CHAPTER II

REVIEW OF LITERATURE

The literature related to the study of Interventional strategies on stress levels among the caregivers of the Intellectually Challenged is reviewed in this Chapter. The survey of available literature gave a deep insight into the problem taken up in the present study. The reviewed chapter are scrutinized and ordered as follows:

1. Intellectually Challenged
   (i) Meaning
   (ii) Definition
   (iii) Causes
   (iv) Characteristics
   (v) Kinds of Intellectually Challenged
   (vi) Classification of Intellectually Challenged

2. Condition Associated with Intellectually Challenged
   (i) Cerebral Palsy
   (ii) Down Syndrome
   (iii) Autism

3. Stress
   (i) Meaning
   (ii) Definition
   (iii) Approaches to stress
   (iv) Family Stress
   (v) Studies related to stress on the caregivers of the Intellectually Challenged

4. Caregivers
   (i) Meaning
   (ii) Impact of care giving on family life
   (iii) Studies related to caregiving

5. Counselling
   (i) Meaning
(ii) Definition

(iii) Counselling parents of the Intellectually Challenged

(iv) Studies related to Counselling parents of the Intellectually Challenged

The survey of literature related to the study enabled the investigator to get a better insight into the various aspects of the earlier result from which the selection of the problem for research was elucidated. The investigator was guided by the survey of related literature.

The review included the studies carried out in India as well as in foreign countries. The literature reviewed is presented under different heading, which explains the concept, definition and the literature reviewed on the topic.

Mental retardation / intellectually challenged

The latest definition of mental retardation according to The American Association on Mental retardation (Luckasson etal; 1992) is as follows:

‘Mental retardation’ refers to substantial limitations in present functioning. It is characterized by significantly sub average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self care, home, living, social skills, community, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before the age of eighteen.

Mental retardation can be caused due to various factors usually divided into segment such as (1) Hereditary, (2) Abnormalities of the brain, (3) Consanguinity, (4) Other prenatal causes, (5) Delivery complication, (5) Postnatal causes

Hereditary

One of the major and probably the most important cause of mental retardation now termed as Intellectually Challenged is hereditary between 50 and 75 percent of mental defectives come from families in which intellectual weakness or less than average intelligence is the rule other than exception.
Studies conducted by Hopwood, Kirth and Penrose have indicated that one major cause of mental defect is the feeble mindedness of the parents. In twins it is very rare that one child is normally intelligent and other one feeble minded.

Studies that Rasanoff and his associates conducted have indicated that 91 percent of identical twins and 53 percent of the fraternal twins show mental defectiveness as a general rule. Other psychologists have adduced statistics that confirm such a view.

**Abnormalities of brain**

In 25 percent of the Intellectually Challenged the root cause is some abnormality of the brain which can be caused by any injury during birth, any infectious or contagious disease, imbalance of glands, psychological conditions etc.,

**Consanguinity**

It is a widespread belief, almost universally held, that ‘sexual relationships with relatives of blood lead to defective children being born and such a view has been put forth even in the Gita. What is almost certainly true in such an opinion is that the case of sexual intercourse with blood relatives can advance the danger of defective genes becoming concentrated and manifesting themselves in the defect in any child that is born. But if there is no defect in either of the two parents, then defective children caused by the mere fact of sexual intercourse with blood relatives will not be necessarily born.

**Prenatal causes**

Preparation for the child bearing is very important. When a mother conceive without preparation she would not take necessary care which is needed to carry a healthy child (for ex.) the mother may take heavy antibiotics or irregular use of family planning pills, attempt improper abortion practices. When all of this is not done without proper consultation the trimester period of pregnancy will certainly be affected which could cause damage to the brain resulting in a birth of an Intellectually Challenged Child.
**Delivery complication**

Pre term or Post term delivery becomes the focus of attention to a higher degree. It could cause under nourished or child in case of pre-term and Birth Asphyxia affected child due to lack of oxygen supply to the brain incase of post term birth.

In appropriate use of forceps, vacuum extraction of the child could also be the cause for the birth of the Intellectually Challenged child.

**Post natal causes**

The maximum growth period of human life is 0-2yrs. whatever diseases affect the child, within this period they will have an effect on developmental process that could be hampered due to infections, toxications, accidents, nutrition defect etc., It could end in making the child intellectually affected.

**Characteristics of the Intellectually Challenged child**

**Limited Intelligence**

As is said in the definition the cause of Intellectually Challenged is mainly due to the lack of intelligence. In that condition the person is unintelligent. Intelligence is the ability of a man in various fields, such as learning, skills of different kinds, adjusting to novel situations and facing problems in life, benefiting from previous experience, creative decisions, avoiding errors, overcoming obstacles and foresight in various subject etc., In an Intellectually Challenged one all these abilities are found to be less efficient than in the normal individual. In an unintelligent person, intellectual activity is difficult and laborious, his training is slow and even what is assimilated is more by rote learning than by any true understanding. Such a person cannot correct his own errors easily, even when he gets to understanding them and despite much repetition continues to make mistakes. In this class of individual the most intelligent can be made to learn a little bit of reading and elementary arithmetic. But even then if there is no constant revival of that learning it is soon forgotten. Yet from this it
cannot be concluded they are completely lacking intelligence since they do have intelligence but it is less than the normal individual.

Even in the most serious case of injury the person suffering from has some elusive spark of intelligence; consequently it is not possible to make a clear cut demarcation between the intelligent and the unintelligent. It is being more a matter of degree than of quantity. They can be classified into various classes such as

<table>
<thead>
<tr>
<th>IQ</th>
<th>Classification</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>140 and above</td>
<td>Very superior</td>
<td>1.5</td>
</tr>
<tr>
<td>120-139</td>
<td>Superior</td>
<td>11.0</td>
</tr>
<tr>
<td>110-119</td>
<td>Bright</td>
<td>18.0</td>
</tr>
<tr>
<td>90-109</td>
<td>Average or normal</td>
<td>48.0</td>
</tr>
<tr>
<td>80-89</td>
<td>Dull normal or Backward</td>
<td>14.0</td>
</tr>
<tr>
<td>70-79</td>
<td>Very dull</td>
<td>5.0</td>
</tr>
<tr>
<td>60-69</td>
<td>Feeble minded</td>
<td>2.5</td>
</tr>
</tbody>
</table>

This is taken from Garretts Great experiments. Other kind in psychology.

Tredgoid Feebleminded (Moron), imbeciles, Idiot
ICD (9) Mild (50-70), Moderate (35-50)
DSM (III) Borderline (70-85), Mild (50-70), Moderate (35-50), Severe (20-35)
AAMD Profound (<20)

*Social inadequacy*

The Intellectually Challenged is inadequate in handling himself in social point of view, it is not possible for him to protect himself from the normal hazards of life and he lacks self control and the means to earn a living. In childhood he is in constant need of assistance from external quarters. And even in the case of grown ups such an individual needs assistance in such simple activities as eating or dressing. His relatives have constantly protected from common hazards and even in playing with
other children of his own age it is necessary to keep an eye on him. Being behind children of his own age in every thing that he does, the backward child prefers to play with children younger than him.

   Even in adulthood the Intellectually Challenged does not become self sufficient in any important respect.

   In the report of British Mental Deficiency Committee published in 1939, it was said that among the Intellectually Challenged only 14% were nearly self sufficient whereas 46 percent contributed some what to the earning of their livelihood but the rest did nothing. In female the rate of dependence on external assistance is even greater. Apart from being dependent upon others for material help to solve their own social are personal problems they also become evil elements. If they are not properly looked after and controlled, they are usually caught in undesirable activities such as crime, theft, murder or sexual violation. In the case of such behaviour of the Intellectually Challenged there is no underlying immoral conception or trait, because he is incapable of making a distinction between the good and the bad, and his actions are more instinctive. He is not even aware of the consequences of his actions. When tempted he will steal, when irritated he may strike or kill another persons and under stimulus may commit some sexual crime, so that his behaviour has to be sympathetically controlled if it is to confirm to social norms.

   AH Wood in his study describes this as a condition of inadequate mental development in which quantity and quality is lacking to such an extent that the individual cannot skillfully and adequately adjust to his social environment.

**Deficiencies of other mental functions**

   The human mind functions in the form of a unit hence the deficiency of mental power influence all the powers and functioning of the mind. Intellectually Challenged individual cannot concentrate on anything for long because his attention wanders very easily. Interest are only few and he cannot apply himself to anyone for any length of time or with any real degree of tenacity. His power of comprehension is low and the range of memory rather narrow. He can remember only the simplest of things besides which proper association between words and pictures is difficult for him. Imagination
and the creative impulse are also low if not absent in such an individual. Mild cases of affected ones are often found day dreaming but in a more advanced condition the mind is often a blank.

**Defects of drives and emotions**

Lacking the mental power, the Intellectually Challenged children suffer from defects of drives and emotion that creep in because of the innate deficiency - some types of Intellectually Challenged show differing stages in the development of various drives and emotions. Some even lack a vital drive such as that of self preservation, they are incapable of even showing their own hunger or thirst, it is difficult for them to escape impending danger, their emotional life is sometimes worse than that of animals. But in mild, Border line case of affect affected ones physical drives are often very well developed, although the ego development concerning hetero sexual relationships does not seem to exist. Normally their affective experiences are limited to pain, pleasure, fear, surprise, anger, hatred and other simple emotion.

**Defects of personality**

The Intellectually Challenged does not maintain its organized appearance, so that among them few exhibit a personality that it’s valuable in respect of dynamicity, courage or any other quality usually they possess, unattractive unstable and easily influenced personality.

**Organic defects**

Intellectually Challenged individual can be observed with many physiological and motor defects, because in childhood he takes longer than that of the ordinary children to learn to talk, move or perform any other activity.

Every activity requiring very little skill is not easily acquired. Their speech is often marred by stuttering and their gait by stumbling, their sensory activity is much less than that of the normal individual. Severely affected individual are not even capable of distinguishing various kinds of smell and factual sensations. They also remain far behind the normal individual in respect of motor or mechanical dexterity,
many of them being short-statured and sickly. The physical energy is far less than that of the normal person. They cannot combat disease with the result that death rate among them is higher than in the normal population. As there is an increase in defective of intellectual ability so does their physical incapacity.

**Kinds of Intellectually Challenged**

They are mainly divided into the following three classes according to the extent of mental deficiency or damage.

**Profound / Severe case of affect**

The Intellectually Challenged child affected severely has the least degree of Intelligence. They cannot manage their self care skills like toileting, bathing, dressing etc., They need complete care from the attendees. They cannot eat their own food. Their linguistic ability is limited to the knowledge of few common words only. They cannot invade an oncoming vehicle, and fully capable of putting their hands in the fire or willfully dumping into the deep water.

**Moderate level of Affect**

They have greater Intelligence than the severe and they can learn to evade ordinary danger, to speak but not to write. The worst among them cannot learn any work, while the normal imbecile cannot indulge in any productive activity, some with higher level of Intelligence can be taught productive work through much diligent training and control, while the best though they can perform bodily functions, but even they require constant vigil and supervision for any productive effort.

**Mild case of affect**

They are the most intelligent among the Intellectually Challenged children. They can be trained to work regularly without constant supervision, and to do work of simple skill. The more intelligent can be taught such work, such as looking after animals, baby sitting, carpet work, lathe work, sewing and the like. But if they are to follow such a work with a view to earn money, they need the supervision and
employment of a sensitive and sympathetic individual who can and is willing to understand their limitations.

According to Lewis out of 100 Intellectually Challenged 5 are severely affected, 20 are in moderate level and 75 are mildly affected. According to report concerning Intellectually Challenged by commerce department of the United States of America stated that some 15 are severely affected, 30 were moderately affected and 45 were mildly affected annually, while the rest defy classification.

**Classification of Intellectually Challenged**

Among many classification made in connection with Intellectually Challenged the two most famous are Tredgolds and Lewis.

In the book of Mental deficiency AF Tredgold has divided Intellectually Challenged into two parts - Primary and Secondary.

*Primary Mental deficiency*

This division includes those kinds of mental deficiency that are the outcome of hereditary or defect of gene or obstacles in normal mental matters and independent social adjustment. According to Tredgold, some 10 percent of mentally defective people fall within the category and of these 5 percent are Mongols.

*Secondary Mental deficiency*

This comprehends the functional kind of mental deficiency in which there is a fundamental or hereditary defect but undesirable external influences have retarded mental progress. Hence secondary mental deficiency is not innate but acquired, for ex. Child becoming an Intellectually Challenged child due to accident injury to brain.

Apart from this Tredgold also says that Mental deficiencies caused by defective environment are present in case of primary deficiency.
E.O. Lewis divides mental deficiency into the following two classes:

**Sub-cultural**

Majority of the mentally affected patients fall within this category, they differ from the normal individual only with respect to quantity. They represent the lowest level of intelligence in the general population. In appearance they resemble the normal individual. They are more intelligent than the normal kind of feeble minded people. Much of their mental deficiency is the outcome of hereditary and they are to be found in slum areas.

**Pathological**

Mentally deficient individuals belonging to this class differ from the normal individual in the same way in which a pigmy differs from the average persons. Their physiological condition differs from the normal and is quite defective. At the root of their defect is some organic defect or abnormality. Every strata of society has its pathological defective.

**Clinical Types**

Among the classifications of mental defectives the most famous is that of simple, Mongols, micro cephalic, hydrocephalic, cretins.

**Simple**

This class include those mental deficiency almost nearly resemble normal people and between 60 and 70 percent of mental deficiency are found in this class. They tend towards short stature and some physiological defects, but about two thirds of them are mildly affected and rest moderately affected. Majority of the Intellectually Challenged children are the offspring feeble minded parents’ unskilled labourers.

**Micro cephalic**

These people are called pinheads because their heads are extremely small and the number of such mental deficient among feeble minded people in general is about
1 percent. The circumference of their head is 17 inches and the weight of their brain approximately one fifth of the normal person’s brain. In their head the forehead is sunken, the rear part of the head is flat and their hair rough & stringy. Emotionally they are affectionate, obstinate and excitable. Spinal cord is thin and they cannot do hard work. According to some scientist the women who are given pelvic X-ray give birth to micro cephalic children.

Morphy examined some 53 such women and found that 36 percent of their children were micro cephalic feeble minded.

**Hydro cephalic**

In this kind as the name indicate some liquid collects to excess within the brain and spinal cord so that the size of the head increases, it circumference varies from 271.030 inches, when this aggravation is within the brain it is called inner hydro cephalic but if the liquid collects between brain and skull it is called hydro cephalic. Severe, moderate and mild case of Intellectual affect can be seen in this case by nature. They are jovial, happy and affectionate, they form one percent of the total feeble minded population.

**Cretins**

In this case of intellectually challenged are one percent individuals. Their physical development is very redoubtable. In stature they are very far short of average. They are not taller than three feet. Motor movement and activities are unattractive, emotionally they are intelligent and slow, although by nature they are peaceable, affectionate and soft spoken. Thyroxin, the glandular excretion of the thyroid gland is the main cause of cretin since its deficiency brings about this condition, if operated some favourable changes could occur.

**Conditions associated with intellectually challenged**

- Cerebral Palsy
- Down Syndrome
- Autism
CEREBRAL PALSY (CP)

CP is an umbrella term encompassing a group of non-progressive, non-contagious diseases that cause physical disability in human development.

Cerebral refers to the affected area of the brain, the cerebrum (however the centres have not been perfectly localized and the disease most likely involves connections between the cortex and other parts of the brain such as the cerebellum) and palsy refers to disorder of movement. CP is caused by damage to the motor control centers of the young developing brain and can occur during pregnancy (about 75 percent), during childbirth (about 5 percent) or after birth (about 15 percent) up to the age of three. It is a non-progressive disorder, meaning the brain damage does not worsen, but secondary orthopedic deformities are common. There is no known cure for CP, Medical intervention is limited to the treatment and prevention of complications possible for CP’s consequences.

Onset of arthritis and osteoporosis can occur much sooner in adults with CP. Further research is needed on adults with CP, as the current literature body is highly focused on the pediatric patient. CP’s resultant motor disorder(s) are sometimes, though not always, accompanied by “disturbances of sensation, cognition, communication, perception, and/or behavior, and/or by a seizure disorder”. CP is the second-most expensive developmental disability to manage over the course of a person’s lifetime (second to mental disabilities), with an average lifetime cost per person of USD$921,1000 (in 2003 dollars). The incidence in the six countries surveyed is approximately an average of 2.12-2.45 per 1000 live births; there has been a slight increase in recent years. Although improvements in neonatal nursing help reduce the number of babies who develop cerebral palsy, they also mean that babies are more likely to have cerebral palsy.

Classification

CP is divided into four major classifications to describe the different movement impairments. These classifications reflect the area of brain damaged. The four major classifications are:
Spastic
Athetoid/Dyskinetic
Ataxic
Mixed

In 30 percent of all classes of CP, the spastic form is found along with one of the other types. There are a number of other, less prevalent types of CP, but these are the most common.

A general classification is as follows:

Spastic

Spastic (ICD-10 G80.0-G80.1) cerebral palsy is by far the most common type, occurring in 70% to 80% of all cases. People with this type are hypertonic and have a neuromuscular condition stemming from damage to the corticospinal tract, motor cortex, or pyramidal tract that affects the nervous system’s ability to receive gamma amino butyric acid in the area(s) affected by the spasticity. Spastic CP is further classified by topography dependent on the region of the body affected; these include:

- Spastic hemiplegia (one side being affected). Generally, injury to the left side of the brain will cause a right sided deficit, and vice versa.

- Spastic diplegia (whole body affected, but the lower extremities affected more than the upper extremities). Most people with spastic diplegia do eventually walk. The gait of a person with spastic diplegia is typically characterized by a couched gait. Toe walking and flexed knees are common. Hip problems, dislocations, and side effects like strabismus (crossed eyes) are common. Strabismus affects three quarters of people with spastic diplegia. This is due to weakness of the muscles that control eye movement. In addition, these individuals are often nearsighted. In many cases the IQ of a person with spastic diplegia is normal.

- Spastic quadriplegia (Whole body affected; all four limbs affected equally). Some children with quadriplegia also have hemiparetic tremors; an
uncontrollable shaking that affects the limbs on one side of the body and
impairs normal movement. A common problem for children with quadriplegia
is fluid buildup. Diuretics and steroids are medications administered to
decrease any buildup of fluid in the spine that is caused by leakage from dead
cells. Hardened feces in a quadriplegia patient are important to monitor
because it can cause high blood pressure. Autonomic dysreflexia can be
caused by hardened feces, urinary infections, and other problems, resulting in
the overreaction of the nervous system and can result in high blood pressure,
heart attacks, and strokes. Blockage of tubes inserted into the body to drain or
enter fluids also needs to be monitored to prevent autonomic dysreflexia in
quadriplegia. The proper functioning of the digestive system needs to be
monitored as well.

Occasionally, terms such as monoplegia, paraplegia, triplegia, and pentaplegia may
also be used to refer to specific manifestations of the spasticity.

**Athetoid/dyskinetic**

Athetoid or dyskinetic (ICD-10 G80.3) is mixed muscle tone - sometimes
hypertonia and sometimes hypotonia. People with athetoid CP have trouble holding
themselves in an upright, steady position for sitting or walking, and often show
involuntary motions. For some people with athetoid CP, it takes a lot of work and
concentration to get their hand to a certain spot (like scratching their nose or reaching
for a cup). Because of their mixed tone and trouble keeping a position, they may not
be able to hold on objects (such as a toothbrush or pencil). About one-fourth of all
people with CP have athetoid CP. The damage occurs to the extra pyramidal motor
system and/or pyramidal tract and to the basal ganglia. It occurs in 40% of all cases.

**Ataxic**

Ataxia (ICD-10 G80.4) type symptoms can be caused by damage to the
cerebellum. Forms of ataxia are less common types of Cerebral Palsy, occurring in at
most 10% of all cases. Some of these individuals have hypotonia and tremors. Motor
skills like writing, typing or using scissors might be difficult, as well as problems with
balance, especially while walking. It is common for individuals to have difficulty with visual and/or auditory processing of objects.

**Incidence and prevalence**

In the industrialized world, the incidence of cerebral palsy is about 2 per 1000 live births. The incidence is higher in males than in females; the Surveillance of Cerebral Palsy in Europe (SCPE) reports a M:F ratio of 1.33:1. Variances in reported rates of incidence across different geographical areas in industrialized countries are thought to be caused primarily by discrepancies in the criteria used for inclusion and exclusion. When such discrepancies are taken into account in comparing two or more registers of patients with cerebral palsy (for example, the extent to which children with mild cerebral palsy are included), the incidence rates converge toward the average rate of 2:1000.

In the United States, approximately 10,000 infants and babies are diagnosed with CP each year, and 1200-1500 are diagnosed at preschool age. Overall, advances in taking care of pregnant mothers and their babies has not resulted in a noticeable decrease in CP. This is generally attributed to medical advances in areas related to the care of premature babies (which results in a greater survival rate). Only the introduction of quality medical care to locations with less-than-adequate medical care has shown any decrease. The incidence of CP increases with premature or very low-weight babies regardless of the quality of care. Prevalence of cerebral palsy is best calculated around the school entry age of about six years, the prevalence in the U.S. is estimated to be 2.3 out of 1000 children.

The SCPE reported the following incidence of comorbidities in children with CP (the data are from 1980-1990 and included over 4,500 children over the age of four whose CP was acquired during the prenatal or neonatal period):

- Mental retardation (IQ < 50): 31%
- Active seizures: 21%
- Mental retardation (IQ < 50) and not walking: 20%
- Blindness: 11%
The SCPE noted that the incidence of comorbidities is difficult to measure accurately, particularly across centers. For example, the actual rate of mental retardation may be difficult to determine, as the physical and communicational limitations of people with CP would likely lower their scores on an IQ test if they were not given a correctly modified version. Apgar scores have sometimes been used as one factor to predict whether or not an individual will develop CP.

**Signs and symptoms**

All types of CP are characterized by abnormal muscle tone, posture (ie., slouching over while sitting), reflexes, or motor development and coordination. There can be joint and bone deformities and contractures (permanently fixed, tight muscles and joints). The classical symptoms are spasticity, spasms, other involuntary movements (e.g. facial gestures), unsteady gait, problems with balance, and/or soft tissue findings consisting largely of decreased muscle mass. Scissor walking (where the knees come in and cross) and toe walking are common among people with CP who are able to walk, but taken on the whole, CP symptomatology is very diverse. The effects of cerebral palsy fall on a continuum of motor dysfunction which may range from virtually unnoticeable to “clumsy” and awkward movements on one end of the spectrum to such severe impairments that coordinated movements are almost impossible on the other end of the spectrum.

Babies born with severe CP often have an irregular posture; their bodies may be either very floppy or very stiff. Birth defects, such as spinal curvature, a small jawbone, or a small head sometimes occur along with CP. Symptoms may appear, change, or become more severe as a child gets older. Some babies born with CP do not show obvious signs right away. Secondary conditions can include seizures, epilepsy, speech or communication disorders, eating problems, sensory impairments, mental retardation, learning disabilities, and/or behavioral disorders.

**Causes**

Despite years of debate, the exact cause of CP remains unclear.
Some contributing causes of CP are asphyxia, hypoxia of the brain, birth trauma, premature birth, and certain infections in the mother during and before birth such as step infections, central nervous system infections, trauma, consecutive hematomas, placenta, abruption and multiple birth. Between 40% and 50% of all children who develop cerebral palsy were born prematurely. Premature infants are at higher risk in part because their organs are not yet fully developed, increasing the risk of asphyxia and other injury to the brain, which in turn increases the incidence of CP. Periventricular leukomalacia is an important causes of CP. About 10% of cases with CP are caused by malformation of the CNS.

Recent research has demonstrated that intrapartum asphyxia is not the most important cause, probably accounting for no more than 10 percent of all cases; rather, infections in the mother, even infections that are not easily detected, may triple the risk of the child developing the disorder, mainly as the result of the toxicity to the fetal brain of cytokines that are produced as part of the inflammatory response. The three most common causes of asphyxia in the young child are: choking on foreign objects such as toys and pieces of food; poisoning; and near drowning. Some structural brain anomalies such as lissencephaly cause symptoms of CP, although whether that could be considered CP is a matter of opinion (some people say CP must be due to brain damage, whereas these people never had a normal brain). Often this goes along with rare chromosome disorders and CP is not genetic or hereditary.

**Prognosis**

CP is not a progressive disorder (meaning the actual brain damage does not worsen), but the symptoms can become worse over time due to ‘wear and tear’. A person with the disorder may improve somewhat during childhood if he or she receives extensive care from specialists, but once bones and musculature become more established, orthopedic surgery may be required for fundamental improvement. People who have CP tend to develop arthritis at a younger age than normal because of the pressure placed on joints by excessively toned and stiff muscles. The full intellectual potential of a child born with CP will often not be known until the child starts school. People with CP are more likely to have some type of learning disability, but this is unrelated to a person’s intellect or IQ level. Intellectual level among people
with CP varies from genius to mentally retarded, as it does in the general population, and experts have stated that it is important not to underestimate CP sufferer’s capabilities and to give them every opportunity to learn.

The ability to live independently with CP also varies widely depending on the severity of the disability. Some individuals with CP will require personal assistant services for all activities of daily living. Others can live semi-independently, needing support only for certain activities. Still others can live in complete independence. The need for personal assistance often changes with increasing age and the associated functional decline. However, in most cases persons with CP can expect to have a normal life expectancy; survival has been shown to be associated with the ability to ambulate, roll and self-feed. As the condition does not directly affect reproductive function, some persons with CP have children and parent successfully. According to OMIM, only 2% of cases of CP are inherited (with glutamate decarboxylate-1 as one known enzyme involved). There is no evidence of an increased chance of a person with CP having a child with CP.

**Treatment**

There is no cure for CP, but various forms of therapy can help a person with the disorder to function and live more effectively. In general, the earlier treatment begins the better chance children have of overcoming developmental disabilities or learning new ways to accomplish the tasks that challenge them. Treatment may include one or more of the following: physical therapy; occupational therapy; speech therapy; drugs to control seizures, alleviate pain, or relax muscle spasms (eg., benzodiazepines, baclofen and intrathecal phenol/baclofen); hyperbaric oxygen; the use of Botox to relax contracting muscles; surgery to correct anatomical abnormalities or release tight muscles; braces and other orthotic devices; wheelchairs and rolling walkers; and communication aids such as computers with attached voice synthesizers. For instance, the use of a standing frame can help reduce spasticity and improve range of motion for people with CP who use wheelchairs. Nevertheless, there is only some benefit from therapy. Treatment is usually symptomatic and focuses on helping the person to develop as many motor skills as possible or to learn how to compensate for the lack of them. Non-speaking people with CP are often successful availing
themselves of augmentative and alternative communication systems such as Blissymbols,

Physical therapy (PT) programs are designed to encourage the patient to build a strength base for improved gait and volitional movement, together with stretching programs to limit contractures. Many experts believe that life-long physical therapy is crucial to maintain muscle tone, bone structure, and prevent dislocation of the joints.

Occupational therapy helps adults and children maximize their function, adapt to their limitations and live as independently as possible.

Orthotic devices such as ankle-foot orthoses (AFOs) are often prescribed to minimize gait irregularities. AFOs have been found to improve several measures of ambulation, including reducing energy expenditure and increasing speed and stride length.

Speech therapy helps to control the muscles of the mouth and jaw, and helps to improve communication. Just as CP can affect the way a person moves his arms and legs, it can also affect the way they move their mouth, face and head. This can make it hard for the person to breathe; talk clearly; and bite, chew and swallow food. Speech therapy often starts before a child begins school and continues throughout the school years.

Hyperbaric oxygen therapy Recent studies have demonstrated a dramatic improvement in CP symptomology when hyperbaric oxygen therapy is used as a treatment. Researchers in Brazil found a significant alleviation in symptomology and other characteristics in a study involving 218 cerebral palsy patients. Significant enhancements were documented showing improved vision, hearing and speech as well as a reduction of spasticity by 50%, which occurred in 94% of study patients.

Nutritional counseling may help when dietary needs are not sufficient because of problems with eating certain foods.

Both massage therapy and hatha yoga are designed to help relax tense muscles, strengthen muscles, and keep joints flexible. Hatha yoga breathing exercises are
sometimes used to try to prevent lung infections. More research is needed to determine the health benefits of these therapies for people with CP.

**Surgery** for people with CP usually involves one or a combination of;

- Loosening tight muscles and releasing fixed joints, most often performed on the hips, knees, hamstrings, and ankles. In rare cases, this surgery may be used for people with stiffness of their elbows, wrists, hands and fingers.

- Straightening abnormal twists of the leg bones, i.e. femur (termed femoral anteverision or antetorsion) and tibia (tibial torsion). This is a secondary complication caused by the spastic muscles generating abnormal forces on the bones, and often results in intoeing (pigeon-toed gait). The surgery is called derotation osteotomy, in which the bone is broken (cut) and then set in the correct alignment.

- Cutting nerves on the limbs most affected by movements and spasms. This procedure, called a rhizotomy, “rhizo” meaning root and “tomy” meaning “a cutting of” from the Greek suffix ‘tomia’ reduces spasms and allows more flexibility and control of the affected limbs and joints.

- Botulinum Toxin A (Botox) injections into muscles that are either spastic or have contractures, the aim being to relieve the disability and pain produced by the inappropriately contracting muscle.

Another way is that a new study has found that cooling the bodies and blood of high-risk full-term babies shortly after birth may significantly reduce disability or death.

**Conductive education** (CE) was developed in Hungary from 1945 based on the work of Andras Peto. It is a unified system of rehabilitation for people with neurological disorders including cerebral palsy, Parkinson’s disease and multiple sclerosis, amongst other conditions. It is theorized to improve mobility, self-esteem, stamina and independence as well as daily living skills and social skills. The conductor is the professional who delivers CE in partnership with parents and children. Skills learned during CE should be applied to everyday life and can help to develop age-appropriate cognitive, social and emotional skills. It is available at specialized centres.
Biofeedback is an alternative therapy in which people with CP learn how to control their affected muscles. Some people learn ways to reduce muscle tension with this technique. Biofeedback does not help everyone with CP.

**Cultural aspects**

Use of terms when referring to people with CP

Many people would rather be referred to as a person with a disability instead of handicapped. “Cerebral Palsy: A Guide for Care” at the University of Delaware offers the following guidelines:

Impairment is the correct term to use to define a deviation from normal, such as not being able to make a muscle move or not being able to control an unwanted movement. Disability is the term used to define a restriction in the ability to perform a normal activity of daily living which someone of the same age is able to perform. For example, a three year old child who is not able to walk has a disability because normal three year old can walk independently. Handicap is the term used to describe a child or adult who, because of the disability, is unable to achieve the normal role in society commensurate with his age and socio-cultural milieu. As an example, a sixteen-year-old who is unable to prepare his own meal or care for his own toileting or hygiene needs is handicapped. On the other hand, a sixteen-year-old who can walk only with the assistance of crutches but who attends a regular school and is fully independent in activities of daily living is disabled but not handicapped. All disabled people are impaired, and all handicapped people are disabled, but a person can be impaired and not necessarily be disabled, and a person can be disabled without being handicapped.

The term “spastic” describes the attribute of spasticity in types of spastic CP. In 1952 a UK charity called The Spastics Society was formed. The term “spastics” was used by the charity as a term for people with CP. The word “spaz” has since been used extensively as a general insult to disabled people, which some see as extremely offensive. It is also frequently used to insult able-bodied people when they seem overly anxious or unskilled in sports. The charity changed its name to Scope in
In the United States the word spaz has the same usage as an insult, but is not generally associated with CP.

**Misconceptions**

A common misconception about those born with Cerebral Palsy is that they are less intelligent than those born without it. Cerebral Palsy is defined as damage to the part of the brain that controls movement; areas of the brain which define a person's intelligence are not affected by CP.

Spastic Cerebral Palsy, the most common form of CP, causes the muscles to be tense, rigid and movements are slow and difficult. This can be misinterpreted as cognitive delay due to difficulty of communication. Individuals with cerebral palsy can have learning difficulties, but sometimes it is the sheer magnitude of problems caused by the underlying brain injury which prevents the individual from expressing what cognitive abilities they do possess.

**Public perception**

Those with CP are sometimes stigmatized and shunned. This has lessened since the 1950s thanks to public education and to United Cerebral Palsy in the U.S. and similar organizations in other countries. Prior to that time the great majority were often sent to asylums or confined to attics. They were perceived to be the products of incest and partial smothering. Often parents kept their children away from them in the mistaken belief that the condition was the product of disease or poor sanitary habits.

Thomas Galton believed that there was a correlation between physical disability and aptitude, and this attitude remained prevalent as concerned CP until the 1970s. At this time, CP was an over diagnosed disorder, and a common misunderstanding then and now is that CP causes mental retardation. In fact, only CP individuals with brain damage in the hippocampus or the frontal cerebral cortex develop mental retardation. While learning difficulties and CP may co-occur, it is common for individuals with CP to lead normal lives.
DOWN SYNDROME

Down syndrome or trisomy 21 (or Down’s Syndrome in British English and WHO ICD) is a genetic disorder caused by the presence of all or part of an extra 21st chromosome. It is named after John Langdon Down, the British doctor who described the syndrome in 1866. The disorder was identified as a chromosome 21 trisomy by Jerome Lejeune in 1959. The condition is characterized by a combination of major and minor differences in structure. Often Down Syndrome is associated with some impairment cognitive ability and physical growth as well as facial appearance. Down syndrome can be identified during pregnancy or at birth.

Individuals with Down Syndrome tend to have a lower than average cognitive ability, often ranging from mild to moderate learning disabilities. A small number have severe to profound mental disability. The incidence of Down Syndrome is estimated at 1 per 800 to 1,000 births, although these statistics are heavily influenced by, in particular, the age of the mother. Other factors may also play a role. Many of the common physical features of Down Syndrome also appear in people with a standard set of chromosomes. They may include a single transverse palmar crease (a single instead of a double crease across one or both palms), an almond shape to the eyes caused by an epicanthie fold of the eyelid, upslanting palpebral fissures, shorter limbs, poor muscle tone, a larger than normal space between the big and second toes, and protruding tongue. Health concerns for individuals with Down Syndrome include a higher risk for congenital heart defects, gastroesophageal reflux disease, recurrent ear infections, obstructive sleep apnea, and thyroid dysfunctions.

Early childhood intervention, screening for common problems, medical treatment where indicated, a conducive family environment, and vocational training can improve the overall development of children with Down Syndrome. Although some of the physical genetic limitations of Down Syndrome cannot be overcome, education and proper care will improve quality of life.

Genetics

Karyotype for trisomy Down Syndrome. Notice the three copies of chromosome 21. Down Syndrome is a chromosomal abnormality characterized by
the presence of an extra copy of genetic material on the 21st chromosome, either in whole (trisomy 21) or part (such as due to translocations). The effects of the extra copy vary greatly among people, depending on the extent of the extra copy, genetic history, and pure chance. Down syndrome occurs in all human populations, and analogous effects have been found in other species such as chimpanzees and mice. Recently, researchers have created transgenic mice with most of human chromosome 21 (in addition to the normal mouse chromosomes). The extra chromosomal material can come about in several distinct ways. A typical human karyotype is designated as 46, XX or 46, XY, indicating 46 chromosomes with an XX arrangement typical of females and 46 chromosomes with an XY arrangement typical of males.

**Trisomy 2**

Trisomy 21 (47, XX, +21) is caused by a meiotic nondisjunction event. With nondisjunction, a gamete (i.e., a sperm or egg cell) is produced with an extra copy of chromosomes 21; the gamete thus has 24 chromosomes. When combined with a normal gamete from the other parent, the embryo now has 47 chromosomes, with three copies of chromosome 21. Trisomy 21 is the cause of approximately 95% of observed Down Syndromes, with 88% coming from nondisjunction in the maternal gamete and 8% coming from nondisjunction in the paternal gamete.

**Mosaicism**

Trisomy 21 is caused prior to conception, and all cells in the body are affected. However, when some of the cells in the body are normal and other cells have trisomy 21, it is called Mosaic Down Syndrome (46,XX/47,XX,+21). This can occur in one of two ways: A nondisjunction event during an early cell division in a normal embryo leads to a fraction of the cells with trisomy 21; or a Down Syndrome embryo undergoes nondisjunction and some of the cells in the embryo revert to the normal chromosomal arrangement. There is considerable variability in the fraction of trisomy 21, both as a whole and among tissues. This is the cause of 1-2% of the observed Down Syndromes.
Robertsonian translocation

The extra chromosome 21 material that causes Down Syndrome may be due to a Robertsonian translocation. In this case, the long arm of chromosome 21 is attached to another chromosome, often chromosome 14 (45,XX, t(14;21q) or itself (called an isochromosome, 45,XX, t(21q;21q). These parents are phenotypically normal. Normal disjunctions leading to gametes have a significant chance of creating a gamete with an extra chromosome 21, producing a child with Down Syndrome, Translocation Down syndrome is often referred to as familial Down syndrome. It is the cause of 2-3% of observed cases of Down Syndrome. It does not show the maternal age effect, and is just as likely to have come from fathers as mothers. Duplication of a portion of chromosome 21.

Rarely, a region of chromosome 21 will undergo a duplication event. This will lead to extra copies of some, but not all, of the genes on chromosome 21 (46, XX, dup(21q) If the duplicated region has genes that are responsible for Down Syndrome physical and mental characteristics, such individuals will show those characteristics. This cause is very rare and no rate estimates are available.

The incidence of Down Syndrome is estimated at 1 per 800 to 1 per 1000 births. In 2006, the center for Disease Control estimated the rate as 1 per 733 live births in the United States (5429 new cases per year). Approximately 95% of these are trisomy 21. Down Syndrome occurs in all ethnic groups and among all economic classes.

Maternal age influences the chances of conceiving a baby with Down Syndrome. At maternal age 20 to 24, the probability is 1/1490; at age 40 the probability is 1/60, and at age 49 the probability is 1/11. Although the probability increases with maternal age, 80% of children with Down Syndrome are born to women under the age reflecting the overall fertility of that age group. Recent data also suggest that paternal age also increases the risk of Down Syndrome manifesting in pregnancies in older mothers.
Causes of Down Syndrome

Normally, at the time of conception a baby inherits genetic information from its parents in the form of 46 chromosomes; 23 from the mother and 23 from the father. In most cases of Down Syndrome, however, a child gets an extra chromosome - for a total of 47 chromosomes instead of 46. It’s this extra genetic material that causes the physical and cognitive delays associated with DS.

Although no one knows for sure why DS occurs and there’s no way to prevent the chromosomal error that causes it, scientists do know that women aged 35 and above have a significantly higher risk of having a child with the condition. At age 30, for example, a woman has less than a 1 in 1,000 chance of conceiving a child with DS. Those odds increase to 1 in 400 by age 35. By 42, it jumps to about 1 in 60.

Cognitive development

Cognitive development in children with Down syndrome is quite variable. It is not currently possible at birth to predict the capabilities of any reliably, nor are the number or appearance of physical features predictive of future ability. The identification of the best methods of teaching each particular child ideally begins soon after birth through early intervention programs. Since children with Down syndrome have a wide range of abilities, success at school can vary greatly, which underlines the importance of evaluating children individually. The cognitive problems that are found among children with Down syndrome can also be found among typical children. Therefore, parents can use general programs that are offered through the schools or other means. Language skills show a difference between understanding speech and expressing speech. It is not uncommon for children with Down Syndrome to have a speech delay, although it is common for them to need speech therapy to help with expressive language. Fine motor skills are delayed and often lag behind gross motor skills and can interfere with cognitive development. Gross Motor Skills can be affected anywhere from minor to major. Some children will walk at around 2 while others around 4. A physical therapist or APE will help a child with this. Individuals with Down syndrome differ considerably in their language and communication skills. It is routine to screen for middle ear problems and hearing loss; low gain hearing aids
or other amplification devices can be useful for language learning. Early communication intervention fosters linguistic skills. Language assessments can help profile strengths and weaknesses; for example, it is common for receptive language skills to exceed expressive skills. Individualized speech therapy can target specific speech errors, increase speech intelligibility, and in some cases encourage advanced language and literacy. Augmentative and alternative communication (AAC) methods, such as pointing, body language, objects, or graphics are often used to aid communication. Relatively little research has focused on the effectiveness of communications intervention strategies.

In education, mainstreaming of children with Down syndrome is becoming less controversial in many countries. For example, there is a presumption of mainstream in many parts of the UK. Mainstreaming is the process whereby students of differing abilities are placed in classes with their chronological peers. Children with Down syndrome may not age emotionally / socially and intellectually at the same rates as children without Down syndrome, so over time the intellectual and emotional gap between children with and without Down syndrome, so over time the intellectual and emotional gap between children with and without Down syndrome may widen. Complex thinking as required in sciences but also in history, the arts, and other subjects can often be beyond the abilities of some, or achieved much later than in other children. Therefore, children with Down syndrome may benefit from mainstreaming provided that some adjustments are made to the curriculam.

Some European countries such as Germany and Denmark advise a two-teacher system, whereby the second teacher takes over a group of children with disabilities within the class. A popular alternative is cooperation between special schools and mainstream schools. In cooperation, the core subjects are taught in separate classes, which neither slows down the typical students nor neglects the students with disabilities. Social activities, outings, and many sports and arts activities are performed together, as are all breaks and meals.
Health

The medical consequences of the extra genetic material in Down syndrome are highly variable and may affect the function of any organ system or bodily process. The health aspects of Down syndrome encompass anticipating and preventing effects of the condition, recognizing complications of the disorder, managing individual symptoms, and assisting the individual and his/her family in coping and thriving with any related disability or illnesses.

Down syndrome can result from several different genetic mechanisms. This results in a wide variability in individual symptoms due to complex gene and environment interactions. Prior to birth, it is not possible to predict the symptoms that an individual with Down syndrome will develop. Some problems are present at birth, such as certain heart malformations. Others become apparent over time, such as epilepsy.

The most common manifestations of Down syndrome are the characteristic facial features, cognitive impairment, congenital heart disease (typically a ventricular septal defect), hearing deficits (may be due to sensory-neural factors, or chronic serous otitis media, also known as Glue-ear), short stature, thyroid disorders, and Alzheimer’s disease. Other less common serious illnesses include leukemia, immune deficiencies, and epilepsy.

However, health benefits of Down syndrome include greatly reduced incidence of many common malignancies except leukemia and testicular cancer - although it is, as yet, unclear whether the reduced incidence of various fatal cancers among people with Down syndrome is as a direct result of tumor-suppressor genes on chromosome 21 (such as Ets2), because of reduced exposure to environmental factors that contribute to cancer risk, or some other as-yet unspecified factor. In addition to a reduced risk of most kinds of cancer, people with Down syndrome also have a much lower risk of hardening of the arteries and diabetic retinopathy.
Life Expectancy

These factors can contribute to a shorter life expectancy for people with Down syndrome. One study, carried out in the United States in 2002, showed an average lifespan of 49 years, with considerable variations between different ethnic and socio-economic groups. However, in recent decades, the life expectancy among persons with Down Syndrome has increased significantly up from 25 years in 1980. The causes of death have also changed, with chronic neurodegenerative diseases becoming more common as the population ages.

Fertility

Fertility amongst both males and females is reduced, with only three recorded instances of males with Down syndrome fathering children.

Genetic research

Down syndrome is “a developmental abnormality characterized by trisomy of human chromosome 21” (Nelson 619). The extra copy of chromosome-21 leads to an over expression of certain genes located on chromosome-21.

Research by Arron et al shows that some of the phenotypes (displayed genetic characteristics), associated with Down Syndrome can be related to the dysregulation of gene-regulating proteins (596). The gene regulating proteins bind to DNA and initiate certain segments of DNA to be replicated for the production of a certain protein (Arron et al. 596). The gene-regulator in interest is called NFATc. Its activities are controlled by two proteins, DSCR1 and DYRKIA; these genes are located on chromosome-21 (Epstein 582). In people with Down Syndrome, these proteins have 1.5 times greater concentration than normal (Arron et al 597). The elevated levels of DSCR1 and DYRKIA mean that most of the NFATc is located in the cytoplasm rather than in the nucleus promoting DNA replication which will produce vital proteins (Epstein 583)

This dysregulation was discovered by testing in transgenic mice. The mice had segments of their chromosomes duplicated to simulate a human chromosome-21
trisomy (Arron et al. 597). A common characteristic of Down Syndrome is poor muscle tone, so a test involving the grip strength of the mice showed that the genetically modified mice had a significantly weaker grip (Arron et al. 596). The mice squeezed a probe with a paw; the modified mice displayed a 2 Newton (measurement of force) weaker grip (Arron et al. 596). Down syndrome is also characterized by increased socialization. Both modified and unmodified mice were observed for social interaction. The modified mice showed as many as 25% more interactions per time period as the unmodified mice.

The genes that may be responsible for the phenotypes associated may be located proximal to 21q22.3. Testing by Olson et al, in transgenic mice show the duplicated genes presumed to cause the phenotypes are not enough to cause the exact features. While the mice had sections of multiple genes duplicated to approximate a human chromosome-21 triplication, they only showed slight craniofacial abnormalities (688-690). The transgenic were compared to mice that had no gene duplication by measuring distances on various points on their skeletal structure and comparing them to the normal mice (Olson et al. 687). The exact characteristics of Down Syndrome were not observed, so more genes involved for Down Syndrome phenotypes have to be located elsewhere.

Reeves et al, using 250 clones of chromosome-21 and specific gene markers, were able to map the gene in mutated bacteria. The testing had 99.7% coverage of the gene with 99.9995% accuracy due to multiple redundancies in the mapping techniques. In the study 225 genes were identified (311-313). The search for major genes that may be involved in Down syndrome symptoms is normally in the region 21q21-21q22.3. However, studies by Reeves et al show that 41% of the genes on chromosome 21 have no functional purpose, and only 54% of functional genes have a known protein sequence. Functionality of genes was determined by a computer using exon prediction analysis (312). Exon sequence was obtained by the same procedure of the chromosome-21 mapping.

Research has led to an understanding that two genes located on chromosome-21, that code for proteins that control gene regulators, DSCRI and DYRKIA can be responsible for some of the phenotypes associated with Down Syndrome. DSCRI and
DYRKIA cannot be blamed outright for the symptoms; there are a lot of genes that have no known purpose. Much more research would be needed to produce any appropriate or ethically acceptable treatment options.

Recent use of transgenic mice to study specific genes in the Down syndrome critical region has yielded some results. APP is an Amyloid beta A4 precursor protein. It is suspected to have a major role in cognitive difficulties. Another gene, ETS2 is Avian Erythroblastosis Virus E26 Oncogene Homolog 2. Researchers have “demonstrated that over-expression of ETS2 results in apoptosis. Transgenic mice over-expressing ETS2 developed a smaller thymus and lymphocyte abnormalities, similar to features observed in Down syndrome.

Sociological and Cultural aspects

Advocates for people with Down syndrome point to various factors, such as additional educational support and parental support groups to improve parenting knowledge and skills. There are also Strides being made in education, housing, and social settings to create environments which are accessible and supportive to people with Down syndrome. In most developed countries, since the early twentieth century many people with Down syndrome were housed in institutions or colonies and excluded from society. However, since the early 1960s parents and their organizations (such as MENCAP), educators and other professionals have generally advocated a policy of inclusion, bringing people with any form of mental or physical disability into general society as much as possible. In many countries, people with Down syndrome are educated in the normal school system; there are increasingly higher-quality opportunities to move from special (segregated) education to regular education settings.

Despite these changes, the additional support needs of people with Down syndrome can still pose a challenge to parents and families. Although living with family is preferable to institutionalization, people with Down syndrome often encounter patronizing attitudes and discrimination in the wider community. The first World Down Syndrome Day was held on 21 March 2006. The day and month were chosen to correspond with 21 and trisomy respectively. It was proclaimed by
European Down Syndrome Association during their European congress in Palma de Mallorca (febr. 2005). In the United States, the National Down Syndrome Society observes Down Syndrome Month every October as “a forum for dispelling stereotypes, providing accurate information, and raising awareness of the potential of individuals with Down syndrome. “In South Africa, Down Syndrome Awareness Day is held every October 20. Organizations such as Special Olympics Hawaii provide year-round sports training for individuals with intellectual disabilities such as down syndrome.

**How does Down Syndrome affect a child?**

Kids with Down Syndrome tend to share certain physical features such as a flat facial profile, an upward slant to the eyes, small ears, a single crease across the center of the palms, and an enlarged tongue. A doctor can usually tell if a newborn has the condition through a physical examination.

Low muscle tone and loose joints are also characteristic of children with DS, and babies in particular may seem especially “floppy”. Though this can and often does improve over time, most children with DS typically reach developmental milestones - like sitting up, crawling, and walking - later than other kids. At birth, kids with DS are usually of average size, but they tend to grow at a slower rate and remain smaller than their peers. For infants, low muscle tone may contribute to sucking and feeding problems, as well as constipation and other digestive issues. In toddlers and older children, there may be delays in speech and self-care skills like feeding, dressing and toilet teaching.

Down Syndrome affects kids’ cognitive abilities in different ways, but most have mild to moderate mental retardation. Kids with DS can and do learn, and are capable of developing skills throughout their lives. They simply reach goal sat a different pace - which is why it’s important not to compare a child with DS with typically developing siblings or even other children with the condition. Kids with DS have a wide range of abilities, and there is no way to tell at birth what they will be capable of as they grow up.
Medical Problems Associated with Down Syndrome

While some kids with DS have no other health problems, others may experience a host of medical issues that require extra care. For example, half of all children born with DS also have congenital heart defects and are prone to developing pulmonary hypertension (high blood pressure in the lungs). A pediatric cardiologist can monitor these types of problems, many of which can be treated with medication or surgery.

Approximately half of all kids with DS also have problems with hearing and vision. Hearing loss can be related to fluid buildup in the inner ear or to structural problems of the ear itself. Vision problems commonly include amblyopic (lazy eye), near or farsightedness, and an increased risk of cataracts. Regular evaluations by an audiologist and an ophthalmologist are necessary to detect and correct any problems before they affect a child’s language and learning skills.

Other medical conditions that may occur more frequently in children with DS include thyroid problems, intestinal abnormalities, seizure disorders, respiratory problems, obesity, an increased susceptibility to infection and a higher risk of childhood leukemia. Fortunately, many of these conditions are treatable.

Parental Screening and Diagnosis

There are two types of parental tests available to detect Down Syndrome in a fetus: screening tests and diagnostic tests. Screening tests estimate the risk that a fetus has DS; diagnostic tests can tell whether the fetus actually has the condition.

Screening tests are noninvasive and generally painless. But because they can not give a definitive answer as to whether a baby has DS, mostly they are used to help parents decide whether to have more diagnostic tests.

Diagnostic tests are about 99% accurate in detecting Down Syndrome and other chromosomal abnormalities. However, because they are performed inside the uterus, they are associated with a risk of miscarriage and other complications. For this reason, they are generally recommended only for women aged 35 or older, those
with a family history of genetic defects, or those who’ve had an abnormal result on a screening test. If you are unsure about which test, if any, is right for you, your doctor or a genetic counselor can help you sort through the pros and cons of each.

Screening tests include:

- **Nuchal translucency testing** This test, performed between 11 and 14 weeks of pregnancy, uses ultrasound to measure the clear space in the folds of tissue behind a developing baby’s neck. (Babies with DS and other chromosomal abnormalities tend to accumulate fluid there, making the space appear larger). This measurement, taken together with the mother’s age and the baby’s gestational age, can be used to calculate the odds that the baby has DS. Nuchal translucency testing correctly detects DS about 80% of the time; when performed with a maternal blood test, it may offer greater accuracy.

- **The triple screen** (also called the multiple marker test) and the **alpha-fetoprotein plus**. These tests measure the quantities of various substances in the mother’s blood, and together with the woman’s age, estimate the likelihood that her baby has Down Syndrome. They are typically offered between 15 and 20 weeks of pregnancy.

- **A detailed ultrasound**. This is often performed in conjunction with the blood tests, and it checks the fetus for some of the physical traits associated with Down Syndrome. However, these screening tests are only about 60% accurate and often lead to false-positive or false-negative readings.

Diagnostic tests include:

- **Amniocentesis**. This test, performed between 16 and 20 weeks of pregnancy, involves the removal of a small amount of amniotic fluid through a needle inserted in the abdomen. The cells can then be analyzed for the presence of chromosomal abnormalities. Amniocentesis carries a small risk of complications, such as preterm labor and miscarriage.

- **Chronic villus sampling** (CVS). CVS involves taking a tiny sample of the placenta, also through a needle inserted n the abdomen. The advantage of this test
is that it can be performed earlier than amniocentesis, between 8 and 12 weeks. The disadvantages is that it carries a slightly greater risk of miscarriage and other complications.

- **Percutaneous umbilical blood sampling (PUBS).** Usually performed after 20 weeks, this test uses a needle to retrieve a small sample of blood from the umbilical cord. It carries risks similar to those associated with amniocentesis.

After a baby is born, just looking at the baby can usually make a diagnosis of Down Syndrome. If the doctor suspects DS, a karyotype - a blood or tissue sample stained to show chromosomes grouped by size, number and shape - can be performed to verify the diagnosis.

**AUTISM**

Autism is a brain disorder that is associated with a range of developmental problems, mainly in communication and social interaction. The first signs of this disorder typically appear before age 3. Although treatment has improved greatly in the past few decades, autism cannot be cured. It persists throughout life. Autism is a development disorder. People with autism have trouble communicating and interacting with other people. A child with autism may seem very withdrawn, may not make eye contact with people, may not talk or play the way other children do, or may repeat certain motions and behaviours over and over again.

Signs of autism can vary from person to person. They can also be worse in some people than in others. People can be said to have “low-functioning autism” or “high-functioning autism”, depending upon the severity of their symptoms and the results of an IQ (intelligence) test. It’s estimated that three to six of every 1,000 children have autism. A recent increase in the number of autism cases in the United States may be the result of improved diagnosis and changes in diagnostic criteria. The disorder occurs three to four times more often in boys than in girls. The severity of symptoms is variable. Some children with autism will grow up able to live independently, while others may always need supportive living and working environments.
The cause of autism is not clear, and there is no cure. But intensive, early treatment can make a difference.

History

A few examples of autistic symptoms and treatments were described long before autism was named. The Table Talk of Matin Luther contains a story of a 12-year-old boy who may have been severely autistic. According to Luther’s note taker Mathesius, Luther thought the boy was a soulless mass of flesh possessed by the devil, and suggested that he be suffocated. Victor of Aveyron, a feral child caught in 1798, showed several signs of autism; the medical student Jean Itard treated him with a behavioral program designed to help him form social attachments and to induce speech via imitation.

The New Latin word autismus (English translation autism) was coined by the Swiss psychiatrist Eugen Bleuler in 1910 as he was defining symptoms of schizophrenia. He derived it from the Greek word autos, meaning self, and used it to mean morbid self-admiration, referring to “autistic withdrawal of the patient to his fantasies, against which any influence from outside becomes an intolerable disturbance”.

Leo Kanner introduced the label early infantile autism in 1943.

The word autism first took its modern sense in 1938 when Hans Asperger of Vienna University Hospital adopted Bleuler’s terminology “autistic psychopaths” in a lecture in German about child psychology. Asperger was investigating a form of ASD now known as Asperger syndrome, though for various reasons it was not widely recognized as a separate diagnosis until 1981 Leo Kanner of the Johns Hopkins Hospital first used autism in its modern sense in English when he introduced the label early infantile autism in a 1943 report of 11 children with striking behavioral similarities. Almost all the characteristics described in Kanner’s first paper on the subject, notably “autistic aloneness” and “insistence on sameness”, are still regarded as typical of the autistic spectrum of disorders. It is not known whether Kanner derived the term independently of Asperger.
Kanner’s reuse of autism led to decades of confused terminology like “infantile schizophrenia”, and child psychiatry’s focus on maternal deprivation during the mid 1900s led to misconceptions of autism as an infant’s response to “refrigerator mothers”. Starting in the late 1960s autism was established as a separate syndrome by demonstrating that it is lifelong, distinguishing it from mental retardation and schizophrenia and from other developmental disorders, and demonstrating the benefits of involving parents in active programs of therapy. As late as the mid-1970s there was little evidence of a genetic role in autism; now it is thought to be one of the most heritable of all psychiatric conditions. The rise of parent organizations and the destigmatization of childhood ASD have deeply affected how we view ASD, its boundaries, and its treatments. The Internet has helped autistic individuals by passing nonverbal cues and emotional sharing that they find so hard to deal with, and has given them a way to form online communities and work remotely. Sociological and cultural aspects of autism have developed; some in the community seek a cure, while others believe that autism is simply another way of being.

**Epidemiology**

Estimates of the prevalence of autism vary widely depending on diagnostic criteria, age of children screened, and geographical location. Most recent reviews tend to estimate a prevalence of 1-2 per 1,000 for autism and close to 6 per 1,000 for ASD; PDD-NOS is the vast majority of ASD, Asperger’s is about 0.3 per 1,000 and the typical forms, childhood disintegrative disorder and Rett syndrome are much rarer. A 2006 study of nearly 57,000 British nine and ten year olds reported a prevalence of 3.89 per 1,000 for autism and 11.61 per 1,000 for ASD; these higher figures could be associated with broadening diagnostic criteria.

The risk of autism is associated with several prenatal and perinatal risk factors. A 2007 review of risk factors found associated parental characteristics that included advanced maternal age, advanced paternal age, and maternal place of birth outside Europe or North America, and also found associated obstetric conditions that included low birth weight and gestation duration, and hypoxia during childbirth. About 10-15% of autism cases have an identifiable Mendelian (single-gene) condition, chromosome abnormality, or other genetic syndrome, and ASD is associated with
several genetic disorders. Autism is associated with mental retardation: a 2001 British study of 26 autistic children found about 30% with intelligence in the normal range (IQ above 70), 50% with mild to moderate retardation, and about 20% with severe to profound retardation (IQ below 35). For ASD other than autism the association is much weaker; the same study reported about 94% of 65 children with PDD-NOS or Asperger’s had normal intelligence. ASD is also associated with epilepsy, with variations in risk of epilepsy due to age, cognitive level, and type of language disorder. Several metabolic defects, such as phenylketonuria, are also associated with autistic symptoms. Boys are at higher risk for autism than girls. The ASD sex ratio averages 4.3:1 and is greatly modified by cognitive impairment; it may be close to 2:1 with mental retardation and more than 5.5:1 without. Recent studies have found no association with socioeconomic status, and have reported inconsistent results about associations with race or ethnicity Phobias, depression and other psychopathological disorders have often been described along with ASD but this has not been assessed systematically.

Reports of autism cases grew dramatically in the U.S. in 1996-2005. It is unknown how much, if any, growth came from changes in autism’s prevalence.

Autism’s incidence rate, despite its advantages for assessing risk, is less useful in autism epidemiology, as the disorder starts long before it is diagnosed, and the gap between initiation and diagnosis is influenced by many factors unrelated to risk. Attention is focused mostly on whether prevalence is increasing with time. Earlier prevalence estimates were lower, centering at about 0.5 per 1,000 for autism during the 1960s and 1970s and about 1 per 1,000 in the 1980s as opposed to today’s 1-2 per 1,000. The number of reported cases of autism increased dramatically in the 1990s and early 2000s. This increase is largely attributable to changes in diagnostic practices, referral patterns, availability of services, age at diagnosis, and public awareness though as-yet-identified contributing environmental risk factors cannot be ruled out. A widely cited 2002 pilot study concluded that the observed increase in autism in California cannot be explained by changes in diaphragm criteria but a 2006 analysis found that special education data poorly measured prevalence because so many cases were undiagnosed, and that the 1994-2003 U.S. increase was associated
with declines in other diagnostic categories, indicating that diagnostic substitution had occurred. It is unknown whether autism’s prevalence increased during the same period. An increase in prevalence would suggest directing more attention and funding toward changing environmental factors instead of continuing to focus on genetics.

**Signs and Symptoms**

In general, children with autism have problems in three crucial areas of development - social skills, language and behavior. The most severe autism is marked by a complete inability to communicate or interact with other people.

Because the symptoms of autism vary widely, two children with the same diagnosis may act quite differently and have strikingly different skills.

If your child has autism, he or she may develop normally for the first few months - or years - of life and then later become less responsive to other people, including you. You may recognize the following signs in the areas of social skills, language and behaviour.

**Social skills**

- Fails to respond to his or her name
- Has poor eye contact
- Appears not to hear you at times
- Resists cuddling and holding
- Appears unaware of other’s feelings
- Seems to prefer playing alone - retreats into his or her “own world”

**Language**

- Starts talking later than other children
- Loses previously acquired ability to say words or sentences
- Does not make eye contact when making requests
- Speaks with an abnormal tone or rhythm - may use a singsong voice or robot like speech
- Can’t start a conversation or keep one going
May repeat words or pin ises verbatim, but doesn't understand how to use them

Behavior

- Performs repetitive movements, such as rocking, spinning or hand-flapping
- Develops specific routines or rituals
- Becomes disturbed at the slightest change in routines or rituals
- Moves constantly
- May be fascinated by parts of an object, such as the spinning wheels of a toy car
- May be unusually sensitive to light, sound and touch

Young children with autism also have a hard time sharing experiences with others. When someone reads to them, for example, they’re unlikely to point at pictures in the book. This early-developing social skill is crucial to later language and social development. As they mature, some children with autism become more engaged with others and show less marked disturbances in behaviour. Some, usually those with the least severe impairments, eventually may lead normal or near-normal lives. Others, however, continue to have severe impairments in language or social skills, and the adolescent years can mean a worsening of behaviour problems. The majority of children with autism are slow to acquire new knowledge or skills. However, some children with autism have normal to high intelligence. These children learn quickly yet have trouble in communicating, applying what they know in everyday life and adjusting in social situations. An extremely small number of children with autism are “autistic savants” and have exceptional skills in a specific area, such as art or math.

Causes

Autism has no single, identifiable cause. The disorder seems to be related to abnormalities in several regions of the brain. Researchers have identified a number of gene defects associated with autism.
Families with one autistic child have a one in 20 chance of having a second child with the disorder. In some cases, relatives of autistic children show mild impairments in social and communication skills or engage in repetitive behaviours.

Children with symptoms of autism have a higher than normal risk and also having:

- Fragile X syndrome, which causes mental retardation
- Tuberous sclerosis, in which tumors grow in the brain
- Tourette’s syndrome
- Epilepsy

Some people believe autism is caused by vaccines - particularly the measles-mumps-rubella vaccine (MMR), as well as vaccines containing thimerosal, a preservative that contains a very small amount of mercury. But extensive studies have shown no link between vaccines and autism.

Although many genetic and environmental causes of autism have been proposed, its theory of causation is still incomplete. Some researchers argue that this is because autism is not a single disorder, but rather a triad of core aspects (social impairment, communication difficulties and repetitive behaviors) that have distinct causes but often co-occur. Genetic factors is the most significant cause for autism spectrum disorders. Early studies of twins estimated heritability to be more than 90%; in other words, that genetics explains more than 90% of autism cases. This may be an overestimate; new twin data and models with structural genetic variation are needed. When only one identical twin is autistic, the other often has learning or social disabilities. For adult siblings, the risk of having one or more features of the broader autism phenotype might be as high as 30%, much higher than the risk in controls.

The genetics of autism is complex. Genetic linkage analysis has been inconclusive; many association analyses have had inadequate power. For each autistic individual, mutations in more than one gene may be implicated. Mutations in different sets of genes may be involved in different autistic individuals. There may be significant interactions among mutations in several genes, or between the environment and mutated genes. By identifying genetic markers inherited with
autism in family studies, numerous candidate genes have been located, most of which encode proteins involved in neural development and function. However, for most of the candidate genes, the actual mutations that increase the risk for autism have not been identified. Typically, autism cannot be traced to a Mendelian (single-gene) mutation or to single chromosome abnormalities such as fragile X syndrome or 22q13 deletion syndrome.

Deletion (1), duplication (2) and inversion (3) are all chromosome abnormalities that have been implicated in autism.

The large number of autistic individuals with unaffected family members may result from copy number variations (CNVs) - spontaneous alterations in the genetic material during meiosis that delete or duplicate genetic material. Sporadic (non-inherited) cases have been examined to identify candidate genetic loci involved in autism. Using array comparative genomic hybridization (array CGH), a technique for detecting CNVs, one study found them in 10% of families with one affected child. Some of the altered loci had been identified in previous studies of inherited autism; many were unique to the sporadic cases examined in this study. Hence, a substantial fraction of autism may be highly heritable but not inherited: that is, the mutation that causes the autism is not present in the parental genome. Although the fraction of autism traceable to a genetic cause may grow to 30-40% as the resolution of array CGH improves, several results in this area have been described incautiously, possibly misleading the public into thinking that a large proportion of autism is caused by CNVs and is detectable via array CGH, or that detecting CNVs is tantamount to a genetic diagnosis. The Autism Genome Project database contains genetic linkage and CNV data that connect autism to genetic loci and suggest that every human chromosome may be involved.

Teratogens (agents that cause birth defects) related to the risk of autism include exposure of the embryo to thalidomide, valproic acid, or misoprostol, or to rubella infection in the mother. These cases are rare. All known teratogens appear to act during the first eight weeks from conception, and though this does not exclude the possibility that autism can be initiated or affected later, it is strong evidence that autism arises very early in development. Although extensive searches are underway
for other environmental causes, evidence for them in anecdotal and has not been confirmed by reliable studies. Several other pre-or post-natal environmental factors have been claimed to contribute to autism or exacerbate its symptoms, or may be important to consider in future research. They include certain foods, infectious disease, heavy metals, solvents, diesel exhaust, PCBs, phthalates and phenols used in plastic products, pesticides, brominated flame retardants, alcohol, smoking, illicit drugs, and vaccines. Although parents may first become aware of autistic symptoms in their child around the time of a routine vaccination, and parental concern about vaccines has led to a decreasing uptake of childhood immunizations and an increasing likelihood of measles outbreaks, there is overwhelming scientific evidence showing no causal association between the measles-mumps-rubella vaccine and autism, and there is no convincing evidence that the vaccine preservative thiomersal helps cause autism.

**Screening**

Parents are usually the first to notice their child’s unusual behaviours. Deficits in joint attention seem to distinguish infants with ASD; for example, they may not follow when a parent points and says “Look! As postponing treatment may affect long-term outcome, any of the following signs is reason to have a child evaluated by a specialist without delay;

- No babbling by 12 months.
- No gesturing (pointing, waving goodbye, etc.) by 12 months.
- No single words by 16 months.
- No two-word spontaneous phrases (non including echolalia) by 24 months.
- Any loss of any language or social skills, at any age.

The American Academy of Pediatrics recommends that all children be screened for ASD at the 18 and 24 month well-child doctor visits, using autism-specific formal screening tests. In contrast, the UK National Screening Committee recommends against screening for ASD in the general population, because screening tools have not been fully validated and interventions lack sufficient evidence for effectiveness.
Genetic screening for autism is generally still impractical. As genetic tests are developed, several ethical, legal, and social issues will emerge. Commercial availability of tests may precede adequate understanding of how to use test results, given the complexity of autism’s genetics.

**Diagnosis**

Diagnosis is based on behaviour, not cause or mechanism. Autism is defined in the DSM-IV-TR as exhibiting at least six symptoms total, including at least two symptoms of qualitative impairment in social interaction, at least one symptom of qualitative impairment in communication, and at least one symptom of restricted and repetitive behaviour. Sample symptoms include lack of social or emotional reciprocity, stereotyped and repetitive use of language or idiosyncratic language, and persistent preoccupation with parts of objects. Onset must be prior to age three years, with delays or abnormal functioning in either social interaction, language as used in social communication, or symbolic or imaginative play. The disturbance must not be better accounted for by Rett syndrome or childhood disintegrative disorder. ICD-10 uses essentially the same definition.

Several diagnostic instruments are available. Two are commonly used in autism research: the Autism Diagnostic Interview-Revised (ADI-R) is a semi-structured parent interview, and the Autism Diagnostic Observation Schedule (ADOS) uses observation and interaction with the child. The Childhood Autism Rating Scale (CARS) is used widely in clinical environments to assess severity of autism based on observation of children.

A pediatrician commonly performs a preliminary investigation by taking developmental history and physically examining the child. If warranted, diagnosis and evaluations are conducted with help from ASD specialists, observing and assessing cognitive, communication, family, and other factors using standardized tools, and taking into account any associated medical conditions. A differential diagnosis for ASD at this stage might also consider mental retardation, hearing impairment, and specific language impairment such as Landau-Kleffner syndrome. In the UK the National Autism Plan for Children recommends at most 30 weeks from
first concern to complete diagnosis and assessment, though few cases are handled that quickly in practice. ASD can sometimes be diagnosed by age 14 months, but a 2006 U.S. study found the average age of first evaluation by a qualified professional was 48 months and of formal ASD diagnosis was 61 months, reflecting an average 13-month delay, all far above recommendations.

Underdiagnosis and overdiagnosis are problems in marginal cases, and much of the recent increase in the number of reported ASD cases is likely due to changes in diagnostic practices. The increasing popularity of drug treatment options and the expansion of benefits have given providers incentives to diagnose ASD, resulting in some overdiagnosis of children with uncertain symptoms. Conversely, the cost of screening and diagnosis and the challenge of obtaining payment can inhibit or delay diagnosis. It is particularly hard to diagnose autism among the visually impaired, partly because some of its diagnostic criteria depend on vision, and partly because symptoms overlap with those of common blindness syndromes.

The symptoms of autism and ASD begin early in childhood but are occasionally missed. Adults may seek retrospective diagnoses to help them or their friends and family understand themselves, to help their employers make adjustments, or in some locations to claim disability living allowances or other benefits.

**Prognosis**

There is no cure. Most children with autism lack social support, meaningful relationships, future employment opportunities or self-determination. Although core difficulties remain, symptoms often become less severe in later childhood. Few high-quality studies address long-term prognosis. Some adults show modest improvement in communication skills, but a few decline; no study has focused on autism after midlife. Acquiring language before age six, having IQ above 50, and having a marketable skill all predict better outcomes; independent living is unlikely with severe autism. A 2004 British study of 68 adults who were diagnosed before 1980 as autistic children with IQ above 50 found that 12% achieved a high level of independence as adults, 10% had some friends and were generally in work but required some support, 19% had some independence but were generally living at home and needed
considerable support and supervision in daily living, 46% needed specialist residential provision from facilities specializing in ASD with a high level of support and very limited autonomy, and 12% needed high-level hospital care. A 2005 Swedish study of 78 adults that did not exclude low IQ found worse prognosis; for example, only 4% achieved independence. Changes in diagnostic practice and increased availability of effective early intervention make it unclear whether these findings can be generalized to recently diagnosed children.

Pathophysiology

Autism affects many parts of the brain

Autism appears to result from developmental factors that affect many or all functional brain systems. Neuroanatomical studies and the associations with teratogens strongly suggest that autism’s mechanism includes alteration of brain development soon after conception. This localized anomaly appears to start a cascade of pathological events in the brain that are significantly influenced by environmental factors. Many major structures of the human brain have been implicated. Consistent abnormalities have been found in the development of the cerebral cortex; and in the cerebellum and related inferior olive, which have a significant decrease in the number of Purkinje cells. Brain weight and volume and head circumference tend to be greater in autistic children. The cellular and molecular bases of pathological early overgrowth are not known, nor is it known whether the overgrown neural systems cause autism’s characteristic signs. Current hypotheses include:

> An excess of neurons that causes local over connectivity in key brain regions.
> Disturbed neuronal migration during early gestation,
> Unbalanced excitatory-inhibitory networks.
> Abnormal formation of synapses and dendritic spines.

Interactions between the immune system and the nervous system begin early during embryogenesis, and successful neurodevelopment depends on a balanced immune response. Several symptoms consistent with a poorly regulated immune response have been reported in autistic children. It is possible that aberrant immune activity during critical periods of neurodevelopment is part of the mechanism of some
forms of ASD. As auto antibodies have not been associated with pathology, are found in diseases other than ASD, and are not always present in ASD, the relationship between immune disturbances and autism remains unclear and controversial.

Several neurotransmitter abnormalities have been detected in autism, notably increased blood levels of serotonin. Whether these lead to structural or behavioral abnormalities is unclear. Also, some inborn errors of metabolism are associated with autism but probably account for less than 5% of cases.

The mirror neuron system (MNS) theory of autism hypothesizes that distortion in the development of the MNS interferes with imitation and leads to autism’s core features of social impairment and communication difficulties. The MNS operates when an animal performs an action or observes another animal of the same species perform the same action. The MNS may contribute to an individual’s understanding of other people by enabling the modeling of their behavior via embodied simulation of their actions, intentions and emotions. Several studies have tested this hypothesis by demonstrating structural abnormalities in MNS regions of individuals with ASD, delay in the activation in the core circuit for imitation in individuals with Asperger’s, and a correlation between reduced MNS activity and severity of the syndrome in children with ASD. A variant theory, EP-M, segments the MNS into an indirect route for goal emulation and planning (EP) and a direct route for mimicry (M), and hypothesizes that only the M route is impaired in autism. A 2007 study of autistic adults found evidence for altered functional organization of the task-negative network, a large-scale brain network involved in social and emotional processing, with intact organization of the task-positive network, used in sustained attention and goal-directed thinking.

Functional magnetic resonance imaging provides some evidence for the under connectivity theory of autism.

The under connectivity theory of autism hypothesizes that autism is marked by under functioning high-level neural connections and synchronization, along with an excess of low-level processes. Evidence for this theory has been found in functional neuroimaging studies on autistic individuals and by a brain wave study that suggested
that adults with ASD have local overconnectivity in the cortex and weak functional connections between the frontal, lobe and the rest of the cortex. Other evidence suggests the under connectivity is mainly within each hemisphere of the cortex and that autism is a disorder of the association cortex.

Neuropsychology

Two major categories of cognitive theories have been proposed about the links between autistic brain and behavior.

The first category focuses on deficits in social cognition. Hyper-systemizing hypothesizes that autistic individuals can systematize - that is, they can develop internal rules of operation to handle internal events - but are less effective at empathizing by handling events generated by other agents. It extends the extreme male brain theory, which hypothesizes that autism is an extreme case of the male brain, defined psychometrically as individuals in whom systemizing is better than empathizing. This turn is related to the earlier theory of mind, which hypothesizes that autistic behaviour arises from an inability to ascribe mental states to oneself and others. The theory of mind is supported by autistic children’s atypical responses to the Sally-Anne test for reasoning about others motivations, and is mapped well from the mirror neuron system theory of autism.

The second category focuses on nonsocial or general processing. Executive dysfunction hypothesizes that autistic behavior results in part from deficits in flexibility, planning, and other forms of executive function. A strength of the theory is predicting stereotyped behavior and narrow interests; a weakness is that executive function deficits are not found in young autistic children. Weak central coherence theory hypothesizes that a limited ability to see the big picture underlies the central disturbance in autism. One strength of this theory is predicting special talents and peaks in performance in autistic people. A related theory - enhanced perceptual functioning - focuses more on the superiority of locally oriented and perceptual operations in autistic individuals. These theories map well from the under connectivity theory of autism.
Neither category is satisfactory on its own; social cognition theories poorly address autism’s rigid and repetitive behaviors, while the nonsocial theories have difficulty explaining social impairment and communication difficulties. A combined theory based on multiple deficits may prove to be more useful.

Management

The main goals of treatment are to lessen associated deficits and family distress, and to increase quality of life and functional independence. No single treatment is best and treatment is typically tailored to the child’s needs. Intensive, sustained special education programs and behavior therapy early in life can help children acquire self-care, social, and job skills; claims that intervention by age two or three years is crucial are not substantiated. Among the available approaches, applied behavior analysis (ABA) has demonstrated efficacy in promoting social and language development and in reducing behaviors that interfere with learning and cognitive functioning; ABA focuses on teaching tasks one-on-one using the behaviorist principles of stimulus, response and reward. Several programs are based on ABA. Some focus on discrete trial teaching; more-comprehensive ones use multiple assessment and intervention methods individually and dynamically. Cognitive therapies based on comprehensive programs in treatment centers are a common alternative; for example, TEACCH focuses on structuring the physical environment and using visual supports for language development tasks. A 2005 California study found that early intensive behavior analytic treatment, a form of ABA, was substantially more effective for preschool children with autism than the mixture of methods provided in many programs, but a 2007 British study found that home-based early intensive behavioral interventions, another ABA form, was no more effective than nursery-based eclectic programs. The limited research on the effectiveness of adult residential programs shows mixed results.

Medications are often used to treat problems associated with ASD. More than half of U.S. children diagnosed with ASD are prescribed psychoactive drugs or anticonvulsants, with the most common drug classes being antidepressants, stimulants, and antipsychotics. In the United States, the antipsychotic risperidone is approved for treating symptomatic irritability in autistic children aged 5-16 years.
Other drugs are prescribed off-label, which means they have not been approved for treating ASD. For example, some selective serotonin reuptake inhibitors and dopamine blockers can reduce some maladaptive behaviors associated with ASD. However, there is scant reliable research about the effectiveness or safety of drug treatments for adolescents and adults with ASD. A person with ASD may respond atypically to medications, the medications can have adverse side effects, and no known medication relieves autism’s core symptoms of social and communication impairments.

Many other therapies and interventions are available. Few are supported by scientific studies. Treatment approaches lack empirical support in quality-of-life contexts, and many programs focus on success measures that lack predictive validity and real-world relevance. Scientific evidence appears to matter less to service providers than program marketing, training availability, and parent requests. Even if they do not help, conservative treatments such as changes in diet are expected to be harmless aside from their bother and cost. Dubious invasive treatments are a much more serious matter: Several treatments for autism are available. Research has shown that very intense behavior and language therapy may help some children. There is no medicine that treats autism itself, but medicine may help with some of the symptoms of autism, such as aggressive behavior or sleeplessness. Talk to your doctor about what kind of therapy can help your child.

Children don’t “outgrow” autism, and it can’t be cured. With therapy, some children may improve as they mature. The individual child’s language skills and overall intellectual level may help predict what will happen with the autism. Treatment is expensive; indirect costs are more so. A U.S. study estimated the average additional lifetime cost due exclusively to autism to be $3.2 million in 2003 U.S. dollars for an autistic individual born in 2000, with about 10% medical care, 30% non-medical care such as child care and education, and 60% the lost economic productivity of individuals and their parents. A British study estimated an average lifetime cost of 2.4 million in 1997-1998 British pounds. Legal rights to treatment are complex, vary with location and age, and require advocacy by caregivers. Publicly supported programs are often inadequate or inappropriate for a given child, and
unreimbursed out-of-pocket medical therapy expenses are associated with likelihood of family financial problems. After childhood, key treatment issues include residential care, job training and placement, sexuality, social skills, and estate planning.

Mechanism: There’s no cure for autism, and there’s no “one-size-fits-all” treatment. In fact, the range of home-based and school-based treatments and interventions for autism can be overwhelming. Your doctor can help identify resources in your area that may work for your child. Treatment options may include:

**Behavioral and communication therapies.** Many programs have been developed to address the range of social, language and behavioral difficulties associated with autism. Some programs focus on reducing problem behaviors and teaching new skills. Other programs focus on teaching children how to act in social situations or how to communicate better with other people.

**Drue therapies.** Right now, there are no medications that directly improve the core signs of autism. But some medications can help control symptoms. Stimulants can help with hyperactivity, while antipsychotic drugs sometimes will control repetitive and aggressive behaviors.

**Complementary approaches.** Some parents choose to supplement educational and medical intervention with complementary therapies, such as art therapy, music therapy, special diets, vitamin and mineral supplements, and sensory integration - which focuses on reducing a child’s hypersensitivity to touch or sound. However, there is no scientific proof that these therapies work. It’s important to talk with your child’s doctor before trying any treatment.

Children with autism often respond well to highly structured education programs. Successful programs often include a team of specialists and a variety of activities to improve social skills, communication and behavior.

A child won’t “outgrow” autism. But he or she can learn to function within the confines of the disorder, especially if treatment begins early. Preschool children who receive intensive, individualized behavioral interventions show good progress.
Coping Skills

Raising a child with autism can be physically exhausting and emotionally draining. These ideas may help:

• Find a team of trusted professionals. You’ll need to make important decisions about your child’s education and treatment. Find a team of teachers and therapists who can help evaluate the options in your area and explain the federal regulations regarding children with disabilities. Make sure this team includes a case manager or service coordinator, who can help access financial services and government programs.

• Take time for yourself and other family members. Caring for a child with autism can be round-the-clock job that puts stress on your marriage and your whole family. To avoid burnout, take time out to relax, exercise or enjoy your favorite activities. Try to schedule one-on-one time with your other children and plan date nights with your spouse - even if it’s just watching a movie together after the children go to bed.

Despite extensive investigation, how autism occurs is not well understood. Its mechanism can be divided into two areas: the pathophysiology of brain structures and processes associated with autism, and the neuropsychological linkages between brain structures and behaviors. The behaviors appear to have multiple pathophysiologies.

STRESS

The term ‘stress’ described as a state of imbalance within the organism that is elicited by an actual or perceived disparity between environmental demands and the organisms capacity to cope with these demands. It is manifested through a variety of psychological, emotional and behavioural responses (Selye 1976). Hence the conceptualization of the term ‘stress’ has been proposed from three perspectives namely, medical, psychological and social. From a medical perspective stress is typically constructed as a defensive bodily response to environmental demands involving specific physiological components such as adrenal stimulation, gastro-
intestinal disturbances and the shrinkage of lymphatic structures (Selye, 1966). Psychological analysis (Apply et al., 1967) plays a greater emphasis on the individual’s cognitive appraisal. It threatens environmental conditions and personal coping resources (Lazarus, 1984, Me. Grath, 1970). Sociological analysis focus on societal conditions such as Economic change and lack of social support resources that adversely affect the well being of specific groups in the community. (Levine and Scotch N. 1970., Brenner, 1973).

Psychologists have considered different approaches to stress. These are

1. Stimulus - oriented approach
2. Response - oriented approach
3. Physiological approach
4. Psychodynamic approach
5. Socially oriented approach

1. **Stimulus - oriented approach to stress**

   Stress is regarded as an external force which is perceived as threatening. Some regard threat itself as stress. Others consider stress to be a stimulus which triggers off a chronic state of anxiety. Occasionally, stress is treated as an environmental condition. Seyle (1976) considers “any external event or any internal drive, which threatens to upset the organic equilibrium” as stress.

2. **Response - oriented interpretation to stress**

   Another approach to stress is from the point of view of responses. The basic question is how do people respond to stress situation? The nature of stress, it is claimed, can be understood in terms of the way people perceive and ascribe meaning to stress producing situation, the values they attribute to actions and the way they interact with events. Psychiatrists identify four phases in reaction to stress. These are

   a. the initial phase of anticipatory threat
   b. the impact of stress
   c. the recoil phase and
   d. the post traumatic phase
3. The Physiological approach to stress

The biologically-oriented approach to stress is pain response oriented. The reactions of the organism are considered as attempts to come to terms with the environment. Response to a threatening situation is looked upon as an emergency reaction, to protect the integrity of the organism. Stressful events trigger automatic responses, bringing about neuro-physiological, muscular and glandular changes.

4. The Psycho-dynamic approach to stress

Events, external or internal, which pose a threat to the integrity of the organism, leading to the disorganization of the personality is called stress. Stress presages loss of ego strength and loss of ego support. Stress may be induced by external or internal factors leading to anxiety. Anxiety produces fear and apprehension, that the learned ways of coping may not suffice. Stress may even result in a catatonic stupor in extreme cases. Sometimes stress is defined in terms of adjustment. The handling of extra psychic stress is looked upon as coping behaviour, whereas intrapsychic maneuvers call defensive mechanisms. Generally, stress has reference to some unsuccessfully resolved situations in the past. It refers to ego capabilities that the individual does not have or has not yet acquired. In either case, stress poses a threat to the individual’s self-esteem as the intra-psychic coherence is being disturbed.

5. Socially oriented approach to stress

Mechanic (1968) attempts to explain the social determinants of stress from the standpoint of the social structure of the community rather than from the personal experiences of the individual alone. The meaning of a crisis is not in the situation but rather in the interaction between the situation and the person’s ability to rise above it. Mechanic (1968) further states that an individual’s ability to cope with problems is influenced by a society’s preparatory institutions, such as schools and the family - the two main social institutions that are designed to develop skills and competencies in dealing with society’s needs. An individual’s emotional control and ability to depend are also related to society’s incentive system - that is,
society’s rewards or punishments for those who do or do not control their behaviour in accordance with societal norms.

Mechanic’s (1968) model represents an important contribution towards the understanding of stress by showing the importance of adaptation and explaining how that adaptation is based upon an individual’s perception of life situation combined with his or her degree of preparation by society to cope with stressful situations. Mechanic thus identifies adaptability as the key variable in whether or not a person will eventually suffer organic damage. The main criticism of Mechanic’s work, however, is that he fails to deal adequately with the relationship between social processes and specific physiological responses (Moss.G. 1973). However his theory provides considerable insight into the social factors involved in understanding stress.

Schwab R. and Prichard John (1950) have classified types of situations that they believe may lead to physiological disorders and chronic disease. Their classification system was based not only upon the type of situation, but also the duration of the influence of the situation and the degree of stress induced by that situation.

1. Short stress or mild stress situations
2. Moderate stress situations
3. Severe stress situations

Prolonged illness or chronic disability can give rise to severe stress interaction which can in turn affect the physical and mental health of the individual.

In general, the studies conducted so far concerning the relation of life stress to illness, falls into two categories namely direct and indirect (Dohrenwend, 1978). The indirect ones are dealing with direct environmental stress like personal awful-experiences. It is only recently such direct studies have been conducted which seek to investigate the relationship between exposure to common stressful life events i.e., circumstances requiring changes in an individuals normal day-to-day routine and the subsequent onset of illness. A systematic programme of research in this regard was
initiated by Holmes and Rahe in 1967. They have identified personal illness as one of the major life event factors that can warrant social readjustments that induce stress.

Family Stress

Planned research efforts to understand and explain family’s response to stressful situations dates back to 1949 by Rubin Hill’s pivotal work in the field of family stress and his publication is entitled “Families under stress”. Using the earlier works of Koos (1949) and Angel (1936), Rubin Hill set forth a two part theoretical model of families under stress. According to this model, families are in a homeostatic state until a stress or event upsets the family unit. Through a period of trial and error, the family achieves a resolution of crisis. In 1965, Hill adopted a few additions to his model and re-designated it as ABC X model in which A refers to the interaction with the family crisis, with the meeting resources called B, the family’s definition of events as threatening is called C and the ultimate reduction of the crisis is X.

After Hill, Burr’s (1973) contribution to the study of family stress is significant. He formulated the ABC X formulation into the bonafide part of a deductive theory. Burr was able to identify and define six variables and advanced nine propositions to explain family behaviour in response to stressors. From this work, his central concepts of vulnerability and regenerative power emerged as major new additions to Hill’s framework. These concepts have subsequently stimulated other researchers to a renewed interest in family stress research and theory building (Hansen et al 1979).

Although the concept of family stress was utilized with considerable frequency in both clinical and research literature, it continued to remain elusive and was frequently used without explicit definition. In general stressors were defined as those life events or occurrences of crisis of sufficient magnitude to bring about change in the family system. A crisis referred to the amount of incapacity or disorganization in the family in which resources were inadequate (Lipman - Blueman, 1975). In this regard, initially researchers tended to approach family stress in terms of the stressful events. Many studies utilized life events as family stress and evolved significant findings. For example. Me Cubbin Wilson and Patterson (1979) have recorded the
identity of various life events by enquiring about family perceptions of botheration, unhappiness and having problems in coping, in order to arrive at “stress scores”.

The parents of children with Intellectually Challenged definitely face more difficult than the parents of normal children, which in turn affect their emotional well-being. There is perhaps no event more devastating to a family than a child born with a birth defect. There is no more severe test of family’s resiliency than the discovery that a child is with an incurable disability. Understanding the emotional reactions and attitude of parents as well as family members of retarded children are of great importance in the management. Children with physical disabilities generally require more care, attention and direct supervision than children without disabilities do. Research demonstrate that these higher care-giving-demands are associated with poorer psychological and physical health states for parents and other family member (Finston 1990)

Many factors scan the influence of the well being of a family. Parents are definitely the heart of the family. They are the ones who deal with the issues associated with child’s disability and also maintain the household therefore it is very important for parents to take some time to care for themselves as individuals getting enough sleep, eating regular meals, taking short walk and doing things that they really enjoy. Parents having a child with Intellectually Challenged experience a variety of stressors and stress reaction related to the child’s disability. Parents are aware of the impacts in many ways of having a special child. These include feeling sad, depression at various stage of life and experiencing other emotional reactions. Their social life may get affected, recreational and leisure activities get reduced, interpersonal relationship with the family members also get affected, financial problems may arise, parents own physical and mental health also there to be at greater risk (Orr, Rutter & Quinton, 1933).

1. In a study by Geetha, Bhaskar (1993) on certain characteristics of the families of mentally retarded children and normal children. It was found that there is significant difference between two groups on all the variable factors studied.
2. Allik, Klassen Miller and Fine (2006) conducted a study aimed to evaluate aspects of health related quality of life in parents of school aged children with Asperger Syndrom (AS), High functioning Autism (HFA) and the correlation with child behaviour-characteristics were assessed using the structural questionnaire. The result showed that mothers of children with AS/HFA had lower SF-12 scores, indicating poorer emotional health. They also had lower physical SF-12 scores compared to the father in the AS/HFA group. Maternal health was related to behaviour problem such as hyperactivity and conduct problem in the child.

3. Studies conducted by Wright, Matlock, and Matlock (1985) attempted to evaluate the effects of stresses of having a child with disabilities on the lives of their parents. The study compared the parents of children with disabilities to the parents of children without disabilities. It was found that the parents of children with disabilities did not differ from the other parents with respect to self image, and quality of life or life satisfaction. We know from experience and the findings of reference that having a child with a disability seriously affects everyone in the family.

4. A study conducted by Altman, co-opor and cunyham (1999) in the case of disability in the family, The impact on health care utilization and expenditure for non-disabled members. It was found that families with a disabled member undergo heightened emotional and financial stress, which can arise from caring for the person with one or more disabilities over the life course or at the end of life. The dates were subjected to t-test to find out the significance of gender difference on the study variables. The t-value obtained from the variables indicate that there is no significant difference on emotional intelligence and quality of life. Both the male and female parents scored some what equally. It can be inferred that the responsibility of child rearing is equally shared by fathers as well as mothers irrespective of the condition of the child.

5. Bekman, Burden, Bradshaw and Lawton found the mothers of mentally retarded children had a high level of stress. The observations of the study was (i) both the parents of profoundly and moderately retarded children perceived high level of stress (ii) mothers in group of severely affected children, Borderline case of
affected children and normal children showed significant difference on the FISC score (iii) mothers of severely affected children and that of normal children differed significantly from their spouse on the FISC scores. Mothers who were housewives without additional help felt restricted in pursuing their social and leisure activities, and experienced more stress. Further the finding of this study is that fathers in group of severely affected, Borderline affect and normal children differed significantly in experiencing stress in accordance with that of Wishort et al.

6. Kumar and Akhatar found mothers of mentally retarded children had a high level of anxiety as compared to mother of normal children. Mothers of severely affected, mildly affected showed high level of anxiety when compared to their spouses and fathers of severely showed comparatively higher level of anxiety than fathers of Borderline case of affected children and the normal children. Number of literature is available to support these results. In addition to this finding there was a positive relationship between the perceived stress and anxiety manifested in all the three groups. Except mothers of normal children other factors need to be confirmed by further research.

7. Emotional Intelligence and Quality of life of parents of children with special needs was done by Vidya Ravindranadan and Rajvis - University of Kerala, Tiruvananthapuram.

The present study intended to examine the emotional Intelligence and Quality of life of parents of children with special needs, the study was conducted on a sample of 200 parents of which 100 pre parents of children with special need and 100 were matched parents of normal children. The five selected categories of special needs are ADHD, Autistic Disorder, Down Syndrome, Mental retardation and Learning disabilities. The tools used for the study are Emotional Intelligence Scale and Quality of life scale. The result reveals that the parents of children with special needs are significantly different from the parents of normal children on the study variables irrespective of the category to which the child belongs. It is also interesting to know that the condition of the child affects both the parents equally.
8. The study conducted by Krauss (1993), to find the similarities and differences in child-related parenting stress between mothers and fathers of 121 toddlers with disabilities. Fathers reported more stress related to their child temperament and their relationship with the child. Mothers reported more stress from the personal consequences of parenting. Differences between mothers and fathers regarding the most powerful predictors of child related and parenting stress were also found. Fathers were more sensitive to the effect of the family environment, whereas mothers were more affected by their personal support networks.

9. The study conducted by Girojameto and Tonnock (1994) also found that both parents reported similarly low levels of child related and parenting stress but mothers perceived more stress than fathers related to the responsibilities associated with parenting child with handicap one way Anova has been done to find out the significant difference on the study variables. The five category of special needs selected for the study are ADHD, Autism, Down Syndrome, MR and CD. The result indicated that there is no significant difference among the parents of different categories of children with special needs on emotional intelligence and quality of life. It can be concluded that all the parents of children with special needs scored more or less same emotional intelligence and quality of life and the parents of children with special needs cannot be differentiated on the category of their child.

10. Girrisen and Semsanande (1988) measures quality of life using five subscales viz, finance, home, family and friends, household, community and environment. The result indicated that the independent, variable gender, race, marital status, age, family income and employment status differentially affected the quality of life subscales. The result obtained in the present study supported the hypothesis that the parents of children with special needs are significantly different from parents of normal children on the study variables. It is also interesting to know that the problem of special needs affect both the mother and father equally.
Caregivers

The social development council (SDC) in New Zealand defines families with special care giving responsibilities as those whose households include people requiring more than usual assistance and attention from others. They include families’ with care giving duty for the aged; the physically disabled; the chronically ill; the intellectually handicapped; the mentally ill; and the emotionally disturbed (Social Development Council 1979 p.1)

More recently Winder and Bray (NZ. 2005) defined on informal caregiver as “A person who perform task for another person, that the recipient is unable to perform independently and showed progress to perform given their age and developmental stage.

Chorlton (NZ.) refers to the opportunity, costs that caregiving often entails; describing an informal caregiver as someone usually but by no means always, a relative whose life is restricted by the need to take responsibility for the care of another person (Chorlton 1992)

Impact of caregiving on family life

Caregiving for a family member occurs in the milieu of the wider family the nature of the impact varies depending on the age of the recipient and their relationship to the caregiver.

Study conducted by Corpinter etal. 2000; Ballerd 1994 proves caregiving for a child or young person with disability puts stress on the whole family system. The mother of a severely disabled child describes going to the beach knowing an adult will be fully occupied in managing their child inappropriate behaviours. Others attempt to be nice and inclusive often had the effect of encouraging inappropriate behaviour.

Parental caregivers of children with high and complex needs struggle in balancing the needs of these children with of the needs of their siblings. Other children in the family may become a focus of guilt for parents who cannot spend
sufficient time with them, or a target of transferred frustrations children may miss out on normal sport activities. Holidays are rare due to lack of energy to arrange it. The lack of discretionary spending and the lack of safe environments for the high needs child is found. Many children are ashamed of and embarrassed by, their high needs sibling.

Marital relationship can suffer due to stress and lack of conjugal happiness. Many parents of disabled children are separated or divorced from their partners. While the separation is not necessarily attributed directly to the high needs-child, it is always a contributing factor. Very few separated parents have formed new partnerships. Other family members were either not a significant support or their support diminishing in due course of time.

Loss of social connection

Opie 1990; Patterson 1997; Peterw and Wing Chung 2005 Loss of social contact is very common consequence of caregiving. This is particularly concerning as social support has been identified as protective against the strains on the role. Informal caregivers of the elderly-affected-individuals are described as leading constricted lives with diminishing social contracts and friends. Few people enter their world parting their family and become staff of day care centres. It becomes increasingly difficult to visit others and friends tend to fly away.

Warral 2005; Janicki etal 2000 Grand parental caregivers experienced a drastic curtailing of social activities. In one study, over a half stated they had no social activities and in other study, over half were assessed as depressed due to social limitations and isolation.

Impacts on employment

Pertine 2006, gave a survey data on informal caregiving suggests lower participation in the work force than the general population on the equivalent age range. Caregiving is harder if it conflicts with work and other activities.
Parkins 2006, pointed that caregiving is harder if it conflicts with work and other activities.

A British study Arksey, 2006 elucidates many of the issues that arise from combining caregiving and paid employment. The research was with 80 caregivers from various range of occupations. They found an inverse relationship between the hours spent on caregiving and participation in paid employment. Women more likely to move from full time to part time paid employment than men. According to the study caregivers who are in paid employment prior to taking on the caregiving role give up paid employment reluctantly.

**Lost opportunities**

The time involved in caregiving can incur considerable loss of opportunity for the caregiver. Time for work, social activity, leisure pursuits, health promoting exercise and normal freedoms of choice is reduced by caregiving.

Cochroni’s survey of informal caregivers as part of Ontario Health Survey found that 48 percent of in-home caregivers reported a great or moderate amount of interference with their lives compared to 37 percent of caregivers who lived separately from the recipient of care (Aoun 2004; Carpinter et al. 2000; Cochrong 1997)

A study by Maclean & colleagues of 24 Dunedin Caregivers of dyslexic children found that three quarters had experienced some loss of contact with friends and about half indicated that caregiving means they could not keep on with previously enjoyed hobbies (Maclean 1995)

**Concern about the future**

Parents of disabled children with high and complex needs have concern about care provision for their child both short and long term. Bray and other surveyed 53 Auckland families (including 10 Maori and five pacific families) about caregiving for their young person (under 25 years old) who had high and complex needs. Despite all the young families knowing they needed a crisis plan to cover emergencies; only one in
five had a plan in place and of these only three had written plans and only one had funding attached to it (Ballard 1994; Bray et al. 2005)

Worrall 2005; Janicki et al 2000 highlighted the anxiety of grand parents to stay well and live long enough to see their dependent grand children through to adulthood.

Lungley et al 1995; Dovey and Keeling 2004 made a study, on caregivers with chronic health condition feared growing older and not being able to look after the recipient. Where they were of a similar age to the recipient, the caregivers were worried about their own factors and health status. In Dovery and Keeling’s study caregivers of elderly dependent recipients expressed concerns arising from uncertainty about what the future holds.

**Financial Implications**

There is a recurring theme in the literature of the financial impacts for informal caregivers. These can be broadly categorized as direct costs incurred, the financial consequences of decisions around caregiving, and the constraints on choices arising form the financial status.

Parental caregivers of children with high and complex needs or children needing palliative care are commonly under financial pressure. This is exacerbated for sole parents and those on low incomes. Financial pressure adds to stress, places constraints on the manner in which they can care for their child and severely limits participation in normal activities for other children in the family. There are additional expenses arising from medical appointments, transport and parking, and home modifications (Carpinter et al. 2000; Horsburgh 2002; Horsburgh and Trenholme 2002)

A Canadian longitudinal study which assessed stress in 330 informal caregivers of elderly people over 30 months, found approximately 20 percent of caregivers experienced financial difficulty. Many incurred additional expenses such as ramps and bath lifts, rails, transport and medications (Armstrong-Esther et al. 2005)
Research on informal caregivers in Hong Kong found that although the main financial impact is the loss of earnings, there are a number of other expenses commonly incurred. These include: incontinence products, medical expenses and medication, transport, additional heating, house adaptations, extra clothing or bedding, mobility aids and special dietary requirements (Petrus and Wing-chung 2005)

Positive Impacts

Although many more studies examine the burdensome aspects of caregiving, there have also been a smaller number highlighting the positive impacts of caregiving.

Two studies noted that the quality of the prior relationship had a strong influence on how positively caregivers regarded the caregiving role. Patterson’s study found positive impacts for most of the 11 women who were caregivers of elderly recipients. Daughters generally reported an improved relationship with parents, and at least one wife felt increased closeness with her husband because she felt needed. Other reported positives included: keeping the person out of residential care, being satisfied at doing a good job, undertaking caregiving as act of love, and for some, the opportunity to move out of the paid work force (Patterson 1997)

A UK study of 34 elderly caregivers conducted a follow-up interview after the recipient of care had died. Many caregivers identified a significant decline in the quality of their lives since their caregiving role had ended due to further reduced incomes, boredom, isolation and a sense of loss of both the person and the caregiving role (Argyle 2001)

A Canadian study of 12 families with 38 family members focused on parental caregivers of children with high and complex need who require ventilator assistance to breathe. The study found parental caregivers experienced caregiving as deeply enriching and rewarding, despite the daily stress (Camevale et al. 2006)

Lopez and colleagues explored predictors of positive outcome for Spanish co-resident caregivers of elderly dependents. The sample included over 80 percent women with an average age of 58 years who undertook 14 hours caregiving a day.
Two-thirds were looking after an elderly parent and a quarter were caregiving for a spouse. The researchers found caregiver satisfaction was correlated with better previous relationship with recipient, being a caregiver by one’s own choice, having leisure time, and not working outside the home. Together these factors explained 43 percent of the variance in satisfaction ratings. The use of religion as a coping strategy was also helpful. Satisfaction with caregiving was unrelated to the characteristics of the recipient, despite many of these recipients being very dependent and some having serious memory and behavioural problems (Lopez et al.2005)

**Stress and Mental Health Problems**

Families of people with mental health problems often take on the role of primary caregiver either voluntarily or by default. This applies even when the family member is receiving in-patient care: There are numerous studies that identify the negative effects on families such as anger, embarrassment, shame, guilt, blame and exhaustion. Families must quickly learn coping skills as well as ways of understanding and helping their relative.

Yun.Hee-Madjar (1998) suggest that some families cope by living each day as it comes. They conclude that caring for a family member with chronic mental health problems is experienced bother personally and in the fabric of family relationships. It is different from the role and experience of the professional carer who is essentially a stranger to the situation.

Pejlert (2001) studied the parents of six adult sons/daughters with mental illness over a period of time, and attempted to illustrate the meaning of parental caregiving, which emerged as a life long effort involving sadness, having difficulties in interpreting the symptoms of mental illness, and struggling to find out what was wrong. Once the diagnosis had been explained they then entered a bereavement process, just as parents of learning disabled children do when they discover their childs ability. At this stage family in Pejlerts study reported emotions of shock, confusion, anger, guilt and despair and grieving for the loss of the son or daughter they once had. Some parents were reminded of this by the presence of healthy siblings.
Some become actively involved in advocacy services, others in their child care package, and others concentrated on thinking positively and having their own interests and activities.

In Pejlert study where the adult children were receiving care in long stage organizations and had regular contact with the families.

In Hong Kong (2000) highlighted additional difficulties in a culture where family care is seen as imperative and where families take on the primary role and responsibility for caregiving even for family members who had mental illness. Many people in UK similarly take on the primary caring role and what makes a difference in Hong Kong are the cultural issues such as “face saving”. In the Chinese culture the face of the family represents the image and prestige of the family in public.

**Family stress in Learning Disabilities**


Beuman 1983, Fried rich & Fried rich 1981 - Although families of children without learning disabilities report more stress than families of children without learning disabilities there is considerable diversity in the way in which this stress is expressed. Thus a number of events such as financial difficulties, marital problems, depression and isolation amongst others have been considered indicators of high levels of stress.

Friedrica & Fried rich (1981) designed a study to determine whether parents of children with learning disabilities differed from parents of children without learning disabilities in terms of variables of stress and also the variable that relieve stress. Findings supported their hypothesis that significant difference would exist within them.

Wilton & Renalt (1986) compared 42 mothers of intellectually preschool children with 42 mothers of non intellectually impaired pre school children, to ascertain whether stress level were different and results showed that mothers of
children with learning disabilities experienced higher levels of stress. Fathers were not included in the stress measures, suggesting that fathers were perceived as not being at risk of stress or not having a major role to play in the family.

Breslau & Davis (1986) reported on the effects of chronic stress of mothers of children with disabilities. The persons who differ with respect to the stress of their life situation show different risk of major depression. Specifically they compared mothers of children with congenital disabilities with mothers of children with disabilities had more depressive symptoms when compared with the control group.

Ryde-Brandt (1990) assessed anxiety and depression in 18 mothers whose children were diagnosed as having learning disabilities and autism or other pervasive childhood psychosis and who were receiving some form of special education. The control group contained 18 mothers of physically handicapped children, none of whom had learning disabilities and all of whom attended main stream schools. The mothers of children with autism scored significantly higher on the Hospital Anxiety and Depression (HAO) scale (Zigmond of Snaith 1983) than mothers of physically handicapped children.

Some studies show contrast finding, that stress is no more likely in families with a child with learning disabilities than in families without Ryde-Brondi (1988) examined the occurrence of anxiety and depression in 13 mothers of children with Down Syndrome aged 8-9 yrs and compared them with 13 female supporting care assistants who were helping the mothers. The HAD scale was used. The score for the mothers of children with Down Syndrome and for the supporting care assistants indicated that there was no evidence of depression or anxiety occurring in either group.

While these results are in contrast to Ryde - Brondt’s later work (1990) this study control group comprised paid care assistants rather than mothers. The difference is therefore perhaps unsurprising for the children and further more, would be unlikely to share the same degree of emotional attachment to the children as the mothers.
Bristol et al (1985) compared depressive symptoms in the mothers and fathers of 31 preschool boys with Autism and other communication disorders with mothers and fathers of 25 non-disabled boys. They hypothesized that the parents of disabled boys would show higher levels of depressive symptoms. One of the specific goals of the study was to determine if adaptation varied with the gender of the parent and the disabled / non-disabled status of the child. Both groups were matched on child race, gender, and mean age as well as parental status, mean parental age and socio economic position. The results of the study show that although mean scores for depressive symptoms for both mothers and fathers of disabled boys were higher than those for the control group, the differences were not statistically significant.

Cameron et al (1991) found the parents of developmentally delayed children do not report stress in their family environment. The aim of their study was to measure the stress experienced by parents of developmentally delayed and non developmentally delayed pre school children. The developmentally delayed children had a variety of conditions including Down’s syndrome and Cerebral Palsy. The child’s characteristics - a high score obtained on this scale indicates that the child displays qualities that might make it difficult for the parents to fulfill their parental role.

The parental domain - a high score in this domain indicates the stress may occur.

When the mothers of the developmentally delayed children were compared with the mothers of the non-developmentally delayed children there were no differences reported in depression, the degree of attachment to the child, the amount of restrictions on the parental role, the amount of social isolation for the mother, or the relation that the mother had with their spouse.

Cameron et al (1991) suggested that the mothers developmentally delayed children had been able to make adjustments in their life and were able to deal with the problems raised by the childs handicapping condition.

Wong 2000 - study showed that carers of people with mental health problems experience difficulties and stress, particularly in relation to the negative symptoms,
such as refusal to perform household duties and neglect of personal hygiene. However they experience less stress in relation to positive symptoms of Schizo Phrenia such as bizarre communication and behaviours resulting from hallucinations and delusions.

Clark & King (2003) have also identified that caring for a family member can have negative effects on the carer in their study of caregivers of people with strokes and Alzheimer’s disease, a large number had depression scores above the level indicating clinical depression even when services such as respite and support were provided.

Kellner & Miller (1990) in relation to the role of carers of people, who have depression, reviewed a range of studies that identified adverse effects on family functioning, communication and problem solving. This was supported by Tamplin et al (1998) whose study showed that the general health of families of young people with major depression was significantly worse than in a control group. However, while the mothers mental health was poor, fathers mental health state was not related to family functioning.

On a positive note, there is a range of research supporting the notion that if families are more involved in the caregiving and treatment of people with mental health problems than they are better equipped to deal with the stress of mental health problems in the family.

Whelton & Pawlick (1997) reported on a community rehabilitation programme in which families of people with mental illness were included in the Rehabilitation Team and were provided in turn with support and educational programmes. With this level of support, families reported increased satisfaction and fewer worries about their caregiving role.

Marriott et al (2000) in relation to Alzheimer’s disease demonstrated how the involvement of the family in cognitive - behavioural interventions can actually improve the mental health of family caregivers.
McInlyre et al (2002) suggested that expressions of mental health in learning disabilities can be expected to heighten family stress and influence parental decisions about services. They also demonstrated that mental health problems in learning disabilities affect maternal stress above and beyond the stress contributed from other young adult and family characteristics. Hence it is important for professional carers to be aware of the potential effects, to involve families in all aspects of care and intervention wherever possible, and to offer appropriate supports.

Effects on the family of the Disability / Illness and relationships with professional carers

Williams & Robinson (2001a) Families have been recognized as the largest group of caregivers and most of the families we spoke to actually felt that they were the sole carers, responsible for the care of their child 24 hours a day. Ideally, professional carers and families should have an agreement about exactly who the client is (in other words, is it the identified ‘client’ or is it the whole family) and where the duty of care lies however this does not always happen.

Barr (1996) has identified a range of models that explain the ways in which professionals work with families. These models range from the professional being classed as an expert, with the family simply obeying instructions and being passive recipients of wisdom and decision, to the negotiating model where the family has control over decisions. In such a model, both parties learn from each other. Our families reported experience with the first model, namely that professionals often took control of the situation and did not allow the family time to reflect and become empowered. Some families were left out of the assessment process even though they felt capable of contributing to such assessments. This could lead to the fragmentation of care, interventions not being fully understood or implemented and a break down of the relationship between the family and professional carers.

Dale (1996) suggest that parental involvement is vital to the care process and suggests the professional carers need family cooperation in order to fulfill their role effectively. Family members are key sources in the implementation of assessments and interventions; however they need support and guidance to help them carry out
these responsibilities. We must also recognize that the clients themselves have their own needs and wishes which may not necessarily be the same as those of the family in which they live.

Grant & Whittell (2000) The partnership between the families and professionals is as complex as the family itself and the creation and development of such a relationship can often be a difficult and complex journey for both sides of the partnership. Both parties must recognize each other’s role; the role of the professional carer is to facilitate the family’s ability to maintain its function in order to support both itself and the member with learning disabilities and mental health problems.

Williams & Robinson (2001a) predicted some of our families had experienced relationship problems and conflict within the family, either between partners or with the clients’ siblings. They had developed their own strategies to deal with these problems, and only one family had sought professional help for relationship problems. Most families expressed concern for the siblings of the client; comments such as, ‘they don’t bring friends home’ or they don’t want to play with their brother because he always breaks their things were common. The majority of families commented on how supportive their own, sometimes elderly parents were and that without them they could not cope. Grandparents were a good source of informal sitting services, counseling respite and financial support.
The History of Counseling and Psychotherapy

Counselling Psychotherapy theories were being developed during the beginning of the 20th century, however it is thought that the roots of this subject originated a long time before this. The most renowned work is that of Sigmund Freud whose research into the human mind began in Vienna in 1881. He received training to become a neurologist and began working with patients who were classed as hysterical. Freud named his method psychoanalysis and continued to practice his theories until the 1930’s.

Although Freud is thought of as the oldest psychological theorist, it was Franz Anton Mesmer, an 18th century physician who discovered animal magnetism (also known as mesmerism) and James Braid who developed hypnotherapy using inspiration from Mesmer’s ideas. Hypnosis was a technique Freud adopted in his early work to treat mind disorders but then concentrated on developing his own theories after recognizing that hypnotherapy was only a useful technique with certain problems. However Freud’s work remains the most well known in recent times.
Frued proposed the division of the mind into ego, superego and id. He also believed that infants pass through oral, anal and phallic stages and becoming ‘stuck’ in one of the phases could lead to disastrous consequences.

Carl Jung was a close colleague of Freud, but eventually split from Freud to pursue his own school of analytical psychology. His ideas are also widely recognized in recent times. Alfred Alder, Sandor Ferenczi, Karl Abraham and Otto Rank are other influential theorists who worked closely with Freud. Carl Jung, and other descendants of Freud’s approach, focused heavily on psychodynamic theories.

The 1940’s and 1950’s marked an important expansion in the field of counseling. The US psychologist Carl Rogers (influenced by Alfred Alder and Otto Rank) established the person centred approach, which is at the heart of most current practice. The person centred approach is now listed under the ‘humanistic’ branch of psychotherapy. There are now thought to be three general types of psychological therapies; behavioural therapies, psychoanalytical and psychodynamic therapies and humanistic therapies.

The word counseling (or counseling) comes from the Middle English counsel, from Old French conseil, from Latin consilium; akin to consulere, to take counsel, consult. Counseling can be defined as a relatively short-term, interpersonal, theory-based process of helping persons who are fundamentally psychologically healthy resolve developmental and situational issues.

There are probably as many definitions of counseling as there are practitioners to describe it. The term was originally used by Frank Parsons in 1908. It was adopted by Carl Rogers in response to widespread prejudice in the U.S. against lay therapists and also because he was not then permitted by the psychiatry profession to call himself as psychotherapist. The difference between definitions of counseling and psychotherapy is less significant than the practitioners’ perceptions of their raison d’etre.

Counseling psychology as a psychological specially facilitates personal and interpersonal functioning across the life span with a focus on emotional, social, vocational, educational, health-related, developmental and organizational concerns.
Through the integration of theory, research, and practice and with sensitivity to multicultural issues, this specialty encompasses a broad range of practices that help people improve their well-being, alleviate distress and maladjustment, resolve crises, and increase their ability to live more highly functioning lives.

Though closely related to clinical psychology, counseling psychology differs from that field in several subtle ways. First, counseling psychologists typically focus on less severe psychopathology (e.g., depression and anxiety), while clinical psychologists deal with more seriously disturbed individuals (e.g., those with schizophrenia or personality disorders). In the UK, however, there is less distinction between the types of cases that clinical and counseling psychologists work with. The difference is emphasized more in how they work with an individual. Second, counseling psychologists are more likely than clinical psychologists to assume a client-centered or humanistic theoretical approach. Finally, counseling psychology is unique in its attention both to normal developmental issues as well as the problems associated with physical, emotional, and mental disorders. Despite these differences, counseling and clinical psychology are becoming increasingly indistinguishable, leading some to suggest that these fields be combined.

Populations served by counseling psychologists include persons of all ages and cultural backgrounds. Examples of those populations would include late adolescents or adults with career/educational concerns and children or adults facing severe personal difficulties. Counseling psychologists also consult with organizations seeking to enhance their effectiveness or the well-being of their members.

Counseling psychologists adhere to the standards and ethics established by the American Psychological Association and the American Counseling Association. Counseling psychologists or counselors who work in K-12 school settings also need to follow the ethic standard established by the American School Counselor Association. In Australia there are several associations offering standards and ethics for counseling. Each professional or trade association has its preferred qualification and practitioner standards and also suggesting other requirements.
Counselling

Some people may be embarrassed to attend therapy, believing they have failed in some way. However, this is not the case. Many people choose professional counseling and find they are able to make a huge success of their life. Just talking to someone confidentially who is not a friend can make all the difference. Counselling provides a regular time for those in distress to explore their feelings and talk about their problems. A counselor should help you develop better ways of coping, allowing you to live the life you deserve.

Choosing the right counselor for your individual needs is essential, and consideration must be given to their training, qualifications and experience. Counsellor accreditation is often important if you are wary about which counselor to choose:

- Counsellor Accreditation
- How do I know which counselor to choose?
- How can I be assured of the counsellors’ professionalism?

Counselling Approaches

Psychological therapies generally fall into three categories. These are behaviourial therapies, which focus on cognitions and behaviours, psychoanalytical and psychodynamic therapies, which focus on the unconscious relationship patterns that evolved from childhood, and humanistic therapies, which focus on looking at the ‘here and now’. This is a generalization though and counseling usually overlaps some of these techniques. Some counselors or psychotherapists practise a form of ‘integrative’ counseling, which means they draw on and blend specific types of techniques. Other practitioners work in an ‘eclectic’ way, which means they take elements of several different models and combine them when working with clients.

Counselling is a young technique that has only really found its niche in the last 50 years. Therefore, the definition of what counselling entails is often a blurry one. The British Association of Counselling defines it as “work with individuals and with
relationships which many be developmental, crisis support, psychotherapeutic, guiding or problem solving” (BAG, 1984). Others have stressed the importance of the professional relationship and reaching ‘self determined goals’ (Burks and Steffire, 1979). The cultural evolution that has been the key for the practice has left definitions unclear and the range of different ideas that have been involved through the years have made the move towards a unifying scientific paradigm very difficult (Ellingham, 1997)

Traditionally, counseling takes one of three core approaches; psychodynamic, cognitive behavioural or humanistic, which all represent different ways of representing human emotional and behavioural problems (Mahrer, 1989). There are often multiple aims to counseling although one approach very rarely aims to achieve all of them. However, psychodynamic counselors focus primarily on gaining insight, the acquisition of an understanding of the origins and development of emotional difficulties; humanistic counselors promote self acceptance and personal freedom and the development of a positive attitude towards self; cognitive-behavioural therapists are mostly concerned with the management and control of behaviour (McLeod, 1993).

**Humanistic Psychology**

Humanistic psychology spawned the “person-centred” approach to counseling in the 1950s. Carl Rogers was the main writer in this approach, and along with the other humanistic psychologists of the time (e.g. Maslow and Buhler), he shared a vision that psychology would have a place for the human capacity for creativity, growth and choice (McLeod, 1993). The idea of counseling from a humanistic direction initially took the form of a “non-directive” approach where the ethos was that clients found their own solutions to their problems (Rogers, 1942). To many this seemed much like a contradictory idea as a client-therapist relationship would automatically infer an influence by both parties. Studies indicated that counsellors using the “non-directive” technique actually subtly reinforced particular statements made by clients but did not offer interest, encouragement or approval for other types (Truax, 1966). Therefore, there were inherent difficulties with the idea of “non-directive” counseling. However, much of the early research noted that the approach
was able to initiate changes in the client. It was eventually more aptly renamed “person-centred” (Rogers and Dymond, 1954)

Following this, the theory underwent an evolution, consolidating the earlier ideas. The resultant model of the therapeutic relationship included what Rogers (1957) called the “necessary and sufficient” conditions of empathy, congruence and acceptance. The condition of empathy required the therapist to experience an understanding of a client’s “inner world” as if it were their own and communicate this to the client. The condition of congruence required that the therapist be is genuine and transparent with the client. Acceptance, otherwise known as unconditional positive regard for the client meant that the therapist should always accept or value the client as a person, despite any behaviour that they might display.

Rogers * Person-Centred Approach

Rogers’ formulation of the person-centred approach was very much based on trust in the client’s humanity, and like most humanistic psychologist, the belief the humans are self actualizing. Indeed, it is supposedly this actualization that is the motivation for change in the client (Van Belle, 1990). As Rogers himself put it (1986b, page 198), person-centred counseling “depends on the actualizing tendency present in every living organism’s tendency to grow, to develop, to realize its full potential. This way of being trusts the constructive directional flow of the human being toward a more complex and complete development”. The theory identifies that it is the directional flow towards actualization that is to be released by the therapist.

The basic person-centred value is that the authority of the person rests in the person rather than in an outside expert (Bozarth, 1990s). This gives emphasis to the internal (i.e., the client’s) rather than the external (i.e., the therapist’s) view. Clients are allowed to go at their own pace and to pursue their growth in their unique ways. The external view is meaningless in the therapy process since the only function of the therapist is to facilitate the client’s actualizing process. Rogers thought the client should be approached naively without preconceptions as a unique individual and be allowed to develop his/her own therapy process. The assumption was that a client’s innate actualizing tendency could be fostered most effectively by the creation of a
distinctive interpersonal environment fundamentally based on the trust and respect. The therapist’s basic task is to listen with respect and understanding and help the client to clarify his/her feelings and thoughts as they are expressed to the therapist.

All counselors agree that a good client relationship is necessary for effective treatment. However, most modern counselors feel that more than just a relationship with the client is needed for constructive change and therefore they often require a set of interventions in addition. These helping strategies are chosen specifically by the counselor for each patient, sometimes considering a relative probability of success for the client. These interventions often reflect the theoretical standpoint of the counselor although some counselors are more eclectic in their approach and therefore prefer a variety.

Solution-Focused Therapy (SFT)

One of the more recently developed theories in use in modern counseling is known as Solution-Focused therapy (SFT). SFT is an approach to counseling based upon the building of solutions rather than more specific problem-solving. It delves into current resources and future hopes of the client rather than present problems and past causes. The approach was first developed by de Shazer et al (1986) and it originated from an interest in what were identified as “inconsistencies” in problem behaviour. The group noted that however serious, fixed or chronic the problem there were always exceptions and these exceptions could contain the origins of the client’s own solution. De Shazer (1988, 1994) and Berg (Berg, 1991; Berg & Miller, 1002) also found that the clearer a client was about their goals the more likely it was that they were achieved. Finding ways to elicit and describe future goals has since become intrinsic to SFT. Theoretically, the approach was evolved from problem focused therapy but believes that problems are not the issue to be dealt with, the solutions are.

A solution focused perspective is essentially interactional. Many typical solution focused questions are phrased in a way designed to elicit information about interactions between key individuals. Thus the solution focused the practitioner gains an interactional perspective about clients concerns and wishes put into a context of
their relationships with others (Saunders, 1998). As the practice of SFT has developed, the ‘problem’ has come to play a lesser and lesser part in the interviewing process (George et al, 1999), to the extent that it might not even be known by the counselor. Instead, all attention is given to developing a picture of the ‘solution’ and discovering the client’s strengths and resource to achieve it (Iveson, 2002). Sometimes clients’ lives are so difficult that they cannot imagine things being different and cannot see anything of value in their present circumstances. One way forward is to be curious about how they cope - how they manage to hang on despite adversity (Letham, 2002). For the Solution focused counselor, problems do not represent an underlying pathology or deficit and sometimes only the smallest of changes is required to set in motion a solution to the problem (George, Iveson and Ratner, 2000).

To build a picture of a client’s preferred future the counselor needs to get a picture of where the client wants to get to, without the problem that has led them to counseling. The miracle question was devised with this in mind: ‘Suppose that tonight, while you a sleeping, a miracle happens and the problem that has been troubling you sorts itself out overnight ... what would you see the next morning that would let you know the miracle had happened? What would you find yourself doing the day after the miracle, what would others notice you, doing (Lethem, 2002; Iveson, 2002). The counsellor then looks for exceptions to the problem in the client’s life and highlights any success and resources they might have. The idea is to empower the client in taking control over their own change and affirming the client as an expert (Greenberg & Ganshorn, 201; Saunders, 1996). A counselor may also use “Scales” where 10 equals the achievement of all goals and zero is the worst possible scenario. The client is asked to identify his or her current position and the point of sufficient satisfaction. Within this framework it is possible to define objectives, what the client is already doing to achieve them and what the next step might be (Greenberg & Ganshorn, 2001)

*How are Person-centres approaches and SFT similar?*

Although the approaches of person-centred therapy and solution-focused therapy have taken a very different theoretical evolution, they seem to have a number
of features that take the same view (Hales, 1999). Primarily both approaches highlight the strengths and the resources of the client during the process. The belief by person-centred counselors, that clients are “self-actualizing” (Rogers, 1961) is played upon explicitly by STF in identifying strengths and resources to a client (Saunders 1998). From a person centred approach, the emphasis placed on these factors by SFT is directly facilitating the self-actualization of the client.

In addition, both approaches look at the “whole picture” of the client’s situation. The importance of the whole person in person-centred counseling equates to interest in the whole context of a person’s life in STF (Iveson, 2002). SFT acts on what the exceptions to the problem there are in other areas. It is seen as useful to point out the wider context of a clients difficulties without belittling them (Lethem, 1994), and this equates very much to the person-centred approach’s gestalt view of looking at the whole and not just individual parts of a person (Rogers, 1980).

It is clear that person-centred therapists like to believe that the client is “in-charge” of the counseling process and that it is the client that makes all the judgements about experiences and decisions. Again, it seems that SFT uses this idea much more explicitly and clients are often asked directly what they want out of counseling has done its job. Both approaches seem to share an emphasis on the client making the decisions during the process even though in SFT, the therapist may seem to be much more active (Hales, 1999).

The implicit understanding of “self-actualization” by person-centred therapist is made explicit by STF where clients are often asked questions related to what they think life will be like when they have overcome their problems and difficulties. Indeed, person centred theorist may suggest the SFT is highlighting the intrinsic nature of a person to self-actualize via methods approaches value the concrete and specific details of actual experience rather than abstract specific details. For example, what exactly is “better”? What would be different if things were better? The specifics of lived experience are detailed in inner thoughts and feelings and are often played out in actions. SFT is more explicit than person centred therapy in linking inner processes and actions. SFT makes explicit what they exactly a person wants to
achieve in their life, so as inner thought or feeling is appeased, while the person-centred approach assumes that this is intrinsic to the client (Hales, 1989).

It is clear and obvious from the evaluation of the two approaches that they share many of the same beliefs and values, yet STF makes them much more explicit to all parties involved. Some have posited that there is a lack of empathy in SFT (Hales, 1999) but as Letham (1994) points out “acknowledgement is the hidden ingredient of solution focused therapy”, and is often used to find a starting point for solution strategies.

**Ethical Considerations**

McLeod (1993) notes that many, if not most people who seek counseling are dealing with a moral dilemma of sorts. In person-centred counseling and STF, many of the decisions that will be made throughout the process will have some moral and ethical components. Although in these approaches the focus is on the client to make the decisions, the counselor must subtly influence the ones that will most help the client.

The level of disclosure and the relationships that are formed between clients and counselors often means that information discussed is of a very detailed and personal nature to the client, and may involve several other parties. Determining the appropriate course to take when faced with a difficult ethical dilemma can be a challenge, especially as the need for trust in the client-counsellor relationship is so vital for success. Indeed, such is the prevalence of ethical dilemmas in the field of counseling the ACA has even developed an “Ethical Decision Making Model” using work combined from several authors.

Much of counseling literature related to ethical consideration refers to Kitchener’s (1984) work. He noted that there are four main areas that a counselor can draw upon when tackling a moral and ethical dilemma. These are personal intuition, ethical guidelines of professional organizations (such as the ones published by the BAG or ACA), ethical/moral principles and general theories of moral action (which includes more general moral theories such as Utilitarian or Kantian ethics),
Kitchener’s (1984) five moral principles often appear as the cornerstone of many professional counseling association’s ethical guidelines:

1. Autonomy is the principle that addresses the concept of independence and allowing an individual a freedom of choice and action. In doing this, it must be remembered that the client should be helped to understand how their decisions and their values may or may not be received within the context of the society in which they live, and how they may impinge on the rights of others. Also, a consideration of the client’s ability to make sound and rational decisions is necessary and clients not capable of making competent choices should not be allowed to act on decisions that could harm themselves or others.

2. Non-maleficence is the principle of not causing harm to others and reflects both the idea of not inflicting intentional harm, and not engaging in actions that risk harming others (Forester-Miller & Rubenstein, 1992).

3. Beneficence is the counsellor’s responsibility to contribute to the welfare of the client by being proactive but also preventing harm when possible (Forester-Miller & Rubenstein, 1992).

4. The principle of Justice does not mean treating all individuals the same. Kitchener (1984) points out that the formal meaning of justice is “treating equals equally and unequals unequally but in proportion to their relevant differences” (page 49).

5. Fidelity involves the notions of loyalty, faithfulness, and honouring commitments. Clients must be able to trust the counselor and have faith in the therapeutic relationship if growth is to occur.

When exploring an ethical dilemma, examining the situation and seeing how each of the five principles may relate to that particular case can help clarify the issues enough that the means for resolving the dilemma become obvious and an ethical decision to be made.
Studies related to Impact of Counselling

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Parents are significant contributors to the development of their children. They are the primary caretakers, managers, behavior models, disciplinarians and agents of socialization and change for their children. It is accepted that parents can be trained as effective teachers of their children with disabilities. In Turkey, there are very limited opportunities, services, schools, parent education and support services for children with disabilities and their parents. Therefore, we have been carrying out studies to contribute to the understanding of the parents, specifically, on how a child with a disability affects their life and how they can be trained to become co-teachers and co-therapists.

*Marital Adjustment in Families of Young Children with Disabilities: Associations with Daily Hassles and Problem-Focussed Coping*


A family systems framework was used to examine associations between stressors/hassles, problem-focused coping, and marital adjustment in 67 families of young children with disabilities. Most of the couples were experiencing average to above average marital adjustment. When daily stressors/hassles were higher, husbands and wives viewed their marriages more negatively. After variance contributed by stressors/hassles was statistically controlled, fathers who employed more problem-focused coping strategies were more positive about their marriages. For wives (but not husbands), a cross-spousal partner effect was found; women reported higher marital adjustment when their husbands employed more problem-focused coping strategies. We reaffirmed the systemic nature of family processes and highlighted the role of parent gender in understanding the relationships among stressors, coping and marital well-being.
Stress and Social Support in Fathers and Mothers of Young Children with and without Disabilities

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This study compared perceived stress and social support in fathers and mothers of children with and without disabilities. The sample consisted of 15 families with special needs children and 15 with children with no known handicapping conditions. The Parent Stress Index and a parental questionnaire were used. Finding indicated higher perceived stress in families with special needs children. Within these families no significant differences were found between fathers’ and mothers’ perceived stress. Significant negative correlations were found between families’ stress and support received from friends and relatives. Negative correlations were found for mothers’ stress in Child Domain and support from the community. Implications include planning for active engagement of fathers in all areas of service delivery in early intervention programs, including encouragement for more participation in programming; opening a direct line of communication through designing tailored workshops, support groups and counseling; recognizing fathers’ strengths beyond their traditional roles; and viewing them as an additional emotional source of support for mothers.

Children with Disabilities: Understanding sibling issues

Nichcy News Digest #ND11,1988

For many families, raising a child with a disability or chronic illness poses many challenges. Some of these challenges focus on the relationship between the siblings in the family which influences the social, psychological and emotional development of each child. The relationship between brothers and sisters in families that have a child with a disability or chronic illness is examined in this of News Digest.

Many factors which affect sibling relationships are described, and research finding concerning siblings, one of whom has a disability or chronic illness, are reviewed. Guidelines and suggestions for parents and siblings, and siblings’ suggestions for parents are discussed. Additionally, several different viewpoints
about sibling relationships are presented from a sibling with a disability, two nondisabled, adult siblings who have a sister with a disability; and a parent of several children, the youngest with a disability. A support section concludes this issue, listing suggested readings and sibling support resources.

**The Impact on a Sibling with a Disability**

Most of the sibling research has focused on the effects of a child with a disability or chronic illness on nondisabled siblings. Also important is the influence of the nondisabled sibling on the child with a disability or chronic illness. Cmic and Leconte (1986) report that the nondisabled sibling’s impact upon the child with a disability may vary across the family’s life, While very little work has been done in this area, researchers do stress the reciprocity of sibling relationships.

Parents of retarded children represent one population for which counseling procedures may be extremely important. Parents of these children are under a great deal of situational stress and often have difficulty with day-to-day child management issues (Menolascino, 1970). There have been a number of attempts to determine the worth of group counseling for these parents utilizing both reflective (Lewis, 1970; Siegel, Sheridan & Sheridan, 1971; Tretakoff, 1969; Wollenberger, 1967) and behavioral (Cone & Sloop, 1971; Lasser, 1970; Morrey, 1971) techniques. However, to date the efficacy of neither model has been reliably demonstrated with this population.

The present study was designed to deal with these issues by comparing the differential effectiveness of behavioral and reflective group counseling in work with parents of mentally retarded children. Multiple success criteria were used to provide a broad-based measurement of outcome of counseling. It was predicted that all parents who received counseling, either behavioral or reflective, would show significant improvement across outcome indices relative to comparable untreated parents. It was predicted that counseled parents would show positive change in their attitudes; report fewer behavioral problems; increase the positive quality of the mother-child interaction; and report an improvement in the quality of family life. It was also predicted that treatment modalities would yield differential changes as a function of
outcome criteria; these changes were predicted to be consistent with previous findings that behavioral counseling mainly changes frequencies of deviant behavior, whereas reflective counseling results in changes in attitudes and feelings.

Counseling Parents of Intellectually Challenged Children

One of the most difficult tasks to be faced is that of counseling the parents of a retarded child. It is far more painful that counseling the parents of a dying child, for death is irrevocable and final and its wounds will often be healed with time. The diagnosis of mental retardation, on the other hand, often brings with it the specter of chronic sorrow for the parents and a life of disability for the child.

Handling this situation depends upon his experiences in such matters, his understanding of the factors underlying parental feelings and the manner in which they are expressed, and all too often his own personal feelings. Rarely will his training either in medical school or residency have prepared him for the task.

The pediatrician has an important role in the diagnosis and management of retarded children live with this problem so that they can cope with the crises as they arise during the various stages of development of their retarded child.

The two medical specialties most involved in the field of mental retardation, pediatrics and psychiatry, view the problem from different perspectives, by training, the pediatrician considers mainly the organic and developmental factors, the psychiatrist mainly the psychosocial. The pediatrician, trained mainly to treat acute conditions, usually has little interest in the care and management of the retarded child with all the attendant chronic, often unsolvable problems. The psychiatrist, on the other hand, tends to rely too heavily on his training in psychodynamic theory and practice. What is most needed is a happy synthesis of these two approaches in a physician who is not only well trained in the organic aspects of mental retardation but who also has an understanding of the emotional impact of this condition on both the child and his family.
Training programs in both psychiatry and pediatrics are now trying for this synthesis, but in the meantime most practicing pediatricians and psychiatrists have not had the benefit of this new training philosophy.

This paper is based upon ten years’ experience by the author in the field of mental retardation, first in a state institution and more recently in a university affiliated teaching and research center for the mentally retarded. An attempt will be made to outline some general principles for practicing pediatricians. It should be borne in mind, however, that each family unit differs from the next and that its manner of handling this problem depends upon such factors as the stability of the marriage, family ties, religious attitudes, economic status, education, environment and, last but not least, socio cultural factors.

Before a pediatrician can discuss the diagnosis and management of a retarded child with the parents, it is important that he reflect upon the hopes and aspirations all parents have for their children. All parents hope that their children will accomplish much more than they as adults were able to accomplish. One can then imagine the shock upon realization that this dream will not come true. Feelings of guilt, shame and despair will arise and the parents will begin to ask questions such as “Why did it happen to me?”, and “Did I do anything wrong?”, and they will very often initially blame themselves. With time, they will begin to recover from this initial shock and then will begin to ask questions such as “Why?”, “Will it happen again?” and, ultimately, the most important of all, “What can be done for my child?”. These last three are fundamental questions which a physician must answer over a period of time.

Sometimes the pediatrician will face extreme reactions which can be quite disturbing to him and, at times, will evoke feelings of hostility within him. The parents might begin to blame all members of the medical profession as well as paramedical personnel for their child’s problem, and to act in a very hostile fashion. The worst thing that pediatrician can do in such circumstances is to react in kind. At the other extreme, some parents will react by either denying that no problem exists or by having their child institutionalized and informing both family and friends that he died. Fortunately, these are extremes, and some parents will even sublimate their
problem in a most productive and useful way by directing their efforts toward establishing programs for the mentally retarded.

*What do you think the future holds for your child?*

The answer to this question will not only give further insight into the parents’ reality orientation, but it will also indicate directions to be taken to avoid putting the child into situations which are non-productive or in which he will continually face defeat. The pediatrician will find out, for instance, whether the parents strongly desire to keep the child at home, and if they do he can avoid making recommendations which will oppose that plan.

*What can we do for your child?*

This question will often help identify the major concerns in question, and will often help identify the major concerns in question, and will also elicit the existence of various problems at home, not only with respect to the child’s behavior and the problem surrounding the daily care of the child, but also with respect to some of the feelings the parents might have concerning the child’s slow development, and the impact of the child’s retardation on the family unit. This is important because any child is part of a family unit, and what he does or does not do affects every other member of that family group. It is well to remember at this particular point that when one talks about counseling parents, one clearly means both parents, not just the mother. In addition, in some cases it may be advisable to include teenage siblings, since the presence of a retarded sibling in their home can have an emotional impact upon them, and also can cause considerable anxiety with respect to future marriage and children.

The physician must avoid simply attaching a medical label and then telling parents that there is nothing one can do. Nothing will more certainly make “shoppers” of parents. Keeping the following points in mind will help in counseling management.
Do what is best for the child.

This requires not only a complete evaluation of the child potential but also the establishment of child defined training goals. Very often parents need to have a strong guide in the management and care of their retarded child. Occasionally their guilt feelings will lead them to believe the child should not be disciplined. In those circumstances he may become unmanageable and in more recent years the technique called behaviour shaping or operant conditioning has come to prominence, mostly through the efforts of psychologists. Such techniques are now used only by psychologists but by educators, physical health nurses and social workers it is based upon methods used by many parents raising normal children - namely, that of rewarding good behaviour. For this to be effective, however, one must establish a set of clearly defined reward for clearly defined behaviour, based upon the functional capacity of the child.

Help parents learn to live with the problem

Basically mental retardation is a condition parents can never really learn to accept; because of this they will, in one way or other search for the rest of their lives for answers and solutions. Most parents fortunately learn on their own what the best solutions are from neighbours, friends, and members of the clergy following their assistance. How they eventually solve this problem depends upon their inner strength as individual and upon the stability of their marriage. Involvement or support by other family members, when they enter the picture, may sometimes give strength, sometime add to turmoil. Regrettably, a retarded child frequently becomes the additional straw on the camel’s back, causing a disintegration of already fragile marriage.

There may also be social pressures which entangle problems within the family. This is particularly true in the case of an upper middle-class executive, who finds the presence of a retarded child in his household to be detrimental to his social success.
Tips for parents

> Learn about mental retardation. The more you know, the more you can help yourself and your child.

> Encourage independence in your child. For example, help your child learn daily care skills, such as dressing, feeding himself or herself, using the bathroom and grooming.

> Give your child chores. Keep her age, pay attention to span, and improve mental abilities in mind. Break down jobs into smaller steps. For example, if your child’s job is to set the table, first ask her to get the right number of napkins. Then have her put one at each family member’s place at the table. Do the same with the utensils, going one at a time. Tell her what to do, step by step, until the job is done. Demonstrate how to do the job. Help her when she needs assistance.

> Give your child frequent feedback. Praise your child when he or she does well. Build your child’s abilities.

> Find out what skills your child is learning at school. Find ways for your child to apply those skills at home. For example, if the teacher is going over a lesson about money, take your child to the supermarket with you. Help him count out the money to pay for your groceries. Help him count the change.

> Find opportunities in your community for social activities, such as scouts, recreation center activities, sports and so on. These will help your child build social skills as well as to have fun.

> Talk to other parents whose children have mental retardation. Parents can share practical advice and emotional support.

> Meet with the school and develop an educational plan to address your child’s needs. Keep in touch with your child’s teachers. Offer support. Find out how you can support your child’s school learning at home.

> Recognize that you can make an enormous difference in this student’s life! Find out what the student’s strengths and interests are, and emphasize them. Create opportunities for success.
Suggestions for families

When planning for the future of the sibling with a disability, you should consider such things as mobility, social and communication skills, education, and the individual’s own ideas about where to live and work. Even after careful planning and the appointment of a guardian or co-guardians, plans should be made for emergencies. A file should be kept in a safe place, known to all family members. The following ideas should be addressed when making future plans and the information should be included in this accessible file:

1. Develop financial plans for future care. If the family is considering establishing a trust for the family member with the disability, it should consider the incomes of the children in the family, including the sibling with a disability. Make a will only with an attorney experienced in devising wills for those who have an heir with a disability. Inheritances must be treated with caution. It is especially important to investigate the continued eligibility for certain social services if assets from an estate, pension, or life insurance are left to the child with a disability.

2. Know your state’s laws regarding guardianship and independence. Do not assume that you as parents will automatically remain your child’s guardian when he or she reaches the age of majority in your state. Establish whether the sibling with a disability requires no, partial, or full guardianship. This information should be in writing, and, if possible, make contingency plans in case the first-choice guardian is unable to assume that role. Be aware of the consequences in your state of not having a guardian appointed.

3. Nondisabled siblings should know where to access the needed educational, vocational, and medical records of the disabled sibling, and be ready to anticipate his or her changing future needs.

4. Families should consider the future health of the sibling with a disability with respect to needed services and care. Parents should document where he or she can receive medical care and the financial resources and arrangements necessary for this care.
5. Families should gain an understanding of the legal and eligibility requirements of programs available to the family member with a disability. Investigate resources through government programs, such as Supplemental Security Income (SSI), Vocational Rehabilitation, and Independent Living Centers, employment services, parent and disability groups.

6. Families should discover the types of community resources available. The range of services and resources varies considerably according to place of residence. Keep abreast of any changes in the availability of these services. Consider the sibling’s need for long-term care, as well as for employment and companionship.

7. Be aware that, as families grow and develop, the members within it change. Living with and caring for a child with a disability is different from living with and caring for an adult with a disability. Family members should continually ask themselves the following questions:

   - What are the needs of the sibling with a disability?
   - How will these needs change?
   - What can be expected from local support groups in the community?
   - What is and will be my level of involvement?
   - Is the involvement financially, emotionally and psychologically realistic for me?
   - How will the responsibility be shared with other family members?
   - Are my career plans compatible with my responsibilities for my brother or sister with disability?
   - Will my future spouse accept my brother or sister with disability?

The care of a sibling with a disability or chronic illness is, in large part, a family affair and a responsibility that should be shared as evenly as possible. By planning effectively for the future, parents can help ease the responsibility and the feelings of stress that uncertainty about the future can bring.
STUDIES RELATED TO THE STRESS / AFFECT OF THE PARENTS / CAREGIVERS OF THE INTELLECTUALLY CHALLENGED

❑ Anxiety, depression and quality of life in mothers of disabled children
   Gonca Bumin, Ayla Gunal, Sermin Tukel

Abstract: The purpose of this study was to investigate the relationship between anxiety and depression with quality of life in mothers with disabled children.

Methods: The study was performed in three Rehabilitation Centres in Ankora. One hundred and Seven disabled children and mothers included in the study. Becks Depression Inventory (BOI), State Trait Anxiety Inventory (STAI) and Nottingham Health Profile Part -1 (NHP) were used to assess Depression, anxiety and quality of life of mothers. The findings indicated that mothers educational level correlated with NHP Pain Scale. Increased depression and anxiety affected the quality of life of the mothers. The effective rehabilitation programs should provide sufficient opportunities for repeated follow-up interviewer which offers not only information on the children’s disabilities but also psychological support for the mothers.

❑ Prevalence of Depressive disorder among caregivers of children with Autism in Thailand
   Cho Wanum Chomist, Norumo Bathia Dept., of psychiatry, Amphor Mvangutoradit, Thailand

Abstract: A total of 27 caregivers were interviewed by using Mini International Neuro Psychiatric Interview, this version to find clinical depression in caregivers.

Results: Almost 26% of the participants demonstrated Depressive disorder, of which 14.8% and 11.1% met diagnostic criteria for major depressive disorder and Dysthymic Disorder respectively. Low education level was a significant factor associated with depression.

Conclusion: The prevalence of clinical depression is higher among care givers of children with Autism than the general population. Hence psychiatrists should include the assessment for caregivers depression in their care plans for autistic children to enhance the development of children and their caregivers.
Carina for caregivers

An investigation of factors related to well being among parents caring for a child with Smith Magerie Syndrome

Rebecca H. foster Stephonie Kozachaic Marilyn Stern - Serai H. Cisee

Smith Magerin Syndrome (SMS) is a complex disorder characterized by numerical challenges, including intellectual disability, speech delay, decreased pain sensitivity, sleep disturbance, hyperactivity, mood instability and Self injury. Caregivers must readily adopt to the ever-changing needs of the child. Due to these demands, caregivers may encounter difficulties in maintaining their own level of well-being. Thus a total of 112 primary caregivers (in parents) of individual diagnosed with SMS responded to online questionnaires to assess demographic and psycho social factors, such as perceptions of child health vulnerability, benefit finding, sleep behaviours, anxiety and depression. Symptomatology and caregivers satisfaction and self efficacy, which may be related to caregiver well being. Result show that among mothers, caregiver well-being was directly related to perceived child health, vulnerability, caregiver satisfaction and benefit finding and a significant moderating effect was observed for depression / anxiety counselling after beginning the caregiver role on the relationship between anxiety symptomatology and caregiver well being.

Early Caregiving and Physiological Stress responses

Linda, J. Luercken, Kothryn S. Lamey, Dept., of Psychology, A 285287 USA.

Abstract: Inadequate early caregiving has been associated with risk of stress related psychological and physical illness over the life span. Three theoretical pathways linking caregiving to physiological stress response are outlined genetic, psychological and cognitive affective. Exciting preliminary evidence suggests that early caregiving can impact long term physiological stress response. Directions for future reference in this area are suggested.
□ **Study of level of stress and burden in the caregivers of children with mental retardation**

Sujatha Sethi, Subhash C. Bhargova, Vishal Dhimon Dept, of Psychiatry, Palms Rohtak India.

*Abstract:* Mental retardation is one of the most prevalent developmental disabilities. Family is the main source of support for the person with disability in any society. Families experience great deal of physical and emotional burden whilst caring for such relative. This study tries to look into the issues such as the impact of severity of mental retardation on the level of stress and burden received by the caregivers.

□ **Stress among mothers of children with Cerebral Palsy attending Special School**

P.V. Vijesh, P.S. Sukumam

*Abstract:* This paper draws attention to the stress experienced by mothers of children with Cerebral Palsy attending special schools in Kerala State, India. The study reveals that stress experienced by mothers of these children is at moderate level and the pessimism expressed regarding the child's ability towards achieving self sufficiency, is found to be most stress producing factor. This article also gives suggestion how the stress level can be minimized among the mother.

□ **Impact of behaviour Problems on caregiver stress in young people with Autism spectrum disorder**

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*Background:* The purpose of this study was to exercise the correlates of caregivers stress in a large sample of young people with Autism Spectrum disorder.

*Method:* Parent or Teachers of 293 young people with ASPS completed measure of stress, behaviour problems and social competence. Parents also completed on
adaptive behaviour scale. Eighty one young people were rated twice at a 1 year interval.

*Result:* Parent and Teacher did not perfectly agree on the nature and security of behaviour problems. Conduct problems in particular were significant predictors of stress. Adaptive skills were not significantly associated with caregiver stress. Parent rating suggested that behaviour problems and stress exacerbated each other over time. This transactional model did not fit the teacher data.

*Conclusion:* Result of the study suggested that it is a specific group of externalized behaviours that are the most strongly associated with both parent and teacher stress.

- **Behaviour Problems of children with Autism, Parental self efficacy and Mental health**

  Richard P. Hstings and Tony Brown University & Southampton! (United Kingdom)

*Abstract:* Self efficacy has been identified in the general parenting literature as an important variable affecting parent outcomes. In the present study, 26 mothers and 20 fathers of children with autism reported on their self efficacy, anxiety and depression, the result showed high levels of potential mental health problems in parents of the Autism especially mothers.

- **Stress in parents of the Mentally Challenged Upadhyaya, G.e and Havalappanavor NB Karnataka Institute of Mental health**

  Dharwad, Karnataka State.

*Abstract:* Fathers and mothers of 628 mentally challenged individuals are assessed for their perceived stress using Family Interview for Stress and Coping in mental retardation (FISC-MR).

*Result:* It shows that mothers report higher stress compared to fathers, most of the parent report mild to moderate stress and none of them report very high stress. In the areas of care, emotional and social stress, mothers report higher stress and in the area
of financial stress both fathers and mothers report equal levels of stress. It is noticed that more than one mentally challenged children in the family, higher level of behaviour disorder, lower age of the mentally challenged individual and parents, and lower income of the family are associated with higher stress.

- **There is significant stress among parents having children with Autism**

  Fazzale Sabin, Wahid Bakhgl Sajid

*Abstract:* The sample included 60 parents 30 mothers and 30 fathers. The sample was taken from different hospitals and institutions of mental retardation in Islamabad. Stress in parents was measured through Parental Stress Scale (PSS)

*Result:* There was significant stress in parents of autistic children. Mothers experienced more stress than fathers. The level of stress was different in parents with the increasing age of the children. The implication is that mothers of children with autism are more prone to experience stress, requiring special attention from mental health professionals.

- **Parent stress and coping with their childrens attending deficit hyperactivity disorder**

  Mary Muser Mitchell - 2006

*Abstract:* In a previous study to NIMH enrolled 579 children diagnosed with ADHD in an randomized controlled trial to test the efficacy of a stimulant medication. ADHD affects 3.5% of children before age 7 and is characterized by difficulties in controlling impulsive and hyperactive behaviours and for paying attention. Studies of children with ADHD indicate that the disorder can be extremely disruptive to family functioning.

While the original NMH study examined the children’s outcomes, this investigation explored quality of life among the parents of these children. Quality of life was considered in terms of emotional well being and social functioning. Various studies within the health psychology discipline have suggested the coping strategy social support, and stress appraisal significantly influence and predict quality of life.
It was hypothesized that stress appraisal, social support, coping skill and symptom severity would predict quality of life indicator (in spouse relationship, parent/child relationship, and psychological/emotional functioning) for parents. This main effect the hypothesis was tested using baseline data and using longitudinal data, while controlling for baseline measures. The second set of hypothesis proposed the social support and coping skill would moderate the relationship between stress appraisal and quality of life the relationship were tested. In addition the relationship between objective and stress appraisal was lifted as well as the direct effects of objective stressors on the quality of life outcome. The result indicated support for both the main effect and moderating hypothesis. Recommendations for health educators, seeking to develop intervention programs for this population of parents were offered.

Parents of children with Mental Retardation coping mechanism and support needs

Samuel Bauman - 2004

Abstract: The purpose of this research was to explore the subjective experience of families of children with mental retardation, specifically the sources of stress and coping for these families. Interviews were conducted with families to shed light on their subjective experience of coping and stress. In on effort to increase understanding of the world view of these families, issues to theory, practice and future research are briefly discussed social support and empowerment oriented professional practice were found to have a mediating effect on family stress.

Parental coping method for managing stresses experienced following out of Home placement of a child with developmental disabilities


Abstract: A model describing the process of parental adaptation to life after voluntarily placing a child with developmental disabilities in out of home care was generated by utilizing grounded theory to analyze 20 qualitative interviews. The resulting model provides on organized understanding of how parents adapt to post
placement stressors. The cognitive appraisals of parents were categorized by their associated emotions, guilt, sadness, fear and worry, anger and frustration, and uncertainty (emotional stresses) and relief (an emotional advantage). Problematic and desirable adaptive responses to placement of both the child with developmental disabilities and his or her siblings, and the critical or supportive messages from others were determined as contextual factors affecting the emotional stresses of the parent. The primary coping method employed by the parents to manage the emotional stress consists of reappraisals regarding the necessity of placement, involvement in the child's life therapy and the passage of time.

Stress faced by mothers of children with Intellectual disability and its impact on their family life

Dr. Shahide Sajjad Associate Professor Pakistan

Abstract: This study was designed to find out the stress factor by the mother of children with Intellectual disability and its impact on family life. In Pakistan culture like western culture the major cause of high level of stress faced by mothers of children with intellectual disability is the inappropriate behaviour of children with intellectual disability. The study revealed the sense of loneliness faced by mother of children with disability has a negative impact on their family life although they get considerable support by other family members to handle the child with disability. They also do not have enough time for any entertainment as they are busy most of the time with their child with disability. The result was supported by study conducted by Hill.F, Newmark.R, and Le Grange L. (2003) and Bumin, Gunal & Tuke (2008) also stated that the mother has to undertake too much stress because they are alone with their children in daily life.

Other studies support these results eg., Moms & Maisto (2001) quoted Koening 1977 that people who attended religious services regularly enjoy better health and have markedly lower rates of depression than those who do not.

A study by Uchino, Calcippo & Kiecolt - Glaser (1996) stated that having a strong network of friends and family who provide social support is lined to good health.
Psychological effects of Parenting Stress or parents of Autistic Children

Lucille C. Wolf, Samuel, Sondre, Mark-Yale University

Abstract: Numerous empirical investigations have suggested that parenting developmentally handicapped children may have an adverse impact on parent well being (Cummings, Bayley & Rie, 1966, Demyer, 1979) the stresses of parenting these children include prolonged dependency and demands for special care (Howard 1978) disappointments with delayed developmental milestone (Bentovim, 1972) and worry regarding future self sufficiency. (Wing, 1985; Wolf & Grloberg, 1986) Delayed or forfeited parents goals (Kohut 1966) isolation from family and friends (Blacher, 1984) and the unpredictable, ambiguous nature of autism are important sources, life stress that impose physical and emotional strains on parents, exceeding levels experienced by parents of normal children (Bristol & Schopler, 1984; Korn, Chess & Fernandoz, 1978)

Behaviour problems of children with Autism, parental self efficacy and mental health

Richard P. Hastings and Tony Brown University & Southampton! (United Kingdom)

Abstract: Self efficacy has been identified in the general parenting literature as an important variable affecting parent out come. In present study 26 mothers and 20 fathers of children with Autism reported on their self efficacy, anxiety and depression. Result showed there was evidence that self efficacy moderated the effect of child behaviour problems on fathers anxiety. No evidence for the moderating effect of self efficacy is apparent for mothers. Methodological issues and the theoretical and practical implications of these results are discussed.

Predictors of stress in parents of Developmentally disabled children

Barbare Mckinney and Rolf A Persian University of Health source / the Chicago Medical School
Abstract: Child diagnosis type of early intervention program, social support network and perceived control were examined as moderators of stress responding in mothers of developmentally disabled children. Sixty seven mothers completed a battery of questionnaire. The child diagnosis and type of intervention did not have significant effect on stress response measure. Spouse support, perceived control and child characteristic each accounted for significant variance in a multiple regression prediction of stress scores. The role of child as a stressor and parent moderators variables in the prediction of parental stress are discussed in terms of models of stress and future research.

Stress and well being among parents of children with rare diseases - a prospective intervention study

Dellve L. Samuelsson. Tallbom A. Faith A. Hall berg L.R. - Sweden

Abstract: The paper reports a study to assess the stress well being and supportive resources experienced by mother and fathers of children with disabilities and how this variables were affected by an intensive family competence intervention. It was found high parental stress physical and emotional strain among mothers especially among single mothers. Parents perceived knowledge and active coping and mothers perceived social support were increased at follow up. Factors related to parents over all life satisfaction changed after the intervention.

An exploratory examination of the effects of support groups on the well being of parents of children with Autism -1 General Counselling

Vicks Bitsilla (Behaviour analysis and consulting) Christopher Sherplay - P.O.Box 378, Coolongatte QLP

Abstract: Parenting a child with Autism has been demonstrated to be a stressful anxiety provoke in and depressing experience (eg., Bebko Konstmitarees & Springer, 1987; Bristol; 1984 leonstantarees 1991). Second parental realization is that the condition of their child suffers from is life long and likely to place great demands upon their personal family and relationship (Gray & Holden 1992). Third the sense of personal isolation which arises from the fact that most members of the general public
have a poor understanding of the nature of autism (Fisman, Wolf & Non, 1989) and therefore see typical autistic behaviour as extremely socially inappropriate (Koeger, Schreibman, Loos, Dirlich Wilhelm, Dunlop, Robbins & Plsents, 1992) the reported data was taken from 219 parents of children with Autism in Victoria. Nearly half indicated that they felt ‘stretched beyond their limits’ between 1 and 5 times each month, with 11.1% of the sample stating that they felt this way more than 15 times per month.

Robbins Dunlop and Planti used parenting stress index to assess the indirect effect of a training programme designed to teach parents how to manage their autistic child's behaviour

Robbins Dunlop and Planti (1991)

Result: It showed a significant inverse correlation between reductions in parental stress as measured by parent domains sun scale of PSI and positive changes in child behaviour that is the process of learning ways of managing their autistic child's unwanted behaviour lowered at least one aspect of parental stress.

Akkore (1994)

Abstract: examined the effect of child behaviour management training upon parental stress as determined by parents attitudes towards their child and scores on the short form of the questionnaire on resources and stress. Results indicated that nine weekly two hour training sessions with six middle class couples (treatment group) showed significant improvement in child behaviour compared to another (control) group of six similar parents. However there was no significant difference in parental attitude towards their children between the treatment and control parents after training, nor any significant change in such attitudes from pre-training to post training within the treatment group.

Physical activity and stress levels among parents of children with Autism. MS in exercise and sport science - Physical education Teaching

M.felix -2010 - Burrow
Abstract: Parents of children with Autism may experience high levels of stress due to the nature of raising a child with Autism. This stress can impact the quality of life and health among this group. These parents are in need of programs (e.g. Respite, wellness, fitness) to help improve their overall well being and quality of life regular participation in physical activity may be one of many strategies used by those parents to effectively manage stress levels. The objective of this study was to determine if a relationship existed between physical activity and stress levels among parents of children with Autism. Parent of Autism children N=183 completed on online survey that included the parenting short form stress Index (PSI-SF) (Abiden, 1995). Result showed that parents of the children with Autism had unusually high level of stress. Aware of worse relationship was found between the parents current participating in exercise (r=-.16) and non-exercise physical activity (r=-.24) while these relationship was statistically significant (pc .05) the correlation is not great enough to be of any practical significance as indicated by their coefficient of determination.

A quantitative in qualitative study Origin of stress, Depression & Anxiety in parents of Autistic children & the Impact on the family

Amende Hert - Department of Biomedical Science - Wollen gong

Abstract: The research has focused on the stress and impact on the parents of family of ASD children and in particular the origin of such stress and depression. A combination of quantitative and qualitative method was used for the study. Self administered questionnaire were sent to parents (n=71) as ASD and (n=40) as control. The result showed children with ASD show significance learning & behaviour problem & parents of ASD children had for greater level of stress, anxiety & depression. A key source of social limitation is the unpredictability of children behaviour and the fear of them having a meltdown. Focus groups represented 27% of the ASD cohort. They reinforced social & personal factors & highlighted the impact on siblings. Disappointment with the medical profession was also identified in the focus groups as a key issue for parents.

Stress trajectories in mothers of young children with Down syndrome

D.E.Most, D.J.Fidler, C.Laforce-Booth & J.Kelly
Abstract: Family & Child Nursing, University of Washington, Seattle, WA, USA

Background. In this study, we investigated the early development of stress in mothers of children with Down syndrome, compared with mothers of children with developmental disabilities of mixed aetiologies. Growth modeling analyses were used to explore: (1) whether mothers of children with Down syndrome demonstrated distinct patterns of stress during their children’s early development, compared with mothers of children with other developmental disabilities; and (2) whether there was a relation between child behavioural characteristics and the level and rate of change in stress observed in each population.

Conclusions: These findings suggest that the cognitive-linguistic and behavioural trajectory observed in early development in Down syndrome may contribute to the changes in maternal stress levels observed throughout these early years. Implications for developing targeted and time-sensitive family interventions for families of children with Down syndrome are discussed.

Swedish parents of children with Down’s syndrome. Parental stress and sense of coherence in relation to employment rate and time spent in child care

G.Hedovl, G.Anneren & K.Wikblad

Abstract: Becoming parents of a child with Down’s syndrome (DS) challenges the adjustment ability in parenthood. Individuals with higher sense of coherence (SOC) are supposed to manage stressors better than those with lower SOC. The aims of this study were to investigate parental self-perceived stress, SOC, frequency of gainful employment and amount of time spent on child care in Swedish DS parents (165 parents; 86 mothers, 79 fathers) and to compare those with control parents of healthy children (169 parents; 87 mothers, 82 fathers). The mean age of the children was 4.7 years.

No differences concerning total employment rate were observed, but the DS mothers were more often employed part-time than control mothers. The DS parents did not spend more time on child care than the control parents and they did not differ in mean SOC score, but the DS parents perceived greater stress. The differences in
stress, particularly between the DS and control mothers, were related to time-demanding areas. Parents with high SOC scores experienced significantly less self-perceived stress.

Fathers of children with Down’s syndrome versus other types of intellectual disability: perceptions, stress and involvement

L.A.Ricci & R.M. Hodapp

Background: The present study examined fathers’ perceptions of, stress relating to and involvement with children with Down’s syndrome (DS) (n=30) versus those with other types of intellectual disability (ID) (n=20).

Methods: Fathers and mothers completed questionnaires about their children’s personalities and maladaptive behaviours, their own parenting stress, and the fathers’ level of involvement.

Results: Both fathers and mothers rated their children with DS as having more positive personality traits and fewer maladaptive behaviours. Possibly because of these positive perceptions, fathers of children with DS also reported less child-related stress.

Less Stress, More Rewarding: Parenting Children With Down Syndrome

Robert M. Hodapp, Tran M. Ly, Deborah J. Fidler, Leila A. Ricci

Abstract: We argue that, compared to other children with disabilities, parents of children with Down syndrome may experience less stress and more rewards. Design. After reviewing changes in studies examining parenting children with disabilities, we note how specific genetic disorders predispose children to different, etiology-related behaviors, which in turn predispose their parents to particular reactions. We then survey studies of both stress and reward in parents of children with Down syndrome versus children with other disabilities.

Results: Parents of children with Down syndrome report less stress and more child-related rewards than parents of children with other disabilities; indeed, parents of
children with Down syndrome may feel equally rewarded compared to parents of same-aged typical children.

**Conclusions.** By comparing feelings of parents of children with Down syndrome versus children with other disabilities, we begin to understand which child behaviors bring about which parental reactions. Such information provides both theoretical and practical benefits to professionals interested in parenting.

- **Positive adjustment in parents rearing children with Down syndrome**

  Flaherty, Evelyn M.; Masters Glidden, Laraine

  Abstract: The current research investigated adjustment in mothers and fathers rearing children with Down syndrome. Families who had a Down syndrome child by birth were compared with families who had knowingly adopted a child with Down syndrome and, therefore, were likely to be well-adjusted. With this design, child characteristic were controlled to assess more accurately the impact of a birth of a child with developmental disabilities on family adjustment. For this study, both mothers and fathers completed the Family Strengths Inventory, the Holroyd QRS, and the Locke-Wallace Marital Adjustment Test. Additionally, 105 mothers only completed the Beck Depression Inventory and the Nelson Index of Parental Satisfaction with Child. Results demonstrated that birth mothers and fathers were functioning quite similarly to adoptive mothers and fathers on the outcome variables. Only one significant difference was found and the adoptive / birth factor accounted for only 8% of it variance. Overall, birth as well as adoptive families appeared to be adjusting well to the challenges of rearing a child with Down syndrome.

- **Self - perceived health in Swedish parents of children with Down’s syndrome**

  Hedov, G.; Anneren, G.; Wikblad, K.

  Abstract: Investigated self-perceived health in parents of children with Down’s syndrome (DS). 165 parents (mean ages 37.8 - 39.6 yrs) of 86 DS children (aged 3.5-7 yrs) completed questionnaires. The survey assessed 8 health domains, including physical functioning, vitality, and mental health. Results show significant differences
in self-perception of health between the mothers and fathers of DS children, with mothers reporting health problems more frequently than fathers. DS mothers reported significantly lower vitality scores than did DS fathers. DS mothers reported lower scores in mental health and tendencies to lower scores in another 4 domains compared with mothers of children without DS. DS fathers had lower mean scores for vitality and mental health compared with fathers of children without DS.

Longitudinal effects of an early family intervention programme on the adaptation of parents of children with a disability

Pelchat, Diane; Bission, Jocelyn; Ricard, Nicole; Perreault, Michel; Bouchard, J.M.

Abstract: Assessed the longitudinal effects of an original early intervention program on the adaptation of parents of children with a disability (Down syndrome [DS] and cleft lip / palate [CLP]). Variations in the effects of the program according to the time of measurement, the type of disability and parent’s gender are also examined. 74 17-52 yr old mothers and fathers of children with DS or CLP who did or did not participate in the program were assessed. A series of analyses was conducted to compare the experimental and control groups on family and demographic variables and treatment. Results show a better adaptation among parents who participated in the intervention program. These parents had lower levels of parental stress, more positive perceptions and attitudes concerning their child’s disability and their parental situation, they were more confident in their own resources and the help they could receive from others, they had lower levels of emotional distress, anxiety and depression and they perceived more emotional support from their spouse. These gains were maintained throughout the year when the children were between 6-18 month of age, they were relatively similar for parents of children with DS and parents of children with CLP, as well as for mothers and fathers.

Mothers and fathers of children with Down syndrome: Parental stress and involvement in childcare

Roach, Mary A.; Ormond, Gael I.; Barratt, Marguerite S.
Abstract: Parental stress was examined in socioeconomically matched samples of mothers and fathers (aged 21-50 yrs) of children with Down syndrome (aged 15-57 mo) and typically developing children (aged 9-57 mo). Parents of children with Down syndrome perceived more caregiving difficulties, child-related stress (distractibility, demandingness, unacceptability), and parent-related stress (incompetence, depression, health problems, role-restriction) than did parents of typically developing children. For the combined groups of parents, mothers’ stress was associated with children’s caregiving difficulties, fathers’ stress with children’s group status (Down syndrome, typically developing). Mothers who reported more responsibility for childcare perceived more difficulties with health, role restriction, and spousal support. Fathers who reported more responsibility for childcare perceived fewer difficulties with attachment and parental competence. Partner stress was associated both with mothers’ and with fathers’ stress.

Parents’ attributions of blame for the birth of a child with Down syndrome: A pilot study

Hall, Sue; Bobrow, Martin; Marteau, Theresa M.

Abstract: Investigated parents’ attributions of blame for, and adjustment to, the birth of a child with Down’s syndrome (DS), within the context of widespread availability of prenatal screening. Parents of 28 children with DS participated in the study; all 28 mothers and 23 of the fathers agreed to be interviewed. Results show that no parent blamed themselves or their partner, but 8 fathers and 5 mothers blamed others. In every case this was a health professional or the health care system in general for not having prevented the birth of their child with DS by detecting the affected pregnancy. Mothers, but not fathers, who blamed were significantly more angry and depressed than those who did not blame. In contrast to parents who did not blame, both fathers and mothers who blamed had higher scores on a parenting stress scale.

Psychological Distress of Parents of Infants with Down Syndrome

Scott, B.S., Atkinson, L., Minton, H. L., & Bowman, T.
Abstract: The distress level of parents who had infants with Down syndrome (study parents) was compared to that of control parents of infants without disability (infants were all less than 2 years of age). Data were collected in two independent surveys. We matched subjects case-by-case on socioeconomic status. Analysis of pooled data indicated significantly greater depression for the study parents. However, effect sizes were small, and the prevalence of clinical depression was 5.56% (n=108) among matched study parents and 4.26% (n=188) among unmatched study parents. Parenting an infant with Down syndrome may cause less distress than previously thought.

Effects of children with Down syndrome on parents’ activities

Barnett, W. Steven; Boyce, Glenna C.

Abstract: Investigated the effects of children with Down syndrome (DS) on parents’ daily activities. Data on the allocation of time to daily activities were obtained from time diaries provided by 2 samples of parents with at least one child under age 17 yrs. Parents in one sample had a child with DS; parents in the other sample did not. Both parents of a child with DS devoted more time to child care and spent less time in social activities. Mothers of children with DS allocated less time to paid employment and increased child care time by 9 hrs per week. Fathers increased child care time by 4 hrs per week and reduced social activities by 2 hrs per week. Time allocated to shopping, passive leisure, personal care, and educational activities was not affected.

Cognitive coping, affective distress, and maternal sensitivity: Mothers of children with Down syndrome

Atkinson, Leslie; Scott, Brain; Chisholm, Vivienne; Blackwell, Janis; et al

Abstract: This study investigated relations among maternal cognitive coping style (approach-avoidance), affective state, and sensitivity. Fifty-six mothers and their children with Down syndrome were followed for 2 years. Cognitive coping and affective distress inventories were administered and sensitivity was rated on the basis of mother-child observations. Results indicated that approach and avoidance have been widely studied under different, designations and are stable across time. These
cognitive copying variables may mediate the stress of parenting a child with a disability in complex ways. Mothers with a strong tendency to monitor stressors report greater affective distress than do mothers who adopt a less vigilant coping style. At the same time, cognitive avoidance of stressors and affective distress reduce the behavioral sensitivity of the mother toward her child.

Father’s views of the effects on their families of children with Down syndrome

Hornby, Garry

Abstract: Examined fathers’ views about the effects of children with Down’s syndrome (DS) on themselves and their families. Taped interviews were obtained from 90 fathers (aged 27-62 yrs) of children (aged 7-14 yrs) with DS. Analysis of the interview data revealed 28 categories of comments made by Ss. The most frequent comment, made by 46% of the SS, was about the cheerful personality of their child with DS. About 42% of the Ss talked about the initial trauma they experienced following the diagnosis. 43% of Ss discussed the restrictions imposed on the family, and 30% commented that the child had minimal effects on family life. The most frequent concern, expressed by 36% of Ss, was the long-term provision for their children. Thus, although many fathers experience some negative effects of having a child with DS, only a small minority of them experience difficulties so great that some form of intervention may be needed.

The stability of the Ways of Coping (Revised) Questionnaire over time in parents of children with Down’s syndrome: A research note

Hatton, Christopher, Knussen, C.; Sloper, P.; Turner, S.

Abstract: Assessed the stability of the Ways of Coping (Revised) Questionnaire. The scores of 68 mothers and 53 fathers of school aged children with Down’s syndrome, were compared over 3 yrs. Five coping strategy subscales were used; mothers’ and fathers’ scores were analyzed separately. The parents’ scores did not change significantly with time. Time 1 and Time 2 scores were strongly associated on all subscales, except for the fathers’ scores on the Stoicism subscale. Test-retest
reliability was adequate for all subscales, except mothers’ scores on Passive Acceptance subscale, and fathers’ on the Stoicism subscale. Results demonstrate the stability of the Ways of Coping (Revised) Questionnaire over the time period studied, and illustrate the utility of this instrument for investigating coping in families with special problems.

☐ **A comparison of couples’ views on caring for their child with intellectual disability**

Ainge, David J.

*Abstract:* Compared the impact of having a child with an intellectual disability (e.g. Down’s syndrome) on parenting views of both fathers and mothers. Fathers and mothers (aged 27-70 yrs) of 19 children (aged 4-31 yrs) with intellectual disabilities completed a rating scale regarding 84 issues involved in parenting a person with intellectual disabilities and rated their feelings about each issue. On over 75% of items, couples either rated identically or disagreed only marginally, supporting the view that children with intellectual disability have a deterministic influence on both their parents.

☐ **Relations among maternal stress, cognitive development, and early intervention in middle - and low - SES infants with developmental disabilities**

Brinker, R.P., Seifer, R., Sameroff, A.J.

*Abstract:* Relations between maternal stress and the development of infants with handicaps was examined in 72 middle - SES and 72 low-SES families who attended a weekly early intervention program. Measures of maternal stress and development of infants were obtained 10 months apart. Regression analyses predicted 81% of variance in later developmental level with initial Bayley MA, initial Mental Development Index (MDI), SES, initial stress, early intervention participation, and SES x Initial Stress x Attendance interaction. Subsequent maternal stress was predicted (42% variance explained) by initial stress, attendance, initial MDI, number
of intervention agencies and MDI x SES x Attendance. Results were interpreted in terms of a transactional model.

❐ Fathers - the secondary partners: Professional perceptions and fathers’ reflections

Herbert, Elaine; Carpenter, Barry

Abstract: Explores professional perceptions and fathers’ reflections of issues surrounding a father’s role in the early stages of parenting a child with a disability. Fathers of 9 infants with Down’s syndrome born in a local health authority in 1986 and 1987 were interviewed. Topics discussed included disclosure of the diagnosis, information seeking, sources of support, and planning for the future, as well as professional predictions and perceptions of the father. Issues of professional accessibility during the period following the birth of a child with a disability are also examined, and implications for the parent-professional relationship are discussed including training, coordination of services, and the addressing of needs within the family.

❐ Psychological adaptation of fathers of children with autism, Down syndrome, and normal development

Rodrigue, James R.; Morgan, Sam B.; Geffken, Gary R.

Abstract: Compared fathers of 20 autistic (mean age 10.8 yrs), 20 Down syndrome (mean age 11.9 yrs), and 20 developmentally normal children (mean age 3.8 yrs) on measures of psychosocial adaptation. Groups were matched on child’s adaptive behavior age equivalent, gender, birth order, family size, and socioeconomic status (SES). The 3 groups differed significantly on measures of intrapersonal and family functioning but not on social-ecological variables. Fathers of children with autism or Down syndrome reported more frequent use of wish-fulfilling fantasy and information seeking as coping strategies as well as more financial impact and disruption of family activities than did fathers of developmentally normal children. There were few differences between fathers of children with autism and those of children with Down syndrome.
The pattern of care in families of adults with a mental handicap; A comparison between families of autistic adults and Down syndrome adults

Holmes, Nan; Carr, Janet

Abstract: Studied the pattern of care in 39 families with a mentally handicapped adult member (20 with Down syndrome; 19 with autism). All Ss were aged 18-38 yrs. Interview data revealed no significant differences between the mothers, the fathers, or the siblings of Down syndrome and autistic adults in the amount of help offered with physical care, domestic tasks, and supervision duties. However, most caregiving fell on mothers, with fathers helping mainly with supervision rather than physical care or domestic tasks. Siblings offered less help than fathers. Autistic Ss exhibited significantly more behavior problems. Methods of coping with problems differed. Parents of autistic were more likely to “give in” and less likely to tell the handicapped person to stop than parents of Down syndrome adults.

Factors related to stress and satisfaction with life in families of children with Down’s syndrome

Sloper, Patricia; Knussen, Christina; Turner, Stephen; Cunningham, Cliff C.

Abstract: In a study of 123 families of children (aged 6-14 yrs) with Down’s syndrome in England, measures of parent, family, and child characteristics were obtained from mothers and fathers. Multivariable analyses investigated their relationships to outcome measures of psychosomatic symptoms of stress and parents’ perceived satisfaction with life. Personality factors were related to outcome for both parents. For mothers, the children’s levels of behavior problems, excitability, and self-sufficiency were strongly related to outcome. Coping strategies, family relationships, and socioeconomic factors also showed significant effects. For fathers, child characteristics were not related to outcome. The marital relationship was an important factor, and there was evidence that factors external to the family acted as stressors.
Leisure patterns of families who have a child with Down’s syndrome

McLachlin, Laura Jane

Abstract: The study investigated the question “How does a child with Down’s Syndrome impact family leisure patterns?” In-depth interviews were conducted with 25 intact nuclear families who had at least three children one or more of whom had Down’s syndrome. Four major conclusions were made. First, subjects perceived family members to be an important element of leisure experiences. Second, the majority of family leisure time was spent in sports-related activities, vacations, and television and video camera recorder (VCR) watching. Third, parents viewed recreation integration as a positive experience for both the child with Down’s syndrome and for other children. However, minimal parental involvement in advocating for community services was reported. Finally, in most cases the presence of a child with Down’s syndrome did not significantly alter family leisure patterns. Some families, however, exhibited extreme adjustments based primarily on the severity of physical complications and behavioral problems associated with Down’s syndrome.

Marital intimacy in parents of exceptional children

Fisman, Sandra N.; Wolf, Lucille C.; Noh, Samuel

Abstract: Examined the role of perceived parenting stress and parental depression on marital intimacy between parents of handicapped children vs developmentally normal children, and investigated discrepancies between husbands’ and wives’ reports of marital intimacy. The parents of 31 autistic children (mean age 9.34 yrs), 31 Down syndrome children (mean age 9.11 yrs), and 62 developmentally normal children (mean age 7.62 yrs), matched for both mental and chronological age were studied. Results indicate significantly greater stress and depression, as well as lower marital intimacy for mothers of autistic children than for mothers of normal children or for mothers of Down syndrome children. Fathers of autistic children experienced significantly higher parenting stress than the other groups, as well as lower marital intimacy.
Self-reported adjustment, chronic sorrow, and coping of parents of children with Down syndrome

Damrosch, Shirley P.; Perry, Lesley A.

Abstract: Analyzed questionnaires from 18 fathers and 22 mothers of children with Down’s Syndrome with an age range from infancy to adulthood (mean age 6.59 yrs). Fathers (83%) depicted their adjustment in terms of steady, gradual recovery, while the majority of mothers (68%) reported a peaks-and-valleys, periodic crises pattern. Mothers also reported higher frequencies for chronic sorrow as well as for behaviors such as self-blame and expression of negative affect. The study suggests that mothers and fathers in the same family may experience distinct differences in adjustment and coping as parents of a handicapped child.

Family background of children with Down’s syndrome and a children with a similar degree of mental retardation

Gath A, Gumley D

Abstract: The families of Down’s Syndrome children and another group with a similar degree of retardation were compared using data collected at interview. Differences in social class distribution were explained by the maternal age effect in the Down’s group. Divorce was more common in the control group but the quality of marriage in those parents who still live together and the health parents were similar. No close associations were found between behaviour disorders in the children and family factors, except that behaviour disorders were likely to be associated with similar disturbance in siblings next in age and to be more common in the less happy marriages.

Family responses to developmentally delayed preschoolers: Etiology and the father’s role

Goldberg, Susan; Marcovitch, Sharon; MacGregor, Duane; Lojkasek, Mirek

Abstract: Parents of 59 developmentally delayed children (aged 2-4.5 yrs) with Down’s syndrome, neurological problems, or unknown etiologies responded to
questionnaires including the Coopersmith Self-Esteem Inventory; Rotter’s Internal-External Locus of Control Scale; and measures of support, coping, and psychological distress. There were group differences in maternal reports of positive experience with the child, self-esteem, reported support, and relations with grandparents. With the exception of self-esteem, all comparisons favored the Down’s syndrome group. The lower self-esteem of the parents of Down’s syndrome children may reflect a feeling of responsibility for the genetic defect. Fathers reported fewer distress symptoms, higher self-esteem, a more internal locus of control, and less support than mothers did, possibly reflecting traditional role divisions in the family. Findings indicate a need to understand individual differences among families of delayed children and illustrate that the effects of a child’s handicap on fathers differ from those upon mothers.

Psychological Distress among parents of children with mental retardation in the United Arab Emirates

Vivian Khamis

Abstract: This study was designed to identify predictors of parental stress and psychological distress among parents of children with mental retardation in the United Arab Emirates. It examined the relative contributions of child characteristics, parents’ sociodemographics, and family environment to parental stress and psychological distress. Participants were parents of 225 mentally retarded children, of whom 113 were fathers and 112 were mothers. Measures of parents stress (QRS-F), psychiatric symptom index (PSI) and family environment scale (FES) were administered in an interview format. Hierarchical multiple regression was used to predict parental stress and psychological distress. The results indicate that the model containing all three predictor blocks, child characteristics, parents sociodemographics, and family environment, accounted for 36.3% and 22.5% of parental stress and parents psychiatric symptomatology variance, respectively. The age of the child was significantly associated with parents feelings of distress and psychiatric symptom status, and parental stress was less when the child was older. Parents reported more psychiatric symptomatology when the child showed a high level of dysfunction. Fathers work appeared to be a significant predictor of parental stress, indicating that for fathers who were not working, the level of stress was higher than fathers who were
working. Lower socioeconomic level was associated with greater symptom rates of cognitive disturbance, depression, anxiety, and despair among parents. Among the family environment variables, only the personal growth dimension stood out as a predictor of parental stress. An orientation toward recreational and religious pursuits, high independence, and intellectual and recreational orientations were associated with lower levels of parental stress. On the other hand, parents in achievement-oriented families showed elevated levels of parental stress. Implications for prevention, and intervention as well as parent training and system-oriented counseling programs are discussed.

Stress and Coping among Parents of Mentally Retarded Children in the Young-in area

Arab emirates Vivian Khami

Abstract: The purpose of this study was to contribute to family nursing for reducing stress and improving coping of the parents of mentally retarded children. Data were collected through self-reported questionnaires during a period of 2 months between November 1994 and January 1995 in the Young-in area. The subjects consist of 180 parents (90 mothers and 90 fathers) of mentally retarded children attending schools for the handicapped and 186 parents (93 mothers and 93 fathers) of normal children. The levels of general stress and of parental role stress were measured with the General stress scale and the Parental role stress scale, respectively, while the Coping scale was adopted to measure the level of coping. The data were analyzed by using Chi-square test, Fisher’s exact test, Repeated measured ANOVA, one-way ANOVA and Scheffe comparison test. The results were as follows; 1. The level of general stress was significantly higher in the mothers and the fathers of the mentally retarded than in the respective parents of the normal. Of the parents, the mothers experienced significantly greater level of general stress than the fathers did in both groups of the retarded and of the normal. 2. As for the parental role stress, the mothers and the fathers of the mentally retarded experienced significantly greater stress than respective parents of normal children did. In particular, the stress was significantly higher in the mothers than the fathers of these children in both groups. The difference in the levels of parental role stress experienced by mothers and by fathers was
significantly bigger among those of the mentally retarded than among those of normal children. 3. No significant difference in the level of coping was observed between the mothers of both groups and the fathers of both groups. By contrast, the fathers revealed significantly greater scores in coping than the mothers in both groups. 4. General stress experienced by the fathers of the mentally retarded was different by health status, satisfaction with spouses, and the supports from their spouses. Health status, satisfaction with spouses, and monthly income influenced parental role stress experienced by those fathers. Their level of coping was associated with their satisfaction with spouses and family life. 5. Of the mothers of the mentally retarded, the level of general stress was different by their health status, while parental role stress was related to the satisfaction with their spouses and the child’s age. The level of coping among the mothers was different by the supports from their spouses. The above findings indicate that those parents of the mentally retarded did not take more coping strategies than those of the normal did, despite greater stress experienced among themselves. Hence, nursing intervention for managing stress should be given to those parents including fathers of mentally retarded children. Mothers of the mentally retarded, in particular, should receive high priority in planning nursing care, since they experience greater levels of both general stress and parental role stress than their spouses, which is most likely due to primary responsibility in child rearing given to them at home.


Ong LC, Afifah I, Sofiah A, Lve MS.

Abstract; A hospital study was carried out to compare parenting stress among 87 Malaysian mothers of children with cerebral palsy and a control group (comprising 87 mothers of children without disability who attended the walk-in paediatric clinic), using the Parenting Stress Index (PSI) questionnaire. Multiple regression analysis was used to determine socio-demographic and medical factors associated with child-domain stress (CDS) and parent-domain stress (PDS). Mothers of children with cerebral palsy scored significantly higher than control subjects on all sub-scales of CDS and PDS (p<0.01), except for the sub-scale of ‘role restriction’. The presence of
cerebral palsy (p<0.001) and activities of daily living (ADL) scores (p<0.001) were significantly associated with CDS. Factors predictive of PDS were ADL scores (p<0.001), number of hospitalizations over the past year (p=0.024), level of maternal education (p=0.018) and Chinese mothers (p<0.001). Although this study demonstrated that Malaysian mothers of children with cerebral palsy experienced higher levels of stress than controls, the impact of cerebral palsy per se on parenting stress was modified by other factors such as increased care-giving demands, low maternal education and ethnic background. Habilitation should be directed at easing the burden of daily care, minimizing hospital re-admissions and targeting appropriate psychosocial support at specific subgroups to change parental perception and expectations.