

IDEAS & STRATEGIES



4/1/2010

Building Success for Adults with FASD

Canada 

Regina
Community
Clinic 

Introduction

This booklet contains three presentations we offer employers, job coaches, and interested agencies that support individuals with FASD in our workplaces and communities.

FASD is a permanent brain injury that occurs during pregnancy. It is a disability that an individual is born with although it may not be diagnosed until later in life. It's also possible that it may never be formally diagnosed.

One of the biggest challenges of FASD is 'information processing disabilities.' That is, the struggle individuals often experience in understanding what they hear and read. The processing disability may be slightly different for each individual, and it is caused by the brain injury that occurs during pregnancy.

Two of the three presentations offer background, insight, and strategies into communication difficulties that individuals with FASD often live with. The third presentation is an attempt to dispel some of the misconceptions about this complex, yet extremely common, disability.

As always, we are available for questions. You can contact us at:
fasd@reginacommunityclinic.ca.

Welcome

Plain Language Workshop

Ideas and Strategies: Building Success for Adults with FASD
OLES and the Regina Community Clinic FASD Centre April 2010

What *is* plain language?

- Plain language is being able to write and speak so that your clients can easily understand what they read, or hear.
- It is simple, clean, and elegant use of English or any language.

The Goal:

- Used properly, plain language allows your clients to:
 - Find what they need,
 - Understand what they find,
 - And use the information to meet their needs.

- Source: www.plainlanguage.gov

Another Goal

- The effective use of plain language allows your clients dignity and builds self-esteem since they will be able to understand the information given to them

Using Plain Language

- Means you are able to
 - Write and speak clearly,
 - Write in a visually appealing style.

Real Life Example

The original statement:

“Make sure that the account holder’s name on the account is the same as the name of the customer to whose account transaction should be attributed.”

Became:

“Make sure that this is the account for the right customer.”

One more example:

“The dietary Guidelines for Americans recommends a half hour or more of moderate physical activities on most days, preferably every day. The activity can include brisk walking, calisthenics, home care, gardening, moderate sports exercise, and dancing” became...

“Do at least 30 minutes of exercise, like brisk walking, most days of the week.”

Writing: Step 1

Who are you writing to?

- Identify your reader and think why she needs to read the document.
- Identify people who will be interested (even if they are not directly affected)
- Write to everyone who is interested, not just the experts

Writing: Step 2

Organize your information:

- People read to get answers.
- They want to know results, what will happen, or what won't happen.
- Describe events as they occur (i.e. application processes).

Step 2a

Consider using a “question and answer format”

- Use questions as headings, with answers immediately following.
- Allows scanning of document to locate needed information.

Writing: Step 3

Pronouns(!)

- Speak directly to the readers by using 'you.'
- Use 'we' to refer to your agency/business.

Writing: Step 4

Use the active voice because it:

- This clarifies who must do what.
- Clarifies responsibilities.

Writing: Step 5

Use the appropriate tone:

- Language can be powerful – remember who your client is and why she is your client.
- A letter can engage or alienate.

Reading Differences:

- Reading abilities that range from post-secondary to Grade 3 or lower.
- Other learning disabilities.
- Cannot read 'black on white' documents because they cannot 'see' black ink on white paper properly.

Grade 3 reading ability:

I am about to walk home. Tom says to me, “School is out. What are you going to do today, Dan?”

“I am going home to get my money,” I say.

“Money?” Tom says.

“I am going to Boss CD.” I say.

Grade 6 reading ability:

It was Tuesday, October 29, 1929. Stock prices fell to a new low. Many had spent all their money on stock. Now they lost that money. They called it Black Tuesday.

A depression had started. Many people had no work. They could not buy things. Places that made things closed. Places that sold things closed. The 1930's was the Great Depression. Life was very hard.

Living was hard in the Great Depression. One-third of the country was out of work. In many houses no one had a job. Families were afraid they would lose their homes

Grade 9 reading ability:

Dear Kitty,

Invasion fever in the country is mounting daily. If you were here, on the one hand, you would probably feel the effect of all these preparations just as I do and, on the other, you would laugh at us for making such a fuss—who knows—perhaps for nothing.

All the newspapers are full of the invasion and are driving people mad by saying that “In the event of the English landing in Holland, the Germans will do all they can to defend the country, if necessary they will resort to.....

Grade 12 reading ability:

Marcelo had already taken hold of the aerial and was waiting while Roy picked up the radio, switched it on and began to turn the dial. He tuned it to a station in Chile which the day before had broadcast nothing but political propaganda; now, however, as he held the radio to his ear, he heard the last words of a news bulletin. "The SAR has requested all commercial and military aircraft overflying the cordillera to check for any sign of the wreckage of the Fairchild Number Five-seventy-one. This follow the cancellation of the search by the SAR for the Uruguayan aircraft because of negative results."

The newscaster moved on to a different topic. Roy took the radio away from his ear. He looked up at Marcelo and told him what he had heard. Marcelo dropped the aerial, covered his face with his hand, and wept with despair,. The others who had clustered around Roy, upon hearing the news, began to sob and pray, all except Parrado, who looked calmly up at the mountains which rose to the west.

Note the differences:

As reading levels advance:

- Sentences get longer,
- Vocabulary is increases,
- Punctuation becomes complex,
- Greater use of abstract thoughts demanding that the reader interpret the writing

HOW to do this?

Tips for the writer

Writing clearly means you:

- Use short sentences
- Write to one person, not to a group (i.e. use pronouns, or use their name)
- Use the simplest tense (i.e. present tense)
- Use 'must' when necessary, rather than 'may' or 'shall'

Writing clearly means **you** (continued):

- Avoid words of confusion – use words consistently
- Skip the jargon
- Be careful of acronyms
- Use contractions

Writing clearly means you (continued):

- Write in short sections with headings – use formatting like **bold** or underline
- Allow white space – no crowding
- Use lists, or identify steps
- Consider font size and colour of paper

Replace (in writing and speaking)

- With regard to ➤ About
- In the event ➤ If
- In view of the fact ➤ Because
- It would appear that ➤ Apparently
- Until such time ➤ Until

More examples:

- Accomplish ➤ Do
- Ascertain ➤ Find out
- Disseminate ➤ Send out
- Endeavor ➤ Try
- Expedite ➤ Speed up
- Facilitate ➤ Help
- Formulate ➤ Work out

Style – Visual Appeal

- Leave enough space, no crowding.
- Consider using a slightly larger font.
- Recommended fonts are: New York, Palatino, Times Roman, Schoolbook, Courier (serif typefaces).

Plain Language - Spoken

Say what you mean.

Say What You Mean

Plain language, or concrete language, is the ability to communicate verbally with your clients so that he or she understands what you want them to do

People with FASD:

- Often have auditory/verbal processing impairments,
- often have learning disabilities,
- often have poor or unreliable memory,
- often have ADD/ADHD

People with FASD:

- Want to understand,
- Want to share their ideas,
- Want to please,
- Want to be respected,
- Want help.

People with FASD:

- Often use fantastic language – have great vocabularies – but understand little of what they are saying.
- They can talk a lot, but say very little.

How can you help?

- Recognize your client as an individual.
- Understand your client's abilities.
- Realize that what you are told may not be the 'truth.'
- Empathize with clients who find the world noisy and overwhelming.

Reduce Distractions

- Forward your telephone if possible.
- Sit quietly.
- Restrain your body movement.
- Be aware of 'humming' from lights and electronics.
- Sit client with her back to door or window.

Say What ?

Visualize the behaviour you want, then say it to her:

- ‘Walk please’ (instead of ‘stop running’)
- ‘Work quietly’ (instead of ‘stop talking’)

If possible demonstrate the behaviour while you say it.

Short and sweet

- Give directions with short sentences.
- Give one or two directions at a time – let her do it – before adding more directions.
- Allow for processing time.

Processing time:

Is the amount of time it takes a person to work through the information given.

- Auditory – processes verbal information quickly.
- Visual – will visualize information in order to process.
- Kinesthetic – needs to ‘feel’ information as it’s processed.

Many people with disabilities are more likely
to be visual or kinesthetic learners
(processing speeds of 8-22 seconds)

They require time to process the information
– give them time to think.

Many people with processing disabilities will hear the words but may not be able to keep them in order.

Many people with processing disabilities will hear your words, but only remember one of four, or 'mis-hear' some words.

Give information in correct order

You must know what you want your client to do
and then clearly outline the steps for them.

If you don't know, you can't tell.

- 1.
- 2.
- 3.

Remember!

Your client can only do what they understand,
and can only do what they remember.

Your responsibility as a professional is to ensure
that the information is understood, and
remembered.*

Tips:

- Give information in one or two sentences using clear, simple words.
- Be quiet – count to 30.
- Check for understanding.
- If necessary, repeat using the same words.
- Be quiet – count to 30.
- Check for understanding.

Visual Clues

- Develop simple pictures that clarify information for your client.
- Label drawers, boxes.
- Print out steps with a pictorial included.
- Demonstrate.

Listen to your language

- Skip jargon and acronyms.
- Slow yourself down.
- Unless there is a hearing problem, speak in a normal voice.
- “More is not better” - small talk may be confusing.

What does your client hear?

- “Pull yourself together” or “pull up your socks” or ‘straighten up.’”
- “Let stand for 5 minutes.”
- “Be good” or “Be positive” or ‘Behave”

Avoid abstracts:

- “Be good” may mean almost anything: “be on time for work” or ‘stay away from your friend, Joe.”
- “Pull yourself together” may mean ____?

Remember, just say what you mean.

Avoid negatives

- Do not use 'don't'
(instead of 'don't do that' say 'do this...')
- Eliminate 'stop'
(“Stop ____!” becomes ‘Do ____, please’)

Watch yourself

- Pay attention to your body language - smile, have eye contact, demonstrate patience and encouragement,
- Offer open-ended questions when seeking information,
- Use their words as much as possible.

- Your comments/ideas?

Thank you.

FASD

Hearing and Understanding
The Basics of Communication

Welcome

- People with FASD often have deficiencies in auditory processing.
- That means that they may not be able to interpret what they hear, or not remember some or all of what they hear, or may not remember what they have said....
- Or all of the above!

- People with FASD will do what they believe they have heard.
- This may not be what you said
- Imagine that you only heard every fourth word....

What?

What a great _____, Bob! I am really
_____ that you are _____ to
improve your _____ and take on
_____ responsibilities!

What did you just say? What did the client hear?

*What a great _____, Bob! I am really _____ that you
are _____ to improve your _____ and take
on _____ responsibilities!*

- A number of words could fill in the blanks. The client cannot make sense of this. Help him out...maybe this is what you meant...

For example:

- Bob *[smile and say his name to get eye contact]... What a great day. [stop] Bob, it's good that you want to do a good job [stop – lots to process]. You do a good job [wait for a second] when [give example] you clean the floor like today [point to the clean floor]*

Processing Information Takes Time:

- Now, let Bob take a second to be proud and process as he needs to. You remain quiet.
- Then, have Bob tell you why he did a good job (because he cleaned the floor well).
- Use your body language to show how you feel (i.e. smile, nod, be relaxed)

Processing Time?

- People need a certain amount of time to process what they've heard. Similar to Autism, people with FASD do best when they are given clear and concrete information.
- Say only what you need to say – chattering and small talk are confusing

Say something...slowly

- Hi Bob...did you finish writing...your story...that Mr. Smith (*language arts teacher*) wanted?

Is better than:

- Hibobihopethatyougotyourhomeworkdonef
ormrsmithoryouwontbeabletogotothegym.

Same something... slowly

- If you've clearly said what you want then you need to WAIT (count to 20 or 30 in your head)
- If the client seems to be confused, repeat the statement again, calmly, using the same words and WAIT....do not interrupt his processing time.

Sa sumthin' ...slolee

- If your client continues to be confused or lost, then start over.
- Use words that he knows.
- Speak in short sentences.
- Be patient and encouraging with your body language

Shift...

- If you've reached an impasse, you can either:
 - Show him what you want by doing
 - Let him watch someone else do it
 - Ask him how he needs to know it

Imagine

- Not being able to understand what's being said to you.
- Not understanding what you did wrong when you were really trying
- Feeling stupid, dumb, moronic or retarded
- Feeling left out All the time.

FASD is a lifelong disability

- Processing information is vital to anyone's success in life
- Being able to communicate (give and receive information in a timely and appropriate manner) is the basis of everything we do
- People with FASD struggle constantly

Hearing and Understanding

These are two different things:

- *Hearing* is easy unless you have a degree of hearing loss
- *Understanding* means that you can take the information, find a reliable memory that is appropriate, link that memory to the new information, and respond...in milliseconds.

The Importance of Memory

- Allows you to link events and expectations
- Allows you to learn from experience
- Allows you to improve performance
- Allows you to anticipate

Processing Problems

If your memory is impaired:

- It is difficult to apply what you've learned
- It is difficult to anticipate the next step
- It is difficult to understand
- It can be difficult to remember what was said long enough to process it....

Helpful Ideas

- Make lists with visual reminders
- Have a time table (if time is understood)
- Have the client work with a buddy who is reliable so he can watch and learn, then 'do'
- Always ask the client what would be best for him or her

A picture is worth 1000 words

Ideas

- Build a photo diary
- Get a bulletin board and stick up pictures of good times and of successful events
- Take pictures of other people that she needs to know
- Use a calendar with stickers

The value of a diagnosis

- If a person has a diagnosis completed it means there is information on file about their processing deficits and how they learn best.
- Whenever possible, use this information to help you client become successful.

Thank you.



FASD

Fetal Alcohol Spectrum Disorder

A Physical Disability

Facts about FASD

- Is the most common cause of mental retardation in the industrialized world
- It is a highly stigmatized disability with many cultural and social barriers
- there are approximately 1700 people in Regina (based on Canadian statistics) with FASD
- There are four 'categories' of FASD

The Four Diagnosis

- **FAS:** (fetal alcohol syndrome) which has the most visible physical signs of the four but is the least common
- **pFAS** (partial fetal alcohol syndrome) & **ARND** (alcohol related neurodevelopment disorder) the most common of the disability with the least visible physical signs)
- **ARBD** (alcohol related birth defects)

Since **1973**, the medical profession has known that alcohol in pregnancy impedes fetal brain development

- affecting intelligence,
- learning skills,
- and behaviour.

FASD exists **worldwide** regardless of race, culture or financial status.

FASD – facts

- FASD only occurs when a pregnant woman drinks alcohol during the pregnancy
- Not every woman who consumes alcohol during pregnancy will give birth to a child with FASD (1:3)
- The impact of alcohol upon the fetus is unique to each fetus and is influenced by the mother's health and wellbeing, the genetic background, the ongoing lifestyle during pregnancy, care of the child after birth.

KEY POINT

All of the diagnoses
involve varying
degrees and complexity of
permanent brain damage

ARND – the invisible disability

Less obvious and *seemingly* milder fetal alcohol damage is sometimes called Fetal Alcohol Effects (FAE). This term has fallen out of use and has been largely replaced by Alcohol-Related Neurodevelopmental Disorder (ARND),

Some experts estimate that about **1%** of North Americans suffer from a fetal alcohol disorder - about four times as many people as those with AIDS/HIV.

There are **three to five** times as many people with ARND as FAS.

Persons with FAS have distinctive physical appearance and lower IQs, but have lower crime and addiction rates than those with ARND

because

they often get earlier diagnosis and can be better protected by society & their caregivers.

Most people with ARND **look** perfectly normal and are never diagnosed.

Research indicates that a high percentage of homeless people, and at least **25%** of juvenile and adult offenders suffer from **undiagnosed FASD**.

Individuals with ARND may look normal and have seemingly normal intelligence, but their damaged brains can result in learning and behaviour disabilities that are easily misunderstood.

learning and behavioural disabilities

- learning disabilities,
- impulsivity,
- lying,
- stealing,
- tantrums,
- violence & aggression,
- inability to predict consequences or learn from experience,
- lack of conscience,
- and being highly addictive.

Of individuals with **ARND** between the ages of 12 - 51,

- 95% will have mental health problems;
- 68% will have "disrupted school experience";
- 68% will experience trouble with the law;
- 55% will be confined in prison, drug or alcohol treatment centre or mental institution;
- 52% will exhibit inappropriate sexual behavior

Current statistics for people with **ARND** show that:

- more than 50% of males and 70% of females will have alcohol and drug problems
- 82% will not be able to live independently;
- 70% will have problems with employment

What to watch and listen for:

People with FASD will often:

- Talk a lot, but say little
- Be easily led astray
- Make up stories to fill in the gaps
- Say what they think you want to hear
- Cannot take the initiative or lead
- Struggle with understanding the passage of time
- Have poor or erratic memories
- Not understand value of money

What can you do?

- Know that people with FASD become what they are surrounded by – they imitate and mimic behaviours around them
- They will respond to your body language **more** than your words
- They want to please everyone, including you
- They are often confused, anxious, scared.

Remember

- People with FASD have a permanent and complex brain injury
- People with FASD in the criminal justice system do not represent ALL people with FASD.
- Many in the criminal justice system have multiple 'disabilities'
- With the right support people with FASD can lead healthy and full lives

Dignity

Individuals with FASD:

- have the right to be treated with dignity
- Are often overlooked and misunderstood
- Are frequently unable to 'keep up' with a fast paced world and fall behind
- Have the right to have institutions and individuals meet their needs as citizens

Respect

All individuals, especially those with 'invisible' disabilities, have the right to be treated with respect and have their needs recognized and supported

Most individuals with 'invisible' disabilities are forgotten by mainstream society.