

Reviews

Autism treatment and family support models review

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Autism is a lifelong neurological disability of unknown etiology. The criteria for a diagnosis of autism are based on a triad of impairments in social interaction, communication and a lack of flexibility in thinking and behavior. There are several factors which are likely to contribute to this variation including the definition of autism and variability in diagnosis amongst professionals, however anecdotally there appears to have been a steadily increasing demand for services. The purpose of this review of research literature relating to the management and treatment of children with autism is to identify the most effective models of best practice. The review includes Comparative evidence supporting a range of treatment and intervention models, across the range of individuals included within autism spectrum disorders, psychodynamic treatment/management which are based on the assumption that autism is the result of emotional damage to the child, usually because of failure to develop a close attachment to parents, especially the mother, biological treatments, educational and behavioral interventions, communication therapies, cost benefits and supporting families.

The research is examined for evidence to support best practice models in supporting families at the time of diagnosis and assessment and an overview of the nature of comprehensive supports that help reduce stresses that may be experienced by families of a child with autism and promote inclusion in community activities.

Key words: Autism, Autism treatment, family support

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Introduction:

Autism is a lifelong neurological disability of unknown etiology. The criteria for a diagnosis of autism are based on a triad of impairments in social interaction, communication and a lack of flexibility in thinking and behavior. There is a spectrum of autistic disorders which includes: Autistic Disorder (Some people with Autistic Disorder with IQ in the typical range may also be described as having High Functioning Autism, HFA), Asperger Syndrome (there is some dispute about the validity of the distinction between Asperger's Syndrome and HFA),

Retts Syndrome, Childhood Disintegrative Disorder, Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS), also known as Atypical Autism. The diagnosis of autism spectrum disorders, referred to throughout this review as autism, is made on the basis of observed behavior. As a result there is some variability across professionals in the assessment and diagnosis of autism (1).

Methods of treatment

The first step is that of informing, to make sufferers aware of the risk that they run, and the opportunities there are for cure and recovery,

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of how many people there are around them, including parents, paediatricians, child minders, kindergarten teachers, trainers, and school teachers, and of practical ways of recognizing disturbance and taking the first steps.

The main symptom of the illness is its main cause, that is to say anaesthesia of feeling. Thus what requires verification is the ability of the person to relate empathetically with others. The absence of use of emotional sensitivity leads the child not to invest emotionally in relations with people and with his surroundings, and, as well as not being very sociable, he may also suffer from difficulty in learning some forms of communication. Language itself is either absent, or stereotyped, or substituted by basic mimicry, reduced to the barest minimum to convey his own elementary needs.

Every situation is characterized by unique manifestations, so that it is not possible in the abstract to outline one procedure for everyone. But there are some fundamental choices necessary for treatment to be successful. Parents are always at the centre of treatment. Their session is central to the cure. All attempts at planning intervention and treatments should involve a close working relationship between the professional and the family, always keeping in mind the need to bridge the gap between science, beliefs, culture, and the individual needs of children and their families (2).

Cultural Perceptions - The impact of cultural perceptions of autism needs to be taken into account in any discussion of intervention outcomes. Every disorder is perceived differently by society and different cultures may define and relate to a given disorder in different ways. The social definition of a particular disorder or aspects of that disorder may influence specific interventions and reflect different societal beliefs and values. For example differences in the amount and 'type' of eye contact, is subject to different cultural norms within Australian society in different cultural groups. Lack of eye contact and/or unusual quality of eye contact are characteristic of autism. There is a view of

autism as a feature of normal biological variation which may have evolutionary advantages as well as disadvantages (3).

Need for a Multi-Dimensional Framework

Autism itself is a condition that straddles many different disciplines in its definition, diagnosis, education and care. As a result it is inevitably best approached in a multidisciplinary way (4). When considering assessment and intervention for children with autism it is essential that we adopt a multi-dimensional framework involving people working in different disciplines. It is essential that our understanding of autism is based on an ecological concept of the disorder and that intervention strategies include parents, teachers, peers, the person with autism and other professionals.

Individual Differences

The range of the autism spectrum and individual variation in autism is a key issue. Is the autism spectrum a series of subgroups or a continuum? "The effects of autistic spectrum disorders are pervasive, affecting the way a person thinks, feels, understands and acts; but the effects are not uniform (3). Possible systems for classifying children with autism into subgroups based on their profiles ...can be invaluable in planning more appropriate interventions in order to better service individuals with autism and their families (5).

Claims of 'Cure' and 'Recovery'

Although autism is a life long pervasive developmental disorder, treatment programs exist that claim to provide a cure for autism. Howlin (6) mentions a number of these therapies, including Holding Therapy, the Options or 'Sonrise' program (7), Auditory Integration Therapy (8), Facilitated Communication (FC), and Applied Behavioral Analysis (ABA) (9). Despite being the subjects of a range of published testimonials, internet articles, anecdotal accounts and research studies, none of these therapies and associated claims have been shown to be supported by adequate research (6).

Classification of treatments

The range of treatments available for autism is

extensive with treatments classified in several different ways by different authors. Mesibov, Adams & Klinger (10), classify intervention approaches into three main groups:

Psychodynamic, Biological and Educational/Behavioral .

This review will deal briefly with the psychodynamic and biological treatments and focus on the educational/behavioral interventions. While educational/behavioral interventions are the primary focus of this review, brief reviews of the research into psychodynamic and biological approaches are included because it is likely that families will pursue more than one approach, often simultaneously. It is important to keep in mind the dilemma for families faced with many, often expensive and sometimes invasive, potential treatments for their child, especially when empirical evidence of the efficacy of these treatments is lacking.

Psychodynamic treatments

Hobson (11) suggests psychoanalytic approach may be useful because of its emphasis on object relations and affective contact. Howlin (12) points out that for older more able individuals with autism individual psychotherapy or counseling may help them deal with anxiety and depression arising from recognition of their difficulties and differences. There is some evidence to support the effectiveness of Cognitive Behavioral Therapy (CBT) with some high functioning individuals with autism (13), however unless therapy is combined with practical advice on how to deal with problems in a functional sense the outcome is unlikely to be effective. Some of Specific Psychodynamically Based Treatments/Therapies are: **Holding Therapy**. This therapy based on the work of the Tinbergens (14) who claim that autism is caused by “an anxiety dominated emotional imbalance, which leads to social withdrawal. **Pheraplay**. This approach was developed by DesLauriers (15), who essentially proposed that autism was a failure of emotional attachment compounded by sensory impairments.

Biological treatments

Medication has been found to be useful in

disorders such as epilepsy and depression. There have been announcements of such treatments; such as secretin (a hormonal compound) (16) and a consequent rush to secure them by families. Typical Anti-psychotics were developed to treat schizophrenia. This class includes drugs such as haloperidol, fluphenazine, thioxene and thioridazine. If the medications are to be stopped they should be gradually withdrawn to avoid withdrawal dyskinesias (17). Atypical Anti-psychotics have been developed in the last 20 years to minimise the effects on the extrapyramidal system of the typical antipsychotics outlined above. The usefulness in children of this class of medications is not yet clear. The most common side effects in those on these medications are weight gain and sedation (17).

Serotonin Reuptake Inhibitors was developed as antidepressant and has proved useful in the management of obsessive-compulsive disorder. Mesibov et al (10) suggest however that clomipramine should be used with caution because of an association with lowering of seizure thresholds. Beta blockers reduce anxiety and aggression in autism has not been well researched, however atenolol and propranolol are used to reduce anxiety in some people with autism (18). Anti-convulsant medications is estimated that up to 30% of people with autism have seizures, which often develop during adolescence (10). Naltrexone is an opiate antagonist that has been hypothesised to be helpful in reducing the symptoms of autism by blocking endogenous opioids that may be released during self-injurious repetitive behaviors (17).

Educational and behavioral interventions.

There are several recent comprehensive reviews of behavioral intervention research. Some of these reviews are included as part of more general reviews of treatment and management of children with autism (19, 20; 13).

Family support models and programs

Evidence to support best practice models to assist families at the time of diagnosis is scarce. In Futagi and Yamamoto’s (21) study of mothers’ views on the disclosure of a diagnosis of

autism, the following factors were identified as contributing to the reduction in stress experienced by families when receiving a diagnosis of autism: early disclosure of a diagnosis relates to early acceptance; increased understanding of autistic behavior; the accumulated experience of how to communicate with their child and the existence of a self-care group to support parents were important factors for the acceptance of the disability.

Research has identified key factors that should be considered by professionals when informing parents of their child's diagnosis; in particular ways to improve the interview process (22, 23). These include; become knowledgeable about autism; establish a family-friendly setting; understand families' needs; communicate effectively; provide lists of resources and interventions; provide follow-up, discuss prognosis and provide hope, and recognise that personal reactions are common when communicating a diagnosis of autism

The Help! Program. An example of a post-diagnostic support program for parents and carers of autistic children is the Help! program developed by the National Autistic Society of the United Kingdom (24). This program aims to provide parents and full-time carers with post-diagnostic information and advice, to develop their knowledge and understanding of autistic spectrum disorders, positive management strategies and local support services. Each program supports ten families and a parent manual including handouts, information booklets and leaflets, together with a child/adult life folder accompanies the program.

Family-centered positive behavior support (PBS) programs. Family-centred behavior interventions that involve a collaborative relationship between professionals and families and consideration of families needs and strengths in addition to child needs and strengths, were

found to increase parental sense of competence, increase parents factual knowledge of autism and issues related to advocacy and to buffer the effects of child adaptive functioning on stress related to parenting (25, 26, 27). A number of studies have demonstrated the efficacy of combining family-centred intervention with PBS which is a collaborative, assessment-based approach to addressing problem behavior (28, 29, 30).

NAS EarlyBird Program. This is a parent-focused rather than family-focused model of early intervention which combines group sessions with the one-to-one support of a professional during home visits (31). Parents learn first to understand their child's autism: to appreciate how people with autism experience the world and how the underlying triad of social deficits influences thinking, development and learning. The goal of the program is to build parents' confidence by explaining why development and behavior may be different in autism, so that parents can work out how best to help their child.

The Hanen Program. The Hanen Centre is a government-funded agency in Toronto, Canada, that specialises in training caregivers to facilitate language development in children from birth to six years of age.

Autism Early Intervention Project. Currently under trial is another parent-focused model of early intervention developed by the Centre for Developmental Psychiatry & Psychology at Monash University, Melbourne (32). This project aims to determine whether a parent education and skills training early intervention (PET) improves the outcome for preschool children with autism.

Conclusion:

In summary, the success of all these programs is clearly dependent on the establishment of a good parent-professional relationship. In particular the ability of health professionals, social and support workers to enhance the well-being of children with autism and their families by addressing the needs of the entire family, facilitating family choice and control of supports, and helping families to navigate the complex service system.

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