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Author(s)	Norman Kee Kiak Nam
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Retrospective Insights on Teaching Literacy by Parents to their child with Autism

Norman Kee Kiak Nam, BSc, MTech, MEd
Early Childhood & Special Needs Education
National Institute of Education
Nanyang Technological University, Singapore

Abstract

Parents of children with autism spectrum disorders (ASD) are confronted and confounded by the multiple and varied types of evidenced-based interventions as well as complementary therapies (Goin-Kochel, Mackintosh & Myers, 2009) which they have to select, adopt and invest resources to support their child. Many claimed efficacy of through publications in peer-reviewed and non peer reviewed research literature on condition that the principles and devices of intervention are faithfully followed through. However, most if not all, did not include the holistic perspective of considering the need of the caregiver parent sense of coherence (Antonovsky, 1987; Mccubbin, Thompson, Thompson & Fromer, 1998) and perceived self-efficacy (Bandura, 1997) to reinforce and maintain the benefits of whatever interventions that has been adopted by the various organizations. The current paper provides retrospective insights by the researcher parent who has children with ASD on tacit learning, supported by research literature that may empower parents to be effective mediators of their child's learning of literacy that is sustainable and permanent.

Introduction

Generally parents of children with ASD are stressed (Tobing & Glenwick, 2006; Montes, & Halterman, 2007; Zaidman-Zait, et al., 2010) by their child's inappropriate behavior (Osborne, & Reed, 2009; Phetrasuwan, & Miles, 2009). A common characteristic of children with ASD are their obsession and demands to work with objects or activities that are of their interest repeatedly for extended periods of time or reacting from inordinate fears of known and unknown causes in the environment (Chia, Kee & Shaifudin, 2010; Kee & Loh, 2009, Mesibov, Shea & Kopler, 2004). Many are worn out and perplexed by their child's behavior that they desperately seek help and solutions from whomever and whatever that promises instant cure/help from their challenging circumstances (Shaw, 2008). Some are challenged with depletion of their savings and resources (Goin-Kochel, Mackintosh & Myers, 2009). Children with autism spectrum disorder (ASD) are often observed to be left alone to play with objects of their obsession or interest for extended periods of time at home. Parents could gainfully use those times to develop their literacy, which is essential for schooling and functioning in mainstream society (Mcguinness, 1997). The author researcher will examine retrospectively as parent of children with ASD of insights on what works that are supported by peer-reviewed research literature, to support parents teaching literacy to their child with ASD.

Sense of Coherence

Many parents may be so stressed and worn out by their child with ASD inappropriate behavior that they could not see themselves endowed with energy and perceived self-efficacy to teach literacy and other skills as with parents with typically developing children. Aaron Antonovsky (1987), a medical sociologist, was curious as to why some people, in spite of very trying, stressful and overwhelming circumstances (e.g. holocaust, women's menopause, death of spouse) still emerge mentally strong and functions well in society. He considers this a salutogenesis question. His thesis from his research findings arrived at the common denominator that all had strong sense of coherence (SOC). Antonovsky defines SOC as:

“a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement” (Antonovsky, 1987, p. 19).

His salutogenesis question addressed by SOC has been studied and published in 33 languages in 32 countries in at least 458 peer-reviewed journal papers (Eriksson & Lindstrom, 2005) over the past 30 years (Hittner & Swickert, 2010; Honkinen, et al., 2009; Eriksson & Linstrom, 2007; Klepp, Mastekaasa, Sorenson, Sandanger & Kleiner, 2007). Mak, Ho and Law (2007) found mothers of children with autism in Hong Kong with strong sense of coherence to perceive lower stress than their counterparts even when their children have more severe autistic symptoms.

Essentially, Antonovsky advocates development towards good mental health qualities of comprehensibility, manageability and meaningfulness. The meaning and implications are unpacked through retrospective insights for teaching literacy.

How should parents comprehend ASD? (Comprehensibility component of SOC)

ASD is neurodevelopmental disorder (Chia, 2008; Shea, & Schopler, 2004). This implies that ASD affects normal development of the nervous system of the body. This normally leads to “unusual, repetitive, or severely limited activities and interest” (Pierangelo & Giuliani, 2007), such that they fail to develop joint attention needed for social communication (Rocha, Schreibman, & Stahmer, 2007). Parents can compensate or circumvent the impacted nervous capability by providing opportunities through scaffolding and engaging their child in modes of learning where there is no impairment to promote similar development seen in typical children. For example, most children with ASD are good visual learners, whereas typical children are taught mainly using auditory modality. Parents can make use of principles and techniques involved in Picture Exchange Communication System (PECS) (Bondy & Frost, 2002) to initiate the development of communication, necessary for development of literacy. My second and third sons who were initially non-verbal when they were below four years of age, developed some speech and literacy from using PECS. PECS, an evidence-based and mainstream approach (Yoder & Stone, 2006), bridges the learning of communication from visual pictures to verbal

language and literacy for my children. Children with ASD do not have impairments in understanding physical causality (Baron-Cohen, Frith & Leslie, 1986). They can therefore understand cause and effect constructs, such as appreciating that pressing buttons of lifts causes lift doors to open or playing video games (Kee, 2010).

Our understanding of cultural artifacts such as language is learnt by association of “hearing those noises as they accompany actual situations in life” (Hayakawa & Hayakawa, 1990, p. 36). “The map is not the territory” (Hayakawa & Hayakawa, 1990, p. 19). The acquisition of language usage is constructed through multiple sociocultural interactions of parents, teachers, peers and the community in defining the type of learning interaction occurring between subjects and their environment (Kozulin, 2002). These interactions are lacking in children with autism and needs to be facilitated for learning of language. (Kee, in-press). Parents thus need to be persistent and continually make explicit the diction and meaning of words through their interactions with the child. The child with ASD is expected with repeated exposure and familiarity of hearing those words and associating it with the experience, comprehend the meaning and usage, for development of literacy.

How to manage challenging behaviors? (Managing component of SOC)

Inappropriate behaviors of children with ASD may perhaps be explained by sensory integration challenges faced by majority of children with ASD. Sensory integration is a process of making sense of all the sensations we experience (tactile, vestibular, proprioception, visual, auditory, gustatory and olfactory (Myles, Cook, Miller, Rinner & Robbins, 2000). When children receive and process inaccurate or unreliable sensory input, their ability to create appropriate responses is disrupted (Dunn, 1991). This results in sensory integration dysfunction (SID), where four possible behavioral responses/self-regulation responses of registration, seeking, sensitivity and avoiding are possible (Dunn, 2007). Tomcheck and Dunn (2007) found that 95 percent of children with autism age 3 to 6 (n=281) have sensory integration problems (see Table 1). Ben-Sasson, et al., (2009) conducted a meta-analysis of sensory modulation symptoms in individuals with ASD and found in 14 studies significant high differences between ASD and typical groups. Others reported 45-95% of children with autism have sensory integration dysfunction (Baranek, 2002; Baranek, Boyd, Poe, David, & Watson, 2007; Ben-Sasson, et al., 2009; Tomcheck & Dunn, 2007; Winnie, Jessica, & Louann, 2002;) which may interfere with performance in many broader developmental and functional domains, generating frustration with explication as behavioral problems. Moreover, parents who are stressed may further cause behavior problems in their children to worsen (Osborne, & Reed, 2009).

Managing challenging behaviors due to SID requires understanding the sensory profile of their child and to adopt practices for successful participation in everyday life by using sensory processing knowledge (Dunn, 2007). The basic principle is to help the child to move from neurological high or low threshold to optimal level for learning and participating in life through appropriate intervention strategies (Dunn, 2006).

Table 1: Comparing SID among children with ASD

Source	Age Group	Size of Sample	Percentage detected
Tomcheck & Dunn, 2007	3-6 years old	N=281 (with ASD)	95% Tactile (79.4%) Taste/Smell (68.0%) Movement (44.1%) Under/Seeks Sensation(93.6%) Auditory Filtering (92.2%) Low Energy/weak (42.0%) Visual/Auditory sensitivity (69.1%)
Lane, Young, Baker & Angley, 2010	3-10 years old		87% (Overall) Tactile (66.6%) Taste/Smell (61.2%) Movement (33.4%) Under/Seeks Sensation(85.2%) Auditory Filtering (92.6%) Low Energy/weak (61.1%) Visual/Auditory sensitivity (57.4%)

A good understanding of the “Culture of Autism” (Mesibov, Shea & Schopler, 2004) will certainly promote a conducive and positive learning environment and possibly avert challenging behaviors. The child with ASD needs a structured environment where predictability and familiarity with a “Work System” is involved as in the TEACCH (Treatment and Education of Autistic and Communication Handicapped Children) (Mesibov, Shea & Schopler, 2004).

Development of literacy thereafter should involve comprehension of the six milestones and applying the Floor-Time approach as proposed by Greenspan and Weider (1998). They have produced three sets of DVDs to explain and coach parents on how to do the intervention.

How to find meaning?

(Meaningful component of SOC)

Perhaps, meaning in caregiving of children with ASD would arise through seeing positive results that are sustainable and permanent, making a significant and positive difference for the child’s well-being. It starts by being an effective mediator of the child’s learning (Kee, in-press). “Right Belief” in believing that one is able to make a positive difference is critical (Feuerstein, 2010). Garland and Howard (2009) found evidences from many neuroscience studies that the adult brain can continue to form novel neural connections and grow new neurons in response to learning or training even into old age (Draganski et al., 2004). Neuroplasticity research suggests that challenging learning experiences lead to brain development analogous to muscle tissue development. The findings imply that children with autism who are provided with appropriate experiences may develop abilities in their strength that may compensate for their weaknesses. For example, if they naturally lack the ability to read facial expressions, intensive teaching and

training to read facial experiences will help them develop the ability over time as the neural connections develops.

We can learn and continue to learn throughout our lifetime. Neurogenesis can even occur through the act of imagining playing the piano (Pascual-Leone, Amedi, Fregni, & Merabet, 2005). The anterior insula in autism is under-connected and under-examined. It is involved in interoceptive affective and empathic processes, and emerging evidence suggest it is part of a “salience network” integrating external sensory stimuli with internal states (Uddin & Menon, 2009). As mediators, we should look for opportunities and persist to stimulate the child’s development in whatever areas the child may be lacking through modes of learning or intelligences that are of their strength. Willis (2007) has even proposed brain-based teaching strategies for improving students’ memory, learning, and test-taking success.

Professor Reuven Feuerstein (Feuerstein, et al., 2006) proposes Structured Cognitive Modifiability (SCM) where the human being is the outcome of triple ontogeny of biological, sociocultural and Mediated Learning Experience(MLE). The human mediator modifies both the biological and the sociocultural elements of experience and existence through good understanding of MLE.

What understanding of intelligence would be useful and constructive for parents with autism to adopt in view of neuroplasticity? I will use Feuerstein, Feuerstein, and Falik (2010, p.7) definition of intelligence as the ability to think adaptively in response to changes in our environment. This definition allows parents/caregivers to improve the child’s intelligence by working on educating the child to think adaptively, with whatever tools, strategies and resources needed and using whatever time that may be needed to fulfill the goals. It is a more functional appropriate definition of intelligence depicting state rather than trait (Feuerstein, et al., 2006, p.74), implicating modifiability rather than stability. This allows all parents to have real hope, especially when Feuerstein’s holistic approaches are practices that are validated from many academics worldwide over the years (White & Dinos, 2010; Anton, 2009; Isman & Tzuriel, 2008; Weitz, 2008; Caffrey, Fuchs & Fuchs, 2008; Skuy, 2002; Schur, et al., 2002) and even by Singapore academics (Tan & Seng, 2008; Tan & Seng, 2005; Seng, Pou, & Tan, 2003) and professionals, for mainstream and non-mainstream students. There are certainly also researchers who do not subscribe to Feuerstein approaches (Frisky & Baden, 1992; Frisby, 1993; Gresham, 1986; Reynolds, 1986). Nevertheless, it remains a learning journey and a marathon.

Asian parents generally send their children for tuition if they can afford or coach them personally, to improve their child’s “intelligence”. Asians commonly believe that children in good classes or in good schools are smarter or more intelligent than their counterparts who are not. This implies that Asian parents generally do not believe that intelligence is fixed but modifiable. Perhaps, as a result, Asians are generally doing better in examinations than their western counterparts (Yamamoto & Holloway, 2010). Parents of children with ASD should adopt “Right Belief” for development of meaning.

Ability to manage challenging behaviors, comprehend ASD and find meaning as caregivers will lead to perceived self-efficacy of parents which “refers to beliefs in one’s capabilities to organize and execute the courses of action required to produce given attainments.”(Bandura, 1997, p.3)

Conclusion

Personally, I have witnessed positive and permanent improvement in my three teenage children who have ASD to different degrees through the understanding and appropriate application of the evidence-based practices by my wife, myself and the “Grace of God”. Literacy can be taught to children with autism. Simply put, the three-pronged approach of *Ready Educator* (Comprehensibility and Meaning component in SOC), *Ready Child* (Manageability in SOC) and *Ready Environment* (Manageability in SOC) (Kee & Loh, 2009) empowers parents with SOC and perceived self-efficacy to effectively mediate learning of literacy .

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