International Scope for Supporting Adults with FASD

D-Term
April 27, 2022

TEAM MEMBERS

Caitlin Bonavita
Grace Casey
Josephine Kim

SPONSOR

The National Organisation
for FASD UK

ADVISORS

Professor Dominic Golding
Professor Lorraine Higgins

An Interactive Qualifying Project submitted to the Faculty of Worcester Polytechnic Institute in partial fulfillment of the requirements for the Degree of Bachelor of Science.

WPI

ABTSRACT

Fetal Alcohol Spectrum Disorder (FASD) affects 2-4% of the UK population, but care provisions remain limited, especially for adults with FASD. This project assisted the National Organisation for FASD by researching policies, practices, and guidelines to support adults with FASD in the USA, Australia, and Canada. We conducted literature reviews to identify which organizations were promoting best practices in support of adults with FASD. We supplemented our background research by interviewing representatives from several of these organizations. We identified legislation and resources on best practices in housing, education, diagnosis, mentorship, and criminal justice. We recommend the National Organisation for FASD advocate for many of these practices to improve support for adults with FASD in the UK.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS

First and foremost, we would like to thank The National Organisation for FASD in the UK for allowing us to work on this project for them. We were constantly inspired by them and the work that they are doing for individuals with FASD. We have all gained valuable insight into the struggles that individuals with FASD face every day and what is needed to better support them. Within this organization we would especially like to thank Sandy Butcher and Joanna Buckard for their unwavering support and encouragement throughout the course of our project. This project would not have been successful without their help.

Our team would also like to thank Professor Dominic Golding and Professor Lorraine Higgins for their continued guidance and honest feedback. Their constant support and encouragement was essential to the success of this project.

INTRODUCTION

In the UK, 2-4% of the population is affected by Fetal Alcohol Spectrum Disorder (FASD). FASD results from alcohol exposed pregnancies and can lead to lifelong neurodevelopmental as well as physical disabilities in their children. These neurodevelopmental disabilities may impair cognitive, behavioral and social skills, as well as academic achievement. Many people believe FASD is a childhood disease; however, it has long-term effects that resonate throughout adult life. The long-term effects of FASD in adulthood include physical disabilities, such as impaired balance, and cognitive and behavior disabilities, such as difficulty focusing and maintaining attention. Many adults with FASD also struggle with mental health issues, drug problems, steady employment, housing, and personal relationships.

In the UK, the National Organisation for FASD provides support for people affected by FASD, their families, and caregiving communities through ample online resources and educational programs. While there is growing awareness of the adverse effects of FASD in childhood, there is a lack of awareness and knowledge about effects that persist in adults with FASD. This means there are few practices, policies, and guidelines that support individuals with FASD in adulthood in the UK. Countries such as the US, Canada, and Australia are beginning to develop such guidelines, policies, and practices that the UK can learn from.

The overall goal of this project is to evaluate policies and best practices in dealing with FASD in adulthood; an inventory of these practices will serve as a basis for developing future policies and programs in the UK. To achieve this goal, the team established four project objectives, each with a set of associated tasks described in Figure 1.

To accomplish these objectives, we conducted background research and interviews with FASD organizations, advocates, and researchers about policies, practices, and guidelines that address FASD in the UK as well as in the US, Canada, and Australia. In the following chapter we provide general background information on rates of drinking during pregnancy in the UK, the risks and negative effects of FASD, and the lack of support in the UK in terms of developing practices and guidelines that address FASD in adulthood. In subsequent chapters we present our findings on what other countries are providing adults with FASD in terms of housing, education, and employment.

Assess the state of knowledge and scientific concensus regarding the lifelong impacts of FASD.

01

Identify the policies, practices, and guidelines proposed and implemented in the UK that address FASD.

02

Identify the policies, practices, and guidelines that address FASD in adulthood and in general in other countries.

03

Create deliverables that summarize the current research, policies, and practices.

04

Figure 1: Four Project Objectives

OVERVIEW OF FASD IN THE UK

In this chapter we will review alcohol consumption of pregnant women in the UK and the risks it creates for Fetal Alcohol Spectrum Disorder. We will describe the causes and effects of FASD, and what kinds of support, if any, are in the UK for those suffering with FASD. This background will serve as the foundation for our research on how other countries are addressing support for adults who have FASD.

Drinking During Pregnancy in the UK

In the UK, around 41% of mothers in the UK drink while they are pregnant and 19% binge[1] drink during pregnancy (Cracker, 2020). In 2020, Massachusetts General Hospital conducted a study of women in 11 European countries. The study found that an average of 16% of women drank four or more alcoholic drinks during pregnancy (see red line in Figure 2). From Figure 2, you can see that the UK leads in alcohol exposed pregnancies amongst the European countries.

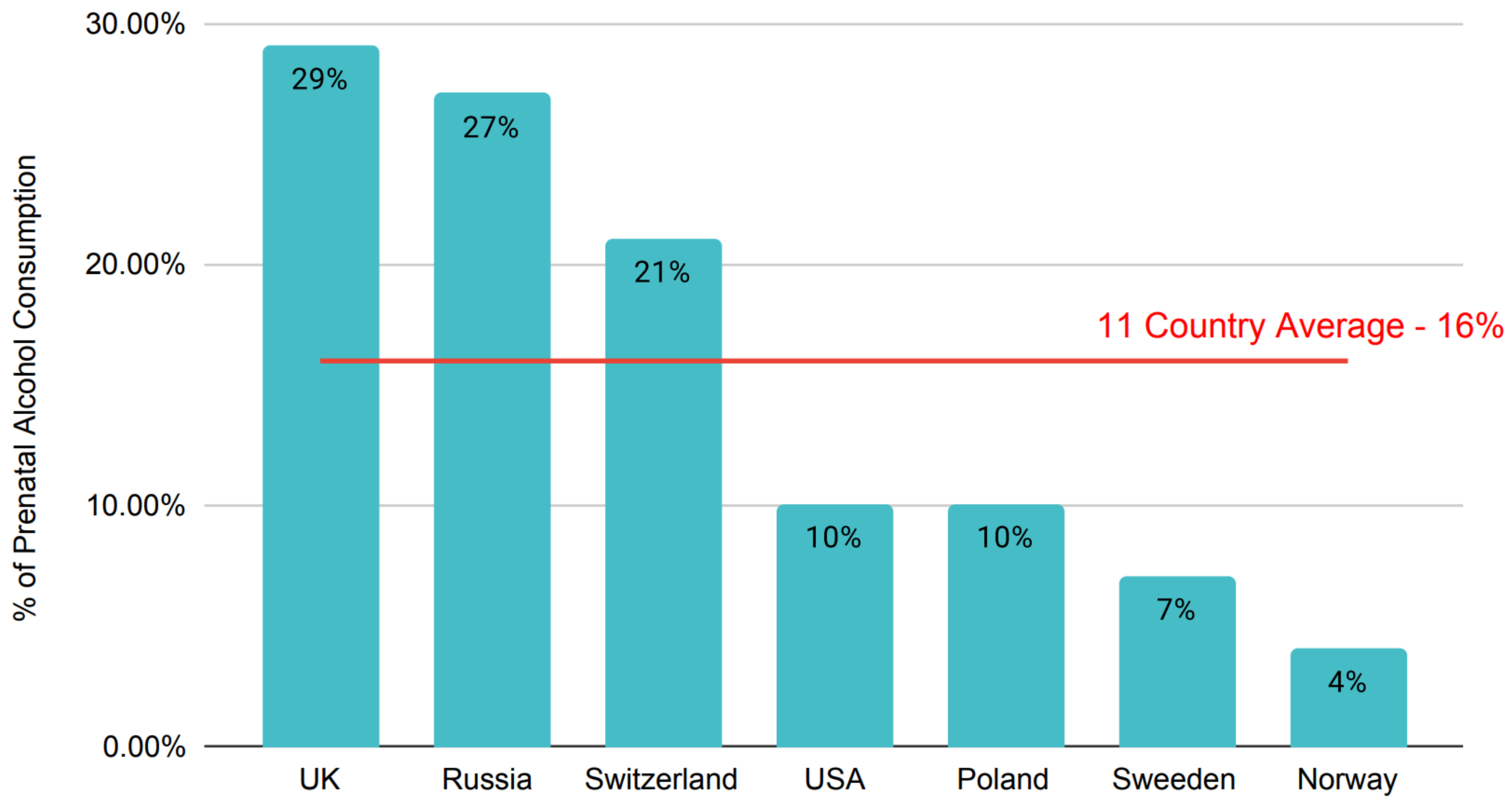

Figure 2: Percent of women who drank four or more alcoholic drinks during pregnancy by country (Massachusetts General Hospital, 2020).

This high rate of drinking during pregnancy in the UK is likely attributed to many different factors including misinformation, lack of knowledge, peer pressure, and the drinking culture in the UK. In 2017, alcohol in the UK was 64% more affordable than in 1987, which when combined with the increase in levels of drinking at home can lead to an increase in binge drinking (Cabinet Secretary for Health and Social Care, 2018). This high rate of drinking amongst women results in a variety of health problems, but is of special concern in pregnant women due to the adverse impacts on the fetus.

Effects of FASD

The adverse impacts of alcohol on the fetus have become clearer over many years and our understanding is still evolving. As noted by Armstrong (1998), American dysmorphologists[2] made the first correlation between drinking during pregnancy and growth deficiencies and developmental delays in 1997. This led to further studies and coining of the term Fetal Alcohol Syndrome (FAS) .

These first studies consisted of small groups of subjects and the unofficial tally of those diagnosed with FAS increased gradually over the next several years (Armstrong, 1998). In the early 2000s, researchers in the field began to use Fetal Alcohol Spectrum Disorder (FASD) as the preferred term for a spectrum of neurodevelopmental disorders that result from exposure of the fetus to alcohol. The research revealed that there was not just one syndrome related to fetal alcohol exposure but a wide spectrum of neurodevelopmental disorders. Following on from SIGN 156 guideline, the diagnostic terms in the UK now are FASD with or without sentinel facial features. Less than 10% have sentinel facial features. As the DHSC says, 'There is no mild FASD.'

As illustrated in Figure 3, the facial abnormalities used to diagnose the more severe cases of FASD include a distinct thin upper lip, microcephaly, and a smooth philtrum (Spohr & Willms & Steinhausen, 2007). More than 80% of people affected by FASD, however, do not show facial abnormalities which makes diagnosis difficult (Popova et al., 2016). Also, the noticeable physical features in those with extreme cases tend to be less prominent after puberty (Moore & Riley, 2019; Spohr & Willms & Steinhausen, 2007).

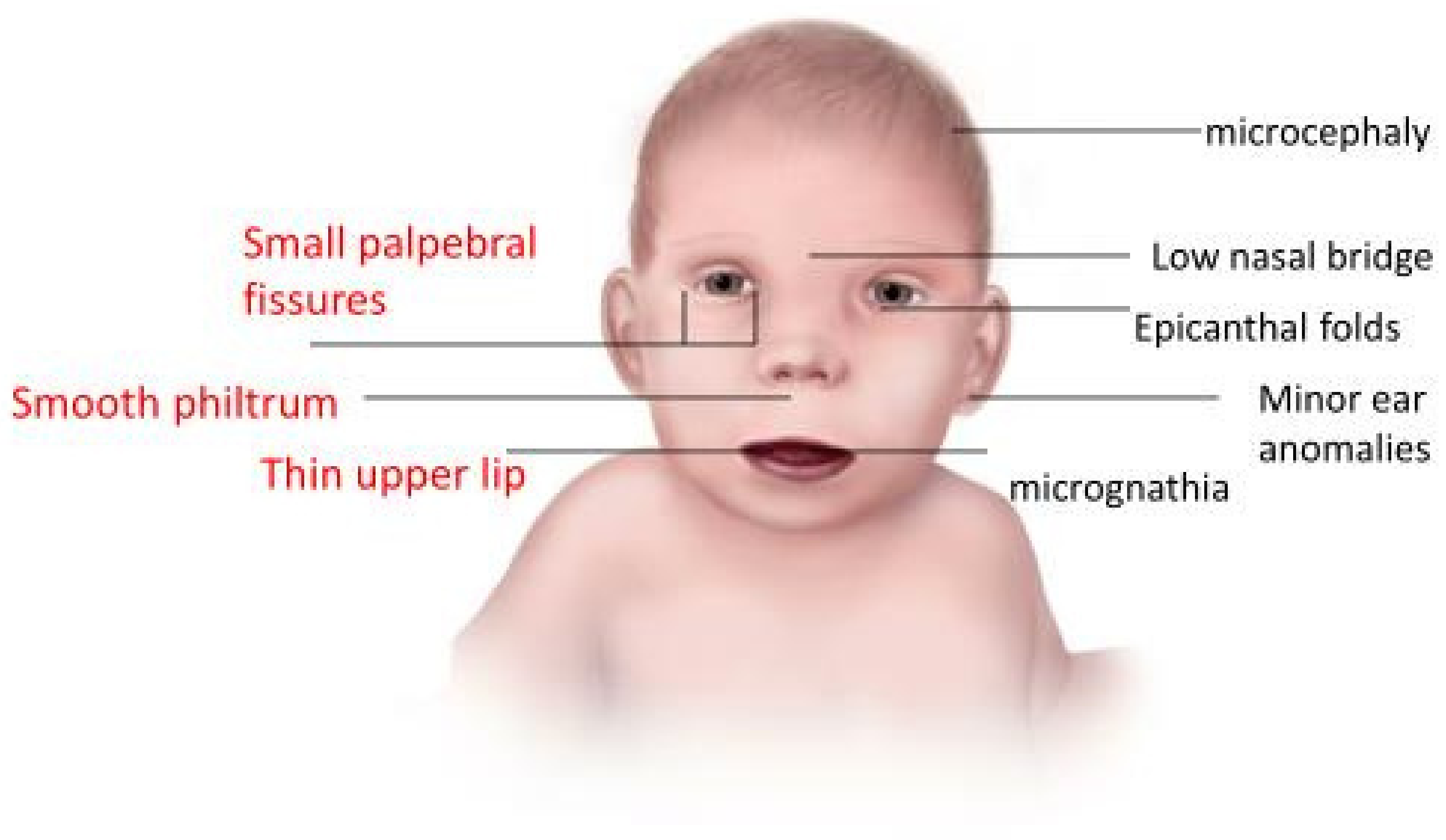

Figure 3: Possible facial abnormalities as a result of FASD (American Academy of Pediatrics, 2018).

To date, researchers have identified a spectrum of 428 different conditions associated with FASD (Popova et al.,2016). The more common symptoms of FASD can be seen in Figure 4 (Center for Disease Control and Prevention, 2022). These symptoms include trouble with executive functioning, which contributes to everyday memory, thinking, and self-control. These can greatly impact everyday life in many ways such as trouble with making decisions, evaluating risk, and following directions. For example, if you were to ask someone with FASD to "clear the table", they might just wipe everything off the table instead of

---

[1] According to the National Health Service, binge drinking in the UK is defined as consuming 8 units of alcohol in a single session for men and 6 unites for women (National Health Service UK, 2019).

[2] A doctor who studies birth defects.

knowing to put the dishes in the sink and to reset the table. These mental obstacles make everyday tasks that we may deem as simple, much more complicated.

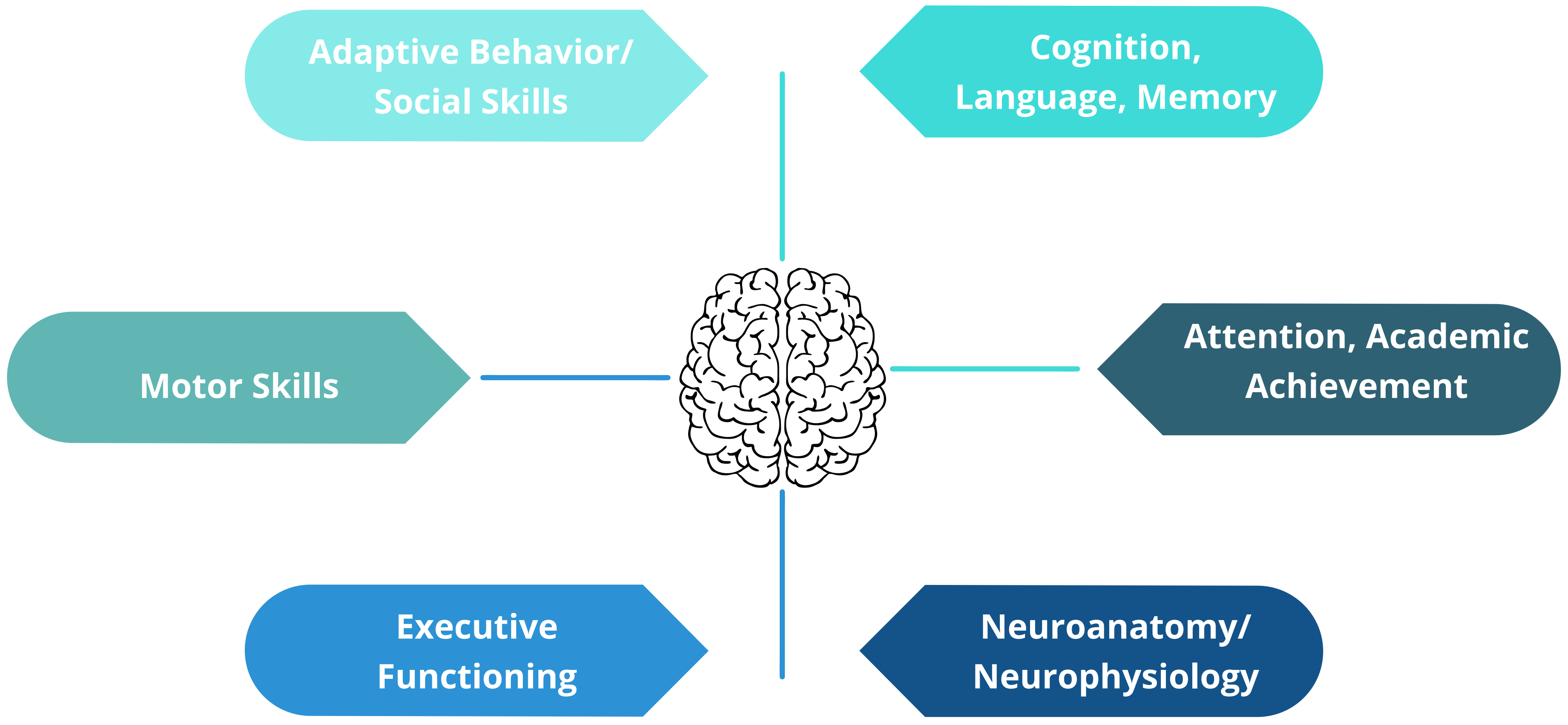

Figure 4: Potential neurodevelopmental effects caused by FASD (Center for Disease Control and Prevention, 2022).

In addition to neurodevelopmental impairments, those with FASD may experience impaired motor skills resulting in poor balance, lack of coordination, and poor sequence of movements (Moore & Riley, 2019). In more extreme cases, those with FASD can suffer from damage to internal organs, seizures, and possible deformities of limbs or joints (Center for Disease Control and Prevention, 2022). Young adults with FASD also present difficulties in focusing and maintaining attention both in visual and auditory settings (Moore & Riley, 2019). A 2010 study compared the memory of adults who had prenatal alcohol exposure (both dysmorphic and nondysmorphic)[3] with two control groups, one controlled by demographics and one controlled by adults who received special education (Coles et al., 2010). The study found both dysmorphic (DYSM) and nondysmorphic (ETOH) people performed worse in memory recall compared to the demographic control group (Coles et al., 2010), confirming that FASD can alter an adult's memory and ability to process given information (Coles et al., 2010). The dysmorphic FASD group and the special education control group had almost identical memory performance trials; this data can be used to argue for support for individuals with FASD in adulthood.

The physical, behavioral, and cognitive impairments of FASD make life difficult, but unfortunately, there are other secondary associated disabilities. This disease carries a heavy burden on those affected and many report mental health issues, trouble with the law, and drug problems. For example (Figure 5), among 415 patients with FASD ranging from ages 21-51 years old 90% suffered mental health issues, 60% got into trouble with the law, and 45% fell prey to drug or alcohol problems (Steissguth et al., 2004).

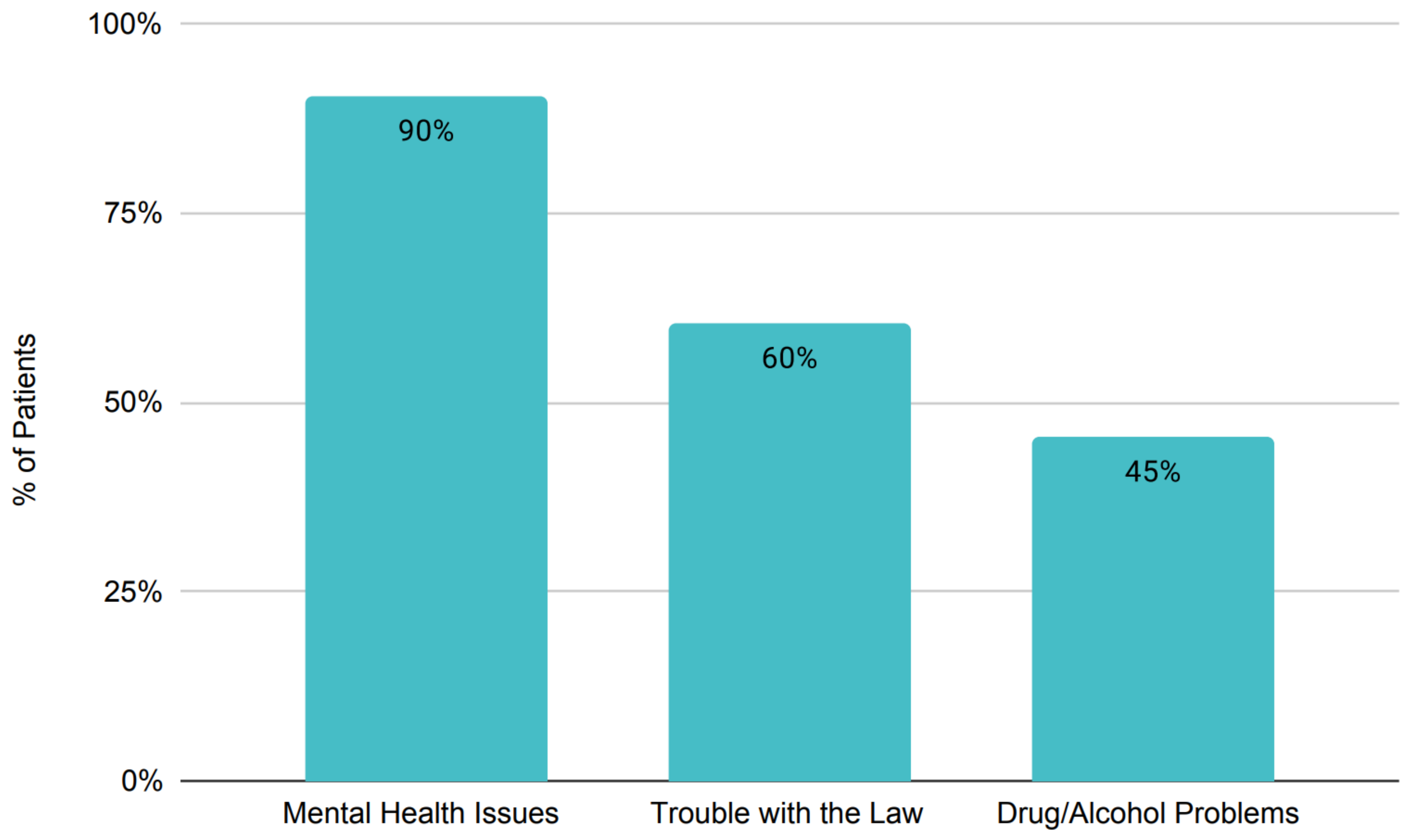

Figure 5: Percent of Various Secondary Mental Disabilities as Result of FASD (Streissguth et al., 2004).

There is limited data on those with FASD who are older than 30, in part because FASD has only recently gained attention as a medical issue and because the life expectancy of those affected by FASD is short (Moore & Riley, 2015). In a 2016 longitudinal study of people suffering with FASD in Canada, the average life expectancy was only 34 years (Thanh & Jonsson, 2016). Fifteen percent of the deaths in the study group (Figure 6) were caused by suicide and 14% by drug or alcohol abuse (Thanh & Jonsson, 2016). Figure 6 compares these two death rates to those of the general Canadian population from 2016.

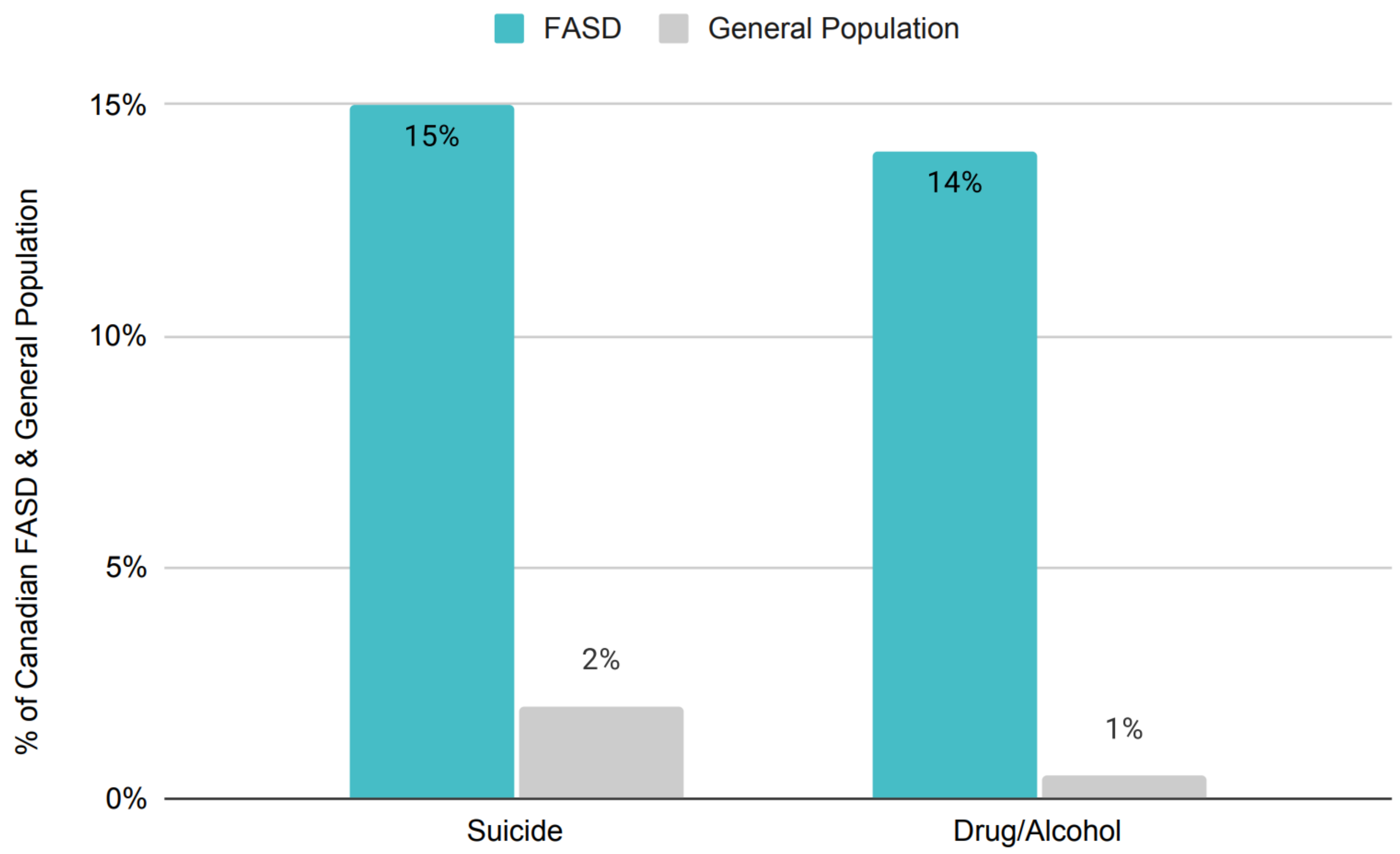

Figure 6: Causes of death among individuals with FASD versus the general population in Canada 2016 (Thanh & Jonsson, 2016; Roser & Ritchie, 2018).

---

[3] Nondysmorphic are individuals who do not present facial features, while dysmorphic are those who do.

Although this study takes place in Canada, it exhibits the life-long mental health effects and drug or alcohol abuse due to FASD. This proves that FASD is a life-long disease and has effects that are impactful on one's well-being that are beyond the initial symptoms.

Diagnoses of FASD

Given the evolving research on alcohol behaviors, consumption, and adverse outcomes in pregnancy, tools for diagnosing FASD has also evolved. Diagnosis was previously based on the symptoms associated with FAS, such as facial abnormalities, but now diagnosis is much more subtle and more complex. Due to the limited number of people that show dysmorphic effects it can often be difficult to diagnose FASD. Diagnosis is also difficult because FASD neurodevelopment symptoms such as adaptive behavior, social skills, attention, and academic achievement overlap with those of Attention-Deficit/Hyperactivity Disorder (ADHD) and autism. Because many health professionals lack knowledge and awareness of FASD, individuals who do not present the sentinel facial features are often overlooked and/or misdiagnosed. Physical features, while only affecting a small portion of the FASD population, are just a minute part of the lasting effects of FASD.

In the UK, diagnostic terms have changed significantly in recent years due to spectrum recognition. FASD with sentinel facial features includes those diagnosed with FAS; FASD without sentinel facial features refers to those diagnosed with ARND, ARBD, pFAS, and NDPAE (Healthcare Improvement Scotland, 2019). An individual can be diagnosed for FASD or identified as at risk of having FASD through multiple pathways using the Diagnostic Algorithm as shown in Figure 7. The diagnosis criteria begin with known or unknown prenatal alcohol exposure and then can be determined through a combination of Central Nervous System Criteria for neurodevelopmental impairments, facial features, and a presence of microcephaly.[4] It is important that individuals get a correct diagnosis in order to get proper care and the specialized support they need. More of the population, than is currently known, is likely affected by FASD. However, due to a lack of research and difficulties with diagnosis, most go misdiagnosed or undiagnosed. Over the years, several practices and guidelines have been put in place to address FASD in the UK and elsewhere. We discuss the UK guidelines and practices in this section.

Low-Risk Drinking Guidelines in the UK

In 2016, the UK Chief Medical Officers released a low-risk drinking guideline to address the risks of drinking during pregnancy. Under the guidelines, pregnant women are advised to not drink at all to minimize risks for the baby. The guidelines also warn that the more you drink, the greater the risk (Department of Health, 2016). While the low-risk drinking guidelines do not prevent drinking during pregnancy from occurring, they have increased awareness of the risks. In 2019, the Institute of Alcohol Studies in the UK explored whether UK women were aware of the CMOs' guidelines which advised pregnant women to abstain completely from alcohol. In the study, women were surveyed and asked whether they were aware of the CMOs' guidelines. On average, 58% indicated that they were aware of the guidelines (Institute of Alcohol Studies, 2019), but Figure 8 shows the percentage of women who were aware of the guidelines varied substantially across four different regions in the UK.

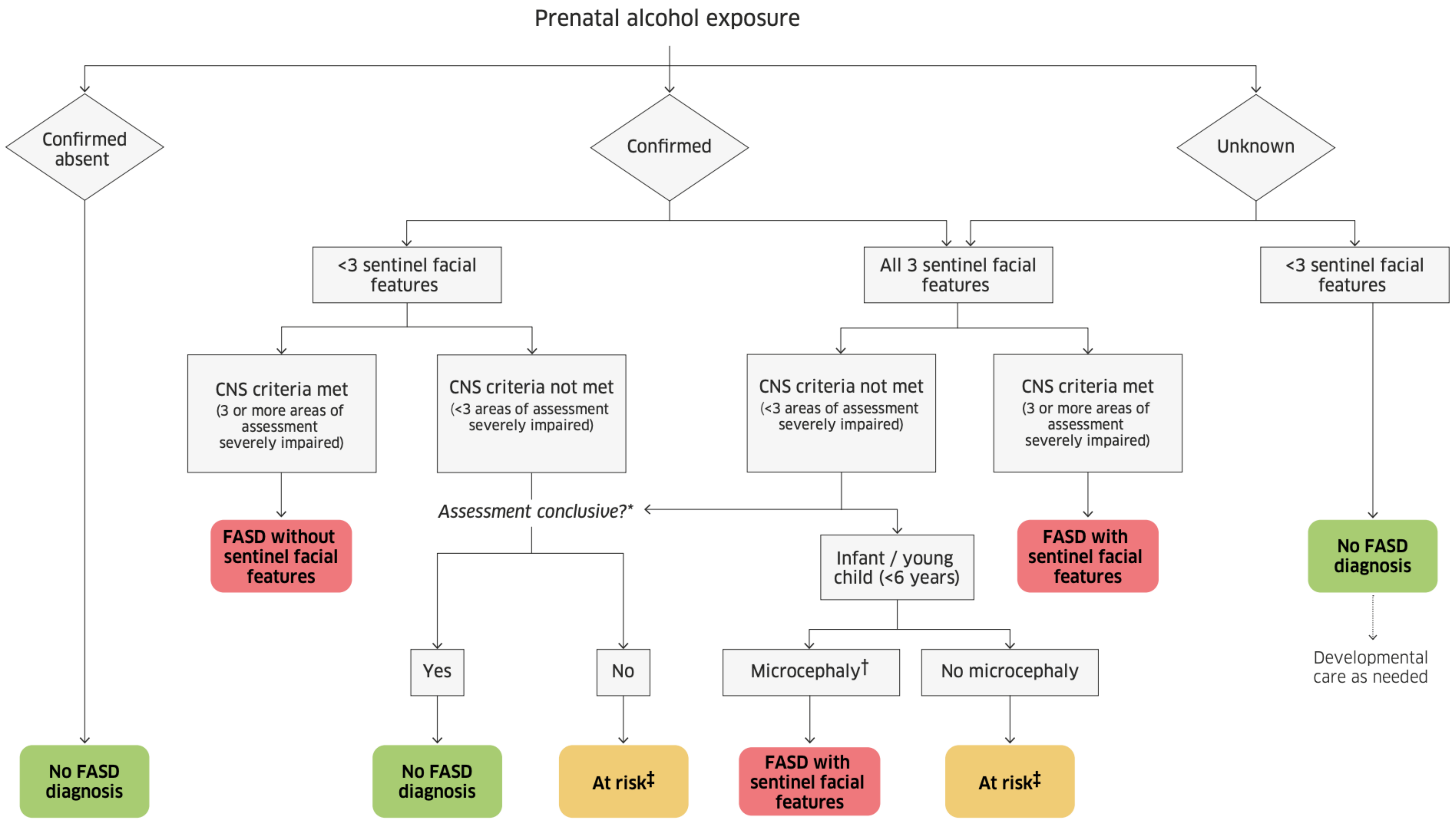

Figure 7: Diagnostic Algorithm for FASD (Healthcare Improvement Scotland, 2019).

---

[4] Microcephaly is a condition where a baby's head is smaller than expected (CDC, 2020).

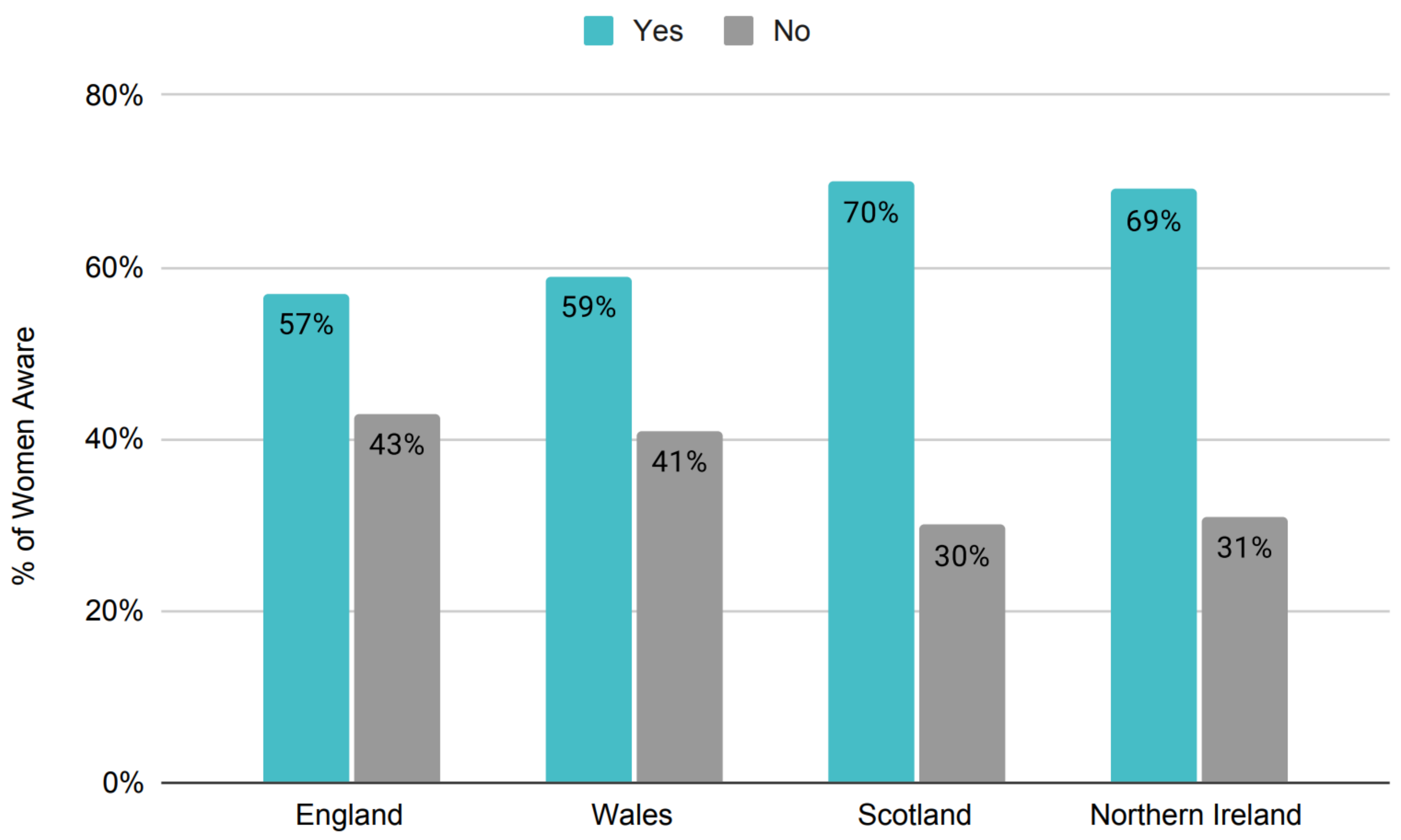

Figure 8: Percentage of Women Aware of the Zero Alcohol Recommendation During Pregnancy by Region (Institute of Alcohol Studies, 2019)

In 2019, National FASD conducted a similar study, polling respondents across 12 regions. Figure 9 shows the percentage of adults who selected the correct answer of the zero-alcohol recommendation during pregnancy.

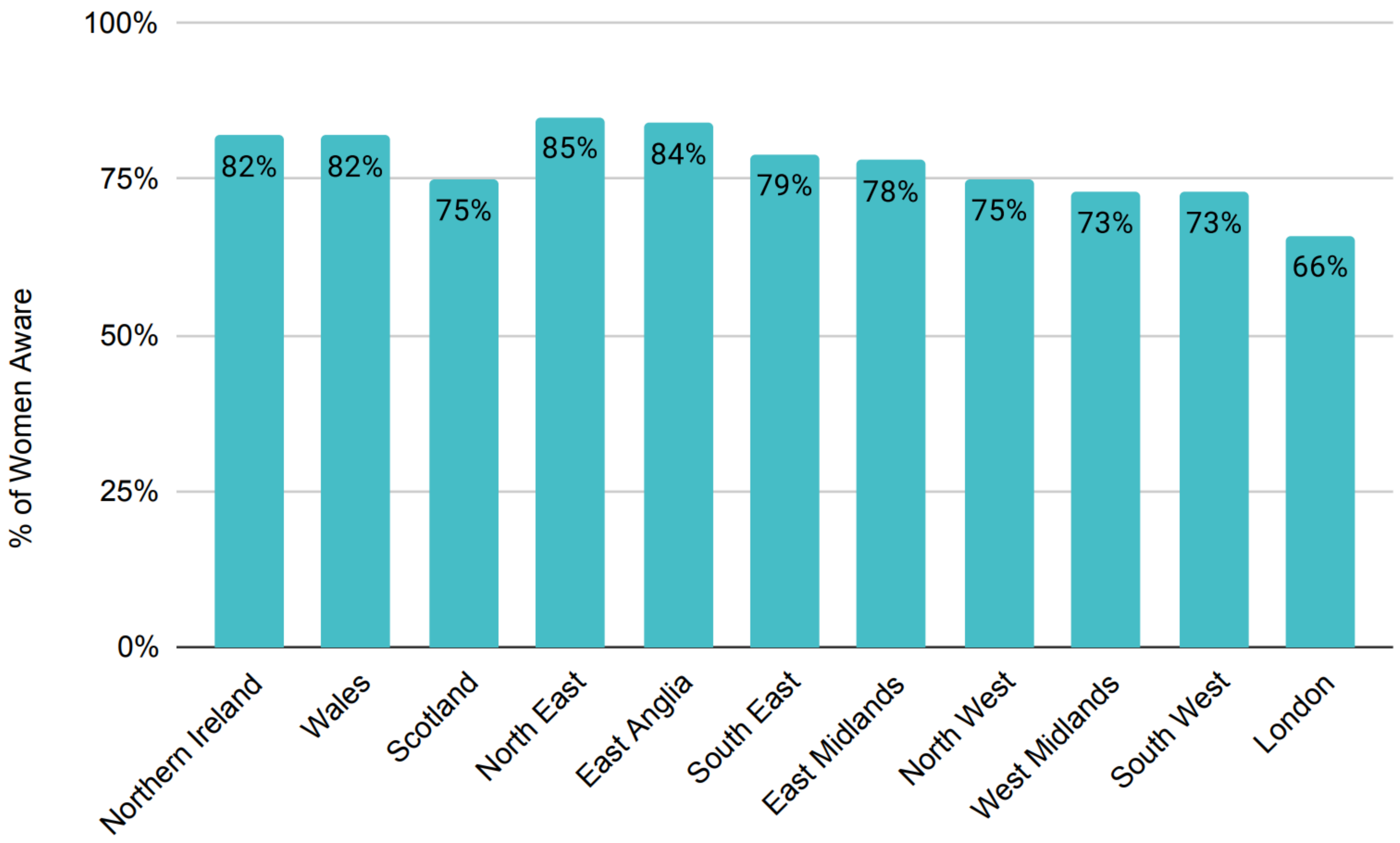

Figure 9: Percentage of adults in the UK who are aware of the Zero Alcohol Recommendation During Pregnancy Across 12 Regions (Fetal Alcohol Spectrum Disorder: Health Needs Assessment, 2019)

While this poll included men and women, comparing the results to those obtained 2 years earlier suggests that awareness of CMO guidelines may have increased.

FASD Practices and Guidelines in the UK

Although awareness of the low-risk drinking guidelines has increased, changing attitudes and behaviors with regard to alcohol and decreasing the prevalence of FASD in the UK is a long-term venture. However, several practices and guidelines have been put in place to address the risks of drinking during pregnancy, raise awareness of FASD, and provide support for individuals living with FASD. Advocacy groups such as the National Organisation for FASD provide support for people affected by FASD, their families, and communities. The organization also promotes public awareness of FASD, while also lobbying for practices and guidelines that seek to increase support and the wellbeing of those with FASD .

In March of 2022, NICE (National Institute for Health and Care Excellence) published Quality Standards that address FASD in children and adults, as well as high-quality care in priority areas for improvement. Their Quality Standard (NICE) is based on the Scottish's SIGN guidance for children and people exposed to alcohol during pregnancy. The new quality standards recommend that:

- Pregnant women are given advice throughout pregnancy not to drink alcohol.
- Pregnant women are asked about their alcohol use throughout their pregnancy, and this is recorded.
- Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioral difficulties are referred to for assessment.
- Children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure have a neurodevelopmental assessment if there are clinical concerns.
- Children and young people with a diagnosis of fetal alcohol spectrum disorder (FASD) have a management plan to address their needs. (NICE, 2022).

These Quality Standards aim to improve the quality of care for individuals with FASD, while also providing support during pregnancy to prevent FASD.

Once an individual is diagnosed with FASD, it is important that healthcare professionals develop a management plan to address the needs of the patient. In the UK, SIGN 156 provides guidelines for the best practices for caring and providing support for individuals with FASD. Under their guidelines, after the results of the FASD diagnostic assessment are presented to the individual and their family, healthcare workers need to educate them about their diagnosis and the complications associated with FASD (Healthcare Improvement Scotland, 2019). Because FASD presents long-lasting behavioral and physical challenges, a management plan is also advised. A management plan may include anything from directing the individual with FASD and their family to support services, to planning for anticipated problems at planned intervals (Quality Standard, 2022). While these guidelines are not required, they provide recommendations that can be used by healthcare professionals to diagnose FASD and to provide resources if a patient is diagnosed (Healthcare Improvement Scotland, 2019).

Lack of Support for Adults in the UK

Most people are under the impression that FASD is strictly a childhood disease; however, FASD presents lifelong effects (Moore & Riley, 2015). The NICE Quality Standards and SIGN 156, while progressive in outlining how to advise and guide those affected by FASD, neglect to address FASD through adulthood in terms of care or support (Quality Standard Consultation, 2020; Healthcare Improvement Scotland, 2019). Most effects of FASD are lifelong and negatively impact one's relationships, occupations, living situations, and mental health (Spohr & Willms & Steinhausen, 2007). Table 1 shows five specific practices and guidelines that are in place in the UK to provide support for individuals with FASD. None of these address FASD in adulthood, nor do they provide support or services for adults living with FASD.

Table 1: Practices and Guidelines in the UK that Address FASD

Area of FASD Addressed	SIGN 156 (NHS Scotland)	NICE (National Institute for Health Care & Excellence)	Low-Risk Drinking Guidelines (UK Chief Medical Officer)	DHSC FASD Health Needs Assessment (GOV.UK)
Drinking During Pregnancy Risks	✓	✓	✓	✓
Providing Support & Awareness	✓	✓		
FASD Best Practices/ Education	✓	✓		✓
Information for Healthcare Workers	✓	✓		
Adulthood				

The Need for FASD Support through Adulthood: Methods for Exploring Approaches in Other Countries

The effects of FASD are evidently long-term and last through adulthood. The need for adult support is vital. A lack of support can lead to heightened secondary disabilities as mentioned previously: troubles with the law, employment issues, struggles with education, poor social interactions, and various mental health issues (Petrenko, Tahir, Mahoney, Chin, 2013).

In the UK, the understanding of FASD is still evolving, and the practices and guidelines that address FASD neglect the long-term impacts and needs of those who are adults with FASD. To assist the National FASD in developing informational materials on FASD in adulthood and lobbying for redressive policies and programs, we looked at efforts made in other countries. The US, Canada, and Australia are ahead of the UK in developing approaches and services that provide support for adults with FASD. These countries were central in our research because they all have similar FASD rates to the UK, but are more proactive and progressive in supporting those in need. Our project investigated FASD policies, provisions, and services for those who are adults in other countries, which may serve as a basis for future policies and programs in the UK. Through background research and interviews with FASD researchers, representatives from leading organizations, and politicians working on FASD related policy, we explored what efforts and approaches these other countries have made to support adults with FASD and the services that they provide, such as housing, education, and employment services. We conducted 13 interviews across 11 different organizations and conducted ample research on each interviewee/organization prior to each interview.

Figure 10: Team Members Prepping Before an Interview

METHODOLOGY

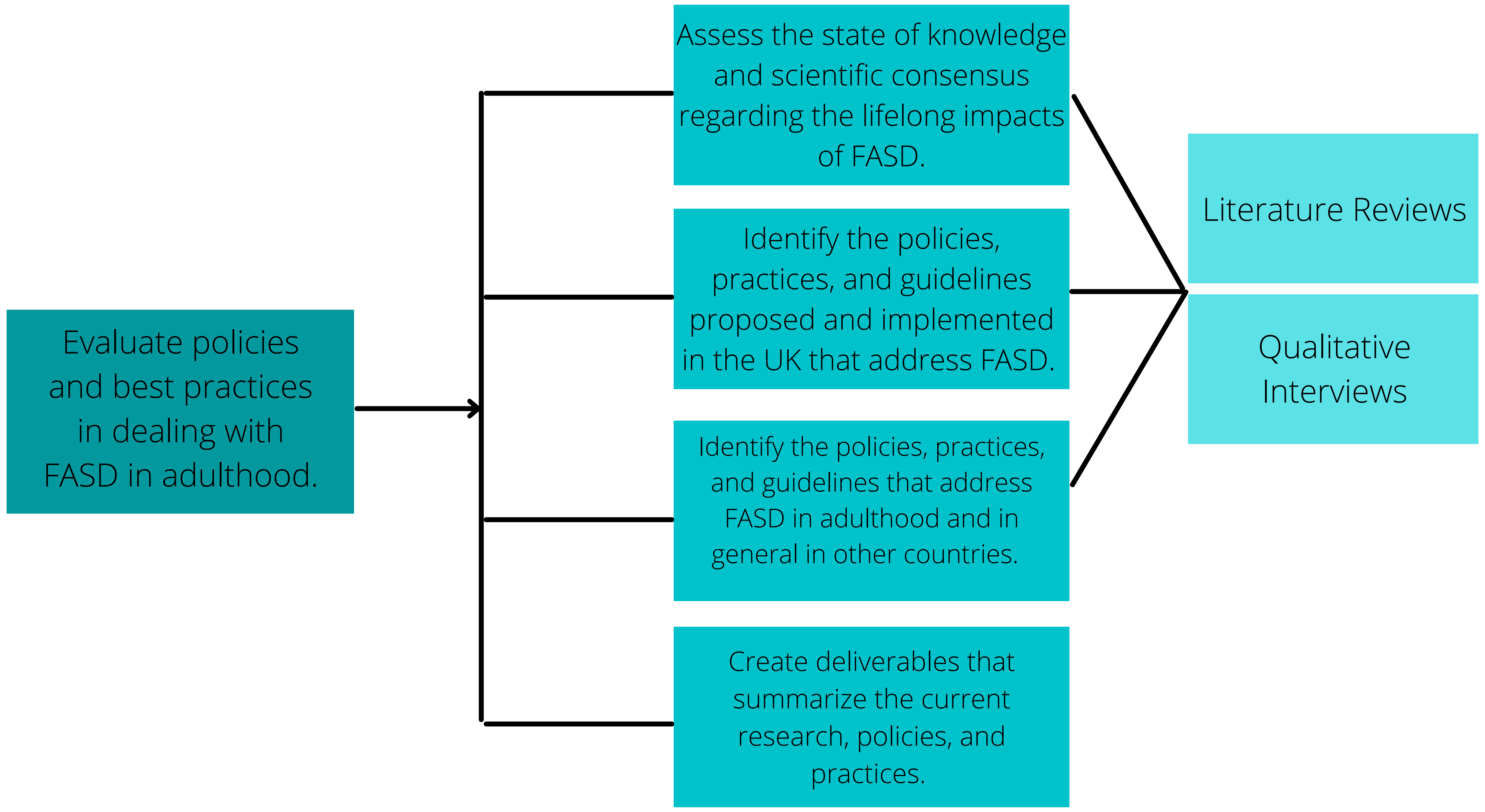

Figure 11: Goals and Objectives

The overall goal of this project was to evaluate policies and best practices in dealing with FASD in adulthood, which will serve as a basis for future policies and programs in the UK. To achieve this goal, the team established four project objectives, each with a set of associated methods described in Figure 11. For objectives 1-3, we conducted extensive reviews of the literature and organizational websites and conducted interviews with FASD organizations, advocates, and researchers in the UK and elsewhere.

Objective 1: Assess the state of knowledge and scientific consensus regarding the lifelong impacts of FASD.

To achieve this objective, we conducted a review of studies, journal articles, organizational websites, and other documents that address specific lifelong impacts of FASD. The long-term impacts that we specifically looked at included:

- How does FASD impact housing/daily living?
- How does FASD impact employment/ education?
- How does FASD impact the transition to independence/adulthood?

We also interviewed four adults with FASD in the UK, which gave us a greater insight into the everyday challenges that these individuals face and what they believe is needed to further support adults with FASD. Under the direction of the National Organisation of FASD, we followed the UK GDPR[5] protocols for dealing with vulnerable groups.

The organization identified participants and sought permission for us to speak with them. We conducted the interviews via Zoom. Our interview preamble, procedures, and our baseline interview questions can be found in Supplementary Materials A (*SM-A*).[6]

Objective 2: Identify the policies, practices, and guidelines proposed and implemented in the UK that address FASD.

Through background research, we identified policies, practices, and guidelines currently in place in the UK. We focused on those designed to raise awareness and provide support to those suffering from FASD or for those who care for them. We also reviewed what the National Organisation of FASD has done to provide support and awareness for FASD by examining their website and completing their online educational courses about FASD.

In London, we attended an event hosted by the National Organisation for FASD, The Time is Now, on March 21st, which focused on increasing prevention, awareness, and support services for FASD in the UK. This event occurred just days after the release of the new NICE Quality Standard on FASD, in which National FASD contributed. The purpose of this event was to identify the next steps needed to keep the pressure on policy makers, so that the momentum gained from the release of the new quality standards was not lost. While the new release was momentous, these documents now need to be operationalized in policies and practices. At the event, several individuals with FASD and those who cared for those with FASD presented very moving, personal anecdotes that gave us firsthand insights into the obstacles people face. These obstacles ranged from prolonged fights with doctors, and health and social services to attain appropriate diagnoses, to the difficulties of securing and maintaining housing and employment.

While there are no policies and few established practices in place in the UK regarding FASD in adulthood, we had intended on interviewing UK organizations such as Mencap, Scope, Mind, and Autistica to see how they were beginning to think about FASD, if at all, and to identify analogues for policies and practices pertaining to other disabilities. Unfortunately, none of the organizations we contacted were willing to speak.

We conducted one interview with an FASD researcher/advocate, who is also a mother to three children with FASD, to discuss why the UK is only now beginning to become aware of the lifelong impacts of FASD and what policies, practices, and guidelines she believes are needed to address the issue. Additionally, in our interviews with adults with FASD, we specifically listened to how FASD policies in the UK, or lack thereof, affect these individuals firsthand.

Objective 3: Identify the policies, practices, and guidelines proposed and implemented in other countries.

While researching the current state of FASD support in the UK, we also identified policies, practices, and guidelines in the United States, Canada, and Australia. We targeted these countries because our initial review and tips from other experts at the National Organisation of FASD suggested that these countries currently have the most developed approaches in addressing adults with FASD.

In order to achieve this objective, we used a combination of literature reviews, a review of FASD organizations' websites and links, and interviews with FASD researchers, advocates, and representatives from leading FASD organizations.

---

5 General data protection regime that applies to most UK; Guide to data protection

6 Supplementary Materials for this project may be found at https://wp.wpi.edu/london/projects/2022-projects-spring/fasd/

Figure 12 shows a visual of our interviewees and where they are located across the world. We conducted the interviews on Zoom and tailored our questions to each person's expertise, knowledge, and interests. Most people involved in FASD organizations have a familial connection to someone with FASD, often their own children; in addition to questions geared toward policy and documented support, we asked the parents for their personal experience with the troubles or worries they have for their children as they approach or have already transitioned into adulthood. We were particularly interested in issues of housing, diagnosis, education, legislation, criminal justice, and mentoring into adulthood services. At the end of each discussion, we asked the interviewees to point us towards other documents and sources on the pertinent topics. The interview preamble, procedures and protocols to be followed, and our baseline interview questions can be found in Supplementary Materials B (*SM-B*) .

Objective 4: Create engaging deliverables that summarize our research.

After conducting background research and interviews, we developed a set of informational resources on FASD in adulthood that could be integrated into the National Organisation of FASD website. The target audience for our deliverable included researchers, UK FASD organizations, and other related professionals that would benefit from this information. We structured the resources to address the major issues of diagnoses, housing, education, mentoring into adulthood, criminal justice, and legislation.

For each category, we synthesized findings from our background research and interviews. We also included links to specific websites or background resources. In addition to these educational materials, we created an annotated directory of professional contacts and organizations.

In the following sections, we present the findings from the literature reviews and interviews. We begin with some first-hand accounts that highlight the lack of support for adults with FASD in the UK. We then explore the current policies and practices in the US, Canada, and Australia in the critical areas of housing, criminal justice, diagnoses for adults, mentoring, education, and legislation. The second chapter of our results includes a brief description of our deliverables, specifically our resource guide of specific services that are provided to adults with FASD from the three countries we identified, which can be found in Supplementary Materials C *(SM-C)*.

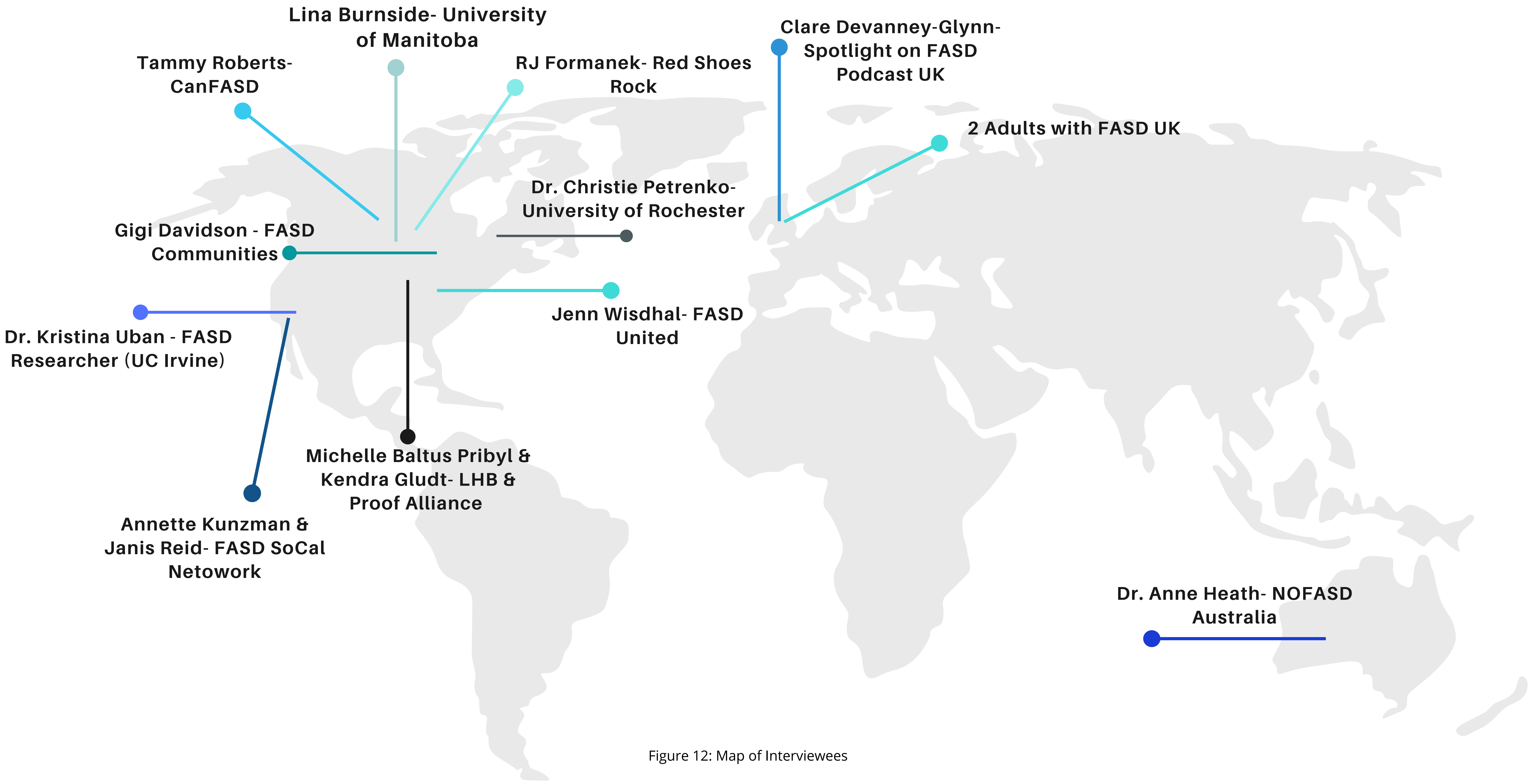

Figure 12: Map of Interviewees

RESULTS

Through our initial background research, we identified the United States, Canada, and Australia as countries that appeared to be more advanced in their awareness and support of adults with FASD. In this chapter we begin by overviewing the FASD organizations we researched in these countries, and we then summarize programs and services they offer in diagnosis, housing, mentoring, criminal justice, education, and legislation/policy proposal.

Overview of Programs in Canada, the US, and Australia

Three Canadian organizations excel in their provision of resources for the FASD community. **CanFASD** is a collaborative research network that works to promote support and information for individuals with FASD, their families, surrounding communities, as well as researchers and policymakers. CanFASD also provides FASD training on their website, with online courses at a small cost to those outside of the country. The **Northwest Regional FASD Society (NWR FASD)** generates FASD awareness in Alberta, Canada by involving communities in various projects that support those affected by FASD: diagnostic clinics, housing projects, and mentorship programs. NWR FASD also collaborates with other organizations, such as **Red Shoes Rock**, to foster visibility and to remove the negative stigma of FASD in the community. Through a hands-on approach, the **Bissell Centre** provides a wide range of supportive housing services to those with FASD. Table 2 shows an overview of the FASD organizations in Canada and their contributions. Additional organizations that are included in the chart but not referenced above are presented in the following sections under diagnosis, criminal justice, and mentoring.

Table 2: FASD organizations and their contributions in Canada.

Organization	Functions/ Contributions	Types of Services/Resources for Adults
CanFASD	A national organization in Canada that promotes education, advocacy, research, and different support systems for individuals with FASD.	The Adult FASD Expert Collaboration Team (AFECT), FASD Guidebook for Police Officers
FASD Justice	The FASD Justice Committee in Canada website provides resources and information about those affected by FASD for justice system professionals.	FASD Justice Comittee
Northwest Regional FASD Society	NWR FASD generates awareness for FASD by educating communities throughout Alberta, Canada by involving them in various projects that support those affected by FASD including mentorship, housing, and diagnostic clinics.	Life Coach Programs, FASD Youth Transition Coach Pilot Program, Mackenzie FASD Adult Diagnostic Clinic
Bissell	Bissell provides a wide range of supportive housing services to those with FASD, these services span from assessing individual circumstances to advice on family living plans and financials.	Permanent Supported Housing, Eviction Support (Community Bridge)
The Asante Center	The Asante Center provides one-on-one as well as group mentorship programs to improve goal setting, money management, and social skills.	Asante Center Group Membership Programs
Edmonton and Area Fetal Alcohol Network	An organization that includes a directory for support specific to adults with FASD in the Edmonton area in Canada including housing and mentorship programs.	Directory of Resources for Adults

The United States has a strong and growing network of FASD organizations, with organizations in more than half of the fifty states. We identified four dominant organizations. **FASD United** acts as a master resource for all the states; it includes general knowledge, resources to be used by caregivers, educators, and individuals with FASD, and acts as a directory for the affiliates in other states. On their site they accessibly link the names, locations, and contact information for the organization affiliates from each state, where to get diagnoses, prevention and treatment, and a plethora of services specific to each state. Of the affiliate network, the three organizations are the **FASD Network of Southern California, the NOFAS Washington State, and Proof Alliance**. These three organizations were chosen due to their abundant information provided on FASD in general as well as their limited, but existing resources for adults with FASD compared to other organizations' websites we reviewed across the United States. **The FASD Network of Southern California** provides an impressive amount of information and resources on FASD for professionals, caregivers, and those with FASD, and is also pushing to pass a California bill which would allow those with FASD to be eligible for special education in schools. Similarly, **NOFAS Washington State** provides extensive information and resources, and is encouraging all schools in Washington to become more FASD aware by providing training. Located in Minnesota, the **Proof Alliance**, like NOFAS Washington State and FASD Network of Southern California, provides extensive resources involving prevention, diagnosis, advocacy, and support for FASD. The Proof Alliance is known for creating a housing guide with LHB Inc.[7] for adults with FASD which outlines methods and plans for ways to help support these individuals in their daily lives to live independently. The Proof Alliance also assisted in promoting legislation that requires all foster parents to receive FASD training every year and that every child who enters the foster care system be scanned for prenatal alcohol exposure in Minnesota. These organizations all have an abundance of resources, yet they are only beginning to discuss and develop resources for adults with FASD. This is progressive in comparison to most other FASD organizations; therefore, these organizations were crucial in our research. Table 3 shows an overview of the FASD organizations in the US and their contributions. Additional organizations that are included in the chart but not referenced above are presented in the following sections under housing.

Table 3: FASD organizations and their contributions in the US.

Organization	Functions/ Contributions	Types of Services/Resources for Adults
FASD United	A national organization in the United States that promotes education, advocacy, research, policy, and different support systems for individuals with FASD.	Advocate for policy to further support adults with FASD
NOFAS Washington State	An organization that provides extensive information and resources, and is encouraging all schools in Washington to become more FASD aware by providing training.	Provides some book resources for adults with FASD as well as location/contact information for Adult FASD evaluation clinic.
FASD Network of SoCal	An organization that provides information and resources on FASD for professionals, caregivers, and individuals with FASD, and is also pushing to pass a bill in California that enables FASD recognition in special education in schools.	Countless resource tabs about common obstacles for adults with FASD on their website.
Proof Alliance	An organization that provides extensive resources involving prevention, diagnosis, advocacy, and support for FASD. With LHB Inc., they also created a housing guide with methods and plans for ways to help support individuals with FASD.	A Place to Call My Own: Housing Design for Young Adults with FASD with LHB Inc.
FASD Communities	A volunteer not-for-profit organization, provides assisted/supported living to adults in the United States.	FASD Housing Communities for Adults

---

[7] LHB Inc. is an architecture and planning company that offers planning, engineering, and architectural services for different types of building projects and programs; they collaborated with Proof Alliance in creating the FASD Housing Guide.

In Australia, the **National Organization of FASD Australia (NOFASD Australia)** supports initiatives across the country that support those with FASD as well as prevention and diagnosis initiatives. Table 4 shows an overview of the FASD organizations in Australia and their contributions. Additional organizations that are included in the chart but not referenced above are presented in the following section under diagnosis.

Table 4: FASD organizations and their contributions in Australia.

Organization	Functions/ Contributions	Types of Services/Resources for Adults
NOFASD Australia	A national organization in Australia that promotes education, advocacy, research, and different support systems for individuals with FASD.	FASD Information Cards for Police Officers
FASD Hub Australia	A website that has information, training, and a directory to find FASD clinics closest to an individual's location.	Directory of locations of FASD Diagnostic Clinics

In the following sections we describe some of the key challenges adults with FASD face, using the experiences of individuals with FASD whom we interviewed. We then describe relevant practices and programs the organizations noted above use to address these kinds of challenges. We address six key areas of support: diagnoses, mentoring, housing, criminal justice, and education. We also note relevant legislation/policy proposals.

Diagnoses

One of the biggest challenges mentioned in our interviews with adults with FASD was receiving a proper diagnosis since diagnosis is essential to qualify for assistance, such as financial help or disability benefits. One of our interviewees explained that it was an eight-year battle to get her diagnosis. Another interviewee explained how “There were two long days of testing, and before we even got [to take these tests] my mom had to fight with my doctor. My general practitioner hadn’t even heard of FASD. My mom had to convince my GP that I had FASD, and after that they were able to send a referral to Doctor Mukherjee. There’s only one location in the UK that specializes in diagnosing FASD.” In the UK, there is only one clinic that specializes in FASD diagnoses, The National Clinic for FASD (https://www.fasdclinic.com), which is in Redhill, Surrey. Testing at this NHS clinic is only free for those living in the Redhill area or for those whose local areas will pay for this service or for those who have partial payment via the Adoption Support Fund. For everyone else, diagnosis tests at this site are over £3,500. There had been one other private clinic, the Centre for FASD in Suffolk, but it has just closed its doors at the end of April 2022. For others seeking local diagnosis, it’s a ‘post-code lottery’. Diagnosis is technical free via the NHS, but few practitioners in the UK are aware of FASD and are unable or unwilling to make the diagnosis. The NICE Quality Standard is expected to begin to change this but the current reality is that for most it is difficult to get access to FASD diagnosis and it’s even more difficult for adults. The SIGN 156 guideline and NICE Quality Standard only focus on children and young people.

In Canada, there are 22 FASD-specific diagnostic clinics that range from Alberta to British Columbia to the Northwest Territories. Diagnostic tests there often cost $3,000-$4,000 (Canadian dollars), which is around $1,000 less than in the UK. However, several clinics such as the Asante Centre FASD clinic works with donors to find continued funding to keep assessment costs to a minimum. In Canada, exact costs for an assessment are not determined until the client completes the initial referral process. The Northwest Regional FASD Society also started the Mackenzie FASD Adult Diagnostic Clinic, which provides adults with assessments and diagnoses. These assessments are intended for individuals who have transitioned to adulthood but have not yet received a diagnosis. Because this adult clinic collaborates with local and regional bodies including North Peace Tribal Council CFS, medical centers, nursing stations, and their local probation office those who need a certified diagnosis by a certain date can get it in a timelier manner, rather than having to wait years to receive their diagnosis. As of 2017, the costs associated with the clinic are covered by the NWR FASD Society.

In Australia, the FASD Hub website provides locations of all clinics and services that provide FASD-specific assessments and diagnoses. There are currently 17 FASD assessment clinics in Australia including both private and public clinics. While Australia is geographically larger than the UK, its population is far lower, and while testing costs vary, tests that are received through the Australian public system are free. If a test is administered through a private practice, depending on the individual's Medicare plan, parts of the costs may be covered.

In a recent update from the University of Washington’s FASD Diagnostic and Prevention Network, approximately 150 providers or hospitals were listed that do occasional FASD diagnosis or have someone that knows about FASD and how to diagnosis it (Clinic Locations Nationwide, 2021). While the number of clinics that focus specifically on FASD diagnoses is lower, it is still greater than the single clinic in the UK that diagnoses FASD. Additionally, on the University of Washington’s FASD DPN website, they list, by state, which clinics that have been trained to use the FASD 4-Digit Diagnostic Code and also list the contact information for each clinic.

Compared to the UK, individuals with FASD in the US, Australia, and Canada have access to more FASD clinics, and the costs for their diagnostic tests are often covered more easily. Adults in the UK should not have to endure long battles or drive thousands of miles to get a diagnosis. The UK would also benefit tremendously from having an FASD clinic tailored to adults, similarly to the adult diagnostic clinic in Canada. Increasing the number of FASD clinics under the auspices of the NHS would allow individuals in the UK to have greater access to more affordable diagnostic tests. Key findings for this section are described in Table 5.

Table 5: Help With Diagnosis Key Findings

Key Findings
• Costs for a diagnostic test in the Canada and Australia are relatively cheaper than in the UK. • Canada and Australia have a much larger number of FASD specific clinics, which allows for greater access to FASD diagnoses and assessments. • Canada has a FASD diagnostic clinic, specifically catered for adults. • Through various collaborations, these clinics can give individuals their diagnosis in a timely manner for those who need a certified diagnosis by a certain date, compared to the UK where many wait years to receive a diagnosis.

Mentoring

One of the most difficult parts of becoming an adult with FASD is learning to live independently. When we asked adults with FASD what they believe could have helped them during their transition to adulthood, all three interviewees emphasized social care support, specifically a social care worker or mentor who would have been there to support them throughout their transition. People affected by FASD have difficulty with assessing risk and decision making, and often have trouble with tasks such as handling finances or applying for and keeping jobs. Therefore, mentorship programs for transitioning into adulthood and beyond could be life changing to some. We interviewed an individual in his 30s with FASD and he said that during his transition into adulthood he was homeless, became addicted to alcohol, and wound up in prison. He did not have a mentor to counsel him or help find resources such as mental health services or housing support. A mentor is someone who will not only check in but will also help with everyday advice.

We identified various mentorship opportunities and programs in Canada. These include:

- **Life Coach Program: NWR/CanFASD;**
- **FASD Youth Transition Coach Pilot Program: NWR/CanFASD;**
- **The Asante Center Membership Programs;**
- **The Edmonton and Area Fetal Alcohol Network; and**
- **'My Health Coach,' an Adult Health App by Dr. Petrenko and team.**

NWR-FASD offers multiple programs that support individuals with FASD. The Life Coach Program provides help with education, health, employment, and many other things. This is for anyone 18 years and older as opposed to the FASD Youth Transition Coach Pilot Program which focuses on ages 16-22. This program targets the transition phase into adulthood. The individuals with FASD are partnered with a mentor who meets with them four times a week and advises them on housing, services, healthcare, and medical needs, treatment for addictions, healthy lifestyle choices, continued education, and goal planning with follow through.

The Asante Center Membership program offers one-on-one mentorship as well as a group mentorship program located in Surrey, British Columbia for those diagnosed with FASD, ages 13-30. This one-on-one mentorship program focuses on teaching someone with FASD about FASD, their diagnosis, and how this can affect them in everyday life, as well as helping support them by creating life goals that they want to achieve. The group mentorship program allows for individuals with FASD to connect and develop leadership and social skills while also providing the same support as the one-on-one program. Individuals with FASD can sign up for these mentorship programs on the Asante Center website where they will be connected with a mentor via email. This program was funded by Coast Capital Savings and is continuously accepting donations.

Edmonton and Area Fetal Alcohol Network is a directory of resources for those affected by FASD as well as their families and caregivers. They have a section specific for adults that includes the Bissell Housing as well as two mentorship services provided by Catholic Social Services and LEDUC County. The Catholic Social Services provides mentorship programs for those transitioning into adulthood, adults, and those parenting and affected by FASD. This includes help with banking, getting groceries, budgeting, problem solving, and crisis intervention as well as connecting them with services that provide things such as housing. The LUDUC County mentorship also involves a lot of similar services. This is a great resource for those who are looking for services in the area and would be useful for those in the UK who are looking for services provided near them. Individuals can qualify if they are diagnosed with FASD and can call to make an appointment. These services are free and funded by Edmonton and Area Fetal Alcohol Network.

In addition to person-to-person mentorship programs, we identified a unique virtual chatbot app under development in the United States. Dr. Petrenko and her team are in the process of creating a health app designed for adults with FASD. This app will act like an assistant, helping the person monitor their health and keep daily tasks on track. It uses a chat bot interface, which is essentially like texting, and it will help adults with FASD with remembering/tracking information. The chat bot will ask the user questions, and based on the response, may suggest different tools within the app so the user does not have to worry about navigating or finding tools within the app. This project is in partnership with a group of adults with FASD from the Adult Leadership Committee (ALC) of FASD Change Makers, which allows them to have direct input on the design and functionalities of the app. The ALC have shown in their own research with their peers that memory problems greatly impact the quality of life of adults with FASD. This finding was also confirmed by all the adults with FASD we interviewed who all listed their poor memory as one of their biggest obstacles.

In the United Kingdom these kinds of mentorship programs or social care workers are not currently available specifically to those affected by FASD in adulthood. Incorporating mentorship programs into the UK would be beneficial during the transition into adulthood and beyond. In our interviews with those affected by FASD, including one parent of children with FASD, a common theme has been the need for regular check-ins and help with setting goals, keeping up health, finding and keeping employment, managing finances, and much more. The key findings for this section are described in Table 6.

Table 6: Providing Mentors for Adults Key Findings

Key Findings
• Unlike the UK, there are specific mentor programs for those with FASD who are transitioning through adulthood. • The US and Canada offer individual and/or group mentoring services for individuals with FASD as they transition into adulthood as well as after they reach adulthood. • Mentoring programs help with a range of things including: developing social skills, grocery shopping, budgeting, crisis intervention, accessing benefits, setting life goals, finding employment, addressing medical needs, and treatment for addiction. • In the US, a health app designed for adults with FASD is the process of being created. This app will help individuals with FASD monitor their health and keep daily tasks on track.

Housing

Housing services are needed for adults with FASD so that these individuals can successfully transition to living independently, while still receiving the support that they need. In the UK, there is no housing support designed specifically for those with FASD, yet often these individuals are unable to live independently without having someone to rely on, such as a parent or significant other. In Canada and the United States, we have identified several housing services/housing support guides for adults with FASD.

The housing services we have identified include:

- **FASD Housing Communities for Adults in the US;**
- **A Place to Call My Own: Housing Design for Young Adults with FASD –Proof Alliance and LHB Inc.;**
- **FASD Permanent Supported Housing – Bissell Centre; and**
- **Community Bridge (Eviction Support) – Bissell Centre.**

FASD Housing Communities for Adults, which is a volunteer based not-for-profit organization, provides assisted/supported living in Platteville, Wisconsin to adults in the United States. These homes house five tenants each. Each tenant has their own bedroom, along with a shared communal space. To qualify, an application must be filled out and the applicant must be over the age of 21. Individuals from anywhere in the US can apply. Once the basic application is submitted, a more in-depth application is conducted after. This includes calling parents and individuals to learn more about their life struggles, interests, and medications. Once this screening is complete, if the individual seems to be a good fit, they are admitted. Currently, as of 2022, the cost to live in these homes is $4,500 a month. FASD Housing Communities is funded by many donors from across the United States. For those who are unable to live safely on their own, FASD Communities provides these adults with a community and home, while also making sure that they are cared for by staff who are trained in FASD. These staff members are also available to these individuals 24/7. This community gives adults with FASD the opportunity to achieve their highest potential by allowing them to gain a sense of responsibility and collaboration. Adults with FASD deserve the right to happy and productive lives. This housing community has become a model for what types of care are needed to support adults with FASD who can no longer live at home. One parent whose daughters are residents of this community said, "We are happy that we have found the right fit and our daughters are happy living in a structured and protected environment with kind and caring staff and want this to be their 'forever home'." (About-FASD, 2018). This not-for-profit organization helps these individuals attain paid employment and also allows these individuals with FASD to develop life skills, such as preparing dinner, while providing continual support.

Proof Alliance and LHB, Inc., in the US, have also recently developed a housing design guide for young adults with FASD. This housing guide provides design principles for housing for young adults, and design prototypes for dwelling units and building layouts for different living situations- with varying building sizes, and unit types. The housing prototypes were designed based on feedback from young adults with FASD, their caregivers, and service providers. While this guide was created for organizations who develop supportive housing for individuals with FASD, this guide will also be useful for caregivers or individuals with FASD who already have housing. For those who already have housing, this guide shows how they can modify their current housing. Figure 1 visualizes a design for an apartment for a young adult with FASD. From figure 1, you can see that many factors were considered when designing this apartment. For example, individuals with FASD may suffer from memory challenges. In this apartment design, there are labels on cabinets to help these individuals remember where items are as well as a whiteboard for reminders and lists. Electric stoves are also recommended over gas stoves because they eliminate combustion safety issues of gas stoves. Because individuals with FASD may also be sensitive to sensory stimulation, LED lighting is encouraged because it eliminates lighting noise, compared to fluorescent lights, which have ballasts that can make humming sounds. In our interview with Michelle Baltus Pribyl, senior architect at LHB who led the team creating the design guide, she explained how the housing guide was intended to address a spectrum of needs of young adults with FASD and each design considered lifelong needs such as sensory issues, memory, and safety. This housing guide can serve as a valuable tool when creating effective housing designs that will enable young adults with FASD to succeed.

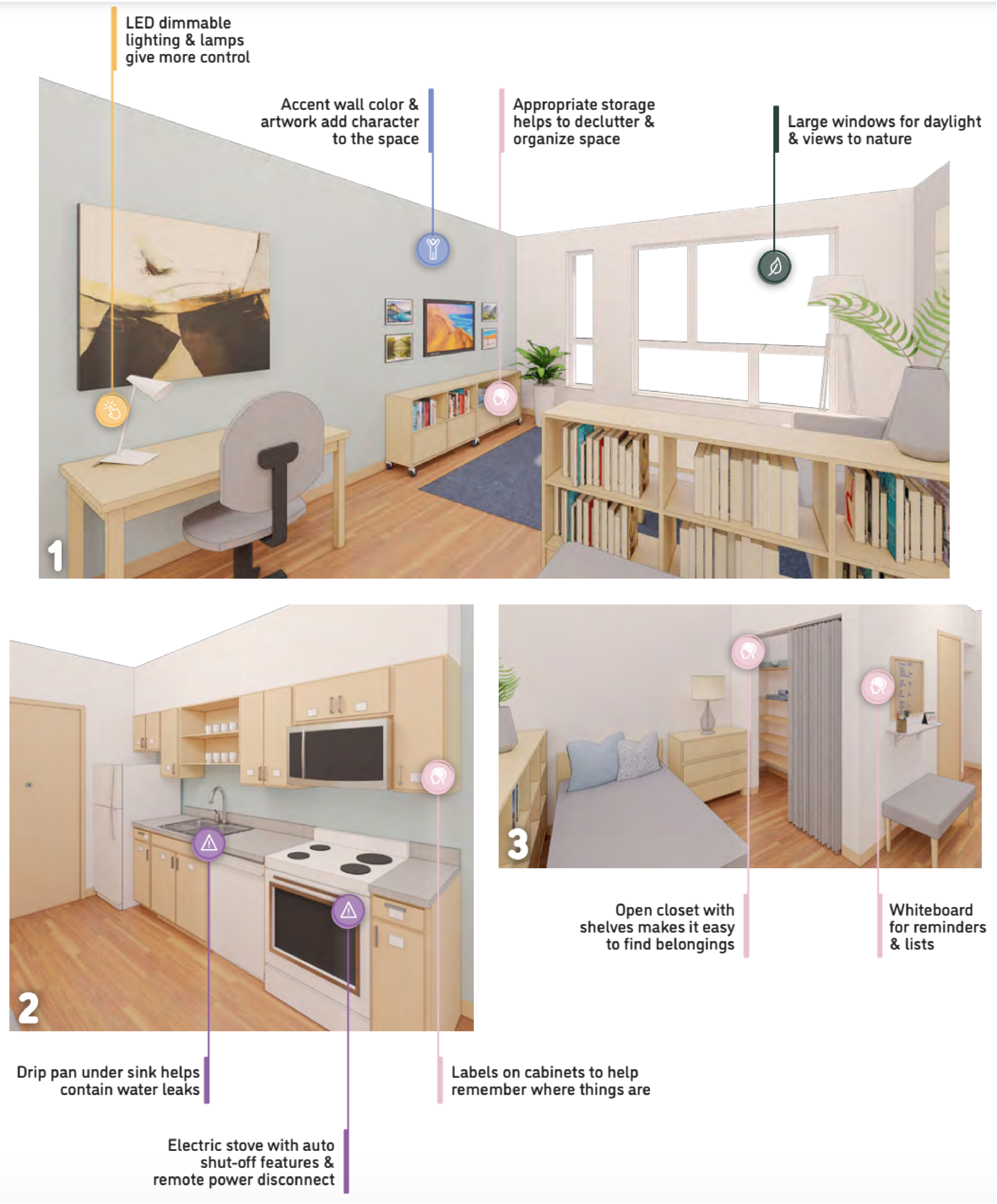

Figure 13: Design Prototype (Proof Alliance & LHB Inc., 2021)

In Canada, Bissell Centre, provides permanent supported housing for adults with FASD. The apartment complex, owned and operated by Homeward Trust, provides 24-hour support for their tenants and is in Edmonton, Canada. This program is funded by Homeward Trust, who receives funds from all three levels of government, the private and not-for-profit sectors, as well as from various donors across Canada. The program currently has five single rooms and nine double room suites that cost $800-$1000 a month depending on whether it is a single or double room. To qualify for the program, the individual must be over the age of 18 and must submit a Permanent Supportive Housing form to Coordinated Access at Homeward Trust Edmonton. If the application is approved, the applicant is contacted by PSH case management team who will assist them in moving into the facility. In Canada, Bissell's permanent housing is also the first facility in Canada to provide 24-hour support services and care for individuals with FASD. Through interviews, we learned that for housing services to succeed for adults with FASD, these individuals need to receive continued support from staff who are trained and educated on FASD. The Bissell staff are not only trained and equipped to support those with FASD, but also provide other services, such as assistance when attending medical appointments or court appearances. The staff are available to these individuals 24/7, 365 days a year. The apartment complex also has an occupational therapist and a mental health coordinator to provide tenants with somebody to talk to about mental health, trauma, and harm reduction.

Along with providing supported housing, Bissell Centre also provides eviction support for adults with FASD (also referred to as Community Bridge). Community Bridge is a fast action intervention plan that provides support to stop an eviction or foreclosure. After filling out an application, the individual is contacted by a worker to provide documentation and to schedule an appointment. After attending the appointment, if an individual is eligible for the loan, the application is approved, processed, and a check is mailed to the creditor. Bissell staff also check in on the individual 1, 3, and 6 months after the check is received to see how they are doing and to provide additional support if needed. This program aids adults with FASD by helping them to keep their current housing by urgently addressing their needs. Along with providing checks, Community Bridge also provides services such as financial planning, help with creating a budget, and support in negotiating with landlords. Like the permanent supported housing, the eviction support is funded by donations to Bissell Centre, along with their various donors.

Adults with FASD in the UK need a place to turn to and resources when they can no longer live at home, want to try living independently, or need support if they are at risk of losing their housing. These four resources may serve as a model or reference for future housing services, support, and initiatives in the UK. The key findings for this are described in Table 7.

Table 7: Housing Support Key Findings

Key Findings
• The United States and Canada provide permanent housing for adults with FASD. • In Canada, one organization provides eviction and landlord negotiation support. • These housing programs group adults with FASD, having them share homes or live together in the same community. • Other forms of support/living assistance, such as learning to prepare dinner or assistance when attending medical appointments and court appearances are available through these programs. • Homes, bedrooms, or apartments can be redesigned to taken into account certain effects of FASD such as safety, memory loss, and sensory sensitivity.

Criminal Justice

Individuals with FASD have trouble with things such as assessing risk, executive functioning, confabulation[8] and processing. These as well as many other factors can affect an individual's ability to assess risks and dangers or resist the influence of those who may lure them into crime. They may also make voluntary statements without recognizing the implications that this could have. It is important for those who work in criminal justice to be aware of these effects and to take them into consideration when individuals with FASD are being accused, the victim, or the witness. We have identified resources in Canada and Australia that address criminal justice for those with FASD. These include:

- **FASD Justice Committee;**
- **FASD Guidebook for Police Officers: CanFASD; and**
- **Information Cards for Police: NOFASD Australia.**

The FASD Justice Committee in Canada website provides resources and information about those affected by FASD to justice system professionals as well as others interested. The website outlines the effects of FASD and how to recognize it and provides information on criminal justice, policing, corrections, civil justice, Indigenous people, and case law. More specifically they refer to Diversion and Specialized Courts which allow the accused to go through programs to receive a shorter sentence than they would have originally received. These options will allow for an individual with FASD to have charges dropped in some cases after diversion requirements such as education and community service are completed. The success of these can depend on the support and understanding of the community as well as arguments presented. Overall, this website is a great resource and provides understanding to those in the justice system that are unfamiliar with FASD.

In Canada, the FASD Guidebook for Police Officers provides information for police officers on FASD and how to approach an investigation dealing with an adult who has FASD. The guide also helps officers recognize the impacts of FASD by providing information pertaining to common characteristics of FASD. For example, when conducting interviews or taking statements, the guide suggests that officers remember that FASD individuals have severe memory impairments, therefore all interviews/statements should be recorded. It is imperative that front-line workers, such as police officers, are educated and aware of the effects of FASD, so that they can conduct their investigations more effectively, while making sure that appropriate accommodations are made.

Police officers and first responders need to be aware of the common behaviors of individuals with FASD, so that they can work with them effectively. There are many cases where those with FASD admit to crimes that they were not involved in because they can be easily manipulated and have trouble recalling events due to memory disability. To prevent this, NOFASD Australia created wallet-sized cards that can be carried by individuals with FASD, as seen in Figure 14. These cards can be handed to the police officers to inform them that this individual has a cognitive impairment and cannot "knowingly waive legal rights."

To learn more about FASD visit:
www.nofasd.org.au

Police Information Card

I have a brain disorder, like Autism, FASD and Acquired Brain Injury, causing cognitive impairment.

Because of this, I may not understand concepts such as legal rights. I could be persuaded to admit to acts that I did not commit. I am unable to knowingly waive any of my rights.

I do not wish to talk to police officers without a lawyer.

My name is: ……………………
For information or assistance please contact:
Name: ……………………
Phone: ……………………

Figure 14: Police Information Cards (NOFASD Australia, 2022)

---

[8] Recalling details or events that did not happen without intentions of deception.

It is important for services like these to be translated to the UK because it will allow for further support and representation for adults affected by FASD. Educating the police and justice system about FASD and how this can affect an individual's behavior is essential for these individuals to get the support they need when being faced with a justice scenario whether they are the accused, a victim, or a witness. These services can also benefit police officers by allowing them to conduct interviews or take statements more efficiently because they will understand the common behaviors of an individual with FASD and how to better approach the situation. It is also important for justice system professionals and police force to feel and be better informed in order to respond properly. The key findings for this section are described in Table 8.

Table 8: Criminal Justice Key Findings

Key Findings
• Canada provides information for police officers as well as justice system professionals in how to approach a situation or investigation more effectively with an individual with FASD. • Canada also provides information on diversion and specialized court options for individuals with FASD. • The FASD Guidebook for Police Officers also helps officers recognize the impacts of FASD and how to recognize it in an individual. • Australia provides police cards for adults with FASD so that if they run into trouble police officers the officers know that they have a cognitive impairment.

Education

For adults with FASD to be supported, it needs to begin in early education. All the adult individuals as well as parents we interviewed thought that if they were given the correct support while in school, it would have helped them throughout their lives and as they transitioned into adulthood. One adult recalled that “school was horrendous, but I didn’t get the support I should have so my grades were G’s and F’s.” This individual expressed how they believed if they were given assistance in various aspects of their learning, such as extra accommodation for assignments or increased teacher assistance, school would have been an easier and more effective place. Although these are older adults with FASD speaking about their experiences in the past, these issues comparatively still occur today in the UK. We asked a mother of three children with FASD what she has learned from being a parent to children with FASD and in a similar trend she responded that “education, as it stands now in the UK, is a harmful place for kids with FASD”. When children are not properly assisted in school, it can not only be a difficult learning environment, but also a frustrating one. Jenn Wisdahl, the policy and training center coordinator for FASD United, elaborates on the importance for FASD inclusion for special education, “you might think that that doesn't impact adults, but the school experience can be really traumatic if you are not understood and accommodated, and a lot of mental health concerns develop as a result of that, so having that in place really will have an impact.” While early education does not have an immediate or direct impact on adult life, it does set a foundation for a child’s growth and development, which is why children with FASD need to be provided with the help they need.

There are forms of disability support that already exist in most education systems around the world, such as special education, but those with FASD are often asked to fit inside a generic disability description, when in reality, their struggles go above and beyond what is already set in place. Those with FASD struggle with following directions, paying attention, having impulsive behaviors, poor memory, and math skills, all of which impact their educational experience. For individuals with FASD to excel in the real world, they should not be expected to try to fit a preexisting mold, rather, their learning environment should adapt to what will make them the most successful.

Individualized Education Program

A common obstacle within the United States for families affected by FASD is attaining an Individualized Education Program (IEP) for their child with FASD. This is because in almost every state, FASD is not recognized as a disability under any of the special education screenings for children; this leads to incorrect support, or lack thereof, which evidently results in poor academic performance which in turn leads to further negative effects down the line. In most states, children with FASD are misdiagnosed as having other learning disabilities and thus they do not receive the right kind of special education support tailored to FASD. Wisdahl explains what needs to be done for support in education and discusses the common problem within the United States' current educational accommodation plan for individuals with FASD: “The mechanism for support for individuals with FASD should be to change the [learning] environment and support so that the person can be successful and focus on their strengths, as opposed to trying to get them to fit into a mold that currently exists.” Wisdahl elaborates on the fact that the education system, as it is now, depends on the individual to adapt to what currently exists, when those with learning disabilities should have accommodations made for their own learning habits. Examples of support for children with FASD in schools could be modifying the curriculum for easier comprehension, using more visuals, reinforcing routines, and reorganizing the physical space to account for auditory and visual sensitivities.

In just the states of Alaska and Minnesota, FASD is recognized as a disability under the “other disabilities” category to enable qualification for the correct support needed in schools. Following the same path, California is in the process of passing SB1016: Special Education Eligibility for Fetal Alcohol Spectrum Disorders. This act would require FASD to be included as a named disorder under the “Other Health Impairment” category for IEPs by the California Department of Education. Having FASD recognized would improve the quality of education for those with FASD and provide the correct forms of support needed for their disability.

Following the correct forms of support for personal special education plans specific to FASD in schools will be the need to train the teachers and staff and to increase overall awareness. Teachers need to be FASD trained for these education plans to be fully effective. In the Canada education system, FASD is identified as a disability under special education, therefore children in need of support in school have it on paper, but when it comes to effectiveness, that is where the line stops. Although FASD is recognized as a separate disability with its own needs, teachers and staff are not properly trained in FASD which results in poor educational support for children with FASD. So, while this recognition of FASD in the special education system is important, it is just as important for educators to be trained for complete effectiveness.

Children granted IEPs in the United States are also given a transition planning period to prepare for further education, employment, or independence if possible. This transition period covers an individual until the age of 21 and focuses on improving academic and functional achievement. Unfortunately, this transition plan is not very well known, so it is not taken advantage of as often as it should be.

Identification of FASD in the special education system will inevitably lead to societal awareness. To promote awareness, NOFAS Washington in the United States is taking initiative to work with all the school districts throughout Washington state to become FASD aware by providing schools with training and support. This type of action will set children with FASD up for success as they are able to grow from personalized help but also in a more aware society that is cognizant of the limitations and obstacles due to FASD.

When we asked the adoptive mother to three what she thinks needs to be done to increase overall FASD awareness in the UK she said "I think it needs to just become part of our absolute, normal, everyday narrative. Going back to early school and with girls. And in secondary schools, because as a female growing up, I absolutely had no idea what alcohol consumption would do to my baby if I was pregnant." Bringing FASD awareness into schools at a young age will not only help with potentially identifying it in students, but also will teach children at a young age the effects of drinking while pregnant from their peers. This type of early implementation will help remove the stigma surrounding FASD many adults experience.

Recognizing FASD as an individual disability with its own needs within schools will significantly benefit those with FASD in the UK. The UK's Education Health Care Plan (EHCP) and/or IEPs would work in the same manner; FASD should be acknowledged as unique disability in the special education system followed by the need for teachers and educators to be provided with FASD training to permit effective support for children with FASD. A simple change of recognition and designed support for FASD will have endless positive advantages for individuals with FASD as they grow older.

While there are growing resources for FASD regarding IEPs in the United States and beginnings of programs elsewhere, there is nothing pertaining to adult education. If an individual with FASD wanted to further their education by attending higher education[9], assistance is needed to complete those degrees. EHCPs are designed to extend to support young adults with FASD in education through age 25, and include supported internships, but few are able to access this. Janis Reid, a board member of the FASD Network of Southern California, has an adopted son with FASD. She shared his struggle with maintaining his education at a community college due to the deficiency of support: "He registered for five semesters and failed each one. And that was sad to us because the support both in high school to get him ready and the in the community colleges to receive him and give him the support were just not there". This saddening story is unfortunately one experienced by many families affected by FASD. Assistance in education needs to be implemented early on and continued to higher education to allow individuals with FASD to live their life without limitations. Both IEPs and EHCPs allow for the extension of support to continue from younger age until ages 21 and 25 respectively, so there is the capacity for this support to exist, it is just a matter of providing teachers and staff with the correct training and tools to do so. The key findings for this section can be found in Table 9.

Table 9: Education & Individualized Education Key Findings

Key Findings

- Individualized Educations Programs (IEPs) are often hard to obtain in the United States because FASD is not listed as a disability in most special education plans, therefore it is hard to qualify for support.
- Alaska and Minnesota are the only states where FASD is identified as a disability under special education
- The state of California is in the process of passing a Special Education Eligibility Act (SB:1016) to include FASD as a unique disability.
- While Canada recognizes FASD as a disability under special education, their teachers are not trained in FASD, so children with FASD still do not receive the correct support they need.
- NOFAS Washington State has an initiative to make all schools across the state more FASD aware by providing training and tools to teachers, staff, and students upon request.
- IEPs and EHCPs can be continued on through the ages of 21 and 25 respectfully which can cover the transition into adulthood, but it is not taken advantage of.
- There is no support for higher education, or adult education.

Legislation and Policy Proposal

Many of the programs and practices described above have been created in an ad hoc fashion at the urging of non-profit advocacy groups, but they lack codified and comprehensive support and funding through formal legislation and government policies. Currently, none of the countries we examined have passed formal legislation at the federal or state level, but several are moving in that direction. The United States is the farthest ahead in this development with two acts of legislation in process, one at each state and federal level, that are being pushed to support those with FASD. Only the United States has pushed for federal legislation at this point, so this section will primarily focus on those efforts.

The FASD Respect Act is the latest line of proposed legislation which has evolved over the past 19 years and is finally coming closer to fruition and gaining support. The push for this legislation can be seen in the efforts made by individual FASD organizations across the country. This act, which is currently introduced to both the House of Representatives and the Senate, has 39 cosigners, which is the most support they have had in the House in the past 19 years. The FASD Respect Act provides funding for adults in terms of employment support, housing support, and training for mental and medical health professionals. This is monumental for the United States because the funding goes directly towards services for adults with FASD, as opposed to the current government funding which is strictly for research and surveillance. The passing of the legislation will increase nationwide funding for research revolving around FASD and will also provide funding for states to further their individual projects and initiatives.

When we asked Jenn Wisdahl from FASD United what the largest benefit is of passing the Respect Act passed, she responded: "I think it's visibility. I think it is confirmation within existing systems that their experience is real. Just some validation that we are here and it ‘s real." Similarly, Dr. Kristina Uban, an assistant professor at University of California Irvine whose research utilizes multi-modal neuroimaging to focus on the impact of prenatal exposure to alcohol for cognitive and mental health problems, believes adults with FASD are most adversely impacted by "Being stigmatized. Misunderstood, not cared about. Not supported in the way that they need to be supported. Feeling like they're not heard, feeling like they're less than." The FASD Respect Act will provide recognition for the FASD community as well as formally making the distinction between FAS and FASD.

This act has evolved over the past 19 years through nine different versions of the bill. Just about a few years ago, the entire bill was rewritten with additional focus on support for individuals living with FASD and particularly for adults. Wisdahl commented on this shift in focus, "this is key because as much as there are limited resources for kids, there is comparatively nothing for adults." She expresses the importance of this shift in policy but also exploits the lack of support for FASD overall. When discussing available resources and legislation for supporting adults with FASD, Dr. Uban commented in the same fashion that "we are so focused on supporting children, which we do a really great job of, at the bare minimum, it's not even a band aid, but then there are adults, and there is totally nothing."

Until this recent rewriting of the Respect Act, the nine previous editions were known as *Advancing Research Prevention and Services Act for FASD*. Wisdahl noted how "research" and "prevention" came before "FASD," which is why the recent version of the act put "FASD" before any other word. Wisdahl explains that the time, effort, and energy geared towards prevention will now be focused on adults living with FASD "will make a change of how people with FASD are visible in our community. And we are actively working to support them, so prevention will follow naturally because people are going to know more about the disability, and it is not going to be this stigmatized thing."

Currently the state of New York is trying to pass a new piece of legislation to add FASD to the list of developmental disabilities recognized in the state. If this amendment passes it will allow more people with FASD to access developmental disability services—potentially housing support communities, habilitation support, respite for caregivers, or recreational activities. Dr. Petrenko commented that "there are a lot of co limitations in our current developmental disability system, but this is a start. At least those affected by FASD will be eligible now. It is a step in the right direction because right now very few can get those services." Again, the simple recognition of FASD as a disability will open the door to many supportive services and tools to help assist those with FASD. In the UK, the DHSC FASD Health Needs Assessment said that "The Government recognises the importance of FASD.", which is a major step.

---

[9] School after secondary school (high school). Either attending college, a university or community college.

Another important form of legislation that could be used as a model for legislation around the world was passed in Minnesota in 2021. This legislation passed requires all children entering the foster care system to be screened for prenatal alcohol exposure as well as foster parents to be trained in FASD. Proof Alliance provides all the training and screening tools. This legislations was created in the hope of establishing early identification of FASD as well as family preparation. Dr. Uban explained a similar mandate has been proposed in Los Angeles, California. While Dr. Uban wishes the California legislation included the same provisions for foster screening and training as in Minnesota legislation, this new mandate requires all social workers to be FASD trained as well as those involved in the placement process of foster care. This training is being done by Doctor Kathy Page and colleagues throughout the LA county. While this does not directly impact adults, the legislation and mandate both are proactive in the identification process and will enable those affected with FASD to earlier diagnosis and treatment.

NHS England similarly said in their statutory guidance from 2015, P*romoting the health and well-being of looked-after children*, that prevalence of FASD in looked-after children is higher and should be considered, but it is not regularly done (NHS England, 2015).

Minnesota also recently passed another form of legislation that does not require mandated reporting of prenatal alcohol use by pregnant individuals to child protection services. This legislation will remove the stigma directed towards mothers who have prenatal alcohol exposure and will make them more open to discussion with their doctors. Mothers are typically afraid to report alcohol exposure to their doctors in fear of losing their child, so this non-required reporting to social services mandate will create a more open dialogue and get the mothers the prenatal care they need during pregnancy to assist the fetus. Dr. Uban shared her ideas on a harm reduction model as opposed to prevention model: "For the last 50 years, we've been overly focused on prevention, and that leads to stigma-- shame towards the mom for being able to prevent this. So, the harm reduction model would suggest not having stigma. As soon as you learn you're pregnant and you're aware that substance exposure could impact your pregnancy, you can have an open dialogue with your care providers about it. The care providers feel okay asking about it and then can give the mothers tools to help the pregnancy." Again, while not directly impacting adults, this legislation is proactive in getting individuals who may have FASD the help they need before it is too late, as well as removing the stigma surrounding FASD. There is no mandatory reporting of AEP to social services in the UK. The NICE Quality Standard does advise stigma-free discussions with pregnant women and that alcohol exposed pregnancies are noted in maternal records, as this is important to help with diagnosis later if needed. The key findings for this section can be found in Table 10.

Table 10: Legislation/Policy Proposal Key Findings

Key Findings

- The United States has the most legislative efforts regarding FASD currently.
- The FASD Respect Act will provide funding for adults in terms of employment support, housing support, and training for mental and medical health professionals. This is different than the current government funding in the US which is strictly for research and surveillance. The FASD Respect Act will also provide individual funding per state.
- New York is trying to amend the Mental Hygiene Law to include FASD as an identified developmental disability.
- In 2021, Minnesota passed pair legislations that required all children entering the foster care system to be screened for FASD and requires all foster parents to be trained in FASD. Proof Alliance provides all screening and training.
- LA County has a similar mandate where all social workers and those involved in the placement process for foster care are required to be trained in FASD. Doctor Kathy Page and colleagues provides all the training.
- In 2020, Minnesota also passed a legislation that does not require mandated reporting to social services of prenatal alcohol use by pregnant individuals.
- DHSC FASD Health Needs Assessment said, "The government recognises the importance of FASD."

An overview of the practices and guidelines in Canada, the United States, and Australia that address FASD into adulthood are shown in Table 11.

Table 11: Practices and Guidelines in Canada, United States, and Australia that Address FASD into Adulthood

Area of FASD in Adults Addressed	Diagnosis	Mentoring	Housing	Criminal Justice	Education	Legislation and Policy Proposal
CanFASD		✓		✓		
Bissell			✓			
NWR FASD Society	✓	✓				
FASD Justice				✓		
The Asanate center	✓	✓				
Edmonton and Area Fetal Alcohol NetworkASD United		✓				
FASD United						✓
NOFAS Washington State					✓	
FASD Network SoCal					✓	✓
Proof Alliance			✓		✓	✓
FASD Communities			✓			
NOFASD Australia				✓		
FASD Hub Australia	✓					

DELIVERABLES

Our final deliverable for this project was a resource guide listing organizations and programs in the US, Canada, and Australia that address housing, diagnoses, mentoring challenges for adults with FASD, and education. The guide also provides links to policy proposals/legislation, as well as other resources that we identified organized by country- US, Canada, and Australia. We provided a brief description of the resource along with a link to the source. By identifying what forms of support are provided for adults with FASD in other countries, our guide can be used by the National Organization for FASD in their endeavors to develop and advocate for support for adults with FASD in the UK. Our resource guide can be found in Supplementary Materials C (*SM-C*), and it can be updated and edited for accessibility as National FASD sees fit in the future.

We also created an excel spreadsheet with professional contacts and organizations that we identified through interviews and research. This list will allow the National Organization for FASD in the UK to network with organizations, researchers, advocates, or political staffers in the United States, Canada, and Australia allowing for the possibility of collaborative projects that aim to increase support and awareness for FASD in adulthood.

CONCLUSION AND RECCOMENDATIONS

While most believe that FASD is a childhood disease, this disorder has long-term effects that resonate throughout adult life. In the UK, there is a lack of awareness of and support for adults with FASD. Lack of support heightens these individuals' risk of trouble with the law, unemployment, struggles with education, poor social interactions, and various mental health issues. To aid the National Organisation for FASD, our project aimed to evaluate and identify policies and best practices in dealing with FASD in adulthood that are implemented in other countries, specifically investigating support for housing, diagnoses, criminal justice, mentoring into adulthood, education and legislation/policy proposal.

In addition to this report, we created a resource guide with links to and descriptions of country-by-country resources for the major categories mentioned above. We also provided the National Organisation for FASD with a spreadsheet of professional contacts and organizations in those countries so that they may contact these individuals for additional information or collaboration. We hope our deliverables will aid the National Organisation for FASD in developing more support and awareness for adults with FASD in the UK.

After reviewing the state of FASD awareness and support across three countries, we summarized specific ways the UK can move forward in providing adults with FASD the support they need. These recommendations include:

- **Remove IQ as the factor in diagnosing a learning disability.** Most individuals with FASD have a higher functioning IQ than the threshold of 70, and in today's science there are better ways to determine a diagnosis, like various neurodevelopmental tests that can signal FASD. Those with FASD need the services for those with autism and other learning disabilities to be open to all neurocevelopmental disabilities, including FASD.
- **Push for FASD special education eligibility.** Of the adults we interviewed with FASD, all of them had mentioned the extreme lack of support given to them while in school, which they felt led to many of the issues they currently face in adulthood. The benefits of FASD special education eligibility are not limited to the support for children in school, it will also provide awareness of FASD at an early age for the rest of society. Other children in school will consequently be educated on FASD, which will foster social awareness as they grow older; optimistically, this will aid in removing the stigma surrounding FASD.
- **Address FASD as its own disability with its own methods of support.** Currently, children with FASD are either receiving support designed for other disabilities, such as AHDH or Autism, or not receiving support at all. By addressing FASD as its own disability with its own methods of support, these children will be able to learn in ways most suitable for them.
- **Begin a program such as NWR's Life Coach Program where an individual with FASD is partnered with a mentor who meets with them weekly to ensure that their transition goes smoothly and so that they are better supported.** In our interviews with adults with FASD, everyone stressed the need for a social care worker or mentor that would be there to provide support and assistance through their transition to adulthood. These programs provide services such as advice on housing services, healthcare, and medical needs to help them with everyday tasks such as grocery shopping and budgeting. The UK would benefit tremendously from having a mentor program such as the ones in Canada.
- **Utilize the housing guide to better accommodate the needs of individuals with FASD in existing houses, rooms, or apartments**. Developing permanent housing for adults with FASD is a long venture, therefore we recommend that the housing guide created by Proof Alliance and LHB Inc. be used. This housing guide can serve as a valuable tool when creating effective housing designs that will consider a spectrum of needs for young adults with FASD.
- **Push for legislation in the UK and put a resource directory in place when the time comes.** With the new Quality Standards (NICE) for FASD being released, right now is an important time to push for legislation within the UK. There cannot be social change without policy change. With policy comes funding for more research, support for housing assistance, job assistance, and mentorship assistance. Because policy change is more successful with advocacy, we recommend that a resource directory be put in place when the time comes. This resource directory would include information on how to connect with local policy makers and representatives to show support for said policy. The directory could also include email templates for examples of what to say to these policymakers to show support and it could outline steps on how to be an individual advocate. An example of this can be seen on the FASD United website and their advocacy for the FASD Respect Act.

AUTHORS PAGE

The introduction, background, methodology, and results of this report were written collaboratively by all the team members. Josephine Kim conducted research on policies, practices, and guidelines implemented in the UK that address FASD in general. Grace Casey conducted research on the policies, practices, and guidelines implemented in the US that address FASD in adulthood, as well as proposed legislation in the US that seeks to increase support for individuals with FASD. Caitlin Bonavita conducted research on the policies, practices, and guidelines implemented in Canada and Australia that address FASD in adulthood. Josephine took on the primary role of creating the booklet report, while Grace and Caitlin took on primary roles of creating our final deliverable and final presentation. Additionally, the team worked collaboratively for each interview conducted.

Grace Casey is a junior Data Science major. She is a part of the Varsity Women's Soccer Team, FCA, ODK, and a member of Phi Sigma Sigma.

Josephine Kim is a junior Management Engineering/Data Scicene major. She is a part of the Varsity Women's Soccer Team, Rho Lambda, and a member of Alpha Phi.

Caitlin Bonavita is a junior Biomedical Engineering major. She is a part of the Varsity Women's Soccer Team, AEMB, and a member of Phi Sigma Sigma.

REFERENCES

About-FASD. (2018). FASD Communities. Retrieved April 24, 2022, from https://fasdcommunities.org/about-fasd/

American Academy of Pediatrics. (2018). *Dysmorphic Features of FASD.* HealthyChildren.org. Retrieved February 15, 2022, from https://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Fetal-Alcohol-Spectrum-Disorders.aspx.

Armstrong, E. M. (1998). Diagnosing moral disorder: The discovery and evolution of fetal alcohol syndrome. *Social Science & Medicine*, 47(12), 2025–2042. https://doi.org/10.1016/s0277-9536(98)00308-6

Cabinet Secretary for Health and Social Care. (2018). Alcohol and drugs. Scottish Government. Retrieved February 17, 2022, from https://www.gov.scot/policies/alcohol-and-drugs/minimum-unit-pricing/

Centers for Disease Control and Prevention. (2022, January 11). Basics about FASD. Retrieved February 17, 2022, from https://www.cdc.gov/ncbddd/fasd/facts.html

Clinic Locations Nationwide. (2021). University of Washington. Retrieved April 26, 2022, from https://depts.washington.edu/fasdpn/htmls/nationwide.htm

Coles, C. D., Lynch, M. E., Kable, J. A., Johnson, K. C., & Goldstein, F. C. (2010). Verbal and nonverbal memory in adults prenatally exposed to alcohol. *Alcoholism: Clinical and Experimental Research*, 34(5), 897–906. https://doi.org/10.1111/j.1530-0277.2010.01162.x

Craker, J. (2020, September 9). About FASD. National FASD. Retrieved January 18, 2022, from https://nationalfasd.org.uk/about-fasd/

Department of Health, Llywodraeth Cymru Welsh Government, Department of Health at Roinn Slainte, Scottish Government. (2016, August). *UK Chief Medical Officers' Low Risk Drinking Guidelines. GOV.UK*. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/545937/UK_CMOs__report.pdf

Facts about Microcephaly | Birth Defects | NCBDDD | CDC. (2020, February 18). Centers for Disease Control and Prevention. Retrieved April 4, 2022, from https://www.cdc.gov/ncbddd/birthdefects/microcephaly.html#:%7E:text=Microcephaly%20is%20a%20condition%20where,in%20a%20smaller%20head%20size.

FASD :: Surrey and Borders Partnership NHS Foundation Trust. (2021). NHS. Retrieved April 28, 2022, from https://www.fasdclinic.com/

Healthcare Improvement Scotland, NHS Scotland, SIGN Evidence-based clinical guidelines. (2019, January). *SIGN 156 Children and young people exposed prenatally to alcohol*. NHS Scotland. https://www.sign.ac.uk/media/1092/sign156.pdf

Institute of Alcohol Studies, University of Hull, The University of Edinburgh. (2019). *Alcohol Guidelines for Pregnant Women*. Institute of Alcohol Studies. https://www.ias.org.uk/uploads/pdf/IAS%20reports/rp37092019.pdf

McCarthy, R., Mukherjee, R. A., Fleming, K. M., Green, J., Clayton-Smith, J., Price, A. D., Allely, C. S., & Cook, P. A. (2021). Prevalence of fetal alcohol spectrum disorder in Greater Manchester, UK: An active case ascertainment study. Alcoholism: Clinical and Experimental Research, 45(11), 2271–2281. https://doi.org/10.1111/acer.14705

Moore, E. M., & Riley, E. P. (2015). What happens when children with fetal alcohol spectrum disorders become adults? *Current Developmental Disorders Reports*, 2(3), 219–227. https://doi.org/10.1007/s40474-015-0053-7

National Institute for Health and Care Excellence . (2008, March 26). *Antenatal care for uncomplicated pregnancies: Guidance*. NICE. Retrieved February 17, 2022, from https://www.nice.org.uk/guidance/cg62

Petrenko, C. L., Tahir, N., Mahoney, E. C., & Chin, N. P. (2013). Prevention of secondary conditions in fetal alcohol spectrum disorders: Identification of systems-level barriers. *Maternal and Child Health Journal*, 18(6), 1496–1505. https://doi.org/10.1007/s10995-013-1390-y

Popova, S., Lange, S., Poznyak, V., Chudley, A. E., Shield, K. D., Reynolds, J. N., Murray, M., & Rehm, J. (2019). Population-based prevalence of fetal alcohol spectrum disorder in Canada. *BMC Public Health, 19*(1). https://doi.org/10.1186/s12889-019-7213-3

Promoting the health and well-being of looked-after children Statutory guidance for local authorities, clinical commissioning groups and NHS England. (2015). https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/413368/Promoting_the_health_and_well-being_of_looked-after_children.pdf

Proof Alliance & LHB, Inc. (2021). *A Place to Call My Own: Housing Design for Young Adults with FASD*. https://www.proofalliance.org/wp-content/uploads/2021/11/LHB-Guide-Housing-Design-for-Young-Adults-with-an-FASD.pdf?blm_aid=0

Quality standard consultation | Project documents | Fetal alcohol spectrum disorder | Quality standards | NICE. (2020, August 20). National Institute for Health Care and Excellence. Retrieved February 16, 2022, from https://www.nice.org.uk/guidance/gid-qs10139/documents/html-content-3

Resources- Information Cards for Police. (2021, October 15). NOFASD Australia. Retrieved April 22, 2022, from https://www.nofasd.org.au/parents-carers-and-families/resources/#police-cards

Roser, Max, and Hannah Ritchie. "Number of Deaths by Cause." *Our World in Data, Number of Deaths by Cause, World*, 1997 to 2016, Global Change Data Lab, 2018, https://ourworldindata.org/grapher/annual-number-of-deaths-by-cause?time=1997..2016.

Spohr, H.-L., Willms, J., & Steinhausen, H.-C. (2007). Fetal alcohol spectrum disorders in young adulthood. *The Journal of Pediatrics*, *150*(2). https://doi.org/10.1016/j.jpeds.2006.11.044

Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental & Behavioral Pediatrics*, 25(4), 228–238. https://doi.org/10.1097/00004703-200408000-00002

Thanh, N. X., & Jonsson, E. (2016, March 9). *Life Expectancy of People with Fetal Alcohol Syndrome*. Journal of population therapeutics and clinical pharmacology = Journal de la therapeutique des populations et de la pharmacologie clinique. Retrieved February 1, 2022, from https://pubmed.ncbi.nlm.nih.gov/26962962/

Warren, K. R. (2015). *An Historically Hidden Health Problem: Alcohol and Pregnancy*. National Institute on Alcohol Abuse and Alcoholism . Retrieved February 10, 2022, from https://www.apa.org/about/gr/science/spin/2015/04/alcohol-pregnancy.pdf