

Report on Representation Agreements and Fetal Alcohol Spectrum Disorder



The following is a summary of activities and results from the 'Representation Agreements and Fetal Alcohol Spectrum Disorder' project (2007-2009) carried out by Nidus with funding from the Victoria Foundation FASD Action Fund. Nidus contracted with Dr. Deborah Rutman to oversee the research and evaluation component of the project. The purpose of the project was to explore how adults with FASD and their personal supporters might use Representation Agreements as a tool for supported decision making. The objective was to identify best practices in providing education about and support with Representation Agreements for individuals and their personal supporters in the FASD community. The primary activities were: 1) conduct free educational workshops in specific communities in three regions of British Columbia; 2) assist adults with FASD to make Representation Agreements; and 3) document all aspects of the process.

Introduction

A Representation Agreement is...

A Representation Agreement is a legal document. It is the only way in British Columbia to appoint someone to assist you or to act on your behalf for health and personal care matters. Representation Agreements can also cover routine financial and legal matters.

Fetal Alcohol Spectrum Disorder is...

FASD is a term that describes a complex range of disabilities associated with pre-natal exposure to alcohol, including restricted growth, neurological and central nervous system impairments, characteristic facial features, and/or learning and behavioural difficulties.

How can Representation Agreements help someone with FASD?

Adults with FASD often have significant challenges with daily living and thus need consistent support with everyday activities, including decision making support. Sometimes informal support is not sufficient to enable someone to help the adult and more formal authority is required. The legal authority of parents or guardians ends when an individual turns 19 years old (the age of majority in B.C.). Representation Agreements provide a way for adults to give legal authority to personal supporters. They balance self-determination and safety within the context of caring relationships and the adult's unique needs.

Note: Opinions expressed in this document do not necessarily reflect the opinions or views of the Victoria Foundation.

Inside

- Project Activities
- Resources
- Thank You's

Presented by

Nidus Personal Planning Resource Centre and Registry

411 Dunsmuir Street
Vancouver, B.C. V6B 1X4

Tel: 604.408.7414
Toll free: 1.877.267.5552
Fax: 604.801.5506
Email: info@nidus.ca

www.nidus.ca

Nidus is a nonprofit,
charitable organization.

Nidus is a Latin
term for nest:
a symbol of
support,
safety and
self-development.

Thank you to our funder



**VICTORIA
FOUNDATION**

CONNECTING PEOPLE
WHO CARE WITH CAUSES
THAT MATTER

Nidus conducted nine workshops in six communities in British Columbia. Workshops were organized and hosted by local groups or FASD Key Support Workers in Duncan, Kamloops, Kelowna, Vancouver, Vernon, and Victoria.

Participants included families/supporters of youth or adults with FASD, and community-based service providers. Workshop attendance ranged from 3 to 32 people.

The workshops provided an introduction to Representation Agreements and included questions and answers in order to address specific issues of interest to the FASD community.

Questions were recorded to assist with subsequent workshops and to gather input for resources and recommendations.

Follow-up Interviews

The researcher conducted follow-up interviews with a sample of workshop participants. The purpose of these interviews was to obtain feedback about both the workshops and how participants used the information obtained. In total, 13 workshop participants were interviewed by phone two to four months after the workshops.

What Participants Told Us

- ▣ Prior to attending the workshops, most participants had little or no knowledge of BC's legal planning tools.
- ▣ Education efforts in the FASD community must target the crucial time of transition from youth to adulthood.
- ▣ Workshops need to be followed up on in a variety of ways and over a much longer period of time. It takes time to go from learning about an RA to making one.
- ▣ Education of professionals is also important to help promote and support the use of Representation Agreements.
- ▣ Most interview participants shared information from the workshop with colleagues who work with individuals with FASD or their personal supporters. Types of colleagues information was shared with:
 - ← High school learning assistance teachers.
 - ← Social workers.
 - ← Staff of supported employment programs.
- ▣ Participants wanted to know more about:
 - ← How to create a Representation Agreement.
 - ← Case studies where a Representation Agreement has been made and used.
 - ← Ways to talk about Representation Agreements with youth who are transitioning into adulthood.

I learned...

That a Representation Agreement doesn't involve giving up legal rights. Also, it was exciting to hear that it was something for people with FASD.

My experience

I was immediately able to use the information. I shared it with a mom whose son has FASD...It was worth going to the workshop for that.

2 FACT SHEET: FREQUENTLY ASKED QUESTIONS ABOUT REPRESENTATION AGREEMENTS & FASD

Based on discussion at the workshops and follow-up interviews, Nidus prepared a fact sheet to answer questions about Representation Agreements as they relate to FASD. This fact sheet is designed to accompany Nidus' general publication on Representation Agreements.

3 PRESENTATION AT 3RD INTERNATIONAL CONFERENCE ON FASD

Nidus and the Principal Researcher made a presentation on Thursday, March 12, 3:30 to 5:00 pm at the Conference called *Integrating Research, Policy, and Promising Practice Around the World: A Catalyst for Change* held in Victoria.

The presentation was titled: *Report on Project to Explore Education and Practice of Representation Agreements: A legal tool to enable support with decision making for adults with FASD*. Approximately 35 people attended. Clearly the presentation raised awareness among participants as most had never heard of Representation Agreements.

4 CONNECTING WITH GOVERNMENT AGENCIES WHO HAVE A ROLE IN TRANSITION TO ADULTHOOD

Nidus and the Principal Researcher provided a presentation to the **Office of the Representative for Children and Youth** on May 27/09, 1:00 pm to 2:00 pm. Staff with Aboriginal and Community Relations attended by teleconference from Victoria, Burnaby and Prince George.

Information was provided to the **Ministry for Children and Families** Youth Policy Division and an offer to conduct an information session. It was suggested to offer a session at a 'Lunch and Learn' which is open to all Provincial office staff. Unfortunately it was not possible to secure a date, however, we have identified a key connection for the future and for disseminating information.

5 ONE-TO-ONE ASSISTANCE IN MAKING & USING A REPRESENTATION AGREEMENT

Two Representation Agreements were customized for adults with FASD through this project. The two situations were different from each other. One situation primarily concerned in dealing with health care and with the justice system. The other situation concerned the adult's living arrangements.

Follow-up Interviews

The Principal Researcher interviewed a personal supporter/representative involved with each of the Representation Agreements to document the experience of making and using the Agreement.

Research Report on Qualitative Interviews

Nidus published a research paper to document the findings from the interviews. *Experiences of adults living with Fetal Alcohol Spectrum Disorder and their personal supporters in making and using a Representation Agreement* is available on the Nidus website at www.nidus.ca/PDFs/Nidus_Research_RA_FASD_Project.pdf

Research Report - Conclusions & Future Directions

Family members, caregivers and others in the adult's support network had numerous experiences of providing ongoing help to the adult with decision making and/or in dealing with staff of different service systems (e.g. Income Assistance workers or managers, financial institutions, health care professionals, care facility staff, lawyers and judges, and so forth). However, informal help was often limited by issues of confidentiality or dismissed as interference or as being unnecessary.

The Representation Agreement gave legal status to supporters for those times that informal help was insufficient for enabling the adult's voice to be heard.

In this project, both of the adults had a support network of trusted individuals who were willing to become representatives and a monitor. However, this is not always the case. Many youth and adults with FASD do not have an obvious support network that they can rely upon. This produces challenges of all kinds especially involving the process of making a Representation Agreement. Indeed, it is for this reason that discussion of Representation Agreements must begin with youth and their family members or caregivers/support people, before the youth turns 19.

Any planning for when a young person with FASD and/or youth in foster care will reach the age of majority should include discussion of Representation Agreements. It may take time to help the youth develop or re-establish trusting and supportive relationships. As well, it takes time to learn about Representation Agreements and the roles and duties of those who may be involved in the Agreement and in the process.

6

DISSEMINATION OF PROJECT RESULTS & RESOURCES

Nidus disseminated the project report information on resources to individuals and organizations who participated in the project. Nidus and the principal researcher all distributing the results and resources more broadly through national and international networks that are either focused on FASD or interested in legal tools for supported decision making.

RESOURCES

Nidus Personal Planning Resource Centre and Registry

www.nidus.ca

FASD Provincial Outreach Program

www.fasdoutreach.ca

FASD Connections Serving Adolescents and Adults with FASD

www.fasdconnections.ca/index.htm

Canada Northwest FASD Research Network

www.canfasd.ca

Thank you to the following individuals and organizations who hosted the community-based workshops

David Gerry // Victoria FASD Community Circle

Jan Kyffin & Jamey Dye // Cowichan Valley FASD Action Team Society

Linette Farmer // Interior Regional FASD/CCY Initiatives, Penticton

John Gotowiec // West Coast Alternate, Trainer FASD Collaboration Roundtables, Pacific Community Resources, Vancouver

Insight Support Services // Kamloops

North Okanagan Foster Parent Support Group