

Social-Sexual Education in Adolescents with Behavioral Neurogenetic Syndromes

Maya Plaks, MD,¹ Ronit Argaman, MSW,² Mike Stawski, MB, BS, MRCPsych,¹ Tova Qwiat, MA,³ Dan Polak, MA,⁴ and Doron Gothelf, MD¹

¹ The Behavioral Neurogenetics Center, Feinberg Department of Child Psychiatry, Schneider Children's Medical Center of Israel, Petah Tikwa, Israel, and Sackler Faculty of Medicine, Tel Aviv University, Ramat Aviv, Israel

² Ram Institute for Sexual, Social and Psychological Treatment, Fontovich Psychological Service Ltd., Tel Aviv, Israel

³ Clinic for the Art Therapy, Savion, Israel

⁴ Shalom School for Special Education, Department for Special Education, Ministry of Education, Culture and Sport, Petah Tikwa, Israel

ABSTRACT

Background: Adolescents with developmental disabilities have unmet needs in their sexual and social knowledge and skills. We conducted a sexual social group intervention in adolescents with neurogenetic syndromes, mainly with Williams and velocardiofacial syndromes and their parents.

Method: Ten adolescents with neurogenetic syndromes and 14 parents participated in a Social Sexual Group Education Program. The program was delivered in 10 bi-weekly sessions to the adolescents and their parents separately.

Results: The focus of psychoeducation in both groups was the adolescents' self-identification, acceptance of the developmental disability, independence, establishment of friendship and intimate relationship, sexual knowledge and sexual development, and safety skills. Change in independent activities of adolescents and in their concept of "Friend" was measured.

Conclusions: Social and sexual education programs are of the utmost importance for adolescents with neurogenetic developmental disabilities. These programs should start already before adolescence and follow the children into young adulthood.

cents without disabilities. Adolescents with disabilities have the same needs, drives, desires and interests as other youth and go through the same changes – physical, emotional, social (1). However, sexuality is a more complicated issue in people with learning disabilities, where the sexual component of growth is often denied by parents and caretakers. The presence of sexuality in this population has frequently been seen as presenting problems rather than a positive human attribute (2, 3).

Parents of adolescents with developmental disabilities often avoid the issue of sexuality as a result of fear: fear that talking about these issues would promote sexual interest, fear of embarrassing situations, fear of sexual abuse, pregnancy or sexually transmitted diseases (4). Parents are also influenced by social stigmas and myths about sexuality in disabled children which may include ideas that adolescents with developmental disabilities do not possess a sexual drive at all or they will inevitably transmit the disability to their offspring (5, 6). Although there is a growing recognition of the need for parents' consultation, only few receive guidance or education regarding sexuality of their disabled child. This lack of information about sexuality leads to a feeling of helplessness and to choosing dysfunctional ways of coping (7). The recommended approach to help disabled children to develop their sexuality lies in educating both the adolescents with learning disabilities and their parents, providing them the necessary information on sexuality (8).

While there is some increasing awareness of the need for psychosexual education in individuals with developmental disabilities, there is lack of awareness for this need in individuals with neurogenetic syndromes.

INTRODUCTION

Issues of sexuality are as important to adolescents with developmental disabilities as they are to other adoles-

In the Behavioral Neurogenetics Center at Schneider Children's Medical Center of Israel we treat individuals with neurogenetic syndromes associated with learning disabilities including Williams syndrome (WS) and velocardiofacial syndrome (VCFS).

Williams syndrome is caused by a microdeletion in the long arm of chromosome 7 (9). Most cases are sporadic and not inherited, which means that most of the patients are single cases in their families. Because of their impaired functioning, most people with Williams syndrome do not get married and do not give birth to children. In addition to some medical comorbidities (e.g., supraventricular aortic stenosis), individuals with WS have a mean IQ in the mild to moderate range of mental retardation (10). Individuals with WS are very friendly towards strangers, and tend to approach them without making appropriate social judgments, asking them personal questions and sometimes initiating physical contact in an undifferentiated way (11). Because of their strong social appetite individuals with WS often reveal submissive and pleasing behavior. Therefore during adolescence and adulthood they are at high risk for sexual abuse. In spite of being outgoing, people with WS, like most of the people with learning disabilities, suffer from social isolation, impaired social skills, loneliness and difficulties in making friends. Parents of adolescents with WS often fear that their children may become sexually abused or remain in social isolation.

Velocardiofacial syndrome (VCFS) also known as DiGeorge syndrome is caused by a microdeletion in the long arm of chromosome 22, and is the most common microdeletion syndrome in humans, occurring in about 1 to 2,000 live births (12). While the physical comorbidities associated with VCFS are often relatively mild and the major ones like the palate and cardiac anomalies can be corrected by surgery, the cognitive deficits and psychiatric disorders have a more profound impact on affected individuals (13). Consequently, following the first years of life, the cognitive deficits and behavioral/neuropsychiatric symptoms become the most debilitating aspect of individuals with VCFS. Individuals with VCFS tend to be shy, withdrawn, stubborn, emotionally labile, and afflicted with social and communication impairments (13). The average IQ in VCFS is within the borderline range and about 25% of individuals with VCFS develop schizophrenia-like psychotic disorder by early adulthood (12, 14). Autistic spectrum disorder symptoms are also common in children and adolescents with VCFS (15). Because of the cognitive deficits and psychiatric comor-

bidity adolescents with VCFS are impaired in their social skills and are also frequently lonely.

As we felt that social and sexual issues of adolescents with WS and VCFS are crucial for the development and well-being we decided to conduct a Social-Sexual Group Education Program and to measure its effectiveness.

METHODS

SUBJECTS

In 2002, 10 adolescents with developmental disabilities and their parents participated in a Social-Sexual Group Education Program. They were recruited from the Behavioral Neurogenetics Center at Schneider Children's Medical Center of Israel. Of the 10 participants five had WS, three had VCFS, one neurofibromatosis, and one idiopathic learning disability. The age range of adolescents was 15 to 24 years, mean = 19.5 years, SD = 2.6 years, and they consisted of five males and five females. Eight of 10 subjects completed the 10 group sessions. Two subjects and their parents discontinued after the first session.

The group for parents included 14 participants: in six cases one parent and in four cases both parents participated in the group sessions. The study was approved by the Institutional Review Board of Rabin Medical Center of Israel.

THE SOCIAL-SEXUAL GROUP EDUCATION PROGRAM

The treatment was delivered in 10 bi-weekly group sessions. Each meeting was devoted to a special topic and was held in the form of psychoeducation promoting attitudes, skills and knowledge. The focus of psychoeducation in both groups was the adolescents' self-identification, acceptance of the developmental disability, independence in social life, establishment of friendship and intimate relationship, sexual knowledge and sexual development, and safety skills.

The specific aims of the adolescents' group were: (1) to help the participants to discuss their attitudes and feelings regarding human sexuality, their own development and future perspectives; (2) to inform the adolescents regarding sexual development, physical, emotional and social changes; (3) to instruct how to develop healthy social and sexual relationships, appropriate sexual behavior and their right over their bodies.

The specific aims of the parents' group were: (1) to support parents in working through their attitudes, feelings and uncertainties regarding their children's devel-

opment and sexuality; (2) to provide parents knowledge on sexual development of adolescents with intellectual disability; (3) to emphasize to the parents the importance of sexual education, and to advise them how to help their children manage their sexuality in a healthy and protected way; (4) to encourage parents to foster more skills of independence in their children according to each adolescent's developmental level.

MEASURES

The following questionnaires were administered before and after the group treatment.

1. *The Skills and Independent Activities Questionnaire* is comprised of a list of 19 questions about independent activities at home and social basic skills (16). It contains two subscales: "Social Entertainment" (9 questions) and "Independent Activities" (10 questions). The questionnaire was completed by the parents.
2. *The Assessment of Sexual Knowledge, Experience and Needs Scale for People with Intellectual Disability* (17). The questionnaire contains eight sections comprised of 170 questions that assess sexual knowledge and behavior (18, 19). In the present study we chose to use three sections. The first section assesses sexual behavior and is composed of seven questions; the second section assesses sexual assertiveness and contains five questions regarding one's reactions in situations of risk for sexual abuse; and the third section evaluates the adolescent's sexual knowledge and contains four questions regarding sexual organs (using pictures) and eight questions about sexual interactions and its consequences.
3. *The Assessment of the Understanding of the Concept of a Friend* (16).

RESULTS

SUMMARY OF SOCIAL-SEXUAL GROUP EDUCATION

MEETINGS WITH THE PARENTS

Acceptance of the adolescents' disability and limitations

Most parents noted that their children aspire to be a part of a normal, healthy society. However, at the same time it was painful regarding their children's experiences of being teased for intellectual disabilities, for their dysmorphic facial features and for their inappropriate social behavior. Some parents admitted that in order to protect their children they pretend as if these insults did not occur. One of the parents frankly disclosed to the

group, "I pretend as if nothing had happened but inside I feel a lot of pain."

The parents differed from each other by the degree of their acceptance of their child's disability. Some of them felt ashamed of their child's limitations and tried to give their children a feeling that they can do everything that regular adolescents do and this way they assume that they provide their child with a feeling of being normal. Other parents were proud of their children being special, and were proud of their investments in their development.

Most of the parents did not inform their children that they carry a genetic syndrome. They thought that their adolescents were not able to understand the meaning of the syndrome and were confident that discussing this issue would be distressful to their child. They also spoke about their guilt over transmitting "a defective gene" to their child. Some of the mothers reported that since their child was born they had left their jobs and devoted themselves to take care of the child and his disability.

At the group sessions we reflected to the parents their difficulties in accepting the child's limitations and disabilities and the guilt feelings the genetic syndrome of their child and its consequent disabilities invoke in them. We stressed their ability to assist their child to develop adequate self-concept. We also emphasized the importance of conducting a dialogue with the child and its role in reducing the feeling of shame for having the syndrome and for reducing the denial of its consequences in his life. We further suggested that adolescents who deny their limitations are prone to be involved in abusing and frustrating relationships. An adequate self-concept is a basis for finding an appropriate social reference which leads to equal and mutual social relationships.

Parenting style

We noticed two poles of parenting styles in the group, one being the overprotective type and the other denying the child's limitation. Overprotective parents would not allow their children to go out of the house unaccompanied, would not leave them alone at home even for a short period of time and would help them in all their activities, including dressing and washing – even when the adolescent was capable of doing it all by himself. The overprotective parents expressed their worries about the naivety of their children in everyday life, their lack of trust in strangers and the fear that their children were prone to sexual abuse. The parents denying their children's limitations encouraged their children to func-

tion beyond their limitations and tended to ignore the disability. They would encourage their children to work hard and get married at an early age.

Parents complained that the adolescents do not share with them the experiences they undergo in their treatment group. We used this issue that they raised to discuss the process of maturation of adolescents with learning disabilities. We explained that similarly to typically developing adolescents, adolescents with developmental disabilities sometimes choose to distance themselves from their parents and that it serves the developmental purpose of creating their self-identity. Some parents raised concerns that without constant supervision their child will be exposed to dangerous situations.

Encouragement of independence

The importance of encouraging the adolescents to acquire independent skills was greatly emphasized during the meeting sessions. Parents were encouraged to enable their children to wash themselves on their own, to choose their own clothing or hair style, etc. Parents were instructed to teach their children how to talk on the phone, to enrich their children's conversation topics, for example by discussing with them the news or favorite tv program, and to encourage the children to develop hobbies. Where appropriate, parents were encouraged to allow their children to go out of the house unaccompanied, after they had learned basic safety skills. Parents exchanged information about possible entertainments for their children.

Parents raised concern regarding who would take care of their disabled child in the future, after they would die. Only one adolescent of the 10 participating in the group was already in a residential facility. The parents of that adolescent shared with the other parents their positive experience with this transition. As a result, other parents started considering out of home placement for their child. Some parents raised guilt feelings as if they were throwing their child out of their home. They also expressed their emotional symbiotic dependency feelings towards their child, as one of the mothers said: "My daughter is like my baby-doll, that provides meaning to my life and when she leaves the house I will feel emptiness." All parents stressed they felt relieved to be able to share these feelings with other parents who face the same dilemmas.

Sexuality and relationship

To warm the parents up to speak on this difficult issue, we asked the parents to recall what their parents had

told them about sexuality when they were at their child's age. All the parents admitted that their parents did not speak at all with them on this matter, and that they felt embarrassed to speak about sexuality with their children. Parents claimed that the issue of sexuality relates to one of the most painful issues of the child's life.

We shared with the parents the ignorance of their children in issues related to sex, such as knowledge of the anatomy and physiology of genitalia and basic social skills. We also educated the parents about the relation of the genetic syndromes with certain types of social behaviors. Adolescents with WS express their feelings in a dramatic and disinhibited way, whereas adolescents with VCFS tend to be shy and not to disclose their feelings.

Parents were instructed how to teach their children cautious measures in intimate relations such as explaining to their child that "it is possible to touch me only if I agree." At the same time parents were encouraged to convey to their children the message that sexuality is a positive and potentially satisfying part of life.

Parents discussed the degree that they should be involved in their child's process of finding an intimate partner. Some parents thought they should choose a partner for their child. We thought that preparing the adolescents to be able to choose a partner is an important developmental challenge to be accomplished by adolescents.

The parents came to the conclusion that a need for an intimate relationship is a universal need for all people. However, they also recognized that the intimate relationship their children could have would be more passive and would rely on much external support. We stressed the importance of a developmental model, where adolescents first need to define their adequate self-concept, and consequently are able to relate to a peer group that is equal to their abilities and limitations. In such a peer group they can have satisfactory social relationships and find romantic relationships.

SUMMARY OF SOCIAL-SEXUAL GROUP EDUCATION MEETINGS WITH ADOLESCENTS

The meeting sessions of the adolescents were held in an entertaining, playful, warm and open atmosphere. The sessions relied less on formal conversations and more on expressive modes including dancing, drawing and role play. While each meeting was devoted to a certain topic the meetings had a routine structure. The sessions started with a summary of the previous session, introduction of the present session content and goals, and summary and conclusions at the end of the session.

Self-concept

The adolescents were requested to compose their own identity card in which they describe themselves. An adolescent with WS gave the following description: "I've got a special face and a good sense of music." Another adolescent with VCFS who suffered from hypernasal speech said: "I've got a strange voice and that's why people look at me in a bus."

Participants shared their bitter experience of social rejection and insults regarding their disability. They were comforted to share this feeling with the group and to learn that other group members are coping with similar experiences. As one of the adolescents in the group stated: "Here in our group I feel confident, I can share all my feelings without being scared of people mocking me."

Social relationships

Participants in the group revealed their wish for developing social and romantic relations and even spoke of their desire to marry and give birth to children. They also expressed feeling lonely and finding it difficult to make friends. Loneliness was pervasive for those participants who graduate the special education schools and found themselves out of any rehabilitation program. Most adolescents did not attend any social group.

We encountered vast social deficits among the adolescents. For example most participants had difficulties approaching somebody and inviting him for a dance. They refrained from making eye contact because of fear of rejection. Only one adolescent had a positive experience of romantic relationships while the others had negative experiences. The sessions were devoted to providing knowledge of the concept of social relationship. For that purpose, in one of the exercises we asked the adolescents to write an advertisement: "looking for a friend." A male with WS wrote: "I am looking for a friend who will love music and discs, who will be my age and will find me a girlfriend." A female with VCFS wrote: "she needs to be a good listener, understanding, and she should not be hurting, cursing or gossiping." The group therapists summarized the desired traits of a friend as they arose from the adolescents' scripts. These traits included trust, mutuality, sincerity and mutual entertainment.

Sexual knowledge and behavior

We encountered ignorance related to knowledge of sexual organs and their function. For example, a female from the group thought that babies are delivered from the gastrointestinal system. The adolescents also seemed

to view sexuality as something forbidden or dangerous. Some of the males were frequent consumers of pornography sites on the internet and some of the males had had sexual relations with prostitutes. The group therapists educated the group using pictures regarding anatomic parts of the sexual system, differences between males and females sexual organs, sexual development, and changes occurring in the body during adolescence. They also educated the group regarding appropriate sexual behavior, for example that masturbation is something one does in private.

Sexual assertiveness and prevention of sexual abuse

Two adolescents shared their experience of being in sexually abusive situations. Both cases happened in their schools for special education by other students with disabilities. During the dance exercises aimed to establishing limits in body touching, they revealed inappropriate touching behaviors, and lack of assertiveness in saying "no" when they do not feel comfortable that another person is touching them. During the meeting we strengthened the assertiveness skills of the adolescents. We repeated the following guidelines: "Touching is allowed only when your friend agrees to be touched and forbidden if he or she does not agree to be touched" and "You are responsible for your body and its sole owner." Participants also developed their skills to identify potentially abusive situations, to resist abusive situations, leaving a place where abuse might happen and immediate report of abuse to their parents or other authorities.

EVALUATION OF OUTCOME

On the Skills and Independent Activities Questionnaire parents reported an improvement in adolescents Entertainment scores (from mean \pm SD of 2.0 ± 1.7 to 3.7 ± 2.9 , $t = -2.7$, $p < 0.05$). No other significant improvement was noted on the other subscales of the questionnaire.

On the Assessment of Sexual Knowledge, Experience and Needs Scale there were no statistically significant differences in total scores before versus after the group treatment intervention.

On the Assessment of Relationship and Social Support of the Family, Friends and Feeling of Loneliness, there was significant improvement in the Friend Concept Subscale (from 1.3 ± 1.2 before intervention to 2.3 ± 1.4 after intervention, $t = -2.7$, $p < 0.05$). This was marked improvement in the approach for choosing

a partner in five of eight adolescents so that following the intervention they mentioned traits like loyalty and equal relations for choosing a friend.

A careful descriptive analysis also suggested several changes occurring following the intervention. Six out of eight adolescents enriched their vocabulary of definitions of sexual activities. For example instead of describing sexual relations as “being with a woman in a bed,” they used the expression “to make love with a woman.”

They began to use more words of pleasure in association with sexual relations. They also had a more positive approach to sexual relations. For example, following the group intervention they used expressions like nice, pleasant, enjoying, one is in love with another, to describe sexual relations.

DISCUSSION

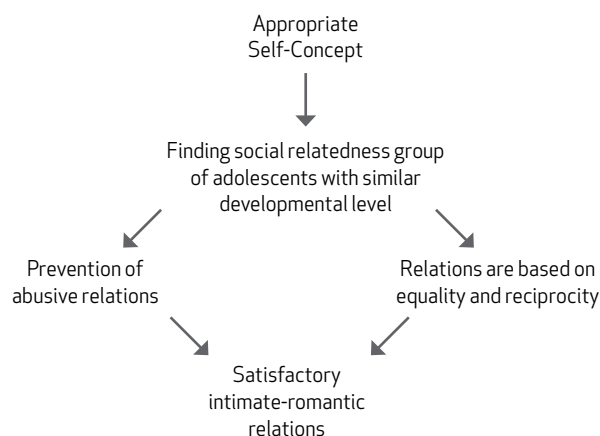
To our knowledge this is the first report on Social-Sexual Education Group Treatment for adolescents with genetic syndromes. Adolescents with genetic syndromes exhibited feelings of social rejection, low self-esteem, and high level of dependence on the environment and internalized negative attitudes towards sexuality. All these factors are considered to be risk factors for sexual abuse and feelings of frustration (16). These negative feelings and overdependence are also common in adolescents with nonsyndromic developmental disability but may be even more intense in adolescents with genetic syndromes because of dysmorphic facial features, medical complications and exceptionally extroverted (in WS) or introverted (in VCFS) behavior (11, 13).

The current treatment program was designed as two groups running in parallel, one of the adolescents and the other of parents. While sexual education interventions with adolescents are conducted in special education schools in Israel, there is rarely any educational or therapeutic work held with their parents. In our work with the parents we learned that they have grave difficulties in accepting developmental changes occurring in their disabled adolescents. The parents expressed anxiety that their children would not be able to cope properly with their social and emerging sexual drive. The parental anxiety tends in some cases to strengthen mutual dependence, limiting the abilities of adolescents with developmental disabilities to develop their social and sexual aspects and skills towards being partially independent adults (20, 21). We identified two patterns of parenting style of parents in the group, one char-

acterized by anxious overprotection of the adolescent and the other characterized by denial of the adolescent's limitation and unrealistic expectations that the adolescent will grow up to live a normal and fully independent adult life (22, 23). Parents exhibited shame regarding the sexuality of their children. They expressed fears of their children being victims of sexually abusive interactions, unwanted pregnancy, and giving birth to a disabled baby. To help the parents to cope with these issues there is an urgent need for receiving support and knowledge from clinicians knowledgeable in working with individuals with developmental disabilities (4, 24, 25). To induce a significant change in sexual and social maturation of adolescents with developmental disabilities requires long-term work with the adolescent and even more so with his parents. In our view one of the main achievements of the group therapy for the long run was to provide some tools and legitimacy to the parents to help their adolescents implement their right to have satisfactory social and sexual lives.

The overarching principles we were following in both the parent and the adolescent groups is shown in Figure 1. To develop safe and satisfactory social and sexual lives, adolescents with genetic syndromes and developmental disabilities first need to acquire an adequate self-concept, that is, knowing their abilities and accepting their disabilities. Adequate self-concept leads to choosing a proper social relatedness group of adolescents with similar developmental level. Only in such social relatedness groups can the adolescent feel equal and have true friendships that are based on reciprocal relations. In cases where adolescents with devel-

Fig. 1: General principles in the social-sexual treatment program



opmental disability fail to develop adequate self-concept and choose as a group of reference typically developing adolescents, they are predisposed to abuse and humiliation (7, 16). The ability to establish intimate-romantic relations is the top stage in this hierarchical pyramid relying on the accomplishment of proper self-concept and proper social group relatedness (7, 16).

As can be expected from such a short-term intervention we did not encounter a dramatic change in the social and sexual maturity of the adolescents following the 10 group sessions. The significant quantitative changes following the group meetings were in social development marked by increase of entertainment activities of the adolescents outside the home and the development of a more mature concept of friendship. There were no significant quantitative differences in the measures of sexual knowledge or behavior suggesting that changes in these domains are more difficult to achieve than changes in the social domain. This also goes in line with the hierarchical model presented in Figure 1 in which intimate-romantic relations are at the top level of the pyramid and follow social developmental changes.

It is unknown what the intensity and extensiveness of social sexual education intervention in adolescents with developmental disabilities should be. However, in our view these interventions should be started at a younger age, even before adolescence, and work with the child and his parents is needed on a long-term basis into adulthood.

Of note, this study has several limitations. The sample is relatively small and heterogeneous and there was no control group that received another intervention or no intervention. We hope this preliminary study will lead to further research on social-sexual interventions in other syndromes and other countries. Although most of the paper focuses on describing the rationale of the program and the content of the therapeutic sessions some qualitative and quantitative statistical analyses were conducted. Obviously, since the sample size is small these results are merely preliminary and cannot be viewed as indicating efficacy of the intervention. While there are differences in the social and sexual behaviors of individuals with Williams syndrome and VCFS, there are also many psychosexual issues common to the two syndromes including ignorance related to sexual issues and deficits in social skills.

References

1. Committee on children with disabilities (COCWD). Sexuality education of children and adolescents with developmental disabilities. *Pediatrics* 1996; 97:275-278.
2. Heshusius L. Sexuality, intimacy, and persons we label mentally retarded: What they think – what we think. *Ment Retard* 1982; 20:164-168.
3. Kreutner A K. Sexuality, fertility, and the problems of menstruation in mentally retarded adolescents. *Pediatr Clin North Am* 1998; 28:475-480.
4. Ballan M. Parents as sexuality educators for their children with developmental disabilities. *Siecus Report* 2001; 29:14-19.
5. Malkin R, Gaylin W. Mental retardation and sterility: A problem of competency and parentalism. New York, Plenum, 1981.
6. Hall JE. Sexual behavior in mental retardation and developmental disabilities. New York: Bruno Mazel Inc., 1975.
7. Argaman R, Lahover Y. Manual for people working in special education system – approaching sexual education from the social point of view. Tel Aviv: Maalot Publishing House, 2007.
8. Aloni R, Ramot A, Riberman A, Dovdovani A, Hovav M. Sexual treatment of people with Learning Disabilities. Parenting and developmental disabilities in Israel. Jerusalem: Magnes, 1998; pp. 151-165.
9. Bayes M, Magano LF, et al. Mutational mechanisms of Williams-Beuren syndrome deletions. *Am J Hum Genet* 2003;73:131-151.
10. Bellugi U, Lichtenberger L, Mills D, et al. Bridging cognition, the brain and molecular genetics: Evidence from Williams syndrome. *Trends Neurosci* 1999; 22:197-207.
11. Doyle TF, Bellugi U, Korenberg JR, et al. "Everybody in the world is my friend": Hypersociability in young children with Williams syndrome. *Am J Med Genet* 2004; 124:263-273.
12. Shprintzen R J. Velo-cardio-facial syndrome: 30 years of study. *Dev Disabil Res Rev* 2008; 14:3-10.
13. Gothelf D. Velocardiofacial syndrome. *Child Adolesc Psychiatr Clin N Am* 2007; 16:677-693.
14. Murphy KC, Jones LA, Owen MJ, et al. High rates of schizophrenia in adults with velo-cardio-facial syndrome. *Arch Gen Psychiatry* 1999; 56:940-945.
15. Antshel KM, Aneja A, Strunge L, et al. Autistic Spectrum Disorders in Velo-cardio Facial Syndrome (22q11.2 Deletion). *J Autism Dev Disord* 2006; 35:461-470.
16. Argaman R. Predicting factors of sexual abuse in people with Learning Disabilities living in institutions. Tel Aviv, Israel: Tel Aviv University, 2003.
17. McCabe M P. Sexuality Knowledge, Experience and Needs Scale for people with intellectual disability (SEX KEN-ID) Melbourne, Australia: Deakin University, School of Psychology, 1992.
18. Ousley OY, Mesibov GB. Sexual attitudes and knowledge of high-functioning adolescents and adults with autism. *J Autism Dev Disord* 1991; 21:471-481.
19. Konstantareas MM, Lunskey YJ. Sociosexual knowledge, experience, attitudes, and interests of individuals with autistic disorder and developmental delay. *J Autism Dev Disord* 1997; 27:397-413.
20. Hauser-Cram P, Warfield M, Shonkoff JP, Wyngaarden Krauss M, Overton WF. Children with disabilities: A longitudinal study of child development and parent well-being. Hoboken, N.J.: Wiley-Blackwell, 2001.
21. Wikler L. Chronic stresses of families of mentally retarded children. *Fam Relations* 1981; 30:281-288.
22. Crnic K A, Friedrich WN, Greenberg M T. Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. *Am J Ment Defic* 1983; 88:125-138.
23. Heiman T. Parents of children with disabilities: Resilience, coping, and future expectations. *J Dev Phys Disabil* 2002; 14:159-171.
24. Floyd FJ, Gallagher EM. Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Fam Relations* 1997; 46:359-371.
25. Champagne MP, Walker-Hirsh LW. Circles: A self-organization system for teaching appropriate social/sexual behavior to mentally retarded/developmentally disabled persons. *Sex Disabil* 1982; 5:172-174.