosis (Burstyn, Sithole & Zwaigenbaum, 2010). As examples, in Alberta, Burstyn et al., (2010) found an average age of diagnosis around 4 years of age and Lowe et al., (2014) identify an estimated prevalence rate of 1 in 94, with higher prevalence rates in elementary school aged children when compared to senior grades. Though Canadian data is limited, this contrasts with earlier epidemiological research identifying a prevalence rate of 10 per 10,000 in Nova Scotia about 30 years previous (Bryson, Clark, & Smith, 1988).

A delayed diagnostic age is of concern as other research indicates that ASD can reliably be diagnosed by around 2 years of age if health care professionals are using standardized measures in the assessment process (Lord, Risi, DiLavore, Shulman, Thurm, & Pickles, 2006) and the use of these tools, in turn can lead to reasonable diagnostic stability (Woolfenden, Sarkozy, Ridley, & Williams, 2012). The lag in age of diagnosis in community settings demonstrated by the Alberta findings (Burstyn et al., 2010) in contrast to research settings (i.e., Lord et al., 2006) is one example of the research to practice gap in the diagnosis of ASD in community settings.

The hope of early diagnosis of ASD is that it leads to early intervention, a recommended practice (National Research Council, 2001) often associated with better child and family outcomes (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Lovaas, 1987; Makrygianni & Reed, 2010; Reichow & Wolery, 2009), though the interpretation of these results are mixed and not without controversy, particularly in regards to measurement of outcome (Howlin, 1997; Jordan, Jones, & Murray, 1998; Matson, 2005) an area that will be covered in more detail later in this review. Despite limitations on how best to measure outcomes, promising results from many of the early intensive behavioural interventions (EIBI) have led to increased public demand for these types of programs, though the quality and quantity of treatment in public settings has been met with mixed success as programs are ‘scaled-up’ to meet community demand (Hume & Odom, 2011). For example, though implementation integrity is fairly well documented within highly structured and controlled treatment settings (e.g., Dawson, Rogers, Munson, Smith, Winter, Greenson, et al., 2010; Makrygianni & Reed, 2010) much less is known about how well treatment integrity is retained in community settings, and whether community adaptations continue to retain “core ingredients” necessary for effective replication (Kasari & Smith, 2013).

In Canada, the outcome of ASD treatments is even less clear, as there is no national autism treatment program, and consequently no framework for evaluating intervention impact. Across the country we see that many of the community-based programs are funded through government funded initiatives that vary from province to province, specifically in regard to cost, intensity, age of entry, objectives, and theoretical foundations. Understanding whether treatments are delivered in the manner they were intended is an important matter as some governments across Canada are spending in excess of $40,000 per child, per year, on community based supports (Madore & Pare, 2006) often with minimal effectiveness data and with high levels of disagreement on the specific support models to be funded (The Standing Senate Committee on Social Affairs, Science and Technology, 2007). Despite formal autism funding for eleven jurisdictions (Madore & Pare, 2006), only three provinces have any peer-reviewed publications describing autism program impact, though positively, all the studies identify positive gains for the children as a result of their participation (i.e., Mirenda, Smith, Zaidman-Zait, Kavanagh, Bopp, et al. (2005) in British Columbia; Perry, Cummings, Dunn-Geier, Freeman, Hughes, La Rose, et al. (2008) and Brian, Smith, Zwaigenbaum, Roberts, & Bryson (2016) in Ontario; Smith, Koegel, Koegel, Openden, Fossum, & Bryson (2010) in Nova Scotia). No peer-reviewed studies of community autism provision were identified for Alberta, despite some of the highest per-child funding for autism supports across Canada (Madore & Pare, 2006) making evaluation of implementation quality and effectiveness a particular concern for this province.

ASD guiding practices and treatment evidence

The National Research Council (NRC, 2001) has published best practice guidelines for ASD intervention after an extensive review of the literature available at that time. These guidelines do provide a general framework for community-based practice, though are limited in providing direction on evaluating the effectiveness of specific interventions or practices and they are also unclear how to apply the guidelines to children under 2 years of age (see Warren & Stone, 2011). Nonetheless, they do provide a minimum foundation for establishing community-based treatment.

The NRC (2001) best practice guidelines include an emphasis on early intervention, minimum guidelines around program intensity (5 hours per day, 5 days per week), the need for accompanied parent training and family generalization of child learning, instructional priorities beginning with functional communication, and the use of positive behavioural supports to manage problem behaviours. Recent literature by Zwaigenbaum, Bryson, Lord, Rogers, Carter, Carver et al. (2009), published as a result of observation of children through high risk infant and sibling studies, emphasize the importance of involving parents in early intervention models, and in ensuring that treatment models for this age group focus on learning in natural learning environments.

Building on a consensus for early intervention, there is an emerging evidence base for agreement on specific strategies for autism treatment, though disagreement is still present on the ideal mix of strategies for comprehensive models of intervention and support for specific children, age groups, and settings (Hume & Odom, 2011; National Autism Center [NAC], 2009; Warren, McPheeters, Sathe, Foss-Feig, Glasser, & Veenstra-VanderWheele, 2011; Wong, Odom, Hume, Cox, Fettig, Kucharczyk, Brock, et al., 2014). For example, after evaluating over 6,000 abstracts on published educational and behavioural intervention programs for individuals with ASD from 1957-2007, the NAC (2009) reported that comprehensive, behaviourally based interventions, as well as those using modeling, naturalistic teaching, peer training, pivotal response treatment, schedules, self-management, and story-based packages - 11 treatments in all total - were identified as efficacious models of practice. In phase 2 of this project, an additional 3 treatments were identified as established (NAC, 2015). A separate review by Wong, Odom, Hume, Cox, Fettig, Kucharczyk, Brock, et al., (2014) substantiate this list of established interventions, indicating a degree of expert consensus, and expand their findings to 27 evidence-based practices for autism support and intervention.

However, there continues to be disagreement and debate in the scientific literature on many autism treatments. An additional 24 practices were identified that fell short of meeting the full criteria for evidence (Wong et al. 2014) and the NAC (2009) report 22 promising practices with limited evidence, decreasing to18 promising interventions in phase 2 (NAC, 2015). These findings suggest that there are more practices with mixed evidence on efficacy than expert consensus, making it confusing for practitioners to consistently choose evidence-based of interventions that are well supported in the research literature.

However, some convergence is also emerging. Smith and Iadarola (2015) summarize the evidence base of interventions for young children with ASD and identify two primary theoretical orientations as informing most EBP: applied behaviour analysis (ABA) and developmental social-pragmatic (DSP). Schriebman et al. (2015) describe the merging of applied behaviour analytic techniques and developmental sciences as Naturalistic Developmental Behavioural Interventions (NDBI), and indicate these merged models of care are a best practice standard for young children with ASD. Core components of NDBI's include a focus on the full range of child development, an emphasis on the child as well as caregiver interactions, and the embedding of development-enhancing strategies within everyday activities and routines. NDBI's have common features such as use of the antecedent-response-consequence contingency model, manualized practice, fidelity of implementation criteria, individualized treatment goals, on-going measurement of progress, child-initiated teaching episodes, environmental arrangement, use of natural reinforcement, use of prompting and prompt fading, modeling, and use of adult imitation for desired child language, play or body movements. Examples of child focused NDBI's cited by Schriebman et al. include several randomized controlled trials [RCT] (e.g. Dawson et al., 2010; Kasari et al., 2010; Yoder & Stone, 2006; Wetherby et al., 2014) as well as controlled, single-subject and quasi-experimental studies (e.g. Ingersoll and Dvortcsak, 2006; Ingersoll et al., 2005).

In summary, there is an emerging body of evidence that we are able to identify ASD early, efficacious practices are available for early intervention, as well, there is a general consensus on the benefit of early intervention. However, there is little evidence that these practices have been fully adopted in the practice community, in part because there is such an array of interventions where the evidence is still emerging. Dingfelder and Mandell (2011) speculate that this slow uptake is also due to practical concerns that are based on perceived relative advantage of the new innovation, potential incompatibility with existing programs and values, low visibility of the innovative value, excessive program complexity for full implementation, and limited opportunity to trial new programs. This is unfortunate as Walker (2004) estimates the lag time between the development of an efficacious practice and full integration into routine school practice to be 20 years, whereas Wood et al., (2014) in a review of implementation science from other disciplines, estimates a lag time of 17 years.

Fortunately, according to some implementation scientists (Metz, Halle, Bartley, and Blasberg, 2013) high quality programs can be implemented more quickly. They suggest that when implementation science is used to scaffold evidence-based programs into practice communities, early childhood programs can be fully implemented, with fidelity, in 2 - 4 years, provided there is a clear needs assessment, stakeholders are involved, resources and staff are in place, clear data management systems are present, and expert coaches are used to guide the overall process. The National Implementation Research Network (2015) defines implementation science as “the study of factors that influence the full and effective use of innovations in practice” (www.nirn.fpg.unc.edu). These processes are built on what is described by Metz et al. (2013) as key implementation drivers that include staff and supervisor core competencies, organizational systems that value data and evidence, and capable leadership to manage technical problems and push through adaptive challenges. The goal of identifying these factors is to facilitate improved dissemination and adoption of EBP through the creation of feedback loops that identify barriers and facilitators of innovation adoption (NIRN, 2015).

Another way of understanding the research-to-practice gap is through the application of diffusion of innovation theory (Rogers, 2003) where all new innovations must go through four stages: 1) dissemination, 2) adoption, 3) implementation and 4) maintenance before full acceptance of the innovation is accepted. These stages inherently describe a *social* process of gradual adoption where administrators evaluate new practices not only on the scientific evidence, but also on their cost, feasibility, relative advantage, training needs, population needs, staff resources, stakeholder values, and complexity of uptake over time. Dingfelder and Mandell (2011) emphasize that to close the research-to-practice gap intervention, the traditional "pipeline" approach of evaluating the efficacy of practices in highly controlled settings and then disseminating efficacious interventions after development, must be re-evaluated. Instead, Dingfelder & Mandell propose

> autism intervention researchers must change current practice by a) partnering with communities to facilitate the successful adoption, implementation, and maintenance of interventions that have already been developed, and b) developing new interventions in collaboration with these communities to ensure that the interventions meet the community's needs and capabilities, thus increasing the likelihood of successful diffusion. (p. 607)

In short, to maximize diffusion of evidence-based practice, intervention research must be participatory, ecologically valid, and partner with the end users of the interventions.

The role of parent training in ASD treatment

Family involvement increases generalizations of learning and enhances the effectiveness of intervention (NRC, 2001). This is particularly important for ASD treatments as it is well established that child language, a central deficit in ASD, develops in response to both the quality and quantity of a child's language environment (e.g., Rowe, 2012) and that this environment varies widely across socio-economic status (e.g., Hart & Risley, 1995), birth order (e.g., Oshima-Takane, & Robbins, 2003), time of day and activity (e.g., Soderstrom & Wittebolle, 2013) and child care environment (e.g., Murray, Fees, Crowe, Murphy, & Henriksen, 2006). Consequently, it is of vital importance to include parents, particularly in early childhood learning, where key pre-linguistic tasks such as the establishment of joint attention and reciprocal play are initially learned (Lieberman & Yoder, 2012).

The literature on the effectiveness of parent training for the ASD population is still under debate, and there is less expert consensus on parent models than on clinician implemented models of treatment. For example, Oono, Honey, and McConachie (2013) completed a meta-analytical review of 17 randomized-controlled (RCT) parent-training programs for preschoolers with ASD across six countries, and reported a high risk of bias in the findings, with non-significant effects for direct child measures of expressive language, comprehension, joint language, child initiations, and parental stress. However, Oono et al., (2013) found moderate consensus in that parents who participated in training reported increased parent-child synchrony and shared joint attention as a result of participation, and also identified that parents were likely to report positive effects on self-report measures of child comprehension. However, independent standardized measures of child development did not substantiate parent reported changes on their children's skills, bringing into question the true impact of these programs on child functioning.

Finally, Oono et al., (2013) recommend "the ability to draw conclusions from studies would be improved by researchers adopting a common set of outcome measures as the quality of the current evidence is low" (p. 2).

A review by Beaudoin, Sebire, & Couture (2014) of 15 studies on parent training programs for really young children with ASD found similar results. Only two of the studies met criteria for "conclusive evidence" (p. 1) and a wide range of participants, intervention types, settings, intensity, teaching strategies, child outcomes, parent outcomes, and parent-child interactions were reported on. Despite this heterogeneity, Beaudoin et al. (2014) conclude that "positive changes can be obtained in young children with ASD following a parent training intervention" (p. 11) and that parental satisfaction, attitudes and skills also generally improved.

For really young children with ASD, naturalistic developmental behavioural interventions (NDBI) appear to be an ideal model as they integrate applied behaviour analysis with developmental science and implement those models in natural settings (Schreibman, et al., 2015). PRT is identified as a NDBI (Brian et al., 2015), as are other models such as the 12-week parent mediated Early Start Denver Model [ESDM] (Rogers, Estes, Lord, Vismara, Winter, Fitzpatrick, et al., 2012). Other NDBI's that have demonstrated promise in a parent mediated format at the RCT level of evidence include Kasari, Gulsrud, Wong, Kwon, & Locke (2010) for joint attention; Green, Charman, Pickles, Wan, Elsabbagh, Slonims, et al. (2015) for increased infant attentiveness and parental non-directiveness; Pickles, Le Couteur, Leadbitter, Salomone, Cole-Fletcher, Tobin, et al. (2016) on improved core ASD symptomology multiple years after intervention; and Wetherby, Guthrie, Woods, Schnatchneider, Holland, Morgan and Lord (2014) for improved social communication.

Despite these promising results, it does not appear that child change is the dominant effect of most parent training initiatives. Consistent with the ASD-specific review by Oono et al. (2013), a meta-analysis by Kaminski, Valle, Filene, & Boyle (2008) identify that greater effects were found for parental outcomes than child outcomes. Kaminski et al. (2008) reviewed 77 published parent training programs across a wide range of behaviour and adjustment for children 0 – 7 years of age. Program components associated with the strongest effects on child externalizing behaviours included increased positive parent-child interactions, emotional communication skills, use of consistency, time outs, and *in vivo* coaching models where parents had to practice the skills with the coach[1] present. Parenting knowledge was identified as much easier to change than parent behaviour and skills and child acquisition skills were much lower than that of the parents.

In addition to a lack of consensus on outcome tools, there was a wide range of content topics, teaching styles and outcome measures, adding to the complexity of reviewing parent education programs. Schultz, Schmidt, and Stichter (2011) reviewed 30 parent education studies for this same population and identified different teaching formats, parent and child outcomes, a variety of research designs, and that up to 60% did not use a formal curriculum or manual. Patterson, Smith, and Mirenda (2011) reviewed 11 parent education single-subject studies and added that the mother was usually the focus of the teaching, child utterances and child imitation were common outcome measures, and parent training varied from 2.5 to 25 hours in length.

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[1] Distinctions have been made between parent coaching and parent training. According to Rush & Shelden (2011) parent training is associated with an 'expert' model of delivery whereby an expert seeks to 'train' parents how to 'best' interact with their child, whereas parent coaching operates on the understanding that parents are the experts on their child. In the context of this paper, parent training has been adopted as that is the terminology used by Koegel et al., (1989), the creators of pivotal response training (PRT) – a primary focus of evaluation in this study.

In order to decrease well established high drop-out rates, Matson, Mahan, and Matson (2009) recommend that parent training programs be functional and behaviourally based, with an emphasis on early intervention; and that parents should be offered different training options during the lifespan of their child to meet different developmental needs. Meadan, Ostrosky, Zaghlawan, and Yu (2009) in a review of 12 home-based parent training programs, identify positive reported outcomes in social and communicative behaviour of young children with ASD, and cite similar methodological concerns about research rigor, lack of reported implementation fidelity, generalization of learning, and other supports the child and/or parent may have been receiving. Similar to the review by Oono et al., (2013), Burrell and Burrego (2012) suggest that parent training can enhance the parent-child relationship, improve the role of collaboration in treatment and goal setting leading to improved skill generalization, and may also contribute to improved parenting practices overall.

Though parental involvement may be important, there may be drawbacks as a result of participation. For example, Strauss, Vicari, Valeri, D'Elia, Arima, and Fava (2012) report that though children respond better on expressive language, adaptive behaviours and core autism symptoms when parents are involved in an early intensive behaviour intervention program, intensive programs may be associated with increased stress for more than less involved parents. Beaudoin et al. (2014) confirm that parents of children with ASD tend to be more highly stressed than parents of children with other developmental disorders and hence parent workload should be minimized to the greatest extent possible. Parents of children who are aggressive may also experience a mismatch between the supports provided and those that they need (Hodgetts, Nicholas, & Zwaigenbaum, 2013). When embedding parent training within the broader umbrella of parent and child well-being, Resch, Benz, and Elliott (2012) report that overall, parents who have adequate access to supports and services, have fewer financial barriers, feel accepted by their immediate community, and report higher levels of well-being than those parents that do not have these resources. They also establish that there is no link between child disability severity and parental well-being, though those parents of a child with a severe disability are more likely to perceive threats in their child's environment.

In Canada, the evidence is particularly limited on parent training programs for ASD with only one large scale rigorous study identified at the level of the randomised controlled trial (RCT). In Brian et. al. (2016) a multi-site pilot study with a foundation in PRT (Koegel & Koegel, 2006) is described where parents of suspected or confirmed toddlers with ASD participated in a 12-week parent training program. Results indicated improved parent-child responsiveness and increased child rate of initiations and vocal utterances that were maintained into the 3-month follow-up period.

In summary, though there are examples of how parent participation and training in autism treatment programs can be of benefit, there are clear difficulties in evaluating and comparing these programs. The lack of common outcome tools, lack of manuals and curriculum, mixed designs, poor fidelity measures on both teaching and implementation models, and poor documentation on other accessed supports make it difficult to draw conclusions about how effective these programs are currently working – particularly in communities where there is typically less rigor than in research settings. There is a need to evaluate parent education practices, as they are commonly implemented in community settings including teaching modality, fidelity of implementation, curricula usage, manual usage, and this must be done using a common set of objectives and direct child and parent measures that are standardized and minimize provider bias.

Disseminating evidence-based practice into community settings

Though there are at least two comprehensive guidelines for selecting evidence-based treatment for children with ASD (NAC, 2009; Wong et al., 2014) it is not clear how well those practices are being disseminated and used in the community, and it is even less clear when it comes to identifying effective parent training programs and their key components for ASD child caregivers (Oono et al., 2013). In order to better understand how these programs are disseminated into schools and other community settings, Kasari and Smith (2013) indicate that it is important to identify the key components of the intervention, to understand local variance, to use manuals that specify how to modify to local circumstances, to ensure goals are selected on meaningful outcomes, and to develop measures that "have relevance for children in their everyday lives and that can be easily gathered in authentic environments" (p. 259).

According to Smith, et al. (2007) efficacious interventions become effective when it can be demonstrated that they maintain their fidelity and expected outcomes in new and diverse treatment settings. In order for a treatment to become evidence-based, Greenberg (2004) makes the distinction on the importance of not only providing evidence of treatment *efficacy*, through rigorous controlled clinical trials, but also providing evidence of treatment *effectiveness*, that is assessed by studying local adaptation and quality of implementation in community settings. As efficacious interventions are moved out of research settings and integrated into community systems, adaptations are required across developmental stages, levels of care, and institutional structures. Unfortunately, these adaptations can impact the implementation quality of the treatments, including fidelity, which can then impact treatment effectiveness.

To be clear, it is only by partnering with service providers at the local level that quality assurance can be properly assessed in these settings, and this partnership is likely to lead to an increased adoption of evidence-based practice (Dingfelder & Mandell, 2011). As mentioned, there is debate on how best to expedite this process. Similar to Smith et al., (2007), Trivette and Dunst (2013) provide a sequential process of translational research as follows:

Type 1) develop evidence-based practices using research;

Type 2) use evidence-based professional development to increase parent and professional use of these practices;

Type 3) actively evaluate the use of evidence-based practices "on the ground" and;

Type 4) disseminate, diffuse and promote evidence-based practice.

Providing a social context to this process, Dingfelder & Mandell (2011) identify the importance of understanding local needs and values when engaging in dissemination, as well as one of empirical investigation, and hence emphasize that partnering with end users of the intervention throughout its development and evaluation will improve the uptake of practices in the future. The focus of the latter two studies in this dissertation, *evaluating the effectiveness of a PRT community-based parent education program,* are a Type 3 model of translational research (Trivette & Dunst, 2013) done through partnership with an autism service provider at the local level. This allows for evaluation of evidence-based practices by end users of the information through measurement of implementation and intervention fidelity, documents variances at the local level, establishes ecological validity, and allows for refinements in program implementation and evaluation.

Measurement issues regarding autism treatment effectiveness

A final area of challenge is that of measurement, particularly as it relates to evaluating program outcomes and quality assurance, as outcomes are often defined by the measurement tools that are chosen. In testing literature, a test must be both reliable and valid for the purpose for which it is chosen, and this is an on-going process that embeds evaluation within a well-defined theoretical context. Messick (1989) states “validity always refers to the degree to which empirical evidence and theoretical rationales support the adequacy and appropriateness of interpretations and actions based on test scores” (p. 13). In contemporary testing theory, Sattler (2001) articulates the importance of establishing content, criterion-related, construct, predictive, and clinical validity when using test results; an important area of concern regarding the ASD treatment literature, as it is not always clear how the tests chosen (e.g. primarily cognitive and adaptive measures) map onto underlying theoretical autism constructs (e. g. social-communication delays and behavioural rigidities and rituals), and the interpretation of test results may not always be clearly linked to their intended usage (Matson, 2005).

Critical interpretation of test results in contemporary ASD treatment can be traced to a seminal study by Lovaas (1987) who reported that up to 47% of preschool children diagnosed with ASD could achieve average scores on standardized measures of intelligence and regular Grade 1 classroom placement after receiving 40 hours per week of behaviourally-based intensive intervention for at least 2 years. This model has been identified as the UCLA Young Autism Project (UCLA YAP) model and still influences much of the current ASD treatment literature (Reichow & Wolery, 2009). Particularly in regards to how these programs are evaluated Jordan, Jones, and Murray (1998) and Howlin (1997) identify numerous measurement shortcomings for the Lovaas (1987) study including 1) the use of different measures before and after treatment, 2) measures that may not reflect important areas of difficulty in addressing autism, 3) non-adherence to standard assessment protocols, 4) lengthy delays between program delivery and outcome assessment and 5) the use of prorated mental age as being psychometrically weak. All of these criticisms are potential indicators of invalid test use and inappropriately inferred conclusions from the test data.

Despite limitation on their usage, these two types of measures – intelligence and adaptive functioning, continue to be used in most current group studies of autism treatment, though measurement concerns continue to be present (Matson, 2005; Stolte, Hodgetts, & Smith, 2016). These concerns are echoed by Bryson, Rogers, and Fombonne (2003) who state "the next generation of studies needs to … isolate variables accounting for change, and move beyond group analyses to examine individual response variability within and between treatments … (and that) … fidelity measurement systems for other main treatments be developed" (p. 511). Individual responsiveness and fidelity measures of implementation are important variables that are often overlooked in large, group-based outcome studies and Hume and Odom (2011) note that the science of implementation can only be increased by paying attention to both quantitative and qualitative variables, as qualitative (process) variables tend to be under represented in the treatment literature.

A core feature of program evaluation is to assess the fidelity of implementation of a program (Meadan, et al., 2009; Schultz, et al., 2011; Wong et al., 2014). Fidelity of implementation is defined as "the extent to which core components of interventions are delivered as intended by the protocols" (Gearing, El-Bassel, Ghesquiere, Baldwin, Gillies, & Ngeow, p. 79, 2011). Hume and Odom (2011) distinguish between *quantity* implementation factors such as the number of lessons, hours, or trials; and *quality* implementation factors such as process measures of fidelity and reliability. Ensuring practices remain informed by the evidence, it is important to measure both quality and quantity factors to ensure effective replication of practice.

As one example of how implementation may lose fidelity - and hence potential effectiveness in community-based practice, Wolery and Garfinkle (2002) reviewed 72 autism intervention studies, and noted that only 13.9% reported on procedural fidelity and that home-based interventions, a common service delivery model in Alberta, only represent about 10% of the published literature. This is unfortunate as higher fidelity is often associated with better outcomes for children, and home-based programs are under-studied regarding their effectiveness. For example, Smith et al. (2010) linked treatment fidelity to positive gains in child receptive and expressive language and decreased behavioural problems after 12 months of PRT and Strain & Bovey (2011) were able to demonstrate that implementation fidelity of a behaviourally based inclusive classroom model, was associated with child improvement on measures of cognition, language, autism symptoms, problem behaviours and social skills in a randomized, controlled trial.

One reason community-based intervention studies may be under-represented is that embedding research into community-based practice is extremely difficult. Stahmer (2007) surveyed 80 autism services providers in California and reported that minimum staff training levels, hours of intensity, practice settings and fidelity of service were highly inconsistent from provider to provider, confirming the gap between the research and community provider continues to exist. Stahmer (2007) also concludes that many community providers are hesitant to adopt highly structured practices required by researchers and that “early collaboration with providers is paramount” (p. 1353) in order to ensure evidence based practices are incorporated into community practice, in a way that will maximize delivery models.

Nonetheless, partnerships are important as providers continue to be responsible for much of the direct service contact with the children and/or the parents of children who have received a diagnosis of ASD. Evaluating community-based intervention models using rigorous methodologies are possible, as has been demonstrated in the large scale service provision of PRT in Nova Scotia (Bryson et al., 2007), the randomized controlled trial of the Learning Experiences, An Alternative Program for Preschoolers and Parents (LEAP) training protocol for inclusive classrooms (Strain & Bovey, 2011), and in the long distance parent training program of the Early Start Denver Model (ESDM), that integrates behavioural principles into developmentally appropriate treatment targets (Vismara, Young, Stahmer, McMahon Griffith, & Rogers, 2009). These studies on three of these models of early autism intervention demonstrated that higher levels of fidelity are associated with positive gains for children after at least 12 months of intervention, and these results were captured by embedding research methodologies into the program design at the community level (Smith et al., 2010; Strain & Bovey, 2011; Vismara et al., 2009).

LENA: One possible solution to increase evidence-based practice

A currently emerging technology is the Language Environmental Analysis system (LENA), a digital language processor with interpretative software that automatically captures and analyzes communication data between a young child and their key communication partners (LENA Research Foundation, 2016). Automated evaluation is of value as it minimizes bias in reporting and interpretation, a concern highlighted by Oono, et al., (2013) in their most recent review of the ASD parent training literature. LENA also directly measures adult and child vocalizations, a component of social communication, a key area of focus for ASD interventions. Integrating measurement processes into community settings through new technologies may also facilitate improved quality control and feedback mechanisms, in an efficient manner, as traditional means of gathering live communication data is a time consuming and difficult task, and many service providers do not have the time or inclination to gather data at the rigor required for a research partnership.

The LENA is a digital language processor that the child wears in special clothing for up to sixteen hours and then the analysis software calculates three key communication indicators: Adult Word Count (AWC), Child Vocalizations (CV), and Conversational Turns (CT) between an adult and a key child (Xu, Yapanel & Gray, 2009). The LENA captures real time data on vocal patterns and transactions, and translates that data into visual graphs, timelines, and developmentally normed algorithms allowing for comprehensive data analysis (LENA Research Foundation, 2016). For advanced users, additional proprietary software, the LENA Advanced Data Extractor (ADEX) allows for the exporting and analysis of raw acoustic data across many additional variables (LENA Research Foundation, 2011). Additionally, the LENA is worn by the child and has the potential to allow for a reliable snapshot of how a child-adult dyad is actually functioning in a naturalistic environment, without formal external observation that may be biasing their performance (i.e., the Hawthorne effect). The development of the LENA was extensive and its original data set was based on 1,486 all-day recordings from 232 children capturing over 3.1 million automatically identified child utterances that were further categorized into 12 infrastructural acoustic features (Oller, et al., 2010).

Bolstering support for its use with the ASD population, the LENA has been used to evaluate individuals with ASD in other settings. Warren et al., (2010) analyzed the vocal patterns of young children with autism and found that during therapy time, increased child talk, adult talk, and conversational turn-taking were demonstrated when compared to non-therapy time; and the LENA was also sensitive enough to distinguish children with ASD from the typical developing population, based on their language patterns. Warlaumont, Richards, Gilkerson, and Oller (2014) have also used the LENA to analyze the micro-structure of over 13,836 hours of naturalistic child-adult interactions and demonstrated differences between ASD and non-ASD children regarding the communication feedback loop with their parents, and also substantiate the presence of this feedback loop. Dykstra, Sabatos-DeVito, Irvin, Boyd, Hume, & Odom (2014) used the LENA to evaluate children with ASD in preschool settings and highlight the importance of efficiently capturing large amounts of communication data in naturalistic settings. They cite the many challenges associated with using traditional, standardized measures such as possible child over-performance in contrived settings, inadequate capture of child-adult communication, impact of disability status on child interaction, and a general paucity of information on typical preschool interaction overall.

The LENA has also been used as a parent training tool. Suskind et al. (2015) used LENA to provide vocalization feedback for 23 parent-child dyads in eight weekly hour long home visits that provided promising results on increased parental knowledge, diversity, and amount of parent talk with their children. These results built on an earlier study by Suskind et al. (2013) that identified even with shorter term interventions, information on enriching a child’s home language environment, coupled with LENA feedback and goal setting, could have a positive impact on parent talk and parent-child interaction. A similar study was completed in China by Zhange et al. (2015) over a 6-month period with 22 dyads and though results were mixed, the largest impact was on improved adult-child interactions for below-median socioeconomic status (SES) families.

The LENA is reported to be a reliable and valid measurement tool. Xu, Yapanel, & Gray (2009) analyzed 70 hours of LENA data, from 70 independent test files, that was manually transcribed by professional transcribers across a child’s natural environment. Positive agreement was achieved at a rate of between 76 – 82% (adult and child word count respectively) between the transcribers and the LENA system, based on audio segmentation analysis into eight groups: adult male, adult female, key child, other child, overlapping speech, noise, electronic media, and silence. They also evaluated two single child cases over a full 12-hour recording period and when in a quiet environment, adult word count agreement between human transcribers and the LENA approached 99%, though agreement diminished by up to 27% when in noisy environments such as an outdoor space where many competing sounds needed to appropriately categorized and processed. The reliability of the LENA for the Spanish language has also been independently evaluated by comparing automated estimates of adult words and transcriber-based word counts, with a reported accuracy of 80% (Weisleder & Fernald, 2013).

Building on these findings, Patterson and Smith (in review) completed community-based pilot work with the LENA evaluating parent-child dyadic interactions after parents participated in the Hanen "More than Words" program (Sussman, 1999) and reported that the LENA demonstrated concurrent validity with MacArthur Communicative Development Inventories (Fenson, Dale, Reznick, Thal, Bates, Hartung, et al. 1993) measures of expressive language, differentiated children with autism when compared to a normative language sample, and was sensitive to changes as a result of the parent training intervention. This same research group was also able to use the LENA to demonstrate how communication opportunities alter dramatically for the child depending on the community setting (Sliwkanich, Smith, & Patterson, 2011). This proposed project is an extension of their research within the same urban setting.

PRT: A special case of evidence-based practice in Alberta

Pivotal Response Treatment [PRT] (Koegel & Schriebman, et al., 1989) has been identified as an efficacious model of autism intervention (NAC, 2009; Odom, Boyd, Hall, &

Hume, 2010). Koegel, Openden, Fredeen, & Koegel (2006) describe PRT as an intervention model that combines developmental and applied behaviour analysis (ABA) procedures, and targets pivotal areas of child functioning such as motivation, responsivity to multiple cues, self-management, self-initiations, and empathy - areas that are hypothesized to result in collateral growth across multiple developmental areas when targeted in this manner. PRT also has an established and published methodology for measuring procedural fidelity (Coolican, Smith, & Bryson, 2010; Symon, 2005) allowing for comparison across settings. Schriebman & Ingersoll (2012) describe PRT as a naturalistic and behaviourally based model of support that uses natural motivators and can be readily taught to teachers, parents, and peers in a child's everyday environment.

This combination of factors makes PRT an ideal training model to evaluate in community settings to establish its effectiveness, as efficacy in controlled settings has already been established, and effectiveness studies are emerging. For example, in Nova Scotia, PRT was taught to parents, trainers and one-to-one interventionists through workshops, in-vivo training and video feedback analysis (Bryson, Koegel, Koegel, Openden, Smith, & Nefdt, 2007; Koegel & Schriebman, et al., 1989) and positive results were reported for both children and interventionists (Smith, Koegel, Koegel, Openden, Fossum, & Bryson, 2010). Additionally, successful implementation of PRT has been demonstrated by caregivers in a clinical setting (Randolph, Stichter, Schmidt, & O'Connor, 2011), group setting (Minjarez, Williams, Mercier, & Hardan, 2011; Wang, Hardan, Boettcher-Minjarez, Berquist, Frazier, & Gengoux, 2012), and in a brief 6-hour training model of a waitlist group (Coolican, et al., 2010).

Based on these encouraging results and to increase dissemination of PRT into community-based practice, the Koegel Autism Centre, a PRT training facility, has developed a long-distance training model, with a certification process, for community-based service providers on PRT intervention and methodology (The Regents of University of California, 2005). In the context of Alberta, this model of PRT has been delivered through one large community-based service provider since 2006, though this community-based model has never been subject to any peer-reviewed type of evaluation. Though PRT has been implemented in multiple ways in this setting, since 2012 it has been delivered in a manualized parent training format by PRT Educators who are Level 4 or 5 certified by the Koegel Autism Centre, and this training model is the focus of the latter part of this proposal.

Dissertation goals and objectives

This dissertation is composed of three studies, each with a slightly different goal, that when combined, contribute to a unique understanding of bridging the research-to-practice gap in community settings. A fourth paper is included in the appendix as an applied example of diffusion of innovation theory through stakeholder engagement (Rogers, 2003) though is not considered a formal part of the dissertation due to its non-traditional design.

The first study is a critical review of the outcomes measures used to evaluate the effectiveness of early intervention treatments for preschool children with autism from 2002 – June, 2015. The goal of this study was to identify outcome tools used and report on strengths and limitations of those tools in light of recommendations published by the *Standards for Educational and Psychological Testing* [The Standards]; AERA, APA, & NCME, 1999). The *Standards* are a best practice framework to guide the development, validation, administration, reporting and appropriate test use. A critical review of this literature reveals a number of shortcomings including measurement bias, over-reliance on parent report, over-use of certain tools, and the use of tools in ways that were never intended by the developers. These findings support the use of new technologies that quantify real time interactions, such as the LENA, where it may become possible to embed automated measurement tools in the community, as one aspect of increasing uptake in evidence-based practice.

The second study was a pilot evaluation of a PRT parent education program that was being implemented in a community setting. The PRT parent training program had been implemented in the community for approximately 2 years with 35 families by an accredited autism therapy service provider in Alberta. The goals of this pilot study were three-fold: 1) to systematically describe the PRT program, as it was being implemented in community practice; 2) to evaluate the viability of the LENA as a potential tool to measure both implementation process and outcomes; and 3) to evaluate parent and child outcomes of the PRT parent training program.

Using a single-subject ABC design, one parent-child dyad was followed for a 16-week period as they participated in the parent training program. The parent-child language and interaction patterns were measured before, during, and after program completion to identify the impact of the PRT program. All sessions were video and audio-taped. Fidelity of PRT implementation, as well as curricula, manuals, and teaching style and content were described and evaluated to gain a better understanding of the model in a community based practice setting.

The third study builds on the two previous studies to explore the impact of the PRT parent training program across multiple participants and to evaluate the viability of using the LENA as a monitoring tool to demonstrate program effect when it is used by multiple parties instead of just the primary researcher. Using a non-concurrent multiple baseline single-subject across-participants design, the same PRT parent training program was evaluated for 3 parent-child dyads using the methodology employed in the pilot. Similar to the pilot, the LENA was the primary outcome tool, the dyads were followed for the duration of the program, including follow-up, and samples of their communication were evaluated over time as they participated in this unique home-based training model.

Finally, a fourth paper is included in the appendix. This was a policy evaluation paper created for the Honorable Minister of Children's Services, Mr. David Hancock, in 2012 as a positive example of closing the research to practice gap not only through empirical science, but also through advocacy and stakeholder engagement. Mr. Hancock served as Alberta's 15th premier in 2014 and this paper was prepared for him at his request by the key author, in consultation with Dr. Smith and my professional colleagues. Key recommendations from the paper were to create an expert advisory panel for the province to support evidence-based care in the practice community for autism treatment and support systems, and this paper has been presented to multiple stakeholders.

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Chapter 3: A critical review of outcome measures used to evaluate the effectiveness of comprehensive, community based treatment for young children with ASD[1][2]

Abstract

Background. This review critically evaluates reporting and use of standardized measures to assess community based treatments for young children with Autism Spectrum Disorder (ASD). *The Standards for Educational and Psychological Testing* (AERPA, APA & NCME, 1999), a best practice framework for reporting standardized test results, guides the evaluation.

Methods. Fifty three different outcome measures are identified across 45 studies representing twelve countries.

Results. Adaptive behaviour, specifically the Vineland Adaptive Behavior Scales and cognitive measures continue to be primary outcome tools, despite a lack of clear fit to core ASD diagnostic constructs. Behavioural, ASD specific, language, social communication, and family wellness tools are under represented. Reporting strengths are use of multiple measures, clear sample descriptions, and use of specialized tools for ASD. Reporting weaknesses are assessment bias, test substitution, and under reporting of test modifications.

Conclusion. A simplified list of standardized tests are summarized including ethical reporting requirements. Clinical and research implications are discussed.

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[1] A version of this chapter was published as follows: Stolte, M., Hodgetts, S., & Smith, V. (2016). A critical review of outcome measures used to evaluate the effectiveness of comprehensive, community-based treatment for young children with ASD. *Research in Autism Spectrum Disorders, 23,* 221-234. Doi: http://dx.doi.org/10/1016/j.rasd.2015.12.009

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Introduction

Autism Spectrum Disorder (ASD) is diagnosed at younger ages and with increased frequency, with current estimates that approximately 1% of school aged children (Blumberg, Bramlett, Kogan, Schieve, Jones & Lu, 2013) meet the diagnostic criteria of qualitative impairment in communication and socialization skills, as well as the presence of repetitive behavioural mannerisms that interfere with daily functioning (American Psychiatric Association, 2013). As the number of children with ASD increases, so has public pressure to provide evidence based treatment. However, though evidence based treatments are established within research settings (e.g., Makrygianni & Reed, 2010) the gap between research and practice is large (Dingfelder & Mandell, 2011; Kasari & Smith, 2013) and despite significant costs associated with treatments in community settings, little is known about how well many treatments developed in research settings generalize into the community. For example, Amendah, Grosse, Peacock and Mandell (2012) estimate costs of $25,099 to $60,000 + per person, per year for behavioural therapies. In Canada, provincial governments are spending up to $40,000 per child, per year on therapies for children with ASD (Madore & Pare, 2006). Lifetime costs are even greater with recent estimates of $2.4 million in the United States and £1.5 million in the United Kingdom (Buescher, Cidav, Knapp, & Mandell, 2014).

The distinction between treatment *efficacy* and *effectiveness* has important implications for bridging research and clinical practice. Treatment *efficacy* is demonstrated through completion of replicable studies in highly controlled research settings, whereas treatment *effectiveness* is the demonstration of the generalizability of efficacious treatments into community settings (Greenberg, 2004). Our understanding of effective treatments for ASD has been consolidated through several extensive and systematic reviews (e.g., The National Autism

Center, 2009 and Wong, Odom, Hume, Cox, Fettig, Kucharczyk, et al., 2014) yet, the evidence base for ASD treatment *effectiveness* is still an emerging field. In addition, predicting what intervention will work best for an individual child, the specificity of the intervention targets, and the individual responsiveness of ASD symptomology to treatment is still unknown, particularly as knowledge is generalized out of university contexts into the community (Minjarez, Williams, Mercier & Hardan, 2011). Moreover, in the context of implementation science, the lag time between the development of an efficacious practice and its eventual adoption is still estimated to be as high as 20 years (Walker, 2004).

One contributing factor to the slow adoption of efficacious practice is the lack of consensus on measurement tools and wide usage of different instruments (Bolte & Diehl, 2013). Matson (2007) reports that measures of intelligence and adaptive functioning are used most frequently though a sole focus on these two constructs in the measurement of ASD treatment response can be problematic. For example, regarding cognition, Matson reports that 1) children often age out of Intelligence Quotient (IQ) measures from pre to post test, forcing substitution of a different IQ instrument normed on an older population, 2) it is not clear whether ASD intervention results in increased scores due to increased compliance, attention, motivation or ability, 3) IQ tests are less reliable at predicting future performance for children at young ages, 4) comorbid psychopathologies may interfere with measurement of the underlying constructs and, 5) IQ tests are not normed on an ASD population. Adaptive measures, though valuable, are normed primarily on the typical developing population (Sattler, 2006), not designed specifically for this group, and consequently only provide a reference point for identifying delays and strengths in the ASD population.

According to Gould, Dixon, Najdowski, Smith and Tarbox (2011) measurement outcomes of intensive ASD programs should be: 1) comprehensive, 2) target early childhood development, 3) consider behaviour function, 4) directly link assessment items to curricula targets, and 5) be used to track child progress over time. Gould et al. (2011) indicate that a combination of direct observation and indirect assessment (e.g., rating scales and checklists) is an ideal manner to track outcomes. However, after reviewing 27 different tools that may be used to measure ASD intervention progress, they were not able to identify any specific tool that met their five criteria. Four tools identified as being 'of promise' were the Verbal Milestones Assessment and Placement Program [VB MAPP] (Sundberg, 2008), the Brigance Diagnostic Inventory of Early Development II [Brigance IED II] (Brigance, 2004), the Vineland Adaptive Behavior Scales Second Edition [VABS II] (Sparrow, Cichchetti, & Balla, 2005), and the Brigance Diagnostic Comprehensive Inventory of Basic Skills Revised [CIBS R] (Brigance, 1999). The VABS was described as "by far the most popular assessment" (p. 998). To strengthen these tools, Gould et al. (2011) recommended simplified administration of the VB MAPP, increased psychometric evaluation of the VB MAPP and Brigance IED II, and content linking of the VABS and CIBS R more clearly to a curriculum.

Bolte and Diehl (2013) reflect the lack of consensus on measurement tool selection to evaluate treatment response in their review of 195 prospective ASD treatment trials from 2001 to 2010. They identified 289 unique measurement tools, of which the vast majority (61.6%) were only used once. The top five utilized tools reported in this review were the Aberrant Behavior Checklist [5%] (Aman, Singh, Stewart, & Field, 1985), Clinical Global Impressions [4.6%] (Guy 1976), VABS [3.9%] (Sparrow et al., 1984), investigator designed video observations (1.9%), and the Bayley Scales of Infant Development [1.7%] (Bayley, 1993). Bolte and Diehl (2013) concluded that “greater consistency in the use of measurement tools in ASD clinical trials is a worthwhile and achievable goal” (p. 2499) as the sheer number of tools and tool symptom combinations make comparison between studies difficult. Improved consistency in test use is important as this will allow for more nuanced and detailed comparisons across program models and funding jurisdictions, allow for a better understanding of how different treatment models influence different areas of child functioning, and lead to improved efficiency in the test selection and completion process for research participants. In summary, based on this review of the literature, one can conclude there is currently no single assessment measure that will capture all aspects of an intensive ASD treatment program, and a combination of consistently used outcome tools is of value.

Common intervention models and outcome tools for ASD

Measurement challenges have been documented for decades in the ASD treatment literature. For example, much of the literature for ASD treatment began with a seminal study by Lovaas (1987) who reported that up to 47% of preschool children diagnosed with ASD could achieve average scores on standardized measures of intelligence after receiving 40 hours per week of behaviourally based intensive intervention for at least 2 years. This model has been identified as the UCLA Young Autism Project (UCLA YAP) model and still influences much of the current ASD literature (Reichow & Wolery, 2009).

Lovaas (1987) used multiple instruments to evaluate treatment effectiveness including four different measures of intelligence that were combined into an IQ “estimate” of mental age, direct recording of behaviour and language, and post intervention classroom placement at 6 or 7 years of age. The pre-measures of intelligence were diverse and the Vineland Social Maturity Scale (Doll, 1953), an earlier version of the VABS, was used to estimate the mental age for participants that were deemed to be untestable. Post treatment measures were equally diverse and included up to six different cognitive measures, with unclear rules for allowable test substitution.

Jordan, Jones, and Murray (1998) and Howlin (1997) identified numerous measurement shortcomings of Lovaas (1987) including 1) the use of different measures before and after treatment, 2) measures that may not reflect important areas of difficulty in addressing ASD, 3) non-adherence to standard assessment protocols, 4) lengthy delays between program delivery and outcome assessment, and 5) the use of prorated mental age, a psychometrically weak metric. Eikeseth (2001) responded to these criticisms by identifying 1) that no one single IQ test covers the age range needed for lengthy interventions, 2) there is high overlap of up to 75% between ASD and mental retardation (citing Lord & Schopler, 1989), 3) the standardized process used would have penalized higher IQ scores, biasing against the intervention group, 4) the lengthy delay between intervention and final testing would also bias against the intervention group, and 5) that ratio IQ is a conservative measure of this construct. Despite these methodological and practical concerns, the same tools and methodological challenges continue to be present in many current studies, and researchers continue to report benefit for the children with ASD that participate in the UCLA YAP model (e.g., Cohen, Amerine Dickens, & Smith, 2006; Howard, Sparkman, Cohen, Green, & Stanislaw, 2004).

In addition to the UCLA YAP behaviour based model, developmentally influenced ASD models also exist, though these models are less prominent in the research literature. These models include the Treatment and Education of Autistic and Related Communication Handicapped Children [TEACCH] (Mesibov, Shea, & Schopler, 2005), the Early Start Denver Model [ESDM] (Dawson et al., 2009), the Joint Attention and Symbolic Play / Engagement and Regulation [JASP/ER] (Kasari, Freeman, & Paparella, 2006), and inclusive classroom models such as Learning Experiences and Alternative Program for Preschoolers and Their Parents [LEAP] (Strain & Bovey, 2011) or the Children's Toddler School [CTS] (Stahmer & Ingersoll, 2004). No review or critique of the outcomes measured used to evaluate these models has identified whether measurement concerns parallel those found in the behaviourally oriented intervention research.

Purpose and aims

This review builds on the previous body of work related to measurement issues in ASD treatment effectiveness literature by systematically identifying and recording the degree to which documented measurement concerns continue in published ASD literature evaluating treatment effects. Ethical practice guidelines established by the American Educational Research Association, American Psychological Association, & National Council on Measurement in Education (AERA, APA, & NCME, 1999) are used to identify strengths and weaknesses in clinical assessment and reporting requirements. We focus specifically on comprehensive, community based (i.e., that reference a preschool, nursery, home or other community setting), outcome effectiveness, group based design ASD studies for young children, as this is where treatment effectiveness is ultimately demonstrated. Given the high volume of ASD studies, those that are single subject design, instrument related reviews, parent education programs, diagnostic studies, or general program descriptions are excluded. Specific aims are to: 1) identify whether the earlier criticisms of instrument usage (Howlin, 1997; Jordan, Jones, & Murray, 1998) in initial ASD efficacy studies have been resolved, 2) identify the dominant instruments used to measure ASD treatment gains and evaluate their construct validity as primary measures for ASD, and 3) develop a standardized checklist to evaluate strengths and weaknesses in test administration, use and reporting requirements for ASD program effectiveness based on a best practice framework for evaluating tool selection, the *Standards for Educational and Psychological Testing* (AERA, APA, & NCME, 1999).

Method

Best practices framework for evaluating tool selection and use

In order to guide the measurement evaluation process, a best practice framework that guides psychological and educational instrument selection and utility for program outcomes was adopted. This framework was guided by the fourth version of the *Standards for Educational and Psychological Testing* (AERA, APA, & NCME, 1999). The *Standards* provides minimum guidelines around test development and test use to ensure ethical assessments, jointly published since 1966, to improve ethical test use and evaluation practices (Plake & Wise, 2014). The topics addressed in the *Standards* include: 1) establishing and reporting validity and reliability evidence, 2) test administration and scoring, 3) establishing and using norms and performance standards and their accompanying cut scores, 4) the use of tests for individuals with disabilities, 5) the responsibilities of test users, and 6) the use of tests in educational and program evaluation settings.

The *Standards* has an entire chapter devoted to testing individuals with disabilities. The following guidelines are highlighted for the present review:

10. 1 In testing individuals with disabilities, test developers, test administrators, and test users should take steps to ensure that the test score inferences accurately reflect the intended construct rather than any disabilities and their associated characteristics extraneous to the intent of the measurement.

10.7 When sampling sizes permit, the validity of the inferences made from test scores and the reliability of scores on tests administered to individuals with various

> disabilities should be investigated and reported by the agency or publisher that makes the modification.
>
> 10.9 When relying on norms as a basis for score interpretation in assessing individuals with disabilities, the norm group used depends upon the purpose of the testing. Regular norms are appropriate when the purpose involves the test taker's functioning relative to the general population. If available, normative data from the population of individuals with the same level or degree of disability should be used when the test taker's functioning relative to individuals with similar disabilities is at issue.
>
> 10.12 In testing individuals with disabilities for diagnostic and intervention purposes, the test should not be used as the sole indicator of the test taker's functioning. Instead, multiple sources of information should be used. (AERA, APA, & NCME, 1999, p. 106-108)

Search procedures and selection criteria

The databases Ebscohost, PsycInfo, Medline, and ERIC were searched for English language studies published from January 2002-June, 2015. Keywords were “Community”, “Intervention”, “Treatment”, “Outcome”, “Preschool” and “Autism” in various combinations. These keywords were chosen in line with the focus of this review on: (1) preschoolers and young children, 6 years of age and under, (2) diagnosed with ASD, (3) receiving community or school based (e.g. daycare, nursery, kindergarten, external service provider or explicit reference to a community based intervention in the study description) intervention, and (4) where the intervention had been evaluated. The rationale for concentrating on children 6 years of age and younger is that many publicly funded ASD treatment programs focus on early intervention and on providing treatment as soon as possible after receiving an ASD diagnosis. A total of 247 potential studies were initially identified. Specific inclusion and exclusion criteria are referenced in Figure 1.

Abstracts for all studies were screened and those that focused on single subject design, older children, parent training, program descriptions and diagnostic studies were excluded. Though single-subject design comprise a large portion of the scientific evidence for ASD treatment evaluation (Wong et al., 2014), these studies were excluded as these designs do not typically use normative, standardized assessment to evaluate treatment effectiveness, and it is these tools that are the focus of this evaluation. Based on inclusion screen, 38 studies met our criteria. Seven additional studies were identified through a manual search of the reference lists of these studies. Therefore, a total of 45 studies met our inclusion and exclusion criteria and are identified in the reference list. Figure 1 depicts our search strategy, reflecting the diverse range of research designs (5 randomized controlled trials, 25 pre-post studies with at least one comparison group, and 15 pre-post studies only) and participant groups (12 countries of origin). American studies were the most frequently reported (USA = 15/45 or 33.33%) followed by the United Kingdom (7/45 = 15.56%) and Canada (6/45 = 13.33%). Other countries with lesser representation were Norway, Israel, Australia, Sweden, Italy, Turkey, Singapore and China.

The studies were evaluated in two ways to determine the appropriate use of standardized tests and test reporting. In the first level of analysis, all outcome instruments were identified in each paper independently and organized by category into one of the following major theoretical constructs: 1) adaptive, 2) cognitive, 3) behaviour / ASD, 4) language / social communication, or 5) family wellness. Though ASD diagnostic scales overlap both language / social communication and behaviour, ASD tools were combined with the behavioural scales as behavioural features are inclusive of all current ASD classifications, as opposed to language ability (APA, 2013). Tools were classified based on reviewing the publishers test manual or test publisher's website, with agreement between the authors, who are registered health professionals, each with a minimum of 10 years of ASD testing experience in their respective discipline (psychology, speech language pathology, and occupational therapy). Two researchers are university faculty and one researcher supervises ASD treatment in a community setting. Normative information, where applicable, was also obtained for each tool in this same manner. Disagreements were resolved by reviewing the testing manuals directly or through consultation with other ASD researchers. Once the purpose of each test was identified, as well as the underlying measurement constructs and normative information, they were organized into a master spreadsheet to allow for comparability across all of the studies.

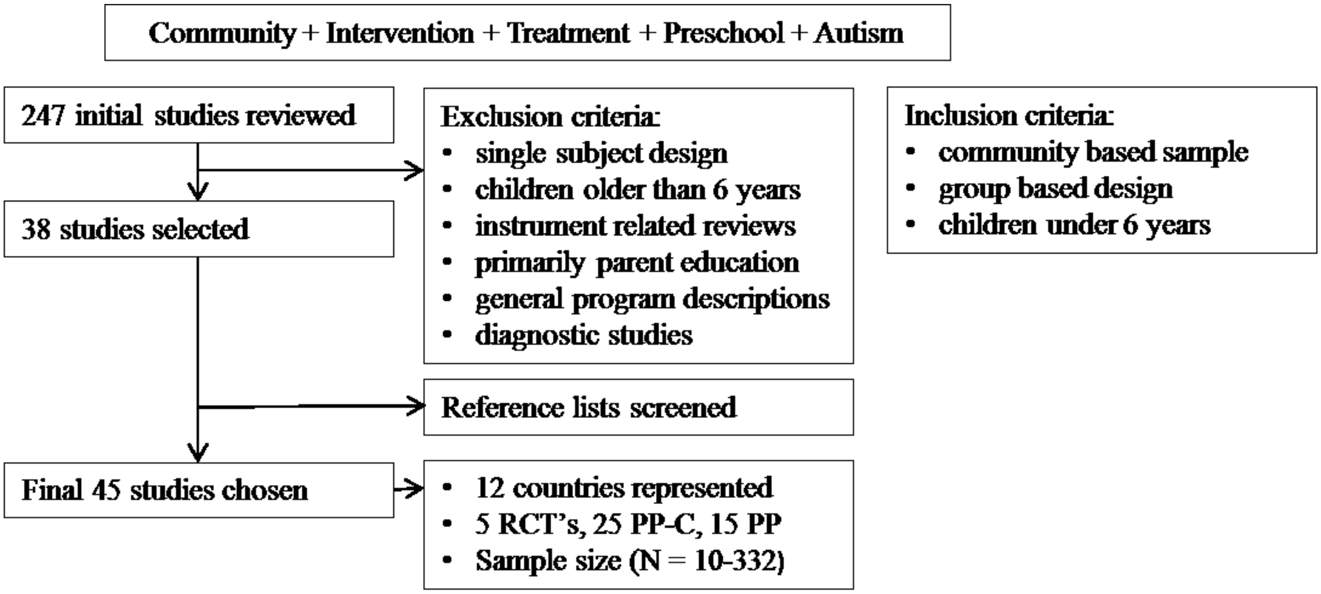

Figure 1: Systematic process for study selection. RCT = randomized controlled trial, PP-C = pre-post design with comparison group, PP = pre-post with no comparison group.

Instrument usage was rank ordered by percentage of studies reporting the instrument used as an outcome measure. For some of the instruments, different versions (e.g., WPPSI II or WPPSI III), or normative age groups (e.g., WPPSI III or WISC IV) were grouped together by the researchers, making it impossible to separate them exactly for detailed reporting. In these situations, instruments were grouped according to their published and underlying construct similarity.

For the second level of analysis, a standardized checklist of recommended test use reporting and administration recommendations based on the *Standards for Educational and Psychological Testing* (AERA, APA, & NCME, 1999) was developed. The checklist was designed over a 2-year period with input from all of the chapters of the *Standards*, particularly for reliability and validity reporting, but special attention was given to Chapter 10 where specific standards are identified for the testing of children with disabilities. The process for developing the checklist, listed in Figure 2, was an iterative process involving feedback from multiple health care professionals and researchers, each with unique expertise in ASD and testing. A copy of the checklist is provided in Table 2. As shown for each item, the chapter and standard are identified in brackets (e.g., 10.2 refers to Chapter 10, standard 2).

Based on the recommendations in Chapter 10 of the *Standards*, as well as input from Gould et al. (2011) on the necessity of comprehensive outcome tools that target early childhood development, it was decided that a minimum of three independent sources of information was necessary to capture this outcome standard. Specific attention was paid to evaluating how well the tests were linked to the underlying diagnostic construct of ASD, how well the sample population was described and matched to the instruments, and if test users reported on reliability,

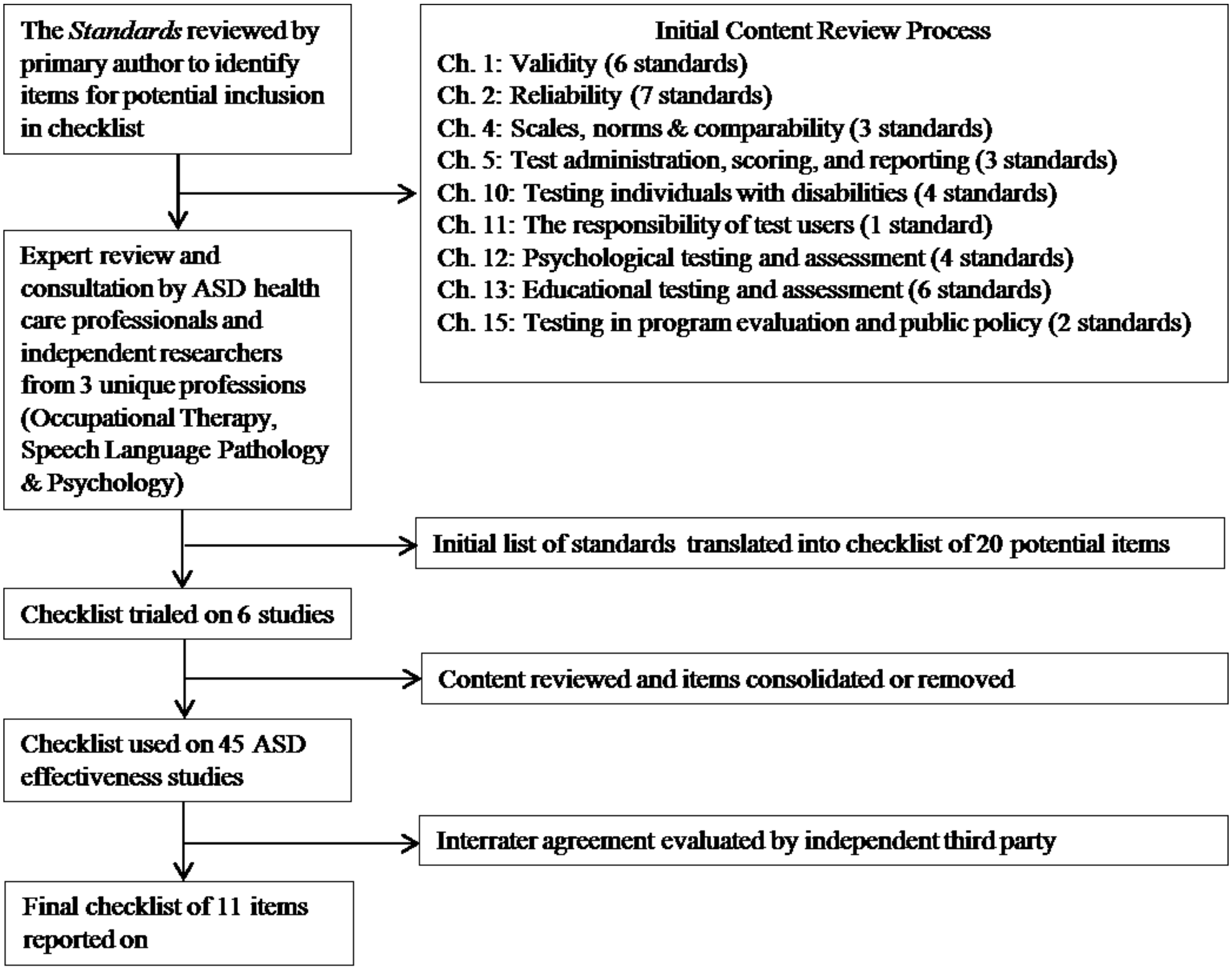

Figure 2: Content review and selection process for Standards checklist.

validity, administration protocols, modifications, test bias, and minimum training requirements. As the use of different cognitive tools at pre and post-test was identified as an area of concern by Matson (2007), this particular practice was also evaluated.

The checklist was piloted on six studies and then revised with input from two other senior ASD researchers to ensure it was accurately capturing the intended domains of interest and that there was agreement on the correspondence between the *Standards* and the chosen evaluative criteria. After finalizing the checklist, all 45 studies were initially reviewed by the primary author, with each study coded prior to any compilation of the results. After all studies were reviewed, a neutral research assistant was trained in the coding schematic by modeling its use with one study, and then coded ten randomly chosen studies independently. Item by item inter rater agreement using a third party blinded rater was calculated by separate analysis on 22.22% of the studies as a representative sample (10/45). Inter rater agreement (IRR) of 89.1% was reached on the final eleven quality indicators (range 0.70 – 1.0). Two items of lower agreement (IRR = 0.70) included reporting on minimum assessor training and technical qualities of the instruments, reflecting the complexity of appraising this quality in some of the studies. Those items of high agreement (IRR = 1.0) included identifying multiple sources of information, clearly describing the sample population, coding assessor blindness to treatment condition, and reporting on modification of standardized administration procedures. Disagreements were resolved through a third, independent review by an additional member of the research team, which was deemed as consensus.

Results

Instrument classifications

For the first level of analysis, each study was reviewed and all of the outcome instruments identified, resulting in a total of 53 different standardized outcome instruments. However, similar to findings by Bolte & Diehle (2013), 24/53 (45.28%) instruments appeared in only one study. As the purpose of this review is to provide an overview of those tools commonly being used in the ASD effectiveness literature only the 21 instruments that appeared in a minimum of three studies are listed in Table 1. When tabulating summative data by theoretical construct, all reported uses of that tool were included in the final calculations, even if the instrument is not listed in Table 1. As shown, the instruments are organized in terms of five major constructs: 1) adaptive (1 instrument), 2) cognitive (7 instruments), 3) language / social communication (6 instruments), 4) behaviour / ASD scales (7 instruments) and 5) family wellness (1 instrument). Each study was systematically coded to identify instrument representation from each of these five underlying constructs. Additionally, the name of each instrument, normative group, underlying construct measured, focus of the administration, and frequency of reported use are reported.

Adaptive functioning was the dominant theoretical construct upon which outcomes were reported, with 39/45 (86.67%) of studies reporting an adaptive measurement tool for treatment evaluation. However, for the adaptive group, this was dominated by one tool – the VABS (Sparrow et al, 2005) as this was the primary tool in the vast majority of the studies, appearing in 36 of the 45 studies (80.0%). The VABS is a standardized parent report measure of adaptive functioning in the areas of communication, socialization, daily living and motor skills. Depending on the specific form used, caregivers or teachers are asked to rate the independence of functioning in a variety of observable skills in a developmental sequence for a specified child.

Cognitive measures were the second most frequently reported outcome instruments with 37/45 (82.22%) of studies reporting use of at least one cognitive tool. For the cognitive measures, the Bayley Scales of Infant Development [Bayley II] (Bayley, 1993); [BSID III] (Bayley, 2006) was most frequently used (16/45 or 35.56%), an expected finding given the target population. The Weschler scales [WPPSI III] (Weschler, 2002); [WISC IV] (Weschler, Kaplan, Fein, Kramer, Morris, Delis, et al., 2004) were reported for 28.89% of the studies and the Mullen Scales of Early Learning (Mullen, 1995) for 26.67%. However, in many of the studies different cognitive tools were combined to generate an "IQ estimate", making it impossible to differentiate the tools from each other. The other cognitive instruments were reported with less frequency.

Table 1

Description, frequency and utilization of most frequently reported standardized outcome tools

Adaptive (39/45 = 86.67%)

	Normative Group	Construct Representation	Administration Target	Frequency
Vineland Adaptive Behavior Scales (VABS, VABS-2)	0-89 years	Communication Socialization Daily Living Motor	Parent Report	36/45 (80.0%)

Cognitive (37/45 = 82.22%)

	Normative Group	Construct Representation	Administration Target	Frequency
Bayley Scales of Infant Development (BSID-II, BSID-III)	1-42 months	Mental Scale Motor Scale	Child	16/45 (35.56%)
Weschler Scales (WISC-III, WISC-IV, WPPSI-III)	WPPSI – 3-7 years WISC – 6-16 years	Verbal Comprehension Perceptual Reasoning Working Memory Processing Speed	Child	13/45 (28.89%)
Mullen Scales of Early Learning	1-5 years	Cognitive ability Motor ability	Child	12/45 (26.67%)
Merrill-Palmer	18 months-4 years	Cognitive Language Motor	Child	10/45 (22.22%)
Stanford-Binet (SB-IV or SB-V)	2-23 years	Verbal Reasoning Abstract or Visual Reasoning Quantitative Reasoning Short Term Memory	Child	8/45 (17.78%)
Differential Abilities Scale (DAS)	2:6 – 17:11 years	Verbal Ability Nonverbal Ability Nonverbal Reasoning Ability Spatial Ability	Child	4/45 (8.89%)
Griffiths Mental Development Scales – Extended Revised (GMDS-ER)	2-8 years	Locomotor Personal Social Language Eye Hand Coordination Performance Practical Reasoning	Child	3/45 (6.67%)

Behaviour / ASD Specific (32/45 = 71.11%)

	Normative Group	Construct Representation	Administration Target	Frequency
Autism Diagnostic Observation Scale (ADOS)	Toddler to adults	4 modules of up to 14 interactive activities that reflect underlying ASD symptoms	Child	10/45 (22.22%)
Achenbach Child Behavior Checklist	1.5-18 years	Social competencies Behavioural and emotional problems	Parent Report	8/45 (17.78%)
Childhood Autism Rating Scale (CARS I or II)	2 years +	Child rated on 15 items associated with ASD on 7 point scale	Child	5/45 (11.11%)

Autism Diagnostic Interview (ADI-R)	Mental age of 2 years +	Language/Communication Reciprocal Social Interactions Restricted, repetitive, and stereotyped behaviours and interests	Parent Interview	3/45 (6.67%)
Gilliam Autism Rating Scales (GARS 1 or 2)	3-22 years	Stereotyped Behaviours Communication Social Interaction	Parent Report	3/45 (6.67%)
Psychoeducational Profile (PEP-3)	6 months – 7 years	Communication Motor Maladaptive Behaviours	Child	3/45 (6.67%)
Social Responsiveness Scale	4-18 years	Social Awareness / Social Cognition Social Communication / Social Motivation / Restricted Interests & Repetitive Behaviour	Parent / Teacher Report	3/45 (6.67%)

Language / Social Communication (23/45 = 51.11%)

	Normative Group	Construct Representation	Administration Target	Frequency
Reynell Developmental Language Scales	1-6 years	Verbal Comprehension Expressive Language	Child	9/45 (20.0%)
Preschool Language Scales (PLS-III, PLS-IV)	0-6.11 years	Auditory Comprehension Expressive Communication	Child	6/45 (13.33%)
MacArthur Bates Communicative Inventories (CDI)	8-37 months	Words and Gestures Words and Sentences	Parent Report	6/45 (13.33%)
Early Social Communication Scales	8-30 months	Nonverbal Communication	Child	5/45 (11.11%)
Expressive One Word Picture Vocabulary Test (EOWPVT 3, 4)	2-95 years	Expressive Language	Child	3/45 (6.67%)
British Picture Vocabulary Scale	3-16 years	Receptive Vocabulary	Child	3/45 (6.67%)

Family Wellness (7/45 = 15.56%)

	Normative Group	Construct Representation	Administration Target	Frequency
Parenting Stress Index	Parent 18-60 years Child 1 month-12 years	Parent Functioning Child Functioning	Parent Report	7/45 (15.56%)

Note: Measurement tools had to be used in at least 3 independent studies to be reported in this table. Due to substitution and overlapping tool use in each study, total instruments reported may not always add up to the overall construct represented. For each theoretical construct, the number reported is inclusive of all instruments grouped in this category, even if not listed directly in the table.

Standardized tools measuring language and social communication skills, which are core deficits in ASD, were only reported in 23/45 (51.11%) of the studies. Researchers often relied on parent report measures of the VABS communication and socialization subscales, or inferred language development from other indirect measures as a means of capturing these theoretical constructs. Of those studies that did measure this construct directly, the Reynell Developmental Language Scales (Reynell & Gruber, 1990) was reported in 9/45 (20.0%) of studies, followed by the Preschool Language Scales [PLS 4] (Zimmerman, Steiner, & Pond, 2002) and MacArthur Bates Communicative Inventories [MCDI] (Fenson et al., 1993) in 13.33% of studies; and the Early Social Communication Scales (Mundy, Hogan, & Doelring, 1996) in 11.11% of studied. Other language measures were reported with less frequency.

For tools measuring broad ASD symptomology or behavioural concerns, 32/45 of studies (71.11%) included tools measuring these theoretical constructs. The Autism Diagnostic Observation Schedule [ADOS] (Lord, Rutter, DiLavore, & Risi, 1999) was the most commonly reported outcome tool, used in 10/45 (22.22%) of the studies. This was followed by the Child Behavior Checklist (Achenbach, 1991) used in 8/45 (17.78%) and the Childhood Autism Rating Scales [CARS] (Schopler, Van Bourgondien, Wellman, & Love, 2010), reported by 5/45 (11.11%) of researchers. Other ASD and behaviour specific tools were reported with less frequency. Family wellness was primarily represented by one instrument, the Parenting Stress Index [PSI] (Abidin, 1995) in 7/45 (15.56%) of studies.

In order to gain a better understanding of how researchers were combining instruments to formulate the construct of ASD, construct combinations were also evaluated. Reflecting the history of instrument use with this population, 33/45 (73.33%) of studies reported using both a cognitive and an adaptive outcome measure, 24/45 (53.33%) used a cognitive, adaptive and behavioural/ASD measure, 12/45 (26.67%) used cognitive, adaptive, behavioural/ASD and direct communication measures, and 4/45 (8.89%) included a family wellness measure in addition to all of these other constructs.

Adherence to reporting requirement of the Standards

The checklist developed as part of the present study was used to assess the quality of the evaluation reporting as described by their authors. Table 2 provides the number of studies that met criteria for each aspect in the checklist, with each item referenced to a particular standard and also identifies the overall study adherence to the *Standards* guidelines for best practice test use. Inter rater agreement for each coding item is also reported.

A wide range of strengths and weaknesses were identified. In terms of strengths, sampling population descriptions were consistently described (95.56%), tests chosen were usually linked to underlying ASD diagnostic constructs (88.89%), normed on or designed for persons with ASD (73.33%) and multiple sources of information were used to measure child outcomes (91.11%) providing support for content and construct validity in the tests chosen. The latter finding provides good evidence of adherence to Guideline 10.12 that states "in testing individuals for diagnostic and intervention purposes, the test should not be used as the sole indicator of the test takers functioning. Instead, multiple sources of information should be used" (AERA, APA, & NCME, 1999, p. 108).

The reporting of technical information on test use was much weaker. The researchers often provided descriptive information on the tests selected, but fewer provided additional technical details (20.0%), and many did not identify why that particular test had been chosen over another. In terms of test administration, scoring, and reporting, only 57.78% reported minimum user training and qualifications. Many studies made vague reference to an assessor being part of the research team, but did not identify qualifications. Adherence to standardized

Table 2

Quality indicator checklist of test selection, reliability, validity, administration and reporting

	Studies Met Criteria Ratio	Studies Met Criteria Percentage	Interrater Agreement Percentage
Test Selection, Reliability and Validity			
Multiple sources of information used to evaluate outcomes (10.12)	41/45	91.11	100
At least one outcome test, or combination of tests used, are clearly linked to autism and its underlying diagnostic constructs (1.1, 10.1)	40/45	88.89	80
At least one test is normed on or designed for the ASD population (1.2, 10.1, 10.9)	33/45	73.33	90
Test Administration, Scoring and Reporting			
Composition of sample population clearly described (1.5)	43/45	95.56	100
Same version of the tests are used pre and post on all measures (4.16, 13.17, 15.3)	28/45	62.22	90
Minimum assessor training or qualification reported (13.10)	26/45	57.78	70
Assessors are reported as independent of treatment (12.2)	21/45	46.67	90
Technical qualities of each test used are reported (13.2)	9/45	20.0	70
Assessors are reported as blind to treatment condition (12.2)	8/45	17.78	100
Standardized administration procedures are followed and reported (5.1)	3/45	6.67	90
Modifications of standardized administration are reported (5.2)	1/45	2.22	100

Note: Numbers in brackets denote reference in the *Standards* by chapter and subsection (e.g. 10.2 refers to Chapter 10, standard 2)

protocols and modifications was significantly under reported with only 3 studies (6.67%) reporting protocol adherence and only 1 study (2.22%) reporting any modification of standardized procedures. No testing modification is unlikely as many of the child direct tools are verbally directed cognitive tools for an often non-verbal population and ethical test administration requires accommodation for sensory or motor deficits (Sattler, 2001). It is common to have a behavioural aide or parent present in the room to ensure behavioural compliance for children with ASD, and if this occurred, it should be documented. Exceptions to accommodate a disability can be made (Standard 5.1) though these exceptions should be reported.

Another test administration concern was that of test bias. Standard 12.2 states “those who select tests and interpret test results should refrain from introducing biases that accommodate individuals or groups with a vested interest in decisions affected by the test interpretation”

(AERA, APA, & NCME, 1999, p. 131). Only 46.67% of assessors were clearly independent and only 17.78% were reported as blind to group assignment. A substantial majority of the assessments were completed by project lead clinicians or members of the research team with a vested interest in finding positive results for their programs. These assessors introduce potential for bias into the administration, scoring and reporting of test results, thereby leading to potentially non-valid interpretations of the results and findings.

Finally, a significant weakness in test administration was identified regarding the use of the same group of tests for both pre- and post measurement of results. Only 62.22% of the studies clearly documented that the same instruments were used for pre- and post measurement of child ability, and this was primarily due to substitution of different cognitive tools to derive an IQ “estimate”, particularly when some of the children were non compliant with traditional verbally delivered intelligence measures. Some studies used up to six different cognitive tools with no regard for differences in their underlying constructs, pooled the data together, and provided few technical details, such as concurrent validity studies, to support their substitution. On occasion, IQ was also derived via the ratio method (MA / CA X 100) using tools such as the VABS (Sparrow et al, 2005), a psychometrically weak means of estimating IQ, with little supportive evidence for calculating the construct in this manner.

Discussion

The purpose of this paper was to provide a critical measurement review of recent community effectiveness outcome studies of treatments for young children with ASD to identify 1) if early criticism of instrument usage in ASD efficacy studies have been resolved, 2) to report on the dominant instruments used to measure ASD treatment gains and evaluate their construct validity as primary measures for ASD, and 3) to develop a standardized checklist to evaluate strengths and weaknesses in ethical test use and reporting.

Issues of adaptive measurement

Based on the outcome studies reviewed in this paper, the VABS (Sparrow et al., 2005) was the most frequently reported instrument to provide a measure of outcome. The VABS is a parent report measure of development that provides standardized and age equivalency scores on the domains of communication, socialization, daily living skills, and motor skills. An optional maladaptive behaviour index is also available, though use of this scale was rarely reported. The most recent version of the VABS was normed on 3,695 children and adults, ages 0-90, and stratified by gender, race/ethnicity, community size, socioeconomic status, and geographic region to correspond to 2001 United States census data (Sparrow et al., 2005). Hence, the VABS has strong psychometric properties. Sattler (2001) reports internal consistency reliabilities that range from 0.86 to 0.98, test retest reliability of .94, and inter rater reliability of 0.73 on the composite scores. Though VABS norms have been published for children with ASD on an earlier version of the instrument (Carter et al., 1998), none of the studies reported using those norms. Despite these strong psychometric properties, the VABS was not normed on children with ASD, and as a primary outcome tool would be inadequate in isolation from other instruments. Updated norms for children and adults with ASD for the most current version of the VABS would be of benefit given its high rate of use.

Additionally, the possibility of systemic measurement bias is high as the entire domain of adaptive behaviour is being measured by only one instrument. It is possible that different results may be found if the underlying constructs of adaptive behaviour were measured in different ways. Other published adaptive measures with strong psychometrics and normative data should be considered, such as the Scales for Independent Behavior – Revised [SIB R] (Bruininks, Woodcock, & Hill, 1996) or the Adaptive Behavior Assessment System, 3rd Edition [ABAS 3] (Harrison & Oakland, 2015). Reporting and use of multiple adaptive tools will increase the concurrent validity of this theoretical construct across ASD effectiveness studies.

Issues of cognitive measurement

Cognitive measures were used in 37 of the 45 studies, continuing the trend identified by Matson (2007) that there is an implicit expectation that most ASD studies include measures of intelligence. However, it does not appear that many of the earlier criticisms of cognitive assessment of children with ASD have been resolved, as 37.78% of the studies continued to use multiple measures of cognitive ability with little regard for different underlying theoretical models of cognition and their associated subtests. For example, some intelligence tests have a strong emphasis on verbal aspects of intelligence (e.g., the WISC IV), whereas others do not (e.g., the Leiter R). Further, little reporting was done on tool modifications. Three main issues emerged regarding the use and reporting of cognitive tools.

The first issue concerns child improvement inferences made from IQ score increases. Sternberg (1986) identifies four major factors that influence performance on intelligence measures: biological, cognitive, motivational, and behavioural (as cited by Sattler, 2001, p.151-152). Of these four factors, motivational and behavioural issues can influence test scores and hence lead to invalid interpretations. Motivational influences are directly related to the level of interest displayed towards the testing material. Behavioural factors include the level of cooperation and participation in the testing process. As this relates to the measurement of intelligence, it is not clear what portion of intelligence score change can be attributed to motivational or behavioural functioning, as opposed to an actual change in underlying cognitive ability. Few of the reviewed studies discussed this interplay of cognitive and behavioural factors, a major potential confound for the preferred interpretation of increased ability. Future studies should evaluate potential interaction effects between motivational and behavioural factors to better control their influence.

A second issue is that of test substitution. Nearly 40% of the studies used multiple intelligence measures for pre- and post measurement of child progress, which substantially increases the possibility of measurement error as each test is based on a unique theoretical model of intelligence, and those models are not always identical. Test substitution presumes that they are the same. However, though cognitive tasks within each test overlap, they are not identical. For example, measures of intelligence for younger children often emphasize a motor component, whereas intelligence tests for older children generally do not. Measures also vary on the degree to which they focus on memory, visual processing tasks, language processing tasks, and processing speed as central constructs contributing to overall IQ. Sattler (2001) indicates that the wide number of published intelligence tests reflects the ongoing debate and disagreement on what constitutes the core underlying factors for intelligence.

Regardless of the preferred cognitive model selected, it is recommended that future researchers ensure that comparative tasks are used pre- and post treatment to measure child outcomes. Eikeseth's (2001) contention that no one cognitive tool spans the necessary age span for long term programs accurately describes the dilemma researcher's face in their choice of instruments. Nonetheless, this dilemma does not dismiss the need to provide supporting information on comparability of tasks across time.

One means to address this issue is for researchers to report on index performance in addition to measures of general intelligence. This reporting will benefit other researchers and may provide insight into the specific cognitive tasks that improve as a result of intervention. For example, the WISC IV (Weschler et al., 2004) has a Verbal Comprehension Index (VCI), a Perceptual Reasoning Index (PRI), a Working Memory Index (WMI) and a Processing Speed Index (PSI). It makes sense to report general intelligence scores if child performance increases across all indices. However, if child performance only increases in one index, then identifying measures more representative of that underlying construct, such as a direct language measure, is more sensible. In parallel, the VCI may be a more appropriate measure rather than the full cognitive score when communication skill is the primary target of a particular ASD intervention. The *Standards* references this in the following:

> 13.3 When a test is used as an indicator of achievement in an instructional domain or with respect to specified curriculum standards, evidence of the extent to which the test samples the range of knowledge and elicits the processes reflected in the target domain should be provided. Both tested and target domains should be described in sufficient detail so their relationship can be evaluated. The analyses should make explicit those aspects of the target domain that the test represents as well as those aspects that it fails to represent (AERA, APA, & NCME, 1999, p. 145).

Unfortunately, none of the studies reviewed in this paper reported on specific indices of performance. This was in part due to the mixing of instruments with little regard for their different underlying theoretical foundations.

A third issue relates to the use of intelligence in particular as an outcome measure for ASD treatment. Intelligence has a long history of being used as a primary outcome measure in ASD studies (Lovaas, 1987; Matson, 2007), yet it is not clear how well the intelligence construct, in isolation from other tools, maps onto current understandings of ASD. Moreover, the *Standards* indicates that “a rationale should be presented for each recommended interpretation and use of a test score, together with a comprehensive summary of the evidence and theory bearing on the intended use or interpretation” (p. 17). With recent revisions to the Diagnostic and

Statistical Manual of Mental Disorders (i.e., DSM 5; APA, 2013), the primary constructs for ASD are social communication impairments across multiple contexts, paired with the presence of restricted, repetitive patterns of behaviour, interests or activities that interfere with daily functioning. As mentioned, the construct of intelligence varies widely, but often consists of some measure of verbal reasoning, which is a central focus of targeted ASD intervention. The relationship of visual problem solving, motor skills, and memory task development to ASD is less clear. Certainly, socialization and behavioural issues would only distally be measured by intelligence measures, making it uncertain whether cognition should continue to be utilized as a primary outcome measure for ASD treatment.

Issues of behavioural measurement

Despite behaviour being a central diagnostic construct of ASD, behavioural tools were under represented in this area of treatment effectiveness research. Approximately 30% of the studies reviewed did not include any measure of behaviour and the most commonly reported tool, the ADOS (Lord et al., 1999) may not be ideally suited as an outcome tool, given its design (see Aman et al., 2004). Those that did report on behaviour typically used indirect, parent report measures or standardized questionnaires, rather than direct behavioural observation of the child. The lack of direct measures of child behaviour is a concern as maladaptive behaviour can significantly interfere with classroom placement, daily functioning, skill acquisition, and social isolation. Further, maladaptive behaviour is a significant contributor to the stress of parents with a child diagnosed with ASD (Hall & Graff, 2010). Matson and Nebel-Schwalm (2007) completed a review of comorbid psychopathology for children with ASD and identified mood disorders, anxiety, obsessions, fears and phobias at much higher rates than the general population, constructs that are evaluated by many behaviourally based instruments, none of which would be captured by cognitive or adaptive tools. Gould et al. (2011) also recommends that behavioural functioning be considered in program evaluation. Future researchers should ensure that child direct standardized measures of behaviour are included in outcome based measurement protocols to ensure that this construct is targeted, evaluated, and its influence as a moderating variable is accounted for in the analysis. Five additional published behavioural measures with strong psychometric properties that should be considered, only one of which was identified in this review, are the Social Responsiveness Scale, 2nd Edition [SRS 2] (Constantino & Gruber, 2012), the Behavioral Assessment System for Children, 2nd Edition [BASC 2] (Reynolds & Kamphaus, 2006), the Pervasive Developmental Disorder Behavioral Inventory [PDDBI] (Cohen & Sudhalter, 2005), the Clinical Assessment of Behavior [CAB] (Bracken & Keith, 2004), and the Autism Impact Measure [AIM] (Kanne et al., 2014).

Limitations

A number of limitations are present in this measurement review. It is possible that our search strategy did not identify all relevant studies. Our findings are limited to comprehensive studies of intense intervention for children younger than 6 years of age, diagnosed with ASD, with an emphasis on receiving those treatments in community settings. Single subject designs were not included in this review, nor were studies evaluating specific program components effecting change. Inclusion of additional research areas and methodologies would yield a broader pool of studies that may yield different outcome tools and standards of practice in regards to their use of instrumentation. Finally, the quality indicator checklist that was based on the *Standards* was limited to those items that could be reliably coded, and consequently some ethical reporting requirements could not be fully captured (e.g., description of test settings).

Future Research and Clinical Implications

This paper critically reviewed 45 studies regarding the outcome measures used to evaluate the effectiveness of comprehensive, community based treatment for young children with ASD. Overall, it was identified that cognitive and adaptive measures continue to be the primary tools of outcome based measurement for this body of research. Behaviour, direct language, and social communication measures were less evident despite being diagnostic constructs for ASD. An emerging trend in more recent studies was to include a measure of family wellness.

A standardized checklist was developed based on the *Standards for Educational and Psychological Testing* (AERA, APA, & NCME, 1999) and studies were systematically evaluated on test use, reporting and administration. Positively, most studies used multiple sources of information, described their samples well, had tools representing each of the underlying diagnostic constructs associated with ASD, and used at least one test normed on or designed for the ASD population. However, multiple concerns were also identified including a lack of technical information for the tests used, justification for using those tests, reporting of minimum administrator training, reporting of test modifications and standardized assessment protocols, few controls for test bias, and the substitution of varying IQ measurements with little regard for their different underlying constructs.

When designing effectiveness studies in the future, researchers should ensure they are selecting multiple instruments that are reflective not only of cognitive and adaptive functioning, but also of the underlying social-communicative and behavioural constructs associated with ASD. This will allow for more nuanced analysis of the interplay between these variables. Researchers also need to be aware of the age parameters of the instruments selected, and particularly for cognitive tools, ensure they are using the same instrument pre- and post treatment. If the same instrument cannot be used due to increased age, researchers need to ensure the cognitive tasks are comparable. A separate concern exists in evaluating adaptive functioning. ASD researchers are overly reliant on one measure (i.e. VABS) and it would be of benefit to include other adaptive measures to ensure adequate representation of this construct is captured. Family measures may also be of value, particularly for evaluating covariates, and to identify ecological impacts of child treatment. Finally, researchers need to control for bias, report more directly on test modifications and minimum assessor qualifications, ensure that standardized protocols are followed and reported, and be more descriptive of the psychometric properties of the tests they have chosen to use. If researchers are able to agree on a common pool of measurement tools with strong psychometric properties, this will allow for better comparison across the ASD effectiveness literature.

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**Denotes study was included as part of the measurement evaluation*

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Chapter 4: Using LENA to evaluate a community based PRT parent training model for autism spectrum disorder: a pilot study[345]

Abstract

Background. ASD prevalence rates are now estimated to be 1 in 68. Though evidence-based practices (EBP) for ASD intervention exist, adoption of EBP is low in community practice. One promising intervention is Pivotal Response Training (PRT), an EBP that may be coached to parents in community.

Methods. Using a single-subject research design matched with new digital language processor technology (The Language Environmental Analysis system [LENA]), a community-based PRT parent training model in community practice is evaluated. Eighteen independent video and audio recordings of baseline, intervention and follow-up data are evaluated on child, adult, conversational turns, and ratio of child initiated conversational turns for one parent-child dyad over a 16-week period. Detailed descriptive information, fidelity of PRT implementation, and hypothesized relationships between training condition and communication patterns are appraised.

Results. A good program description of the training model was obtained. A functional relationship between adult talk and parent training participation was identified. Child talk and conversational turns increased post intervention. Parent talk frequency was observed to be inversely related to child talk frequency and requires further study.

Conclusion. The PRT parent training model is an EBP that holds promise for community-based implementation and the LENA is a useful adjunct evaluation measure, allowing for more in depth analysis of longitudinal communication patterns. Parent-child ASD communication patterns were identified in a reliable, valid and user friendly manner over time, using new

technologies, as they participated in this EBP parent training model, providing a window into communication patterns that would not be readily accessible without this technology.

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[4] A version of this chapter was accepted and published in a poster format as follows: Stolte, M. & Smith, V. (2016, May). *Using the Language Environmental Analysis System (LENA) to evaluate a community based pivotal response treatment (PRT) parent coaching model for autism spectrum disorder.* Poster session presented at the International Meeting for Autism Research: Baltimore, Maryland, USA.

[5] A version of this chapter was orally presented to the community as follows: Stolte, M. (2014, Sept). *Evaluating the effectiveness of a community-based PRT parent education program*, Oral presentation presented at the Glenrose Rehabilitiation Hospital Autism Research Rounds: Edmonton, AB, Canada.

Introduction

As Autism Spectrum Disorder (ASD) prevalence rates are now estimated to be 1 in 68 (Centres for Disease Control and Prevention, 2014) and because community settings are where the vast majority of children with ASD receive their primary treatment, there is increased pressure to disseminate evidence-based practices (EBP) into community settings in an efficient and efficacious manner. Unfortunately, despite significant government investment, the gap between research and practice continues to be large, especially for parent training programs that address early intervention needs (Oono, Honey, & McConachie, 2013). Parent training has long been recognized as an essential component of autism treatment (National Research Council, 2001) with demonstrated effects in enhancing parent-child relationship and improving the role of collaboration in treatment and goal setting leading to improved skill generalization (Burrell & Burrego, 2012). Parent training is particularly important for ASD treatments as it is well established that child language, often developmentally delayed in ASD, develops in response to both the quality and quantity of a child's language environment (Rowe, 2012) and that this environment varies widely across socio-economic status (e.g., Hart & Risley, 1995), birth order (e.g., Oshima-Takane, & Robbins, 2003), time of day and activity (e.g., Soderstrom & Wittebolle, 2013) and child care environment (e.g., Murray, Fees, Crowe, Murphy, & Henriksen, 2006). Consequently, it is of vital importance to include parents in early childhood intervention programs, where key pre-linguistic tasks such as the establishment of joint attention and reciprocal play are initially learned (Lieberman & Yoder, 2012).

Due to the importance of parent training, community partnerships are needed to better assess how parent training programs are delivered in these settings, and to create feedback systems that will not only add to the research evidence, but will also increase overall quality

(Stahmer, 2007). Dingfelder and Mandell (2011) criticize traditional models of EBP dissemination and argue there is a need to partner with end users of ASD treatment to improve adoption of EBP during all stages of treatment research, as effectiveness research can be delayed by as much as 20 years (e.g. Walker, 2004). Finally, Kasari and Smith (2013) indicate it is important to identify the key components of a intervention, to understand local variance, to use manuals that specify how to modify to local circumstances, to ensure goals are selected on meaningful outcomes, and to develop measures that "have relevance for children in their everyday lives that can be easily gathered in authentic environments" (p. 259).

Unfortunately, evaluating community-based programs is difficult. For example, gathering data is a time consuming and difficult task, particularly in home-based, natural environments, an understudied area of autism treatment (Wolery & Garfinkle, 2002). However, improved dissemination and evaluation of EBP may be eased through the use of new technologies, provided those technologies are reliable, valid and user-friendly. One potential system for evaluating autism support programs, The Language Environmental Analysis system [LENA] (LENA Research Foundation, 2016) is comprised of a digital language processor that uses proprietary software to analyze communication information on day-long audio recordings between a key child and others in their immediate environment (Xu, Yapanel & Gray, 2009).

The LENA Research Foundation (2016) reports that the LENA captures real time data on vocal patterns and transactions, and translates that data into visual graphs, timelines, and developmentally normed algorithms allowing for comprehensive data analysis. Additionally, the language processor is small, unobtrusive, and is worn by the child and has the potential to allow for a reliable snapshot of how a child-adult dyad is actually functioning in a naturalistic environment, without formal external observation that may be biasing their performance.

Warren, Gilkerson, Richards, Oller, Xu, Yapanel, and Gray (2010) analyzed the vocal patterns of young children with autism and found that during therapy time, increased child vocalizations (CV), conversational turns (CT) and adult word count (AWC) were demonstrated when compared to non-therapy time; and the LENA was sensitive enough to distinguish children with ASD from the typical developing population, based on their language patterns.

This pilot study aimed to bridge the gap between research and practice by partnering with a large community service provider in Alberta, Canada to gain an iterative and face valid understanding of community-based practice by 1) evaluating how that service provider delivers one model of efficacious practice, Pivotal Response Treatment [PRT] (Koegel, Schreibman, Good, Cerniglia, Murphy, & Koegel, 1989) in a parent training format and 2) evaluating the use of the LENA as an outcome and process tool to automatically analyze communication patterns between a key child with ASD and their parent to determine if this tool has potential as a user friendly, reliable, and valid measurement device in community-based evaluation.

PRT was chosen as the intervention model for evaluation as it is an EBP (National Autism Center, 2009; Wong, Odom, Hume, Cox, Fettig, Kucharczyk, Brock, et al., 2014) and implementation in community-based settings is under-reported. Encouraging results have been demonstrated in at least one Canadian province, Nova Scotia, suggesting this is one model of ASD treatment that should be given strong consideration (Bryson, Koegel, Koegel, Openden, Smith, & Nefdt, 2007; Smith, Koegel, Koegel, Openden, Fossum, & Bryson, 2010). Promising results were also demonstrated in a brief 6-hour training model of a waitlist group (Coolican, Smith, & Bryson, 2010) and a randomized controlled trial of a PRT based parent-training program was completed in Ontario with encouraging results (Brian, Smith, Zwaigenbaum, Roberts, & Bryson, 2016). Additionally, in the USA, successful implementation of PRT has been demonstrated by caregivers in both clinical settings (Randolph, Stichter, Schmidt, & O'Connor, 2011; Symon, Koegel, & Singer, 2006) and group settings (Minjarez, Williams, Mercier, & Hardan, 2011; Wang, Hardan, Boettcher-Minjarez, Berquist, Frazier, & Gengoux, 2012).

A pilot study format was chosen for this initial study to build trust with the provider and to determine if this model of evaluation was viable in this practice setting. A single-case methodology was chosen as it is an applied research design that can be used in natural settings while allowing for increased experimental control (Kazdin, 2011).

Building on the empirical support for PRT, the service provider designed a 12-week community-based PRT parent-training model that consisted of weekly training, a manualized curriculum, worksheets, fidelity measures and the use of in-vivo feedback on the 7 points associated with the model. The PRT parent-training model was based on materials provided by the Koegel Autism Centre (The Regents of the University of California, 2005) who developed a certificated training model for community service providers for individuals impacted by ASD. During the pilot study period, the service provider employed PRT Parent Educators who delivered the program to community families. Though this model was regularly delivered by the provider, it had never been formally evaluated in a research partnership.

The PRT Parent Educator was a community service provider staff who completed the Level 5 (Trainer of Trainers) criteria established by the Koegel Autism Centre. These criteria involved completion of PRT workshops, objective evaluation of fidelity of implementation on multiple children via objective video analysis, and specialized training in self-management, socialization, or initiations (The Regents of the University of California, 2005).

The pilot study was the first part of a two-phase study. In phase 1, the focus was on building trust with the provider, describing the training model, and demonstrating if the LENA could be used to efficiently capture parent-child communication. In phase 2, the results of the pilot will inform a larger study utilizing a non-concurrent multiple-baseline ABC across-participants single-subject design. This project is an extension of Patterson and Smith's (in review) research on evaluating efficacious community-based support models for children with ASD.

Specific research questions and hypotheses were as follows:

1) How well is the PRT parent training model being delivered in this community setting?

    Hypothesis A: The PRT parent training model will be implemented with fidelity resulting in improved parent PRT skills across participants.

2) Do child and parent communication patterns change as a result of participation in the PRT parent training model?

    Hypothesis B: The pattern of parent-child communication will change as a result of participation in the PRT parent training model.

3) Can LENA be used as an outcome measure in a community setting to inform program effectiveness?

Method

Participants

Participants were one parent-child dyad of a newly diagnosed female child (age 39 months) with Autism Spectrum Disorder and one parent education coach, a paraprofessional PRT Educator with specialized training in PRT employed by the community service provider. The child, Ava*, was diagnosed by the community hospital at 31 months of age using a multi-disciplinary team and was referred to the service provider for intensive government funded supports. Ava was the second sibling of an intact two-parent family, with the mother staying at home with the children and the father working in the trades. The mother was the focus of the PRT parent training program, though the father also participated in scheduled sessions when available. The mother reported previously completing modules from the Hanen "More than Words" program (Sussman, 1999) delivered by a community nurse, though not the full program.

File review indicated a formal diagnosis of Autism Spectrum Disorder. Supporting documentation included completion of the Autism Diagnostic Observation Scales, 2nd Edition [ADOS-2] (Lord, Rutter, DiLavore, Risi, Gotham, and Bishop, 2012) Module 1 with scores above the cut-off for autism with impaired joint attention, inconsistent eye contact, poor initiation of communication, repetitive behaviours, and significant delays in language and social communication. File review also indicated a moderate fine motor delay and significant sensory processing issues were noted by way of observation, particularly around body movement and awareness. Cognition was reported to be in the Low Average range, with an Age Equivalency of 25 months at 31 months of age, and adaptive skills as Severely Delayed with age equivalency scores ranging from 12 - 17 months of age. Language regression was reported at 11 months of age.

To augment diagnostic report information, baseline independent evaluation data was gathered on Ava by the community Speech Language Pathologist, who completed the MacArthur-Bates CDI [MCDI] (Fenson, Marchman, Thal, Reznick, and Bates, 2006) Words and Gestures form. At time of program entry, MCDI baseline results indicated expressive vocabulary of 15 words, use of 12 early gestures, use of 6 later gestures, and receptive understanding of 75 words and 19 phrases. A summary table of the child's diagnostic and baseline information including evaluation measures is presented in Table 3.

Table 3

Child and parent characteristics at baseline and time of diagnosis

Child	Gender	Diagnosis	Communication at Program Entry (39 months)	Cognitive Ability at Diagnosis (31 months)	Adaptive Skills at Diagnosis (31 months)	Motor Skills at Diagnosis (31 months)
Ava*	F	Autism Spectrum Disorder	15 words Expressive 75 words 19 phrases Receptive 12 Early Gestures 6 Later Gestures	Low Average 25 months (AE)	Severe Delay 12-17 months (AE)	Fine Motor Delay
Measures		ADOS-2[a] Module 1	MCDI[b]	BSID-III[c]	ABAS-2[d]	PDMS-II[e]

Parent	Gender	Age	Ethnicity / Primary Language in the Home	Highest Education	Current Profession	Marital Status
Jane*	F	33 years	Caucasian / English	College Degree	Domestic Caregiver	Married

*Pseudonyms; [a]Autism Diagnostic Observation Scale, 2nd Edition (Lord et al., 2012), diagnostic; [b]MacArthur-Bates CDI Words and Gestures (Fenson et al., 2006); [c]Bayley Scales of Infant and Toddler Development, 3rd Edition (Bayley, 2006); [d]Adaptive Behavior Assessment System (Harrison & Oakland, 2003); [e]Peabody Developmental Motor Scale, 2nd Edition (Folio & Fewell, 2000)

Study design

The study was conducted in partnership with a large, non-profit community-based service provider in a large metropolitan Western Canadian city. The service provider is an accredited rehabilitation facility for autism supports that has been in operation since 1997, has over 100 employees, and provides comprehensive home, school and community-based supports for individuals and their families impacted by autism. The service provider was consulted on the original study design, identified this particular program as benefiting from external evaluation, and provided written consent and access to the participants and program staff.

An ABC single subject research design was used to conduct the study. The three conditions are A = baseline, B = PRT training, and C = follow-up. The independent variable (IV) was training condition and the dependent variables (DV) were child talk, parent talk, and parent-child talk. It was hypothesized there would be a functional relationship between training condition and parent-child communication on these three automated LENA outputs.

Participants remained in the baseline condition for up to 2 weeks (pre-training), during which five independent 20 minute measures of child and parent communication data were collected in both audio and video formats in the child's natural environment, their home setting. After baseline data collection was completed, the parents began their regularly scheduled 60 minute weekly PRT parent education sessions, once per week, for 12 weeks. All sessions were audio and video recorded and detailed notes were taken on session topics, teaching formats, and any unusual interruptions or changes to the delivery format. Upon completion of the training, another five independent 20 minute measures of child and parent communication data were collected in the same format as the baseline condition, providing a total of up to 20 recordings for the analysis.

Parent training intervention

Parent training sessions. The parent received 12 weekly training sessions, in their home, by a PRT Parent Educator employed by the service provider who had completed formal training and certification in this model of practice, including demonstration of teaching efficacy and implementation of PRT treatment fidelity across multiple children. Two published training manuals associated with the PRT certification model were provided by the PRT Educator to the parents at the beginning of the training, with assigned readings associated with each visit: 1) *Teaching first words to children with autism and communication delays using pivotal response training* (Koegel et al., 2003) and 2) *Using pivotal response treatment to teach first words to children with autism* (Koegel PRT certification, n.d.).

Audio and video recordings. A handheld FLIP video camera was used to collect baseline, training and follow-up video for all training sessions. A LENA digital language processor (DLP) and specially designed shirt with a front mounted pouch to hold the DLP were purchased from the LENA Foundation and were used to collect the audio data. Both devices were turned on simultaneously at the beginning of each session to ensure recordings were aligned chronologically.

Child outcome measures

Communication and language. Two methods were used to evaluate child language and communication skills. The first was a direct measure of child vocalization (CV) activity during all three phases of the study using the LENA automated analysis system (LENA Research Foundation, 2016). A second supplementary measure included completion of the MCDI by an independent Speech Language Pathologist employed by the service provider during baseline and follow-up phases; a reliable and valid pre-post parent-report measure of a child's receptive and expressive language, including gestures (Fenson et al., 1993).

The LENA is an emerging technology and is a digital language processor that the child wears in special clothing for up to sixteen hours and the analytic software calculates key communication indicators including Adult Word Count (AWC), Child Vocalizations (CV), and Conversational Turns (CT) between an adult and a key child (Xu, Yapanel & Gray, 2009). The LENA has been used to evaluate individuals with ASD in other settings (Warren et al., 2010) and is reported to be a reliable and valid measurement tool, based on 70 hours of transcriptional analysis by trained coders, with concurrent agreement between 76 – 82% (adult and child word count respectively) between the transcribers and the LENA system (Xu, et al., 2009).

Algorithms for the LENA audio segmentation software categorizes sound around the key child into eight groupings: adult male, adult female, key child, other child, overlapping speech, noise, electronic media, and silence (Xu, Yapanel, Gray, & Baer, 2008) with accuracy approaching 99% for two full 12 hour recordings of AWC in quiet environments, though accuracy can diminish by up to 27% when in noisy environments with competing sounds (Xu et al., 2009). Given these research findings on the accuracy of the LENA, inter-observer reliability for this instrument was not calculated as is typically done in single subject designs.

Parent outcome measures

Fidelity of PRT implementation. PRT fidelity was independently assessed by a blinded, third party coder using a modification of the Symon (2005) protocol during the baseline phase, at Week 6 in the intervention phase, and then during two follow-up conditions, 4-days post training, and 9 days post-training. To assess PRT fidelity and consistent with service provider practice, 10-minute video samples of the PRT sessions were sent to the Koegel Autism Centre for manual coding according to a standardized one-minute rating checklist. Raters were blind to treatment condition and the order of videos was randomized. Fidelity in PRT was considered achieved when the parent reached the established criterion of 80% on each of the PRT domains. These include: a) gaining child attention, b) shared control, c) using child choice, d) use of multiple cues, e) provide natural and contingent reinforcement, f) intersperse easy and difficulty tasks, and e) reinforcement of communication attempts (Koegel, et al., 1989). Inter-coder reliability of the PRT fidelity was independently coded for 50% of the 10 minute samples by service provider staff and was reasonable (Krippendorff's alpha = 0.7257) though not as robust as expected.

Adult language. The LENA automated analysis system provides a summary of Adult Word Count (AWC) in five minute summaries across all treatment conditions. AWC is calculated by parsing out clear human speakers from other ambient noise, based on sound wave amplitude analysis, and only reports on those adult words that are “near and clear” to the child, with inter-rater agreement between adult vs. non-adult speaker classification reported at 88% (Gilkerson, Coulter, & Richards, 2008). To analyze AWC across all conditions, the 5 minute AWC average was calculated for each independent time measure, and then plotted across all conditions (baseline, intervention, and follow-up).

Parent-child outcomes

Conversational turns. This is an automated output created by the LENA software, available in five minute increments, and is based on an algorithm combining Adult Word Count (AWC) and Child Vocalizations (CV) that takes into account distal noise and the proximity of the adult to the key child (Gilkerson et al., 2008). Warren et al. (2010) operationally define conversational turns as “blocks of turn taking with another person bounded by 5 seconds or more of silence” (p. 37) and this was chosen as a proxy measure of interpersonal synchrony. Five-minute CV estimates were calculated by the LENA during all three conditions and then averaged for comparability across each independent data collection point.

Results

PRT parent training model description

All parent training sessions were audio and video recorded by the primary researcher, with the exception of the introductory meetings that involved signing the informed consent and providing a general introduction to PRT. Detailed notes were scribed during the teaching sessions and topics covered are listed in Appendix A, as they were presented to the parents.

These were compared with the seven principles of PRT published by Koegel et al., 1989. All topic areas were covered with the exception of multiple cues, a decision made a priori by the service provider based on the developmental presentation of the child, indicating this PRT program has sufficient implementation integrity to be representative of this model of practice. The observed parent completed 10/12 (80%) of scheduled sessions and missed sessions were not re-booked as per the service providers policy. Session length varied from 44 to 57 minutes.

PRT fidelity

Results are shown in Figure 3 and indicate that parental demonstration of PRT skills was observed, though full implementation fidelity was not achieved. PRT fidelity was demonstrated in only 2/7 (28.57%) of the skill domains and this was only during the follow-up session immediately following the completion of the training. Unfortunately, during the second follow-up observation, PRT fidelity had almost returned to the baseline condition.

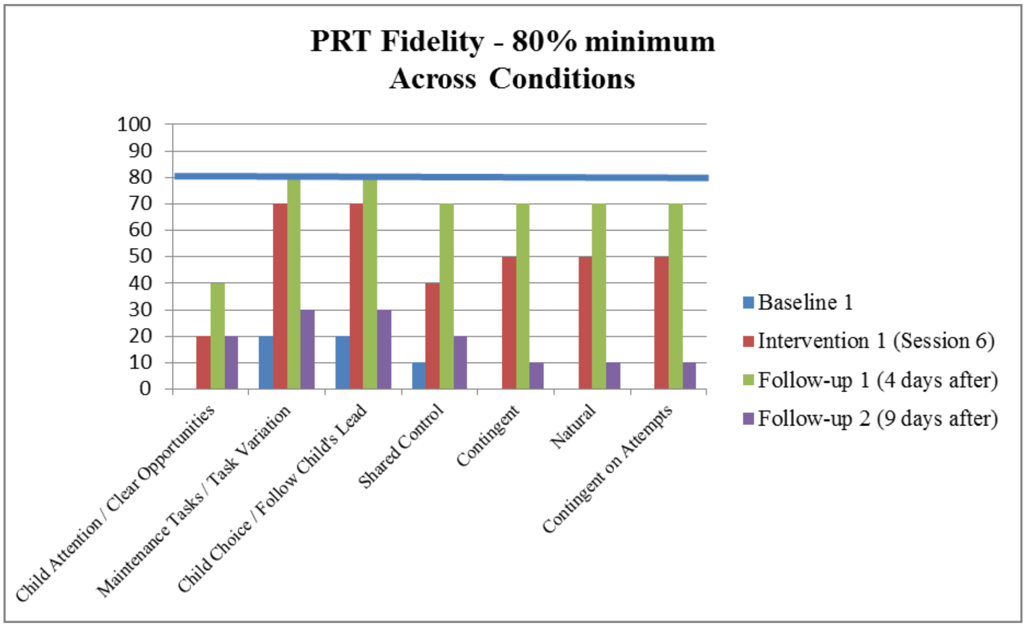

Figure 3: Parent achievement of PRT fidelity.

Changing child and parent communication patterns

Child talk. Child vocalization averages were calculated per 5-minute block, as reported by the LENA analysis software. For the baseline and follow-up sessions these were based on 20 minutes of parent-child interaction, whereas in the intervention sessions they were based on up to 60 minutes of data. Twenty minute blocks were chosen as a minimum block of time for each independent calculation to ensure reliability of the interpretative software, based on previous published analysis that the LENA demonstrates increased reliability as a function of time (Xu, et al., 2009) and to balance out time demands on the child and family participants.

Baseline stability of CV was moderate with some variability, though visual analysis indicated value in comparison across conditions. Trend analysis during all three phases indicated a slightly negative trend with reasonable stability during the baseline phase (A), a positive trend during the intervention phase with less stability, particularly right after the training started (B), and a flat trend during the follow-up phase with good stability. This suggests that on-going parent training was associated with a more stable child vocalization pattern, even when the training ended. To assess if change occurred between adjacent conditions (A to B, B to C) percentage of non-overlapping data (PND) was calculated using the process described by Scruggs and Mastropieri (1998). For child talk, PND comparing A to B was 50% (4/8 X 100), an unreliable effect, and comparing B to C was 100% (8/8 X 100), a clear and strong effect. To assess if change occurred as a result of program participation, PND was calculated between A and C and no effect was found at 40% (2/5 X 100). Results are visually displayed in Figure 4. Mean score calculations indicated higher CV in the baseline phase ($A\mu = 36.85$), decreased CV in the training phase ($B\mu = 24.27$) and an increase in the follow-up phase that was higher than baseline ($C\mu = 45.08$). Summary information on LENA outcomes across conditions is reported in Table 4 and mean scores across conditions are reported in Table 5.

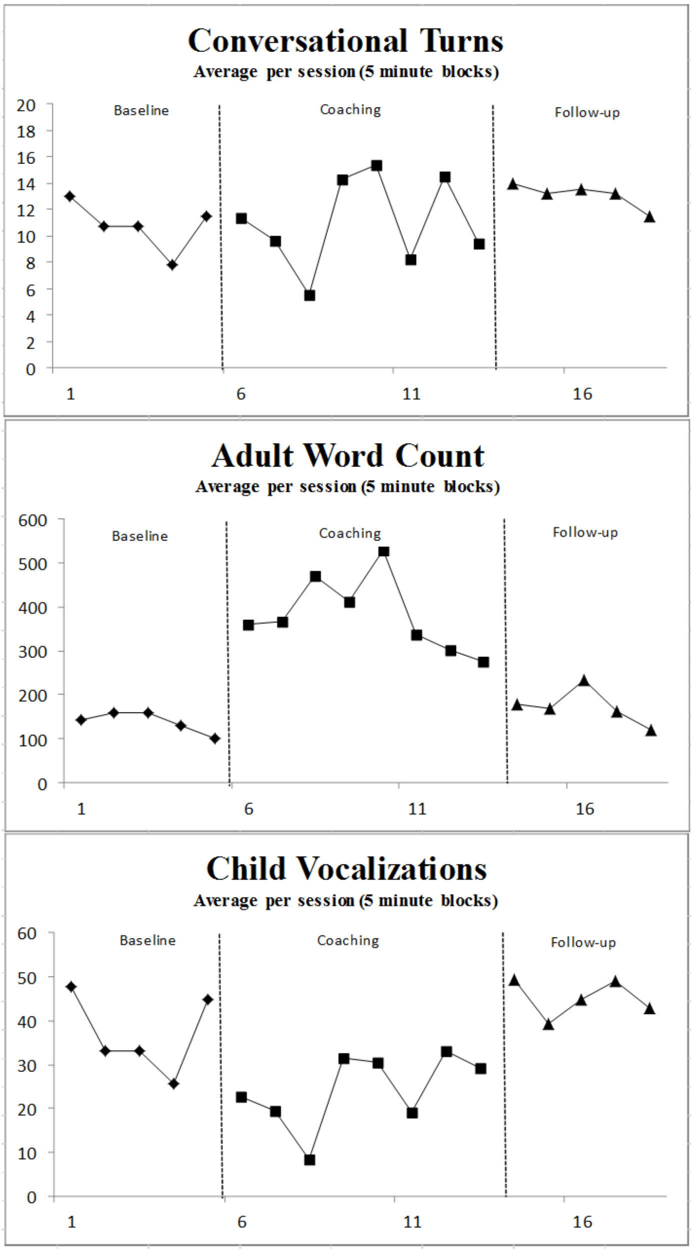

Figure 4: Parent and child communication change across conditions.

Table 4

Summary of LENA outcomes and effects across conditions

LENA variable	PND (AB)	Effect	PND (BC)	Effect	PND (AC)	Effect
CV	50%	No	**100%**	**Yes**	40%	No
AWC	**100%**	**Yes**	**100%**	**Yes**	**80%**	**Yes**
CT	37.5%	No	0%	No	**80%**	**Yes**

LENA variables: CV = child vocalizations, AWC = adult word count, CT = conversational turns. Research conditions: baseline (A), intervention (B), follow-up (C). PND = Percentage of non-overlapping difference (e.g. A/B X 100).

Table 5

Summary of LENA mean scores across conditions

LENA variable	Baseline (A = μ)	Intervention (B = μ)	Follow-up (C = μ)
CV	36.85	24.27	45.08
AWC	139.15	382.16	173
CT	10.75	11.04	13.02

LENA variables: CV = child vocalizations, AWC = adult word count, CT = conversational turns. μ = mean.

Parent talk. Adult word count (AWC) was calculated per 5-minute block, as reported by the LENA analysis software in the same manner as reported for CV. Visual analysis indicated a stable baseline was achieved. To assess if change occurred between adjacent conditions, PND comparing A to B was 100%, a reliable and strong effect, and comparing B to C was also 100%, a clear and strong effect. To assess if change occurred after program participation, PND was calculated for A to C and a moderate effect was found at 80% (4/5 X 100), suggesting adult talk did increase slightly once the intervention was completed. Results are visually displayed in Figure 5.

AWC was stable across all conditions and there was a clear effect on AWC between all three conditions. AWC was low in the baseline condition (AWC Aμ = 139.15, increased substantially in a clear and observable manner during the intervention phase (AWC Bμ = 382.16), and then decreased substantially when the parent training ended (AWC Cμ = 173), though maintained at a higher rate than in the baseline phase. This means that there was a substantial increase in “near and clear” adult words in the child’s proximity during the parent training phase, and that this effect maintained beyond the active training phase.

Parent-child talk. Conversational Turns (CT) were calculated per 5-minute block, as reported by the LENA analysis software in the same manner as reported for CV and AWC. Visual analysis and comparison across conditions indicated poor stability and no effects across conditions. Consequently, PND was not calculated for any comparisons. Calculation of the mean suggested a moderately positive increase in parent-child talk across conditions ($A\mu = 10.75$; $B\mu = 11.04$; $C\mu = 13.02$) but not in a manner that could be clearly attributed to the parent training condition.

Usability of the LENA

Manual comparison of LENA recordings and log notes for all sessions, including baseline and follow-up recordings, indicated 100% of active teaching sessions were captured by LENA. The five baseline recordings ranged from 22 minutes (m.) 43 seconds (s.) to 34 m. 17 s. in length, $\mu = 26$ m. 52 s., for a total of 2 hours 14 minutes 20 seconds. The eight teaching sessions ranged from 43 m. 58 s. to 57 m. 58 s. in length, $\mu = 51$ m. 48 s., for a total of 6 hours 54 minutes 27 seconds. The five follow-up recordings ranged from 21 m. 53 s. to 33 m. 28 s. in length, $\mu = 25$ m. 31 s., for a total of 2 hours 7 minutes 33 seconds. No errors by LENA were recorded or identified.

Supplementary measures

Child communication. Independent MCDI results by Ava’s speech language pathologist (SLP) indicated improvement on all aspects of child communication and are listed in Figure 5, though her scores were significantly below those expected for a child her age. Ava was reported to have an increased ability to understand phrases (+2), words (+63), to express words (+3), increased use of early gestures (+1), increased use of later gestures (+5), and an overall increase in gesture use (+5). No delays or regression were identified. Normative data was not calculated as this tool was developed for children ages 8-18 months of age, though this measure was selected as an appropriate measure of child communication by her community SLP.

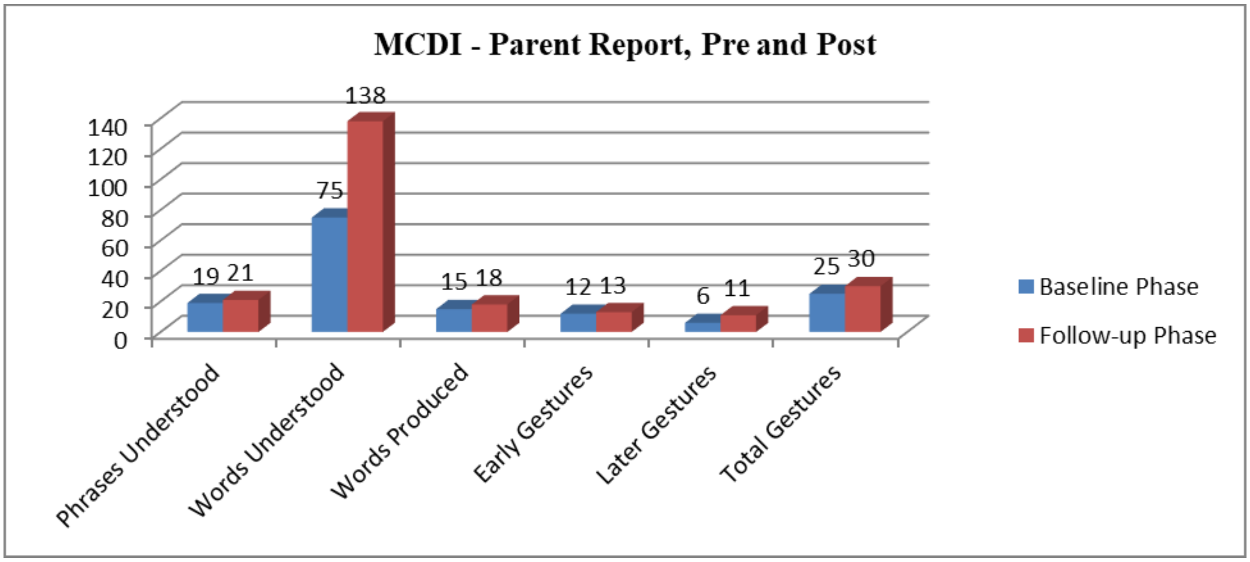

Figure 5: Changes in MCDI scores pre- and post.

Discussion

The purpose of this study was to 1) evaluate an efficacious model of parent training in community-based practice to determine whether this model could be effectively delivered within this setting and 2) to evaluate the use of a new digital language processor technology and its accompanying software (LENA) to determine if it could be used as an outcome tool in community-based practice in a reliable, valid and user friendly manner.

How well is the PRT parent training model delivered in this community setting?

The descriptive portion of this evaluation indicates this community-based PRT parent education model was delivered as intended when compared to theoretical descriptions of PRT and uses a wide variety of teaching modalities across its 12 weeks of parent training. The teaching format followed a predictable schedule that involved introducing a new topic, review of the previous session, live demonstration of the new skill with the child, live in-vivo coaching for the parent with the child, and summarized the session through formal notes. Video feedback was incorporated into two sessions. Session lengths were reasonably consistent averaging 52 minutes. This compares with Minjarez, Williams, Mercier, & Hardan (2010) with nine 90-minute group sessions plus one 50-minute individual session; Randolph, Stichter, Schmidt, & O'Connor (2011) with nine 45 to 55-minute training sessions plus one 30 minute overview, and Coolican, Smith, & Rogers (2010) with three 120 minute training sessions. However, in this community setting, contrary to what has been reported in the research literature, there were gaps in gathering data in the introductory sessions and two family cancellations that may have impacted the final results. This highlights a challenge with maintaining research fidelity in community settings. Additionally, a need was identified for more formal coding system of teaching methodology, topic, and parent-child interaction to better allow for systematic reporting of teaching content and process variables across conditions. This became particularly important for documenting the implementation of the teaching program in this community setting where fewer external controls were in place.

Do parents participating in this training model demonstrate PRT implementation fidelity?

Unfortunately, implementation fidelity was not achieved by the parent in this pilot study and this limited the interpretation of the results. Demonstration of parental skill improvement was observed and demonstrated in the presence of the coach, but did not consistently maintain once the coach was no longer present. Implementation fidelity was highest in the recordings immediately following the teaching sessions, and was strongest in the areas of child choice, following the child's lead and task variation. Providing clear opportunities was an area of weakness. The parent did have a college degree so educational background was not likely to have been a negative contributing variable to achieving PRT fidelity (see Randolph et al, 2011).

This contrasts with other PRT parent training models. For example, Minjarez, et al., (2010) provided a 10-week parent education package consisting of group and individual training and used similar 10 minute probes to gather fidelity data pre- and post training. They did not report on individual parental learning, or fidelity achievement on individual PRT domains, but provided summative fidelity data. Results demonstrated a statistically significant improvement in summative fidelity scores pre- and post training though no follow-up data was provided. In a later study using the same teaching format, Hardan et al., (2015) indicated a 80% criterion was required across six PRT domains in order to meet fidelity and after training, 21/25 parents met their fidelity level. No follow-up data was provided.

Randolph, et al., (2011) used a multiple baseline design to evaluate parental implementation of PRT after 10 training sessions, captured fidelity in every teaching session, and reported that two of the three parents were able to consistently demonstrate fidelity at the 80% level. Follow-up data was provided and did indicate stability of fidelity. Importantly, coders were not blinded to condition, nor were they independent of the study. In the current study PRT coders were both independent and blind to condition. Finally, Coolican et al., (2010) report on PRT fidelity for a brief, 6-hour parent training model for 8 parents of preschoolers with ASD. Fidelity was quantified slightly differently, averaged across five PRT strategies (clear opportunities, child choice, contingent, natural rewards, and reward attempts) with fidelity implementation of 75%. Five of the eight parents (62.5%) met fidelity in the post training phase and follow-up data was provided. Given these other studies, it seems reasonable that individual parents may not reach

PRT implementation fidelity within a brief PRT training model and additional time or an alternate teaching format may be required.

Do child and parent communication patterns change as a result of participation?

Results regarding the relationship between parent-child communication patterns and participation in the parent education model using the LENA reported findings were mixed. There was a clear increase in adult vocalization frequency during the teaching sessions that nearly returned to baseline once the teaching was completed. Child vocalizations were slightly less stable with a decrease during the training phase and then a rebound to moderately higher levels than baseline in the follow-up phase. Child vocalizations in general increased as the teaching proceeded and were modestly higher than baseline in the follow-up phase. A pattern of increased child vocalizations in response to PRT parent training is consistent with results reported by Coolican et al., (2010), Randolph et al., (2011), Minjarez et al., (2010) and Brian, Smith, Zwaigenbaum, Roberts, & Bryson (2015).

Conversational turns were less stable across all conditions precluding the establishment of a functional relationship, however there was a clear trend of increased frequency of conversational turn taking over time and as the teaching proceeded. Additionally, the frequency and stability of conversational turns was higher in the follow-up phase than in the baseline phase, suggesting that the training was having a positive impact. No specific studies of PRT parent training reported on this variable though Brian et al., (2015) reported an increase in adult responsivity, and shared smiling as a result of PRT training. Buckley, Ente, and Ruef (2014) reported that when parents were coached on select PRT strategies such as increased choice and task variation, child cooperation increased, as did overall reported family quality of life. This result would need to be replicated across multiple participants to be confirmed as a true effect.

LENA reports on simultaneous reporting of child and adult communication data allowed for an analysis of interactive effects between variables. Visual analysis over time and between communication patterns suggested an inverse relationship between adult and child language frequency. Notably, as adult vocalizations increased in the parent teaching sessions, a decrease in child vocalization frequency was observed, and then this pattern reversed during the follow-up condition. This type of effect would have been difficult to detect without the use of automated software such as LENA, given the large quantities of information. One possible interpretation is that the child may have been overwhelmed by all of the adult language stimuli and that this resulted in a corresponding decrease in language use during the teaching sessions. Another possible interpretation is that having multiple adults in the room multiplied the presence of adult language stimuli. This pattern of communication between child and adult communication partners is important information for program delivery staff and future studies should code parent-child-trainer interaction more systematically to allow for more nuanced analysis.

Can the LENA be used in a community setting to inform program effectiveness?

The utility of the LENA was supported through concurrent validity of the MCDI results by independent assessment of child vocalizations, and the LENA was found to be a useable and efficient tool for gathering complex communication data. The automated vocalization device was easy to use, reliable, and fit well into the accompanying clothing. Uploading the data into the interpretative software was also intuitive and resulted in readable and accessible color coded charts, by timeline, for CV, AWC and CT. Participation in a 2-hour training session was sufficient to learn how to use the LENA in this setting in its most basic reporting format. No errors were reported in the software and the charts were easy to interpret and understand.

The use of the LENA has been used to evaluate parent-child interactions for ASD and non-ASD children. Warlaumont, Richards, Gilkerson, and Oller (2014) used LENA to identify differences between ASD and non-ASD children and their parents by analyzing feedback loops in naturalistic communication settings. Suskind et al. (2015) used LENA to provide vocalization feedback for parent-child dyads on their communication patterns in their home setting and were able to demonstrate a positive impact on parent-child interaction. LENA holds promise as a user friendly, reliable and valid measurement tool of parent-child communication data in naturalistic settings, though requires further evaluation in community-based settings.

Future Research and Limitations

This study makes a number of important contributions to the literature. First, it demonstrates that the PRT parent education model, delivered in community practice holds promise, even though did not demonstrate the same strength of effect as seen in research settings. Second, it demonstrates a novel use of the LENA automated software package to measure the delivery process and outcomes to provide feedback for a community-based service provider for children with ASD. Third, it demonstrates that despite evidence of practices working in controlled or highly supervised settings, there may be a loss in quality control that impacts their effectiveness in the community (Smith, Scahill, Dawson, Guthrie, Lord, Odom, et al., 2007). This is of concern, as community service providers provide the majority of autism support services, particularly in Canada. Finally, this study completes the first phase of two-part study on using LENA to evaluate ASD community-based supports. Future effectiveness research in partnership with community providers is required to evaluate the impact these programs are having, particularly with multiple participants and settings.

Despite these promising results there are limitations. The first limitation is that LENA is an emerging measurement tool and there may be bias or errors as yet undetected. Second, true experimental control was limited as threats to internal validity (e. g. history and maturation) could not be fully accounted for. Finally, only one parent-child dyad was evaluated as they participated in the community program. This means effects observed have limited generalizability and further replication is required across parents, children, setting, and other educators. This study forms the foundation for future research that will evaluate if effects maintain across participants.

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Appendix A: Overview of Parent Training Sessions

Week 1: Introduction to PRT, goal confirmation & baseline data

Week 2: Capturing child attention and the natural environment (antecedent)

Week 3: Using child choice / shared control (antecedent)

Week 4: Providing clear instructions and questions (antecedent)

Week 5: Using natural rewards to shape behaviour (reinforcement)

Week 6: Connecting rewards and behaviour (contingencies)

Week 7: Mixing difficult and easy tasks (motivation)

Week 8: Responding to multiple cues (generalization)

Week 9: Integration and practice

Week 10: Integration and practice

Week 11: Integration and practice

Week 12: Wrap-up and summary

Chapter 5: Evaluating the effectiveness of a PRT community-based autism parent training program using LENA[67]

Abstract

Background. The gap between research and practice is wide despite increased awareness of the need to adopt evidence-based practices (EBP). A key component of effective ASD early intervention is parent training. This study extends pilot work on using the Language Environmental Analysis System (LENA), a new technology, to provide feedback on a PRT parent training model in community practice (Stolte & Smith, in preparation).

Objectives.

1. To provide a description of the implementation of a community based pivotal response training (PRT) parent training model and extend previous pilot study findings
2. To evaluate the effectiveness of the model on child, parent and parent-child interactional communication patterns
3. To evaluate the use of LENA as a new technology to measure program effectiveness in a real world setting

Method. Using a non-concurrent multiple-baseline single-subject across-participants research design, a community-based PRT parent training model was evaluated for pre-schoolers with ASD. Three parent-child dyads participated in a 5-week training model, 2 hours per week. Using LENA Advanced Data Extraction (ADEX) software, video analysis, standardized communication measures and PRT fidelity coding, baseline, intervention and follow-up data were evaluated on child talk, adult talk, and conversational turns. Detailed child and parent information, PRT fidelity, implementation integrity, and functional relationships between training condition and communication patterns are appraised.

Results. A program description and detailed parent and child information was obtained. Parent PRT skills improved for all parents though only one met full fidelity. A functional relationship between the frequency of adult language use and training condition was clearly identified for two of the three dyads indicating that parent talk increased during the presence of a trainer and decreased when the trainer was no longer present. A functional relationship between conversational turn taking, child vocalizations and training condition could not be established. Visual analysis identified child talk and turn taking improved for one child, whereas for the other two dyads child talk and turn taking was highly variable across conditions.

Conclusions. Findings revealed that the PRT parent training model holds promise for community practice. By using new technology paired with single subject design methodology, detailed communication information and functional relationships were evaluated over time. All parents demonstrated improvement in PRT skills though fidelity was inconsistent. Analysis of LENA data also indicated distinct parent-child communication patterns between dyads. This study demonstrates the importance of evaluating EBP in community settings and how new technologies, such as LENA, can support this objective.

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Introduction

The gap between research and practice is wide despite increased awareness of the need to adopt evidence-based practice (EBP) in the support and treatment of children and adults with autism spectrum disorder [ASD] (Dingfelder & Mandell, 2011). ASD is a neurodevelopmental disorder characterized by deficits in social communication paired with rigid, repetitive behavioural mannerisms (American Psychiatric Association, 2013). Adding further urgency to the need to bridge research and practice, diagnostic rates have increased from 1 in 5000 in 1975 to an estimated 1 in 68, a substantial increase in the last 40 years (Centres for Disease Control and Prevention, 2016).

Despite a lack of clarity on the exact type and amount of treatment required to support individuals with ASD, EBP for ASD are well documented and published standards exist (National Research Council, 2001; National Standards Report, 2015; Hume & Odom, 2011). As one example, Smith & Iadarola (2015) provide a summary of the evidence base for ASD interventions for children 5 years of age and under, limiting their review to studies of high quality. Based on this review, two interventions were identified as “well established”, three as “probably efficacious” and five as “possibly efficacious”. Smith and Iadarola also identified that the foundation for EBP arises out of two primary theoretical orientations for ASD: applied behaviour analysis (ABA), developmental social-pragmatic (DSP) and models that are comprised of both orientations.

In a parallel line of inquiry, Schriebman, Dawson, Stahmer, Landa, Rogers, McGee, Kasari, et al., (2015) describe the merging of applied behaviour analytic techniques and developmental sciences as Naturalistic Developmental Behavioural Interventions (NDBI), and indicate these merged models of care represent the current best practice standard for young children with ASD. Core components of NDBI's include a focus on the full range of child development, an emphasis on the child as well as caregiver interactions, and the embedding of development-enhancing strategies within everyday activities and routines. NDBI's have common features such as use of the antecedent-response-consequence contingency model, manualized practice, fidelity of implementation criteria, individualized treatment goals, on-going measurement of progress, child-initiated teaching episodes, environmental arrangement, use of natural reinforcement, use of prompting and prompt fading, modeling, and use of adult imitation for desired child language, play or body movements. As cited by Schriebman et al., child focused NDBI's are supported with evidence from several randomized controlled trials [RCT] (e.g. Dawson et al., 2010; Kasari et al., 2010; Yoder & Stone, 2006; Wetherby et al., 2014) as well as controlled, single-subject and quasi-experimental studies (e.g. Ingersoll & Dvortcsak, 2006; Ingersoll et al., 2005; Stahmer et al., 2011; Stahmer & Ingersoll, 2004).

Though preliminary evidence is just emerging, NDBI's can also be successfully delivered with a focus on parent training, such as an RCT completed in the United Kingdom (Green et al., 2010; Pickles et al., 2016) and the Social ABC's parent training model, based on PRT delivered in Canada (Brian, Smith, Zwaigenbaum, Roberts, & Bryson, 2015). PRT is considered a naturalistic intervention based on ABA principles (Brian et al., 2015) and hence is considered an NDBI (Schreibman et al., 2015). PRT also has well established foundation of effectiveness research that indicates it can be successfully integrated into community practice both at a child treatment level (Mohammadzaheri, Koegel, Rezaee, & Rafiee, 2014; Smith, Flanagan, Garon, & Bryson, 2015; Smith, Koegel, Koegel, Openden, Fossum, & Bryson, 2010) and at a parent training level (Brian et al., 2015; Minjarez, Williams, Mercier, & Hardan, 2011). In research settings, PRT as a parent training model has also been identified as efficacious using a randomized controlled trial, the highest level of research evidence available (Hardan, et al., 2015).

Despite the available evidence and agreement around the core components of ASD early interventions, adoption of EBP in community practice is low. Dingfelder and Mandell (2011), in their application of diffusion of innovation theory (Rogers, 2003), articulate that the adoption of EBP is often low due to 1) a failure of understanding local circumstance and situational variables, 2) a failure of researchers to partner with end users of treatment models, and 3) a failure of researchers to clearly articulate the relative advantage of EBP. Dingfelder and Mandell propose that if researchers offered more simplified program uptake models that recognize the complexity administrators often face when trying to disseminate new models of practice there would be better adoption of EBP in community settings. Metz, Halle, Bartley, & Blasberg (2013) indicate improved dissemination and adoption of EBP is more likely when implementation drivers such as staff and supervisor core competencies, organizational systems, capable leadership, and technical knowledge are aligned. Building on this line of argument, Kasari and Smith (2013) identify that the provision of clear manuals with explicit instruction on key ingredients of change can greatly increase uptake of EBP, as can the utilization of community-partnered participatory research that adapts research models to community settings.

A final barrier to adoption of EBP is that of measurement. As described in Stolte, Hodgetts, and Smith (2015) in their review of measurement tools across 45 ASD treatment studies, there is a lack of consensus on measurement, frequently the tools chosen do not map well onto ASD diagnostic constructs, and there is an under representation of behavioural, ASD-specific, language, social communication, and family wellness tools. Similar issues were identified by Bolte and Diehl (2013) who reported that of 289 unique measurement tools across

195 prospective ASD treatment studies, the vast majority (61.6%) were only used once, confirming the lack of consensus regarding measurement in ASD intervention research. Further, it has been noted by others (Gould, Dixon, Najdowski, Smith, & Tarbox, 2011), that standardized tools, the benchmark for reliable and valid measurement, are expensive and time intensive to administrate, creating a substantial barrier to uptake in community practice.

One means of building bridges between measurement and practice is to identify new technologies that are easier and less costly to use in community settings yet provide reliable and valid feedback on core ASD constructs. One emerging technology is the Language Environmental Analysis system (LENA), a digital language processor that records child-parent vocal interactions and then the accompanying analytic software that calculates child and adult communication variables in 5 minute, 1 hour, daily, or monthly increments (Xu, Yapanel & Gray, 2009). The LENA captures real time data on vocal patterns and transactions, and applies an algorithm to translate the audio data into visual graphs and timelines, allowing for comprehensive time efficient data analysis, as well as comparison to developmental norms (LENA Research Foundation, 2016). The LENA has been used with the ASD population in home (Warren et al., 2010) and preschool settings (Dykstra, et al., 2013) and is a promising tool that requires further evaluation in community settings.

Stolte & Smith (in preparation) describe how the LENA was used to evaluate PRT parent training over 12 weeks in a community-based setting in Western Canada. Results from the pilot study indicated LENA was a promising technology, effectively detecting changing communication patterns for one parent-child dyad across training conditions. Video measures indicated that parent fidelity of PRT skill improved, and positive child improvement was demonstrated by standardized evaluation. However, there were limitations as only one parent-child dyad participated in the study and despite significant improvement in the core skills associated with PRT, parents did not demonstrate full fidelity of PRT implementation. Readers are encouraged to consult the original study for a full review of the initial study design and findings as these significantly informed the current study.

The present study is an extension of the pilot and builds on the study design and key findings. The specific research questions with two key hypotheses are:

1. How well is the PRT parent training model being delivered in this community setting?

   Hypothesis A: The PRT parent training model will be implemented with fidelity resulting in improved parent PRT skills across participants.

2. Do child and parent communication patterns change as a result of participation in the PRT parent training model?

   Hypothesis B: The pattern of parent-child communication will change as a result of participation in the PRT parent training model, and communication patterns identified in the pilot study will be replicated.

3. Can LENA be used as an outcome measure in a community setting to inform program effectiveness?

Method

Participants

Participants were three parent-child dyads of newly diagnosed young children with ASD and one parent education trainer, a registered Speech Language Pathologist with specialized training in Pivotal Response Training (PRT) employed by the community service provider. Two of the children were diagnosed by the community hospital with ASD using a multi-disciplinary team and a standardized evaluation process (JIK, HIK). The third child (KIP) was diagnosed at a separate site in a different provincial jurisdiction though file review indicated similar standardized tools and multi-disciplinary team evaluation. All children were formally diagnosed through completion of the Autism Diagnostic Observation Scales, 2nd Edition [ADOS-2] (Lord, Rutter, DiLavore, Risi, Gotham, and Bishop, 2012).

The children were a range of ages, sex, ethnicity, caregivers and language reflecting the diverse community served by the community provider. For example, all children were exposed to a second language in the home in addition to English. JIK was 2 years, 7 months at time of entry to the program, male, and his family spoke Punjabi at home. HIK was 4 years, 2 months at time of entry, female, and the family spoke Urdu at home. KIP was 4 years, 11 months at time of entry, male, and his family also spoke Punjabi at home. Two of the families were intergenerational with grandparents living in the same home and taking on some of the parenting responsibilities while the biological parents worked outside of the home. All of the children had at least one sibling.

All the children had been referred for intensive home-based supports, funded through the provincial government. Families were offered the option of participating in the research portion of the program by the supervisor of the team that worked directly with the child and family, and if they indicated interest, they were referred to the research team for further information. In all communication with the families it was clearly stated that the research was optional and not a required component of the service delivery. The primary researcher applied inclusion and exclusion criteria criterion for study acceptance. Inclusion criteria for the child included an Autism Spectrum Disorder diagnosis confirmed by the Autism Diagnostic Observation Schedule (ADOS) - considered a "best practice" standard in autism diagnosis (Gotham, Bishop, & Lord, 2011) as well as a developmental age of at least 18 months and a chronological age of 6 years of age and under. Child exclusion criteria included any other major medical, genetic or physical conditions (Down's Syndrome, Fragile X Syndrome, deafness, blindness, etc.) beyond the autism diagnosis as PRT was being evaluated as an autism therapy. Inclusion criteria for the parent included no previous experience with the PRT training model and a willingness to participate in the research project. Parental exclusion criteria included a poor understanding of spoken English, low interest in learning the PRT parent training model, prior experience with PRT, or an inability to access provincially funded services through the community provider. In two of the dyads, the mothers were the focus of the PRT parent training program (HIK, KIP) and the father was the focus in the third dyad (JIK).

At time of program entry, all three children had considerable delays in their language development, though JIK and HIK were more delayed than KIP. By parent report, JIK was reported to use 0 words expressively, to understand 110 words and 16 phrases receptively, and use 6 early gestures and 14 later gestures from a standardized list. HIK was reported to use 16 words expressively, to understand 76 words and 19 phrases receptively, and use 9 early gestures and 33 later gestures. KIP had better developed language and was reported to use 455 words expressively, though did not talk about past events, point to objects consistently, use word endings appropriately, and sentence complexity was underdeveloped.

Diagnostic file review of all three children is listed in Table 6 and indicates the results of formal evaluation by the multi-disciplinary team in the regional settings. Age of diagnosis ranged from 2 years (JIK / HIK) to 3 years, 6 months of age (KIP). JIK was able to enter formal programming shortly after the diagnosis (6 months) whereas for KIP and HIK there were considerable delays – 18 months and 23 months respectively. File review also indicated borderline (JIK / HIK) to low average (KIP) cognitive ability and extremely low adaptive skills (< 1st percentile) for all three children. Communication subscale scores on the ABAS-3 at time of

Table 6

Child and family characteristics at diagnosis and time of program entry

Child	Gender	Diagnosis	Age at Diagnosis	Cognitive Ability at Diagnosis	Adaptive Skills at Diagnosis	Age at Program Entry	Communication at Program Entry	Adaptive Skills at Program Entry
JIK*	M	ASD	24 months	Borderline 17 months (AE)	Extremely Low 1st percentile	30 months	0 words Expressive 110 words 16 phrases Receptive 6 Early Gestures 14 Later Gestures	Extremely Low 2nd percentile
HIK*	F	ASD	27 months	Borderline 20 months (AE)	Extremely Low 1st percentile	50 months	16 words Expressive 76 words 19 phrases Receptive 9 Early Gestures 33 Later Gestures	Extremely Low <1st percentile
KIP*	M	ASD	41 months	Low Average 25 months (AE)	Extremely Low <1st percentile	59 months	455 words Expressive 0 Word Forms / Endings 3.7 ML3 Sentence Complexity 7/37	Extremely Low <1st percentile
Measures		ADOS-2[a]		BSID-III[c]	ABAS-2[d]		MCDI[b]	ABAS-3[e]

Child	Gender	Parental Role	Age	Siblings	Languages Spoken in Home	Highest Education	Current Profession	Marital Status
JIK*	M	Father	35	1 Sister	Punjabi / English	University	Professional	Married
HIK*	F	Mother	33	1 Sister 1 Brother	Urdu / English	Not Reported	Homemaker	Married
KIP*	F	Mother	36	1 Sister	Punjabi / English	University	Customer Service	Married

[*] A pseudonum; [a] Autism Diagnostic Observation Scale, 2nd Edition (Lord et al., 2012), diagnostic; [b] MacArthur-Bates CDI Words and Gestures (JIK/HIK) or MacArther-Bates CDI Words and Sentences (KIP) (Fenson et al., 2006); [c] Bayley Scales of Infant and Toddler Development, 3rd Edition (Bayley, 2006); [d] Adaptive Behavior Assessment System (Harrison & Oakland, 2003); [e] Adaptive Behavior Assessment System (Harrison & Oakland, 2015).

program intake indicated severe delays for all children (JIK = < 1 percentile, scaled score = 1; HIK = < 1 percentile, scaled score = 1; KIP = < 2.2 percentile, scaled score = 3).

To augment diagnostic report information, baseline and follow-up independent evaluation data was gathered on all three children by the community Speech Language Pathologist (SLP), who completed the MacArthur-Bates CDI [MCDI] (Fenson, Marchman, Thal, Reznick, and Bates, 2006) Words and Gestures form for two children (JIK / HIK) and the Words and Sentences form for one child (KIP). These assessments were completed at time of program entry and then once the training program was complete. A summary table of parent information as well as the children's diagnostic and baseline information including evaluation measures is presented in Table 6.

Study design

A non-concurrent multiple-baseline ABC single-subject across-participants design was used to evaluate the effectiveness of the PRT parent training program. The three conditions were A = baseline, B = PRT training, and C = follow-up. The independent variable (IV) was training condition and the dependent variables (DV) were child talk, parent talk and parent-child talk. It was hypothesized there would be a functional relationship between training condition and parent-child communication on these three automated LENA outputs.

Participants remained in the baseline condition for up to 3 weeks (pre-training). During this time, multiple recordings were collected. Each individual recording was a minimum 20 minutes of child and parent communication in both audio and video formats. To allow for controlled comparison across participants and conditions the frequency of baseline recordings were systematically lengthened consistent with non-concurrent multiple baseline methodology

(Gast, 2010). JIK had two baseline recordings, HIK had three baseline recordings, and KIP had four baseline recordings.

After baseline data collection was completed, the parents began their regularly scheduled 60-minute parent training sessions, twice per week, for 5 weeks. All sessions were audio and video recorded with live attendance by the first author or a research assistant (RA).

Upon completion of the parent training curriculum, an additional three independent 20 minute measures of child and parent communication data were collected in the same format as the baseline condition, providing follow-up data. All videos and supporting documentation identifying recording time and dates were reviewed by the first author to identify missing or conflicting information and 100% of the recordings were accounted for. A total of 47 independent recordings were available for the final analysis (KIP / HIK = 16 each; JIK = 15).

Parent training intervention

Parent training model description. The parent received 10 twice-per-week 60 minute training sessions, in their home, by a parent trainer employed by the service provider who had completed formal training and certification in PRT, including demonstration of teaching efficacy and implementation fidelity across multiple children. Two published training manuals associated with the PRT certification model were provided by the parent trainer to the parents at the beginning of the training, with assigned readings associated with each visit: 1) *Teaching first words to children with autism and communication delays using pivotal response training* (Koegel et al., 2003) and 2) *Using pivotal response treatment to teach first words to children with autism* (Koegel PRT certification, n.d.).

The topics covered in each sessions are summarized and listed in Appendix A and were compared with the seven principles of PRT published by Koegel et al., 1989. All topic areas were covered with the exception of multiple cues, a decision made a priori by the service provider based on the developmental presentation of the children. This suggests this PRT program has sufficient implementation integrity to be representative of this model of practice.

Two of the dyads completed 100% of the scheduled sessions (10/10) whereas one dyad completed 90% (9/10). Missed sessions were not re-booked as per the service providers policy. Session length varied from 35 to 68 minutes (HIK, $\mu = 59.30$, range 54 - 68; JIK $\mu = 47.70$, range 35 – 56; KIP $\mu = 53.22$; range 47 - 63).

Audio and video recording. All training sessions were both audio and video recorded. A Sony “Handycam” digital video camera mounted on a small tripod was used to collect video and the LENA digital language process (DLP) was used to collect audio. Both devices were turned on simultaneously at the beginning of each session to ensure recordings were aligned chronologically. A second video camera was used to collect 10 minute probes of PRT parental fidelity video data for external evaluation.

Procedures and data organization. Parent training activities were summed and reported on using minute-by-minute data sheets (Appendix B) adapted from a published tool on a similar parent training model for children with developmental delays (Brown & Woods, 2015). Each teaching session had its own data sheet identifying the name of the child, name of the parent, trainer, other participants, session, condition, time, teaching topics, teaching format and observed adult learning strategies. Coding instructions and operational definitions for each of these terms are listed in Appendix C and data collection instructions are listed in Appendix D. Each training session was attended by the lead researcher or a research assistant who coded training activities minute-by-minute. After completion of each training set, data sheets were screened for any missing information by the primary author. One data sheet was not completed due to a cancellation by the RA and no video was taken of that training session, so that data could not be recovered. A total of twenty-eight parent training sessions were available for review across 3 parent-child dyads.

To identify the reliability of the data sheets, a second rater, blinded to initial ratings, watched six teaching sessions (21.43%) via recorded video, independently rated the observed training activities and inter-rater reliability was calculated. Overall coding agreement was moderate across 8 nominal categories (Krippendorff's Alpha = 0.744). Simple agreement was calculated for each sub-category: setting the stage (0.667), direct teaching (0.647), goal selection (0.718), modeling (0.863), caregiver practice (0.769), video review (0.00), fidelity check (0.956), and summing up (0.818). Video review was poorly coded though accounted for less than 2 minutes per session (μ = 1.54 minutes). Training activities with the highest time allocation were modeling of strategies by the trainer (μ = 13.39 minutes) followed by guided feedback and practice by the parent (μ = 12.21). Activities with the lowest time allocation were setting the stage (μ = 2.39), summing up session information (μ = 2.25) and video review. A description of training activities are displayed in Figure 6.

Research assistant training. Volunteer research assistants (RAs) were recruited in partnership with the service provider. Training consisted of an orientation to the research program, group training to review video examples and practice coding the data sheets, and individual training within a PRT training session in the parental home. Of the six RA's initially trained, three RA's participated in the full spectrum of training including data collection. All data collection sheets were stored in a central child binder with available instructional materials, coding sheets, maps, and detailed contact information. These were stored in a secure bin at the service provider with the special clothing and video and audio recording equipment that needed to be checked out prior to each home visit and then returned to the provider after usage.

Social validity. A volunteer employed by the service provider used a structured interview and contacted participating families after they completed the parent training sessions. For parental learning, parents reported high satisfaction, knowledge of the PRT principles, and all indicated they had learned practical skills on how to better respond to their child. As an example, a parent described "I learned how to communicate … and help her verbalize". Parents also reported child improvement in response to the training. For example, "he learned how to express his words" and "he went from random babble to purposeful babble". Regarding program feedback, all three parents indicated a desire for improved flexibility in scheduling and a longer teaching duration. One parent wished for a longer program length overall, one parent wished for lengthier individual teaching sessions, and one parent wished for increased duration in both areas with the addition of a follow-up training session 6 months later.

Child outcome measures

Communication and language. Two methods were used to evaluate changes in child language and communication skills. The first was a direct measure of child vocalization (CV) activity during all study conditions using the LENA automated analysis system (LENA Research Foundation, 2016). The LENA is an emerging technology and is a digital language processor that the child wears in special clothing for up to sixteen hours and the analytic software calculates reliable and valid communication indicators including Adult Word Count (AWC), Child Vocalizations (CV), and Conversational Turns (CT) between an adult and a key child (Xu, Yapanel & Gray, 2009). Algorithms for the LENA audio segmentation software categorize sound around the key child into eight groupings: adult male, adult female, key child, other child,

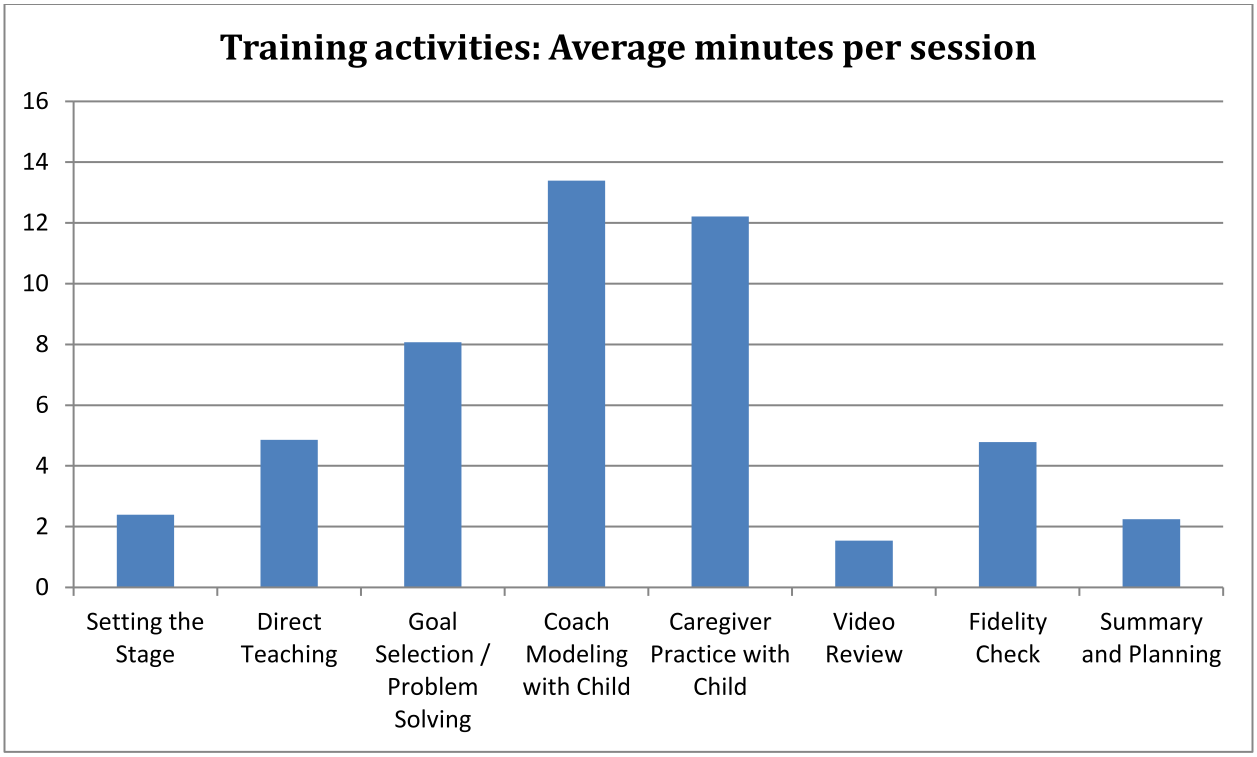


Figure 6: Summary of observed teaching methodology.

overlapping speech, noise, electronic media, and silence (Xu, Yapanel, Gray, & Baer, 2008) with a high degree of accuracy (Xu et al., 2009) even when language speakers are non-English (Weisleder & Fernald, 2013). The LENA DLP and specially designed shirt with a front mounted pouch to hold the DLP were worn by each child during the baseline, training and follow up phases to collect the audio data. Given these research findings on the accuracy of the LENA, inter-observer reliability for this instrument was not calculated as is typically used in single subject designs.

Child talk (CV) was captured in 5-minute reporting blocks across all conditions. These summaries are based on background analysis of “conversational blocks” that may be accessed in second-by-second reporting using a separate software package, the LENA Advanced Data Extractor [ADEX] (LENA Foundation, 2011). ADEX allows for reporting of Interpreted Time Segment (ITS) files that generate a line-by-line report of LENA automated coding in a time sequenced manner and reports on child identification, initiator of the communication (adult male, adult female, child, other child), vocalization and non-vocalization duration, as well as other detailed data (LENA Foundation, 2011).

For the analysis, the most detailed level of reporting available, a line by line analysis of each vocalization activity block (VAB) was generated for all of the available 46 recordings (HIK – 16 recordings; KIP – 16 recordings; JIK – 14 recordings) producing 33,984 vocalization blocks (HIK – 11,451; JIK – 11,779; KIP – 10,754). To ensure accuracy of reporting, the “one file per ITS file” option was chosen from ADEX, and then each automatically generated ADEX report was individually compared to the dated coding sheets on the following variables: child number and date of recording. If a recording was missing or miscoded a new ADEX report was generated until 100% correspondence was obtained between the manual and the ADEX files. All ADEX reports were saved and re-named by child identification and date to ensure 100% correspondence between the data sets.

As a result of this analysis, it was identified that 3 sessions were not properly recorded and this LENA data was not included and could not be recovered. Two recordings were due to equipment malfunction (1 – recording full, 1 – battery low) and one recording was due to improper location of the LENA (e.g. placed in a pocket on the child where he sat on the device and sound quality was poor) resulting in removal of 336 vocalization blocks. Partial blocks (< 4 min, 30 seconds) were removed from the data set to ensure comparability across conditions. For the final analysis, 33,648 vocalization blocks were available across all three conditions.

The LENA analysis was completed using a modified form of the data to ensure comparability across conditions. Initially, the data was summarized and reported on in its raw format in the same manner as was done in the pilot study. Then, using the standardized coding sheets, parent-child only interactions were identified and extracted from the data set during the training condition, using ADEX, to allow for parent-child only communication comparisons only across all conditions. LENA reporting for this study was restricted to only those recordings that included the parent and child. All other recordings involving the parent educator or other family members were set aside for future analysis.

A second supplementary measure of child language included completion of the MacArther-Bates Communicative Development Inventory (MCDI), a reliable and valid parent-report measure of a child's receptive and expressive language, including gestures (Fenson et al., 2006). Based on developmental level of each child, the MacArthur-Bates CDI Words and Gestures was completed by parents of two of the children (JIK/HIK) and the MacArther-Bates CDI Words and Sentences for one child (KIP).

Parent outcome measures

Fidelity of PRT implementation. PRT fidelity was independently assessed by a third party coder using a modification of the Symon (2005) protocol during the baseline phase, midway through the training phase, and during the follow-up condition. To assess PRT fidelity and consistent with service provider practice, 10-minute video samples of the PRT sessions were sent to the Koegel Autism Centre for manual coding according to a standardized one-minute rating checklist. Raters were not blind to treatment condition as their feedback was used to guide training sessions with the provider, though were objective and had no contact with participants. Fidelity in PRT was considered achieved when the parent reached the established criterion of 80% on each of the 7 PRT skills, as reported by the Koegel Autism Centre. These include: a) child attention and clear opportunities, b) maintenance tasks and task variation, c) child choice and following the child's lead, d) shared control, d) contingent, e) natural, and f) contingent on attempts.

Adult language. Similar to CV, the LENA automated analysis system provides a summary of parent talk (Adult Word Count or AWC) in five minute summaries across all treatment conditions. AWC is calculated by parsing out clear human speakers from other ambient noise, based on sound wave amplitude analysis, and only reports on those adult words that are "near and clear" to the child, with inter-rater agreement between adult vs. non-adult speaker classification reported at 88% (Gilkerson, Coulter, & Richards, 2008). To analyze AWC across all conditions, the 5 minute AWC average was calculated for each independent time measure, parent-child only conditions were extracted using the ADEX reporting software, and then plotted across all conditions (baseline, intervention, and follow-up).

Parent-child outcomes

Conversational turns. This is an automated output created by the LENA software, also available in five minute increments, and is based on an algorithm combining Adult Word Count (AWC) and Child Vocalizations (CV) that takes into account distal noise, the proximity of the adult to the key child, and observed turn taking vocal activity between parent and child (Gilkerson et al., 2008). This was chosen as a proxy measure of interpersonal synchrony. For the analysis, five minute CT estimates were calculated by the LENA during all three conditions. Parent-child only conditions were extracted using the ADEX reporting software, and were then averaged for comparability across each independent data collection point.

Results

Child outcomes

Child vocalizations. To identify functional relationships between the treatment and child outcomes, child vocalization averages were calculated per 5-minute block, as reported by the LENA analysis software. Baseline stability was first calculated. For JIK, baseline mean was calculated at 25.75 with a range from 21.25 – 30.25. For HIK, baseline mean was calculated at 3.97 with a range from 3.34 – 4.29. For KIP, baseline mean was calculated at 14.31 with a range 6.75 – 21.75. Visual analysis indicated baseline stability for JIK and HIK and poorer stability for KIP. To assess if change occurred between adjacent conditions (A to B, B to C) percentage of non-overlapping data (PND) was calculated using the process described by Scruggs and Mastropieri (1998) for each dyad. For JIK, PND comparing A to B was 50% and B to C was 0%. For HIK, PND comparing A to B was 66.67% and B to C was 0%. For KIP, PND comparing A to B was 33.34% and B to C was 66.67%. A functional relationship between training condition and child talk was moderately supported for HIK, but not for JIK or KIP. Results are visually displayed in Figure 7 and Table 7 provides a summary of LENA comparisons across three conditions child talk (CV), parent talk (AWC), and child-parent talk (CT).

To assess if change occurred after program participation, PND was calculated between A and C and is reported as follows: JIK 66.67%, HIK 66.67%, and KIP 33.34% suggesting a moderate effect for JIK and HIK. Trend analysis indicated a positive slope for HIK, a negative slope for JIK, and a flat slope for KIP. HIK demonstrated the strongest positive effect overall for increased child talk. KIP also demonstrated a marked increase in the training phase, though the effects did not maintain and had high variability.

In the overall analysis, when compared across the dyads, a distinct pattern emerged with HIK that was not evident in JIK or KIP. For HIK, the baseline was flat and low (CV $A\mu = 3.97$) but then demonstrated a clear and positive trend in the training condition (CV $B\mu = 9.6$) that was variable in the follow-up condition, though still higher overall than baseline (CV $C\mu = 8.17$). This suggests that training was impacting child talk in a positive manner that maintained into the follow-up phase. Though an increase was also seen in the training phase with KIP, this effect was inconsistent and did not maintain into the follow-up phase. No functional relationship between training condition and child talk was identified for JIK, though of concern, child talk appeared to be decreasing over time, an unexpected finding. Table 8 provides a summary of LENA results across CV, CT, and AWC and is reported as an average 5-minute summary within baseline, follow-up and both training conditions.

Table 7

Summary of LENA communication changes across conditions

Child	LENA variable	PND (AB)	Effect	PND (BC)	Effect	PND (AC)	Effect
JIK	CV	50	No	0	No	**66.67**	**Moderate**
	AWC	**100**	**High**	**100**	**High**	**66.67**	**Moderate**
	CT	50	No	0	No	33.34	No
HIK	CV	**66.67**	**Moderate**	0	No	**66.67**	**Moderate**
	AWC	**100**	**High**	**100**	**High**	**66.67**	**Moderate**
	CT	60	No	0	No	33.34	No
KIP	CV	33.34	No	**66.67**	**Moderate**	33.34	No
	AWC	33.34	No	33.34	No	33.34	No
	CT	0	No	**66.67**	**Moderate**	**66.67**	**Moderate**

LENA variables: CV = child vocalizations, AWC = adult word count, CT = conversational turns. Research conditions: baseline (A), intervention (B), follow-up (C). PND = Percentage of non-overlapping difference (e.g. A/B X 100). PND > 90% = highly effective; 70 – 90% = fairly effective; < 50% = unreliable / ineffective (Scruggs et al, 1987)

Table 8

Summary of LENA results across conditions – average per 5-minute block

	LENA variable	Baseline (A = μ)	Training (B = μ)	Follow-up (C = μ)
JIK	CV	25.75	22.25	18.067
	AWC	347.5	504.25	302.13
	CT	12.375	13	11.1
HIK	CV	3.97	9.6	8.17
	AWC	152.35	323	178.11
	CT	2.34	5.2	3.72
KIP	CV	14.31	22.34	9.58
	AWC	464.11	485	391.75
	CT	14.31	13.5	5.83

LENA variables: CV = child vocalizations, AWC = adult word count, CT = conversational turns. μ = mean

Parent outcomes

Adult language. Adult word count (AWC) was calculated per 5-minute block, as reported by the LENA analysis software in the same manner as reported for CV. Baseline stability was first calculated. For JIK, baseline mean was calculated at 347.5 with a range of 329.5 – 365.5. For HIK, baseline mean was calculated at 152.35 with a range of 139.34 – 158.86. For KIP, baseline mean was calculated at 464.11 with a range of 393.67 – 521.25. To assess if change occurred between the adjacent conditions, PND was calculated. For JIK, PND comparing A to B was 100% and B to C was 100%. For HIK, PND comparing A to B was 100% and B to C was 100%. For KIP, PND comparing A to B was 33.34% and B to C was 33.34%. A functional relationship between adult talk and training condition was identified for JIK and HIK, but not KIP. To assess if change occurred after program participation, PND was calculated between A and C as follows: JIK, 66.67%; HIK, 66.67%; and KIP 33.34% suggesting a moderate effect for JIK and HIK, though similar to child talk, in opposite ways across participants.

Trend analysis indicates both JIK and HIK had a clear increase in adult talk during the training phase, though returned near baseline when the trainer was no longer present.

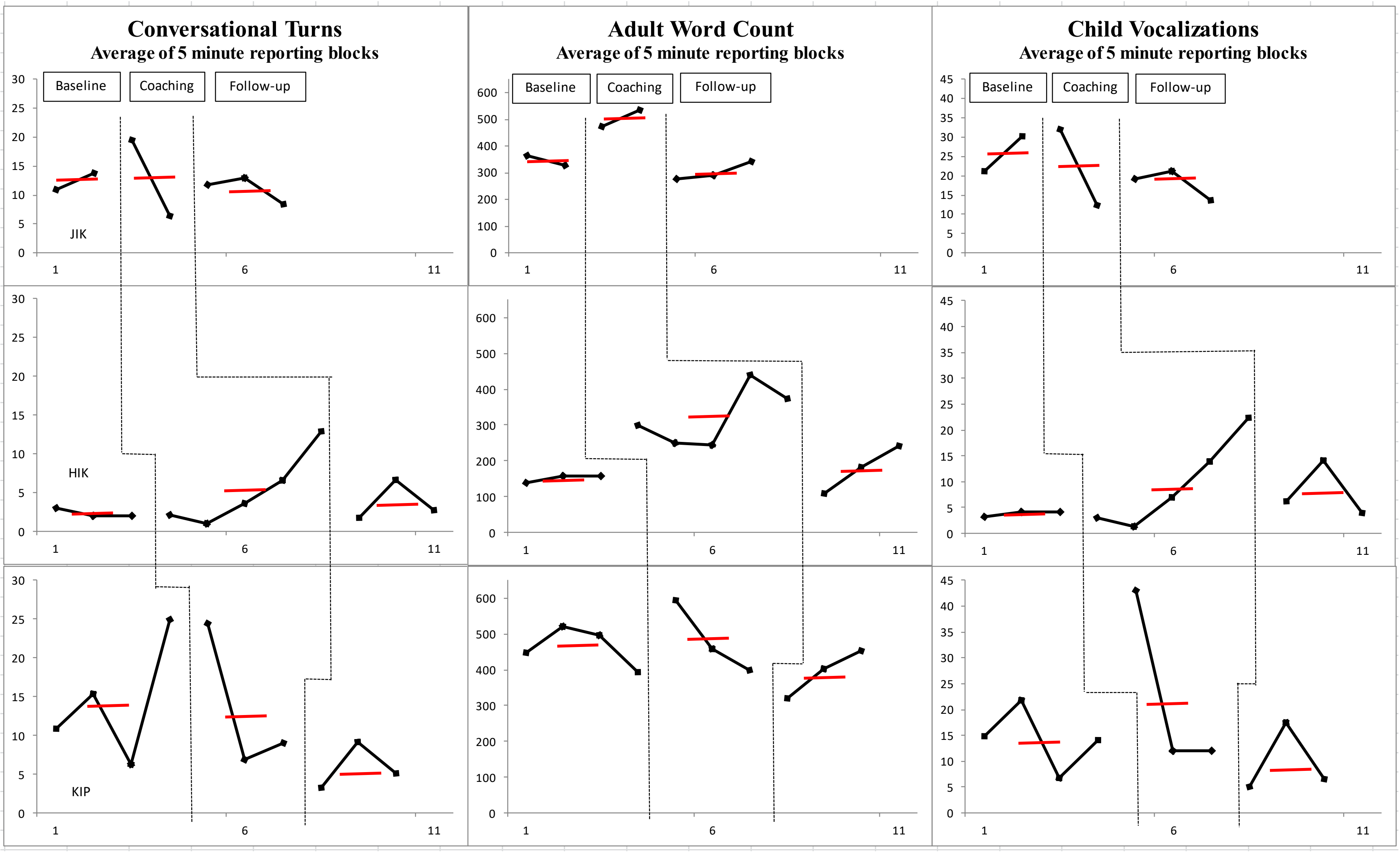
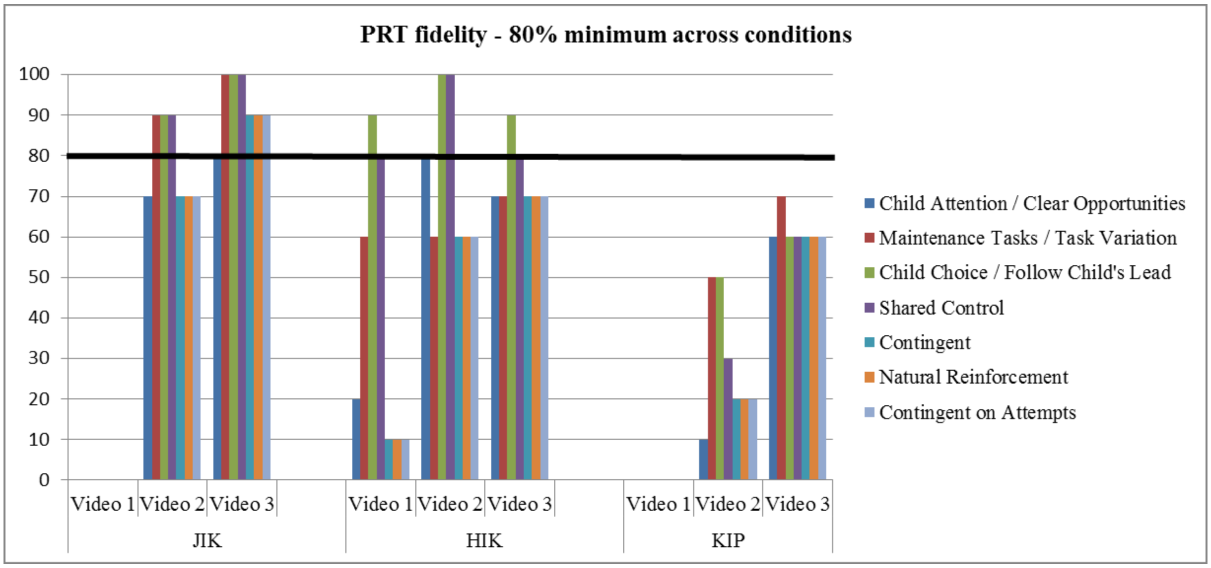


Figure 7: Parent and child communication changes across conditions. Note: Each data point = a minimum of 10 minutes of extracted "parent-child only" dyadic communication and does not include the PRT trainer. To provide comparability across conditions, only data that was at least 10 minutes in length and only included the parent child dyad is visually presented.

For HIK, baseline was flat (AWC Aμ = 152.35) but then demonstrated a clear and distinct upward shift in the training condition (AWC Bμ = 323), that decreased substantially in the follow-up condition (AWC Cμ = 178.11), but was higher than baseline. For JIK, baseline was also flat (AWC Aμ = 347.5), with a similar increase in the training condition (AWC Bμ = 504.25), and then a decrease to below baseline in the follow-up phase (AWC Cμ = 302.13). Similar to CV, KIP demonstrated high variability with no clear trend identified across conditions.

PRT fidelity. Results are shown in Figure 8 and demonstrate a clear increase in application of PRT principles according to three independently coded 10-minute video clips. Baseline videos were taken at program start (video 1), sessions 6 or 7 (video 2) and session 10 (video 3). Raters were not blind to condition as feedback was also used to guide parent training, though they were independent as videos were externally coded by a trained third party. Full PRT



Note: Video 1 = baseline (sessions 1). Video 2 = mid-training (sessions 6-7). Video 3 = end training (session 10) as coded by independent rater. If no ratings, there were insufficient observed opportunities to rate PRT fidelity (fidelity = 0).

Figure 8: Parent PRT fidelity across participants.

fidelity was demonstrated across all domains (7/7) at the 80% criterion by only one parent (JIK) as a result of participation in this training model. HIK demonstrated fidelity in 2/7 (28.57%) of the PRT areas, and achieved 70% fidelity in the remaining 5 areas. KIP did not achieve PRT fidelity in any of the 7 domains, though did demonstrate improvement in all areas, achieving a minimum of 60% fidelity in 6/7 domains.

Parent-child outcomes

Conversational turns. Conversational Turns (CT) were calculated per 5-minute block, as reported by the LENA analysis software in the same manner as reported for CV and AWC. Baseline stability was first calculated. For JIK, baseline mean was calculated at 12.375 with a range of 11 – 13.75. For HIK, baseline mean was calculated at 2.34 with a range of 2 – 3. For KIP, baseline mean was calculated at 14.31 with a range of 6.25 – 25. Stability was highest for HIK and JIK and variable for KIP. To assess change between adjacent conditions, PND was calculated. For JIK, PND comparing A to B was 50% and B to C was 0%. For HIK, PND comparing A to B was 60% and B to C was 0%. For KIP, PND comparing A to B was 0% and B to C was 66.67%. No functional relationship between teaching condition and CT was clearly identified. To assess if change occurred after program participation, PND was calculated between A and C: JIK, 33.34%; HIK, 33.34%, and KIP, 66.67%. For KIP, a moderate effect was identified in the opposite direction expected.

Visual and trend analysis provided additional information. JIK demonstrated a stable trend across conditions with variability in the training phase. For HIK, baseline was relatively flat (CT $A\mu = 2.34$) but then demonstrated a clear and distinct upward shift in the training condition with a positive trend (CT $B\mu = 5.2$), and then a slight correction in the follow-up condition (CT $C\mu = 3.72$). Notably, frequency of CT was higher than baseline. For KIP, baseline was highly variable (CT Aµ = 14.31), decreasing during the training phase (CT Bµ = 13.5), and then dropping dramatically in the follow-up phase (CT Cµ = 5.83). Despite high variability, KIP demonstrated a slightly downward trend over conditions with wide variability.

Supplementary Measures

Upon completion of the parent training phase, two of the children were reported to have modest improvement in their communication abilities (JIK/KIP) and in one case a more mixed profile was reported, with some skills increasing and others decreasing (HIK). JIK was reported to have an increased ability to understand phrases (+3), words (+1), increased use of early gestures (+3), increased use of later gestures (+1), and an overall increase in gesture use (+4). No change was reported in words produced. No delays or regression were identified. HIK was reported to have increased use of early gestures (+3), but a decreased ability to understand phrases (-8), words (-1), use of later gestures (-3). No change was reported in words produced or total gesture use. KIP was reported to have an increase in words produced (+22), increase in word endings (+1), increase in morpheme length (+0.6) and increase in sentence complexity (+8). No change was reported for word forms.

Discussion

The primary purpose of the present study was to bridge the research to practice gap by partnering with an accredited provider implementing EBP in the community to provide a clear description of a PRT training model used in the community, and its potential effects on child and parent learning. A secondary purpose was to evaluate a new technology, the LENA and its accompanying software (LENA Research Foundation, 2016) as a process and outcome tool for potential use in community practice.

Do parents and children demonstrate improved learning as a result of participation in this training model?

Parents demonstrated improved learning in the application of PRT though the effect was variable across participants and had limited impact on child talk. All participants improved in PRT fidelity over time, though only one parent demonstrated full fidelity of implementation at the 80% criterion across all 7 areas of PRT within a 10 minute externally coded video (JIK), by the end of the training program. HIK demonstrated PRT fidelity in 2/7 domains whereas KIP did not meet criterion in any of the PRT domains. Given that 10 training sessions are quite brief compared to other PRT training models (e.g., Minjarez, Mercier, Williams, & Hardan, 2012) additional sessions may be required for a greater portion of parents to reach PRT fidelity. Symon, Koegel, and Singer (2006) describe a standard PRT parent education program taking 25 hours of instruction to complete.

Cadogan and McCrimmon (2015) completed a review of 17 PRT studies and found the high level of variability in fidelity of implementation was common, particularly for those studies using the 80% criterion. They also report high variability in how PRT fidelity is measured across studies. In their review, only 9 of the studies explicitly reference the instructional manuals by Koegel et al. (1989), 7 studies reported interventionists did not meet fidelity criteria, 5 studies made no reference to treatment fidelity measures, only 8 studies reported follow-up data, and only 11 studies used objective coders to rate fidelity, suggesting that bias may impact reported results. Positively, this PRT training model explicitly referenced PRT training materials, captured PRT fidelity in a rigorous and objective fashion, reported on follow-up data, and used external coders. Nonetheless, it is of concern that only one parent met full PRT fidelity of implementation and suggests that additional training time or an alternate model of teaching may need to be considered by the provider.

Changes in child talk were also observed, though were less evident and more variable than that of the parent learning. Automated communication measures were inconsistent across dyads and direct links between improved child communication and participation were weak. Only one dyad (HIK), demonstrated a clear change in communication patterns during the training condition. For HIK there was a measurable increase in child vocalizations and interpersonal communication midway through the training phase that maintained into follow-up. This effect was not observed in JIK or KIP, a particularly perplexing finding for JIK as PRT fidelity was demonstrated by the parent. The variability of these findings was inconsistent with other studies that identify a general increase in child vocalizations as a result of PRT parent training (e.g., Brian et al., 2015; Hardan et al., 2015). Further study of this interaction between fidelity, child vocalizations and interpersonal communication is required. MCDI score improvement on communication was reported for two of the three dyads (KIP/JIK) and a mixed profile of skill increase and loss was reported for the third dyad (HIK).

Are communication patterns identified in the pilot study replicated in this more rigorous design*?*

In the pilot study, it was found that parent and child talk were inversely related across conditions. Additionally, child talk decreased during the training phase but then increased to a higher level than baseline in the follow-up phase. Effects observed in the pilot were only partially replicated in this more rigorous design, were restricted to those parents with higher PRT fidelity, and for those children with emerging expressive language skills (JIK / HIK). For these dyads, parent talk followed a similar pattern to the pilot study, though was not observed for the remaining dyad (KIP). KIP demonstrated the lowest level of PRT fidelity of implementation, as well as the highest levels of child spoken language, and this may have impacted the results. Child talk did not replicate the pattern as expected. Taken together, one possible interpretation is that parent talk only increases during training for those parents with higher levels of PRT fidelity. An alternative interpretation is that parent talk only increased for younger children with ASD where expressive language was an emerging skill. The variability in child and parent talk may also be due to the alternate data collection methods used in this design. Further research is required in this area and this is one example of how automated natural language sampling can assist with the identification of communication patterns.

Is LENA reliable and user friendly for community practice?

LENA performed reliably for the majority of the data collection. Only one recording was lost due to a hardware error, providing a 97.82% (45/46) success rate. However, even after considerable training, user error led to a loss of two further recordings, dropping the success rate to 93.48%. One of those errors would not have been detected without careful analysis of the accompanying video, and this may be a challenge in less supervised settings. The other error was due to a failure to properly charge the device, a common problem with new technology.

The three main LENA reporting outputs (CV, CT and AWC) were easily accessed and the software for accessing these reports was intuitive and user friendly at either the 5 minute, hourly, daily or monthly reporting modules, organized by child and date of recording. It was particularly helpful to be able to listen to the raw recordings directly from the graphs associated with child output, and this increased the user friendliness and validity of the recordings. When aligning the video and audio recordings, and when confirming the extracted ADEX data, the ability to identify raw recordings to the second, and listen to them in real time, made the LENA a real asset for automatically calculating communication information that would be extremely time intensive using other manualized formats. In this manner, the LENA is a technology that holds strong promise and is well designed.

Tager-Flusberg et al., (2009) report on recommended measures to capture expressive language development in young children with ASD that include 1) natural language sampling, 2) parent report, and 3) direct assessment using standardized tests. Natural language sampling can be time consuming and difficult to complete, including transcription and analysis, and this may be a barrier to disseminating evidence-based practice in community settings. Finestack, Payesteh, Disher, and Julien (2014) report that even in research settings, there is a need for standardized transcription and coding procedures, minimum sample length, and better reporting on natural language sampling context. In this respect, LENA may serve well as an augmentative measure to assist with natural language sampling by 1) systematically coding large amounts of communication data in natural settings and 2) doing so in a reliable and valid manner.

However, a significant limitation with the LENA automated outputs is that it is restricted to frequency data. Though important, a sole focus on frequency count allows for little analysis about the quality of the interaction within a conversational dyad, an important consideration for understanding effective child-adult communication. This is of particular importance for the ASD population, as non-verbal behaviour (gestures, coordinated eye gaze, pointing) is often discordant with verbal communication. Tager-Flusberg et al., (2009) recommend that to properly identify a child’s language level in the early years, phonology, vocabulary, grammar and pragmatics should all be evaluated.

Most published LENA studies report do not report on ADEX findings or usage, instead reporting on full day recordings (e.g., Warren et al., 2010). However, when reporting on select portions of the data, ADEX is needed to capture more discrete units of parent-child communication, as was done in this study. ADEX is an advanced software package that required additional training and practice to use it successfully. The online written manual was clear and concise and provided step-by-step instructions, with visual supports, that were easy to follow and intuitive. The output from ADEX was readily exported to MS Excel 2007 and converted into spreadsheets that could be readily analyzed using other statistical software. This made ADEX a real asset for organizing and gathering complex information. However, one challenge with ADEX is that it allows for so many reporting options that for the average user, this could easily become overwhelming and lead to errors across multiple systems and users. Using ADEX in a large-scale setting such as community practice could be challenging if clearly defined protocols and training were not provided.

Limitations and Conclusions

In conclusion, this study is an example of bridging the research to practice gap by partnering with an existing autism service provider, evaluating an EBP in community setting, evaluating the use of new technology in that setting, and providing feedback on the effectiveness and modifications of the model on child and adult learning. Results support the use of LENA as a augmentative outcome measure for younger children with ASD, though less evidence was found for its use with older children, and high variability limited interpretation. Moreover, by quantifying large amounts of communication data in an accessible format, feedback on the effectiveness and impact of the parent training model was enhanced, particularly using a single subject design methodology that evaluated change over time. This PRT parent training model of practice demonstrated promising outcomes for parents and children with ASD that participated, though future research is needed on this training model as well as the use of LENA in community practice.

Despite this positive direction, these findings support the challenges in translating research to practice. Only one parent was able to demonstrate full PRT fidelity limiting the conclusions that can be drawn. It is possible that with a longer training period improved parental learning may have been demonstrated. A secondary limitation is parent and child communication patterns were not replicated consistently across all dyads providing mixed evidence on effectiveness. Finally, as this model was delivered in community practice, a level of experimental control was necessarily lost, and though this increased the ecological validity of the experiment, extraneous events may have influenced the results in unexpected ways, despite the best efforts of the researchers to control these variables.

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Appendix A: PRT Parent Training Topics

Session 1: Introduction to PRT, goal confirmation & baseline data

Session 2: Capturing child attention and providing clear opportunities

Session 3: Modeling and use of ABC

Session 4: Balancing maintenance and acquisition tasks

Session 5: Shared control and child choice

Session 6: Following the child’s lead and reinforcing attempts

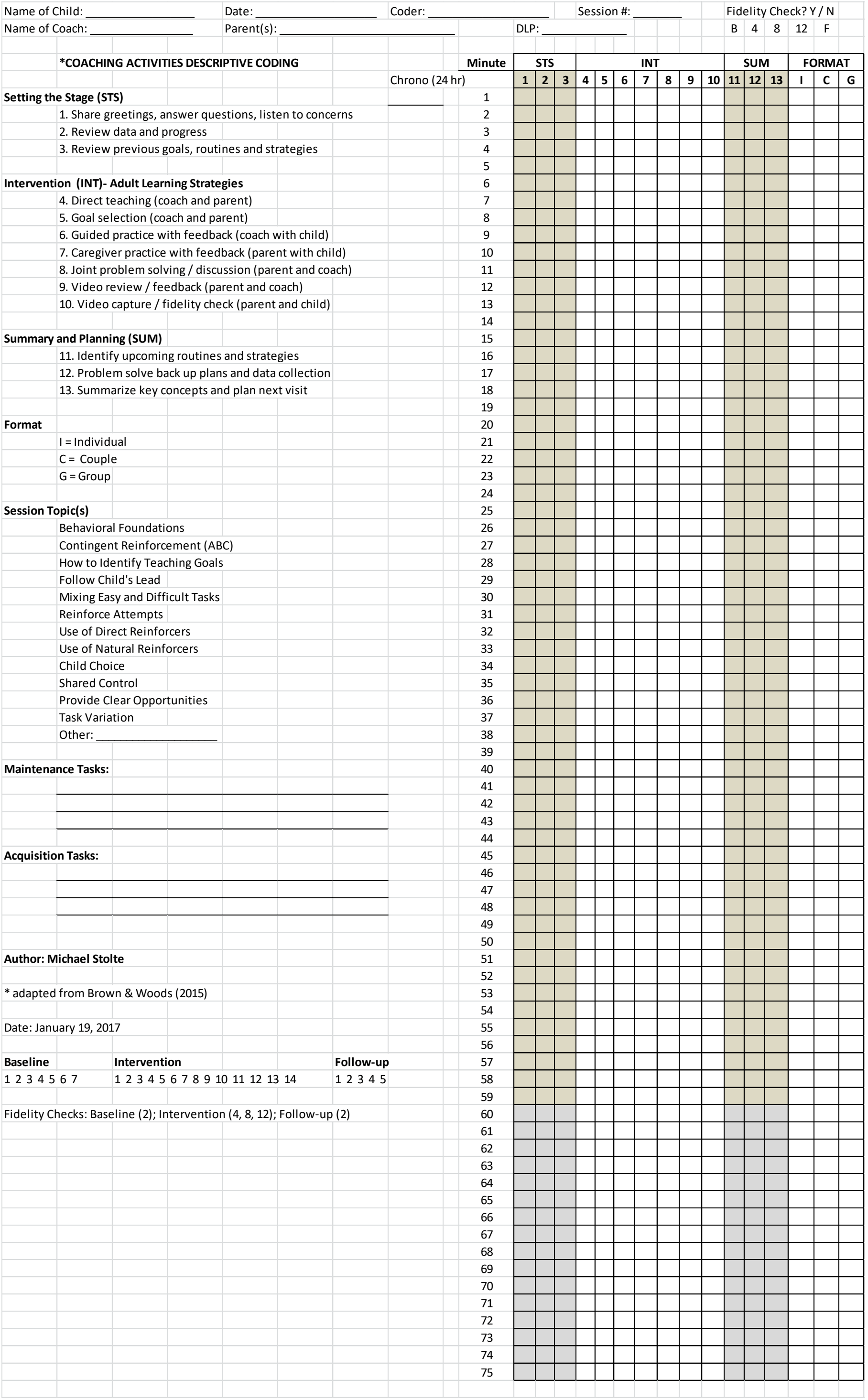
Session 7: Contingent reinforcement

Session 8: Direct and natural reinforcement

Session 9: Integrating practice into everyday routines and activities

Session 10: Maintaining motivation and follow-up data

Appendix B: Descriptive Coding Sheet



Name of Child: ________________ Date: __________________ Coder: ___________________ Session #: ________ Fidelity Check? Y / N
Name of Coach: ________________ Parent(s): ____________________________ DLP: _____________ B 4 8 12 F

*COACHING ACTIVITIES DESCRIPTIVE CODING	Minute	STS			INT							SUM			FORMAT		
Chrono (24 hr)		1	2	3	4	5	6	7	8	9	10	11	12	13	I	C	G
Setting the Stage (STS)	1																
1. Share greetings, answer questions, listen to concerns	2																
2. Review data and progress	3																
3. Review previous goals, routines and strategies	4																
	5																
Intervention (INT)- Adult Learning Strategies	6																
4. Direct teaching (coach and parent)	7																
5. Goal selection (coach and parent)	8																
6. Guided practice with feedback (coach with child)	9																
7. Caregiver practice with feedback (parent with child)	10																
8. Joint problem solving / discussion (parent and coach)	11																
9. Video review / feedback (parent and coach)	12																
10. Video capture / fidelity check (parent and child)	13																
	14																
Summary and Planning (SUM)	15																
11. Identify upcoming routines and strategies	16																
12. Problem solve back up plans and data collection	17																
13. Summarize key concepts and plan next visit	18																
	19																
Format	20																
I = Individual	21																
C = Couple	22																
G = Group	23																
	24																
Session Topic(s)	25																
Behavioral Foundations	26																
Contingent Reinforcement (ABC)	27																
How to Identify Teaching Goals	28																
Follow Child's Lead	29																
Mixing Easy and Difficult Tasks	30																
Reinforce Attempts	31																
Use of Direct Reinforcers	32																
Use of Natural Reinforcers	33																
Child Choice	34																
Shared Control	35																
Provide Clear Opportunities	36																
Task Variation	37																
Other: ___________________	38																
	39																
Maintenance Tasks:	40																
____________________________________	41																
____________________________________	42																
____________________________________	43																
	44																
Acquisition Tasks:	45																
____________________________________	46																
____________________________________	47																
____________________________________	48																
	49																
	50																
Author: Michael Stolte	51																
	52																
* adapted from Brown & Woods (2015)	53																
	54																
Date: January 19, 2017	55																
	56																
Baseline **Intervention** **Follow-up**	57																
1 2 3 4 5 6 7 1 2 3 4 5 6 7 8 9 10 11 12 13 14 1 2 3 4 5	58																
	59																
Fidelity Checks: Baseline (2); Intervention (4, 8, 12); Follow-up (2)	60																
	61																
	62																
	63																
	64																
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Appendix C: Coding Instructions and Operational Definitions

Coding Instructions / Operational Definitions for START Training Activities Datasheet

Primary Investigator: Michael Stolte Supervisor: Veronica Smith

General Rules:

1. Code in a discrete (either/or fashion) for STS, INT and SUM and their subcategories
2. Begin timing and note time on data sheet <u>after</u> video camera and LENA have been activated and set up and START coach actively starts the session
3. For the last 15 seconds of each minute identify the category using the operational definitions below. ONLY PICK ONE!

Operational Definitions

<u>Setting the Stage (STS)</u>

1. Sharing greetings, answer questions, listen to concerns **(caregiver with coach)** (STS-1)
   DEFINITION: No information provided by coach. Formal or informal greetings offered. Coach may use questions such as "tell me about how things have gone since the last session?" or "how are you doing today?" Focus is on general interactions rather than specific data or a particular goal.

2. Review data and progress **(caregiver with coach)** (STS-2)
   DEFINITION: Coach shows general summary of data (visual, written, or video) and brings to the attention of the family to demonstrate progress. This could include fidelity coding or past data sheets completed. Family shares any current data they have collected.

3. Review previous goals, routines and strategies **(caregiver with coach)** (STS-3)
   DEFINITION: Coach reviews and summarizes past goals, routines and strategies. Coach may ask about general homework that may have been completed and success in implementing chosen strategies. If advice is provided on a strategy or goal by the coach, code as INT (8) – Joint problem solving.

<u>Intervention (INT): Adult Learning Strategies</u>

4. Direct teaching **(caregiver with coach)** (INT-4)
   DEFINITION: Coach identifies the topic of the day and provides direct didactic teaching on the subject. This could include presenting written or verbal instruction as well as handouts that may be linked to prescribed readings.

5. Goal selection **(caregiver with coach)** (INT-5)
   DEFINITION: Coach and caregiver discuss maintenance and acquisition goals for the child, document these and select on a goal(s) to focus on for the session.

6. Guided practice with feedback / modeling **(coach with child)** (INT-6)
   DEFINITION: Coach models the new concept with the child and may talk or describe the strategies to the caregiver as they are being implemented. The primary interaction is between the coach and the child.

7. Caregiver practice with feedback **(caregiver with child)** (INT-7)
   DEFINITION: The caregiver practices the strategies with the child and the coach provides supportive and directive feedback on how to implement the strategy with fidelity. The primary interaction is between the caregiver and the child. In-vivo training.

8. Joint problem solving / discussion **(caregiver with coach)** (INT-8)
   DEFINITION: The primary interaction is between the caregiver and the coach. The focus is on discussing and problem solving how the strategy is working and to gain clarification on any perceived difficulties or modifications that may be required.

9. Video review / feedback **(caregiver with coach)** (INT-9)
   DEFINITION: The caregiver and coach watch a pre-recorded video of the caregiver interacting with their child to gain another perspective on how they are implementing the strategies. The coach may provide feedback to the caregiver on strategy implementation and potential modifications. If they are watching a video together code and the child is not involved in the interaction code INT-8.

10. Video capture / fidelity check **(caregiver with child)** (INT-10)
    DEFINITION: The caregiver and child interact in a normalized fashion practicing the strategies as directed. During fidelity checks there is no active training provided and the coach is not actively involved in the interaction sequences.

Summary and Planning (SUM)

11. Identify upcoming routines and strategies **(caregiver with coach)** (SUM-11)
    DEFINITION: The coach provides an indication of the topic for the next week, summarizes new strategies learned for the day, and describes how to implement the strategy in daily routines.

12. Problem solve back-up plans and data collection **(caregiver with coach)** (SUM-12)
    DEFINITION: The coach and caregiver agree and discuss a data collection system for how and when to practice the strategies, and how to gather formal or informal data on progress.

13. Summarize key concepts and plan next visit **(caregiver with coach)** (SUM-13)
    DEFINITION: The coach provides an overview of previous teaching topics, how the topic presented today fits within those topics, and the next visit is confirmed.

Appendix D: Research and Data Collection Procedures

Title: Evaluating a home-based parent training program for autism spectrum disorder

PI: Michael Stolte (contact info) Supervisor: Veronica Smith

Baseline Phase (3-7 twenty minute measures)

Supplies Needed:

1. LENA digital language processor
2. LENA special shirt
3. Video camera
4. Tripod to mount video camera
5. Clipboard and pen
6. Contact and location information
7. Watch or cell phone for timer

Process:

1. Arrive at home or Centre 10 minutes prior to scheduled start time
2. Introduce self to family and set up camera and tripod in room
3. Remind family of need to have minimal interruptions for 20 minutes of free play and interaction between parent and primary caregiver
4. Remind family of importance to establish a stable baseline of information before we start the parent training program
5. Have parent put special LENA shirt on the child

When parent and child are ready:

1. Start the video camera and LENA device at the same time
2. Give the LENA DLP to the parent to put in special pocket in the shirt
3. Check that the camera is recording
4. Instruct the parent to play as naturally with their child as possible with the following:
   > "*Please start playing with your child now in whatever way feels comfortable and do something you both enjoy. Don't worry about doing anything special. Please try to stay in the room and avoid external interruptions as this may invalidate the data collection for the day. At this point, we just want to get an accurate picture of your normal play interactions as a baseline before the parent training program starts. Thanks again for doing this. We really appreciate it*".
5. Note the start time on the attached data sheet
6. Note that the LENA only tabulates in 5 minute intervals so it is ideal to start 1 minute prior to the next interval (eg. 3:59 PM; 4:04 PM, etc.) to maximize efficiency
7. Gather 20 minutes of data up to a whole 5 minute # (eg. 5:15, 5:20, 5:25, etc.)

When data collection is completed:

1. Have parent remove the LENA shirt from the child
2. Stop the LENA and video camera at the same time
3. Verify the time of the recordings on the data sheet
4. Verify the DLP#, name of child and parent on the data sheet
5. Thank the family again for their support
6. Verify the next scheduled visit
7. Be respectful of the family's time and don't linger longer than necessary
8. Bring data sheet, LENA and video camera back to the Centre for secure storage, charging and uploading (give to Michael or RA if Michael not in the office)
9. Complete mileage sheets (monthly submission)

NOTE: At end of baseline the parent is given a $10 gift Tim Hortons gift card as a token of appreciation.

Parent Training Phase (up to 12 seventy-five minute measures)

Supplies Needed:

1. LENA digital language processor
2. LENA special shirt
3. Video camera
4. Tripod to mount video camera
5. Clipboard and pen with data sheets
6. Contact and location information
7. Watch or cell phone for timer

Process:

1. Arrive at home or Centre 10 minutes prior to scheduled start time
2. Wait for parent coach to arrive so that you enter the home together. The parent coach (name of coach) is the primary person in charge and sets the tone for each meeting
3. Introduce self to family and set up camera and tripod in room
4. Have parent put special LENA shirt on the child
5. While parent is putting on shirt, ask parent coach for a) the session topic for the day b) the maintenance tasks and c) the acquisition tasks. Write these down verbatim on the data sheet.

When parent and child are ready:

1. Start the video camera and LENA device at the same time
2. Give the LENA DLP to the parent to put in special pocket in the shirt

3. Check that the camera is recording
4. Note the start time on the attached data sheet
5. Find a comfortable place in the room to observe the training session and remain in the background
6. Begin coding on minute-by-minute intervals for the duration of the teaching session using the datasheet and clipboard
7. If you are unclear on how to code a section, leave it blank and make a note. We can code it later through the videotape.
8. Note that the teaching sessions may vary in length up to 75 minutes

When parent training session is completed:

1. Have parent remove the LENA shirt from the child
2. Stop the LENA and video camera at the same time
3. Verify the time of the recordings on the data sheet
4. Verify the DLP#, name of child and parent on the data sheet
5. Confirm the maintenance and acquisition tasks (these sometimes change)
6. Thank the family again for their support
7. Verify the next scheduled visit
8. Be respectful of the family's time and don't linger longer than necessary
9. Bring data sheet, LENA and video camera back to the Centre for secure storage, charging and uploading (give to Michael or RA if Michael not in the office)
10. Complete mileage sheets (monthly submission)

NOTE: At end of the training phase, the parent is given a second $10 gift Tim Hortons gift card as a token of appreciation.

Follow-up Phase (3-7 twenty minute measures)

Supplies Needed:

1. LENA digital language processor
2. LENA special shirt
3. Video camera
4. Tripod to mount video camera
5. Clipboard and pen
6. Contact and location information
7. Watch or cell phone for timer

Process:

1. Arrive at home or Centre 10 minutes prior to scheduled start time

2. Introduce self to family and set up camera and tripod in room
3. Remind family of need to have minimal interruptions for 20 minutes of free play and interaction between parent and primary caregiver
4. Remind family of importance to have stable follow-up information after finishing the parent training program
5. Have parent put special LENA shirt on the child

<u>When parent and child are ready</u>:

1. Start the video camera and LENA device at the same time
2. Give the LENA DLP to the parent to put in special pocket in the shirt
3. Check that the camera is recording
4. Instruct the parent to play as naturally with their child as possible with the following:

   > "*Please start playing with your child now in whatever way feels comfortable and do something you both enjoy. Please use the strategies you were taught to encourage vocal interaction to the maximum extent possible. Please try to stay in the room and avoid external interruptions as this may invalidate the data collection for the day. At this point, we want to see if the training program has changed the way you interact with your child. Thanks again for doing this. We really appreciate it*".

5. Note the start time on the attached data sheet
6. Note that the LENA only tabulates in 5 minute intervals so it is ideal to start 1 minute prior to the next interval (eg. 3:59 PM; 4:04 PM, etc.) to maximize efficiency
7. Gather 20 minutes of data up to a whole 5 minute # (eg. 5:15, 5:20, 5:25, etc.)

<u>When data collection is completed</u>:

1. Have parent remove the LENA shirt from the child
2. Stop the LENA and video camera at the same time
3. Verify the time of the recordings on the data sheet
4. Verify the DLP#, name of child and parent on the data sheet
5. Thank the family again for their support
6. Verify the next scheduled visit
7. Be respectful of the family's time and don't linger longer than necessary
8. Bring data sheet, LENA and video camera back to the Centre for secure storage, charging and uploading (give to Michael or RA if Michael not in the office)
9. Complete mileage sheets (monthly submission)

NOTE: At end of the follow-up phase, the parent is given a third $10 gift Tim Hortons gift card as a token of appreciation.

Chapter 6: Discussion and Integration

The Science to Practice Gap in Psychology

The science to practice gap is a challenge that extends beyond autism and encompasses all of psychological practice. Forman, Gaudiano, & Hebert (2016) summarize many of the common approaches used by the research community to bridge the gap including empirically supported treatment lists (e.g., Chambless & Hollon, 1998; Chambless & Ollendick, 2001); adoption of national registries that include evidence based treatments (e.g., National Registry of Evidence-Based Programs and Practices published by the Substance Abuse and Mental Health Services Administration, 2016); the creation of task forces on the dissemination of EBP (e.g., APA Presidential Task Force, 2006; Dozois et al., 2014); pressure to move beyond treatment packages to "common factors" models that transcend specific theories or approaches (Beutler & Castonguay, 2006); the adoption of large scale treatment guidelines for particular psychological disorders and problems (e.g., American Psychiatric Association, 2010; National Institute for Clinical Excellence, 2011); and the adoption of rating systems using techniques such as meta-analysis or systematic review to classify treatment models into determinations such as weak, strong or very strong (e.g., Shea, Bouter, et al, 2007; Berger & Alperson, 2009).

The Canadian Psychological Association Task Force on Evidence-Based Practice of Psychological Treatments (Dozois, et al, 2014) was launched in 2011 and adopted a definition of EBP that parallels that of the APA Task Force emphasizing the importance of using the best available evidence to make clinical decisions, matched with patient characteristics and clinical judgement. Dozois et al. also describe the rich history of scientist-practitioner training in psychology and outline a process of EBP decision making that integrates the ethical decision making principles of the CPA Code of Ethics, 3rd edition (CPA, 2000). In their recommendations for adopting EBP, psychologists are encouraged to use the "best available evidence" (p. 159), to systematically monitor the impacts of those treatments, and alter treatment models based on the reaction of client characteristics and the changing scientific basis for those treatments. For reference, their recommended model of decision making to evaluate EBP is identified in Figure 9.

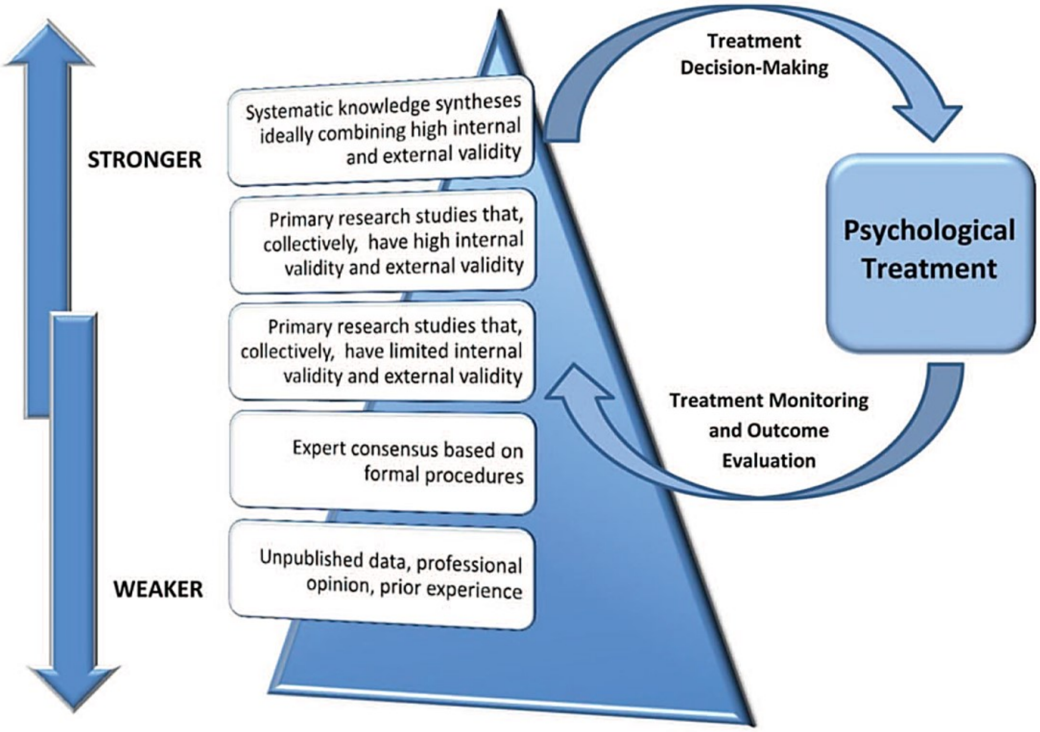

Figure 9: The hierarchy of research evidence related to clinical practice (*Source*: Dozois et al, 2014)

Despite progress in awareness of EBP, adoption of these practices can take up to 20 years to be fully implemented (Walker, 2004). Criticisms of current models of dissemination include confusion in the application and systematic criteria in the development of treatment lists (Tolin, McKay, Forman, Klonksy, & Thombs, 2015), an over-representation of proprietary and commercialized treatments (Hennessey & Green-Hennessy, 2011), inaccessible EBP lists that are difficult to use, treatment guidelines that are expensive and difficult to create, are of varying quality, and of limited usability for a particular clinician working with the complexities of an individual with varying needs (Forman et al., 2016). All of these factors make the application of these lists and guidelines difficult to implement in clinical practice.

In addition to the systemic challenges of adoption, there are also barriers of both clinician and researcher attitude. Tasca et al. (2014) identify negative clinician attitudes towards research applicability and utility, personal beliefs that other clinicians hold the same perception of research, low perceived control over incorporating evidence into practice, and limited clinician access to high quality technological tools to increase their use of EBP. However, researchers are also held responsible as Tasca et al. indicate that research granting systems and academic institutions often do not place value on clinician expertise, clinicians are often excluded from funding and academic status, that research is often done without clinicians as part of the formal research team, and that granting and funding agencies often do not value or overlook clinical expertise.

Yet despite all these challenges, possible solutions are emerging. Forman et al. (2016) indicate pragmatic steps including direct advocacy and awareness to consumers to be more mindful of EBP when purchasing services, to target government and insurance providers so that they will only pay for EBP, to link licensure more closely to the adoption of EBP, to encourage the use of malpractice suits to change clinician behaviour, to incentivize changes in existing psychology training programs through increased adoption of accreditation and the teaching of scientifically based treatments, and finally, to make the available guidelines more useful by reducing complexity and linking them to real-world case examples. Dozois et al. (2014) recommend strengthening the ethical principles around the adoption of EBP in future ethical codes. Bloom and Tam (2015) propose that in order to bridge this gap there is need for scoping reviews of practical interest to clinicians, that reviews need to involve community partners to ensure their practical relevance, and that the next generation of students are an ideal resource to build bridges on this issue both in training and review participation. Tasca et al. (2014) conclude that one approach to bridging the gap would be for researchers to increase community based partnerships and to do applied research in clinical settings that is of interest and value to clinicians. The studies described in this dissertation are examples of this type of practice.

The Science to Practice Gap in ASD

A parallel literature exists in the ASD research community. Effective, early treatment for autism symptomology is often associated with better child and family outcomes (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Lovaas, 1987; Makrygianni & Reed, 2010; Reichow & Wolery, 2009). Large practice reviews have been completed to try and increase the adoption of EBP (National Autism Center, 2015; Wong, Odom, Hume, Cox, Fettig, Kucharczyk, Brock, et al., 2014). There are also best practice guidelines on EBP for young children with ASD (National Research Council, 2001). Using meta-analytic data, a review has also been published by the Cochrane Collaboration’s Database of Systematic Reviews on parent training programs for young children with autism (Oono, Honey, and McConachie, 2013) and also on early intensive behaviour intervention (Reichow, Barton, Boyd, & Hume, 2014). There have also been publications on identifying the “active ingredients” of autism treatment (Kasari & Smith, 2013) and attempts to identify “common factors” that bridge theoretical models to bring unity to the field of ASD treatment (Schriebman, Dawson, Rogers, Ingersoll, Kaiser, Kasari, et al., 2015).

Yet, despite these models and resource guides, adoption of EBP in autism is low, particularly in community practice (Dingfelder & Mandell, 2011). The assumption behind many of the frameworks identified above is that models are not adopted due to a lack of evidence. However, Layzer (2013) articulate a conceptual framework that goes beyond the selection of a particular EBP and focuses instead on the various *processes* that impact the eventual adoption of practices within practice settings. These include agency readiness and preparation factors (i.e., system and partner capacity, staff selection and preparation, specificity of program model, site-specific implementation plan, administrative and supervisory supports, and stakeholder supports); staff and facilitator behaviours (i.e., fidelity adherence to core components, service quality, and adaptation); participant behaviours (i.e., responsiveness, community context); and program outcomes (i.e., service and participant outcomes).

Indeed, many of these barriers were observed while completing this research. Though the researcher had administrative support for the project, some staff initially expressed resistance to the PRT parent training model and indicated preference for other parent training models. This led to challenges both with parent recruitment, staff training and fidelity of the model when implemented. Additionally, staffing turnover and capacity was an on-going issue and one of the level 5 PRT trainers was recruited by another organization mid-way through the project, setting back implementation timelines significantly. It also became clear that as the project proceeded, cultural and language factors needed to be taken into consideration, as they were not fully identified prior to the onset of the research. Finally, the training model was adjusted between the pilot and full study based on fiscal and staffing issues that were extraneous to PRT implementation integrity. For example, the model was changed from 1 hour weekly sessions for 12 weeks (12 sessions) to 1 hour bi-weekly sessions for 5 weeks (10 sessions). To increase adoption and acceptance of the training model, a more senior practitioner was also recruited as the primary implementer. During the pilot study, a paraprofessional trainer implemented PRT, whereas in the second study, a registered speech language pathologist led the implementation. All of these factors influenced the adoption of PRT in this setting and made implementation and evaluation much more complex than originally anticipated.

As another way of understanding the complexity of implementation, Rogers (2003) frames the adoption of new technologies and practices within diffusion of innovation theory. In this model, adoption of a practice is dependent on social context, the innovation itself, time, communication channels and adopter characteristics. Within the framework, the decision to accept a new practice is based on a process consisting of four stages: dissemination, adoption, implementation and maintenance. During the dissemination stage, potential users are made aware of a new practice, and during the adoption stage, potential users choose to accept or reject the new technology. Once a decision to adopt an intervention is made, implementation begins. Dingfelder and Mandell (2011) comment that in autism intervention, this is a common time for modification and change of the new technology to fit local context, a finding observed in this project. Finally, once a technology has been adopted and implemented, a shift is made to maintenance and sustainability.

Rogers theory is comprehensive and can inform the research to practice gap in many ways. First, by paying attention to social context, researchers and practitioners are more apt to choose interventions for implementation that are a better fit for local values, needs, and family, individual, and administrator priorities. Dingfelder and Mandell (2011) comment that in traditional research models contextual factors are often treated as “nuisance variables” (p. 603) rather than as a rich source of adoptive characteristics. Second, by better understanding communication channels, staged models of adoption and adoptee characteristics, researchers can better tailor intervention models to ease implementation adoption, and can provide better support in the implementation and maintenance phases. Finally, understanding the process of how technologies are adopted or not, as well as the social processes informing that adoption, informs researchers as to how to better present novel interventions for practice, and to do so in a manner that facilitates higher adoption rates.

As one applied example, Rogers identifies that new technologies are more likely to be adopted when they display 1) relative advantage to the user; 2) are perceived as simpler to use than current technologies; 3) are compatible with existing practices, values, and needs; 4) there is opportunity to trial new innovations on an experimental basis before committing to full adoption, and; 5) the positive results are observable to others – particularly stakeholders. Relative advantage is a key aspect of the decision to adopt a new technology. In this stage, the decision to adopt a novel practice is based not only on better evidence, but the perception of relative advantage for the user of the new technology. As such, users of new technologies must be persuaded that the new innovation will be "better than the idea it supersedes" (p. 229). In this respect, enhancing adoption of EBP must pay attention to these social processes, as well as levels of evidence, and it is through these processes that this package of studies aims to bridge the research to practice gap in autism treatment.

Aspects of Roger's theory were observed as this research project proceeded. Staff that were initially resistant to PRT were more likely to adopt its use when they observed its relative merit, identified its unique contributions, were able to trial it without fully committing, saw that it was compatible with their current practices, observed it being implemented by a trusted and senior staff member and heard from both parents and trainers on the value of the model.

Administrative support for the PRT model also increased potential adoption. Reporting back to the research community on contextual modifications also informs on those aspects of the program that are of value to adoptees, and identifies if program effectiveness is maintained treatment when modifications are made. Though this aspect of the research program was not directly measured, the service provider had made a more decisive commitment to fully adopt PRT as a central model of practice by the end of the research project providing evidence of improved sustainability of an EBP.

Bridging the Gap between ASD Research and Practice

This dissertation builds on this current literature by bridging the research to practice gap in an applied setting in Western Canada. Building on Rogers (2003) diffusion of innovation theory, EBP are more likely to be adopted if they are perceived as less complex, have better anticipated outcomes, there is opportunity to trial the new practice, there is access to trained expertise and training, resources are available, and results are visible to external stakeholders. This series of studies extends this literature by demonstrating partnership with an existing community ASD provider to evaluate adoption of a manualized EBP, demonstrates trialability and experimentation with a new measurement technology (LENA), and enhances visibility of an evidence based training model to internal and external stakeholders.

Goal 1: Critical Measurement Evaluation

The first goal was to critically evaluate measurement tools that are used in community-based treatment evaluation, in a critical review similar to that described by Bloom & Tam (2015). Key objectives were to include identification of tool use, shortcomings and strengths, and to explore whether new measurement technologies could be used as a means of embedding process and outcome oriented tools into community settings in a feasible, ecologically valid, and effective manner.

In the first study, *The Standards for Educational and Psychological Testing* (AERPA, APA & NCME, 1999), a best practice framework for reporting standardized test results, guided the evaluation of 45 ASD treatment studies of young children. Representing twelve countries, fifty-three different standardized outcome measures were classified into one of five theoretical constructs (cognitive, adaptive, language/social, behaviour/ASD, and family wellness) and the name of each instrument, normative group, underlying construct measured, focus of the administration, and frequency of reported use were reported of those tools most frequently used. A secondary analysis was conducted on researcher adherence to published ethical guidelines on test selection, reliability, validity, administration, scoring and reporting using a standardized rating checklist for each study.

Results for the test summaries indicated that adaptive and cognitive tools were the most frequently reported and language, social, behaviour, ASD specific, and family wellness measures were under-presented. An over-reliance on the Vineland Adaptive Behaviour Scales [VABS] (Sparrow, Cichhetti, & Balla, 2005) was identified, as was a plethora of different outcome tools reported on across different treatment studies. A positive finding was the generation of a list of twenty-two most commonly used instruments across all of these categories, providing a more accessible reference for clinicians and researchers to select measurement tools from. This was a specific difficulty identified by Bolte and Diehl (2013) after reviewing 195 prospective ASD treatment trials and identified 289 unique measurement tools, of which the vast majority (61.6%) were only used once.

Ethical test use and reporting results indicated a mixture of strengths and weaknesses. Strengths included clear sample descriptions, linking tests to ASD diagnostic constructs, use of tests normed or designed for individuals with ASD, and the use of multiple sources of information to evaluate treatment outcome. Weaknesses included providing few technical details on the tests chosen, a lack of reporting on minimum user qualifications and training, a lack of reporting on adherence to standardized protocols and test modifications, possible test bias, and test substitution, particularly for cognitive measures. Specific recommendations were provided on adaptive, cognitive, and behavioural measurement as a means to 1) increase the adoption of a smaller pool of standardized tools in ASD treatment studies; 2) to allow for better comparison between treatment groups across different settings regarding outcome, and; 3) to enhance the likelihood of community-based adoption of those tools - as this will allow for a better understanding of treatment effectiveness in various practice settings.

This study serves to improve the research to practice gap by reducing the complexity of measurement tool selection to evaluate ASD outcomes, by reporting on test use in different research settings across international boundaries, by identifying strengths and weaknesses of particular test selection, by educating on ethical test reporting practices, and by sharing these results with stakeholders. Based on Rogers' (2003) diffusion of innovation theory, these are all factors that are likely to increase the probability of adoption of these measurement technologies.

Goal 2: Applied Evaluation of an EBP using LENA

The second goal was completed in partnership with an accredited ASD early intervention service provider in Alberta, Canada, and it was to evaluate if one model of efficacious practice, PRT (Koegel, Openden, Fredeen, & Koegel, 2006) when delivered in a community setting, was implemented as intended by the program developers and demonstrated effectiveness. Key objectives were to provide a comprehensive description of the PRT program as it was implemented in a practice setting, to evaluate fidelity of implementation and teaching, and to determine if participation in this training model improved parent-child communication patterns. A secondary objective was to utilize a new technology, the Language Environmental Analysis System [LENA] (Lena Research Foundation, 2016) as an evaluative process and outcome tool within this practice setting and to explore whether this digital language processor and its accompanying analytic software, has potential as an efficient, reliable, and valid measurement of program effectiveness.

This goal was achieved through two independent effectiveness studies, using single subject design methodology, one building on the results of the other. In the first pilot study, one-parent child dyad was followed as they participated in a community-based PRT parent training model over a 16-week period. In the second study, three parent-child dyads were followed as they participated in a modified version of the PRT training program.

In the pilot study, eighteen independent video and audio recordings of baseline, intervention and follow-up data were evaluated on automated LENA outputs (child, adult, and conversational turns), as well as standardized measures and more advanced LENA analysis using proprietary ADEX software (i.e., ratio of child initiated conversational turns). Detailed descriptive information, fidelity of PRT implementation, PRT content and hypothesized relationships between training condition and communication patterns were appraised.

Results from the pilot study provided a clear program description of the PRT training model in community practice. The LENA was able to be used successfully as an outcome and process measure in this community setting with minimal error and difficulty, providing access to large quantities of reliable and valid communication data, though there were challenges with data stability, and this limited the interpretation. Despite these limitations, a functional relationship between adult talk and training condition was identified, and this relationship was inversely related to child talk. This was an unexpected finding, as most PRT studies report an increase in child vocalizations as a result of PRT parent training (Coolican et al., 2010; Minjarez et al., 2013; Randolph et al., 2012). Unfortunately, given the study design, it was not possible to separate out more select interactions between the key parent and child, and this was adjusted in the follow-up study with a more structured data collection system. In the summary it was concluded that there was value in using new technologies such as LENA as part of an embedded evaluation model, and that evaluating community based practice provided valuable information on knowledge dissemination and the adoption of EBP.

This initial pilot study improved the research to practice gap by focusing on Rogers' (2003) notion of trialability – for both the new LENA technology as a potential measurement tool and for community participation in a formal evaluation partnership. The community provider had not entered into this type of partnership before and this particular training model, though based on an EBP, had never been subject to formal research evaluation. Trialing the new technology, identifying if its use was compatible with existing measurement practices, and sharing the results with the provider, the practice community, and broader ASD research community, all increased the likelihood of eventual adoption.

This likelihood of adoption and active participation of the community provider was demonstrated in the second study. In this study, the same single subject design methodology was utilized across multiple participants and was designed based on results from the pilot, with some important modifications. First, the provider shortened the parent training program from 12 to 5 weeks and provided it in a much more intensive format (hourly training sessions twice per week vs. hourly training sessions once per week). This decision was based on situational variables of value to the service delivery system, not research efficacy evidence. Second, the provider increased the base training level for the parent trainer, from a paraprofessional general trainer with PRT certification to a Master's level regulated health professional with PRT certification. This decision was based on some measure of efficacy evidence, as the provider identified performance concerns with a parent trainer implementing at the paraprofessional level.

Based on results from the pilot study, the research team made the following modifications. First, the collection of information regarding the training format and model was systematized using a standardized minute-by-minute coding sheet across all data collection sessions. This allowed for more advanced analysis of data collected within sessions and allowed for more nuanced comparisons within the training condition. This also allowed for more complex analysis using the LENA and ADEX software systems that was not possible in the pilot study. Second, the research collection process was expanded to include the training and usage of research assistants to increase adoption of research capacity in community practice. This involved further partnership with the provider, accessing and training from their volunteer pool, further increasing awareness and observability of the training model in practice, as well as the use of the LENA technology.

With these modifications, a non-concurrent multiple-baseline single-subject research design across participants was implemented for three parent-child dyads of pre-schoolers with ASD. Dyads participated in a 5-week training model, 2 hours per week, producing 46 independent recordings and data was collected on baseline, training and follow-up phases. Similar to the pilot, independent video and audio recordings were evaluated on automated LENA outputs (child, adult, and conversational turns), as well as standardized measures and more advanced LENA analysis using proprietary ADEX software. Detailed descriptive information, fidelity of PRT implementation, PRT content and hypothesized relationships between training condition and communication patterns were appraised.

Results from this more comprehensive design provided an updated program description, including teaching formats and topics, and detailed parent and child participant information. Good implementation integrity of PRT was again identified and demonstration of PRT learning improved for all parents though only one parent met full fidelity. The LENA as a data collection tool was highly reliable and few errors were observed.

Extending the pilot findings on LENA results, patterns of parent and child talk were evaluated and results were mixed. First, it was apparent that the presence of a trainer highly impacted the frequency of adult talk and this effect moderated substantially when the trainer was no longer present. Second, expected increases in child utterances were inconsistently observed as a result of participation in the training model and this was not moderated by fidelity of implementation in PRT. This was an unexpected finding as other studies on PRT parent training have identified increased child utterances as a result of participation in these types of models (e.g. Hardan et al., 2015). Third, within the shortened teaching period (10 hours), the majority of parents did not demonstrate PRT fidelity, and this indicates that there may be benefit to a longer or more intensive training period. This latter finding exemplifies the difficulties in bridging the research to practice gap, as PRT parental fidelity did not meet hypothesized expectations, and supports the loss of integrity in treatment models as they are disseminated out of research settings. Fourth, the use of LENA demonstrated the high variability that results in parent-child communication when observing children and their parents in natural settings, and this provides a window into how difficult it can be to impact and evaluate change within those settings.

In conclusion, the opportunities and barriers of using new technology such as LENA to evaluate community based EBP are discussed and evaluated – particularly as an augmentative form of natural language sampling that is a recommended component of expressive language evaluation. This paper also compares and contrasts PRT fidelity of implementation data with other published PRT parent training programs and identifies strengths and weaknesses in this particular model of implementation. This study contributes to reducing the research to practice gap by embedding research into community practice, evaluating the use of new technology across multiple participants, sharing both strengths and weaknesses in implementation with the provider, and documenting process variables impacting service delivery systems. In particular, this study demonstrated the importance of evaluating EBP in community settings, as significant modifications and adjustments were made based on administrative and practical considerations, and these changes would not have been documented if this partnership had not been established.

Summary and Conclusions

Autism Spectrum Disorder (ASD) is a social communication disorder of unknown origin that has risen in prevalence over the last 40 years (Centers for Disease Control and Prevention, 2016) and often impacts not only the individual, but also those that support the individual with an ASD diagnosis (Strauss, Vicari, Valeri, D’Elia, Arima, & Fava, 2012). Parallel to this increasing diagnostic rate, there has been an increase in the science of how to provide evidence-based practice (EBP) for this vulnerable population (Wong, Odom, Hume, Cox, Fettig, Kucharczyk, Brock, et al., 2014). Despite the availability of practice guidelines and EBP for individuals with ASD (e.g. National Research Council, 2001; National Autism Center, 2015), the gap between research and practice continues to be large (Dingfelder & Mandell, 2011; Kasari &

Smith, 2013; Stahmer, 2007). It is important to close this gap in community based treatment as this is where the vast majority of individuals with ASD receive their primary supports.

This series of studies demonstrate that paying attention to social context enhances traditional understandings of EBP, an important consideration as adoption has been poor (Gyani, Shafran, Myles, & Rose, 2014). Using Rogers (2003) diffusion of innovation theory, this series of studies aims to reduce the research to practice gap by increasing perceived advantage of adopting EBP through trialing new models and technologies, assessing compatibility with existing processes, structures, and values, minimizing complexity, and sharing innovations with important stakeholders. This combination of studies; as well as the policy paper attached in the appendix - are practical examples of how researchers can engage with decision makers to influence the adoption of evidence-based practice in community settings.

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Appendix A: Introduction to Policy Paper

Title. An analysis of autism policy, supports and best practices in Alberta: Literature review, recommendations and key questions for a provincial clinical advisory panel

Background. Bridging the research to practice gap is not only a process of empirical inquiry, but it is also a social process that requires research innovations be communicated through multiple channels, over time, and through the social system (Rogers, 2003). Common barriers to implementation of these innovations include practitioner motivation, organizational barriers in service sector settings, training needs, and supervision requirement for practitioners in practice settings (Wood, McLeod, Klebanoff, & Brookman-Frazee, 2014). Evidence-based practices are more likely to be adopted if they are perceived as less complex, have better anticipated outcomes, there is opportunity to trial the new practice, there is access to trained expertise and coaching, resources are available, and results are visible to external stakeholders (Dingfelder & Mandell, 2011).

In Alberta, despite having one of the most generous funding models for autism supports (Madore & Pare, 2006) there is no clear framework for evaluating the implementation of evidence-based practice in the community, despite expert panel recommendations to do so (Alberta Children's Services, 2002). This report was prepared at the request of the Honorable Minister of Children's Services, Mr. David Hancock, to outline key questions, and highlight gaps between policy and practice, as they impact autism service provision across the lifespan in Alberta. This paper was presented to Mr. Hancock, and at his request, was also distributed to the departments of Education and Children's Services for information. The paper was also submitted as part of a social policy review process that was undertaken by the Alberta Government in 2012-2013.

Organization of the Report. The 47-page report was divided into three sections to make it more accessible to a lay audience: 1) background and context for autism supports in Alberta, 2) diagnosis and support guidelines, 3) Alberta legislation and policy for autism, 4) autism supports across the lifespan and 5) lifetime costs and future questions. The report was professionally published and formatted to make it more accessible to government. The first section outlines prevalence rates and the history of autism supports in Alberta, including a historic expert panel review and recommendations (ACS, 2002). The second section outlined diagnostic information, stability of diagnosis, common comorbidities, family stressors and the evidence base for best practices literature on treating ASD. The third section interprets and applies three bodies of legislation that impact individuals with autism in Alberta: 1) Children's Services and the Family Support for Children with Disabilities Act, 2) Alberta Education and the School Act and 3) Adults and Persons with Developmental Disabilities Community Governance Act. The fourth section summarizes intervention literature across key developmental life stages included infant and toddler, preschool, school-aged, adolescent, and adulthood. The fifth section summarizes costs associated with supporting autism across the lifespan, and identifies 17 questions for a recommended clinical advisory panel to consider.

Analysis. Each legislative Act and its implementation were evaluated on alignment with ASD best practice and treatment evidence for each developmental stage. Key successes and concerns were highlighted for each Act, and concrete questions were provided to guide policy makers in each of these areas.

Conclusion. Bridging the research to practice gap is a social process that requires a complex integration of empirical and translational research practices. This paper summarizes the state of evidence for autism supports across the lifespan, identifies policy gaps and successes, and is a positive example of influencing key decision makers not only through science, but also through policy evaluation and stakeholder engagement.

Appendix B: Policy Paper on ASD Supports Across the Lifespan

An Analysis of Autism Policy, Supports and Best Practices for Alberta

Literature Review, Recommendations and Key Questions for a Provincial Clinical Advisory Panel

October 1, 2012

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An Analysis of Autism Policy, Supports and Best Practices for Alberta

Literature Review, Recommendations and Key Questions for a Provincial Clinical Advisory Panel

Prepared For:

Honorable Dave Hancock
Minister of Human Services
Legislative Assembly of Alberta

Report Date:

October 1, 2012

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Executive Summary

Autism Spectrum Disorder (ASD) is a complex, lifelong neurodevelopmental condition that is estimated to impact 1 in 88 children in the general population (Centers for Disease Control and Prevention, 2012). ASD is diagnosed on the basis of established patterns of social communication delays, paired with rigid, repetitive behavioral mannerisms that interfere with daily living (American Psychiatric Association, 2004). ASD is also often associated with a wide variety of other health difficulties, resulting in heightened family distress and a need for coordinated supports across multiple ministries, settings (home, school and community) and service delivery mechanisms.

In the context of Alberta, specialized supports for ASD have been funded primarily through Children's Services since the 1990s, and at this time home-based supports are embedded within the more general Family Supports for Children with Disabilities (FSCD) legislation, and school-based supports embedded in the School Act. Adult supports are funded through Persons with Developmental Disabilities (PDD). Despite significant advances in the research literature around evidence based practice for this condition, no specific FSCD, School Act or PDD legislation specifically addresses autism support in Alberta at this time.

In this report, it is recommended that an updated provincial clinical advisory panel for ASD supports, with input from families and individuals impacted by autism, provide updated recommendations for the Alberta government on an integrated lifespan model that would span funding mechanisms (health, education, human services), practice jurisdictions (urban and rural), ages, family types, and cultural communities. The need for an updated clinical advisory panel is as follows:

- In 2002, Alberta Children's Services commissioned a report "A System of Care for Children with Autism" with 16 recommendations. After 10 years, it is time to revisit those recommendations to determine if they have been fulfilled, can be discarded, or need to be revised.
- Prevalence estimates for ASD have been increasing from 5 in 10,000 (1965) to 1 in 88 (2012) and autism supports are poised to consume increasing amounts of public dollars, particularly if there is no coordinated plan.
- Though ASD diagnostic services for young children have become far more consistent and timely, diagnostics for older children, adolescents and adults continue to be fragmented, making it unclear if individuals diagnosed in one region would qualify for an ASD diagnosis in another. Qualification for supports and support models also vary significantly across regions.
- Evidence-based treatments exist for ASD (National Autism Center, 2009) and practice guidelines and best practice recommendations are well documented (National Research Council, 2001). Despite these publications, evidence-based supports in Alberta are still lacking and there are few quality controls, training mechanisms, legal requirements, or policy guidelines to increase their presence.

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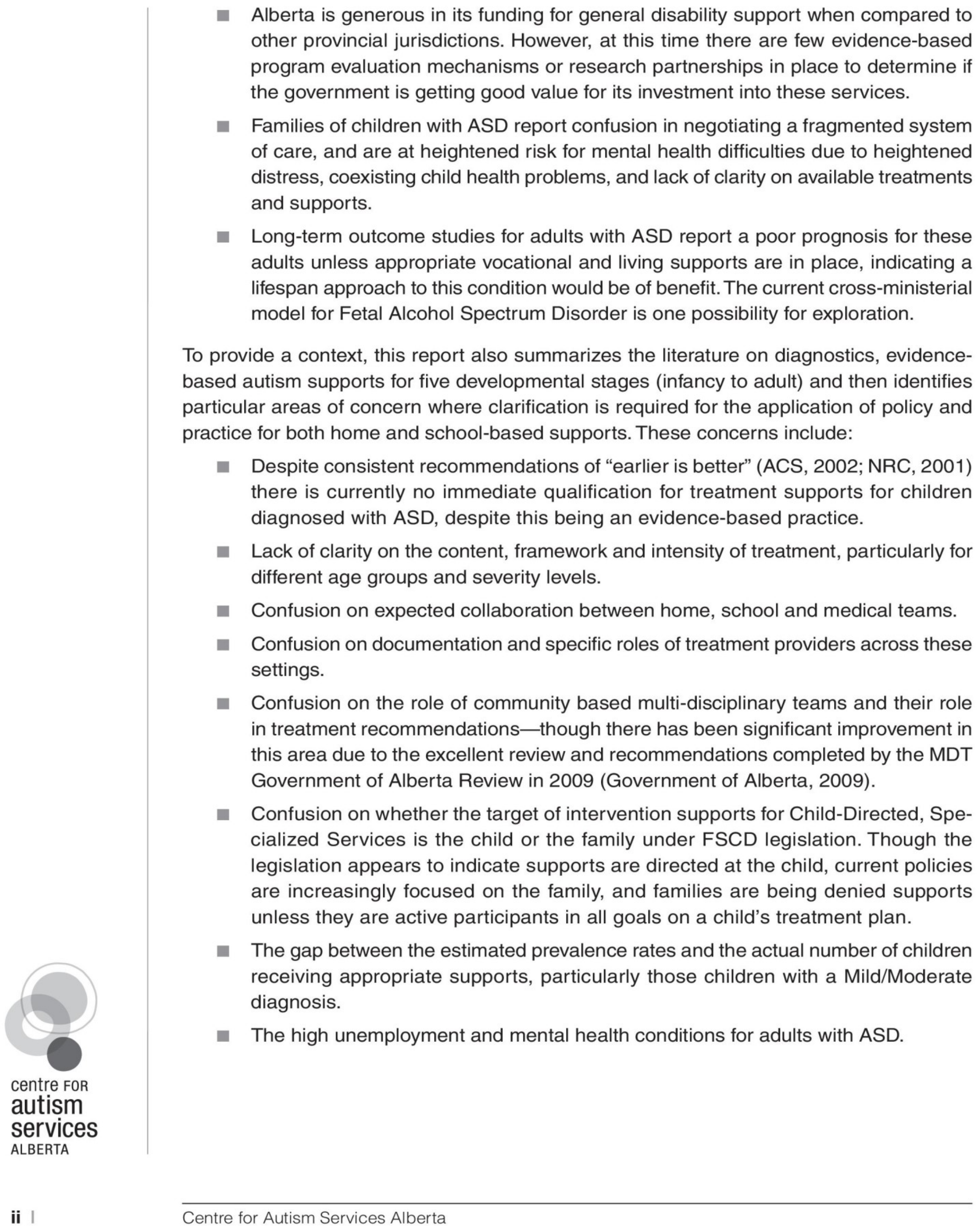

- Alberta is generous in its funding for general disability support when compared to other provincial jurisdictions. However, at this time there are few evidence-based program evaluation mechanisms or research partnerships in place to determine if the government is getting good value for its investment into these services.
- Families of children with ASD report confusion in negotiating a fragmented system of care, and are at heightened risk for mental health difficulties due to heightened distress, coexisting child health problems, and lack of clarity on available treatments and supports.
- Long-term outcome studies for adults with ASD report a poor prognosis for these adults unless appropriate vocational and living supports are in place, indicating a lifespan approach to this condition would be of benefit. The current cross-ministerial model for Fetal Alcohol Spectrum Disorder is one possibility for exploration.

To provide a context, this report also summarizes the literature on diagnostics, evidence-based autism supports for five developmental stages (infancy to adult) and then identifies particular areas of concern where clarification is required for the application of policy and practice for both home and school-based supports. These concerns include:

- Despite consistent recommendations of “earlier is better” (ACS, 2002; NRC, 2001) there is currently no immediate qualification for treatment supports for children diagnosed with ASD, despite this being an evidence-based practice.
- Lack of clarity on the content, framework and intensity of treatment, particularly for different age groups and severity levels.
- Confusion on expected collaboration between home, school and medical teams.
- Confusion on documentation and specific roles of treatment providers across these settings.
- Confusion on the role of community based multi-disciplinary teams and their role in treatment recommendations—though there has been significant improvement in this area due to the excellent review and recommendations completed by the MDT Government of Alberta Review in 2009 (Government of Alberta, 2009).
- Confusion on whether the target of intervention supports for Child-Directed, Specialized Services is the child or the family under FSCD legislation. Though the legislation appears to indicate supports are directed at the child, current policies are increasingly focused on the family, and families are being denied supports unless they are active participants in all goals on a child’s treatment plan.
- The gap between the estimated prevalence rates and the actual number of children receiving appropriate supports, particularly those children with a Mild/Moderate diagnosis.
- The high unemployment and mental health conditions for adults with ASD.

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Introduction

Autism is a neurodevelopmental condition of unknown origin that consists of delays in communication skills, socialization skills and is accompanied by repeated and restricted behavioral interests (American Psychiatric Association, 2000). The average age of diagnosis in Alberta is between 3-4 years of age, males outnumber females by approximately 5:1 (Burstyn, Sithole, & Zwaigenbaum, 2010), and an autism diagnosis is often accompanied by other mental health and physical difficulties, resulting in heightened family stress and an array of integrated supports (The Standing Senate Committee on Social Affairs, Science and Technology, 2007). The purpose of this review is to provide a summary of current literature regarding a lifespan approach to autism supports and services, to provide key questions on autism supports that would benefit from recent input from a panel with autism expertise, and to identify gaps between current government policy and legislation and evidence-based practice.

In this review for the government of Alberta, Part I describes recommendations from an earlier expert panel of both parents and autism experts, “A System of Care for Children with Autism” (ACS, 2002). Part II reviews diagnostic practices and incidence rates in Alberta, as well as additional family stressors, best practices literature and how other provinces are responding. In order to understand the present day context of autism in Canada, Part III reviews Alberta legislation and policy as it intersects with these identified needs with a focus on the following: the Family Support for Children with Disabilities Act, the School Act, and the Adults and Persons with Developmental Disabilities Community Governance Act. Part IV offers a current review of the literature on supports for autism across the lifespan, including the following age categories: 0-3 years, 4-6 years, 7-12 years, 13-17 years and adulthood and finally, in Part V, specific recommendations and areas of focus that require support from a clinical advisory panel, including parents, are identified.

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Part 1: Background and context for autism supports in Alberta

In 2002 an expert panel report entitled “A System of Care for Children with Autism” was commissioned by the Government of Alberta through the Ministry of Children’s Services. The specific aim of the report was to address the increased demand for Intensive Behavioural Intervention (IBI), a program that consists of “intensive one-to-one teaching based on behavioral strategies, a structured, routine program that is developmentally appropriate and based on the child’s individual goals as well as health therapies … as recommended by the assessing health professional” (Alberta Children’s Services, p. 10, 2002). IBI for young children with autism had been funded through Children’s Services since the late 1990s.

Much of the support for ASD treatment and IBI began with a seminal study by Lovaas (1987) who reported that up to 47% of preschool children diagnosed with ASD could achieve average scores on standardized measures of intelligence after receiving 40 hours per week of behaviourally based intensive intervention for at least 2 years. Dominant features of the behavioural model are an emphasis on discrete trial teaching, one-to-one teaching, the use of behavioural methodologies to shape desired behavior, use of a curriculum, and treatment intensity by well-trained personnel (Lovaas, 1987). More recent versions of the model have placed additional emphasis on parent training and natural teaching opportunities (e.g., Goin-Kochel, Myers, Hendricks, Carr, & Wiley, 2007). In general, this comprehensive, behavioural based model for autism intervention is called IBI, and when provided to preschoolers and younger children, it is called Early Intensive Behavioural Intervention (EIBI). EIBI and IBI continue to be a dominant influence in much of autism intervention literature (Reichow & Wolery, 2009) and EIBI is now considered to be an evidence-based intervention with significant research support (The National Autism Center, 2009).

Since 1987, numerous EIBI studies have provided complexity to the early Lovaas findings with additional moderating variables such as initial I.Q., emergent language, and age of treatment entry effecting outcomes (Howard, Sparkman, Cohen, Green, & Stanislaw 2005). Makrygianni & Reed (2010) in a meta-analysis of 14 studies concluded that EIBI programs were more effective than controls at improving intellectual, language and adaptive functioning and that program intensity was positively correlated with intellectual ability and adaptive behavioural functioning for preschoolers diagnosed with an ASD.

In Alberta, intensive behavioural intervention (IBI) was initially funded through Resources for Children with Disabilities (RCD, later renamed Family Support for Children with Disabilities in 2004) and in 2002 funding was supposed to be restricted to three years of programming per child with autism, up until to the age of 6 years, though this time restriction has rarely been enforced. In fact, for children under 6 years of age, Alberta Education and FSCD; Preschool Unit Funding (PUF) and Specialized Services funding were originally combined to provide a full 40 hours of intensive support, though this funding model has gradually faded over time, and is much less prevalent currently.

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According to the ACS (2002) report, at the time of school entry, schools were expected to provide an appropriate level of support, as per the School Act. However, at the time of the 2002 report many families indicated they were not getting appropriate support through the schools, and hence were requesting extensions for school-aged children through RCD for additional IBI supports to augment their school programming. In fact in 2002, 50% of the 318 children receiving IBI supports were reported to be school aged, despite IBI being designed at that time as primarily a preschool aged intervention. One primary reason for the discrepancy was a reported lack of appropriate community-based supports for school-aged children with autism—hence families continued to lobby for ongoing after school home-based IBI support for their children (ACS, 2002). The report also identified concerns about regulatory standards for autism service providers, quality assurance, and a lack of clarity over which government agency should be providing the funding for school-aged children (i.e., Alberta Learning or RCD).

At that time, the ACS (2002) 12-member expert panel of parents, government representatives, and health-care professionals, chaired by Dr. Margaret Clarke, Division Head of Developmental Pediatrics and Adolescent Medicine, Alberta Hospital, made 16 recommendations to guide an overall system of care for children with autism, and to provide guidance on how to address the needs of children diagnosed with autism. The paraphrased recommendations are as follows:

1. Ensure availability of Early Intervention Programs in all regions for early screening and one component of early treatment in very young children (under 18 months of age).
2. Adopt a new diagnostic entry system in order “to ensure appropriate intervention as early as possible”.
3. Diagnostic assessments should include statements on a child’s developmental needs and functional abilities to recognize the degree of variability within autism, and to ensure an appropriate matching of intervention supports.
4. Establish at least two Centres of Excellence in Edmonton and Calgary with specialized cross-disciplinary autism teams to guide diagnostics, monitor progress, liaise with community providers, support transition planning, and be “closely linked” to Children’s Services and Alberta Learning.
5. Implement a developmentally based system of care with Enhanced Early Intervention (18-30 months of age), Intensive Early Autism Intervention (2.5 years to Grade 1 entry), and School Aged Services (6 years +). A three year pilot was recommended for school-aged supports, with a program evaluation component to determine its effectiveness.
6. Use regular developmentally appropriate and functional assessments to guide individual programming.
7. Enhance cross-ministerial funding for school-aged children with complex needs who require coordinated involvement from all three ministries: Alberta Learning (AL), Children’s Ministry (CM) and Health and Wellness (HW).

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8. Develop a multi-disciplinary Clinical Advisory Panel, with parent representation, to provide expert consultation to all three ministries (AL, CM, and HW). Possible areas for expert guidance identified included diagnostics, service provider qualifications / certifications, development of best practice guidelines for autism, monitoring of existing programs, facilitating a distance learning program for professionals and para-professionals, and to identify research needs.
9. Move away from regional Children's Services funding to a provincial funding model to ensure consistent access to services, and high quality, cost-effective service.
10. Develop an "Essential Components" document for school programs to provide guidance on appropriate educational strategies for children with autism.
11. Develop "Best Practice" guidelines for "Intensive Intervention" for preschool children with autism, with a goal of using these guidelines to establish a service provider certification process.
12. Develop a certification process for service providers based on "Best Practice" standards to support home, centre and school based program options.
13. Develop an information resource kit for parents and professionals.
14. Develop training packages providing a core of essential information for professionals.
15. Provide incentives and supports for professionals to access training including release time and local mentorship.
16. Collect data on outcomes for IBI programs and introduce a strong program evaluation and accountability framework for those providing intensive intervention. (ACS, 2002).

As of 2012, it is not clear how many of these recommendations have been implemented, if they are still relevant due to changing policy and new research, and if additional concerns have arisen in the current context of Alberta. The purpose of this review is to provide updated literature on the current state of research support for intervention for individuals with autism, to identify areas that require input from a clinical advisory panel on the provision of appropriate lifespan supports for those impacted by autism, to extend the focus of support beyond school-aged children and into adolescence and adulthood, and to identify key questions for an updated clinical advisory panel to address for the government of Alberta.

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Part II: Diagnosis and support guidelines

Prevalence and diagnosis

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder of unknown origin that is typically diagnosed in childhood based on qualitative impairment in communication and socialization skills, as well as the presence of repetitive behavioural mannerisms that interfere with daily functioning (American Psychiatric Association, 2000). ASD can be differentiated from the more generic term "autism" which is more narrowly defined in the Diagnostic and Statistical Manual, 4th edition (APA, 2000) as requiring documented delays in language ability prior to 3 years of age, and has a more stringent criteria of "meeting six symptoms across three domains of qualitative impairment in social interaction, communication, and restricted repetitive and stereotyped patterns of behaviour, interests and activities" (Gotham, Bishop, & Lord, p. 32, 2012). The full diagnostic criteria for Autism are listed in Appendix A as an attachment.

By comparison, ASD encompasses a wider variety of pervasive developmental disorders including Autism, Asperger's Syndrome, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). These diagnostic distinctions are currently being collapsed in the proposed criteria in DSM-V (APA, 2011) as they have not been supported in the more general research literature, and have not been applied uniformly (Zwaigenbaum, 2012) leading some researchers to speculate that diagnostic rates will decrease with a more consistent algorithm (Matson, Hattier, & Williams, 2012). The proposed DSM-V diagnostic criteria includes the identification of 5 symptoms across 4 criteria: a) persistent deficits in social communication and social interaction across contexts, b) restricted repetitive patterns of behavior, interests or activities, c) symptoms must be present in early childhood, and d) symptoms must limit and impair everyday functioning (APA, 2011). In short, what all of these conditions share in common are functional problems with social communication, social-cognitive deficits, impairment in social reciprocity, difficulties in verbal and non-verbal communication, and restricted interests and behaviours that interfere with daily living (Gotham, Bishop, & Lord, 2012) and these symptoms are consistent with the proposed DSM-V criteria. For the purposes of this paper, autism and ASD are used interchangeably as this reflects common clinical practice.

Best practices for autism diagnoses include pediatric screening prior to 24 months to facilitate early diagnosis and intervention (American Academy of Neurology, 2012), an emphasis on understanding the unique strengths and challenges of the child through comprehensive, multi-disciplinary assessment; the use of specially designed, standardized tools to measure autism symptomatology; demonstrated sensitivity to family circumstances; inclusion of the family in the assessment process; a full medical work-up to address medical complexities in the diagnostic process; and the need for follow-up and referral supports to ensure appropriate supports and intervention are provided and available (Warren & Stone, 2012).

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In Alberta, no specific guidelines for autism diagnosis have been endorsed to my knowledge, and an autism diagnosis may be provided by an individual health care provider such as a psychologist, psychiatrist or family practitioner, or by a regional health care team. However diagnosis for young children, under the age of six, is generally completed at regional hospitals using multi-disciplinary teams to ensure that other health conditions have been considered and consist of standardized testing in intellectual, language, social, adaptive and behavioural functioning by specially trained professionals over multiple days. The specific percentage of at-risk children for ASD that receive this type of comprehensive assessment is unknown, though it is likely a small percentage given estimated diagnostic rates of 1 in 88 children in the general population (Centers for Disease Control and Prevention, 2012). In order to be considered for a formal ASD diagnosis, children must demonstrate considerable delays in their ability to play and relate to others, in their functional use of language, and must have a high number of readily identifiable unusual behavioural rigidities and mannerisms in order to qualify for a diagnosis.

Positively, in Edmonton, all ASD diagnoses for young children referred from Northern Alberta are completed using the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, Goode, Heemsbergen, Jordan, Mawhood, & Schopler 1989) considered the "gold standard" in ASD diagnosis. The ADOS is completed by presenting the child with a variety of standard tasks, coding the child's performance on those tasks, and then applying an algorithm to identify the presence of ASD symptomology. The ADOS is only one part of a diagnostic battery that includes clinical interviews, a medical work-up, a multi-disciplinary assessment of cognitive, language, adaptive, and motor skills, and a comprehensive report recommending specific services and supports. For older children, adolescents and adults, there is no systematic means that I am aware of to facilitate diagnosis of ASD. I am also unclear how much the ADOS is used as a primary diagnostic support tool in Southern Alberta.

However, at least for young children who are assessed by a full multi-disciplinary team, this level of diagnostic rigor means that 1) ASD diagnoses are highly stable and unlikely to change, 2) children must display significant developmental delays across multiple domains in order to obtain the diagnosis, and 3) the actual rate of diagnosis is much lower than other published ASD estimates in the general population. For example, Burstyn, Sithole & Zwaigenbaum (2010) analyzed 218,890 singleton birth records of Alberta children born between 1998-2004 and reported that peak ASD diagnosis was between 3-4 years of age for both genders, that ASD was 5 times more prevalent in males than females, children were getting diagnosed at increasingly younger ages, and that actual prevalence rates were between 3.0-5.2 per 1000 children depending on type of analysis used. This contrasts with recently published estimates by the Centers for Disease Control and Prevention (2012) of 11.3 per 1000 children (see Figure 1), a much higher estimate that has been rising consistently since measurement began in the 1970s, and is more than double that reported by Burstyn, Sithole, & Zwaigenbaum (2010).

Rising ASD rates have raised concern that autism is now becoming an "epidemic". However, Holmes & Jones (2012), citing Centers for Disease Control and Prevention (CDC) data, attribute rising ASD rates to better surveillance, changes in coding criteria within the public

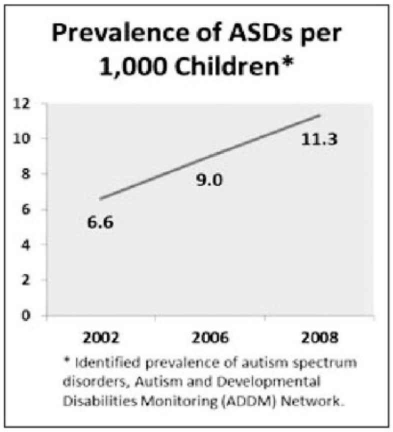

Figure 1: Autism prevalence rates in the United States (Centers for Disease Control, 2012)

education systems that provide higher allotments of funding for children coded with autism, the inclusion of children with higher cognitive functioning in the autism category that previously would not have been included, and the likelihood that many children who used to be diagnosed with developmental delay (i.e. an "intelligent quotient" of below 70 points) are now being diagnosed with co-morbid autism. Regardless, rates of ASD have been rising, are of concern, and a coordinated response by government would be beneficial to ensure that available resources are utilized in the most effective manner.

In the United States, we see evidence of a government response in the Combating Autism Act of 2006, an Act that was reauthorized in 2011 and provides comprehensive federal funding for autism screening, diagnosis, research, the establishment of Centres of Excellence, and the provision of evidence-based intervention—particularly for young children and those within the school systems (Congressional Research Service, 2012). Under the Act, children can qualify for evidence-based intervention through a variety of initiatives and funding partners and for fiscal year 2011, $21,000,000 was allotted for developmental disabilities surveillance and research, $52,000,000 was allotted for autism education, detection and early intervention, and $158,000,000 was allotted for interagency collaboration (United States Government Printing Office, 2006). No parallel legislation currently exists in Canada as Health, Education and Children's Services are considered provincial jurisdictions. As an example of how this translates into clinical practice, under Part C of the Individuals with Disabilities Education Act (IDEA) legislation, it is mandatory for any child under 36 months, identified by a health professional with risk factors for autism to be referred for appropriate intervention, that intervention must be provided in natural settings as much as possible, interventions must be evidence based, and an individualized family service plan is required (United States Government, 2004). The full IDEA act that identifies what is "free appropriate public education" (USG, p. 6, 2004) for children with disabilities, up to the age of 21, is available at http://www.copyright.gov/legislation/pl108-446.pdf.

If conservative diagnostic estimates of 5.2 per 1000 children (Burstyn et al., 2010) are applied to Statistics Canada (2006) census data for Albertan children 0-14 years of age (631,515) it is then estimated that up to 3,284 children in this age group would conservatively qualify for an ASD diagnosis in Alberta. However, using CDC (2012) most current estimates of 1 in 88 children, it is possible that up to 7,176 children may lie somewhere on the ASD spectrum, though there is debate about how best to classify many of these children, given the possibility of overlapping diagnoses with other health conditions (Rapin, 2011). Regardless, these diagnostic estimates indicate that ASD is more prevalent than many of the other leading children's diagnostic categories, requiring an informed response by government. By way of comparison, Fetal Alcohol Spectrum Disorder (FASD) has an estimated prevalence rate of 2 to 9 per 1000 children in Alberta (Tough, 2009) and proactively, the government has created an Alberta FASD cross-ministerial committee to support a lifespan strategy to FASD initiatives including awareness and prevention, assessment and diagnosis, and research and support for individuals and caregivers (Alberta Human Services, 2012). Given the above ASD estimates, a similar plan may be of benefit for autism.

Additional Stressors and Concerns

Though ASD is diagnosed on documented delays in language, social abilities and repetitive, restricted behaviours it is also associated with a wide range of other health, emotional and behavioural difficulties. Based on a review by Geschwind (2009) 94% have sensory abnormalities (spinning, rocking, hand-flapping, etc.), 15-40% have developmental regression (gaining skills normally and then losing some of them), 60-80% have motor signs (unusual gait, toe walking, poor muscle tone), 5-10% have gross motor delay, 50% have sleep disturbances, 4-50% have gastro-intestinal problems, 6-60% display seizures, and 25-70% have an additional psychiatric diagnosis (depression, anxiety, aggression, conduct problems, attention deficit hyperactivity disorder are most prevalent). These additional difficulties can place immense tolls on families and support systems for these children and an array of multi-disciplinary supports are often necessary.

Compounding these concerns, parents and families of children with ASD are also often at risk due to increased parental stress. Baker-Ericzen, Brookman-Fazee, and Stahmer (2005) surveyed parents of toddlers diagnosed with autism and report that both mothers and fathers of children with ASD report much higher levels of stress than the typical population, and that mothers in particular were at a higher risk of depression. Supporting these findings, Meyer, Ingersoll, and Hambrick (2011) identified elevated maternal rates of depression in families of a child with ASD, as well as sibling adjustment difficulties, and found that maternal depression also played a significant role in predicting how well adjusted siblings were. Estes, Hus, & Elder (2011) report that approximately 33% of mothers of children with ASD report clinically significant levels of depression, rates much higher than for similar conditions such as Down Syndrome (10.3%). Finally, Holmes and Jones (2012) report that up to 80% of families are at risk for divorce, if they have a child diagnosed with autism.

Fragmented funding, poor policy coherence, and a lack of integrated supports can compound these stressors. The Standing Senate Committee on Social Affairs, Science and Technology (2007) in the report "Pay Now or Pay Later: Autism Families in Crisis" identified a patchwork system of autism supports across Canada with provincial inconsistency on treatment funding, disagreement on the best combination of treatment options, and varying wait times and treatment options from region to region. It also found that parents and families often had great difficulty negotiating a complex system coordinated through multiple governance bodies, providing additional stress to an already overloaded family system. Specific recommendations included development of a national autism strategy for child, adolescent and adult treatments and supports, identification of funding mechanisms and criteria for those supports, the creation of knowledge centres for autism research, and work with provincial partners to support training and diagnostic needs.

Madore and Pare (2006) in a review of provincial funding across Canada support these concerns and identified a wide range of differences in funding levels and models across the country. In general, funding was supported for children under 6 years of age ranging from $40,000 + per year in Alberta to $6,000 per year in Manitoba, though qualification for the supports was inconsistent. Ten provinces and territories separated out preschool funding from other supports whereas in Alberta this distinction was not made, as all children under 18 years of age are treated equally under the FSCD legislation. Provinces other than Alberta also allocated higher funding amounts to preschool children and then diminished supports as children entered the school system. Specific funding comparisons were difficult as some provinces only reported lump sum funding, rather than on a per-child basis, but in general Alberta provided one of the highest funding levels, with few specifics as to how that funding was to be allocated.

Unfortunately, the effectiveness of community funded interventions for children with ASD are only partially known, as only three provinces (Ontario, Nova Scotia and British Columbia) have any published peer-reviewed mechanism in place for evaluating program impact, a recommendation that was also put forward by the ACS (2002) report for the development of autism supports in Alberta. Alberta has no formal program evaluation model to evaluate autism related services, despite providing the highest funding level of intervention support. As a summary of the kind of program evaluation occurring in the other three provinces, Perry, Cummings, Dunn-Geier, Freeman, Hughes, La Rose, et al. (2008) reported on 322 children receiving Early Intensive Behavioural Intervention (EIBI) in Ontario; Smith, Koegel, Koegel, Openden, Fossum, and Bryson (2010) reported on 45 children receiving EIBI in Nova Scotia; and Mirenda, Smith, Zaidman-Zait, Kavanagh, Bopp, et al. (2005) reported on 70 children receiving EIBI or Interim Early Intensive Intervention (IEII) in British Columbia. Many of the programs used archival data available through diagnostic and follow-up sites, including standardized measurement results on cognitive, adaptive, and language functioning, and in some cases, parental stress.

Encouragingly, all three of these Canadian studies demonstrated positive results for children with ASD, as measured by increased cognitive ability and increased adaptive functioning. Perry et al. (2008) reported estimated intelligent quotient (I.Q.) gains of 12 points for the general sample, a doubling of developmental rate during the intervention period, and for the high functioning group, an I.Q. gain of 21 points. Smith et al. (2010) reported a mean I.Q. gain of 16 points overall, but quite different trajectories on adaptive functioning and autism symptomology when comparing low and high I.Q. participants, with high I.Q. participants demonstrating increased responsiveness to the intervention. After 2 years of intervention, Mirenda et al. (2005) reported I.Q. results on testable and untestable children at intake, and found a 23.7 point gain in testable children, with only a 3.7 point gain in untestable children. As 15 points represents 1 standard deviation, this is a substantial gain in cognitive improvement for this group. Mirenda et al., (2005) also reported a substantial increase in daily living skills and associated decreases in parental stress. Of some concern, even though outcome data were reported by all three of these groups, only Smith et al. (2010) provide detailed description of the intervention model and had appropriate quality control mechanisms to ensure fidelity of practice, so it is difficult to ascertain what specific interventions were associated with the positive gains.

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Best Practices for Intervention

Despite concerns about intervention quality, the National Research Council (NRC, 2001) has published best practice guidelines for ASD intervention after an extensive review of the literature available at that time. These guidelines have been reaffirmed more recently, though how to apply the guidelines to children under 2 years of age is less clear (see Warren & Stone, 2011). Nevertheless, they are an effective starting point for developing policy guidelines for ASD support. The NRC (2001) best practice guidelines are as follows:

- Entry into program as soon as ASD is suspected
- Active engagement in intensive instruction for a minimum of 5 hours per day, 5 days per week
- Use of repeated planned teaching opportunities that are structured over brief periods of time
- Sufficient individualized adult attention on a daily basis
- Inclusion of a family component, including parent training
- Mechanisms for ongoing assessment with corresponding adjustments in programming
- Priority for instruction in a) functional, spontaneous communication, b) social instruction across settings, c) play skills, with a focus on peer interaction, d) new skill maintenance and generalization in natural contexts, and e) functional assessment and positive behaviour support to address problem behaviours (p. 175).

More recent literature by Zwaigenbaum et al. (2009), published as a result of observation of children through high risk infant and sibling studies, define additional guidelines for supports for children 2 years of age or younger, and are summarized as follows:

- Programs developed for older children with autism cannot just be extrapolated to younger children
- Positive parent-child connection and interaction can have a tremendous impact on child development
- Interventions should focus on natural learning environments, following the child's lead, sensory-motor exploration, the development of non-verbal intentional communication, and reciprocal play with others
- Use of responsive, rather than directive, teaching styles
- Ensure the children have an active role in their own learning
- Interventions should be individualized

Though no specific intervention framework has been supported consistently in the literature, the National Autism Center (NAC, 2009), an advocate for evidence-based treatment, used criteria developed by 20 ASD research experts to review over 6,000 abstracts on published educational and behavioural intervention programs for individuals with ASD from 1957-2007. By applying clear inclusionary and exclusionary criteria, 775 full studies on ASD intervention were evaluated. These studies were systematically rated on their research rigor,

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treatment effect, classification, and strength of evidence and placed into the following categories: 1) established treatments, 2) emerging treatments or 3) unestablished treatments. Positively, these categories roughly align with FSCD's (2008) report on "Guidelines for Demonstrating Effectiveness" as either a 1) scientifically based practice, 2) promising practice, 3) practice with limited supporting information, or 4) not a recommended practice.

According to the NAC (2009) report the following 11 treatments were identified as "established" treatments with significant research support in the literature for individuals up to 22 years of age:

1. Antecedent Package {99 studies}
2. Behavioural Package {231 studies}
3. Comprehensive Behavioural Treatment for Young Children {22 studies}
4. Joint Attention Intervention {6 studies}
5. Modeling {50 studies}
6. Naturalistic Teaching Strategies {32 studies}
7. Peer Training Package {33 studies}
8. Pivotal Response Treatment {14 studies}
9. Schedules {12 studies}
10. Self-management {21 studies}
11. Story-based Intervention Package {21 studies}(NAC, 2009).

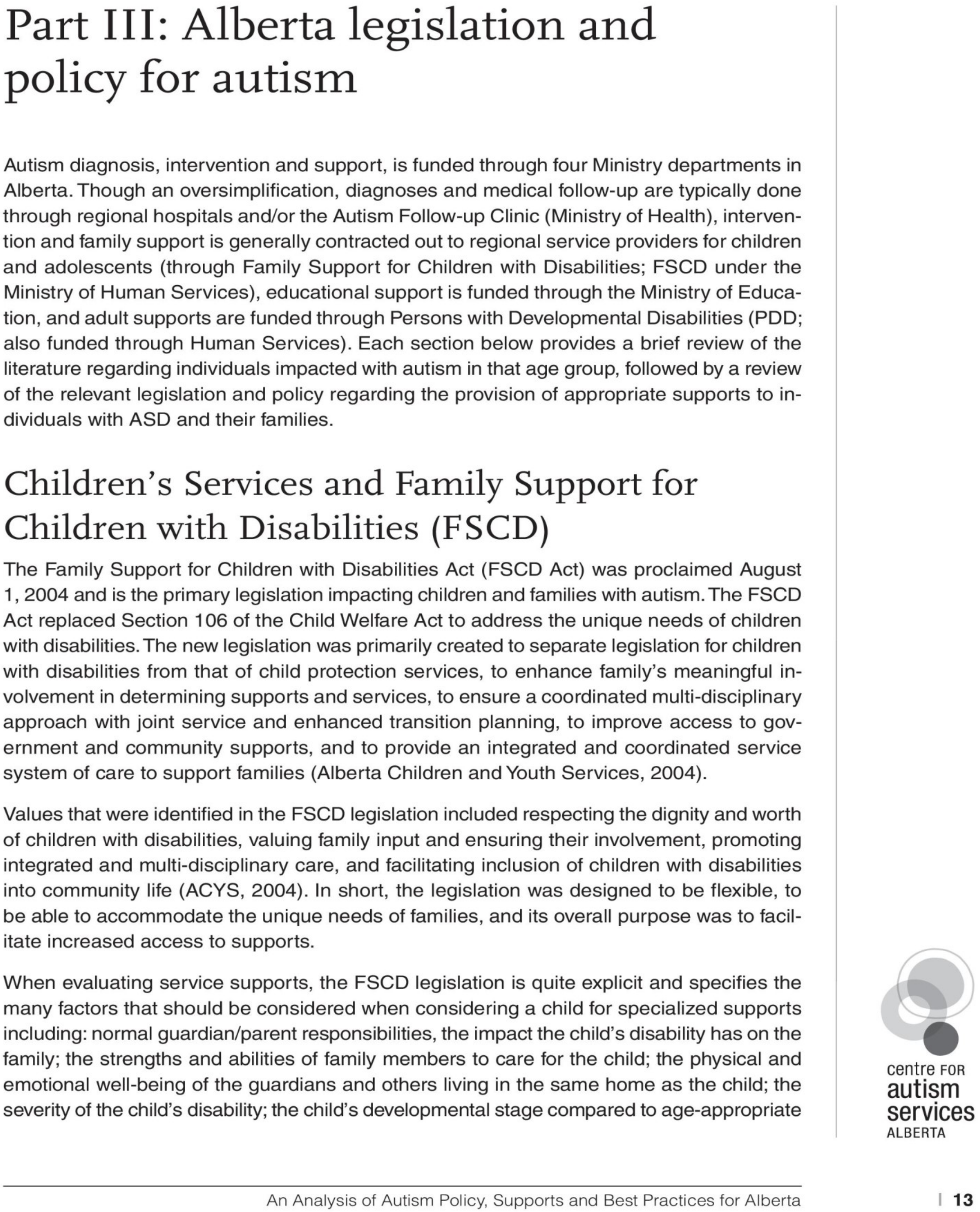
Basically, intervention models that were supported were comprehensive, used integrated behavioural principles, used strategies to facilitate reciprocal communication in natural settings, integrated peers into the teaching of skills, used visual supports and stories, and integrated self-management techniques. Given the weight of research support for their effectiveness, the NAC (2009) recommends that these treatment approaches be given serious consideration prior to trying other strategies for a child with autism. That being said, the NAC (2009) also caution against expecting uniform results across children and acknowledge the need for clinical judgement in choosing an effective strategy for a particular child, local values and preferences, and the capacity of the child to respond.

An additional 22 treatments were identified as emerging. These were areas of practice where the state of evidence was not as strong as the established treatments, sufficient studies had not yet been completed, or the research support was still somewhat mixed. These treatments were as follows, with the number of studies that were evaluated to assess their efficacy.

1. Augmentative and Alternative Communication Device {14 studies}
2. Cognitive Behavioural Intervention Package {3 studies}
3. Developmental Relationship-based Treatment {7 studies}
4. Exercise {4 studies}
5. Exposure Package {4 studies}
6. Imitation-based Interaction {6 studies}

7. Initiation Training {7 studies}
8. Language Training (Production) {13 studies}
9. Language Training (Production & Understanding) {7 studies}
10. Massage/Touch Therapy {2 studies}
11. Multi-component Package {10 studies}
12. Music Therapy {6 studies}
13. Peer-mediated Instructional Arrangement {11 studies}
14. Picture Exchange Communication System {13 studies}
15. Reductive Package {33 studies}
16. Scripting {6 studies}
17. Sign Instruction {11 studies}
18. Social Communication Intervention {5 studies}
19. Social Skills Package {16 studies}
20. Structured Teaching {4 studies}
21. Technology-based Treatment {19 studies}
22. Theory of Mind Training {4 studies}

Finally, five treatments were identified as having little evidence at this time for their continued use and these included generic traditional teaching methods not designed for children with autism, auditory integration training, facilitated communication, gluten and casein free diets, and sensory integrative packages. As mentioned, the NAC (2009) report recommends that treatment teams begin with established treatments prior to considering emerging or un-established treatments, or, if in their professional judgement, the established treatments are not appropriate for a particular child. Positively, no harmful treatments were identified by this particular report based on the available evidence.



Part III: Alberta legislation and policy for autism

Autism diagnosis, intervention and support, is funded through four Ministry departments in Alberta. Though an oversimplification, diagnoses and medical follow-up are typically done through regional hospitals and/or the Autism Follow-up Clinic (Ministry of Health), intervention and family support is generally contracted out to regional service providers for children and adolescents (through Family Support for Children with Disabilities; FSCD under the Ministry of Human Services), educational support is funded through the Ministry of Education, and adult supports are funded through Persons with Developmental Disabilities (PDD; also funded through Human Services). Each section below provides a brief review of the literature regarding individuals impacted with autism in that age group, followed by a review of the relevant legislation and policy regarding the provision of appropriate supports to individuals with ASD and their families.

Children's Services and Family Support for Children with Disabilities (FSCD)

The Family Support for Children with Disabilities Act (FSCD Act) was proclaimed August 1, 2004 and is the primary legislation impacting children and families with autism. The FSCD Act replaced Section 106 of the Child Welfare Act to address the unique needs of children with disabilities. The new legislation was primarily created to separate legislation for children with disabilities from that of child protection services, to enhance family's meaningful involvement in determining supports and services, to ensure a coordinated multi-disciplinary approach with joint service and enhanced transition planning, to improve access to government and community supports, and to provide an integrated and coordinated service system of care to support families (Alberta Children and Youth Services, 2004).

Values that were identified in the FSCD legislation included respecting the dignity and worth of children with disabilities, valuing family input and ensuring their involvement, promoting integrated and multi-disciplinary care, and facilitating inclusion of children with disabilities into community life (ACYS, 2004). In short, the legislation was designed to be flexible, to be able to accommodate the unique needs of families, and its overall purpose was to facilitate increased access to supports.

When evaluating service supports, the FSCD legislation is quite explicit and specifies the many factors that should be considered when considering a child for specialized supports including: normal guardian/parent responsibilities, the impact the child's disability has on the family; the strengths and abilities of family members to care for the child; the physical and emotional well-being of the guardians and others living in the same home as the child; the severity of the child's disability; the child's developmental stage compared to age-appropriate

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functioning; the family's composition; the needs of the child's siblings; the cultural values and beliefs of the guardians; the needs of the family in caring for the child during scheduled school breaks and school holidays; the child's and family's involvement in community programs and activities; the availability of persons other than the child's guardians to provide support and assistance in caring for the child; the availability and accessibility of appropriate programs, services and other resources within the community where the child lives; the geographic location of the child's home community; and any other relevant matter (Section 4-12, FSCD Legislation).

However, in practice, not all children diagnosed with ASD, particularly young children under 6 years of age, qualify for support offered through the FSCD legislation. This contradicts the NRC (2001) best practice recommendations on immediate access to supports as is being done through the current interpretation of qualification for Specialized Services funding—the arm of the legislation that offers sufficient funding for multi-disciplinary care, coordination with other community services and supports, family training, and direct child supports. Qualification for Child Focused, Specialized Services is made through the following criteria:

> m) if a child has a severe disability resulting in significant limitations and service needs in 2 or more of the following areas:
>
> (i) behaviour;
>
> (ii) communication and socialization skills;
>
> (iii) cognitive abilities;
>
> (iv) physical and motor development;
>
> (v) self-help skills and adaptive functioning;
>
> and if
>
> (vi) the level and complexity of the child's needs require an array of integrated and coordinated services, including one or more specialized services,
>
> (vii) a multi-disciplinary team has completed an assessment that identifies that the child has a critical need for a specialized service and recommends to the director that a specialized service be provided,
>
> (viii) an individualized plan, satisfactory to the director, has been developed to coordinate and direct the delivery of services, including a specialized service,
>
> (ix) the proposed specialized service is likely, in the opinion of a multi-disciplinary team, to achieve measurable improvement in a reasonable and predictable period of time or to sustain or to prevent a regression or dependency in the child's activities of normal daily living,
>
> (x) the proposed specialized service is based on established rehabilitative practices, strategies and approaches that are reasonable, least intrusive and demonstrated to be effective, and

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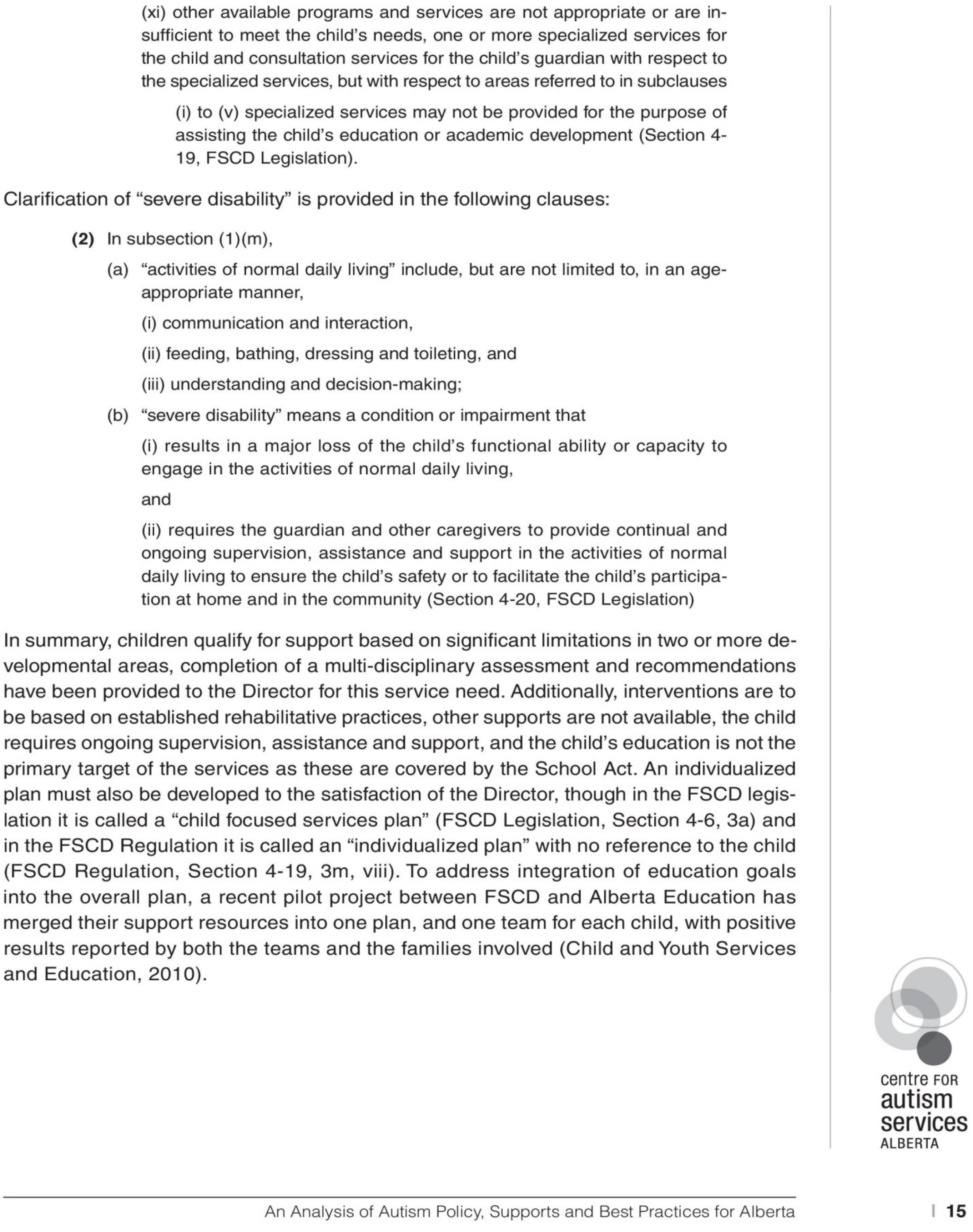

(xi) other available programs and services are not appropriate or are insufficient to meet the child's needs, one or more specialized services for the child and consultation services for the child's guardian with respect to the specialized services, but with respect to areas referred to in subclauses

(i) to (v) specialized services may not be provided for the purpose of assisting the child's education or academic development (Section 4-19, FSCD Legislation).

Clarification of "severe disability" is provided in the following clauses:

(2) In subsection (1)(m),

(a) "activities of normal daily living" include, but are not limited to, in an age-appropriate manner,

(i) communication and interaction,

(ii) feeding, bathing, dressing and toileting, and

(iii) understanding and decision-making;

(b) "severe disability" means a condition or impairment that

(i) results in a major loss of the child's functional ability or capacity to engage in the activities of normal daily living,

and

(ii) requires the guardian and other caregivers to provide continual and ongoing supervision, assistance and support in the activities of normal daily living to ensure the child's safety or to facilitate the child's participation at home and in the community (Section 4-20, FSCD Legislation)

In summary, children qualify for support based on significant limitations in two or more developmental areas, completion of a multi-disciplinary assessment and recommendations have been provided to the Director for this service need. Additionally, interventions are to be based on established rehabilitative practices, other supports are not available, the child requires ongoing supervision, assistance and support, and the child's education is not the primary target of the services as these are covered by the School Act. An individualized plan must also be developed to the satisfaction of the Director, though in the FSCD legislation it is called a "child focused services plan" (FSCD Legislation, Section 4-6, 3a) and in the FSCD Regulation it is called an "individualized plan" with no reference to the child (FSCD Regulation, Section 4-19, 3m, viii). To address integration of education goals into the overall plan, a recent pilot project between FSCD and Alberta Education has merged their support resources into one plan, and one team for each child, with positive results reported by both the teams and the families involved (Child and Youth Services and Education, 2010).

Issues in Application of Specialized Services

Three main issues arise in the application of the FSCD Act that are relevant to the diagnosis of ASD: 1) the role of independent multi-disciplinary professionals in assessing supports, 2) confusion as to whether the intended support is a form of child treatment or a general family support mechanism, and 3) the lack of a coherent developmental framework for assessing service needs for the ASD population at different ages.

First, there appears to be confusion and role overlap in the assessment of child and family support needs. Multi-disciplinary teams from both diagnostic services (Alberta Health and Wellness) and community service providers are recommending specific supports for children, but families are then required to attend an additional multi-disciplinary team (MDT) review of their support needs through a) a paperwork review and/or 2) attending a formal meeting with contracted community professionals through FSCD. The MDT's role is to indirectly assess the child and family's functioning and the severity of the child's disability—despite much of this being present in the documented paperwork and having no direct contact with the child in question—and to make recommendations to the Director on the type and amount of appropriate supports. At times, there is disagreement on the level of needs and thus families face additional stress in negotiating for appropriate assistance. This appears to run contrary to the spirit of the FSCD Act, where the role of FSCD is to decrease additional demands and stressors, not increase it. It also runs contrary to recommendations provided in the ACS (2002) "Systems of Care" report that multi-disciplinary teams could be comprised of a loose network of professionals who are familiar with and have worked with the child, and do not necessarily have to be contracted directly by FSCD.

Positively, a Multi-Disciplinary Team Review was created by the Government of Alberta and they produced a report with recommendations on this process (Government of Alberta, 2009), all of which were accepted and linked to an implementation plan (Government of Alberta, 2010). The paraphrased recommendations were as follows: 1) clarify decision making processes, 2) clarify the purpose and role of the member 3) ensure service providers play an integral role, 4) ensure timely and local access, 5) support parents in preparation for MDT, 6) improve information sharing, and 7) ensure consistent and transparent decision making (Government of Alberta, 2009). This report also identified the frustration many stakeholders reported due to a fragmented funding structure from multiple ministries, concerns over service provider capacity, quality, and availability, and the need for established standards of care and accountability within government funded service provision. Improving "information sharing and communication with parents, service providers and FSCD staff" was identified by the reviewers as "key" to ensuring adequate preparation for and understanding of MDT reviews (Government of Alberta, p.12, 2009).

Though this report does provide clarity on roles and responsibilities, families continue to contact FSCD at the time of this report for support on written recommendations by community based health professionals, but are often told they don't qualify for those supports, despite written recommendations from the professionals involved in their care. Further communication and shared decision making is required, as early intensive intervention and di-

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agnosis leads to a better prognosis and outcome (ACS, 2002; National Standards Report, 2009; National Research Council, 2001). In short, clarity is required on what specific documentation is required in order to qualify for intensive autism supports, and the role of community, health and education-based multi-disciplinary teams that are often involved in assessing child and family needs.

Second, it is not clear in the application of the FSCD legislation as to whether the focus of the funding is to be child treatment, parent support, or a combination of both. This lack of clarity was also identified in the ACS (2002) report, as FSCD was initially created to provide family support, not intensive treatment, though simultaneously was the conduit through which Intensive Behavioural Intervention (IBI) was originally funded (an intensive child focused treatment model). This confusion is further reflected in the different wording that requests a “child focused services plan” in the FSCD legislation and an “individualized plan” in the supporting regulations and policy.

FSCD policy has also changed over time in respect to the expected role of the family in service provision, though there have been no changes to the actual legislation. In 2007, Section 10-77 describes the intent of Specialized Services to be the following:

- The intent of specialized service is to ensure children who have severe disabilities that result in a major loss of the child’s functional ability in two or more areas receive appropriate, coordinated and effective services.
- Specialized services are intended for children who are severely impacted by their disability and require an array of intensive, integrated and coordinated specialized services (Alberta Children and Youth Services: FSCD Policy and Procedures, 2007)

However, in 2010, the same section (10-77) has been significantly revised with a much greater focus on the family involvement. The intent is now described as the following:

- Specialized services involve consultation to the guardian and are intended to support them in acquiring specific skills and learning strategies to help promote their child’s participation in outcomes of daily living
- FSCD recognizes the family as the primary source of care and support for a child and respects and values a family’s ability to care for and promote their child’s development. As such, guardians are involved in developing and implementing their Individualized Service Plan and through specialized services learn skills and strategies that help strengthen their ability to care for their child (Alberta Children and Youth Services: FSCD Policy and Procedures, 2010).

The NRC (2001) best practice recommendations for child treatment clearly support active involvement of the family in treatment planning. However, the NRC (2001) standards would not support treatment models without adequate child-directed intensity, frequency and duration or without sufficient individualized, child-directed adult attention. Some regions of FSCD currently have a policy that the family must be actively involved in every child goal, making it difficult to meet the minimum recommended supports of 25 hours per week (NRC, 2001). While aspirational, this policy is not always feasible, nor child centered, given family time constraints, stressors, and the need for high levels of practice for children with autism.

Clarity is needed on the level of family involvement required in order to receive specialized service supports, particularly as the FSCD legislation also demands sensitivity and accommodation for family context and values.

There is also considerable confusion around appropriate supports for young children who do not qualify for Program Unit Funding (PUF) through Alberta Education, which requires that children be 2.5 years of age and restricts program entry to certain times of the year. Specialized program availability may also vary from region to region, dependent on local resources and capacity. At the same time, the FSCD legislation prohibits assistance in child education, an activity covered under the School Act. Clarification is required on how to address the support needs of children under 2.5 years of age that are diagnosed with ASD as access to early intervention is associated with better outcomes and policy should support this.

Third, age and developmental distinctions are not made in the FSCD Act leading to some confusion in the application of support types and amounts for children of different ages. Types and amounts of supports are to be determined in consultation with FSCD, multi-disciplinary teams and established rehabilitative practices. At this time, service provider philosophies and standards of care vary widely and there is little community consensus as to the appropriate model of care for children of different ages, despite evidence-based programs existing in the research literature. In general, Madore and Pare (2006), when describing provincial funding models across Canada, report that younger children with autism generally receive intensive supports prior to the age of six, and then child and family supports are significantly modified as children enter into a full-time school setting. This parallels recommendations initially put forward in the ACS (2002) report. Clarification is required on developmentally appropriate types and levels of supports for the following age categories:

1) Infants and Toddlers (0-3 years of age)
2) Preschoolers (3-6 years of age)
3) Elementary School Age (6-12 years of age)
4) Adolescence (13-17 years of age)
5) Adults (18 years +)

Alberta Education and the School Act

Education for Alberta students is governed under the School Act where a distinction is made between students and children. Individuals younger than 6 years of age, as of September 1 of the school year, are identified as children, and those 6 years of age or older, are identified as students (Alberta Education, 2006). Each of these age groups are treated differently under the School Act. The Standards for the Provision of Early Childhood Special Education (Alberta Education, 2006) outlines how children with disabilities or delays, between the ages of 2.5 to 6 years of age, can be eligible for up to three years of educational programming, depending on age, severity of the disability / delay, and the impact on child learning. Approval is obtained through an application process to the formal board or school authority, and is required prior to the provision of services. The Standards (Alberta Education, 2006)

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provide guidelines for how services for young children with special needs should be structured, including the need for consent by parents prior to education provision, the use of assessments (informal and specialized) to guide individual programming, the requirement of an individual program plan (IPP) for each registered child that is completed with the input of parents and other professionals involved in the child's care, the need to coordinate services with other providers and professionals, maintain appropriate records, adhere to professional standards, ensure family involvement while respecting unique family strengths and differences, ensure regular communication with families, and monitor the effectiveness of the programming provided.

The Standards is quite clear that the integration and coordination of care for children with special needs, informed by family strengths and needs, is key to effective service provision. As stated in the Standards under Coordinated Services:

> Children with disabilities/delays may have special education needs that cross multiple developmental domains. Educational programming for these children requires input from professionals from a number of disciplines. An integrated working plan is developed by taking into consideration the knowledge and expertise of each of these disciplines. School authorities must ensure that services accessed through Alberta Education funding are relevant to children's educational programming and are in direct support of the goals and objectives in children's IPPs.
>
> Often, a number of provincial and community-based agencies are involved in providing funding and services to young children. School authorities should take the lead in collaborating with other funding agencies and service providers to ensure coordinated service delivery (Alberta Education, 2006, p. 9).

Unfortunately, at this time, collaboration between educational programs and community service providers is the exception and not the rule. Many children have multiple teams of providers, one funded through FSCD for home and family based service provision, another funded through Alberta Education for education provision, and finally another through Alberta Health and Wellness for medical follow-up and support. At present, there is little directed funding for communication between these providers, and it could be argued, that there is often a duplication of services leading to fragmented and uncoordinated care. Children with special needs should have an integrated service/health/individual program plan that takes into account both educational, medical and community/family needs. As mentioned earlier, one option that has been explored in some regions is the establishment of one multi-disciplinary team with funding from the Ministries of Education and Children's Services.

Providing further direction on the details required for coordinated care, The Standards (Alberta Education, 2006) states

> 5. School authorities must:
>   b. initiate and participate in working with other community agencies to improve services for children with special education needs

c. ensure that the ideas, recommendations and suggestions of parents, educators and service providers are considered in the development of IPPs
d. identify in IPPs the type, frequency and format of coordinated services to be provided
e. ensure that service delivery models consider child and family needs, effective practice and available resources
f. ensure that services directed by the school authority are:
    - delivered in the most natural setting possible
    - in direct support of educational goals and objectives identified in IPPs
    - coordinated in their delivery
g. provide staff and, where appropriate, parents with the training and support necessary to implement programming suggestions arising from coordinated support services (p. 10).

As "effective practice" is identified in the Standards (2006), clarification is required on what this constitutes for children diagnosed with autism—particularly those under 6 years of age and diagnosed with autism, as they make up a large portion of children in the PUF category of Alberta Education funding. Training and support needs are also indicated in order to provide effective services for this age group, and clarity is required on what training needs would best be supported by the government to ensure effective care. As the FSCD legislation (2004) also references the need to use "established rehabilitative practices" when applying Specialized Services, both Ministries would benefit from a document that more carefully specifies what this means for ASD.

School-based support for students with autism, aged 6 years of age and older, is primarily defined through the Setting the Direction Framework: Government of Alberta Response (STDF: GAR, 2010). The STDF:GAR document discusses Alberta Education's systematic review of its files regarding children with severe disabilities in 2007 that found only 56% met its policy requirements. A major review was launched in 2008, including consultation with more than 6,000 Albertans and multiple stakeholders. The primary recommendation was to adopt an inclusive education framework for all children with special needs that would be supported by effective funding, policy and accountability. Though this policy was to be proclaimed in the newly revised Education Act (2012) that was to replace the School Act (1998) through Bill 18, it was not formally passed and has been referred on for further consultation (Policy Monitor, 2011).

Nevertheless, the principles of Setting the Direction continue to guide current educational programming decisions. Twelve key strategies of STDF:GAR were identified and of those twelve, the following seven were selected as areas requiring key contributions to an overall system of care for individuals impacted by autism:

Strategic Direction 2
Gather information at the Ministerial, jurisdictional, school and classroom levels to support all students.

Government Response

Government will continue to collaborate with stakeholders to develop and implement a data collection approach to support student learning and capture student records and information regarding achievement and progress.

Strategic Direction 5

Implement a province-wide expectation that school-based expertise will be in place to support teachers in meeting the needs of students with disabilities and diverse needs within learning environments.

Government Response

Government will work with stakeholders to develop guidelines outlining role descriptions for teachers, learning coaches, educational assistants, administrators, parents and specialized service personnel who are working in an inclusive education system. Government will also work with stakeholders to build capacity to support an inclusive education system. This would include appropriate instruction and training for undergraduate students enrolled in Bachelor of Education programs, and continual professional development opportunities for teachers as their careers progress.

Strategic Direction 6

Develop a set of standards so that instructional excellence in inclusive education practices becomes the norm in all schools.

Government Response

Government will work with stakeholders and partners to develop and implement guidelines for working in an inclusive environment and determine ways to identify and share best practices from highly successful schools that are practicing effective inclusivity.

Strategic Direction 8

Develop a provincial service delivery model for specialized supports and services to address the needs of students in the context of their schools, family and community in a timely and culturally sensitive manner.

Government Response

Government will work with stakeholders to develop a regional collaborative service delivery model to support students in an inclusive education system.

Strategic Direction 9

Develop and support a seamless, Alberta-wide wraparound approach that provides timely access to coordinated supports and services to students and families and schools in the right place at the right time.

Government Response

Government and other organizations, through shared responsibility, will develop and implement protocols for a wraparound approach, including a definable planning process, comprehensive, coordinated supports and services offered through multiple professionals and agencies that support working in a collaborative way.

Strategic Direction 10

Develop and implement a model of support for young children who experience at-risk factors that enable programming and support in the most natural pre-school environment along with a seamless transition into grade 1.

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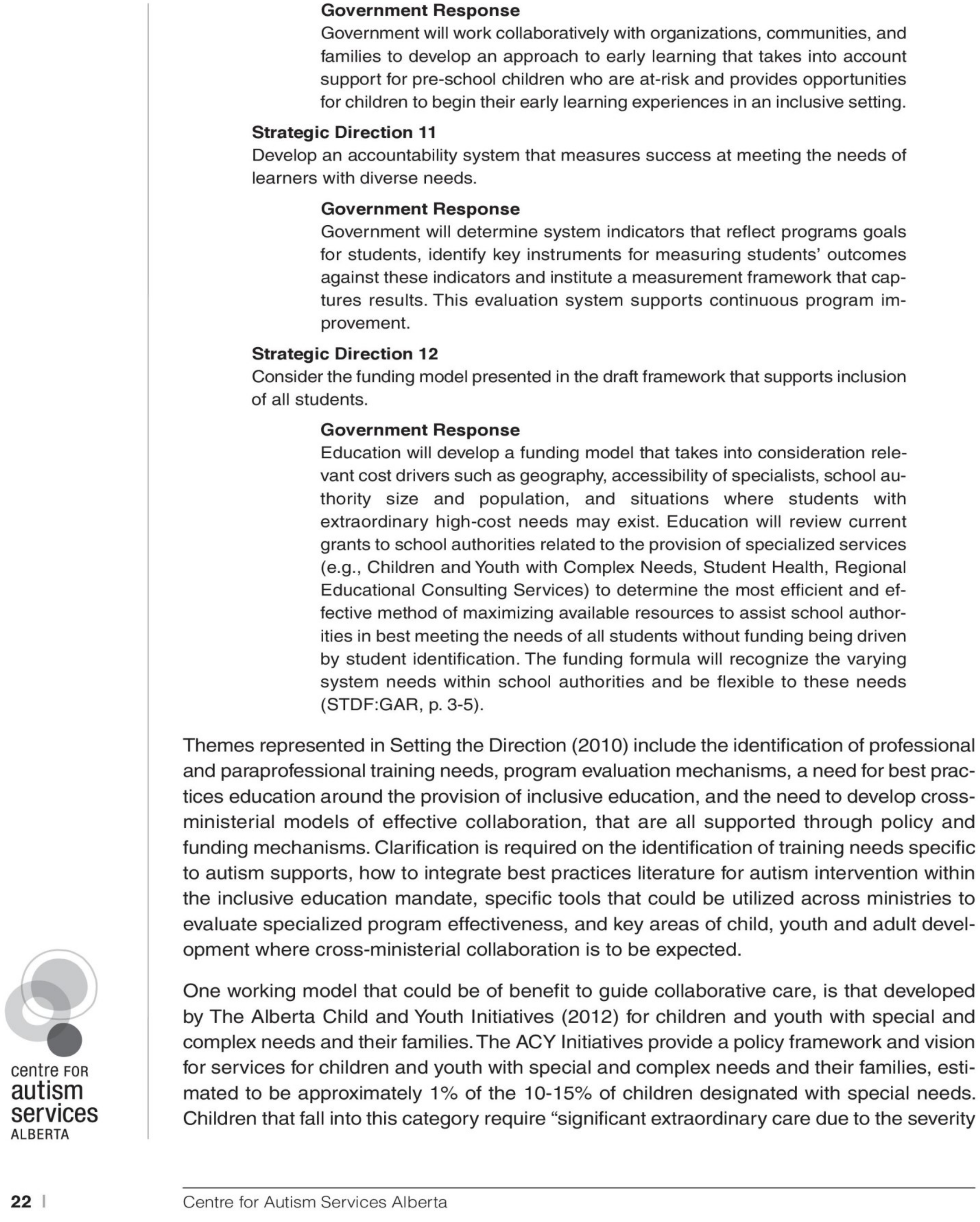

Government Response

Government will work collaboratively with organizations, communities, and families to develop an approach to early learning that takes into account support for pre-school children who are at-risk and provides opportunities for children to begin their early learning experiences in an inclusive setting.

Strategic Direction 11

Develop an accountability system that measures success at meeting the needs of learners with diverse needs.

Government Response

Government will determine system indicators that reflect programs goals for students, identify key instruments for measuring students' outcomes against these indicators and institute a measurement framework that captures results. This evaluation system supports continuous program improvement.

Strategic Direction 12

Consider the funding model presented in the draft framework that supports inclusion of all students.

Government Response

Education will develop a funding model that takes into consideration relevant cost drivers such as geography, accessibility of specialists, school authority size and population, and situations where students with extraordinary high-cost needs may exist. Education will review current grants to school authorities related to the provision of specialized services (e.g., Children and Youth with Complex Needs, Student Health, Regional Educational Consulting Services) to determine the most efficient and effective method of maximizing available resources to assist school authorities in best meeting the needs of all students without funding being driven by student identification. The funding formula will recognize the varying system needs within school authorities and be flexible to these needs (STDF:GAR, p. 3-5).

Themes represented in Setting the Direction (2010) include the identification of professional and paraprofessional training needs, program evaluation mechanisms, a need for best practices education around the provision of inclusive education, and the need to develop cross-ministerial models of effective collaboration, that are all supported through policy and funding mechanisms. Clarification is required on the identification of training needs specific to autism supports, how to integrate best practices literature for autism intervention within the inclusive education mandate, specific tools that could be utilized across ministries to evaluate specialized program effectiveness, and key areas of child, youth and adult development where cross-ministerial collaboration is to be expected.

One working model that could be of benefit to guide collaborative care, is that developed by The Alberta Child and Youth Initiatives (2012) for children and youth with special and complex needs and their families. The ACY Initiatives provide a policy framework and vision for services for children and youth with special and complex needs and their families, estimated to be approximately 1% of the 10-15% of children designated with special needs. Children that fall into this category require "significant extraordinary care due to the severity

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of their impairments and require services from more than one ministry" (p. 5). A portion of children with autism fall into this category, though specifics are not publicly available. Within this framework, the Ministries of the Alberta government commit to "work(ing) together to plan and implement supports for children and youth with special and complex needs" (p. 2) to ensure the needs of these children and families are met. The framework was developed in consultation with the Ministry of Health and Wellness, Children's Services, Alberta Learning, and Community Development and consists of the following key principles:

1. Formalization of an integrated case management model will be implemented for children and youth with complex needs so that various ministry partners, regional authorities, and service providers involved in the child's life work together to address the child's and family's needs.
2. Ministry partners, regional authorities, and service providers will be proactive and collaborate in resolving issues for families with special needs when the issue affects more than one ministry.
3. Formal transitional planning for children and youth with special and complex needs will be guided by transitional planning protocols, including transitional planning beginning 24 months prior to a youth turning 18 years and resulting in the development of a transitional plan 12 months before the youth turns 18 years. The transitional plan will address issues such as placement, educational, social and other pertinent needs.
4. Cross-ministry information sharing initiatives will be implemented, including development of information sharing guidelines and training tools for delivery staff; regularly updated resource information for families; and steps to improve ministry and regional information systems to identify common language definitions, diagnostic and prognostic coding (p. 9-11).

However, though the importance of cross ministerial information sharing is identified within this document, specific guidelines are not in place to identify when this information sharing would be most appropriate, other than the transition to adulthood, particularly as it applies to individuals with autism. Regarding children and youth with autism, times of transition that could be identified include the 1) initial time of diagnosis, 2) entry into school services, 3) discharge from school services, and 4) entry into adult programming as appropriate. Clarity is required on when information sharing between specific ministries would be most appropriate for children, youth and adults with autism, and what the specific aim of the information sharing should be accomplishing.

Adults and Persons with Developmental Disabilities Community Governance Act

Adult supports vary widely in the community, though the primary legislation impacting adults with severe and chronic disabilities is the Persons with Developmental Disabilities (PDD) Community Governance Act. The PDD Act supports approximately 9,300 adults with developmental disabilities in Alberta and is administered through local community boards. Its vision is to "honour and respect the dignity and equal worth of persons with developmental

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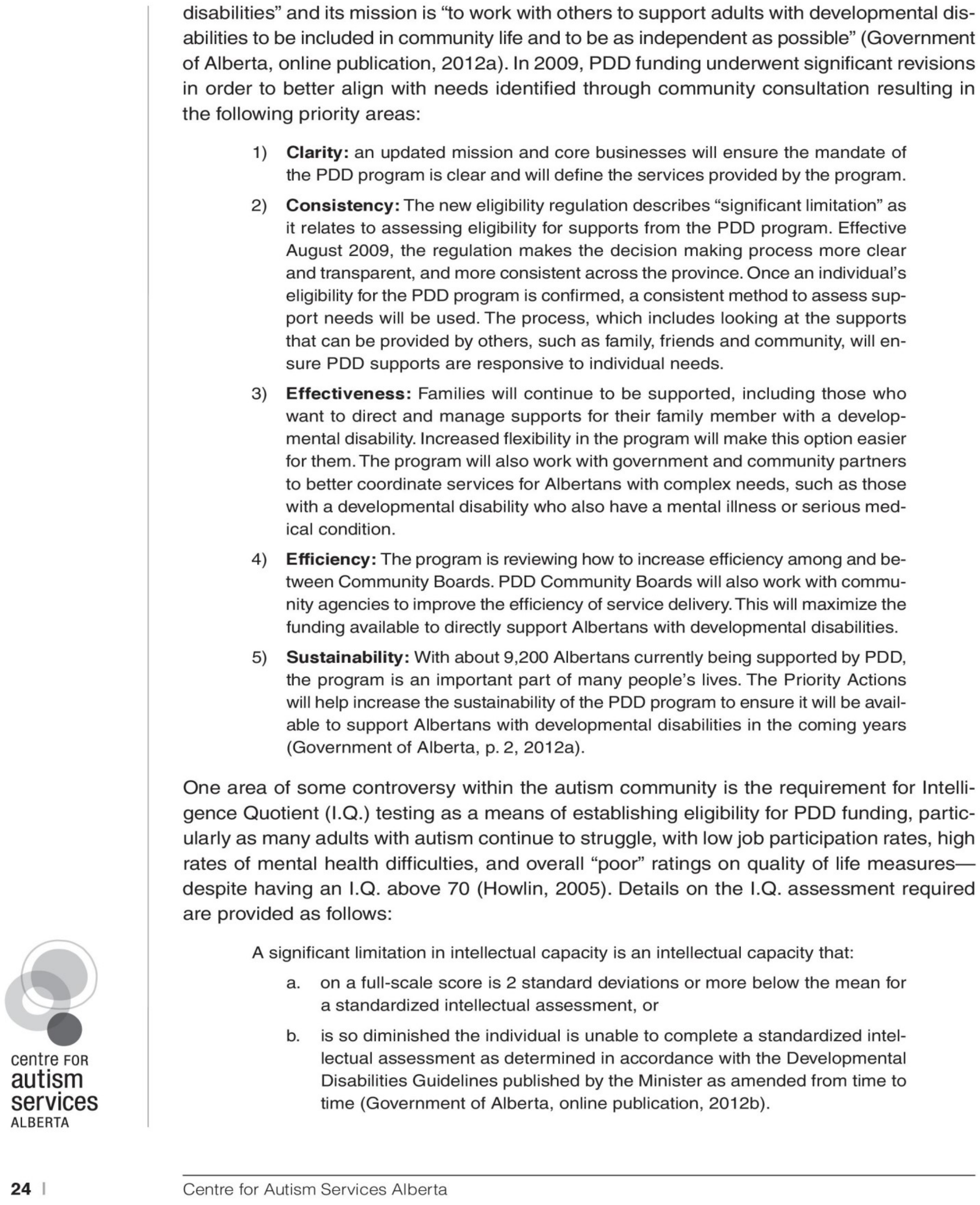

disabilities” and its mission is “to work with others to support adults with developmental disabilities to be included in community life and to be as independent as possible” (Government of Alberta, online publication, 2012a). In 2009, PDD funding underwent significant revisions in order to better align with needs identified through community consultation resulting in the following priority areas:

1) **Clarity:** an updated mission and core businesses will ensure the mandate of the PDD program is clear and will define the services provided by the program.
2) **Consistency:** The new eligibility regulation describes “significant limitation” as it relates to assessing eligibility for supports from the PDD program. Effective August 2009, the regulation makes the decision making process more clear and transparent, and more consistent across the province. Once an individual’s eligibility for the PDD program is confirmed, a consistent method to assess support needs will be used. The process, which includes looking at the supports that can be provided by others, such as family, friends and community, will ensure PDD supports are responsive to individual needs.
3) **Effectiveness:** Families will continue to be supported, including those who want to direct and manage supports for their family member with a developmental disability. Increased flexibility in the program will make this option easier for them. The program will also work with government and community partners to better coordinate services for Albertans with complex needs, such as those with a developmental disability who also have a mental illness or serious medical condition.
4) **Efficiency:** The program is reviewing how to increase efficiency among and between Community Boards. PDD Community Boards will also work with community agencies to improve the efficiency of service delivery. This will maximize the funding available to directly support Albertans with developmental disabilities.
5) **Sustainability:** With about 9,200 Albertans currently being supported by PDD, the program is an important part of many people’s lives. The Priority Actions will help increase the sustainability of the PDD program to ensure it will be available to support Albertans with developmental disabilities in the coming years (Government of Alberta, p. 2, 2012a).

One area of some controversy within the autism community is the requirement for Intelligence Quotient (I.Q.) testing as a means of establishing eligibility for PDD funding, particularly as many adults with autism continue to struggle, with low job participation rates, high rates of mental health difficulties, and overall “poor” ratings on quality of life measures—despite having an I.Q. above 70 (Howlin, 2005). Details on the I.Q. assessment required are provided as follows:

> A significant limitation in intellectual capacity is an intellectual capacity that:
>
> a. on a full-scale score is 2 standard deviations or more below the mean for a standardized intellectual assessment, or
>
> b. is so diminished the individual is unable to complete a standardized intellectual assessment as determined in accordance with the Developmental Disabilities Guidelines published by the Minister as amended from time to time (Government of Alberta, online publication, 2012b).

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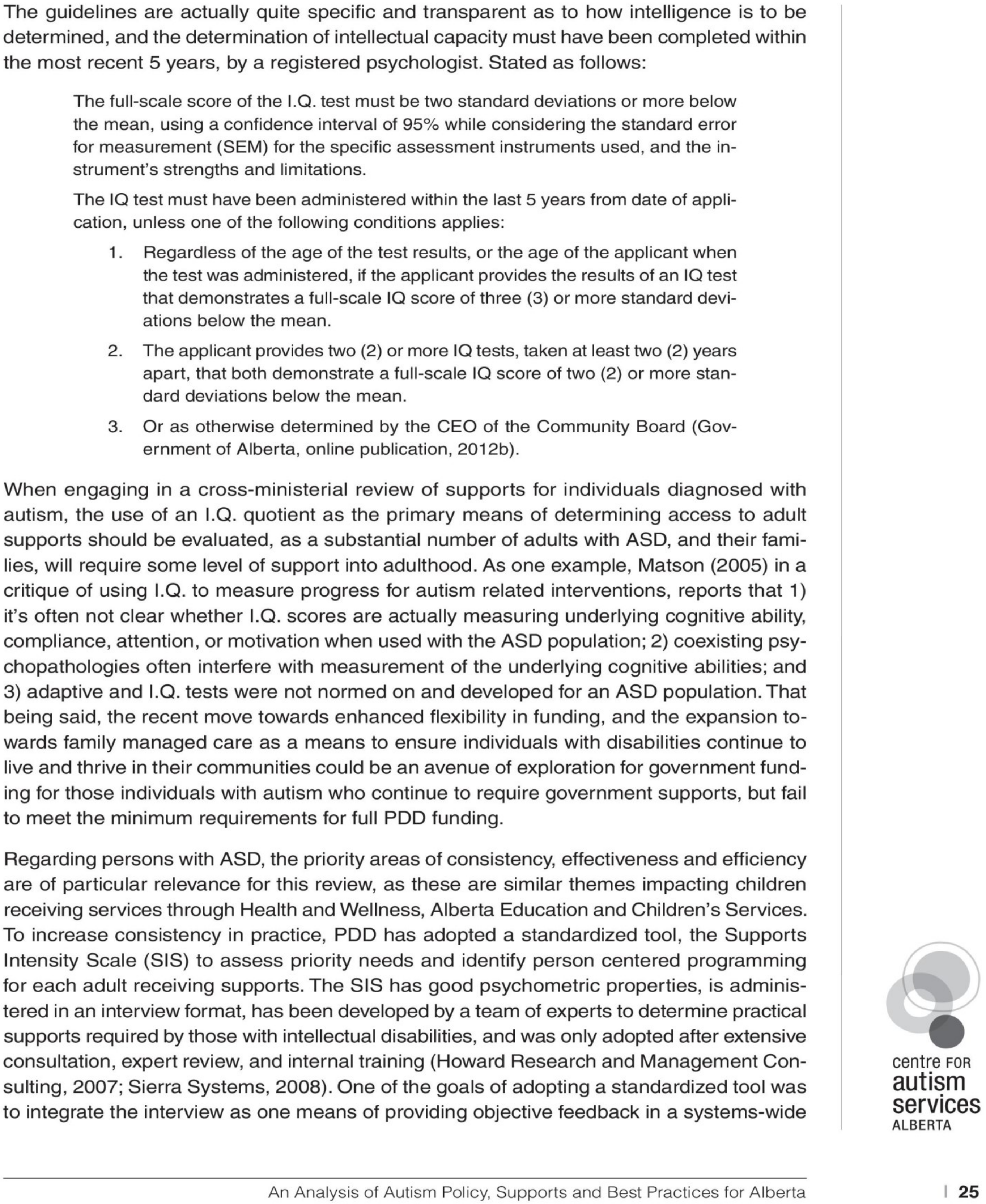

The guidelines are actually quite specific and transparent as to how intelligence is to be determined, and the determination of intellectual capacity must have been completed within the most recent 5 years, by a registered psychologist. Stated as follows:

> The full-scale score of the I.Q. test must be two standard deviations or more below the mean, using a confidence interval of 95% while considering the standard error for measurement (SEM) for the specific assessment instruments used, and the instrument's strengths and limitations.
>
> The IQ test must have been administered within the last 5 years from date of application, unless one of the following conditions applies:
>
> 1. Regardless of the age of the test results, or the age of the applicant when the test was administered, if the applicant provides the results of an IQ test that demonstrates a full-scale IQ score of three (3) or more standard deviations below the mean.
> 2. The applicant provides two (2) or more IQ tests, taken at least two (2) years apart, that both demonstrate a full-scale IQ score of two (2) or more standard deviations below the mean.
> 3. Or as otherwise determined by the CEO of the Community Board (Government of Alberta, online publication, 2012b).

When engaging in a cross-ministerial review of supports for individuals diagnosed with autism, the use of an I.Q. quotient as the primary means of determining access to adult supports should be evaluated, as a substantial number of adults with ASD, and their families, will require some level of support into adulthood. As one example, Matson (2005) in a critique of using I.Q. to measure progress for autism related interventions, reports that 1) it's often not clear whether I.Q. scores are actually measuring underlying cognitive ability, compliance, attention, or motivation when used with the ASD population; 2) coexisting psychopathologies often interfere with measurement of the underlying cognitive abilities; and 3) adaptive and I.Q. tests were not normed on and developed for an ASD population. That being said, the recent move towards enhanced flexibility in funding, and the expansion towards family managed care as a means to ensure individuals with disabilities continue to live and thrive in their communities could be an avenue of exploration for government funding for those individuals with autism who continue to require government supports, but fail to meet the minimum requirements for full PDD funding.

Regarding persons with ASD, the priority areas of consistency, effectiveness and efficiency are of particular relevance for this review, as these are similar themes impacting children receiving services through Health and Wellness, Alberta Education and Children's Services. To increase consistency in practice, PDD has adopted a standardized tool, the Supports Intensity Scale (SIS) to assess priority needs and identify person centered programming for each adult receiving supports. The SIS has good psychometric properties, is administered in an interview format, has been developed by a team of experts to determine practical supports required by those with intellectual disabilities, and was only adopted after extensive consultation, expert review, and internal training (Howard Research and Management Consulting, 2007; Sierra Systems, 2008). One of the goals of adopting a standardized tool was to integrate the interview as one means of providing objective feedback in a systems-wide

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performance evaluation mechanism (Schalock, 2010). Evaluating the benefits and drawbacks of utilizing other specific standardized tools across different ages and stages of development, as a means of measuring program performance across the lifespan for those receiving autism related supports would be of benefit.

Part IV: Autism supports across the lifespan

Recent peer-reviewed autism support literature is presented to provide a context for the types and amounts of supports that could be considered for different age groups across the lifespan (0-3 years, 4-6 years, 6-12 years, 13-17 years, adult). This review is meant to be a starting point for determining policy recommendations and is not a comprehensive review—further expert consultation is required. For a contemporary review of this literature, two texts are recommended, though many others could be considered: *Autism Spectrum Disorders* (2011). Eds. D. Amaral, G. Dawson, & D. Geschwind, New York: Oxford University Press and *Handbook of Autism and Pervasive Developmental Disorders*, *Volume 1 & 2* (2005). Eds. F. Volkmar, R. Paul, A. Klin, and D. Cohen, Hoboken, New Jersey: John Wiley & Sons, Inc. As autism research literature changes quickly, it is recommended that all of these resources be supplemented by extensive consultation with those actively involved in the provision of clinical and research activities related to autism.

Infant and Toddler support

Children from birth to 12 months of age are classified as infants and children from 1-3 years of age are classified as toddlers (Davies, 2004). Brain development is most rapid in the first two years of life, with key developmental goals over the first 12 months including healthy attachment and emotional responsiveness to a primary caregiver, development of sensual acuity and coordination (sight, smell, taste, sound, touch, and motor skills), the beginnings of regulation of body rhythms, arousal and emotion, early social interaction with others, the emergence of exploratory play with sounds and objects, development of early memory, social referencing, joint attention, imitation, first words between 9-12 months of age, object permanence and an emerging sense of self that is strongly linked to responsive caregiving (Davies, 2004).

Most of these abilities develop in a predictable sequence, with each foundational ability building on a set of pre-existing skills, creating increasingly complex developmental tasks at each age. Alongside this dynamic, the brain is biologically organized to learn certain skills during specific developmental periods called "sensitive periods". Hertzman (2008) summarizes the interaction between sensitive periods of learning and developmental tasks in Figure 2, demonstrating how important it is for foundational developmental tasks to be acquired in the preschool years, as this is the time when the brain is most receptive to learning them.

Rogers and Wallace (2011) in a review of autism interventions for infants and toddlers, identify that most of the efficacious treatments have been developed for 2-5 year olds, and that intervention models for children younger than this is an emerging area. Many comprehensive models are based on the principles of Applied Behaviour Analysis (ABA) such as Dis-

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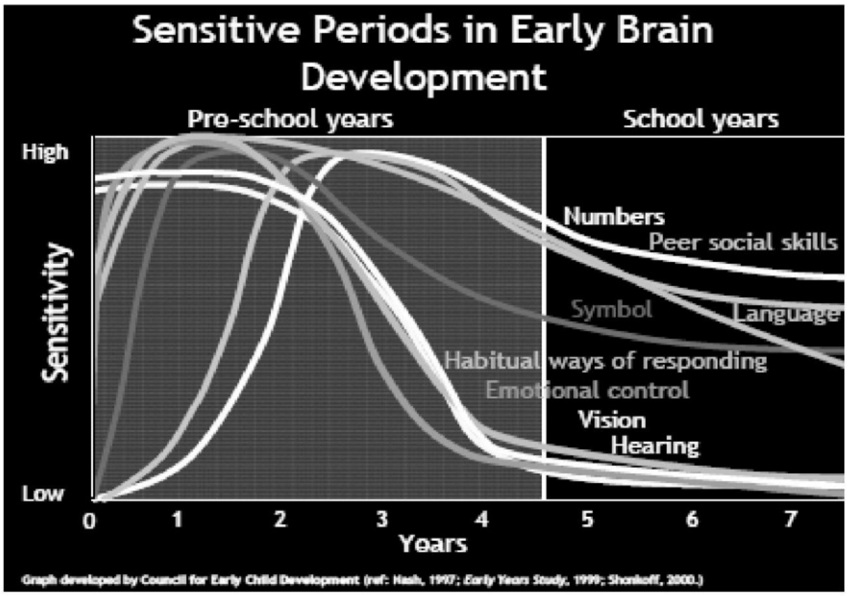

Graph developed by Council for Early Child Development (ref: Nash, 1997; *Early Years Study*, 1999; Shonkoff, 2000.)

Figure 2: Sensitive periods in early brain development (Hertzman, 2008)

crete Trial Teaching (DTT, Lovaas, 1987) or Pivotal Response Training (PRT, Koegel, Koegel, Harrower, & Carter, 1999). However, other models also exist and are based on developmental principles such as Social Communication, Emotional Regulation and Transactional Supports (SCERTS, Prizant, Wetherby, Rubin, Laurent, & Rydell, 2006), the Early Start Denver Model (ESDM, Rogers & Dawson, 2009), Hanen (McConachie, Randle, Hammal, & LeCouteur, 2005) and classroom-based models such as that developed by Treatment and Education of Autistic and Related Communication-handicapped Children (TEACCH, Schopler, Mesibov, & Hearsey, 1995). No one model has emerged as the best model for the infant and toddler population, with varying outcomes depending on a variety of child and parent characteristics. Rogers and Wallace (2011) identify the following effective aspects of well-designed programs for infants and toddlers with developmental delays, including those diagnosed with autism:

1) Regular parent coaching by trained therapists with frequent home visitation,
2) Weekly sessions in a clinic or at home across a substantial portion of the 0-3 year age range,
3) Individualization of activities and goals to match the developmental needs of the child, often based on an established curriculum,
4) Starting the interventions and support as soon as possible,
5) A strong focus on increasing parental sensitivity and responsivity to infant cues,
6) Interventions should be broad based and focused on many areas of functioning, such as language, motor skills, and self-help skills, rather than one or two narrow developmental areas and,
7) Offer parental support, such as grief counselling, above and beyond the learning of child-specific child rearing skills (p. 1086).

In terms of intervention targets, Landa (2011) identifies early warning signs that are associated with an early ASD diagnosis include a lack of shared positive affect, unusual eye gaze, lack of joint attention or desire to share personal experiences with others, lack of interest in engaging others, low imitation of others, low response to a caregiver's desire for attention, little response to one's name being called, delays in spoken language, posturing of hands, arms or mouth in unusual positions, intense, repetitive, or unusual play with toys, low muscle tone or poor motor coordination, unusual squealing, and echoing (repeating back) verbal speech, rather than responding. All of these warning signs are important foci for early intervention goals and activities.

Sufficient levels of program intensity continue to be an area of debate for this younger population, particularly given a small child's limited ability to tolerate a high number of hours of structured programming. A review by the Canadian Pediatric Society (CPS, 2004) recommends a minimum target of 15 hours per week for structured, individualized teaching for young children with autism, whereas others insist that a minimum of 25 hours per week is required (Granpeesheh, Tarbox, & Dixon, 2009).

Preschool support

The preschool period is from 3-6 years of age. Developmental changes include decreased egocentricity, increased capacity in logical thought, self-control, the ability to empathize with others, increased engagement in pro-social behaviour, the development and enjoyment of friendships, an emergence of cooperative and imaginative play, and an increased mastery of language including attention to context, grammar, and tailoring its use to specific audiences (Davies, 2004). Children of this age demonstrate rapid language development with vocabulary increases of about 50 words per month by 2 years of age and a typical vocabulary of 14,000 words by the age of 7 (Davies, 2004). Berk (1994) reports that preschoolers are also able to understand simple metaphors and use sophisticated social strategies to help sustain social interaction. Basically, communication and socialization skills, two key areas of delay in an autism diagnosis, are in rapid development during this aging period, making them ideal intervention targets at this time.

Charman (2011) in a review of preschoolers with ASD, identifies that the diagnosis of autism is quite stable, with less certainty for really young children and those with milder symptoms of the condition—though heterogeneity continues to be the rule, not the exception, making predictability of response to intervention problematic. However, Freeman and Perry (2010) have identified that those children with mild/moderate delays, are more likely to respond to intervention than those with severe delays, creating concern about focusing solely on children with severe delays as a matter of policy (particularly as a qualification criteria for intensive supports).

As children age into the preschool period, delays in language, social, cognitive and adaptive development become more apparent, often leading parents to pursue an ASD diagnosis at this time consistent with Burstyn, et al.'s (2010) reported peak diagnosis rates of between 3 and 4 years of age in Alberta. Charman (2011) reports that developmental gaps often continue to widen as one enters school and adolescence, hence language, social, cognitive

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and adaptive skills need to be targeted by intervention and, for a subset of ASD children, psychiatric concerns may begin to emerge in the form of obsessions, phobias, hyperactivity, poor attention, and mood dysregulation. As mentioned, there are many different behavioural and developmental models for preschoolers, as it is this age group, along with school-aged children, for which the most evidence exists for effective intervention (Rogers & Wallace, 2011; Hume & Odom, 2011).

Hume and Odom (2011), in an attempt to translate the complex body of research for practitioners and policy makers, identify 24 evidence-based practices and strategies for autism intervention, and they also reviewed 30 comprehensive training models published in the peer reviewed literature. According to their criteria, evidence-based behavioural strategies and positive behavioural support strategies for preschoolers are listed as follows:

1. Prompting
2. Reinforcement
3. Task analysis and chaining
4. Time delay
5. Computer aided instruction
6. Discrete trial training (DTT)
7. Naturalistic interventions
8. Parent implemented interventions
9. Peer mediated instruction/intervention (PMII)
10. Picture Exchange Communication System (PECS)
11. Pivotal Response Training (PRT)
12. Functional Behaviour Assessment (FBA)
13. Stimulus control / environmental modifications
14. Response interruption/redirection
15. Functional communication training
16. Extinction
17. Differential reinforcement
18. Self-management
19. Social narratives
20. Social skills training groups
21. Structured work systems
22. Video modeling
23. Visual supports
24. VOCA/Speech generating devices (Hume & Odom, p. 1298, 2011).

All of the 30 comprehensive models reviewed had to be published, have a guide or manual, address multiple developmental domains, be intensive (a minimum of 25 hours per week or more), have longevity (minimum of a typical school year), and have been implemented in the United States. Comprehensive models receiving the highest ratings included the Denver model, Learning Experiences: an Alternative Program for preschoolers and parents (LEAP), Lovaas Institute, May Institute and the Princeton Child Development Institute (Hume & Odom, 2011).

The Early Start Denver Model (ESDM, Rogers & Dawson, 2009), a downward modification of the Denver model for children 12-48 months, integrates the principles of Applied Behaviour Analysis (ABA) and developmental, relationship-based theory. The ESDM model includes 25 hours per week of classroom instruction, uses a developmental curriculum, has a parent training component, fidelity standards for staff training, and is individualized for each child. A 2 year randomized controlled trial (RCT) that compared 24 ESDM children to 24 Treatment As Usual (TAU) children found the model had positive impacts on receptive and expressive language, cognitive functioning, and adaptive functioning.

The LEAP model (Strain & Bovey, 2011) is an inclusive preschool model focused on high quality classroom inclusion, incidental teaching, use of prompts, embedded routines, pivotal response training, picture exchange, and the integration of behavioural principles into a preschool setting. The LEAP model includes 15 hours per week of classroom instruction, has a parent training component, fidelity standards for staff training, a minimum ratio of two typical developing children per ASD child, and a minimum of one adult per five children. A 2 year RCT that compared 56 classrooms (177 LEAP vs. 117 TAU; average age = 50 months at intake) found that the LEAP children had decreased autism symptomology, better social and language skills, and improved cognitive functioning when compared to the TAU group at the end of the study. Additionally, not only were outcomes reported to be statistically significant, with strong effect sizes for most standardized measures, but teachers and classroom support staff also reported the program to be highly useful. Finally, fidelity of implementation (replication accuracy of the intervention) was associated with positive outcomes for the children.

In their closing statements, Hume & Odom (2011) comment that in order to increase the science of therapy implementation for ASD, fidelity of implementation needs to be assessed at each intervention site, a multi-level training plan needs to be developed in conjunction with policy developers and government, and infrastructure and planning support needs to be provided in order to increase the use of evidence-based practice in the community. Both the LEAP and ESDM models hold strong promise for well designed early intervention models that could be implemented in the Alberta context, within the mandate of PUF and SS legislation, for children 2.5 to 6 years of age. Additionally, Early Intensive Behavioural Intervention (EIBI) and parent training programs such as the ones described above, have been associated with decreased parental stress and increased family adaptive functioning (Estes, Hus, & Elder, 2011).

School-Aged Support

The school-aged child is from the age of 6 to around 12 years of age, when puberty begins. Physical development begins to slow, gross and fine motor skills become refined, logical thinking becomes more evident, more time is spent in skill acquisition activities such as academics, cognitive abilities become more complex and abstract, pro-social standards and behaviour become internalized, gender differences become more prominent, long-term friendships stabilize, social reputation becomes more important, hobbies develop, play becomes more organized in the form of games with rules, and attention, memory, executive functioning and self-regulation all increase (Davies, 2004). As the child spends most of their time in school, attachment patterns change and time with caregivers decreases, replaced by time with friends and in structured, school-related activities. Mastery of school and school-related activities becomes the primary developmental task.

Little distinction is made in the ASD literature between those programs designed for preschoolers and those for school-aged children. The same principles apply as they are consistent with NRC (2001) best practices literature for this age group including entry into a formal program as early as possible, a high frequency of child engagement, the inclusion of parent involvement, the use of repeated and planned teaching opportunities, sufficient daily adult attention, and instruction in functional communication, social and play skills, generalization of skills to natural contexts, and the use of positive behaviour supports to address problem behaviours. Of course, as the children are typically enrolled full time in a school placement, it is usually less difficult to meet minimum intensity requirements of 25 hours per week for programming, provided there is adequate individualized attention.

Koegel, Freeden, Koegel, & Lin (2011) describe how school settings are ideal environments for children with ASD to practice their communication and social skills, particularly as these children often continue to struggle with spontaneously communicating their needs, misinterpret social context and non-verbal cues, are highly reliant on prompts by adults, and tend to use language primarily for requests and protests, rather than for social purposes. Children with ASD also have great difficulty with generalizing skills from one social context to another.

Koegel et al. (2011) identify inclusion with typical peers in community and school settings as essential, citing previous research that children in inclusive settings have more frequent social interactions than segregated settings (Kamps, Dugan, Potucek, & Collins, 1999), better generalization of skills to different settings (Licciardello, Harchik, Luiselli, 2008), increased communication spontaneity, and children with ASD show better outcomes when both the child and their peers are targets of intervention (Harper, Symon, & Frea, 2008). Koegel et al. (2011) also report that school-based activities such as integrated play groups with adult direction, peer-buddy dyads, social skills training, practicing of activities prior to classroom presentation (priming), incorporating restricted areas of interest into classroom activities to increase motivation and compliance, the formation of “clubs” or “circles” with typical developing peers, video modeling, and self-management of behaviour are all interventions with some research support, particularly when delivered within the framework of pivotal response training (PRT), a naturalistic behavioural method.

Kasari & Locke (2011) report that successful social skills training programs target specific contexts (school, family, community), integrate siblings as natural teachers, integrate unstructured activities such as recess and the playground, target and teach identifiable skills in a systematic way with adequate time for practice, utilize both adults and peers, use groups and individual teaching methods, and must be developmentally appropriate and

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flexible. Collateral benefits of targeting social interaction within school and community settings include decreased loneliness, enhanced esteem, less likelihood of victimization, prevention of depression and anxiety disorders, and more positive well-being overall (Koegel et al, 2011).

Adolescent Support

The adolescent, aged 13-17 years of age, marks the transition from childhood to adulthood with many developmental changes. School often continues to be the primary source of social support until graduation. Gabriels (2011) remarks that a different set of challenges arise for those with ASD including a greater physical presence, increased expectations by others, less tolerance for emotionally immature behaviour in the community, and continued problems with communication, social engagement, restricted interests, delayed daily living skills, and problems with vocational planning. For example, Stokes, Newton, & Kaur (2007) report that adolescents and adults with ASD are more likely to use inappropriate and threatening behaviour when pursuing a romantic partner—often due to a misunderstanding of social rules and expectations. Self-injurious or aggressive behaviour is also more likely to occur if there are communication difficulties, low cognitive abilities and sensory processing problems—often making community and school-based programming difficult (Cox & Schopler, 1993). Finally, mood disorders often peak during this age period, including comorbid diagnoses of anxiety, depression, and obsessive-compulsive disorder, as adolescents with ASD tend to continue to think concretely, struggle to understand the intentions of others, tend to focus on details at the expense of “the big picture”, have trouble with organizing and sequencing, and can be highly distractible (Gabriels, 2011).

In order to mitigate many of the difficulties, Gabriels (2011) recommends that programming for this age group focus on independent, functional life skills, vocational planning, expanded social networks, continued education, and reduced dependency on immediate families for primary support. Sample curriculums often focus on sexuality, safety, relationship skills, diet and meal planning, exercise, hygiene, household chores, managing money, shopping, and friendships. The transition into adulthood may include preparation for independent living, residential or vocational programs, supportive college programs, or employment training programs.

One example of an evidence-based program for social skills training is the PEERS program, a parent-assisted social skills group for high-functioning adolescents with ASD, aged 13-17 years, that consists of fourteen 90-minute training sessions, based on a manual, delivered once per week, with separate group sessions for both the teens and their parents (Laugeson & Frankel, 2010). Session topics include conversational skills, electronic communication, choosing appropriate friends, appropriate use of humour, peer entry and exit strategies, get-togethers, good sportsmanship, handling teasing, bullying, bad reputations, disagreements and gossip. In a recently published RCT of 28 middle and high school students, the intervention group demonstrated improved social skill knowledge, responsiveness, motivation, assertion, cooperation and responsibility after completing the program, and these gains maintained after a 14 week follow-up (Laugeson, Frankel, Gantman, Dillon, & Mogil, 2012). Social skill programs such as these should be considered for adolescents with ASD.

Adult support

Adulthood is marked by independence, increased responsibility and generally a transition into advanced education, training or the workplace. Howlin (2005) reports that due to the stress of entering adulthood, many individuals manifest with increased psychiatric disturbance and up to 50% display problematic behaviour. However, reflecting the difficulty in predictions with this population, for up to 40% there is improvement in overall functioning. Unfortunately, few long-term studies on adults with ASD exist, though Gabriels (2011) indicates that of those that have been done, a substantial number of adults continue to be dependent on their families for support, few live independently, many are dependent on service providers for daily living assistance, and many have limited social networks. Cederlund, Hagberg, Billstedt, Gillberg, and Gillberg (2008) followed 70 males diagnosed with Asperger's syndrome (a milder form of autism), and found that only 27% met the criteria of a "good outcome"—being employed or in higher education, living independently by 23 years of age, and having two or more friends, despite higher intellectual functioning (I.Q. > 70).

By comparison, Cederlund et al. (2008) also followed individuals meeting more stringent autism criteria, with onset of symptoms prior to the age of 3 and delayed language onset, and none of those individuals met the "good outcome" criteria in adulthood and 56% had "very poor outcomes." A "very poor outcome" was defined as an inability to function independently and continued demonstration of poor communication skills. Reflecting an ongoing need for support, only 8% of the latter autism group were reported to live independently and the vast majority continued to require caregiver support, highlighting the need for practical life skill interventions, regardless of intellectual functioning.

Howlin (2005) reports that a minimum childhood I.Q. of 70 is typically needed for a "good outcome" on virtually every measure of adult adjustment including academic attainment, communication skills, reading and spelling, employment status, and social independence. However, by no means is I.Q. a positive predictor for adult outcome as Howlin (2005) also reports that up to 44% of adults diagnosed with ASD and reported childhood I.Q.'s of over 100 (average range) continue to obtain ratings of "poor" or "very poor" on objective measures when followed in adulthood. Somewhat surprisingly, a better predictor of adult adjustment may be the presence of useful speech by age 5 (Lord & Bailey, 2002), as communication skill is strongly related with many of these other measures, though other studies have found even this factor to be only weakly associated (Howlin, Goode, Hutton, & Rutter, 2004). The development of useful language may be a mitigating factor for poor long term prognosis, though at this time its utility as a long-term predictor of support needs is still not clear.

Other contributors impacting adult outcome are access to appropriate education for later employment and social independence, participation in inclusive settings for as long as feasibly possible, vocational planning including some type of formal qualification, the development of functional life skills for independent living, and supportive transitions into employment settings (Howlin, 2005). In a review of 13 long term studies dating back to 1969, the job participation rate for adults with ASD ranged from 8-34% indicating that unemployment continues to be a major area of concern for this population (Howlin, 2005).

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In summary, there is research support for developing a lifespan approach for individuals with autism, and specific goals and curriculum should match the developmental stages of the individual. Children of different ages have different needs and support systems must be flexible and responsive to those needs in order to be most effective. Though more evidence is available for treatment designed for preschool and school-aged children, many of the evidence-based strategies are transferable to both the really young (infants and toddlers) as well as the adolescent and adult population. A well-developed lifespan approach to autism, based on research and best-practice evidence, is critical to ensuring that goals and curriculum are appropriate to the individual and family.

Part V: Lifetime costs and future questions

The prevalence of autism is rising, children are diagnosed at younger ages, and an integrated and cross-ministerial plan is required by government in order to respond. This plan should have input from parents, professionals, best practice guidelines, and peer-reviewed research literature in order to best address the needs of ASD children and families. Integrating all of these resources will also ensure the government is receiving good value for its provision of autism supports.

As one means of assessing value, Amendah, Grosse, Peacock, & Mandell (2012) consider autism costs from a lifespan approach and reviewed 40 studies to obtain cost estimates of the diagnosis in four areas: medical, nonmedical, productivity and caregiver time. By their estimates average expenditures were estimated as follows:

Medical:

- from $2,100 to $11,200 per person, per year.

Nonmedical:

- from $25,099 to $60,000+ for behavioural therapies per person, per year,
- from $2,199 to $128,275 for adult residential care, per person, per year,
- from $4,334 to $20,445 for supported employment per person, per year.

Loss of work productivity due to higher required parental demands:

- from $5,400 per child, per year in Sweden to $16,700 per child, per year in the U.S.A.

Lifetime costs:

- from $1.2 million to $4.7 million depending on the severity of the diagnosis and levels of intellectual functioning.

Though not an entirely accurate science, these cost estimates exemplify the need for a coordinated autism response as government often inherits a high portion of these costs.

This can best be done by building on the work of previous panels, such as that formed by Alberta Children's Services (2002) who formulated the report "A System of Care for Children with Autism." In order to continue the work of previous panels, and to provide an updated summary of the current literature, it is recommended that a clinical advisory panel, including parents and with cross-ministerial support, be appointed to address the following questions:

1. Review the sixteen ACS (2002) expert panel recommendations to determine if they have been fulfilled, no longer apply, require further study or adaptation, or should be implemented.

2. Determine if it would be of benefit to establish a permanent cross-ministerial committee similar to that established for Fetal Alcohol Spectrum Disorder (FASD), to provide continuity, cross-ministerial collaboration, research support, and to increase efficiency and integration of services. Alternately, other integrated models could be recommended.
3. Provide input into a provincial program evaluation mechanism, with input from autism researchers and ASD experts in Alberta, to determine if the programs provided are matching their intended mandates.
4. Determine if there would be benefit to establishing quality and accreditation standards for autism service providers and, if so, what this would entail.
5. Provide quarterly, updated summaries of best practices literature to the government for the following age groups: 0-3 (Infant and Toddler), 4-6 (Preschool), 7-12 (School aged), 13-17 (Adolescents) and 18 years of age and older (Adults). The summaries would provide direction for the following specific policy-related questions:
   a) Should all infants and toddlers with an ASD diagnosis be eligible for early intervention support? How do infants and toddlers qualify?
   b) How should individuals diagnosed with mild/moderate ASD be considered under the current funding structures?
   c) How should supports be differentially structured for toddlers, children, adolescents and adults diagnosed with autism, particularly those who do not qualify for supports under the current funding structure?
   d) What should the intensity targets (hours of service) be for each age group and what professionals and paraprofessionals need to be involved?
   e) What models of intervention support should be provided for each age group to be eligible for financial support by the government of Alberta? What are the criteria for eligibility?
   f) What training requirements would be beneficial to increase evidence-based supports for those impacted by autism?
   g) How to facilitate better transition planning?
   h) How can the government work towards ensuring that application for supports minimize stress for families of children with ASD?
   i) What is the ideal role of community, health, and school professionals when determining whether children qualify for specialized supports?
   j) How is the balance between child treatment and family support to be structured for each stage of intervention? Should the provision of child supports be dependent on a family's ability to implement the strategies? Is the family or the child the target of the intervention?
   k) What does "best practices" and evidence-based educational inclusion look like for the ASD population in educational settings?

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l) What is "effective practice" for school-aged children with ASD, particularly given the mandate to a more inclusive educational model?

m) What are the essential components for an integrated, cross-ministerial individualized care plan for those children with complex needs?

n) What support needs should be considered for adults with ASD, particularly those with an I.Q. over 70?

o) How to enhance cross-ministerial collaboration and sharing, particularly at times of transition?

p) Are there specific tools that would be recommended, such as the Supports Intensity Scale (SIS) used through PDD that could be useful for standardizing the application process, measuring progress and be part of an overall program evaluation plan?

q) What adaptations need to be made for rural populations or those with less access to health care professionals?

Though comprehensive, this list is designed to be a starting point for conversation between the different stakeholders to determine some initial agreement on framework questions that will help shape autism supports in the future. It is expected that needs and priorities will change as other stakeholders participate in the process. However, though the task is large, it is necessary. An initial step would be set up a government appointed panel, with a regular reporting mechanism to the ministries impacted, to increase the basis of evidence-based care for those impacted by this most difficult condition.

Appendix A: Criteria for Autism Spectrum Disorders

DSM-IV-R (APA, 2000) criteria for Autistic Disorder, PDD-NOS, and Asperger's Disorder

299.00 Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) qualitative impairments in communication, as manifested by at least one of the following:

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) apparently inflexible adherence to specific, nonfunctional routines or rituals

(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements)

(d) persistent precoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

299.80 Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder. For example, this category includes "atypical autism" —presentations that do not meet the criteria for autistic disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

299.80 Asperger's Disorder (or Asperger Syndrome)

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

  (1) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

  (2) failure to develop peer relationships appropriate to developmental level

  (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)

  (4) lack of social or emotional reciprocity

B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

  (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

  (2) apparently inflexible adherence to specific, nonfunctional routines or rituals

  (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

  (4) persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

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E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia.

NOTE: Though Childhood Disintegrative Disorder and Rett's Disorder are also considered Pervasive Developmental Disorders they have not been included here due to their low prevalence rates.

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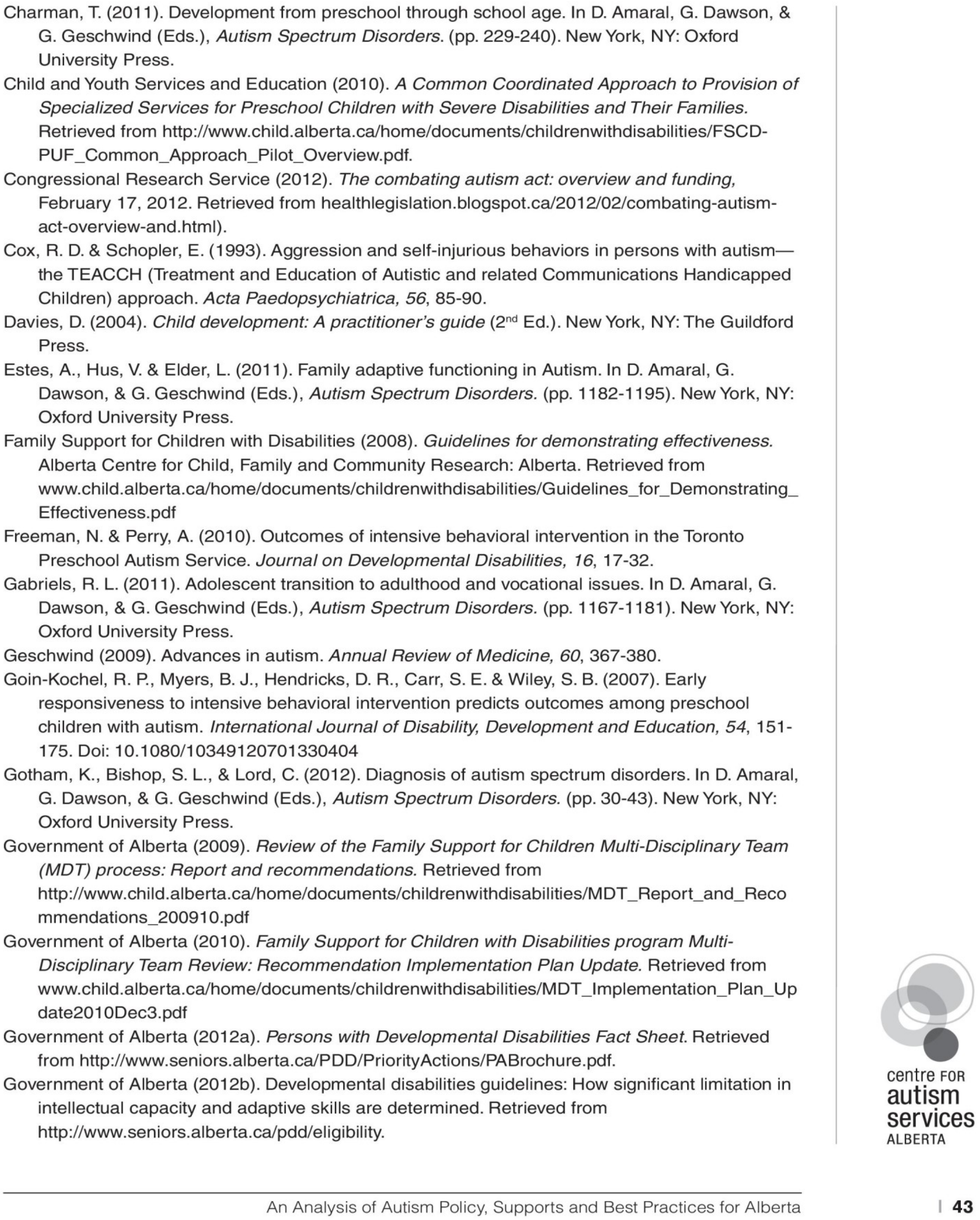

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