



FASDcare: Understanding the Experiences and Needs of Family Caregivers of People With Fetal Alcohol Spectrum Disorders (FASD) in Ireland

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Foreword

This report shines a light on the lives of families in Ireland raising a child/children with Fetal Alcohol Spectrum Disorders. Its' subject matter relates to what is most likely one of the most stigmatized of all health issues and one that we are only slowly beginning to acknowledge and understand here in Ireland. Pre-natal alcohol exposure is the leading cause of preventable intellectual disability in the world. Despite the fact that alcohol has been documented as a toxic teratogenic substance for over 40 years, it is only recently that FASD has received any meaningful consideration by researchers, policy makers and service providers here. This report makes an important contribution to our understanding of the issues, challenges and unmet support needs of families raising a child with FASD.

While the prevalence of FASD in Ireland is not known, a 2017 systematic review and meta-analysis estimated prevalence of alcohol use during pregnancy showing Ireland to have one of the highest prevalence of all countries studied. It estimated that between 2.8 – 7.4% of the population of Ireland might have FASD.

Earlier this year, the Irish Government committed to introducing health warning labels on alcoholic drinks from 2026, a move that will make Ireland the first country in the European Union to do so. Labels will warn consumers of the dangers of drinking alcohol while pregnant or planning a pregnancy. The announcement on labelling sparked a backlash across the EU, with nine member countries filing objections and the alcohol industry branding the move as an attack on the single market and on 'moderate' drinking.

There is little doubt that raising awareness at a population level about the risks associated with consuming alcohol when pregnant is of crucial importance. However, we also need to see, hear and respond to the needs of children and adults with FASD, and their families. This report gives those families a voice. We urge policy makers, politicians and all who are committed to protecting and promoting the rights and wellbeing of children in Ireland to listen and to respond.

Huge thanks are due to Dr Katy Tobin and the research team in Trinity for their work on this report. Thanks also to the Irish Research Council who funded the study and in doing so have shone a light on FASD in Ireland. Above all, thanks are due to each and every participant who took time out to participate in this research and share their experiences. This report would not exist without you.

Paula Leonard

CEO, Alcohol Forum Ireland

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Executive Summary

Fetal Alcohol Spectrum Disorders (FASD) are a range of adverse health effects attributable to alcohol consumption during pregnancy. Ireland does not have services for the diagnosis and management of FASD, despite estimates placing Ireland third highest in the world for FASD prevalence, and highest for alcohol use in pregnancy. A major gap exists in the availability of support services to meet the complex needs of people living with FASD in Ireland, including educational, social and medical services.

The FASDcare study was funded by the Irish Research Council under a New Foundations grant. The study aimed to explore the experiences of caregivers of people living with FASD in Ireland using an anonymous online survey. The final sample for the study included 70 caregivers. Almost three quarters of respondents were caregivers of a person with a confirmed diagnosis of FASD, and most stated that they received their diagnosis in Ireland (73%), though Ireland does not provide formal diagnostic services for FASD.

FASD are associated with a wide range of complex co-morbidities. The most common co-morbidities reported in the study were emotional or behavioural disorders including Attention Deficit Hyperactivity Disorder (ADHD) / Attention Deficit Disorder (ADD) (64%) and Autism Spectrum Disorder (ASD) (21%). The rate of ASD in this study far exceeds that reported in the literature, potentially indicating misdiagnosis.

Caregivers report a clear need for access to specialist FASD services and for FASD informed services in education and healthcare settings. Almost 1 in 10 caregivers reported that services for FASD were inadequate, and 62% reported that school staff did not understand FASD. Results show a high level of financial burden with almost half of respondents using their savings, giving up necessities and not being able to afford certain extras due to the costs associated with caregiving. Caregiver burden was consistently high across various subgroups of the study sample. Caregiver burden can lead to strained relationships and could be a contributing factor in placement breakdown for children/young people in care, represented by a large proportion of this study sample.

The findings presented here represent a preliminary analysis of the experiences of caregivers of people with FASD in Ireland. Due to the limitations in the sampling approach and overall sample size, the reliability of the statistics cannot be guaranteed, and additional studies are required to confirm some of the findings.

Authors Of The Report

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Katy is an Assistant Professor of Biostatistics in the Global Brain Health Institute and Public Health and Primary Care in the School of Medicine, Trinity College Dublin. She holds a double honours BSc. In Biology and Applied mathematics from NUI Maynooth, a PGDip in Statistics and a Ph.D. in Biomathematics from Trinity College Dublin. Katy's research focuses on the application of statistics and biomathematical methods to address health related research questions in topics including infectious disease, adolescent alcohol use, HPV transmission and age-related cognitive decline. Recently her research has focussed on alcohol and other substance use and brain health over the life course. She has experience in the areas of epidemiology and statistics, health services research and health economics. Katy is the Principal Investigator of the FASDcare study presented in this report. In 2016 she led the analysis and reporting of the results of the Prevalence of Drug Use and Gambling in Ireland and Drug use in Northern Ireland 2014/15 Drug Prevalence Survey, funded by the National Advisory Committee on Drugs and Alcohol.

Dr Elizabeth McCarthy

Elizabeth is a Visiting Research Fellow working with Professor Catherine Comiskey and The Population Health and Behaviour Research Group, Trinity College Dublin. Elizabeth is also affiliated to the School of Medicine and the GBHI at TCD working with Dr. Katy Tobin on the FASDcare study. Recently Elizabeth has been working on the Practice Enhancement for Exclusive Breastfeeding (PEEB) HRB funded study led by Professor Patricia Leahy-Warren. Elizabeth's research interests are in breastfeeding, peer support, population health, FASD, Cultural Historical Activity Theory, human computer interaction (HCI), Information and Communications Technology (ICT), mental health, mixed methods' research, and psychology (coaching, health, work, and organisational). Elizabeth McCarthy, BA, MA, MSc (Occ.Psy), MPhil by research, IBCLC, PhD. Member of PSI, Work and Organisational Psychology (DWOP), Coaching Psychology Group

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Anna-Marie worked as a Visiting Research Assistant in the FASDcare study, at the School of Medicine, Trinity College Dublin. She holds a Master of Social Sciences in Social Psychology from the University of Helsinki. Her research interests are in addictions and rehabilitation research. She has experience in qualitative and mixed methods research and in health services and systems research. Her past research projects have related to regional differences in access to rehabilitation in Finland, chronic pain and problem gambling. Currently, Anna-Marie works as a Researcher at the Social Insurance Institution of Finland (Kela).

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We would like to express our gratitude to the organisations and individuals who collaborated on the study offering support and assistance with promoting and facilitating the circulation of the study and providing useful suggestions and information that informed the survey. Among others, these include: ENDpae, TUSLA, the HSE expert advisory group for FASD, the Irish Foster Care Association, FASD Ireland, Dr. Alan Price and Dr. Bridget Johnston.

In particular we wish to thank all caregivers who took the time to share their experiences of caring for someone with FASD through completion of the survey.

Background And Introduction

Fetal Alcohol Spectrum Disorders (FASDs) are a range of adverse health effects attributable to alcohol consumption during pregnancy. Individuals with FASD may experience cognitive, behavioural, emotional, physical and developmental deficits, with lifelong implications and high societal costs¹. Prenatal alcohol exposure is the most common preventable cause of intellectual disability. At birth, an individual with Fetal Alcohol Syndrome (FAS) has a life expectancy of 34 years².

There is currently no national Irish register for FASD. The predicted prevalence of FASD in Ireland is 47.5 per 1000 population³, the third highest in the world.

Most individuals with FASD are undiagnosed/misdiagnosed⁴, resulting in inappropriate care and potentially preventable secondary disabilities including mental health difficulties, substance misuse, and imprisonment. Ireland does not have published clinical guidelines on the diagnosis and management of FASD. A major gap exists in the availability of support services to meet the complex needs of people living with FASD in Ireland including educational, social, and medical services.

Aims/Objectives

The FASDcare study aimed to

- Improve the supports available to families affected by FASD by generating information regarding access to services.
- Promote equitable access to healthcare services for those living with FASD, and their caregivers.

The specific objectives of the study were

1. To examine the core difficulties experienced by caregivers and/or people with FASD, the amount and type of support required, and how much of these needs are currently met.
2. Identify the level of burden experienced by caregivers of people with FASD in Ireland.
3. Describe the pathway to diagnosis with FASD.
4. To examine variations in the amount and type of out-of-pocket spending related to FASD (e.g., spending on consultations with healthcare professionals on the journey to diagnosis, or related to diagnosed FASD and/or co-morbidities, or spending on support services such as social care or educational support)

Methodological Approach

Research Design

This study was a cross sectional survey with caregivers of people living with FASD in Ireland. The study was conducted online using Qualtrics software. The study used a mixed methods approach, gathering quantitative and qualitative data (through open survey questions).

Ethics

Ethical approval was obtained from the Faculty of Health Sciences in Trinity College Dublin and The Child and Family Agency (Tusla).

Funding And Study Partner

Dr. Katy Tobin received funding for this study from the Irish Research Council under the New Foundations grant NF/2020/21940303 in partnership with Alcohol Forum Ireland.

Alcohol Forum Ireland (AFI) is a national charity which provides support and services to individuals and families impacted by alcohol harm, while working at the wider community, policy, and advocacy levels to challenge and change Ireland's problematic relationship with alcohol. They have been advocating for an improvement in supports for people with FASD, and their families, and the adoption of clear clinical guidelines for diagnosis.

Study Recruitment

The survey was open for responses from November 2021 to January 2022. After removing responses that had an excess of missing values, the final sample size included for analysis was 70.

Inclusion Criteria

- Adult caregivers of a person living with FASD (including someone undergoing assessment for FASD, previously assessed for FASD, or those suspected of having an FASD) on the island of Ireland.
- Able and willing to participate in the study.
- Sufficient fluency in English to be able to understand and participate in this survey.

Exclusion Criteria

- Under 18 years of age at time of consent
- Not caregivers of a person living with FASD (including someone undergoing assessment for FASD, previously assessed for FASD, or those suspected of having an FASD) on the island of Ireland.
- Unable and/or not willing to participate in the study.
- Did not have sufficient fluency in English to be able to understand and participate in this survey.

Sampling

This piece of work was designed as an initial exploration into the needs of caregivers of people with FASD in Ireland. The study aimed to access a largely hidden population making sample size estimates difficult prior to data collection. We aimed to recruit a sample size of 30–50 caregivers to allow for some simple descriptive statistics to be performed. We used a convenience sampling approach. The survey was promoted through the professional networks of the research team and AFI. Study collaborators also advertised the survey to groups known to include caregivers of people with FASD, social workers and others who may be eligible to take part.

Informed Consent

A Letter of Invitation, Participant Information Leaflet (PIL) and consent section were provided on the online survey link. Participants were informed that no personal data would be collected or processed and that the survey was completely anonymous. Consent was sought at the end of the information leaflet on the online survey and if participants wished to take part in the study, they could then proceed to completing the online survey.

Confidentiality

The survey was completely anonymous. No identifying data was collected. All data and documents were stored securely on the Trinity College Dublin's server and devices. Data is stored and protected in accordance with the GDPR and Trinity College Dublin's data protection guidelines.

Quantitative Data Analysis

Quantitative data were analysed using SPSS software⁵ (Version 27). Quantitative findings are reported through frequency tables, charts, simple descriptive statistics, and bivariate analysis. Questions in the survey were not mandatory and participants could choose to skip questions. As a result, there was a higher number of responses to questions appearing earlier in the survey. Data in this report are presented without adjustment for missing data. Sample sizes for each question are reported in the findings.

Qualitative Data Analysis

The open-ended questions of the survey were analysed using content analysis⁶. Analysis was conducted using NVivo and Microsoft Excel. The replies for the open-ended questions were read through multiple times and similar responses were categorised and counted to present the most common replies to the questions. Some of the quantitative questions included Other as an optional response. The replies given to these questions were also analysed using content analysis.

Results

1. Study Demographics

This section presents descriptive statistics of the study sample, caregiver demographics and demographics of the child/young person with FASD under the care of the study participants.

Study Sample Descriptives

Demographic details of the study sample are presented in Table 1. Most respondents (n=65, 93%) were living in the Republic of Ireland. Caregivers were asked to share their experiences of caring for a child/young person with FASD. Of those surveyed, 51 (73%) were caregivers of a child who had an FASD diagnosis or other prenatal alcohol exposure diagnosis. A further 15 (21%) were caring for a child/young person who may have been exposed alcohol prenatally but had not accessed treatment. Adoptive parents (n=25, 36%) and foster parents (n=34, 49%) make up the majority of the sample of respondents. One quarter of respondents (n=17, 25%) were caring for more than one child/young person with FASD.

Caregiver Demographics

Caregiver demographics are shown in Table 2. The mean age of respondents was 52.5 years (standard deviation, SD = 7.8). The sample contained more females (n=47, 81%) than males (n=10, 17%). Most participants were married/cohabiting/in a civil partnership (n=46, 79%). The sample had a high level of education with more than one third completing postgraduate education (n=21, 36%), while the next largest group were those who had a technical/vocational qualification (n=13, 22%). More participants lived in rural areas (n=38, 69%) than urban (n=17, 31%) and most lived with the child/young person with FASD that they care for (n=50, 86%). Many caregivers were looking after the family/home (n=24, 43%), and a further 22 (39%) were working for payment/profit.

Child/Young Person Demographics

Caregivers were asked to provide demographics for the child/young person they care for. The average age of the young people was 15 years with SD of 0.5 (Table 3) and there were more males (n=43, 61%) than females (n=27, 39%). Most were either healthy or very healthy (n=59, 86%). A large proportion had multiple diagnosed co-morbidities (41% had 1-3 co-morbidities, 39% had 4-6 co-morbidities). Three-quarters were still in education (n=49, 75%).

Table 1: Study sample descriptives.

Study sample descriptives	n (%)
Where do you currently live?	
Republic of Ireland	65 (92.9)
Northern Ireland	5 (7.1)
Which of the following best describes you?	
Parent/Caregiver of a child/young person with an FASD diagnosis or other prenatal alcohol exposure diagnosis	51 (72.9)
Parent/Caregiver of a child/young person who is currently in the assessment process.	3 (4.3)
Parent/Caregiver of a child/young person who has been through the assessment process, but it did not result in an FASD or other prenatal alcohol exposed diagnosis.	1 (1.4)
Parent/Caregiver of a child/young person who may have been exposed to alcohol prenatally, but for whatever reason, has never accessed an assessment (this could be by choice or due to other reasons)	15 (21.4)
Which of the following best describes your relationship to the person you care for?	
Adoptive mother/father	25 (35.7)
Foster mother/father	34 (48.6)
Biological mother/father	1 (1.4)
Stepmother/stepfather/partner of child/young person's parent	3 (4.3)
Aunt/Uncle	2 (2.9)
Other relative/in-law	2 (2.9)
Other	3 (4.3)
Which of the following best describes your relationship to the person you care for?	
Yes	17 (24.6)
No	45 (65.2)
Other	7 (10.1)

Table 2: Demographics of study caregivers

Caregiver demographics	n (%)	Mean (SD)
Age		52.5 (7.8)
Gender		
Male	10 (17.2)	
Female	47 (81.0)	
Prefer not to say	1 (1.7)	
Marital status		
Single	4 (6.9)	
Married/cohabiting/civil partnership	46 (79.3)	
Separated/divorced	5 (8.6)	
Widowed	2 (3.4)	
Prefer not to say	1 (1.7)	
Education		
Primary school	1 (1.7)	
Secondary school	9 (15.5)	
Technical/vocational	13 (22.4)	
Degree	10 (17.2)	
Postgraduate	21 (36.2)	
Other	4 (6.9)	
Urban/Rural		
Urban (population >1500 inhabitants)	17 (30.9)	
Rural (population <1500 inhabitants)	38 (69.1)	
Living with the child/young person with FASD that you care for?		
Yes	50 (86.2)	
No	8 (13.8)	
Present principal status		
Working for payment/profit	22 (39.3)	
Unemployed	1 (1.8)	
Student/pupil	1 (1.8)	
Looking after family/home	24 (42.9)	
Retired from paid employment	4 (7.1)	
Unable to work due to permanent sickness or disability	3 (5.4)	
Other	1 (1.8)	

Table 3: Demographics of the child/young person under the care of the study respondents (the caregivers).

Child/Young person demographics	n (%)	Mean (SD)
Age (n=70)		15.0 (0.5)
Gender (n=70)		
Male	43 (61.4)	
Female	27 (38.6)	
In general, how would you describe your child/young person's health in the past 12 months? (n=68)		
Very healthy, no problems	22 (32.4)	
Healthy, but a few minor problems	37 (54.4)	
Sometimes quite unwell	7 (10.3)	
Almost always unwell	2 (2.9)	
Number of diagnosed co-morbidities listed (n=70)		
0	9 (12.9)	
1-3	29 (41.4)	
4-6	27 (38.6)	
7 or 8	5 (7.2)	
Education status (n=65)		
Still in education	49 (75.4)	
Left education more than six months ago	16 (24.6)	

2. Journey To Diagnosis



**“We got a diagnosis but very little else.
The diagnosis definitely made things easier” ...**
Quote from caregiver.

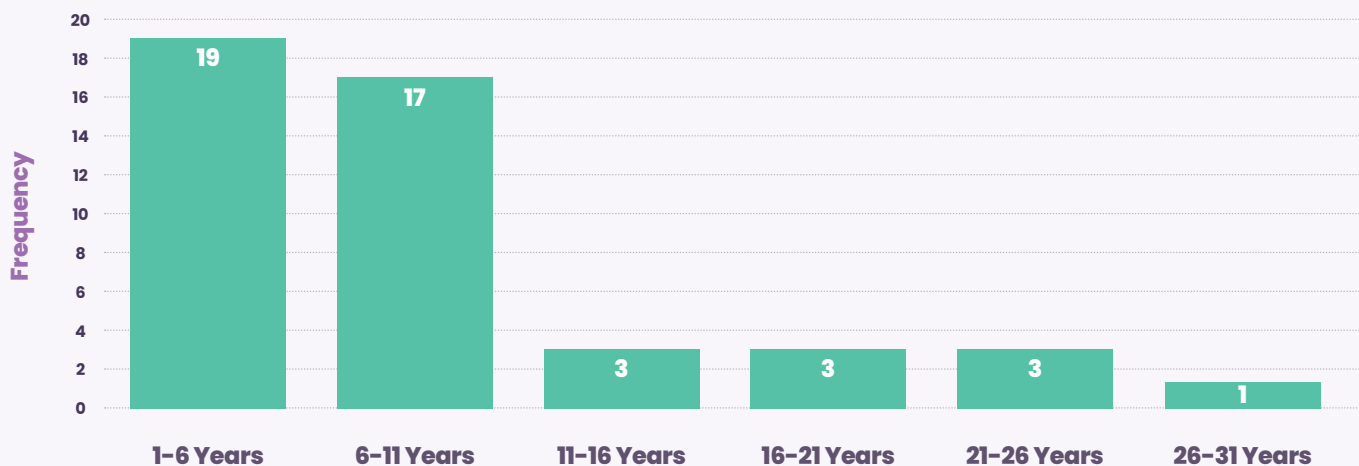
This section outlines the journey to receiving an FASD diagnosis for the child/young person under the care of the study participants. The majority (n=51, 73%) of participants reported that their child/young person has a confirmed diagnosis of FASD. Figures 1 and 2 and table 4 present findings from the participants who reported a confirmed diagnosis.

Years Since Diagnosis

Most children/young people had received their diagnosis of FASD in the last 1-6 years (n=19) or 7-11 years (n=17) (Figure 1). Just one had their diagnosis more than 26 years ago.

Figure 1: Years since FASD diagnosis (n=46)

Years since diagnosis



Diagnosis Details

Diagnosis details are presented in Table 4. The most common diagnosis type in the sample was Fetal Alcohol Syndrome (FAS) (n=13, 19%), followed by FASD without sentinel facial features (n=12, 17%), FASD with sentinel facial features n=10, 14%), Alcohol related neurodevelopmental disorders (ARND) (n=8, 11%), and less than ten percent in each of the remaining categories (partial FAS, neurodevelopmental disorder with prenatal alcohol exposure, and not sure). Three quarters of diagnoses were received in Ireland (n=37, 76%), while the remainder were split between Northern Ireland, UK, USA, other EU country (all n=3, 6%). This question was an open-text response and

was coded into categories during analysis. It is not possible to determine whether all responses in the Ireland and UK categories include or do not include Northern Ireland as a possible response. Most children/young people attended a paediatrician on their journey to diagnosis (n=37, 73%). Other professionals attended include GP, occupational therapist, psychologist/neuropsychologist (all n=24, 47%), psychiatrist (n=23, 45%), and speech and language therapist (n=21, 41%). Other professionals seen by families included autism spectrum disorder services, developmental paediatrician, neurologist, plastic surgeon, endocrinologist, and paediatric neurologist.

Table 4: Details of diagnosis of FASD

Diagnosis details	n (%)
FASD diagnosis type (n=51)	
FASD with sentinel facial features	10 (14.3)
FASD without sentinel facial features	12 (17.1)
Fetal Alcohol Syndrome (FAS)	13 (18.6)
Partial Fetal Alcohol Syndrome (pFAS)	2 (2.9)
Alcohol Related Neurodevelopmental Disorders (ARND)	8 (11.4)
Neurodevelopmental disorder with PAE	2 (2.9)
I'm not sure	4 (5.7)
Country of Diagnosis (n=49) †	
Republic of Ireland	32 (65.3)
Ireland	5 (10.2)
Northern Ireland	3 (6.1)
UK	3 (6.1)
USA	3 (6.1)
Other EU country	3 (6.1)
Which professionals did your child/young person see on their journey to diagnosis? (n=51)	
GP	24 (47.1)
Paediatrician	37 (72.5)
Geneticist	15 (29.4)
Psychiatrist	23 (45.1)
Speech and language therapist	21 (41.1)
Occupational therapist	24 (47.1)
Psychologist/neuropsychologist	24 (47.1)
Other	8 (15.7)

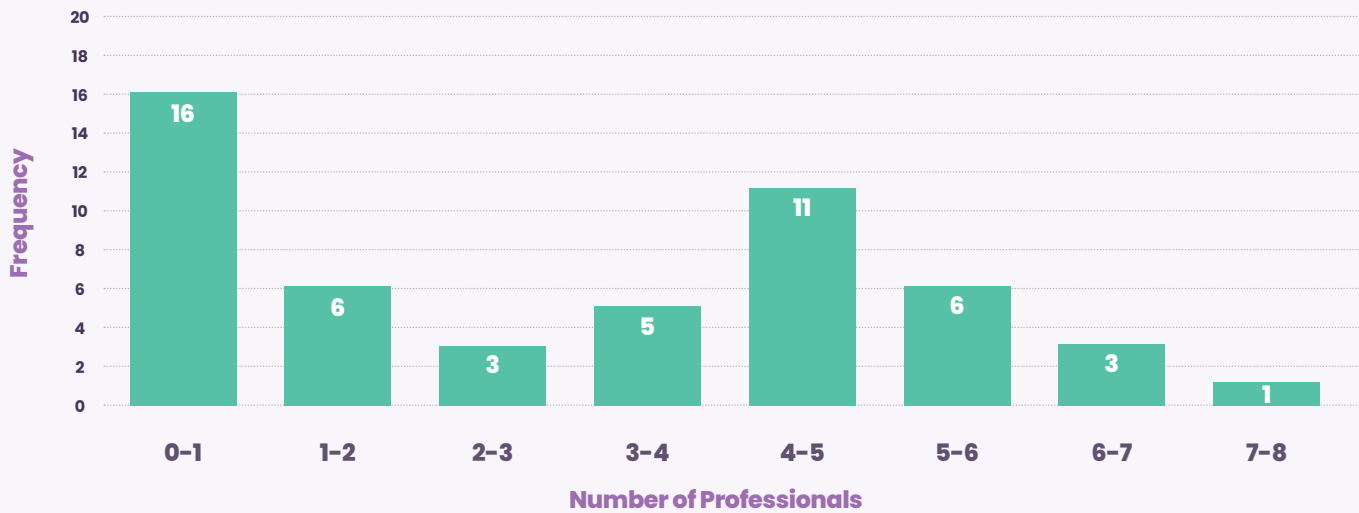
†This open text question was coded during analysis. It is not possible to determine whether all responses in the Ireland and UK categories include or do not include Northern Ireland as a possible response.

Number Of Professionals Seen On The Journey To Diagnosis

On average, caregivers reported attending 3.5 (SD = 2.2) professionals on the journey to diagnosis with their child/young person (Figure 2). The maximum number of professionals seen on the journey to diagnosis was 8.

Figure 2: Total number of professionals seen on the journey to diagnosis (n=51)

Total number of professionals seen on the journey to diagnosis



Description Of The Journey To Diagnosis

Participants were asked two open-ended questions about the journey to diagnosis. Participants who reported a confirmed diagnosis of FASD were asked to outline the journey or pathway to achieving a diagnosis of FASD. Those without a confirmed diagnosis were asked to outline the journey or pathway to trying to achieve a diagnosis. A summary of the responses is given below.

Please outline the journey or pathway to achieving a diagnosis of FASD (for example, the type of professionals you consulted and the outcomes)

Many of the caregivers described that their journey to receiving a diagnosis had taken multiple years and that they had consulted multiple health care professionals until their child/young person was understood. These had included a paediatrician, neurologist, psychiatrist, occupational therapist and speech and language therapist. Many children and young people were diagnosed with multiple other comorbid conditions along the journey to a FASD diagnosis. These included Autism Spectrum Disorders, Attention Deficit Hyperactivity Disorder, developmental delays and sensory processing disorder.

Please outline the journey or pathway to trying to achieve a diagnosis (for example, the type of professionals you consulted and the outcomes)

The caregivers had seen multiple professionals, such as social workers, occupational therapists, psychologists, and professionals within disability services, but their child had not received an assessment or an official FASD diagnosis. Some professionals had assumed FASD, but formal assessment was not done. Some professionals were unable to make the diagnosis, thought the conditions were impossible to diagnose or did not have enough information, for example, on the birth mother's alcohol use during pregnancy to make the diagnosis.

3. Child/Young Person Health And Co-Morbidities

This section describes the co-morbidities of the child/young person under the care of the study participants. As shown in table 3, most of the children/young people were healthy (n=37, 53%) or very healthy (n=22, 31%).

Table 5 shows the diagnosed co-morbidities within the study sample. The mean number of diagnosed comorbidities was 3.2 (SD = 2.2). The minimum number of co-morbidities was zero, and the maximum was eight. Almost two thirds of respondents reported a diagnosis of an emotional or behavioural disorder (n=45, 64%), with a further 13% awaiting consultation. More than half reported general learning disabilities (n=37, 53%), while 40% had a diagnosis of a specific learning disability (n=28, 40%). More than one-third had a diagnosed speech or language difficulty (n=27, 39%), 37% (n=26) had mental health difficulty, 33% (n=23) had a physical disability or visual or hearing impairment. Twenty-one percent of children/young people had a diagnosis of autism spectrum disorder (n=15), with a further 11% (n=8) awaiting consultation.

Thirteen participants (19%) listed other co-morbidities in the free text space. Additional co-morbidities include sensory processing disorder, bi-polar, auditory processing disorder, reactive attachment disorder, oppositional defiant disorder, emotional difficulties, social delay, gastric problems, anxiety, emotional developmental issues, impulsive behaviour.

One third of participants reported that their child/young person had other ongoing chronic physical or mental health problem (n=24, 34%).

Table 5: Comorbidities among the study sample (n=70)

Comorbidity	Diagnosed by healthcare professional n (%)	Awaiting consultation with healthcare professional n (%)
Physical disability or visual or hearing impairment	23 (32.9)	5 (7.1)
Specific learning disability (e.g., Dyslexia, Dyscalculia, Dyspraxia)	28 (40.0)	5 (7.1)
General learning disabilities (mild, moderate, severe/profound)	37 (52.9)	6 (8.6)
Autism Spectrum Disorders	15 (21.4)	8 (11.4)
Emotional or behavioural disorders (e.g., ADHD (Attention Deficit Hyperactivity Disorder) / ADD (Attention Deficit Disorder))	45 (64.3)	9 (12.9)
Mental health difficulty	26 (37.1)	11 (15.7)
Speech or language difficulty (including speech impediment)	27 (38.6)	2 (2.9)
Assessed syndrome (e.g., Down Syndrome, Tourette's Syndrome)	1 (1.4)	2 (2.9)
Slow progress (reasons unclear)	18 (25.7)	3 (4.3)
Other	13 (18.6)	3 (4.3)

4. Supports, Services And Education



“I want the very best for him however the services keep overlooking him. He is slipping through the net and because of that he is struggling severely with life.”

Quote from caregiver.

This section outlines the type of services and supports available/required and the quality of these supports/ services. It also describes the education experience of the children/young people with FASD.

Frequency And Accessibility Of Services

Table 6 shows the mean number of times caregivers accessed medical or other professionals about their child/ young person in the last 12 months. On average, caregivers saw or spoke to a GP about their child/young person 2.4 times in the last year (SD = 2.8) and other medical doctors 2.1 times (SD = 3.4). Other professionals (including psychologists, psychiatrists, counsellors etc) were accessed on average 6.3 times in the last year (SD = 8.7) with a range of responses from zero times to 52 times.

Table 6: Frequency of medical consultations

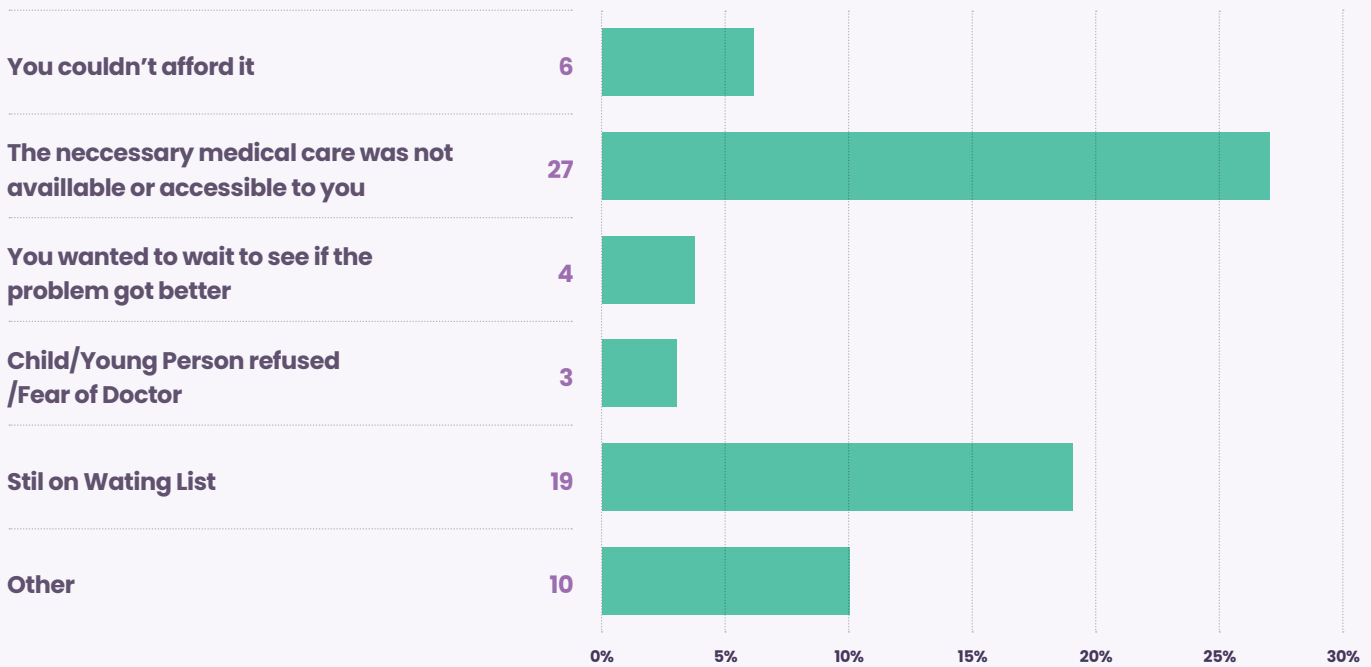
In the last 12 months, how many times have you seen or talked on the telephone with any of the following about your child/young person's physical, emotional, or mental health?	Mean (Standard Deviation)	Minimum - Maximum
GP (n=50)	2.4 (2.8)	0 - 12
Another medical doctor (e.g., in hospital) (n=41)	2.1 (3.4)	0 - 20
Other professional (psychologist, psychiatrist, counsellor etc.) (n=51)	6.3 (8.7)	0 - 52

Forty percent of caregivers (n=28) answered yes to the question “Was there any time in the last 12 months when, in your opinion, your child/young person needed medical care or treatment for a health problem, but they did not receive it?” The reasons given are shown in Figure 3. Participants were asked to tick all that apply. The majority (n=19, 27%) stated that the necessary care was not available or accessible to them and a further 19% (n=13) were still on a waiting list. Seven caregivers (10%) selected Other in their response. Reasons for their child/young person not receiving medical care or treatment included health care professionals' lack of awareness of FASD and support needs related to it. Some health care professionals had, for example, refused to discuss the possibility of FASD and some were unaware of the support needs related to FASD.

Figure 3: Reason for not receiving medical care or treatment.

Was there anytime in the last 12 months when, in your opinion, your child/young person needed medical care or treatment for a health problem but they did not receive it, % (n=28)

Reason



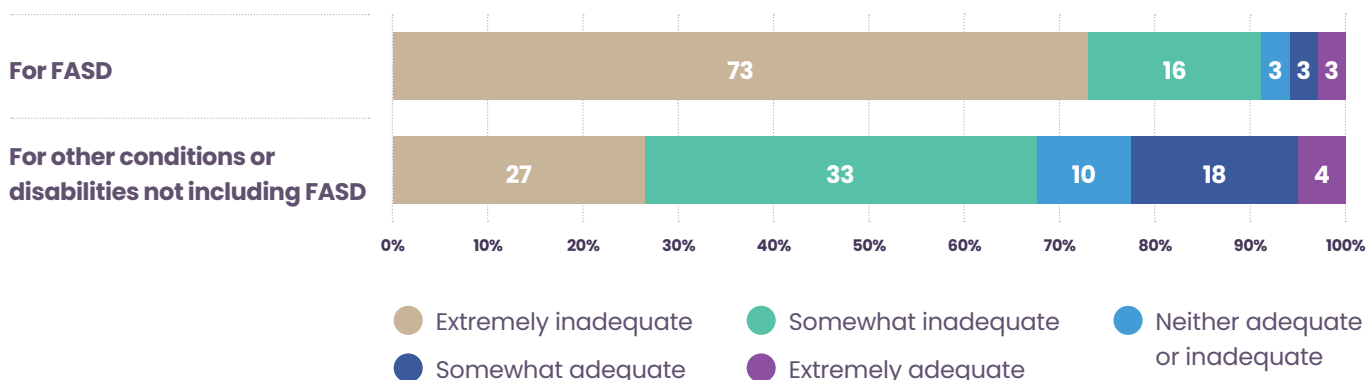
Adequacy Of Supports/Services

Caregivers were asked about how adequate the supports are for their child/young person in two categories: services/supports for FASD, and services/supports for conditions or disabilities not including FASD (Figure 4). Most caregivers (n=60, 89%) reported that services for FASD were either somewhat or extremely inadequate. For conditions/disabilities not including FASD, 60% (n=40) reported that services were somewhat or extremely inadequate, while 22% (n=15) reported that these services/supports were either somewhat or extremely adequate.

Caregivers were asked if there are other supports/services that they were aware of that would be of benefit but that they do not have. Several services/supports were listed. These include: Play therapy (n=4), respite/more respite (n=3), mental health therapy, counselling, psychology and psychiatry (n=12), support/training for caregivers/siblings/families (n=6), occupational therapy (n=12), FASD-aware support from health professions/teachers/guards, speech and language support (n=5), education/school support (n=6), disability supports (n=3), CAMHS (n=3), FASD specific service/multidisciplinary clinic/FASD assessment/diagnosis (n=4), opportunities for child and caregivers to meet others living with FASD (n=3), physiotherapy (n=2).

Figure 4: How adequate are the supports your child/young person receives?

In general, how adequate are the supports your child/young person receives?



Experience In Education

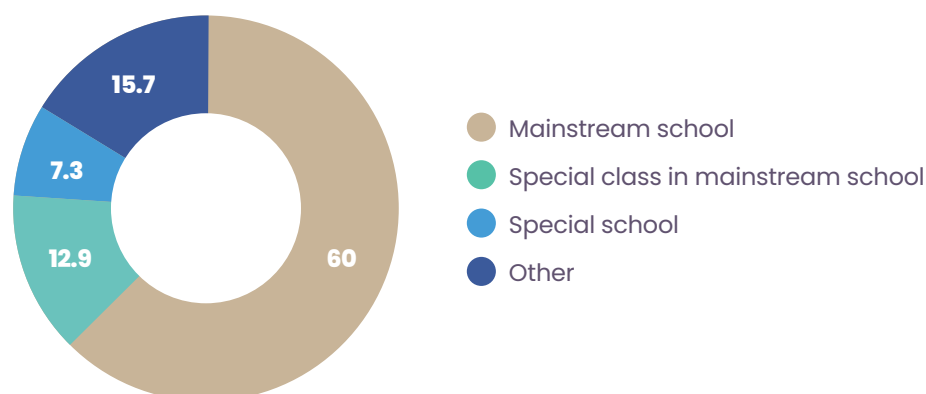
Most children/young people mentioned in the survey were still in education (n=49, 75.4%), while the remainder had left education more than six months previous (n=16, 24.6%) (Table 3).

Most children/young people attend(ed) mainstream school (n=42, 60%), 12% attend(ed) a special class in a mainstream school, 7% attend(ed) a special school and 16% attended a different education setting (Figure 5). Various other types of education setting were listed by eleven caregivers. These included the national learning network, homeschooling, residential setting, day centre, pre-school with an AIMS worker, and two cases where multiple education settings were involved.

More than half of caregivers reported that their child/young person had/has an adapted education plan (n=34, 51.5%), while the remainder did not (n=32, 48.5%). Of those without an adapted plan, three had been offered a plan, the remainder had not. A variety of plans were described, including additional support for English and mathematics classes, reduced hours, exemption from Irish and foreign languages, SNA (Special Needs Assistant) support, breaks throughout the day, personal plans/ individual education plans.

Figure 5: Type of school attended.

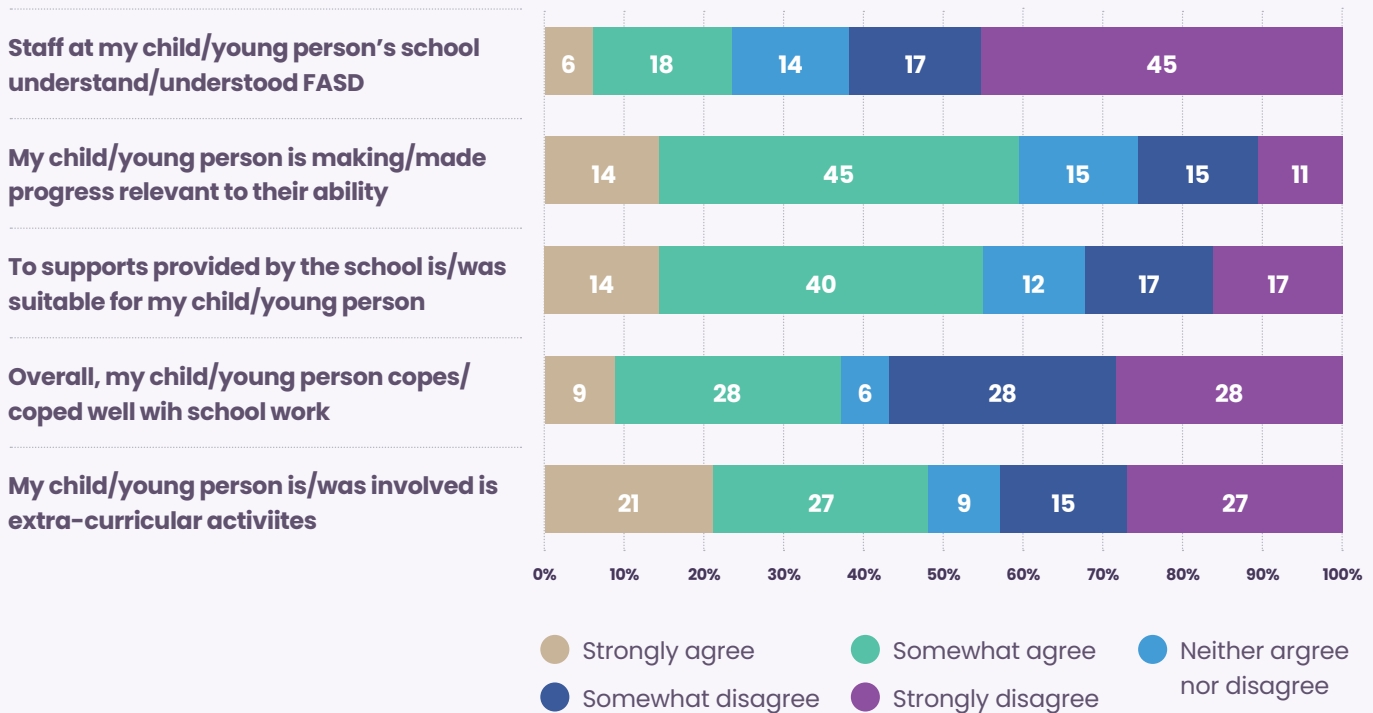
What type of school does/did your child/young person attend? %



Caregivers were asked to state how much they agree/disagree with a series of questions about their child/young person’s experience in school. A summary of the responses is presented in Figure 6. Twenty-four percent agreed that staff at their child/young person’s school understood FASD, while 62% disagreed with this statement. More than half (59%) agreed that their child/young person was making progress relevant to their ability, and 26% disagreed with this. When asked if support provided by the school was suitable for their child/young person 54% of caregivers agreed that it was, while 34% disagreed. More than one-third (37%) agreed that overall, their child/young person coped well with schoolwork, and 56% disagreed with this statement. Almost half (48%) of caregivers agree that their child/young person is involved in extracurricular activities, and 42% disagreed.

Figure 6: School experience of the child/young person with FASD

How much do you agree/disagree with the following statements:

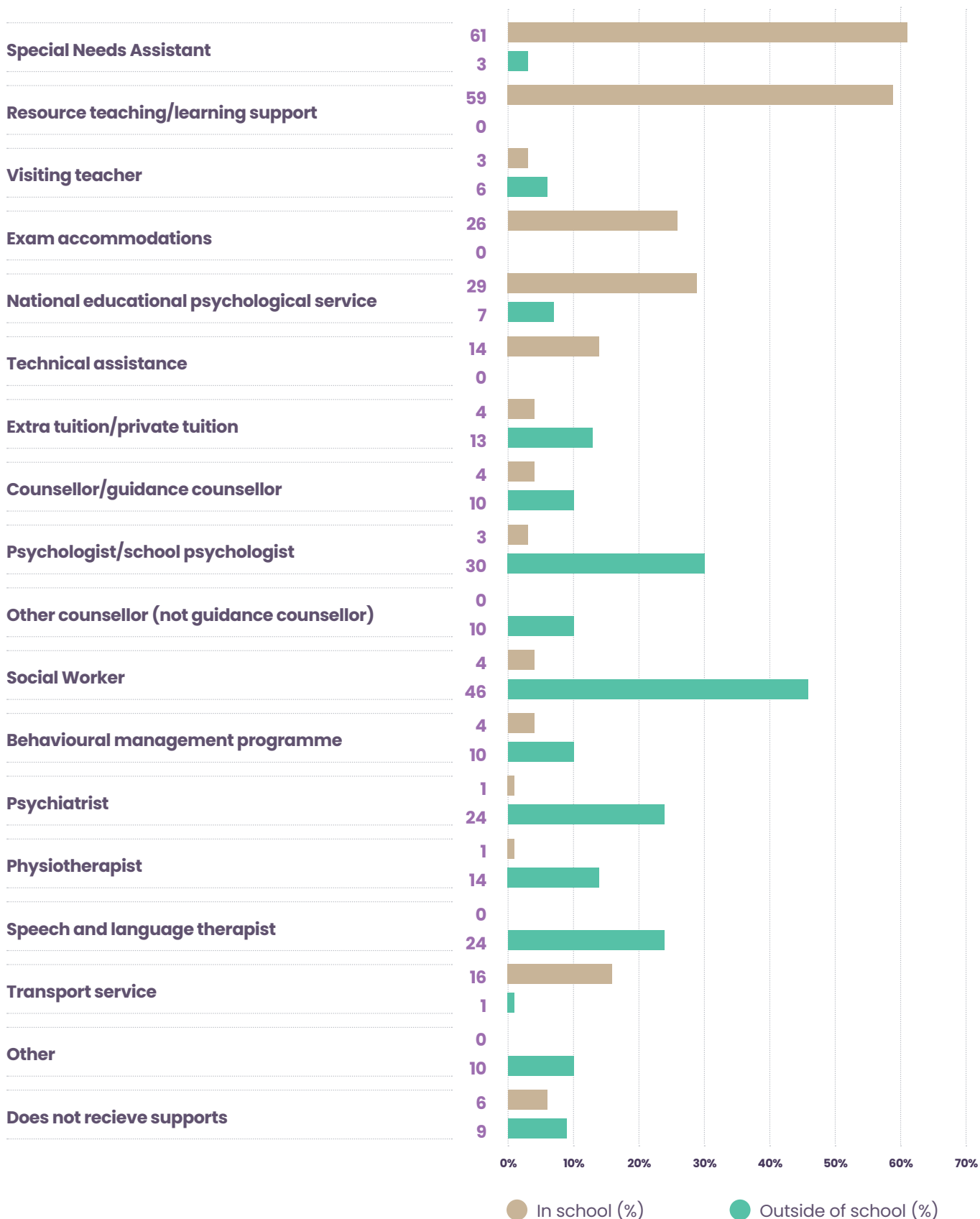


Supports In School And Outside School

Figure 7 presents the types of supports available in school and outside of school. The most common supports available in school are SNAs (n = 43, 61%) and resource teaching/learning support (n=41, 59%). Outside of school the most common supports are from social workers (n=32, 46%) and psychologists/school psychologist (n=21, 30%). Seven caregivers (10%) selected the Other category and reported that their child/young person had access to occupational therapy outside of school.

Figure 7: Supports in school and outside of school.

Please indicate if your child/young person receives support from any of the following in school or outside school. [Tick all that apply]



5. Costs Associated With Care

“

“I have been reaching out for help for my son [many] years now without success. Because of this I am now [more than €20,000] in debt for help for my son.”

Quote from caregiver.

Caregivers were asked a series of questions about the costs associated with caring for someone with FASD including questions about household income, changes in employment status and financial supports. A detailed analysis of this topic will be published separately. This report summarises the findings on the costs associated with caring for someone with FASD in Ireland.

More than half of caregivers reduced their working hours/did not return to work because of their caregiving duties (n=33, 58.9%). Four (7.1%) reported that they could not financially afford to reduce work, while 10 (17.9%) stated that it was not necessary. A further nine caregivers (16.1%) described various other caregiving arrangements including retirement and other family members reducing/giving up work to be a caregiver.

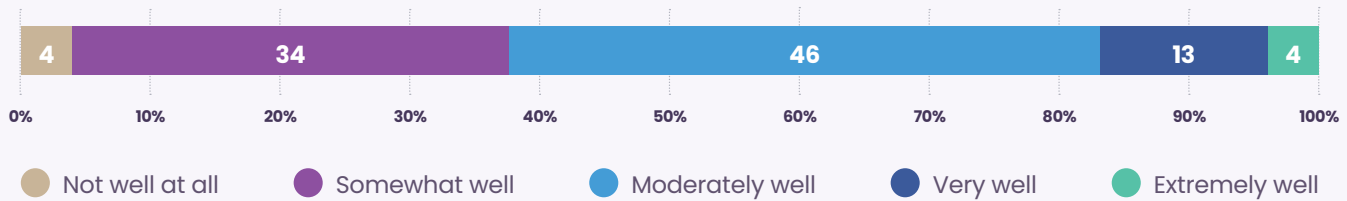
A large proportion of caregivers reported that their child/young person had a medical card (n=48, 69%) and one-third (n=19, 33%) were covered by private health insurance.

Financial Situation In The Last 12 Months

Most caregivers reported that financially, they managed moderately well over the last 12 months (n=26, 46%), 38% (n=21) managed somewhat well or not well at all, and 17% (n=9) managed very or extremely well (Figure 8).

Figure 8: Perception of financial situation over the last 12 months (n=56)

How well would you say you have managed financially in the last 12 months?

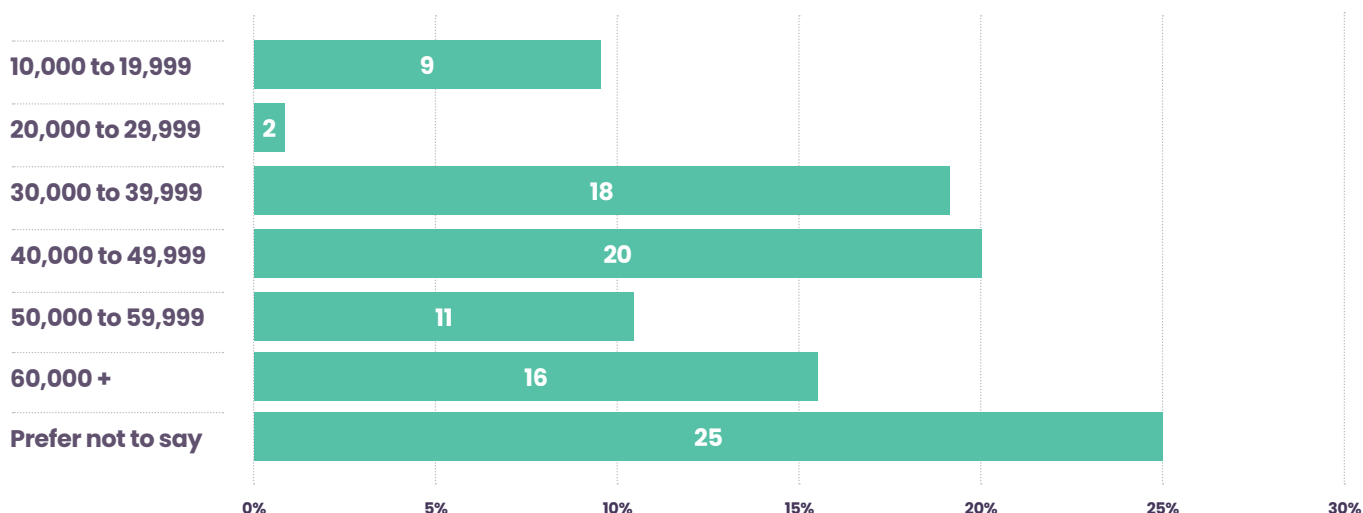


Annual Household Income

One quarter of participants declined to answer when asked about their annual household income (n=14, 25%) (Figure 9). Most caregivers reported an annual income of €/£ 40,000 to 49,999 (n=11, 20%). Sixteen percent (n=9) had a household income of €/£ 60,000 or more, and nine percent (n=5) had an income of €/£ 10,000 to 19,999. No participants reported an annual income lower than €/£ 10,000 to 19,999.

Figure 9: Net household income (n=56)

Total annual net household income? (Euros/Pounds)

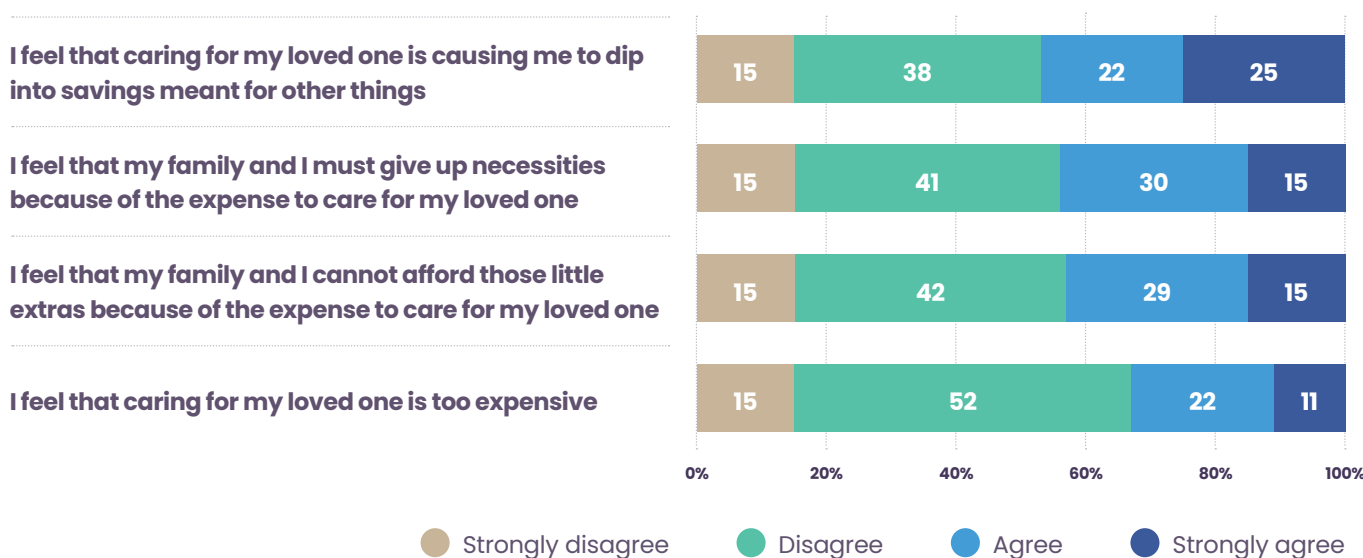


Cost Of Care Index

The financial costs of informal caregiving were measured using the financial costs dimension of the Cost of Care Index⁷. The index consists of four questions, each with a four-point scale. The mean score on the index was 9.7 (SD=3.2) with a minimum score of 4 and maximum of 16. Almost half of caregivers (n=26, 47%) agreed that caring for their loved one is causing them to dip into savings meant for other things, the remaining proportion disagreed (n=29, 53%) (Figure 10). Almost half (n=24, 45%) felt that they and their family must give up necessities because of the expense associated with caring for their child/young person with FASD. Forty-four percent (n=24) of caregivers felt that they and their family cannot afford little extras because of the expense of caregiving and 33% (n=18) felt that caregiving was too expensive.

Figure 10: Cost of care index (n=53)

Cost of Care Index



6. Caregiver Burden

Caregiver burden was measured using the short-form Zarit burden interview (ZBI-12)⁸. The mean burden score in the study sample was 24.9 (SD=9.3). A summary of the responses to each of the 12 questions in the ZBI-12 is presented in Figure 11.

Figure 11: Zarit caregiver burden scale (n=56)

Do you feel.....?

That because of the time you spend with your relative that you don't have enough time for yourself?

Stressed between caring for your child/young person and trying to meet other responsibilities (work/family)?

Angry when you are around your child/young person?

That your child/young person currently affects your relationship with family members or friends in a negative way?

Strained when you are around your child/young person?

That your health has suffered because of your involvement with your child/young person?

That you don't have as much privacy as you would like because of your child/young person?

That your social life has suffered because you are caring for your child/young person?

That you have lost control of your life since your child/young person's illness?

Uncertain about what to do about your child/young person?

You should be doing more for your child/young person?

You could do a better job in caring for your child/young person?

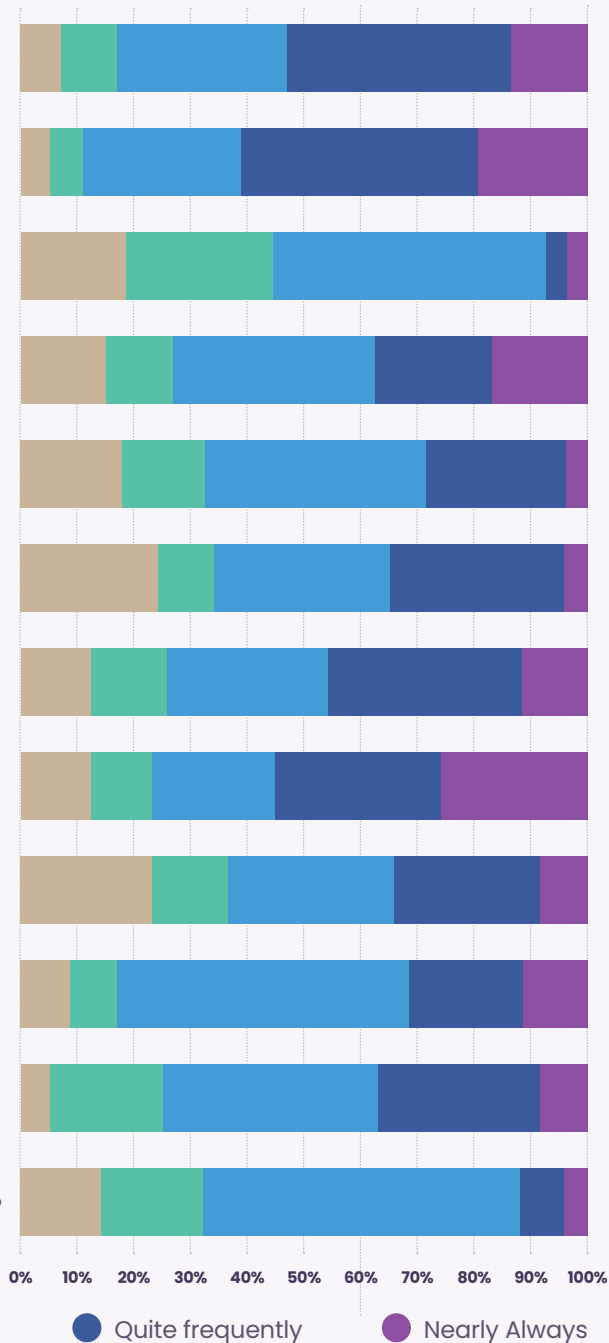


Table 7 presents a simple analysis of the factors associated with caregiver burden. The significance level for level of the ANOVA comparison of means test was set at 0.05. There was a statistically significant difference between mean burden score related to caregiver working status. Those who did not need to reduce/give up work had a lower mean burden score than others. Caregiver burden is consistently high across all groups shown in Table 7. No significant drivers of burden were found. Sample sizes were small across many categories which reduces the power of the statistical tests to draw meaningful conclusions about the differences between groups.

Table 7: Factors associated with caregiver burden (n=56)

Variables	Mean Zarit Score (SD)	n
Caregiver gender		
Male	27.6 (9.2)	10
Female	24.7 (8.9)	45
Caregiver Age at last birthday		
< 50	26.0 (10.7)	22
50-59	24.6 (6.6)	19
>60	25.6 (9.7)	12
Caregiver education level		
Primary school	18.0 (-)	1
Secondary school	24.6 (9.0)	8
Technical/vocational	26.9 (10.5)	13
Degree	24.7 (9.8)	10
Postgraduate	24.6 (10.0)	20
Other	22.5 (1.3)	4
Caregiver relationship status		
Single, separated, widowed	24.5 (10.9)	11
Married/cohabiting	25.0 (9.0)	45
Child/young person number of diagnosed co-morbidities		
0	20.7 (12.0)	6
4+	25.4 (9.0)	50
Have you reduced or stopped working as a result of your caregiving duties? *		
Yes	26.2 (7.4)	32
No, this was not needed	18.7 (12.1)	10
No, I could not financially afford to reduce work	32.8 (6.4)	4
Other	22.4 (10.1)	9
Age of child		
<15 years	25.9 (10.4)	27
>=15 years	23.9 (8.3)	29

*p-value <0.05 for the ANOVA test comparing means across groups

7. Additional Details About Caregiver Experience

At the end of the survey caregivers were given the opportunity to include additional thoughts/experiences in an open text space. The text box below summarises the qualitative data from this final question.

Finally, is there anything else you would like to share about your experience of caring for someone living with FASD (for example, impact on the family, challenging behaviour, loneliness/isolation, or anything else).

Caregivers reported their child/young person's multiple needs for support. Difficulties in self-care, self-regulation, and challenging behaviour, such as unpredictable and aggressive behaviour were identified. The caregivers reported having received insufficient support for their child/young person and for themselves, especially from the health care services. Lack of FASD diagnosis had made accessing support more challenging. The caregivers reported feeling exhausted, emotionally drained, and low because of the care work related to FASD. The child/young person's multiple needs for support and their need for continuous supervision had made the caregivers feel lonely and isolated. The caregivers also expressed worries about the future and who would support their child when they were no longer able to.

Discussion

This study describes the experiences of caregivers of people with FASD living in Ireland. Although estimates suggest that the prevalence of FASD in Ireland is one of the world's highest, it receives little emphasis across many sectors of our society. Awareness and understanding of FASD is low among the public as well as healthcare professionals and those working in the education sector as demonstrated in the findings of this report. Clinical guidelines and specialised services/supports for FASD are needed.

As FASD is largely a hidden and difficult to reach population in Ireland, the sample for this study was recruited through convenience sampling. It is therefore unlikely that the findings contained in the report are representative of the many thousands of families caring for someone with FASD in Ireland. There is a possible over representation of FAS cases in the sample (19% of those with a diagnosis had FAS) and underrepresentation of those with a neurodevelopmental diagnosis (14%). International studies suggest that FAS makes up approximately 11% of cases of FASD and 52% will have a diagnosis of neurodevelopmental disorder⁹. Most caregivers were adoptive or foster parents and birth parents are not adequately represented. Birth parents may be particularly difficult to access for various reasons including a lack of awareness of FASD and stigma associated with prenatal alcohol exposure and FASD.

Of those who reported a confirmed diagnosis of FASD, three quarters (n=37, 76%) were received in Ireland (Table 4). As Ireland does not have published clinical guidelines for the diagnosis of FASD, it is not possible to say how these diagnoses were made, which guidelines were followed, or which professionals were involved in the diagnosis. Although it is encouraging that some medical professionals are treating FASD in Ireland, diagnosis of FASD is challenging and a widespread consistent approach in line with international best practice guidelines is required.

FASD is associated with more than 400 co-morbid conditions¹⁰. On average, children/young people with FASD (both diagnosed and undiagnosed) in the study had three diagnosed comorbidities. The most common co-morbid diagnosis reported were emotional or behavioural disorders including Attention Deficit Hyperactivity Disorder (ADHD) / Attention Deficit Disorder (ADD) with 64% reporting a diagnosis in this category. This is a similar rate to the rate reported in published literature of 52%¹¹. More than one fifth (21%) of the study sample had a co-morbid diagnosis of Autism Spectrum Disorder. This is far in excess of the rate of 2.6% found in the literature¹¹ and may represent considerable misdiagnosis of ASD. As Ireland does not have specialist services for diagnosis or management of FASD, it is possible that many are misdiagnosed with ASD, leading to incorrect management of the disorder and poorer outcomes.

Most caregivers report difficulty in accessing support, with 89% reporting that services for FASD were inadequate. Awareness of FASD is low in the education sector, with 62% reporting that staff at their child/young person's school did not understand FASD. There is a clear need for the development of specialist services for FASD in Ireland, and for training and education for those working directly with children in education and healthcare settings.

The financial cost of informal caregiving was measured using the the financial costs dimension of the Cost of Care Index⁷. Results show a high level of financial burden with almost half of respondents using their savings, giving up necessities and not being able to afford certain extras due to the costs associated with caregiving. Caregiver burden was high in the sample population with a mean burden score of 25⁸. Burden scores were consistently high across different subgroups including gender, age, education. Burden scores were statistically significantly different between those who had reduced/given up work because of caregiving and those who had not. Although all groups in this category had high burden scores (range 19–33), those who have reduced work/given up work had a mean score of 26, those who could not afford to give up/reduce work had a mean score of 33 (although the sample size was small for this group), while those who did not need to give up/reduce work had a lower mean score of 19. Caregiver burden can have significant implications for the caregiver, care recipient and

their families. High caregiver burden is associated with increased stress, anxiety, depression, and reduced quality of life. This can lead to strained relationships and could be a contributing factor in placement breakdown for children/young people in care¹², represented by a substantial proportion of this study sample.

This study has some limitations, most notably in its representativeness of the FASD community in Ireland. As previously stated, Ireland does not have a defined diagnostic pathway for FASD, and it is likely that most people living with FASD are undiagnosed. This is a difficult to reach, largely hidden proportion of the population and this study recruited using a convenience sampling approach. It is likely that the group represented in this study are more knowledgeable on FASD, financially better off and more highly educated than many caregivers of people with FASD in Ireland.

Conclusion

This study represents a preliminary analysis of the experiences of caregivers of people with FASD in Ireland. More research is needed to further investigate the themes explored. The study findings echo what is already known in other countries. FASD is complex and caregivers experience enormous stress, burden, and financial strain. Diagnosis, early interventions and prevention or management of secondary disabilities are urgently needed to improve outcomes for young people with FASD and their families. FASDs are a range of mostly preventable conditions affecting approximately 5% of young people in Ireland, the third highest rate worldwide³. Ireland is reported to have the highest rate of alcohol use in pregnancy globally¹³ with low awareness of the implications and devastating outcomes. We hope that the results of this report will be of use to continue advocacy work in this area.

Recommendations

Improving the lives of people living with FASD in Ireland and supporting their caregivers requires a collaborative effort from healthcare professionals, policymakers, educators, and the wider community to create a more inclusive and understanding society. The findings of this study suggest that developments in several key areas would improve the lives of caregivers and people with FASD in Ireland. These include

- **Development of specialist caregiver support** such as support groups with other caregivers, counselling to help with the emotional challenges faced by caregivers and improved availability of respite care to reduce burden and prevent burnout.
- **Development of a national diagnostic pathway for FASD.** Access to early and accurate diagnosis, specialist services, appropriate interventions and therapies are critical for improving outcomes and quality of life for those with FASD and their families.
- **Access to FASD-informed services** in healthcare, education, and social services to ensure that all interactions with services are tailored for the specific needs of the individual with FASD.
- **Increased awareness** about the consequences of prenatal alcohol exposure in all sectors of society will promote prevention of FASD, improve screening and diagnosis of FASD and the development of suitable interventions and therapies for individuals with FASD.

Additional Quotes From Caregivers

“

“Our daughter is a joy. She has so many strengths and gifts.”

Quote from caregiver.

“

“My daughter has this awful disorder but she is funny, caring, joyful and beautiful.”

Quote from caregiver.

“

“I love both of my children and will continue to care for them as long as I am able.”

Quote from caregiver.

“

“We love him and couldn't imagine life without him.”

Quote from caregiver.

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