

Toward professionalization of diagnosis, prevention and treatment of Foetal Alcohol Spectrum Disorder



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Introduction

Foetal Alcohol Spectrum Disorder (FASD) is a life-long disability with a very broad phenotype complicated by high rates of comorbidity, most often occurring within the congenital malformations, deformities and chromosomal abnormalities and mental and behavioural disorders [1]. Diagnosis and management of FASD requires cooperation of a wide range of professionals including health, community and remedial education specialists.

Problem

For almost two decades, medical doctors and other professionals have been playing rather marginal role in the area of FASD in Poland. Activities to improve diagnosis, prevention and interventions have been mostly implemented by adoptive and foster parents of children with FASD.

Objectives

1. To increase the engagement of medical professionals in FASD diagnosis, prevention and treatment.
2. To increase the geographical and financial availability of FASD related services by increasing their funding from public sources (national and municipal).

Method

In accordance with the Social Development Strategy, the process of increasing medical professionals involvement in the area of FASD may be described as:

- 01 getting started (activating a small group of catalysts, assessing how ready the society is to begin the process, inviting various stakeholders to get involved);
- 02 getting organized (learning about FASD, organizing workgroups);
- 03 collecting evidence (reviewing national data, identifying barriers, gaps and resources);
- 04 creating an action plan
- 05 implementing and evaluating.

Milestones

- 01
 - 1978 First publication in a Polish medical journal concerning the syndrome of a foetus exposed to alcohol, [2] followed by a few more medical case studies
 - 1990-2000 Some reviews of foreign studies which presented general issues and problems connected with FASD
 - 1990s Initiation of activities in the area of FASD by adoptive parents' organizations
- 02
 - 2000-2010 Popular publications completed and extended by Polish adoptive parents raising children with FAS
 - 2007-2008 Public awareness campaign "Pregnancy without alcohol" followed by many local and regional campaigns (from 2008)
 - From 2007 Ongoing dialog with NGOs active in the area of FASD
- 03
 - 2009 Opening of the first FASD Diagnostic and Therapeutic Centre funded by local government !!!
 - From 2010 Original Polish research on FASD, including doctoral dissertations
 - 2014 First official statement on FASD of the Polish Gynaecological Society [3]
 - 2012-2015 Assessment of the prevalence of FASD among children at school age in the population-based survey [4]
- 04
 - 2013-2014 Formulation of strategic objectives and action plan aimed at professionalization of diagnosis, prevention and treatment of FASD in Poland
- 05
 - 2013 The Centre for Comprehensive Diagnosis and Therapy of Children with FASD, funded by National Health Fund, established in the St. Ludwick Specialist Children's Hospital in Cracow by
 - 2014-2015 Pilot training course for multi-professional teams on the diagnosis of children with FASD (in cooperation with the Collegium Medicum of the Jagiellonian University in Cracow)
 - From 2015 Established cooperation with leading clinical centres and medical professionals
 - 2017 Recommendations to prevent alcohol use by pregnant and/or pregnancy planning women (published in cooperation with the Polish Society of Gynaecologists and Obstetricians) [5]
 - From 2017 National Health Program research grants stimulate the research activities in the area of FASD
 - 2018 Pilot training program on FASD for students of the Warsaw Medical University
 - From 2018 Multi-professional experts panel working on national guidelines for FASD diagnosis

Conclusions

Although FASD is not recognized in international statistical classifications of diseases, this neurodevelopmental disorder is clearly a condition requiring medical diagnosis and treatment. Medical activities can be significantly supported, but not substituted, by other professionals. The key challenge is to involve medical professionals without losing the engagement of non-medical professionals and activists who at present are more experienced in work with children with FASD and their families.

Literature

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