

TOWARDS OPTIMAL MENTAL HEALTH OF PERSONS WITH DOWN SYNDROME

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This paper outlines the risk of mental health disorders in adults with Down syndrome and considers the practical ways in which positive well-being can be promoted. It emphasises that prevention begins at birth and parents need to be alerted to positive child-rearing strategies from infancy.

Keywords: Mental health, adults, adolescents

Introduction

Numerous previous reports indicate that there is a high prevalence of psychiatric disorders and behaviour problems in persons with Down syndrome. Cuskelly and Dadds (1992) noted that children with Down syndrome display more behaviour problems and show significantly more attentional concerns than their siblings.

Concerning psychiatric disorders, Menolascino (1965) reported that 11 of 86 (13%) children in his study had psychiatric conditions. A study by Gath and Gumley (1986) revealed that 73 of 193 (38%) children and adolescents with Down syndrome displayed psychiatric disorders. In another investigation, Lund (1988) observed that 25% of persons with Down syndrome had psychiatric problems. Myers and Pueschel (1991) examined 497 persons with Down syndrome and found the overall prevalence of psychiatric disorders to be 22.1%. These authors noted a wide range of psychopathology in persons with Down syndrome including major depressions, obsessive-compulsive disorders, anorexia nervosa, phobias, conversion reactions, paraphilias, eating disorders and others. From these and other studies, it is apparent that persons with Down syndrome may be at a higher risk for behaviour and psychiatric disorders when compared with a normal population.

The question arises whether it is feasible to prevent, at least in part, certain behavioural and

psychiatric conditions in individuals with Down syndrome? Although no long-term studies have investigated this question, there are a number of considerations that will be detailed in the following discussion that could lead to a better mental health in persons with Down syndrome.

The importance of a positive approach to counseling parents

Learning that their infant has Down syndrome is an extremely traumatic experience for the parents. Most parents who have lived through such a crisis describe sensations of overwhelming shock and disbelief. What was anticipated as a joyous event has turned into a catastrophe. During this initial period of shock, many parents will display a wide variety of emotional responses including anger, inadequacy, shame, and disappointment. Cognitive dysfunction and a disturbance of personality integration are often observed in the distressed parents. Parents do not know what the future may hold for their child. The feelings of helplessness and emotional disorganisation usually last for a number of days, in some parents even weeks, depending on the individual parent's emotional strengths, maturity, religious convictions, and previous life experiences. For many parents, however, the sadness and the depressed feelings may take a long time to fade.

During this initial crisis, the physician should provide optimal counselling and genuine support for the traumatised parents. This difficult task

demands tact, wisdom, compassion, and truthfulness. The physician should communicate his/her message sympathetically and supportively. His/her approach will greatly influence the parents' attitude and subsequent adjustment. It will set the tone for the atmosphere that will prevail in future years. The physician who emphasises that the child with Down syndrome is first and foremost a human being who needs the love of caring parents will pave a positive way for this child's future. Parents need hope and encouragement to see positives in their child. The physician should attempt to identify and mobilise emerging parental strengths.

If parents are counselled appropriately during the initial time period, their mental well-being will be enhanced. They will be able to cope better and this in turn should have a beneficial effect on the child's emotional development.

Beyond the very traumatic, emotional experience surrounding the child's birth, there may be subsequent stress situations. As the child grows, he/she will pass through a series of developmental stages and experiences such as entering school or engaging in vocational activities.

With each stage, parental patterns of coping may reactivate unresolved issues from the past. In such situations, the parents may be in need of support and guidance by the caring professionals. If parents are provided with the appropriate assistance and counselling, they will cope more effectively and their child's mental health will be enhanced.

Strategies for improving mental health in people with Down syndrome

Discipline, rules, and limits

All children including youngsters with Down syndrome will require some form of discipline. Clearly defined rules and limits will need to be established in the upbringing of the child with Down syndrome as for any other child. Rules give order and substance to the environment and limits define the line between what is and what is not acceptable. Parents need to establish certain limits in order to help their child with Down syndrome to learn behaviours that are appropriate. In setting up rules and providing discipline, parents should display positive interactions with the child. Children have to receive positive messages about themselves and what they do. Children thrive on positive reinforcement of good behaviour. Many behaviour problems can be avoided if such an approach is used in the rearing of children with Down syndrome.

Developing self-competence and self-esteem

It has been emphasised that the family atmosphere and parenting practices are major factors underlying the development of self-competence in the child (Powers and Sikora 1997). Mink, Nihira, and Meyers (1983) reported that family conditions that are high in cohesion and relatively low in conflict, where there exists a high level of involvement and pride in children such circumstances will help the child develop a high self-esteem and lead to a positive psychosocial adjustment. Powers, Zinger, and Todis (1996) as well as Ferguson and Asch (1989) underline the importance of parents focusing on the children's strengths. According to Powers and Sikora (1997), parenting practices that promote self-competence include:

1. positive supportive interaction,
2. providing opportunities to practice and develop autonomy,
3. focusing on the individual's strengths,
4. providing accommodation to reduce the restrictiveness of disability, and
5. using reasoning and limit-setting.

The development of certain skills are important for the expression of self-competence. Powers et al. (1996) indicate that the self-competence of youngsters with Down syndrome can be enhanced through the acquisition and application of specific achievement, partnership, and coping skills. In addition, an important skill for expressing self-competence is goal setting (Gardner, 1986). Other essential skills for developing self-competence are problem-solving, assertiveness, self-advocacy, self-monitoring, frustration management, access to support by others, and the development of friendships (Powers and Sikora, 1997). Thus, in fostering self-competence, persons with Down syndrome will feel better about themselves which again will enhance their mental health.

Self-determination

Self-determination assumes that individuals with Down syndrome have a greater control over decision and resources (Nisbet, Crowley, and Crowley, 1997). Self-determination is a concept that can provide direction for families and human service professionals. Self-competence, self-esteem, and self-determination that can bring about mental well-being should be fostered in the home environment, in the educational and vocational settings, as well as in the community by and large.

Promoting recreational activities

Heyne and Schleien (1994) stressed the importance of developing leisure repertoires that will teach individuals with Down syndrome to learn new skills, and strengthen their physical and mental well-being. On the other hand, the absence of a meaningful leisure program will foster maladaptive or aggressive behaviours (Wehman and Schleien 1981). Successful involvement in recreational skills will enhance the self-confidence and the self-esteem in many people with Down syndrome. Heyne, Schleien, and Rynders (1997) point out the significance of leisure education and the importance of physical activities which will expand the social network, promote friendships, and introduce a sense of autonomy. Songster et al. (1997) emphasise that consistent training and sports competition in Special Olympics are essential to the physical, mental, and social developments of young people with Down syndrome. The benefit of such training and competition stimulates self-confidence and promotes acceptance by society. Individuals with Down syndrome participating in Special Olympics activities have been inspired to celebrate the unlimited potential of the human spirit by sharing the skill, courage, and joy expressed in the lives of the athletes (Songster et al., 1997) There are many other activities people with Down syndrome can engage in that will promote self-confidence, self-worth, and a greater self-esteem. For example, martial arts, dancing, hiking, bicycling, gymnastics, and just having plain fun all of which can lead to a better mental well-being of the person with Down syndrome.

Treatment modalities

In spite of the various preventive measures and positive approaches described above, and in spite of assisting the young person with Down syndrome to achieve optimal physical and mental health, there may be situations where an individual with Down syndrome may display aberrant behaviors or is found to have a psychiatric disorder. If significant behaviour problems become apparent, professional help may be necessary. There are various strategies for behaviour management as detailed by Cuskelly and Gunn (1997) including self-regulation, appropriate positive reinforcement, and other behaviour modification approaches. Often a close collaboration of counsellor, school personnel, parents, and other caregivers will

benefit the person with Down syndrome. If a person with Down syndrome has been diagnosed with a specific psychiatric disorder, then the person may be in need of specific psychotropic medications and/or psychotherapy and parental counselling should be provided. Although proactive prevention is of primary importance, those children who are exhibiting behaviour or psychiatric disorders should be treated effectively so that they will be able to interact well with other people in the community and will enjoy a good quality of life.

Conclusion

If at the birth of their child with Down syndrome, parents are appropriately counselled and if they are provided with positive guidance, most of them will be able to adjust and cope well. Parents then will be able to foster the child's optimal physical and mental well-being. It is important that the person with Down syndrome can live in a nurturing environment that promotes self-confidence and self-esteem and avoids undue stressful situations. There are numerous leisure activities as detailed above persons with Down syndrome can become involved in that will result in a well-adjusted lifestyle and should ultimately lead to optimal mental well-being. If an individual with Down syndrome should exhibit a severe behaviour or psychiatry disorder, professional help and appropriate treatment should be forthcoming. In order to live a happy, well-adjusted life and to be able to contribute to society, persons with Down syndrome should be offered a status that observes their rights and privileges as citizens in a democratic society and, in a real sense, preserves their human dignity.

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