**Symposium Title:** Access to Early Intervention for Children with Intellectual and/or Developmental Disabilities and their Families

**Chair:** Suzi J. Scott¹

**Discussant:** Mélina Rivard²

**Overview:** Despite the evidence-base for the provision of early intervention (EI) for children with intellectual and/or developmental disabilities (IDD) and their families, concerns regarding access to EI have been raised in both research and practice. Whilst there is an increasingly large body of research on EI for IDD, especially around the development, feasibility and efficacy of EI, at present there is a paucity of research exploring access to EI. To ensure families are able to benefit from high quality support when they need it, should research focus on understanding disparities in access to support?

Our symposium will explore improving access to EI for children with IDD and their families, through investigating recognition, identification and early intervention. Recent research findings from the United Kingdom (UK), United States (US) and Canada will be shared covering current access to support, barriers and facilitators of access, and improving access to support. The first presentation in our symposium will share findings on current access to EI for families of young children with suspected or diagnosed IDD across the UK, in addition to barriers and facilitators of access for this population. Our second presentation highlights barriers and facilitators of access across the service trajectory for families of children with ID in Québec, Canada. Our third presentation explores the recognition and identification of autism for Hispanic families in the US, through examining the cultural validity of an autism diagnostic assessment. Finally, our fourth presentation explores the timeliness of diagnostic and EI services, through examining the impact of an assessment centre to reduce waitlists for families of children with autism and ID. These presentations demonstrate the potential benefit of considering the accessibility of support across recognition, identification and EI for children with IDD. Considering the findings shared, we invite delegates to join a discussion around the importance of exploring the accessibility of support and the role of research in improving access to support for families.

**Paper 1 of 4**

**Paper Title:** Access to Support in the Early Years for Families of Children with Intellectual and/or Developmental Disabilities in the United Kingdom: What Support Do Families Access and What Influences Access?

**Authors:** Suzi J. Scott¹, Vasiliki Totsika³ ⁴, Richard P. Hastings¹ ⁴

**Introduction:** Intellectual and/or developmental disabilities (IDD) onset during early development and are lifelong (Patel & Merrick, 2011). In addition to cognitive and adaptive delays which are present by definition, other mental health, physical health and social inequalities also emerge in the early years, such as poorer parental well-being and increased child behavior problems (Hastings, 2016; Totsika et al., 2011). Research clearly highlights the importance of early identification and early intervention (EI) to improve child and family outcomes (e.g. Majnemer, 1988; Wallace & Rodgers, 2010). Despite this, relatively low levels of access to EI for children with IDD and their families is indicated in research (e.g., Crane et al., 2016; Roberts et al., 2007). A recent international review identified several factors at multiple levels (i.e. child, family, service, system, intersection, contextual) that influence access to EI for this population, such as parental socioeconomic status, receipt of formal diagnosis and the financial set-up of service systems (Scott et al., submitted for publication). However, research on access to EI is limited at present. In order to improve outcomes and ensure families are able to benefit from high quality support when they need it, it is critical to explore this issue further. The aims of the present study were: (1) to explore current access to EI for families of children with suspected or diagnosed IDD across the UK; and (2) to identify barriers and facilitators of access to EI experienced by this population.

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**Methods:** We developed a survey to collect both quantitative and qualitative data on experiences of access to EI, which covered: (1) access to formal and informal support sources; (2) unmet support needs (i.e., support wanted but not accessed); (3) ease of access; (4) barriers and facilitators of access; and (5) helpfulness of support. The Family Support Scale (FSS; Dunst, Jenkins, & Trivette, 1984) was adapted to include 50 formal and 12 informal sources of support, following consultation with a group of parents and professionals. Open-ended questions were used to measure access to specific support approaches or interventions, and barriers and facilitators of access. Additional data on a range of child and family characteristics and background information was collected, such as child age, gender, diagnosis, family composition, socioeconomic factors, etc. Between September 2018 and May 2019, parental caregivers of children aged 0-6 years with IDD (either diagnosed or suspected) in the UK were invited to complete our anonymous survey. Participants were recruited via social media and from the networks of organizations that work with families of young children with DD in the UK, such as charities, specialist schools, and independent service providers.

**Results:** Overall, 673 parental caregivers of children with a mean age of 4.8 years (SD 1.5) participated in the study. Children had a range of suspected or diagnosed IDDs; the most common were autism (77.9%; 50.4% diagnosed, 12.0% in assessment, 15.3% assessment waitlist), intellectual disability (48.7%; 33.4% diagnosed, 6.8% in assessment, 8.5% assessment waitlist) and developmental delay (47.1%; 37.4% diagnosed, 5.7% in assessment, 4.0% assessment waitlist). EI sources accessed by the highest percentage of families were pediatrics (84.6% of participants), speech and language (84.3%) and general practice (78.8%). Around one-third (32.8%) of families were on a waitlist for EI, most commonly for occupational therapy (7.0%), educational psychology (6.8%) and health or social teams to assess needs (4.5%). EI rated as the most difficult to access included mental health specialists, social workers, and health or social teams to assess needs. Unmet need for EI was highest for behaviour specialists (34.5%), sleep practitioners (26.9%) and respite carers (23.2%). In the past 12 months, less than one-third (29.3%) of participants or their child had accessed interventions. Thematic analysis highlighted several common barriers and facilitators of access, such as the availability of information and services, waitlists, recognition of need, communication, and service systems.

**Discussion:** Our results illustrate the current state of access to support in the early years for families of children with IDD in the UK and indicate several barriers prevent families from accessing support when they need it. Practical implications for the provision of support in the early years and recommendations for future research will be discussed.

**References/Citations:**


**Paper 2 of 4**

**Paper Title:** Barriers and Facilitators of Access to Support across the Early Service Trajectory for Families of Children with Intellectual Disabilities in Canada

**Authors:** Justine Grenier-Martin⁵, Méлина Rivard⁶

**Introduction:** Among families of children with global developmental delay (GDD) or intellectual disability (ID), most of the challenges faced during childhood are increased by consequences related to the child’s diagnosis. Specialized services in Québec are generally accessed after a long waiting period, and services offered vary depending on where the family lives, as resources are managed by sectors independently. Families’ experiences surrounding diagnostic evaluation and early intervention (EI) services can have important repercussions on the family’s quality of life and the child’s development (Rivard, Lépine, Mercier, & Morin, 2015). It therefore needs to be addressed. We set out to assess parents’ perceptions of their early service trajectories including the diagnostic evaluation process, specialized EI services and the management of problematic behaviors.

**Methods:** To acquire better understanding of the present situation for families of children with GDD or ID aged under 8 years old in Québec, this study documented the perceptions of 61 parents’ surrounding diagnostic evaluation and EI service trajectory in Québec. Data was collected from an online survey comprised of several multiple choice and open-ended questions. Questions addressed parents’ experiences from the evaluation process leading to diagnosis, specialized EI services for the child and family, and the management of problematic behaviors. Participants were recruited online through multiple social media community groups for parents of children with special needs. The survey was available in French and English.

**Results:** Participants were mostly Canadian women with a mean age of 36 years (range 23-50). In order to start the diagnostic process, most of the families were referred to public services by their physician. The mean waiting time was 6 months to start the diagnostic process, and another 6 months to complete it, but some families waited >48 months overall. There was heterogeneity between the reality brought by families in the survey, mostly related to the child’s diagnosis (GDD or ID related to a genetic syndrome). As for access to EI, families mainly reported child-oriented services, but they also asked for family-oriented services, such as psychological support for parents and siblings. The most critical quality determinant of the service trajectory was the accessibility of services, which was perceived the most negatively by families. Nonetheless, families positively assessed services offered directly to the child, while those offered to the rest of the family were evaluated more negatively.

**Discussion:** This study helps build a clear vision of the priorities that should guide improvements to the current specialized EI services offered. Different suggestions emerged from this study and will be discussed. Mainly, a family-centered approach is suggested to maximize the support received by each family member, both in terms of orientation through the various services and psychological support for the whole family. Implications for future research and clinical practice will be discussed.

**References/Citations:**


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**Paper Title:** Exploring the Recognition and Identification of Autism: A Qualitative Analysis of Hispanic Caregivers Responses to Selected Autism Diagnostic Interview-Revised (ADI-R) Spanish Items

**Authors:** Maria Elizabeth Jaramillo6 7

**Introduction:** In the United States (US), Hispanic children tend to be diagnosed with autism approximately 2.5 years later than non-Hispanic White children and are more likely to be missed despite meeting diagnostic criteria (Zuckerman, 2014; Mandell et. al., 2002, 2009). How healthcare providers elicit and respond to parent reports of developmental concerns may influence the age of autism diagnosis (Zuckerman, 2015). While systematic factors influence diagnosis, there may be differences in how Hispanic mothers report autism symptoms (Blacher, 2014). This is an important issue, as autism is diagnosed based on both behavioral observation and caregiver report. US-based Hispanic mothers may under-report autism symptoms in their children in comparison to reports by White mothers (Blacher, 2014). One reason for this discrepancy may be the design of developmental assessments. The development of assessment tools that are appropriate for culturally and linguistically diverse populations is important for the collection of accurate surveillance data and equitable health service delivery. Developmental assessment is an area of research which poses opportunities to increase social justice and health equity.

The Autism Diagnostic Interview-Revised (ADI-R; Lord, 1994) is a widely used autism diagnostic instrument that was developed and revised by researchers in Canada, the US and UK (Le Couteur, 1989). The Spanish version of the ADI-R was translated by both professional translators using a forward and back translation method and bilingual psychologists, but has not been culturally adapted (Vrancic, 2002). Generally, this project considers the assumption that a Spain-based rendition of an instrument may not match the cultural and linguistic needs of US-based Latin American families. Research to understand the behavior of the instrument in a new population, such as the psychometric validation (Vanegas, 2016), may be necessary. The objective of this study is to explore the cultural relevance of commonly used items on the ADI-R Spanish to a US-based population of Latin American decent. This study seeks to generate themes that characterize the responses to items by a US-based Latina population.

**Methods:** The present study is a qualitative analysis of caregivers’ responses to the ADI-R Spanish. This version was translated into Spanish by a TEA Ediciones, a well-established publisher specializing in psychological measures based in Madrid, Spain. Item selection and analysis was limited to the diagnostic algorithm. In this study, we used inductive analysis to explore theories of cultural mismatch of the items and deductive analysis to generate themes that characterize how mothers report symptoms. The primary researcher transcribed five videos into notes to create a codebook. A review by a secondary researcher was conducted to explore points of researcher bias. The data for this study was drawn from a sample of 50 previously recorded and de-identified administrations of the ADI-R Spanish (Magaña, 2017). Interviewees in this sample were of Latin American decent, spoke Spanish as their primary language, and were the primary caregiver of a 4-16 year-old child with autism (Magaña, 2017). Participants for the sample were recruited from clinics and parent support groups in two Midwestern US cities (Magaña, 2017).

**Results:** This study identified various themes, including terminology and concept mismatch, respondent-introduced vocabulary, and child-caregiver language mismatch concerns. Results reveal some mismatches between item intent and respondent interpretation due to the use of certain terminology in several ADI-R items. For example, “pronunciación (pronunciation)” versus “articulación (articulation)” caused some confusion. There were also some conceptual mismatches, such as with the phrases “frases raras (weird phrases)” as well as “small talk” and “hobby”. Additionally, this study identified respondent-introduced vocabulary for child behaviors, particularly related to speech, social communication, and socially inappropriate behaviors. For example, mothers used the terms “mochos” and “chipilón” to describe their child’s speech production. Lastly, analysis of the

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responses revealed that some US-based Hispanic mothers feel they cannot adequately judge their child’s communication abilities, due to language differences in the parent-child dyad.

Discussion: Results of this study can inform the use of the ADI-R Spanish in a clinical setting among US-based Hispanic mothers. Results may also help autism researchers understand how US-based Hispanic mothers represent and describe their child’s symptoms. Researcher characteristics and assumptions that may influence qualitative results will be discussed. Future research may explore the cultural validity of the ADI-R Spanish among Latin American (US and non-US based) populations through the Cognitive Interview.

References/Citations:


Paper Title: Increasing the Timeliness of Access to Diagnostic and Early Intervention Services: The Impact of an Assessment Centre to Reduce Waitlists for Families of Children with Autism and Intellectual Disabilities in Canada

Authors: Nadia Abouzeid8 9, Méliana Rivard8, Diane Morin8, Marjorie Morin8, Céline Chatenoud8, Céline Mercier8

Introduction: To help eliminate current waitlists in Montreal (Canada) for young children requiring assessments of autism, global developmental delay (GDD) or intellectual disabilities (ID), the See Things My Way (STMW) assessment centre was launched in 2015. Since then, an interdisciplinary evaluation team has been offering assessment services based on best practice, to support...
families in accessing the much-needed early intervention (EI) services. To achieve the highest standard of evaluation services and to ensure the viability, sustainability and replicability, a research project was developed to evaluate the implementation, efficiency and social validity of the STMW assessment centre from the start of its operation. The objectives of this presentation are to present the evaluation of the both the implementation and the satisfaction with the STMW assessment services.

Methods: Participants included 8 professionals and 209 families. To measure implementation, data was collected from: Administrative records (number of referrals, completed evaluations, efficiency); Semi-structured interviews with staff members; Self-report questionnaire on implementation completed by staff members; List of implementation indicators. To measure satisfaction with services, data was collected using the Client Satisfaction Questionnaire (CSQ-8) and the Perceived Quality of Services questionnaire (Evaluation of the Trajectory in Autism for Parents; ETAP). Descriptive and frequency analysis was conducted on quantitative data and thematic analysis was conducted on qualitative data.

Results: Between April 2015 and September 2019, the STMW assessment services received over one thousand referrals for diagnostic evaluation, completing on average 275 interdisciplinary assessments per year. The interdisciplinary team consists of professionals from diverse disciplines and corresponds to 7 full-time equivalent roles. These results demonstrate the efficiency of the model. In addition, the implementation evaluation indicates that the centre has implemented best practice and reached a satisfactory level of implementation (80% or more) for each of the five implementation dimensions observed in the first year of operation. In regard to families’ satisfaction, at least 93% of parents responded to each item to indicate that they were either sufficiently satisfied or very satisfied with the STMW assessment services.

Discussion: The results demonstrate that the STMW assessment service is well implemented, efficient and socially valid. Findings indicate a statistically significant difference in the experience and trajectory of families who accessed the STMW assessment service, compared to families who did not access the STMW service. The STMW assessment centre successfully increased the timeliness of access to diagnosis and EI. Furthermore, the STMW assessment centre appears to adhere to the quality determinants of services (continuity, accessibility, availability, and flexibility). However, the research highlighted some challenges, namely the extensive wait time to access early intensive interventions. In order to bridge these gaps, the STMW centre has developed other initiatives to promote more seamless transitions and to improve families’ well-being and quality of life. For instance, a parent coaching program based on the Early Start Denver Model was launched in 2017 to provide transitional services to families waiting for intensive services.

References/Citations: