Enhancing Employment Supports for

Persons Affected by

Fetal Alcohol Spectrum Disorder

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Community Futures Treaty Seven

Facilitators:

Johnathon Red Gun

Sean McEwen

Diane McGregor

Day 1:

Understanding and Supporting Youth and Adults with FASD

Facilitator: Diane McGregor

Understanding and supporting people living with FASD means changing the way that **WE** *think and behave.*

FASD Awareness:

Characteristics and Challenges

"When I first heard about FASD, I was like, so what…FAS, FAE, ADD, ODD…I figured if it was a disorder, then I had it!"

Peter,

Young Adult with FASD

Fetal **A**lcohol **S**pectrum **D**isorder

The language we are now using to describe the range of possible effects that can occur when a fetus is exposed to alcohol.

FASD is not a diagnosis—rather, it is an "umbrella" term that characterizes a *spectrum* of disorders.

The spectrum encompasses effects that range from severe growth, intellectual and physical deficits to apparently normal growth, facial and intellectual abilities.

Life long challenges.

Other Terms and Acronyms

- FAS
- FAE
- ARND
- NDBD

- ADD
- ODD
- CD

How is FASD caused?

Prenatal exposure to alcohol.

Alcohol is a neurobehavioral teratogen: an agent that raises the incidence of congenital abnormalities.

Many teratogens: x-rays, heavy metals (lead), thalidomide, cocaine…most recently, BPA

Alcohol is the most pervasive.

FASD is 100% preventable.
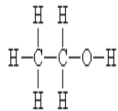
Is it really???

Alcohol reaches the embryo or fetus by passing through the mother's blood.

It crosses the placenta and enters the fetal bloodstream.

It can then pass into all developing tissues.

Alcohol Impacts the Formation of the Brain during Fetal Development

Cell production
Cell death
Cell mobility
Cell migration

$$H-\overset{\overset{\displaystyle H}{|}}{\underset{\underset{\displaystyle H}{|}}{C}}-\overset{\overset{\displaystyle H}{|}}{\underset{\underset{\displaystyle H}{|}}{C}}-O-H$$

This affects the size, organization and structure of affected areas.

Areas of the brain that appear to be most affected by prenatal exposure to alcohol

Corpus Callosum
Hippocampus
Cerebellum
Prefrontal Cortex

A Spiritual Perspective

The baby's spiritual connection to his/her mother can be disconnected when she uses alcohol during the pregnancy.

The baby is not able to grow in an environment of peace and security – the development of a healthy, calm baby is thus Interrupted.

Aboriginal Approaches to Fetal Alcohol Spectrum Disorder
Special report of the Ontario Federation of Indian Friendship Centers

2002
www.ofifc.org

**Factors that
Increase Risk
of
Fetal Susceptibility**

**Health
Factors**

• Birth order (>3 previous births)

• Maternal age >30 years

• Maternal stress

• Maternal health factors, malnutrition, pre-natal care

Substance Use

•Co-occurrence of maternal smoking and/or drug use

•Chronicity of maternal alcohol consumption

•Timing and amount of dose: chronic exposure, binge drinking (5-7 drinks), occasional exposure.

•No reduction during pregnancy

Family and Social Factors

•Drinking behavior of others in the home, including the father/woman's partner

•Loss of other children to foster or adoptive placement

•Social network/community that supports drinking behaviors

Clinical Features of
Fetal Alcohol Spectrum Disorder

(from Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis, *CMAJ*, 2005)

1. Confirmed maternal alcohol exposure

2. Evidence of a characteristic pattern of facial anomalies

3. Evidence of growth retardation

4. Evidence of central nervous system neurodevelopmental abnormalities that result in behavioral or cognitive challenges that are inconsistent with developmental level and cannot be explained by familial background or environment alone.

Neurobehavioral challenges:

• Learning disabilities (particularly in mathematics)

• Delays in language and motor skills

• Problems with executive function and working memory

• Difficulties understanding and processing complex information

• Impairments in adaptive functioning (particularly social competence)

•ADHD present in approximately 70%

• Mental health problems, particularly anxiety and depression

Current Myths and Misconceptions

Myth: People with FASD suffer severe intellectual impairment.

Fact: We now know that fewer than 50% of individuals are intellectually disabled. Most people diagnosed with FASD have IQ scores within the average range and many score above average.

Myth: People with FASD show distinctive facial features.

Fact: Approximately 12% of people with FASD evidence overt characteristics of the "FASD face".

In fact, the facial features are primarily associated with individuals who are most severely affected.

Because of these beliefs, many individuals go undiagnosed.

This also means that assumptions and judgments are made about a person's behaviors and motives when the real truth is an underlying neurological disability.

Myth: People with FASD will never be able to live independently and will require constant supervision thorough-out their lives.

Fact: While the journey can be very challenging for many individuals with FASD, many, many, many people create lives of meaning and purpose….including long term employment, having families, developing strengths and abilities,

"Growing up, like my Dad literally said, 'Oh, you can never have kids. Never support kids. You can never have this. You can never do that'. Well, I am going to prove him wrong!"

Allan, 19-year-old man with FASD

"When I was a baby, my parents were told that I would never be able to learn and that I would never be able to take care of myself. I guess they were wrong."

Jane, 28-year-old woman with FASD

"Never say never!"

Is There One FASD Profile?

FASD is a complex neurodevelopmental disorder that involves an array of biological, environmental and psychological factors.

(Gibbard, W. B., Alberta Children's Hospital)

This means that…

…no one explanation or diagnosis accounts for the array of challenges people face,

…no one intervention or program or treatment can make everything right,

…and, no two people are alike.

Take Another Look: FASD Our Way!

Video written and produced by

Kaleidoscope Participants

Growing Up with FASD

We are all a human puzzle, but we didn't get all the pieces when we were born. It's up to us to find the other pieces and complete ourselves.

Myles Himmelreich,
Public Speaker, Peer Mentor

Prognosis and Life Course

- The cognitive and behavioral effects persist into childhood and early adulthood, leading to a poor prognosis over the life span.

- The risk of adverse life outcomes is doubled for those with more subtle effects as early diagnosis has been identified as a protective factor.

Secondary Disabilities

Prevalence of Secondary Disabilities Across the Life Span

ages 6-51 (n=408-415) ages 21-51 (n=89-90)
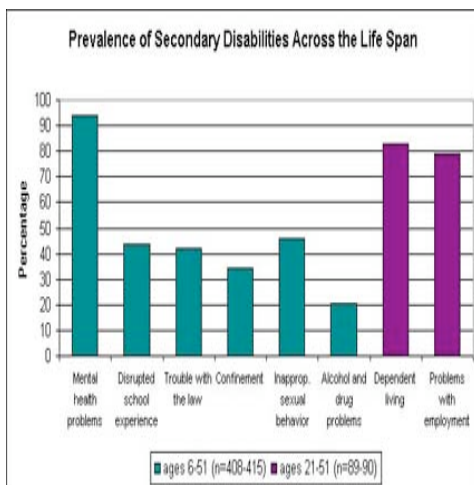
Source: Streissguth, A. University of Washington

Childhood for a Person with FASD: "Pretty normal" or "pretty wild"?

- Often describe self as "just a normal kid"

- Often identify a range of behavior challenges but they do not talk about these behaviors as "problems"

- They are just things kids do

  "I got in trouble lots for the stupid things normal kids do."

Behavioral problems typically start in early childhood although often are not identified until child enters the school system.

Aggression
Hyperactivity
Impulsivity
Inattentiveness
Early learning problems
"Drive teacher nuts"
Poor sleeping and eating habits
Medications
Special programs--learning and/or
    behavior

Into the Abyss: When 'pretty normal' ends.

Although childhood may have seemed "pretty normal", adolescence is a terrible struggle.

Peers

Bullied
Feel weird
"Used"

Longing for belonging
Do anything to connect

"what is wrong with me"

School

Begins to break down in Jr High
Problems with teachers
Can't do the work
Failing grades
Special placement
Moves make it difficult to fit in

By high school, they are skipping or missing most classes

Core credits not attained

Home

Arguing
Fighting over HW
Sneaking around
Withdrawal
Ineffective Discipline
Nothing really works
"Stupid Rules"

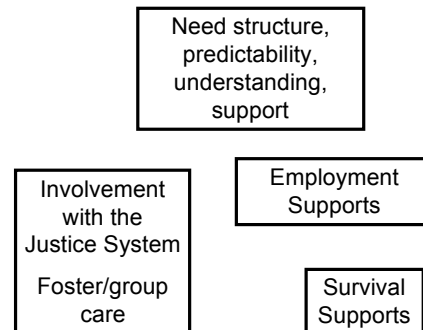Out of home placement?

Later Adolescence/Early adulthood
(16 - 29, approximately)

1. Struggle and Survival

- In and out of school--In and out of work
- Leave home, return for brief periods: *kicked out or choose to leave?*
- Live on welfare or other government support
- **Onset of significant addictions or substance abuse problems**
- Depression, loneliness and feelings of hopelessness.
- Thoughts of suicide or make suicide attempts during this time.
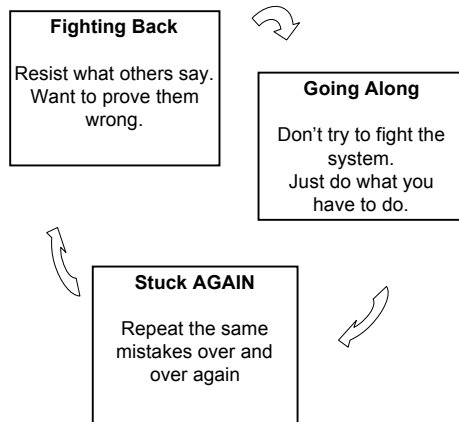- "I should be dead by now"

Reject Support

Don't want help.
Don't like the help that is offered,
"it doesn't fit for me".
Don't like the rules or conditions of programs or services.
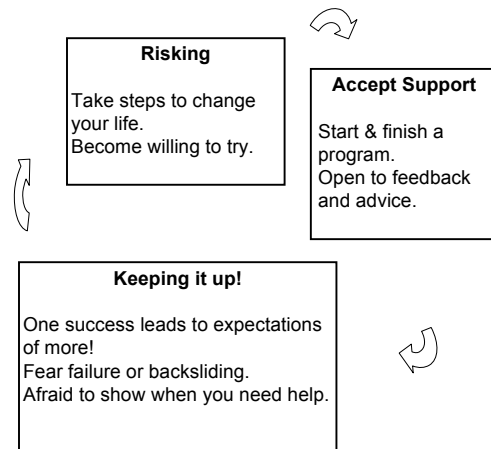Start things only to fail.

Need structure, predictability, understanding, support

Involvement with the Justice System

Foster/group care

Employment Supports

Survival Supports

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2. Searching

The struggle to survive becomes a search--a search for something, anything, that will make a difference.

Fighting Back

Resist what others say. Want to prove them wrong.

Going Along

Don't try to fight the system.
Just do what you have to do.

Stuck AGAIN

Repeat the same mistakes over and over again

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3. Trying, REALLY Trying

There is a shift now, toward a willingness to try to do things differently. To accept the supports that are available.

Risking

Take steps to change your life.
Become willing to try.

Accept Support

Start & finish a program.
Open to feedback and advice.

Keeping it up!

One success leads to expectations of more!
Fear failure or backsliding.
Afraid to show when you need help.

What makes the difference?

Getting Chances

• Getting the chance to do it again

• Needing chances does not mean the person can't learn.

"If we make the same mistake 50 times over, just say, Hey! You made a mistake 50 times over. It's not over yet though. Try 51!"

Allan

Someone to believe in you when you don't.

• Someone who can see past the problems you are having.

• Someone who will stick with you even when they shouldn't.

• Someone who keeps you accountable without judgment or punishment.

Emerging Adulthood: Late Teens through the Twenties.
(Arnett, 2000)

• Traditionally, a time when we define who we are and want to be into the future

• Completing education, establishing a career, creating one's own family

• Should be a time when the young person will take on more demanding roles, develop the skills and personal strengths to cope with those roles and find meaning and purpose in the roles they adopt

• ……however the "timing" of these accomplishments has changed considerably

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Young people of today face a very different world from that of their parents and grandparents….

Now, "emerging adulthood" has become a period of exploration and "milling about".

Can also be a period of "floundering".

What are the experiences of youth in your communities?

The Good News:

By the mid 20's, there is another shift in the development as young adults tend to become more actively engaged in creating a deliberate pathway for themselves.

Emerging information about significant neurological growth and re-wiring during this time sheds light on why and how this happens.

Neurological Re-organization

Increase in myelination of white matter tracts (connective tissue) particularly in the frontal-temporal connections

Neurological Re-organization

Reduction of grey matter density through pruning of overproduced or "weak" neurons

Changes are in the parts of the brain responsible for higher order processing such as executive functioning, abstract thinking and complex reasoning.

Corpus Callosum
Hippocampus
Cerebellum
Prefrontal Cortex

An Emerging Developmental Pathway….

"Pretty Normal" Childhood

Adulthood

The Abyss of Adolescence

Trying

Searching

Surviving
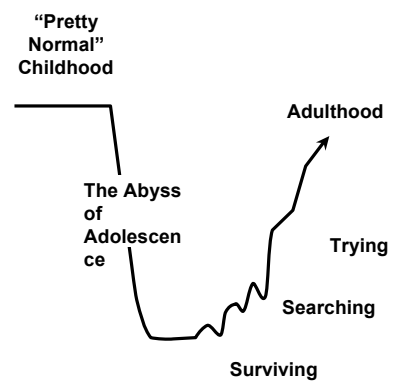
Into Adulthood: The Ongoing Struggle

Battle many of these issues for the rest of their lives.

Still need support.

Still need someone to believe in him or her.

Still need chances to try again .

Engaging Youth and Adults with FASD

I learned about FASD last year.

I grew up mostly ADHD and now I am like, FETAL Alcohol Syndrome!

Oh, crap!

How is THAT? How did I get THAT?

Allan,

21 year old man living with FASD

Embracing Possibility:

4 Pathways to Engagement

Meaningful support for a youth or adult with FASD and their families, teachers, employers and support networks requires an **"attitude of possibility".**

This means that we…..

1. "Walk the talk" of strength and ability.
2. Stay alert to developmental factors.
3. Hold onto hope.
4. Recognize resilience.

1. Strengths-Based Focus

- *A*bility not *Dis*ability
- Building on strengths and competencies
- Identifying barriers to success vs needs and deficits
- Developing the skills to navigate the barriers as they arise
- Finding and supporting unique ABILITIES
- "Raising the roof" on potential
- See past the problems you.
- Maintaining accountability without judgment or punishment

2. Developmental Awareness

- Paying attention to developmental factors

- A combination of lingering adolescence and delayed adulthood

- **"Developmental oscillation"**—development is not a linear progression. It is like a dance…two steps forward, one step back…with a little doh-see-doh of individuality

- Respect the pace of learning and growth

- Narrowing the gap between opportunity and readiness

3. Hopeful Perseverance

- Hanging in there through the tough times, the set backs, the times of hopelessness
- Resisting traditional approaches for managing challenging behaviors
- Planning for tomorrow
- Starting again, tomorrow
- 50 + 1 Chances

4. Discovering Resilience

Resilience: "….positive adaptation in the context of risk or adversity"
Ann Masten, 2001

- Self-advocacy---telling our life stories
- Resilience in self narrative
- Discovering and connecting with others
- Developing skills---coping, problem solving, self regulation, life skills
- Resisting assumptions of inability
- Understanding and learning about FASD

Day 2:

Service Delivery & STRATEGIES

Facilitator: Sean McEwen

THE EMPLOYMENT SERVICE CONTINUUM

History & Development

- Supported Employment started in the early 70s as part of a trend towards community-based service for people with intellectual disabilities.

- Combines the principles of Career Development Theory, Counseling techniques and Disability Services Best Practices (dignity, person centred, informed choice,

Supported Employment:

Supported Employment is the term used when referring to *assisted*
- career exploration,
- employment placement
- and job retention services
  for persons who need support to be successful in the achievement of these goals.

Supported Employment initially started to serve people with intellectual disabilities.

Supported Employment??

- -What is meant by Support?
- -What will a job seeker with a disability need to reach their goals?
- -What are the resources required to do this effectively?
- -What will the employer need to know?
- -What are the indicators for success?

Service Strategies & Interventions:

- Intake and Assessment
- Career Exploration
- Employment Preparation
- Job Search & Placement
- Employer Support and Education
- Follow-up and Retention Supports

Assessment & Disability

- The primary issue is the person's current **abilities** – not abstract diagnostic info
- Encourage discussion and exploration around strengths and limitations (addressing issues of emotion and acceptance as they arise)
- Career practitioners **need** to know the strengths and limitations of their clients
- Self awareness is critical for our success

Possible Indications Of Disability:

- Limited literacy, vocabulary and comprehension

- Limited success in academic history (special ed.)

- Difficulty focusing, remembering meetings etc.

- Agitation, anxiety, (medications, hospitalization)

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- Poor social competency / communication

- Irrational fears – overly rigid behaviours / interactions

- Most people with disabilities have some previous assessments which can be accessed with their consent (intellectual and mental health disabilities in particular).

- Source schools and medical / psychological resources

Talking To PEOPLE About Disability

- A disability is **part** of the person – not the sum total of who they are
- A disability is not who you are – it's a barrier that you learn to work around.
- Diversity leads to solving problems in new ways.
- Difference / Diversity makes the group stronger.
- Einstein, Lincoln, Mozart, Van Gogh etc. Disability doesn't mean you can't succeed

Multiple Barriers To Employment

- Poverty / limited resources (transportation etc.)
- Post-Traumatic-Stress / Esteem Issues
- Addictions / Substance Abuse
- Cultural differences and family / work values
- Fear, racism - Shame
- Family Dysfunction

Multi-Barrier clients –assessment:

We want to help everyone find a job but,….

- How functional / engaged is this person right now?
- Should our agency recommend them for hire?
- Do we have the resources to meet his/her needs?
- What criteria would need to be met for service?
- What **other resources** should be enlisted?
- What if any service elements **could** proceed now?

Multi-barrier clients – strategies:

- Address the issue and ensure the client is invested in becoming safe, reliable, healthy etc
- Develop an 'employability plan' **with** the client
- Set criteria for success and timelines
- Enlist other resources, services, supports
- Provide what services are appropriate
- Provide encouragement and

Strategies for supporting stability

- Set 'standing meetings' to simplify engagement and measure punctuality etc. (chances and reminders required)
- Identify 'steps and time-lines' (Eg. a phone and address by Dec 01, WHMS Training by Jan 01)
- Identify 'social assets' (relatives, mentors, spouse, etc. helpful people with positive influence)
- Identify and facilitate connection to other required

Employability Planning

'Jack' is 21 and presents with undiagnosed issues which affect his attention and ability to organize himself. He has been told that his mom drank during pregnancy and that he has learning disabilities. Jack has been couch-surfing at friends' homes and partying for the last couple of years but is growing tired of this lifestyle. He wants to get a job and a place of his own. Jack is close to his girlfriend's family and his uncle and aunt; he thinks he could stay temporarily with them.

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Task / Step	Supported By:	Time-Line
Residence required	Uncle – Housing Resources	Immediate & 3 - 6 months
Treatment ?	Girlfriend – Treatment Program	Immediate
First Aid Certification	Us - Referral	By February 01, 2012
Health & Safety Training	Us - Referral	By February 01, 2012
Driver's License	Uncle – CASS Program	By February 01, 2012

Multi-barriers – professional advice;

- Be aware of your own biases & their affect on you
- You're here to help not to judge – stay positive
- Never be **more** invested in a person's problems than they are – causes resentment and burn-out
- You're Employment Support – get help with the rest
- Not everybody is ready for what he have to offer right now – be patient and don't beat yourself up

Intake –Best Practices

A   When meeting an individual seeking service, provide him or her with as much information as possible about the nature, strengths and limitations of the service.

B   Explore the person's support needs & goals.

C   Establish expectations, time-lines, and criteria for personal success.

The initial meeting should focus on the services you provide and the client's goals and support needs. Is this a good 'match?'

The following issues are usually explored during this Intake and at later meetings:

- What is this person's previous training / work history?
- What previous experiences did they enjoy / not enjoy – why?
- What kind of work is the person looking for? – and why?
- How many hours per week / per day?
- What locations / times of day are preferred?
- What current life circumstances need to be considered?

…..continued:

•What current barriers and limitations exist? (disability, residential stability, health, behaviour etc.)

•How are these issues best overcome or accommodated?

•What does this person really want or need from the service?

Relationship-Based Supports

Most elements of supported employment are relationship driven. We develop relationships with…

- Clientele to better understand and support their goals
- Employers - in order to market the people we serve
- Supervisors & Co-workers - in order to maintain the job and develop natural supports
- Be familiar with the 'whole person' – get to know them (while maintaining healthy professional boundaries)

Trust and good communication are essential.

Basic Counselling Principles

- Active Listening
- Body Language
- Asking Questions
- Paraphrasing / Tone
  - Summary
  - Note Taking

Active Listening

- Active listening happens when you "listen for meaning". The listener says very little but conveys empathy, acceptance and genuine interest.

- The listener only speaks to find out if a statement (or two or twenty) has been correctly heard and understood.

Body Language – Some Things to Consider

- Posture – either strong or passive

- Positioning of feet (when standing) i.e. the amount of room you are taking up

- Hand / Arm position i.e. arms crossed, hands in pockets

- Open versus closed posture

Asking Questions

- The way we ask questions and the types of questions we use is extremely important in gathering information.
- Both open and closed questions can be useful for establishing rapport and helping us understand the person.
- They can help a person open up or close them down.

Paraphrasing

- Paraphrasing is when you tentatively **restate** what the person has said - conveying empathy, acceptance and genuineness.
- By doing this you are letting the person know that you understand and, if you don't, are willing to be corrected.
- AND you are helping them to "cut to the chase."

Summarizing

- Summarizing is when you focus on the main points of a meeting in order to highlight them.
- At the same time you are giving the "gist", you are checking to see if you are accurate.
- Your tone needs to imply that you are open to some changes in perspective.
- It's important the both the client and you are "reading

Professional Relationship Building

- Seek to understand the person,
- Ensure the message you are giving is consistent between your words, tonality and body language
- The person may not remember what was said, but they'll remember how you made them feel!

Career Exploration & BEST PRACTICES Planning

A The client's perceptions, capacities & aspirations are explored.

B It is demonstrated that the occupational goals for individuals in service were determined by those individuals through consultation with them.

C "Informed Choice" is facilitated in order to ensure that persons are fully aware of the range of options and supports available to them.

Career Exploration & Planning

BEST PRACTICES:

<u>D</u>   Conduct all assessment and planning in a manner which reflects person-centred support, choice and self-determination. Respect the client's time and preferences in this regard.

<u>E</u>   Foster and facilitate career goals within the context of an individual's lifestyle, non-work priorities, goals and commitments.

Exploration & Planning – Tools, and Resources

- Client Investment Plan / Action Plan
- Resume Development
- Job Site Tours
- Informational Interviews & Job Shadows
- Volunteerism / Skill Building
- Ability and Skills Profile
- Traits, Skills, Values & Interests Checklist
- ALIS website – Occinfo – Occupational Profiles
- Lots of discussion / listening

Pre-Employment – Ready To Work

Some clients will require some assistance to prepare for the interview process and integration into the workplace. Career practitioners can facilitate this preparation through strategies like

- Mock Interviews
- Workplace Culture and Expectations discussions
- Personal Presentation discussions

Job Development - Disclosure

Focus on your role as a human resource and placement service.

Employers are seeking competent, reliable staff and your clients represent an able human resource pool

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It is reasonable to advise employers, **during the course of conversation,** that you serve individuals with disabilities. It is also important to advise employers that your services include direct employment support and ongoing consultation to ensure that their performance expectations are met.

Specifics about the individual's disability, life circumstances, etc. should <u>not</u> be disclosed until such time as an interview with the client has occurred.

SELLING dis-ability – (job development)

- Think like an employer
- Make a 'business case' for hiring the client
- You are 'free H.R. & Recruitment Support'

The person I'm assisting is…
- Extremely interested
- Genuinely Passionate about working in your field – specifically at your company.
- Experienced, reliable, social, incredibly focused, etc

SELLING dis-ability – (cost / benefit)

Employers need to know…
- The hiring / firing rules are the same
- Performance & reliability are the same
- The Service Provider is their 'consultant'

Resource: The Conference Board of Canada –

Tapping The Talents of People with Disabilities

http://www.conferenceboard.ca/documents.aspx?DID=85

UNIVERSAL HIRING RULE…

Any employer will hire any applicant as long as he / she is convinced the person will bring more profit than they cost.

-Denise Bissonnette

Supporting integration & retention

- Inform & Train Employers / Mentors
- Expect issues to arise – have contingency plans
- Focus on social integration, skill development and work performance – concrete
- Use the strategies that work – discard the ones that don't.

Follow-Up & Retention Supports

C Evaluation of the work placement is based on two crucial elements; the employee's enjoyment / investment in the job – and their ability to meet performance and workplace culture expectations (with reasonable accommodation and support.)

Follow-Up supports include, but are not limited to…

  –Emotional support, goal setting and encouragement

  –Mediation, advocacy and conflict resolution

  –Helping to develop skills and social competencies

  –Development of natural supports in the work environment

Follow-Up Supports –Training & Orientation

Training approaches may consist of any or all of– but not limited to – the following…

- Discussion of goals and performance expectations
- Usual work-site orientation and training processes
- Involve supervisor / co-workers to demonstrate
- Job descriptions and/or list of duties for literate individuals

….continued

- Direct Support, Observation and Discussion of options / techniques
- Informal task analysis – breaking things down into smaller steps
- Modelling of the required tasks
- Encouragement, and praise of successes
- Setting small goals and challenges

Natural Support Definition:

- Those supports which are not paid for by a service provider agency but rather are offered freely and naturally as part of the workplace
- Connecting clients with existing social supports and training supports
- Utilizing co-workers as trainers and promoting **mentorship**
- Utilizing supports and strategies inherent to the workplace and its culture

Benefits of a Natural Support Approach:

- -increased social inclusion
- -more effective training
- -increased job retention
- -cost effectiveness
- -control and empowerment

Managing Natural Supports:

- Teach people about the support options available
- Provide information and ideas to clients and their natural supports
- Monitor goals and outcomes – provide assistance as required
- Remain accessible to clients and employers

Resources

- The Canadian Association for Supported Employment www.supportedemployment.ca
- The Alberta Association for Supported Employment www.aase.ca
- Training Resource Network www.TRNINC.com

- 30 Ways To Shine By Denise Bissonnette
- Working Together By Dale DiLeo & David Hagner