

Stereotypic Behaviors in Children with Autism Spectrum Disorder:
Observations of Stereotypic Engagement after Receiving Early Intervention

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TABLE OF CONTENTS

LIST OF TABLES.....	4
LIST OF FIGURES.....	5
ACKNOWLEDGEMENTS.....	6
ABSTRACT.....	7
RÉSUMÉ.....	9
 CHAPTER ONE: Introduction.....	 11
CHAPTER TWO: Literature Review.....	21
Autism Spectrum Disorder (ASD).....	21
Prevalence.....	21
Age at Diagnosis.....	21
Restricted and Repetitive Behaviors (RRBs) and Stereotypy.....	23
Sub-Types of Stereotypy.....	26
Terminology and Classification.....	26
Development of Stereotypy in Typical and Atypical Populations.....	29
Prevalence across Populations.....	31
Infants and Children.....	31
Adolescents and Adults.....	35
The Function of Stereotypy.....	37
Neurobiological Perspectives.....	38
Behavioral Perspectives.....	38
Factors that Influence Development Outcomes.....	39
Impact of Stereotypy on Child and Parent Outcomes.....	41
Child Outcomes.....	41
Stigmatization.....	42
Parental Stress.....	44
Early Intervention Approaches.....	45
Family-Centered Care (FCC)	46
Guralnick's Principles of Early Intervention.....	47
Pharmacological Interventions.....	48
Behavioral Interventions.....	50
Carolina Curriculum and the Treatment and Education of Autistic and Re-	
lated Communication Handicapped Children (TEACCH) models.....	50
Early Intensive Behavioral Intervention (EIBI)	51
Antecedent-Based Interventions.....	52
Consequence-Based Interventions.....	53
Efficacy of Behavioral Interventions.....	55
Efficacy of TEACCH.....	55
Efficacy of Consequence-Based Interventions.....	57
Efficacy of EIBI.....	60

Present Study and Rationale.....	66
Research Questions.....	68
CHAPTER THREE: Methods.....	70
Participants.....	70
Early Intervention Sites.....	73
Site One.....	73
Site Two.....	73
Site Three.....	74
Procedure and Research Design.....	75
Measures.....	76
Socio-Demographic Questionnaire.....	76
Video Recordings.....	76
Data Collection and Reliability.....	78
Data Conservation.....	80
CHAPTER FOUR: Results.....	81
Stereotypy Behaviors Prior to Intervention (Baseline)	81
Stereotypy Between 10-s Intervals at Baseline.....	84
Comparisons of Stereotypy Behaviors between Baseline and Post-Intervention Phases.....	84
Stereotypy Between 10-s Intervals at Post-Intervention.....	87
Group Comparison: Stereotypy Behaviors between Baseline and Post-Intervention Phases.....	88
Group Comparisons Based on Length of EI Treatment.....	88
Individual Participant Analyses from Baseline to Post-Intervention Phases.....	89
Complete Elimination of Stereotypy.....	90
Reductions and Partial Elimination of Stereotypy Sub-Types.....	91
CHAPTER FIVE: Discussion and Conclusion.....	95
Stereotypic Engagement Prior to the Onset of EI Services.....	95
Stereotypic Engagement After Receiving Early Intervention.....	98
Limitations and Future Research.....	104
Implications and Conclusion.....	108
REFERENCES.....	113
APPENDIX A.....	144
APPENDIX B.....	145
APPENDIX C.....	150

LIST OF TABLES

Table 1	Subtypes of Repetitive Behaviors: Classification and Definitions.....	25
Table 2	Subtypes of Stereotypy and Operational Forms.....	28
Table 3	Child Demographic Characteristics.....	71
Table 4	Characteristics of Early Intervention Services Participants Received and Additional Private Services Received.....	72

LIST OF FIGURES

Figure 1.	Factors that influence developmental outcomes for children by Michael Guralnick.....	40
Figure 2.	Percentage of all stereotypic behaviors at baseline; prior to the onset of EI services.....	82
Figure 3.	Frequency of stereotypy sub-types each participant engaged in, at baseline; prior to the onset of EI services.....	82
Figure 4.	Frequency of stereotypy sub-type engagement by all participants at baseline; prior to the onset of EI services.....	83
Figure 5.	Number of participants that engaged in at least one form of stereotypy sub-type between the 10-s intervals, at baseline; prior to the onset of EI services.....	84
Figure 6.	Percentage of stereotypic behaviors each participant engaged in at baseline and at post-intervention; after two years or upon completion of EI, whichever came first.....	85
Figure 7.	Frequency of stereotypic engagement, based on sub-type, from baseline to post-intervention for participants who received EIBI services after two years or upon completion of EI, whichever came first.....	87
Figure 8.	Number of participants that engaged in at least one stereotypy sub-type between the 10-s intervals, at baseline (prior to the onset of EI) and post-intervention (after two years or upon completion of EI, whichever came first).....	88
Figure 9.	Frequency of stereotypic engagement, from baseline to post-intervention, grouped by length of time in EI services receiving either EIBI or Carolina Curriculum and TEACCH for less than one year, over one year, or two or more years.....	89
Figure 10.	Noah and Paul's percentage of stereotypic behaviors at baseline and again at post-interventions. Line graphs depict their complete elimination of behaviors after receiving EIBI or Carolina Curriculum & TEACCH across a two to three-year period.....	90-91
Figure 11.	Sam, Craig, and Ben's percentage of stereotypic behaviors from baseline to post-intervention. Line graphs depict participant's reduction and complete elimination (of some sub-types) of stereotypy after two to three years of early intervention services (EIBI or Carolina/TEACCH).....	92-93

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Abstract

Stereotypy is one type of repetitive behavior observed in individuals with autism spectrum disorder (ASD). Researchers have found that engaging in stereotypic behaviors can impede opportunities for socialization and skill development (Ashburner et al., 2008; Cunningham & Schreibman, 2008), and can inadvertently cause stress and stigma for families (Farrugia, 2014; Guralnick, 2005). Luckily, early intervention (EI) has been found to improve certain ASD symptomology, such as deficits in communication and socialization (Cohen et al., 2006; Howard et al., 2005; Lovaas, 1987; Makrygianni & Reed, 2010; Peters-Scheffer et al., 2011). Yet, only five publications to date have examined the effectiveness of EI (specifically early intensive behavioral intervention; EIBI) on stereotypic behaviors and although reductions have been noted, results have been overwhelming mixed (Ben-Itzhak & Zachor, 2007; Dawson et al., 2010; MacDonald et al., 2014; McGarrell et al., 2009; O'Connor & Healy, 2009). The present study aimed to contribute to the small body of literature in an effort to provide some insight into, if and, to what extent stereotypic engagement changes after EI. A quasi-experimental non-equivalent within-group design was conducted with a sample of children (N=20) with ASD, receiving either EIBI or a combination of the Carolina Curriculum and TEACCH models from EI centers in Montreal. A socio-demographic questionnaire and video recordings were administered at two time periods, at baseline and post-intervention, and data was collected on seven different forms of stereotypy. Results showed positive behavioral outcomes at post-intervention. Compared to baseline, two participants completely eliminated their stereotypy and 15 participants showed a 1% to 41% reduction in their engagement, regardless of the type of intervention received. EIBI group means specifically reduced from 24.7% at baseline to 17.7% at post-intervention. Participants who received less than one year or more than two years of EI were

found to show the most reductions, both in terms of changes in the frequency and diversity of stereotypic engagement. Results are expected to contribute to the existing research literature and inform educators and service providers in the field early intervention.

Keywords: autism spectrum disorder, stereotypy, early intervention, child outcomes

Résumé

La stéréotypie est un type de comportement répétitif observé chez les personnes atteintes d'un trouble du spectre de l'autisme (TSA). Les chercheurs ont constaté que s'engager dans des comportements stéréotypés peut entraver les possibilités de socialisation et de développement des compétences (Ashburner et al., 2008; Cunningham & Schreibman, 2008) et peut causer par inadvertance le stress et la stigmatisation pour les familles (Farrugia, 2014, Guralnick, 2005). Heureusement, l'intervention précoce (IP) a été trouvée pour améliorer une certaine symptomatologie TSA, comme les déficits de communication et de socialisation (Cohen et al., 2006; Howard et al., 2005; Lovaas, 1987; Makrygianni & Reed, 2010; Peters- Scheffer et al., 2011). Pourtant, seulement cinq publications, à ce jour, ont examiné l'efficacité de l'assurance-emploi (spécifiquement l'intervention comportementale intensive précoce, ICIP) sur les comportements stéréotypés et bien que des réductions aient été notées, les résultats ont été massifs (Ben-Itzhak & Zachor, 2007; Dawson et Al., 2010; MacDonald et al., 2014; McGarrell et al., 2009; O'Connor & Healy, 2009). La présente étude visait à contribuer à la petite littérature dans le but de donner un aperçu, si et dans quelle mesure l'engagement stéréotypé change après l'AE. Une conception quasi expérimentale non équivalente à l'intérieur des groupes a été menée avec un échantillon d'enfants (N = 20) avec TSA, soit ICIP, soit une combinaison du programme Carolina Curriculum et des modèles TEACCH des centres IP à Montréal. Un questionnaire sociodémographique et des enregistrements vidéo ont été administrés à deux périodes, à la ligne de base et après l'intervention, et les données ont été recueillies sur sept formes différentes de stéréotypie. Les résultats ont montré des résultats comportementaux positifs lors de la post-intervention. Par rapport à la ligne de base, deux participants ont complètement éliminé leur stéréotypie et 15 participants ont montré entre une réduction de 1% à 41% de leur engagement,

quel que soit le type d'intervention reçue. Le groupe ICIP signifie spécifiquement réduit de 24,7% à la base à 17,7% à la post-intervention. Les participants qui ont reçu moins d'un an ou plus de deux ans d'assurance-emploi ont montré le plus de réductions, tant en termes de changements dans la fréquence que dans la diversité de l'engagement stéréotypé. Les résultats devraient contribuer à la littérature de recherche existante et informer les éducateurs et les prestataires de services dans le domaine de l'intervention précoce.

Mots-clés: trouble du spectre de l'autisme, stéréotypie, intervention précoce, résultats des enfants

Stereotypic Behaviors in Children with Autism Spectrum Disorder:
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Early on researchers such as Skinner, Dewey, Vygotsky, and Piaget found that infants and children engage in a range of behaviors tied to learning and exploration, which in turn guide their development and their understanding of the world (Dewey, 1966; Ginsburg, 2007; Piaget, 1969; Skinner, 1954/1968; Tayler, 2015; Vickerius & Sandberg, 2006; Vygotsky, 1966). Information gathered through learning and play behaviors help to produce habits (Hull, 1966), help children learn to communicate, socialize, practice skills, and assists in the formation of a variety of interests and hobbies (Buriss & Tsao, 2002; Casby, 2003; Childress, 2011; Tayler, 2015; Vickerius & Sandberg, 2006).

For non-typically developing children such as those with a developmental disorder (such as autism spectrum disorder; ASD) learning, exploration, and interactions can happen less often as socialization and communication are two out of three areas most affected (American Psychiatric Association [APA], 2013). Children with ASD specifically struggle with deficits in communicating and socializing, and exhibit restricted interests, and engage in repetitive behaviors (APA, 2013); meaning that many children with ASD initiate fewer play interactions, stay confined to a particular hobby, and may engage in odd sounding or looking behaviors (Childress, 2011; Cress, Moskal, & Hoffman, 2008). The repetitive behaviors children with ASD engage in can look different from the non-repetitive behaviors their typically developing peers engage in; in so far as they occur out of context, for short or long durations, are rigid, and repetitive in presentation (APA, 2013; Rapp & Lanovaz, 2011). Unlike exploratory behaviors that provide context and assist children in their development and learning, problem behaviors such as repetitive behaviors can impede children's development and can cause social and

developmental consequences, including stigma (Goffman, 1966; Guralnick, 2005) social seclusion (Farrugia, 2009; Gray, 2002) interfere with learning, and impede communication and socialization skills (APA, 2013; Guralnick, 2005; Goffman, 1966).

Researchers have reported many different forms of restricted and repetitive behaviors (RRBs) and have classified them into approximately twelve different forms (e.g., see chapter two; Rojahn & Meirer, 2013; Scahill et al., 2013; World Health Organization [WHO], 2007). The present study will focus on one specific type, called *stereotypy* which is defined as rigid and repetitive motor and vocal mannerisms (Chebli, Martin, & Lanovaz, 2016; Lam, Bodfish, & Piven, 2008). Stereotypic behaviors are less widely understood and are considered under researched (Harrop et al., 2014; Richler, Bishop, Kleinke, & Lord, 2007), compared to other diagnostic features of ASD; such as socialization and communication. Due to the topographical complexity of stereotypic behaviors (i.e., the various forms, styles, and intensities of the behaviors that can be observed) researchers have attempted to understand the functionality (Cunningham & Schreibman, 2007; Rapp & Vollmer, 2005; Sayers, Oliver, Ruddic, & Wallis, 2011), the prevalence (Chebli et al., 2016; Thelen, 1979; Watt, Wetherby, Barber, & Morgan, 2008), differences across populations (DiGennaro Reed, Hirst, & Hyman, 2012; Goldman et al., 2008; Matson, Dempsey, & Fodstad, 2009; Neil & Jones, 2016), as well as what impact they have on children and parents (Ashburner, Ziviani, & Rodger, 2008; Crutchfield et al., 2015; Cunningham & Schreibman, 2008; Gabriels et al., 2015; Harrop et al., 2016; Richler et al., 2007).

Due to their topographical nature, identification and classification of stereotypy is based on the observation of the behavior, rather than the affiliation of a particular disorder (Chebli et al., 2016; Cunningham & Schreibman, 2008). For example, stereotypic behaviors are not only

unique to individuals with ASD (MacDonald et al., 2007; Wolff et al., 2014) and have been observed in typically developing infants (i.e., in the first three years of life; Berkson & Tupa, 2000; Chebli et al., 2016; MacDonald et al., 2007; Thelen 1979, 1981) as well as in infants, children, adolescents, and adults with other developmental disabilities (DD; such as Down syndrome, Retts syndrome, Fragile X syndrome, Angelman syndrome, Williams syndrome, Cri Du Chat syndrome, intellectual disability, Comelia de Langes snydome, and Prader-Willi syndrome; Chebli et al., 2016; Chowdhury, Benson, & Hillier, 2010; Mayes & Calhoun, 2011; Neil & Jones, 2016; Ruzzano, Borsboom, & Geurts, 2015; Totsika, Toogood, Hastings & Lewis, 2008). The prevalence of stereotypy in different populations range from 31-66% of individuals with a DD (Bhattacharya, Sanyal, Roy, & Saha, 2009; Chebli et al., 2016; Lundqvist, 2013) and 69-99% of individuals with ASD (Chebli et al., 2016; Goldman et al., 2008; McTiernan, Leader, Healy, & Mannion, 2011; Murphy, Healy, & Leader, 2009). For the purpose of this paper, *developmental disabilities* will be defined as “a group of severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22, that result in substantial limitations in three or more areas of major life activities: capacity for independent living, economic self-sufficiency, learning, mobility, receptive and expressive language, self-care, self-direction” (Administration on Developmental Disabilities, 2007; Gellman & Turner, 2013).

Although stereotypy is a behavior that typically developing children also engage in (Berkson & Tupa, 2000; Chebli et al., 2016; MacDonald et al., 2007; Thelen, 1979), concerns arise when children become preoccupied and engage in abnormal rates and intensities. For example, in typically developing infants, stereotypic behaviors will begin to disperse and decline after the second to third year of life (Chebli et al., 2016; MacDonald et al., 2007). Stereotypic behaviors can become problematic for a child’s development and can impact the family if they

continue into childhood and are not addressed (Bitsika, Sharpley, Bell, 2013; Cunningham & Schreibman, 2008; Rojahn & Meirer, 2013). The impact that certain factors (such as those associated with a child's disability) have on child development and the family unit has been largely explored by psychologist Michael Guralnick.

In his early work, Guralnick (1998) put forth an overarching framework called the *developmental systems model* to outline the interplay between normative child development, risk, and a disability. In his model, Guralnick (1998) outlined how distinct family patterns of interaction, such as quality parent-child transactions, family structured child experiences, and a child's health and safety are integral components in supporting child development. His work uncovered that a biological risk or an established disability (such ASD) and environmental risks such as family characteristics (including personal characteristics of parents, financial resources, social supports, and child characteristics related to personality and temperament) can cause added stress on family patterns of interaction and in turn inhibit child development (Guralnick, 1998, 2001, 2005, 2017).

Parents of children with a disability tend to face greater parenting demands, compared to parents of typically developing children, which can cause added strain on the family unit (Davis & Carter, 2008; Estes et al., 2009) Guralnick (2005) has pointed out that a biological risk or an established disability can generate a category of "resource needs" which can cause physical, psychological, emotional, and financial strain for families (Estes et al., 2009; Guralnick, 2005, p. 9). Researchers have found that parents of children with special needs work reduced hours (Coley et al., 2011), report difficulties retaining employment (Gordon, Rosenman, & Cuskelly, 2007) and are more likely to leave paid employment (Nes et al., 2014) compared to parents of children without a disability. Moreover, subsequent researchers have found that parents of

children with ASD report more mental health problems (such as stress, anxiety, and depression symptoms) and are at higher risks for depression (Alvarez, Meltzer-Brody, Mandel, & Beeber, 2015; Singer, 2006) compared to parents of typically developing children (Benjak, 2009; Davis & Carter, 2008; Falk, Norris, & Quinn, 2014; Hastings et al., 2005; Resch, Elliott, & Benz, 2012; Tomanik, Harris, & Hawkins, 2004).

As noted earlier, characteristics of a disability can cause an increase of demands on the family unit, which can affect family interactions that are considered vital for optimal child development (Farrugia, 2009; Guralnick, 2005). Characteristics of a disability, such as stereotypy have also been found to directly impede child development (Chebli et al., 2016; Cunningham & Schreibman, 2008; Dunlap, Dryer, & Koegel, 1983; Reese, Richman, Belmont & Morse, 2005). More specifically, researchers have found that similar to engaging in RRBs, engaging in stereotypic behaviors can restrict children and adolescents' opportunities for community involvement (Cunningham & Schreibman, 2008; Digennaro Reed et al., 2012; Wolery, Kirk, & Gast, 1985), social interactions (Reese et al., 2005; Sparapani et al., 2016; Wolery et al., 1985) have been found to produce negative educational outcomes by impacting skill acquisition (Dunlap et al., 1983), interfere with task completion (Ashburner, Ziviani, & Rodger, 2008; Crutchfield et al., 2015; Dunlap et al., 1983), and impede cognitive attention (Ashburner et al., 2008; Fernandez-Andres, Pastor-Cerezuela, Sanz-Cervera, & Tarraga-Minguez, 2015; Patterson, Smith, & Jelen, 2010).

Researchers have found that parents of children with ASD report experiencing stigma, attributed to their child's disability and their child's behavioral problems (Farrugia, 2009; Gabriels et al., 2005; Gray, 2002; Jones, Wint, & Ellis, 1990; Kinnear, Link, Ballan, & Fischbach, 2016; Nadig et al., 2010). Stereotypies have been referred to as inappropriate modes

of behaviors (Cunningham & Schreibman, 2008; Neil & Jones, 2016) and when individuals engage in these behaviors they do so in high frequencies (several occurrences in a given time timeframe), high volumes (loud), and in a variety of environments (e.g., home, school, church, and the play-ground; Rapp & Lanovaz, 2011). Stereotypy behaviors also appear inappropriate when they do not coincide with the age of the person manifesting the behavior (Cunningham & Schreibman, 2008; Falcomata, 2004). Studies have found that although both mothers and fathers of children with ASD report experiencing stigma, mothers are more likely to report hostile social stigma such as avoidance, hostile looks, staring, and rude remarks by strangers, friends, and parents at school (Farrugia, 2009; Gray, 2002). Both mothers and fathers of children with ASD reported stigma related to social exclusion such as friendship loss, social avoidance from other families with children, social opportunity loss for children with ASD and their siblings (Farrugia, 2009; Gray, 2002; Jones et al., 1990; Matson, Minshawi, Gonzelez, & Mayville, 2006). In addition to stigma, parents of children with ASD also report experiencing stress.

Parental stress, in particular, refers to adverse physical, psychological, and physiological responses that occur in relation to responsibilities and/or situations associated with parenting (Abidin, 1992; Belsky, 1984; Fernandez-Andres et al., 2016; Kissel & Nelson, 2016). At some point, all caregivers will experience stress related to parenting; however, parents of children with ASD report the highest rates of stress compared to parents of children without ASD (Davis & Carter, 2008; Estes et al., 2013; Hayes & Watson, 2013; Kirby, White, & Baranek, 2015). Mothers of children with ASD are more likely to report higher rates of parental stress, compared to fathers of children with ASD (Bitsika et al., 2013; Herring et al., 2006). Core deficits of ASD have been found to contribute to caregiver stress, above and beyond other child characteristics (such as cognitive functioning; Hayes & Watson, 2013). For example, Harrop, McBee, and Boyd

(2016) and others (Gabriels et al., 2015; Richler et al., 2007) and have found associations between child repetitive behaviors and caregiver reported stress; as child's repetitive behaviors increase researchers have found that parents report higher rates of stress, this association is true above and beyond other factors (including ASD severity, developmental functioning, and age, ethnicity, and gender of child and parent; Harrop et al., 2016).

Part of being a parent means providing a child with opportunities that will support their development. However, it can be difficult for families to ensure that quality parent-child transactions occur, family structured child experiences are planned, and a child's health and safety is secured given the increased strain that caregivers face when parenting a child with a disability (Guralnick, 2005). Additional strain can impede these vital family interactions and in turn limit children's abilities to engage in meaningful conversations and interaction with peers. As Guralnick (2005) has argued, effective and inclusive family patterns of interaction support optimal child development. Children with ASD are already at a developmental disadvantage, given their areas of impairment, and unintended strain on the family unit can further limit children's possibilities for optimal development (Chebli et al., 2016; Cunningham & Schreibman, 2008; Digennaro Reed et al., 2012; Sparapani et al., 2016; Wolery et al., 1985).

However, early intervention (EI) services, such as early intensive behavioral intervention (EIBI), can help mediate the unintended strain caused by a child's disability and ensure that families acquire the necessary resources and support to promote their children's overall development (Guralnick, 2005). EI refers to a range of child and family support services that focus on the optimal development of young children who may exhibit deficits in a number of cognitive, social-emotional, and adaptive related areas of development (Boyd, Odom, Humphreys, & Sam, 2010; Bradshaw, Steiner, Gengoux, & Koegel, 2015; Koegel, Koegel,

Ashbaugh, & Bradshaw, 2014; Underwood & Frankel, 2012). EI has been found to produce positive developmental changes in children with ASD, especially when children begin services at a younger age, compared to children that receive services later in life (Bradshaw et al., 2014; O'Connor, Bocian, Beebe-Frankenberger, & Linklater, 2010; Underwood & Frankel, 2012). Providing early effective intervention is vital due to the brains neuroplasticity and crucial period of development in the first few years of life (Bradshaw et al., 2014; Brown & Jernigan, 2012; McCain, Mustard, & Shanker, 2007). Researchers find that children who receive EI services show more favorable outcomes, including improvements in cognitive ability (based on improvements in IQ scores; Guralnick, 1998; Orton et al., 2009; Smith, Groen, & Wynn, 2000), improvements in adaptive behavior related to daily living skills, and reductions in maladaptive behaviors (Dawson et al., 2010; Eikeseth, Klintwall, Jahr, & Karlsson, 2012; Eldevik et al., 2009; Eldevik et al., 2011; Virues-Ortega, 2010), improvements in social skills related to imitation and play (Ben-Itzhak & Zachor, 2007) and increases in communication via expressive and receptive language (Cohen, Amerine-Dickens, & Smith, 2006; Howard et al., 2005; Lovaas, 1987; Makrygianni & Reed, 2010; Peters-Scheffer et al., 2011).

An integral component of Guralnick's (1998) developmental systems model is an emphasis on family centered care. In a response to the variability that existed in the field of early intervention at the time, Guralnick (1998, 2005) proposed a set of principles to guide the implementation and utilization of best practices in the field of early intervention service delivery. He outlined ten key principles and highlighted the importance of utilizing a developmental framework to inform all components of the EI model. In doing so, he emphasized that EI models should center on families and that the inclusion and participation of both children and families should be prioritized (for a review of the principles see chapter two; *Literature Review*;

Guralnick, 2005). Since then, researchers have found that parent-mediated and family-centered EI is related to positive child and parent outcomes, including greater child emotion regulation strategies, improvements in child social and communication skills, increases in parenting satisfaction, and decreases in reports of parental stress (Blackman, 2002; Grindle, Kovshoff, Hastings, & Remington, 2009; Hodgetts, Nicholas, Zwaigenbaum, & McConnell, 2013; Remington et al., 2007; Schertz & Odom, 2007).

As noted previously, the field of early intervention is comprised of research studies that have examined the effects of EI on various ASD characteristics (such as communication, socialization; cognitive functioning, and adaptability). However, less is known about the effects of EI, in particular EIBI, on one specific characteristic: stereotypy. To date, less is known about improvements in stereotypic behaviors for children with ASD after receiving EIBI. More specifically, only five research studies have examined the effectiveness of EIBI on the reduction of stereotypic behaviors in children with ASD (Ben-Itzhak & Zachor, 2007; Dawson et al., 2010; MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014; McGarrell, Healy, Leader, O'Connor, & Kenny, 2009; O'Connor & Healy, 2010) and the results have been mixed.

Thus, a more detailed review of the research literature is warranted in order to understand the interplay between early intervention, specifically EIBI, and stereotypic behaviors. The following chapter will examine the broad research literature on stereotypy, with a particular focus on individuals with ASD, and the types of EI approaches that are used in attempts to reduce or change stereotypic engagement. A review of the literature will inform and guide the present study which seeks to examine stereotypic engagement in children with ASD, prior to and after receiving consistent early intervention services, in Montreal, Quebec, Canada. The purpose of the present study is to contribute to the existing research literature in an effort to provide

further insights into stereotypy in children with ASD. Child and parent demographic information will be examined, with an in-depth analysis of observational video recordings of children conducted at two separate time periods: prior to and after receiving early intervention. Analyses will be conducted to examine changes between and across child participants.

Chapter Two: Literature Review

The following chapter will provide a review of the research literature on stereotypy which will be covered in several sections. These sections will address: (a) an introduction to ASD, estimation of prevalence, and diagnosis; (b) what stereotypy is and how it varies from restricted and repetitive behaviors (RRBs); (c) how various stereotypic behaviors are understood in terms of their forms/sub-types; (d) the prevalence and development of stereotypy in typical and atypical populations; (e) the function of stereotypy; (g) a review of the factors that influence individual and familial outcomes; (h) a review of early intervention approaches; (i) Guralnick's (1998) *developmental systems model* and his principles of EI services, which serve as the theoretical framework for this study; and (j) what previous researchers have found regarding the efficacy of several behavioral based interventions used to target stereotypy. The chapter will end with a section on the rationale, objectives, and research questions of the present study.

Autism Spectrum Disorder (ASD)

Prevalence. From the early 1940s to 1990s, ASD was thought to occur between 1-4 in 10,000 children (Kaufman, 2010; Uno et al., 2012). Reports from the Centers for Disease Control and Prevention (CDC) estimate that roughly one in every 68 children is diagnosed with ASD in the United States (CDC, 2010). More recent reports approximate ASD to occur in approximately 1% of the population worldwide (i.e., equivalent to 70,000,000 people; Uno et al., 2012). In Canada, these prevalent rates have exceeded for cohorts of children born after 1999 (Lazoff, Zhong, Piperni, & Fombonne, 2010; Noiseux, 2011).

Age at diagnosis. In the United States, children will typically receive a diagnosis of ASD at approximately three years of age (Barbaro & Diszsanyake, 2009) while in Canada, recent reports indicate that age at diagnosis varies considerably across provinces (i.e., in Newfoundland

and Labrador M=3 years, while in Southern Ontario M=4.5 years; Ouellete-Kuntz et al., 2009). Similar to other neurodevelopmental disorders, ASD can co-occur with other impairments and disorders including intellectual impairments (intellectual developmental disorder), anxiety disorders, and obsessive-compulsive disorder (APA, 2013; Mannion, Brahm, & Leader, 2014). Developmental trajectories, as well as the comorbidity of neurodevelopmental disorders, can make it difficult to detect autism at a young age (Mannion et al., 2014; Matson & Nebel-Schwalm, 2007). Moreover, in Canada, access to funding and health resources are distributed at the provincial level, rather than federally.

The availability of resources can vary dramatically from one province to another (Norris, Paré, Starky, 2006). For instance, in 2006 the annual funding allowance per province varied from zero dollars (i.e., for Nunavut and the Northwest Territories) to as high as \$30 million to \$112.6 million dollars for some provinces (i.e., such as Ontario and Quebec; Madore & Rodrigue Pare, 2006). At the time, no specific program or funding resources existed for families of children with ASD living in Nunavut (Madore & Rodrigue Pare, 2006). Although provincial allowances can appear sufficient, the actual funding that families receive can vary greatly. In 2007, families living in Prince Edward Island and Quebec received from \$200 dollars a week to \$1,500 dollars annually while, in the same year, families living in British Columbia were funded up to \$20,000 dollars annually (Madore & Rodrigue Pare, 2006). For families living in provinces where a low funding package is provided, this can make it immensely difficult to adequately seek out and afford services to diagnose ASD and to acquire the necessary resources/supports needed to help their child.

However, before families can seek out resources, a diagnosis has to be made by a trained medical professional or child psychologist. To diagnose ASD, professionals use the fifth edition

of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) to assess whether the three core diagnostic features (i.e., communication, socialization, and restricted interests and repetitive patterns of behavior) of ASD are present (APA, 2013) and what severity level children fall under. There are three severity levels and each outlines the level of support that is needed; an ASD diagnosis with a level one severity means *support is required*, level two means *substantial support is required*, and level three means *very substantial support is required*. The following sections of the present study will focus on the last diagnostic feature of ASD which is repetitive patterns of behavior.

Restricted and Repetitive Behaviors (RRBs) and Stereotypy

Repetitive behaviors were first recorded in Dr. Leo Kanner's early work with children with, what he referred to as, "autistics disturbances". In 1943, Kanner described a case study of 11 children with autistic disturbances, who appeared to dislike change and incompleteness and engaged in a range of repetitive behaviors (e.g., sensory related fascinations, repetitive interests from light reflecting from mirrors, and heightened sensitivities to certain stimuli; Baranek, et al., 2006; Harrop et al., 2014; Kanner, 1943). Kanner (1943) found that engaging in repetitive behaviors limited the children's ability to engage in spontaneous activity. He also noticed that the children had to carry out the repetitive behavior, or what he referred to as the ritual, from beginning to end and if disrupted children seemed to experience anxiety and distress (Kanner, 1943; Rojahn & Meier, 2013). A year later, Dr. Hans Asperger described observing similar behaviors in four children between the ages of six to 11 years old, what he referred to as, "autistic psychopathy" (Klin, Volkmar, & Sparrow, 2000).

From the 1940's onward, researchers began publishing studies on abnormal modes of interests and behaviors exhibited in children with severe emotional disturbances, those with

physical disabilities (such as blindness), and autism (i.e., referred to as autistic children; Thelen, 1981). Since Kanner's ground breaking discovery, up to 12 different restricted and repetitive patterns of behavior have been reported in the literature (Rojahn & Meirer, 2013; Scahill et al., 2014; WHO, 2007). Restricted and repetitive patterns of behaviors have been found to range considerably in form based on the type of heterogeneous behaviors observed, which has made them difficult to identify and universally categorize (Rojahn & Meirer, 2013; Scahill et al., 2013; WHO, 2007). Authors such as Rojahn and Meirer (2013) have classified the various forms into distinct subtypes based on an early review of the research literature and a comprehensive list provided by research conducted by Lewis and Bodfish (1998). See Table 1, on the following page, for an overview of Rojahn and Merier's (2013) list.

Table 1

Subtypes of Repetitive Behaviors: Classifications and Definitions

Classification	Definition
Akathisia	Movement disorder that can manifest as repetitive and restless movements such as pacing or a hyperkinetic restless state such as the inability to remain still when sitting or standing
Compulsions	Repetitive intentional behaviors that appear to follow certain rules
Dyskinesia	Repetitive and involuntary movements that can be subdivided into three types: non-rhythmic and jerky movements (chorea) or slow, writhing movements (athetosis), or slow and sustaining muscle tensing (dystonia)
Echolalia	Repetitive use of speech immediately, such as repeating all or part of what was just heard or after a delay. Echolalia can be “parrot speech” defined as repeating whatever is heard and “perseverative speech” in which a small number of words or phrases is repeated in a ritualistic or persistent manner
Obsessions	Repetitive, persistent thoughts, impulses, or images that are experienced as intrusive or inappropriate and that caused marked anxiety or distress in the individual
Perseveration	Behavioral responses in which non-aberrant adaptive responses are repeated beyond what is necessary to reach a goal. This can include the perseveration of attention
Restricted behavior	Behavior with a limited range of focus, interest, or activity
Ritualistic behavior	Performing activities of daily living in a similar manner
Sameness	Involves overall repetitive routines and preferences rather than the discrete repeated acts or thoughts that define compulsions or obsessions
Tics	Often considered involuntary movements, tics are repetitive behaviors that can be simple or complex and that are executed repeatedly in an “explosive” manner and out of context

Note: Reprinted with permission from *Repetitive Behaviors*, by Johannes Rojahn and Lisa J. Meirer, Copyright 2013 by Springer.

Of the 12-distinct restricted and repetitive patterns of behavior, there is a smaller body of literature where researchers have specifically studied *stereotypy* (e.g., Chebli, Martin, & Lanovaz, 2016; Cunningham & Schreibman, 2008; Lam, Bodfish, & Piven, 2008; Lanovaz & Sladeczek, 2012; Sayers, Oliver, Ruddick, & Wallis, 2011). As noted in chapter one, stereotypy refers to rigid and repetitive motor and vocal mannerisms outwardly visible through external behaviors (Chebli et al., 2016; Lam et al., 2008). Stereotypic behaviors are viewed as seemingly purposeless repetitive body movements (Rojahn & Meirer, 2013). They are wide in topography, vary in occurrence, severity, and frequency (Patterson, Smith & Jelen, 2010; Ventola et al., 2016).

More specifically, behaviors may be vocal or motor (both fine or gross), simple in repetitive form or more complex with longer durations and engagement of one or more body parts, and may occur with or without objects (Cunningham & Schreibman, 2008). The simplicity and complexity of stereotypic behaviors can vary depending on several factors including environment, physiological state, and mood, while the function and what reinforces engagement will be discussed in subsequent sections (Rojahn & Meirer, 2013). Specific examples of stereotypy include motor and vocal repetitions such as whole body rocking, partial body movement, finger flicking/flapping, object banging, object twirling, repetitive visual gazing, pacing, humming, mouthing objects, and repetitive smelling (Chebli et al., 2016).

Sub-Types of Stereotypy

Terminology and classification. Researchers have used a variety of terms to describe stereotypy such as *repetitive behaviors*, *stereotypic behaviors*, and *stereotypies*. Stereotypy has generally been divided into broad vocal and motor categories; however, other sub-types of stereotypy have also been examined in the research literature (Chebli et al., 2016; Goldman et

al., 2009; Lam et al., 2008). Sub-types of stereotypy are classified by the body part an individual uses to engage in a particular behavior. For example, if an individual uses their hands to flap and clap this would be categorized as hand stereotypy. In their examination of motor stereotypies in children with ASD and other developmental disabilities (DDs), Goldman et al. (2009) assigned repetitive movements to eight discrete mutually exclusive subtypes and included a list of the body parts utilized and the types of movements exhibited by children. Goldman and colleagues' (2009) list consists of face, head/trunk/shoulders, arm/leg, hand/finger, hand/finger object manipulation, gait (whole body movement), self-directed, and visual stereotypy.

In their systematic review of prevalence rates of stereotypy in individuals with DDs and ASD, Chebli et al. (2016) developed a classification system, similar to that of Goldman et al.'s (2009), to subdivide forms of stereotypy reported in 44 research studies. Chebli and colleagues (2016) classified engagement in stereotypy into seven sub-categories, based on the 6-item *Stereotyped Behavior Subscale* in the *Repetitive Behavior Scale-Revised* (RBS-R; Bodfish, Symons, Parker & Lewis, 2000) with the addition of vocal stereotypy and examples of operational forms. The seven subcategories of stereotypy and their operational forms are listed in Table 2 on the next page.

Table 2

Subtypes of Stereotypy and Operational Forms

Subtypes	Operational Forms
Whole body	Rocking, body stereotypy, clenching-stiffening-posturing, whole body stereotypy, body and torso tending movements
Head	Head movements, head nodding, head rolling, head stereotypy
Hand/finger	Hand, finger stereotypy; hand, finger movements; hand, finger mannerisms; hand flapping or shaking, finger wiggling, waving or sharing arms
Locomotion	Whirling, turning around; pacing, jumping, bouncing, running, locomotion, twirling (on one's self)
Object	Object usage, watching same video continuously, twirling things, spinning objects, repetitive use of objects, manipulating objects, object stereotypy
Sensory	Gazing, sensory stereotypy, rubbing self, repetitive behavior involving sensation, sniffing objects, eye/vision, ear/hearing, mouthing, unusual sensory interest
Vocal	Yelling, screaming, repetitive talk about one topic, echolalia, stereotyped and repetitive use of language, verbal rituals, facial grimacing and vocalization, vocal stereotypy

Note: Information on the sub-types of stereotypy and operational forms from *Prevalence of Stereotypy in Individuals with Developmental Disabilities: a Systematic Review*, by Sabine S. Chebli, Valérie Martin, and Marc J. Lanovaz, Copyright 2016 Springer Science+Business Media New York.

There are many different types of stereotypy and researchers have found that they are not solely unique to infants, children, and adolescents with ASD (Chebli et al., 2016; Esbensen, Seltzer, Lam, & Bodfish, 2009; Patterson, Smith, & Jelen, 2010; Roth, Gillis, & DiGennaro Reed, 2014; Van Wijngaarden-Cremers et al., 2014). The following section outlines the development of stereotypy in typical and atypical populations.

Development of Stereotypy in Typical and Atypical Populations

Stereotypic behaviors have been observed in typically developing children as well as in children, adolescents, and adults with ASD and other developmental disabilities; such Down syndrome, intellectual disability, and obsessive-compulsive disorder (Chebli et al., 2016; Chowdhury, Benson, & Hillier, 2010; Mayes & Calhoun, 2011; Neil & Jones, 2016; Ruzzano, Borsboom, & Geurts, 2015; Totsika, Toogood, Hastings & Lewis, 2008).

Stereotypic behaviors are considered part of typical motor development and are often present prior to vocal development in typically developing infants and children with ASD and DDs (Harrop et al., 2014; MacDonald et al., 2007; Thelen 1979, 1981). In young infants, stereotypy is observed as attempts at developmental mastery, by engaging in the refinement of fine and gross motor control and vocal development through repetitive actions (Harrop et al., 2014; Thelen, 1979, 1981). Using an ethologist approach, Esther Thelen (1979) was the first researcher to directly examine, observe, and propose a developmental theory for stereotypies exhibited in the first year of a typically developing infant's life; by purposing that stereotypy is a reflection of the maturation of proper neuromuscular pathways. Thelen's (1979) interests were guided, in part, by (a) previous studies that found stereotypic behaviors in 'abnormal populations'; and (b) by several motor development theories at the time, such as the second sub-stage (i.e., primary circular reactions) of Piaget's (1952) theory of cognitive development; which looks at the sensorimotor stage of early development in children.

Thelen (1979) conducted a naturalistic, longitudinal, observation of 20 typically developing infants between 4-52 weeks of age. Age-related changes in stereotypy were observed and behaviors were recorded based on the frequency and diversity of behaviors using an operational definition. 'Rhythmical stereotypy' was defined as "Movements of parts of the body

or the whole body that was (*sic*) repeated in the same form at least three times at regular short intervals of about a second or less” (Thelen, 1979, p. 700). Thelen (1979) found a total of 16,000 occurrences of stereotypy and 47 distinct motor movements across the 20 participants. All participants engaged in at least one form of stereotypy. The most frequent stereotypies observed were those associated with motor activities such as flexing and banging feet, fingers, arms, and legs. Thelen (1979) also found that certain behaviors were more frequent during the infants’ exposure to environmental stimuli, such as seeing their mother or a moving object. However, Thelen (1979) has argued that the onset of stereotypy is most predictive based on the developmental stage in the first year of life and therefore a reflection of cognitive maturation which in turn assists in skill acquisition. For example, typically developing children often follow a general sequence of motor development, with a high occurrence of stereotypy in the first year of life and reductions observed after age two (Lanovaz, Robertson, Soerono & Watkins, 2013; Thelen, 1981).

Thelen’s (1979, 1981) work provides insight into why young infants and typically developing children engage in stereotypy; however, there are some limitations. Her research findings and references to development do not answer the question of why children with ASD continue to engage in stereotypic behaviors, at varying rates and of varying sub-types, well into adulthood. For instance, stereotypy in typically developing children tend to decrease after age two (Chebli et al., 2016; Harrop et al., 2014; MacDonald et al., 2007; Thelen, 1981). Concerns arise when the frequency and severity of the behaviors appear abnormal in nature and a child continues to engage in the behaviors, after the age of two, rather than reducing their engagement (Chebli et al., 2016, Harrop et al., 2014; Patterson et al., 2010). If children engage in stereotypy as a process of developmental mastery, related to cognitive and motor skill development, then

why do adolescents and adults with ASD continue to engage in these behaviors, far after crucial cognitive and motor skills are developed and mastered? The following section will provide information regarding the prevalence of stereotypic engagement across children, adolescents, and adults with ASD and with a DD.

Prevalence across Populations

Infants and children. Various estimates of stereotypic behaviors in infants and children have been reported in the literature. However, researchers have found the highest prevalence of stereotypy in infants and children with, and at risk for, ASD. For instance, Mederios et al. (2013) used parental reports to examine self-injurious, stereotypic, and aggressive behavior in 160 infants, between 4 months to 3.5 years of age ($M=2.2$, $SD=2.28$), at risk for ASD, Down syndrome, or a developmental delay. Using the *Behavior Problems Inventory* (BPI-01; Rojahn et al., 2011) and the *Bayley Scales of Infant Development, Third Edition* (Bayley-3; Bayley, 2000), Mederios and colleagues (2013) found that self-injurious, stereotypic, and aggressive behavior remained consistent over a 12-month period. The authors also found that the percentage of stereotypic engagement varied across children, where children at risk for ASD engaged in the highest percentage at a rate of 99%. Children at risk for a developmental delay engaged in the second highest percentage of stereotypy (84%), followed by children at risk for Down syndrome (68%; Mederios et al., 2013). A strength of the study was the examination of differences in stereotypic engagement, across a 12-month period, in children at risk for ASD and other developmental disabilities. However, a limitation of the study was the use of parental ratings, rather than direct observations; while the latter may have provided insight into the large variability observed across the at-risk groups.

Matson et al. (2009) examined motor stereotypies in 760 infants between one and a half

to three years of age ($M=2.08$, $SD=.529$) with ASD, pervasive development disorder (PDD-NOS), and typically developing children deemed at risk for a developmental delay. Using the *Baby and Infant Screen for Children with Autism Traits* (BISCUIT; Matson Boisjoli, & Wilkins, 2007), Matson and colleagues (2009) found varying percentages of stereotypy, defined in their study as repetitive motor movements for no reason, across all three groups. However, an examination of the responses on the repetitive behavior/restricted subscale demonstrated that stereotypic behaviors were significantly correlated with development. The authors found that children with ASD engaged in the highest percentage of stereotypy, at a rate of 71%, followed by children with PDD-NOS who engaged in a rate of 34%. Matson and colleagues (2009) found that typically developing children at-risk for a developmental delay engaged in the lowest percentage (9%) of stereotypy. Similar to the strengths observed in Mederios et al.'s (2013) study, a strength of Matson et al.'s (2009) study is that motor stereotypies were examined across disabilities, allowing for a greater examination of the variability of stereotypy among children with different profiles of development. A limitation of the study is the use of a questionnaire (BISCUIT), rather than direct observations, to examine engagement and frequencies of stereotypy.

In an attempt to better understand and examine the prevalence of stereotypy, past researchers have used a number of different methodological approaches. The most common methodological approaches used to examine stereotypy in children with ASD have relied on parental reports and questionnaires (Harrop et al., 2014). In their systematic review of the research literature, Chebli and colleagues (2016) found that the most common forms of measuring stereotypy were based on the use of informant-based questionnaires. The most common questionnaires included the *Diagnostic Assessment for the Severely Handicapped*

(DASH-II; Matson, Smiroldo, & Hastings, 1998), the *Autism Diagnostic Interview-Revised* (ADI-R; Lord, Rutter, & Le Couteur, 1994), the *Aberrant Behaviour Checklist* (ABC; Aman et al., 1985), the RBS-R (Bodfish et al., 2000), and the *Behavior Problem Inventory* (BPI; Rojahn et al., 2001).

Fewer research studies have used observational methods, compared to informant based questionnaires, to capture the frequency and severity of stereotypy in children with ASD and DDs and only a handful of research studies have used free play observational sessions (e.g., Boyd et al., 2010; Goldman et al., 2008; Harrop et al., 2014; Lanovaz, Sladeczek, & Rapp, 2012; Militerni et al., 2002). Moreover, researchers such as Harrop et al. (2014) have brought up methodological concerns in using diagnostic instruments which may not provide clear non-independent measurements of stereotypic behaviors.

The use of observational methods allows researchers to observe free play in participants in naturalistic and clinical settings (Harrop et al., 2014). Gardenier, MacDonald, and Green (2004) have suggested that observational methods can allow researchers to examine the topography of stereotypy, how often the behavior occurs, how much time the behavior consumes, and under what conditions it does or does not occur by manipulating the environment and stimuli present. Moreover, using observational methods can provide researchers with critical information regarding a child's baseline and pre-intervention profiles of functioning. Specific observational methods, such as video and audio recordings, can also be used as a tool for educational information and training and can also be provided to families who are interested in observing their child's changes across time. From a measurement standpoint, direct observational methods are viable and reliable options, especially given some of the problems that can arise with using second-person perspective questionnaires and rating scales; such as low

inter-rater agreement, high subjectivity, falling to capture inter-individual variations, and unknown accuracy (Gardenier et al., 2004). The following two research studies are promising in that they used observational methods, control and comparison groups, and compared differences in behaviors across time.

Harrop et al. (2014) examined restricted and repetitive behaviors in two to 4-year-old children with ASD and matched them to typically developing children, based on non-verbal development (based on the severity of language deficits). Using 20-minute video recordings, the frequency of stereotypic behaviors was observed during the entry of the study, seven months after entry, and 13 months after entry. Results indicated that, across the three time periods, children with ASD engaged in significantly higher frequencies (T1 7.31%, T2 8.14% and T3 8.35%) and greater variability of repetitive behaviors compared to typically developing children (T1 2.68%, T2 2.77% and T3 1.70%; Harrop et al., 2014). The authors also found that specific stereotypic behaviors, such as hand object manipulation (i.e., “fiddles with objects/uses objects in repetitive and non-functional manner”), increased in children with ASD while other stereotypic behaviors, such as hand motor (i.e., “bangs/taps/shakes/throws objects”) and sensory behavior (i.e., “looks at objects at certain angles/brings objects close to eyes”) were more common and consistent across time (Harrop et al., 2014, p. 1212).

Goldman et al. (2009) examined motor stereotypy in 277 children divided into four diagnostic subgroups based on diagnosis and cognitive functioning. Motor stereotypy was examined from video recordings that took place between 1985-1988. Participants included 129 children with a diagnosis of “autistic disorder” and, based on the third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III-R), were divided into two subgroups based on lower and higher cognitive functioning. The higher functioning autism group included

children with a nonverbal IQ (NVIQ) of >80 and the lower functioning autism group included those with a NVIQ equal to or <80. The authors matched 148 children on IQ with a developmental language disorder and “non-autistic” low IQ to the two autism groups. Using 15-minute observational video recordings of standardized play, Goldman et al. (2009) found a significant association between diagnosis, severity, and cognitive functioning. The authors found that children with low-functioning autism exhibited the highest number (16.4 occurrences) and widest range of stereotypy sub-types (3.2 sub-types), compared to children with low IQ (i.e., 9.9 and 2.3), and children with high-functioning autism (i.e., 6.9 and 2.2). Across both ASD groups, Goldman et al. (2009) also found that approximately 70% of children exhibited at least one type of stereotypy. The lowest occurrence of stereotypy was observed in children with a developmental language disorder (Goldman et al., 2009).

As discussed previously, neurodevelopmental disorders can co-occur with other impairments, including and not limited to intellectual disabilities, which can impact cognitive functioning, IQ, and adaptive skills (APA, 2013). Goldman et al.’s (2009) findings demonstrate how these impairments, such as low IQ, may be associated with greater occurrences of stereotypy. More specifically, Goldman and colleagues (2009) found that children with low IQ engaged in the second highest frequencies of stereotypy. Goldman et al.’s (2009) findings are consistent with other research studies that have found associations between stereotypy, IQ, and adaptive abilities (e.g. Harrop et al., 2014; Lam et al., 2008; Mayes & Calhoun, 2011; Watt et al., 2008).

Adolescents and adults. Stereotypy is not specific to infants and children and have been observed in adolescents and adults with ASD, as well as by those with developmental disabilities, such as Down syndrome and intellectual disability (Bodfish et al., 1995; Chebli et

al., 2016; Chowdhury, Benson, & Hillier, 2010; Lundqvist, 2013; Mayes & Calhoun, 2011). For example, in their study of 82 participants with a developmental disability and an intellectual disability (with and without ASD), Hill and Furniss (2006) found that 79% of adolescents between the ages of 16 to 19 engaged in at least one form of stereotypy.

In their systematic review of 44 research studies, Chebli et al. (2016) examine the prevalence rate of stereotypic behavior across infants, children, adolescents, and adults with ASD and DDs. Their systematic review classified child studies (which included adolescents) as those that included participants between the ages of one to 17 and 11 months, and adult studies based on participants aged 18 and above. Criteria for study inclusion relied on participants having had engaged in at least one form of stereotypy. Using descriptive statistics, Chebli et al. (2016) found a 61% average prevalence rate of stereotypy in individuals with DDs; suggesting that 61% of individuals diagnosed with a developmental disability engage in at least one form of stereotypy.

The highest prevalence rates (88%) were found in individuals with ASD who engaged most frequently in motor stereotypy; specifically, 73% engaged in sensory stereotypy and 30% engaged in head stereotypy (Chebli et al., 2016). Adults with ASD were found to engage in the highest rates of stereotypy (61%) followed by children and adolescents with ASD who had similar but lower rates (57%; Chebli et al., 2016). Children with ASD were found to engage in higher rates of motor stereotypy, specifically sensory stereotypy at a rate of 70%, while adults engaged in motor stereotypy, at a rate of 50% as depicted by whole body stereotypy engagement (Chebli et al., 2016).

Chebli and colleagues' (2016) systematic review provides valuable insight into the research literature on stereotypy in adults with ASD. The findings are supported by other

research studies that have examined stereotypy in adults with ASD and intellectual disabilities (Bodfish et al., 1995; Chowdhury et al., 2010; Mayes & Calhoun, 2011; Lundqvist, 2013).

Chebli et al.'s (2016) findings are important to highlight as they indicate that children and adults appear to engage in variable rates of stereotypy, suggesting that stereotypic behavior is not age specific and continues into adulthood. However, prevalence rates of specific forms of sub-types of stereotypy appear to vary depending on diagnosis (i.e., ASD vs. DD) and age (i.e., child vs. adult), suggesting that differences may exist between engagement in repetitive behaviors versus engagement in specific forms sub-types of stereotypy.

Disparities between the types of stereotypy engaged in suggest that certain sub-types may serve different functionalities for different people, especially at different ages of development (Lundqvist, 2011). Considering the prevalence, severity, and abnormality of stereotypy in children, adolescents and adults with ASD (Chebli et al., 2016), the assumption cannot be made that the presence of stereotypy, in both atypical and typical populations, serve the same function (Sayers et al., 2011). In the following section, the function of stereotypy will be closely examined using two dominant perspectives.

The Function of Stereotypy

Engaging in stereotypic behaviors appear to serve a specific function for typically developing children as continued engagement in behavioral related activities lead to early development, through neuromuscular maturation, and assist in the development of goal directed movements (Harrop et al., 2014; Patterson et al., 2010). However, the functionality behind stereotypic behaviors in children with ASD and DDs are not as readily understood. In an attempt to understand the function of stereotypy, over the years, researchers have put forth several theoretical perspectives and the most dominant are based on neurobiology and behavior

(Cunningham & Schreibman, 2008; Halls, Thorns, & Oliver, 2003; Hughes, Russell, & Robbins, 1993; Joseph, 1999; Lewis, Baumeister, & Mailman, 1987; Lovaas, Newsom, & Hickman, 1987; Rapp & Vollmer, 2005; Sayers et al., 2011). Neurobiological and behavioral perspectives are outlined below.

Neurobiological perspectives. Rapp and Vollmer (2005b) have written extensively on neurobiological perspectives and note that this perspective has evolved from research with humans and animals. Sayer and colleagues (2011) note that researchers who endorse a neurological perspective tend to support the notion that stereotypy is influenced by cognitive “biological rhythms” (p. 700). Early definitions in the research literature often allude to stereotypy as having no apparent function (DiGennaro Reed, Hirst, & Hyman, 2012; Lewis et al., 1987). Rather than engaging in such behavior, due to an implicit or explicit function, theorists have proclaimed that stereotypies are a representation of behavioral manifestations of involuntary cognitive disturbances (Halls et al., 2003; Lewis et al., 1987; Sayers et al., 2011).

In line with this neurobiological perspective, Hughes et al. (1993) and Joseph (1999) purposed an executive dysfunction theory. Their theory is based on the notion that neurological impairments in neurochemical systems (serotonergic and dopaminergic) and executive control regions of the brain (such as the frontal lobe) produce deficits in behavior which result in stereotypy (Rapp & Vollmer, 2005b; Sayers et al., 2011). However, Rapp and Vollmer (2005b) have pointed out that no single neurobiological model/theory of behavior has independently accounted for the etiology of ASD and the occurrence of stereotypy. Using a neurobiological perspective, researchers and clinicians would suggest that a hypothetical 5-year-old boy named Johnny engages in frequent stereotypy due to a neurological impairment.

Behavioral perspectives. Behavioral perspectives that are used to explain stereotypy are

derived from the concept that stereotypy is an operant behavior mediated, reinforced, and maintained by internal and external consequences that follow the behavior (DiGennaro Reed et al., 2012; Sayers et al., 2011). Using a behavioral perspective, researchers and clinicians would alternatively argue that Johnny's stereotypic behavior is a response to and maintained by (a) automatic positive reinforcement (i.e., Johnny receives some form of internal or external sensory stimulation by engaging in stereotypy); (b) social negative reinforcement (i.e., Johnny is trying to avoid or escape a situation or unpleasant task); (c) social positive reinforcement (i.e., Johnny receives some form of attention and/or engaging in a specific stereotypic behavior becomes desirable); and (d) a combination of reinforcements such as social and non-social reinforcements (Lanovaz & Sladeczek, 2012; Lovaas et al., 1987; Rapp & Vollmer, 2005a)

A combination of reinforcements can produce and maintain stereotypy. Picture Johnny in his kindergarten classroom. His teacher could be speaking at the front of the class, but Johnny catches the splashes of light from the window paint and begins to repeatedly turn his head from side to side. He receives visual stimulation by turning his head from side to side; however, at that moment his teacher notices his behavior and calls out his name. Johnny tries to avoid what the teacher is saying by vocally repeating his favorite toy sounds over and over again. In this hypothetical scenario, Johnny has engaged in three forms of stereotypy (sensory, motor, and vocal) due to two reinforcements in his classroom.

Factors that Influence Development Outcomes

The following sections will cover factors that can influence development and outcomes for both children and families. Guralnick's (1998, 2001, 2005) *Developmental System Model* is used as the theoretical framework within which to examine these factors. Using a developmental systems approach, Guralnick (2005) argues that child developmental outcomes are mediated by

family patterns of interaction. Developmental outcomes are mediated and bolstered by quality parent-child interactions, family-orchestrated child experiences, and the health and safety that a family provides to their child. In Guralnick's (2005) model, he proposes that an interplay of family and child characteristics can also influence these patterns of interaction, which in turn can lead to less favorable child developmental outcomes. Family characteristics can come in the form of personal characteristics of parents, financial resources, social supports, and child temperaments (Guralnick, 2005). Child characteristics, specific to as an established disability, such as ASD, can also cause stressors on family patterns of interaction. Figure 1 outlines the family and child characteristics that can have an impact on family patterns of interactions, which in turn impact child development outcomes.

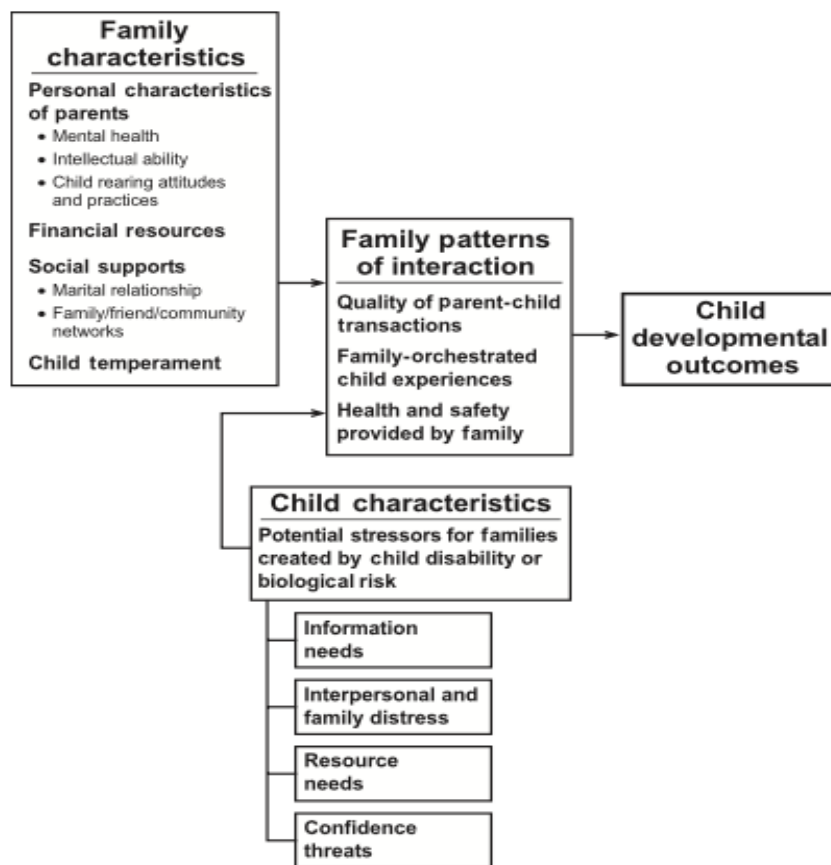


Figure 1. *Factors that influence child developmental outcomes by Michael Guralnick (2005).*

In the next sections, Guralnick's (2005) analysis of an established disability will be used to address the impact that stereotypy has been found to have on parent and child outcomes.

Impact of Stereotypy on Child and Parent Outcomes

Child outcomes. Ashburner et al. (2008) explored the relationship between the engagement in sensory-related behaviors and emotional, behavioral, and educational outcomes exhibited in the classroom for children with ASD. A case-control research design was conducted to compare differences in 28 children with ASD and 51 typically developing peers, aged six to 10, who were matched on age and gender (Ashburner et al., 2008). Significant differences were found in the engagement of sensory-related behaviors and impact of academic performance among children with an ASD and those without. Children with ASD engaged in higher amounts of sensory related stereotypy and were found to be less academically engaged.

The authors further found that 47% of the variance in academic performance could be explained by the sensory related deficits, reported on the *Short Sensory Profile Scale*, suggesting that sensory-related behaviors are negatively associated with academic performance and attention needed to complete cognitive tasks (Ashburner et al., 2008). The findings from the study contribute to the research literature by demonstrating that stereotypy can significantly impede academic engagement by interfering with attention otherwise needed for cognitive tasks (Ashburner et al., 2008; Fernandez-Andres et al., 2015). Moreover, academic engagement is a key area of educational inquiry, due to its mediating effects and predictive value for future academic performance (Sparapani et al., 2016). In summary, stereotypy can negatively impact educational outcomes and opportunities for skill acquisition for children. However, challenging behaviors, such as stereotypy, have also been found to impact parents and caregivers. For example, stereotypy has been found to be socially stigmatizing (Cunningham & Schreibman,

2008; Digennaro Reed et al., 2012; Jones, Wint, & Ellis, 1990).

Stigmatization. Greek philosophers originated the term *stigma* to refer to “bodily signs designed to expose something unusual and bad about the moral status of the signifier” (Goffman, 1963, p. 1). Goffman (1963) proposed that individuals may experience social stigma in response to an external deformity, physical manifestation, and/or physical disability that would visibly set them apart from a majority group. Social stigma in relation to a disability has garnered ample focus in sociological research on health and disability (Birenbaum, 1970; Farrugia, 2009; Gray, 1993; Gray, 2002; Landsman, 2003; Voysey, 1972; Whitmarsh et al., 2007), especially as it pertains to family experiences.

For instance, Farrugia (2009) conducted 12 parent interviews with 16 parents of children with ASD in order to understand their experiences related to stigmatization. Participants were recruited from an Australian support group for parents of children diagnosed with ASD. The sample size consisted of 11 mothers and five fathers. All parents in the study reported experiencing some form of stigmatization either from their social circle (family members and previous friends), from the public sphere (at community events and after school programs, etc), or from institutions (schools; Farrugia, 2009). Parents who had more than one child with ASD shared particular instances of social stigmatization, such as the one below:

... they stopped hanging out with us. All of a sudden you know it was ‘come around to our place but don’t bring the kids’ or um they’d come around and they’d just be sitting here rolling their eyes all the time because like Daniel and Alex you know will interrupt and everything and they just didn’t have patience for it.

Parents also spoke of the shared-stigma that siblings of children with ASD experience, such as disruptions to social opportunities, as well as the burden that parents felt when planning

social activities in response their child's problem behaviors (Farrugia, 2009). Although the study aimed to understand the experiences of parents of children with ASD, Farrugia (2009) also found that participants shared stories of resilience and strength in the face of adversity.

A strength, as well as a limitation of Farrugia's (2009) study, is that participants were recruited from a support group in Australia, that specifically targeted parents of children diagnosed with ASD. Parents who seek out support services, and take part in these groups, may be more inclined to share and discuss their unique experiences of parenting a child on the spectrum. However, the present study does not take into account the contribution that demographic variables (such the participant's gender and participants' place of residence) and engagement in therapeutic resources (such as a support group) might play as potential mediating factors in participants' perceptions of stigmatization and parenting.

Kinnear, Link, Ballan, and Fischbach (2016) examined the extent to which parents and caregivers of children with ASD report stigma to be problematic. Kinnear et al. (2016) recruited 502 families from the United States (US) and Canada; (35 from the US and three from Canadian provinces). Ninety-four percent of the sample size were mothers between the ages of 28-65 ($M=43.7$, $SD=5.36$). Ten different measures were administered in an attempt to discern parental perceptions of having a child with a disability, along with the extent to which parents report stigma to be problematic. Kinnear and colleagues (2016) found that over 90% of the participants thought that the general public held negative perceptions about the capabilities of children with ASD, such as that they would never be a good friend, live independently, get married, or hold a job. Between 60-73% of parents also reported that they thought that the general public believed that individuals with autism are mentally ill and dangerous (Kinner et al., 2016). Almost 60% of parents reported that individuals with ASD are stigmatized, in some form or another due to their

deficits and problem behaviors exhibited. In respect to the stigmatization experienced as a result of parenting a child with ASD, Kinnear et al. (2016) found that almost all parents reported feeling isolated and excluded from friends and family and that the stigma experienced adds to the difficulty of raising a child with ASD.

To date, Kinnear et al.'s (2016) study is the largest quantitative study to have examined stigma associated with ASD. However, a few limitations of the present study are the use of unstandardized measures (specifically developed for the study) which were not previously tested, a lack of fathers presented in the sample, and a lack of families with two or more children with ASD which may have provided unique insights not addressed in the study.

Parental stress. Having a child with a disability can not only be stigmatizing, but it can also be stressful for parents. A review of the literature suggests that deficits in communication, cognitive abilities, and social interaction in children with ASD have been found to trigger elevated stress in mothers and fathers of school-aged children (Davis & Carter, 2008; Estes et al., 2009). In their longitudinal study of 293 parents and teachers of young children with ASD, Lecavalier, Leone, and Wiltz (2006) found that child problem behaviors (specifically related to conduct, adaptability, and repetitive hyperactivity) were the most significant predictors of distress for parents. Using the *Parental Stress Index-Short Form*, the authors found that 58% of the sample scored in the clinically significant range (Lecavalier et al., 2006). Similarly, in their review of 123 parents of children with and without ASD, Herring et al. (2006) found that a child's emotional reactions and behavioral problems had the largest impact on mother's stress.

Tomanik, Harris, and Hawkins (2009) examined stress responses of 60 mothers of children, with ASD, in relation to child behaviors. The authors found higher rates of stress in mothers of children that exhibited externalizing problem behaviors and deficits in socialization

(i.e., socially withdrawn and noncompliant), communication, and self-regulation (Tomanik et al., 2009). Their analysis also revealed that child adaptability was directly related to maternal stress; parents of children with greater deficits in adaptability reported higher responses of stress (Tomanik et al., 2009).

Specific characteristics, or specific sub-types, of stereotypy may also cause higher rates of stress in parents. For example, researchers have noted that certain sub-types of stereotypy, such as vocal stereotypy, can present unique challenges for parents and clinicians as they cannot be readily prompted or stopped (Lanovaz & Sladeczek, 2012). For example, motor, whole body, and sensory stereotypy can be physically redirected and stopped with the use of a physical reinforcement, replacement object, and/or punishment technique. However, vocal stereotypy is unique in so far as it cannot be physically stopped, but attempts can be made to redirect or reinforce a more appropriate behavior. Continuously addressing stereotypy can also be demanding for parents and in turn may contribute to elevated parental stress.

Monitoring the frequency and severity of stereotypic engagement in infants can assist in the early identification and prediction of future developmental deficits; including maladaptive behavior, impairments in socialization, and the impact of stereotypy on other child and parent outcomes, as discussed above (Harrop et al., 2014; Neil & Jones, 2016; Watt et al., 2008). By monitoring infants early developmental progression, families can identify red flags and seek out a range of resources to better address the needs of their child. These range of services are called *early intervention services* and will be discussed in the following section.

Early Intervention Approaches

Providing effective early intervention (EI) approaches early in life is a key component in fostering optimal development for children with ASD (Dawson, 2008; Guralnick, 1998, 2001,

2005, 2017; Underwood & Frankel, 2012). Researchers have found that when children receive EI services in infancy they show more beneficial developmental outcomes (Barbaro & Dissanayake, 2009; Carpenter, 2005; Lovaas, 1987; O'Connor, Bocian, Beebe-Frankenberger, & Linklater, 2010). Early intervention approaches have been developed and utilized that vary in approach, intensity, and design. The most prominent forms of intervention use pharmacological, developmental or behavioral approaches (Patterson et al., 2010) which will be outlined in subsequent sections of this chapter; however, family-centered care (FCC) and Guralnick's principles of early intervention will be discussed first.

Family-centered care (FCC). FCC is a type of approach used in the field of early intervention with families of children with disabilities (Tomasello, 2010). More specifically, it refers to the collaborative partnership between a family and health care professionals (Zajicek-Farber et al., 2017) and is based on "Practice principles that are designed to enhance self-determination of parents of [children and] youths with a disability, care-provider collaborative decision-making processes, and parent self-efficacy" (Tomasello, 2010, p. 165). FCC practices focus on the needs of the family, in partnership with the needs of the child, collaborate and ensure that families are well informed in the decision-making process of any and all intervention decisions, and view families' perspectives and opinions as resources (Tomasello, 2010).

The concept of FCC dates back to 1960 when the term was first used to describe parental involvement in early intervention service delivery (Bruder, 2000). A decade later, the concept became associated with family empowerment in relation to principles developed to guide early intervention service delivery for children with special needs (Bruder, 2000). Over the years, FCC has been associated with an emphasis on understanding families' strengths, promoting family agency over desired resources, and developing collaborative relationships between health care

professionals and parents of children with disabilities (Bruder, 2000; Tomasello, 2010; Zajicek-Farber et al., 2017).

Over the years, researchers have found positive implications related to FCC and parental involvement in service provisions. Researchers suggest that families involved in FCC are more likely to report satisfaction with services (Ngui & Flores, 2006), report reductions in parental stress and heightened perceptions of self-efficacy (Hodgetts et al., 2013), are better aligned with health care professionals (Emerson & Hatton, 2014), and in turn are more likely to provide quality care for their child with a disability (Zajicek-Farber et al., 2017). Moreover, researchers have acknowledged that FCC and parental involvement in service provision are also linked with positive outcomes for children including improved social communication skills (Grindle et al., 2009) and improved emotion regulation (Gulsrud, Jahromi, & Kasari, 2010). Families thus play an integral role in children's early development, while FCC can help facilitate and promote the well-being of the entire family unit. In the following section, Guralnick's principles of early intervention are discussed in relation to and the importance of FCC in EI service delivery.

Guralnick's principles of early intervention. In his *developmental systems model*, Guralnick (2005) outlined several key principles that he recommends *early intervention service providers* need to incorporate in a manner appropriate to their setting. Guralnick's (1998, 2001, 2005, 2017) work and research has focused on understanding the factors that inhibit and promote the positive development of children and families. In his model, Guralnick (2005) highlights the importance of family patterns of interaction and family involvement in the optimal development of child outcomes. His model provides a basis for understanding key principles and guidelines that all service provision workers should adhere to when coordinating, planning, and implementing EI services for families and children (Guralnick, 2005).

The first and most fundamental principle is that a developmental framework centers on families and should inform all components of the EI system. Integration and coordination make up the second principle and Guralnick (2005) notes that this should be apparent in all phases of the EI service delivery, including in “Interdisciplinary assessments, assessments for program planning, developing and implementing comprehensive intervention plans, and systems level integration” (p. 8). The third principle highlights the importance of the inclusion of families and their children in *typical* community-based programs whereby participation in activities can be maximized. The fourth and fifth principles note the importance of early detection and identification procedures as well as surveillance and monitoring, which are integral components in identifying and ensuring best practices (Guralnick, 2005).

The following sections will cover the types of early intervention approaches that are often used with individuals with ASD. Interventions will be discussed as they relate to stereotypic behaviors.

Pharmacological interventions. Pharmacological interventions are in line with theories based on neurobiological perspectives and researchers who endorse this intervention approach attempt to address the neural mechanisms behind stereotypy (Patterson et al., 2010). Rather than attempt to intervene when the behavior occurs, pharmacological interventions focus on mapping where cognitive deficits lie and attempt to target those regions of the brain with medical and drug based remedies. For example, in past studies, researchers have examined the use of the drug naltrexone to treat stereotypy as one form of pharmacological intervention, by reducing and or attempting to eliminate the desire to engage in the behavior altogether (Rapp & Vollmer, 2005b). Antipsychotics, opioid antagonists, and serotonin reuptake inhibitors are the most commonly used pharmacological treatments of ASD (Leekam, Uljarevic, & Prior, 2011). More recent

research findings in the field of pathophysiology with animals (specifically deer mice) indicate potential therapeutic targets in the basal ganglia pathway of the brain (Lewis & Kim, 2009).

However, in reviewing pharmacological interventions there are several drawbacks to consider. Pharmacological interventions are not always accessible, especially for families located in remote locations who lack travel accommodations. Secondly, pharmacological interventions can be expensive, especially for families who do not have the financial resources or for those who do not have health insurance. Thirdly, pharmacological interventions can cause adverse side effects including weight gain, nausea, anxiety, tremors, and sleep problems. Lastly, a review of past research suggests that pharmacological interventions lack empirical support for reducing stereotypy in children with ASD.

Leekam and colleagues (2011) conducted a systematic review of the efficacy of pharmacological interventions for reducing stereotypic behaviors. The authors found that pharmacological interventions had a limited degree of effectiveness in improving children's behaviors (Leekam et al., 2011). A few years later, Mulligan, Healy, Lydon, Moran, and Foody (2014) conducted a systematic review of research studies, published between 1993 to 2009 that used pharmacological interventions to target stereotypy and repetitive behaviors. Mulligan et al. (2014) uncovered five studies with over 249 participants that used some type of prescription based intervention (Gordon et al., 1993, Hollander et al., 2005, Hollander et al., 2006, Hollander et al., 2012; King et al., 2009). The type of prescription interventions used included antidepressants (Clomipramine, Desipramine, and Fluoxetine), anticonvulsants (Divalproex sodium), and selective serotonin reuptake inhibitors (Citalopram; Mulligan et al., 2014). Mulligan and colleagues (2014) found that, across all studies, there was a lack of sufficient empirical evidence for the use of pharmacological interventions to reduce stereotypy in

individuals with ASD; results either varied, lacked sufficient information, or were promising but lacked sufficient evidence. A limitation of the five studies reviewed is that the percentage of reduction in stereotypic behaviors were never reported, making it difficult for researchers to review if a reduction in stereotypy even occurred. Moreover, of the five studies that sought to examine the impact of prescription medication on stereotypic behaviors, three had the same first-author.

Behavioral interventions. As an alternative to pharmacological interventions, early intervention approaches have relied heavily on behavioral based interventions that attempt to intervene prior to, when, and after the behavior and/or action occurs. Behavioral interventions are considered less intrusive, compared to pharmacological interventions, are individualized based on the child and their needs, and can be alternated and modified as needed.

Carolina Curriculum and the treatment and education of autistic and related communication handicapped children (TEACCH) models. The Carolina Curriculum and TEACCH are two behavioral approaches in the field of early intervention, used with children with developmental disabilities, including those with ASD. The *Carolina Curriculum* (Johnson-Martin, Jens, Attermeier, & Hacker, 1991) is an intervention program that is used with young children, from birth to five years of age, with a mild to severe disability. The curriculum uses observational methods, such as informal observation and directed assessment to examine children's strengths and weaknesses during activities in a naturalistic setting (Johnson-Martin et al., 1991). Areas that need improvement are recorded using assessment logs and developmental progress charts, and intervention teaching activities are set based on the curriculum sequence and criterion-referenced system (Johnson-Martin et al., 1991).

The Treatment and Education of Autistic and Related Communication Handicapped

Children (TEACCH; Mesibov et al., 2004; Schopler & Reichler, 1976) model is described as a service, a form of training, and a research program specifically tailored for individuals with ASD, regardless of age (Mesibov et al., 2004). The TEACCH model is based on a developmental behavioral and multidisciplinary framework and encompasses a wide range of approaches to helping individuals with ASD. Interventions are developed based on a structured TEACCHing approach that emphasizes the use of visual aids, are developed in collaboration with parents and professionals, and then implemented and generalized to classrooms, and community-based settings (Mesibov et al., 2004; Probst, Jung, Micheel, & Glen, 2010). The approach recognizes individual differences and was developed with two main goals in mind: (a) to strengthen individual skills; and (b) to help make an environment more suitable based on an individuals' needs (Mesibov et al., 2004).

Early intensive behavioral intervention (EIBI). Similar to the Carolina Curriculum and the TEACCH model, EIBI is another behavioral early intervention service implemented specifically for infants and children with ASD. EIBI has garnered much interest from the research community since Ole Ivar Lovaas' grounding-break research with children with ASD in 1987. EIBI interventions are based on the principles of applied behavior analysis (ABA) which takes into account learning theory to understand the functional relationship between behaviors and the environment (Klintwall & Eikseth, 2014). Although EIBI interventions are often individualized to the child they share common elements of best-practices (Eldevik et al., 2009; Klintwall & Eikseth, 2014). EIBI interventions are often delivered in a one-to-one setting, by a trained professional/clinician, or paraprofessional, in the field of ABA. Programming can vary from 20-30 hours of intervention per week and the duration can last for 2 or more years, depending on the child's needs and progress. The clinician should have experience with young

children with ASD and will use a normal developmental sequence to guide the selection of the intervention objectives, both short-term and long-term. A key component of EIBI is the involvement of parents and caregivers as well as community members, such as a child's school or daycare, who act in part as co-therapists for the child. One-to-one intervention is often administrated at home and is gradually introduced to other community settings including the playground, home or outside the home play-dates, daycare, preschool, kindergarten, social skills groups, and elementary school (Eldevik et al., 2009).

Behavioral interventions are used in a range of EI programs and center on identifying effective techniques to examine and reduce problematic or unwanted behaviors and increase functioning, in individuals with ASD, by addressing the behavioral symptom (DiGennaro Reed et al., 2012). Service provision workers who utilize behavioral interventions attempt to build new repertoires while at the same time attempt to reduce interfering behavior (Eldevik et al., 2009). Two of the most commonly used behavioral strategies in the intervention of stereotypy in children with ASD have centered on (a) the antecedents and (b) the consequences or reinforcement of the behavior (DiGennaro Reed et al., 2012; Einfeld, Tonge, & Clarke, 2013; Lanovaz & Sladeczek, 2012).

Antecedent-based interventions. Antecedent-based interventions center on the manipulation of when an event occurs, independent of the occurrence of the stereotypic behavior (Lanovaz & Sladeczek, 2012). Antecedent-based interventions involve altering a specific environment, which is sometimes referred to as “environmental enrichment”, prior to the occurrence of the problem behavior (i.e., stereotypy; Rapp & Vollmer, 2005a). For example, if Johnny engages in high frequencies of vocal and motor stereotypy, especially in places with loud sounds and music, a service provision worker could adapt the environment ahead of time and

ensure a reduction in stimuli. Behavioral interventions can also involve non-contingent reinforcement, which includes continuous access to sources of stimuli (via over exposure) or using a set time frame independent of the behavior, and matched or unmatched stimuli to assist with the reduction of stereotypic behavior (Lanovaz & Argumedes, 2010; Lanovaz & Sladeczek, 2012; Lanovaz, Sladeczek, & Rapp, 2011; Lanovaz, Sladeczek, & Rapp, 2012; Rapp, Cook, McHugh, & Mann, 2016; Rapp & Vollmer, 2005a). An example of a non-contingent reinforcement could be a fixed-time schedule in which Johnny's kindergarten teacher gives him attention (e.g., verbal or physical praise, reminders, or general comments on his work ethic) throughout the school day. This would be an example of an intervention approach that is not based on Johnny's unwanted behavior but instead provides Johnny with continuous access to sources of stimuli (i.e., attention) in an attempt to reduce the likelihood of his problematic behavior (i.e., stereotypy).

Consequence-based interventions. Consequence-based interventions center on the manipulation of an event, contingent on the occurrence of the stereotypic behavior (Lanovaz & Sladeczek, 2012). Consequence-based interventions may involve a single or combination of strategies including stimuli extinction (terminate item or action that reinforces problematic behavior), functional communication training (FCT), differential reinforcement of alternative behaviors (DRA), differential reinforcement of incompatible behaviors (DRI), response interruption and redirection (RIRD), and the presentation of aversive stimulation (also known as punishment; Franzone, 2009; Lanovaz et al., 2016; Lanovaz & Sladeczek, 2012; Prelock, 2013; Rapp & Vollmer, 2005a; Zane, 2013). FCT, DRA, and DRI procedures attempt to decrease unwanted behavior by reinforcing more appropriate behaviors that can fulfill similar functions (Franzone, 2009; Zane, 2013). The difference between the latter two is that the replacement

behavior should be incompatible with the unwanted behavior in DRI (i.e., cannot be done at the same time; Zane, 2013), while it does not matter if the replacement behavior is incompatible when using DRA. FCT differs, from the two, in that more conventional communicative forms are taught to replace the unwanted behavior (e.g., picture exchange, pointing, picture drawing, verbalizations, and signing; Franzone, 2009). RIRD procedures are used to block/interrupt unwanted behaviors and this is followed by redirection to a more appropriate behavior or activity (Rapp & Vollmer, 2005a). Examples of how to implement FCT, DRI, DRA, and RIRD are depicted via the example of Johnny.

If Johnny repeatedly smells his hands, an example of DRI would be to have Johnny put his hands in his pockets; this would be a more appropriate behavior and Johnny would not be able to smell his hands and have his hands in his pockets at the same time. If Johnny engaged in loud and frequent outbursts in class, an example of FCT and DRA would be to have him raise his hand or point to the teacher. Having Johnny do this would be a more appropriate behavior (although incompatible with the unwanted behavior) and would rely on the assumption that the function of Johnny's outbursts is based on his desire to communicate in class. If Johnny engaged in frequent vocal stereotypy a teacher, or intervention aid, could use RIRD for example and block/interrupt the behavior by asking Johnny a question or having him complete a series of tasks (e.g., reciting the alphabet and counting to 10). By using RIRD, the stereotypy is interrupted, Johnny works on completing his tasks, and once completed the teacher can redirect him to another activity (e.g., coloring or a worksheet). Within consequence-based interventions, DRI, DRA, and RIRD have received the most empirical support in the research literature (Lanovaz & Sladeczek, 2012).

Efficacy of Behavioral Interventions

In 1968, Colligan and Bellamy were the first researchers to report positive effects after using behavioral interventions for children with ASD (Klintwall & Eikesth, 2014). Since then, researchers have examined the use of behavioral interventions on a range of ASD characteristics (Eikeseth, Klintwall, Jahr, & Karlsson, 2012; Peters-Schaffer et al., 2011, Rapp, 2007).

Researchers who have examined the efficacy of behavioral interventions on stereotypy, in particular, have reported a reduction in ASD symptomology and have noted support for the use of behavioral approaches (Eikeseth et al., 2012; Peters-Schaffer et al., 2011, Rapp, 2007).

Efficacy of TEACCH. Researchers who have examined the benefits of the TEACCH model suggest positive behavioral outcomes for children with ASD including reductions observed in repetitive and disruptive behaviors (Probst, Jung, Micheel, & Glen, 2010), improvements found in transition-related behaviors (Probst & Leppert, 2008), and improvements noted in adaptive behaviors, such as independent functioning (i.e., assessed by the completion of independent tasks; Panerai, Ferrante, & Zingale, 2002; Sevin, Rieske, & Matson, 2015; Welterlin et al., 2012). Researchers have also examined the benefits of TEACCH on parent outcomes and have found reductions in caregiver stress and maternal depression (Bristol, Callagher, & Kathleen, 1993; Probst & Glen, 2011; Probst & Leppert, 2008; Sevin, Rieske, & Matson, 2015). Recent meta-analyses conducted by Mesibov and Shea (2009) and Ospina et al. (2008) have noted support for the efficacy of home-based and center-based TEACCH programs when compared to groups of children receiving either general special needs services or no services at all (Probst et al., 2010).

Probst and colleagues (2010) conducted two separate studies to examine the effectiveness of a TEACCH based intervention for individuals with ASD. The first study used a controlled-

individual subject design to examine changes in challenging behaviors (including stereotypic behavior), social-communication, and developmental functioning (based on motor, verbal, and cognitive performance skills) in a 7-year-old girl with ASD and intellectual disability. The intervention program was developed based on the TEACCH principles of structured teaching (with the use of a picture schedule, pictures of objects and spaces, and a visual work sheet with tasks to complete) the use verbal instructions (e.g., gestural and verbal prompts), verbal and nonverbal reinforcements (e.g., praise and treats) and mild forms of punishment (e.g., verbal reprimands such as “no”; Probst et al., 2010). Changes in behavior were measured using the *Behavior Problems Inventory* (BPI; Rojahn, Matson, Lott, Esbensen, & Smalls; 2001), video recording observations, the *Psychoeducational Profile-Revised* (PEP-R; Schopler et al., 2000), and with informal conversations with caregivers at baseline and again after the intervention. After two months of intervention, across 12 sessions, results indicated a 10% decrease in stereotypic behaviors, improvements in social-communication with less assistance needed using a communication board, and improvements noted in developmental functioning (i.e., increases noted in all subscales of the PEP-R; Probst et al., 2010). The study provides insight into the benefits of TEACCH on a number of child outcomes, including stereotypy. Strengths and limitations of the study are noted. The use of a pre-test/post-test comparison design provided a greater understanding of the changes observed. A limitation is the use of a single participant, which *can* make it difficult to generalize the results to the larger population (Probst et al., 2010).

In their second study, Probst and colleagues (2010) examined the effectiveness of a TEACCH intervention for three adults, between the ages of 23 and 30, with ASD living in vocational and residential settings. Two of the participants were diagnosed with severe mental retardation and the third was diagnosed with PDD-NOS and moderate mental retardation. The

intervention was provided based on the TEACCH principles of structured teaching and each participant used daily schedules and work systems. Challenging behaviors (including stereotypy), social skills, and social behaviors were measured using the German version of the *Developmental Behavior Checklist for Adults* (DBC-A; Einfeld, Tonge, and Steinhausen, 2007), a German translation of the *Matson Evaluation of Social Skills for Individuals with Severe Retardation* (MESSIER; Matson, Jung, Micheel, & Probst, 2008), the *Behavior Problems Inventory* (BPI; Rohjan et al., 2001), and a semi-structured interview with staff members (Probst et al., 2010). Results on the BPI indicated a 5% mean reduction in stereotypic behaviors and significant reductions were observed in disruptive behaviors, self-absorbed behaviors, while increases were noted in social skills and social behavior (assessed by the MESSIER; Probst et al., 2010).

The study provides insight into the efficacy of TEACCH for adults with ASD and other intellectual disabilities; however, limitations are apparent. Probst and colleagues (2010) failed to mention the duration of the intervention, as well as the number of sessions each participant received; making it difficult to discern the effectiveness of the intervention. Moreover, Probst and colleagues (2010) failed to mention if the participants were receiving other intervention services. Since the participants were living in community and vocational settings, it could be possible that they were also receiving some other form of intervention, which makes it difficult to discern whether the changes in their behaviors were due to the intervention and not some other confounding variable. The following section discusses the efficacy of DRI, DRA, and RIRD interventions for individuals with ASD, with a particular focus on the impact on stereotypic engagement.

Efficacy of consequence-based interventions. The impact of DRI, DRA, and RIRD

interventions have been commonly examined with a particular focus on motor and vocal stereotypy in children, adolescents, and adults with ASD. A review of the research literature indicates support for the use of DRI, DRA, and RIRD to reduce stereotypy in individuals with ASD with the percentage of reduction ranging as low as 36% (Ahearn, Clark, MacDonald, & Chung, 2007; Fritz et al., 2012; Mulligan et al., 2014; Wolff et al., 2013) to as high as 90% to 100% (i.e., the latter value suggesting complete elimination of behaviors; Liu-gitz & Banda, 2010; Mulligan et al., 2014; Shillingsburg, Lomas, & Bradley, 2012).

Ahearn et al. (2007) examined the impact of an RIRD intervention on vocal stereotypy present in four children with ASD, aged three to 11 years old ($M=7$). All participants were receiving “Intensive vocal and augmentative communication training” before and during the duration of the study (Ahearn et al., 2007, p. 265). Video recordings were conducted to measure the occurrence of vocal stereotypy and appropriate vocalizations (defined as contextually appropriate vocalizations such as requests for breaks, comments, or requests to do an activity which was not directed by the teacher). An ABAB withdrawal design was used to observe behaviors at baseline, during response intervention (RI) and response redirection (RD), without RI+RD, and again with the interventions. Each phase lasted five minutes. At baselines, a teacher provided praise every time the participant engaged in appropriate vocalizations; however, nothing was done when the participant engaged in a vocal stereotypy. During the RIRD phases, positive reinforcement was used when appropriate vocalizations occurred and when a vocal stereotypy occurred the teacher said the child’s name, initiated eye contact, and issued simple prompts (e.g., asked questions about where participants lived or what was on their shirt) or requested a vocal imitation (e.g., say dog or say ball) which required the participant to respond. Vocal demands were continuously issued, during vocal stereotypy until participants complied

with three consecutive demands and did not omit a vocal stereotypy (Ahearn et al., 2007).

The authors found reductions in the frequency of vocal stereotypy and increases in appropriate vocalizations in three out of the four children (Ahearn et al., 2007). Two out of the four children showed visible reductions in stereotypy from the first baseline to the second baseline after RIRD was implemented. A limitation of the study is that RIRD was introduced briefly in short durations (five minutes per session) across a total of four sessions per participant; equaling a total of twenty minutes of intervention. Due to the shortness of the intervention, limited information was collected. Information regarding the environment (e.g., natural setting or clinic setting) in which the intervention was implemented was also not provided (Ahearn et al., 2007).

In their review of treatment efficacy for stereotyped and repetitive behaviors in children with ASD, Mulligan, Healy, Lydon, Moran and Foody (2014) examined eight studies published between 1997 to 2012 that used some type of reinforcement based treatment, such as teaching appropriate alternative behaviors, non-contingent reinforcement, and differential reinforcement (Frea, 1997; Lanovaz et al., 2012; Loftin et al., 2008; Nuzzolo-gomez et al., 2002; Rapp, 2006; Rapp 2007; Rozenblat et al., 2009; Saylor et al., 2012). The percentage of reduction of stereotypic behaviors (PRB) was calculated for six of the eight studies that provided sufficient frequency information to analyze. PRB values ranged from as low as 36% to as high as 100% (i.e., the latter indicating complete elimination of stereotypic behaviors; Mulligan et al., 2014). Based on the PRB's, Mulligan and colleagues (2014) determined that reinforcement based interventions were effective in reducing stereotypy in children with ASD.

Mulligan and colleagues (2014) also examined the efficacy of four research studies that used some type of consequence-based intervention, (i.e., RIRD, differential reinforcement, and

punishment; Boyd et al., 2011; Pastrana et al., 2013; Rapp, 2006; Schumacher & Rapp, 2011) and five research studies, published between 1990 to 2013, that used a mixture of behavioral interventions (i.e., DRA, discrimination training, environmental enrichment, exposure and response prevention; Boyd et al., 2013; Matson & Newsom, 1990; Sigafoos et al., 2009; Stahmer & Schreibman, 1992; Watkins et al., 2011). In the consequence-based studies, PRB were found to range from 61% to 100% and 38% to 100% reductions were noted in the studies with a mixture of interventions (Mulligan et al., 2014). Based on these values, Mulligan and colleagues (2014) determined that studies that used either consequence-based or mixture-based interventions demonstrated efficacy in the reduction of stereotypy.

Efficacy of EIBI. Researchers have also found widespread support for the use of EIBI to produce positive outcomes for children with ASD. The efficacy of EIBI can be traced back to Lovaas' (1987) research study. In 1973, Lovaas and colleagues made important discoveries that would guide the design of the 1987 study. In their earlier study, Lovaas and colleagues (1973) found that younger children in the sample made the greatest developmental gains, intervention results varied depending on the environment in which the intervention was administered, parents were allies and their opinions and feedback were resources, and consistent intervention across several years was critical to observe change (Klintwall & Eikseth, 2014).

Following these discoveries, Lovaas (1987) conducted a group comparison study to examine differences in treatment effect between three groups of children with ASD. The first group consisted of 19 children with ASD who received 40 hours of EIBI, per week, across a two-year period. The second group consisted of 19 children with ASD who received between zero to 10 hours of EIBI per week. The third group consisted of 21 children with ASD who received general autism-related services available to the public. Across all three groups, Lovaas (1987)

found that children in the experimental group made the greatest gains. At post-intervention, Lovaas (1987) found that children who had received the 40 hours of EIBI for two-years showed increases in cognitive functioning (measured by increases in IQ scores) and adaptability. At post-intervention, 47% of the children in the experimental group were also placed in regular classrooms without assistance (Klintwall & Eikseth, 2014; Lovaas, 1987). At a six-year follow-up, McEachin, Smith, and Lovaas (1993) found that eight out of the nine children in the original experimental group (with the strongest outcomes) had maintained the developmental gains made, based on the outcomes observed after they had received EIBI.

Since Lovaas' (1987) ground-breaking study, over 24 peer-reviewed research studies have been published on the efficacy of EIBI outcomes (Klintwall & Eikseth, 2014). A handful of these research studies have examined EIBI outcomes for IQ and adaptive functioning in children with ASD and have found strong empirical support.

Eldevik et al. (2009) conducted a meta-analysis of 34 studies that reported the effects of EIBI on two outcome variables: intelligence and adaptive behavior. Effect sizes were computed for each study and then compared against comparison and control groups. The authors found an "Average large effect size for IQ change" (i.e., $g=1.10$, 95% confidence interval=.87, 1.34) and an "Average medium effect size" (i.e., $g=.66$, 95% confidence interval=.41, .90) for adaptive behavior change following EIBI treatment (Eldevik et al., 2009, p. 447); indicating that EIBI was effective in producing change for children with ASD.

A few years later, Reichnow (2012) reviewed five different meta-analyses (including Eldevik and colleagues' 2009 study) that examined the effectiveness of EIBI on IQ and adaptive behavior for children with ASD (Eldevik et al. 2009; Makrygianni & Reed 2010; Reichow & Wolery 2009; Spreckley & Boyd, 2009; Virue's-Ortega, 2010). Reichnow (2012) found that four

of the five meta-analyses reported that EIBI was an effective treatment for children with ASD. In the four studies (Eldevik et al. 2009; Makrygianni & Reed 2010; Reichow & Wolery 2009; Virués-Ortega, 2010) effect sizes for IQ and adaptive behavior ranged from $g = .38$ – 1.19 and $g = .30$ – 1.09 (Reichnow, 2012).

A smaller number of studies have examined the use of EIBI in the treatment of stereotypic behaviors. To date, five research studies have been published with promising, yet varying results (Ben-Itzhak & Zachor, 2007; Dawson et al., 2010; MacDonald, et al., 2014; McGarrell et al., 2009; O'Connor & Healy, 2010).

Ben-Itzhak and Zachor (2007) assessed the outcomes of child cognition, socialization, communication, play, and stereotyped behaviors in 25 children (between the ages of 20-32 months, $M = 26.6$ months) with ASD. Children were divided into groups based on cognitive functioning, social interaction, and communication deficits (assessed with the *Autism Diagnostic Observation Schedule*; ADOS). All children received individualized intervention for at least 35 hours per week over the course of one year. The authors used a pre-test/post-test design to assess outcomes at baseline and again after one year of intervention (Ben-Itzhak & Zachor, 2007).

The authors found that after one year of intervention, all children in the study showed improvements in all areas assessed including reductions in stereotypic behavior (i.e., behavioral assessment means for stereotypic behaviors reduced from $M = 6.48$, $SD = 3.23$ to $M = 3.36$, $SD = 2.62$ at post-intervention; Ben-Itzhak & Zachor, 2007). This study provides initial support for the use of individualized intervention on the reduction of stereotypic behaviors; however, several limitations are present. The authors failed to describe whether the intervention used was, in fact, EIBI, or an eclectic program based on the principles of ABA, and they failed to describe the instrument used to acquire behavioral assessment means for stereotyped behaviors. An

additional limitation is the absence of a comparison group.

Dawson et al. (2010) conducted a randomized controlled trial to evaluate the efficacy of an EIBI program (specifically the Early Start Denver Model; ESDM) in 48 children diagnosed with ASD. Children between the ages of 18-30 months were randomly assigned, based on composite IQ at baseline, to the intervention group or were referred to EI service providers in the community (Dawson et al., 2010). For the first group, the intervention was administered by trained therapists across a two year-period. Using the *Autism Diagnostic Interview-Revised*, *Autism Diagnostic Observation Schedule* (ADOS), *Mullen Scales of Early Learning* (MSEL), *Vineland Adaptive Behavior Scales* (VABS; Sparrow, Balla, & Cicchetti, 1984), and the *Repetitive Behavior Scale* (RBS), the authors found that after two years, compared to children who received community-intervention, children who received EIBI showed significant improvements in adaptive behavior and IQ (Dawson et al., 2010). However, for repetitive behaviors, an examination of the results indicated no significant difference between intervention groups (Dawson et al., 2010). Moreover, the authors found that from baseline to two years, repetitive behaviors appeared to slightly increase for the EIBI group (i.e., baseline $M=15.2$, $SD=10.8$, at 1-year $M=15.5$, $SD=12.3$, and at 2-years $M=16.7$, $SD=13.1$). A limitation of this study is the lack of a third comparison group.

McGarrell, Healy, Leader, O'Conner, and Kenny (2009) presented case reports of six children with ASD who had received EIBI. Participants were children, between eight years and nine months to 10 years and 11 months, diagnosed with ASD. All children attended a special school for a minimum of 30 hours per week. The age at EIBI onset varied for each participant (i.e., three years and 10 months to five years and three months); however, most children received services for at least three years (McGarrell et al., 2009; O'Connor & Healy, 2010). Children's'

learning and engagement in stereotypy were evaluated and assessed using the PIRK curriculum (Greer & McCorkle, 2003). The PIRK is used as an assessment instrument to identify a student's current level of skills. It covers six areas including self-management skills, social self-management, and physical/motor skills (McGarrell et al., 2009). Results from the PIRK physical/motor skills assessment indicated that four out of the five participants showed a complete elimination of stereotypic behaviors (McGarrell et al., 2009). The authors noted that the case report findings were confirmed by interviews with school staff members (McGarrell et al., 2009). Although promising, McGarrell et al.'s (2009) study has several limitations to consider such as the use of an unstandardized educational assessment (the PIRK) to measure changes in repetitive behaviors, across time, and the use of staff interviews to confirm research findings. The lack of a comparison group also limits the validity of this study.

O'Connor and Healy (2010) examined the outcomes of the children from the McGarrell et al. (2009) study who had previously received EIBI. At the time of the follow-up study, the five participants were between the ages of nine and 12 ($M=11$ years). Up to date assessments were conducted over a one month period, in the school and home setting, to compare outcomes since the completion of EIBI (approximately one year). A number of standardized instruments were used including the *British Ability Scales: Second Edition* (Elliot, Smith, & McCulloch, 1996), the *VABS-Second Edition* (Sparrow, Balla, & Cicchetti, 1984), the *Gilliam Autism Rating Scale: Second Edition* (GARS-2: Gilliam, 1995), *The Mainstreaming Social Skills Questionnaire* (MSSQ; Salend & Lutz, 1984), the *Conner's Rating Scales—Revised* (CRS-R; Conners, 2000), and the *Strengths and Difficulty Questionnaire* (SDQ; Goodman, 1997). Between-group comparisons revealed that stereotypy increased for four out of the five participants (O'Connor & Healy, 2010). The findings of this study, in comparison to McGarrell et al.'s (2009) findings,

suggest that EIBI may have been effective in reducing these behaviors, but after one-year intervention may not have been effective in maintaining long-term change (O'Connor & Healy, 2010).

MacDonald, Parry-Cruwys, Dupere, and Ahearn (2014) conducted a comparison study with 83 children (between one to three years of age) with ASD and 58 typically developing children, of the same age, in order to assess outcomes of EIBI. Children with ASD aged 17 to 36 months received between 20 to 30 hours of home-based EIBI, per week. Children with ASD aged 36 to 48 months received 28 to 30 hours of a preschool program of EIBI, per week. At the time, EIBI was the only intervention that the children were receiving. The typically developing children were either enrolled in a community or on-site daycare, or an on-site integrated preschool. The authors used the *Early Skills Assessment Tool* (ESAT; MacDonald et al., 2014) to directly observe children's cognitive skills, play, joint attention, and stereotypic behaviors. Percentage of stereotypy was scored from 10-minute video recordings of children engaged in five minutes of work and five minutes of play.

Macdonald and colleagues (2014) found that although EIBI did not have a significant effect on the reduction of stereotypy in children with ASD, at follow-up older children with ASD (regardless of intervention group) were found to engage in slightly less stereotypy, compared to engagement at baseline (MacDonald et al., 2006). Specifically, engagement of stereotypic behaviors in the 30 to 36-month group decreased from $M=16.57$, $SD=14.94$ at entry to $M=15.10$, $SD=13.17$ at follow-up. Children in the 37 to 48-month group also showed decreases in engagement from $M=17.44$, $SD=15.19$ at entry to $M=16.53$, $SD=14.83$ at follow-up (MacDonald et al., 2014).

In the following sections, the author will discuss the present study, the rationale for

conducting the study, and the research questions.

Present Study and Rationale

There currently exists a large body of literature dedicated to the study of restricted and repetitive behaviors (RRBs) in children with autism spectrum disorder (ASD). However, RRBs are wide and diverse, encompassing various definitions and forms, while stereotypic behaviors are one specific form (e.g., see Table 1 on page 25; Rojahn & Meirer, 2013). Researchers, such as Harrop et al. (2014), Richler et al. (2007), and Sevin and colleagues (2015) have argued that stereotypic behaviors are less widely understood and under researched, compared to other diagnostic features of ASD; such as deficits in socialization and communication. To date, there is widespread support for the use of EIBI as a treatment to reduce other ASD symptomology. Researchers have found that EIBI can improve receptive and expressive language, social communication, adaptive skills, cognitive skills, and can even support children's transition to school (Cohen, Amerine-Dicken, & Smith, 2006; Dawson & Burner, 2011; Eikeseth et al., 2012; Einfeld et al., 2013; Eldevik et al., 2009; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011).

However, to date, only five research studies have examined the effectiveness of EIBI on stereotypic behaviors and researchers have found promising, but mixed results (i.e., all found variable decreases in stereotypy at post-intervention, while some noted behaviors returned to baseline or were shown to increase after intervention; Ben-Itzhak & Zachor, 2007; Dawson et al., 2010; MacDonald, et al., 2014; McGarrell et al., 2009; O'Connor & Healy, 2010). The use of specific behavioral based interventions, such as reinforcement and consequences based strategies, have been found to be largely effective in the reduction and elimination of stereotypic behaviors in individuals with ASD (i.e., percentage reduction of behaviors; PRB; of 50% to 100%; Ahearn, Clark, MacDonald, & Chung., 2007; Fritz et al., 2012; Lanovaz & Argumedes,

2010; Lanovaz et al., 2011; Lanovaz et al., 2012; Lanovaz et al., 2016; Liu-gitz & Banda, 2010; Mulligan et al., 2014; Rapp et al., 2016; Shillingsburg et al., 2012; Wolff et al., 2013).

Behavioral strategies are used in a range of EI programs, including EIBI; as a means to reinforce appropriate behavior and reduce unwanted or challenging behavior (DiGennaro Reed et al., 2012; Eldevik et al., 2009). The current review of the literature suggests that EIBI programs that employ behavioral interventions, such as consequence or reinforcement based approaches that specifically target stereotypy may be effective in reducing stereotypic engagement in individuals with ASD.

Researchers have found that children with ASD who are properly supported are more likely to show positive outcomes later in life. For instance, research studies have shown that in supporting children in their early years of childhood they are more likely to graduate high school, become active members of society, and substantially reduce economic costs by requiring less rehabilitative services in the future, compared to children who are not properly supported, or are not supported at all with any type of EI service (Chasson, Harris, & Neely, 2007; Herrod, 2007; Schweinhart et al., 1993). Given these findings and the negative impacts that engaging in stereotypy can have on both child and family outcomes (i.e., as discussed in the previous sections), the present study will aim to contribute to the limited research literature that has examined changes in stereotypic engagement, in children with ASD, after receiving EI services. More specifically, the present study seeks to contribute to the existing literature by investigating if and how stereotypic behaviors change after early intervention in the form of either EIBI or a combination of the Carolina Curriculum and TEACCH models is given to children under the age of five with a diagnosis of ASD. Information regarding the type of behavioral strategies used in each EI programs will also be described.

If reductions are noted in stereotypic behavior at post-intervention, the research findings from the present study can help solidify the use of behavioral based EI services, such as EIBI, to target stereotypic engagement in children with ASD. If reductions, or complete elimination of behaviors are found, results can help to inform families who are seeking information on different types of EI programs (i.e., EIBI and Carolina Curriculum and TEACCH) that take into account the needs and suggestions of families, via a family-centered care approach, in the development of programming. In providing this information, this could help reduce the overall cost that families currently spend on alternative types of interventions (that may not specifically target stereotypy), leading to greater cost-saving measures for families and less financial burdens to the economy (Chasson et al., 2007; Herrod, 2007). Lastly, contributing to the research literature will provide educators and researchers with more insights and will enable them to use the findings of the present study to improve programming and EI approaches for children with ASD.

Research Questions

The overarching objective of the present study is to explore the potential influence of two types of EI programs and the changes of stereotypic behaviors exhibited by children with ASD. More specifically, the goals of the present study are to examine: (a) in general, what rate and what types of stereotypic behaviors young children, with ASD engage in; (b) if and how children's stereotypic engagement changes after receiving early intervention services in the form of EIBI or a combination of the Carolina Curriculum and TEACCH models; and (c) if and how stereotypic engagement varies, from one participant to another, based on the length of time children with ASD receive EI services. The data of the present study is secondary data from a larger research project, entitled *Early Intervention Services for Autism Spectrum Disorders in Quebec: Evaluation of their Impacts on Children and their Families*, which took place from

2011-2015. Dr. Ingrid Sladeczek of McGill University spearheaded the study, in collaboration with Dr. Katherine Moxness from the West Montreal Centre intégré universitaire de santé et de services sociaux and adjunct professor at McGill University, Dr. Nathalie Garcin from the Gold Centre, and Dr. Marc Lanovaz from Université de Montréal and Ste-Justine Research Center.

The research questions for the present study are:

1. What are the rates (i.e., frequency) and sub-types (i.e., diversity) of stereotypic behaviors that children, under the age of five with autism spectrum disorder (ASD) engage in?
2. Does stereotypic engagement change for children, with ASD, after receiving (6-months to 2.5 years) early intervention services in the form of EIBI or a combination of the Carolina Curriculum and TEACCH models?
3. Does the rate of stereotypic engagement at post-intervention vary in children, with ASD based on the length of time in EI services (either EIBI or a combination of the Carolina Curriculum and TEACCH models)?

Chapter Three: Methods

Participants

Thirty-five children, between the ages of two to five and their parents and caregivers, participated in the larger study. Demographic information was collected from families prior to their children beginning early intervention services (i.e., Time 1) and again after the intervention had been completed, or after two years (i.e., Time 2) whichever came first. Researchers from the larger project collected demographic information from 27 families and their children at pre-intervention. At pre-intervention, the average age of the children was two ($M = 2.16$, $SD = .891$). Twenty-four of the children were boys and three were girls. Twenty-seven of the children had a diagnosis of ASD. At post-intervention, information from 21 families was collected and the children were approximately five and a half years old ($M = 5.7$, $SD = .667$).

A sample of 29 children, from the 27 families, participated in a video recording portion of the study. Between Time 1 and Time 2, nine participants dropped out. Upon completion of the project, parents/caregivers were contacted in an attempt to discern their reasons for dropping out. The parents who provided follow-up information noted medical issues, dislike of the early intervention sites, and disinterest in continuing the intervention as reasons for dropping out. Taking into account the sample size and the number of participants who dropped out, the total sample size for the present study for pre-intervention and post-intervention is 20. Tables 3 and 4 provide a detailed description of child demographic information and the characteristics of the EI services that participants received.

Table 3

Child Demographic Characteristics

Characteristics	Frequency <i>n</i> (N=20)	Percentage %
Sex		
Male	16	80%
Female	4	20%
Diagnosis		
ASD	20	100%
Medical/Genetic Conditions		
Duplication in 22Q11 Chromosome	2	10%
CFC Syndrome and Epilepsy	1	5%
None	17	85%
Age (years)		
Baseline		
2-3	2	10%
3-4	6	30%
4-5	10	50%
5-5.5	2	10%
Post-Intervention		
4-5	2	10%
5-6	9	45%
6-7	8	40%
7-7.5	1	5%

Note: Cardiofaciocutaneous Syndrome is abbreviated to CFC Syndrome. Differences in the age groups at post-intervention are due to the differences in the duration of treatment; some participants received EI services for less than a year, over one year, or over two years.

Table 4

Characteristics of Early Intervention Services Participants Received and Additional Private Services Received

Characteristics	Frequency <i>n</i> (N=20)	Percentage %
Type of EI service received		
EIBI	15	75%
Carolina Curriculum & TEACCH	5	25%
Delivery mode		
Baseline		
1:1 Instruction	17	85%
Small Group Instruction (less than 5)	8	40%
Large Group Instruction (more than 5)	1	5%
Post-Intervention		
1:1 Instruction	13	65%
Small Group Instruction (less than 5)	4	20%
Large Group Instruction (more than 5)	1	5%
Additional EI services received		
Baseline		
ABA	4	20%
TEACCH	1	5%
IBI	1	5%
OT	1	5%
ABA Shadow (School)	1	5%
None	12	60%
Post-Intervention		
ABA	2	10%
OT	1	5%
Speech therapy	1	5%
Ergotherapy	2	10%
Osteopathy and ergotherapy	1	5%
Variety (motor, language, social, play therapy)	1	5%
None	12	60%

Note: Some participants received EI in more than one type of instruction. Values represent information provided by participant's parents and caregivers. ABA refers to applied behavioral analysis; IBI refers to intensive behavioral intervention, and OT refers to occupational therapy. An ABA shadow refers to a psycho-educator who supports a child in an academic setting based on a set of goals and targets in mind.

The following sections of this chapter will cover a description of each early intervention site from which participants were recruited, the procedure and research design used, the measures used, the data collection process, and the data conversion procedure.

Early Intervention Sites

Directors and supervisors recruited participants on a rolling-basis, during the intake process, from three early intervention sites located in Montreal, Quebec, Canada.

Site One. *Site one* is a government-funded rehabilitation center that provides early intervention services for families of children with ASD, up to the age of six, in the form of EIBI. Programming is developed in accordance with parents and community partners (such as a child's school or daycare) and is individualized based on the child's need. EIBI programs are offered in group settings on site, or individually in a one-to-one ratio between the child and a therapist in the child's home or daycare. Each EIBI program targets specific areas of development, including daily living, communication, language (expressive and receptive), play, social skills, imitation, gross and fine motor skills, and more pre-school skills. Information regarding if and how stereotypic behaviors are targeted in children with ASD was not made available. Behavior modification agents and psycho-educators supervise and train intervention aids to deliver the individualized or group programs. Intervention aids are students or graduates from a psychology, education, or psychoeducation related program. *Site one* provides EIBI services up to a maximum of 20 hours per week and 10 hours per week once a child is integrated into a school.

Site Two. *Site two* is a not-for profit private program which provides early intervention services in the form of EIBI to families of children with ASD, of suspected ASD, or other developmental disabilities, aged 18 months to six years. The site provides an individualized

approach to child services in accordance with the principles of ABA and programming is adapted in consultation with parents and caregivers. Early intervention services are provided in a one-to-one ratio between the child and therapist over the course of 20 to 40 hours per week either on site, in the child's home, or community-setting. Services are supervised by Board Certified Behavior Analysts and are implemented by trained professionals, referred to as interventionists. Service providers tailor intervention plans to strengthen and maintain prosocial behavior, assist children in new skill acquisition, diminish maladaptive behavior, and generalize learning targets across environments. Stereotypic behaviors are mediated through functional communication training, response interruption and redirection (RIR), differential reinforcement of alternative behaviors (DRA), and differential reinforcement of incompatible behaviors (DRI).

Site Three. *Site three* is a not-for profit program which offers early intervention services based on a combination of the Carolina Curriculum (Johnson-Martin et al., 1991; Mesibov et al., 2004; Schopler & Reichler, 1976) and the TEACCH model (Mesibov, Shea, & Schopler, 2004; Schopler & Reichler, 1976) to children aged 18 months to six years who do not yet have a diagnosis, have a global delay, or have a developmental disability including ASD, intellectual disability, communication disorder, attention deficit disorder, motor development or learning disability. Individualized intervention plans are developed in consultation with parents and caregivers and services are provided onsite across 10.5 or 17.5 hours a week. The site relies on the Carolina Curriculum and TEACCH model to strengthen children's social skills, individual and group communication, fine and gross motor skills, management of challenging behavior, daily living skills (e.g., personal grooming, dressing, eating, and toilet training), and pre-school cognitive skills (such as basic academic concepts). Sensory and behavioral approaches such as over exposure to stimuli, extinction, redirection, and matched stimulus are used to mediate

stereotypic behaviors. Intervention is provided one-to-one or in a group setting whereby targeted skills are generalized and maintained. The program is overseen by clinical supervisors who train therapists on how to implement the services. Visits to natural and community settings, such as the home or school, are provided based on the needs of the child.

Procedure and Research Design

The study received ethical approval from the McGill Research Ethics Board (REB-III) and the Comité d'éthique de la recherche conjoint des CRDITED (CÉRC/CRDITED; see Appendix A). Each participant had to meet the following inclusion criteria at the time of recruitment (a) the child had to have a diagnosis of ASD (i.e., autistic disorder, Asperger disorder, or pervasive developmental disorder-not otherwise specified; PDD-NOS); (b) the child had to be less than five years of age; and (c) the child had to be receiving early intervention services from one of the three aforementioned early intervention centers.

During recruitment, either a staff member from the early intervention site or a research assistant explained the details of the study to potential participants. Written parental consent was acquired from parents interested in participating in the study. Parental consent served as consent for both parent and child participation. After parental consent was acquired, a research assistant contacted each family to schedule a meeting to complete the measures.

A quasi-experimental non-equivalent pre-test/post-test within-group design was used for the present study. Each participant in the study served as their own control, whereby comparisons were made based on each of their behaviors prior to and after intervention. Prior to the intervention, parents completed a socio-demographic questionnaire on-site and children and were audio and video recorded during a 10-minute unstructured play session. The video recordings were conducted either on-site or in the families' home by a research assistant.

Standard video recording equipment (a tripod and video camera) was used to record children during one 10-minute unstructured play sessions. Children were given a box with a set of standard toys (e.g., blocks, puzzles, musical box) and were encouraged to play. At post-intervention, children were audio and video recorded once more for the same duration and under the same conditions. Post-intervention was determined by either the completion of EI services or two years, whichever came first. Data was collected by seven research assistants in different educational programs (e.g., undergraduate and doctoral students in psychology and social work).

Measures

Socio-demographic questionnaire. A socio-demographic questionnaire was developed to acquire child and parent information. The questionnaire contains 26 items and is divided into three parts; the child's profile, socio-demographic information pertaining to the parent, and information pertaining to EI services. The first section includes specific demographic questions about the child such as date of birth, language spoken, diagnosis, date of diagnosis, diet, if they received childcare, if they attended school, and if the child received any other type of EI service, outside of the services provided in the study. The second section includes specific questions about the parent such as place of birth, education, occupation, income, number of children, and language spoken. The last section includes specific questions pertaining to EI services the child received such as the start and end date, what kind of intervention was given by parents, total number of weeks and hours in service, what type of instruction was the EI given in (e.g., one-to-one, small group, or large group instruction), and if children received private EI services. For a full review of all 26-items on the demographic questionnaire see Appendix B.

Video recordings. Children were video recorded to observe their behaviors during naturalistic play sessions to examine their engagement in seven different forms of stereotypic

behavior. Operational definitions were developed based on the *Stereotyped Behavior Subscale* of the *Repetitive Behavior Scale-Revised* (RBS-R; Lam & Aman, 2007). The RBS-R is a 44-item questionnaire used to measure repetitive behavior in individuals with ASD. It contains six subscales that measure self-injury, compulsions, ritual, sameness, and restricted behavior; the latter defined as limited range of focus, interest or activity (Lam & Aman, 2007). *Stereotypy* is defined as apparently purposeless (does not fit the context) movements or actions that are repeated (two or more times) in a similar manner (Lam & Aman, 2007). The list of stereotypic behaviors used for the present study includes the addition of vocal stereotypy, which is not part of the original subscale. Vocal stereotypy was added as a review of the literature suggests that vocal stereotypy may also occur frequently in children with ASD (Capone et al., 2005; Chebli et al., 2016; Chowdhury et al., 2010; Fodstat et al., 2012; Hattier et al., 2013; MacDonald et al., 2007). The operational definitions used for the present study include the addition of examples of behaviors not included in the original subscale (e.g., items added include: individual uses body to hit surfaces, uses object to hit surface, rubs face, and sings out of context and in a high and repetitive manner). The following is the list of operational definitions for stereotypy examined in the present study:

1. Whole Body (e.g., body rocking, body swaying)
2. Head (e.g., rolls head, bobs head, turns head)
3. Hand/finger (e.g., flaps hands, wiggles or flicks fingers, claps hands, waves or shakes hand or arm, rubs face)
4. Locomotion (e.g., turns in circles, whirls, jumps, bounces, uses body to hit surfaces)
5. Object usage (e.g., spins or twirls objects, twiddles or slaps or throws objects, let's objects fall out of hands, uses objects to hit surfaces)

6. Sensory (e.g., covers eyes, looks closely or gazes at hands or objects, covers ears, smells or sniffs items, rubs surfaces)
7. Vocal (e.g., repeating words, grunting, snorting, making animal sounds, laughing out of context, singing out of context and in a high and repetitive manner)

Data Collection and Reliability

Prior to the onset of the data collection, the author of the present study and an independent research assistant (a master's student in social work) met to ensure mutual agreement of the definitions. The stereotypy definition was modified, from the RBS-R, which ensured a more clear and concise understanding between the observers. Additional examples were included in four of the seven stereotypy sub-types (locomotion, object usage, hand/finger, and vocal) which provided a broader range of behavioral examples and a greater understanding of stereotypic behaviors that children may exhibit. Next, both individuals took part in a training session whereby participant videos were randomly assigned, watched, and behaviors were coded in an attempt to reach 80% interval-by-interval inter-observer agreement (IOA). Across six consecutive video sessions, training scores ranged from 86-90% IOA. Interval-by-interval IOA was determined by taking the number of agreements, per interval per video, and dividing that by the total number of agreements and disagreements and converting this number into a percentage (Mudford, Taylor, & Martin, 2009).

To assess interrater reliability, the author of the present study viewed and coded all 40-participant videos and the research assistant randomly selected, viewed, and coded 30% the videos. Interval-by-interval IOA was calculated, for each of the twelve videos, for all observable behaviors such as when the child engaged in stereotypy, the sub-type they engaged in, when the child was out of a frame, when the child did not engage in any behavior, and when the child

engaged in functional play. The mean IOA score for all behaviors observed was 63% and values ranged from 35% to 87% with more than half of the scores falling between the 70-80% IOA range. The mean IOA score for only stereotypic behaviors, based on IOA of sub-type, was 42%; with half of the scores falling between the 40-60% IOA agreement range.

Using the block-by-block method with 10-s intervals, behaviors were coded based on the frequency of stereotypic engagement observed at the 10-s intervals. The block-by-block method provides researchers the ability to code for the occurrence of behavior using a continuous and uninterrupted audio interval beep set to occur every 10-seconds (Mudford et al., 2009). Using the block-by-block method, a 10-minute play session allows researchers to observe up to 60 possible occurrences of behavior (six 10-s intervals per minute multiplied by 10 minutes). Using the block-by-block method also allows researchers to observe behaviors that occur between the set intervals (Mudford et al., 2009). Observers did not code for the frequency of stereotypic engagement between the 10-s intervals due to the inability to code for every single occurrence; however, coders noted whether a participant engaged in a stereotypy (and the sub-type).

The frequency of stereotypic engagement was recorded on a data collection sheet (see Appendix C) and data was inserted into an Excel spreadsheet and later transferred to a statistical software database using IBM SPSS 24.0 (Statistical Package for the Social Sciences; IBM Corp, 2016). Stereotypic behaviors at baseline and at post-intervention were analyzed by acquiring the frequency of each sub-type, based on the behaviors each participant engaged at the 10-s intervals. Frequency sub-totals were calculated by adding the total number of behaviors that occurred throughout each video (e.g., participant 1 engaged in one whole body, 13 sensory, one object usage, and two vocal stereotypies in their baseline video). Based on the sub-totals, the total frequency of stereotypic engagement (i.e., the accumulation of all sub-type occurrences)

was then derived for each participant by dividing the frequency of behaviors by 60 (or the total number of intervals where the child was in the frame) and multiplying by 100 (to convert the decimal value to a percentage). For example, the calculations for the first participant are $1+13+1+2=17$ and $17/50=.34/100=34\%$. These values provide a means by which to interpret the data (e.g., participant one engaged in a total of 17 stereotypic behaviors and spent 34% of their play session, prior to receiving EI, engaged in stereotypy).

The frequency of stereotypic behaviors that occurred between the 10-s intervals were also calculated at baseline and again at post-intervention using the same mathematical approach. A tally of the number of participants that engaged in a stereotypic behavior and the sub-type each engaged in was calculated using simple addition (e.g., participant one engaged in at least two occurrences of stereotypic behaviors [1 vocal and 1 sensory] between the 10-s intervals in their first video, prior to receiving EI). Percentages were not calculated for the behaviors between the 10-s intervals as only the data of whether these behaviors occurred or not (and what sub-types) were collected and not the frequency of engagement.

Data Conservation

Participant information was kept confidential using an alphanumeric code appointed to each participant. The code replaced any identifying information. The master list, with the corresponding participant name and code, is kept on a password-protected server. Paper and electronic documentation are stored in a locked cabinet at a research office. Subsequent data, such as the video and audio recordings, are kept on an external hard drive in a locked and secure location. All statistical databases are kept on a secured and password protected server. All video recordings will be destroyed after five years.

Chapter Four: Results

The results will be presented for the three research questions being entertained in this study and the findings will be displayed via bar charts and line graphs, which are customary in depicting findings of observational interval data of behaviors and in analyzing baseline and post-intervention phases for individuals (Alberto & Troutman, 2013; Sheehey & Jenny, 2016). The use of graphed data to describe, analyze, and summarize observational data transformed to quantitative data, as will be depicted herein, allows for the identification of changes in behavior (or lack thereof) both within and across participant phases via a visual analysis (Alberto & Troutman, 2013; Tufte, 2001). Applied behavior analysis practices rely on the consistent observational measurement of behavior (Cooper, Heron, & Heward, 2007; Fahmie & Haley, 2008; Kahng et al., 2010). It is thus commonplace to see research findings graphically displayed and discussed in articles published in, for example, the *Journal of Behavior Modification*, *Journal of Applied Behavior Analysis*, and *Journal of Behavioral Intervention* (e.g., Lanovaz, Sladeczek, & Rapp, 2012; Rapp et al., 2013; Roscoe, Iwata, & Zhou., 2013; Wunderlich & Vollmer., 2015). In the following section and subsequent chapters, pseudonyms are used for the participants in place of their real names to ensure participant confidentiality.

Stereotypy Behaviours Prior to Intervention (Baseline)

Research Question 1: *What are the rates (i.e., frequency) and sub-types (i.e., diversity) of stereotypic behaviors that children, under the age of five with autism spectrum disorder (ASD) engage in?*

An examination of Figure 2 reveals that participants' engagement in stereotypic behaviors at baseline, prior to the onset of EI services, varied from as low as 3% to as high as 51%. The mean engagement of stereotypic behaviors, at baseline, across all participants was

22.3%. Figure 2 shows the percentage of stereotypic engagement each participant exhibited at baseline. Percentages reflect the average number of stereotypic behaviors participants engaged in across their 10-minute videotaped session. For example, out of 60 10-s intervals in his baseline video, Paul spent 3% of those intervals engaged in stereotypic behaviors, while Craig spent 51% engaged in stereotypy.

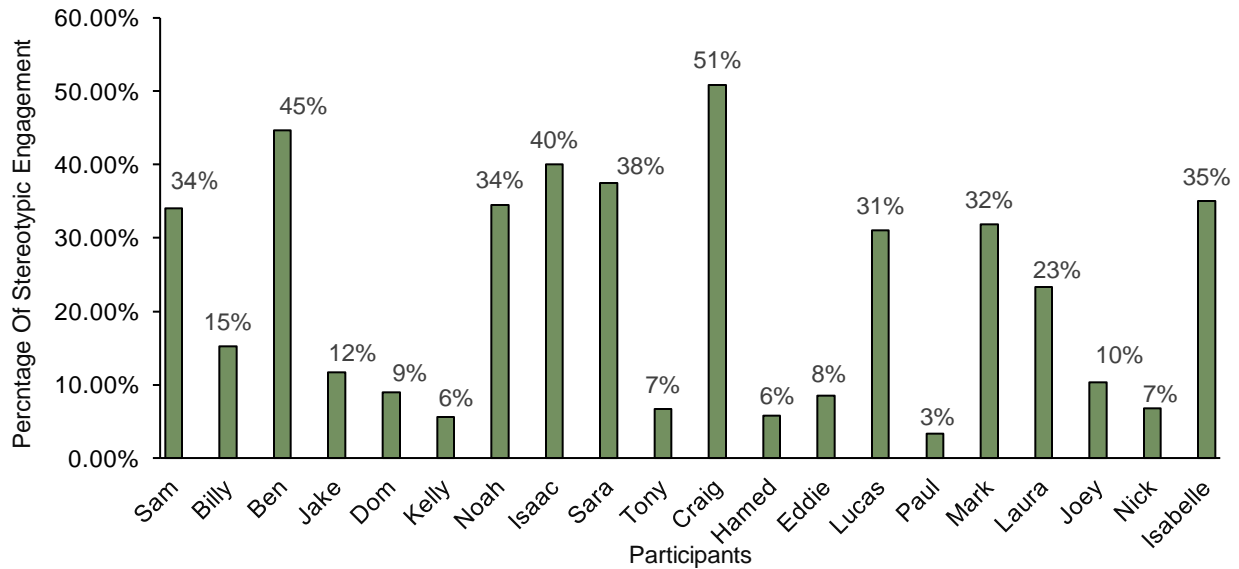


Figure 2. *Percentage of all stereotypic behaviors at baseline; prior to the onset of EI services.*

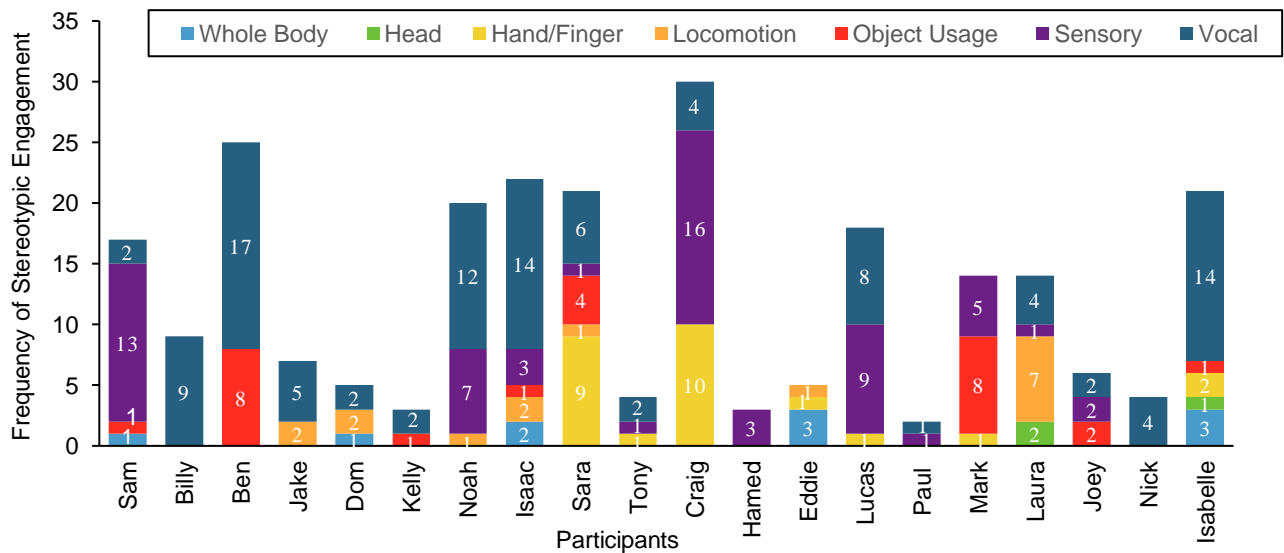


Figure 3. *Frequency of stereotypy sub-types each participant engaged in, at baseline; prior to the onset of EI services.*

An examination of Figure 3 shows that most children in the sample engaged in a variety of different stereotypy sub-types and at different, rather than similar, rates. A total of three participants (15%) engaged in one form of stereotypy, while 17 (85%) engaged in two or more and 13 participants (65%) engaged in three or more stereotypy sub-types. Engagement in stereotypy sub-types varied from one occurrence to as high as 17. For example, 13 participants including Isabelle engaged in one or more occurrence over several stereotypies while Ben engaged in 17 occurrences of vocal stereotypy. The total number of stereotypic behaviors per video and per participant also varied. For example, Tony engaged in five stereotypic behaviors across his entire videotaped observation period, while Craig engaged in 30 behaviors.

The frequency of stereotypic engagement across the entire sample, based on the sub-type, prior to the onset of EI services is depicted in Figure 4. Although most participants engaged in a variety of sub-types, the most common form was vocal stereotypy with 108 occurrences observed across the entire sample, while the least common form was head stereotypy, with three occurrences observed.

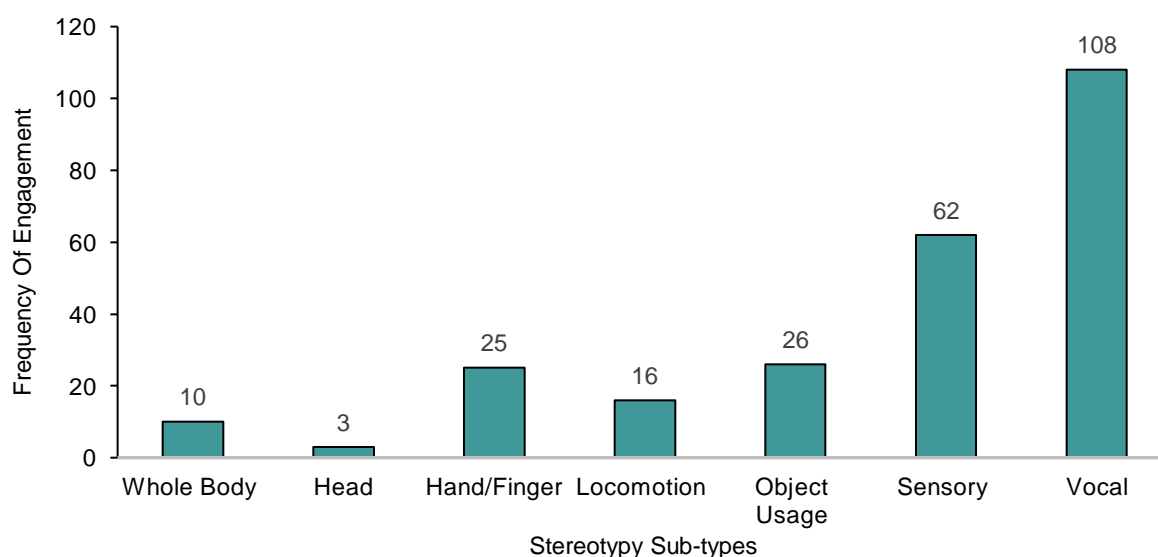


Figure 4. *Frequency of stereotypy sub-type engagement by all participants at baseline; prior to the onset of EI services.*

Stereotypy Between 10-s Intervals at Baseline

Participant's stereotypic behaviors observed between the 10-s intervals were recorded in order to gain a clearer understanding of whether they occur between the given time frame. Given that not all individuals engage in a specific behavior at exactly every 10 seconds, behaviors recorded between (or outside) of the 10-s intervals assist in providing a more thorough understanding of the results. Figure 5 provides a breakdown of the number of participants that engaged in at least one stereotypy sub-type, between the 10-s intervals, at baseline. Consistent with Figure 4, an examination of Figure 5 shows that vocal stereotypy was the most prominent stereotypy. A review of the results revealed that almost all participants (95%; 19 out of 20) engaged in vocal stereotypy, at least once, between the 10-s intervals. A closer examination of the results further revealed that between 40% to 60% of the sample also engaged in sensory, hand/finger, and locomotion stereotypy at least once during the 10-s intervals.

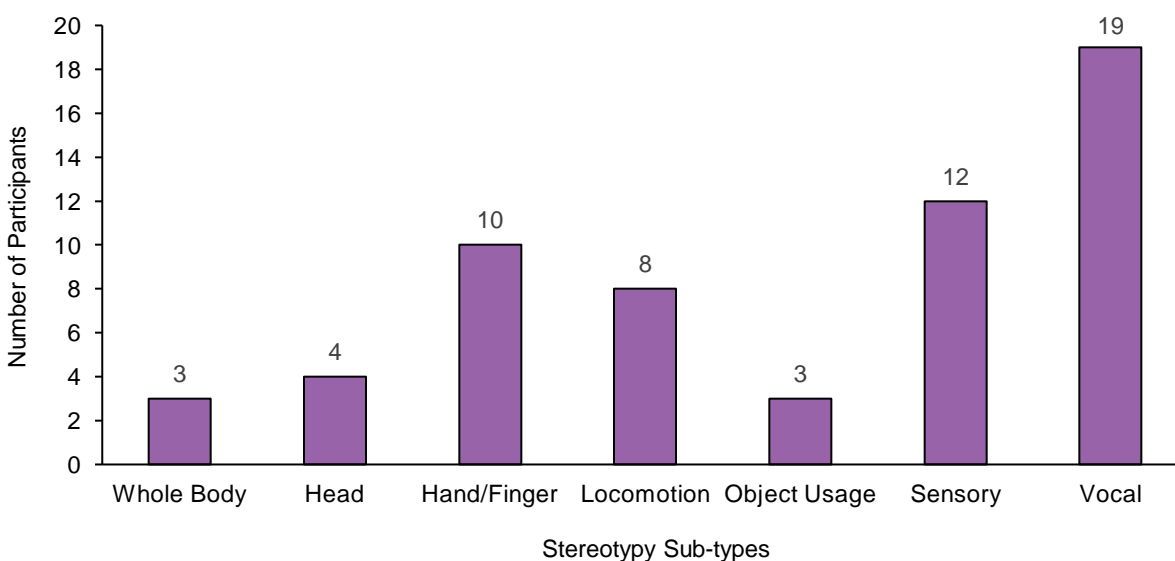


Figure 5. *Number of participants that engaged in at least one form of stereotypy sub-type between the 10-s intervals, at baseline; prior to the onset of EI services.*

Comparisons of Stereotypy Behaviors between Baseline and Post-Intervention Phases

Research Question 2: *Does stereotypic engagement change for children, with ASD, after*

receiving consistent (6-months to 2.5 years) early intervention services in the form of EIBI or a combination of the Carolina Curriculum and TEACCH models?

Figure 6 depicts the percentage of stereotypic behaviors each participant engaged in at baseline and again at post-intervention. A visual examination of the percentage of stereotypic behaviors provides a means by which to assess the rate of within-group change that occurred after participants received early intervention services (either EIBI or Carolina Curriculum and TEACCH).

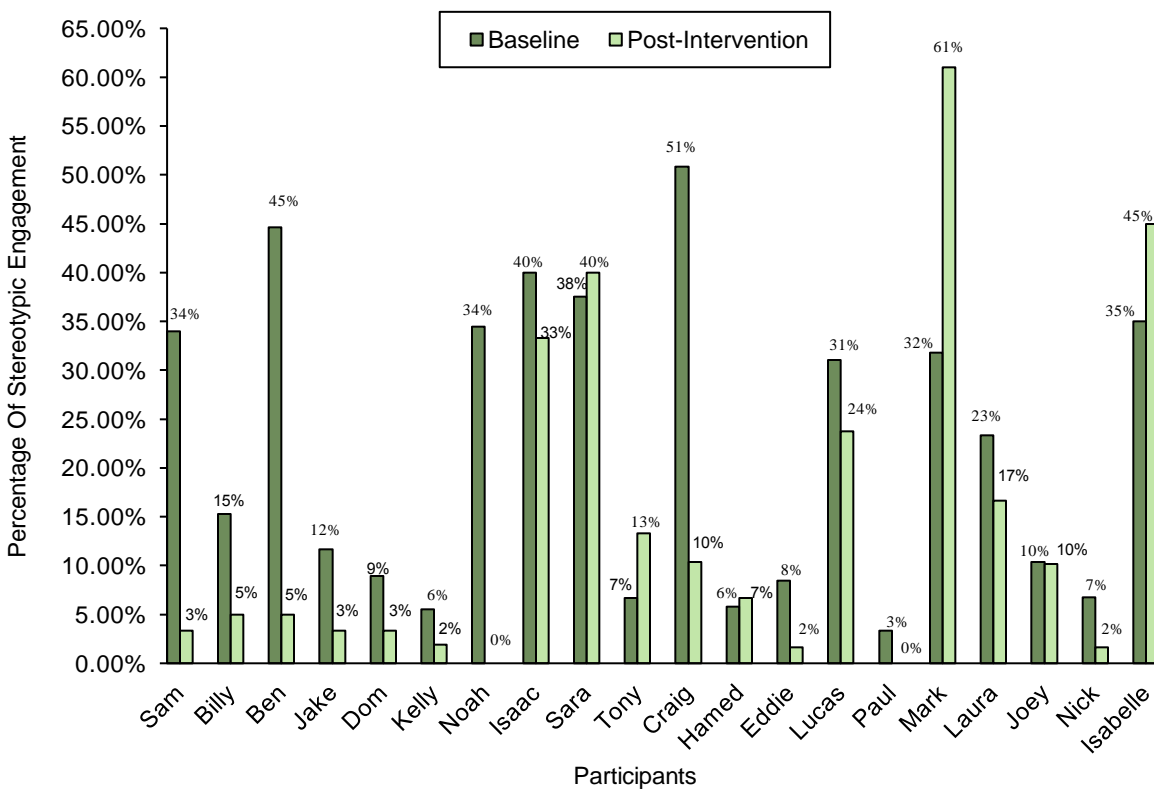


Figure 6. *Percentage of stereotypic behaviors each participant engaged in at baseline and at post-intervention; after two years or upon completion of EI, whichever came first.*

Preliminary results revealed that, on average, participants showed a reduction in their percentage of stereotypic behaviors at post-intervention. Group means reduced from 22.3% at baseline to 14.3% at post-intervention, resulting in an 8% group mean decrease in stereotypic behaviors. Results also revealed that 15, out of 20, participants showed reductions in stereotypic

engagement at post-intervention (see Figure 6). Decreases in stereotypy varied from ~1% to as high as 41%, with a sub-group mean decrease of 13.9%. Two participants (Noah and Paul) showed complete eliminations of stereotypic behaviors from baseline to post-intervention. Three participants (Sam, Ben, and Craig) showed the highest reductions from baseline to post-intervention; ranging from 31% to a 41% drop in stereotypic behaviors. Five participants (Sara, Tony, Hamed, Mark, and Isabelle) showed increases in stereotypic behaviors at post-intervention.

Sam, Billy, Ben, Jake, Dom, Kelly, Noah, Isaac, Sara, Tony, Lucas, Mark, Laura, Joey, and Isabelle all received EIBI. Out of the 15 participants, 11 showed reductions in stereotypic behaviors from a group mean of 24.7% at baseline to a group mean of 17.7% after receiving EIBI. A 7% group mean drop in stereotypic engagement occurred at post-intervention. As visible in Figure 6, the drop-in percentages varied for each participant. Stereotypy engagement dropped by 1% for some (such as Joey) and dropped as much as 40% for others (such as Ben). Noah was one of two participants who showed a complete elimination of behaviors at post-intervention and was one of the participants who received EIBI. Four out of the five participants that showed increases at post-intervention received EIBI.

The frequency of stereotypic engagement, per *sub-type*, was examined from baseline to post-intervention for participants who received EIBI. Results depicted in Figure 7 demonstrate that participants, as a whole, engaged in six out of the seven stereotypy sub-types and a total of 165 occurrences at baseline. At baseline, the group mean was 23.6% and the most common sub-type was vocal, sensory, and object usage. In contrast, at post-intervention participants who received EIBI engaged in a total of 144 behaviors at post-intervention and reduced their sub-type engagement by 3%; post-intervention group mean dropped to 20.6%. Participants also showed a

decrease in sensory, object usage, and hand/finger stereotypy. Increases were noted in vocal, locomotion, and whole body stereotypy. See Figure 7 on the following page.

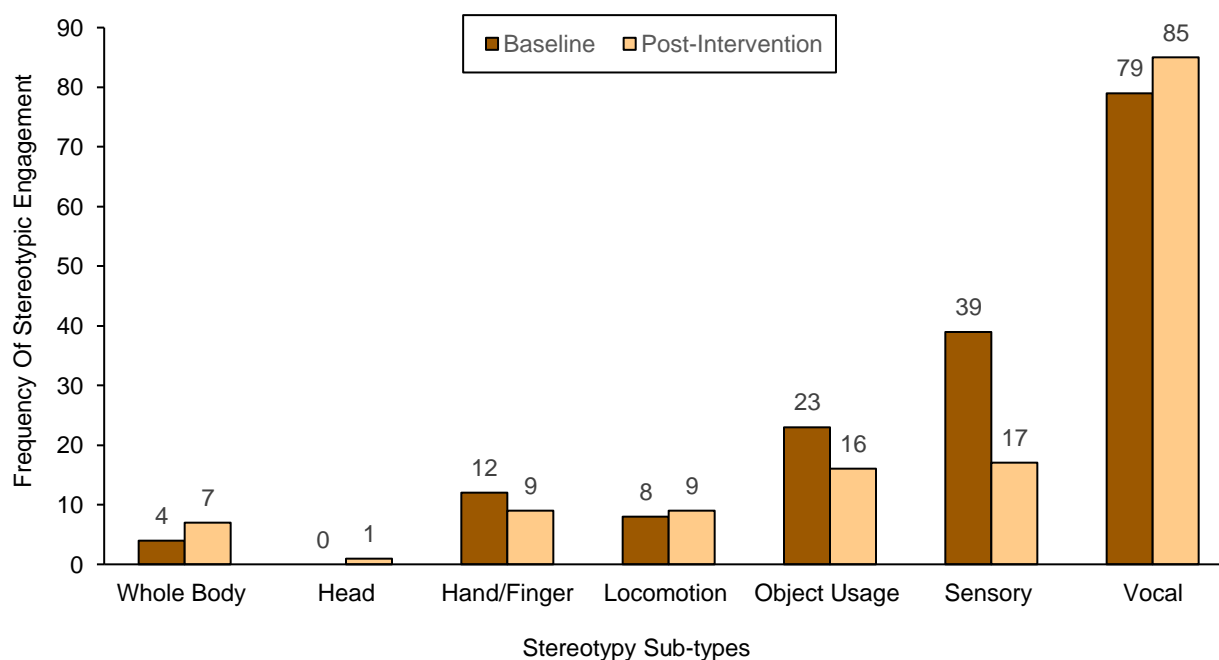


Figure 7. *Frequency of stereotypic engagement, based on sub-type, from baseline to post-intervention for participants who received EIBI services after two years or upon completion of EI, whichever came first.*

Stereotypy Between 10-s Intervals at Post-Intervention

Figure 8 provides a breakdown of the number of participants that engaged in at least one stereotypy sub-type, between the 10-s intervals, at baseline and again at post-intervention. The number of participants represents the entire sample group, regardless of early intervention services received. At baseline, the majority of the participants (19 out of 20) engaged in vocal stereotypy and between 40% to 60% engaged in sensory, hand/finger, and locomotion stereotypy, at least once, between the 10-s intervals. At post-intervention, participants reduced their engagement in almost all sub-types of stereotypy (excluding object usage). Less than 30% of the sample (9 out of 20) engaged in sensory and locomotion stereotypy after receiving early intervention. Moreover, apart from vocal stereotypy, fewer than 45% of the sample engaged in at

least one form of stereotypy, between the 10-s intervals, at post-intervention. See Figure 8 on the following page.

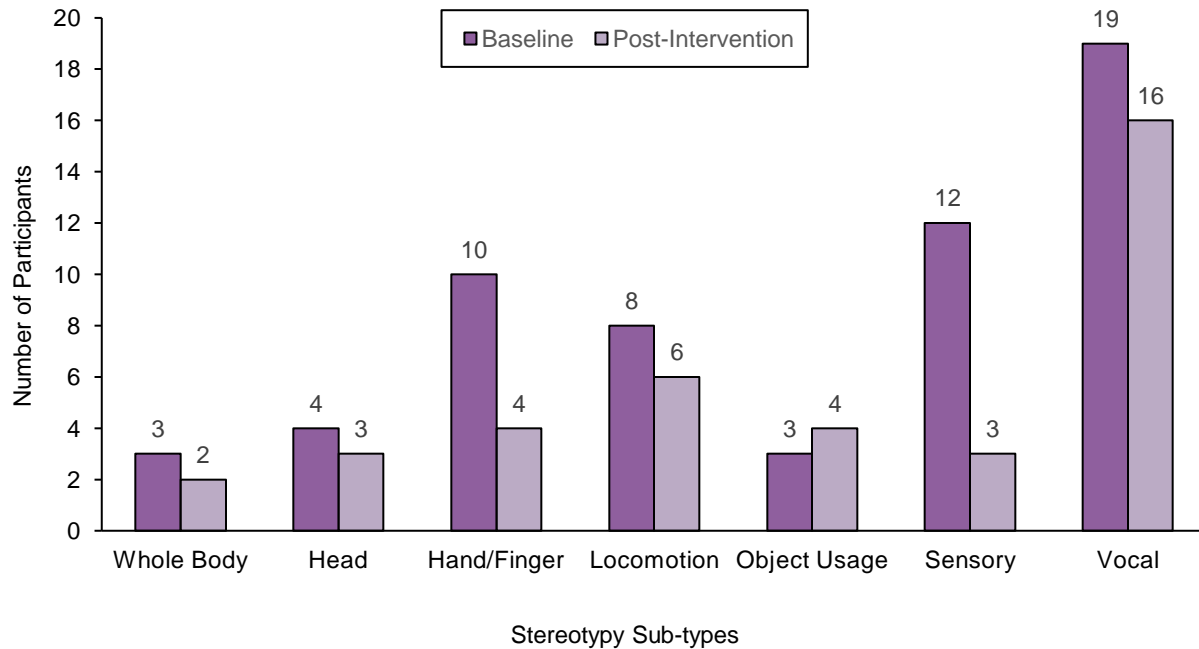


Figure 8. *Number of participants that engaged in at least one stereotypy sub-type between the 10-s intervals, at baseline (prior to the onset of EI) and post-intervention (after two years or upon completion of EI, whichever came first).*

Group Comparison: Stereotypy Behaviors between Baseline and Post-Intervention Phases

Research Question 3: *Does the rate of stereotypic engagement at post-intervention vary in children, with ASD based on the length of time in EI services (i.e., either EIBI or a combination of the Carolina Curriculum and TEACCH models)?*

Group comparisons based on length of EI treatment. Participants were divided and grouped into one of three categories based on the length of time they received EI services; from less than one year (4 participants), over one year (7 participants), and two or more years (9 participants). The length of time was gathered from the information provided by parents on the demographic questionnaire. The frequency of stereotypic behaviors, grouped by length of time in EI, from baseline to post-intervention are depicted in Figure 9 on the following page. A review

of the results revealed that as a group, participants who were in early intervention services (either EIBI or Carolina Curriculum and TEACCH) for less than one year (ranging from six months to 10 months; group mean of 8.25 months) or more than two years (ranging from two years and one month to three years and three months; group mean of 1.5 years) showed the most reductions in stereotypic behaviors from baseline to post-intervention. As a group, participants who received EI services over the course of one year (ranging from one year and one month to one year and 11 months; group mean of 2.4 years) showed the least amount of reductions in stereotypic behaviors from baseline to post-intervention.

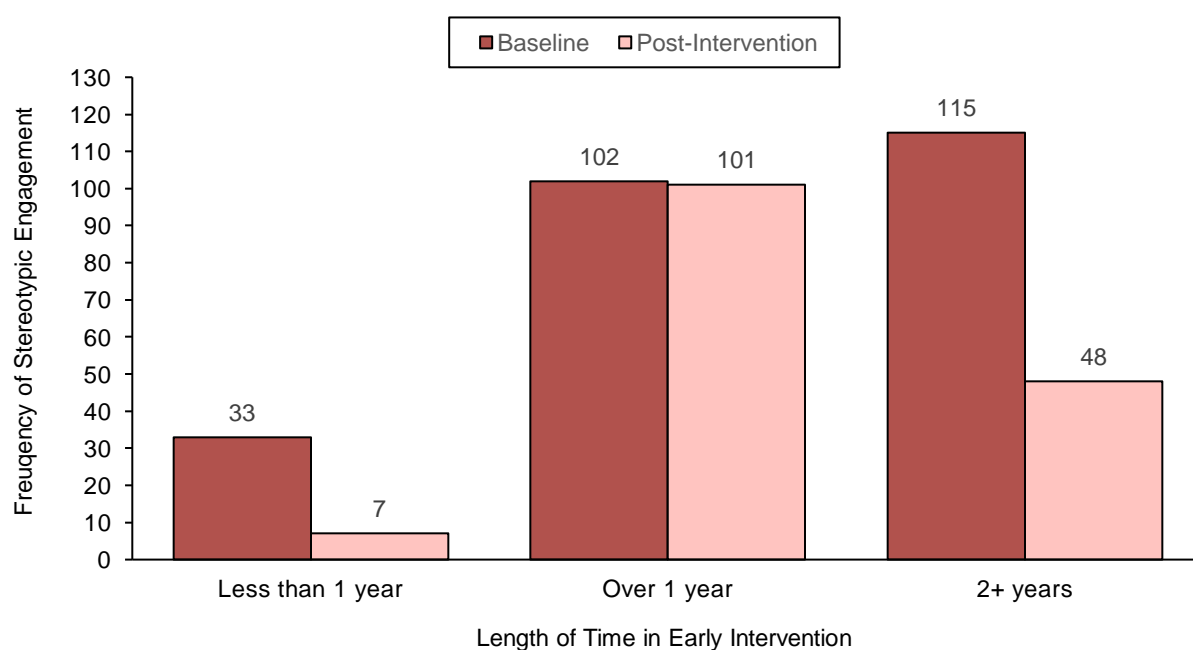


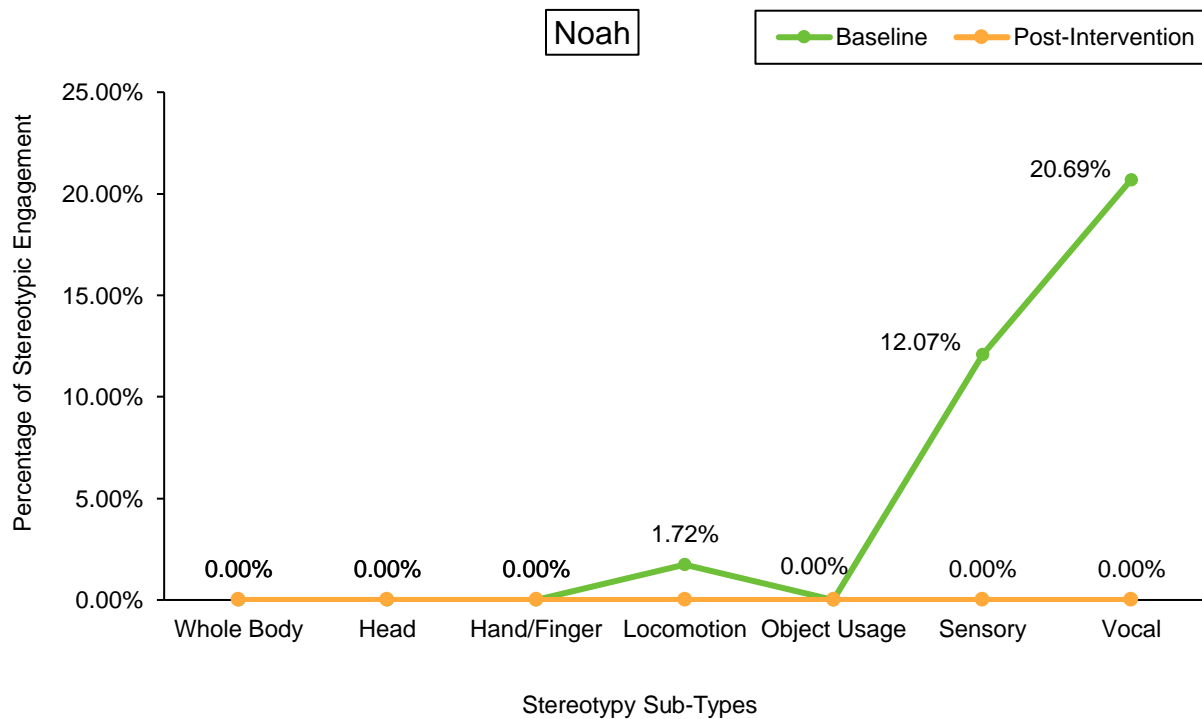
Figure 9. *Frequency of stereotypic engagement, from baseline to post-intervention, grouped by length of time in EI services receiving either EIBI or Carolina Curriculum and TEACCH for less than one year, over one year, or two or more years.*

Individual Participant Analyses from Baseline to Post-Intervention Phases

The following section will outline specific results of participants who showed the most reductions in stereotypy, as well as those who showed complete eliminations of stereotypic behaviors after receiving early intervention services. Additional demographic information is also

provided for each participant in order to a showcase how participants differed.

Complete elimination of stereotypy. Figure 10 depicted on the following two pages shows the results for Noah and Paul at baseline and after receiving EI services. Noah received EIBI services from *site two* over a three-year period. At baseline, he also received private ABA services that were separate from his EIBI therapy. He did not have any pre-existing medical or genetic conditions. During his first play session recorded in his baseline video, out of 60 intervals, Noah spent approximately 34% of his time engaged in stereotypic behaviors. He engaged most frequently in three different forms of stereotypy: vocal (21%), sensory (12%) and locomotion (2%). At follow up (i.e., post-intervention video), Noah spent 0% of his play session engaged in stereotypic behaviors. He did not engage in any forms of stereotypy, showing a complete elimination of behaviors. At post-intervention, Noah was also no longer receiving private ABA services.



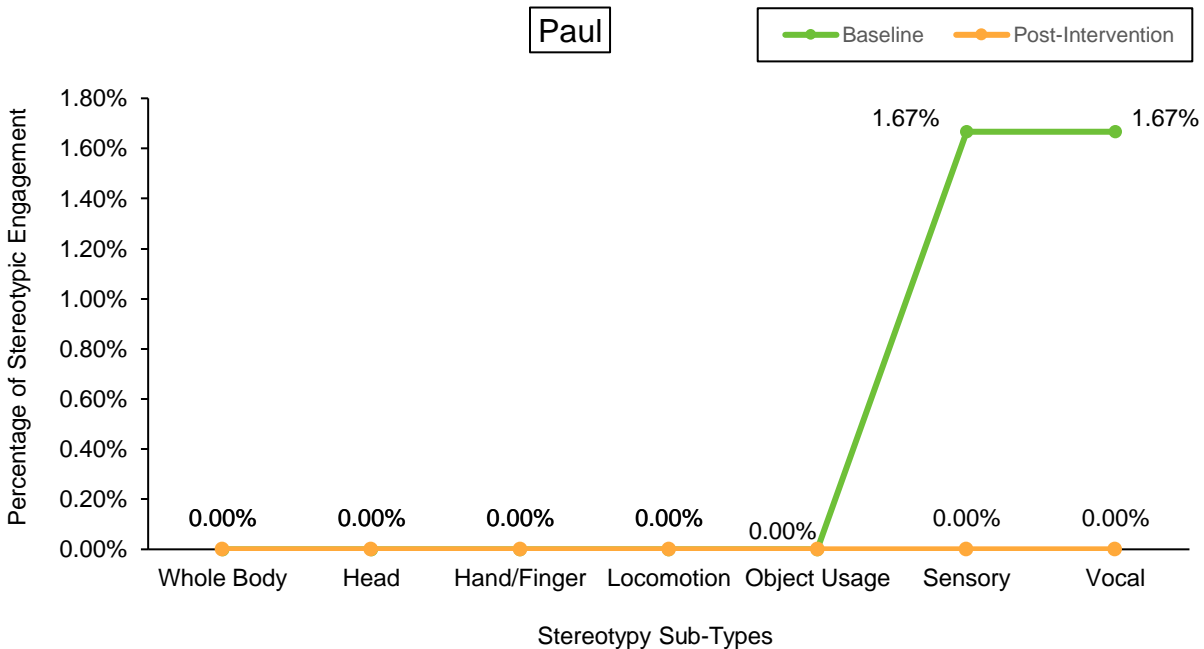
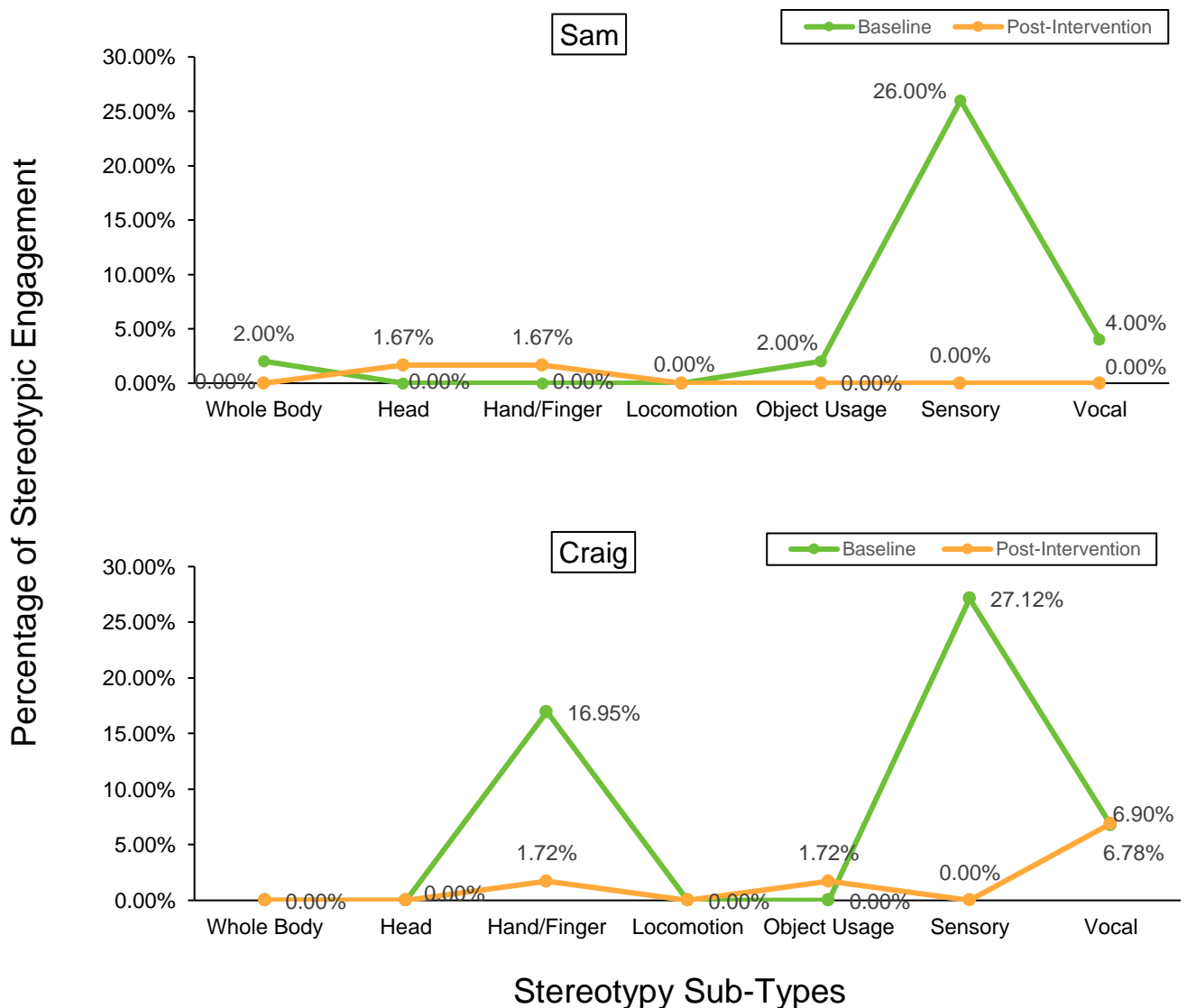


Figure 10. *Noah and Paul's percentage of stereotypic behaviors at baseline and again at post-interventions. Line graphs depict their complete elimination of behaviors after receiving EIBI or Carolina Curriculum & TEACCH across a two to three-year period.*

Paul received TEACCH and the Carolina Curriculum from *site three* over the course of almost three years (i.e., two years and 10 months). At baseline, Paul was not receiving any additional forms of early intervention. He did not have any pre-existing medical or genetic conditions. Prior to receiving EI, Paul spent approximately 3% of his first play session, recorded in his baseline video, engaged in stereotypic behaviors. He engaged most frequently in object usage (2%) and vocal stereotypy (2%). At his follow-up (i.e., post-intervention video), Paul spent 0% of his play session engaged in stereotypic behaviors. He did not engage in any forms of stereotypic behaviors and showed a complete elimination. At post-intervention, Paul was receiving private EI services in the form of osteopathy and ergotherapy.

Reductions and partial elimination of stereotypy sub-types. Figure 11, presented on the following two pages, shows the results for Sam, Craig, and Ben at baseline and after EI

services. Sam received EIBI services from *site one* over a two-year period. At baseline, Sam was also receiving private occupational therapy. He did not have any pre-existing medical or genetic conditions. During his first play session recorded in his baseline video, Sam spent 45% of his time engaged in sensory (26%), vocal (4%), object usage (2%), and whole body stereotypy (2%). During his second play session recorded in his post-intervention video, Sam showed a 31% reduction in stereotypic engagement. He showed a complete elimination of sensory stereotypy and moderate reductions in other forms with slight occurrences (1-2%) of head and hand/finger stereotypy. At post-intervention, Sam was no longer receiving occupational therapy.



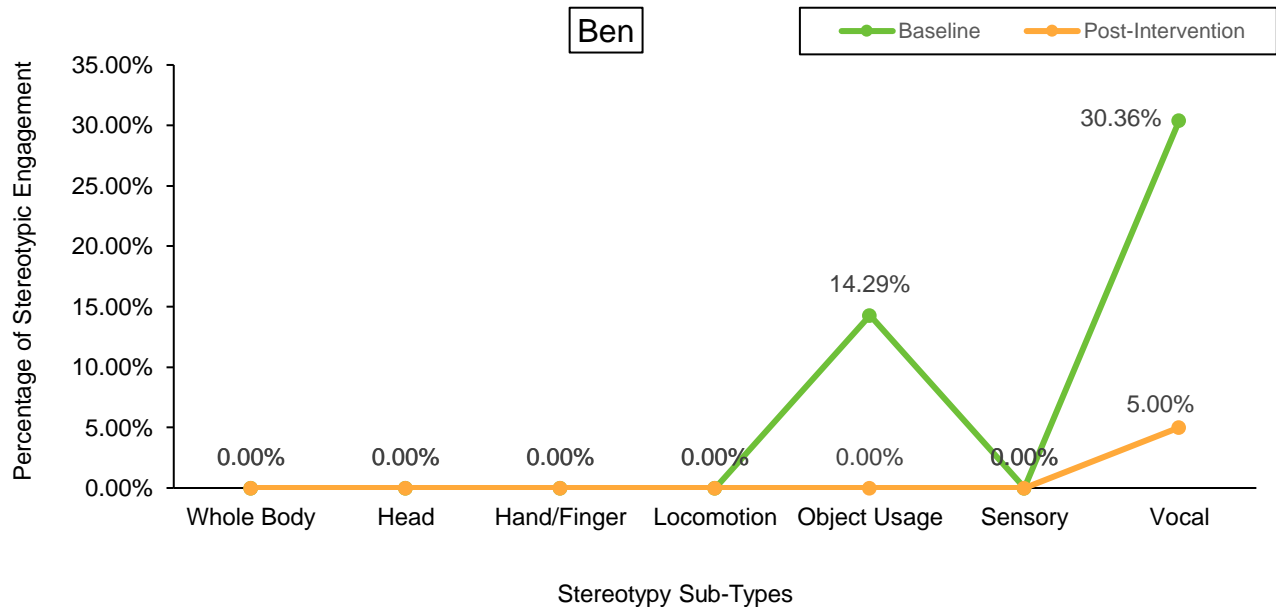


Figure 11. *Sam, Craig, and Ben's percentage of stereotypic behaviors from baseline to post-intervention. Line graphs depict participant's reduction and complete elimination (of some sub-types) of stereotypy after two to three years of early intervention services (EIBI or Carolina/TEACCH).*

Like Paul, Craig also received TEACCH and the Carolina Curriculum from *site three* over a two-year period. At baseline, he was receiving private ABA services. He did not have any pre-existing medical or genetic conditions. During his first play session, Craig spent 51% of his time engaged in stereotypic behaviors. Across the entire sample group at baseline, Craig demonstrated the highest percentage of stereotypic engagement. He divided his baseline play session between sensory (27%), hand/finger (17%), and vocal (7%) stereotypy. At post-intervention, Craig showed a 40% reduction in stereotypic engagement. Visually represented in Figure 11, his results show a complete elimination of sensory stereotypy and a 15% decrease in hand/finger stereotypy. At post-intervention, Craig was receiving private ergotherapy.

Ben received EIBI services from *site one* over the course of three years. At baseline, he was not receiving any additional forms of early intervention. He did not have any pre-existing

medical or genetic conditions. During his first play session (i.e., baseline), Ben spent approximately 45% of his time engaged in stereotypic behaviors. He engaged in 30% of vocal stereotypy and 14% of object usage stereotypy. At post-intervention, Ben showed a 39% reduction in stereotypic behaviors. The bottom of Figure 11, found on the previous page, highlights changes in Ben's behavior from baseline to post-intervention. After intervention, Ben showed a complete elimination of object usage stereotypy and a substantial 25% reduction of vocal stereotypy. Unlike Sam and Craig, at post-intervention, Ben did not engage in any new stereotypic behaviors. Ben was also the only participant of the subsample explored in this section, that did not receive additional EI services at baseline or at post-intervention.

In the following chapter, the author will provide a discussion of the results, followed by the contributions of the present study, the limitations, considerations for future research, and concluding remarks.

Chapter Five: Discussion and Conclusion

The objective of the current study was to examine stereotypic engagement in a sample of children, from Montreal, Quebec, diagnosed with ASD, in an attempt to understand changes in the engagement that may occur after the onset or completion of early intervention services. Using audio and video recordings, the rates (i.e., frequency) and types of stereotypes (i.e., diversity) that children engaged in were examined prior to the commencement of early intervention, in the form of either EIBI or a combination of the Carolina Curriculum and TEACCH models, and after (i.e., 6-months to 2.5 years) involvement in early intervention services had ceased, or upon the completion of two years of service, whichever occurred first. Changes in stereotypic engagement, based on the length of time children were in EI services was also examined. In the following sections, the results of the present study will be briefly discussed as they relate to findings outlined in the research literature. The strengths and limitations will be discussed, and implications and recommendations for future research will be outlined.

Stereotypic Engagement Prior to the Onset of EI Services

The first research question posed in this study queried the rates and types of stereotypic behaviors children with ASD, under the age of five, engage in. The present study found that across the entire sample, every single participant engaged in stereotypy prior to the commencement of early intervention services (i.e., baseline). An examination of the results further revealed that 85% of the sample engaged in two or more sub-types and 65% of the sample engaged in three or more stereotypy sub-types. Participants engaged most frequently in vocal, sensory, and hand/finger stereotypy. The findings of the first research question are consistent with previous results published in the literature. In previous studies, researchers have reported similar medium to high percentages of stereotypy in children with, or those at risk for,

ASD. For instance, Chebli et al. (2016), Goldman et al. (2008), McTiernan et al. (2011), and Mederios et al. (2013) reported a 57% to 99% prevalence of stereotypy in children with, or those at risk for, ASD. Consistent with the present research findings, previous researchers have also found that children tend to engage in one or more stereotypy subtypes. More specifically, Goldman and colleagues (2009) found that 70% of children, with ASD, engaged in at least one type of motor stereotypy. Harrop et al. (2014) and Chebli et al. (2016) found that in the absence of EI, children engaged most frequently in motor related stereotypy (i.e., object manipulation and hand stereotypy) and sensory stereotypy. Moreover, several researchers, including and not limited to Capone et al. (2005), Chowdhury et al. (2010), Fodstat et al. (2012) Hattier et al. (2013), Lanovaz and Sladeczek (2011), and MacDonald et al. (2007), have also reported the presence of vocal stereotypy in children with ASD; however, at lower occurrences (i.e., 48% median prevalence found across 40 studies; Chebli et al., 2016) than what was found in the present study (i.e., 108 occurrences observed across the sample, at baseline).

The medium to high overall percentages of stereotypy reported in the literature, and the 100% prevalence found at baseline as well as the high prevalence of vocal stereotypy found in the present study, could be explained, in part, to differences in methodological approaches and instruments used to observe and assess stereotypy. Informant-based questionnaires commonly used to examine stereotypy, such as *Diagnostic Assessment for the Severely Handicapped* (DASH-II; Matson, Smiroldo, & Hastings, 1998), the *Autism Diagnostic Interview-Revised* (ADI-R; Lord, Rutter, & Le Couteur, 1994), the *Aberrant Behaviour Checklist* (ABC; Aman et al., 1985), the RBS-R (Bodfish et al. 2000), and the *Behavior Problem Inventory* (BPI; Rojahn et al., 2001), rely on second-hand reports from parents, caregivers, and school personnel. Informant-based questionnaires are limited in so far as they rely on second-hand reports of

stereotypy, which can be misconstrued by an examinee's memory and biases and result in variable reports of stereotypic behaviors. Moreover, a sub category with items that specifically address vocal stereotypy is not included in the ABC, ADI-R, and the RBS-R. Thus, as Chebli and colleagues (2016) have suggested, results from previous studies where researchers have used the ABC, ADI-R, or RBS-R, may not represent complete and precise estimates of vocal stereotypy. Unlike, previous studies, the present study aimed to examine several types of stereotypy, including vocal stereotypy. The present study also used video recordings, which is one type of observational method that is commonly used to examine stereotypy in children in structured and unstructured environments (e.g., Boyd et al., 2010; Goldman et al., 2008; Harrop et al. 2014; Lanovaz, Sladeczek, & Rapp, 2012; Militerni et al., 2002). Observational methods allow researchers to directly observe, view, and record behaviors. Unlike informant-based questionnaires, researchers do not need to rely on memory to note the occurrence of a stereotypic behavior. Thus, the addition of an operational definition of vocal stereotypy and the use of video recordings in the present study may explain the high prevalence of vocal stereotypy found.

However, in light of these methodological considerations, it may be more plausible that the variability in stereotypy estimates (not based on sub-types) reported in the literature and the overall prevalence of stereotypy, including vocal stereotypy, found in the present study are a representation of participant differences rather than differences in methodological approaches. ASD affects every individual differently, meaning that individuals experience impairments in socialization, communication, and restricted interests and repetitive behaviors on a spectrum (APA, 2013). In the literature, it is commonly reported that stereotypic behaviors vary in occurrence, severity, and frequency and are thus highly variable within and across individuals (Lanovaz & Sladeczek, 2012; Patterson, Smith, & Jelen, 2010; Ventola et al., 2016). Consistent

with current knowledge, participants in the present study showed a wide range, rather than similarities in the percentages of engagement at baseline. As depicted in Figure 2, in chapter four, Paul spent 3% of his play session engaged in stereotypy, while Craig, for instance, spent 51%. Moreover, as depicted in Figure 3, participants also varied considerably in their vocal stereotypy engagement. For instance, Paul, Joey, Nick, Tony, and Kelly engaged in two to four occurrences of vocal stereotypy, while Ben, Isabelle, Isaac, and Noah engaged in eight to 17 occurrences.

Stereotypic Engagement After Receiving Early Intervention

The second and third research questions posed in this study sought to query whether stereotypic engagement changed for children with ASD, after receiving early intervention services, and whether rates of engagement varied based on the length of time in EI services. A review of the results indicated that all 20 participants showed changes in their stereotypic engagement at post-intervention. More specifically, 15 participants showed reduced stereotypic behaviors, from as little as ~1% to as high as 40% reductions with an 8% overall mean reduction, while five participants showed increases in stereotypic engagement. Out of the 15 participants who showed reductions, two participants showed complete eliminations of stereotypic behaviors at their post-intervention sessions. In terms of changes observed across the sample, vocal, locomotion, and whole body stereotypy were found to occur more frequently at post-intervention. Rates of engagement also appeared to vary based on the length of time each participant received EI services for. Participants who received up to one year of intervention or over two years (i.e., maximum of two and a half years) of intervention showed the greatest decreases in their stereotypic engagement at post-intervention.

The variability in the reductions, as well as the increase of stereotypy found in the present sample, are consistent with previous studies published in the literature that have reported mixed findings. More specifically, a review of the literature suggests that in general children's stereotypic engagement does change over time; with increases as well as decreases reported in the literature. Previous researchers have found that children with ASD tend to show considerable reductions and even complete eliminations of stereotypic behaviors after receiving TEACCH based EI programs that specifically target stereotypy (i.e., 5% to 10% reductions reported; Panerai et al., 2002; Probst et al., 2010; Sevin et al., 2015; Welterlin et al., 2012), EIBI programs that specifically targeted stereotypy (i.e., between 0% to 100% reductions reported; Ben-Itzhak & Zachor, 2007; Dawson et al., 2010; MacDonald, Parry-Cruwys et al., 2014; McGarrell et al., 2009), and EI programs that specifically utilized single or multiple reinforcement or consequence based intervention strategies to target stereotypy (i.e., such as DRI, DRA, and RIRD, ~36% to 100% reductions found; Mulligan et al., 2014).

However, previous researchers have also found that children with ASD show an increase in stereotypic behaviors in the absence of EI services and after receiving EI services, which was consistent with five participants in the present study (Dawson et al., 2010; Harrop et al., 2014; O'Connor & Healy, 2010). For instance, Harrop and colleagues (2014) found that children between the ages of two to four, with ASD who were not receiving any type of EI service, showed a 1-2% mean increase in stereotypic engagement and greater variability of stereotypic behaviors across a 13-month period. While Dawson and colleagues (2010) also found that children between one and a half to two and a half years of age who received EIBI over a two-year period showed on average a 2% increase in stereotypy from baseline behaviors.

The variability noted in the previous studies and in the variability and increases in stereotypic behaviors observed in the present study speak to the overall complexity of stereotypic behaviors. As discussed previously, variability in the prevalence of stereotypic engagement may be a reflection of the differences in ASD symptomology among individuals with autism. Taking this factor into consideration and that large variabilities were observed in the present sample prior to the onset of EI services (i.e., baseline), it is not unexpected that there were differences observed, among participants, in terms of the number of decreases and increases found in stereotypic engagement at post-intervention. However, based on the review of the literature and considerations of internal threats to the validity of pre-test/post-test designs, there are several alternative explanations to consider as to why reductions were variable across individuals, as well as why stereotypy increases were observed in a subset of the sample.

Researchers such as Lundqvist (2011) and others have noted that individuals engage in stereotypic behaviors for different reasons which may serve different functions (e.g., such as receiving some form of stimulation, to draw someone's attention, a form of communicating, or a way to avoid an unpleasant task; Lanovaz & Sladeczek, 2012; Lovaas et al., 1987; Rapp & Vollmer, 2005a; Rojahn & Meier, 2013) and in turn complicates our understanding of stereotypic behaviors and how stereotypy can be targeted in EI programs. According to the research literature, the function of stereotypy can be a response to and maintained by a combination of automatic positive reinforcement, social negative reinforcement, and positive social reinforcement (DiGennaro Reed et al., 2012; Lanovaz & Sladeczek, 2012; Rapp & Vollmer., 2005a; Rojahn & Meier, 2013; Sayers et al., 2011). However, Rapp and Lanovaz (2011) have noted that individuals will engage in stereotypic behaviors regardless of the environmental conditions they experience. Moreover, they note that the extent to which

individuals engage in multiple forms of stereotypy may also complicate EI services (Rapp & Lanovaz, 2011). As noted previously, over 85% of the sample in the present study engaged in two or more sub-types of stereotypic behaviors, at baseline, suggesting that the present sample demonstrated a complex range of behaviors, to begin with.

Moreover, regardless of the number of sub-types individuals engage in, addressing and eliminating stereotypic behaviors can be a difficult task for parents and clinicians unless stereotypy is specifically targeted (Lanovaz & Sladeczek, 2012; Rapp & Lanovaz, 2011). Rapp and Lanovaz (2011) explain this difficulty by indicating that "...the consequence that reinforces an individual's stereotypy cannot be directly manipulated...instead treatments focus on providing alternative sources of social and nonsocial reinforcement to compete with engagement in stereotypy" (p. 128). Parents and clinicians cannot physically stop the consequence (e.g., stimulation) that a child receives when they engage in stereotypy (e.g., such as when they clap their hands and receive physiological vibrations in response to the clapping). Thus, from a clinical standpoint, it can be difficult to compete with the automatic consequence that a child receives when they engage in stereotypy. The present study did not specifically target and manipulate stereotypy; workers at the early intervention sites utilized several reinforcement and consequence based interventions, such as DRI, DRA, FCT, and RIRD, to remedy stereotypic behaviors, challenging behaviors, deficits in socialization, communication, and other areas of development. The rise in stereotypic behaviors found in the five participants at post-intervention thus may have been a result of difficulties that may have arisen in attempting to mediate, rather than specifically target, stereotypic behaviors in the EI programs. For example, and as previously noted, several researchers have found that children with ASD show complete eliminations and considerable reductions in the percentage of stereotypic engagement after receiving EI programs

that specifically target stereotypy (e.g., Ben-Itzhak & Zachor, 2007; MacDonald et al., 2014; Mulligan et al., 2014; Probst et al., 2010; Sevin et al., 2015).

The present study used a pre-test/post-test within-group design to examine stereotypic behaviors in one sample of children with ASD prior to and after receiving EI. The use of a pre-test/post-test within-group design allows for researchers to examine behaviors prior to the onset of any type of intervention (Trochim, 2016), which permits for a greater analysis of individual changes in behavior upon or after an intervention has been provided. However, pre-test/post-test designs have some threats to internal validity (Campbell & Stanley, 1963; Cook & Campbell, 1979) that may, in turn, explain the increases in stereotypic engagement found in the five participants at post-intervention. For instance, increases in stereotypic engagement may be a reflection of *maturation*. As previously noted, researchers have found that children with ASD increase their stereotypic engagement, both in the absence of EI and after receiving early intervention services (Dawson et al., 2010; Harrop et al., 2014; O'Connor & Healy, 2010). Moreover, a review of studies on the prevalence of stereotypy across time suggests that stereotypy behaviors continue well into adolescence and adulthood (Bodfish et al., 2016; Chowdhury et al., 2010; Lundqvist, 2013; Mayes & Calhoun, 2011).

An additional factor that may explain the increases in stereotypic behaviors found at post-intervention is *history* or the events that do or do not occur between baseline and post-intervention that may influence changes in behavior (Campbell & Stanley, 1963; Cook & Campbell, 1979). Changes, or the lack thereof, in involvement in private EI services, may help to explain some of the increases found at post-intervention. As depicted in Table 4, in chapter three, eight participants were enrolled in EI services prior to the commencement of the study specific EI services. At post-intervention, three participants continued to receive services, while five new

participants were receiving some form of private services. Of the five participants that showed increases in stereotypic behaviors at post-intervention, Sara continued to receive private EI services at post-intervention and Hamed joined private EI services, while Tony, Mark, and Isabelle continued to not receive any type of private service. As depicted in Figure 6, in chapter four, Sara and Hamed showed the lowest percentages of increases at post-intervention (i.e., 1-2% increases), while Tony, Mark, and Isabelle showed the highest percentages of increases (i.e., 6% to 31% increases). Based on the differences in percentages, it may be argued that involvement in private EI services may have helped to mediate the increases in stereotypic behaviors observed in Sara and Hamed,

A review of the literature suggests that other child and program specific characteristics may also influence outcomes at post-intervention and thus could explain the increases in stereotypic behavior observed at post-intervention. For instance, Goldman et al. (2009), Harris and Handleman (2000), Reed et al. (2007), and Zachory and colleagues (2010) found that intelligence, age at onset of EI services, ASD symptom severity, and program characteristics (e.g., such as number of hours per week) were several factors that influenced child outcomes. However, in the present study, age at baseline did not vary considerably from one participant to another. More specifically, prior to the onset of EI services (i.e., baseline), 80% of the sample were between the ages of three to five, while 85% of the sample at post-intervention were between the ages of five to seven. The five participants that showed increases in stereotypic behaviors at post-intervention, also did not appear to vary considerably between age (i.e., between 6-months to less than one year age difference between participants). Hamed and Isabelle who were the two youngest participants (two years and five months and three years and 2 months) out of the five that showed increases in stereotypy at post-intervention varied

considerably in their percentage of engagement at baseline (i.e., as depicted in Figure 6 in chapter four, 6% engagement exhibited by Hamed and 35% engagement exhibited by Isabelle) and at again post-intervention (i.e., 7% by Hamed and 45% by Isabelle; demonstrating a 1% increase by Hamed compared to a 10% increase by Isabelle).

Increases in stereotypic engagement, at post-intervention, did not appear to vary based on the length of time each participant received EI services for; however, decreases in stereotypic engagement did appear to vary based on the length of time. Stereotypic reductions noted in the present study for participants who received less than one year of EI and more than two years are consistent with researchers who have noted that approximately two to three years of intervention is optimal to observe behavioral changes (Green, 1996; Lovaas et al., 1987). The reductions noted in the present study are also consistent with Ben-Itzhak and Zachary (2007) and Probst and colleagues (2010) who observed positive changes in ASD symptomology and reductions in stereotypic behavior after just two months, one year, and 14 months of intervention.

Limitations and Future Research

There are a couple of limitations to consider for the present study. The first limitation to consider is the use of convenience purposive sampling, a non-probability sampling technique, to recruit participants for the present study. More specifically, families of children with ASD were recruited by program directors from the early intervention sites. As a result, a limitation is the possibility of sample selection bias, otherwise referred to as sampling bias, which can undermine the external validity, or the generalizability, of a study. However, unlike studies that undertake convenience sampling with no specific recruitment parameters in mind, the present study acquired a purposive sample using several inclusion criteria, including that the child had to have a diagnosis of autism spectrum disorder (i.e., autistic disorder, Asperger disorder, or pervasive

developmental disorder-not otherwise specified; PDD-NOS), that the child had to be under the age of five, and that the child had to be receiving EI services from one of the three EI sites.

Researchers that employ an experimental group design use random selection and random assignment which in turn support the ability to generalize to a specific population and reduce the likelihood of confounding variables affecting an outcome (National Research Council, 2001, Richards, 1999). However, researchers note that experimental groups designs, recruitment of representative or a probability sample from the population, and random assignment are methodological approaches not often employed in studies with children with ASD due to the heterogeneity of the population and the ethical issues that can arise from assigning children into comparison or control groups whereby not all children receive intervention services (National Research Council, 2001).

It is recommended that future researchers use sampling methods that are appropriate to their individual study, appropriate and ethical to the population under examination, and reflective of their research questions. For future researchers who would like to examine changes in stereotypic behaviors in children with ASD, while using a control group, a viable alternative to experimental group designs is the use of a multiple baseline design. In a multiple baseline design researchers acquire baseline behaviors from all participants involved in the study (i.e., three or more participants or a small sample representative of a single-subject design; Morgan & Morgan, 2009; National Research Council, 2001) and an intervention is then given to the first participant, while the rest of the sample remains in the baseline phase (Morgan & Morgan, 2009; National Research Council, 2001; Richards, 1999). When changes are observed in the first participant, the intervention is then introduced to the second participant and the same process is followed until the last participant is reached. Thus, in a multiple baseline design study with two children with

ASD, for example, future researchers could have the second child serve as a control, while the first child receives the intervention. In using this type of design, researchers would be able to make cause and effect statements, observe the effectiveness of a particular intervention on stereotypic engagement, and observe changes within and between participants, thus yielding greater insights into stereotypic engagement prior to and after children receive early intervention.

The second limitation of to the present study is the low inter-observer agreement (IOA) found between both coders. However, researchers have noted that inter-rater reliability may be lower than expected in observational studies where behaviors are difficult to discriminate and in situations influenced by the *complexity* of an observational task, defined by the "...number of response categories of an observational system" (Gwet, 2014; Hartmann, 1977; Kazdin, 1977, p. 145). For instance, early researchers in the field found that observers who use a less complex category system of behaviors are more likely to show greater inter-observer agreement, compared to those who use a more complex category system (i.e., a four-category versus an eight-category system; Kazin, 1977; Mash & McElwee, 1974). With this in mind, past researchers have suggested that reliability estimates should be considered in relation to the complexity of the observational task (Kazdin, 1977).

For future studies where researchers examine a wide range of complex behaviors, such as stereotypy, it is recommended that researchers employ either the addition of a third observer, or multiple observers, whereby IOA scores can be pooled with one another (Gwet, 2014; Hartmann, 1977). As an alternative to the IOA calculation used in the present study, future researchers can use pooled scores of two or more observers and calculate inter-rater agreement using the Kappa coefficient, also known as Cohen's Kappa (Cohen, 1960, 1968; Watkins & Pacheco, 2000). An advantage of using Cohen's Kappa is that the calculation takes into account agreement between

two or more observers that is likely due to chance, thus yielding more precise estimates of agreement that are not likely due to chance based on a correlation coefficient of -1.00 to +1.00 (Watkins & Pacheco, 2000). The addition of a third observer in future studies can ensure the precision of inter-rater reliability and can help to limit any potential biases, (i.e., such as over and under reporting of behaviors), limit observer drift, and ensure agreement in the face of complex behavioral assessments (Gwet, 2014; Kazdin, 1977). Moreover, the use of Cohen's Kappa to calculate inter-observer agreement can assist future researchers in correctly identifying reliability between two or more observers not based on chance agreement.

Although the present study found a high prevalence of stereotypy and previous researchers have also reported high estimates of engagement, authors such as Harrop et al. (2014) and Richler et al. (2007) argue that stereotypic behaviors are still under researched, compared to other diagnostic features of ASD (i.e., socialization and communication). As the field of early intervention continues to grow and expand, it is highly recommended that future researchers continue to study stereotypy in children with ASD and continue to contribute to the knowledge base that currently exists. It is also recommended that future researchers use observational methods, rather than informant-based questionnaires, to examine stereotypy in children with ASD, as the former will provide a more clear and concise understanding not reliant on memory or second-hand reports. Finally, based on the high prevalence of vocal stereotypy found in the present study, at baseline and at post-intervention sessions, and the complete lack of vocal stereotypy representation in several commonly used research instruments (i.e., the ABC, ADI-R, and the RBS-R), it is recommended that in future studies researchers utilize instruments that are representative of various stereotypy sub-types and that authors design future instruments with vocal stereotypy in mind. By taking these recommendations into consideration and even

putting one recommendation into future practice, future researchers can contribute to the scientific knowledge base which in turn will help provide greater insights for other researchers, educators, and professionals working and conducting research in the field early intervention.

Implications and Conclusion

The present study was conducted in response to a review of the literature which indicated variable differences in stereotypic engagement in children with ASD prior to and after receiving early intervention services (such as early intensive behavioral intervention). The purpose of the present study, thus, was to better understand the extent to which children under the age of five with ASD engage in stereotypic behaviors and how engagement *potentially* changes after two years of intervention or upon the completion of early intervention services (i.e., early intensive behavioral intervention or a combination of the Carolina Curriculum and TEACCH based models) whichever occurred first. The purpose of the present study was also to understand how children's stereotypic engagement differed, based on the length of time in early intervention services. The 100% prevalence of stereotypy found in the present study is consistent with percentages found in past studies, indicating that stereotypy is highly prevalent in children with ASD.

The high prevalence of stereotypy in children with ASD is concerning given that engagement can impede social skills and social interactions (Reese et al., 2005; Sparapani et al., 2016; Wolery et al., 1985) and can produce negative educational outcomes by impacting skill acquisition in children (Dunlap et al., 1983). While engagement in stereotypy has also been found to contribute to stigma and stress in parents (Hayes & Watson, 2013). These negative implications highlight the need for effective early intervention programs that will specifically target stereotypy and provide children with the skills needed for successful development.

It's thus imperative that early intervention service provision workers, EI program developers, and new school psychologists are aware of the prevalence as well as the complexities of stereotypic behaviors. Rapp and Lanovaz (2011) have noted that not all interventions will be effective in reducing stereotypy and no single intervention will effectively reduce stereotypy for every individual. As previously discussed, Lanovaz and Sladeczek (2012) also note that certain stereotypic behaviors may be more difficult to treat; such as vocal stereotypy which was found to occur the most frequently at baseline and again at higher occurrences at post-intervention, in the present study (i.e., 79 and 85 occurrences, depicted in Figure 7 in chapter four). The findings from the present study can help inform and guide service providers and clinicians working in the field of early intervention. For example, the findings outlined in the present study may help motivate service providers to reflect on the extent to which their own EI programs do or do not target stereotypy and whether the same behavioral strategies are used to target all sub-types. In turn, this reflection may result in the modification and improvement of EI programs that children with ASD currently receive.

Based on Rapp and Lanovaz's (2011) "keys to remember", and in congruence with Guralnick's principles of early intervention, there are several recommendations that service provision workers may find helpful when planning and modifying EI programs for stereotypic behaviors. First and foremost, it is recommended that service providers identify and utilize early intervention programs that are evidence-based and family-centered, thus ensuring that guidelines for best practices are met and parents are involved in the planning and implementation of services (Guralnick, 2005; Kratochwill & Steele, 2004). When family-centered approaches are utilized children and parents benefit greatly; better child emotion regulation strategies, improvements in social and communication skills in children, and increases in parenting

satisfaction, and decreases in parental stress are observed (Blackman, 2002; Grindle et al., 2009; Hodgetts et al., 2013; Remington et al., 2007; Schertz & Odom, 2007).

It is also recommended that providers conduct a preference assessment to identify items and stimuli that will be effective tools for redirection and replacement during the intervention; if response interruption and direction is the chosen intervention strategy. Moreover, prior to the administration of the intervention, providers may wish to confirm that the stereotypic behavior observed from their client continues in the absence of social and non-social consequences, which will provide insight into the function of the behavior. Service provision workers thus need to understand their client's stereotypic behaviors, the goals of the client, and the environments that their clients spend the most time in when creating and implementing an intervention. After the implementation of the intervention, provision workers need to adequately document occurrences and frequencies of stereotypy before, during, and after the intervention to measure the extent to which the intervention reduces immediate and subsequent stereotypy. In terms of which behavioral strategies to employ, it is recommended that providers use empirically supported or empirically-sound behavioral strategies, such as differential reinforcement of alternative behaviors (DRA), differential reinforcement of incompatible behaviors (DRI), response interruption and redirection (RIRD), which were employed by the research sites in the present study and have garnered ample support in the literature (Kratochwill & Steele, 2004; Mulligan et al., 2014).

Apart from informing service provision workers and guiding practice, the findings from the present study can also help educate parents of children with ASD. For instance, according to recent studies, many parents report that they do not have enough information regarding their child's disability (Dillenburger et al., 2010; Osborne & Reed, 2008; Renty & Roeyers, 2006).

Parents also report that they want to receive more support, information, and services for their child with ASD (Bromley, Hare, Davison, & Emerson, 2004) and report difficulties in understanding services and obtaining services due to restrictive admission criteria and long wait times (Mulligan et al., 2012). The findings from the present study can meet the needs of parents and help inform those who are seeking information regarding intervention programs. More specifically, the present study can shed a light on particular EI programs and behavioral approaches utilized to combat stereotypy, which in turn can help parents make more informed decisions about the types of intervention services needed for their child.

Moreover, by providing families with more in-depth knowledge about ASD and EI services, specific to their child's needs, parents may be better equipped to seek out effective early intervention services for their child. This implication is of importance as researchers have found that when children receive EI during the first few years of infancy, they show more beneficial developmental outcomes in childhood (Barbaro & Dissanayake, 2009; Carpenter, 2005; Lovaas, 1987; O'Connor et al., 2010) as well as later in life; they are more likely to graduate high school, become active members of society, and substantially reduce economic costs by requiring less rehabilitative services in the future (Herrod, 2007; Saracino, 2011; Schweinhart et al., 1993).

Financial support provided to families of children with ASD vary from province to province. EI services for children with ASD can be time-sensitive and cost-intensive. EI programs that focus on the elimination of disruptive behaviors can cost more than \$50,000 dollars per child (Sharp et al., 2016; Williams, Riegel, Gibbons, & Field, 2007). By informing families of children with ASD of the present findings, this can not only help parents make more informed decisions, but it can also help reduce the overall cost that families currently spend on

alternative forms of interventions that may not specifically target stereotypy, which in turn can lead to greater cost-saving measures for families and less financial burdens to the economy (Chasson et al., 2007; Herrod, 2007). This is of particular importance given that researchers have found little to no empirical support for sensory integration therapy, for instance, which is a commonly used intervention in the field of occupational therapy to reduce stereotypic and sensory related behaviors (Lang et al., 2012).

In closing, this research study was conducted in an attempt to provide meaningful insight into an area of research, within in the field of ASD, that has often been noted as underrepresented and has shown mixed findings in the literature. Guralnick's developmental systems model was used as the theoretical framework to examine factors that influence and promote child outcomes. This study contributed to current knowledge by confirming that stereotypic behaviors are highly prevalent, highly variable and, for the majority of participants, appear to reduce over time (i.e., after two years of intervention or upon completion of services). Although stereotypes are not harmful on their own, engagement is negatively associated with unfavorable child and parent outcomes. Based on current knowledge, results of the present study, and clinical implications, several suggestions were made for future research and recommendations on how to specifically target stereotypy were outlined for service provision workers, early intervention program developers, and new school psychologists working in the field of early intervention. In closing, it is important to continue to conduct research on stereotypic engagement in children with autism spectrum disorder. In doing so, researchers can continue to uncover the complexities behind stereotypic behaviors which will hopefully lead to greater insights into the third core feature of ASD and provide valuable tools to inform clinical practice, which in turn can be used to improve the quality of life for children with ASD.

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Appendix A

Ethics Certificate

Appendix B

**QUESTIONNAIRE OF
SOCIODEMOGRAPHIC AND CLINICAL DATA**

Identification Number: _____ **Date of data collection:** _____
(dd-mm-yyyy)

CHILD PROFILE	
1.	Child's date of birth _____ (dd-mm-yyyy)
2.	Sex of child <input type="checkbox"/> Boy <input type="checkbox"/> Girl
3.	Chronological Age
4.	Child's first language <input type="checkbox"/> French <input type="checkbox"/> English <input type="checkbox"/> Other, specified: _____
5.	Ethnic group <input type="checkbox"/> White <input type="checkbox"/> Asian <input type="checkbox"/> Hispanic <input type="checkbox"/> Black <input type="checkbox"/> Indian (Native American) <input type="checkbox"/> Other, specified: _____
6a.	Does the child received a diagnosis? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Waiting
6b.	If so, what is the principal diagnosis of the child? <input type="checkbox"/> Autism <input type="checkbox"/> PDD not otherwise specified (NOS) <input type="checkbox"/> Asperger syndrome <input type="checkbox"/> Rett syndrome <input type="checkbox"/> Childhood disintegrative disorder <input type="checkbox"/> PDD with ID <input type="checkbox"/> PDD without ID <input type="checkbox"/> Other, specified: _____
6c.	Date of diagnosis _____ (dd-mm-yyyy)
7.	Does the child have a medical and/or genetic associated problem? <input type="checkbox"/> Yes, specified : _____ <input type="checkbox"/> No

8a.	In the last few months, has the child been following a special diet? <input type="checkbox"/> Yes <input type="checkbox"/> No			
8b.	If so, wich one? <input type="checkbox"/> Gluten free (flour, cereals) <input type="checkbox"/> Vitamins <input type="checkbox"/> Casein free (Dairy products) <input type="checkbox"/> Secretin free (hormone) <input type="checkbox"/> Gluten free / Casein free <input type="checkbox"/> Other(s), specify : _____ <input type="checkbox"/> Yeast free diet (Bakery)			
9a.	Other than those received at <u>(name of centre)</u> , has the child received other types of therapy or treatments? <input type="checkbox"/> Yes <input type="checkbox"/> No			
9b.	If the answer is yes, which type of treatments or therapies is it? (please specify the start and the end date, the number of hours and the weeks of frequentation for each establishments)	Start date (dd-mm-yyyy)	End date (dd-mm-yyyy)	Number of hours/week
	<input type="checkbox"/> TEACCH			
	<input type="checkbox"/> Private services, please specify : _____			
	<input type="checkbox"/> Other 1, please specify : _____			
	<input type="checkbox"/> Other 2, please specify : _____			
	<input type="checkbox"/> Other 3, please specify : _____			
10a.	Does the child frequent a childcare service or a school? <input type="checkbox"/> Yes <input type="checkbox"/> No			
10b.	If the answer is yes, which type of establishment is it? (please specify the start and the end date, the number of hours and the weeks of frequentation for each establishments)	Start date (dd-mm-yyyy)	End date (dd-mm-yyyy)	Number of hours/week
	Childcare services or other daycare <input type="checkbox"/> Regular <input type="checkbox"/> Special <input type="checkbox"/> Other, please specify : _____			
	Pre-kindergarten (4 years old) <input type="checkbox"/> Regular group			

<input type="checkbox"/> Special group in regular school <input type="checkbox"/> Special school <input type="checkbox"/> Other, please specify : _____			
Kindergarten (5 years old) <input type="checkbox"/> Regular group <input type="checkbox"/> Special group in regular school <input type="checkbox"/> Special school <input type="checkbox"/> Other, please specify : _____			
School 1 st year <input type="checkbox"/> Regular group <input type="checkbox"/> Special group in regular school <input type="checkbox"/> Special school <input type="checkbox"/> Other, please specify : _____			

SOCIODEMOGRAPHIC DATA (INFORMATION ABOUT THE PARENTS)

11.	What is your annual gross family income?	<input type="checkbox"/> Less than 10 000\$ <input type="checkbox"/> 10 000\$ à 29 999\$ <input type="checkbox"/> 30 000\$ à 49 999\$ <input type="checkbox"/> 50 000\$ à 69 999\$ <input type="checkbox"/> 70 000\$ à 89 999\$ <input type="checkbox"/> 90 000\$ and more
12.	Where is your place of birth?	Mother: _____ Father: _____
13.	What is the language spoken at home?	Mother: _____ Father: _____
14.	What is your level of education? Mother (last level completed)	<input type="checkbox"/> High School (unfinished) <input type="checkbox"/> High School (graduated) <input type="checkbox"/> College (CEGEP) <input type="checkbox"/> University (BA) <input type="checkbox"/> Graduate studies (Master's, PhD) <input type="checkbox"/> Other, specify : _____
	Father	<input type="checkbox"/> High School (unfinished) <input type="checkbox"/> High School (graduated) <input type="checkbox"/> College (CEGEP) <input type="checkbox"/> University (BA) <input type="checkbox"/> Graduate studies (Master's, PhD) <input type="checkbox"/> Other, specify : _____
15.	What is your current occupation? Mother	<input type="checkbox"/> Full-time employee <input type="checkbox"/> Part-time employee <input type="checkbox"/> Contract <input type="checkbox"/> At home

	<p style="text-align: right;">Father</p> <p><input type="checkbox"/> Other, Specify : _____</p> <p><input type="checkbox"/> Full-time employee</p> <p><input type="checkbox"/> Part-time employee</p> <p><input type="checkbox"/> Contract</p> <p><input type="checkbox"/> At home</p> <p><input type="checkbox"/> Other, Specify : _____</p>
16.	<p>Besides ____ (name of the child) ____ do you have other children?</p> <p>If so, does he/she (do they) have a diagnosis of autism or of another pervasive developmental disorder?</p> <p><input type="checkbox"/> Yes, Number of siblings: ____</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Yes, Number of siblings diagnosed : ____</p> <p><input type="checkbox"/> No</p>

EARLY INTERVENTION SERVICES

17.	Is the child receiving early intervention services	<input type="checkbox"/> Yes <input type="checkbox"/> No
18.	Starting date of early intervention services	<p>_____</p> <p style="text-align: center;">(dd-mm-yyyy)</p>
19.	Ending date of early intervention services	<p>_____</p> <p style="text-align: center;">(dd-mm-yyyy)</p>
20.	What kind of intervention is given by the parents?	<p>_____</p>
21.	Total number of hours given by the parents	
22.	Total number of weeks of services	
23.	Number of hours per week	
24.	Total number of hours of services	
25.	<p>Where early intervention services took generally place</p> <p><input type="checkbox"/> House</p> <p><input type="checkbox"/> Childcare services or other daycare</p> <p><input type="checkbox"/> Readaptation centre (WMRC or CRLD)</p> <p><input type="checkbox"/> School</p> <p><input type="checkbox"/> Abili-T Centre</p> <p><input type="checkbox"/> Trampoline Centre</p> <p><input type="checkbox"/> Others (specify): _____</p>	

26.	<div><div>_____ %</div>One on one instructions</div> <div><div>_____ %</div>Small group instructions (less than 5 children per adult)</div> <div><div>_____ %</div>Large group instructions (5 children and more per adult)</div>

Appendix C

Data Collection Sheet: ENGAGEMENT IN STEREOTYPY AND FUNCTIONAL PLAY

Child's code: _____

Date: _____

Sessions number: _____

Time start: _____

Minutes	Seconds					
	0	10	20	30	40	50
0						
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						

Percentages

A	B	C	D	E	F	G	H	At least 1

Stereotypy

(apparently purposeless [does not fit the context] movements or actions that are repeated [two or more times] in a similar manner)

- A. WHOLE BODY (Body rocking, Body swaying)
- B. HEAD (Rolls head, Nods head, Turns head)
- C. HAND/FINGER (Flaps hands, Wiggles or flicks fingers, Claps hands, Waves or shakes hand or arm, Rubs face)
- D. LOCOMOTION (Turns in circles, Whirls, Jumps, Bounces, Uses body to hit surfaces)
- E. OBJECT USAGE (Spins or twirls objects, Twiddles or slaps or throws objects, Lets objects fall out of hands, Uses objects to hit surfaces)
- F. SENSORY (Covers eyes, Looks closely or gazes at hands or objects, Covers ears, Smells or sniffs items, Rubs surfaces)
- G. VOCAL (Repeating words, grunting, snorting, making animal, laughing out of context, singing out of context and in a high and repetitive manner)
- H. FUNCTIONAL PLAY (use of play materials with their intended function)