

ANALYTICAL SUMMARY

Lourdes MORO GUTIÉRREZ

Departamento de Psicología Social y Antropología. Facultad de Psicología. Universidad de Salamanca. Avda. de la Merced, 109-131. 37005 Salamanca
moro@usal.es

Cristina JENARO RÍO

INICO/Departamento de Personalidad, Evaluación y Tratamiento Psicológicos. Facultad de Psicología. Universidad de Salamanca

María SOLANO SÁNCHEZ

Máster en Antropología: Salud y Desarrollo Comunitario. Departamento de Psicología Social y Antropología. Facultad de Psicología. Universidad de Salamanca

Fears, Hopes and Demands by Parents of Children With ASD

ABSTRACT: The term “autism spectrum disorders” (ASD) designates a set of varying conditions that have in common the presence of difficulties in social communication and restricted and repetitive behaviors. Without denying the relevance of research seeking to understand the etiology of this disorder, the implementation of measures to improve the conditions of people with ASD and their families needs to address this disorder from a psycho-social and cultural perspective. In this article this condition is addressed from three perspectives: disease, illness and sickness. Specifically, from a group of thirteen families of children with ASD, we aimed to: (1) Identify the process of communicating the diagnosis and providing information (*disease*). (2) Assess the perceived relationship with professionals of these families (*illness*). (3) Understand the perceived supports and barriers by parents in addressing the ASD (*sickness*). By using open and closed questions this study reveals: (1) The need to improve the communication of the diagnosis and the professionals’ training and sensitization. (2) The importance of empowering parents as focus for care and offer support and health and education services in settings as normalized as possible. (3) Increase the support received in the various life domains and continued efforts to promote the social acceptance of this group.

KEYS WORDS: Autism Spectrum Disorders; disease; illness; sickness; families; supports.

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Claudia GRAU RUBIO

Departamento de Didáctica y Organización Escolar. Facultad de Magisterio. Universidad de Valencia. Av. Tarongers, 4. 46022 Valencia

Claudia.grau@uv.es

María FERNÁNDEZ HAWRYLAK

Departamento de Ciencias de la Educación. Facultad de Humanidades y Educación. Universidad de Burgos

José Luis CUESTA GÓMEZ

Departamento de Ciencias de la Educación. Facultad de Humanidades y Educación. Universidad de Burgos

The Fragile X Syndrome: Behavioral Phenotype and Learning Disabilities

ABSTRACT: In this article, we describe the behavioral phenotype of individuals with Fragile X Syndrome and its impact in the educational scope. This syndrome is characterized by difficulties in sensory integration, cognitive deficits (verbal reasoning, abstract/visual and quantitative skills, short term memory, sequential processing, attention and executive processes), language disorders (phonetic-phonologicals, semanticals, morphosyntacticals and pragmatics) and communication disorders, social anxiety, general hyperarousal, autism, non autistic social difficulties, attention deficit and hyperactivity, and learning disabilities. The behavioral phenotype is highly variable and depends on sex, age, and mutation status (full mutation or premutation). The behavioural phenotype has important repercussions in education, as it enables us to understand the learning disabilities and to develop specific intervention strategies.

KEYS WORDS: Fragile X Syndrome; neurobehavioral manifestations; cognitive symptoms; psychopathology; language.

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Leticia VIZCAINO LUQUE

Máster en Psicología de la Educación. Universidad de La Laguna

Ramón ACIEGO DE MENDOZA LUGO

Psicología Evolutiva y de la Educación. Facultad de Ciencias de la Salud. Universidad de La Laguna. Campus de Guajara. 38071. La Laguna. Tenerife. Islas Canarias

raciego@ull.es

Assessment of Emotional-Sexual Education Experience for People with Intellectual Disabilities

ABSTRACT: This article responds to the demand for a Special Education Center on the island of Tenerife (Canary Islands - Spain) to develop training on emotional health and sexuality. The intervention is carried out in two groups. One, consisting of eight members of the Special School of 16-22 years, and other with seven other members of the Occupational Center of between 22-39 years. Intervention is designed with reference to the folders of affective and sex education (Bolaños González Jiménez, Ramos-Rodríguez and Rodríguez, 1994). The evaluation was realized in three levels (users, educators and families), before and after the intervention. Regarding the baseline assessment, these three groups have detected similar levels in all areas of intervention, although they indicated some gaps in the knowledge and skill of different erotic-sex practices. Through the contrasts between pre and post-evaluation significant effects are evident in affective, social skills and sexual areas. That means that users, educators and families believe that after-intervention, users have greater knowledge about the manifestations of affection, enhance positive samples (hugging, touching, etc.) and differentiate between contexts (private / public) and relationships (friends, acquaintances and strangers).

KEYS WORDS: psychoeducational intervention; intellectual disabilities; special education; sexual-affective education.

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Jesús Miguel MUÑOZ CANTERO

Departamento de Métodos de Investigación y Diagnóstico en Educación. Facultad de Ciencias de la Educación. Universidad de A Coruña (UDC). Campus de Elviña, s/n. 15071 A Coruña
jesus.miguel.munoz@udc.es.

Luisa LOSADA PUENTE

Programa de Doctorado en Equidad e Innovación en Educación. Facultad de Ciencias de la Educación. Universidad de A Coruña

Eva María ESPIÑEIRA BELLÓN

Área de Métodos de Investigación y Diagnóstico en Educación. Facultad de Ciencias de la Educación. Universidad de A Coruña

Profile and Competency on the Professional as Evaluator in Institutions Dedicated to People with Intellectual Disability

ABSTRACT: Evaluation in the field of intellectual disability has been related, traditionally, to practices based on measurement, control and punishment, generating

a rejection or disinterest by professionals due, among other factors, the absence of a professional profile specifically defined and formed to develop this work and training deficiencies of professional evaluators. This paper aims to identify evaluators' professional profile and the type of competency that they master and apply in institutions dedicated to people with intellectual disability, and the perception of these actors on the need for continuous training. The study used a qualitative methodology, descriptive, focus on documents analysis (books, articles, legislation, etc.). Documents are selected by theoretical sampling and are analyzed by a theoretical coding process. The results indicate that the figure of evaluator is not fully consolidated during college or vocational education, but requires continuous learning that allows him to upgrade and better understand the complexity of the field of disability where the primary is to ensure, through evaluation, improvement the processes involved in promoting the quality of life of people with intellectual disabilities.

KEYS WORDS: evaluators; intellectual disability; profile; professional staff; competency based education; lifelong learning.

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