

Changes in research, prevention and interventions in the area of FASD in Poland in the recent decades

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STATE AGENCY FOR PREVENTION OF
ALCOHOL - RELATED PROBLEMS

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PARPA

PAŃSTWOWA AGENCJA ROZWIĄZYWANIA
PROBLEMÓW ALKOHOLOWYCH

Disclosure of conflict of interests

I, as well as co-authors of this presentation, we do not have any affiliation (financial or otherwise) with a pharmaceutical, medical device or communication organization

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Objectives

- To explore the history of development of the activities in the area of FASD in Poland
- To provide an overview of the complex determinants of the current situation and future possibilities in the area of prevention and interventions of FASD
- To explore the current challenges in FASD related research and practices

Method

- Systematic review of Polish publications, studies, legislation, stands, preventive and treatment services in the area of FASD

Introduction – Polish "culture of prevention and intervention" in the area of FASD

The term "**culture of prevention and intervention**" :

- Is neither a set of practical guidelines nor a leading theory,
- Is multidimensional,
- Reflects the general orientation and/or readiness of policymakers, researchers and practitioners to address specific problems
- Covers broad range of social determinants, including:
 - historic/contextual background,
 - public awareness,
 - scientific evidence and research,
 - trainings of policymakers and practitioners,
 - policies and legal framework,
 - commitment to provide adequate resources to sustain the system in the long term.

Publications, dissemination of knowledge

1978
1980s

First publication in the Polish **medical journal** concerning the syndrom of a fetus exposed to alcohol, followed by few more medical case studies

1990/
2000

Some reviews of foreign studies which presented general issues and problems connected with FASD

2000-
2010

Rather popular publications **completed and extended by Polish adoptive parents who were raising children with FAS**

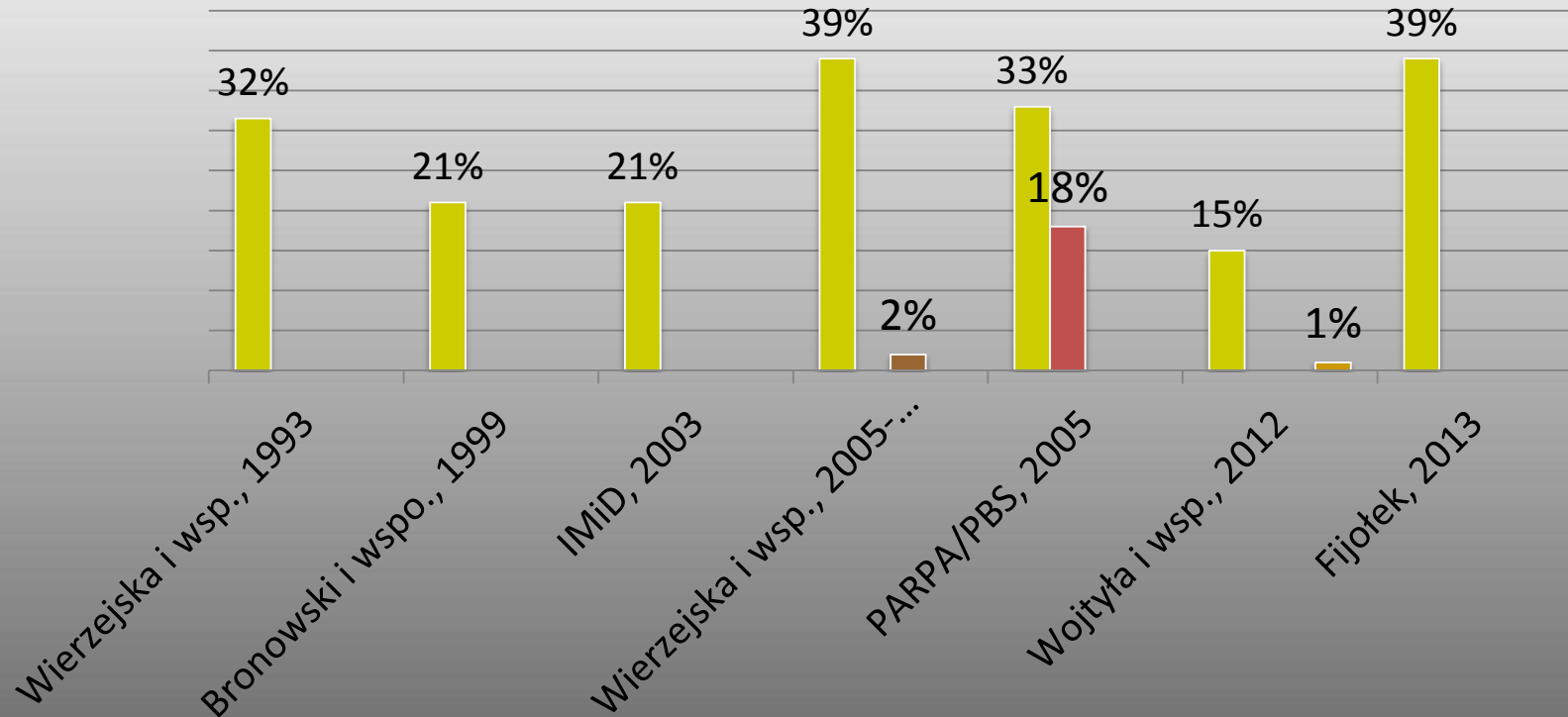
2008-

Peer-reviewed publications citing popular publications mentioned above

2010-

Original Polish research on FASD, including doctoral dissertations and assessment of the prevalence of FASD among schoolchildren

Prevalence of alcohol use by pregnant women in Poland



Chosen Polish research on FASD

- Doctoral dissertations:
 - **Klecka M.** (2012) Validation of the Polish version of the 4-Digit Code image scale for the evaluation of dysmorphic features, Silesian Medical University
 - **Liszc K.** (2012) Pregnancy and alcohol from the perspective of health care providers, Medical University, Łódź
 - **Jadczak-Szumiło T.** (2014) Diagnostic problems of children with Fetal Alcohol Syndrome (FAS) – opportunities for the use of the WISC-R test in differential diagnosis. Adam Mickiewicz University in Poznań
 - **Nardzewska-Szczepanik M.** (2014) Evaluation of structural changes of the corpus callosum in MRI examinations of children exposed to alcohol in utero., Jagiellonian University, Collegium Medicum
 - **Fijołek E.** (2015) Assessment of risk and protective factors associated with the fetal alcohol syndrome (FAS), Medical University, Łódź
- The population survey based on active case ascertainment approach indicated that the prevalence of FASD among school age children in Poland is not lower than 20 cases per 1000, including FAS, which by itself is not less than 4 cases per 1000 children (Okulicz-Kozaryn et al., 2015).
- Some studies on psycho-social situation of children with FASD and their families indicate:
 - lack of information about child's health status and history when parents/caregivers were making the decision for adoption (Kaczmarska, 2011);
 - insufficient support for families raising a child with FASD (Kaczmarska, 2011; Dudek, 2014), especially for biological parents addicted to alcohol (Okulicz-Kozaryn and Borkowska, 2015);
 - Lack of knowledges among teachers regarding how to deal with a child with FASD (Adamek, 2011).



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Public awareness and preventive efforts



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FASDay and other campaigns

- **2001** – for the first time the international FAS Day was celebrated in **Lędziny**
- Since then September 9th has become an important date for many organizations and local communities.
- Producers of alcoholic beverages are taking active part in raising public awareness next to central bodies, also local governments and NGOs,



Zaglebie Sosnowiec



FASSTOP.pl

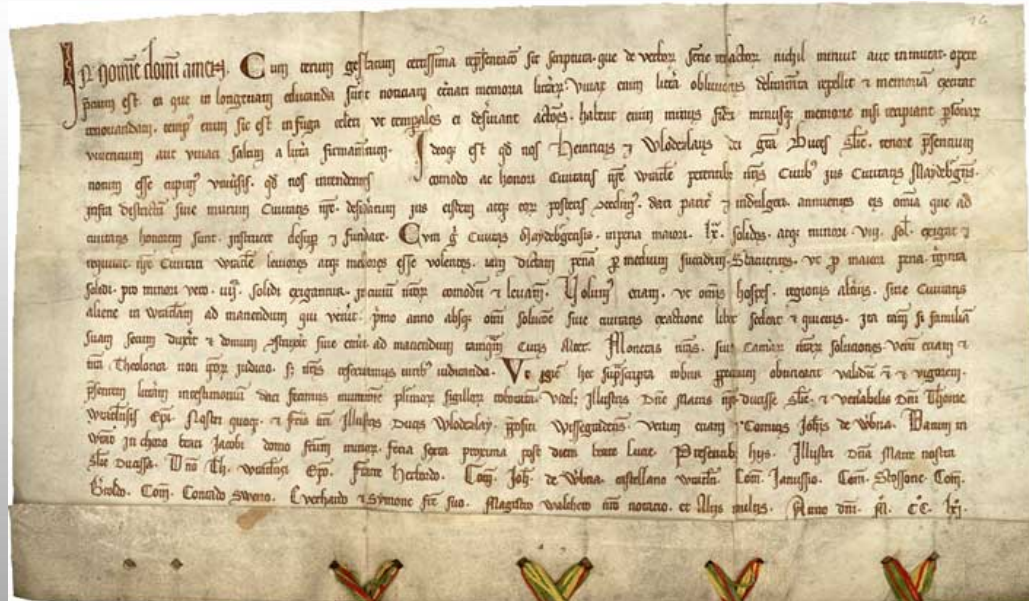
Kampania

“Pregnancy without alcohol” 2007-2008 (PARPA)

- Included:
 - TV and radio spots, TV programs, billboards, the website www.ciazabezalkoholu.pl,
 - press and other publications (mentioned above) addressed to the general public and to representatives of certain professional groups
 - education (preventive program) for secondary schools (2-hours workshops)
 - **training of app. 200 educators** to carry out workshops, discussions and conferences for professionals working in health care, education, social care, justice and other sectors in their communities
 - ‘FAScinating kids’ – photo exposition
- Nearly 700 local authorities (30%) and numerous NGOs collaborated in the campaign.
- Prevention activities initiated at the beginning of the campaign have been continued to date.



Policies and official statements



- The **National Programme for Prevention of Alcohol-Related Problems** for the years 2011-2015 and the **National Health Programme 2016-2020** - indicate specific activities to be taken by different ministries and local governments, mainly to spread knowledge about FASD, to train specialists and to promote the introduction of systemic solutions in the area of prevention, diagnosis, therapy and support of people with FASD in Poland
- **Children's Ombudsman** calls for integrated measures to ensure children's well-being, and point to the Constitution of the Republic of Poland providing for the obligation of public services to ensure special care for children and pregnant women
- Polish **legal authorities** have no doubts that in both the Civil Code and the Family and Guardianship Code there are provisions to protect the well-being of the nasciturus and to ensure that from the moment of birth, the child may claim compensation for damage suffered before birth. However, the enforcement of these rights may be restricted due to the legal protection of the rights of future mothers, whose freedom (also, to drink alcohol) must not be restricted
- **Polish Gynecological Society** - clearly states that during pregnancy and lactation, any dose of alcohol is a danger to the development and health of the child and therefore, medical personnel should routinely collect from pregnant women information about their alcohol consumption habits and, in their professional capacity, inform them about the harmful influence of ethanol on the fetus and pregnancy, recommending to eliminate it from the mother's diet completely.
- **National Health Fund (NFZ)** - FASD is heterogenetic and therefore there is no justification to create a specific range of services or a health program for children diagnosed with FAS or with determined FASD. Making a diagnosis remains within the competence of every medical doctor

Treatment facilities and trainings for professionals



Treatment facilities

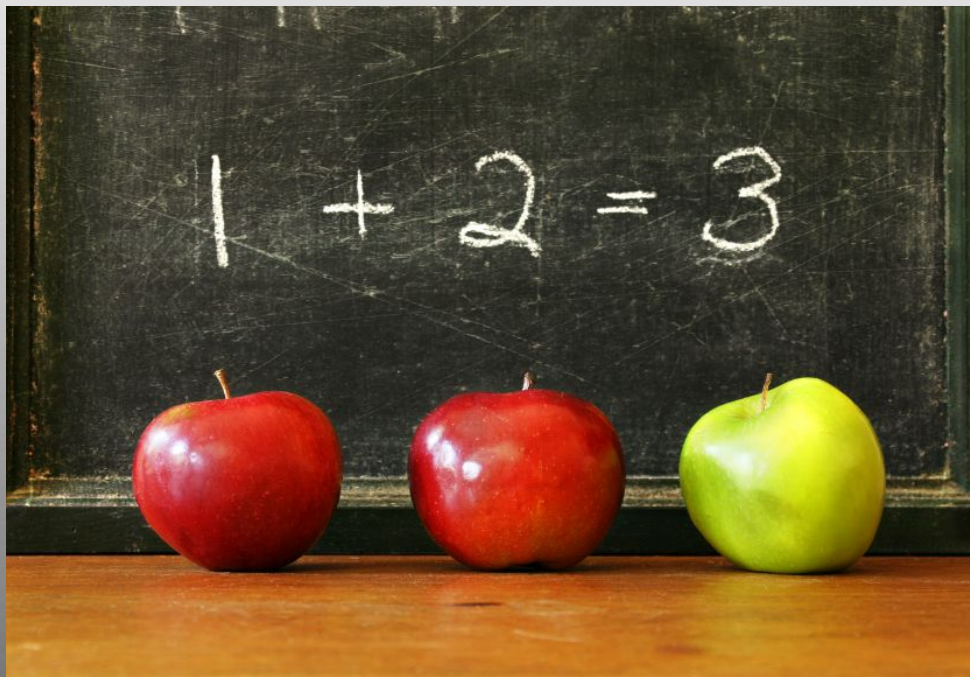
- First(s) created after year 2000
- 2 (out of 3) established on the initiative of adoptive parents raising children with FASD.
- Followed by:
 1. new NGOs,
 2. facilities established within structures of local authorities,
 3. 2013 - the first FASD center financed by National Health Fund [NFZ] and therefore providing free-of-charge services



Trainings for professionals

- 2005-2010 – extended (80-125 hours) training courses organized by PARPA
 - for educators of the socio-therapeutic out of school centers and other educational care facilities (n=66)
 - in order to prepare guardians for therapeutic and rehabilitation work with children with FASD.
- Since mid 2000s the oldest FASD diagnostic and therapeutic centers also provide trainings for various groups of professionals, e.g.
 - FASTRYGA Foundation (Łędziny), www.fas.org.pl – 4-Digit Code
 - Psychological Centre ITEM (Żywiec), http://www.item-psychologia.pl/szkolenia_1 – attachment, neurodevelopment
- 2014-2015 - a pilot training course, regarding the diagnosis of children with FASD, organized by PARPA and the Department of Radiology of the Jagiellonian University in Cracow
 - For teams consisting of a medical doctor and a psychologist (n=12).
 - Modules common for all participants: the basic knowledge on the prevalence, causes and consequences of FASD, assistance to patients, contact with the biological mother of the child and communicating feedback to the parents/guardians and establishing cooperation with them
 - Modules for psychologists: the key areas of psychological diagnosis of CNS damage, the possibility of using standardized tests available in Poland, and the clinical assessment of the areas for which the tests are not available.
 - Modules for medical doctors: measurement of dysmorphia and the connection between the external features and CNS damage.

Summary and discussion



Contemporary culture of prevention and intervention in the area of FASD in Poland

- Public awareness
 - Although 10 years ago, some were still claiming that the problem of FAS did not actually exist in Poland currently, nobody denies its existence.
 - Campaigns, often associated with dissemination of basic knowledge (via brochures, leaflets, lectures) are popular
- Policies and legal framework;
 - Growing interest of policymakers, researchers and practitioners in addressing problems associated with alcohol use by pregnant women
 - The Polish Gynecological Society is the first professional organization which formulated the official stand
- Trainings of policymakers and practitioners,
 - Most often provided by more experienced colleagues and PARPA
- Prevention
 - **Low motivation of medical staff to screen pregnant women for alcohol use and to provide adequate interventions**

Contemporary culture of prevention and intervention in the area of FASD in Poland

- Interventions and therapeutic facilities
 - Are not readily available in Poland (only in a few places) and the scope of support is insufficient.
 - But, ... the availability increases
 - The cooperation between FASD centers is rather weak
 - It is hard to get oriented in the diagnostic and therapeutic procedures applied in each of them
 - **National diagnostic standards are missing!**
- Scientific evidence and research;
 - The process of sharing scientific information is rather invalid as many original studies on FASD, e.g. doctoral dissertations, remain unpublished
- Commitment to provide adequate resources and to sustain the system in the long term.
 - Strong in some municipalities
 - Rather weak at the national level (National Health Fund).

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