Autism Spectrum Disorder (ASD)

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This information is not intended to replace qualified medical or professional advice. For further information about a condition or the treatments mentioned, please consult your health care provider.

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Introduction

The Mental Health Foundation's mission is to improve the mental health of all people and communities in New Zealand. Mental health is a positive sense of emotional, psychological and spiritual wellbeing. We define mental health as being the capacity to feel, think and act in ways that enhance our ability to enjoy life and deal with the challenges we face.

People who have information can make informed choices. It is up to each person to decide what mental health is and what it means for them. We believe that providing accurate and helpful information is vital to the process of enabling people to gain control over and enhance their mental health and wellbeing. This includes considering factors that determine our mental health status such as age, gender, ethnicity, income, education, housing, sense of control over life circumstances and access to health services.

The aim of this Mental Health Information New Zealand (MHINZ) project is to provide people with a range of information that can be a starting point for ongoing learning and personal development. It is primarily designed to meet the needs of people working with the discovery that they or those close to them may have a mental health problem sufficiently distressing to warrant medical intervention. This may carry with it some of the stigma associated with mental illness and a loss of personal power in the face of medical labelling and control. So while for some, being given a diagnosis may be a relief, for others it may be upsetting.

We have developed this resource for a range of people including those who have been given a diagnosis, family, whanau, friends and others involved in support and treatment. The information provided is largely from a clinical perspective as it includes psychiatric diagnosis and information on current medical treatment options. We acknowledge that this is one perspective and that different cultures define mental health and wellbeing in a variety of different ways. We invite people to use the resources, references and contacts listed in these booklets to find further information.

Fact sheets summarising information from some of the booklets are available from the foundation's resource centre or may be downloaded from the foundation's website.

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Autism Spectrum Disorder

Autism is a language and social disorder. Children with autism cannot make sense of what they see or hear in the way that other children learn to do. Their senses seem to operate differently although their hearing and eyesight may be normal - there is a problem of interpretation. For some, the texture of a fabric, the taste of a common food, or a particular sound may be unbearable. For such a child the world can be a bewildering, frustrating and often frightening place. It is rather like being dumped in a different planet where you can't understand the language, facial expressions, or indeed any of the culture or ways of doing things.

Because autism is a variable and complex condition it is now described as autism spectrum disorder (ASD). Experts understand it as occurring on a spectrum (or scale) ranging from severe at one end where classic autism is found, to milder high functioning forms such as Asperger syndrome, at the other. Children with Asperger syndrome may have a high level of intelligence and no significant delay in language development but have difficulty with social interaction. Atypical autism may not meet the criteria for autistic disorder, sometimes because of late age at onset or absence of symptoms which feature in classic autism.

To complicate things even more, autism is the most common of a category of disorders called the pervasive developmental disorders or PDD.

Although people talk about diagnosis, autism is not a disease in the true sense and generally does not need medical treatment. Sometimes medication helps with particular problems such as hyperactivity, obsessive behaviour or epilepsy. Educational management and parent support at all stages of a child's development are more helpful than medical treatment in most cases.

Autism is diagnosed by observing a child's behaviour over time, but there are common autistic features. For children with classic autism:

- The child's ability to respond to others does not develop normally in the first three years. The child will often make quite bizarre responses to their environment.
- They seem to lack interest in others, acting as if they were deaf. They are often unable to sustain eye contact, seem to not care whether they are cuddled or held, sometimes actively resisting any physical contact.
- They may fail to develop language, or have a tendency towards repeating or echoing what is said to them (called echolalia). They will often also say "you" when they are talking about themselves. Some children may communicate through behaviours such as taking you by the arm and placing your hand on the thing they want.
- They are usually unable to develop the forms of imaginative play that other children do. They will often have a fixation on a particular object or objects, show obsessive or rigid behaviour and insist on certain routines or rituals.
- They may make strange flapping movements with their hands or fingers, or sometimes complex body movements, such as flicking fingers, standing on tiptoe or rocking their whole body.
- They may be very active.

- They may seem not to notice pain the way other children do, often not crying after a heavy fall.
- They are unable to form two-way give and take social relationships with others.
- In their play, habits might appear quite odd - spinning or flicking objects, tearing up pieces of paper, collecting and arranging items into patterns or taking an obsessive interest in making collections of special items.
- Some children become unusually upset when their routines are changed. Even a small change might upset them.

Children whose autism is diagnosed as higher functioning Asperger syndrome may have normal developmental milestones, although they may differ in how they use language. Their major problem is that they just don't seem to understand social behaviour. They have severe problems reading other people's body language, find it hard to make friends and play appropriately with other children. They may talk incessantly about one topic about which they will know a lot, although their range of interests will probably be quite narrow. Other children might see them as being a bit odd or eccentric.

Classic autism affects around one child in every 1000. Asperger syndrome is thought to affect one child in 300. Four out of every five children with autism are boys. While there are common features, no one child with autism is exactly like another. Like all children, they have different personalities, families and whanau, and life experiences which affect their responses to other people.

There is no known cure for autism, although many children improve over time, with specialised support and intervention. Some are eventually able to live an independent, almost normal life, while others, more severely affected, need life-long care.

Up to 50 percent of children with autism also have some degree of mental retardation, meaning that they will be delayed in some area of development. Others may develop epilepsy as they grow older.

Early recognition of autism is crucial because it can promote good management and treatment and provide access to support groups, services and state allowances. Early recognition also relieves parents of the burden of feeling guilty about their child's bad behaviour. The right kind of education programmes and care can make a real difference to the child's life enabling each one, whatever their level of ability, to achieve as great a degree of independence as possible.

Many children with autism have specially developed talents such as music, art or an obsessive interest in computers or mechanical things. It is important that such talents are encouraged as they may well form the basis of future employment and leisure pursuits. Other young people with autism will need extra support to help with the transition from school to adulthood and will need to be supported through specialist adult training services

While some adults may appear just a little eccentric or odd to others, those with higher functioning autism or Asperger syndrome often make careers which have developed from their special interests and abilities.

Myths about autism

NOT TRUE *Autism has an emotional cause.*

Understanding of autism has changed over the past 30 years and it is likely to change over the next 30. Autism used to be blamed on cold, intellectual, rejecting 'refrigerator' parents, especially mothers, who supposedly caused their child to withdraw into their own world. Of course this held out more hope for a cure - endless psychotherapy for the parents. But it failed miserably. Autism is not an emotional disability, although parents of autistic children say the myth still lingers.

NOT TRUE *There is a genius hidden within the child with autism, if only the key could somehow be found.*

This myth arose because of the uneven nature of the skills many children with autism exhibit. Some display specific and quite brilliant skills such as memorising a telephone directory (known as savant skills). Children with autism exhibit a full range of IQ scores. However, a child may read perfectly and not understand the meaning of what he or she has read (known as hyperlexia).

NOT TRUE *Children with autism never make eye contact, they often do not speak and they cannot show normal affection.*

They may not do these things in the way most children do, but those who love and work with these children learn to appreciate their special ways of giving and receiving love.

Causes of autism

The exact cause of autism is not known - other than that there is some kind of problem with the brain. It is likely that there is more than one cause, with most evidence pointing to autism spectrum disorder being biological.

Autism affects children from all levels of society, intellectual ability and ethnic origins. It is thought to have a very strong genetic base, although this is not always the case. Boys with autism out-number girls by about four to one, which is further evidence that autism is not caused by parental behaviour toward the child, but relates to different organisation of the brain in boys and girls. Relatives of people with autism are more likely than average to also have autism, and their families and whanau have an unusually high percentage of members with learning difficulties, speech disorders and other minor cognitive disabilities. They may also have members who are solitary or somewhat eccentric, or rigid in their habits.

Certain physical disorders have also been known to be associated with autism including maternal rubella (German measles), and other viruses, such as herpes simplex and candida albicans, a common yeast infection causing thrush. One theory maintains that a virus can affect a baby in the uterus, but remain 'sleeping' until it is activated by the normal stress of life. This would account for reports from some parents that a previously normal child became autistic.

Children with autism have higher levels of blood serotonin than most other children. There is also a theory that autism is an immune system disorder. Latest research suggests that the neurons in the brain make too many connections which results in

muddled circuitry.

In summary, autism appears to be caused by a number of factors, which, when they occur together affect the brain - especially the development of those parts of the brain which affect language and information processed from the senses, such as sight, taste and hearing. While recent research suggests there may be neurons in the brain that make too many connections, research into the causes of autism is ongoing.

Living with Autism Spectrum Disorder (ASD)

Often, for as long as two years or more the parents will have believed that their often difficult, somewhat odd or puzzling child was normal, if not bright. At worst they may have thought their child was slow in learning to speak. To learn that their child has autism can come as a terrible blow. By that time, many parents will be exhausted from telling their story to a number of doctors and other health professionals - many of whom may have responded by saying that the child will grow out of it.

All ASD experts stress the importance of early diagnosis, and that health professionals take parents' concerns seriously. After diagnosis, the first worries are usually about the child's future. "Will our child be able to have a job and be independent? Will he/she get married and have children? Are we going to have to look after this child forever?"

Coming to terms with the diagnosis of autism can be very painful. Parents have to consider a future for their child and themselves which is very different from their previous expectations. At this stage many parents may go diagnosis shopping to find out what is *really* the matter. They are especially vulnerable to any miracle cures which are on offer from time to time.

One of the most painful things for families and whanau is that children with autism look like other children. In fact they are often extremely attractive-looking children. Their behaviour can be anything but attractive and this leads to a lot of misunderstanding and 'tut-tutting' from other adults, especially when the child is in public. One mother of a child with autism carries specially printed cards from the Autistic Association with her when she is out with her child, handing them out to people who give her disapproving looks or comment on her misbehaving child.

The behaviour of a child with autism can cause families and whanau to become socially isolated, as tantrums, screaming and headbanging can sometimes last for hours. Added to this stress is the fact that, because of their sensory problems, the children can be poor sleepers, may be very rigid and picky in their choice of foods, or may insist on repeating particular words or activities for days on end. Because they may be sensitive to touch, the child's aversion to being cuddled can make a parent or caregiver feel hurt, rejected and inadequate.

The child tends to grow out of many of their more distressing early behaviour problems although they are likely to have some ongoing problems. The parents grieving process can be ongoing as a child grows and is not invited to birthday parties or able to take part in the social activities normal for a child of his or her age.

Single parenting a child with autism is probably the most difficult situation of all. Here a parent faces not only all the problems of single parenthood, but also the social and emotional costs of having a child with autism.

Other children in the family or whanau may suffer because life revolves around the child with ASD. Brothers or sisters face a number of special problems. They may have

to put up with constant disruptions in their lives. They may feel ashamed of their brother or sister's behaviour, or not see him or her as different until another child cruelly points it out. However, studies of the effects of living with children affected by autism have shown that the effects vary, depending on the severity of the disorder, whether there are behavioural problems, the attitudes of the parents towards the child with autism and the personalities of the brothers or sisters themselves.

Some children take on more than normal responsibility for the sibling with autism or feel obliged to help in parenting the child. Other children withdraw, resentful of the intrusions of their sibling with autism. Yet others feel obliged to become super-achievers as if to make up for what the child with autism cannot do. Even if there are no other children, the relationship between partners can become stressed. There may be difficulties in trusting babysitters or differences of opinion on how to handle the child's behaviour.

Not all children with ASD are difficult to live with, but most will need special help - at home and at school. The most important advice to family or whanau of a child with autism is to get as much information and help as possible. The best resource is your nearest branch of the Autistic Society. They have up-to-date information on State support and allowances and offer a wide range of resources. The last thing many people feel like after receiving their child's diagnosis is joining a society. It can feel like accepting a life sentence - but the autistic disorder experts in this country are parents who have been there. Extended family, whanau or sympathetic friends are also vital in helping to manage the care of a child with autism.

Families and whanau from non-European cultures may wish to seek the support of groups within their community, which can provide support, information, advice and other assistance. They should feel free to make use of such groups.

The best services for people with ASD and their families and whanau are those which focus solely on ASD, but, as yet, none exists in New Zealand. This means the quality of service, people with ASD receive can be very hit and miss. For instance, if a person with ASD has an associated intellectual disability or motor disorder they are eligible to get support from IHC or CCS. Some people with ASD and their families and whanau miss out on these services and are poorly supported.

The burden of care on families and whanau looking after a person with autism varies. Some families and whanau need regular access to short-term and long-term respite services where the child or young person can be cared for outside the home. There is a lack of such facilities in New Zealand. Their availability tends to vary in different places up and down the country.

When the child with ASD reaches school age, options can include regular school or being placed at a special school. Often, one of the major worries for parents is having teachers or teacher aides whose training has not included current techniques which help and support children with ASD to cope successfully at school.

There may be particular problems with getting adequate help, especially for higher functioning children. Their behaviour can be interpreted as naughty rather than something requiring special treatment.

Families and whanau who can access services sometimes find that the services do not listen to their views or give them enough information. Ideally, families and whanau need to be able to communicate freely with professionals about their relative.

Although autism will always be there, the child will continue to grow, change and

develop new skills and abilities. All children with ASD have aspects of normality which can be enjoyed, and, as with other children, they will bring both pleasure and pain to their parents.

Children with ASD are often astute in their observations of the world around them, but do not respond in a typical manner. Their communication disorder and their social difficulties mean that it is a challenge for those who love and teach them to help make things meaningful to them. As one parent wrote in a poem to her son:

"... But I affirm your fear

And hence your heroism

I know the difficulty of your journey:

To move every day in your space and time

Is to move to a country of fear

That I can only imagine."

Treatment of Autistic Spectrum Disorders

Autism is so complicated it cannot be treated by a single method or drug. Each individual child may need different treatments at different stages of life. What may work for one child may be actively harmful to another. When considering treatment for your child it is extremely important to ask questions and carefully assess the treatment being offered. It is also important to remember that, as with all children, children with autism also develop of their own accord. Therapy alone can never be wholly responsible for positive changes.

Unlike the United States, the United Kingdom and some other European countries, there are no specialist centres in New Zealand which deal only with autism. Help outside the family or whanau will come from a variety of sources, including early intervention teams, to work out just what support the child will need. The Special Education Service may draw up an individual plan for learning. Sometimes the IHC (an organisation that supports people with an intellectual disability and which offers a range of services) will be involved, offering some out of home care for the child when needed. Speech language therapists and occupational therapists are trained to work with the child's language and motor development; community child and family services attached to the local hospital have specialists in mental health issues for children, though few are trained in dealing with the special problems that autism brings.

These services are publicly funded and available free of charge. Any special treatments or therapies for autism outside the State care system have to be met out of parents' own pockets.

Guidelines for autism treatments

If it sounds too good to be true it probably is! Parents have given up lifestyles, jobs and taken out mortgages to pursue so-called cures for autism which have proved to be treatment fads promising more than they ever delivered. There have been many such fads for autism, but no major breakthroughs.

Unless claims for successful treatment can be supported by objective evidence, parents and professionals should continue to remain sceptical and wary. If you have any doubts contact the Autistic Society. Good advice should be available from any child and

adolescent mental health service in the public health service (usually at your local hospital). The following questions are useful for parents to ask about different or alternative treatments:

- What is the treatment programme?
- Is there written information, a programme description, detailed brochure etc.?
- Exactly what is involved for the child and the family or whanau?
- What are the financial costs?
- How much parent time is involved?
- Does the programme focus on one particular skill or is it a general one?
- Is there co-ordination between the treatment and other individuals/services working with the family or whanau (e.g. teachers, therapists, GP)?
- Is there follow up and/or support after the treatment has ended?
- What is the underlying philosophy of the programme?
- How is that tied to specific techniques?
- How were the philosophy and treatment methods developed?
- What training and qualification so the staff have?
- What is the supporting evidence for the effectiveness of the programme?
- What are the possible negative effects or side effects of the treatment?
- What impact might the programme have on the family or whanau's lifestyle?
- What do specialist child and adolescent mental health professionals think?

Summary of treatment options

The best treatment is usually a package which may include, at times, behavioural management, social skills training, speech language therapy and sometimes medication. These are the most usual, generally proven treatments, although with a disorder as complex as autism it is very difficult to scientifically show the benefit of a particular treatment.

Psychosocial treatments

Behaviour management and social skills training use the principles of learning theory to provide encouragement and support for the child at home, school, and in social situations. A particular type of behaviour modification therapy (the Lovaas method) has been used with some success with autism. All types of therapy should be provided to children, adolescents and their families and whanau in a manner which is respectful of them, and with which they feel comfortable and free to ask questions. It should be consistent with and incorporate their cultural beliefs and practices.

Medication

While autism itself can't be treated by medication, certain behaviour displayed by children with autism may respond to medication. Medication is effective in helping some specific symptoms, for example to control seizures (epileptic fits), to help a child who has difficulty with sleeping and to relieve obsessive-compulsive symptoms. A number of medications have been used to reduce particular symptoms or behaviour such

as hyperactivity, aggression, hand-flapping and self-injury, obsessions or depression. You are entitled to know the names of any medicines prescribed; what symptoms they are supposed to treat; how long it will be before they take effect; how long they will have to be taken for and what their side effects (short and long-term) are.

Complementary therapies

Complementary therapies which enhance the young person's life may be used in addition to psychosocial treatments and prescription medicines.

Psychosocial treatments

Behaviour management

Children with autism often have behaviour problems and are sometimes unable to recognise how inappropriate their behaviour is. Behaviour management plans can be drawn up by health or educational workers to help parents modify undesirable behaviours. Behaviour management generally rewards the child for doing things well, and imposes consequences (e.g. withdrawal of a privilege) for not getting things right - positive reinforcement.

There are special difficulties in working with these children because of their lack of communication and the programme therefore needs to be simple, clear and concrete. In a child whose speech does not develop, assistance to develop a communication strategy will assist the child and family or whanau to develop more appropriate communicative behaviours.

Social skills training

Social relationships are extremely difficult for children with ASD. Group training, sometimes using videos and role plays, has been used, particularly for those with higher functioning autism, to help them to understand the way that relationships usually work. They may learn specific skills for relating to other people in social situations.

For any form of behavioural or social skills training the child needs to be able to apply the new learning to all situations. It is important that families and whanau learn the methods of behavioural management so that they can help their child.

These treatments should be available through the Special Education Service or, where they exist, specialist Child and Family clinics attached to hospitals.

Behaviour modification (Lovaas)

The Lovaas behaviour modification treatment was pioneered in the early 1960s.

While it has been well researched, some parents are wary because of its earlier association with aversion therapy (children were given electric shocks to stop certain behaviours) and because of its intensity. To be successful, the Lovaas method must be used for as much as 40 hours a week to produce major improvement on a one-to-one basis. The Lovaas teachers deliver the programme in a way that some parents feel is too vigorous. Lovaas aims to prepare children for eventual mainstreaming. Several New Zealand parents have their children on Lovaas programmes with an overseas trainer. This is very expensive, costing upwards of $10,000 in some cases.

Medication

While autism itself can't be treated by medication, certain behaviour displayed by children with autism may respond to medication. 'Start low and go slow' is the usual advice about medication dosage for ASD. The biochemical systems of children and young people with autism are usually already sensitive and it is easy to overmedicate them. This group of children and young people are not often able to provide feedback about symptoms or side effects which means that it is important to be cautious when beginning any new medication.

Puberty may bring on anxiety or depression in some young people with autism. Often, attention deficit/hyperactivity disorder (ADHD) and obsessive compulsive disorder (OCD) will be diagnosed as well.

One early finding about autism was that many people with the condition had high levels of blood serotonin. A drug called fenfluramine was used to decrease these levels, but carefully controlled studies failed to show any notable benefit from fenfluramine. Fenfluramine was also found to have caused significant heart problems in some adults taking it for weight reduction and was withdrawn in 1997, is no longer prescribed and no longer thought to be useful in the treatment of autism.

Trials of naltrexone (Revia), a drug which acts on brain chemical systems in a similar way to fenfluramine, have shown some effect on hyperactivity and self-injury behaviour in ASD. Naltrexone does not cause significant side effects in most people and is used occasionally in extreme situations where non-drug treatments have not worked, although it does not appear to have any positive effect on the core social deficit associated with autism.

Unfortunately, it had been hoped that fenfluramine and naltrexone were better replacements for the antipsychotic medications, such as haloperidol (Serenace) or chlorpromazine (Largactil). Used in the treatment of schizophrenia, they have been found to lessen hyperactivity, aggression and rigid patterns -such as flapping- in children with autism. Because of side effects these drugs must be used cautiously, in low carefully monitored doses and where the behaviour cannot be managed by non-drug treatments.

Both haloperidol and chlorpromazine have side effects (especially when used in high doses) and these can include sleepiness, tremors, slowness of movement and rigid muscles, dry mouth, blurred vision, constipation, difficulty in passing urine and changes to heart function. Some people get distressing sudden muscle spasms which affect the face and throat.

Over long periods of time, people on antipsychotics can develop a movement disorder known as tardive dyskinesia. This involves involuntary movements such as smacking of the lips, pouting and chewing movements, or rhythmic movements of other areas of the body. It is important to monitor for onset of this effect, as the longer it goes undetected, the less chance it will stop when the medicine is stopped. (For further information on antipsychotic medication refer to the medication section of the article on schizophrenia).

Risperidone (Risperidal) is one of the newer antipsychotic medications which has far fewer side effects (compared with those above), and is being used more frequently as first-line medication (with the cautions as outlined above) in autism. There have also been case reports in which olanzapine (Zyprexa), another of the newer antipsychotic medications) has been used in autism, but further research is required before its efficacy is established.

Stimulants

Not uncommonly, other conditions in addition to autism are also diagnosed, including attention deficit/hyperactivity disorder (ADHD). ADHD symptoms usually respond to the stimulant medications methylphenidate (Ritalin) and dexamphetamine.

Methylphenidate is more commonly prescribed in New Zealand than dexamphetamine for which there is a part-prescription charge. Methylphenidate comes in a 10mg tablet. The child's weight provides a rough guide to dosage. New Zealand doctors tend to be conservative, with children often starting off with a low dose which may be increased depending on how effective they feel it is and whether there are side effects. The final dose should not be higher than 0.5mg per kg of the child's weight. Methylphenidate acts quickly and does not last in the system for more than six hours. It is usually obvious within the first month whether or not the drug will work for the person.

Short-term side effects of stimulants

Side effects, if there are any, will tend to show up early and will often lessen or disappear completely over several weeks. Potential side effects include appetite loss, finding it hard to sleep, headaches, stomach aches, increased pulse and blood pressure, tearfulness and irritability. Some children's ADHD symptoms seem to get worse on stimulants, making them more disorganised and aggressive.

Some children have a drug rebound effect, their symptoms worsening as the level of the stimulant in their system is reduced later in the day. This can be managed by giving an extra half dose later in the day, taking care that this does not cause major problems with getting to sleep at night.

Long-term side effects of stimulants

There has been some concern about stimulants suppressing children's growth, either by lessening their appetites or possibly affecting the growth centre in the brain. Height and weight need to be closely monitored as part of the routine follow-up for children on stimulant drugs. If the medication is stopped, children will grow normally and reach their expected adult height and weight. With the doses that are ordinarily prescribed in New Zealand, weight loss is not often a problem.

Some children with ADHD develop muscle twitches or tics on stimulants. Previously it was thought that stimulants could cause tics, but more recent evidence shows they can be used safely and cautiously in such cases.

There is no evidence of addiction or withdrawal symptoms in childhood, but with increasing diagnosis of ADHD in adolescence and adulthood, much caution is needed as amphetamine-type drugs could be dangerous for those at risk of a substance abuse problem. There is also a theoretical risk of worsening psychotic symptoms or the development of a psychotic disorder such as schizophrenia in those taking stimulants, though in practice this is not often seen.

Stimulants need to be used cautiously by people with other health problems, particularly heart problems. They should not be combined with nasal decongestants in tablet form as a high pulse and high blood pressure can occur (although this problem is not common). Some children will respond badly to combining antihistamine drugs with stimulants, becoming overactive and irritable.

Currently stimulants can be prescribed by a child medical specialist such as a paediatrician or child psychiatrist, with ongoing prescriptions available from other medical practitioner, including general practitioners.

Clonidine (Catapres)

Symptoms of sleep problems, hyperactivity, impulsivity and disturbed behaviour have also been treated with clonidine (Catapres), a drug used to treat high blood pressure in adults. A major side effect of clonidine is sedation or sleepiness and there have been occasional reports of sudden death of children on high doses who also had heart problems. There are some reports of benefits of clonidine, but there are no well-controlled scientific studies recommending its use. It is generally thought that it is more likely to be of use for sleep problems than in helping with the child's behaviour.

Antidepressants

Autism is often associated with obsessional and ritualistic behaviour, similar to that seen in obsessive compulsive disorder (OCD). Based on the similarity of symptoms, medications used to treat OCD such as clomipramine (Anafranil & Clopress) and fluoxetine (Prozac, Lovan, Plinzine & Fluox) have been used in autism and there is some recent evidence of their limited effectiveness. Clomipramine is from a group of medications known as tricyclic antidepressants. These have a range of side effects which limit their use and effectiveness. They are being replaced by a new generation of antidepressants - the Selective Serotonin Re-uptake Inhibitors (SSRIs). Fluoxetine is probably the most well known of these. Early reports on fluoxetine show that it does help to improve ritualistic and obsessional behaviour. Side effects of fluoxetine include nausea, headache, sleeping problems, tummy upsets and loss of appetite and, for some, agitated or jittery feelings.

These medicines are available in tablet or capsule form. Some are also available as a syrup. Antidepressants are not seen to be addictive, but there may be withdrawal effects if stopped suddenly including symptoms of feeling shaky.

Different types of antidepressants should not be mixed unless instructed by a doctor as this can be very dangerous. Caution should be used in combining any antidepressants with other medications. Tricyclics are dangerous in overdose. Prescription drugs should be kept in a safe place by parent or caregiver if there are any concerns for the young person's safety. (For further information on antidepressants refer to the medication section of the article on depression).

Other medications

Various anxiolytics (anti-anxiety medications) have been used in the treatment of autism and related conditions, although this is sometimes associated with an increase in behavioural disinhibition and disorganization. Further studies are required, but some researchers have reported variable results with buspirone (Buspar). The mood stabilizing medications, including lithium carbonate (Lithicarb & Priadel), have also not been shown to have major therapeutic benefit.

Medicine interactions

Most psychiatric medicines tend to react with each other when taken in combination. Their sedative effect in particular may cause sleepiness. A doctor will, where possible, limit the number of medications prescribed.

It is important the doctor knows all the medications (including any herbal medicines) being taken, as some taken together can be dangerous.

Complementary Therapies

Health, healing and healing practices are varied and differ according to how people view illness. Any health-related practice that increases an individual's sense of wellbeing or wellness is likely to be of benefit. Talking things over with people you feel comfortable with can be useful and may help to define a problem and ways to begin to tackle it.

The term complementary therapy is generally used to indicate therapies and treatments which differ from conventional western medicine and which may be used to complement, support or sometimes replace it. There is an ever-growing awareness that it is vital to treat the whole person and assist them to find ways to address the causes of mental health problems rather than merely alleviating the symptoms. This is often referred to as an holistic approach. Complementary therapies often support an holistic approach and are seen as a way to address physical, nutritional, environmental, emotional, social, spiritual and lifestyle needs.

Many cultures have their own treatment and care practices which many people find helpful and which can often provide additional benefits to health and wellbeing. Rongoa Maori is the indigenous health and healing practice of New Zealand. Tohunga Puna Ora is a traditional healing practitioner. Traditional healing for many Pacific Islands' people involves massage, herbal remedies and spiritual healers.

When considering taking any supplement, herbal or medicinal preparation we recommend that you consult a doctor to make sure it is safe and will not be harmful.

Girls who may be pregnant or breastfeeding are advised to take extra care and to consult a doctor about any supplements, herbal or medicinal preparations they are considering using, to make sure they are safe and that they will not harm their own or their baby's health.

For more information see the MHINZ booklet ***Complementary Therapies in Mental Health***.

Legislation

New Zealand has laws with specific implications for people who experience mental illness. The following information is a brief introduction to some of these Acts, and gives details on where to get specific information or assistance.

More information may be obtained from the local Community Law Centre or Citizen's Advice Bureau – look in a telephone directory for details. The local library is a useful place to obtain information or books and resources on the law. Copies of New Zealand legislation are available from government bookshops and can be seen at most public libraries, or on the internet at www.rangi.knowledge-basket.co.nz/gpacts/actlists.html

Recommended publication

Mental Health and the Law: A Legal Resource for People who Experience Mental Illness, Wellington Community Law Centre, 2002. Available from Wellington Community Law Centre, Ph 04 499 2928.

Government agencies can provide advice, information and publications in relation to mental health and the law.

Ministry of Health
133 Molesworth Street
PO Box 5013
WELLINGTON

Ph 04 496 2000
Fax 04 496 2340
Email EmailMOH@moh.govt.nz
Web www.moh.govt.nz

Mental Health Commission
PO Box 12479
Thorndon
WELLINGTON

Ph 04 474 8900
Fax 04 474 8901
Email info@mhc.govt.nz
Web www.mhc.govt.nz

Department for Courts
PO Box 2750
WELLINGTON

Ph 04 918 8800
Fax 04 918 8820
Email family@courts.govt.nz
Web www.courts.govt.nz/family

More contact details for government agencies are listed in the following sections.

The Health and Disability Commissioner Act 1994

This Act governs all actions taken by the Health and Disability Commissioner, the office and advocacy services. It is the legal document which gives the authority to ensure the rights are delivered. The purpose of the Act is

> *"To promote and protect the rights of health consumers and disability services consumers, and, to that end, to facilitate the fair, simple, speedy, and efficient resolution of complaints relating to infringements of those rights" (Section 6).*

The Act's objective is achieved through

- the implementation of a Code of Rights (see below)
- a complaints process to ensure enforcement of those rights, and
- ongoing education of providers and consumers.

Code of Health and Disability Services Consumers' Rights

There are ten rights set out in the code and these rights apply to all health and disability support services in New Zealand, both public and private services. The code gives rights to all people who use health and disability services and describes the obligations of all providers of health and disability services. The Health and Disability Commissioner contracts advocates in each region to ensure the code is upheld.

To make a complaint to the advocate in your region, contact the office of the Health and Disability Commissioner.

The Health and Disability Commissioner

Freephone 0800 11 22 33
E-mail hdc@hdc.org.nz
Web www.hdc.org.nz

AUCKLAND
Level 10, Tower Centre
45 Queen Street
PO Box 1791
Auckland

Ph 09 373 1060
Fax 09 373 1061

WELLINGTON
Level 13, Vogel Building
Aitken Street
PO Box 12 299
Wellington

Ph 04 494 7900
Fax 04 494 7901

The Human Rights Act 1993

Discrimination on the basis of disability is illegal under the Human Rights Act. If you feel you have been discriminated against you can make a complaint to the Human Rights Commission.

Human Rights Commissioner
Freephone 0800 496 877
TTY (teletypewriter) access number 0800 150 111
Email infoline@hrc.co.nz
Web www.hrc.co.nz

AUCKLAND
4th Floor, Tower Centre
Corner Queen & Custom Streets
PO Box 6751, Wellesley Street
Auckland

Ph 09 309 0874
Fax 09 377 3593

WELLINGTON
Level 8, Vogel Building
8 Aitken Street
PO Box 12411, Thorndon
Wellington

Ph 04 473 9981
Fax 04 471 0858

CHRISTCHURCH
7th Floor, State Insurance Building
116 Worcester Street
PO Box 1578
Christchurch

Ph 03 379 2015
Fax 03 379 2019

The Privacy Act 1993

The Privacy Act sets out general rules about the protection of our personal information. Extra rules have been developed to protect health information. These rules are set out in the Health Information Privacy Code, which is contained within the Privacy Act.

The Health Information Privacy Code sets out 12 rules that agencies must follow when dealing with health information. These rules cover the collection, storage, use and disclosure of health information, and give you the right to access and correct your health information.

The code applies to you whether you are receiving health services voluntarily or under the Mental Health Act.

Under the code, health services can develop their own policies for dealing with health information. You are advised to ask for a copy of their policies. Health services must appoint a Privacy Officer, so find out who that person is in the service you are dealing with. You may request information from or make a complaint to the service's Privacy Officer.

The Privacy Commissioner.
Freephone 0800 803 909

Office of the Privacy Commissioner
PO Box 466
AUCKLAND

Ph 09 302 8655
Email privacy@iprolink.co.nz (Auckland)
privacy@actrix.gen.nz (Wellington)
Web www.privacy.org.nz

Further information

On the Record: A Practical Guide to Health Information Privacy, Office of the Privacy Commissioner, 2nd edition, July 2000.

Protecting Your Health Information: A Guide to Privacy Issues for Users of Mental Health Services. Mental Health Commission, 1999.

The Mental Health (Compulsory Assessment and Treatment) Act 1992

For a person to be compulsorily assessed and treated it must first be determined that they have a mental disorder. The definition of 'mental disorder' is described in the Act.

The Act sets out clear procedures that must be followed when a person is compulsorily assessed and treated. People under the Act lose their right to choose and consent to assessment and treatment. All other rights as described in the Health and Disability Commission's Code of Rights remain.

To ensure a person's rights are upheld and correct procedures are followed the Minister of Health appoints District Inspectors for each area. They are lawyers and you may request information from or make a complaint to them. You can find out who the District Inspector for your area is by contacting the Ministry of Health or your local community law centre. (Contact details are at the front of this section)

In general, the Act gives young people (16-19 years) the same rights as adults. For people under 16 there are additional protections.

The Ministry of Health publishes helpful user information guidelines on the Mental Health Act. Contact details for the Ministry are at the front of this section.

Further information

The Mental Health Act: Information for Families and Whanau, Schizophrenia Fellowship.

The Schizophrenia Fellowship (SF)
Freephone 0800 500 363

National Office
PO Box 593
Christchurch
Ph 03 366 1909
Fax 03 379 2322
Web www.sfnat.org.nz
Email office@sfnat.org.nz

Look in your telephone directory for the local Schizophrenia Fellowship.

The Children, Young Persons and Their Families Act 1989

This Act applies in two situations.

- When it is decided that children and young people are defined as needing care or protection and,
- where children or young people offend against the law.

This Act defines a child as someone under the age of 14, and a young person as someone who is 14 or over but under 17 years of age. If concerns have been raised about a child or young person's care or protection in the first instance, an informal meeting is usually called with the family and a social worker.

Formal options available through this Act are:

- family group conference
- application to the Family Court
- removal of the child or young person.

Care and protection issues may mean the involvement of The Child Youth and Family Service (CYFS). Look in your telephone directory under Government Agencies for contact details for your local CYFS.

For more information, it may be helpful to contact:

The Office of the Commissioner for Children
PO Box 5610
WELLINGTON

Ph 04 471 1410
Fax 04 471 1418
Email children@occ.org.nz
Web www.occ.org.nz

Youthlaw Tino Rangatiratanga Taitamariki
Provides free, confidential legal information and advocacy for young people under 25, anywhere in Aotearoa New Zealand.

PO Box 7657
Wellesley Street
AUCKLAND

Ph 09 309 6967
Fax 09 307 5243
Email youthlaw@ihug.co.nz
Web www.youthlaw.co.nz

The Criminal Justice Act 1985

This Act sets out rules that apply to people who have been charged with, or found guilty of committing some kind of criminal act.

One part of the Act applies to situations where a person is experiencing a mental illness AND has been charged with or found guilty of committing some kind of criminal act. A person in this situation can become a 'special patient' under the Mental Health (Compulsory Assessment and Treatment) Act 1992.

The Protection of Personal Property Rights Act 1988

This Act describes what can happen legally when a person is unable to make all or some of their own decisions about their personal and property matters. This is called a lack of capacity. The Family Court decides if a person lacks capacity.

In some cases, the Family Court may appoint a welfare guardian for someone who is unable to make these decisions. A welfare guardian has the power to make a wide range of decisions, such as where a person lives and how they should be cared for. A welfare guardian can act and consent to treatment on that person's behalf.

Family Court contact details are listed at the front of this section.

Further Information

Groups and organisations

Autism New Zealand Inc.
Autism New Zealand has branches and contacts throughout New Zealand. They provide support, resources and information on Autism and Asperger syndrome to those with these conditions, their family or whanau, caregivers and professionals working with them. They have extensive resources, including books for hire.

P O Box 7305
Sydenham
CHRISTCHURCH

Freephone 0800 AUTISM
Ph 03 332 1038
Fax 03 332 1024
Email autismnz@xtra.co.nz
Web www.autismnz.org.nz

ASK (Autism Spectrum Kiwis)
A New Zealand support group, with international links, run by and for adults on the autism spectrum. It is a charitable trust, whose prime roles are as a support group (providing members with newsletters, pen pal lists, opportunities to meet, etc), and as a resource for those seeking "insider perspectives". For further information contact ASK.

P O Box 19 654
Christchurch
Email ask_trust@snap.net.nz

Websites

The Mental Health Foundation's website has information about the mental health sector and mental health promotion, news of upcoming conferences both here and overseas, links to other sites of interest and the Foundation's on-line bookstore. It also contains the full text of all the MHINZ booklets which can be downloaded as pdf or Word files.
www.mentalhealth.org.nz

Autism New Zealand Inc.
www.autismnz.org.nz

The National Autistic Society
www.nas.org.uk/asd/

Autism Connect
www.autismconnect.org/

Center for the Study of Autism
www.autism.org

Books

An Anthropologist on Mars by Oliver Sacks. Picador, 1995.

Emergence: Labelled Autistic by Temple Grandin and Margaret Scariano. 1986.

Nobody Nowhere by Donna Williams. Avon Books, 1994.

The Autistic Spectrum: a Guide for Parents and Professionals by Lorna Wing. Trans-Atlantic Publications, 1997.

The Handbook of Autism: a Guide for Parents and Professionals by Maureen Aarons and Tessa Gittens. Routledge, 1992.

A Parent's Guide to Autism: Answers to the Most Common Questions by Charles A. Hart. Pocket Book Publishers, 1993.

Mental Health Foundation Resource & Information Centre

The Mental Health Foundation Resource and Information Centre is at the Foundation's Auckland offices and is open to the public. Information and resources are available in a range of formats including pamphlets, books, journals videos, research papers and directories. Anyone living in Auckland may borrow books and videos are lent throughout New Zealand. The extensive collection includes resources on

· Mental Health · · Mental Illness · · Mental Health Services ·
· Depression · · Discrimination · · Workplace Wellbeing ·
· Stress · · Maori Mental Health · · Support Groups ·
· Recovery · · Relaxation · · Self-Help ·
· Older People's Mental Health · · Young People's Mental Health ·

The centre is open Monday to Friday, 9am to 4.30pm.

Mental Health Foundation of New Zealand
PO Box 10051
Dominion Road
Auckland

81 New North Road
Eden Terrace
Auckland

Ph 0064 9 300 7010
Fax 0064 9 300 7020
Email information@mentalhealth.org.nz
Web www.mentalhealth.org.nz

Titles in the MHINZ series of booklets

Attention Deficit / Hyperactivity Disorder
Alcohol Problems
Anorexia Nervosa
Attachment Disorder
Autism
Bipolar Affective Disorder
Brief Psychotic Disorder
Bulimia Nervosa
Cannabis Problems
Conduct Disorders
Complementary Therapies in Mental Health
Dementia
Depression
Depression in Children and Young Adults
Obsessive-Compulsive Disorder
Panic Disorder
Personality Disorders
Phobias
Postnatal Depression & Psychosis
Problems with Tranquilliser Use
Schizophrenia
Separation Anxiety Disorder
Solvent and Inhalant Problems

Delusional Disorders	*Tourette Disorder*