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



Katarzyna Okulicz-Kozaryn

State Agency for Prevention of Alcohol-Related Problems



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,

Method

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



getting started (activating a small group of catalysts, assessing how ready the society is to begin the process, inviting various stakeholders to get involved);



getting organized (learning about FASD, organizing workgroups);



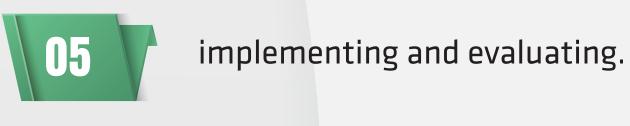
collecting evidence (reviewing national data, identifying barriers, gaps and resources);



creating an action plan

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).



Milestones



- First publication in a Polish medical journal concerning the syndrome of a foetus exposed to alcohol, [2] followed by a few 1978 more medical case studies
- Some reviews of foreign studies which presented general issues and problems connected with FASD 1990-2000
 - Initiation of activities in the area of FASD by adoptive parents' organizations **1990s**



Popular publications completed and extended by Polish adoptive parents raising children with FAS 2000-2010 2007-2008 Public awareness campaign "Pregnancy without alcohol" followed by many local and regional campaigns (from 2008) Ongoing dialog with NGOs active in the area of FASD **From 2007**

2009 Opening of the first FASD Diagnostic and Therapeutic Centre funded by local government !!!



- From 2010 Original Polish research on FASD, including doctoral dissertations
 - First official statement on FASD of the Polish Gynaecological Society [3] 2014
- Assessment of the prevalence of FASD among children at school age in the population-based survey [4] 2012-2015





diagnosis, prevention and treatment of FASD in Poland

- The Centre for Comprehensive Diagnosis and Therapy of Children with FASD, funded by National Health Fund, established in 2013 the St. Ludwick Specialist Children's Hospital in Cracow by
- Pilot training course for multi-professional teams on the diagnosis of children with FASD (in cooperation with the Collegium 2014-2015 Medicum of the Jagiellonian University in Cracow)



- Established cooperation with leading clinical centres and medical professionals From 2015
 - Recommendations to prevent alcohol use by pregnant and/or pregnancy planning women (published in cooperation with the 2017 Polish Society of Gynaecologists and Obstetricians) [5]
- National Health Program research grants stimulate the research activities in the area of FASD **From 2017**
 - Pilot training program on FASD for students of the Warsaw Medical University 2018
- Multi-professional experts panel working on national guidelines for FASD diagnosis **From 2018**

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

- 1. Popova S. et al. (2016) Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. Lancet. Mar 5;387(10022):978-987
- 2. Lolodice, G., Prusek, W., Scianaro, L., (978) Zespół płodu alkoholizowanego Spostrzeżenia własne Pol Tyg Lek, 33, pp. 1857-1858
- 3. Dębski, R., Paszkowski, T., Wielgoś, M., Skrzypulec-Plinta, V., Tomaszewski, J. (2014).
- 4. Okulicz-Kozaryn, K., Borkowska, M., Brzózka, K. (2015) FASD Prevalence among Schoolchildren in Poland. Journal of Applied Research in Intellectual Disabilities
- 5. Kociszewska-Najman B., Pietrzak B., Mazanowska N. i in. (2017) Zaburzenia rozwoju płodu spowodowane spożywaniem alkoholu przez kobietę w ciąży. Karmienie piersią a alkohol. Ginekologia i Perinatologia Praktyczna 2017 tom 2, nr 4, strony 176–190



2014 rok. Ginekologia i Położnictwo, 9 (2), 66-78