Overview of webinar

- Introduction
- What is Fetal Alcohol Spectrum Disorder (FASD) & how does it affect people?
- FASD & Employment
- What helps people with FASD on the job: Promising practices and approaches
- Tuning in to FASD: Applying promising practices in your work setting
Introduction

Webinar is based on *Adults Living with FASD* project.

Research & video production project aimed to:

- Explore the challenges, accomplishments and support needs of adults with FASD, particularly in relation to:
  - **Employment**;
  - **Parenting**; and the
  - **Criminal Justice System**.

- Identify promising approaches, practices, programs & policies that better address needs of adults with FASD.
What is Fetal Alcohol Spectrum Disorder?

FASD is an umbrella term describing several diagnoses including:

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (pFAS)
- Alcohol-Related Neurodevelopmental Disorder (ARND)

FASD is a brain-based, invisible physical disability with behavioral symptoms (Malbin, 2011).

FASD is caused by prenatal exposure to alcohol.
Complexity of FASD: Prevalence

- Until several years ago, estimated prevalence in North America:
  - FAS: 1 in 1,000 live births
  - FASD: 1 in 100

- Thus, 350,000+ people living with FASD in Canada

- Most recent estimates:
  - FASD: 2–5 % of the population

Even at this high reported rate, the true occurrence of FASD is suspected as being higher...
Complexity of FASD: Under-diagnosis

- Whether we know it or not, as community service providers, we are often working with people who have been prenatally exposed to alcohol.

- The disorders associated with prenatal exposure to alcohol remain underdiagnosed and under-recognized.
Key Information about FASD

- Because FASD is about brain damage, it is an invisible disability.

- It also is a permanent disability – effects won’t go away over time.
Key Information about FASD

- Developmental age is far younger than chronological age
Key Information about FASD

Primary effects of FASD (Streissguth et al, 1996; Conry & Fast, 2000)

- **A**daptive functioning
- **L**anguage
- **A**ttention
- **R**easoning
- **M**emory

- Individual differences – particularly in relation to behaviour - are paramount.
Secondary/Tertiary effects of FASD…
Secondary Behavioural Symptoms (Malbin, 2008)

➢ Fatigue, frustration, anxiety, poor self-esteem, feeling isolated

Tertiary effects (Malbin, 2008) / a.k.a. Secondary effects (Streissguth et al, 1996)

• Mental health problems (90%)
• Problems with employment (80%)
• Not completing high school (60%)
• Troubles with the law (60%)
• Drug and alcohol use/addiction (30%)
Strengths of people with FASD

- Outgoing, caring, helpful
- Hardworking
- Determined, persistent
- Expressive language skills
- Artistic, musical, creative
- Good with computers
- Good with animals and/or children

Source: Diane Malbin/FASCETS (www.fascets.org)
“FASD and Employment: Supporting Adults with FASD on the Job”

Project Methodology:

- 5 communities in BC
- In-depth, face to face qualitative interviews, most of which were videotaped
  - 15 adults (prenatally exposed to alcohol)
  - 8 support people
  - 37 service providers
FASD & Employment: Success experiences

“Melanie’s” story

I am working in a video store. It’s been a great experience. And this has been really one of the first jobs that I’ve had that I really felt comfortable and haven’t wanted to quit after the first week.

Melanie’s key strategy:

• Writing out all the job tasks, step by step, using recipe cards:

So I got out my recipe cards and I made (my boss) go through every step with me. Now it’s just a comfort to know that those are in the drawer if I ever need them.
FASD: Challenges to Employment

Primary effects of FASD

• Memory problems
• Generalization
• Planning & organization
• Time
• Language & communication
• Anger/patience & impulsivity

I do better when I know the routine of what I am doing.

- Adult with FASD, “FASD & Employment” project
FASD: More Challenges to Employment…

Secondary effects of FASD / Social Determinants of Health
FASD: **Barriers** to employment…

FASD as an invisible disability

- Lack of understanding of FASD leads to over-estimation of abilities and unrealistic expectations

  *Everyone assumes that you’re ‘normal’. But the reality is that you have a significant learning disability.*

- People with FASD often appear to be **NURMU** (Dubovsky, 2005)
  - Non-compliant
  - Uncooperative
  - Resistant
  - Manipulative
  - Unmotivated

FASD & Employment: Strategies for Success

- Simple, concrete communication
- Break down how to do a task, step by step
- Show how to do the task (visual learning)
- Memory aids (write everything down)
- Shifts at the same time and day, if possible
- Supportive and flexible employer

Very plain and clear instructions (work best). The more cut and dry, the better. That way I know what is expected of me.
- Adult with FASD

It’s really helpful for me to have someone say, ‘This is what you do, I’ll show you how to do it’, as opposed to ‘This is what you need to do, here’s a sheet.’
- Adult with FASD, “FASD & Employment” project
FASD & Employment: 
Suggestions for Supported Employment programs

- FASD-related training for employers
- Provide assistance in completing application forms
- Role playing of the job interview & dealing with anger
- Advocate for shifts at the same time/day
- Reminder calls and transportation
- “Communications Book”
FASD & Employment: Suggestions for Employers

- Shifts on the same day/time, if possible
- Gradual entry into the job, if possible
- Job shadowing
- Buddy system on the job
- Assistance with transitions during the day
- Reminders and check-ins on an ongoing basis
- Work environment as free of visual distractions as possible
- Paying wages as direct deposits
Tuning in to FASD…

If FASD is a largely “invisible” disability, what are clues *in your work setting* that a employee might have FASD?
Reframing views on behaviours a.k.a Paradigm Shifts & FASD (Malbin, 2008)

<table>
<thead>
<tr>
<th>From:</th>
<th>To:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Won’t</td>
<td>Can’t</td>
</tr>
<tr>
<td>Trying to make me mad…</td>
<td>Can’t remember</td>
</tr>
<tr>
<td>Lazy</td>
<td>Tries hard</td>
</tr>
<tr>
<td>IS the problem………</td>
<td>HAS a problem</td>
</tr>
<tr>
<td>Doesn’t try…………….</td>
<td>Tired of failing</td>
</tr>
<tr>
<td>Doesn’t care…….</td>
<td>Can’t show feelings</td>
</tr>
<tr>
<td>Bad</td>
<td>Frustrated, challenged</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Diane Malbin/FASCETS (www.fascets.org)
Parting Messages

For adults living with FASD:

- Be open and honest with employers and say, “I have FASD and this is what it is.”

- Believe in yourself and believe you are someone worthwhile.
Parting Messages

For employers, service providers, community members

- Educate about FASD, involving those with FASD as educators
- Shift our expectations
- Recognize cost effectiveness of ongoing support for adults who (may) have FASD

Know that adults affected by FASD are not lazy or stupid or unmotivated. They just have special needs. Get to know them, talk to them, and they will let you know what their needs are.
Resources & contact info

Deborah Rutman, PhD
Nota Bene Consulting Group
&
School of Social Work, UVic
drutman@uvic.ca
www.notabenegroup.ca

The FOCUS Program:
A Program for Adults with FASD
By Linda Schmidt
http://www.cnc.bc.ca/visiting/cnc_pres.htm