

# Supplementary Materials for International Scope for Supporting Adults with FASD

Caitlin Bonavita

Grace Casey

Josephine Kim

London D'22

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Advisors:

Professor Dominic Golding

Professor Lorraine Higgins

Sponsor:

The National Organisation for FASD

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# Table of Contents

<b>Table of Contents</b>	2
<b>SM-A: Adults with FASD Interviews</b>	3
Preamble	3
Baseline Interview Questions	4
<b>SM-B: International Interviews</b>	5
Preamble	5
Baseline Interview Questions	6
<b>SM-C: Resource Guide Deliverable</b>	7

## **SM-A: Adults with FASD Interviews**

### ***Preamble***

We would be delighted if you would take 20 minutes to answer some questions about your experiences of FASD as an adult and what kinds of support might be helpful to you and those around you. Your participation in this interview is completely voluntary. You may stop the discussion at any time or choose not to answer any question. We shall be taking notes during our conversation and may wish to quote you in our final report, but we will not use your name or any information that may reveal your identity. We will give you an opportunity to review any materials we use from this conversation prior to publication or presentation. We will also be happy to provide you with a copy of our report when it is completed.

Are you willing to participate in the interview? Do you have any questions about this interview or our research before we begin? If you have any concerns or questions after the interview, you can contact us at [gr-lon22\\_fasd@wpi.edu](mailto:gr-lon22_fasd@wpi.edu) or our faculty advisor, Dominic Golding, at [golding@wpi.edu](mailto:golding@wpi.edu). Thank you for your support in this research.

### ***Baseline Interview Questions***

1. How old are you?
2. When did you first get diagnosed with FASD?
3. What is your current living situation?
4. What is your current job status?
5. What is your educational history?
6. What forms of support do you use?
7. Do you feel supported and represented?
8. Do you have access to any benefits?
9. What do you think is needed so that people better understand FASD and its diagnosis?
10. As an adult with FASD, what helped you the most when you became an adult?
11. What do you think is needed to further support/help those with FASD?
12. What are some challenges you face every day?

# SM-B: International Interviews

## *Preamble*

We are a team of students from Worcester Polytechnic Institute in Massachusetts, USA working in collaboration with the National Organisation for FASD in the UK. We are conducting research on the impacts of FASD after the age of 18 years and what kinds of policies, guidelines, and practices are needed to address this issue.

We would be delighted if you would take 30 minutes to answer some questions about [complete based on interests and expertise of interviewee]. Your participation in this interview is completely voluntary and you may stop at any time. We shall be taking notes during our conversation and may wish to quote you in our final report. Do you mind if we quote you by name, or would you prefer we anonymize your responses? We will, of course, give you an opportunity to review any quotations prior to publication. We will also be happy to provide you with a copy of our report when it is completed.

Do you have any questions before we begin? If you have any concerns or questions after the interview, you can contact us at [LON22\\_FASD@wpi.edu](mailto:LON22_FASD@wpi.edu) or our faculty advisor, Dominic Golding, at [golding@wpi.edu](mailto:golding@wpi.edu).

Do you mind if we record this interview or would you prefer we just take notes? Thank you and let's begin.

### ***Baseline Interview Questions***

1. Can you provide us with some background of your experience at [organization/group]?
2. What is your position and main responsibilities?
3. What does your organization do to support FASD?
4. In your experience, what do you think impacts adults with FASD the most?
5. How does your organization help those who have been affected by FASD in terms of support?
  - a. Housing
  - b. Education
  - c. Mentoring
  - d. Criminal Justice
6. What methods of support provided by your organization do you feel have translated well into the FASD community and why?
7. What methods of support provided by your organization do you feel don't translate as well into the community and why?
8. Are there any other organizations you partner with that also provide support for those affected by FASD in adulthood?
9. Do you believe that your initiatives are well supported by the government?
10. What more do you think could be done to support these adults with FASD in general?
11. Do you have any suggestions of people within your organization that we could contact to get more information?

## SM-C: Resource Guide Deliverable

# Resource Guide for Supporting Adults with FASD: DIAGNOSIS

### Canada

**Mackenzie FASD Adult Diagnostic Clinic: NWR FASD Society** - The Mackenzie FASD Adult Diagnostic Clinic in Canada provides adults with assessments and diagnoses who have not yet received an assessment. These assessments are intended for individuals who have transitioned to adulthood and have not yet received a diagnosis. This clinic provides adults with the opportunity to get an FASD diagnosis who have been unable to, while also supporting them pre and post clinic. The adult referral for a FASD assessment can be found here:

<http://nwr-fasd.ab.ca/wp-content/uploads/2021/09/Adult-FASD-Referral-Package-Sep-17-2021.pdf>

### Australia

**FASD HUB Clinic Directory** - In Australia, the FASD Hub website has a service directory of all clinics that provide FASD specific assessments and diagnoses, along with where they are located in Australia. This directory allows those looking for a FASD diagnosis to easily find health professionals and services with FASD experience and expertise.

<https://www.fasdhub.org.au/services/>

## MENTORING

### Canada

**Life Coach Program: NWR FASD Society** - The Life Coach Program provides access to community support that includes help with education, health, employment, and many other things. 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.

<http://nwr-fasd.ab.ca/our-work/>

**FASD Youth Transition Coach: NWR FASD Society** - The Youth Transition Coach Pilot Program 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.

<http://nwr-fasd.ab.ca/our-work/>

**Adult FASD Expert Collaboration Team (AFECT): CanFASD** - This team advises on priority areas of research for individuals with FASD and helps translate the results of the research to make sure they are understood by and available to people with FASD. It is a group of adults with FASD across Canada who meet monthly with CanFASD members to talk about FASD research.

<https://canfasd.ca/about/afect/>

**The Asante Centre Mentorship Program** - The Asante Centre offers peer mentorship and consultation services provided by consultants with FASD who have training in mentorship, advocacy, and leadership, creating opportunities for children, youth, and adults with FASD. 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.

<https://www.asantecentre.org/peer-mentorship-and-consultation>

**Fetal Alcohol Spectrum of Services: Bissell Centre** - These services include short term support, parent child assistance program (PCAP), and adult advocate. The short-term support services include income support, AISH (Assured Income), and identification. If one requires longer term support, they are assisted until they relate to an adult advocate. An adult advocate is for role modeling, connections to services, and help with creating routine and stability.

<https://bissellcentre.org/programs/individual/fetal-alcohol-spectrum-of-services/>

## United States

**FASD Transition for Ages 14-21: Proof Alliance** - Proof Alliance discusses supervision and patience required for the transition from adolescence to adulthood for those with FASD. It touches on the specific topics of supervision, healthy sexuality, peer relationships, housing, school strategies, decision making, mental health, and substance abuse. It is explained why each of these topics present a challenge to those with FASD, and then identifies ways families/caregivers can help with these challenges as well as ways for individuals themselves to adapt.

<https://www.proofalliance.org/article/home-adolescence-and-transition-ages-14-21/>

**Health App Designed for Adults with FASD** - Dr. Christie Petrenko, a research associate professor of psychology from the University of Rochester, is in the process of creating a health app designed for adults with FASD. This app will act like an assistant, making sure daily tasks are on track as well as making health-based assessments. It can serve as a medication tracker to ensure individuals do not forget if or when they took medication and can remind them when to eat. This app will be a great resource for adults with FASD as they navigate daily life, whether it is independently, or in addition to caregivers. It uses a chatbot interface, which is essentially like texting, and it will help adults with FASD with remembering/tracking information.



# HOUSING

## United States

**FASD Communities** - FASD Communities provides assisted/supported living to adults 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. This community gives adults with FASD the opportunity to achieve their highest potential by allowing them to gain a sense of responsibility and collaboration.

<https://fasdcommunities.org/about-fasd/>

### **A Place to Call my Own: Housing Design for Young Adults with FASD: Proof Alliance and LHB Inc.**

- Through research of existing housing and service providers in the US and Canada, as well as input from caregivers and young adults with FASD, Proof Alliance created a Housing Guide to best support young adults with FASD. The guide focuses on eight main design principles, identified from research, that will best support young adults with FASD. Each principle has a detailed rationale as to why it is pertinent to those with FASD and is then followed by ideas on how to implement these principles in a housing situation. The guide provides design prototypes for building layouts for different living situations- with varying populations, services, building size, and unit type. These designs range from independent living to a common house.

[https://www.proofalliance.org/wp-content/uploads/2021/11/LHB-Guide-Housing-Design-for-Young-Adults-with-an-FASD.pdf?blm\\_aid=0](https://www.proofalliance.org/wp-content/uploads/2021/11/LHB-Guide-Housing-Design-for-Young-Adults-with-an-FASD.pdf?blm_aid=0)

**Independent Living (A Highlight on Money Management): FASD SoCal Network** - The FASD Network of Southern California outlines what to expect in terms of housing and living independently as someone with FASD approaches adulthood. It is stressed that sole independence is rare, parents or caregivers should expect interdependence, or continuance of their role as the “external brain”. They discuss the worries of homelessness, options of support to best avoid homelessness, and housing options for FASD adults who have substance abuse issues. One topic they discuss in relation to independent living is money management and tips to help.

<https://fasdsocalnetwork.org/independent-living/>

## Canada

**FASD Permanent Supportive Housing: Bissell Centre** - 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. 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. 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 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.

<https://bissellcentre.org/programs/individual/fasd-permanent-supportive-housing/#:~:text=Bissell%20Centre%20provides%20permanent%20FASD,services%20for%20people%20with%20FASD.>

**Eviction Support (Community Bridge): Bissell Centre** - This is a quick response intervention program that prevents loss of housing including eviction. This is used as a last resort for a one-time service that will help prevent loss of housing and one must be willing to explore all options. This also includes assistance with financial action plans and applying for grants that they are eligible for to prevent eviction. One can apply for this by filling out an application provided on the website and attending a 90-minute appointment. If the loan is approved, it will then be processed, and a cheque will be mailed to the creditor. Follow-up calls will be put into place to check in on the individual after the loan is in place.  
<https://bissellcentre.org/programs/individual/community-bridge/>

## CRIMINAL JUSTICE

### Canada

**FASD Guidebook for Police Officers: CanFASD** - 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.

**FASD Justice Committee** - The FASD Justice Committee's 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.

<https://fasdjustice.ca/en-ca/criminal-justice/adult/court-%E2%80%93-bail-and-pre-trial.html>

### Australia

**Information Cards for Police Officers: NOFASD Australia** - 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. To prevent this from occurring, NOFASD Australia created wallet-sized cards that can be carried by individuals with FASD. These cards can be handed to the police officers, if needed, which will inform the officers that this individual has a cognitive impairment and cannot "knowingly waive legal rights." Often, those with FASD are unable to defend their legal rights, therefore these cards act as tools to inform police officers of their disability.

<https://www.nofasd.org.au/parents-carers-and-families/resources/#police-cards>

# EDUCATION

## Canada

**Interactive Website for FASD: CanFASD** - This interactive website provides information for individuals with FASD across a variety of lifespans, but in particular adulthood. On this website, individuals can choose the age range they belong to, for example 21-25 years or 35 years and above. Once an age range is chosen, neurobehavioral difficulties that they may face are explained. For example, for 35 years and above, the website provides information regarding managing money/finances to trouble with the law. For 17-20 years, the interactive website provides information about how to handle school withdrawal or substance abuse. While every individual with FASD experiences a range of different things, this website provides support for these individuals by explaining common effects of FASD and what types of interventions are available.

<http://knowfasd.ca/about>

## United States

**Minnesota Department of Education** - The Minnesota Department of Education is one of the two states within the United States that lists FASD under the category of “other disabilities” when it comes to children receiving the correct assistance in school due to their disability. This link breaks down the common issues of FASD as well as symptoms, signs, and educational implications a teacher might notice. It then goes into discussing potential educational options to assist a child with FASD.

<https://education.mn.gov/MDE/dse/sped/cat/ohd/info/059855>

**California SB-1016 Special Education Eligibility Act** - In California, like most states in the US, FASD is not recognized as a disability under any category for special education in schools. This act would require FASD to be included as a named disorder under the “other health impairment” category for Individualized Education Plans (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.

[https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill\\_id=202120220SB1016](https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=202120220SB1016)

**Advocating for a Student with FASD: Steps to Attaining an IEP** - This is an outline designed to help parents/caretakers advocate for their child in receiving an Individual Educational Program based on the disability of FASD in the United States. Similar protocol could be followed in a like-conversation regarding a child’s EHCP (Education Health Care Plan).

<http://www.come-over.to/FAS/schooladvocacy.htm>

**Ten Comments you May Hear at an IEP Meeting and How to Respond** - Friendship Circle is a nonprofit that provides support for children with special needs and their families. Here they explain 10 common comments you might hear in an IEP meeting and how to respond accordingly. Again, a similar conversation could be had regarding a child’s EHCP.

<https://www.friendshipcircle.org/blog/2013/01/02/ten-comments-you-may-hear-at-iep-meetings-and-how-you-should-respond/>

**Adolescence and Transition: Accommodation and Modifications for Ages 14-21** - This information provided by Proof Alliance outlines the services FASD individuals are entitled to under special education in the United States- in particular transition planning. It then goes into outlining four different categories of ways to provide support: modifying the learning environment, tools for self-regulation, support during transition, and understanding the brain differences.

<https://www.proofalliance.org/article/school-adolescence-and-transition-ages-14-21/>

**Information and Training Clearing House: NOFAS Washington State** - This site is a great resource catalog for all things related to FASD all in one location provided by NOFAS Washington State. It has a section that contains books about FASD, and the challenges individuals might face with summaries of each book. The next section contains selected FASD Related Websites for further education. Following is another section containing articles and publications for more information. Finally, they have a section at the bottom of the page designated to training where you can contact their training coordinator for a quote to see the cost of having NOFAS Washington FASD train your organization.

<https://www.nofaswa.org/info-and-training>

## **POLICY**

### **United States**

**FASD Respect Act** - The FASD Respect Act is the first step in creating a conversation with lawmakers in the United States to identify and support FASD. It allows for federal funding of over \$100 million dollars in the United States to be designated towards looking for supported housing for adults with FASD, training for mental health and medical professionals, and job support for adults with FASD. Above all, it provides visibility and validation for FASD community.

<https://www.congress.gov/bill/117th-congress/house-bill/4151/text?r=1&s=3>

**New York Mental Hygiene Law, S7672** - The New York Mental Hygiene Law identifies which conditions are considered ‘developmental disabilities.’ Although the part mentioning FASD is only a sentence long, if passed it will allow more people with FASD to access developmental disability services—potentially housing support communities, habilitation support, respite for caregivers, or recreational activity jobs. The New York Mental Hygiene Law will open the door to many supportive services and tools to help assist those with FASD.

<https://www.nysenate.gov/legislation/bills/2021/s7672>

**Minnesota Statute 260C.219 Agency Responsibilities for Parents and Children in Placement** - This statute passed in Minnesota in 2021 requires that all children entering the foster care system be screened for FASD as well as requiring foster parents to be trained in FASD. Proof Alliance provides all the training and screening.

<https://www.revisor.mn.gov/statutes/cite/260C.219>

**Minnesota Statute 260E.31 Reporting of Prenatal Exposure to Controlled Substances**- This statute passed in Minnesota in 2020 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 mandate will create a more open dialogue and get the mothers the prenatal care they need during pregnancy to assist the fetus.

# Additional Resources

## EMPLOYMENT

### United States

#### **Helping FASD-Affected Teens and Adults to Be Successful in the Workplace: FASD SoCal Network**

- The FASD Network of Southern California outlines ways to help teens and adults who have FASD be successful in the workplace. It explains the need for vocational rehab and ongoing support which will help aid in keeping jobs. It further discusses the common problems experienced with employment and how parents and caregivers can help.

<https://fasdsocalnetwork.org/job-training-employment/>

### Australia

**Guide for Employment Professionals: NOFASD Australia** - This guide provides information and support for individuals who employ adults with FASD. This guide also helps these individuals/agencies assist FASD adults so that they can prepare for and maintain their employment. The overall goal of this guide was to help employers understand the strengths and needs of adults with FASD, so that they can help facilitate success throughout these individuals' employment journey. This guide allows employers to better understand how to support adults with FASD in the workplace so that they can ensure their well-being and success.

<https://www.nofasd.org.au/wp-content/uploads/2018/08/Guide-for-Employment-Professionals.pdf>

### Canada

**Supported Employment Pilot Program: NWR FASD Society** - The Supported employment pilot at NWR FASD in Canada was a project conducted in 2015 for 11 individuals with FASD. This project included funds from Alberta Works to support and prepare these individuals for employment. The project found that there is a much longer timeline for those with FASD in order to ensure they have appropriate identification, health coverage and to ensure some training has been received.

<http://nwr-fasd.ab.ca/our-work/>

**Employment and Casual Labor Services: Bissell Centre** - The Employment and Casual Labour Services help individuals search for meaningful and sustainable employment. These services include referrals, workshops, assessments, employment counseling, help with resumes, safety courses, etc. They also work with over 500 local businesses in the Edmonton area so they can properly refer individuals.

<https://bissellcentre.org/programs/individual/employment-services-casual-labour/>

## **MONEY MANAGEMENT**

### **Canada**

**Financial Empowerment Services: Bissell Centre** - These Financial Empowerment services provided by Bissell include financial literacy education, one-on-one financial coaching, support to open saving plans, support in accessing benefits, and tax filing support. One can access this program by email or by going to drop-in office hours. They also provide a booklet on their website for instructions on how to access benefits as well as projects, clinics, and workshops.

<https://bissellcentre.org/programs/individual/financial-empowerment-services/>

**Free Tax Filing: Bissell Centre** - Bissell offers free tax filing for individuals with FASD and can be eligible for this service based on how many people they live with as well as their income. This can be found by the chart on their website. They have instructions on their website for what to bring to the drop-in office hours for this service in person at their headquarters.

<https://bissellcentre.org/programs/individual/taxes/>

**The Disability Tax Credit (DTC): CanFASD** - This is a non-refundable tax credit that helps people with prolonged disabilities, or their supporting persons reduce the amount of income tax they may have to pay. On the CanFASD page they also provide additional information including frequently asked questions, application guides for physicians, letter template for physicians, and tips for applying.

<https://canfasd.ca/caregivers/information-for-individuals-with-fasd/>