

## **Education on functional skills and sexual health for children with Autism**

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### **ABSTRACT**

Autism affects individuals in a variety of ways and poses many challenges to their caregivers. It frequently causes much stress to parents, affecting their family life and marital relations. Parents focus much on medical treatments, special education services and various therapies for their children, but tend to neglect the areas where they can educate and empower their children. This is especially true in the areas of functional skill education and sexual health education for their children. This paper looks into the characteristics of autism, the role of parents in the education of children with autism and the importance of education on functional skills and sexual health education for children with autism.

**Key Words :** Autism, Education, Functional skills, Parents, Sexual health

### **INTRODUCTION**

#### **Autism :**

According to the National Research Council [NRC], (2001), autism is a complex neurological disorder that affects the functioning of the brain. It is considered to be one of the most severe disabilities affecting young children, because it adversely affects nearly every aspect of the child's development (Wetherby and Prizant, 2000). Autism is characterized by persistent deficits in social communication and social interaction across multiple contexts, combined with restricted, repetitive patterns of behaviour, interests, or activities. These symptoms are present in the early developmental period and continue to exist during later developmental periods causing significant impairments in social, occupational, or other important areas of current functioning. These disturbances are not better explained by intellectual disability or global developmental delay (American Psychiatric Association [APA], 2013, Diagnostic and Statistical Manual [DSM] V).

The symptoms of autism manifest before three years of age and it is a lifelong developmental disability. Most individuals achieve developmental gains in some areas to a certain degree (e.g. greater interest in socializing during adolescence), but continue to show deficits across multiple domains throughout their lives (Shattuck *et al.*, 2007). Autism, referred to as a spectrum disorder, implies that the symptoms can be present in a variety of combinations, ranging from mild to severe. Some individuals with the condition are able to lead independent and fulfilling lives when trained, whereas for some the impact is severe, drastically lowering their quality of life (Farley *et al.*, 2009).

**How to cite this Article:** Venkat Lakshmi, H., Joel, Gifty and Chingangbam, Sanatombi (2018). Education on functional skills and sexual health for children with Autism. *Internat. J. Appl. Soc. Sci.*, **5** (5) : 550-568.

### Classification :

According to the DSM V, individuals with autism are classified into three groups based on the level of support they require :

**Level 1** : “Requiring support”: Without supports in place, deficits in social communication cause noticeable impairments. They have difficulties initiating social interactions, respond inappropriately when others initiate social interactions, and in general appear to have decreased interests in social interactions. The inflexibility of their behaviour causes significant interference with functioning in two or more contexts. They have difficulty switching between activities. Their independence is hampered by problems in planning and organization.

**Level 2** : “Requiring substantial support”: Show marked deficits in verbal and non-verbal social communication skills. Their social impairments are apparent even with supports in place. They initiate limited social interactions, and give reduced or abnormal responses to the social overtures from others. The inflexibility of their behaviour, difficulty coping with change and other restricted/repetitive behaviours appear frequently enough to be obvious to the casual observer. These behaviours interfere with functioning in a variety of contexts. They show distress and/or difficulty while changing focus or action.

**Level 3** : “Requiring very substantial support”: They have severe deficits in verbal and non-verbal social communication skills leading to severe impairments in functioning. They have very limited initiation of social interactions, and minimal response to social overtures from others. Their inflexibility of behaviour, extreme difficulty coping with change, or other restricted/repetitive behaviours markedly interferes with functioning in all spheres of their life. They are greatly distressed when they are required to change focus or action.

### Prevalence :

The prevalence rates of autism spectrum disorders rose substantially over time (Gurney *et al.*, 2003). While the reasons behind this increase are not clear, (Shattuck, 2006; Gernsbacher *et al.*, 2005) and at times controversial, (Kirby, 2005; Williams *et al.*, 2005) it is generally accepted that there are more individuals being diagnosed with autism spectrum disorders now due to improved medical and diagnostic facilities, reflecting the steadily growing numbers of individuals on the autism spectrum. It is said to be among the most heritable of all mental disorders (Lichtenstein *et al.*, 2010) and also the most commonly diagnosed developmental disorder. The increase in prevalence has created an increased demand for appropriate services for adolescents and young adults with autism spectrum disorders, especially owing to their many varied and challenging characteristics.

Autism spectrum disorders are about 4.5 times more common among boys (1 in 42) than among girls (1 in 189) (Christensen, 2016). The prevalence of autism spectrum disorders has been steadily increasing over the last decade. Estimates from the Centers for Disease Control and Prevention (CDC) suggested in 2008 that one in every 150 children have autism or an autism spectrum disorder. While Elsabbagh *et al.* (2012) estimated that the worldwide prevalence of autism spectrum disorders is 62/10,000 (*i.e.* 1 in every 162). Further, the CDC reported that 1 in 88 children have been diagnosed with an autism spectrum disorder in the year 2012 in the United States of America. The CDC (2012), estimated that the prevalence of autism in the United States is 1 in 68 children (1 in 42 boys and 1 in 189 girls). While in India, Deshmukh *et al.* (2013) reported that the estimated prevalence of autism is 1 in 66, among children between 2 and 9 years of age.

**Characteristics :**

There are a number of characteristics that are seen in individuals with autism spectrum disorders, but all these characteristics are not always present in the same individual and are often change over time. Although those with autism share a range of core symptoms, the severity and the exact nature of symptoms displayed vary widely between individuals. Even in the same person, the characteristics may change not only in frequency but also in the quality, type and intensity (Militeri *et al.*, 2002). The emergence of symptoms is usually noted by parents when children are between the ages of 12 months and 36 months (Strock, 2007).

The most apparent characteristic of those with autism is delayed language development; often this delay is the first sign to parents that something is abnormal with their child's development (Perko and McLaughlin, 2002). Estimates reveal that one-third to one-half of children with autism have minimal to complete lack of 'functional speech', which is defined as the ability to convey a message to others and understand the symbolic or representational nature of speech (Preston and Carter, 2009; Yoder and Stone, 2006). One of the common autistic behaviours is 'echolalia' which is the meaningless repetition of words just spoken by another person. Autists do this because they cannot understand the rules of communication that make it possible to create statements of their own or express themselves in a meaningful manner (Grandin, 1996). Malhi and Singhi (2014) in their case studies on 21 children with ASD found that during the first 2 years of life more than two-third of them lacked speech, inability to follow verbal commands, lack of pretend play, no index finger pointing, difficulty in playing with toys in a constructive manner, lack of joint attention, and motor stereotypies.

Individuals with autism spectrum disorders are noted for their restricted repetitive and stereotyped patterns of behaviour, interests and activities. Repetitive behaviours are understood to be behaviours with no obvious goals or functions and sometimes take the form of relentless, intense preoccupations. These restricted interests may be preoccupations with a toy, hobby, or topic (e.g. dinosaurs, automobiles, etc.) that is so intense that a child has difficulty transitioning to other topics or activities (Souders *et al.*, 2002). They obsess over specific objects, repetitive body movements, specific routines and rituals which they obsessively follow throughout their day (Willis, 2006).

They also have the need for sameness. A slight change in any routine—in meal times, dressing, taking a bath, going to school at a certain time and by a particular route—can be extremely disturbing, causing the child to throw a tantrum. Children with autism may be overwhelmed by even minimal change. They may find coping with everyday life a bewildering task, without sameness and routine to help them make sense of and control their environment (Carrington and Graham, 2001).

In general, social skills refer to specific behaviours that result in positive social interactions and encompass both verbal and non-verbal behaviours necessary for effective interpersonal communication (Ex: smiling, making eye-contact). Unfortunately, profound deficit in social reciprocity skills is one of the core features of those with autism spectrum disorders, regardless of the individual's cognitive or language abilities (Carter *et al.*, 2005). They have substantial difficulties in peer interactions; they lack appreciation of social cues, are egocentric, and frequently display socially and emotionally inappropriate behaviours (Gillberg *et al.*, 2001). Solish *et al.* (2010) found that children with autism participated in fewer social and recreational activities than typically developing children, and their participation tended to involve parents or caregivers, rather than peers. Social skills do not improve with age; on the contrary, impairment and distress may increase as children approach adolescence because social situations become more complex (Tantam, 2003) and they feel very misunderstood.

Although not universal, it is common for individuals with autism spectrum disorders to have difficulty regulating their emotions. They display exaggerated or amplified emotional responses and poor emotional control (Mazefsky *et al.*, 2013). This can take the form of “immature” behaviour such as crying or laughing inappropriately. They have a tendency to “lose control”, particularly in new environments, or when angry and frustrated. They may at times break things, attack others, or hurt themselves and be irritable, aggressive, self-injurious, anxious and impulsive (Sofronoff *et al.*, 2007; Lecavalier, 2006).

It is estimated that about 40% of children diagnosed with an autism spectrum disorder have some cognitive impairment (Phetrasuwan *et al.*, 2009). About 70% of them are said to have an IQ less than 70 (Ghaziuddin *et al.*, 2002). In addition to the core diagnostic criteria for autism, individuals with autism exhibit problems with attention and orientation, and an odd response to the environment and sensory stimuli (Scarpinato *et al.*, 2010). They may be painfully sensitive to certain sounds, textures, tastes, and smells. Whereas, some individuals with autism seek extra sensory stimulation, and may become fixated on certain stimuli, and constantly seek gratification while being unaware of others (Frith, 1992). This may not only hinder the performance of certain activities of daily living (Kern *et al.*, 2006) but also cause them to perform behaviours that are inappropriate in public. Jasmin *et al.* (2009) in their study on children with autism spectrum disorders found them to show atypical sensory responses, very poor motor and daily living skills.

### **Parenting a child with Autism:**

#### **Challenges in parenting a child with Autism :**

Due to such varied characteristics, severe deficits and behavioural problems of children with autism, parents who deal with them continually on a daily basis report parenting as a major source of stress (Domingue *et al.*, 2000). As providing care for a child with autism becomes a central commitment, often over-riding and altering parents’ other life priorities (Gray, 1998). It takes so much effort, energy and time that it may lead to detrimental effects on marital relations (Piven *et al.*, 1991).

Nyoni and Serpell (2012) studied the impact of raising a young child with autism on parents in Lusaka, Zambia. Findings indicated that parents experienced frustration, pain, confusion, doubt and disempowerment in the pre-diagnostic period; then, at diagnosis, shock, denial and having a feeling like that of losing a normal child through death, followed by some acceptance. Stoneman and Gavidia-Payne (2006) conducted a study on “marital adjustment in families of young children with disabilities: associations with daily hassles and problem-focused coping”. They found that most of the couples considered their marriages more negatively, when daily stressors/hassles were high. According to Pisula (2011), parental stress is a complex set of non-specific, persistent and significant challenges associated with parents’ important roles, *i.e.* taking care of their child. Parents of children with autism have less time for themselves as individuals such as getting enough sleep, eating regular meals, taking a short walk, and doing things that they really enjoy (Ravindranadan and Raju, 2008); this in turn affects their life satisfaction and adjustment.

Marital conflicts emerged which included separations and fighting. Single mothers suffered special challenges, combining study with child caring. Parents also incurred significant financial costs for medical attention and transport, and social and emotional costs due to child and parent stigmatization. It is also found that extended family members reject the child with autism or distance themselves from the family and parents often describe relatives as cold, distant, and generally unhelpful (Schall, 2000). Parents also tend to gradually lose touch with their friends because of the

time constraint and also because the friends may feel they are unable to help or understand the situations. When parents receive less support from their families or from their social circles, their stress levels increase (Preece and Jordan 2007). Heiman (2002) found that most parents expressed high levels of frustration and dissatisfaction when they needed to make changes in their social life; many of them tried to follow a routine life. Gray and Holden (2014) conducted a study on “Psycho-social well-being among the parents of children with autism”. The results indicated that those parents, who received more social support, had lower scores of depression, anxiety and anger. The age of onset of autism was positively related to depression, but was not significant in terms of anxiety and anger. Parents with older children, females and larger families reported lower scores of anger.

Further, Freeman and Cronin (2002) found that parents often feel that they receive no concern from professionals and that many people in their family and in the community blame them for their child's limits in adaptive behaviours. Hastings (2003) found that mothers and fathers did not differ in their levels of stress and depression, but mothers reported more anxiety than fathers. This may be because most often mothers are the full-time primary caregivers of their autistic children (Cidav *et al.*, 2012). They take care of their children's personal needs on a daily basis, and also accompany their child/children to school, for therapies and treatments. However, not only do present struggles cause concern to parents, many families having young children with autism reveal that worries about the future are a significant source of current stress (Bouma and Schweitzer, 1990).

### **Role parents in educating a child with Autism :**

The National Research Council in their official document ‘Educating children with autism: Committee on educational interventions for children with autism’ (2001) define education for children with autism as the fostering of acquisition of skills or knowledge that not only includes academic learning, but also socialization, adaptive skills, language and communication, and reduction of behavior problems to assist a child to develop independence and personal responsibility. Comprehensive education programs for children with autism aim to achieve goals that are both academic and non-academic, across a range of areas (Handleman and Harris, 2001) such as social and cognitive development, verbal and nonverbal communication, adaptive skills, increased competence in motor activities, and reduction of behavior difficulties.

It is commonly said “No two individuals with autism are alike” because autism varies widely in severity of symptoms, age of onset, and the presence of co-morbid features such as mental retardation and specific language delay. Due to the nature of the disorder, children with autism require special education services and also education at home, and in community settings. Their education should not only involve the children, but also their parents because of the complexities involved. It is acknowledged that the involvement of families in the education of young children with autism is necessary and must occur at multiple levels (National Research Council, 2001).

In their attempt to deal with their autistic children, many families express concern about their children's behavior usually to doctors and health professionals, trying to seek treatment or find a ‘cure’ to their children's problems. They also actively seek specific educational services/interventions and therapies such as physio-therapy and speech therapy to improve the condition of their child. However, many parents fail to understand the importance of functional skills education (FSE) and sexual health education (SHE) for their autistic children. It is to be noted that both FSE and SHE are often not considered in the school curriculum, and teachers find that it is out of their purview. Hence the responsibility of teaching FSE and SHE to children with autism, most often rests on the

shoulders of parents themselves. Therefore, parents require both initial training and on-going support for trouble shooting if they are to sustain their effort at home teaching (Harris, 1987).

Although, initially parents may feel inadequate to teach and train their autistic children, they can make an attempt to learn useful techniques for teaching adaptive skills and managing the behavior of their child. Their perseverance and constant involvement will maximize the child's learning, and improve the quality of family life. This will ultimately encourage parents to sustain their efforts with their child over time. The use of effective teaching methods for a child with autism can have a measurable positive impact on family, lessening their stress. As a child's behavior improves and his or her skills become more adaptive, families will have a wider range of leisure options and more time for one another (Koegel *et al.*, 1984).

### **Functional skills :**

According to Collins (2008), functional skills are defined as—skills that are used every day, in different situations at home, school and community. It includes self-care skills, functional academics skills, vocational skills, social skills and community living skills. Children with autism have poor day to day living skills which are referred to as functional skills (Chingangbam and Venkat Lakshmi, 2018; Jasmin *et al.*, 2009). The Ministry of Health and Welfare and Korea Institute for Health and Social Affairs (2011), stated that most autistic children require assistance from their parents or caregivers to perform their daily living activities such as toileting, brushing their teeth, dressing, appropriate eating, bathing, changing clothes, etc. But parents are the ones who deal with the issues associated with their child's disability and also maintain the household chores and other responsibilities (Ravindranadan and Raju, 2008). Children with autism place a set of extra demands, challenges and burdens on the family system leading to increase the parental stress (Kirk *et al.*, 2000).

In addition, children with autism are likely to have more positive life outcomes if they are able to master basic daily living skills. There are many behaviours that ordinary children learn without special teaching, but that children with autism may need to be taught (Klin, 1992). So, parents should teach daily living skills to their children from an early age (Carothers and Taylor, 2013) to help them improve in self-help skills and develop independent in their day to day life. As they grow into adulthood it will also help them generate a better vocational skills training reducing behaviour problems and will facilitate them towards self-reliance at home, school and community as well as decreasing parental stress and caregiver strain (Chingangbam and Venkat Lakshmi, 2016). Most importantly, learning basic functional skills helps the child in enhancing his/herself-concept a sense of accomplishment and the confidence that comes from doing it—all by himself/herself (Willis, 2009) and to make their child become a successful adult (Carothers and Taylor, 2013).

Research has shown that there are many effective strategies to teach children with autism various skills that are important to them, including self help skills and socializing skills. Meister and Salls (2015) investigated the efficacy of video modelling as an intervention strategy to improve self-help skills in children with Autism. A single-subject A-B design was implemented with eight school-aged children ages 7.5 years to 13.5 years. Six of the students participated in general education classes with varying levels of support, and two were in a special education classroom. All were able to follow basic directions and answer simple questions verbally. Results suggested that video modelling; using an iPad may be an effective technique for teaching students with ASD self-care and daily living skills, with students showing an average of 50.5% improvement in task performance during a 6-week study period.

When children with autism are taught a new skill or set of skills, they may require a prompt to use the skill in an appropriate setting; as skill-generalization is something that most children with autism tend to struggle with. Kern *et al.* (2007) conducted a case study to investigate the effectiveness of adding songs embedded in ongoing classroom routines as structural prompts to increase the independence of a 3-year-old boy with autism during multi-step self-care tasks (*i.e.*, hand washing, toileting and cleaning up). The effectiveness of the musical versus verbal presentations of the task sequence was compared. The results indicated that the implementation of both forms of the intervention were successful in increasing the child's independent performance for each task though task-specific differences were noted.

Toilet training is a particularly sore-topic for some parents of children with autism. They find it difficult to teach their child with communication issues about how to indicate the need to use the toilet, and also maintain appropriate hygiene. Cicero and Pfadt (2002) investigated the effectiveness of a reinforcement-based toilet training intervention on three children with autism. Procedures included a combination of positive reinforcement, graduated guidance, scheduled practice trials and forward prompting. The procedures were implemented in response to urination accidents. The result found that all the three participants reduced urination accidents to zero and learned to spontaneously request use of the bathroom within 7-11 days of training. Gains were maintained over 6 month and 1-year follow-ups. In another study conducted by Keen *et al.* (2007) the effectiveness of an animated toilet training video for teaching daytime urinary control was assessed. The sample consisted of five young boys with autism, and the training occurred across several settings for 2-week baseline-monitoring period. Children in the treatment condition received video modelling plus operant conditioning strategies, whereas children in the control condition received only operant conditioning strategies. The results found that, for young children with autism who were resistant to toilet training, acquisition of urinary control were facilitated by use of an animated toileting video in conjunction with operant conditioning strategies. Parents are likely to be successful in teaching their children if they use similar procedures to toilet train their children.

It is a well accepted fact that individuals with autism are more tech-savvy and have difficulties in human interactions. Therefore, using technology, it may be possible to train them in a number of skills for real life. Costescu *et al.* (2015) investigated the role of the robotic toy Keep on in a cognitive flexibility task performed by children with ASD and typically developing (TD) children. 40 TD children and 41 children with ASD (81 children) participated in the study. Each participant had to go through two conditions: robot interaction and human interaction in which they had performed the reversal learning task. The results of the study showed that children with ASD were able to engage in the task and they seemed to enjoy the task when interacting with the robot compared to the interaction with adults.

Exposure to peers and casual socialization on a regular basis may also help children with autism learn the much-needed social skills. Barry *et al.* (2003) examined the effectiveness of an outpatient clinic-based social skills group intervention with four high-functioning elementary-aged children with autism. The group was designed to teach specific social skills, including greeting, conversation, and play skills in a brief therapy format for eight sessions. At the end of each skills-training session, children with autism were observed in play sessions with typical peers. Results indicated that a social skills group implemented in an outpatient clinic setting was effective in improving greeting and play skills, with less clear improvements noted in conversation skills. In addition, children with autism reported increased feelings of social support from classmates at school following participation in the group.

During childhood and the pre-pubertal years, parents need to focus on teaching their children functional skills, so that children will learn skills they require to make a smooth transition into adolescence. As children approach puberty, parents need to also address the emerging sexuality of their growing children and teach them sexual health education.

### **Sexual health education :**

#### **Need for sexual health education for children with Autism :**

All children mature as they grow. However, children and youth with disabilities, including those on the autistic spectrum are often erroneously viewed as being asexual (Irvine, 2005; Di Giulio, 2003). Despite limitations in other developmental areas, they experience physical development *i.e.* the physical and emotional changes of puberty in the same way as their typical peers (Schroeder, LeBlanc and Mayo, 1996), as physical maturity and development are linked not to mental age but to chronological age and other biological factors (Tissot, 2009).

Owing to the debilitating features of autism, individuals with autism spectrum disorders are vulnerable to a range of sexual behaviour outcomes, not only such as sexual abuse, but also normative sexual behaviours associated with maturation (Edelson, 2010). Normative behaviours are 'common, appropriate and expected' during a particular age or developmental level (O'Sullivan and Thompson, 2014). Normative sexualized behaviours appear at various stages of sexual development for typical children (Cavanagh, 1999). The same behaviours may seem more pronounced in children with autism because the age at which children with autism reach various developmental stages may be delayed when compared to typical children. For example, Edelson explains that although it is quite common for preschool children to explore and stimulate their own bodies, at times even in public, children and adolescents with autism may also engage in these behaviours, but at an older age – which is not socially acceptable.

Children with autism frequently exhibit a wide range of problematic and socially deviant characteristics and behaviours (Schreibman *et al.*, 1999) that include sexual behaviours such as undressing and masturbating in public and initiating inappropriate physical contact with other individuals (Hellemans and Deboutte, 2002; van Bourgondien and Palmer, 1997; van Son-Schoones and van Bilsen, 1995; Ruble and Dalrymple, 1993; Haracopos and Pedersen, 1992). Studies show that some children with autism may have an excessive curiosity about the human body and the way it functions (Lee, 2004) prompting them to explore their own bodies as well as those of others. Masturbation is the most commonly reported sexual expression for individuals with autism spectrum disorders (Hellemans *et al.*, 2007). Although masturbation is a normal part of an individual's sexual development (Duncan *et al.*, 2003), it often becomes problematic as children with autism engage in such behaviours in the presence of others, being unmindful of their social environment. Research reveals that some individuals with autism indulge in deviant forms of masturbation, using unusual objects to masturbate, and they hyper-masturbate *i.e.* masturbate too frequently, even disrupting their daily functioning (Hellemans *et al.*, 2007).

Owing to their emotional need for intimacy, individuals with autism may sometimes direct their sexual behaviours towards other non-consenting people. Some of the behaviours documented in research include kissing strangers (Clements and Zarowska, 2000), fixated behaviours such as stalking (Newport *et al.*, 2002), looking up skirts of women, looking into their blouses, touching private parts of others and even touching their parents inappropriately (Ruble and Dalrymple, 1993).

Although many behaviours of autists may be inappropriate and disturbing, those that are sexual in nature upset people more, and sexual offences are likely to be taken more seriously. People may



tend to perceive the individual with autism as a pervert or threat, and fearfully withdraw themselves. Yet, these seemingly inappropriate sexual behaviours may not always be stemming from sexual deviancy, but merely from the core features of autism, such as their predisposition for self-stimulatory behaviour, impairment in social awareness, and their inability to empathize with others. They also lack a clear understanding of appropriate sexuality (Stokes and Kaur, 2005) as they do not have the ability to acquire socio-sexual skills on their own. Hence, they require sexual health education to enable them to understand their sexuality and express it in safe and socially acceptable ways (Joel and Venkat Lakshmi, 2016).

Parents stand at a unique position with reference to sexual health education because they are the first socializing agents in their children's lives. Parents ought to be the primary sexuality educators for their children (Murphy and Elias, 2006) as they can positively influence their child's beliefs and attitudes about sex and sexuality more than anybody else. They are more likely to know their child's needs than professionals and, as a result, are better equipped to teach their child about sexuality. The Committee on Children with Disabilities (1996), suggested that parents may be reluctant to discuss sexuality with their adolescents with developmental disabilities for fear that it may promote sexual behaviour or lead to sexual experimentation. They are uncertain about how they can communicate, when they must start, and how much they should reveal to their child about sexual health. Whatever their reasons be, it is of utmost importance that they take initiative to teach and train their children in aspects regarding sexual health, hygiene, appropriate behaviours and so on.

### **Sexual health concepts to be taught to children with Autism :**

Like all other children, those with autism also require information about sexual health. Their sexuality must be accepted and addressed in the right context. Gougeon (2010) reports that some of the most neglected areas of research on individuals with autism spectrum disorders are the areas of sex, sexuality and sexual health education.

As they grow up, they need to be taught about their body, the changes they may undergo during puberty, the sexual feelings and urges that they may experience, etc. Greiert (2016) developed guidelines for the sexuality education of high functioning individuals with autism spectrum disorders, by obtaining consent and consensus of experts in autism, representing families, school based professionals and researchers. Through an interactive process, Greiert asked the participants questions about what content should be delivered, how content should be delivered, how knowledge acquisition should be measured, and what role professionals and families play in delivering sexual health related information to the high functioning autists. As per the developed guidelines, the topics to be covered included anatomy, physiology, sexually transmitted infections, healthy relationships, personal safety, legal issues, social aspects of sexual relationships, knowledge of different sexual acts, use of common slang and specific sensory needs of autists. The guidelines also suggest that individual needs of learners must be kept in mind, the learning environment should be suitable to the learner, and that teaching should preferably be one to one. The guidelines further recommended the usage of visuals, real world examples, direct and honest explanations, breaking down information / instructions into smaller steps, role plays and repetition to teach sexual health education. Lastly, the guidelines insisted on family-school planning, partnering and collaboration while imparting sexual health education to children with autism.

To understand the experiences of physical and sexual maturation during puberty Cridland *et al.* (2014) interviewed mothers and their daughters with autism spectrum disorders. Mothers reported

that their daughters accepted menstruation in a very ‘matter-of-fact’ manner, however, they found it difficult to adjust to the increased demands of adolescent hygiene routines. They also reported that their daughters did not understand the importance of maintaining personal boundaries while interacting with others, especially with members of the opposite sex. Therefore there is a need to address the aspect of personal boundaries and safety in sexual health education. Also Lee (2004) reported case studies of teen-aged girls with autism, describing an increase in agitation and problem behaviours at menarche. This was frequently followed by cyclical amplification of their autistic symptoms, self-injurious behaviours and mood swings four to five days before their monthly period. Lee suggested that girls on the spectrum need to be taught menstrual management and hygiene to help them deal with puberty.

Dekker *et al.* (2015) developed a training program to improve the psycho sexual knowledge of autistic teens in Netherland. The program was called Tackling Teenage Training (TTT) originally designed by Boudesteijn, van der Vegt, Visser, Tick and Maras in 2012. This program was intended for those children with autism between 11 and 19 years of age. They used the pre-test – post-test design with an intervention that lasted nearly 6 months *i.e.* 18 individual sessions covering the following topics – puberty, appearances, first impressions, physical and emotional developments during puberty, establishing and maintaining friendships, falling in love, sexuality, sex, masturbation, pregnancy, respecting boundaries, safe internet usage, etc. The results of their study proved that autistic adolescents’ psychosexual knowledge improved significantly after taking part in the TTT program. Therefore they stressed on the specific need to develop specialized training programs for adolescents with autism spectrum disorders as they do not benefit from general sexual education programs and also because they are unable to pick up lessons about sexuality from their environment due to the deficits and impairments caused by autism.

Gougeon (2010) reviewed literature on sexuality and autism and highlighted that educators ought to keep in mind the fact that autistic youth lack some basic communicative and relationship skills such as the ability to read facial expressions and to anticipate emotional responses, and the ability to initiate and end social interactions. He mentioned that most sexuality education curriculums assume that youth have learned these skills previously. Such an assumption cannot be made for youth with autism since they lack even basic social skills. The study highlighted the need for sexuality education programs to include instruction on socially acceptable behaviour. Also, Volkmar *et al.* (2005) advocated that sexual health education programs should be established with the assumption that the individual with autism can learn relationship skills.

It is further recommended that as children diagnosed with autism move towards adolescence, problem behaviours must be addressed, so that their developmental progression through adolescence is not impeded and parents are not unduly stressed. Untreated problem behaviours only tend to worsen over time, increasing parental stress and also hindering their inclusion in group homes, care programs and the society in general (Howlin, 1997). Because self-pleasuring is a common occurrence among people with autism, it should be addressed in sexuality training. Caregivers must address masturbation in a matter-of-fact, individualized manner. It is suggested that instructors teach appropriate time and place and intervene when an individual with autism masturbates in public (Haracopos and Pedersen, 1992).

Sullivan and Caterino (2008) in their paper titled “Addressing the Sexuality and Sex education of Individuals with Autism Spectrum Disorder” recommended that due to the high frequency of sexual behaviours in the autistic population, parents, caregivers and staff must be prepared to facilitate appropriate sexual expression. Sullivan and Caterino stressed on the need for specialized

sex education programs for children with autism, -that adequately addresses the social deficits, developmental delays and other issues they may face. The contents of sexual health education programs need to be individualized to suit the need of the individuals and their families in their specific community settings.

Shakespeare (1996) recommended that education regarding sexual abuse should be a component of responsible sexuality education. Increased vulnerability among children with disabilities is probably due to their inability to understand or communicate what has happened or what will happen as a consequence of the abuse meted out to them.

### **Methods to teach sexual health education to children with Autism :**

According to a study titled 'Sexuality and people with developmental and intellectual disabilities' by Fegan *et al.* (1993), individualized instruction should be concrete rather than abstract, be brief, specific, and clear, be visual, and utilize imitation of real life settings.

Some of the educational strategies suggested by Sweeney (2007) to teach sexuality education to students with special needs include the use of multi-sensory activities by way of illustrations, anatomical models, slides, photos, audio-visual materials, and interactive games. Further, it is recommended that learning strategies include opportunities for monitored interactions with their typically developing peers and strategies that closely approximate real life situations, such as role-plays. In trying to teach disabled individuals certain skills and maximize skill generalization, real life practice of skills has been found to be effective. This can often be achieved by doing role plays to give the child opportunities to practice new skills in a simulated environment, eventually enabling them to correctly implement the same skills in real life situations. Liberman, Glynn, Blair, Ross and Marder (2002) found that role plays improve learning of skills, promote skill generalization and independent living in clients with mental illnesses.

Children with autism may feel comfortable when step-by-step instructions are given to them to complete any task. Also an on-going positive reinforcement and the use of a reward system have been proven to be helpful while teaching them (Thorne, 2007). In another study, MacDuff, *et al.* (1993) used photographic activity schedules (step by step picture procedures for activities) to teach four boys with autism on-task and on-schedule behaviours. The results indicated that photographic activity schedules produced sustained engagement and skill generalization to new sequences of photographs. Children through this procedure acquired schedule-following skills and were able to display lengthy response chains, independently transition from one activity to another in home settings, even in the absence of supervision and prompts from others.

Social stories are an effective way to teach children with autism appropriate social behaviour and societal norms. Social stories were developed by Gray and colleagues. They are first person accounts of ways to increase the child's awareness of social situations. The story contains a description of what is happening, why it might be happening and how people think and feel about the situation. Social stories should be in line with the child's level of understanding and comprehension level (Gray and Garand, 1993). Social stories can be used to teach children with autism various concepts about sexuality.

Since children with autism spectrum disorders often lack knowledge of what to do or how to respond to a social situation, Krantz and McClannahan (1993) used social scripts to teach them what to say. They found that when scripts were introduced, peer interactions increased. They gradually faded the scripts from end to beginning (leaving the last words out) and found that as scripts faded, children with autism initiated unscripted interactions with peers. Since children with

autism have difficulty communicating and expressing their needs (including sexual needs), they could be taught social scripts to help communicate their needs (e.g. 'I need to use the restroom', or 'I think I got my period, can I have a sanitary pad please').

After studying various interventions and transitional strategies for children with autism, Fouse and Wheeler (1997) suggested the following intervention strategies to handle masturbation in their book titled "A treasure chest of behavioural strategies for individuals with Autism". When an individual with autism is found masturbating at an inappropriate time and place- firstly, interrupt the behaviour, then remind the person of the appropriate time and place for the behaviour. Redirect the person to another activity or to an activity that preferably requires the use of both hands, or redirect the person to an activity that involves intense focus or high amounts of physical movement. Also redirect the person to an appropriate place to have privacy, such as a bathroom, shower, or private bedroom. Provide reinforcements to encourage them to stay in assigned areas and take breaks only as scheduled. Lastly, provide visual evidence of scheduled breaks or private leisure time, so the person can anticipate and plan for personal needs.

Hatton and Tector (2010) who previously worked in a school reported that finding suitable curriculum materials and teaching resources for sexuality and relationship education for young people with autism spectrum disorders can be quite a challenge. They used questionnaires and in-depth interviews to enable autistic pupils share what would have helped them learn sexuality and relationship education better. Through the findings of their research Hatton and Tector developed teaching materials to support a personalized approach to impart sexuality and relationship education suitable for both classroom and residential settings. Despite developing suitable teaching materials, they stressed on the need for training teaching and support staff in educational settings on issues related to sexuality, as only well-equipped trainers with good resource materials will be effective in imparting sexuality and relationship education to children with autism. Therefore, those who attempt to teach sexual health education to children with autism may have to prepare individualized teaching material that will suit the needs of each child, to address the areas where they require help.

### **Outcomes of sexual health education for children with Autism :**

In a study to look at the outcomes of sexual health education programs for youth, Henault and Attwood (2002) evaluated the effectiveness of a general socio-sexual education program for older teens with Asperger Syndrome. The study found that social skills increased and inappropriate behaviours decreased, these changes were continued to be observed after a three-month follow-up. In another study by Horner *et al.* (2002) analyzed research papers on behavioural interventions to reduce problem behaviour in children with autism published between 1996 and 2000. The analysis revealed that in 23 of the 37 studies (62%) the intervention agent and the intervention context were typical, *i.e.* the intervention to address the problem behaviour of a child with autism either occurred in the home or school and the intervention agent was most likely to be a parent or teacher, indicating the important role of parents and teachers in the lives of children with autism. However, they also pointed out that parents and teachers may require higher level of skill and knowledge and may need to learn effective procedures in the long run. Joel and Venkat Lakshmi (2018) pointed out that parents are bound to feel hesitant to teach their children with autism. Albeit, their negative attitudes act as a major barrier, preventing them from imparting the much needed education to their children. However, intensive educational interventions can positively influence their attitude, provided parents consider for themselves the merits of the information presented to them. In the long run, parents must periodically refresh their knowledge and skills in imparting sexual health education in order to

deal with the challenges they will face as their child grows up. Tried and tested comprehensive educational intervention programs on functional skills and sexual health can be documented and replicated for the benefit of many more parents of children with autism in the future.

### Conclusion :

The education of children with autism is not limited only to academics taught in schools or a special education set-up. It includes the learning of other skills such as functional skills and sexual health education that is mostly taught at home by parents. These skills will help the children take good care of their personal needs, and reduce the burden of care-giving on their parents. They will also enjoy better inclusion in society because they have learnt necessary skills related to functional skills and sexual health. Parents play an important role in teaching and training their children. Initially, they may feel overwhelmed with their child's diagnosis, and feel incompetent to deal with the challenges of parenting a child with autism. However if they learn to support their child by using suitable methods to teach them skills that are generally not taught in schools, they will be empowering their children for a better and brighter future.

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