SOCIAL WORK
WITH CHILDREN WITH AUTISM
IN MAURITIUS

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Declaration form
ABSTRACT

Autism Spectrum Disorder (ASD) is a lifelong neurological disorder which affects the brain in the social, communication and behavioural spheres. The research question was: How can social work interventions improve the situation of children with autism in Mauritius? The aims of this study were to investigate the present situation concerning autism in Mauritius and to determine to what extent the present structures and measures are responding to the needs of those children and their respective family.

Publications on Autism are very rare if not practically unavailable in Mauritius. The absence of research on the Mauritian context is more crying. Fortunately, the internet came to the rescue. Theories like ecological systems theory, family systems theory and problem-solving model inter alia were found to be useful in family support, strengthening and empowerment.

A qualitative research approach was used based on 10 interviews from educators in the special needs field. Educators were targeted due to their experience with children with autism. From findings, 4 primary themes were developed: training needs of educators, support services for families, support services for children, and need for social work interventions. It is expected that the findings of this research may contribute even in a modest way to help social workers who choose to work with children with autism and their family.
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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>APEIM</td>
<td><em>Association de Parents d’Enfants handicapés de l’île Maurice</em> (Association of Parents of Handicapped Children of Mauritius)</td>
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<tr>
<td>AS</td>
<td>Asperger Syndrome</td>
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<td>ASD</td>
<td>Autism Spectrum Disorder</td>
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<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
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<td>CRC</td>
<td>Convention on the Rights of the Child</td>
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<td>IASSW</td>
<td>International Association of Schools of Social Work</td>
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<td>IDEA</td>
<td>Individuals with Disabilities Education Act</td>
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<td>IFSW</td>
<td>International Federation of Social Workers</td>
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<td>IPC</td>
<td>Institute of Public Care</td>
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<td>IQ</td>
<td>Intelligence Quotient</td>
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<td>MIE</td>
<td>Mauritius Institute of Education</td>
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<td>NAS</td>
<td>National Autistic Society</td>
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<td>NASW</td>
<td>National Association of Social Workers</td>
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<tr>
<td>NCRD</td>
<td>The National Centre for the Rehabilitation of the Disabled</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>PDD</td>
<td>Pervasive Developmental Disorder</td>
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<tr>
<td>SEN</td>
<td>Special Educational Needs</td>
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<tr>
<td>TAC</td>
<td>Team Around the Child</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>UNCPRD</td>
<td>United Nations Convention on the Rights of Persons with Disabilities</td>
</tr>
<tr>
<td>UNICEF</td>
<td>The United Nations Children's Fund</td>
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<td>U.S.</td>
<td>United States</td>
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CHAPTER 1

1.0 Introduction

Autism has been defined as a lifelong developmental or neurological disorder which leads to brain dysfunctions (Vatanoglu-Lutz et al. 2014, p. 426). Autism is also known as Autism Spectrum Disorder (ASD) because it affects individuals differently and to various degrees. According to Carey (2004), it has no cure so far. The symptoms appear between 0 to 3 years. It handicaps the person’s relationship, social skills and communication with others and the environment (Autism Society, 2014).

Chowdhury (2009 p.15) describes the main characteristics of ASD as being:

- “Qualitative impairment in social interaction
- Qualitative impairment in communication
- Restrictive, repetitive and stereotyped patterns of behaviour, interests and activities”.

According to Dr. Joffrey Bodet, a psychologist, a child with autism is unable to communicate or relate to others (Azemia, 2015). He or she has repetitive and non creative activities, finds comfort in routines and rejects change. The autistic child concentrates only on his self without being concerned with the outside world (Frith 2003, p.5).

According to the data and statistics of the Centers for Disease Control and Prevention (CDC) in 2014, “about 1 percent of the world population has autism spectrum disorder” which is equal to approximately 35 to 67 million people around the world, including “about 1 in 68 children among which 1 in 42 boys has been identified” (Autism Speaks, 2014) which gives a total of approximately 60 million children worldwide (News on Sunday, 2012).
Children with autism around the world face discrimination, abuse and isolation. They “lack adequate support and have limited access to services such as schools and health care” (UNICEF, 2012).

Autism produces a ‘ripple effect’ as it does not only affect the individual but also his or her family, environment including the community and society at large. In the light of these problems that children with autism face together with their families, this study endeavours to find out how social work interventions could help to bring change and improve the situation.

1.1 Background

One of the first references made to autism was by the French physician Jean-Marc-Gaspard Itard (1775-1838), when he referred to Victor, also known as “Wild Boy of Aveyron.” Itard treated him with a behavioural programme to help him interact socially and to induce speech by imitation (Frith 2003, p.39).

It is thought that Paul Eugen Bleuler, a Swiss psychiatrist, coined for the first time the term ‘autism’ in 1910 while defining symptoms of schizophrenia. It was obtained from the Greek word autos, which means self (Vatanoglu-Lutz et al. 2014, p.427).

In 1938 Hans Asperger, a specialist in the autism field investigated on a form of ASD, now known as Asperger Syndrome – named after him – which is a form of high functioning autism. It was not widely recognized as a separate diagnosis until 1981.

Asperger called children with AS “little professors,” because they can give detailed accounts on things they like. He followed one child named Fritz V, until he reached adulthood. “V became a professor of astronomy and solved an error in Newton’s work he originally noticed as a child” (McGuinness, 2006).
This positive outlook of Hans Asperger contrasts with Leo Kanner’s description of autism. The Austrian Leo Kanner, of the Johns Hopkins Hospital, first used the term ‘autism’ when introducing the “label ‘early infantile autism’ in a 1943 report of 11 children with striking behavioural similarities” (McGuinness, 2006). The fact that Kanner reused the term autism led to years and years of confusion in terminology. It was, for example, confused with “infantile schizophrenia”. His focus on maternal deprivation also led to misconceptions, as according to him autism was due to poor parenting (Wolff 2004, p.205).

1.2 Social work profession

Social work has been defined as “a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing.” (IFSW, 2014). This definition was approved by the IFSW General Meeting and the IASSW General Assembly as the Global Definition of Social Work.

Social workers play the role of change agents at micro, mezzo and macro levels in order to help improve the lives of individuals in their families, their environment and society at large. Social work can be said to be both interdisciplinary and transdisciplinary. It draws on a variety of scientific theories and research, a few of which will be referred to in more detail in the Literature Review.
1.3 Research question

In Mauritius, it has been observed that there is a lack of professional social workers working directly with children with autism and their families. This research will try to show how social work intervention with those children may improve their situation.

1.4 Aims and Objectives of the study

1.4.1 Aims

The aims of this study are to investigate the present situation concerning autism in Mauritius and to determine to what extent the present structures and measures are responding to the needs of those children and the part that social work can play in the improvement of the situation.

1.4.2 Objectives

In order to reach the aims of this study, there are four objectives:
- Assess the support services offered to children with autism in Mauritius.
- Explore training needs of educators working with children with autism.
- Examine the need for professional social work intervention with children with autism and their families.
- Compare the existing facilities in Mauritius to those available abroad.

1.5 Scope of the study

There is no research so far linking social work with autism in Mauritius. Consequently, this study modestly endeavours to show how social work interventions can effectively complement the therapeutic, psychological
treatments, pedagogical approaches and other strategies aimed at the overall improvement of the situation of children with autism in Mauritius.

However, there were few limitations for this study. First, the sample was limited to educators and its size of 10 participants is not representative of the whole population. Second, there is a scarcity of literature concerning children with autism and role of social work in that field in Mauritius. Finally, only 4 participants were reported verbatim and translated, among which one general response and 3 different responses.

1.6 Structure of the dissertation

Chapter 1 starts with the definition of autism and its impact on children in the autism spectrum, together with the historical background. Then it describes the situation of autism in Mauritius and its lacunas and gives an insight into the profession of social work.

In chapter 2 the researcher shall attempt to apply social work intervention theories when working with children with autism and their family. Furthermore, examples of social work interventions in other countries will be taken into consideration. A few social workers’ roles will also be explored in a way to show how he or she can contribute to alleviate the overwhelming load of the children with autism and their families.

Chapter 3 details about how the research will be conducted and methods used. The results of the research will be presented in chapter 4 where the researcher examined the suitability of the strategies adopted in Mauritius, especially the intervention of NGOs dealing with children with autism.

Chapter 5 will resume the study by drawing conclusions regarding the possible introduction of social workers in the field of autism in Mauritius and make recommendations where appropriate.
CHAPTER 2

2.0 Introduction

This study focuses primarily on the situation of children who suffer from autism in Mauritius, and of their environment with the view of finding how social work interventions can contribute to improve the condition of the affected children. With that perspective, an overview on the main characteristics of autism and its impact on children in the autistic spectrum will be dealt with. Certain experiences in terms of interventions in the world as well as in Mauritius will be explored. The study will endeavour to find out how Social work intervention theories, together with some roles of the social worker, could apply in the field of autism especially in the Mauritian context.

2.1 Characteristics of autism and their impact on children in the Autistic Spectrum

Autism is part of the autistic spectrum and is sometimes described as an autism spectrum disorder (ASD). It is known that autism is “a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them”, which is also known as the ‘triad of impairments’ (National Autistic Society, 2015).

Autism is one of the 5 Pervasive Developmental Disorders (PDD). PDD are said to have problems in social interaction but differ in terms of severity. Under the PDD list there is the Asperger’s syndrome (AS), named after Hans Asperger, which compared to autism does not show language delay and where the child has an Intelligence Quotient (IQ) above 70. There are also PDD not otherwise specified which are applicable to less affected children who do not meet neither autism or AS criteria (Chowdhury 2009, p.15).
While all people with autism share certain difficulties, no two persons with autism present identical symptoms. Some people with autism can lead relatively independent lives while others may have accompanying learning disabilities and need specialist support. “People with autism may also experience over- or under-sensitivity to sensory stimulations like sounds, touch, tastes, smells, light or colours.” (National Autistic Society, 2011).

Some people with autism may wonder why they are ‘different’ from other people for whom it is innate to communicate and interact with each other. The “world, to them, is a mass of people, places and events which they struggle to make sense of, and which can cause them considerable anxiety. In particular, understanding and relating to other people, and taking part in everyday family and social life may be harder for them.” (National Autistic Society, 2015).

Examples of how children with autism may react:

- Exhibit repeated body movements (hand flapping, rocking, shake head side to side, spin around in circles etc.) (Vatanoglu-Lutz et al. 2014, p.427).
- Unusual responses to people
- Attachment to objects
- Resistance to change in routine
- Sensory sensitivities
- Anxiety and confusion in school (Eveslage 2012, pp.8-13).

Autism being a “multifaceted condition” (Limbrick, 2009), it has been noted that some problems related to autism can include epilepsy, eating disorders, disrupted sleeping patterns, challenging behaviour, addiction and so on (Chowdhury 2009, p.16). Due to these problems and in order to give support to parents, early childhood intervention services are delivered in certain countries, through the transdisciplinary practice model, to work as early as possible on “child’s developmental, health and support needs” (Northcott [ca.2013], p.4).
2.2 Autism in the world

According to the U.S. Centers for Disease Control and Prevention in 2002, the prevalence of autism was 1 in 68, which totals to approximately 60,000 U.S. teens that have autism nowadays (Fournier, 2014), and in UK, 700,000 people or 1 per cent of the population, are believed to have autism (National Autistic Society, 2013).

Nowadays, children from different social backgrounds suffering from autism still face stigmatisation, their families face social stigma due to the negative perception of the community towards the child’s behaviours (Vatanoglu-Lutz et al. 2014, p.432). Families are “immobilized by the unrelenting stress” of raising a child with autism. They suffer from lack of support may it be human or financial. Some families are even shattered which is shown in an increasing divorce rate of 80% (Naseef, 2013). The children with autism themselves “suffer silently in pain from untreated medical issues; they are abused, bullied, and may be at increased risk of suicide” (Fournier, 2014). There are so many such situations in which the social worker can intervene and improve the situation of those children and their families.

According to the Article 23 of the Convention on the rights of the child (CRC), a child with disability “should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.” (UNICEF, 2014). The child with autism has the same rights as every typical child in the world as stipulated by the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) also. The UNCPRD states “that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children” (UNCPRD, 2006).

The Individuals with Disabilities Education Act (IDEA) in USA has the same vision as the CRC and the UNCPRD in providing free education to children with disabilities including autism. It “governs how states and public agencies provide
early intervention, special education and related services” to those children (The Individuals with Disabilities Education Act, 2004).

The National Autistic Society (NAS), the leading UK charity for people with autism, made provision for adults with autism through the Autism Act. It stipulates a strategy to help adults with autism to find a job or help at home (National Autistic Society, 2015).

2.3 Practice support models

The fact that it is said that there is no cure to autism, research carried out shows that the situation of persons with autism can be improved and coping skills learnt that can significantly alleviate their daily chores. There is always hope where there exists the determination to find ways and means in the therapeutic field of alleviating the suffering of humanity (Michel, 2012). As has been said, history has examples of pioneers for whom as the saying goes, ‘there can always be a way where there seems to be no way!’ For example, only a few years back the notion of nerve and brain plasticity was inexistent as well as cognitive behavioural therapy. But this is a topic which would require by itself a whole study.

Education is important in special needs field. Autism demands deepened training to understand the complexity of the disorder and other related problems attached to the disorder. Concerning educators, Mardar and deBettencourt (2012) observed that specific training in Autism result in positive outcome in children as well as noticeable progress in their challenging behaviours. This concept can also be applied to parents with children with autism as well as the TAC.

Banach et al. (2010) stated that among parents upon getting their child’s diagnosis, “52% felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame”. Apart from the diagnosis itself, the child’s behaviour and other effects related to autism, Naseef (1989) stated that the diagnosis tend
to put stress on the couple’s life with increasing financial problems and the isolation they put themselves in.

2.3.1 Transdisciplinary practice model and the Team Around the Child (TAC)

In some developing countries like UK, USA, Canada and Australia there are specialised organisations in autism which use the transdisciplinary practice model. This model exists since 1960s (York et al. 1990, p.73). It consists of a team of professionals who work in collaboration to give better service delivery to families having a child with disabilities (Northcott [ca.2013], p.5). Together they design a care plan for the child, which covers every area special needs have to be catered for. Its aim is “to provide more family-centered, coordinated, and integrated services” (King et al. 2009, p.211). The TAC comprises of different professionals (Figure 1) including the social worker. The latter, who normally has the role of the key worker or lead professional, is the link between other members of the team and coordinates the service delivery to the family (Northcott [ca.2013], p.6).
According to Children’s Workforce Development Council (2009), the lead professional identify and assess the needs of the child. Furthermore, he or she forms the team around the child, coordinates and ensures service delivery. Finally, the lead professional reviews the progress together with other members of the TAC including the parents.

Limbrick (2009) stated that the TAC, which was developed in UK, uses a holistic approach. Instead of exposing the child and the family to numerous different separate professionals, “a small team of key practitioners around each child communicate and interact with each other”. The role of the TAC is to assess, plan, intervene and review processes along the child’s pathway.
York et al. (1990) stated that the whole team in the interdisciplinary model collaborates together with the parents in every decision-making be it for assessment, establishing priorities and designing and implementing individualised educational programs (IEP).

One of the existing support for family in Wales is the Institute of Public Care (IPC) (2012). The Welsh Government created a family support pathway for children with disabilities. It is a plan which “tells everyone involved what should be happening”, stretches over events from the child’s birth to his or her adult life and “it can help families and professionals make sense of a complex world”. At every stages of the life of the person with disabilities, there is assessment and goals are set together with different professionals needed at each stage and members of the family, given that parents need “to be included in decisions about their child’s care” (Estrella, 2013).

Another organisation in UK, contact a family, offers support to parents, practical advice and emotional support. The groups are run by the parents themselves (Contact a family, 2012).

### 2.4 Autism in Mauritius

Three ministries in Mauritius namely Health, Education and Social Security are concerned with children with Special Needs. It has been observed that there was plenty of room for improvement in that field. Dr. Jean-Marc Michel, a Mauritian native based in UK, international Consultant and Fellow of the Royal College of Pediatrics and Child Health of London, declared in an interview with Le Mauricien newspaper, that there were indications that the number of children with autism would be on the increase as more local persons were trained in the detection of autism. There were moves to establish resource centres called Child Development Centres in at least three localities in Mauritius. (Le Mauricien, 2012).
A few NGOs are most actively involved in the field of autism. For example, *Autisme Maurice* and APEIM (*Association de Parents d’Enfants handicapés de l’île Maurice*), are the main ones working with those children in Mauritius. APEIM was founded in 1970 and is open to all mental disabilities including autism whereas *Autisme Maurice*, officially registered in 2010, is open to persons who are directly linked with the syndrome (Baijoo, 2011).

In general, the therapeutic team consists of psychologists, occupational therapists, speech therapists and educators. In other countries like UK, USA or Canada there are also specialised social workers for children with autism.

Autism affected 1 in 2,500 children some thirty years ago compared to 1 in 68 nowadays (Fournier, 2014). Autism is a “fastest growing disability” (Mardar and deBettencourt, 2012). There are about 67 million people with autism in the world (Le Mauricien, 2011) and in Mauritius about 10,000 to 12,000 according to Dr. Joffrey Bodet, the psychologist at *Autisme Maurice*, in an article on 5-plus newspaper (Azemia, 2015). Mauritius together with other countries will have more to invest in this growing population of children with autism. When growing up, they will need help in other ways; different kind of services for different degree of severity of autism. Laws do exist to protect those children but the appropriate implementation and training are crucial aspects. Above all awareness to overcome stigma and ignorance that unfortunately keep too many children away from society should be tackled urgently.

In Mauritius, laws concerning children with autism are the CRC and the UNCPARD. The protection of persons with disabilities is provided by the Ministry of Social Security within The National Centre for the Rehabilitation of the Disabled (NCRD). The NCRD is an advisory body which “attends to all questions concerning the different handicaps and to advise Government accordingly” for example the restructuring of buildings which suit wheelchairs. Other facilities given to children with disabilities and their family is financial support, the help of the Ministry of Health and Quality of Life in providing a Speech Therapist that is useful in certain cases of autism. Furthermore, when a child is diagnosed with a certain disability, contact is maintained with parents
who also benefit from Home Therapy Programmes. In order to integrate the child with a disability in the community, the Ministry of Health conducts the Community Based Rehabilitation (CBR) programme. Finally, government bodies work with NGOs in implementing programmes which benefit the child with a disability (Ministry of Women’s Rights, Child Development, Family Welfare and Consumer Protection, 2006).

In a presentation to the Ministry of Education in 2012, Dr. Jean-Marc Michel, a Mauritian native based in UK, international Consultant and Fellow of the Royal College of Pediatrics and Child Health of London, stated that there is approximately 13,000 children with autism in Mauritius (Global Rainbow Foundation, 2012).

Concerning private sector initiatives, there is the active participation of NGOs like Anou Grandi, Joie de Vivre Universelle, APEIM and more recently Autisme Maurice that specialised itself in autism. Those NGOs are funded through Corporate Social Responsibility funds to which companies contribute a percentage and individual sponsorship.

In Mauritius, NGOs have recourse to the TAC which is a multidisciplinary team. A multidisciplinary team differs from a transdisciplinary team in the way that professionals work on their own regarding assessment and diagnosis and meet other professionals only to see if their findings are complementary or different from other members’ assessment. The multidisciplinary team comprises of the following professionals: School based Occupational Therapist (OT), Speech Language Therapist, Educational Psychologist, Special Educational Needs (SEN) Educator, Physiotherapist, SEN carers and in some cases a Psychiatrist (Le Mauricien, 2012).
2.5 Social work interventions with children with autism and their family

Social work has its own source of theories and research which is constantly developing, as well as theories from other human sciences “including but not limited to community development, social pedagogy, administration, anthropology, ecology, economics, education, management, nursing, psychiatry, psychology, public health, and sociology.” (IFSW, 2012).

Social work interventions include counselling, family therapy as well as “community organisation and engaging in social and political action to impact social policy and economic development” (IFSW, 2014). Social workers are prepared to address problems at micro, macro and mezzo levels by using the ecological perspective. Children with autism can benefit from specialised training and assistance of those social workers (Dente and Coles, 2012).

2.5.1 The Ecological Framework

The ecological framework is one model which social workers use with children with autism and their families. It uses the concept of ‘person-in-environment’ and bears the thinking that ‘no two individuals, families, groups, or neighborhoods are the same’. “Ecological systems theory posits that individuals constantly engage in transactions with other humans and with other systems in the environment, and that these individuals and systems reciprocally influence each other.” (Hepworth et al. 2009, p.15). The systems that affect a child with autism are his or her family, school, community and society inter alia (Figure 2).
In an ecological perspective, social workers first bring support to families after the diagnosis and educate them on the disorder. They collaborate with the TAC and the family, assist in the assessment process, support and motivate family members, support the school which the child attends and advocate for policy changes. The assessment process includes the process for special education services. In an ecological perspective, the social worker focus is on the child as a student as well as his or her interaction with the school, home and the community, which involve intervention at mezzo level. A social worker has the role of educator with the child’s classmates, parents and the community who more than often do not understand the disorder (Eveslage 2012, p.22-23). He or she could also implement programmes for the family like respite facilities and holiday schemes which would allow parents to have a social life and spend time with their typical children.

Intervention at macro level with children with autism includes advocating for policies and providing trainings about the disorder (Eveslage 2012, p.24). The
social worker would implement programs like public awareness campaigns which aim at not to discriminate the child but also to make parents-to-be aware of the symptoms, management and available services for autism.

“Through their professional training and ecological orientation, social workers are, however, well suited to act as case manager (or coach) and to assist with the assessment, planning, and interventions needed” (Dente and Coles, 2012). Casework, a psychosocial therapy, is employed to help clients achieve better social functioning (Hollis 1972, p.34). It is an important tool used within the ecological systems theory, while dealing with children with autism because it is “a response to the needs of human beings for protection against social and natural deprivations” (Hollis 1972, p.14). However, due to the children’s inability to have self-determination, the assistance of the parents would be required. Case management is not only for the child with autism but also within the professional team in the TAC, to ensure that communication happens between members and to focus on the family’s strengths and needs in order to help the family and the child achieve their goals (Autism Ontario, 2011).

An Australian study concluded that as “a challenge to the family, autism must rank among the most stressful of childhood developmental disabilities” due to the child’s impairment in communication, social interaction and imagination (Interactive Autism Network, 2009). Nathan Ackerman, a pioneer in family therapy, pointed out that the family is the major force in shaping mental health (Thorman 1997, p.3).

### 2.5.2 Family Systems Theory

Another theory which meets the ecological systems theory is the family systems theory. The family is probably the most important unit in the life of the child. The child’s development is influenced by members of the family, who are known to “affect the thoughts, feelings, and behaviors of one another”. The whole family has to cope with the disorder and professional social workers can identify family influences on the child (Hartmann 2012, p.26).
Family being a social institution (Thorman, 1997), it is important to empower parents until they are able to deal with professionals and services but also educational and behavioural problems of their children by themselves. The Social workers’ role is to help families “lead a more satisfying life by creating their own goals” (Eveslage, 2012).

Parents are drained and often leave out the rest of the family members. “Mothers are consumed by the day-to-day needs of raising a different kind of child. It’s hard to take a break from needs that do not diminish. Fathers have a difficult time talking about their feelings especially when unable to fix the problem.” (Naseef, 2013). The social worker would also help the parents as a couple. In many cases, differences and disagreements are created leading to breakups and divorce after the diagnosis has been given. The social worker can help the couple to opt for couple counselling or family counselling (Autism Ontario, 2011). Family therapy is a tool used to help members of the family solve their problems through a family-centred approach (Thorman 1997, p.3). It enables social participation and restore the functions of the family.

### 2.5.3 Counselling

Counselling is another tool used by different professionals including social workers. It is a method used with both children and the parents. People with autism are more vulnerable to anxiety or depression than typical ones (National Autistic Society, 2015). Counselling enables “accommodations that might help to repair some of the injury of chronic experience of ‘misfit’: the incongruity between mind and/or body and environment.” Counselling helps in restoring back the ‘performative’ self (Hodge 2013, p.107).

Children who have progressed in the communication field and are able to express their feelings do have counselling sessions with the social worker, which is the case for the step by step academy in the USA. Children with autism face challenges in the family, at school and the community (Autism Ontario, 2011). Counselling includes “work on discussing and identifying feelings, social
interaction with others, providing therapeutic listening, engaging in creative play, engaging in age-appropriate group activities, etc.”, which can be done in groups but also on an individual basis (Special Learning, [no date]).

Family therapy also benefits behaviour management towards the child with autism. The child with autism acts and reacts differently from the neurotypical child. As mentioned earlier, autism has an impact on the brain in the areas of social interaction and communication. The child has difficulties in communicating with others and relating to his or her environment. He or she can be aggressive with others or self-injurious or behave inappropriately. A family break up can ignite those behaviours in the child, and family therapy as well as counselling can be beneficial for both parents and children (Autism Ontario, 2011).

2.5.4 The Problem solving model

Problem solving model is used in social work practice models to engage families to deal with their own problems. May it be in casework or family therapy, the social worker works with the whole family to identify goals and develop a plan of action for goals achievement (Thorman 1997, p.95). First step to problem solving is exploring problems, then identify target problems which need to be solved and finally developing tasks and a social work intervention plan to deal with specific issues together with the clients.

The social worker’s main role in problem solving model is to keep members of the family motivated throughout the process, in order for them to reach their goals. Plans are designed according to the families’ needs including those of the child with autism (Thorman, 1997).
2.6  Roles of social workers with children with autism and their family

The roles of social workers can embrace a wide range of areas. The vulnerable groups touched by social workers include the elderly, women, disabled persons, and children with special needs. Thus, social workers can address the obstacles, discrimination and isolation children with autism are facing. Roles of the social worker are seen in (Figure 3).

In order to work with children with autism and meet their needs, it is vital that social workers understand autism and its impact because without “the right training, community care assessors will struggle to understand the complexities
of autism, which can lead to some people receiving inadequate or even no support.” (Social workers need extra training to fully understand autism, 2013).

The social worker can act as enabler with the individual, the family system but also the community to facilitate the inclusion of children with autism within the social and physical environments (Hepworth et al., 2009). Social workers can “address the various emotions and stress of having a child with ASD” at the time of diagnosis. Thus, a social worker would educate the parents on autism and help them to accept the diagnosis. Moreover, he or she would help the family to bring change in their lifestyle by helping parents to integrate different activities with the child. (Autism Ontario, 2011).

Social workers would also find appropriate resources and services for the family. He or she might refer the family to available specialised schools and appropriate professionals. The professional would also help in identifying financial resources for families in need (Autism Ontario, 2011).

A social worker in the field of autism would be a key worker and a lead professional working together with other professionals in the field. He or she is the single point of contact for the family who is more than often overwhelmed by these processes (Institute of Public Care, 2012). Moreover, the social worker can advocate for more services on behalf of the child if needful, schedule and keep track of meetings and appointments with other professionals and could also accompany the child and/or the parents (Northcott [ca.2013], p.8).

### 2.7 Conclusion

It is observed that Mauritius lacks, *inter alia*, structures regarding the application of social work intervention in the autism field compared to developing countries like UK or USA. Social workers through their different roles have a virgin territory to be explored in Mauritius. In some countries like Australia or Canada, social workers form part of a transdisciplinary team with an integrated care
pathway which uses a holistic approach to better care for the child with autism before, during and after birth.
CHAPTER 3

3.0 Introduction

The aim of this research was to investigate the present situation of children with autism in Mauritius and draw conclusions from those findings to see if the needs of those children are fully met. It also seeks to find out how social work interventions can complement the work that is being done in that field. A qualitative approach was used, through the face-to-face interviewing of special needs educators working with children with autism.

3.1 Epistemology

“Social action can only be understood by interpreting the meanings and motives on which it is based.” (Haralambos et al. 2000, p.971). In order to answer the research question as to how could social work interventions help in the improvement of the situation of children with autism in Mauritius, there was a need to first understand what was the current situation concerning those children as it would be “impossible without some understanding of the subjective states of the individuals concerned.” (Haralambos et al. 2000, p.972). Therefore, an interpretive approach was deemed most suitable to “construct a meaningful reality” through a qualitative method by means of interviews (Cohen and Crabtree, 2006).

Qualitative research enables the collection of primary data through observation in different ways, for example in words or pictures. It consists of collection and analysis of data, and drawing conclusions (Hartmann, 2012). The qualitative approach gave a richer and deeper picture of the needs of children with autism. This was best captured by their educators who are also in contact with the parents and therapists. As will be seen in the findings in Chapter 4, the detailed
information collected confirmed the need for social work interventions with those children.

3.2 Research Method

Due to the nature of the subject and the lack of research which linked social work with autism, a qualitative approach was found to be the most convenient. This was done by administering questionnaires, using a mixed mode design that is with open and close-ended questions. The interviews were on a one to one, face to face basis. The questionnaire method was chosen as it was more practical, easily administered and quicker.

3.3 Selection of Participants

Educators were targeted for this study and selected from 3 different organisations namely Autisme Maurice, APEIM and Joie de Vivre Universelle. Site visits were carried out before hand where the researcher spent time in the different institutions and was able to discuss with the responsible of each organisation. In order to get a variety of data, different participants were selected by taking the following characteristics into account:

- level of education,
- training (formal or informal),
- length of experience in the field of special needs.

3.4 Description of Processors to ensure ethical conduct

Every participant was given information about the researcher, the aim of the study and how the interview would proceed. Further questions about unclear matters were answered. Prior to the interview, each interviewee was ensured
verbally that their details would not be publicly disclosed and the contents of the questionnaire were only for the benefits of the study.

A consent form was also given to participants, which they signed acknowledging that their participation was voluntary (Appendix B).

In order to keep the participants and other human subjects anonymous, their name and personal details did not appear in the study. All confidential data including questionnaire and notes were kept in a locked filing cabinet in the researcher’s home to which only she had access. They were then destroyed after the completion of this study.

### 3.5 Conducting interviews, questionnaires…

A pilot study was carried out before conducting the interviews with two educators. Amendments were brought to a few questions and some irrelevant questions were deleted after the pilot study. It was also found that 9 on 10 educators preferred to respond in French and one participant in English.

Participants were contacted for appointments which were held in confidential places at each participant’s convenient time. A sample of 10 participants was selected randomly from 3 different NGOs for this study. Confidentiality was respected throughout the interview process.

Every single answer was noted in the questionnaire itself and in front of the participant. It took approximately 45 minutes for each questionnaire. It is important to note that in the questionnaire, social work jargon was avoided. In order to facilitate discussion and for better expression of ideas, French language was used throughout the interviews except for one participant for whom it was easier to use English language.
3.6 Data Analysis

Content analysis was used in this study. Coding was used as a method because it enables the organisation of similar data into categories (Saldana 2009, p.8). Content analysis allowed the identification of similarities and differences which were coded and then categorised. They were put under different major themes/concepts which were identified through the educators’ personal and working experience with children with autism. The themes were then linked to the theoretical framework and interpreted to reach the objective of improving the situation of children with autism in Mauritius through social work interventions.

3.7 Conclusion

The research was carried out using a qualitative approach through the administration of questionnaires. Ethical conduct and confidentiality were respected during the whole process and after analysis, findings are presented in the next chapter.
CHAPTER 4

4.0 Introduction

As mentioned before, the purpose of these interviews was to investigate the present situation concerning autism in Mauritius and to determine to what extent the present structures and measures are responding to the needs of children with autism. Where necessary, the study endeavours to show how social work interventions can improve the situation of those affected children.

4.1 Profile of respondents

Most if not all educators in that field are females. 10 educators, chosen from 3 different NGOs, were interviewed for the purpose of this study considering different characteristics (see Table 1).
Table 1: Characteristics of respondents

<table>
<thead>
<tr>
<th>Respondents</th>
<th>Level of Education</th>
<th>Training in social work</th>
<th>Length of Experience (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent 1</td>
<td>Special Educational Needs at MIE</td>
<td>Formal and Informal</td>
<td>3</td>
</tr>
<tr>
<td>Respondent 2</td>
<td>Secondary</td>
<td>Informal</td>
<td>14</td>
</tr>
<tr>
<td>Respondent 3</td>
<td>Special Educational Needs at MIE</td>
<td>Formal and Informal</td>
<td>5</td>
</tr>
<tr>
<td>Respondent 4</td>
<td>Special Educational Needs at MIE</td>
<td>Formal and Informal</td>
<td>10</td>
</tr>
<tr>
<td>Respondent 5</td>
<td>Tertiary</td>
<td>Formal</td>
<td>2</td>
</tr>
<tr>
<td>Respondent 6</td>
<td>Tertiary</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Respondent 7</td>
<td>Tertiary</td>
<td>Formal and Informal</td>
<td>18</td>
</tr>
<tr>
<td>Respondent 8</td>
<td>Special Educational Needs at MIE</td>
<td>Informal</td>
<td>8</td>
</tr>
<tr>
<td>Respondent 9</td>
<td>Secondary</td>
<td>Informal</td>
<td>40</td>
</tr>
<tr>
<td>Respondent 10</td>
<td>Tertiary</td>
<td>Formal and Informal</td>
<td>9</td>
</tr>
</tbody>
</table>

4.2 Findings

Interviews were focused on 4 main themes: (a) Training needs of educators, (b) Support services for families, (c) Support services for children, and (d) Need for social work interventions. Findings were translated from French and original answers are presented as Footnotes. For a detailed account of findings, see Appendix C.
4.2.1 Training needs of educators

As mentioned in the Literature Review, relevant training is crucial in caring for children with autism (Mardar and deBettencourt, 2012). Findings show that only 9 on 10 participants had received training on autism. Among these 9, 5 participants who followed Special Educational Needs courses in 2 different institutions pointed out that there was only a module pertaining to autism. Moreover, trainings were not formal and deepened on autism and other related problems attached to the disorder like epilepsy, sleeping disorder and others mentioned in Chowdhury’s article (2009, p.16).

4 participants’ reports are as follows regarding their specialised trainings in autism:

Participant 1 reported:
“I had an internal training with professionals, like the speech therapist and the psychologist, from APEIM. I also received training on autism with educators from Autisme Réunion, when they came to Mauritius.”

Participant 2 stated:
“I received basic training with Mrs Natalie Faucher and Jacqueline Gibiard from Reunion Island. Recently, I received training in Reunion Island on different methods such as TEACCH/ABA.”

Participant 3 had the following response:
“I received training on medico-psychological support in Reunion Island.”

Participant 4 reported:
“I received training on the field in Mauritius and I was on placement in South Africa, at UNICA School for Autism.”

1 «J’ai eu une formation interne avec des professionnels comme l’orthophoniste et le psychologue de l’APEIM. J’ai aussi eu une formation sur l’autisme avec des formateurs de Autisme Réunion lors d’une visite à Maurice. »

2 « J’ai eu une formation à l’Aide Médico-Psychologique à l’île de la Réunion. »
4.2.2 Support services for families

Literature shows that families “suffer from lack of support may it be human or financial” (Naseef, 2013). Findings support current literature and indicated that there was minimum emotional, practical and financial support for families with children with autism. Regarding the types of support parents received after the diagnosis, out of the 10 participants, 3 acknowledged that nothing was done for the parents. 4 participants reported as follows:

Participant 1:
“Government help families by giving social aid. Some children are sponsored in order to attend classes, as school is not free.”

Participant 2 reported:
“They have therapies in different hospitals once a month which is not enough. Hospitals refer them to different associations where the child would be taken care of every day of the week according to the school calendar. Some are left on their own and do not know what to do.”

Participant 3 reported:
“We refer them to the psychologist or to Autisme Maurice. Educators also accompany parents.”

3 « J’ai eu une formation sur le terrain ici même, a Maurice et j’ai été faire un stage en Afrique du Sud, a l’UNICA School for Autism. »
4 « Le Gouvernement aide ces familles par une aide sociale. Certains enfants sont parrainés côté scolarité, vu que l’école est payante. »
5 « Ils sont suivi par des thérapeutes de différents hôpitaux une fois par mois ce qui n’est pas suffisant, les hôpitaux les réfèrent a différentes associations ou l’enfant sera pris en charge tous les jours de la semaine suivant le calendrier scolaire. D’autre sont livrées a eux mêmes et ne savent pas quoi faire. »
6 « Nous les dirigeons vers le psychologue ou vers l’association Autisme Maurice. Aussi, l’accompagnement des parents se fait par les éducatrices. »

30
Participant 4 stated the following:

“Support varies according to needs. There is a home-based service (social, medical, therapeutic), just like a service with specialists who help, frame, counsel, train and do follow-up of the families and the children.”

4.2.3 Support services for children

Some children progress and some regress in their development, and one major factor is the follow-up done or not at home. It can be deduced that there is a lack of follow-up due to the absence of home visits. As to how educators make sure there is proper follow-up at home, the findings report as follows for 4 participants:

Participant 1:

“For every child there is a communication notebook which enables us to stay in contact with the parents, if parents have an issue they write or phone us. At the end of each semester we call the parents for an appraisal with the supervisor, the educator and the psychologist to see if the objectives are reached.”

Participant 2:

“We invite parents to attend a work session with the educators to see how they work with their children. We also have frequent meetings, workshops with parents.”

Participant 3 reported:

“We need to inform parents, meet them and explain what is being done. We need to meet at the end of each term with the parents, the educator and the

7 « Les supports varient selon les besoins. Il y a un service à domicile (niveau social, médical et thérapeutique), tout comme un service avec des spécialistes qui aident, encadrent, conseillent, forment et suivent les familles comme les enfants. »

8 « Chaque enfant a un carnet de liaison qui nous permet de rester en communication avec les parents, si les parents ont un souci ils nous écrivent ou ils nous téléphonenent. A la fin de chaque semestre nous convoquons les parents pour faire un bilan avec le chef de service, l’educatrice et le psychologue pour voir si les objectifs ont été atteints. »
psychologist. We need to tell them that the development of the child depends also on parent’s collaboration.”

Participant 4:
“It's difficult to be 100% sure that the parents are doing what they have to. But we can suppose when we observe the progress of the children. Progress settles quicker in certain cases if apprenticeships are taken at home - But we must not forget that parents are not specialised educators.”

4.2.4 Need for social work interventions

There is a lack of research which links social work to autism. However, in countries like UK or Australia, there is the TAC. It comprises of different professionals including the social worker who normally has the role of the key worker or lead professional. He or she is the link between other members of the team and coordinates the service delivery to the family (Northcott [ca.2013], p.6). Participants were asked in what ways a social worker can contribute to the improvement of children with autism in Mauritius. Reports for 4 participants are as follows:

Participant 1:
“The social worker must stay informed about autism so as in turn he or she is able to inform parents and other persons around the child with autism. He or she must also meet parents in order to bring support and also visit specialised schools to target problems that children face so as to find solutions.”

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9 « Il faut informer les parents, les rencontrer et leur expliquer ce qui est mise en place. Il faut les rencontrer à la fin de chaque trimestre entre les parents, l’éducateur et le psychologue. Il faut leur dire que l'épanouissement de leur enfant dépende aussi de leur collaboration. »
10 « C’est difficile d’être sure à 100/100 que les parents font ce qu’il faut ou pas. Mais on peut le supposer quand nous observons le progrès chez les enfants. Le progrès s’installe plus vite dans certains cas si les apprentissages sont repris à la maison. Mais n’oublions pas que ce sont des parents mais pas des Educateurs Spécialisés ! »
11 « Le travailleur social doit rester informé sur l’autisme pour pouvoir à son tour informer les parents et toutes les personnes qui entourent l’enfant autiste. Il doit aussi rencontrer les parents... »
Participant 2:

“Social workers can help family in the following ways:

1. think about how you feel about the disability
2. figure out what you and your family member need
3. help you find resources in the community that may help you
4. help you with applications for services
5. connect with other families of children with the same disabilities
6. connect with support groups

Social workers can also offer support and advice on services such as play schemes, parents’ groups and short breaks. Social workers are involved in assessing the care needs of children with autism and their families. They’re also involved in arranging help to meet those needs.”

Participant 3:

“He or she must take into account the specific and concrete needs of the child with autism and his or her family. There is already a struggle committed to the recognition of rights and equality of children with or without special needs. We must maintain the struggle. It is necessary to listen, understand and act when necessary. There is a great lack of infrastructure and facilities for our children with special needs, the social worker must contribute to this fight for recognition and also the establishment of these structures. With those structures, activities can be implemented, work can be done. It is important in the case of autism that the social worker works in collaboration with other professionals, the specialised institution and the child’s parents.”

12 « Il doit prendre en compte les besoins spécifiques et concrets de l’enfant autiste et de sa famille. Il y a une lutte déjà engagée pour la reconnaissance des droits et l’égalité des enfants avec ou sans besoins spéciaux. Il faut maintenir la lutte. Il faut être à l’écoute, comprendre et agir quand il le faut. Il y a un grand manque d’infrastructures et de structures pour nos enfants à besoins spéciaux, le travailleur social doit contribuer à ce combat de reconnaissance et aussi de la mise en place de ces structures. Avec des structures, on peut mettre en place des activités, le travail peut être fait. Il est important dans ce cas précis d’autisme que le travailleur social travaille en collaboration avec les professionnelles, l’établissement spécialisé et les parents de l’enfant. »
Participant 4:

“Maybe precisely to empower parents and also find ways to reach for children with autism who do not have access to school and stay at home.”

4.3 Discussion

4.3.1 Training needs of educators

In a growing population of children with autism, it is observed that there is a lack of specialised training in autism in Mauritius. Findings show that, either professionals come to Mauritius or educators have to move to other countries, mainly Reunion Island, to receive specialised trainings. Apart from parents, educators are the ones who spend more time with the children. In the 9 participants who had specialised training in autism, 7 had learned about techniques to be used in class. Autism being a complex disorder, it is of utmost importance that further training in autism is needed. Literature agrees with this statement with Mardar and deBettencourt (2012) observation about the positive outcome on children, of having specific training in autism.

Furthermore, it can be deduced that with appropriate structures which distribute specialised training in autism there would be less expenses on either inviting professionals or the need to move to other countries. Thus, funds could be re-allocated for better services for those children and their families.

4.3.2 Support services for families

According to an Australian study, autism is the most challenging and stressful disorder (Interactive Autism Network, 2009). This can have a negative impact on families. A problem solving model would suit families with children with

13 « Peut-être justement chercher à autonomiser les parents et aussi chercher comment atteindre les enfants autistes qui n’ont pas accès a l’école et qui restent a la maison. »
autism. The whole family thus work in collaboration with a professional to identify goals and develop a plan of action for goals achievement (Thorman, 1997).

Parents are sometimes victims of personal problems like separation or abandonment and on top of that have to deal with the challenging behaviours of their child with autism. Family being a social institution (Thorman, 1997), it is important to empower parents until they are able to deal with professionals and services but also educational and behavioural problems of their children by themselves. Social workers’ role is to help families “lead a more satisfying life by creating their own goals” (Eveslage, 2012). Participants were asked about ways to empower parents. One participant reflected on the following: “Empowerment can be in the form of learning teaching techniques and ways to structure the physical environment of the child. It is also important to read and do research on how to deal with a child with autism. The parents should also attend training/workshops regularly. Moreover, there should be referrals, adequate support system, therapy and counselling.”

In Mauritius, compared to UK, there is no support groups especially designed for parents like the Contact a Family organisation. Naseef (2013) stated that as a consequence from a lack of human and financial support, some families are broken. In the findings, 3 out of 10 acknowledged that there is no support. One participant stated: “In public services there are none!”

As for the rest, 4 of them found that parents are referred to NGOs with specialised schools which their children will attend, and depending on the institution, they can have access to the institution’s psychologist. Concerning support from the extended family, findings show that it differs depending on the way they get the news.

Effects of autism tend to put parents on stress (Naseef, 1989). A respite area for parents would help them to share experiences with other parents and spend time with their neurotypical children. According to findings, all 10 participants found the idea really interesting for parents. One of the participants reported: “It would

\[14\] “Dans les services publiques il n’y a rien!”
be a really good move because parents need to talk and confide themselves and it would be a good thing that from an early age the other children learn to accept those children who are not like them.”

4.3.3 Support services for children

In the case of children with autism, support services should be strong enough to enable them to “engage in transactions with other humans and with other systems” in their environment (Hepworth et al. 2009, p.15). Some children with autism “suffer silently in pain from untreated medical issues; they are abused, bullied, and may be at increased risk of suicide” (Fournier, 2014) which shows a dysfunction in their eco-system.

When questioned about follow-up at home, a participant stated: “It’s difficult to be 100% sure that the parents are doing what they have to. But we can suppose when we observe the progress of the children. Progress settles quicker in certain cases if apprenticeships are taken at home - But we must not forget that parents are not specialised educators.”

Other findings show that to ensure that there is follow-up, some educators meet with parents at end of each term, which means thrice a year. It can be assumed that, there is paucity in home visits. The role of the social worker, among others, is to assist, support and motivate family members in order for them to reach their goals (Thorman, 1997).

“It’s something difficult.” said a participant about the question as to how their organisation reaches children who do not have access to school. There is much to do in communities to reach those children and to raise public awareness, which could be a social worker intervention according to IFSW (2014).

15 « Ce serait une très bonne initiative car les parents ont besoin de parler, de se confier et ce serait une bonne chose que depuis leur jeune âge les autres enfants apprennent à accepter ses enfants qui ne sont pas comme eux. »
16 « C’est difficile. »
Infrastructure is another important factor. It can be deduced from findings that there is a lack of funds in those NGOs and that they rely heavily on CSR funds and sponsorships. When asked about how well their organisation is well equipped, a participant reported: “I would say relatively well equipped considering how difficult it is to get funds. The organisation strived hard to get where it is at. But there is still a massive work to be done. We need to get more funds in order to improve the services given to children with autism.”

Concerning the improvement of services for children, a participant reported what was missing: “Home visits, counselling sessions with the family, more infrastructures in terms of building (schools, internship/residency) and services such as transport."

### 4.3.4 Need for social work interventions

From findings, there is evidence that the work of a social worker is not recognised as such. 4 of the participants said that a social worker’s role is voluntary. One of the participants stated: “If possible to make children and parents go for a walk for example, so as to distract them.”

According to the ecological perspective, interventions occur at micro, mezzo and macro level (Dente and Coles, 2012). The social worker’s role is to work within the family as well as in the community and finally reach society. Micro level intervention includes working for better services for the children with autism and their family. Findings show that both counselling and family therapy are performed by the psychologist of the institution. However, there are other ways to help families starting with bringing support and help in finding appropriate services like one participant observed when asked about support that families

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17 « Je dirais relativement bien équipé en considérant combien il est difficile d'obtenir des fonds. L'organisation a travaillée dur pour arriver où elle est. Mais il y a encore un énorme travail à faire. Nous avons besoin de plus de fonds afin d'améliorer les services offerts aux enfants autistes. »

18 “Si possible faire sortir les enfants et les parents pour une promenade par exemple, pour se distraire.”
get: “Government help families by giving social aid. Some children are sponsored in order to attend classes, as school is not free.”

Mezzo intervention includes educating the community about the disorder. One participant had the following observation on how the community can help in the well being of the child with autism: “By being non-judgmental and getting to know more about autism, thus accepting the child. By providing necessary structures for children with autism.” Parents tend to isolate themselves due to their child’s challenging behaviours and even refuse to go to relative’s place or in public places with the child. They have a feeling that “they cannot socialize or relate.” (Hartmann, 2012). Intervention at mezzo level would maximise the “goodness of fit” between the needs of the person with disabilities and the environment (Hepworth et al. 2009, p.16). Examples of interventions are rehabilitation programs, education for the community, and social support systems.

Intervention at macro level with children with autism includes advocating for policies and providing trainings about the disorder (Eveslage 2012, p.24). Early identification would be enabled with increased awareness (Global Rainbow Foundation, 2012). Thus, public awareness and programmes aiming at reaching children with autism who do not have access to special needs services are possible practical interventions by the social worker. Another big challenge of social work is advocacy for policies. One participant reflected on the following: “Laws already exist even if I’m not fully satisfied with them. But for sure they need to be amended for more equity and equality. But are our leaders willing or ready to change things? This will take a lot of time according to me.” Other countries like UK have their own Autism Act (National Autistic Society, 2015).

19 « Le Gouvernement aide ces familles par une aide sociale. Certains enfants sont parrainés côté scolarité, vu que l’école est payante. »

20 « Les lois sont déjà en place même si je ne suis pas tout à fait satisfait. Mais c’est sure qu’il faut les améliorés pour plus d’équitable et d’égalité. Ce que j’aimerai est une chose, mais ce que nos dirigeants sont-ils disposés ou prêts pour faire changer les choses ? Cela prendra encore beaucoup de temps selon moi. »
Findings show that 8 out of 10 participants acknowledged that there is a gap in the laws.

When referring to disability services, “one size does not fit all” (Institute of Public Care, 2012). It can be deduced that casework is the answer as it helps clients achieve better social functioning (Hollis 1972, p.34). Within an ecological system ‘no two individuals, families, groups, or neighborhoods are the same’ (Hepworth et al., 1997). According to the findings, all 10 participants were for the idea of having casework for each child and their family. This reflects the saying ‘no two persons with autism present identical symptoms’. One participant observed that in order to introduce Casework there should be “Proper data collection to target families and their specific needs and difficulties. Set up a support structure also.”

4.4 Conclusion

Findings show that there is ample scope for social work interventions although social work is not yet recognised in Mauritius as a profession. Due to a lack of literature, attempts were however made to link social work theories to working with children with autism supported by the reports of the interviewees.

21 « Collecte de données pour cibler les familles et leurs besoins et difficultés spécifiques. Mettre en place une structure de prise en charge aussi. »
CHAPTER 5

5.0 Conclusion

The ecological systems theory, family systems theory and problem-solving model *inter alia* referred to in this research are aimed at strengthening the whole family of the child with autism and attending to their needs. In this study, a qualitative approach was used by administering questionnaires. The research was based on 10 interviews from educators in the special needs field due to their experience in the field. After analysis, 4 primary themes were found, namely training needs of educators, support services for families, support services for children, and need for social work interventions.

Findings show that social work interventions could be implemented in the field but lack of funds was a major problem faced by NGOs in Mauritius. Concerning services to children with autism and their family, pathways could be adapted from abroad to better alleviate problems faced by these families.

There was however some limitations in this research due to scarcity of literature and the sample size of 10 which is not representative of a whole population.

5.1 Recommendations

The Mauritius Government Budget Speech 2015, lay emphasis on welfare and social aspects, it has been deplored by NGOs that but no specific provision for the special needs and especially children with autism was observed. This study endeavours to act as an eye opener for all parties concerned especially government bodies that have the power of decision-making. It is never too late, especially if a country wants to care for the most vulnerable members of its society.

It is also expected that avenues are open for more research in the field, especially for school social work in special needs institutions.
REFERENCES


MARDAR, T.J. AND DEBETTENCOURT, L.U., 2012. Using a Hybrid Model to Prepare Special Educators to Teach Students Identified with ASD. *Rural Special Education Quarterly*, 31 (3) 12-23.


[http://www.5plus.mu/node/4061](http://www.5plus.mu/node/4061) [Accessed 26 March 2015].


MARDAR, T.J. AND DEBETTENCOURT, L.U., 2012. Using a Hybrid Model to Prepare Special Educators to Teach Students Identified with ASD. *Rural Special Education Quarterly*, 31 (3) 12-23.


### APPENDICES

#### APPENDIX A: QUESTIONNAIRE

**Section A**

**Educator’s trainings**

<table>
<thead>
<tr>
<th>Question no.</th>
<th>Questions</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q A.1</td>
<td>Level of education</td>
<td>1. No formal education</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Primary</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Secondary</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Tertiary</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Other ………………</td>
</tr>
<tr>
<td>Q A.2</td>
<td>What specialised trainings in autism have you received?</td>
<td></td>
</tr>
<tr>
<td>Q A.3 (a)</td>
<td>Have you received any social work training?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td>Q A.3 (b)</td>
<td>If yes, was it formal or informal?</td>
<td>1. Formal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Informal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Both</td>
</tr>
<tr>
<td>Q A.3 (c)</td>
<td>What did the training cover?</td>
<td></td>
</tr>
</tbody>
</table>
Section B

Experience as Educator

<table>
<thead>
<tr>
<th>Question no.</th>
<th>Questions</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q B.1</td>
<td>For how long have you been working in the field of special needs?</td>
<td></td>
</tr>
<tr>
<td>Q B.2</td>
<td>How many children do you have in your class?</td>
<td></td>
</tr>
<tr>
<td>Q B.3 (a)</td>
<td>What are the strategies used in your class?</td>
<td>1. ABA (Applied Behaviour Analysis)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Floor time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Other ……………………</td>
</tr>
<tr>
<td>Q B.3 (b)</td>
<td>How did you/your organisation come to choose this/these strategy/strategies?</td>
<td></td>
</tr>
<tr>
<td>Q B.4</td>
<td>Knowing that what you do at school is essential for parents to reproduce at home, how do you ensure that there is proper follow-up by parents?</td>
<td></td>
</tr>
<tr>
<td>Q B.5</td>
<td>What are your roles as an educator?</td>
<td></td>
</tr>
<tr>
<td>Q B.6 (a)</td>
<td>What are the laws / rights concerning children with autism in Mauritius?</td>
<td></td>
</tr>
<tr>
<td>Q B.6 (b)</td>
<td>Are you satisfied with those laws? What would you add or improve?</td>
<td></td>
</tr>
</tbody>
</table>

Section C

Support services to families

<table>
<thead>
<tr>
<th>Question no.</th>
<th>Questions</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q C.1</td>
<td>What type of support do parents get after the diagnosis?</td>
<td></td>
</tr>
<tr>
<td>Q C.2</td>
<td>How do families at large (grand-parents, aunts, cousins, brothers…) usually react to diagnosis?</td>
<td></td>
</tr>
<tr>
<td>Q C.3</td>
<td>What do you think of a respite area / group for the parents where they can socialise and spend time with their other children?</td>
<td></td>
</tr>
<tr>
<td>Q C.4</td>
<td>In what ways can parents be empowered in order for them to cope with their child with autism, other issues related to autism (behaviour management, education) and personal issues (financial problems, separation, abandonment)?</td>
<td></td>
</tr>
<tr>
<td>Q C.5</td>
<td>How do you/your organisation reach children with autism who do not have access to school or stay at home or parents who do not send their children with autism at school?</td>
<td></td>
</tr>
</tbody>
</table>
## Section D

### The Institution

<table>
<thead>
<tr>
<th>Question no</th>
<th>Questions</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q D.1</td>
<td>How can social workers contribute to the improvement of the situation of children with autism and their family?</td>
<td></td>
</tr>
<tr>
<td>Q D.2</td>
<td>How is a child assessed presently? (In terms of needs, educational level, and degree of autism)</td>
<td></td>
</tr>
<tr>
<td>Q D.3 (a)</td>
<td>Are there counselling sessions for parents?</td>
<td>1. Yes 2. No</td>
</tr>
<tr>
<td>Q D.3 (b)</td>
<td>If yes, with whom?</td>
<td></td>
</tr>
<tr>
<td>Q D.3 (c)</td>
<td>Are there counselling sessions for children?</td>
<td>1. Yes 2. No</td>
</tr>
<tr>
<td>Q D.3 (d)</td>
<td>If yes, with whom?</td>
<td></td>
</tr>
<tr>
<td>Q D.3 (e)</td>
<td>Do they have family therapy sessions?</td>
<td>1. Yes 2. No</td>
</tr>
<tr>
<td>Q D.3 (f)</td>
<td>If yes, with whom?</td>
<td></td>
</tr>
<tr>
<td>Q D.4</td>
<td>Who is the mediator/coordinator between the parents, school, therapeutic team and medical body?</td>
<td></td>
</tr>
<tr>
<td>Q D.5 (a)</td>
<td>Do you feel there is a lack of awareness of autism?</td>
<td>1. Yes 2. No</td>
</tr>
<tr>
<td>Q D.5 (b)</td>
<td>How can this lack of public awareness be remedied?</td>
<td></td>
</tr>
<tr>
<td>Q D.6</td>
<td>In what ways can the community bring its contribution to the well being of the child with autism?</td>
<td></td>
</tr>
<tr>
<td>Q D.7</td>
<td>Who implements new programmes <em>(e.g. designing a special programme for parents who want to talk about sexuality with their child with autism reaching adolescence)</em>?</td>
<td></td>
</tr>
<tr>
<td>Q D.8</td>
<td>How equipped is your organisation in terms of infrastructure (building, transport, equipment) to welcome children with autism?</td>
<td></td>
</tr>
<tr>
<td>Q D.9 (a)</td>
<td>Are you satisfied with the overall services given in your organisation?</td>
<td>1. Yes 2. No</td>
</tr>
<tr>
<td>Q D.9 (b)</td>
<td>What more can be done or improved in terms of services for children with autism and their family?</td>
<td></td>
</tr>
<tr>
<td>Q D.10 (a)</td>
<td>Do you think there should be casework for each child and their family?</td>
<td>1. Yes 2. No</td>
</tr>
<tr>
<td>Q D.10 (b)</td>
<td>How can this be done?</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX B: CONSENT FORM

Your signature indicates that you have agreed to voluntarily answer the questions asked and understood that it is for the purpose of the research.

I consent to participate in the study carried out by Ms. Nathalia Elizabeth.

_______________________________________  __________________________
Signature of Participant                      Date

_______________________________________  _________________
Signature of Researcher                        Date

• Please note that you may decide to withdraw from the study at any time and no further data will be collected from you.
APPENDIX C: DETAILED FINDINGS

Findings
The following is a detailed account of the findings. The verbatim which has been translated from French is presented as Footnotes. It is important to note that only 4 participant’s report have been accounted below.

Training needs of educators

Only 9 on 10 participants had received training on autism. Among these 9, 5 participants who followed Special Educational Needs courses in 2 different institutions pointed out that there was only a module pertaining to autism.

4 participants’ reports are as follows regarding their specialised trainings in autism:
Participant 1 reported:
“I had an internal training with professionals, like the speech therapist and the psychologist, from APEIM. I also received training on autism with educators from Autisme Reunion, when they came to Mauritius.”

Participant 2 stated:
“I received basic training with Mrs Natalie Faucher and Jacqueline Gibiard from Reunion Island. Recently, I received training in Reunion Island on different methods such as TEACCH/ABA.”

22 « J’ai eu une formation interne avec des professionnels comme l’orthophoniste et le psychologue de l’APEIM. J’ai aussi eu une formation sur l’autisme avec des formateurs de Autisme Réunion lors d’une visite à Maurice. »
Participant 3 had the following response:
“I received training on medico-psychological support in Reunion Island.”\textsuperscript{23}

Participant 4 reported:
“I received training on the field in Mauritius and I was on placement in South Africa, at UNICA School for Autism.”\textsuperscript{24}

**Support services for families**

Findings indicated that there was minimum emotional, practical and financial support for families with children with autism. Regarding the types of support parents received after the diagnosis, out of the 10 participants, 3 acknowledged that nothing was done for the parents. 4 participants reported as follows:

Participant 1:
“Government help families by giving social aid. Some children are sponsored in order to attend classes, as school is not free.”\textsuperscript{25}

Participant 2 reported:
“They have therapies in different hospitals once a month which is not enough. Hospitals refer them to different associations where the child would be taken care of every day of the week according to the school calendar. Some are left on their own and do not know what to do.”\textsuperscript{26}

\textsuperscript{23} “J'ai eu une formation à l'Aide Médico-Psychologique à l’île de la Réunion.”

\textsuperscript{24} “J'ai eu une formation sur le terrain ici même, à Maurice et j'ai été faire un stage en Afrique du Sud, à l’UNICA School for Autism.”

\textsuperscript{25} “Le Gouvernement aide ces familles par une aide sociale. Certains enfants sont parrainés côté scolarité, vu que l’école est payante.”

\textsuperscript{26} “Ils sont suivi par des thérapeutes de différents hôpitaux une fois par mois ce qui n’est pas suffisant, les hôpitaux les réfèrent à différentes associations ou l’enfant sera pris en charge tous les jours de la semaine suivant le calendrier scolaire. D’autre sont livrées a eux mêmes et ne savent pas quoi faire.”
Participant 3 reported:
“We refer them to the psychologist or to *Autisme Maurice*. Educators also accompany parents.” 27

Participant 4 stated the following:
“Support varies according to needs. There is a home-based service (social, medical, therapeutic), just like a service with specialists who help, frame, counsel, train and do follow-up of the families and the children.” 28

Extended family is perhaps the first to bring emotional support to parents. Unfortunately it is not the case sometimes. As to how family at large react to the diagnosis, the report is as follows for 4 participants:

Participant 1:
“Some accept and do their best to help the child progress. Unfortunately others don’t. Some of them even talk about the disorder as a curse and abandon the child.” 29

Participant 2:
“They are unable to understand the characteristics of autism. Some of them deny the diagnosis.” 30

27 « Nous les dirigeons vers le psychologue ou vers l’association Autisme Maurice. Aussi, l’accompagnement des parents se fait par les éducatrices. »
28 « Les supports varient selon les besoins. Il y a un service à domicile (niveau social, médical et thérapeutique), tout comme un service avec des spécialistes qui aident, encadrent, conseillent, forment et suivent les familles comme les enfants. »
29 « Certains acceptent et font de leur mieux pour aider l’enfant à progresser. Malheureusement d’autres non, certains parlent même de malédiction et abandonnent l’enfant. »
30 « Ils ont du mal à comprendre les caractéristiques de l’autisme. Certains sont dans le déni total. »
Participant 3:
“Some will find it hard but will come to terms with the news and accept the child. Others might not feel at ease with the idea of having a child in the family who is different and hence will cut ties with the family or distance themselves.”

Participant 4:
“In few words, they are confused, lost, angry, anxious and find it difficult to accept.”

Participants were asked if a respite area would be useful for parents who need to socialise with other adults and find time for their other children. 4 participants reported:

Participant 1:
“It’s really interesting because parents are tired and stressed too.”

Participant 2:
“It would be a really good move because parents need to talk and confide themselves and it would be a good thing that from an early age the other children learn to accept those children who are not like them.”

Participant 3:
“It would be nice for families with children with autism and neurotypicals. They could share their experiences.”

31 « En quelques mots : ils sont confus, perdus, en colère, angoissés et éprouvent de la difficulté a accepté. »
32 « C’est bien intéressant parce que les parents sont fatigués et stressés aussi. »
33 « Ce serait une très bonne initiative car les parents ont besoin de parler, de se confier et ce serait une bonne chose que depuis leur jeune âge les autres enfants apprennent à accepter ses enfants qui ne sont pas comme eux. »
34 « Ce serait bien pour les familles qui ont des enfants autistes et « normaux ». Ils pourront partager leurs expériences. »
Participant 4:
“Why not, if those concerned are not against the idea! This would help to share and exchange ideas. However, it will depend on: are the parents ready to spend time with other parents who have children with autism, as it takes a lot of time to supervise children. Food for thought, on the organisation and also on activities to offer.”

Participants were asked about ways to empower parents. Parents are sometimes victims of personal problems like separation or abandonment and on top of that have to deal with the challenging behaviours of their child with autism. Findings for 4 participants are as follows:

Participant 1:
“First, by explaining to them what autism is, how to raise a child with autism, the Ministry should have given regular training for those parents like some NGOs do.”

Participant 2:
“Empowerment can be in the form of learning teaching techniques and ways to structure the physical environment of the child. It is also important to read and do research on how to deal with a child with autism. The parents should also attend training/workshops regularly. Moreover, there should be referrals, adequate support system, therapy and counselling.”

35 « Pourquoi pas, si les principaux concernés sont partant ? Cela aiderait à partager et se changer les idées. Mais cela dépendra aussi : est-ce que les autres sont prêts à passer du temps avec des parents qui ont des enfants autistes, vu que cela demande beaucoup de temps pour surveiller les enfants ? Matière à réfléchir sur la manière de mettre en place et aussi sur les activités à proposer. »

36 « Tout d’abord en leur expliquant vraiment c’est quoi l’autisme, comment élever un enfant atteint d’autisme, le ministère aurait pu faire des formations régulière pour ces parents comme le font certaine ONG. »
Participant 3:
“There should be financial and social support. They should also get a psychologist to follow-up and help them to ventilate stress and frustration.”

Participant’s 4 responses were:
“In order to empower parents, there need to be solid structures. Training is essential. But are the parents ready to train themselves? And there is a tendency to impose a way of doing through training while the situations are different. We need to help them become proactive in crisis situations. It’s already hard to find solutions to divorce or couple’s problems and adding to that a child with autism; the family tends to break sooner or later. Some parents stay together just for the sake of their disable child but they do not have a couple life. The desire to find real solutions must come from parents first then an empowerment project can be concretely implemented.”

**Support services for children**

Some children progress and some regress in their development, and one major factor is the follow-up done or not at home. As to how educators make sure there is proper follow-up at home, the findings report as follows for 4 participants:

---

37 "Il faudrait qu’il y ait un support financier et social. Il faudrait aussi avoir le support d’un psychologue pour faire le suivi et les aider à évacuer le stress et la frustration."

38 "Pour pouvoir autonomiser les parents, il faut qu’il y ait des structures solides. La formation est primordiale. Mais est ce que les parents ont du temps à se former ? Et puis la tendance est plus d’imposer une manière de faire à travers la formation alors que les situations varient largement. Il faut les aider à devenir proactif selon les situations « on the spot ». Il est difficile déjà de trouver des solutions réelles concernant le divorce ou le problème de couples et ajouté à cela l’arrivée d’un enfant autiste ou avec une autre déficience, la famille à tendance à éclater tôt ou tard. Certains parents continuent d’être une famille pour leurs enfants à cause de leur affliction, mais ils ne sont pas épanouies car il n’y pas de vie de couple. Le désir de trouver des solutions réelles doivent venir des parents et de là, un « empowerment » pourra être mis en place concrètement. »
Participant 1:
“For every child there is a communication notebook which enables us to stay in contact with the parents, if parents have an issue they write or phone us. At the end of each semester we call the parents for an appraisal with the supervisor, the educator and the psychologist to see if the objectives are reached.”

Participant 2:
“We invite parents to attend a work session with the educators to see how they work with their children. We also have frequent meetings, workshops with parents.”

Participant 3 reported:
“We need to inform parents, meet them and explain what is being done. We need to meet at the end of each term with the parents, the educator and the psychologist. We need to tell them that the development of the child depends also on parent’s collaboration.”

Participant 4:
“It's difficult to be 100% sure that the parents are doing what they have to. But we can suppose when we observe the progress of the children. Progress settles quicker in certain cases if apprenticeships are taken at home - But we must not forget that parents are not specialised educators.”

39 « Chaque enfant a un carnet de liaison qui nous permet de rester en communication avec les parents, si les parents ont un souci ils nous écrivent ou ils nous téléphonent. A la fin de chaque semestre nous convoquons les parents pour faire un bilan avec le chef de service, l’éducatrice et le psychologue pour voir si les objectifs ont été atteints. »

40 « Il faut informer les parents, les rencontrer et leur expliquer ce qui est mise en place. Il faut les rencontrer à la fin de chaque trimestre entre les parents, l’éducateur et le psychologue. Il faut leur dire que l’épanouissement de leur enfant dépend aussi de leur collaboration. »

41 « C’est difficile d’être sure à 100% que les parents font ce qu’il faut ou pas. Mais on peut le supposer quand nous observons le progrès chez les enfants. Le progrès s’installe plus vite dans certains cas si les apprentissages sont repris à la maison. Mais n’oublions pas que ce sont des parents mais pas des Educateurs Spécialisés ! »
The 10 educators were asked how they can reach children with autism who are ‘unreachable’, children who stay at home due to their disorder or school inaccessibility. The answers of 4 participants were:

Participant 1:
“Nothing is done for now because of financial problems. In the future maybe we will have a mobile caravan just like PILS for AIDS.”

Participant 2:
“Word of mouth makes information flows and we also visit nursery schools.”

Participant 3:
“It’s something difficult.”

Participant 4:
“By means of sensitisation campaigns for the public and publicised programmes.”

Infrastructure in terms of building, transport and equipment, is important to welcome the child with autism within an institution. Educators were asked to what extent their institution was equipped to welcome those children. The answers of 4 participants are as follows:

Participant 1:
“I would say relatively well equipped considering how difficult it is to get funds. The organisation strived hard to get where it is at. But there is still a massive

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42 « Pour le moment rien n’est fait à cause d’un problème budgétaire. Dans le future peut être nous aurons une caravane mobile comme l’association PILS. »
43 « L’information circule de bouche-a-oreille et nous faisons aussi des visites dans les écoles maternelles. »
44 « C’est difficile. »
45 « Par des campagnes de sensibilisation pour le public et des programmes médiatisés. »
work to be done. We need to get more funds in order to improve the services given to children with autism.”  

Participant 2:  
“Thanks to the director’s means, we had the building and most of the equipment is offered by the sponsors or parents.”

Participant 3:  
“Thanks to various donations from various organisations around the island we are well equipped where I work, but we always need new equipments.”

Participant 4:  
“The establishment of infrastructures is there, but there are still shortcomings.”

It was observed that there were shortcomings in services for children with autism and their family. Participants were asked about what more can be done or improved. 4 participants reported the following:

Participant 1:  
“Home visits more often, more educational games.”

Participant 2:  
“Home visits, counselling sessions with the family, more infrastructures in terms of building (schools, internship/residency) and services such as transport.”

46 « Je dirais relativement bien équipé en considérant combien il est difficile d'obtenir des fonds. L'organisation a travaillé dur pour arriver où elle est. Mais il y a encore un énorme travail à faire. Nous avons besoin de plus de fonds afin d'améliorer les services offerts aux enfants autistes. »

47 « D’après les moyens de la directrice, nous avons eu le bâtiment et la plupart des équipements sont offert par les sponsors ou les parents. »

48 « Grâce aux différents dons de différentes organisations de l’île nous sommes bien équipés ou je travaille, mais nous avons toujours besoin de nouveaux équipements. »

49 « La mise en place des infrastructures est là, mais il y a encore des manquements. »

50 « Des visites à domicile un peu plus souvent, plus de jeux éducatifs. »
Participant 3:
“How to improve will depend on the willingness to improve things.”

Participant 4:
“The specific care management of children with autism is new in Mauritius, for example the integration of children into mainstream school is missing.”

**Need for social work interventions**

There is a lack of research which links social work to autism. Participants were asked in what ways a social worker can contribute to the improvement of children with autism in Mauritius. Reports for 4 participants are as follows:

Participant 1:
“The social worker must stay informed about autism so as in turn he or she is able to inform parents and other persons around the child with autism. He or she must also meet parents in order to bring support and also visit specialised schools to target problems that children face so as to find solutions.”

Participant 2:
“Social workers can help family in the following ways:

1. think about how you feel about the disability
2. figure out what you and your family member need
3. help you find resources in the community that may help you
4. help you with applications for services
5. connect with other families of children with the same disabilities
6. connect with support groups

51 « Comment améliorer dépendra de la volonté d’améliorer les choses. »
52 « La prise en charges spécifique pour les enfants autistes est nouvelle à Maurice par ex : Il manque l’intégration des enfants en milieu scolaire ordinaire »
53 « Le travailleur social doit rester informé sur l’autisme pour pouvoir à son tour informer les parents et toutes les personnes qui entourent l’enfant autiste. Il doit aussi rencontrer les parents pour les soutenir et aussi faire des visites dans les écoles spécialisées pour cibler les problèmes auxquels les enfants font face et ainsi trouver des solutions. »
Social workers can also offer support and advice on services such as play schemes, parents’ groups and short breaks. Social workers are involved in assessing the care needs of children with autism and their families. They’re also involved in arranging help to meet those needs.”

Participant 3:
“He or she must take into account the specific and concrete needs of the child with autism and his or her family. There is already a struggle committed to the recognition of rights and equality of children with or without special needs. We must maintain the struggle. It is necessary to listen, understand and act when necessary. There is a great lack of infrastructure and facilities for our children with special needs, the social worker must contribute to this fight for recognition and also the establishment of these structures. With those structures, activities can be implemented, work can be done. It is important in the case of autism that the social worker works in collaboration with other professionals, the specialised institution and the child’s parents.”

Participant 4:
“Maybe precisely to empower parents and also find ways to reach for children with autism who do not have access to school and stay at home.”

54 « Il doit prendre en compte les besoins spécifiques et concrets de l’enfant autiste et de sa famille. Il y a une lutte déjà engagée pour la reconnaissance des droits et l’égalité des enfants avec ou sans besoins spéciaux. Il faut maintenir la lutte. Il faut être à l’écoute, comprendre et agir quand il le faut. Il y a un grand manque d’infrastructures et de structures pour nos enfants à besoins spéciaux, le travailleur social doit contribuer à ce combat de reconnaissance et aussi de la mise en place de ces structures. Avec des structures, on peut mettre en place des activités, le travail peut être fait. Il est important dans ce cas précis d’autisme que le travailleur social travaille en collaboration avec les professionnelles, l’établissement spécialisé et les parents de l’enfant. »

55 « Peut-être justement chercher à autonomiser les parents et aussi chercher comment atteindre les enfants autistes qui n’ont pas accès à l’école et qui restent à la maison. »
Implementation of programmes at micro and macro level

Participants were asked if they feel there is a lack of awareness about autism. 9 out of 10 responded positively. Moreover, those 9 participants were asked about ways to fill this gap and the reports are as follows for 4 participants:

Participant 1:
“Through advertising, by means of mini-clips or short films on the Internet and by organising public workshops on the subject.”

Participant 2:
“By means of sensitisation campaigns with advertisings, more regular trainings, by organising talks in parishes or in different community centres of the different areas of the island.”

Participant 3:
“By providing information to those concerned but also through schools. Also by distributing pamphlets.”

Participant 4:
“We need to sensitise decision makers.”

Findings also show that the way the community perceives the child with autism has an impact on the latter as well as his or her family. Participants were asked about ways that the community can adopt to contribute to the well-being of the child with autism. Reports of 4 participant show:

56 « En faisant de la publicité, par des mini-clips ou court-métrage sur internet et en organisant des conférences sur le sujet ouvert au public. »
57 « En faisant des campagnes de sensibilisation avec des publicités, plus de formation régulière, en organisant des causeries dans les paroisses ou dans leur centre communautaire des différentes parti de l’île. »
58 « En donnant les informations aux personnes concernées mais aussi à travers les écoles. Aussi en distribuant des pamphlets. »
59 « Il faut sensibiliser les décideurs. »
Participant 1:
“Raise awareness, inform and show what those children can do.”

Participant 2:
“By being non-judgmental and getting to know more about autism, thus accepting the child. By providing necessary structures for children with autism.”

Participant 3:
“Of course it is feasible. But under certain conditions. Training, change of mentality, the look, hospitality etc. there is all this to be taken into consideration. I said it and I will say it over and over again, there are all kinds of training and workshop for x, y and z. But is society aware of this? Does society really understands the meaning of special needs? NO. So why not educate and train the country instead of always end up with several types of understanding, way of acting and especially of free interpretive ideas. While there are clauses and “white papers” on the subject. Ask a passerby to talk about autism or mental retardation. He or she will associate it with a disease, a curse or “craziness”.

Participant 4:
“By giving time to the child, by accepting him or her the way he or she is and by initiating the child to activities which would enable him or her to socialise.”

60 “Conscientiser, informer et montre ce dont les enfants sont capable. »
61 « Bien sûr que c’est faisable. Mais à certaines conditions. La formation, le changement de mentalité, le regard, l’accueil etc. il y a tout cela à prendre en considération avant. Je l’ai dit et je le redirai encore et encore, il y a toutes sortes de formations et d’atelier de travail pour x, y et z. Mais est-ce que la société est au courant de cela ? Est-ce que la société comprend vraiment c’est quoi les besoins spéciaux ? NON. Alors pourquoi ne pas éduquer et former tout le pays au lieu de toujours se retrouver avec plusieurs types de compréhension, de manière d’agir et surtout d’idées d’interprétation gratuites. Alors qu’il existe des clauses et des « white papers » sur le sujet. Allez demander à un passant de vous parler de l’autiste ou de retard mental. Il/elle associera cela à une maladie, une malédiction ou « fou ». »
62 « En donnant du temps à l’enfant, en l’acceptant comme il est et en l’initiant à des activités qui l’aiderait à se socialiser. »
Casework
Every participant reported that casework is important for both children with autism and their family. Concerning the question about how can casework be introduced, the report of 4 participants is:

Participant 1:
“By having a good schedule and by setting home visits at least once a week. We must mobilise trained and dynamic teams.”

Participant 2:
“Parents and children need to be helped by a psychologist. There is also the need of a follow-up for parents.”

Participant 3:
“Proper data collection to target families and their specific needs and difficulties. Set up a support structure also.”

Participant 4:
“Trainings for more professionals who love their work, adequate infrastructure, appropriate activities, follow-up and time. Special educators are not even recognised as a mainstream educator. We work with what we have. The salary is more than deceiving. But the work is done with the heart because we love these children as our children. To get things moving, we should have the active participation and willingness of the government to provide facilities in all its forms. So may be then, most children with autism or with other special needs will benefit from a real individual support as well as their parents.”

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63 “En ayant un bon emploi du temps et en fixant des visites au moins une fois par semaine. Il faut mobiliser des équipes formées et dynamique.”
64 “En aidant les parents et les enfants par le biais d’un psychologue. Il faut aussi que les parents ont un suivi.”
65 “Collecte de données pour cibler les familles et leurs besoins et difficultés spécifiques. Mettre en place une structure de prise en charge aussi.”
66 “La formation pour plus de professionnelles qui aiment leurs travaux, les infrastructures adéquates, les activités adaptées, le suivi et le temps. Les éducateurs spécialisés ne sont même
Counselling and Family Therapy

Concerning the question on counselling sessions for both children and parents in their respective institutions, 7 out of 10 participants claimed there was counselling sessions with a psychologist. 3 out of these 7 participants added that educators also do counselling.

Participants were also asked about family therapy sessions and 6 out of the 10 participants responded positively and sessions were carried out by the psychologist. 3 in those 6 participants added that educators also carry out family therapy.

Advocacy

About what they would like to add to present legislations concerning children with autism, 4 respondents said:

Participant 1:
“That the Government takes care of the child with autism financially.”67

Participant 2:
“That the laws be known and acknowledged.”68

Participant 3:
“That children with autism receive free education and that Government takes charge of employees’ salary. I wish there be equality in terms of services for children with autism and that transport is free.”69

67 « Que le Gouvernement prenne l’enfant autiste en charge sur toute l’aspect financière. »
68 « Que les lois soient connues et reconnues. »
Participant 4:
“Laws already exist even if I’m not fully satisfied with them. But for sure they need to be amended for more equity and equality. But are our leaders willing or ready to change things? This will take a lot of time according to me.”

69 « Que l’éducation soit gratuite et que le gouvernement prenne en charge le salaire des employés. J’aimerais aussi qu’il y ait une parité en terme de service pour les enfants autistes et que le transport soit gratuit pour eux. »

70 « Les lois sont déjà en place même si je ne suis pas tout à fait satisfait. Mais c’est sure qu’il faut les améliorés pour plus d’équitable et d’égalité. Ce que j’aimerai est une chose, mais est ce que nos dirigeants sont-ils disposés ou prêts pour faire changer les choses ? Cela prendra encore beaucoup de temps selon moi. »
APPENDIX D: Progress log