'Specialization in ICTs and Special Education: Psychopedagogy of Integration' Postgraduate Program DEMOCRITUS UNIVERSITY OF THRACE Department of Greek Philology in collaboration with NCSR DEMOKRITOS Informatics and Telecommunications Institute

PARENTS' CONTRIBUTION TO THE SEX EDUCATION OF THEIR MENTALLY DISABLED CHILDREN

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ABSTRACT

This Master Thesis is a literature research review on the parents' contribution to the sex education of their mentally disabled children and it is being held for the needs of the Postgraduate Program entitled: «ICT Specialization and Special Education – Psycho Pedagogic of Integration». Its overall aim is to study the attitudes, perceptions and role of parents in the sex education of their mentally disabled children. First, the term "Mental Disability", its main causes, symptoms/ comorbidities and the main features of the mentally disabled are presented. Then, there is a detailed reference to the sexuality of the mentally disabled through the passing of time and issues relevant to their sexuality and sexual needs are discussed. Furthermore, typical and deviant sex behaviors are mentioned and at the same time, the importance is stressed on the increasing danger of victimizing the particular target group of people and the conditions, causing sexual exploitation and maltreatment. Thus, the necessity of sex education (programs) for the mentally disabled is vital, since it will enable them to adapt to the society, comply with its rules and norms, avoid possible dangers and obtain the necessary skills, in order to cope with difficult situations and live with dignity. Finally, it focuses on the family's attitudes and perceptions and their essential contribution to their children's sex education. In total, 13 researches from international bibliography were recorded. The results of the study showed that the majority of parents of mentally disabled children recognized both the necessity of sex education for their children and also their essential role in it.

Key words

Mental Disability, Sexuality, Sex Education, Sex Exploitation, Family

References

- Alcorn, D. A. (1974). Parental views on sexual development and education of the trainable mentally retarded. *The Journal of Special Education*, 8(2), 119-130.
- American Academy of Pediatrics Committee on Children with Disabilities. (1996). Sexuality education of children and adolescents with developmental disabilities. *Pediatrics*, 97(2), 275- 278.
- Αρμπουνιώτη, Β., Κουτσοκλένη, Ι. & Μαρνελάκης, Μ. (2007). Νοητική υστέρηση. ΕΠΕΑΕΚ: Πρόσβαση για όλους. Αθήνα
- Brown, H. (1994). An ordinary sexual life? A Review of the Normalization Principle as it applies to the sexual options of people with learning disabilities. *Disability and Society*, 9 (2), 123-44.
- Clatos, K., & Asare, M. (2016). Sexuality education Intervention for parents of children with disabilities: A pilot training program. *Am. J. Health Stud.* 31, 151-162.
- Cuskelly, M., & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff, and a community sample. *Journal of Intellectual & Developmental Disability*, 29(3), 255-264.
- Dupras, A., & Dionne, H. (2014). The Concern of Parents regarding the Sexuality of Their Child with a Mild Intellectual Disability. *Sexologies*, 23 (4), 79–83.
- Dwi, K. A., Prabandari, YayiSuryo, P., & Sumarni, D. W. (2017). Parents' Perception Having Children with Intellectual Disability Providing Sex Education: A Qualitative Study in Yogyakarta. *Galore International Journal of Health Sciences and Research*, 2(3), 1-6.
- Eastgate, G. (2008). Sexual health for people with intellectual disability. *Salud Publica*, 50(2), 255–259.
- Furey, E. M. (1994). Sexual abuse of adults with mental retardation: who and where. *Mental Retardation*, 32(3), 173-180.
- Galea, J. M., Butler, J. A., Iacono, T. & Leighton, D. G. (2004). The assessment of sexual knowledge in people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 29(4), 350 365.

- Gatens-Robinson, E., & Rubin, S. E. (2001). Societal values & ethical commitments that influence rehabilitation service delivery behavior. *Foundations of the vocational rehabilitation process*, (5), 185–202.
- Gil-Llario, M. D., Morell-Mengual, V., Ballester-Arnal, R. & Díaz-Rodríguez, I. (2018). The experience of sexuality in adults with intellectual disability. *Journal of Intellectual Disability Research*, 62(1), 72-80.
- Gougeon, A. N. (2009). Sexuality education for students with intellectual disabilities, a critical pedagogical approach: outing the ignored curriculum. *Sex Education*, 9(3), 277-291.
- Grossman, H. J. (1973, 1977). Manual on terminology and classification on mental retardation. Washington DC: American Association on Mental Deficiency.
- Gürol, A., Polat, S., & Oran, T. (2014). Views of Mothers Having Children with Intellectual Disability Regarding Sexual Education: A Qualitative Study. *Sex Disabil*, 32, 123–133.
- Haffner, D. W. (1990). Sex education 2000: A call to action. New York: Sex Information and Education Council of the U.S. (B)
- Hammar, S. L., Wright, L. S., & Jensen, D. L. (1967). Sex Education For The Retarded Adolescent: A Survey of Parental Attitudes and Methods of Management in Fifty Adolescent Retardates. *Clinical Pediatrics*, 6 (11), 621–627.
- Heber, R. (1961). A manual on terminology and classification on mental retardation (Rev. ed.). Washington, DC: American Association on Mental Deficiency.
- Isler, A., Beytut, D., Tas, F., & Conk, Z. (2009). A Study on Sexuality with the Parents of Adolescents with Intellectual Disability. *Sex Disabil*, 27, 229-237.
- Kaeser, F. (1992). Can people with severe mental retardation consent to mutual sex?. Sexuality and Disability, 10(1), 33–42.
- Kempton, W., & Kahn, E. (1991). Sexuality and people with intellectual disabilities: A historical perspective. *Sex Disabil*, 9, 93–111.
- Kirby, D. (2001). Understanding what works and what doesn't in reducing adolescent sexual risk-taking. *Family Planning Perspectives*, 33(6), 276-281.
- Koller, R. (2000). Sexuality and Adolescents with Autism. *Sexuality and Disability*, 18, 125–135.
- Leutar, Z., & Mihokovic, M. (2007). Level of knowledge about sexuality of people with mental disabilities. *Sexuality & Disability*, 25(3), 93-109.

- Levy, H., & Packman, W. (2004). Sexual Abuse Prevention for Individuals with Mental Retardation: Considerations for Genetic Counselors. *Journal of Genetic Counseling*, 13, 189–205.
- Lumley, V. A., & Miltenberger, R. G. (1997). Sexual abuse prevention for persons with mental retardation. *American Journal on Mental Retardation*, 101, 459-472.
- McCabe, M., & Cummins, R. A. (1996). The sexual knowledge, experience, feelings and needs of people with mild intellectual disability. *Education and Training in Mental Retardation and Developmental Disabilities*, 31, 13-21.
- Muccigrosso, L. (1991). Sexual abuse prevention strategies and programs for persons with developmental disabilities. *Sexuality and Disability*, 9, 261-272.
- Patel, D. R., Apple, R., Kanungo, S., & Akkal, A. (2018). Intellectual disability: definitions, evaluation and principles of treatment. *Pediatr Medicine*, 1 (11), 1-10.
- Penny, R. E., & Chataway, J. E. (1982). Sex education for mentally retarded persons. Australia and New Zealand Journal of Developmental Disabilities, 8, 204-212.
- Podell, D. M., Kastner, J., & Kastner, S. (1996). Adolescents with mental retardation: Perceptions of sexual abuse. *American Journal of Orthopsychiatry*, 66(1), 103–110.
- Pownall, J. D., Jahoda, A., Hastings, R., & Kerr, L. (2011). Sexual understanding and development of young people with intellectual disabilities: Mothers' perspectives of within-family context. *American Journal on Intellectual and Developmental Disabilities*, 116(3), 205-219.
- Pownall, D. J., Jahoda, A., & Hastings, P. R. (2012). Sexuality and Sex Education of Adolescents with Intellectual Disability: Mothers' Attitudes, Experiences, and Support Needs. *Intellectual and Developmental Disabilities*, 50(2), 140-154.
- Schalock, R., Luckasson, R. A., Shogren, K. A., Borthwick-Duffy, S., Bradley, V., Buntinx, W. H. E., Coulter, D. L., et al. (2007). The renaming of mental retardation: Understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities*, 45(2), 116–124.
- Shea, S. E. (2006). Mental retardation in children ages 6 to 16. *Seminars in Pediatric Neurology*, 13(4), 262-270.
- Shree, A., & Shukla, P. C. (2011). Intellectual Disability: Definition, Classification, Causes and Characteristics. *International Journal of Disability, Development and Education*, 58(3), 9-20.

- Siebelink, E. M., de Jong, M. D. T., Taal, E., & Roelvink, L. (2006). Sexuality and people with intellectual disabilities: assessment of knowledge, attitudes, experiences and needs. *Mental retardation*, 44 (4), 283-294.
- Sobsey, D. (1994). Violence and abuse in the lives of people with disabilities. The end of silent acceptance?. Baltimore: Paul H Brookes Publishing Co.
- Swango-Wilson, A. (2009). Perception of Sex Education for Individuals with Developmental and Cognitive Disability: A Four Cohort Study. *Sex Disabil*, 27, 223-228.
- Swango-Wilson, A. (2011). Meaningful Sex Education Programs for Individuals with Intellectual/Developmental Disabilities. *Sex Disabil*, 29, 113–118.
- Turchin, G. (1974). Sexual attitudes of mothers of retarded children. *Journal of School Health*, 44(9), 490–492.
- Watson, G., & Rogers, R. S. (1980). Sexual instruction for the mildly retarded and normal adolescent. *Health Education Journal*, 39(3), 88-95.
- Tharinger, D. J. J, Burrows Horton, C., & Millea, S. (1990). Sexual abuse and exploitation of children and adults with mental retardation and other handicaps. *Child Abuse and Neglect: The International Journal*, 14, 301-312.
- Thomas, N., Nattala, P., Seshadri, S., & KrishnaKumar, P. (2016). Issues and challenges in sexuality and sex education in Intellectually Disabled. International Journal of Child Development and Mental Health, 4(2), 39-51.
- Woodard, L. J. (2004). Sexuality and Disability. *Clinics in Family Practice*, 6, 941-954.