Developing a Psychological Management Guideline for Parents of Children with Autism Spectrum Disorder

THESIS

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Statement of Approval

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Declaration of Originality

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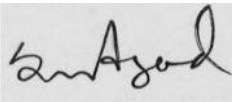

S. M. Abul Kalam Azad

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Dedication

This thesis is dedicated to My respective parents, M A Kader & Momtaz Begum

who are my constant inspiration and have never let me quit.

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Publications During Candidature

Peer-reviewed papers

1. Azad, S. M. A. K., Shilvy, N. E. N., & Rabby, A. A. (2020). **Adaptation of the Quality of Life in Autism Scale for use in Bangladesh**. *Bioresearch Communications, 7*(1).

2. Rebeiro, M.J., Azad, S.M.A.K. & Mahmud, A.Y. (2019). **Psychological service needs of parents in the management of ASD**. *Bioresearch Communications 5(2)*

Conferences & Presentations

1. In 2017, I presented a paper on "Psychological Service Needs of Parents of Children with ASD" in the Conference of the International Developmental Pediatrics Association (IDPA-2017), Mumbai, India.

2. In 2017, I presented a paper in the 1st National Rehabilitation Conference of the Bangladesh Physiotherapists Association, Dhaka, Bangladesh.

3. In 2018, I attended the Pathological Demand Avoidance Conference in Manchester, organized by the National Autistic Society, UK.

4. In 2018, I presented a poster in the 6th Asian CBT conference, Dhaka, Bangladesh.

5. In 2019, oral presentation on Autism & Evidence based Practice" in the 5th Bangladesh Clinical Psychology Conference

Abstract

Background: Autism Spectrum Disorders (ASDs), similar to other neuro-developmental disorders, are generally not curable and chronic management is required. It is more difficult for parents to understand and cope as it produces stress and anxiety in life-long care of these children. Therefore, a psychological management guideline needs to be developed in our cultural context. The study aimed to develop a psychological management guideline for parents of children with ASD in Bangladesh. In order to develop the guideline, parents psychological support needs were explored for these children.

Participants: The study was conducted in 2 separate phases. In Phase one, 16 parents took part (mean age = 39.13 years; SD = 6.80 years) of children with ASD who were attending a special school in Dhaka, Bangladesh. In-depth interviews were conducted on 6 mothers and 10 parents (7 mothers and 3 fathers) in a focus group discussion (FGD). Mean age of the children during the study was 10.22 years (SD = 4.97 years). Two mothers were also working as special-teacher in the special school. In the second phase, feedbacks were taken from 8 experts and 5 parents to finalize the development of the psychological management guideline of ASD.

Procedure: Using a topic guide, parents' responses were collected regarding emotional and behavioural support needs in caring a child with ASD. The topic guide consisted of questions on understanding the diagnosis of autism, emotional reactions, experiences and so on. All participants completed intensive interviews, mostly conducted face-to-face and subsequently over phone. All interviews were digitally recorded, professionally transcribed and were analyzed following Interpretative phenomenological analysis (IPA) theory.

Results: The results of the phase-1 are presented in terms of ten core overarching themes emerged from the qualitative data analysis: (1) Parents' reactions to the diagnosis; (2) Understanding the consequences of the diagnosis; (3) Stress of raising a child with autism; (4) Concerns about core and secondary problems; (5) Anxiety about child's future; (6) Parents' sacrifices arising from caring the child; (7) Uncertainty about child's future; (8) Parents feelings or prevailing mood; (9) Professional support needs, and (10) Support needs from the Government of Bangladesh.

In the phase-2, a draft version of the psychological management guideline was developed based on in-depth interviews of parents. The guideline was then evaluated by 8 experts on autism. Final version of the psychological management guideline was developed after incorporating suggestions from 5 parents.

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List of Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
BSMMU	Bangabandhu Sheikh Mujib Medical University
DD	Developmental Disabilities
DSM	Diagnostic & Statistical Manual
DGHS	Directorate General of Health Services
EIBI	Early Intensive Behaviour Therapy
EF	Executive Functioning
JPUF	Jatiyo Protibondhi Unnayan Foundation
ICD	International Classification of Diseases
ICDDRB	International Center for Diarrhoeal Disease Research, Bangladesh
IPNA	Institute of Paediatric Neurology and Autism
MoHFW	Ministry of Health and Family Welfare
NDD	Neuro-developmental Disorders
PDD	Pervasive Developmental Disorders
RCT	Randomized Control Trial
SBK	Shishu Bikash Kendra
ToM	Theory of Mind
WHO	World Health Organization

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Chapter 1

1.1 Background

Autism Spectrum Disorder (ASD) represents a heterogeneous set of neurodevelopmental problems characterised by deficits in social communication and reciprocal interaction as well as stereotype behaviour. In the fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-5, 2013), all subtypes of autism are merged into one umbrella diagnosis of ASD. Earlier, they were five subtypes of autism: autistic disorder, childhood disintegrative disorder, Rett's disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome. The DSM-5 also provides levels of severity the individual's support requirements (Level 1-requiring support, Level 2- requiring substantial support and Level 3-requiring very substantial support).

Severity and expression of ASD symptoms varies from child to child. Some children with ASD might be verbal but may not socialize well with others. ASD also can be manifested differently in children many ways. Around 50% children with ASD might have intellectual disability (IQ <70) on the other hand some children might not have low IQ (Szatmari, Bartolucci, Bremner, Bond & Rich, 1989). Often symptoms of developmental disabilities (DD) might be similar to the symptoms of ASD. Some distinct features of ASD are different from DD. For instance, social interaction with others is a unique feature of ASD.

Around 70% children with ASDs also might be affected by intellectual disability, epilepsy, ADHD and other mental health problems (NICE, 2011).

Autism also is a neurodiversity of the nature where children with ASD are distinguishable from other neuro-typical children. Autism can be a psychiatric disorder on the basis of certain

behaviours. Autism is primarily a deficit in social functioning based on the Theory of Mind (ToM) hypothesis (Baron-Cohen, Leslie & Frith, 1985). According to Executive Functioning theory (Ozonoff, Pennington & Rogers, 1990) it is a deficit in information processing. Therefore, ASD becomes a neurodiversity where children with ASD are different from normally developing children. Whatever the concept of ASD, these children need special care and support from the society.

Parenting a child with ASD is very challenging in comparison with parenting a typically developing child as it leaves heavy toll on parents (Hastings & Johnson, 2001; Koegel et al.,1992). Parenting a child with ASD is linked to poor mental health in parents and these parents might be affected by variety of mental health problems such as anxiety, depression and adjustment problems (Rebeiro, Azad and Mahmud, 2019; Weiss, Wingsiong & Lunsky, 2013). Parents of children with ASD also faces various challenging issues in managing their children in everyday life such as dealing with the child's communication difficulties, disruptive behaviors-aggressiveness, tantrums, melt downs, self-injurious behaviours, financial issues, informal and formal support.

In Bangladesh, the burden of childhood disability as a public health problem remains unrecognized. Bangladesh Government has already taken the necessary steps as evidenced by the passing of the NDD Protection Trust Act 2013 and the setup of the National Steering Committee for Autism & NDDs (NSCAND) in 2012. Additionally, the comorbidities and other associated health problems compound the challenges they face. These children require an array of necessary services and supports like special education, psychological and medical support services across their lifespan. To address the needs of children with ASDs, from 2008, Directorate General of

Health Services (DGHS), Ministry of Health and Family Welfare (MOHFW), Government of Bangladesh (GOB) established multidisciplinary Child Development Centres (in Bangla: Shishu Bikash Kendras) over the country in most of the government hospitals. So far, 35 Shishu Bikash Kendras (SBKs) are fully operational till date (DGHS, GOB, 2016).

International Center for Diarrhoeal Disease Research in Bangladesh (Icddr, b) has collected lists of autism service providing organizations (Ministry of Health and Family Affairs, 2016). In the lists, there are 18 government organizations and 28 non-governmental organizations. Among them, 45 organizations provide autism services. Three organizations – Institute of Paediatric Neurology and Autism (IPNA) at Bangabandhu Sheikh Mujib Medical University (BSMMU), Shishu Bikash Kendras (SBKs i.e., Child Development Centres) in Government hospitals and the Jatiyo Protibondhi Unnayan Foundation (JPUF i.e., the National Foundation for the Development of Disabled Persons) – are already established under the government and many special schools and service centres have been established to provide the services under non-governmental or private sector. Services at the government level provide speech and language therapy, occupational therapy and physical therapy. Additionally, early intervention programs, assessment, medical support and counselling are also provided by all these organizations. Seventeen of the organizations were using psychological support, sensory integration therapy, play therapy and behaviour therapy. All of these organizations also maintain referral systems.

In 2003-2004 I have seen many parents seeking management for their children with developmental problems in Child Development Centers of Dhaka Shishu (Children) hospital. In 2014, I represented the Department of Clinical Psychology in an interactive seminar organized by Centre for Resource & Information, where stake holders expressed their views. Chief guest was Saima Wazed Hossain, Chair of national steering committee for Autism and NDDs, Health

ministry of Bangladesh. In 2016, I visited a school for special children in Dhaka city & I interviewed some parents who were receiving services from the school. All these events motivated me to overcome the situation highlighting the role of multidisciplinary professionals.

Prevalence

It has been estimated that globally 1% of the world children suffer from an ASD (Elsabbagh et al., 2012). Some research findings from Asian, European and North American countries indicate that the prevalence rate of ASD varies between 1% and 2% (Elsabbagh et al., 2012. The prevalence is increasing exponentially with rates as high as 2.3% in USA (Maenner et al., 2022) to 2.6% in South Korea (Kim et al., 2014).

In Bangladesh, a community-based study reported 0.8% prevalence of ASD among children aged 5 to 17 years (Rabbani et al., 2009). In 2013, a pilot project indicated overall prevalence of 0.15%for ASD where 3% for Dhaka city and 0.07% in rural areas (Hossain et al., 2017). Male-female ratio of ASD shows that boys are more affected than girls in a ratio of 5:1 (Baio et al., 2018).

Prognosis of ASD

Generally, outcome of the children with ASD is highly linked with intellectual functioning (Landa, 2007). Children with low IQ never might be independent and they might need home or residential care. While, high-functioning children are capable of independent living, can work in jobs and even can enjoy a married life.

Aetiology

The root pathways of ASD are not yet discovered, though investigators believe that both genetics and environment are responsible here. The siblings of children with ASD are in a greater risk of having a diagnosis of ASD (Folstein & Rosen-Sheidley, 2001). In most cases, ASD might come from a mix of similar variantion of gene alleles or from a few rare alleles but the full genetic analyses have not been discovered yet. In a few numbers of children (5%) a single genetic disorder or chromosomal anomaly might be the cause, e.g., fragile X syndrome. In a nutshell, it is not possible to answer the question - why a child has autism and in most of the cases, it ca not be answered.

1.2. Problem Statement

Once autism was a rarely seen problem for mental health professionals in our country, now ASD is a vital concern for mental health professionals and health administrators as well. It is well established that caring a child with ASD results stress, depression, anxiety and poor quality of life among parents (Benson & Karlof, 2009; Davis & Carter, 2008; Hastings, 2003). As a diagnosis of ASD is overwhelming and confusing to parents, they become desperate and might select management strategies that are not validated (Ryan et al. (2011). It is vital for parents to receive appropriate information as appropriate information determines the best course of management for the ASD. In Bangladesh, parents have to manage their children with ASD most of the time as professional guidance and support is not readily available. However, there is little research on exploring how parents can overcome these difficulties arising from caring a child with ASD.

This challenging scenario requires an in-depth understanding of the managements available by the parents. The study addressed the psychological support needs of their children with ASD within the educational environment.

1.3 Research questions

The study raised following vital questions to explore:

1. What are the psychological support needs of Bangladeshi parents of children with ASD who are receiving services from special schools in Dhaka city?
2. What psychological management can be effectively used for these support needs and coping with the stress of caring these children?

1.4 Objectives

To achieve the goals of the present study, following objectives have been set:

1. Explore management problems which are burdensome for the parents of children with ASD
2. Developing guidelines empowering parents for the best management of their children with ASD

1.5 Overview of research methodology

To answer the research question 1 (What are the psychological support needs of Bangladeshi parents of children with ASD who are receiving services from special schools in Dhaka city?), parents' concerns and opinions collected through in-depth interviews. Solution to the question 2 (What psychological management can be effectively used for these support needs and coping with the stress of caring these children?) requires to develop a resource for the parents, this could be a guideline consisting of information and low-cost coping strategies.

1.6 Significance of the Study

In our country, parents of children with ASD search for management especially post-diagnostic support such as dealing with core and secondary problems of autism, special schooling, teaching daily living skills etc. First of all, parents struggle with the implication of ASD diagnosis itself. According to Kubler-Ross and Kessler (2005) there are five stages of adjustment after a negative incidence: denial, anger, bargaining, depression, and acceptance. Parents manifest similar emotional reactions as a loss of normal child after the diagnosis of ASD in their children (Penzo & Harvey, 2008). It is easier for parents to adopt effective psychological management strategies for their children with ASD if problem is properly defined, proper knowledge and skills are acquired. Autism is not curable but learning how to cope with it is critical. No, single mode of psychological management strategy ever likely to be effective for all children (Howlin, 1998). Therefore, the importance of early diagnosis and early practical advice for families is needed.

When a child is born with special needs, parents are overwhelmed by lot of issues from reaction to diagnosis, information and understanding of the condition, care and management of the child's needs, future of the child etc.

Parents struggle with their child as appropriate guidance is lacking on diagnosis to ongoing care and support. Thus, it is critical to explore parents' reaction to diagnosis of autism, various concerns regarding their child's management needs in our country and cultural context.

Chapter-2

Literature Review

Raising children with ASD is stressful for parents in daily life (Duarte, Bordin, Yazigi, & Mooney, 2005). Parents of these children might become angry, depressed and anxious in the post-diagnostic phase (Benson & Karlof, 2009). Many studies found high parenting stress with comparison to other developmental disorders (Griffith, Hastings, Nash, & Hill, 2010) and compared to typically developing children (Ingersoll & Hambrick, 2011; Montes & Halterman, 2007). Some factors such as severity of the symptoms, low accessibility of professional supports and capability of the parents in the management of their children with ASD influence parental stress (Eapen, Črnčec, Walter, & Tay, 2014). Evidences suggest that adaptive coping styles might play a protective role for parents of these children (Essex, Seltzer, & Krauss, 1999).

2.1 Management of ASD

Core symptoms of ASD are not treatable or manageable by medications as efficacy of pharmacotherapy has not been established (DeFillipis& Wagne, 2016). Pharmacological managements are applied for overcoming associated problems of ASD such as irritability, aggression, self-injurious behaviours, hyperactivity, impulsivity, insomnia and anxiety (DeFillipis & Wagne, 2016).

Multiple bio-psycho-social factors influence parents' burden of care of a child with autism. Parents are stressed by these various influences and they manifest anxiety, depression, couple conflicts are and other psychological problems. Notable factors are well-evident in the literature and are depicted here.

2.2 Factors that influence parental stress

Fathers and mothers felt stress differently and results of parental stress are mixed (Hastings et al. 2005; Rimmerman, Turkel & Crossman, 2003). In some studies, mothers reported hiher stress on child behaviour problems, regulation problems, disruptive behaviour problems (Hastings, 2003; Hastings et al., 2005) whereas fathers reported higher stress on some destructive behaviours e.g., hitting (Davis & Carter, 2008). Mothers reported dissatisfactions on married life compared to fathers (Gau et al., 2012). Mothers reported increased stress as they play the larger role in daily care of their children (Beckman 1991; Moes et al. 1992; Sharpley et al. 1997).

2.3 Child's Characteristics

Parents of younger children with ASD felt more stress compared to parents of older children (Osborne & Reed, 2010). Adolescence is a period of stress and confusion similar to the typically developing teenagers. Increased aggressive behaviour might be one way some of expressing newfound anxiety. Adolescents with ASD are at a greater risk for bullying by others, both in general and in special educational institutions. Adolescents with ASD and co-morbid Attention-Deficit/Hyperactivity disorder are more likely to be the victim of bullying than normally developing peers (Montes & Halterman, 2007). Gender differences in children with ASD also create different concerns in these parents. Mothers of adolescent girls with ASD experience heighten fears of sexual abuse (Cridland, Jones, Caputi & Magee, 2013).

2.4 Severity of the Disorder

Poor mental health and wellbeing are commonly seen in parents of children with severe symptoms of ASD. In a longitudinal study, wellbeing of these parents improved significantly

after 10 years of interventions (Gray, 2002). Though these parents showed anger, depressed mood and anxiousness after the diagnostic results, over the time parental wellbeing depended on the severity of the child's behaviour. It was evident that the severity of the disorder was associated higher stress of the parents (Ingersoll & Hambrick, 2011; Osborne, McHugh, Saunders, & Reed, 2008; Stuart & McGrew, 2009).

In another study, researchers (Benson, 2006) reported that child severity of ASD and some other factors such as, stressors at work, finances, additional siblings, cohesion among family members were associated with depressed mood.

2.5 Resources in the management of ASD

Some background factors are significantly associated with the management of ASD. Researchers have classified all kind of resources into two broad categories e.g., individual resources and family resources. Individual resources include personality, beliefs, coping styles and socio-economic factors (Perry, 2004).

Family resources include the cohesiveness and adaptation in the family (Olson, 1986). It was als found that parents who used a positive coping behaviour (Altiere and von Kluge, 2009) improved more.

Other important resources are financial resources, which is vital in enabling a family's ability to utilize formal supports and services. Siblings could be an additional resource in the sense that they could provide respite care for the children with ASD (Bloch & Weinstein, 2010).

2.6 Social Support

Notable social supports are emotional or help actually provided by the grand parents, friends, social organizations and religious leaders (Perry, 2004). In fact, researchers (Benson, 2006) reported that social support decreases stress and depressive symptoms of parents. Some researchers reported significant link between esteem-boosting friendship and among mothers of children with ASD (Weiss, 2002).

2.7 Formal Support

Formal supports are professional or paraprofessional interventions, including education or psychological interventions for the individuals, couples or for the whole family (Perry, 2004). Some researchers found that professional supports is linked to a reduction of distress in these parents (Singer, 2006).

In our country parents of children with ASD are stressed even after sending their children with autism to special school. In a study conducted in Bangladesh (Rebeiro, Azad & Mahmud, 2019), it was found that despite receiving special service from a special in Dhaka city, 84.60% of the parents of younger children (4-6 years old) and 64.30% parents of the older children (7-12 years old) with ASD suffered from mild to severe levels of anxiety measured by Anxiety Scale (Deeba & Begum, 2004) and 84.60% of the parents of younger children (4-6 years old) and 78.60% parents of the older children (7-12 years old) with ASD suffered from mild to severe levels of depression measured by Depression Scale (Uddin & Rahman, 2005). Literature suggests that in addition to raising a child with ASD, parents may also need to cope with their emotional distress (Rao & Beidel, 2009).

2.8 Psychological managements for ASD

Although many psychological interventions exist for autism spectrum disorders, only some of these are established as evidence-based practices. Most of the evidence based psychological interventions are grounded on behavioural learning theory or Applied Behaviour Analysis (ABA). Specific psychological interventions reported as evidence based are Discrete Trial Training, Pivotal Response Training (Koegel & Koegel, 2006), modelling, Schedules, Naturalistic Teaching Strategies, Picture Exchange Communication System, Antecedent Based Intervention and Parent Implemented Training (McConachie, Randle, Hammal & Le Couteur, 2005) are notable.

A number of psychological managements have been developed over the years for the core symptoms and associated symptoms of ASD. One notable psychological management is parent-mediated early interventions i.e., teaching parents' interventions that they can then apply in the home. Parent-mediated interventions have shown mixed results as these studies include small sample sizes. One large randomized controlled trial proved that parent training is superior to parent education alone (Bearss et al., 2015). some RCTs have found parent-training was effective (Kasari et al., 2014).

2.8.1 Early Behavioural Intervention

As most of the signs and symptoms of autism develop between 2 and 3 years of life, early intervention with proven effectiveness can improve functioning. Research suggests that intensive behavioural intervention, begun when a child is between 2 and 5 years old, can have a significant

and lasting positive impact. Studies have established that early intensive behavioural management improves learning, communication and social skills in young children with ASD.

The early intensive behavioural intervention or EIBI developed by Lovaas (1987) for 2- to 6-year-old children with autism is the classic example the most intensive (40h per week for 2 years or more) EIBI. The study showed improvement in IQ among ASD children compared to their neurotypical peers. Other published studies using the Lovas model also yielded similar results (Rogers et. al., 2006; Howlin 2009). Some studies report improvements in the intellectual functioning in the intervention group in comparison with control group.

EIBI programmes are highly structured and costly even in the developed countries of the world (Knapp, Romeo & Beecham 2009) and the families are not fully satisfied with these programmes. Outcomes of these behavioural interventions depend on objective measurements rather than real-life performances.

Teaching parents behavioural strategies in the home setting, without support from mental health professionals, showed positive outcomes in parents' mental health, knowledge of autism and self-efficacies (Jocelyn et. al., 1998; Tonge et. al., 2006).

2.8.2 Communication-based programmes

Interventions focusing on enhancing functional communication, rather than emphasising spoken words, such as applied behavioural analysis (ABA) have been effective in increasing functional communication skills (Howlin, 2005). The difficulty in expressing needs and feelings verbally might be the cause of aggressive or disruptive behaviours in children with ASD. Many single-case/case-series studies showed reduction of disruptive behaviours with the replacement of

effective communication skills (Durand & Merges, 2001; Prizant, Wetherby, Rubin, & Laurent, 2003).

2.8.3 Picture exchange communication systems

The Picture Exchange Communication System (PECS; Bondy & Frost, 1998) has been systematically evaluated in RCTs. This is a strategy to enhance communication ability of the children. The strategy is a combination of stages starting with prompting the child to make requests through nonverbal ways (Howlin, 2006). Another study reported that training of teachers in PECS enable students with ASD for the better communication (Howlin et.al., 2007).

2.8.4 Teaching and Education of Autistic and related Communication-handicapped Children (TEACCH)

This programme uses developmental, educational and behavioural strategies in enhancing communication and in minimising behavioural problems in the children (Schopler, 1997). There is a specific focus on environmental structure rather than verbal instructions and maximum use of visual cues. inconsistent. In a study, The TEACCH method showed improvements in perception and motor skills in a sample of children without improvement in IQ (Tsang et. al., 2007).

2.8.5 Interventions focusing on parent–child interaction

Some interventions not only focus on the child but also focus on parent-child interactions. For example, the ‘More than Words’ programme (Pepper & Weitzman, 2004), showed improvement in communication and coping skills and a reduced stress in mothers. Vocabulary and

communication skills as well as a reduction in behavioural problems were found in the children (McConachie 2005).

The Early Bird programme of the National Autistic Society of UK supports parents of nursery school children. This programme focusses on guiding parents developing effective management strategies for their children with ASD. Parents in the programme reported more satisfaction in the post-intervention period (Shields, 2001).

Parent–child interaction programmes are also supported by a number of RCTs, for example, in a study, (Aldred, Green, & Adams, 2004) the effectiveness of the 'Child's Talk' programme was established.

The Responsive Education and Pre-linguistic Milieu Teaching (RPMT) technique (Yoder & Stone, 2006) is another excellent example of programme focusing on the parent-child interactions. Such programme focuses on language development by helping parents to learn to follow the child's lead (children learn best with things that interest them), motivating communication (by placing desired objects just beyond reach) and use of social games to provide natural reinforcement.

2.8.6 Programmes focusing on social competencies and understanding

Some fundamental deficits of children with ASD such as imagination, social and emotional understandings are the focus of these programme. Mindfulness-based program for children with ASD and parents of these children (Ridderinkhof, de Bruin, Blom & Bögels, 2018) is an example of such programme.

2.8.7 Interventions focusing on joint attention and symbolic play

Investigators (Kasari, Freeman & Paparella, 2006) demonstrated the effectiveness of the short-term interventions to improve joint attention or symbolic play in children receiving EIBI in a study. This strategy focus on expressive language rather than behavioural intervention.

2.8.8 Programme focusing on the Theory of mind deficits

Deficits in 'theory of mind' are another cardinal features of ASDs. These deficits are addressed in group teaching programmes using books, cartoons, photographs and toys. Now a days, digital technology, such as interactive DVDs and virtual reality can be a resource for this programme. Published findings are generally positive showing improvements in the specific skills (Hadwin, Baron-Cohen, Howlin, & Hill,1996).

Outcomes of these programme depend on objective evaluation and generalisation of the improvements do not reflected in the outside world. Thus, effects of these interventions are not always transferable in the home environment or in the real life.

2.8.9 Social skills

Some notable strategies designed in the enhancement of social competencies in children with ASDs are groups for social skills learning, modelling etc. Recent reviews (Rao 2007; White, Koenig & Scahill, 2007; Ruble, Willis & McLaughlin, 2008) highlighted the unavailability accepted definition of social skills, the lengthy procedures and heterogenous participants. These types of programmes can be run with a low-cost budget both in clinical and educational settings. Both parents and children will be benefitted from the interactions of these groups.

2.8.10 Social stories

Social stories (Gray, 1998) are the example of strategies to engage children in social events and social understanding. Social stories could be made of simple animated drawings to help young children with ASD to realize social behaviours. Several positive accounts of effectiveness but systematic research is scarce (Ali & Frederickson, 2006).

2.8.11 Educational programmes

Very few children with ASDs can enjoy highly technical educational programmes. Educational service provided in the early years is a significant management strategy for these children.

Educational programmes are a mix of strategies developed from developmental, educational and behavioural principles (Harris, Smith & Veale, 2005; Howlin, 2010). Mainstream schooling may be just as effective as intensive home-based behavioural managements for some children with ASD (Magiati, Charman & Howlin 2007; Spreckley, 2009). Therefore, it is important that educational provisions should be highly structured and is provided by professionals who can deal with these children. Liasson between school and parents are also crucial in developing the individualized educational plan (IEP).

2.8.12 Interventions for mental health problems

Mental health interventions have been evaluated with younger children with ASDs aged below 6 years. Mental health problems such as anxiety and depression affect many children as they grow. These children have a great risk of co-morbid mental health disorders.

2.8.13 Cognitive–behavioural therapy

A few positive RCTs reported on the anxiety disorders, anger management and social skills deficits (Sofronoff, Attwood & Hinton, 2005; Chalfant, Rapee & Carroll, 2007; Reaven 2009; Wood et.al., 2009). Whether cognitive–behavioural approaches are more effective for these population, rather than behavioural approaches, needs for exploration.

2.8.14 Assessing treatment outcomes

In summary, it is clear from the above literature, that any one type of intervention is not more effective than another one. So far, the focus of research tried to prove the superiority over other (Koegel 1999).

2.8.15 Quality of life

It has been reported that children with autism and their families have compromised quality of life (Lee, Harrington, Louie & Newschaffer, 2008). Caring for a child diagnosed with autism could affect the quality of life of the caregivers in various different ways (Kheir, et. al., 2012).The concept of Quality of life (QoL) highlights a person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship with the surrounding ((WHOqol Group, 1998). QOL domains such as social activity, family burden, family activities, schooling, independence and parental concerns about their children's quality of life should be considered when determining the impact of autism rather than examining symptoms alone (Allik, Larsson and Smedje, 2006). Quality of life of parents should be measured as autism brings special demands on parent's' life as children with autism are less able to express their needs and these children may also have secondary diagnosis such as epilepsy or intellectual impairment

(Fombonne, 2003). In 2017, I translated and adapted the Quality of Life in Autism scale (QoLA: Eapen et.al. 2014) for use in Bangladesh funded by the Psychological Assessment Clinic (PAC) of the Department of Clinical Psychology, University of Dhaka (Azad, Silvy and Rabby, 2021). The original Quality of Life in Autism scale was developed in Australia to assess quality of life in parents of children with ASD aged 2–18 years (Eapen, et. al., 2014). The QoLA has 48 items in two subscales: Part A comprises QoL items and Part B of the scale comprises parent report of how problematic their child's ASD symptoms are. This scale for parents of children with ASD is suitable for both clinical and research settings.

2.9 Conceptual Framework based on some relevant theoretical models

Three relevant theoretical models were reviewed to draft a conceptual framework for this study. First of all, the ttheory of planned behavior (Ajzen, 1991) is a theoretical framework that can be used to explain parental involvement in ASD management.

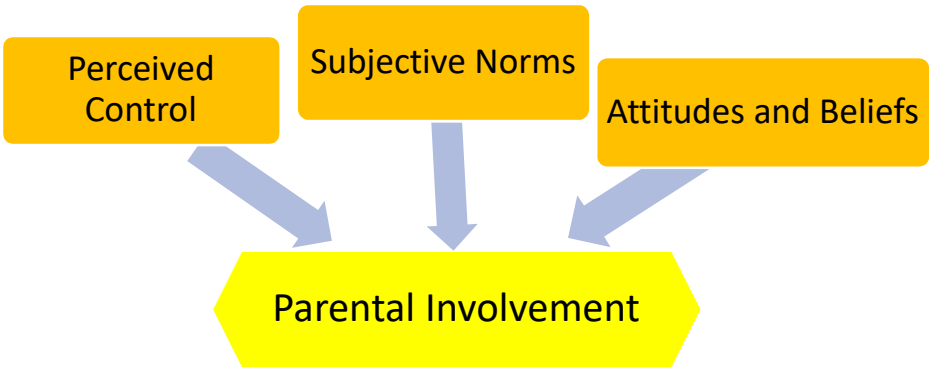

Figure 1: Theory of Planned Behavior (Ajzen, 1991)

The theory sets a model for human's action in which intentional behavior is determined by (a) attitudes and beliefs, (b) subjective norms, and (c) perceived controls (figure 1). Attitudes include feelings and believing that a certain behavior has positive outcomes which will surely

lead more intention to perform the behavior. Subjective norms are the opinions of the people surrounding the person wishing to engage in a certain behavior. Perceived controls are one's own perception of her/his ability to perform a certain behavior. The theory of planned behavior needs to elaborate some of the cultural aspects in our country.

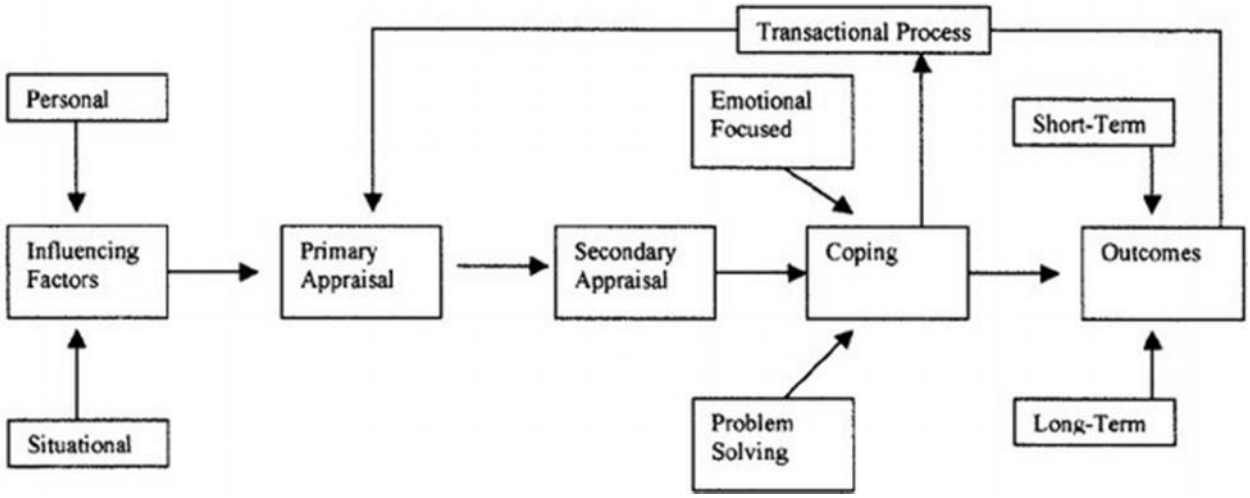

Figure 2: Transactional Model of coping (Lazarus and Folkman, 1984)

Secondly, Transactional model of coping with stress (Lazarus and Folkman, 1984) is pertinent for parents caring a child with ASD. The use positive coping strategies such as problem solving, reframing the situation, is linked to positive outcomes, whereas the use of negative coping strategies (e.g., emotion focused coping, active-avoidance coping) is associated with increased negative outcomes (Dabrowska & Pisula, 2010; Pottie & Ingram, 2008). Therefore, parents of children with ASD benefits from using adaptive coping strategies such as reframing stressful situations, despite the challenges they experience. However, parents who adopt coping behaviours that are avoidant seem to increase their risk for stress. Having a hardy personality (Weiss, 2002) is negatively linked to coping.

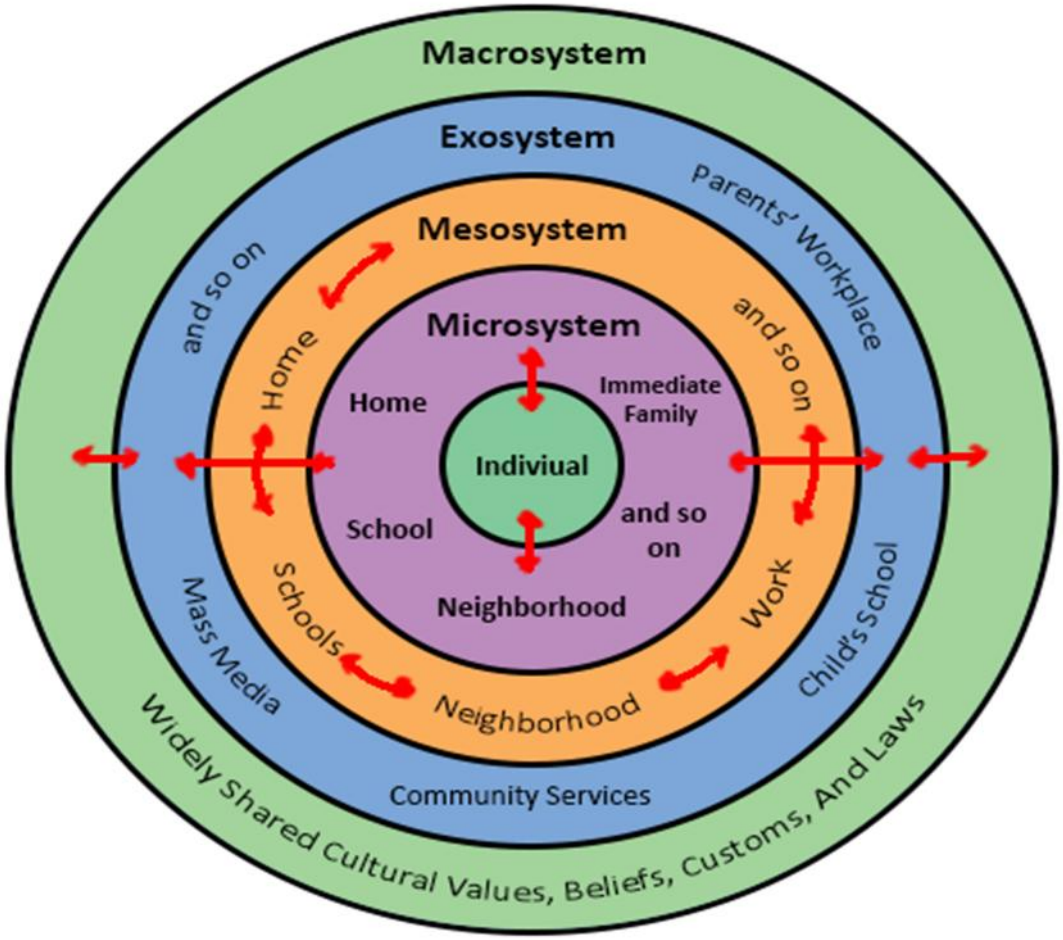

Figure 3: Bio-ecological model of human development

Thirdly, a holistic bio-ecological approach needs to incorporate including the social environment of the child. Bronfenbrenner's (1977, 1979) theory on human development is very pertinent to understand the bio-ecological perspective of ASD management. Bronfenbrenner (1977, 1979) described human development in terms of interrelated, nested ecological levels, which can is similar in the environmental context of children with ASD.

The **micro-system** is the most basic ecological level in which consists of all the inter-relationships and influences the relationships between a child's family and their school

environment. Within this microsystem, parents play the most vital role by applying evidence-based strategies after receiving training from professionals following an effective guideline.

The **meso-system** includes the relationships between a child's family and their school teachers. Any direct interaction between the child and the society becomes the part of this system and influence the development of the individual child in this bio-ecological environment.

Exo-system includes elements of the bio-ecological systems which do not directly affect the child but may have an indirect influence. For instance, if a parent has to reduce her/his working hours, this would then indirectly affect their child in that such events would create parental stress and reduce the family income.

Macrosystem, the outermost layer of the bio-ecological model encompasses cultural and societal beliefs, decisions and actions which influence an individual child's development. This might include, for example, religious influences or parliamentary legislation.

Above literature reveal that most of the ASD interventions and treatments is largely aimed at the child with some minimal attention to parents. ASD management will be most effective if managements are focussed on all ecological levels rather than on the child.

Therefore, I am proposing a conceptual framework for Clinical Psychology service in Bangladesh.

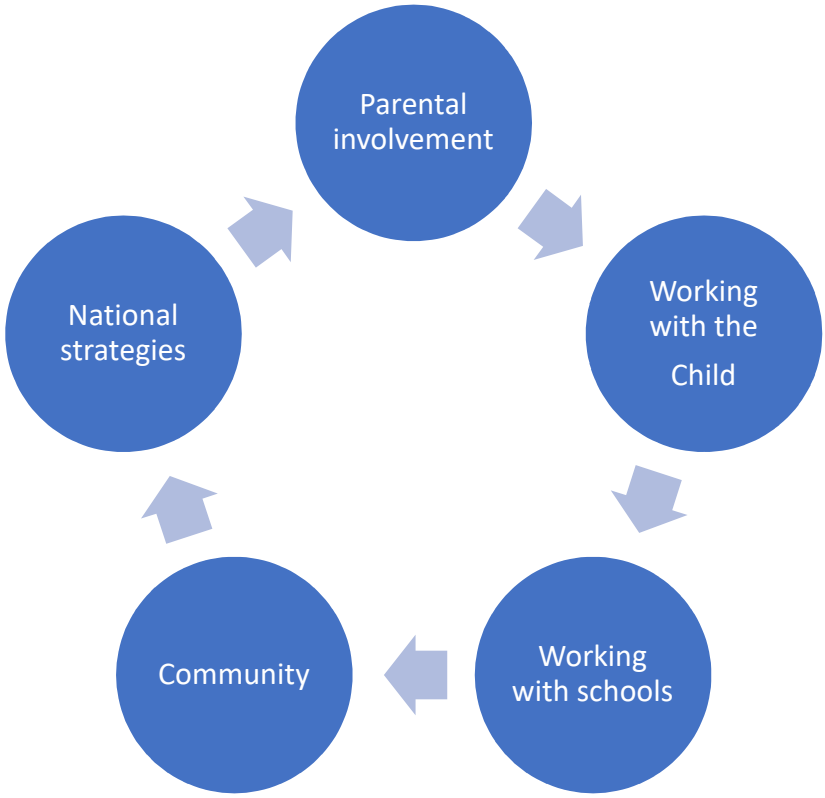

Figure-4: Proposed Framework for psychological management of ASD

First of all, we have to take into consideration the child's needs and are the main areas that are affected by ASD. These should be the main focus of attention in clinical and psychological management of ASD. Assessments should be made on specific child's cognitive and social development and on specific behavioural problems. Interventions should be made on all bio-ecological levels, attempting to change the child and to facilitate his/her adjustment to external environment.

2.10 Management guideline for parents of children with ASD

A management guideline is a resource in improving children's life as well as reducing parental stress. One of the utilities of the guideline is to deliver practical information and tools to ease the burden on the parents of children with ASD. In developed countries, specific guidelines have been developed for parents, caregivers and relevant professionals, few examples are cited here- *A Parent's Guide to Evidence-Based Practice and Autism* (National Autism Centre, USA 2011), A Parent's Guide to Autism Spectrum Disorder (NIMH, USA 2011), *Life Journey Through Autism: A Parent's Guide to Research* (Organization for Autism Research, USA 2003). It is designed to address the needs of parents of children just diagnosed with autism. Guidelines are also developed by individual researchers, for example -Guidelines in Nursing Care of Children with Autism Spectrum Disorder in High Technology Health Care Settings (Berglund, 2017).

In Bangladesh, DGHS, MOHFW developed some booklets, IEC materials which are written in Bangla and all of these are available in the website.

Chapter 3

Methodology

The study attempted to answer the question: “What are the psychological support needs of parents in our country even after sending their children with autism to special school?”.

The study was conducted in two separate phases. In phase one, a qualitative study was conducted to explore psychological support needs of parents who are sending their children in a special school.

In the second phase of the study, a draft version of the psychological management guideline was developed based on in-depth interviews of parents.

3.1 Scope of the Guideline

Psychological management needs of parents for their 3 to 18 years old children with ASD w covered in this guideline.

1. Definition: Education module for parents of children (3 to 18) with ASD.
2. General Information: Perceived problems of the child, available treatment and expectations from health care providers, screening, assessment/diagnosis, management for 3 to 18 years old children
3. Parents are appropriately guided on assessment issues and on diagnosis process
4. Psychological management strategies for social interaction, communication, repetitive behaviour and other challenging behaviours of the children with ASD.

3.2 Ethical considerations

Ethical approval was granted by the Ethics Committee of the Department of Clinical Psychology, University of Dhaka (Appendix-A) and from the school authority (Appendix-B). All parents were given a participant Information Sheet and they were asked to sign a Participant Consent Form (Appendix-C) prior to the interview. Meanwhile, the procedures were explained verbally, in easy-to-understand language to all participants. Ethical guideline and code of ethics involving human participants was strictly followed during the study.

3.2 Sample

All participants were biological parents of a child with ASD whose child lived at home, were not in long-term care in Bangladesh. Parents of children with severe ASD and other associated disabilities such as cerebral palsy were excluded.

A purposeful sampling technique (Patton, 1990) was followed in the study. Participants comprised 16 parents (mean age = 39.13 years; SD = 6.80 years) of children diagnosed with ASD who were attending a special school in Dhaka, Bangladesh. In-depth interviews were conducted on 6 mothers and there were 10 parents (7 mothers and 3 fathers) in a focus group discussion (FGD). Average age of the children at the time of the study was 10.22 years (SD = 4.97 years). Two mothers were also working (parent-teacher) as special educators of the special school.

In the second phase, feedbacks were taken from 8 experts on autism including paediatrists, psychiatrists, clinical psychologist, educational psychologist, special educators. Finally, suggestions from 5 parents were incorporated to develop the psychological management guideline of ASD. Demographic details of the participants are presented in Table 1.

Table 1

Demographic characteristics of the participants

N	16 parents of children with ASD (13 mothers and 3 fathers)
Age of the parents (Mean & SD)	39.13 years (6.80 years)
Age of the children (Mean & SD)	10.22 years (4.97 years)
Gender of the children	3 Girls (18.75%) 13 Boys (81.25%)
Educational background of the parents	Up to SSC 31.3% HSC 12.5% Graduate & above 56. 3%

3.3. Measures:

3.3.1 Topic Guide:

Using a topic guide parents' concerns and opinions were collected regarding emotional and behavioural support needs managing a child with ASD (Appendix-E). The topic guide consisted of questions on understanding the diagnosis of autism, emotional reactions, experiences etc. Core questions included:

1. What did you think when the doctor told you that your child suffers from autism?
2. What were your feelings after learning/realizing the diagnosis?

3. Did you, to your opinion, get a clear picture of (child's name) ASD characteristics, at the moment when you received the diagnosis?
4. How has your daily life been affected by your child's autism?
5. How do you assist yourself to cope with the stresses of taking care of your autistic child?

3.3.2 Family Background Questionnaire

A questionnaire entitled "Family Background Questionnaire" was developed to collect demographic data and family circumstances (Appendix-D).

3.4 Procedure

A total of 16 participants in the study, where 6 mothers participated in the in-depth interviews that were about 45 to 60 minutes long. Some parents also interviewed for the second time over phone. Another 10 parents (7 mothers and 3 fathers) took part in a focused group discussion (FGD) meeting, where participants shared their concerns based on the topic guide questions and their responses were recorded for analysis. All the interviews were conducted face-to-face in a special school. Interviews were digitally recorded and transcribed verbatim. A draft version of the psychological management guideline was developed based on in-depth interviews of parents. Pre-final version of the psychological management guideline was developed after incorporating feedbacks from 8 experts on autism. Final version of the guideline was developed after incorporating parents' suggestions.

3.7 Data Analysis

Parents were then elaborated further with the aid of probing and follow-up questions. Interviews were recorded and transcribed verbatim. Transcripts were then analyzed using the techniques of thematic analysis (Braun & Clarke, 2006) based on interpretative phenomenological analysis (IPA). Transcripts were first read in full to get an overall sense of interview responses. Themes in the data were identified by the focus of questions asked (for example 'challenges faced', 'support needed'), and from what emerged in the data. A list of codes was developed and structured according to themes and subthemes. Data has been anonymized by removing references to people's names in order to protect confidentiality.

Chapter 4

Results

Participants took part in in-depth interviews conducted face-to-face before school closure due to COVID-19 pandemic and over smart-phones using digital platforms such as WhatsApp or Zoom. All interviews were audio-recorded, professionally transcribed and cleaned. Qualitative data were analyzed following Interpretative phenomenological analysis (IPA). Initial coding yielded 60 codes then axial coding yielded 22 codes. Themes were then discovered from all these codes. Codes were first organized in different themes for each of the five main questions that were presented. The five questions were about the participants' thoughts and emotional reactions autism diagnosis, parents' understandings of autism diagnosis, how raising children with autism affects their daily life, how they cope with the stresses of parenting a child with autism, and what are their psychological support needs (Appendix-I). Finally, overarching themes were discovered combining parents' responses to the questions asked in the interviews.

An overview of the findings of the phase-1 are presented in Table 2 from the qualitative data analysis as major themes: (1) Parents' reactions to the diagnosis; (2) Understanding the consequences of the diagnosis; (3) Stress of raising a child with autism; (4) Concerns about core and secondary problems; (5) Uncertainty about child's future; (6) Parents' sacrifices arising from caring the child; (7) Parents feelings or prevailing mood; (8) Family life related concerns; (9) Professional support needs, and (10) Support needs from the Government of Bangladesh.

Table 2
Themes and sub-themes emerged in the interviews

Themes	Sub-themes
1. Parents reactions to the diagnosis	Shattered dream of not having a typical child
	Denial of the harsh reality
	Anger toward the doctor or health professionals
	Feelings of stress
	Feelings of helplessness
	Anxiousness
	Shock or unexpectedness
	Depressed feeling
2. Understanding the consequences of the diagnosis	Not understanding the complex nature of autism
	Not understanding the prognosis of the disorder
	Not understanding the complex interventions
	How to raise the child for typical development.
3. Stress of raising a child with autism	Concerns of raising a child normally
	Spending additional time caring the child.
	Rare disorder of the child in the family.
	Lack of prior knowledge to deal with these children.
4. Concerns about core and secondary problems	Challenges of teaching daily living skills
	Overcoming child's communication difficulties
	Co-morbid health problems
	Co-morbid mental health problems
	Challenging behaviours

	Emotional problems
	Sensory problems
	Nutritional deficiencies
	Safety concerns outside home
	Fear of sexual abuse
	Academic progression
	Lack of quality recreational activities
5. Uncertainty about child's future	Uncertainty after the death of both parents.
	Concerns about future financial management.
	Leaving the child independent
6. Parents' sacrifices arising from caring the child	Quitting job for taking care of the child
	Not attending family program
	Avoiding recreational activities
	Avoiding social invitation
	Sleep deprivation
	Poor mental health
	Poor quality of life (Poor living condition)
7. Parents feelings or prevailing mood	Low mood most of the time
	Depressed feelings
	Helplessness
	Frustration
	Low self-esteem
	Anger
	Emotional burnout or exhaustion

	Helplessness
	Unhappiness
	Marital disharmony
	Poor relationship with family members
8. Family life related concerns	Marital discord
	Lack of co-operation from spouse
	Poor relationship with in-laws
	Negative attitude of the neighbours
	Negative attitude of the relatives
9. Professional support needs	Finding a quality special school
	Lack of psychological service
	Lack of early intensive behaviour therapy
	Lack of special educators
	Lack of autism-friendly paediatricians
	Lack of developmental therapists
	Lack of qualified occupational therapists
	Lack of qualified physiotherapists
	Lack of qualified music teacher, dance teacher
10. Support needs from the Government	Lack of full-fledged residential care facilities for children with ASD
	Lack of respite care facilities
	Lack of multi-disciplinary professional services
	Lack of vocational support for these children

	Lack of integrated mental health service linked with health and education system
	Lack of training-facilities for parenting a child with ASD
	Lack comprehensive materials, website and relevant resources
	No functional parents-support group

During the interviews, some topic guide questions elicited parents' thoughts and feelings on parenting a child with ASD. Participants' responses clearly indicated strong emotions and thoughts reflected in the themes and subthemes, some quotations are presented within brackets:

"Then suddenly I felt very anxious, I did not know such thing before (autism), when I learn suddenly about this, I thought all these days that I can cure my child with medical treatment."

> "When doctor told me that my child was diagnosed as an autistic child, I did not understand what are the natures of an autistic child?"

"Initially, few questions popped-up in my mind "How can I raise or develop my child gradually or step by step?"

One participant expressed stress on caring her child in the interview as cited below,

> "I thought "Alas! Autism is not easily curable. Now, I have to work hard, learn many things from different workshops, and spend more time caring my child. I felt this tension in my mind first. I have to send my child in a special school"

One mother expressed her anxiety on teaching daily living skills as below,

"I have to teach my child daily living skills as doctor told me that the child will not do everything of her own**. "**

"I was searching for special school for my child's better development."

Another mother talked about quitting full-time job in a statement as

"I had to quit my job for taking care of my child"

All parents expressed their worries of their children's future after their death, as expressed by one parent,

"I am concerned about my child's future. I want to leave my child independent."

In the second phase, a draft version of the psychological management guideline was developed based on in-depth interviews of parents. The guideline was then evaluated by 8 experts on autism. Final version of the psychological management guideline for parents of children with autism spectrum disorder (ASD) was developed after incorporating suggestions from 5 parents. Brief descriptions of the psychological management guideline for parents of children with ASD are presented in Table 3. Full guideline is attached in the appendix-F.

Table 3
Contents of the Psychological Management Guideline

Chapter Heading	Brief summary
1. Autism spectrum disorder: 1.1. Characteristics 1.2. Diagnosis 1.3. Psychological assessment	Chapter 1 of the Guideline focuses on the characteristic features of autism spectrum disorder (ASD), its diagnosis and initial assessment of children with ASD. Monitoring of developmental milestones at home or visits to a child

1.4. Prognosis	development centres (Shishu Bikash Kendra) of any Government hospital in Bangladesh might ensure early identification. Psychological assessment might consist of testing the child's intellectual development. The prognosis in children with ASD was described in easy to understandable way.
2. Parents' emotional reactions 1.1. Shock 1.2. Denial 1.3. Anger 1.4. Depression	Chapter 2 describes strategies for coping with emotional reactions. Parents frequently experience a range of negative emotions after the diagnosis of autism. Coping with these uncomfortable emotions includes use of cognitive-behavioural strategies and gradual acceptance of the diagnosis and seeking ongoing mental health supports.
3. Parenting a child with autism 1.5. Behavioural management 1.6. Emotional management	Chapter 3 focus on equipping parents to apply evidenced-based psychological strategies to manage challenging behaviours and thereby increasing parental skills.
Psychological services for parents of children with ASD	This chapter depicts professionals' roles toward progress of specific goals and assisting the parent to further refine their parenting plan if needed and discussions of ideas to maintain positive changes.
4. Professional supports	Chapter 4 is on professional guidance to teach their children how to carry-out daily living skills or tasks.

5. Government services	Chapter 5 discuss on appropriate information, collaboration and referral for case management.

Chapter 5

Discussion

The study attempted to empower parents of children with ASD by developing a psychological management guideline for our country. In the development process of the guideline, parents' experiences and concerns of raising a child with ASD were explored and the data were analyzed using interpretative phenomenological analysis (IPA). In order to achieve the objectives, a multi-phasic mixed method research design was followed. In phase-1, a qualitative study was conducted to explore psychological support needs of parents who are sending their children in a special school. In the phase-2, a draft version of the psychological management guideline was developed based on thematic analysis of the interview responses from phase-1 of. Finally, feedbacks about the draft version of the guideline were collected from parents and relevant professionals. All participants completed intensive interviews, conducted either face-to-face or by phone, audio-recorded, professionally transcribed. Participants' responses were coded resulting ten overarching themes were discovered. All the themes emphasized the psychological support needs for parents of children with ASD.

Theme-1 indicated parents' manifestation of negative emotional reactions after the diagnosis of autism in their children including denial, anger, anxiety, depression and stress. Many of these concerns may be similar to the previous studies done in the area of ASD, such as negative impact of late diagnosis (Kabot, Masi & Segal, 2003); challenges of transitions and coping with aggression (Card et.al., 2008); problems of adolescents adjusting to the increased demands of adolescent hygiene (Chan and John, 2012).

Theme-2 highlights the unclear understandings of the diagnosis of the complex disorder by the parents including the prognosis, choice of appropriate management and challenges in raising the child (Hastings & Johnson, 2001).

Theme-3 demonstrated that parents face multiple stresses ensuring child's education, health and overall child development. Choosing the right child care strategies from a vast option is very difficult for the parents who work. When both parents work, they feel the stress of overscheduled lives, spouses often have little or no time together and this time-crisis can put strain on parent-child relationship (Griffith, Hastings, Nash, & Hill, 2010).

Theme-4 revealed parents' concerns of trying to raise a child with ASD by searching answers from hundreds of burning questions, such as "How can I make our daily lives feel more manageable?", "How do I deal with my child's mental health problems?", "What is the safest way to keep my child cool?", How can I help my child falling asleep at night?", "My child does not want to eat vegetables, is that ok?", "What is the best method of toilet training?, "How can I ensure safety of my child and prevent missing?, "How can I manage my child during school holidays and vacations?" and so many questions.

Theme-5 showed concerns related to uncertainty after parents' death expressed by questions like "What should we do for those time of emergencies when we are no more?"

Theme-6 depicted how these children take up a significant portion of parents' time from their life dealing with the problem behaviours. Parents feel inadequate and try to be perfect when encountering dilemma of attending a family program over a non-compliant child.

Theme-7 uncovered prevailing mood of parents from a series of cancelled festivals, reunions, family gatherings resulted feelings of depression, low self-esteem, anger and frustration as a part of life. This kind of life-style also brings marital disharmony, poor relationship with other family members and overall unhappiness.

Theme-8 depicted the issues of family dynamics where individual members of the family have their own goals and dreams. When these goals are disrupted by the distraction of the child with ASD, adverse consequences such as marital discord, lack of spousal involvement, poor relationship with in-laws starts to emerge.

Theme-9 picked up parents' voice on the scarcity of qualified professionals for the management of ASD in our country. Any program works best when parents have access to the guidance, instruction and encouragement from trained professionals.

Theme-10 emphasized the Government commitment in developing facilities and quality support systems so that parents can be convinced by the overall services.

The guideline was developed based on theories that explains how guidelines can be useful by increasing parent's perceived control and the guidelines also contain practical information by using pictures to break down tasks into a series of small steps, illustrates how the guidelines can potentially be useful, for example helping parents develop skills of behavioural and emotional management.

Findings of this study revealed the complex needs of families caring for a child with ASD is consistent with Bronfenbrenner's (1979) theoretical framework of multifaceted layered supports for optimum development. Parents spoke a lot about the various challenges they faced being a parent of a child with autism. Most of them pointed to how stressful the child's challenging behaviour was for them. While most parents and caregivers do their best to raise their children with ASD, they may feel overwhelmed or they may not know the best way to manage these challenges.

Due to the time limitation, it was not possible to follow up parents using the guidelines and giving feedback on the extent to which the guidelines have been useful in practice using a structured interview to get parents evaluation. For example, how the guideline changed their behaviours, how the guideline empowered them, how they thought it benefitted the child, what the guideline missed out and how the guideline needs to be further developed.

The researcher contacted more than 25 parents before he was able to secure the respective participants. While eager to support, it was difficult for many to find the time to participate. This was due to the COVID-19 pandemic situation both for parents and for the expert professionals as well. This psychological management guideline was developed to support and promote a positive future for these children during the challenging period.

Chapter 6

Conclusion

When a child is diagnosed with autism, parents might take many roles as care coordinator, therapist, parent, teacher and advocate etc. In the life-long journey, parents require different skills depending on the child's need. Without proper guidance, parents lack the resources to appropriately participate in their children's managements that are implemented in their learning communities (2006).

Globally, childhood disability is not a priority in health systems (Cieza et al., 2021). The situation is becoming more threatening as the number of children with ASD is increasing. More children are surviving but not all of them are thriving. Children with ASD may need specific services related to their impairments. Yet evidence-based interventions often do not exist or are underdeveloped or under-resourced. When available, services are often costly, not physically inclusive or accessible only in urban areas.

In this study, strong consensus was found among parents on the need for much more comprehensive autism services. All health care and education professionals need to be alert to possible signs of ASD and be open to parents' concerns about their children.

Chapter 7

Recommendations

Based on the observations in study, some points are recommended for health practitioners, teachers and parents of children with ASD:

1. Professionals should be more familiar to the complex nature of ASD and this special attention by the professionals will facilitate less challenging diagnostic pathways and enable earlier access to support services.
2. A strong collaboration between education and health sectors to empower the parents (or individuals) to make decisions, based on the provision of quality health information and personal preferences.
3. All parents should engage in social support services where gender specific groups might be formed for these children as they face different challenges.
4. Parent and professional partnership is very crucial in alleviating stress of parenting a child with ASD.

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Appendix A

Certificate of Ethical Approval

Project Number : **PH200201**

Project Title : **Developing a Psychological Management Guideline for Parents of Children with Autism Spectrum Disorder**

Investigators : **S. M. Abul Kalam Azad, Dr. M. Mahmudur Rahman** and **Dr. Graham Powell**

Approval Period : **23 February 2020** to **22 February 2023**

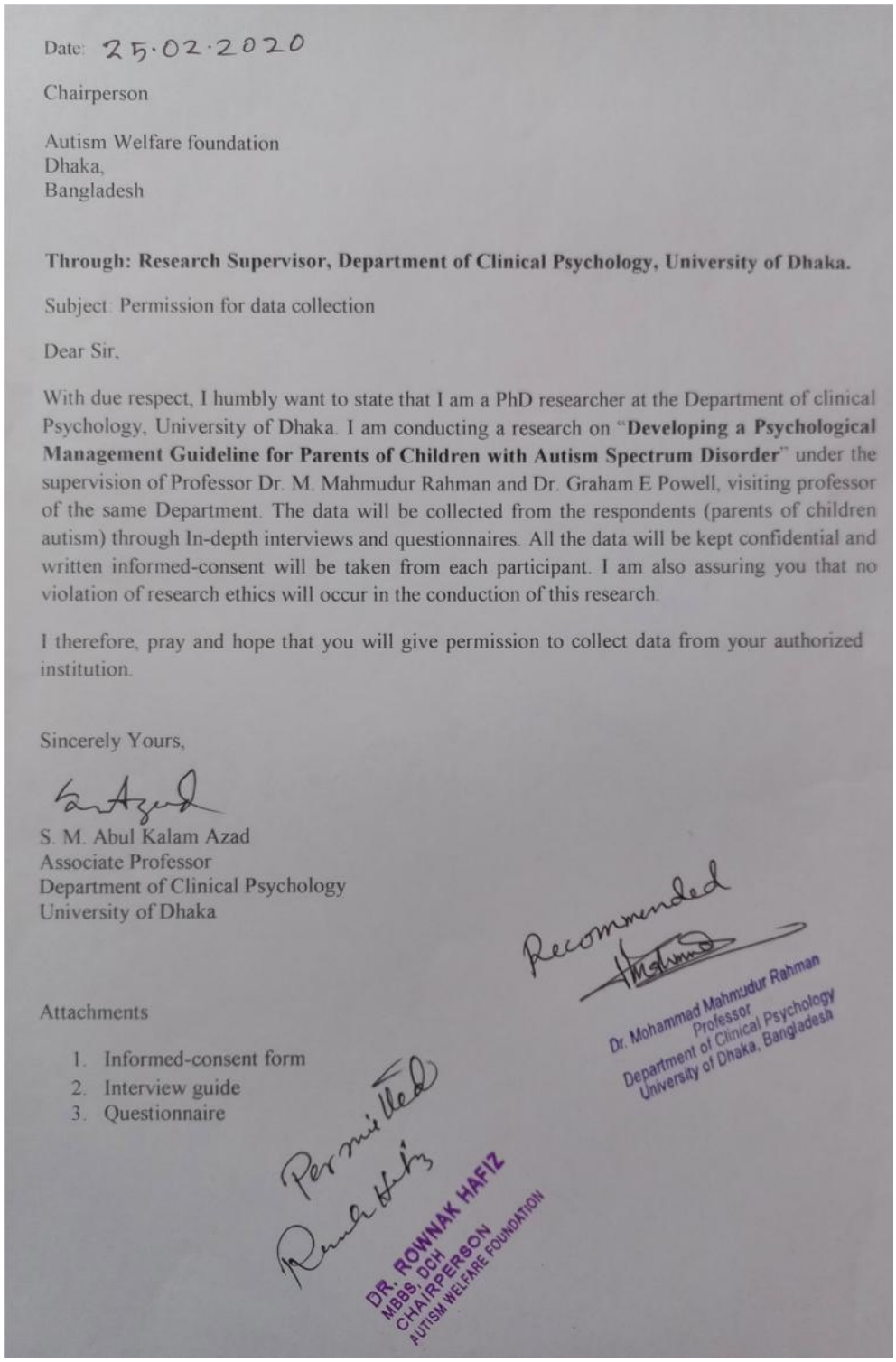
Terms of Approval

1. Any changes made to the details submitted for ethical approval should be notified and sought approval by the investigator(s) to the Department of Clinical Psychology Ethics Committee before incorporating the change.
2. The investigator(s) should inform the committee immediately in case of occurrence of any adverse unexpected events that hampers wellbeing of the participants or affect the ethical acceptability of the research.
3. The research project is subject to monitoring or audit by the Department of Clinical Psychology Ethics Committee.
4. The committee can cancel approval if ethical conduction of the research is found to be compromised.
5. If the research cannot be completed within the approved period, the investigator must submit application for an extension.
6. The investigator must submit a research completion report.

Chairperson
Ethics Committee
Department of Clinical Psychology
University of Dhaka

Appendix B

Permission letter from School Authority



Date: 25.02.2020

Chairperson

Autism Welfare foundation
Dhaka,
Bangladesh

Through: Research Supervisor, Department of Clinical Psychology, University of Dhaka.

Subject: Permission for data collection

Dear Sir,

With due respect, I humbly want to state that I am a PhD researcher at the Department of clinical Psychology, University of Dhaka. I am conducting a research on "**Developing a Psychological Management Guideline for Parents of Children with Autism Spectrum Disorder**" under the supervision of Professor Dr. M. Mahmudur Rahman and Dr. Graham E Powell, visiting professor of the same Department. The data will be collected from the respondents (parents of children autism) through In-depth interviews and questionnaires. All the data will be kept confidential and written informed-consent will be taken from each participant. I am also assuring you that no violation of research ethics will occur in the conduction of this research.

I therefore, pray and hope that you will give permission to collect data from your authorized institution.

Sincerely Yours,

S. M. Abul Kalam Azad
Associate Professor
Department of Clinical Psychology
University of Dhaka

Recommended

Dr. Mohammad Mahmudur Rahman
Professor
Department of Clinical Psychology
University of Dhaka, Bangladesh

Attachments

1. Informed-consent form
2. Interview guide
3. Questionnaire

Permitted

DR. ROWNAK HAFIZ
MBBS, DCH
CHAIRPERSON
AUTISM WELFARE FOUNDATION

Appendix C

Informed Consent for PhD study in Bangla গবেষনায় অংশগ্রহনের সম্মতিপত্র

প্রিয় অংশগ্রহনকারী,

আমি ঢাকা বিশ্ববিদ্যালয়ের একজন শিক্ষক এবং পিএইডি গবেষক। গবেষনাটি তত্তাবধান করছেন অধ্যাপক ড. মোঃ মাহমুদুর রহমান এবং ভিজিটিং প্রফেসর ড. গ্রাহাম পাওয়েল, ক্লিনিক্যাল সাইকোলজি বিভাগ, ঢাকা বিশ্ববিদ্যালয়। পিএইডি থিসিসের অংশ হিসেবে আমি একটি গবেষনা করছি। উক্ত গবেষনায় অংশগ্রহনের জন্য আপনার সম্মতি কামনা করছি।

বিনীত

এস. এম. আবুল কালাম আজাদ
ক্লিনিক্যাল সাইকোলজি বিভাগ
ঢাকা বিশ্ববিদ্যালয়

গবেষনার শিরোনামঃ

Developing a Psychological Management Guideline for Parents of Children with Autism Spectrum Disorder

গবেষনার উদ্দেশ্যঃ

আমরা অটিজম আছে এমন শিশুদের পিতা-মাতা (বাবা-মা) দৈনিক জীবনে কি কি ধরনের সমস্যা মোকবেলা করেন ও কিভাবে ঈত্যাদি কাটিয়ে ওঠেন এবং আরো ভালো উপায় বের করা যায় তা নিয়ে গবেষনা করছি।

গবেষনার সুফলঃ

অটিজম ব্যবস্থাপনার নীতিমালা প্রনয়নে গুরুত্বপূর্ন ভূমিকা রাখবে। এখানে আপনার অভিজ্ঞতার ভিত্তিতে কিছু প্রশ্নোত্তর ও মতামত দিতে হবে। এই গবেষনায় আপনার অংশগ্রহন অসামান্য অবদান রাখবে।

অংশগ্রহনকারীর অধিকার ও গোপনীয়তাঃ

এই গবেষনায় অংশগ্রহণ সম্পূর্ণ আপনার ইচ্ছার উপর নির্ভর করে। আপনি চাইলেই অংশগ্রহণ না করার সিদ্ধান্ত নিতে পারেন এবং যে কোন সময় গবেষনা হতে নিজেকে প্রত্যাহার করতে পারেন।

আপনি এক্ষেত্রে নিশ্চিন্ত থাকতে পারেন যে, আপনার প্রদানকৃত তথ্য অত্যন্ত গোপনীয়তার সাথে সংরক্ষিত হবে এবং অন্য কাউকে এটা দেখানো হবেনা।

আপনি যদি অংশগ্রহণে সম্মত হন তাহলে আপনার এবং আপনার পরিবারের ব্যাপারে আমি কিছু প্রশ্ন করব।

আমি গবেষকের কাছে সাক্ষাৎকার প্রদানে সম্মতি দিচ্ছি হ্যাঁ/না

আমি সাক্ষাৎকারটি ক্যসেটে রেকর্ডকরার সম্মতি দিচ্ছি হ্যাঁ/না

আমি প্রয়োজনে পরবর্তীতে আবারও সাক্ষাৎকার প্রদানে সম্মতি দিচ্ছি হ্যাঁ/না

আমি আমার পূরন করা গবেষনায় অন্তর্ভূক্তি বিষয়ক প্রশ্নমালাটি আমার

সাক্ষাৎকারের তথ্যের সাথে সংযুক্ত করার সম্মতি দিচ্ছি হ্যাঁ/না

অংশগ্রহনকারীর নামঃ

স্বাক্ষর

তারিখঃ

Appendix D

Family Background Questionnaire

1. **Code:**
2. **Age of parent and relationship with the child:**
3. **Age of child:**
4. **Gender of the child:**
5. **Education of the parent:**
6. **Occupation of the parent:**
7. **Monthly income:**
8. **SES:**
9. **Child receiving services (Current):**
10. **History of diagnosis/ at what age you noticed symptoms?**
11. **Autism Diagnosis report:**
12. **Intelligence test done and level of severity:**
13. **Any co-morbidity/other health problems:**
14. **Mode of Contact: e-mail, mobile, mailing address**

Appendix E

Interview guide (Bangla)

আমরা অটিজম আছে এমন শিশুদের পিতা-মাতা (বাবা-মা) দৈনিক জীবনে কি কি ধরনের সমস্যা মোকাবেলা করেন ও কিভাবে সমস্যা গুলো কাটিয়ে ওঠেন এবং কিভাবে আরো ভালো উপায় বের করা যায় তা নিয়ে গবেষনা করছি।

১। ডাক্তারের কাছ থেকে আপনার সন্তানের অটিজম আছে শোনার পর আপনার কি চিন্তা হয়েছে এবং কি অনুভব করেছেন?

২। যে মুহূর্তে আপনার সন্তানের অটিজম ডায়াগনসিস হাতে পেলেন, সেই মুহূর্তে কি আপনি একটি পরিস্কার চিত্র পেয়েছেন?

৩। এই সংবাদ শোনার পব (সন্তানের সেবা-যত্ন করতে গিয়ে) অনেকের কিছু মানসিক চাপ তৈরি হয়- এ সম্পর্কে কিছু

বলবেন কি/ ধারনা কি?

৪। এ সব ক্ষেত্রে বাবা-মা কি করেন বা কিভাবে সামলান/মোকাবেলা করেন?

৬। আপনার কি মনে হয় এই পদ্ধতি/উপায় ব্যাতিত আরও অন্য কিছু হতে পারে? এ সম্পর্কে কিছু বলুন।

Interview guide (English)

1. **What did you think when the doctor told you that your child suffers from autism?**
2. **What were your feelings after learning the diagnosis?**
3. **Did you, to your opinion, get a clear picture of (child's name) ASD characteristics, at the moment when you received the diagnosis?**
4. **How has your daily life been affected by your child's autism?**
5. **How do you deal or manage these issues?**
6. **What can be better alternative strategies?**

Appendix F

Psychological management guideline for parents of children with autism spectrum disorder

অটিজম বৈশিষ্ট্য সম্পন্ন শিশু-কিশোরদের মনোবৈজ্ঞানিক ব্যবস্থাপনায় মা-বাবা

S M Abul Kalam Azad
University of Dhaka
February 2022

Users' responsibility

ব্যবহারকারীর জ্ঞাতব্য/কর্তব্য

The recommendations in this guideline represent the view of the author. The guideline was developed from PhD research work based on an empirical study.

Contents

Preface

This guideline covers psychological management needs of parents for their 3 to 18 years old children with ASD. The guideline addressed following issues:

1. **General Information: Perceived problems of the child, available treatment and expectations from health care providers, screening, assessment/diagnosis, management for 3 to 18 years old children**
2. **Psychological management strategies for social interaction, communication, repetitive behaviour and other challenging behaviours of the children with ASD.**

Who is it for?

- **Parents of children with autism spectrum disorder**
- **Autistic children and young people, children and young people who may have autism and their families and caregivers**
- **Special educators**
- **Health professionals**

প্রথম অধ্যায়

১.১ অটিজম ধারনা

(Autism spectrum disorder: characteristics and prognosis)

অটিজম মস্তিষ্কের স্নায়ু-বিকাশ জনিত সমস্যাসমুহের মধ্যে অন্যতম। প্রকাশিত প্রধানতঃ দুই ধরনের লক্ষণসমুহ অটিজম নির্দেশ করে, এগুলো হলো ভাষার মাধ্যমে যোগাযযোগ ও সামাজিক মেলামেশা, একই আচরন বারবার করা ও একই বিষয়ে আগ্রহ দেখানো (ডিএসম ৫, এপিএ ২০১৩)। এই ঘাটতিসমুহ মৃদু থেকে তীব্র আকারে দেখা দিতে পারে অর্থাৎ ভিন্ন ভিন্ন শিশুর ক্ষেত্রে ভিন্ন ভিন্ন তীব্রতা বা লক্ষণসমুহ কম-বেশি মাত্রার হতে পারে। মেয়েদের তুলনায় ছেলেদের মধ্যে ৪ গুন বেশি অটিজম হতে দেখা যায় (ডিএসম ৫ অনুযায়ী), যদিও মেয়েদের মধ্যে এই কন্ডিশনটি নির্নয় হতে দেরী হয় অথবা ভুলভাবে অবহেলিত হয় (মিসডায়াগনিসস হয়)। বাবা-মা হয়তো ২ বছরের মধ্যে খেয়াল করেন তাদের সন্তান চোখের দিকে তাকায় না, ডাকলে সারা দেয় না, বাবা-মা এর সাথে আবেগীয় বন্ধন তৈরি হয় না।

অটিজম এর নির্দিষ্ট কোন পরিনতি নেই অর্থাৎ শিশু প্রাপ্ত বয়স্ক হলে লক্ষন/বৈশিষ্ট্য সমুহ মৃদু, মাঝারি বা তীব্র আকার ধারন করতে পারে। এই অনিশ্চয়তা বাবা-মার জন্য অনেক চাপ-মূলক পরিস্থিতি তৈরি করে।

১.২ অটিজম নির্নয় প্রক্রিয়া

(Understanding diagnosis and assessment processes)

প্রাকচিহ্নিতকরন ও নির্নয় কয়েকটি ধাপে সম্পন্ন হয় বিধায় এটি নিশ্চিত হওয়া একটি জটিল প্রক্রিয়া। স্ক্রিনিং এর পর ডায়াগনসিস একটি ধারাবাহিক প্রক্রিয়া ও সময় সাপেক্ষ বিষয়। যদিও আপনার সন্তানের মধ্যে ১২-১৮ মাসের মধ্যে কিছু আচরন লক্ষ্য করে থাকবেন তবুও চুড়ান্তভাবে নিশ্চিত হতে আরও কিছু পরীক্ষা-নিরিক্ষার পর রিপোর্ট পাওয়া যায়। এ ক্ষেত্রে সন্তানের স্বাভাবিক বিকাশকাল পর্যবেক্ষণ করতে হয় এবংএই কন্ডিশনটি নিশ্চিত হওয়ার জন্য দুই স্তরের পরীক্ষা-নিরীক্ষা করা হয়, যথাঃ (১) বিকাশ জনিত স্ক্রিনিং অর্থাৎ বয়স অনুসারে সঠিক বিকাশ খতিয়ে দেখা এবং (২) সমন্বিত (ডায়াগনসিস) মূল্যায়ণ করা হয়।

(১) বিকাশ জনিত স্ক্রিনিংঃ ৯, ১২, ১৮, ২৪ ও ৩০ মাস বয়সে আপনার সন্তানের বিকাশ পর্যবেক্ষন করুন। কোন অসামঞ্জস্য দেখা দিলে নিকটস্থ হাসপাতালের শিশু বিকাশ কেন্দ্র অথবা শিশু বিশেষজ্ঞের পরামর্শ নিন। বিশেষ করে শিশুটি যদি অপূর্ণ সময়ে ভূমিস্ট হয় বা কম ওজন নিয়ে জন্মগ্রহন করে অথবা অন্য কোন বিকাশজনিত সমশ্যা চিহ্নিত হয় অর্থাৎ আপনার সন্তানের কোন উচ্চ ঝুকি থাকে, তাহলে এটা আরো বেশী গুরুত্বপূর্ন।

(২) সমন্বিত মূল্যায়ণ বা ডায়াগনসিসঃ এই স্তরে ডাক্তার শিশুর আচরন ও বিকাশ সম্পর্কে কিছু পরীক্ষা-নিরিক্ষা করেন এবং বাবা-মায়ের সাক্ষাৎকার গ্রহন করেন। এ ছাড়াও আপনার সন্তানের দৃষ্টিশক্তি ও শ্রবনশক্তি, মস্তিষ্কের পরীক্ষা এবং প্রয়োজন অনুসারে অন্যান্য পরীক্ষা করা হতে পারে।

চিত্র-১: অটিজম এর প্রধান লক্ষণ সমুহ

(Figure-1: Early Signs of Autism)

দ্বিতীয় অধ্যায়

২.১ বাবা-মা এর প্রতিক্রিয়া মোকাবেলা

(Managing parents' emotional reactions)

সন্তানের অটিজম নিশ্চিত হলে বাবা-মা স্বাভাবিকভাবেই কিছু তীব্র আবেগ অনুভব করেন। এই সময়ে বাবা-মায়ের মনে অনেক ধরনের নেতিবাচক চিন্তা ও আবেগ কাজ করে, যেমনঃ রাগ, হতাশা, দুঃখবোধ, না পাওয়ার বেদনা, আত্মত্যাগ, পাপবোধ, স্বপ্ন ভঙ্গ বা স্বপ্ন পরিবর্তন ইত্যাদি। সহজ কিছু উপায়ে এসব আবেগের মোকাবেলা করতে পারেন-

১. দৃষ্টিভঙ্গি পরিবর্তন করুন

আপনার সন্তানের ভালো দিকটি দেখুন, যেমন, সে কি কি বিষয়ে পারদর্শী বা পটু এবং কোন কোন ক্ষেত্রে উন্নতি করছে ইত্যাদি। পৃথিবীতে কোন কিছুই ত্রুটিমুক্ত নয় আর এই নিরপেক্ষ দৃষ্টিভঙ্গিই আপনাকে সামনে এগিয়ে যেতে শক্তি যোগাবে।

২. নিজের যত্ন নিন

নিজের প্রতি সদয় হোন এবং নিজেকে সময় দিন। মাঝে মাঝে বিভিন্ন কারণে মনের ভেতর তীব্র আবেগ-অনুভুতি হানা দিয়ে উঠতে পারে। এ সময় শরীরকে হাল্কা বা রিলাক্স করুন ও মনে ইতিবাচক চিন্তা আনুন।

৩. অন্যদের সাথে আনন্দ ভাগাভাগি করুন ঃ

যখনই সম্ভব, পরিবারের সবাইকে নিয়ে মজার কিছু করুন। বন্ধুদের সাথেও সময় উপভোগ করুন।

৪. অন্যদের সহায়তা নিন

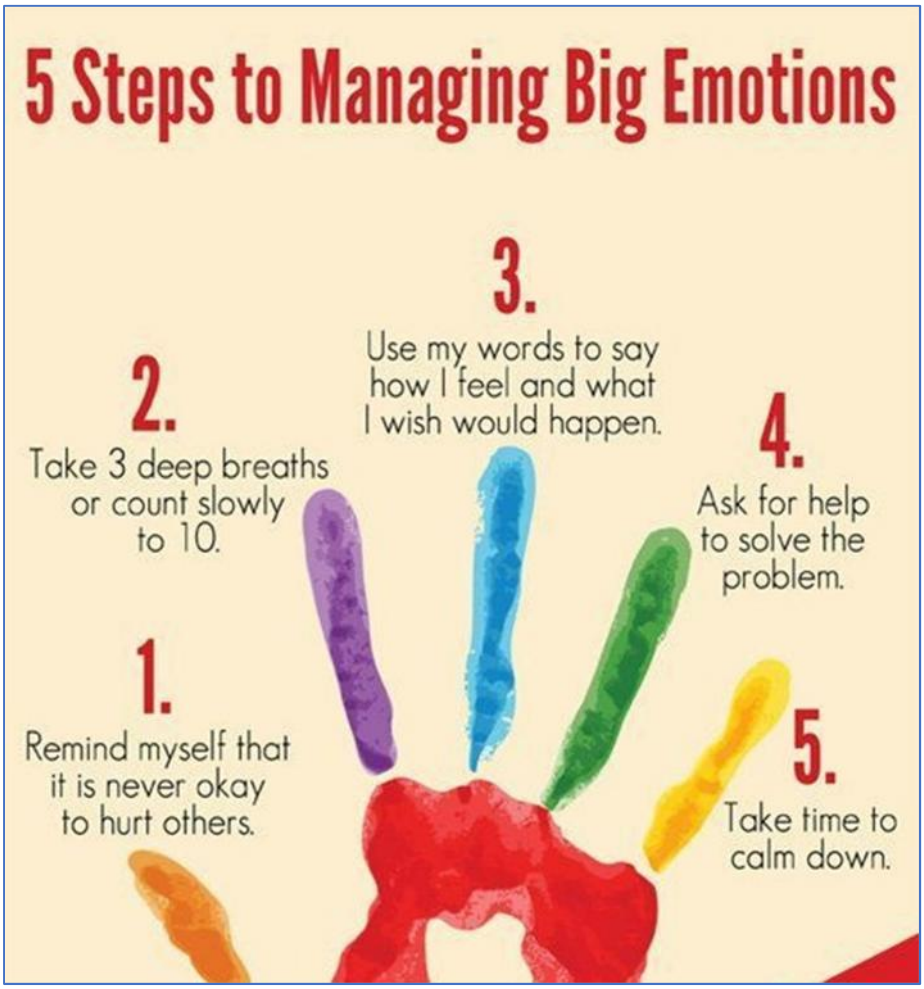
যে কোন বিষয়ে পেশাজীবিদের অথবা পরিচিত অভিবাবকদের পরামর্শ নিয়ে বাস্তব সমস্যা সমাধানের উপায় বের করুন।

৫. ধৈর্য্য ধারন করুন

সন্তানের বয়স এবং প্রয়োজনীয় চাহিদা অনুযায়ী দীর্ঘমেয়াদি পরিকল্পনা করুন।

চিত্র-২ ঃ বাবা-মা এর আবেগ মোকাবেলার উপায়

(Figure-2: Managing emotional reactions)



তৃতীয় অধ্যায়

৩.১ অটিজম শিশুর লালন-পালন

(Parenting a child with autism)

এটা অনস্বীকার্য যে, সন্তান লালন-পালন করা যে কোন বাবা-মার উপর একটি চ্যালেঞ্জিং দায়িত্ব, কিন্তু বিশেষ বৈশিষ্ট্য সম্পন্ন্য/বিকাশ জনিত-স্নায়ুবিক সমস্যায় আক্রান্ত শিশুর ক্ষেত্রে বাবা-মা অতিরিক্ত চাপ ও বাঁধার সম্মুখীন হন। এই স্নায়ু-বিকাশ জনিত সমস্যা সমুহের মধ্যে অটিজম অন্যতম। বাংলাদেশে অটিজম শিশুদের বাবা-মায়েরা যাতে সন্তান লালন-পালন করার ক্ষেত্রে বিভিন্ন উদ্বেগ ও সমস্যা কাটিয়ে ওঠতে পারেন, তার জন্য এই নির্দেশিকা'টি রচনা করা হয়েছে।

৩.২ অটিজম শিশুর সমস্যামূলক আচরন এর ব্যাবস্থাপনা পদ্ধতি

(Behavioural management of the child)

অতিমাত্রায় মানসিক চাপ, দূঃশ্চিন্তা ও বিষন্নতায় থাকার কারণে অনেক পিতা-মাতা অটিজম সম্পন্ন সন্তানের আচরন পরিবর্তনের চিকিৎসায় (বিহেভিয়ার থেরাপিতে) সক্রিয়ভাবে অংশগ্রহন করতে পারেন না। অটিজম সম্পন্ন সন্তানের আচরন পরিবর্তনের চিকিৎসায় পিতা-মাতাদের প্রতিনিয়ত বিভিন্ন শিডিউল মেনে চলতে হয় এবং আর্থিক ব্যয় যোগান দিতে হয়। এক্ষেত্রে বাবা-মাকে যথেষ্ট মনোবল বা ধৈর্য্য পরীক্ষা দিতে হয় যা তাদের সন্তানের জীবনের গুনগত পরিবর্তনের আশা জাগায়।

➢ প্রত্যাশিত আচরন বৃদ্ধি করা (Increasing desired behaviour)

কয়েকটি উপায়ে আপনার অটিজম সন্তানকে নতুন কিছু শেখানোর জন্য উৎসাহিত করা যেতে পারে, যেমন-

➢ ভালো আচরনকে উৎসাহিত করা (Reinforcing desired behaviour)

আপনার সন্তান ভালো আচরন করার সাথে সাথে তাকে খাবার, খেলনা, প্রশংসা করা,আদর করা, স্টিকার, টোকেন ইত্যাদি প্রদানের মাধ্যমে ভালো আচরনকে উৎসাহিত করতে পারেন। এ ক্ষেত্রে আপনার সন্তানের আগ্রহ, পছন্দ, সামর্থ ইত্যাদি বিবেচনায় রাখতে হবে। যদি আপনার সন্তানের মধ্যে এসব বস্তু উৎসাহ তৈরি করতে না পারে, তার মানে আপনার সন্তানের জন্য হয়তো উক্ত বস্তু আগের মতো চাহিদা নেই বা ক্লান্তি ও বিরক্তি বোধ করছে। অর্থাৎ সন্তানের প্রয়োজন বুঝে পরিকল্পনা করে সামর্থ্য অনুসারে কার্যকর বিষয়-বস্তু (উদ্দীপক) নির্বাচন করে রাখা গুরুত্বপূর্ন।

শেপিং (Shaping)

কোন একটি কাজকে ছোট ছোট অংশে ভাগ করে প্রতিটি পদক্ষেপকে বারবার উৎসাহিত করার মাধ্যমে শেখানো একটি ফলপ্রশু প্রক্রিয়া যাকে শেপিং বলা হয়।

উদাহরন- নিজে স্বাধীনভাবে খাওয়ার শেখানোর জন্য আপনার সন্তান যদি চামচ ধরে তাহলে এই পদক্ষেপেই তাকে উৎসাহিত করুন, প্রথম দিকে চামচ এর দিকে অগ্রসর হওয়ার জন্যই তাকে উৎসাহিত করতে হবে, চামচ ধরতে শেখার পর প্লেটের খাবার মুখে দেওয়ার পদক্ষেপ উৎসাহ বা পুরস্কার প্রদানের মাধ্যমে ধাপে ধাপে শেখানো যায়।

➢ পরিকল্পিতভাবে অবজ্ঞা (Extinction)

শিশু যখন অনাকাংক্ষিত আচরন প্রদর্শন করে তখন সেই আচরনটিকে অবজ্ঞা করা বা মনোযোগ না দেওয়া। এটা গুরুত্বপূর্ন যে, প্রথমবার এই পদ্ধতি প্রয়োগ করলে আপনার সন্তান হয়ত আরো বেশি অপ্রিয় আচরনটি করবে বা সে থামতে চাইবে না অর্থাৎ আচরনটি কমার পরিবর্তে আরো বেড়ে যেতে পারে। এই অবস্থায় আপনাকে হাল ছেড়ে দিলে হবে না ও ধারাবহিকতা বজায় রাখতে হবে। তবে মনে রাখতে হবে, শিশু যদি নিজেকে বা অন্যকে আঘাত করে তবে এই পদ্ধতি প্রয়োগ করা উচিৎ নয়।

➢ রাগ বা জিদ এর ব্যাবস্থাপনা (Anger management)

অটিজম শিশুরা কিছু আবেগের নিয়ন্ত্রন করতে অসুবিধা হয়, এসব আবেগের মধ্যে রয়েছে দুঃশ্চিন্তা, হতাশা, মানসিক চাপ ইত্যাদি আর এর বর্হিপ্রকাশ হচ্ছে রাগ বা জেদ।

উদাহরন- আপনার সন্তান উত্তেজিত হওয়ার আগে শারিরীক পরিবর্তন লক্ষ্য করবেন এবং সাথে সাথে শান্ত করার কিছু কৌশল অবলম্বন করতে পারেন, যেমনঃ মনোযোগ সরানো, গান শোনানো, হাটতে নেওয়া, গননা করা ইত্যাদি।

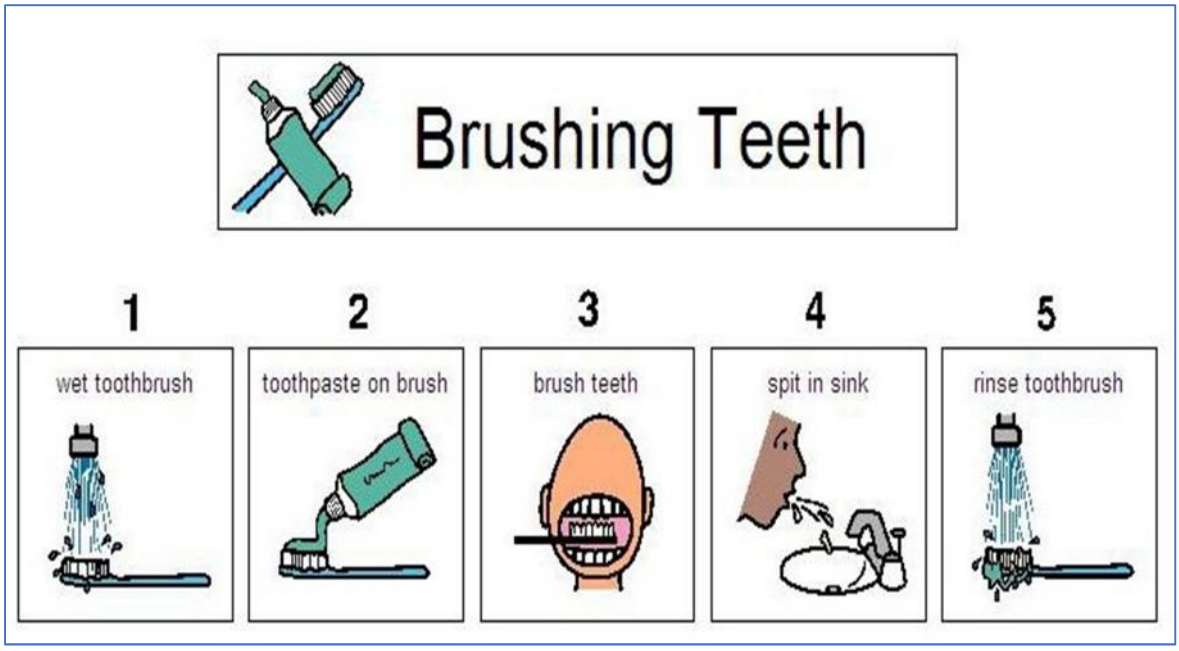
➢ প্রতিদিনের কাজ শেখানো (Teaching daily living skills)

যে কোন প্রত্যাশিত আচরন বা কাজগুলোকে ধাপে ধাপে শেখানো যেতে পারে।

উদাহরন ঃ টুথপেষ্ট ব্যবহার করে দাঁত ব্রাশ করা অথবা জামার বোতাম লাগানো শেখা।

চিত্র-৩ঃ টুথপেষ্ট ব্যবহার করে দাঁত ব্রাশ করা

(Figure-3: Graded tasks assignment using task analysis)



চিত্র-৪ঃ প্রতিদিনের কাজ শেখানো

(Figure-4: Teaching activities of daily living)

Shower Routine

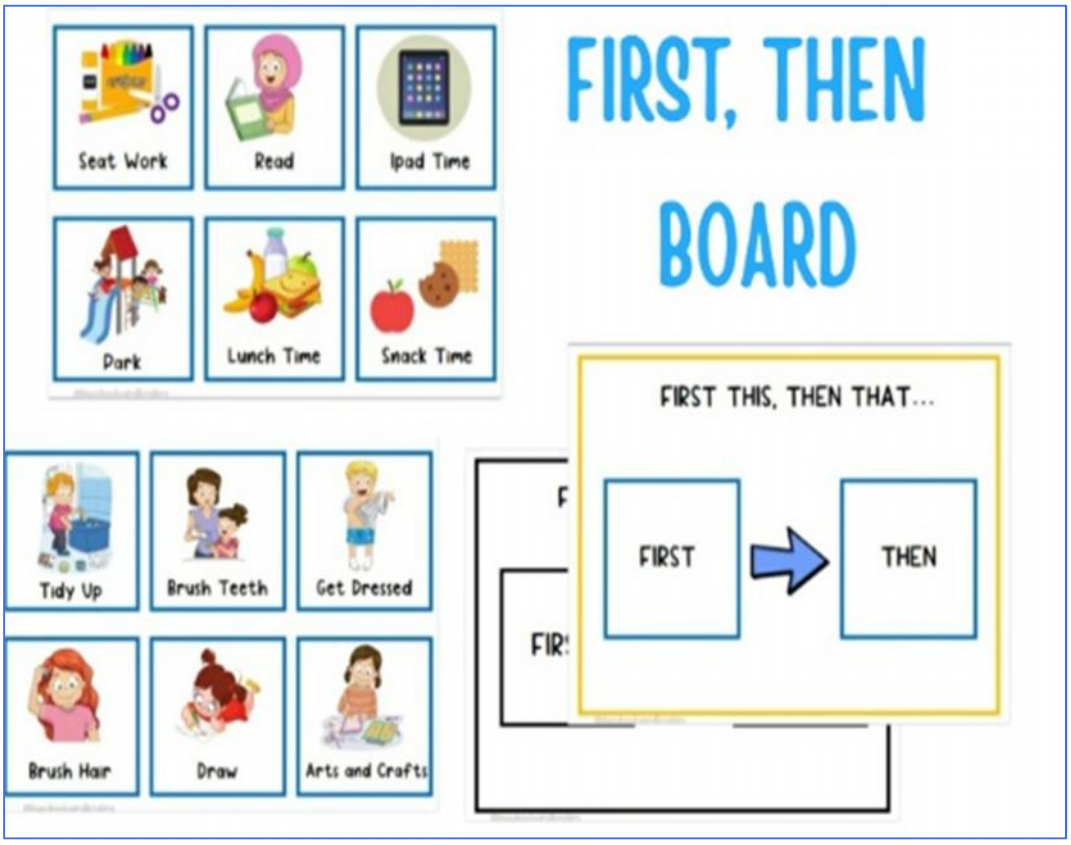
get undressed 	turn on water 
get in shower 	wet hair wet face 
put shampoo in hand 	shampoo hair 
rinse hair 	put cream rinse in hand 
work through hair 	rinse hair 
wash face 	rinse face 
wash body 	rinse 
dry off dry face dry hair 	get dressed 

চিত্র-৫ ঃ ছবির মাধ্যমে যোগাযোগ

(Figure-5: Visual communication)

চিত্র-৬ ঃ প্রত্যাশিত আচরন বৃদ্ধি করা

(Figure-6: Reinforcing desirable behaviors)



চিত্র-৭ ঃ প্রতিদিনের সূচি তৈরি করা

(Figure-7: Scheduling behaviors)

চিত্র-৮ ঃ ভালো আচরনকে উৎসাহিত করা

(Figure-8: Positive reinforcements)

চিত্র-৯ ঃ পুরস্কার এর মাধ্যমে ভালো আচরনকে উৎসাহিত করা

(Figure-9: Token economy)

চিত্র-১০ঃ প্রাত্যহিক জীবন দক্ষতা শেখানো

(Figure-8: Teaching independent living skills)

চথুর্থ অধ্যায়

পেশাজীবিদের ভূমিকা

সুনির্দিষ্ট কিছু উপায়ে পেশাজীবিরা পিতা-মাতাদের অগ্রগতি পর্যবেক্ষণ করে থাকেন। দৈনন্দিন জীবন দক্ষতা অর্জনে সহায়তা করেন।

পঞ্চম অধ্যায়

এই অধ্যায় সরকারের বিভিন্ন প্রকার সেবাসমুহ, সমন্বয় ও ব্যবস্থাপনা সম্পর্কে অলোচনা করা হয়েছে।