

A Survey of Irish Health Care, Social Care, and Education Professionals Knowledge, Attitudes and Experience of Fetal Alcohol Spectrum Disorders (FASD)



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Abstract

The HSE Alcohol Programme established a Fetal Alcohol Spectrum Disorders (FASD) Expert Advisory Group in September 2020, a multidisciplinary group, to support the HSE Alcohol Programme work on FASD prevention. In 2022, it undertook a survey of Irish healthcare, social care, and education professionals' knowledge, attitudes and experience of FASD. There were 702 valid responses. 152 respondents reported having ever referred a child/young person with suspected FASD and 39 reported having ever diagnosed a child or young person with FASD. Some of the findings indicated key needs such as a model of care, care pathway, need for training and support.

Purpose of survey

To assess knowledge and attitudes of key health, social care, and education professionals in Ireland towards Fetal Alcohol Spectrum Disorders (FASD), FASD prevention and response to persons with FASD. Explore FASD service needs and staff training needs in Ireland through a survey of paediatricians, general practitioners, child and adolescent psychiatry teams, social workers, educators (principals, resource teachers, and primary school teachers) and educational psychologists (NEPS). To identify key staff requiring education and training to a level of competency that enables them to provide information and interventions to pregnant women and their partners. Further training is required to support families impacted by a son/daughter with FASD so that they receive a diagnosis and an assessment of their strengths and the right intervention to help them address and cope with their difficulties. Raise awareness of FASD

Method

A subgroup of the HSE FASD EAG developed the survey materials. This included survey questionnaire design, participant information leaflet (PIL), consent form, intended professional groupings for the survey, ethical approval and survey distribution. The subgroup consulted nationally and internationally on the draft questionnaire with academic colleagues. A pilot trial of the questionnaire was done. Ethical approval was sought and secured on the basis of participant informed consent, data anonymised at point of collection, no personal identifiers collected, resulting in a truly anonymised dataset for analysis. A dissemination plan was devised and implemented. Qualtrix online survey.

Results quantitative

The results refer to the 702 respondents who completed the survey questions, in addition to demographic data. Most respondents were female, 87%, reflecting the largely female staff of the professions surveyed. Over 60% of respondents were in mid-career, aged 30-49 years. Responses from all Community Health Care Organisation (CHO) areas. A majority of respondents worked in health care with 69% (485) health care staff, 15% (102) social care and 11% (74) from education. Over 99% had heard of FASD. Half (49%) of all respondents were not confident on the presentation of FASD with only 32% of healthcare staff reporting they were able to recognise FASD symptoms and signs or behaviours. More social care professionals (40%) and educators (41%) than healthcare workers reported the ability to recognise FASD. More than a fifth of healthcare staff were unaware of encountering any child with FASD. The vast majority of respondents were aware of guidance on drinking in pregnancy (94%) and correctly identified 'no alcohol' as the guidance (96%). However 26% did not agree that the guidance is clear and understandable. A little more than a half of GP (52%) and midwife (54%) respondents routinely ask women of childbearing age about alcohol. Less obstetricians (40%) and paediatricians (11%) do so. While a higher percentage of GP, midwife and obstetricians ask pregnant women about alcohol, 16%, 23% and 20% respectively do not routinely ask pregnant women about alcohol. Only GPs were using a standardised assessment method to assess maternal alcohol use, and then only 36% of GPs did so. Of the 702 full respondents to the survey only 13 respondents, 1.9%, reported being aware of FASD care pathways. Over 86% of respondents are interested in future training on FASD

If you were concerned about a woman's consumption of alcohol in pregnancy, who would you refer her to? N=629

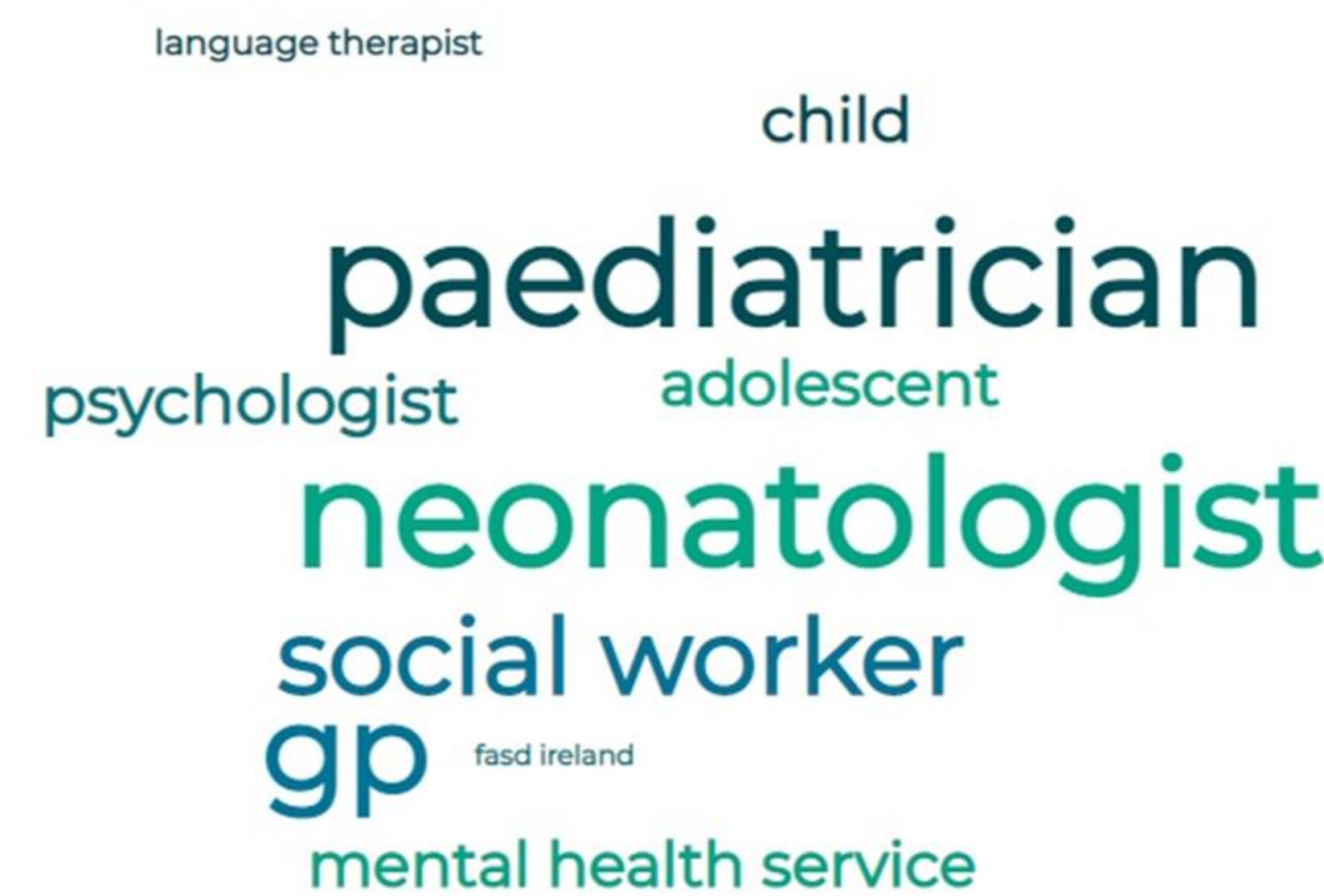


GPs were the overwhelming first port of call for referrals. GP respondents noted a lack of referral service. Where hazardous alcohol intake, referral across a broad spectrum was reported. A very small number would make their own interventions.

"Nothing available as far as I know" GP
"Drug & Alcohol Liaison Midwife" Obstetrician
"Not a clue" GP
"No services available locally" GP
"I am a GP, I would deal with it myself initially, next I would raise it with the antenatal clinic and their attached mental health staff; lastly the formal addiction services." GP

Results Qualitative

If a child in your care was suspected of FASD, who would you refer to for support? N=661 responses (38 N/A, 7 would not refer, 8 Other) 608 for analysis. 41 blanks



"Whatever services will actually accept the referral" GP

"There are no diagnostics pathways. The only children with diagnoses that I am aware of are children in care. Tusla paid for private assessments of FASD." Educator

"Taboo associated with cause of FASD. Lack of societal acceptance that alcohol causes damage in pregnancy" Educator
"Cultural defence of alcohol" Public Health Nurse

What barriers do you face in supporting children and young people suspected of having FASD?

N=460 responses, 27 N/A to role, 433 answers for analysis. 242 blank

Barriers under 9 themes:

ACCESS to specialist support services
STIGMA associated with an FASD diagnosis
LACK OF PROFESSIONAL KNOWLEDGE and training
DIAGNOSIS - barriers in diagnosing FASD
REFERRALS – lack of referral pathways
Lack of RESOURCES
WAITING TIMES
PARENTAL ENGAGEMENT
SOCIETAL ACCEPTANCE of FASD

STIGMA a barrier identified across all professions

"Stigma and shame. Parents not disclosing alcohol use in pregnancy" Midwife

"There is a stigma associated with it which makes it difficult to bring up with their parent without seeming judgemental/critical" GP

"Shame and stigma for the mother that drinking caused FASD" Social Care Worker
"There is a lot of shame in admitting a diagnosis of FASD. The mother is immediately labelled as a bad mother and the child is the child of a bad mother. ... This sounds crass to say but in all fairness, who wants to know they are messed up now because their mom was a pisshead?" Educator

Discussion The survey confirmed that there are no standard diagnostic policies or guidelines for diagnosing or treating children with FASD in Ireland. Amongst healthcare, social care, and education professionals themselves there is not a consensus on how to address this matter. Fetal alcohol spectrum disorders (FASD), including Fetal Alcohol syndrome (FAS) are little understood even amongst staff who regularly interact with pregnant women or with persons with FASD. Pregnant women do not consistently receive timely maternity care or support for their alcohol and drug issues. Health, social care, and education professionals do not consistently provide information on the risks of drinking during pregnancy or routinely screen for alcohol issues. Most clinicians lack the capability to diagnose FASD.

Conclusions There is a need for training of Irish Health Care, Social Care, and Education Professionals in Fetal Alcohol Spectrum Disorders (FASD). A diagnosis and care pathway is needed for children and young persons with FASD.

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