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## A Triple-E Framework on Parental Involvement of Children with Autism Spectrum Disorder in Early Intervention

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### Abstract

Parents of children with autism spectrum disorder are often highly stressed due to the severity of the core deficits of social interaction, communication, and stereotypical behaviours of the disorder. Early identification, diagnosis, and intervention is crucial to remediate such deficits. Research has shown that parental involvement is important in the early years of the child development. Hence, it is important that parents work collaboratively with the professionals during the early intervention of the child. The main focus of this paper is on establishing a working framework for parents so that they are better informed how they can work best to help their children with autism. The author have proposed a triple-E model that comprises of *Enablement*, *Engagement*, and *Empowerment*. Each of the three main phases of the framework is briefly discussed.

**Keywords:** Parental Involvement, Parental Stress, Autism Spectrum Disorder, Early Intervention

### 1. Introduction

One of the most pressing problems among educators and parents in Singapore is the escalating number of children with developmental disorders such as autism spectrum disorder (ASD). The number of preschool children diagnosed with ASD is alarming. After a formal diagnosis from the psychologists, parents are recommended to enroll their children with ASD in early intervention centres (EIC) where their core deficits in autism would reap benefits from the various therapies received. However, the waiting list for children with ASD attending the early intervention programme is very long due to the increased prevalence of the disorder. In addition, the number of EIC, which are run by Voluntary Welfare Organizations (VWOs), is not enough to cater to the rising numbers of children diagnosed with ASD. Currently, there are 10 VWOs running 17 Early Intervention Programme for Infants and Children (EIPIC) in Singapore.

Parents whose child/children diagnosed with ASD often are at a loss and highly stressed when they know that their children has been diagnosed with the disorder. In Singapore, parents are often busy working to make a living and have not much time on their children's education. Parent training in ASD is often insufficient in Singapore. The Autism Resource Centre (ARC) run by a VWO, is training both parents and educators how to work with their children with ASD. How then can parents be actively involved in their children's learning journey? Hence, the author proposed a framework on parental involvement within an early intervention setting for children with ASD.

The intent of this paper is to propose a framework for parents with children with ASD so that they can be actively involved in their children's educational needs. With this framework, the author hopes that parents can be enabled (i.e., will not feel helpless) with the relevant knowledge to help their child/children with ASD. After parents are equipped with the knowledge, they are then engaged to work in close collaboration with the various allied health professionals (e.g., physiotherapists, occupational therapists, speech therapists, and psychologists) in EIPIC. When collaborative partnership is established, parents can then be empowered with the provision of skills, resources, opportunities, and motivation so that they can make decisions for their children.

### 2. What is Autism Spectrum Disorder?

According to the latest Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-V), Pervasive Developmental Disorders (PDD) is used as a collective term to include autistic disorder while Asperger's Syndrome, Fragile-X Syndrome, Rett's Syndrome, Childhood Disintegrative Disorder and PDD-Not Otherwise Specified (PDD-NOS) are the non-autistic

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PDD (American Psychiatric Association, 2013). In DSM-V, Asperger's Syndrome is no longer used to classify autism spectrum disorder.

Autism Spectrum Disorder is a neurological disorder characterized by a triad of impairments which usually include social interaction, communication, and repetitive and stereotyped patterns of behavior (Pierangelo & Giuliani, 2007) [38]. It refers to a continuum of disorders which includes Autistic Disorder, Asperger's Syndrome, Rett's Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified. The age onset of ASD appears usually within the first three years of the child and the prevailing characteristics will be more evident until the child reach toddlerhood (Pierangelo & Giuliani, 2007) [38]. Behaviours such as aggression, tantrums, and self-injury are not in the diagnostic criteria for ASD, rather they are secondary symptoms that develop when primary symptoms are not addressed (Koegel, Koegel, Ashbaugh, & Bradshaw, 2014) [22].

### 3. Prevalence

The number of children diagnosed with ASD in Singapore is increasing steadily. There is no exact number of the prevalence of ASD reported locally. According to a recent article by Neik, Lee, Low, Chia and Chua (2014) on the prevalence of ASD, it was reported that the first overview study about children with ASD was conducted in 2001 (Bernard-Opitz, Kwook, & Sapuan, 2001) [8]. The authors also reported that there is no official records of the total number of young children with ASD from both the Singapore Ministries and local autism website. Health records from 2003 to 2004 indicated that ASD is the most common clinical development diagnosis among young children from government hospitals (Lian *et al.*, 2012) [26].

### 4. Diagnosis and Treatment

When parents suspect their child/children manifesting traits of autism, they can send their child for an initial screening to any Singapore government hospitals. The clinical diagnosis of ASD in Singapore is performed by pediatricians and child psychology departments in private or national hospitals. When a child has been diagnosed with ASD, psychologists will make referrals for parents to consider enrolling their child to early intervention centres where therapy and educational services are available.

In Singapore, the government has provided more places in the Early Intervention Programme for Infants and Children (EIPIC). EIPIC has expanded its capacity by 40%, from 1350 EIPIC places in 2006 to 1900 in October 2011. With this expansion, the number of EIPIC centres also increased from 9 in 2006 to 17 in 2015. With more children being diagnosed with ASD, the government has also set up another 7 new EIPIC centres within the next few years to meet the projected demand for 2700 places (Ministry of Social and Family Development, 2015) [30].

### 5. Early Intervention

Early intervention (EI) is a term that refers to a broad spectrum of activities that are designed to enhance a child's development, usually from birth to age six. EI usually commences with a comprehensive screening of the child's and the family's strengths, challenges, and needs (Ramey & Ramey, 1998) [39]. The early years of a child's life are recognized as being crucial to the development of various skills such as motor (gross motor and fine motor), adaptive (dressing and undressing, and feeding), cognitive,

communication, and social. EI can minimise the effects of the disabilities or risk, and maximise the child's development, thereby enhancing his potential for independence in adulthood (Bailey, *et al.*, 2006; National Research Council, 2001) [4, 31]. It is also crucial in that children's learning opportunities and development can be enhanced during the first three years of life (Ramey & Ramey, 1998) [39]. The same authors also suggested that children's learning outcomes have improved when the EI programs are intensive and systematic with parents being the active partners in their children's developmental progress. If children with ASD are intervene before the age of 5, there will be improvement in outcomes. For example, evidence suggest that children diagnosed with autism who are completely non-verbal and begin early intervention in their early pre-school years were more likely to become verbal than children who begin intervention over the age of 5-years (Koegel, 2000) [21]. The importance of starting intervention early is also further supported other researchers (Landa, 2007; Reichow, 2012; Rogers, 1996) [24, 40, 41]. If parents adopted a "wait-and-see attitude" to enrol their child for EI, there will be a negative impact on children with ASD (National Research Council, 2001) [31]. Thus, EI aims to address the core deficits of ASD (i.e., impairments in social, communication, and limited play skills) that may prevent secondary symptoms (e.g., aggression, tantrums, and self-injury behaviours) and reduce the need for more substantial and expensive interventions in children's later life (Koegel *et al.*, 2014) [22].

Parents needs to be aware that early intervention (EI) is different from early childhood education as its focus is on family-centered services. EI focusses on individually planned educational programs and specialized teaching approaches that caters to the needs of the children with the partnership from parents. The aim of EI is its focus on early developmental skills that are precursors for current and later school success (Odom & Wolery, 2003) [33].

When a child has been diagnosed with autism, parents are often helpless and lost. The following questions may ring in their head: "How can I help my child?" What is best for my child?" and "Where can I find help?" How does parenting a child with ASD differ from a child who is typically developing?

### 6. Parenting a Child with ASD

It is never easy to parent children, let alone one with autism. Parents have to face many challenges and stress as they have to deal with their children social-emotional and behavioral problems. There have since been a plethora of studies in the past examining parental stress of children with ASD (Baker-Ericzen, Brookman-Fraze, & Stahmer, 2005; Brobst, Clopton, & Hendrick, 2009; Hastings, Kovshoff, Brown, Ward, Espinosa, & Reminton, 2005; Ornstein Davis & Carter, 2008; Tehee, Honan, & Hevey, 2009) [5, 9, 17, 35, 42]. Results had shown that parents of children with ASD generally reported higher level of parenting stress than parents with typically developing children (Tomanik, Harris, & Hawkins, 2004) [43] and Down's syndrome (Dabrowska & Pisula, 2010) [11].

There were also studies conducted to ascertain which parent has higher stress when they have children with ASD. Mixed results were found when mothers and fathers stress levels of children with ASD were compared. In three studies conducted, it was found that parents' stress levels were similar (Hastings, 2003; Hastings, *et al.*, 2005; Ornstein Davis & Carter, 2008) [15, 17, 35] while others reported that mothers had higher levels of stress than fathers (Dabrowska & Pisula,

2010; Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006; Olsson & Hwang, 2001; Tehee, *et al.*, 2009) [11, 18, 34, 42]. None of the studies reported that mothers experienced lower stress levels than fathers of children with ASD. Though fathers of children with ASD experienced lower total stress scores than mothers, two studies found that fathers experienced higher stress levels when compared to fathers of typically children (Herring *et al.*, 2006) [18] and children with other disabilities (Olsson & Hwang, 2001) [34]. However, Dabrowska and Pisula (2010) [11] found contrasting results in that parents' gender did not indicate any differences in stress levels when compared to children with Down syndrome and typically developing children. Children receiving intervention services may not benefit when parents are highly stressed. Results have shown that the effectiveness of early intervention is reduced when parents' stress levels are high (Osborne, McHugh, Saunders, & Reed, 2008) [36].

There are many factors that can cause high parental stress when rearing a child with ASD. The following subsections briefly discusses a few sources of stress that parents encountered when raising children with autism.

### 7. Child's Behavioral Problems

For many years, debates had been going if it is the core symptoms of autism (i.e., deficits in social, communication, restricted play skills, or behavior problems) of the children that contribute to high levels of parental stress. Many studies found that children behavioral problems were strongly associated to high parenting stress (Beck, Hastings, & Daley 2004; Lecavalier, Leone, & Wiltz 2006; Konstantareas & Papageorgiou, 2006; Tomanik, Harris & Hawkins, 2004) [7, 25, 23, 43]. Lecavalier *et al.* (2006) [25] studied ratings of parents and teachers of young participants with ASD using a correlational design. Results indicated that behavioral problems such defiance, disobedience and aggression were more associated with stress as compared to any other child or caregiver characteristics. In another study by Hasting (2002), a strong and positive relationship was found between parental stress and behavior problems of children with ASD. Children behavior problems, but not severity of ASD symptoms and adaptive behavior, were a strong predictor to maternal stress. There was no significant relationship of paternal stress to the children behavior problems. However, paternal stress was found to be related to their partners' depression. Similar results using correlational design were found in a study by Tomanik *et al.* (2004) [43] who found that 40 out of 60 mothers experienced high stress levels and was significantly related to their children aberrant and adaptive behavior levels. For example, children who had limited social and communication skills posed a significant source of stress for their mothers. Maternal stress was also related to the child's adaptive daily living skills such as dressing, undressing, and feeding skills.

### 8. Child's Social Interaction

Besides behavioral problems, relationship between social interaction and parenting stress was also studied by researchers. Baker-Ericzen *et al.* (2005) [5] found mothers' stress were significantly associated to the level of social skills in children with ASD as compared to typically developing children in an inclusive toddler school program. However, this significant relationship was not found for fathers. Identical findings was also supported by Ornstein Davis and Carter (2008) [35] who found that parental stress was associated with child's characteristics. Parents were highly stressed with their children social skills impairment and parent-child relationship

problems. For example, mothers were more stressed when their children had problems in self-regulation skills such as emotional regulation, sleeping, and eating while fathers found externalizing behaviors such as temper tantrums more stressful than mothers.

### 9. Child's Autism Severity

Another source of high parenting stress has been found in the autism severity of the child. This may include high intensity stereotypical and repetitive behavior, social-emotional problems, self-injurious behavior, and presence of seizures. A study was done by Konstantareas and Papageorgiou (2006) [23] to investigate the effects of child temperament, symptom severity, verbal ability and level of functioning on maternal stress with mothers of children with ASD. Results showed that mothers were more distressed when interacting with their children who were non-verbal than those who were verbal. Child characteristics such as low cognitive ability, engagement in severe ritualistic behaviors and social-emotional problems also contributed to elevated stress levels in mothers.

### 10. A Framework of Parental Involvement

A framework on parental involvement for children with ASD in early intervention from 2 to 7 years of age is proposed by the author (see Figure 1 below). This framework comprises of three phases: (1) parent enablement, (2) parent engagement, and (3) parent empowerment. Each of the phases is briefly discussed below.

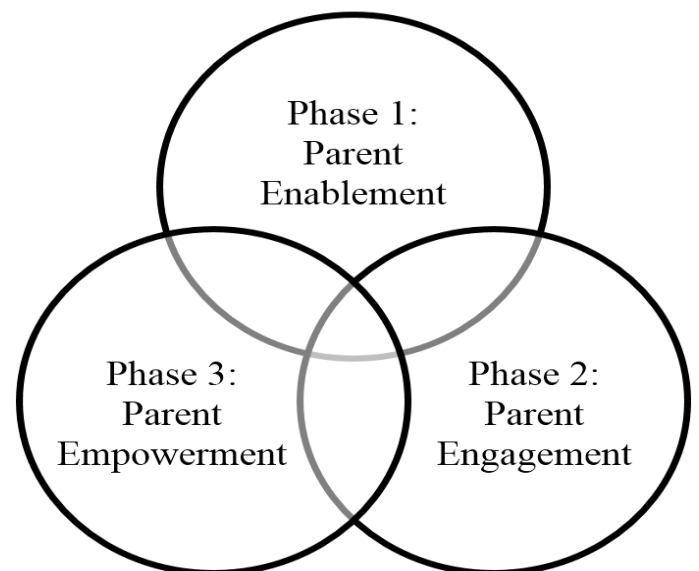


Fig 1: Proposed Triple-E Framework on Parental Involvement of Children with ASD

#### Phase 1: Parent Enablement

The term "Enablement" refers to any approaches which provide the necessary means or opportunities. When a child has been diagnosed with autism, parents find it hard to accept the reality of the diagnosis. They are usually at a loss on who and how to seek help from. Under this circumstances, parents need to be equipped with the relevant information and resources on autism for their child such as (1) the place to enroll after the confirmed diagnosis of ASD, (2) the educational path of the child (either admission into the mainstream or special school education), and (3) available support provided. According to Tehee *et al.* (2009) [42], parents feel a sense of hopelessness when they do not have enough information provided by schools or support systems.

In Singapore, the ARC provides a wide range of services which include assessment and diagnosis, therapy services, early intervention, training and consultancy, and many more. ARC is the only special school in Singapore with mainstream curriculum for children with ASD. However, a psychological assessment to assess the child's intelligence level is necessary to gain admission into Pathlight School. Other vocational schools like Eden School has curriculum such as functional academics in literacy and numeracy. Another track is the vocational skills where individuals with ASD can seek open employment in the area of baking, housekeeping, IT, and general office skills. The Ministry of Education in Singapore has provided a booklet to guide parents on how to choose the right school for children with special needs (refer to <http://www.moe.gov.sg/education/special-education/files/parents-guide-children-special-educational-needs.pdf> for more information).

Besides EIPIC, another source of support that parents can get is from hospitals. Parents may wish to participate in the Caring and Sharing Parents Ever Resilient (CASPER) Parent Support Group which consists of a group of parents whose children are on the follow-up at Kandang Kerbau Women's and Children's Hospital-Department of Child Development. CASPER aims to bring parents together to care for and share with one another in their journey in parenting their children with autism.

Parents are encouraged to visit the Raising Children Network website to access comprehensive information about child development and parenting by clicking on the Special Needs tab, followed by Children with Autism to get valuable information about ASD. Parents may also like to visit ARC's website to know more about the various programs that may be helpful for their child (refer to <http://autism.org.sg/resources/lonks.php>). A strong support network for autism in the community has also allowed many parents to seek assistance from specific autism centres such as ARC where clinical assessment and diagnosis are provided. Some of these facilities offer subsidies for diagnosis and treatment to affected families too (ARC, 2013).

Parents need to know that not all children with ASD are the same. Each individual is unique and has his/her own preferences, learning style, strengths, and challenges. While there are different interventions to ASD (e.g., Applied Behaviour Analysis, Treatment and Education of Autistic and Related Communication-Handicapped Children, occupational therapy, speech and language therapy), parents need to be aware that there is no one-size-fits-all approach to treatment. Interventions should be specifically planned by professionals, together with parental input to cater to an individual's strengths and learning and/or behavioural challenges.

Some parents who lack knowledge on autism resorted to complimentary and/or alternative treatment as they heard that such treatments are effective or can even "cure" autism. These include, but not limited to, diet therapy (e.g., gluten free-casein free diet), vitamin supplement, psychotropic treatment (medication), chelation therapy, herbal treatment, and homeopathy. As ASD is a lifelong developmental disorder, there is no cure for ASD currently. Simply to find a cure to the disorder with the hope to eradicate the characteristics of ASD is unrealistic. A recent newspaper article by Chua (2015) advised parents who opted complementary and/or alternative medicine, such as a special diet or vitamin-supplement treatment, should seek professional advice. A qualified doctor should also be consulted on any possible adverse side effects should interventions involve psychotropic treatment.

## Phase 2: Parent Engagement

The term "*Engagement*" indicates a shared and continuous responsibility for students' achievement and learning that occurs across multiple settings. In other words, parent engagement is a collaborative partnership between school members and parents where they undertake all activities that can help their children achieve their learning outcomes. Thus, parents' engagement can be defined as parents and school staff working closely together to support and improve the learning, development, and health of children (Epstein, 2011)<sup>[13]</sup>. This engagement is a shared responsibility in which schools and other community agencies and organizations are committed to reaching out to engage parents in meaningful ways, and parents are committed to actively supporting their children's and adolescents' learning and development (Epstein, 2011)<sup>[13]</sup>. This relationship between schools and parents cuts across and reinforces children's learning in different settings - at home, in school, and the community. Engagement is different from involvement in that the focus of *involvement* is that the school/teacher is driving the outcome. Engagement encompasses parents to be active partners so that they can share information and provide feedback of their child, share decision making, and determination of learning goals.

According to Epstein (2011)<sup>[13]</sup>, schools can engaged parents with the following six areas:

1. Provision of parenting support
2. Communication with parents
3. Provision of volunteer opportunities
4. Supporting learning at home
5. Encourage decision making
6. Collaboration with the community

### 11. Provision of Parenting Support

Elevated stress may lead parents to seek social support when parenting children with ASD. According to Boyd (2002), mothers who generally received support from their husbands were reported to have lower levels of stress and depression and were much happier with their marriages when they have children with ASD. Active fathers' involvement in their children may help to alleviate maternal stress. As Osborne and Carter (2008) reported that the effectiveness of the intervention outcomes would be affected by higher levels of parenting stress, it is important to encourage fathers to actively participate and involve in their children. When fathers' involvement in school and at home is increased, it may help to ease mothers' workload, thereby reducing maternal stress and increase family bonding. Apart from spousal support, other support from extended families and friends was also useful for mothers who found they had lower stress levels. In addition, sources of formal support are equally important as well. Mothers find it beneficial when they joined the parent support group where they can freely discuss their problems and experiences with other parents of children with identical disabilities. In this way, their stress levels are buffered through sharing and discussion in the parent support group.

Whilst majority of the studies emphasized that rearing children with ASD is a stressful experience, there were also studies that mentioned about the positive experiences of parenting children with ASD. A study by Kayfitz, Gragg and Orr (2010) found that mothers of children with ASD reported having more positive experiences than fathers. They had positive perceptions which include better acceptance of life tragic events, had bigger circle of friends, and more sensitive

towards people with disabilities. This is further supported by Hasting, Beck, and Hill (2005) <sup>[16]</sup> and Hastings *et al.* (2005) <sup>[17]</sup> where mothers' perceptions were more positive of their children disability than fathers when they are younger and these experiences remain stable when their children become older.

## 12. Communication with Parents

Clear communication channels between parents and school staff should be established as this allows opportunities to discuss on the child's learning outcomes. The communication should be a two-way communications (school-to-home and vice versa) so that teachers can obtain valuable feedback from parents on how the children are generalizing their learning and parents can also receive teaching resources and/or strategies from teachers to improve child's learning outcome. The constant communication among parents and all the allied health professionals are crucial so that the relevant persons working with the child is aware on how best to help the child to achieve his/her learning needs. For example, teachers can provide valuable information to parents on how their child perform in preschool settings during a school visit. During the visit, preschool teachers can address their concerns and also enlist help from early intervention teacher on how best to help the child. In this way, a working partnership can be fostered between teachers and the ultimate aim is to help the parents who is working with the child at home.

Communication should not be limited to a yearly or bi-annually parent-teacher-conferences (PTC) and it can take many forms. A variety of communication methods can be used such as phone calls, emails, home visits, parent-teacher-conferences, and even face-to-face conversations with teachers when parents pick their children from school. Parents should provide open lines of communication to receive comments and suggestions from teachers on their child's learning outcomes.

Alternatively, early intervention teachers can conduct home visits to and understand more about the parents' concerns on their child's learning outcomes/challenges, and/or behaviours. Teachers can suggest intervention strategies for parents to work with the child at home (e.g., setting up a learning corner for the child). Differences in perspectives may also hinder communication between parents and educators. A survey of school-family relationships indicted that "there is a real need for training teachers about how to relate to parents" (Margaritoiu & Eftimie, 2011, p. 46) <sup>[27]</sup> and that teachers and parents have different perceptions of barriers to parental involvement. The survey to teachers and families found that school teachers felt parental involvement was low due to a lack of parent responsibility, indifference, low educational levels of parent, attitudes of superiority, fear of confrontation with the teacher, or health problems. Answering the same question, parents cited lack of time being the main reason for low involvement, lack of confidence in the school system, hostile attitude of the school staff, large number of family members, lack of information available, and health problems. With these differing perceptions, it is not surprising that effective communication can be established. Only when this barrier of communication is removed, the learning outcome of the children can be achieved with effective teacher-parent partnership.

Finally, it should be noted that successful intervention programs need ongoing communication between parents and teachers. Mutual understanding from each other perspectives will allow a two-way communication where teachers can help parents by providing teaching resources/strategies required to

teach skills at home and parents providing feedback on the remediation techniques being taught at home (Abel, 2012) <sup>[1]</sup>.

## 13. Provision of Volunteer Opportunities

Schools should encouraged parents to take up volunteering work during special events such as Teacher's Day, Children's Day, and some festival celebration. Such volunteering work allows parents to understand their child better. For example, parents can know if their child can generalize their learning in multiple settings and the problems the child might face. Increasing volunteerism can also establish bonding among other parents and their own children. It can also provide another form of social support when views can be shared on issues such as parenting children with ASD.

A survey study conducted by Miedel and Reynolds (1999) <sup>[29]</sup> on parents and interviewed teachers at an early intervention program for at-risk preschoolers. Results found a strong relationship between a parent's involvement in school activities, reading achievement, and the child's possibility of being retained in a special education classroom. It can be concluded that the more activities the parents were involved in, the less likely their child was to be retained in special education. The activities parents involved were helping on field trips and in the classroom, attending school meetings and parent-teacher conferences, and allowing a home visit by the teacher. Thus, when the rate of parent involvement is high, this signaled that the volunteering work program is successful. It is important that schools encourage parents to be involved in volunteering work. However, schools should also be find out why parents find it hard to volunteer. It could be that parents may not know what volunteer opportunities are available, lack of time may not have time to volunteer due to younger children at home, or may work during school hours, (Margaritoiu & Eftimie, 2011) <sup>[27]</sup>.

## 14. Supporting Learning at Home

One way to help and engage parents is to offer a Home Instruction Program (HIP). The HIP actually extends the school-based programme where parents can implement to their children at home prior to the coaching by the school health professionals (e.g., occupational therapist or speech therapist). For example, parents can be taught by a qualified occupational therapist to provide deep pressure massage to a child with autism who has sensory needs. Both school members and parents have to work hand in hand so that sharing and feedback are closely communicated on the outcomes of the HIP. According to Ozonoff and Cathcart (1998) <sup>[37]</sup>, the use of HIP with TEACCH model on children with ASD, it was found that the children improved in their imitation, fine and gross motor, and cognition skills. Other studies have also shown the impact of parental involvement on early intervention programs conducted in homes (Dillenburger *et al.*, 2004; Ozonoff & Cathcart, 1998) <sup>[12, 37]</sup>.

## 15. Encourage Decision Making

In terms of a child's specific Individualized Education Plan (IEP), parents are encouraged to participate at all levels. At the beginning of each school year, parents are invited to attend the PTC with the EIPIC team members. The aim of the PTC is held to review how the present level of performance with the input from the various allied health professionals. After the review, the next move is to develop new learning goals that are to be implemented as the year progresses. Parents' input is important and any additions and/or concerns that might have regarding their child's learning goals can be discussed and developed in the IEP with all authorized signatories.

There may be occasions that parents may not agree with the team members in terms of the child's IEP. When this occurs, it is important to encourage open lines of communication between parents and team members, actively listening to one another's views. It must also be noted that parents are the most important advocate for their child and team members must respect parents' final decision. After all, both parties have to compromise and work to meet the needs of the child.

When the child has reached the age of six, parents may require help from schools on the future educational pathway. In order to ensure a seamless transition to post-EIPIC services, some EIPIC centres offer talks for parents whose children with ASD are about to complete the program. Information such as where to go for psychological assessment for school placement, choice, programmes and services of various special education schools, mainstream school curriculum, and application for special education schools. During the talks, parents' concerns and/or enquiries can be answered by the EIPIC staff with the hope of assisting decision making for their child for the next transition.

### 16. Collaboration with the Community

Partnership with other organisations can be fostered to parents and professionals in the early intervention setting (e.g., general or special education teachers, therapists, social workers, psychologists) through workshops, seminars, and courses. Utilizing collaborative partnerships, educators from EIPIC centres can be encouraged to attend training on ASD to increase their knowledge and skills on how to teach children with autism. A fundamental course in ASD conducted by ARC is regularly held for parents or educators to gain an overall knowledge of autism. To progress further to teach children with ASD, participants may wish to take up a Certificate in Autism where intervention strategies will be taught during the course.

EIPIC centres can coordinate information, resources, and services from social service agencies, universities, and other community groups that can be beneficial to children and families. In this way, centres can help parents obtain useful information and resources from these community and provide parents quick accessibility to community programs, services, and resources. Knowing such information can also allow parents to be involved in volunteering work in the community, should there be any.

### Phase 3: Parents' Empowerment

There are many different definitions of empowerment in the literature review, but the most commonly cited definition states that empowerment is "an intentional, ongoing process ... through which people lacking an equal share of valued resources gains greater access to and control over those resources" (Cornell Empowerment Group, 1989, p. 2). On the contrary, the opposite end of the spectrum is unempowerment which encompasses the stress, frustration, and hopelessness that can pervade the lives of caregivers (i.e., parents) for individuals with developmental disabilities (Koegel, Brookman, & Koegel, 2003).

Increasingly, empowerment is being understood as a process of change (Cornell Empowerment Group, 1989). McClelland (1975) has suggested that in order for people to take power, they need to gain information about themselves and their environment and be willing to identify and work with others for change. In a similar vein, Whitmore (1988) defines empowerment as: an interactive process through which people experience personal and social change, enabling them to take

action to achieve influence over the organizations and institutions which affect their lives and the communities in which they live (Whitmore, 1988, p.13).

Research has found a relationship between improvement in children's outcomes and parent empowerment. A small-scale study conducted by Koegel, Brookman, and Koegel (2003) demonstrated an association between child improvement and parent empowerment through collaborative partnerships between parents and professionals using Pivotal Response Training (PRT). In PRT, parents are involved in the treatment of their child with ASD by providing them an empirically supported set of procedures to increase their child's motivation to participate in social-communicative and play interactions. Results found that parents whose children made significant gains tended to exhibit increased level of empowerment (Koegel *et al.*, 2003).

One way to look at parent empowerment is to examine the effectiveness of parent training programs. Bickman, Heflinger, Northrup, Sonnichsen, and Schilling (1998) evaluated the effects of a training program designed to enhance the empowerment of caregivers of children receiving mental health services. The training program was designed to enhance: (a) knowledge of the service system, (b) skills needed to interact with the mental health system, and (c) the caregiver's sense of self-efficacy in participating in a collaborative relationship with service providers. In this study, 250 parents were randomly assigned to a treatment group, which received the training curriculum. The participants were assessed using self-report questionnaires at a follow-up period of 12 months. The results of this study indicated that empowerment training was effective in increasing parent's sense of self-efficacy in working with mental health services.

Another study by Kaminski, Valle, Filene, and Boyle (2008) to examine the effectiveness of training programs for parents of children with problem behaviors found that parents were more involved in their children's social interaction, cognitive, and academic skills. The authors reviewed 77 published evaluations of parent training programs and found such programs have a positive effect on parenting behavior and the impact on the behavior of their children. In another conducted by McConachie and Diggle (2006) [28] found that parent-implemented intervention programs for children with autism and parent training is effective as children demonstrated improvement in children's social communication skills, behaviours, and better parent-child interactions.

### 17. Conclusions

The basic supposition of early intervention lies in families. Families and homes are the primary nurturing contexts for children with learning disabilities. The need to promote family involvement is a critical element of successful early intervention. There is an urgent need to shift towards a family-centred practice model, where the family's needs, priorities and available resources are considered in planning for the school programme. This encompasses affirming the family's competence and participation as equal partners, involving the family in decision-making and providing support for their decisions, and assessing potential family stressors. Family-centred approach also acknowledges the importance of the family's interaction patterns in improving the child's development, emphasizing the importance of fostering a partnership with the working staff in the early intervention setting. Besides understanding the family's needs and providing them with the right information, parents should also be empowered to make informed decisions about priorities

and intervention strategies through a partnership with professionals and service providers. In this way, the family's strengths and competencies will be harnessed to help both the child and the family.

By proposing a triple-E framework on parental involvement of children with autism spectrum disorder in the early intervention setting, the author hopes that parents can be active partners who work closely with both the professionals in the early intervention and the child. With this triad partnership among the parents, professionals and the child, only then can learning of the child be generalize across different settings so that the fullest potential of the child be realized and finally integrate into the community. This framework may also provide allied health professionals (psychologists, therapists, teachers, and social workers) how best to enable, engage, and empower parents whose children are diagnosed with ASD.

## 18. References

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