The Impact of a Child with Autism
on the Family System

by

97

Beverley-Anne Joyce

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in Partial Fulfillment of the Requirements
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Sciences	0714
Secondary	0533
Social Sciences	0534
Sociology of	0340
Special	0529
Teacher Training	0530
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Tests and Measurements	0288
Vocational	0747

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General	0679
Ancient	0289
Linguistics	0290
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General	0401
Classical	0294
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African	0316
American	0591
Asian	0305
Canadian (English)	0352
Canadian (French)	0355
English	0593
Germanic	0311
Latin American	0312
Middle Eastern	0315
Romance	0313
Slavic and East European	0314

PHILOSOPHY, RELIGION AND THEOLOGY

Philosophy	0422
Religion	
General	0318
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Clergy	0319
History of	0320
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Theology	0469

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Anthropology	
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Banking	0770
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Marketing	0338
Canadian Studies	0385
Economics	
General	0501
Agricultural	0503
Commerce-Business	0505
Finance	0508
History	0509
Labor	0510
Theory	0511
Folklore	0358
Geography	0366
Gerontology	0351
History	
General	0578
Ancient	0579
Medieval	0581
Modern	0582
Black	0328
African	0331
Asia, Australia and Oceania	0332
Canadian	0334
European	0335
Latin American	0336
Middle Eastern	0333
United States	0337
History of Science	0585
Law	0398
Political Science	
General	0615
International Law and Relations	0616
Public Administration	0617
Recreation	0814
Social Work	0452
Sociology	
General	0626
Criminology and Penology	0627
Demography	0938
Ethnic and Racial Studies	0631
Individual and Family Studies	0628
Industrial and Labor Relations	0629
Public and Social Welfare	0630
Social Structure and Development	0700
Theory and Methods	0344
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Women's Studies	0453

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Animal Pathology	0476
Food Science and Technology	0359
Forestry and Wildlife	0478
Plant Culture	0479
Plant Pathology	0480
Plant Physiology	0817
Range Management	0777
Wood Technology	0746
Biology	
General	0306
Anatomy	0287
Biostatistics	0308
Botany	0309
Cell	0379
Ecology	0329
Entomology	0353
Genetics	0369
Limnology	0793
Microbiology	0410
Molecular	0307
Neuroscience	0317
Oceanography	0416
Physiology	0433
Radiation	0821
Veterinary Science	0778
Zoology	0472
Biophysics	
General	0786
Medical	0760

EARTH SCIENCES

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Geochemistry	0996
Geodesy	0370
Geology	0372
Geophysics	0373
Hydrology	0388
Mineralogy	0411
Paleobotany	0345
Paleoecology	0426
Paleontology	0418
Paleozoology	0985
Palynology	0427
Physical Geography	0368
Physical Oceanography	0415

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Environmental Sciences	0768
Health Sciences	
General	0566
Audiology	0300
Chemotherapy	0992
Dentistry	0567
Education	0350
Hospital Management	0769
Human Development	0758
Immunology	0982
Medicine and Surgery	0564
Mental Health	0347
Nursing	0569
Nutrition	0570
Obstetrics and Gynecology	0380
Occupational Health and Therapy	0354
Ophthalmology	0381
Pathology	0571
Pharmacology	0419
Pharmacy	0572
Physical Therapy	0382
Public Health	0573
Radiology	0574
Recreation	0575
Speech Pathology	0460
Toxicology	0383
Home Economics	0386

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Inorganic	0488
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Physical	0494
Polymer	0495
Radiation	0754
Mathematics	0405
Physics	
General	0605
Acoustics	0986
Astronomy and Astrophysics	0606
Atmospheric Science	0608
Atomic	0748
Electronics and Electricity	0607
Elementary Particles and High Energy	0798
Fluid and Plasma	0759
Molecular	0609
Nuclear	0610
Optics	0752
Radiation	0756
Solid State	0611
Statistics	0463

Applied Sciences

Applied Mechanics	0346
Computer Science	0984
Engineering	
General	0537
Aerospace	0538
Agricultural	0539
Automotive	0540
Biomedical	0541
Chemical	0542
Civil	0543
Electronics and Electrical	0544
Heat and Thermodynamics	0348
Hydraulic	0545
Industrial	0546
Marine	0547
Materials Science	0794
Mechanical	0548
Metallurgy	0743
Mining	0551
Nuclear	0552
Packaging	0549
Petroleum	0765
Sanitary and Municipal	0554
System Science	0790
Geotechnology	0428
Operations Research	0796
Plastics Technology	0795
Textile Technology	0994

PSYCHOLOGY

General	0621
Behavioral	0384
Clinical	0622
Developmental	0620
Experimental	0623
Industrial	0624
Personality	0625
Physiological	0989
Psychobiology	0349
Psychometrics	0632
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Danse	0378
Histoire de l'art	0377
Journalisme	0391
Musique	0413
Sciences de l'information	0723
Théâtre	0465

ÉDUCATION

Généralités	515
Administration	0514
Art	0273
Collèges communautaires	0275
Commerce	0688
Économie domestique	0278
Éducation permanente	0516
Éducation préscolaire	0518
Éducation sanitaire	0680
Enseignement agricole	0517
Enseignement bilingue et multiculturel	0282
Enseignement industriel	0521
Enseignement primaire.	0524
Enseignement professionnel	0747
Enseignement religieux	0527
Enseignement secondaire	0533
Enseignement spécial	0529
Enseignement supérieur	0745
Évaluation	0288
Finances	0277
Formation des enseignants	0530
Histoire de l'éducation	0520
Langues et littérature	0279
Lecture	0535
Mathématiques	0280
Musique	0522
Orientation et consultation	0519
Philosophie de l'éducation	0998
Physique	0523
Programmes d'études et enseignement	0727
Psychologie	0525
Sciences	0714
Sciences sociales	0534
Sociologie de l'éducation	0340
Technologie	0710

LANGUE, LITTÉRATURE ET LINGUISTIQUE

Langues	
Généralités	0679
Anciennes	0289
Linguistique	0290
Modernes	0291
Littérature	
Généralités	0401
Anciennes	0294
Comparée	0295
Médiévale	0297
Moderne	0298
Africaine	0316
Américaine	0591
Anglaise	0593
Asiatique	0305
Canadienne (Anglaise)	0352
Canadienne (Française)	0355
Germanique	0311
Latino-américaine	0312
Moyen-orientale	0315
Romane	0313
Slave et est-européenne	0314

PHILOSOPHIE, RELIGION ET THÉOLOGIE

Philosophie	0422
Religion	
Généralités	0318
Clergé	0319
Études bibliques	0321
Histoire des religions	0320
Philosophie de la religion	0322
Théologie	0469

SCIENCES SOCIALES

Anthropologie	
Archéologie	0324
Culturelle	0326
Physique	0327
Droit	0398
Économie	
Généralités	0501
Commerce-Affaires	0505
Économie agricole	0503
Économie du travail	0510
Finances	0508
Histoire	0509
Théorie	0511
Études américaines	0323
Études canadiennes	0385
Études féministes	0453
Folklore	0358
Géographie	0366
Gérontologie	0351
Gestion des affaires	
Généralités	0310
Administration	0454
Banques	0770
Comptabilité	0272
Marketing	0338
Histoire	
Histoire générale	0578
Ancienne	0579
Médiévale	0581
Moderne	0582
Histoire des noirs	0328
Africaine	0331
Canadienne	0334
États-Unis	0337
Européenne	0335
Moyen-orientale	0333
Latino-américaine	0336
Asie, Australie et Océanie	0332
Histoire des sciences	0585
Loisirs	0814
Planification urbaine et régionale	0999
Science politique	
Généralités	0615
Administration publique	0617
Droit et relations internationales	0616
Sociologie	
Généralités	0626
Aide et bien-àtre social	0630
Criminologie et établissements pénitentiaires	0627
Démographie	0938
Études de l' individu et de la famille	0628
Études des relations interethniques et des relations raciales	0631
Structure et développement social	0700
Théorie et méthodes.	0344
Travail et relations industrielles	0629
Transports	0709
Travail social	0452

SCIENCES ET INGÉNIERIE

SCIENCES BIOLOGIQUES

Agriculture	
Généralités	0473
Agronomie.	0285
Alimentation et technologie alimentaire	0359
Culture	0479
Élevage et alimentation	0475
Exploitation des péturages	0777
Pathologie animale	0476
Pathologie végétale	0480
Physiologie végétale	0817
Sylviculture et faune	0478
Technologie du bois	0746
Biologie	
Généralités	0306
Anatomie	0287
Biologie (Statistiques)	0308
Biologie moléculaire	0307
Botanique	0309
Cellule	0379
Écologie	0329
Entomologie	0353
Génétique	0369
Limnologie	0793
Microbiologie	0410
Neurologie	0317
Océanographie	0416
Physiologie	0433
Radiation	0821
Science vétérinaire	0778
Zoologie	0472
Biophysique	
Généralités	0786
Medicale	0760

SCIENCES DE LA TERRE

Biogéochimie	0425
Géochimie	0996
Géodésie	0370
Géographie physique	0368
Géologie	0372
Géophysique	0373
Hydrologie	0388
Minéralogie	0411
Océanographie physique	0415
Paléobotanique	0345
Paléoécologie	0426
Paléontologie	0418
Paléozoologie	0985
Palynologie	0427

SCIENCES DE LA SANTÉ ET DE L'ENVIRONNEMENT

Économie domestique	0386
Sciences de l'environnement	0768
Sciences de la santé	
Généralités	0566
Administration des hìpitaux	0769
Alimentation et nutrition	0570
Audiologie	0300
Chimiothérapie	0992
Dentisterie	0567
Développement humain	0758
Enseignement	0350
Immunologie	0982
Loisirs	0575
Médecine du travail et thérapie	0354
Médecine et chirurgie	0564
Obstétrique et gynécologie	0380
Ophtalmologie	0381
Orthophonie	0460
Pathologie	0571
Pharmacie	0572
Pharmacologie	0419
Physiothérapie	0382
Radiologie	0574
Santé mentale	0347
Santé publique	0573
Soins infirmiers	0569
Toxicologie	0383

SCIENCES PHYSIQUES

Sciences Pures

Chimie	
Genéralités	0485
Biochimie	487
Chimie agricole	0749
Chimie analytique	0486
Chimie minérale	0488
Chimie nucléaire	0738
Chimie organique	0490
Chimie pharmaceutique	0491
Physique	0494
PolymÇres	0495
Radiation	0754
Mathématiques	0405
Physique	
Généralités	0605
Acoustique	0986
Astronomie et astrophysique	0606
Electronique et électricité	0607
Fluides et plasma	0759
Météorologie	0608
Optique	0752
Particules (Physique nucléaire)	0798
Physique atomique	0748
Physique de l'état solide	0611
Physique moléculaire	0609
Physique nucléaire	0610
Radiation	0756
Statistiques	0463

Sciences Appliqués Et Technologie

Informatique	0984
Ingénierie	
Généralités	0537
Agricole	0539
Automobile	0540
Biomédicale	0541
Chaleur et ther modynamique	0348
Conditionnement (Emballage)	0549
Génie aérospatial	0538
Génie chimique	0542
Génie civil	0543
Génie électronique et électrique	0544
Génie industriel	0546
Génie mécanique	0548
Génie nucléaire	0552
Ingénierie des systömes	0790
Mécanique navale	0547
Métallurgie	0743
Science des matériaux	0794
Technique du pétrole	0765
Technique minière	0551
Techniques sanitaires et municipales	0554
Technologie hydraulique	0545
Mécanique appliquée	0346
Géotechnologie	0428
Matières plastiques (Technologie)	0795
Recherche opérationnelle	0796
Textiles et tissus (Technologie)	0794

PSYCHOLOGIE

Généralités	0621
Personnalité	0625
Psychobiologie	0349
Psychologie clinique	0622
Psychologie du comportement	0384
Psychologie du développement	0620
Psychologie expérimentale	0623
Psychologie industrielle	0624
Psychologie physiologique	0989
Psychologie sociale	0451
Psychométrie	0632

THE IMPACT OF A CHILD WITH AUTISM ON THE FAMILY SYSTEM

BY

BEVERLEY-ANNE JOYCE

A Thesis submitted to the Faculty of Graduate Studies of the University of Manitoba in partial fulfillment of the requirements for the degree of

MASTER OF EDUCATION

TABLE OF CONTENTS

Abstract

The impact of the presence of an autistic child on the family system was assessed. Participants were interviewed regarding the impact of a child with autism on family integration, the sibling subsystem and the extended family as well as the adequacy of social supports. Consistent with other reports the presence of the child with autism had both negative and positive effects on family life. Results indicated a major impact on family integration and the sibling subsystem, and a moderate effect on the extended family system. Moreover, social supports were generally seen as inadequate to ease the demands on the family.

Concepts inherent to family system theory were found to be useful in developing the framework for the data collection process.

Acknowledgements

Sincere appreciation is extended to the members of my thesis committee: Dr. Paul Madak, Professor Richard Carreiro, and Professor Marilyn Boyd.

Dr. Madak, who served as the final advisor for my committee, gave direction to my process and helped me achieve clarity and precision.

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My deepest regard and respect goes to the Autism Society Manitoba and in particular the families from the society who opened their homes and hearts to the interview process. I am deeply indebted to these families without whom this project would never have existed.

Dedication

This thesis is dedicated to the memory of my mother, Kathleen May Privat.

LIST OF TABLES

Chapter 1

Introduction

Background to the Study

The identification of the syndrome known as autism began with Kanner's (1943) description of his observations on eleven children with a previously unrecognized disorder. Kanner (1943) noted a variety of behavioural features which seemed both to be characteristic of all eleven children and also to differentiate them from children with other psychiatric disorders. These features included: an inability to develop relationships with people, a delay in speech acquisition, the noncommunicative use of speech after it develops, repetitive and stereotyped play activities, an obsessive insistence on the maintenance of sameness, a lack of imagination, a good rote memory, and a normal physical appearance.

During the next decade workers reported observations on children with similar features (Bakwin, 1954; Despert, 1951; Van Krevelin, 1952). While identification of autism as a clinical entity became evident there was considerable confusion over the boundaries of the disorder as well as its nature and etiology.

Definitional problems have occurred for several reasons: there is wide variation in the severity of the disorder, the prominence of certain symptoms alters with age, and associated intellectual ability can range from profound retardation to within normal limits. Other characteristics such as phenomenal memory and good motor skills serve to further complicate the picture (Pomeroy, 1990).

Rutter (1978) stipulated four criteria as essential in defining childhood autism: onset before the age of 30 months, impaired social development out of keeping with the child's intellectual level, delayed and deviant language development also out of keeping with the child's intellectual level, and insistence on sameness. Gillberg (1990) reported general consensus that autism encompasses a set of three major behaviourally defined criteria: delay and deviance in the fields of social relatedness, communication, and behaviour/imagination, but dismisses age of onset from among the essential and necessary criteria. Pomeroy (1990) supported the notion of a triad of abnormalities in language development, social functioning and flexibility of behaviour patterns and noted that these are not merely delays in acquisition of skills, but they are also deviant in nature.

A variety of developmental and behavioural problems are observed in autistic children. Most autistic children show marked delay in language development and as many as 50% do not develop useful speech. Early language development is either delayed in onset, fails to progress or regresses after initial acquisition. Communication problems include a lack of flexibility in expressive language, an impaired modulation, and an inability to reciprocate in conversational speech (Pomeroy, 1990).

All autistic children show deviant social relationships. Social deficits are seen in inappropriate responses to social cues, inability to modify behaviour to a social context, and a lack of empathy for others' emotions (Pomeroy, 1990). As infants many autistic children do not cuddle and may even stiffen and resist affection. They may fail to develop normal relationships with their parents or become extremely anxious if separated from one or other parent. They typically avoid eye-to-eye gaze, rarely greet others, and may either not seek comfort even if they are hurt or ill or seek comfort in a strange way. As they grow these children fail to develop friendships and generally prefer to play alone.

Autistic children also demonstrate inflexible behavioural patterns reflecting a need to impose rigidity and routine on everyday functioning and an inflexible and unimaginative style of thinking. These children become distressed when any part of their environment is changed. They may throw tantrums when their place at the dinner table changes or magazines are not placed on the shelf in a precise order. They may go through ritualistic and repetitive body movements such as twisting or flicking their hands, flapping their arms or banging their heads. Some children become preoccupied with parts of objects or they may become extremely attached to unusual objects such as a piece of string or a rubber band.

The etiology of the disorder continues to be a source of controversy and conflict. It remains to be determined whether autism is a single disease entity, a syndrome of biological impairment, or a collection of symptoms resulting from a group of influences both biological and psychological (Rutter, 1974). Earlier psychogenic theories placing emphasis on the parents' part in the causation of the disorder seem without merit and have given way to research seeking a biological basis.

Autism is viewed as a rare disorder with most studies finding between four and five clear cases of autism per 10,000 children (Gillberg, 1990; Pomeroy, 1990). Epidemiological studies also show a significant excess of boys with a ratio of approximately four boys to every girl (Pomeroy, 1990). The disorder has been found throughout the world in families of all ethnic, and social backgrounds. There is some evidence to suggest that a higher than expected number of autistic children are first-born or late-born (fourth or more in sibling rank), although this relationship between sibling rank and autism remains controversial. The vast majority of autistic children test in the mentally retarded range (I.Q. below 70). Specific rates do vary, but about 50% of the autistic population have scores in the moderate to profound range of mental retardation and only 10% to 20% of these children have

I.Q. scores within the normal range (Pomeroy, 1990). Autism continues to be a severe lifelong disability for which there is no known cure. Despite many enthusiastic claims including pharmacotherapy, diet therapy, family therapy, and social skills programming, a major breakthrough in the treatment of autism has not yet materialized.

Statement of the Problem

Living in a family can be a difficult task; living in a family with a handicapped child, particularly a child with a disability as serious as autism, can impact significantly on the family system and on individual family members. Although a wide range of differences in severity and degree of disability can occur, any form of autism implies chronicity, a poor prognosis for treatment and little hope for a cure.

Given the constants of chronicity and poor prognosis, different families react and adjust uniquely to crisis, dependent on a wide variety of factors. Families bring with them to each new problem their collective history of strategies for relating, the individual needs and resources of the members, and their bonds to extended family and community. Bearing in mind the variability possible in response to problems, the question arises as to whether common themes exist among families in terms of the impact of the autistic child and the family's methods of coping.

The purpose of this study is to examine variables that may have an impact on reactions to this disorder and subsequently, how these variables affect adjustment and coping strategies.

Definition of Terms

Autism, variously alluded to as autistic syndrome, autistic disorder or infantile autism is best described as a behaviourally defined syndrome. The diagnostic criteria for this disorder are considered to be met only if the behaviour is abnormal for the person's developmental level. The criteria include: (A) qualitative impairment in reciprocal social interaction, (B) qualitative impairment in verbal and nonverbal communication, and in imaginative activity, (C) markedly restricted repertoire of activities and interests, with onset during infancy or childhood (American Psychiatric Association, 1987). The criteria lists 16 items in the three major domains. A diagnosis of autistic disorder requires the presence of ten or more items with at least two from (A), one from (B), and one from (C). Age of onset previously specified to be before 30-36 months of age (American Psychiatric Association, 1980); Rutter, 1978) is no longer included among the essential and necessary criteria (APA, 1987; Denckla, 1986; Wing, 1990).

Family system is defined as parents and children of the nuclear family as well as grandparents, absent parents, and/or siblings considered by the members to be part of the family unit.

Chapter 2

Review of the Literature

The impact of an autistic child on the family system is a complex matter. While the literature regarding etiology dates back to the 1940's, only recently have researchers begun to examine in a balanced fashion the autistic child's powerful effect on the family system.

Historically the autistic child's family, particularly the parents, were studied for their presumed role in the cause of the disorder. With research evidence now favouring organic rather than psychosocial causation, the family is being studied from a different perspective (Morgan, 1988). While questions are beginning to be asked about the impact on family members and their interactions (Schopler & Mesibov, 1984), a review of the literature on the etiology of autism as well as the impact of the disorder on the family system reflects continuing controversy as to causation and interactive effects.

Etiology

The literature reflects a diversity of factors theorized to have a role in the causation of autism. These factors can be grouped under the following general categories: psychogenic, biogenic, and psychological.

Psychogenic Factors. Kanner (1943) in his original description of the syndrome of infantile autism commented that the parents tended to be highly intelligent, obsessive people interested in abstractions and lacking real warmth. These so called "refrigerator parents" were described as cold, withdrawn, isolated people who had difficulty in forming relationships with adults and children. Although Kanner (1943) acknowledged that autism was probably an inborn defect, he proposed that environmental factors might be important in symptom manifestation. As research continued a number of reports supported psychogenic factors as important elements in the etiology of autism.

Bettleheim's (1967) view constituted a clearly expressed psychogenic hypothesis. He suggested that autism develops as a response to extreme negative feelings shown by the parent; feelings so marked that the child perceives the world as a dangerous place, feels without hope, and withdraws. The severity of the child's response is explained in terms of the critical periods in development at which he/she experiences these extreme situations. These critical periods were seen as during the first six months of life when real object relationships begin, at six to nine months when language and locomotion begin, and at 18-24 months when the child starts to shape his/her relations with the environment. The child lacks speech and emotional expression because there is no receptive audience as perceived by the child. Siblings are not affected because the parental reaction was specific to the one child and because only the autistic child experienced the rejection at the critical period in development (Bettleheim, 1967). It was advocated that the child be completely removed from the parents and be treated in a residential setting with parent substitutes (Bettleheim, 1967).

Deviant maternal personality characteristics (Despert, 1951) and bad mothering (Rank, 1949) were emphasized as factors in the causation of autism. The autistic child's withdrawal from the rest of the environment was really an extension of his/her initial withdrawal from or failure ever to make a normal relationship with the mother. This impairment in the emotional relationship between mother and child was usually associated with separation, either physical or emotional. Physical separation may be due to illness, desertion by the mother, prolonged holiday away from the child, or the arrival of the next baby. Emotional separation may be due to the mother's inability to relate because she is suffering an emotional illness or perhaps may be clinging to an infantile dependence on her own mother so that she cannot accept the maternal role. If the child cannot relate to the mother, the parent gets no response or feedback in her efforts to love the child and a vicious circle is set up. The more the mother detaches herself from the baby, the more the child withdraws from her. The more the child withdraws, the less lovable he/she is. If this first relationship with mother fails one would expect the child to have difficulty forming satisfactory relationships with other people. Human relationships will tend to be unrewarding and unsatisfactory for the child resulting in a lifelong failure to connect with other persons.

Other reports also indicated dysfunctional family dynamics which promoted autism. Goldfarb (1967) described a family atmosphere in which the parents displayed extreme indecisiveness, an unusual absence of control and authority, lack of spontaneity and empathy with the child, and an inability to grasp or gratify their child's needs. Putnam (1955) described mothers of autistic children as incapable of performing their maternal function, narcissistic, immature, and devoid of genuine maternal drive. Fathers of autistic children were seen as passive and unable to counteract the negative influence of the mother. Ferster (1961, 1966) argued that autism consists of an impoverished repertoire of normal behaviours which became impaired because parents fail to reinforce or respond to the child's initial social advances, while Tinbergen and Tinbergen (1972) suggested that autistic children withdraw because parents are too intrusive and give too much response to the child's social approaches.

The arguments for psychogenesis of autism appear to rest on a number of arguments and assumptions outlined by Rimland (1964). The absence of consistent physical or neurological abnormalities in autistic children could suggest that factors other than genetic or biological could be important. In the absence of biological evidence a psychogenic hypothesis is therefore possible. The high incidence of first-born and only children with autism suggests that parental attitudes may be causative. The observance of parents apparently deficient in emotional responsiveness could have pathogenic effects on the child. Certain incidents in the life of the child, particularly related to maternal contact, appear to be pathogenic and could permit the autistic disorder to be traced to them. Support for the psychogenic theory was also gained during observations of the interaction between the autistic child and their parents while undergoing psychotherapeutic treatment, when placing the child in a kind and understanding environment was seen to have beneficial effects.

Biogenic Factors. The search for a biological cause of autism gained momentum in the 1960's based on clinical experiences with autistic children and their families and on empirical evidence. It was noted that some autistic children were born of parents who clearly did not fit the "autistic parent" personality profile and the parents who did fit the profile also had normal non-autistic children. The occurrence of autism approximately four times more often in boys than in girls is consistent with the greater vulnerability of males to organic damage and strongly suggestive of biological genesis. Observations that autistic children are behaviourally unusual almost from the moment of birth gave further credence to biological theories (Rimland, 1964).

A biological theory of etiology was further supported when it was observed that there was an increased evidence of mental retardation, epilepsy, and clear-cut medical disorders in autism (Pomeroy, 1990). While autism has been associated with numerous disease entities, in no instance does any specific disease universally produce autism. Congenital rubella was one of the first disorders shown to lead to an increased incidence of autism, and postnatal central nervous system infections such as herpes, encephalitis and mumps have preceded the onset of autistic syndrome. A number of metabolic disorders and congenital neurocutaneous disorders appear to be associated with autism as well as a complex relationship between seizure disorders and autism (Pomeroy, 1990).

Gillberg (1990) offered further support for the biological aspects of autism and regarded the disorder as a behaviourally defined syndrome of neurological impairment with a wide variety of underlying medical etiologies. In the vast majority of instances these biological factors have been shown or have been suggested to concur with autism in a stronger than chance fashion. While the support for autism as a biological disorder is strong, the neural circuitry which needs to be dysfunctional for autism to occur has not yet been identified. Perhaps the most consistent recent findings in the study of a neurological etiology have been studies in the area of brainstem pathology (Gillberg, 1990).

A further compelling argument in support of the biogenic theory lies in the family and twin studies area. Pomeroy (1990) reported that siblings of autistic children have 50 times the risk of the normal population for developing the disorder. According to Pomeroy (1990) monozygotic twins have an 80% to 90%

concordance for autism as opposed to a 15% to 25% concordance for dizygotic twins. Rimland (1964) pointed out that as early as 1940 there were identified situations of monozygotic twins with autism. Folster and Rutter (1977) studied 21 pairs of same sexed twins, one or both of whom had autism. Results of this study showed that 11 monozygotic but none of the ten dizygotic pairs were concordant for autism. In addition, six non autistic co-twins showed a cognitive abnormality or scholastic difficulties requiring special schooling. Rivto, Freeman, Mason-Brothers, Mo, and Rivto (1985) also studied the occurrence of autism in twins to test the hypothesis that genetic factors may be etiologically significant in the development of the disorder. They reported a concordance for autism in 40 out of 61 pairs of twins; 95% concordance with monozygotic twins and 23% concordance in the dizygotic twins.

In the area of family studies Piven, Gayle, Chase, Rink, Landa, Wzorek, and Folstein (1990) studied the adult siblings of 37 autistic persons. They found that two of 67 siblings were autistic, three siblings had severe social dysfunction and isolation, ten had cognitive disorders, and ten had received treatment for affective disorder. Wolff, Narayan, and Moyes (1988) attempted to identify personality traits in parents that may be a marker for a genetic component in the etiology of autism. They interviewed parents of 21 autistic children and 21 children with other handicaps on a scale known to discriminate between schizoid and non schizoid persons. Results indicated higher rates of schizoid personality traits in the parents of autistic children. These results were contradictory to an earlier study by Wolfe and Morris (1971) in which they used the Minnesota Multiphasic Personality Inventory and found no evidence of greater pathology in parents of autistic children. Piven (1990) pointed out that the Wolfe et al. (1988) study has been the only empirical study to date which supports the observation of specific personality characteristics in the family members of autistic individuals.

It is suggested that chromosomal disorders may also play a role in the etiology of autism. The fragile X syndrome (which refers to a fragile site on the X chromosome when observed in a folate-deficient medium) has been found in as many as 16% of some autistic populations. Surveys vary in their findings but reports indicated that an excessive number of fragile X syndrome males and some carrier females will exhibit autism (Bregman, Dykens, & Watson, 1987). Other factors such as birth trauma and neurochemical abnormalities have been suggested as significant in the etiology of autism (Pomeroy, 1990). While the precise biological element that may cause autism remains unknown it would appear that this area of research merits further investigation.

Psychological Factors. There is some evidence that psychological factors are significant elements in the development of autism. Experimental evidence has been presented that suggests autistic children may suffer from an impaired capacity to conceive of other people as having minds (Baron-Cohen, Leslie, & Frith, 1985, & 1986). Severely affected individuals might lack this capacity and therefore treat people as objects, misunderstand premeditated human behaviour, and be disconcerted by the seemingly unpredictable actions taken by humans when they do not follow restricted routines. Such individuals would not be able to understand that activities may not be so unpredictable if one attributes various states of mind to the people performing them. This inability to infer anything from the context of what other people may be thinking would lead to a lack of empathy and intuition with respect to a social situation (Baron-Cohen et al., 1985, & 1986).

Rutter (1983) also speaking from a psychological perspective, concluded that cognitive deficits are basic in autism in that they are not secondary to other features of autism and that they underlie many of the important handicaps of children with autism. Rutter (1983) further suggested that the social abnormalities in autism stem from a basic cognitive deficit in the field of dealing with social and emotional cues, particularly in dealing with stimuli that carry emotional or social meaning.

Hobson (1989) developed a theory of autism proposing that autistic children have a biologically based impairment of affective-conative relatedness with the environment. This theory proposed that the social and communication problems of autistic children are secondary to a primary irreducible affective disorder. This affective disorder involves a dysfunction in the autistic child's ability to perceive other people's mental states as reflected in their bodily expressions. The autistic child, according to Hobson (1989), fails to construct a concept of persons and is unable to fathom the nature of other persons' relatedness to the world and each other. This impairment in affective relations with other people is the most significant aspect of the child's disability, going beyond any cognitive deficit. The basic cognitive deficit is the child's inability to think abstractly and to symbolize, the primary source of creative flexible thinking and imagination. Because the autistic child thinks concretely he/she cannot understand similarities, differences, absurdities or metaphor, and is unable to define properties of objects independent of ego centered and situational use. Hobson (1989) concluded that autistic children do not have an inborn capacity to respond with those patterns of action and feeling that normally serve to connect one thing with another. Because they fail to connect with other people and with other's relations to the world their surroundings remain anchored to particulars, lacking in depth and fixed in orientation. The autistic child becomes "embedded in context" and fails to understand the nature of "I" who exists in personal relationship with "you" (Hobson, 1989).

Through further research into the psychological aspects of autism further knowledge of the relationship between the brain and behaviour may be gained. The discovery of a psychological deficit necessary and sufficient to cause autism could lead to advancement in diagnosis and intervention.

Summary of Etiological Theories

While a variety of theoretical factors have been proposed as important elements in the causation of autism, recent literature clearly indicates movement away from the psychogenic perspective and towards the biological and psychological aspects of the disorder.

Psychogenic theories are disputed on a variety of levels. Bristol and Wiegerink (1979) pointed out that much of the research proposing a psychogenic theory lacks diagnostic and methodological precision and is based mainly on clinical impressions. Controlled studies on families demonstrate that parents of autistic children are, for the most part, no different from other parents while studies on autistic children themselves produce more and more evidence of a primary neurophysiological dysfunction. Lack of support for the psychogenic theory has been demonstrated by studies on early trauma (Rutter, 1968), parental attitudes and practices (DeMyer, Pontius, Norton, Barton, Allen, & Steele, 1972), and the personality characteristics of parents of autistic children (Creak & Ini, 1960; Schopler & Ruchler, 1972).

Cantwell, Baker, and Rutter (1978) reviewed over 100 studies on autistic children and pointed out many flaws in the psychogenic theory's assumptions regarding severe early stress, parental deviance and disorder, parental I.Q. and social class, and deviant parent child interaction. Cantwell et al. (1978) concluded that the patterns of interaction in families of autistic children are much the same as those in families of children with other developmental handicaps.

While it is evident that the focus of causation is currently on biological and psychological factors the precise cause or causes of autism remains a mystery. It may be that in some children a basic cognitive deficit is both necessary and sufficient cause for the syndrome of autism to develop. In other cases this basic deficit may be a necessary but not sufficient cause and some other additional factors may contribute to the etiology. While in the present state of knowledge only tentative conclusions are possible there is growing evidence that autism has an organic basis with manifestations that are explicable in terms of cognitive and perceptual deficits.

Impact on the Family

The Family System.

Most families anticipate the birth of a child with eagerness and happiness. Parents and siblings, singly and together, develop certain expectations about the unborn child. When the child is finally born the dreams, expectations and desires instantly come together and are invested in the child. If the child is handicapped the emotional and psychological impact can be profound, as the dreams and hopes painfully die.

The family system functions as an organized whole with its components necessarily interdependent. The potential impact of an autistic child within the family goes beyond the effects on individual functioning or dyadic relationships, altering the functioning of the family system as a whole and changing its course of development. Family life may begin to revolve around the autistic child, with interactions inside and outside the family altered to accommodate the child's needs. As they become increasingly isolated from relatives, friends, and community activities the family may develop into a closed system which further aggravates the problem (Helm & Kozloff, 1986).

Diverse and often contradictory reports are found on examination of the literature on the autistic child and the family. In an attempt to understand the needs of the family with an autistic child, DeMyer and Goldberg (1983) interviewed 23 families, and reported on several adverse effects of living with an autistic family member. Family recreation was the aspect of family life judged by its members to be most seriously affected by the symptoms of the autistic child. Parents expressed difficulty in doing things together as a family because of the autistic child's unpredictable behaviour. Even simple outings or tasks required a great deal of planning and continuous supervision. This particular problem took on new forms and did not diminish over time with many parents reporting accumulated fatigue and a sense of being "burnt out". Family finances were ranked second in terms of adverse effects. This included both direct costs, such as expenses for child care and therapy as well as indirect costs such as lost work time, special residential needs, and interference with career advancement. Mothers in particular felt frustrated by their inability to work outside the home. Parents also expressed concerns for future security when retirement generally means a decrease in income but not release from the financial burden of the autistic child.

In the DeMyer and Goldberg (1983) study emotional and mental health of the parents were judged as worsened by the stress of rearing, treating, and educating the autistic child. Anxiety and recurring depressive feelings and symptoms were a common complaint, particularly in the case of mothers. Families of older aggressive adolescents feared physical injury to themselves.

Physical health of the parents was affected, with mothers especially reporting excessive fatigue, increasing as a problem as the mothers aged. Fathers nearing retirement age felt encumbered and burdened and both parents expressed concerns about who would care for the autistic child as aging and illness took their toll.

Siblings were also affected by the presence of the autistic child, according to the DeMyer and Goldberg (1983) study. Parents felt that they had succeeded only partially in meeting the needs of the other children. Siblings frequently felt bitter, and resented that the autistic child took a large chunk of the family time, energy, and effort. Typically, siblings were embarrassed to bring friends home, and had to deal with feelings of social ostracism and hurt from tactless remarks made by people in the community. Early in the life of the autistic child families felt alone and bewildered and were inclined to fight among themselves. Tensions in the family eased somewhat when treatment and education were made available but some families reported frequent fighting and bickering until the autistic child was placed in residential care. Other families reported a decrease in tension when they realized they were not alone in their struggle, stopped blaming themselves or each other and learned to pull together.

Families also reported that relations with friends, neighbours, and relatives were affected by the presence of the autistic child. Parents mentioned difficulties in having friends in or going to the homes of others because of the irritating or destructive behaviour of the autistic child. Conflict between parents and their family of origin were seen as more severe in preschool than in later years. The marital relationship was similarly reported as more strained early in the life of the autistic child. DeMyer and Goldberg (1983) suggested that if parents did not learn early in the life of their autistic child to be supportive of and not blame each other that divorce can be an outcome of the continual strain of the autistic child's needs.

Palfrey et al. (1989) also studied the patterns of response in families of chronically disabled children. Parents reported stresses related to obtaining child care, choice of family friends, and family vacation plans. Some families reported that their job situation was compromised by the presence of the disabled child and that the choice of house and community that the family lived in was constrained. In this study parents less frequently stated that the child's handicap affected their marriage.

Coping in families of autistic adolescents was studied by Bristol and Schopler (1984) who suggested that the stress of caring for an autistic child was both real and acute. Elements which were operational in determining levels of parental stress included: the age of the child (older autistic children were seen as creating more stress than younger autistic children), the permanency of the child's handicap, the lack of services for autistic adolescents, and conflict between the child's and parents' needs leading to parental "burn out." This study further suggested that whether the stress of having an autistic adolescent will result in family crisis and disintegration depended on coping strategies available to the family, personal and family resources, and formal and informal support supplied by extended family and the community.

Because families with an autistic child are for the most part "ordinary" families to whom an extraordinary event has occurred, it is useful to look at their experiences from a perspective that appreciates the normal context in which they live as well as the extraordinary stress created by the child's condition. Wikler, Warsow, and Hatfield (1981) pointed out that families with an autistic child face many of the same life cycle challenges as other families, but the demands may be intensified by the additional stress of a child with a handicap. The added stresses may prolong or intensify the family's response to life problems making an effective resolution more difficult. Harris and Powers (1984) suggested, for example, that integrating a baby into family routines always demands some degree of accommodation and change. Integrating an autistic child may pose extraordinary challenges because of the pain related to learning about the diagnosis, and the need to meet intensive demands for special management. Meeting the needs of the autistic child, caring for the other nonhandicapped siblings, maintaining satisfying marital relationships, fulfilling school and work commitments as well as the more mundane concerns of daily living can be overwhelming for families with a child who needs to be fed, dressed, toileted, and so on several times a day each day for years.

Another way to look at family vulnerability to stress is in terms of accumulated demands (McCubbin & Patterson, 1983; Patterson & McCubbin, 1983). Although the family of an autistic child may be as capable of coping with normal demands as any other family adding to that the need to cope with the child's extraordinary needs may push the family to at least temporary and sometimes sustained periods of maladaptive responding. Bristol (1984) studied resilient families and pointed to successful adaptation as related to the degree of family cohesion, expressiveness, and active recreational orientation. Less resilient families may be those coping with a higher level of chronic stress for whom the addition of one or more stressors disrupts a delicate balance. It is not that some families of autistic children are exempt from the sadness of living with an autistic child's disability, but that some families seem to be able to recover more rapidly from periods of stress.

Other factors which create stress for the family of a disabled child were reviewed by Seligman and Darling (1989). These authors saw the chronicity of care as a major feature distinguishing families of autistic children from families confronting other crisis. The autistic child's lifelong dependence can take its toll psychologically, physically, and financially. Family members can see little relief when they look to the future. Instead of independence, growth and differentiation, a family may see only despair, dependence and social isolation. The degree to which the family is troubled depends on factors such as how it conceptualizes its life circumstance, how supportive family members are of one another and the availability of social support outside the family (Seligman & Darling, 1989).

Flexibility and adaptability are seen as important to the success of any family, but most particularly to the family of a disabled child. Siblings may need to help with caretaking more than they otherwise would, fathers may need to be more psychologically supportive, and mothers have to learn to promote as much growth and independence as their child is capable of achieving. The family system also needs to be open to help from outside the system. Wikler (1981) reported that respite care leads to a decrease in negative maternal attitudes toward the disabled child and increased positive family interaction.

Stigma and its consequences is another element which affects families of an autistic child. Goffman (1963) suggested that families of the stigmatized come to bear a "courtesy stigma" and may suffer from similar reactions of avoidance, rejection, or ridicule. In a social or interactional context these families may feel devalued or experience a sense of shame. Even as we learn more about the biological basis of autism, parents of autistic children are still often considered responsible for their child's illness and therefore suffer the social stigma that accompanies this disorder.

The severity of the disability has also been suggested as a factor effecting the impact of the autistic child on the family system. Severity of disability has implications for families in terms of dependency, increased attention for the autistic child, frequent contact with service providers, and the prospect of lifelong care. Fewell and Gelb (1983) pointed out that children seen as mildly or moderately disabled are more difficult to assess educationally and in terms of emotional adjustment, making treatment alternatives less obvious. Ambiguity about diagnosis may cause families to "shop" for a favourable diagnosis, thus delaying initiation of a treatment plan and thrusting the family into a state of stress. Marginality implies ambiguity not only in terms of diagnosis, but also in terms of family concerns about the child's future, social acceptance, and level of functioning.

Children with a severe degree of disability create similar as well as different problems for the family. A major consequence of severe impairment is that these children manifest great difficulty in developing appropriate social skills. Bizarre behaviours are difficult to treat, and often necessitate extreme effort by the family to remedy or even tolerate them (Lyon & Press, 1983). The autistic child's inability to communicate generates a number of problems and concerns for the family. An autistic child who demonstrates coldness or rejection towards parents or siblings weakens family members' self-esteem and confidence and causes them to question the child's ability to care for anyone.

Some studies paint a more positive picture of the family with an autistic child. Byasse and Murrell (1975) compared the interaction patterns in families of autistic, disturbed, and normal children. Their findings suggested that families with autistic children did not differ from families with normal children in their interactional functioning measured by tests of spontaneous agreement, choice-fulfillment, and decision-making. Marcus (1977) suggested that for many families coming to grips with the emotional strains of living with an autistic child results in adjustments that lead to personal growth and awareness of themselves. Parents sometimes report that siblings are stronger and better adjusted and can develop a tolerance and empathy for handicaps that is rarely seen in children. Older siblings take on limited caretaking responsibilities and often feel a sense of pride and fulfillment in their sibling's progress. Rather than retreat behind a wall of ignorance and isolation parents may seek out information, often becoming experts on the disorder of their child. Despite the strain and pressure, very rarely does a family not fully accept the responsibility of caring for their autistic child. Although there is a fine line between burden and responsibility most families carry out their perceived duty with resourcefulness and energy and often with little outside help.

In a survey of parents and professionals Blackard and Barsch (1982) compared the appraisals of these two groups on the impact of a severely handicapped child upon the family. The results indicated that special education personnel tended to overestimate the negative impact of the handicapped child upon the family as compared to parents' appraisals. Families' difficulties were centered around practical matters such as obtaining respite care more than around psychological reactions. Jacobson and Humphrey (1979) proposed that the negative effects of a severely handicapped child on the family have been overstated, that the positive aspects have been ignored, and that many other family variables have been neglected from study. Support for this view is also offered by Gath (1977) and Farber (1976) who stated that families of handicapped children often report that they feel more drawn together emotionally as a result of the event. When families do experience stress it is usually due to the failure of the service delivery system, not necessarily a consequence of the disabled child (Bristol & Schopler, 1983).

The Parent Child Subsystem. There are a variety of reports which describe the psychological and emotional impact upon parents and their reaction and subsequent adaptation to a handicapped child. The emotional adjustment of parents may follow a pattern similar to that noted among those who are grieving over the death of a loved one. This concept is important to an understanding of the psychological trauma experienced, for these parents are actually mourning the death of the perfect child of their dreams. Sloman and Konstantareas (1990) suggested that the parent's recognition that their child is handicapped represents the loss of the hoped-for normal child and the fact that they have produced such a child becomes a major threat to the parent's sense of self. Solnit and Stark (1961) discussed parental mourning of the loss of the hoped-for normal child in a society where intellectual achievement is highly valued. They stressed the importance of mourning and its resolution in adapting to the child's disability. Olshanky (1962) described the long term parental reaction as one of "chronic sorrow" and Seligman and Darling (1989) pointed out that parents may have to renegotiate their sadness at key developmental milestones in the child's growth cycle.

Strain and uncertainty start as parents begin to suspect that there may be something wrong with their child, themselves, or both. When the appropriate language and social skills fail to appear, when the child becomes aloof without apparent reason, and when odd motor patterns and preoccupations arise and persist the parents are essentially alone with their autistic child. These parents must cope with the insidious onset of autism and the growing awareness and fear that there is something seriously wrong with their child before they can seek out professional advice (DeMyer, 1979).

The parents' first and natural response in dealing with their child's perceived deficits and excesses is to question their own competence. The early bewilderment or shock gives way to increasing anxiety and despair. If the child is among those who resist being held, parents may feel rejected or angry which often leads to self-recrimination or blaming others (Paluszny, 1979).

Parents report that their lives become a daily struggle for personal and family survival and that the price they pay for that survival is mental and physical exhaustion. The degree of struggle and self-deprecation may vary from family to family but the elements of struggle, (shock, anxiety, and exhaustion) persist (Cutler & Kozloff, 1987). Over time and with help some of the stressors will diminish, a few will vanish, some will be managed, and a few new ones will appear.

Obtaining the diagnosis of autism marks a turning point for many parents. The uncertainty of not knowing what the child suffers from is replaced by the knowledge of what the disability is. But with this comes the uncertainty of how to deal with the handicap and the concern over what it will mean to the child and family. In many cases parents do not get an unambiguous diagnosis and prognosis, creating the potential for continued anxiety and stress.

Schell (1981) and Marion (1981) identified certain factors that influenced parental reaction to the identification of a handicapped child. Among those identified were: the severity of the child's handicap, the social acceptability of the handicap and the socio-economic level of the family. To these factors may be added the manner in which the parents are informed of the disability and the age of onset or of the child when the diagnosis is made.

DeMyer's (1979) study indicated that a major source of stress for parents of an autistic child is the inability of the child to master the usual developmental tasks of childhood or to understand what is expected of him/her. Far from being aloof and akin to disinterested spectators, parents were intensely affected by the developmental failure of their child. While many members of the extended family tried to be helpful in childrearing, the parents, already beleaguered and supersensitive, sometimes felt more stress than help from the family. Remarks from neighbours, friends, and strangers made generally in a spirit of helpfulness were nevertheless often critical in substance and contributed to the parents' distress.

DeMyer (1979) further reported that multiple stresses continuing over months or years had effects on the parents as individuals and marriage partners and eventually on the other children. Scattered throughout interviews with parents were many expressions of parental guilt, anger, feelings of sadness and failure, anxiety and tension, and a general decrease of joy in life. Because mothers took so much larger a share than fathers in the day to day care of the children, the effects on mothers were more direct. Mothers in this study mentioned feeling guilty at some time about something they had or had not done and some of the mothers expressed serious doubts about their mothering ability. Feelings of anger at some symptom or feature of the condition were expressed by several mothers, but rarely did a mother say she felt anger toward the child. Mothers sometimes reported that they felt they could not deal with the situation anymore and some expressed a desire to escape or slip away somewhere.

Fathers in the DeMyer (1979) study were also touched deeply by the autistic child's disability but they had their work outside the home and not only could derive self-esteem from it but would also gain a legitimate escape hatch. Fathers expressed feelings of guilt about what their role might have been in producing the symptoms, anger at some of the symptoms, and hurt over lack of affection from the child. DeMyer (1979) hypothesized that fathers had the same troubling feelings of guilt, inadequacy, frustration, and anger as the mothers but that most did not, or could not, express them. An important effect on many fathers was their reaction to the mother's pain and preoccupation over the autistic child's problems. Fathers mentioned that this preoccupation and the need to be at home with the child cut down on their pleasure in life because they could not go out much as a couple.

Studies by Holyroyd, Brown, Winkler, and Simmons (1975), Holyroyd and McArthur (1976), and Bristol and Schopler (1983; 1984), suggested that parenting autistic children may be associated both with additional stressors and with a characteristic pattern of stress. In Holyroyd and McArthur's (1976) study these additional stressors were linked to upset and disappointment about the child's personality and behaviour and a loss of activity and vocational possibilities, especially for mothers. Bristol (1979) reported that mothers found older children somewhat more stressful than younger, a finding supported by

DeMyer and Goldberg (1983). Autistic boys were associated with greater stress than girls according to Bristol and Schopler (1984) who further reported family stress influenced by the child's behavioural difficulties, the availability of social supports, and prospects for the child's living independently.

In a review of previous studies Lamb (1983) noted that fathers and mothers initially respond differently to the news that they have produced a child with a disability. Fathers tend to respond less emotionally and focus on possible long term concerns, whereas mothers respond more emotionally and are concerned about their ability to cope with the burden of childcare. Because of the high expectations fathers have of their sons, they may be especially disappointed when they have disabled sons, manifested in extremes of intense involvement or total withdrawal.

Fathers' reactions to their disabled children may have implications for the response of other family members. For example, Peck and Stephens (1960) found a strong relationship between the degree of paternal acceptance of the disabled child and the amount of acceptance and rejection generally observed in the family system. When fathers experience stress and withdraw from their families, the development of the disabled child is likely to be affected, other family members (especially the mothers) must take up the slack, tensions increase, and the entire family suffers.

In a study of families of autistic children Bristol and Schopler (1983) reported a developmental progression of family stresses. Mothers of very young autistic children focused on constant caretaking demands, lack of sleep, and concern for the physical survival of the children, who might run into the streets or get up and wander in the middle of the night. As children got older, many of these problems abated and management problems shifted from survival to self-help issues, difficulties with the children's behaviour in public, and attempts to maintain some semblance of normal family functioning. Management problems with older children, although less frequent, took on greater importance because of the increased physical size and strength of the children and the decreased strength and energy of the mothers. If physical aggression became a problem in adolescence this had the potential for acute family crises unless parents were highly skilled or help was available. As children grew older and larger, parents also noted less community acceptance of deviant and bizarre behaviour and began to worry about the child's survival in the community. Social support was also enumerated as an important factor related to parental stress in the Bristol and Schopler (1983) study. The perceived adequacy of social support was one of the factors that distinguished between the highest and lowest stress groups.

Konstantareas and Homatidis (1989) studied the relationship between child symptom severity and stress in the parents of autistic children. Symptom perception was influenced by the child's age, with younger children seen as less symptomatic by parents when compared to clinician's assessment. Parents agreed on the issue of symptom severity, with poverty in human communication, unevenness in cognitive ability and impairment in human relations as being the most stressful. Mothers were also stressed by the child's hyper-irritability while fathers reported self-abusive behaviours as highly stressful.

In terms of the impact of the autistic child on the marital bond DeMyer (1979) reported that while general ratings of marital happiness and unhappiness were not significantly different between couples who had an autistic child and those who did not, there were more strains on the parents of the autistic child. More happy and extremely happy marriages were reported in the normal group and more extremely unhappy marriages among couples with an autistic child. Normal children were likely to have a positive effect on a marriage while problems associated with rearing the autistic child seemed to weaken the affectional bond for about 51% of the autistic children's parents. The nerve wracking effects of worry and some of the autistic child's more irritating symptoms put parents on edge resulting in increased tension. The sadness, depression, and worry often took the joy out of marriages. Mothers of autistic children also tended to report more often than normal mothers that worries about the child interfered with their interest in sex.

In a later study DeMyer and Goldberg (1983) suggested that the marital relationship is more strained with younger than with older autistic children. In a group of 23 parents there were six divorces with five of the divorced parents saying that the strain of dealing with the autistic child played a moderate to major role in contributing to the divorce. In families where the marriage survived, several mothers reported that placing the child in a residential facility either saved the marriage or greatly improved its quality.

Commenting on the impact on the marital bond Fisman and Wolff (1991) concluded that there appears to be a relationship among the stress of parenting an autistic child, the effect that the child has on the mother's mental health, and the quality of the marital relationship. The difficult child generates a high stress situation that adversely affects marital intimacy, the strained marriage impacts on the parent-child relationship, the child becomes more difficult, stress escalates further and a vicious circle is perpetuated. Similarly there is a reciprocal influence within the husband-wife relationship. A depressed spouse is likely to affect the quality of the marital relationship and the escalating tension in the marriage may further affect the psychological health of the spouse.

Morgan (1988) suggested caution in drawing firm conclusions about the typical impact of the autistic child on the parents' marital relationship. The evidence would not indicate that the child necessarily impairs this relationship and/or increases the chances of divorce. Under certain conditions the child may foster a stronger relationship; under other conditions the child may contribute substantially to marital discord, dysfunction, and divorce. Morgan (1988) suggested that perhaps there are certain mediating variables such as the age of the child, severity of the autistic behaviour, and availability of services that affect marital adjustment.

While the majority of reports comment on the negative impact of the autistic child on the parent subsystem other studies suggest different conclusions. Koegel, Schreuban, O'Neill, and Burke (1983) studied various aspects of parental functioning in 49 mothers and fathers of autistic children. The parents of the autistic children produced scores similar to a normative group of happily married couples and showed no differences from a normative group on a scale which assessed interpersonal relationships among family members. Koegel et al. (1983) concluded that these results failed to support a general stress reaction by parents to an autistic child and suggested instead that parental stress is highly situational and specific to anxiety-producing situations.

DeMyer (1979) also indicated support for the notion that an autistic child can have positive affects on the family system. In the DeMyer (1989) study some parents, especially mothers reported expanded awareness of human suffering and found a cause they could fight for. Some mothers found strength of character and resolve not believed possible in interactions with educators, physicians, and others in the community. About one third of the parents in this study believed that their non disabled children were strengthened by the experience and achieved a sense of empathy beyond their years. Marcus (1977) pointed out that for many families coming to grips with the pressures of raising an autistic child results in adjustments that lead to personal growth and awareness of themselves. Parents in this study reported that siblings were stronger and better adjusted, not ashamed. Marcus (1977) suggested that families who recognize the need to develop strategies by consensus may feel a sense of increased family cohesion.

The Sibling Subsystem. For some time clinicians working with chronically ill or handicapped children and their families have suspected that the siblings of these children are also at risk. Despite this concern the literature on the effects of the disabled child on the nondisabled siblings remains sparse and what does exist is often inconclusive and contradictory.

In some cases higher levels of anxiety, negative self-esteem, behavioural problems, and somatic complaints have been described among the siblings of handicapped children (Brownmiller & Cantwell, 1976; Lavigne & Ryan, 1979; Tew, Payne, & Lawrence, 1974). Conversely, some studies on families with an autistic child show no negative effects on the siblings (Lobato, Barbour, & Hall, 1987; McHale, Sloan, & Simeonsson, 1986).

A study by DeMyer (1979) reported increased parental tension which inevitably affected the siblings and created tension throughout the family system. The most prominent negative effect was that one or more children in the family felt neglected because so much attention was paid to the autistic child and so much time was spent in finding help for the disabled child. Some parents reported that at least one sibling seemed worried and upset about the autistic child's condition and felt that regression in habit training (toileting and eating) seemed related to the autistic child's effect on the sibling. Other effects reported were inordinate teasing by school friends, nearly complete ignoring of the autistic child by the nondisabled siblings, and an unusually high level of jealousy on the part of normal siblings. One sibling refused to go to school and two siblings ran away from home saying that their responsibilities to the autistic child provoked it. DeMyer (1979) cautioned however, against concluding that the presence of the autistic child actually stimulated these reactions as most of these events can also occur in normal homes. The difference proposed by DeMyer (1979) was that in the family with an autistic child, the disabled child was blamed for the events rather than the normal child.

Among other types of difficulties reported in nondisabled siblings are feelings of guilt and fear that they might in some way be responsible for the autistic child's condition. Identity problems have been noted with the nondisabled child harbouring secret fears that he/she might be affected in some way and become like the autistic sibling in the future. There are also difficulties associated with the nondisabled child being expected to do more household tasks, having to care physically for the autistic sibling or carry out other chores because of the greater amount of time and attention required by the disabled child (McHale, Simeonsson, & Sloan 1984); McHale, Sloan, & Simeonsson 1986). Resentment and anger over caretaking can last well into the normal siblings' adulthood. The combination of resentment over excessive caretaking responsibilities and perceived limited parental attention can produce profound negative psychological reactions in some siblings.

August, Stewart, and Tsai (1983) noted a higher incidence of learning problems in siblings of autistic children. Rates of language-related problems such as early speech delays or later reading and spelling problems were significantly higher in the siblings of autistic children than in other families. It remains unclear however, whether these are genetic defects or whether they are related to the stress of living with an impaired child.

Consistent across some studies has been the finding that the effects of a handicapped child on the siblings may be mediated by the gender and relative birth order of the sibling. Lobato (1983) suggested that in most typical Western families the firstborn female usually assumes greater responsibility for care of her siblings than either a firstborn male or later-born female. This sibling position might be particularly vulnerable to psychological stress attributed to greater care responsibilities. Fowle (1968) and Grossman (1972) supported the evidence that indicated eldest female children to be most adversely affected by the presence of a disabled child while Gath (1974) reported vulnerability of older sisters and younger brothers pronounced in small, two child families and in large families with more than seven children. Children who are younger than the disabled child may experience role tension when the older disabled child becomes the youngest child socially. In such instances the nondisabled younger siblings may be expected to care for and subordinate their needs to their older disabled sibling (Farber, 1960). Contrary to Gath (1974), Howlin (1988) reported that risk to siblings tends to be greatest in small families, particularly where there is just the impaired child and one other child and where the age gap between the two is small. Howlin (1988) suggested that in larger families the burden can be more easily shared and attention from other siblings can help to compensate for any reduction in parental attention. Also, parents' disappointment and grief at having an impaired child can be reduced to some extent by experiencing their other children growing up successfully.

Hayden (1974), Klein (1972), and Sullivan (1979) reporting on personal accounts of their family lives suggested that siblings of handicapped children often felt their parent's expectations of them exceeded what was appropriate for their age or self-perceived capabilities. These children felt they had to excel in order to make up to their parents for the limitations of the handicapped child.

Other problems encountered by siblings of a handicapped child were reported by Mori (1983). Normal siblings may lack a sense of belonging to the family because parents must devote so much time and energy to the needs of the disabled child. Normal siblings may also fear that they may somehow "catch" the disability and even more frightening for adolescent sisters that they may produce a child like their handicapped sibling. Negative sibling reactions seem to decrease according to Mori (1983) when parents honestly share information within the family and involve the normal siblings in the handicapped child's program only to the extent that is tolerated.

Siblings may also experience "survivor guilt" for their healthy lives which are in sharp contrast to those of their disabled siblings (Bank & Kahn, 1982). They may experience considerable guilt over the advantages they have and the only recourse to expiate such guilt lies in taking care of the disabled sibling. The nondisabled child may feel overly responsible to the disabled sibling in order to justify the fact that he/she is not the disabled one.

Seligman and Darling (1989) suggested that nondisabled brothers and sisters understandably look anxiously to their future. They wonder whether the responsibility their parents at present assume will later fall to them. They wonder whether they can cope with the decisions that need to be made in future years, in addition to worrying about whether they can physically or psychologically manage to care for the disabled sibling. A further related concern of some significance is the doubt a sibling may have about whether his/her future or present spouse will accept or be able to cope with the disabled brother or sister.

Social isolation, withdrawal, and loneliness may also be experienced by the siblings of a disabled child (Seligman & Darling, 1989). Peer reactions may isolate siblings from their social groups; they may be embarrassed to be seen in public with their disabled sibling or curtail activities such as sleepovers and parties because of the disruptive behaviour of the disabled child.

Several studies speculated on which variables may be operational in mediating the impact of an autistic child on the nondisabled sibling. Poor family relationships, marital strain, depression or other psychiatric illness in the parents all increase the risk of disturbance in both normal and impaired children (McHale et al., 1984). Economic and social issues may also exert important influences. The financial complications of having to care for a disabled child are considerable and financial strains can add greatly to the other burdens on families. Different conflicts may arise more in different families because of their higher expectations and inevitable discrepancy between their aspirations and the level the impaired child will actually achieve (Howlin, 1988). Other factors to be considered include the nature of the disabled child's impairment (Howlin, 1988), the age and developmental stage of the nondisabled sibling (Bank & Kahn, 1982), and parental feelings and reactions, especially those of the mother (Seligman & Darling, 1989).

Bristol and Wiergerink (1979) commented that the effect of the autistic child on his/her siblings may be directly related to the adequacy of support services available to the parents. For example, the mother whose child is enrolled full time in a school program and who has access to good short-term child care and respite care is more apt to be able to have sufficient time for her other children. In contrast the mother who attempts to fulfill all the roles herself with no outside support may find she is just too drained to respond to the needs of other family members. Access to programs may also provide relief for the nondisabled sibling from some of the daily responsibilities of care for their handicapped brother or sister.

In direct contrast to studies reporting negative aspects of the presence of a disabled child are reports which indicate neutral or positive impacts on the nondisabled siblings. McHale et al. (1986) compared the sibling relationships of children with autistic, mentally retarded, and nonhandicapped brothers and sisters. Group comparisons indicated that children with autistic and mentally retarded siblings did not differ on any self-report measures and that both children and mothers rated the sibling relationships positively. Children with nonhandicapped siblings reported that their family relations were slightly more cohesive but otherwise did not differ in terms of their self reports from children with handicapped siblings.

Surprisingly, mothers of nonhandicapped children rated the sibling relationships more negatively than did mothers of handicapped children. McHale et al. (1986) pointed out that when children perceive their parents and peers as reacting positively to the handicapped child and when they have a better understanding of the disabled child's condition the sibling relationship tends to be more positive. Also of note in this study is that children with autistic or retarded siblings showed a wide range of responses, in both positive and negative directions, whereas children with nonhandicapped siblings tended to cluster around the mean on each interview item.

Howlin (1988) suggested that living with impairment is not necessarily a harmful experience and that various factors are likely to influence the risk on siblings. Siblings of autistic children are often remarkably well-adjusted and frequently show greater maturity and responsibility than their peers. They have been reported as being more altruistic and tolerant generally; many tending to go into the helping/caring professions when they grow older (Cantwell & Baker, 1984). McHale et al. (1984) found that as a group, siblings of autistic and mentally impaired children were significantly less hostile, less socially embarrassed, more acceptive and more supportive than the siblings or normal children. DeMyer (1979) noted that the autistic child's problems may evoke a helpful attitude in one or more of the nondisabled siblings. Finally, Grossman (1972) reported that a number of siblings of retarded children appeared to have benefited from the experience, seemed to be more tolerant and more aware of the consequences of prejudice. As well they were more certain about their own futures and about personal vocational goals than comparable young adults who had not had such an experience. Siblings of the disabled child expressed involvement in the growth and developments of their sibling and a sense of pride at being a part of it.

The Grandparent Suprasystem. A full understanding of childhood disability and family adjustment also includes intergenerational relationships. Seligman (1991) suggested that to conceptualize the family apart from its ancestral past is to ignore integral parts of its family life because family dynamics within the nuclear family may be affected by the attitudes and actions of extended family members such as the grandparents.

Wilcoxin (1987) identified the following grand parental roles. Grandparents serve as historians in linking with the cultural and familial past and as role models demonstrating an example of older adulthood. As wise adults experienced in life transitions they serve as mentors. Grandparents can fulfill the role of master story teller to foster creativity and imagination and provide nurturance and support during family crises and transitions.

Grandparents have much to offer in providing guidance and coping strategies about child care as well as in providing community resources. They can assist with child care and errands, providing respite from the daily chores of care for a disabled child. Grandparents can offer companionship and use their contacts in the community to help find services for the parents of the disabled child (Minuchin, 1974).

Sonnek (1986) reported that maternal grandmothers in particular help with shopping and gifts for special occasions. They also helped out with the child's homework, provided financial help when needed and served as playmates for the disabled child. By offering emotional support during the diagnostic phase and throughout the child's development, grandparents help their children cope. Mothers sometimes report an increased bond of mutual understanding as their own mother supports them in dealing with the puzzling problem of autism (DeMyer & Goldberg, 1983).

There can also be conflict and tension between the generations in response to a disabled grandchild. The birth of a grandchild with a disability evokes emotions that are very different from those evoked by the birth of a healthy grandchild (Meyer & Vadasy, 1986). Grandparents experience pain for their grandchild as well as for their own child, whom they perceive as burdened for life. In an effort to avoid pain grandparents may trivialize a grandchild's problem, deny the problem or hope for unrealistic cures, creating additional burdens for parents who are attempting to cope with the crisis.

Farber and Ryckman (1965) reported that frequent contact between a disabled child's mother and her own mother promotes marital integration while frequent contact with her mother-in-law can be a negative event.

Pieper (1976) discussed the interaction between herself and her mother-in-law after the birth of her disabled son. Her mother-in-law was reluctant to visit her in hospital, blamed her for the child's disability, and accused her of burdening her son for life. Weisbren (1980) reported that fathers engaged in more activities with their disabled child if they perceived that their parents were supportive. Weisbren (1980) also noted that the father's relationship with his parents was more important than any other relationship among support services and that mothers felt more positive about their disabled child if they perceived their in-laws as supportive.

Harris, Handleman, and Palmer (1985) questioned parents and grandparents of autistic children, asking them to describe their view of the autistic child, the impact of the child on the parents, and the relationship between the parents and grandparents. One of the consistent findings of this study was that when the two generations differed, it was always the grandparents who took the more positive, optimistic, or less burdened view. This was most strikingly true of grandmothers who adopted a significantly more positive stance toward the autistic child's limitations and impact upon the family.

The apparent discrepancies between the generations can be explained in several ways. Grandparents do not regard themselves as responsible for the grandchild's failures, shortcomings, or mistakes. As a consequence they may feel less pain and personal distress about the severity of the child's disability. Because grandparents have less frequent contact with the child the child's disability may affect them less, be less obvious to them and create less disruption in their lives than it does for the parents (Albrecht, 1954). Harris et al. (1985) pointed out that grandparents may tend to deny the child's handicap long after it has been realized by the parents. Neugarten and Weinstein (1964) found that the majority of grandparents idealized the grandparent role and focused upon its positive aspects. Thus they may be less inclined to evaluate the child in negative terms or acknowledge their distress as directly as do the parents.

Nevertheless, it is likely that grandparents experience a mourning period for the loss of the idealized grandchild they had expected. Vadasy, Fewer, and Meyer (1986) reported that grandparents' initial reactions to the birth of a disabled child were most often sadness, shock, and anger. Just as the parents experience the "death" of the expected normal healthy child so too may the grandparents feel a great loss and mourn the death of what they wished for. Grandparents may be mourning at the same time as the parents and may therefore be unable to offer much support to the grieving parents.

Summary: Impact on the Family System

Attempts to assess the impact of an autistic child on the family system have resulted in a diverse and often confusing array of reports. Because family members vary so widely on their specific characteristics and because any number of different psychological, social, and practical day-to-day factors affect each family differently, attempts at a characteristic profile of families of autistic children are difficult. The literature in this area is mixed, with some authors reporting relatively little negative impact of autistic children on their families, and others suggesting that the impact is predominantly negative.

While it may be difficult to develop a clear picture of the impact of an autistic child on the family system the search for themes, patterns and commonalities between families can play an important role in expanding our knowledge in this area. The autistic child resides within a reactive larger system, affects it, and is in turn affected by it. Neither the autistic chid nor the system within which it operates exist in isolation from each other. It would therefore appear that an appropriate model to study the interaction between the child and the child's environment would be a family system approach.

Chapter 3

Family Systems Theory

The development of family systems theory was influenced by Von Bertalanffy's (1968) concept of a system defined as a set of objects or elements together with the relationship between the elements and their attributes. The objects are the component parts of the system, the attributes are the properties of the objects, and the relationships tie the system together. These interlocking systems can be further defined in terms of hierarchical relationships. While the family is a subsystem in relation to the larger social system, it is also a suprasystem in relation to an individual. The individual member is in turn a suprasystem in relation to his/her own biological system (Von Bertalanffy, 1968). Maintaining the awareness of the biological subsystem as well as interpersonal transactions is particularly important when considering how the autistic child's biological dysfunction affects and is affected by the broader family system (Sloman and Konstantareas, 1990).

In family systems theory a further important distinction to be made is that the whole is greater than the sum of the parts (Carter & McGoldrick, 1980). That is, the system is not merely the sum of the individual personalities in a family but includes the interaction of these parts which creates characteristics not contained in the separate entities. In order to understand the family system we must therefore study the connections between individuals and see how they interact.

Within the framework of family systems theory are a number of concepts useful in examining the dynamics of family interaction. Some of these concepts include the following:

Wholeness

An essential postulate of systems theory states that a system is a whole and that its elements or components and their attributes or characteristics can only be understood as functions of the total system. A system is not a random collection of components but an interdependent organization in which the behaviour and expression of each component influences and is influenced by all the others (Walrond-Skinner, 1976).

Boundaries

A system's identity is determined by its boundary. The system's boundary provides an interface with its external environment and with its own subsystems and circumscribes its identity in time and space. The nature of the boundary will determine whether it is a closed or open system. Systems are seen as being linked hierarchically to other systems. Superordinate systems are generally designated as suprasystems while subordinate systems are called subsystems. For example, a nuclear family considered as a system is seen as interfacing with its extended family networks (suprasystems) while it itself contains subsystems (e.g. the parental subsystem) (Walrond-Skinner, 1976).

Boundaries determine who participates in the family system and how each participates. In a healthy family the boundaries are clearly understood. The marital subsystem (husband and wife) boundary is exclusive and includes behaviours which are private and off limits to others inside or outside the family. Children ideally do not intrude on the marital subsystem. Similarly the siblings form a subsystem which tells them how to interact with peers and to develop appropriate social skills apart from undue interference from the parents. Still another subsystem is the parent-child subsystem. In this subsystem the boundaries are less rigid, the children have access to the parents and they are able to elicit certain behaviours from the parents.

Some families may construct boundaries across subsystems as when a parent and one child will relate to the exclusion of the rest of the family. In other cases the boundaries are too rigid and do not allow entry of others or are too loose so as not to be sure where one subsystem ends and the other begins.

Open and Closed Systems

The concept of the family as an open and closed system can be seen as a continuum moving from relatively open to relatively closed (Walrond-Skinner, 1976). In a relatively open family system, members engage in a high degree of communication with the community and extended family and between individual members and sub-groupings. A relatively closed family system engages in minimal interchange with either its supra or subsystems.

Rules

Rules are the patterns of behaviour which are developed over time with regard to how a family handles certain issues, how certain feelings are shared, what is or is not safe to talk about, and who makes the decisions (Satir, 1972). Relationship rules, both explicit and implicit, organize the family and function to maintain a stable system by prescribing and limiting members' behaviour. They provide expectations about roles, actions, and consequences that guide family life.

Homeostasis

Homeostasis can be defined simply as "steady state" and is the quality which enables a system to remain stable and in a steady state through time. Homeostasis is made possible by the use of information coming from the external environment and being incorporated into the system in the form of feedback. Feedback triggers the system's "regulator" which, by altering the system's internal condition maintains the "steady state" (Walrond-Skinner, 1976).

Homeostasis need not be equated with dysfunction but can rather be seen as a functional protective mechanism. Nor does homeostasis imply something set and immobile. It means a condition which may vary but is relatively constant.

An additional concept, the notion of morphogenesis, helps to explain phenomena such as growth, change, and creativity. In contrast to homeostasis which is concerned with the protection of what is, morphogenic mechanisms are concerned with growth and change. The result of morphogenesis is an increase in the system's component parts whereby each is able to develop in its complexity, while remaining in functional relationship to the whole (Walrond-Skinner, 1976).

Communication

Because systems theory is concerned with the interrelationship between system components and between systems and suprasystems a great deal of emphasis is placed on communication i.e. how the system components interact. Communication in systems theory involves the notion of feedback. In the feedback model of information exchange each link in the chain is modified and hence changed by its interaction. This modification occurs in a circular process, known as a feedback loop (Walrond-Skinner, 1976).

Feedback is considered to be either positive or negative. In the case of positive feedback, information is used to trigger off morphogenic mechanisms leading to the upset of homeostasis and the movement toward growth and change. In the case of negative feedback, this information is used by the system to trigger off its homeostatic mechanisms, acts as a means of decreasing the system's output deviation, and thus maintaining its "steady state" (Walrond-Skinner, 1976).

Causality

At a theoretical level the concept of linear causality carries with it the implicit idea that it is a past event that is the cause of the current situation. Systems theory stresses circular causality i.e. a cause is also an effect, and an effect is also a cause in a never-ending sequence. In this concept the "here and now" is emphasized, for it is in the here and now that the whole circle can be seen in operation (Walrond-Skinner, 1976).

Impact of an Autistic Child on the Family: A Systems Perspective:

The principles from family systems theory appear to be applicable in examining the interaction between the autistic child and his/her family system.

The autistic child is embedded in multiple systems that can interact in direct and indirect ways to influence behaviour (Fisman & Wolfe, 1991). Among the systems involved in this interaction the most important is the family which includes parent-child subsystems, the marital relationship, and sibling subsystem. Systems external to the family including extended family and friends, the neighbourhood, school, and helping agencies may generate a social support network and offset the high levels of stress generated within the family system.

Family systems theory also proposes that any system functions as an organized whole, with components of the system being necessarily interdependent (Minuchin, 1985). The system has certain homeostatic features that perpetuate the stability of its patterns. In some families, where the system is open, this self-regulatory process tends to be adaptive. Other families may incorporate maladaptive patterns as necessary components of the system; in such families the system may become less open and more resistant to change (Morgan, 1988).

The family system is irrevocably changed by the arrival of a new member and the new member is imprinted by the particular family's history, rules, boundaries, and style of communication. To understand the impact of an autistic child on the family we must study the connections between individuals in the system and see how they interact.

The specific purpose of this study was to determine patterns or themes relating to the effect of the autistic child on the parental subsystem, the sibling subsystem, and on the extended family. The questions asked were:

Does the presence of the autistic child impact on family integration, the sibling subsystem, and the extended family?

Do social supports effect the impact of the autistic child on the family system?

Are the principles from family systems theory applicable in studying the impact of the autistic child?

Chapter 4

Method

Subjects

Subjects for this study were recruited from the members of the Autism Society Manitoba. The researcher attended a regular meeting of the Society as arranged with the Society's president, presented an overview of the project and requested that interested families sign their names on a sheet. These families were then contacted by telephone and interview times arranged as mutually agreed upon.

The study was restricted to parents of autistic children. A total of four two-parent families were interviewed. The upper age limit for the autistic child was set at 16 years. Families had to include at least one child other than the autistic child. For the family to be included the disabled child needed to be diagnosed as autistic and meet the diagnostic criteria outlined in the DSM-III (R), (1987).

Instruments

Each family participated in an in-depth interview. An interview schedule was used so that each family received as similar an experience as possible. The schedule began with an explanation of the purpose of the interview, assurances of anonymity, and permission to terminate the interview at any point. The schedule also included a facesheet to allow for the securing of demographic data such as age, education, occupation, ethnicity, and religion. A list of topics covered formed the major part of the schedule (See Appendix A).

The topics to be covered during the interview were based on the following sources:

1) Literature review. Several factors common to families were suggested by a review of the literature. These factors served as guides during the family system interviews.

2) Systems theory. Epstein and Bishop (1973) suggested a conceptual framework for assessing family interaction known as the McMaster Model of Family Functioning. This model incorporates the major assumptions of systems theory. These assumptions are: the parts of the family are interrelated; one part of

the family cannot be understood in isolation from the rest of the system; family functioning cannot be understood simply by understanding each of the parts; family structure and organization are factors in determining the behaviour of the family; and transactional patterns of the family system shape the behaviour of family members. The concepts of this model provide parameters within which an investigation of the family system can be made.

3) Coping Health Inventory for Parents (CHIP), (McCubbin, McCubbin, Cauble, & Nevin, 1981). This scale was developed to assess parents' perception of their response to the management of family life when they have a child member who is seriously and/or chronically ill. It is hypothesized that families possessing a larger repertoire of coping behaviours will manage the situation of the chronically ill child more effectively. Reliability of this scale is reported as follows: (a) questions regarding maintaining family integration, co-operation and an optimistic definition of the situation - Internal Reliability = .79 (Chronbach's alpha); (b) questions regarding maintaining social support, self-esteem and

psychological stability - Internal Reliability = .79 (Chronbach's alpha); and, (c) questions regarding understanding of the medical situation through communication with other parents and consultation with medical staff - Internal Reliability = .71 (Chronbach's alpha).

Validity assessments of CHIP were made with hypothesized correlations found between parental coping and family environment ($p \leq .05$) and parental coping and indices of children's health status ($p \leq .05$).

4) Family Inventory of Resources for Management (FIRM), (McCubbin, Comeau, & Harkins, 1981). This scale was developed to assess the family's repertoire of resources in order to describe or predict how a family adapts to stressful events. It is hypothesized that families possessing a larger repertoire of resources will manage more effectively and will be better able to adapt to stressful situations. Internal reliability for the four scales of FIRM is reported as .89 (Chronbach's alpha). The intercorrelation matrix of the FIRM scale was examined and the scales were found to correlate moderately ($p \leq .001$).

The elements highlighted in the above four sources were incorporated to form the structure of the interview schedule. The two scales (CHIP) and (FIRM) were used only as reference sources to develop the interview schedule and were not actually applied during the interview process. Results are therefore those reported by applying only the interview schedule.

Design

Data on the impact of an autistic child on the family was collected by interviewing the parents of the autistic child. Parents were interviewed separately from each other as to their perceptions of the autistic child's impact on their family system.

Procedure

Each recruited parent was contacted by telephone to arrange for the date, time, and place of the interview. A total of four one hour interviews was required for each of the four families in the study for a total interview time of 16 hours. Each of the 8 parents who participated in the study were interviewed separately in a one to one situation. Only parents were interviewed, not siblings, the autistic child, nor extended family members. The interviews were conducted in two parts in order to prevent fatigue on the part of the interviewee and to allow the interviewer to follow up on questions generated during the first interview. The reasons for the follow up interview were explained during the recruitment process and again at the time of the interview.

Prior to beginning each interview permission was sought from the subject to audio tape record the interview. The purpose of obtaining the tape was explained and the subject's signature obtained on a release form (See Appendix B).

Each interview began with the reading of the introduction to the interview schedule, outlining the purpose of the study, the focus of the interview, probable length of time required, and the assurance of anonymity.

The introduction also included assurances that the interview could be terminated by the subject at any point, the reasons for the follow up interview, and an explanation that the researcher would provide names of counselling agencies at the subject's request. Subjects were instructed that there were no right or wrong answers. The purpose of the interview was to gain the opinions, perspectives, and personal experiences of each separate family.

The interview schedule was piloted with one family of an autistic child other than those recruited for the study prior to beginning the subject interviews. Comments and reactions of the pilot family were incorporated into the final interview schedule.

The list of topics outlined in the interview schedule served as a reminder of themes to cover and probe for. The information elicited in the interviews formed the material to be analyzed.

Limitations of this Study

Despite the fact that autism has been specified as a recognizable disorder since the early 1940's the syndrome's parameters, definition, and diagnostic criteria continue to be topics of controversy. The apparent discrepancies in past and current literature result in confusion of information and require caution regarding the development of conclusions. While there is some specific literature concerning the impact of the autistic child on the family system, much of the research refers to handicapped or retarded children in general, requiring an assumption of similarity in issues.

Caution must be taken in generalizing findings from this study to all families with autistic children. This sample was unique in that it was obtained on a voluntary basis from members of the Autism Society Manitoba, a population who has already publicly acknowledged the presence of the autistic child in their family. Membership in the Society implies that these families have specific experiences and characteristics different from parents who have not utilized a support and education group. The sample is even more specific in that it includes only two parent families with at least one child other than the autistic child. As well the parents interviewed were all well educated middle to high income families.

In addition, self-report data is subject to error as reality may be distorted, memory may be vague, and omissions or embellishments may occur in effort to please or impress the interviewer.

The cross-sectional research design used in this study has certain disadvantages when compared to longitudinal studies. A major concern in any cross-sectional study is choosing a sample which truly represents all relevant subgroups in the population. As well, studying these families at only one particular point in time does not give us a sense of how the impact of the autistic child varies through the lifespan of the family. Finally, though reference will be made to etiological and family systems research, this is not to imply that this study reflects an exhaustive review of these issues.

Chapter 5

Results

Group Characteristics

The subjects of this study consisted of four two-parent families, all married for the first time. All four fathers were employed full time at middle to high income "white collar jobs". In the first family the father was a 43 year old university trained environmental consultant and the mother was a 40 year old nurse who was not employed outside the home. There were four children in this family; a boy aged 11½ years, another boy aged seven years, a girl aged three years and a seven month old baby boy. The three year old daughter was the autistic child.

In the second family the father was a 40 year old university trained product manager and the mother was a 32 year old high school graduate who did some volunteer work. There were two children in this family; a boy aged nine and a second boy, the autistic child, aged seven years.

In the third family the father was a 49 year old university graduate employed as a social worker and the mother was a 30 year old grade ten graduate who worked part time in a florist shop. There were five daughters in this family aged 19, 16, 14, 12 and 10 years. There were two autistic children in this family but to fit the criteria for the study information was collected only regarding the youngest disabled child (age 10 years).

In the fourth family the father was a 33 year old Community College graduate working as a bank manager. The mother was a 35 year old grade 12 graduate who worked part time outside the home. There were three boys in this family aged 14, 12 and 8 years; the eight year old was the autistic child.

The Autistic Child

Parents were asked to give their perceptions as to the autistic child's degree of disability on a three point scale of mild, moderate or severe. The degrees referred to the amount of input required from the caregiver plus the extent to which the disability interfered with the autistic child's daily living. That is mild degree of disability required minimal time and energy on the part of the caregiver and only slightly interfered with the child's life while severe degree of disability required maximum time and energy from the caregivers and severely hampered the autistic child's daily living.

Parents noted the child's degree of disability in five areas: verbal communication, nonverbal communication, social interaction, repertoire of interests, and intellectual ability. The results of the ratings are presented in Table 1.

With the exception of rating their autistic child's intellectual status there was a high degree of agreement between parents estimating their autistic child's level of disability. All eight parents rated their child as severely disabled in the area of communication skills ranging from no speech at all to being able to say a few words. The degree of disability of nonverbal communication skills, social interaction skills, and repertoire of interests ranged from severe to mild.

A marked difference in the responses regarding the autistic child's intellectual ability was apparent

Table 1:

Characteristics of the Autistic Child

	Degree of Disability				
N	Verbal Communication	Nonverbal Communication	Social Interaction	Repertoire of Interests	Intellectual Ability
Mother (A)	severe	moderate	severe	moderate	none
Father (A_1)	severe	severe	moderate	severe	unknown
Mother (B)	severe	moderate	moderate	moderate	moderate
Father (B_1)	severe	moderate	moderate	moderate	none
Mother (C)	severe	moderate	severe	severe	severe
Father (C_1)	severe	moderate	severe	severe	mild
Mother (D)	severe	mild	mild	mild	unknown
Father (D_1)	severe	mild	severe	mild	unknown

across all four families. All eight parents found it difficult to accurately rate their child's intellectual status and there was more variation between the couple's responses. That is, there was consensus between the couples four out of four times rating verbal communication, three out of four times rating nonverbal communication and repertoire of interests, two out of four times rating social interaction skills but only once out of four times in rating intellectual ability. Parents found it difficult to comment on their child's intellectual ability mainly due to the degree of the autistic child's inability to communicate verbally. There was also a hesitancy on parents' parts to "label" their child as intellectually inferior.

Family Integration

The responses regarding the effect of the autistic child on family integration were collapsed into three main areas; family dynamics, family support and the marital relationships. The responses to the questions regarding family integration are presented in Table 2.

Content analysis of the family integration questions revealed several themes. All of the parents indicated personal frustration and exhaustion as well

Table 2:

<u>Impact of the Presence of the Autistic Child on Family Integration</u>

Does the presence of the autistic child effect?

Category	Mother		Father	
	Yes	No	Yes	No
Family dynamics				
Family interaction	3	1	3	1
Communication	4	0	3	1
Decision making	4	0	4	0
Attention to others	3	1	4	0
Family time together	3	1	3	1
Future plans	4	0	4	0
Family support				
Cooperation	3	1	3	1
Emotional support	4	0	4	0
Amount of tension	4	0	4	0
Family closeness	4	0	4	0
Marital relationship				
Responsibility	4	0	4	0
Spousal responsibility	4	0	4	0
Marital bond	4	0	4	0
Time with spouse	3	1	3	1
Attention from spouse	4	0	3	1
Opportunity for private time	2	2	3	1
Spouse's opportunity for private time	2	2	4	0

as an increase in the stress level for the whole family. They also expressed concern about the amount of time and attention required by the autistic child resulting in a decrease in responding to the other children's needs. One father, commenting about his autistic daughter, put it this way:

> She has changed the equation for everybody...from my baby to my eldest child, to my wife and myself ...to the way we interact with each other and our other kids. Her needs are more evident - they're not necessarily greater, but they're more evident and so they get addressed first.

The parents described living in a constant state of vigilance and tension. One mother put it this way:

> You start to realize there's a lot of underlying anger going on all the time. I've noticed that my other kids have gotten really scrappy this year and I don't think it's just sibling rivalry. Lots of background anger...and grieving too!

Two mothers felt their communication patterns had become more abrupt and negative, while the two other mothers experienced closer and more open communication with their nondisabled children and felt that new channels of communication had been opened up.

All the parents agreed that the presence of the autistic child effected the family decision making process. The areas most influenced were family recreation, outings or vacations and housing options. One mother said:

> There are a lot of things we can't really do anymore. We can't go for a bike ride together or if you want to go to a restaurant you better go somewhere you know you can get in and out of real quick!

Three mothers and three fathers within the same family believed that they had less time together as a family unit because of the time and attention required by the autistic child. They commented on a decrease in the variety of activities they could do as a family as well as diminished pleasure in the activities. One mother and one father from different families felt a sense of isolation and one mother missed the ability to be spontaneous. One mother put it this way:

> It's an awful lot of extra work with an autistic child. Everything has to be planned out - you lose a lot of the spontaneity. You can't just decide to do something - you always have to prepare the child. Be prepared - ever alert! That's not exactly relaxing!

All the parents believed that the presence of the autistic child affected the ability of the family to plan for the future. One father commented:

> It's hard to plan because you're faced with a major unknown. What are his developmental handicaps going to be - his shortcomings? Is he going to be in the family home until he's thirty? Is he going to be able to drive a car or get a job? There are some major things like that we just don't have any answers to.

Another father was gravely worried about his son's future to the point where the couple chose not to think about it at all:

> It's just too scary to even think about what lies ahead of us.

Comments from one of the mothers described the difficulties around future planning:

> It changes how you look at the future because there is nothing really predictable about her future at all. Things we thought we might have chosen, lifestyle, living in the country, we might not now. Immediate future plans are different too because we always have to plan around considering how Z will manage or not manage or whatever.

In terms of the questions related to family dynamics there was consensus between all four families regarding the impact of the autistic child on decision making and future planning but no consensus in the other areas (communication, attention to others, family time together and family interaction). Mothers and fathers within the same family disagreed as to the effect on communication and attention to others but agreed on the impact on family interaction, decision making, family time together, and future planning.

The ability of the family to provide support for nuclear family members was also affected by the presence of the autistic child. One father and two mothers felt that family co-operation was enhanced and the degree of patience increased because of the autistic child. One mother described the following scenario:

> I just think everybody co-operates more with each other. When he has his spells and sits beside you and starts grabbing at you the kids will say "Okay, Mum I'll sit with him for a while"...everybody tries to settle him down; they all pitch in for different things.

Two mothers and two fathers felt that the presence of the autistic child had a more disruptive effect, again based on the need to focus the majority of family energy, time, and attention on the disabled child.

All eight parents agreed that the presence of the autistic child affected the family's ability to provide emotional support for each other and their children but there was variation as to the direction of the effect. One mother described her situation this way:

> I know I needed a lot of emotional support when Z was young and I never felt I got it. Just needing it was a black mark against me because you're not supposed to need it. I really needed a lot of support and not only couldn't ask for it, I wasn't even allowed to need it.

A father from another family commented this way:

> We've learned that we need lots of emotional support. We used to go along living as a family in the same house without realizing that other people in this family need caring for. Z has given us the ability to love unconditionally... she's brought a lot of richness into our lives. I think we're more patient in general because we've slowed down for Z and for other people now too.

One mother believed that the other children fought with each other more while two parents felt their family was more sensitive to each other's needs because of the presence of the autistic child. Three fathers indicated an increased stress level for the whole family with one father remarking on a strain on the marital bond.

All the parents agreed that the presence of the autistic child effected the amount of tension on the family. The responses covered a variety of issues including disruption of daily routines, feelings of anger, fatigue and worry, the need for constant vigilance, the stress of dealing with support agencies and the chronicity of the child's disability. One father put it this way:

> You're always concerned that you haven't done enough and that you're not going to do enough and of course the scary part is that if you don't do enough he'll end up being institutionalized or end up living a very mediocre life.

A mother from another family describes this scene:

> It's horrible to have someone screaming and not being able to do anything about it. It's horrible to have somebody grab your hair or punch your face or bite you every time you do something for them. It's horrible that at the end of every meal she's food from top to bottom, day after day, month after month. You know that this is going to go on - that it might never be over.

All of the eight parents agreed that the presence of the autistic child had an effect on how close family members felt to each other but again there was a variation in the direction of the effect. Three parents felt the presence of the autistic child had a mixed effect on family closeness, two parents felt more distanced and three parents felt a sense of the family unit as a team pulling closer together.

One father summed up the effect this way:

> It cuts both ways. On the one hand we're sort of "Z's team"; but on the other hand because of the stresses that are permanent we don't always relate to each other as we would like to.

In terms of the questions related to family supports there was consensus between all four families regarding the impact of the autistic child on emotional support, amount of tension, and family closeness but no consensus in the area of cooperation. Mothers and fathers within the same family agreed in all four areas of family support i.e. cooperation, emotional support, amount of tension, and family closeness.

The majority of parents believed the presence of the autistic child had in some way influenced the marital relationship. All the parents indicated that both partners had increased responsibilities related to having a disabled family member. Three mothers felt overburdened by their role as primary child caregiver while three fathers felt pressured to provide financial support for an essentially one income family as well as share in child care and home management. Mothers in particular commented on the need to forgo personal career goals while both parents felt the pressure to advocate and systems manage for their disabled child's needs. The complexity of the impact on the marital bond is exemplified by these comments from a father:

> We've got a solid foundation, but you still have to do maintenance to keep anything together and we don't do the maintenance we should. We're concerned that our relationship may be precarious without even realizing because we're not doing the things that people who are in love, who are married, do.

A father from another family said:

> It sometimes brings us closer together. We have to deal with these things together and we go through things together and hopefully end up stronger because of it. There's both sides to it.

Perceived attention and support from their partner as well as time with their spouse was affected by the presence of the autistic child. As well, opportunities for private time for themselves and their spouses was impacted upon. Two mothers and three fathers felt they had less opportunity to pursue hobbies and outside interests. Two mothers and all four fathers indicated their partner had less time and energy to pursue personal goals and interests. This father's comments eloquently describe the impact on his family:

> You start to think of the compromises you live with on a daily basis - that aren't temporary - that are a part of our family's way of life. What are the costs that aren't apparent today? I know they're there. Although we try to give our kids and ourselves as much love as possible, there are scars. Right now we are just surviving.

Questions regarding the impact of the presence of the autistic child on the marital relationship achieved a varying degree of agreement. There was consensus among the families in terms of the effect on their own spousal responsibility and the marital bond but no agreement in the areas of time and attention for themselves or their spouses. Mothers and fathers within the same family agreed on the impact on their own responsibility, spousal responsibility, the marital bond and time with their spouse. There was no consensus within families on the topics of attention from spouse, opportunity for private time and spouse's opportunity for private time.

The Sibling Subsystem

Parents were asked to give their perception of the effect of the autistic child on the other children in the family. Responses to these questions fell into three categories: emotional effect, social relationships and perceived benefits. Data on the sibling subsystem are presented in Table 3.

Three mothers and three fathers within the same family believed their other children had been affected emotionally because of the presence of their autistic sibling. These parents felt that the other children felt neglected, were sometimes embarrassed by their autistic sibling's behaviour and had concerns about their future in connection with the disabled child. One mother reported this conversation:

> X is worried about the future...what will happen to Z? Will I have to take care of her when you're not able to? Will she have to live with me? What happens to people like her?

Parents believed their other children's friendships and social opportunities were effected. Three of the mothers felt their other children avoided having friends over due to the disruptive nature of the

Table 3:

Impact of the Presence of the Autistic Child on the Sibling Subsystem

Are the other children in the family effected by the presence of the autistic child?

Category	Mother		Father	
	Yes	No	Yes	No
Emotional effect				
Embarrassment	3	1	3	1
Feeling neglected	3	1	3	1
Worrying about future	3	1	1	3
Social relationships				
Social opportunities	3	1	2	2
Friendships	3	1	1	3
Family roles	4	0	4	0
Responsibilities	3	1	4	0
Benefits	2	2	4	0

autistic child's behaviour. A mother said this about her 11½ year old son and his autistic sister:

> He's worried that people will make fun of her. If we go somewhere he's worried that she'll act up and that everybody will look at us. He doesn't want to go somewhere if Z's coming along.

One father mourned the fact that his abled son was missing the opportunity to have a "brother relationship" with his autistic sibling. Two mothers commented on an increased demonstration of compassionate and empathic behaviour by their abled children.

All of the parents agreed that their other children's roles in the family were effected by the presence of the autistic child. Three mothers and one father felt that their other children were more independent and mature and were expected to put their own needs aside. Two mothers and one father indicated that their abled children assumed a heightened protective caregiver stance with their autistic sibling.

Four fathers and two mothers felt that their other children had benefited from the experience of a disabled sibling. Sensitivity to others and increased tolerance were mentioned by two fathers and one mother. Other benefits are demonstrated by the following comments:

> Father # four:
> I think they respect other people more. They respect others and are much more compassionate.

> Father # two:
> He's learning early in life to empathize with people and sympathize too.

> Mother # four:
> They accept other kids. They're more understanding. They have more patience. I think there's been more positive things than negative.

> Mother # one:
> They're more independent and capable in some areas at an earlier age. They are more patient with me and not as demanding of my time. They are both more organized.

> Mother # two:
> He's able to be sensitive and nurturing to other people. He's much more appreciative of us as parents. I think it makes him a more loving person.

> Father # one:
> I think that Z's presence in our lives has given them a greater sensitivity to other people, to others' kids, to all groups. They understand that all people aren't the same...tolerance and understanding is so much a part of their life here.

There was no consensus among the families in terms of the emotional effect on the sibling subsystem or perceived benefits for the siblings as a result of the presence of the autistic child. In regards to social relationships families agreed on the impact of the autistic child on roles but disagreed on the other effects (social opportunities, friendships, and responsibilities). Mothers and fathers within the same families agreed that other children in the family felt embarrassed and neglected but disagreed on the siblings' worries about the future. There was consensus within families regarding family roles but lack of agreement regarding the other effects (social opportunities, friendships, responsibilities, and perceived benefits).

The Extended Family

Parents were asked to respond to questions regarding the impact of the autistic child on relatives outside the nuclear family unit. Two major themes were identified; emotional support and social relationships. Responses to these questions are presented in Table 4.

Three fathers indicated an absence of support and understanding from extended family members while the

Table 4:

Impact of the Presence of the Autistic Child on Extended Family

How does the presence of the autistic child effect relationships with extended family members?

Category	Mother		Father	
	Yes	No	Yes	No
Emotional support				
Relatives demonstrate understanding	2	2	1	3
Relatives offer help	1	3	1	3
Relatives listen to concerns	2	2	1	3
Relatives appreciate caregivers	3	1	1	3
Social relationships				
Roles changed	1	3	3	1
Family closer together	1	3	1	3
Family farther apart	3	1	3	1

responses from mothers demonstrated more variation. Comments from the parents exemplify the variety of responses:

Mother # one:

> All our family members say, "It must be really hard for you." But the only person that actually <u>does</u> anything about it is my mother-in-law. She actually takes action. She comes and helps - she'll come over and give of her time; she'll come and clean my house for me if she comes and sees it needs it.

Mother # three:

> I have a grandmother who is just totally embarrassed by the whole situation. She's just kind of dropped us out of her life completely.

Mother # four:

> In the last year they've been starting to slowly come around. We've had talks about it and they say "Oh, I'm so sorry. I never realized before how hard it must have been at the start and I wish we would have helped you more."

Father # three:

> They never talk about it. No one talks about it.

Father # four:

> My mother really still doesn't seem to appreciate it or understand, although she's better than she used to be. She still doesn't seem to want to get involved.

Mother # two:

> My family has always been supportive and encouraging.

There was no consensus between families in response to the questions regarding the impact of the autistic child on perceived emotional support from extended family. Mothers and fathers within the same family agreed on the impact of the presence of the autistic child regarding relatives offering help but disagreed on the other effects on emotional support (demonstrate understanding, listen to concerns and appreciate caregivers).

Some of the parents offered explanations as to their extended family reactions. One father explained that his decreasing ability to be spontaneous in attending family gatherings had moved his nuclear unit out of the extended family circle.

One mother speculated in the following way:

> They don't want to talk about it. I don't know if it's just too painful, or if it's just a drag - they want to have a good time - or they're just not interested.

Three of the fathers and one of the mothers believed that family members' roles had been affected by the presence of the autistic child. These changes included an enhancement of the grandparent role, an influence on a relative's career choice and, in one instance, a diminished relationship with extended family members. One father put it this way:

> One side pulled away and the other side is just not here. I feel very isolated...like a family in a fortress.

The response to the question regarding extended family closeness or distance elicited a variety of responses. One of the mothers and one of the fathers from different families believed that family members had drawn closer together. Three mothers and three fathers believed extended family members were more distant as a result of the presence of the autistic child.

Social Supports

The responses to questions regarding utilization of social supports beyond the nuclear and extended family were collapsed into three categories: formal social supports (both present and future), informal social supports (such as friends and neighbours), and personal supports. The responses to these questions are reflected in Table 5.

Table 5:

<u>Use of Social Supports</u>

Are supports adequate?

Category	Mother		Father	
	Yes	No	Yes	No
Formal supports				
School programs	3	1	2	2
Respite care	1	3	2	2
Child care	2	2	1	3
Recreation/sport	1	3	1	3
Post schooling	0	4	0	4
Independent living	0	4	0	4
Informal supports				
Friends/neighbours	1	3	2	2
Community	2	2	2	2
Personal supports				
Emotional support	1	3	3	1
Easy to ask for help	0	4	1	3
Family sees self as different	4	0	4	0

Within the formal support system school programs and child care services were seen as fairly adequate. Respite care and recreation/sport services were rarely seen as adequate. None of the parents believed that post schooling resources and independent living opportunities would be adequate when their autistic child would reach the stage of life to require these supports. One of the father's comments best summarizes the parents' concerns:

> Our society isn't geared to provide adequate services because we just don't have the values to do that. We don't see these children as being special and human like we are. We see them as THEY, as disadvantaged people.
> Adult autistic people face inadequate services - they face kind of an oblivion of being ignored and disregarded. There's no job skill programs to develop work skills. There's very few homes who will be able to deal with Z's behaviour problems.
> The scariest part is the future. What sort of behaviour problems may yet surface. It's easy to handle him now because he's just a little kid, but when he gets to be six feet tall and weighs two hundred pounds, if he has any sort of violent behaviour, who is going to want to look after him?

The informal support systems (neighbours and friends) were generally viewed in neutral terms. One mother felt that some old friends had backed off. The majority of the families tended to "keep to themselves" so that neighbours and friends did not play a large role in their lives at this point. Reasons given for this included lack of time and energy, concern regarding neighbours' reactions and parents not wanting to "impose" their autistic child on others.

Personal support systems were given directly opposite ratings by the parents. One of the mothers and three of the fathers believed their personal supports were adequate while three of the mothers and one of the fathers believed the opposite. All of the parents saw their family as different from other families due to the presence of the autistic child and only one of the fathers felt it was easy to ask for help. These comments are examples of some of the responses:

> Father # two:
>
> It's difficult to ask for help. People really don't know how to attend to his needs, without having spent a great deal of time around him. So it's hard to ask people to do something because you know it's going to be difficult for them...it feels like an imposition.

Father # one:

> There's not a whole lot of personal support. I say my prayers.

Father # one:

> The Autism Society is a great support because you can get together with people who actually understand what has happened and what you're going through.

Mother # one:

> I think it's not hard to ask for help, I think the hard part is finding out who to ask.

Mother # four:

> We are different...a disabled child means a disabled family.

Mother # two:

> It's very difficult to ask for help because we always have the feeling that we're asking for too much. We should be able to do this on our own and we'd like to be able to. If you have to keep asking for help your sense of accomplishment is always being eroded.

There was consensus between families regarding the lack of post schooling and independent living resources as well as these families seeing themselves as different from other families. There was no agreement between families regarding the remaining formal supports (school programs, respite care, child care and recreation), no agreement regarding informal supports and no agreement regarding personal emotional support and comfort with asking for help.

Within the families mothers and fathers reached consensus regarding recreation supports, post schooling and independent living resources, community support and seeing their families as different but disagreed on all the other parameters of social supports.

In the final part of the interview parents were asked to give their opinion regarding which aspects of family life were most negatively and positively effected by the presence of the autistic child and to share any further information they considered important. The negative aspect commented on most often was related to family recreation. Four mothers and three fathers ranked this item first. Disruptions in the daily life of family routine were mentioned by three mothers and three fathers. One father rated financial concerns as a primary negative aspect and one other mother felt forgoing her career had been the most difficult element. Other negative aspects included feeling constantly tired or worn out, the aggressive behaviour of the autistic child and feeling unaccepted by the school system. One mother put it this way:

> Her presence is always a factor. That can be a plus, but it gets tiring sometimes. Always having to consider Z - or deal with Z - nothing's smooth. It's always... first we have to deal with Z, then we'll do whatever it is we're doing. It gets tiring.

Responses to the question regarding the most positive aspects of family life were concentrated in three general areas: enhanced nuclear family closeness, increased tolerance for others and appreciation for the simpler pleasures of life. Some of the comments were:

Father # three:

> We have an increased awareness of people as just humans no matter what shape or form they come in.

Mother # two:

> ...that it's okay to be different - actually that it's nice to be different. Our differences should be celebrated.

Father # three:

> Having Z reminds us about what it means to give and what it is to receive. It teaches the other kids responsibility and self-reliance. I think I feel a lot better and more confident about myself.

Mother # three:

> I don't think you take things for granted. Any little thing that's positive brings you great joy.

Father # two:

> The relationship within the family can be very close and positive. It allows you to...as an individual and a family to experience life more, to be more appreciative of every day as it is.

Mother # one:

> You slow your lifestyle down to accommodate the demands your autistic child is placing on your family. By doing so, you're able to see things happening in your relationships and you're able to understand them more clearly and pay more attention to them.

Father # two:

> We're just happy to be all together still and enjoying whatever day we're presently having.

Mother # four:

> He's allowed me to appreciate people more for who they are and what they are.

Father # one:

> We are all thankful for Z...for what she brings into our lives. She demands that we accept her the way she is. She gives us an opportunity to have unconditional love and I think that's a real gift.

Finally parents' responses to the information they considered important for other families was analyzed. Their opinions were varied and included some of the following:

Mother # one:

> I think people need to know it's not realistic to think you can do it by yourself. You need a lot of support and encouragement; you need respect - you need people that can listen so you can tell your story.

Father # two:

> Find some time for yourself because if you don't feel good about yourself you won't be able to deal with the problems that your wife or your child or your other kids are having.

Mother # two:

> Life is going to be a lot harder for you than it is for other people - it's very tough and you deserve a medal for surviving day to day.

Father # three:

> Parents need to have confidence in themselves that they will know what's best for their child and that they should seek out people who value their child. Their child's value is foremost...people that give them strength and confidence are people they need to work with.

Mother # four:

> Your child is not broken, your child is good the way s(he) is.

Mother # three:

> Aim for true acceptance and maintain your hope.

The finding that dominates the data is that the presence of the autistic child significantly effected the family system. There were 17 questions regarding the impact on family integration. As each question was asked eight times (once to each parent) there were a total of 136 possible yes or no responses. Mothers responded "yes" 59 times to these questions (86% of the time) and fathers responded "yes" 61 times (89% of the time) for a total of 120 "yes" responses (88% of the time).

The section on the impact of the autistic child on the sibling subsystem was made up of eight questions for a possible 64 yes or no responses. Mothers responded "yes" 24 times (75% of the time) and fathers responded "yes" 22 times (68% of the time) for a total of 46 "yes" responses (71% of the time).

There were seven questions regarding the impact on extended family for a possible 56 yes or no responses. Mothers responded "yes" 11 times (39% of the time) and fathers responded "yes" 10 times (35% of the time) for a total of 21 "yes" responses (37% of the time).

In the section on the use of social supports there were 11 questions for a possible 88 yes or no responses. Mothers responded yes to the adequacy of social supports 15 times (34% of the time) and fathers responded "yes" 18 times (40% of the time) for a total of 33 "yes" responses (37% of the time).

Chapter 6

Discussion

Based on the percentages of "yes" responses the results from this study indicate that the presence of an autistic child has a major impact on family integration and the sibling subsystem and a moderate effect on the extended family. Parents in this study also clearly indicated their concerns regarding the lack of formal external involvement in easing the demands created by the disabled child.

The results also point to the sense of isolation and the solitary struggle expressed by the parents in this study. The extent of the effect of the autistic child on family integration and the sibling subsystem coupled with diminished support from extended family and outside sources creates a dynamic in which the nuclear family becomes similar to a "walled fortress". It must be left to other researchers to discover the genesis of this dynamic. Does the nuclear family isolate itself as protection from misunderstanding and stigma or are the "walls of the fortress" created by external elements?

Family Integration

Consensus among the families in this study regarding the impact on family dynamics and emotional support are consistent with previous findings of negative effects such as increased stress and tension, decreased pleasurable time together, and influences on family future plans and decision making (DeMyer & Goldberg, 1983; Palfrey et al., 1989; DeMyer, 1979).

Not all of the families agreed however as to the negative impact of the presence of the autistic child. No consensus between families was reached in the areas of family interaction, communication, attention to others, family time together, and family cooperation.

There are several possible explanations for the variation between families. First, parents in this study were at different stages in the family life cycle. One family had two young boys aged nine and seven years, one family had a 7 month old baby born after the autistic child and the other two families were facing the demands of coping with the autistic child's adolescent siblings. It is therefore possible that the ages of the siblings, including the autistic child, had an effect on the parents' perception of family dynamics.

Secondly, the families in this study bring with them to each new situation the unique resources and needs of individual members, their developed history of problem solving strategies and ways of relating, as well as their connections to the extended family and their community (Harris, 1988). While the families in this study shared some aspects (age range of the parents, first time marriage, educational level, income range) they differ as do other families in their adaptability and capacity for flexible problem solving.

Finally, the parents may have been at different stages in the grieving process. As discussed earlier the emotional adjustment of parents of an autistic child has often been compared to the process of mourning the loss of the perfect child of their dreams (Sloman & Konstantareas, 1990).

The findings of this study regarding the effect of the autistic child on the marital bond are consistent with other studies which reported an increased strain on this relationship (DeMyer, 1979; DeMyer & Goldberg, 1983; Fisman & Wolff, 1991). Parents in this study reported keenly feeling their increased responsibilities: mothers felt overburdened and mourned their missed career opportunities while fathers worried about providing financially for their family. It is important to note, however, that these parents also pointed out the positive effect of the autistic child in fostering a stronger relationship and in some circumstances strengthening the marital bond. This effect has also been commented on by other researchers (Morgan, 1988; DeMyer, 1979; Koegel, Schreubman, O'Neill & Burke, 1993).

Parents in this study gave some hints as to the source of lack of consensus among families regarding the impact of the presence of the autistic child on spousal attention, time together, and opportunity for time alone. Two couples stressed the importance of scheduling time out both together and alone, one other couple commented on the importance of articulating emotional support needs and a fourth couple saw trying not to think too far ahead as a positive coping strategy. It is possible that these approaches have a mediating effect on the strain the presence of the autistic child brings to the marital bond.

The percentage of times (88%) that parents in this study responded "yes" to questions regarding the impact of the autistic child on family integration indicates that the negative effects of a severely handicapped child have not been overstated. Previous reports (Barsch, 1982; Jacobson & Humphrey, 1979; Gath, 1977; Farber, 1976) lead us to believe that the negative impact of the handicapped child upon the family has been overestimated, that positive aspects have been ignored and that families more often draw closer together as a result of the event. Parents in this study openly described the degree of both negative and positive effects on the family. Although the sample is small three of the four couples believed that their relationships with extended family had grown farther apart due to the presence of the autistic child.

The Sibling Subsystem

The reports from parents in this study support the diverse results found by other researchers who pointed out that a disabled child in the family may have differential outcomes: little effect, negative impact or positive outcome on subsequent sibling adjustment or coping (Seligman & Darling, 1989).

The negative impact on the sibling subsystem including feelings of being neglected and embarrassment due to the autistic child's behaviour and the siblings' concerns about their own future have been reported in other studies (DeMyer, 1979; Seligman & Darling, 1989) as well as in the present study. Parents in the present study also described missed social opportunities and sibling role changes which have been recorded by other researchers (McHale, Simeonsson, & Sloan, 1984; Farber, 1960; Seligman & Darling, 1989).

The positive effects on siblings reported by parents in this study gives further support to previous research (McHale et al., 1986). While there was not consensus between all families two mothers and four fathers in the present study clearly believed their other children had benefited in terms of altruistic values such as compassion, empathy, and tolerance.

There are several possible explanations for the difference between the families' perception of the impact of the autistic child on the sibling subsystem. Siblings in this study were at different stages in their personal development and may have worked through various stages of adjustment and coping. For example, the teenage children in this study may be spending more time outside the nuclear family unit and therefore may be less affected by day to day home life. The father of one of the siblings said that his nine year old boy keenly felt his missed "brother relationship" with his younger sibling. The pre-adolescents are worrying about their future in relation to their autistic sibling while for a seven year old it may be harder to cope with all the attention going to his younger autistic sister. It is also possible that the parents are so absorbed in meeting the needs of the autistic child that the other children's problems or issues may get overlooked.

Another mediating factor may be that these parents are all to some extent gaining support from membership in the Autism Society, a self-help group. Support sources available to the parents have been shown to effect the impact of the autistic child on his/her siblings (Bristol & Wiegerink, 1979). It would be of interest for other researchers to compare the parents in this study with families who are not members of a support group.

Finally, the value system of the parents in this study may effect their view of the disabled child's impact. Throughout the interviews it was apparent that the parents highly valued ideals such as co-operation, self-reliance, and tolerance of others. A worthwhile project to be pursued by other researchers would be to interview the siblings discussed in this study to obtain their points of view in comparison or contrast to their parents. Other researchers such as Wallinga et al (1989) found that parents thought their healthy children were coping considerably better than the children thought they were.

The Extended Family

The parents' comments regarding the impact of the autistic child on the extended family demonstrated the sense of isolation and loneliness often experienced by families of disabled children. While parents in this study did not feel criticized or overtly express being stigmatized there was a clear sense of absence of support from relatives.

Feeling isolated from family and friends is an experience shared by many parents of handicapped children. The attention and demands of the autistic child leave little time and energy left over to maintain relationships outside the nuclear family. As well withdrawal from their circle of family and friends may be a protective reaction. Rather than face the possibility of embarrassment or rejection the nuclear family may avoid social occasions. Staying "within the fortress" protects the disabled child from stigmatization, the parents from criticism and lack of understanding and the extended family from feeling uncomfortable around the disabled child. This "circling the wagons" approach may strengthen the nuclear family bond while at the same time it serves to cut off the family unit from a potential source of support and assistance.

While it is important to maintain cohesion within the nuclear units families of autistic children must be encouraged and supported in "coming out of the fortress". Public education and awareness as to the day to day struggles of these families must be enhanced. Lack of understanding and support from extended family members could be modified through attendance at Support Group events with the nuclear family. Sibling support and education groups could be helpful and the formal support systems' educators and other professionals must pay attention to what these families are saying.

Social Supports

The mediating effect of social support as a variable in family's ability to cope with an autistic child has been reported in other studies (Bristol & Schopler, 1984; Bristol & Schopler, 1983; Bristol & Wiegerink, 1979). While there was no attempt in this study to assess parents' ability to cope, the availability of supports external to the family network helps complete the overview of the impact of the autistic child. The parents in this study clearly indicated a concern in terms of fears for the future well being of their disabled child. While school programs, respite, and child care services are available, a great deal of parents' time and energy is spent accessing and managing the various systems required to support their child. Life decisions are often complicated by the presence of the autistic child. Families considering a move to a new area must have reassurances that appropriate services are available. In many matters involving major decision making, parents struggle with priorities and loyalties more often than families with nondisabled children.

Awareness of the lack of future services for their autistic child also impacts on these families. Some parents in this study are already organizing and planning how best to advocate for independent living and post-schooling resources. Other parents, finding the future too frightening to even contemplate, try not to think too far ahead but try to take each day as it comes. As organizations seem to offer fewer services there is less social sharing of the burden of parenthood of the autistic child which further impacts on the strain on the family of the disabled person.

There are many opportunities for intervention and change which could mediate the stresses reported by the families in this study.

Beginning from the outer ring of external support, services that will give the family relief from physical and time demands are needed, services such as day care, babysitting, homemaker services and self-care training.

Families need easy access to a variety of resources such as early intervention specialists, parent training programs, respite care, family support groups, and advocates. They also need professionals who will both introduce parents to services and provide follow-along support.

While communities and neighbours may bond together to help during crisis periods they are frequently insensitive to the ongoing need for regular support to help with more mundane tasks such as shopping, walking the dog or cleaning the house. Neighbours and friends can often provide this ordinary help; getting a few moments of good supportive listening and conversation may lend the confidence to carry on.

A major resource for material aid, physical assistance, and respite care exists within the extended family system. Parents of autistic children could benefit by mobilizing and using family members as a source of support and may need help improving the connection with extended families. If the extended family is unavailable or unwilling to provide assistance "foster" extended families may be developed through strengthening of informal friendship networks.

General Conclusions

There is a growing awareness of the problems of the family of an autistic child and the stress produced in the family by such a child. These families face real day-to-day problems not experienced in "normal" families, such as care of the child, time and physical demands, monetary cost, social isolation and pressures. The parents in this study indicated that the most negative aspects of family life involved the total inability to have an undisrupted daily routine and the inability to engage in social activities. This sense of isolation and the loss of normal family activities was viewed by these parents as one of the major problems. The absence of support from extended family and formal services further contributes to the situation of the nuclear unit dealing with the chronicity of the child's disability with only their own already strained internal resources.

Attention must also be paid however to the positive effects noted by the parents in this study. Reports of enhanced nuclear family relationships and increased tolerance and empathy for others are consistent throughout the interviews. There exists a special strength and resilience in these families, the origins of which require further study. For some of these families coming to grips with the demands and pressures of raising an autistic child results in adjustments that may lead to personal growth and increased awareness of themselves.

Of prime importance is the advice these parents offered to other families of autistic children. The need to continue to advocate for earlier diagnosis and adequate support services was a theme as well as the need for further research into the causes of autism. Parents also encouraged other families to look after themselves, to take time out to renew and refresh their own selves. Of key importance was believing that they themselves know their child the best and to be firm in this belief particularly when dealing with service agencies. One father's comments sum up the important factors:

> You have to trust yourself - your opinions and thoughts. And you have to have faith that things will get better, because they do. Amazingly enough they do. The child grows up just like any other child and becomes a lot less demanding, a little more independent, a little more functional. You have to keep on hoping!

Using the Systems Model

The concepts inherent to family systems theory were useful in developing the framework for the data collection process. Using questions based on systems theory enriched the type of information obtained and appeared to encourage openness and spontaneity on the part of the subjects. The general concepts thus served as a useful guide in keeping the interview process focused and on track.

Some useful data directly related to systems theory concepts was also obtained. Several of the questions asked about the family's boundaries as it interfaces with the suprasystems (extended family networks) and interacts within its own subsystems (e.g., sibling, marital). For example parents were asked a series of questions about interaction with extended family members, the effect of the autistic child on the marital relationship and how the other siblings were effected by the presence of the autistic child in an attempt to explore the permeability or rigidity of the family boundaries. Responses to these questions indicated that families in this study had fairly rigid boundaries between the nuclear and extended family while boundaries within the parental subsystem were more open.

By applying the concepts of systems theory it was possible to ascertain one of the key findings of this study regarding social isolation and loneliness. The majority of the families appeared to have developed a closed almost fortress-like system within which the intimate nuclear unit struggled to adapt to living with a disabled child. Even within the nuclear family the parental/autistic child system was somewhat closed to the sibling subsystem.

This type of information can be useful in suggesting enhanced coping strategies. For example, one of the recommended sources of support for parents of autistic children is to seek out closer ties with extended family members.

Many of the questions elicited responses about family rules; who is responsible for caretaking, how are decisions made in the family, how are the sibling roles influenced, what are the rules about asking for help. In the families in this study the rules were fairly clear and well defined. Parents saw themselves as being responsible for caretaking tasks around the autistic child and did not for the most part expect nondisabled siblings to take on extended caregiver roles.

A unique rule around decision making in these families was the degree to which choices affecting the entire family revolved mainly around the needs of the autistic child. Rules about asking for outside help were also clear. Families in this study generally found it difficult to ask for outside help and felt somehow that they "should" be able to manage to provide all the emotional and physical care on their own. Throughout the interviews the parents described strong rules, both spoken and unspoken, regarding communication patterns; who speaks to whom, what issues are talked about, which topics are off limit for discussion.

This study clearly demonstrates a core principle of the systems orientation, that is that any system functions as an organized whole, and its components are necessarily interdependent (Minuchin, 1985). Any change in any part of the family system is expected to have an effect across the entire system, and to demand adaptational strategies to bring about a new state of equilibrium. This concept is well demonstrated by the presence of the autistic child which effects almost all aspects of family life and demands that the nuclear unit adapt a new lifestyle. Parents in this study indicated that the presence of the autistic child clearly affected the nuclear family's ability to function as an organized whole as demonstrated through the percentage of "yes" answers to the questions on family integration.

It is more difficult to demonstrate the other specific concepts of causality and homeostasis. These concepts were helpful in developing the interview schedule but did not appear to enhance analysis of the data.

Despite this difficulty, applying the concepts of systems theory is a useful approach in that it helps to focus on the entire family rather than on only the parents or the disabled child. Subjective reports from the parents indicated they found the interview process stimulated new elements of their family dynamic they had not previously considered. All parents indicated they found the process thought provoking and helped them gain new insights into the functioning of their own family systems.

Conclusion and Future Directions

The findings that the presence of an autistic child has a significant effect on family integration is not surprising. What is intriguing is that coupled with clear indicators of stress and tension are statements regarding perceived benefits as a result of the autistic child. While some positive experiences accompany living with an autistic child there are great stresses on the families who must alter their lifestyles in order to accommodate the symptoms of autism. It would be interesting to assess these families again at a later developmental stage to review the balance of strain and benefit.

A rich area for further investigation could include broadening the target population by moving away from parents and looking at siblings, grandparents, and other close relatives. While this study did attempt to gain the parents' perspective as to the impact on siblings and extended family members it would be worthwhile for other researchers to interview the children and grandparents of those same families to obtain their point of view. In the past studies have not sufficiently acknowledged the intense, long term, reciprocal nature of sibling relationships nor have they pursued the consequences of an autistic child from a transgenerational point of view.

It would be of great interest to include the autistic child in the interview process. While this approach is open to difficulties it could play an important part in completing the overall picture of the family system. It is this researcher's experience that meeting the autistic child in their own family setting enriched the overall understanding of the complex effect of living with a disabled child.

Of major importance for both researchers and clinicians is to attend to what families with autistic children articulate as their needs. Parents desperately want to know the "why" of autism; they need clear answers as to causation and continuing assurance that the disorder is not their fault. Further studies would be of great benefit in focusing on factors leading to successful adaptation and the type of support perceived helpful by the family. At the present time it remains unclear as to what the best methods are for helping these families in distress and research is desperately needed in this area.

There would appear to be merit in examining characteristics of systems that contribute to effective coping. The relative merits of internal supports, access to normal social activities, and a readily available network of formal resources are possible factors to study as they relate to adequacy of adjustment. Further application of the systems model could be useful in tying together disparate research efforts and illuminating the significance of each.

This study has added to the general body of knowledge regarding families of autistic children in several ways. First, although autism is not a common disorder, the chronicity, poor prognosis, and degree of disability result in a disorder which merits the interest of researchers and clinicians. While research in this area is expanding there are still significant gaps in knowledge. This study is one attempt at filling a gap and generating further research questions.

Most studies of the adjustment of families with a chronically disabled child focus on the impact on individuals within the family system rather than on the family as an entire system (Palfrey, Walker, Butler, & Singer, 1989). This study attempted to address both individual and family system variables.

Adopting a systems approach to understanding families of autistic children makes possible a more meaningful understanding and allows for the development of more effective means of meeting families' needs. Several authors have called for a family systems approach to understanding and working with families of disabled children (Berkowitz & Graziano, 1972; Chin, Winn, & Walters, 1978; Turnbull, 1982; Zucman, 1982).

Although much has been written about the stresses induced by a chronically disabled child, less literature reflects cases in which the disability has actually engendered strengths in the family unit (Palfrey, 1989). Professionals, attempting to enhance the coping potentials of families, must understand which types of families are most vulnerable and which factors mediate the effect of a chronic disability. This study was open to assessing the positive as well as the negative impact of the autistic child on the family system.

Discrepancies sometimes occur between the kinds of findings produced by research on families and the findings culled from direct experience with families (Cutler & Kozloff, 1987). Findings derived from direct experience with families are not necessarily limited by the hypotheses and assumptions of other types of research. Through interviews with the families of autistic children this study gave voice to their experience as well as indicated what other sources report.

This study reflected current trends in researching the effect of the autistic child on the family, in contrast to the predominant earlier preoccupation with parents' presumed adverse influence on autistic children. Previous literature tended to reduce parents to mother and to ignore the father (Konstantareas & Homatiditis, 1991). Research on the impact on brothers and sisters or grandparents of the autistic child is sparse and still in the preliminary stages. This study attempted to enhance our knowledge of the reciprocal effect of parents and children within the family system.

An assumption made by some researchers is that problems that arise in a family with a handicapped child are primarily a product of the child's special needs (Harris, 1988). Because multiple factors converge to create stress, it is important to assess all the relevant sources of stress that act on a family. This study attempted to examine the extent to which factors other than the autistic child's needs impact on the family system.

By examining a small number of families intensively and attempting to understand the meaning of the experience of having an autistic child some universal themes and patterns emerged that have potential generalizability to other families with such a disabled child.

In general this study has supported the work of other researchers who have reported both positive and negative effects on the family due to the presence of the autistic child. Further areas of study could be guided in the direction of factors which mediate the negative and enhance the positive impact of the disabled child.

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Appendix A

Interview Schedule

Introduction

The purpose of this study is to collect information on the impact of an autistic child on the family system. This interview will focus on your opinions, perspectives, and personal experiences of being a member of a family with an autistic child. There are no right or wrong answers to these questions. Your personal point of view is the best response.

The initial and follow up interviews will each take approximately one hour. The purpose of the follow up interview is to avoid fatigue, and to allow for clarification of questions which may arise during the first interview.

All audio tapes and written material will be treated in strictest confidence. You will remain anonymous and will be identified only by a subject number. The audio tapes will be transcribed into written format by a research assistant and will otherwise be reviewed only by the researcher. The audio recorded material will be erased after the transcription process is complete. The written material will be retained for the purpose of preparing the thesis report with any identifying data omitted.

Your participation in this interview is voluntary. You may terminate the interview at any point. If you wish any additional information about this study or have any concerns you may contact Professor Richard Carreiro (Telephone # 474-8784). If you wish, the researcher will provide names of counselling agencies that could be contacted to provide support for any issues that may arise as a result of this interview. A summary of the study results can be forwarded to you at your request.

Interview date:

Initial or follow up:

Subject number:

A. <u>Demographics</u>

1. How old are you?
2. How old is your spouse?
3. What is your marital status?
4. What are the ages and gender of your children, beginning with the eldest and including the autistic child?

5. What is the highest level of education you have achieved?
6. What is your present occupation?
7. What is the range of your average yearly income?
8. What is your ethnic background?
9. What is your religious affiliation?

B. Information regarding the autistic child

10. How old was the autistic child at the time of diagnosis?
11. How would you rate the autistic child's degree of disability (i.e. mild, moderate or severe) in the following areas:
    - verbal communication?
    - nonverbal communication? (e.g. eye contact, touching)
    - social interaction?
    - repertoire of interests? (e.g. enjoys a variety of games)
    - intellectual ability?

C. Family integration

12. Does the presence of the autistic child effect how family members interact with each other? If yes, in what way?

13. Does the presence of the autistic child effect how family members communicate with each other? If yes, in what way?

13.1 Does the presence of the autistic child effect how decisions are made in your family? If yes, in what way?

13.2 Does the presence of the autistic child effect family members' agreement on important matters? (e.g. where to go on vacation). If yes, in what way?

14. Does the presence of the autistic child effect your family's ability to cooperate and help each other out? If yes, in what way?

14.1 Does the presence of the autistic child effect your family's ability to provide emotional support for each other? If yes, in what way?

14.2 Does the presence of the autistic child effect how much responsibility you have in your family? If yes, in what way?

14.3 Does the presence of the autistic child effect how much responsibility your spouse has in the family? If yes, in what way?

14.4 Does the presence of the autistic child effect the amount of tension in your family? If yes, in what way?

14.5 Does the presence of the autistic child effect family members' feelings of being neglected or left out? If yes, in what way?

14.6 Does the presence of the autistic child effect the amount of time and attention received by other family members? If yes, in what way?

15. Has your marital relationship been effected by the presence of the autistic child? If yes, in what way?

15.1 Does the presence of the autistic child effect the amount of time you spend alone with your spouse? If yes, in what way?

15.2 Does the presence of the autistic child effect the amount of attention and support you get from your spouse? If yes, in what way?

16. Does the presence of the autistic child effect your family's ability to spend time together as a unit? If yes, in what way?

17. Does the presence of the autistic child effect your opportunity to get out on your own? If yes, in what way?

17.1 Does the presence of the autistic child effect your spouse's ability to get out on their own? If yes, in what way?

18. Does the presence of the autistic child effect how close family members feel to each other? If yes, in what way?

19. Does the presence of the autistic child effect your role in the family? If yes, in what way?

19.1 Does the presence of the autistic child effect your spouse's role in the family?

20. Does the presence of the autistic child effect your family's ability to plan for the future with reasonable confidence? If yes, in what way?

D. <u>Effect on the sibling subsystem</u>

21. Are the other children in the family ever upset or embarrassed by the behaviour of the autistic child? If yes, in what way?

22. Do the other children ever feel neglected because of the presence of the autistic child? If yes, in what way?

23. Are the other childrens' social opportunities effected by the presence of the autistic child? If yes, in what way?

23.1 Does the presence of the autistic child effect the other childrens' friendships? If yes, in what way?

24. Are the other childrens' roles in the family effected by the presence of the autistic child? If yes, in what way?

24.1 Are the other childrens' responsibilities effected by the presence of the autistic child? If yes, in what way?

25. Are the other childrens' concerns about their future effected by the presence of the autistic child? If yes, in what way?

26. Have the other children benefited from the presence of the autistic child? If yes, in what way?

E. Effects on the extended family

27. Do relatives demonstrate their understanding of the effect of the autistic child on your family? Please explain your response.

27.1 How do relatives explain the autistic child's disability to themselves or others?

27.2 Do relatives offer help and support because of the presence of the autistic child? Please explain your response.

27.3 Do relatives demonstrate willingness to listen to your concerns about the autistic child? Please explain your response.

27.4 Do relatives show they appreciate your ability to provide care for the autistic child? Please explain your response.

28. Have extended family member's roles been effected by the presence of the autistic child? Please explain your response.

28.1 Have relatives become closer together or farther apart because of the presence of the autistic child? Please explain your response.

F. Use of social supports

29. Are community resources related to the autistic child's needs of the right type? Please explain your response.

29.1 Are community resources related to the autistic child's needs adequate? Please explain your response.

29.2 Are community resources related to the autistic child's needs easily accessible? Please explain your response.

30. Are school programs related to the autistic child's needs of the right type? Please explain your response.

30.1 Are school programs related to the autistic child's needs adequate? Please explain your response.

30.2 Are school programs related to the autistic child's needs easily accessible? Please explain your response.

31. Is respite care related to the autistic child's needs of the right type? Please explain your response.

31.1 Is respite care related to the autistic child's needs adequate? Please explain your response.

31.2 Is respite care related to the autistic child's needs easily accessible? Please explain your response.

32. Are child care services related to the autistic child's needs of the right type? Please explain your response.

32.1 Are child care services related to the autistic child's needs adequate? Please explain your response.

32.2 Are child care services related to the autistic child's needs easily accessible? Please explain your response.

33. Are recreation and sports services related to the autistic child's needs of the right type? Please explain your response.

33.1 Are recreation and sports services related to the autistic child's needs adequate? Please explain your response.

33.2 Are recreation and sports services related to the autistic child's needs easily accessible? Please explain your response.

34. Are post schooling resources related to the autistic child's needs of the right type? Please explain your response.

34.1 Are post schooling resources related to the autistic child's needs adequate? Please explain your response.

34.2 Are post schooling resources related to the autistic child's needs easily accessible? Please explain your response.

35. Are independent living opportunities related to the autistic child's needs of the right type? Please explain your response.

35.1 Are independent living opportunities related to the autistic child's needs adequate? Please explain your response.

35.2 Are independent living opportunities related to the autistic child's needs easily accessible? Please explain your response.

36. Are personal supports of the right type? Please explain your response.

36.1 Are personal supports adequate? Please explain your response.

36.2 Are personal supports easily accessible? Please explain your response.

37. Is it easy or difficult for your family to ask for help related to the autistic child's needs? Please explain your response.

38. Do friends and neighbours demonstrate understanding and support related to the autistic child's needs? Please explain your response.

39. Does your community demonstrate acceptance of the autistic child? Please explain your response.

40. Does your family see themselves as different from other families due to the presence of the autistic child? Please explain your response.

G. <u>Negative aspects of family life</u>

41. In your opinion, which aspects of family life are most negatively affected by the presence of the autistic child?

H. <u>Positive aspects of family life</u>

42. In your opinion, which aspects of family life are most positively affected by the presence of the autistic child?

I. Other information

43. What further information do you consider important for other parents of autistic children to know?

Appendix B

Consent Form

The University of Manitoba
Faculty of Education
Department of Educational Psychology
Winnipeg, Manitoba

I agree to take part in this study as part of a Master's Thesis work on the topic of "The Impact of an Autistic Child on the Family System". I realize that participation in this study will have no direct benefit to me but will contribute to the general body of knowledge in this area.

I understand that I will be interviewed regarding my opinions and personal experiences of being a member of a family with an autistic child. I understand that this interview will take approximately one hour.

I understand that all the information obtained is confidential and the only time my name will appear in this study is when I sign this consent form. Also, my name will not appear in any publications that result from this study.

I give permission to tape record this interview. I understand that all data recorded will remain anonymous and strictly confidential and will be used only as the anecdotal component of the thesis, with anonymity maintained in the written report. Audio tapes will be transcribed into written format by a research assistant and will otherwise be reviewed only by the researcher. I understand that the audio recorded material will be erased after the transcription process is complete. The written material wil be retained for the purpose of preparing the thesis report with any identifying data omitted.

I understand that my participation is voluntary and that I can terminate this interview at any point. Also, if I change my mind during or after the interview the tape will be immediately erased.

If I wish any additional information about this study or have any concerns I understand that I can contact Professor Richard Carreiro.

__________________________ __________________________

Signature (researcher) Signature of consent

If you wish a summary of the study results, please write your address below:

____

Street number City Province Postal Code