



CHAPTER THREE

AUTISM IN MIDDLE CHILDHOOD AND THE IMPACT ON THE FAMILY

3.1. INTRODUCTION

This study is focused on developing and evaluating a play technique programme for autistic children in middle childhood. In the previous chapter (Chapter 2) the focus was on the phenomenon of autism, and more specifically at definitions, characteristics, prevalence, treatment and the impact of autism on society. In this chapter it is necessary to focus on autism specifically within the stage of middle childhood. This will be done through a comparison of development in different areas of a child, between neurotypical (non-autistic) and autistic children. The focus will then shift to the impact that this (autism in middle childhood) has on the family unit.

According to the National Network for Child Care (2006), middle childhood refers to the years between 6 and 12 years, generally when children starting attending school until they reach adolescence.

Middle childhood can be defined as “a time when children are beginning to assume a larger share of responsibility for their own behaviour in relationship to their parents, peers and others” (Child & Family Canada, 2006).

These above definitions give an indication of the particular time of middle childhood within an individual’s life as well as particular roles that the individual might fulfill. It is necessary to revisit some definitions of autism at this stage, in order to begin to highlight the difference between a normal child and a child who is diagnosed with autism and is growing through the stage of middle childhood.



The Autism Checklist (2006) states that “autism, which affects thought, perception and attention, is not just one disorder with a well defined set of symptoms; autism is a broad spectrum of disorders, which ranges from mild to severe”.

According to The Source (2006) autism is “a life-long developmental disability which impairs various aspects of typical development and lasts a lifetime”.

The National Alliance for Autism Research (2006) states that autism is “a complex brain disorder that often inhibits a person’s ability to communicate, respond to surroundings and form relationships with others”.

In the following sections, given that the goal of the study is to develop a play technique programme for autistic children in middle childhood, the researcher aims to orientate the reader with regard to the stages of middle childhood, particularly with regard to autistic children in order to contextualize the study. The focus will then be on the impact of autism in middle childhood on the family. In order to understand the autistic child in middle childhood it is important to discuss the meaning of the concept middle childhood.

3.2. DEFINING MIDDLE CHILDHOOD

Middle childhood is a stage that all individuals, both autistic and neurotypical, go through. It is a stage in which a great deal of development and challenges in all areas of an individual’s life occur.

According to Craig (1996: 328) “middle childhood – the period from 6 to 12 years – is a time for slower growth, for developing more fully those patterns that have already been set”.



The National Network for Child Care (2006) describes middle childhood as a time when “the child’s world expands outward from the family as relationships are formed with friends, teachers, coaches, caregivers, and others”.

The Future of Children (2006) comments that “during middle childhood, children begin to navigate their own ways through societal structures, forming ideas about their individual talents and aspirations for the future”.

Health 24.com (2006) states that middle childhood is “a time for slower physical growth and children concentrating more on refining skills. On a cognitive level the child develops rapidly and will show great ability to learn, communicate, memorize and cope within their new school environment”.

Child and Family Canada (2006) consider the following to be important issues in middle childhood:

- Self-esteem: The middle years are vital to a child’s growing sense of self-esteem. The child is getting a stronger idea of who he/she is.
- Relationships with parents: Successful interaction with parents contributes greatly to a positive sense of self.
- Relationships with peers: The child will go to great lengths to gain a sense of accomplishment in relation to his/her peers.
- Physical abilities: During the middle years a child will gain a growing sense of competence in relation to their physical abilities.
- Cognitive and language development: The child now has the ability to know what to do on a day-to-day basis as well as the ability to do it.
- Siblings: The middle years are a time when siblings will usually work together.

All the above definitions and descriptions give a good indication of the development and focus areas of a neurotypical child going through the stages of



middle childhood. With a child who has been diagnosed with autism, the stages and changes of middle childhood are significantly different. The researcher will now focus on the particular difference between neurotypical and autistic children, within this stage of middle childhood.

3.3. DEVELOPMENTAL STAGES WITHIN MIDDLE CHILDHOOD: COMPARISON BETWEEN NEUROTYPICAL AND AUTISTIC CHILDREN

Human development can be defined as “the changes over time in the structure, thought, or behaviour of a person as a result of both biological and environmental influences (Craig, 1995: 5). Within the human body there are seven life stages, namely infancy; preschool child; middle childhood; adolescence; early adulthood; middle adulthood and late adulthood (Craig, 1995: 6).

Within this study the focus is on middle childhood. As previously mentioned there are many differences between the development of a neurotypical child and an autistic child in middle childhood. In the following section the researcher will focus more specifically on these differences, looking at the different areas of development in middle childhood.

When looking at development Craig (1995: 332) writes that it is important to remember “that physical, cognitive, and socio/emotional factors interact to produce individual development”. Therefore the researcher will look at the differences in development within middle childhood according to the physical, intellectual and emotional development that takes place.

3.3.1. Physical Development

Physical development, according to Craig (1996: 7), “involves the basic growth and changes that occur in the individual’s body. These include external change,



such as in height and weight, as well as internal changes in muscles, glands, the brain, and sense organs”.

On a physical level, the differences between a neurotypical child and an autistic child are not that marked. Exhorn (2005: 7) comments that “you can’t tell that a child has autism simply by looking at a picture of him or her ... a two-year-old with autism can be the same height and weight and be just as adorable as a ‘typical’ two year old”. This can be accredited to the fact that autism “is a neurological disorder” (Robledo and Ham-Kucharski, 2005: 1). Exhorn (2005: 7) states that “what distinguishes a child with autism from a typical peer is what you can’t see: the brain”. Therefore, it does not have a direct impact on a child’s physical development.

Within middle childhood the following developments take place with regard to physical changes (Development in Middle Childhood, 2006; Middle Childhood, 2006; Middle Childhood and Adolescent Development, 2006; Childhood Years: ages six through twelve, 2006; Middle childhood: ages ranging from 7 to 12 years, 2006; Middle Childhood and early adolescence, 2006):

- Growth in height and weight is consistent but slower than in earlier childhood;
- Small sex differences emerge;
- Large muscles in arms and legs are more developed than small muscles;
- Uneven growth of bones, muscles, and organs can result in awkward appearance;
- Eyes reach maturity in both size and function;
- Permanent teeth replace baby ones; and
- Motor skills become smoother and more coordinated.

When looking at the physical development of a child in middle childhood, the one area that can be identified as a concern for an autistic child is the development of



motor skills. As noted by The Autism Society of America (2005), “autistic children often show uneven gross/fine motor skill development”.

Ben LaSalle (LaSalle, 2003: 65), who was diagnosed with autism, stated that “There was no way I could be the best at baseball”.

Robledo and Ham-Kucharski (2005: 37) comment on this, stating that autistic children often suffer from sensory integration problems. The authors state that sensory integration is when “a child has difficulty processing information they receive from their senses”. A child can have sensory integration dysfunction in three different systems, namely (Robledo and Ham-Kucharski, 2005: 38):

- Tactile: a child’s sense of touch is impaired;
- Proprioceptive: the child has sensory receptors that cannot read signals from his/her surroundings, as to where his/her body parts are positioned in relation to one another; and/or
- Vestibular: the child’s ability to sense balance and how he/she takes up space in the world is lost.

If an autistic child does battle with sensory integration dysfunction, which is often the case, it will have a direct impact on his/her ability to move and function on a physical level, within the environment.

Therefore, although on a physical level there are no developmental differences between neurotypical and autistic children, there is definitely a difficulty with regard to an autistic child’s functioning within his/her physical abilities.



3.3.2. Intellectual Development

Intellectual or cognitive development is defined, according to Craig (1995: 7), as “involving the mental processes related to thinking and problem solving. Changes include those in perception, memory, reasoning, creativity, and language”.

On an intellectual level there are a great many differences between neurotypical and autistic children. However, these differences cannot always be attributed to autism, but at times to the co-morbid disabilities associated to the diagnosis of autism.

According to BambooWeb Dictionary (2005) there are many co-morbid disorders associated with autism, which may include:

- Attention deficit hyperactivity disorder (ADHD);
- Mental retardation;
- Obsessive-compulsive disorder (OCD);
- Tourette’s syndrome;
- Depression;
- Anxiety disorder;
- Post-traumatic stress disorder; and/or
- Social anxiety disorder

Putrakembara (2005) states that

Children with Autism Spectrum Disorder usually have accompanying learning difficulties. The range of intellectual abilities amongst children with Autism Spectrum Disorder is vast. The presence of additional disorders, such as epilepsy, sensory and intellectual impairments can co-exist with Autism Spectrum Disorder.



Clearly any of these above-mentioned co-morbid disorders would have a direct impact on a child's ability to function, particularly on an intellectual level.

3.3.2.1. Neurotypical children

In middle childhood, a child shows "rapid development of mental skills, with a greater ability to describe experiences and talk about thoughts and feelings" (Child Development, 2006).

There is also, according to Middle Childhood (2006), "an increased ability to remember and pay attention, which leads to an increased ability to speak and express ideas". The article goes on to state "although they (children) are still self centered, they are beginning to think of others".

According to Middle Childhood and Adolescent Development (2006) a child in middle childhood is able to "accumulate general knowledge; is able to apply learned concepts; and show frequent interest in learning life skills".

The National Network for Child Care (2006) states that during middle childhood a child will:

- Begin go think about his/her own behaviour and see consequences for actions;
- Begin to read and write;
- He/she can think through their actions and trace back events;
- He/she is able to talk through problems to solve them;
- He/she can develop a plan to meet a goal; and
- He/she can focus attention and take time to search for needed information.



According to Health 24.com (2006), at the age of middle childhood, “cognitive, language and perceptual-motor skills have developed to such an extent that learning becomes easier and more efficient”.

The researcher is of the opinion that during middle childhood a neurotypical child is developing a great deal of his/her skills for future life, particularly on an intellectual level. It is at this time that a child will normally start formal schooling, therefore developing and building on various academic skills.

3.3.2.2. Autistic children

It is at this time that autistic children might also start attending formal schooling, although it may be special education, according to the specific child’s needs.

Trevarthen, et al. (1996:172) highlights that:

However varied the severity of autism may be, and whatever the precise form of disability may come with the autism in different children, autism is a disorder of relating. Whether the child may speak or make inarticulate sounds, all autistic children communicate in a way that makes sharing of experience, and especially teaching, difficult. This means that the fundamental task of anyone, parent, teacher, playmate or friend, who wants to help the child to communicate and learn better, is to find a way to be as accessible and comprehensible to the child as possible.

The researcher is of the belief that this paragraph highlights various aspects. Firstly, one of the core aspects of autism is mentioned, that autism is a disorder of relating. Secondly, autistic children do communicate in some way, although in most cases it is not audible. And, finally, there is the vital factor that is necessary for all individuals to grasp: one needs to be accessible to the autistic child at all times. However, when one considers this in the classroom situation, it appears almost impossible.



When looking at the development of a neurotypical child with regard to intellectual ability, various areas need to be focused on. When looking at an autistic child the same areas can be focused on as a neurotypical child, but they generally should be considered areas of concern.

The Autism and Pervasive Developmental Disorder Fact Sheet (2006) states that “communication problems (such as using and understanding language); difficulty in relating to people, objects, and events; unusual play with toys and other objects; difficulty with changes in routine or familiar surroundings; and repetitive body movements or behaviour patterns, can be considered some or all the characteristics observed in mild to severe forms of autism”.

This comment highlights the various difficulties for an autistic child with regard to intellectual ability. Autistic children generally have a problem with communication on some level, which has a direct impact on an individual’s ability to learn. There is also the concern of difficulties in changes of routine and environment, which is something that occurs within the school environment.

The Autism and Pervasive Developmental Disorder Fact Sheet (2006) defines autism according to the ‘The Individuals with Disabilities Education Act’, where it is stated that autism is “a developmental disability significantly affecting verbal and non-verbal communication and social interaction, usually evident before age three, that adversely affects a child’s educational performance”.

This statement clearly indicates that the diagnosis of autism has a direct impact on the child’s educational performance.

The Autism and Pervasive Developmental Disorder Fact Sheet (2006) states that “communication problems (such as using and understanding language); difficulty in relating to people, objects, and events are typical with an autistic child”.



Again this statement highlights the communication difficulties experienced by autistic children, which has a direct impact on the ability to learn. The statement also highlights the fact that autistic individuals have difficulty relating to people, which is something that occurs on a regular basis within the educational environment.

According to the DSM-IV (in Exhorn, 2005: 10) autistic individuals show restricted repetitive and stereotyped patterns of behaviour, interests and activities. This will have an impact on the child's willingness or ability to learn, owing to his/her restricted behaviours and interests.

According to Autism South Africa (2006) autistic individuals can experience the following speech and language problems:

- Delayed development of speech;
- Superficially, perfect expressive language;
- Formal, pedantic language;
- Odd prosody, peculiar voice characteristics; and/or
- Impairment of comprehension, including misinterpretations of literal/implied meanings.

The again highlights the difficulties that an autistic child will experience in developing his/her intellectual abilities.

The above information makes it clear that an autistic child will have various deficits with regard to intellectual ability and intellectual development.



3.3.3. Social/emotional Development

Craig (1995: 7) describes social/emotional development as “the development of personality and interpersonal skills. These two areas are interrelated and include self-concept and emotions, as well as social skills and behaviour”.

The social and/or emotional development of children in middle childhood is the area that will show the biggest differences between neurotypical and autistic children.

As Robledo and Ham-Kucharski (2005: 1) state, “autism is a neurological disorder ... it hampers a child’s ability to learn how to communicate, interact with others socially, and indulge in imaginative play”. Stone (2006: 13) comments that “children with autism do not show the expected development of early social interaction skills ... in fact; impaired social interactions are the hallmark of autism and are present in all children with this diagnosis”.

The researcher is of the opinion that this is the area of development which is vital for this particular study, owing to the fact that the focus is on improving or impacting the autistic child’s social functioning.

3.3.3.1. Neurotypical children

In middle childhood, neurotypical children develop to become more independent, with a stronger sense of right and wrong. They begin to show an awareness of the future, with a growing understanding of their place in the world (Centers for Disease Control and Prevention, 2006).



Middle Childhood (2006) states that a child begins to want to do things by and for him/herself, although the child will still need guidance, rules and limits. The child will begin to see things from another child's point of view.

In Middle Childhood and Adolescent Development (2006) it is noted that a child begins to develop a conscience, with him/her wanting to gain social approval and live up to the expectations of people close to him/her. A child will also start to develop deeper friendships, mainly with children of the same sex, based on proximity, common interests/hobbies or other perceived commonalities.

The National Network for Child Care (2006) states that a child will "show signs of growing independence; will begin to see the point of view of others more clearly; and inner control will be formed".

According to Indian Child (2006) a child in middle childhood begins to show improvement in his/her social skills, with the child often developing one or two special friends. Friendships become quite important to the child.

In Middle Childhood and Early Adolescence: Growth and Change (2006) it is noted that a child will

Begin to encounter more – and more diverse – people between the ages of five – 13 than in earlier years. For many of the children these larger networks are important sources of earning and social support. They value social resources more and they seek them out more readily and use them more effectively.

The researcher believes, therefore, that the following changes take place on a social/emotional level within middle childhood:



- A child will become more independent, with a greater sense of right and wrong;
- Friendships become more important, normally with children of the same-sex and based on commonalities;
- A child will become less egocentric and more generous, beginning to see things from another person's point of view; and
- A child will show an improvement in his/her social skills, with more meaningful relationships developing.

The researcher is of the opinion that all these explanations show how children in middle childhood begin to develop their social skills, forming meaningful relationships with adults around them, as well as their peers. This is a time that will have a big impact on the individual child's ability to continue successfully through his/her life, and to develop into a balanced adult.

3.3.3.2. Autistic children

According to the DSM-IV (in Exhorn, 2005: 10) an autistic individual will show qualitative impairment in social interaction, as manifested by at least two of the following:

- Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures and gestures to regulate social interaction;
- Failure to develop peer relationships appropriate to development level;
- Lack of spontaneous seeking to share enjoyment, interest or achievements with other people; and/or
- Lack of social or emotional reciprocity.

These criteria offer a clear indication of an autistic child's difficulty to develop and maintain relationships with others.



Williams (1996:8-9), considers the symptoms of autism to include the following:

- An impairment in the ability to interact socially;
- Lack of communication, both verbally and non-verbally;
- Certain 'bizarre' behaviour/s;
- 'Bizarre' responses to sensory stimuli; and
- Impairment in the use of imaginary play.

The above statement again indicates an autistic child's difficulty in interacting with those around him/her, as well as the important aspect that an autistic child shows impairment in imaginary play. This will have a negative impact on the child's interaction with his/her peers, because imaginary play is so important to children of this age, as experienced by the researcher in her professional capacity as a play therapist.

The Autism and Pervasive Developmental Disorder Fact Sheet (2006) states that an autistic child will have "communication problems (such as using and understanding language) and difficulty in relating to people, objects, and events".

Robledo and Ham-Kucharski (2005: 1) comment further on this, stating that "autism hampers a child's ability to learn how to communicate, interact with others socially, and indulge in imaginative play".

The National Alliance for Autism Research (2006) agrees with these comments, stating that autism "often inhibits a person's ability to communicate, respond to surroundings and form relationships with others".

The Autism Society of South Africa (2006) comments that an autistic individual will show severe impairment in reciprocal social interaction in at least two of the following:



- Inability to interact with peers;
- Lack of desire to interact with peers;
- Lack of appreciation of social cues; and/or
- Socially and emotionally inappropriate behaviour.

The above statement, according to researcher, gives the best indication of an autistic child's inability to build social relationships, thereby affecting his/her development in middle childhood.

The researcher is of the opinion that all the above statements give a clear indication of how an autistic child will battle in developing relationships and building independence in middle childhood. It is normally at this time, according to the researcher, that one will begin to notice a great deal more the deficits that an autistic child may show, particularly in relation to social behaviour.

Through all the information given, with regard to the development of a child in middle childhood, particularly the differences in development of a neurotypical and autistic child, it is clear, according to the researcher, that an autistic child faces many challenges in meeting the developmental tasks of middle childhood.

With this previous section the researcher aimed to highlight the differences that are present with an autistic child in middle childhood. These differences not only impact the child diagnosed with the disorder, but also those individuals around him/her, more specifically his/her family members and significant others. In the following section the focus will be on the impact of autism, in middle childhood, on the family unit.

3.4. THE IMPACT OF AUTISM ON THE FAMILY

As has been noted in the previous section of this chapter, as well as in the previous chapter (Chapter 2), autism is a complex and challenging disorder. The



researcher is of the opinion that the diagnosis of autism is one that is difficult to make but it is even more difficult then to adjust to and live with, both for the individual and his/her significant others.

The National Alliance for Autism Research (2006) states that “few disorders are as devastating to a child and his/her family, as that of autism”.

Aarons and Gittens (1996:88) state, “almost as soon as parents learn that their child may have autism, their thoughts inevitably turn to the future – what will the outcome be?” The effect that autism has on a family is almost incomprehensible.

The researcher is of the opinion that a diagnosis of any disorder would be devastating for a family. However, the researcher agrees with the National Alliance for Autism Research (2006), when they state that autism is one of the most devastating disorders.

All the above information indicates that, besides the everyday challenges that are faced within the home of an autistic child, there is the added pressure faced when dealing with the autistic child within his/her society.

In order to understand the impact that autism has on a family, it is first necessary to look at what a family constitutes and the definitions that are given.

3.4.1. Definition of a family

Meyer (in Hepworth and Larsen, 2006: 241) defined a family as “Two or more people who are joined together by bonds of sharing and intimacy”. Hepworth and Larsen (2006: 240) go on to state that the family is the “a social system in which each of its constituent parts and subsystems interact with one another in a predictable, organized fashion”.



This definition highlights the fact that the family should interact with one another, in a “predictable and organized fashion”. When a child is diagnosed with autism the challenges of achieving this are increased.

Thompson and Rudolph (2000: 313) state that

Definitions of family range from the nuclear family of breadwinner father, homemaker mother, and two children to multiple families living together. Between the two extremes are at least eight types of families: extended, blended, common-law, single parent, communal, serial, polygamous, and cohabitation. Families are also defined by their organizational structure, characterized by degrees of cohesiveness, love, loyalty, and purpose.

When looking at this definition one’s attention can be drawn to all the different family systems that exist. However, for this study the different types of family are not necessarily that important; rather it is necessary simply to get an indication of what the family system might involve.

Within a family there are different individuals who make up the whole. This includes parents and their child or children. Within the family these individuals will fulfill different roles, with the parent/s carrying the vital role of caregiver and nurturer.

According to the Oxford Pocket Dictionary (2004: 166) a family is “parents and their children, sometimes including grandchildren and other relations”.

A parent, according to Google.com (2006) is “a father or mother; one who begets or one who gives birth to or nurtures and raises a child; a relative who play the role of guardian”. It goes on to state that



Parenting comprises all the tasks involved in raising a child to an independent adult. Parenting begins even before the child is born or adopted and may last until the death of the parent or child. Parenting is a part of the relationship within a family.

A child, according to The Oxford Pocket Dictionary (2004: 78) is “a young person; a boy or girl; someone’s son or daughter”.

All the above definitions give a clear understanding of what a family is and what a family involves. Although an autistic child in middle childhood is involved in or exposed to various environments, such as school or an aftercare facility, it is normally with his/her family that the child will spend the majority of his/her time and he/she will therefore have a tremendous impact on the family system.

3.4.2. Impact on the family

“The symptoms of autism are not the kind that are either there or not there ... the behaviours that are disrupted in autism are complicated” (Stone, 2006: 38). This comment brings to one’s attention the difficulty of living with an autistic child and the fact that autism definitely has an impact on the whole family.

Exhorn (2005: 191) comments that “adjusting to your new life (with a child with autism) will take some time, especially since it was completely unplanned”. In this regard, Stacey (2002), a parent with an autistic child, writes that:

Living with an autistic child is exceptionally hard. It does put a damper on your life. We are always tense as such when Michael (the autistic child) is around. Even when he is being good. You are tense because you don’t know what is going to happen next. Everything you do has to be planned, and thought through carefully, as to accommodate Michael.

A family undergoes a great deal of changes when a child is experiencing or is diagnosed with autism. The following characteristics of an autistic child, as



documented by Braude (1999: 24–26), will have a serious impact on the family system:

- Reaction to changes in routine: As has been previously stated, autistic children require the most rigid of routines. As soon as this routine is altered the child becomes unsettled. This is related to the insistence on sameness as one of the symptoms of autism.
- Temper tantrums: 50% of parents reported that their children exhibited temper tantrums when a change of environment occurred. This, according to the researcher, places a great strain on the parent/s and/or family to maintain an environment of sameness in order to decrease the likelihood of a temper tantrum.
- Avoidance of physical contact: Many autistic children tend to avoid any form of physical contact. This forms an essential part of the lives of many autistic children, although it does appear that when the child is approached sensitively, he/she is not totally averse to physical contact.
- Social interaction: Attwood (1995: 28) commented that autistic children might have an inability to interact with peers, as well as a lack of desire to interact with those around them. They may display socially and emotionally inappropriate behaviour.
- Behaviour characteristics: Many parents mentioned that their children displayed specific behaviour such as a dislike of bathing; food preferences; and/or mood swings and tics.

These behaviours point to the great difficulty that the diagnosis of autism can place on a family.

Exhorn (2005: XIV) writes: “the diagnosis of Jake’s (their son) autism came as a shock to both me and my husband ... every aspect of our lives metamorphosed with Jake’s diagnosis”.



The researcher understands adherence to a strict routine, with any changes bringing about a temper tantrums, to be one of the most challenging aspects. The reason for this is that within most typical families parents attempt to stick to a relatively good routine although there are always times when this is not possible, owing, for instance, to illness in the family or special occasions. It would also be unfair on the other siblings to always have a routine that is only for the one (autistic) child. Therefore this behaviour must be very frustrating.

The lack of physical contact that autistic children often display can lead to great anguish for many parents. One mother, Judy (in Stone, 2006: 51) wrote, with a real tone of sadness, "I love my son so dearly; I want to hold him close and sing to him and read to him – but he just won't let me". In this regard Stacey (2002) also confirms that the most difficult thing to deal with was "accepting the fact that Michael will never get better, that this is a lifelong problem and worry".

It is clear that all the above behaviours place a great deal of stress on the family within its social environment. Science News (2002) stated that "by age three, children diagnosed with autism have already begun a retreat into social isolation ... even an inability to distinguish their own mothers' faces from those of strangers".

Each aspect, depending on the individual child, will vary in severity, and may even lead to the family avoiding social events/situations at all costs. The researcher is of the opinion that, in cases where there are other siblings, the constant attention that is required by the autistic child and his/her routine could severely affect the sibling/s.

Within the family, the presence of an autistic child may have an impact on various areas within the particular family unit. This may include an impact on finances, socializing and emotional development/coping of the family members. This will be discussed in more detail in the next section.



3.4.2.1. Financial Impact

Exhorn (2005: XIV) emphasized the financial impact by stating that there was “continuous and impending financial stress, in relation to dealing with Jake’s diagnosis”.

On a financial level the most obvious cost/financial strain would be for the education of the autistic child. This, according to the researcher, does not only relate to school, but any extra treatments/therapies to assist the child in achieving his/her educational goals.

Therefore, educational costs may include the following:

- Schooling, in most cases, in a Specialized Education School;
- Therapy, which may include: speech therapy; occupational therapy; physiotherapy; and/or some form of behavioural therapy;
- Aftercare facility if both parents are working.

In South Africa, the facilities available for autistic individuals are limited, as noted by Botha (2005). Given this fact, and the amount of financial assistance that an autistic child may require, the cost of educating an autistic child, particularly in South Africa, is very high.

"Autism knows no boundaries, no nations and no race. It seems to be as much a part of us as love, and the common cold, as genius, as art" (Autism Primer, 2002). Therefore, autism is a disorder that impacts many families, from different walks of life and in different financial positions, but the cost of caring for an autistic child remains high.



As Botha (2005) states, on various occasions the family will run into financial difficulties in trying to find placement and appropriate care and treatment for their autistic child.

Therefore, it is clear that the financial strains placed on a family supporting an autistic child are great, and will have a big impact on the family's ability to function successfully.

3.4.2.2. Social Impact

Autistic children engage in unusual behaviour. Encarta (2002) explained that:

Autistic children often engage in repetitious activities, such as arranging objects in meaningless patterns, flipping a light switch on and off, or staring at rotating objects. Some engage in repetitious body movements, such as spinning, flapping their arms, swaying, rocking, snapping their fingers, and clapping or flapping their hands. In some cases these movements may be harmful, involving repeated biting of their wrists or banging their heads.

This comment, coupled with the comment made previously by Braude (1999: 24–26) at the beginning of this section discussing the changes that a family might experience when a child is diagnosed with autism, highlights the great influence that an autistic child's behaviour will have on a family's opportunities to engage in social activities.

As Stacey (2002) comments, “we are always tense as such when Michael (the autistic child) is around. Even when he is being good. You are tense because you don't know what is going to happen next. Everything you do has to be planned, and thought through carefully, as to accommodate Michael”.

The researcher is of the opinion that this highlights a family's difficulty in just doing something as a family in a social context, as the autistic child and his/her



behaviours have to be considered very carefully before any decisions or plans are made.

The Autism Society of America (2005) considers the following to be traits of autism:

- Insistence on sameness; resistance to change
- Preference for being alone; aloof manner
- Tantrums
- Difficulty in mixing with others
- Sustained odd play
- No real fears of dangers

These traits will have a direct impact on a family's ability to interact with others on a social level.

3.4.2.3. Emotional Impact

The researcher is of the opinion that, on an emotional level, an autistic child's family, both parents and/or siblings, are placed under a great deal of stress.

Exhorn (2005: 179) states that "you (a parent) may experience a range of emotions after learning your child is autistic ... these may include a sense of loss, which may pertain to a loss of one's old life or a loss of one's future life. You may experience feelings of fear, worry, confusion, guilt, embarrassment, resentment, and a sense of existential loneliness".

This paragraph highlights the many feelings that parents might experience when initially dealing with the diagnosis, and these feelings will continue into the family's future. These feelings, according to the researcher, can have a profound



affect on the family as a unit, as children are normally in tune with the feelings of their parents, and react accordingly.

Gardner (2005), a mother of an autistic child, states that “he feels our warmth; he feels our love. But whether or not he truly understands the word ‘I love you,’ I don’t know”. Botha (2005) comments that she learnt to “live on the raw edge of fear”, trying to cope with her child’s disability. Botha (2005) states that her husband commented that “there are things that are worse than death, and seeing your child like this is one of them”.

All of the above comments, given by a parent of an autistic child, highlight the difficulty and emotional pain associated with living with an autistic child.

In *My Child May Be Affected by ASD* (2005) the following is noted: “parents of a child who has been diagnosed with ASD (Autism Spectrum Disorder), almost have to go through the process of mourning the loss of a ‘normal’ child and coming to terms with the ‘new and different’ child that now stands before them”.

This comment highlights the emotional difficulty a family experiences in hearing, accepting and then living with the diagnosis of autism of a child.

Baron-Cohen and Bolton (2002: 23) also mention the emotional strain that the diagnosis of autism might have on the marriage of the parents. In this regard Exhorn (2005: XIV) comments that “our marriage took huge blows under the stress of our son’s diagnosis”. The researcher is of the opinion that this is a very real concern and agrees with Baron-Cohen and Bolton (2002: 23) when they state that “it is important to tackle the difficulties that arise in the marriage ... set aside time for ourselves as partners (rather than just as parents) when you can talk openly, and share and discuss difficulties”.

My Child May Be Affected by ASD (2005) uses a diagram (reproduced as Diagram 2, below) to illustrate that a parent/family member will most likely experience the following feelings, as they start dealing with the diagnosis of autism.

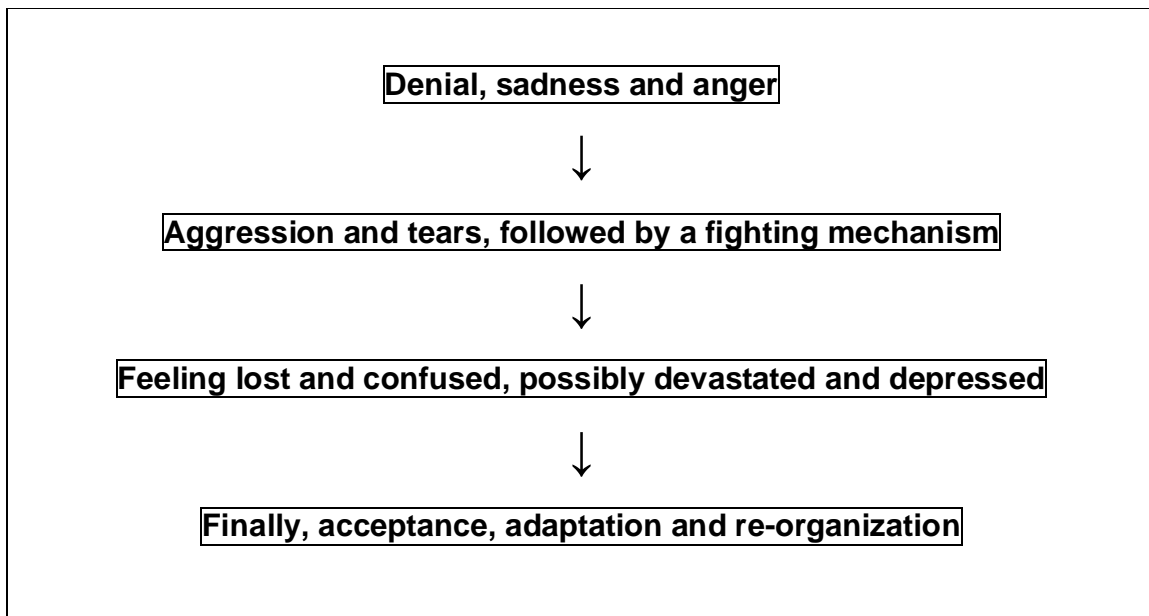


Diagram 2: Feelings, of family members, associated with the diagnosis of autism

Baron-Cohen and Bolton (2002: 21–22) also focus on very similar feelings when first dealing with the diagnosis. This can be seen in the following paragraph:

The immediate reactions are sometimes similar to those seen following bereavement: an initial phase of shock and disbelief. to some extent, the numbness helps prevent parents from being overwhelmed by their distress. At this stage it is difficult to assimilate new information. The shock is then followed by a period of denial, with people sometimes acting as if nothing has occurred. The next phase if often full of feelings of anger and guilt. Anger at the injustice of the situation and guilt, which turns into sadness and despair. Finally most parents adapt and become able to form a realistic picture of the problems, as well as of their child's strengths and special qualities, and begin to focus on practical ways of coping.



The researcher feels that the best description of the feelings associated with dealing with the diagnosis of autism is that it is as if one is going through bereavement, owing to the loss of many things. As previously mentioned, this may include mourning the loss of the life you had before or the life that you thought you would have in the future. It may also include mourning the loss of a child, as one was hoping and dreaming of many things to come. It may also include mourning the loss of the family life as it was before. In the researcher's view, all these feelings can be considered valid and important to work through. However, as Baron-Cohen and Bolton (2002: 22) state, "sometimes individuals get 'stuck' in certain stages, or miss some out altogether, and this can lead to difficulties". The researcher is of the opinion that parents and family members must allow themselves to experience their feelings, but must also ensure that they deal with them and move on to dealing with the situation practically and looking to the future.

In this regard Exhorn (2005: 193–194) gives the following guidelines to help cope with the diagnosis and all the feelings that are attached:

- Organize your time, with the use of a schedule
- Put first things first, in other words, set your priorities
- Set goals and objectives
- Work as a team
- Motivate your team, including your family as well as the various therapists

3.4.3.4 Impact on the siblings

The researcher feels that it is also important to focus on the impact that living with an autistic child has on his/her siblings, as they too are affected by this. In some cases there might not be siblings, but in a lot of cases there are siblings involved.



The impact on siblings is clearly worded in the following joint letter from a brother and sister of an eleven-year-old boy with autism (Exhorn: 2005: 246).

We kids have a little bit of trouble having an autistic sibling. The autistic child gets more attention than the other just because he needs more help. Our names are Diane and Scott, and we have an autistic brother that no longer lives with us. Scott and I were not doing as well as we could have in school when my brother was here. This was because my parents were always chasing after our brother in the neighbors' yards, getting him ready, cleaning up the food he threw on the floor, and a lot of other things. So we were never able to study. This gave us no time for what we had to do. We love our brother very much and were sad he left, but it had also made him and my family happier.

In this situation the family decided to place the child into a respite facility, but this is not always possible. In this insert one is able to identify various feelings that siblings might experience, such as jealousy at the attention that the autistic child is getting; frustration, due to the distraction that the autistic child's behaviour may cause; and sadness at the loss of a sibling.

Baron-Cohen and Bolton (2002: 23) comment on the difficulty of informing the sibling/s of the child's diagnosis. They state that "precisely what is said will depend on the age of the particular child and their ability to grasp the problems ... the news may be a source of distress to them, and will need to be shared in a sensitive manner".

Exhorn (2005: 245) gives the following tips to help "maintain a sense of 'normalcy' in the family:

- Provide consistency
- Set realistic expectations for your children, your spouse, and yourself
- Be patient and show compassion
- Demonstrate love and respect to all of your children



- Focus on positives
- Say thank you to your children for making adjustments to accommodate the child with autism and for helping him/her.

The researcher is of the belief that it important also to recognize the feelings of a sibling/s as the diagnosis of autism also has a profound impact on their lives. As within any family unit, it is important to spend time with and show love to all the family members, even in a challenging situation where there is an autistic child.

A parent (in Stone, 2006: 101) gave the following comments, which accurately summarize the impact on and feelings of parents:

The advice I would give other parents of children with autism is this: (1) Seek therapy and dive into it like your child's life depends on it (because it does). (2) Step away from your world occasionally and breathe some fresh air. (3) Remember, your child's behaviour doesn't reflect on you as a parent. The opinions of the people in the grocery store don't matter; you don't owe the world an apology. You don't have to explain the autism spectrum to everyone who gives you a dirty look. Is your child safe and happy? Is your child getting his needs met and being gently guided toward progress? That makes you more than a good parent – you're the parent of a special-needs child. That's what it's about.

As can be seen, autism has a tremendous impact on the functioning of a family and its members. This can be on a financial, social or emotional level, with the impact being substantial and at times devastating.

3.5. SUMMARY

Middle childhood is a challenging and greatly changing time for a child. It is a time when a child shows development in the physical, intellectual and social spheres.



An autistic child goes through the same phases of development as a neurotypical child. However, because of the severity of the disorder, an autistic child will be faced with various other challenges, as has been discussed in this chapter.

The researcher is of the opinion that the area of development that shows the most significant differences between neurotypical and autistic children is that of social/emotional development. This is because autism is a disorder which mainly affects social functioning and in some cases an autistic child will not reach any developmental milestones with regard to social/emotional development.

Throughout this chapter the researcher aimed to give the reader a good understanding of the differences between a neurotypical and autistic child in middle childhood. These differences are noted in all areas of development, but more so in intellectual and social/emotional development than physical development.

However, it is important to remember that each child is unique in reaching his/her developmental milestones as well as being unique on the autism spectrum. Therefore, although there are generalizations that can be made with regard to the developments that take place in middle childhood, it is important to look at and deal with each child individually.

As mentioned previously, autism is a complex and challenging disorder. A child who is diagnosed with autism and is going through middle childhood faces many challenges and experiences, on a physical, cognitive and social/emotional level. It was important for the researcher to have a good understanding of these challenges and differences so that she could handle the autistic children dealt with in this study in as appropriate a manner as possible.

The goal of the study is to develop a play technique programme for children in middle childhood. The researcher has therefore contextualized the study in



Chapters 2 and 3 by focusing on what autism is (Chapter 2) as well as by gaining an understanding of autism in middle childhood and the impact that this has on the family (Chapter 3). It is necessary now to turn attention to play techniques within play therapy, more specifically the use of play techniques with autistic children (Chapter 4). This will then lead on to a description of the particular play technique programme that will be used with the autistic children in this study (Chapter 5).