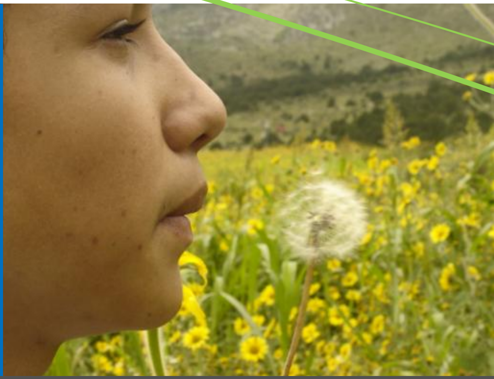
Nidus Personal Planning Resource Centre and Registry



Experiences of adults living with Fetal Alcohol Spectrum Disorder and their personal supporters in making and using a Representation Agreement

An analysis of Representation Agreements as a tool for supported decision making for adults with FASD

This paper documents the experiences of adults and their personal supporters who made and used Representation Agreements with standard powers.

QUICK GLOSSARY

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 (FASD) 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.

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Inside

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ABSTRACT

This paper presents findings from qualitative interviews with personal supporters who assisted adults with Fetal Alcohol Spectrum Disorder (FASD) to make and use a Representation Agreement.

These interviews were part of a project undertaken by the Nidus Personal Planning Resource Centre and Registry, with funding from the Victoria Foundation. 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 of the project was to identify good practices in providing education about and support with Representation Agreements for individuals with FASD and their personal supporters, as well as for those who work with people living with FASD.

This paper reveals that Representation Agreements played a critical role in ensuring the adults involved had support from people they trust to assist them and advocate for them with respect to decisions affecting their lives.

NOTE

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

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Experiences of adults living with Fetal Alcohol Spectrum Disorder and their personal supporters in making and using a Representation Agreement

Section 1: Introduction and Background

Background on Project

This paper discusses findings from a project undertaken by the Nidus Personal Planning Resource Centre and Registry, a non-profit charitable organization which promotes alternatives to adult guardianship. The exploratory project, 'Representation Agreements as a Tool for Supported Decision Making for Adults with Fetal Alcohol Spectrum Disorder' was funded by the Victoria Foundation FASD Action Fund. Nidus contracted with Dr. Deborah Rutman to oversee the research and evaluation component of the project.

The objective of the project was to identify good practices in providing education about and support with Representation Agreements for individuals and families/caregivers in the FASD community. The project's major activities were: 1) conducting educational workshops in specific communities in three regions of British Columbia; 2) assisting adults with FASD to make Representation Agreements; and 3) documenting and evaluating all aspects of the project.

The focus of this paper is on the experiences of adults living with FASD and their personal supporters (e.g. family, friends) in making and using a Representation Agreement (RA) in two communities in B.C. The findings are based on qualitative interviews conducted with two personal supporters/representatives who each were involved in helping the adult they support to make and use a Representation Agreement.

Law Reform and the Representation Agreement Act

The *Representation Agreement Act* (proclaimed February 28, 2000) is the result of a unique community-driven initiative to reform the laws and systems related to adult guardianship in B.C.

Adult guardianship involves legal procedures whereby a person, institution or the state obtains authority to take over the adult's affairs, in instances in which an adult needs assistance with decision making. The procedures require a determination that the adult is mentally incapable, which is stigmatizing and intrusive and results in a loss of civil rights for the adult. (For more information about adult guardianship in B.C., please see Section 4 starting on page 14.)

The goal of law reform was to create an alternative to adult guardianship. This way an adult who needs assistance with decision making does not have to be determined mentally incapable in order to get help from the people he or she trusts and who know him or her best. In turn, supporters would not have to apply to court or the state would not have to intervene and assume control of the adult's affairs.

The need for a legal mechanism to give recognition to personal supporters extends to situations where adults may not be found mentally incapable under adult guardianship provisions, but who nevertheless need some assistance with decision making due to illness, injury or disability.

Support may be provided informally, for example, through helping the adult to sort his or her mail and keep track of bill payments or by accompanying the adult to medical appointments.

There are times, however, when family and friends need legal status in order to provide support. The *Representation Agreement Act* provides a way to give legal authority with accountability.

The *Representation Agreement Act* views decision making as an interdependent activity that depends on any number of variables including access to support. The *Representation Agreement Act* recognizes that when you need help expressing yourself, having personal supporters who care about and respect you is what enables you to be self-determined and stay safe.

The *Representation Agreement Act* also acknowledges that competency is multifaceted. It is not all or nothing; it depends on a variety of factors including task and context. Determinations of incompetency are as much a reflection of others' perceptions and expectations of the individual as they are related to the individual's abilities; such measures are essentially social constructs. With Representation Agreements the emphasis is on the adult's need for support, rather than the adult's competency or incompetency.[1]

Representation Agreements: A General Overview

The following information highlights key features of Representation Agreements in the context of this project. Contact Nidus (see page 16) for greater detail and information on Representation Agreements for other populations and situations.

A Representation Agreement is a legal document and must be in writing. In order to make a Representation Agreement, an individual must be a resident of B.C. and at least 19 years old (the age of majority in B.C.).

The *Representation Agreement Act* describes three roles that can be given to those named in the Agreement: representative, alternate representative and monitor. The duties and authority of each are set out in the Statute. Each person named in the Agreement must sign and certify acceptance of his or her role and duties.

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[1] The presumption of adult competency is a fundamental tenet of our Canadian law and legal system and is stated in the *Representation Agreement Act*. This presumption puts the onus on others to prove incompetency; the adult does not have to prove his or her competency. Requiring proof of competency is thus inappropriate.

A Representation Agreement names one or more individuals as representative(s), who have legal authority to help the adult with decision making.

The first duty of a representative is to assist the adult to make his or her own decisions. Often this involves helping others to understand the adult's type of communication. This is different from traditional legal approaches such as adult guardianship, the enduring Power of Attorney and health care consent, which are based on the concept of substitute decision making whereby another party takes over and acts in the place of the adult.

Representatives have access to information and documents to which the adult is entitled. They must also keep information about the adult confidential, but can release information in the context of their authority and duties.

A Representation Agreement is voluntary – it is an agreement between the adult and his or her personal supporters. As in a contract, the adult may revoke (withdraw) his/her Representation Agreement and the representative(s) and monitor may resign.

Representation Agreements with Standard Powers

Section 7 of the *Representation Agreement Act* describes the standard powers that may be included in a Representation Agreement: routine management of financial affairs, legal matters, minor and major health care, and personal care.

In Section 8, the *Representation Agreement Act* says an adult may make a Representation Agreement with standard powers even if he or she cannot manage his or her own affairs or make decisions about his or her care.

A Representation Agreement with standard powers is signed by the adult in the presence of two independent witnesses. Notarization or consultation with a lawyer is not required.

The *Representation Agreement Act* has a number of built-in safeguards for making and using a Representation Agreement. For example, the law requires that if the authority for routine management of financial affairs is included in the Agreement, someone must be named as monitor or two or more representatives must act jointly. The role of monitor is a new one for B.C. legislation but is proving to be very effective in practice. One feature of the monitor role that may prove especially important for the adult's safety is the legislative provision that no one can prevent the monitor from visiting or speaking with the adult.

Fetal Alcohol Spectrum Disorder

Please see Section 6 of this paper (page 16) for a list of resources for more information on FASD.

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.

FASD is considered the leading cause of preventable birth defects and developmental delays in North America.

FASD is a lifelong, neuro-developmental disability. This means that people living with FASD do not outgrow its effects. As well, for most people living with it, FASD is an invisible disability in that people do not always recognize that the individual has a disability.

Primary effects and behavioural symptoms of FASD include: speech and language disorders; poor judgement and problem solving abilities; difficulties in relating behaviours to consequences; difficulties in generalizing information, forming linkages and abstract reasoning; difficulties in planning and organization; impulsivity; social and emotional challenges, including difficulties in reading social cues; lack of boundaries; and trouble with understanding and expressing emotions.

At the same time, children and adults with FASD demonstrate significant individual differences in their strengths and in the nature and degree of their difficulties and thus the disabilities experienced.

Given that FASD is an invisible disability, people's difficulties with learning or in day-to-day living situations are often misinterpreted as being due to a lack of motivation, laziness or wilful non-compliance. This is one reason why it is important that all who live and work with the person have a common understanding of the disability. This also speaks to the importance of ongoing support.

Most adults who have FASD have not had a diagnosis or an assessment. At the same time, they generally recognize that they have difficulties with learning and memory, with aspects of decision making, and that they are vulnerable to being taken advantage of socially and/or financially. They know they are "different" from their peers even if they do not know about FASD or self-identify as having FASD. Many adults living with FASD recognize the importance of having someone who can help them on a regular basis – i.e., someone who provides them with practical, day-to-day support and/or emotional support.

Representation Agreements and their application to Fetal Alcohol Spectrum Disorder

As noted above, adults with FASD often have significant challenges with daily living and thus need consistent support with everyday activities, including decision making support. At the same time, programs and services for adults with FASD are essentially non-existent and most adults do not qualify for supportive services that are available, for example, to people with developmental disabilities.

Personal supporters and service providers of adults with FASD report that many need help managing their affairs; some have suggested adult guardianship as a solution. However, many adults with FASD would not be found 'mentally incompetent' under adult guardianship legislative provisions. Moreover, such an approach is also clearly out-of-step with current principles and policies related to disability rights.[2]

Representation Agreements provide a way to balance self-determination and safety within the context of caring relationships and the adult's unique needs.

Despite the evident need for community-based ways to support adults with FASD in daily living, knowledge about the adult guardianship system in general and Representation Agreements in particular is very limited amongst the FASD community in B.C. This lack of community awareness was a primary impetus giving rise to this project.

Section 2: Experiences in Making and Using a Representation Agreement

Why a Representation Agreement? What prompted support people to think about the benefit of a Representation Agreement?

In each situation, it was an experience of frustration, hardship or the desire to prevent a potential crisis for the adult that precipitated the making of a Representation Agreement.

After learning that Representation Agreements provide legal status to supporters so they can assist the adult in interactions with systems, the personal supporters sought out more information about Representation Agreements and talked with the adult and other supporters about making one.

> *I was trying to help my son with his legal and financial issues – e.g. dealing with Income Assistance and with [my son's] medical issues as well. [The FASD Key Worker] in our community told us that Representation Agreements could give us a voice in helping our son with decision making. [Professionals] just wouldn't listen to him – lawyers and judges in particular.*[3]

The major concern for one supporter was the plan to change the adult's living situation without consideration of the adult's seizure condition which causes disorientation and memory loss, and without sufficient knowledge of FASD. Her perception was that this plan was set in motion

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[2] The United Nations Convention on the Rights of Persons with Disabilities (2008) includes reference to supported decision making. Article 12 of the Convention states that people with intellectual disabilities have the same right to the benefits of legal capacity in all aspects of life, as enjoyed by other citizens, and are entitled to support, if required, in order to exercise their legal capacity. The *Representation Agreement Act* has received international recognition as a legal model that embodies these principles. The Canadian Government is expected to ratify the Convention; hopefully in time for the Paralympics in Vancouver, which begin March 12, 2010.

[3] The B.C. Ministry of Children and Family Development established the Key Worker and Parent Support program in 2006 as a means to support families of children and youth with FASD. In the B.C. program, the Key Worker acts as a facilitator who assists family members, caregivers and service providers to learn about FASD and to develop supportive environmental accommodations accordingly.

as a response to the challenges of the adult's behaviour rather than the needs of the adult. The adult's experience and voice was not represented in the decision making and the supporter feared the adult's disability was being used against her.

> *There was an incident of [my former foster daughter] getting aggressive at her day program – the staff there found her too much to handle. [It was my perception that to] get her out of the day program, a staff person there coached her to say to a social worker who had never met her before that she wanted to move out to live on her own. The staff talked to [my former foster daughter] about how this would give her more freedom and she would not have to share with others. But to me, this plan would be disastrous; I'd never sleep at night knowing that she was out there on her own. I was treated as 'just the caregiver'. I had no rights. That's when I remembered about Representation Agreements and I researched them.*

What information was helpful in starting the process of making a Representation Agreement?

Learning about Representation Agreements from a knowledgeable worker (e.g. from an FASD Key Worker) and/or from the Nidus website was said to be very helpful according to participants in this project. As one participant stated:

> *I read through all the information on Nidus' website. I liked that Nidus didn't have an agenda.*

How was the adult involved in the process of making a Representation Agreement?

In this project, the adults who were involved in making a Representation Agreement appreciated that they needed ongoing support and advocacy – someone who could 'go to bat for them'.

According to each of the representatives, when the adults learned about Representation Agreements, the adults liked the idea that a Representation Agreement enabled their personal supporters to help them access services and to speak up for their rights and safety.

The adults were involved in the process of making their Representation Agreement in a number of ways. With the assistance of personal supporters, one of the adults read through all the information that was available through the Nidus website. The adults were involved in the process of choosing their representative(s) and in communicating with the representative(s) their preferences – what they wanted to have happen in their life. According to the representatives:

> *[My former foster daughter] isn't really literate. She functions at a Grade 3 level; but, she is a self-advocate by telling me what she wants. That's the crucial piece in this. …I gave her the draft Agreement to read. I made sure that she read it. [By having a*

> *Representation Agreement] there was a great sense of relief for her, like 'Mom is going to help me. Mom has a way of helping me.'*
>
> *My son was involved. It was for him. He was included in the whole process.*

Who was involved in the process of making a Representation Agreement?

The representatives sought information and assistance with making the Representation Agreement from staff at Nidus, and in one case also the FASD Key Worker in the community.

In terms of who was chosen to be the representative(s), in one situation it was the adult's former foster parent along with the former foster parent's adult children. In the other situation, the adult's mother and members of the adult's extended family were chosen as representatives, with the role of monitor being undertaken by a longtime friend of the family who also was very knowledgeable about FASD.

What was the best thing about the process of making a Representation Agreement?

In this project, there was consensus amongst those interviewed that the help received from the staff at Nidus was extremely valuable and made the process of making a Representation Agreement a good experience. In both situations, the process of making the Representation Agreement required multiple phone discussions and lots of communication to ensure that all documents were properly completed and signed, and that the wording in the Agreements was appropriate and respectful.[4] In the words of the personal supporters:

> *I was really impressed with the ladies at Nidus. They were kind and patient. You have to be so careful with words. The wording is so important. [The staff at Nidus are] so patient. They're top notch.*
>
> *[The best thing was] the support. Being able to do it with the staff at Nidus. They walked us through it; they helped me. They were available to answer questions.*

Were there any challenges or barriers to the process of making a Representation Agreement?

One representative reported that there were no challenges in making the Representation Agreement. This person again emphasized that the support she received from the staff at Nidus and Nidus' written information available on the website were instrumental in ensuring that the process was smooth and accessible.

By contrast, the other representative acknowledged that she experienced challenges. However, in this situation the challenge was primarily emotional and had to do with coming to terms with

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[4] To address the lack of knowledge and stigma related to FASD, Nidus used the Representation Agreement to provide context for the adult's situation. Nidus created a section called "Purpose of this Representation Agreement" and individualized it to the adult's experiences living with FASD. Nidus also helped to individualize preferences and wishes.

the reality that the adult she supported would always be vulnerable and likely would face lifelong difficulties of a potentially serious nature. In her words:

> *There were [challenges] for me. You have to be totally honest about your real situation. One thing that I've found with handicapped people is that they lay their shortcomings out on the table.*

What has been the experience of using the Representation Agreement?

Representatives spoke of having success in using the Representation Agreement. The degrees of success varied, as did the situations in which the Representation Agreements were used. In one situation, the Representation Agreement was used to enable the adult's representative to advocate on the adult's behalf in relation to her living situation based on her health needs and living preferences. With the Representation Agreement, the representative helped the adult's voice to be heard in the decision in response to the proposal by staff that seemed linked to challenges dealing with the adult's behaviour. From the perspective of the adult and the representative, this was a very positive outcome.

According to the representative, following the making of the Representation Agreement, both the adult and the representative were treated more respectfully by residence staff. The Representation Agreement provided concrete evidence that the adult had personal supporters who were watching out for her.

As well, the Representation Agreement permitted the representative to be present in care planning discussions, which is important for communication purposes, transparency and good decision making process. It allowed the representative to share valuable information about the adult's seizures and life with FASD. The representative was able to report on the positive effects of the adult's current living situation and on the ways the adult expresses this to her former foster family, which may not be so evident to those involved in the day-to-day.

> *They are treating both her and me differently because they know there is someone there watching. The Representation Agreement has legal weight. …The whole point of the Representation Agreement for me was to make sure that she wasn't moved from the group home. I think the staff there now realize that she can't be on her own. It's worked out well for us. It was a godsend in [her] case.*

The experience of the other family involved using the Agreement in a number of situations and systems. For example, the Representation Agreement was helpful in allowing the adult's representative (his mother) to help the adult manage his finances, which he had been asking his mother to do. The Representation Agreement also enabled the representative to be present and to support her son during medical appointments, which had not been permitted by doctors in the past.

Moreover, given her legal status as a representative, she gained the strength needed to put in a formal complaint against a doctor whom she believed made racist comments about her family. She said:

> *The Representation Agreement has been helpful in financial matters - for example with banks and loans - and for medical issues. I told off a doctor who was racist and threatening. We put in a complaint against that doctor. In the past I've not been able to come into my son's appointments.*

At the same time, this representative did not believe that the Representation Agreement was respected by the legal system and professionals (e.g. lawyers) or by staff at an addictions treatment facility. In terms of the legal system, the representative perceived that lack of understanding and stigmatization of people with FASD were at the root of the lawyers' ignoring the Representation Agreement even though it would actually enable the adult to be better represented by his lawyer.

> *The lawyer wouldn't accept it. 'No one cares about FASD', the lawyer said. My son lost his case and had to spend two weeks in jail. My words didn't matter to his lawyer or to the probation officer. They think I'm making excuses for my son. But I don't, I'm the first one to make him be responsible for his actions.*

Ultimately, a positive outcome of this situation was that the adult's lawyer came to treat the adult and his representative with additional respect because the lawyer saw that the adult had a support network behind him.

> *So… the Representation Agreement wasn't successful with most lawyers, though it was with one lawyer. And I wasn't expecting this one lawyer to pay attention to me and to the Representation Agreement, but he did in court. He acknowledged my son's social support network and the fact that my son had a Representation Agreement.*

Following initial discouraging experiences, this representative emphasized that the Representation Agreement has led to positive outcomes for the adult (her son). Through her legal status as a representative, she was able to educate service providers' about FASD as a lifelong disability. In her words:

> *I've been able to use the Representation Agreement. I am able to go into the mental health, treatment and counselling centres. We do that together now. My son also now has a new doctor and a lawyer who recognizes Representation Agreements – finally – and the disability of FASD. We've got to keep advocating for people with FASD.*

What could improve how Representation Agreements are used and recognized?

Representatives commented on the need for greater awareness about the existence of Representation Agreements amongst community members and service providers from all sectors.

In this regard, it was suggested that funding be available for information sessions in communities across B.C.

One of the representatives noted that she had not been aware that she could continue to contact Nidus after the Representation Agreement had been made; thus, she thought it was important that community members understand that Nidus is available to support adults and their representatives and monitors before, during and following the process of making a Representation Agreement.

Section 3: Conclusions and 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.

Section 4: Information about Adult Guardianship in B.C.

In B.C., adult guardianship is governed by the *Patient's Property Act* and is called Committeeship. Committeeship can happen in one of two ways: 1) by court order or 2) by a Certificate of Incapability, signed by the director of a provincial mental health facility which includes most public hospitals. Both routes require a finding that the adult is 'mentally incompetent' and subsequently, the adult's decision making rights are taken over by another party.

In the case of a court order, a private party, which is usually a family member, may apply to court to become Committee of Estate (i.e. guardian). If a judge finds the adult mentally incompetent of managing his or her own affairs, the Committee would then take over the adult's financial and legal affairs. Similarly, Committee of Person gives someone authority over the adult's health care and personal care if the judge finds the adult mentally incompetent to manage his or her own care.

In the case of a Certificate of Incapability, the focus is only on the adult's mental incompetence to manage his or her financial and legal affairs. Under a Certificate, the Public Guardian and Trustee (a state official) becomes Committee of Estate and takes over the adult's financial and legal affairs.

Adult guardianship views decision making as an independent activity that relies on cognitive ability. It sees mental competency as 'all or nothing' and imposes a plenary approach in granting decision making authority. That is, it does not matter if the adult can manage his or her daily spending money or can do banking with assistance; if a Committee of Estate (guardian) is in place, the Committee has authority and responsibility for all of the adult's financial and legal matters. Being declared mentally incompetent through the legal procedures of adult guardianship results in the adult's loss of civil rights and personhood and is difficult to reverse.

B.C.'s law reform that created the *Representation Agreement Act* was guided by a set of principles, one of which was that adult guardianship "must be the absolute last resort." [5]

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[5] B.C.'s law reform produced a package of four new Statutes with the *Representation Agreement Act* as the foundation of reform. A new *Adult Guardianship Act* was passed to reform adult guardianship procedures based on the law reform principles. The reform provisions outlined in the *Adult Guardianship Act* abolished the Certificate procedure and plenary authority by introducing limits on court-appointed decision-makers (including the Public Guardian and Trustee) by time and task. These amendments were never proclaimed and have been rewritten (passed but not yet in effect) to put aside reform in favour of a makeover of the *Patients Property Act* in the image of Ontario's 1992 legislation. Such emulation retains the traditional approach, including the Certificate procedure, plenary authority and loss of personhood. It also entrenches the medical model, which emphasizes illness and disability rather than supporting capability and strengths.

Section 5: Information about Nidus and Project Staff

Nidus Personal Planning Resource Centre and Registry

Nidus (formerly known as the Representation Agreement Resource Centre) was established in 1995 by the citizens and community groups who were involved in the reform of adult guardianship legislation. Nidus is a non-profit, charitable organization serving the province of British Columbia.

Nidus promotes alternatives to adult guardianship and provides education on B.C.'s legal planning tools. Nidus also operates a centralized Registry for personal planning documents, in partnership with the Law Society of B.C.'s Juricert Program.

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

Joanne Taylor (Executive Director, Nidus)

From 1993 to 2000, Joanne was volunteer chair of the community-based Representation Agreement Task Group, the only planning and policy group focused on the *Representation Agreement Act*. She is also a founding member of the Representation Agreement Resource Centre (R.A.R.C.) and in 2000 was hired as Executive Director of the R.A.R.C., now called the Nidus Personal Planning Resource Centre.

Joanne represented the R.A.R.C in the consultation group that produced amendments to the *Representation Agreement Act Regulations* enacted in 2001. She coordinated community input to government in response to legislative reviews and most recently produced a policy paper with recommendations that formed the basis of the *Adult Guardianship and Planning Statutes Amendment Act*, 2007.

Deborah Rutman, PhD (Principal Researcher)

Deborah is a registered psychologist who specializes in research and program evaluation. She worked as the Psychology Fellow in a multi-disciplinary Competency Clinic in Ontario, has undertaken research on the interface between Mental Health law and psychiatry, and was involved in the reform of Adult Guardianship legislation in B.C.

Deborah is an Adjunct Associate Professor with the Faculty of Human and Social Development at the University of Victoria; her current/recent UVic-based projects focus on: support issues for (young) adults with Fetal Alcohol Spectrum Disorder; substance use during pregnancy; and young people's transitions from government care. As a consultant, Deborah and her colleagues at Nota Bene Consulting Group have undertaken a number of evaluations of programs providing support for children, youth or adults living with FASD, including the B.C. Key Worker and Parent Support program.

For more information:

Representation Agreement Act and Regulation at
www.bclaws.ca

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Section 6: Resources on Fetal Alcohol Spectrum Disorder

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Malbin, D. (2002). *Trying Differently Rather Than Harder, 2nd Edition*, Portland, Oregon: FASCETS.

Stratton, K., Howe, C. & Battaglia, F. (Editors) (1996*). Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment.* Committee to Study Fetal Alcohol Syndrome, Institute of Medicine. Washington, DC: National Academy of Sciences.

Streissguth, A., Barr, H., Kogan, J. & Bookstein, F. (1996). *Understanding the occurrence of secondary disabilities in clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Final Report to the Centers for Disease Control and Prevention (CDC).* Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06.

Relevant Websites:

FASD Provincial Outreach Program
http://www.fasdoutreach.ca/

FASD Connections Serving Adolescents and Adults with FASD
http://www.fasdconnections.ca/index.htm

Canada Northwest FASD Research Network
http://www.canfasd.ca/