

Centre of Excellence for the Physically, Intellectually and Multi-Challenged Newsletter



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UPCOMING EVENTS

Applied Behaviour Analysis (ABA)Training

Oct. 7 - Dec. 9, 2015 Wednesday evening sessions: 6:00 - 9:00 pm Gold Centre, 5331 Ferrier, Montreal, QC H4P 1M1

ALDI Symposium October 14 & 15, 2015

Holiday Inn Pointe Claire

Copy Editor Robin Colyer

What Self-Advocacy Looks Like

The following is a guest post in the form of an open letter from Special Olympics athlete and global messenger John Franklin Stephens to Ann Coulter after her tweet during October 22, 2012 Presidential debate.

Dear Ann Coulter,

Come on Ms. Coulter, you aren't dumb and you aren't shallow. So why are you continually using a word like the R-word as an insult?

I'm a 30 year old man with Down syndrome who has struggled with the public's perception that an intellectual disability means that I am dumb and shallow. I am not either of those things, but I do process information more slowly than the rest of you. In fact it has taken me all day to figure out how to respond to your use of the R-word last night.

I thought first of asking whether you meant to describe the President as someone who was bullied as a child by people like you, but rose above it to find a way to succeed in life as many of my fellow Special Olympians have.

Then I wondered if you meant to describe him as someone who has to struggle to be thoughtful about everything he says, as everyone else races from one snarky sound bite to the next.

Finally, I wondered if you meant to degrade him as someone who is likely to receive bad health care, live in low grade housing with very little income and still manages to see life as a wonderful gift.

Because, Ms. Coulter, that is who we are – and much, much more.

After I saw your tweet, I realized you just wanted to belittle the President by linking him to people like me. You assumed that people would understand and accept that being linked to someone like me is an insult and you assumed you could get away with it and still appear on TV.

I have to wonder if you considered other hateful words but recoiled from the backlash.

Well, Ms. Coulter, you, and society, need to learn that being compared to people like me should be considered a badge of honor.

No one overcomes more than we do and still loves life so much.

Come join us someday at Special Olympics. See if you can walk away with your heart unchanged.

A friend you haven't made yet,

John Franklin Stephens Global Messenger, Special Olympics Virginia

Getting Schooled on the Meaning of Self-Determination by Individuals with Intellectual Disabilities by Kymberley Morin

Professionals working with individuals with disabilities are well aware of the importance of promoting personal development of skills and attitudes associated with self-determination, especially for individuals with intellectual disabilities.

When discussing best practices in the field of special education, self-determination is receiving a lot of attention. Research shows that self-determination plays a key role in an individual's quality of life and is a key predicator of one's possibility of independent living and employment.

Research also provides us with ample examples of evidence-based practices that promote self-determination in a school setting, environmental characteristics that encourage the expression of self-determination of individuals with disabilities and insightful information on the perceptions of self-determination of those working with or living with individuals with disabilities.

What about the perception of individual's with intellectual disabilities? Although most research is focused on the perceptions of individuals with learning disabilities, it is difficult to find research that gives us insightful information on the perceptions of individuals with intellectual disabilities.

In 2011, Karrie A. Shogren and Ricky Broussard published an article in *Intellectual and Developmental Disabilities* discussing the results of their interviews conducted with 17 individuals who had intellectual disability. The aim of these interviews was to "expand their understanding of the impact of self-determination in these individuals' lives and to facilitate the identification of common issues and priorities that cut across the diverse self-determination initiatives and underlying theoretical frameworks." p.87

Participants were asked a series of questions that "enabled them to describe their life and the meaning of self-determination in their life. Questions were reworded and rephrased as necessary during each interview to ensure that the interviewee was clear about the meaning of the question and able to respond in a meaningful way." p.89

Results were grouped into three categories: the meaning of self-determination, learning about self-determination, and dreams for the future. Here is an overview of what was said.

The Meaning of Self-Determination

Choice and Control

Participants described self-determination as "making choices and being the person in control of his or her own life and the decisions made about their life." They also mentioned the importance of being responsible and having self-control. "The role of the environment and the opportunities it provided (or did not provide) for choice and control was also emphasized by many participants, who described the influence of where they lived on the ability to be self-determined." p. 90. Some participants wanted to have more choice and control over where, when, and what types of activities they did in the community.

Setting and Working toward Goals

Participants mentioned the importance of setting their own goals and "having ways to follow through on goals. Others emphasized the importance of having people that were supportive of your goals." p.91

Advocacy

Some participants encountered discrimination when applying for jobs. The ability to speak up for themselves and stand up for their rights is not always easy. They explained the necessity of being given opportunities to advocate for themselves and not only have others do it for them.

Learning about Self-Determination

Participants mostly learned about self-determination from attending conferences, trainings and materials, established self-advocates and allies, school-based and community experiences. Being given opportunities to socialize and learn from other self-advocates has had a significant impact on their lives. One participant said, "I think I found my voice when I went to my first self-advocacy meeting and people were talking about dreams and hopes. I got thinking about my dreams and hopes." p.91

Sadly, all the participants learned about self-determination as adults and were given little support to become self-determined during elementary and high school. One participant said, "I went all the way through school but didn't learn it (self-determination) in school." p.92

I was not surprised when I read this. At the moment, teaching of skills and attitudes that promote self-determined behaviour are mostly discussed or considered when we start thinking about transition planning from school to adult life for our students with disabilities.

Dreams for the Future

Having a real life

Participants mostly had long-term goals relating to living in a location of their choice, having a real job they enjoyed, and having more community connections. Many expressed the desire to have a 'real life'. They defined a real life "as living in a place of one's own and working a meaningful job as well as being close to family and friends and connected to the community through ongoing engagement in activities, volunteer work, and fun social activities." p.93

Barriers

Most mentioned was the attitudes of others. They explained that one of the biggest barriers is people not believing in their abilities and frequently being told that they can't achieve their dreams.

Others mentioned that having overprotective parents made it difficult for them to grow up and to self-advocate. "Participants talked about how important it was that families understand that although individuals with disabilities might always

need support, they could also be more independent." p.93

Other barriers such as waiting lists and accessing supports worked against them to achieving their dreams.

And, many mentioned fear as their biggest barrier. They get scared when faced with major life changes. "I get scared. I was scared when I moved because I did not know anyone," as one participant explained. Being constantly reminded or told that they can't do things played a role on their self-confidence and made it difficult for them to try and do things for themselves.

As we can see from what the participants said, having opportunities to make simple to complex choices and being in control of their life, living and learning in an environment where they can advocate for themselves and demonstrate their abilities, setting their own goals, learning skills that promote self-determined behaviour starting at an early age, and having access to support can significantly determine their level of independence and success in life.

School's Responsibility

I believe schools can play a significant role in teaching our students with intellectual disabilities the skills needed to become self-determined individuals. Students shouldn't have to learn about self-determination as they prepare to leave school and begin their adult life. I leave you with these words from Nancy because I couldn't have said it any better. "Teachers don't teach us that [selfdetermination] in high school because they don't know what self-determination means to them. When I entered as a freshman they wanted me to be in a special class but I didn't because my parents fought for me to be in a regular class. And that's where I met my friends. They never taught us that [self-determination] because they just didn't know it. They're uneducated but we can educate them in different ways." p.92

For further reading:

Shrogen, K.A. & Broussard R., (2011). Exploring the Perceptions of Self-Determination of Individuals With Intellectual Disability. *Intellectual and Developmental Disabilities*, vol. 49, 86-99.

Student-Led IEPs: Not a New Idea, but a Winning One by Peter Hamilton

Most people in the educational setting are familiar with what are known as 'student-led', or 'self-directed', IEPs. In this article I will give a brief history of this concept, some reference to research and materials followed by some of my own ideas about how to facilitate their usage in a school setting, gleaned from 30 years as a psychoeducator in schools and as Director of Special Education.

The general definition of a student-led IEP is an IEP in which the student participates in the development and writing of any part (dependent on adult judgment) of the IEP, and/or holds a leadership role in the actual IEP meeting. Research has established links between elements of the student-led IEP associated with self-determined individuals and a student's ability to become engaged in learning more about themselves and methods for attaining their goals (Eisenmen et al., 2005). It must be kept in mind that the parents and school personnel (adults) always remain in the overall director's chair, deciding the appropriate level of responsibility that should and can be given to each student.

The concept of a student-led IEP has been around since the 1990's. In 1997, Martin et al. developed and published a program to support teachers in implementing student-led IEPs. Other programs have been developed since (Konrad and Trela, 2007) and research has been conducted on their effectiveness (Arndt et al., 2006). These programs offer the teacher a set of research-based teaching materials that provide them with a starting point for implementation.

Konrad and Test (2004) developed a template for use in the school to teach students how to write sections of their IEPs. This was developed in a workbook format and included sections for writing a vision statement, current level of performance, annual goals, services and the least restrictive environment for attaining annual goals. Another example of a format for a student-led IEP can be found on the following website: http://iepmeetings.weebly.com/how-to-run-a-self-directed-iep.html. The powerpoint found at this website was actually developed by a student and used to lead their IEP meeting.

All this to say that student-led IEPs are a research-based practice, one that empowers all students to take an active role in their own education, within the obligatory overriding structure provided by the adults. I would like to conclude with a list of best practices to facilitate caring, professional, respectful, relaxed and efficient IEP meetings, no matter the format chosen.

- 1) **Prepare the parents:** notify the parents well in advance of the meeting time, supplying them with a preagenda and an open invitation to phone you before the meeting with any questions or agenda items they would like included. Tell them in advance who will be attending the meeting and make sure they are comfortable with the number of people. If not, adjust the numbers by getting some of the teachers' input in writing before the meeting. Allow parents to bring support people to the meeting, and let them know that this is a possibility if they are not aware. Ask them beforehand if they have any special needs or requests, often cultural in nature, for the meeting.
- 2) **Prepare the school personnel:** hold as much of a pre-meeting with school personnel (15 minutes immediately before the actual IEP meeting is usually sufficient) to make sure they are prepared, and have rehearsed how best to express their ideas to a sometimes nervous and defensive student and/or family. A de-brief meeting immediately afterwards is also a good idea. The entire process can take less than 1 hour.
- 3) Provide water, juice, healthy snacks, etc. (coffee and tea usually take too long): Breaking bread together is a primordial opportunity to create equality among participants.

An IEP meeting should be an event looked forward to by all participants. It is a precious opportunity to surround a child with a team of caring and professional adults, and where the child can see first hand the relationship between their parents and the school personnel. Consider each one as if it may be a turning point for a child and family (and school personnel), and have fun!

References

Ardnt, S.A., Konrad, M., and Test, D.W. (2006), "Effects of the Self-Directed IEP on student participation in planning meetings", in: Remedial and Special Education, 27, 194-207.

Konrad, M. and Test, D.W. (2004), "Teaching middle school students with disabilities to use an IEP template", in: Career Development for Exceptional Students", 27, 101-124.

Knorad, M. And Trela, K., (2007), "GO 4 IT ... NOW! Extending writing strategies to support all students", in: Teaching Exceptional Students, 39(4), 42-51.

Martin, J.E., Marshall, L.H., Maxsom, L. and Jerman, P., (1997), "Self-directed IEP", Longmont, CO: Sopris West.

Mason, C.Y., McGahee-Kovac, M., and Johnson, L., (2004), "How to Help Students Lead their IEP Meetings", in: Teaching Exceptional Children, 36(3), 18-24.

Myers, A., and Eisenman, L., (2008), "Student-Led IEPs: Take the First Steo", in: Teaching Exceptional Students, 37(4), 52-58.

Success Story

Costco Hires Hundreds of "Model Employees" through Ready, Willing, and Able Story posted on August 11, 2015

"Vice President of Operations, Eastern Canada at Costco Wholesale, David Skinner, never



anticipated how much an inclusive workforce would enhance his company's success and corporate culture. "The outcomes are a lot better than we could ever imagine," says Skinner, describing the candidates Costco has hired with intellectual disabilities as generally "model employees" who over time [...]"

To read the whole story follow this link.

http://readywillingable.ca/blog/stories/costco-hires-hundreds-of-model-employees-through-ready-willing-and-able/

Organizations of Note!



http://www.peoplefirstofcanada.ca/

"People First of Canada is the national organization representing people with intellectual disabilities. They are about rights – human rights, citizenship rights, accommodation rights, and language rights. They believe in the right to freedom, choice, and equality for all."



http://www.cacl.ca

"The Canadian Association for Community Living is a family-based association assisting people with intellectual disabilities and their families to lead the way in advancing inclusion in their own lives and in their communities."

READY WILLING & ABLE BUILDING AN INCLUSIVE LABOUR FORCE

http://readywillingable.ca

"Ready, Willing and Able (RWA) is a national partnership of the Canadian Association for Community Living (CACL), the Canadian Autism Spectrum Disorders Alliance (CASDA) and their member organizations. Funded by the Government of Canada and active in 20 communities across the country, RWA is designed to increase the labour force participation of people with intellectual disabilities and Autism Spectrum Disorder (ASD)."

Centre for the Arts in Human Development CAHD

"Located at the university's Loyola Campus in Montreal, Quebec, the Centre is under the auspices of the Department of Creative Arts Therapies in the Faculty of Fine Arts. Unique in Canada, the Centre uses four types of creative arts therapies – art, drama, music and dance/movement – to promote autonomy, improve self-confidence and social skills, and enhance overall quality of life for its participants."

http://www.concordia.ca/research/cahd/about.html

Upcoming Conferences

October 14 & 15, 2015
ALDI Symposium
Holiday Inn Pointe Claire



Literacy / Assistive Technology / Numeracy / Resource Support / Teaching and Learning Frameworks / Health & Wellness

Registration for ALDI 2015 taking place at the Holiday Inn Pointe Claire is now live! Click on the links below to get to the registration page and to see the program.

Registration
ALDI 2015 Symposium Program



April 25 - 27, 2016 CQJDC Conference

6th Biennial Conference of the Comité québécois pour les jeunes en difficulté de comportement/ Québec Committee for Youth with Behavioural Difficulties

WEBSITE

The program will be available on line shortly and registration will open in October.

EMAIL: gro.cdjqc@mda

Workshops

ABA Training

October 7 - December 9, 2015 Wednesday evening sessions: 6:00 - 9:00 pm Gold Centre, 5331 Ferrier, Montreal, QC H4P 1M1 Information & Registration: https://goldlearningcentre.thankyou4caring.org/ gold-centre/aba/english---fal15

ALDI/LEARN web events:

Archived webinars

To access a series of webinars covering a range of interesting subjects visit:

http://blogs.learnquebec.ca/wordpress-mu/aldi/category/webinars-2/

Youtube clips - ID & Advocacy

A Day in the Life of Tanisha Bridgeforth https://www.youtube.com/watch?v=zzTCrz9Xynw asks questions about you perceptions shows mother encouraging independence

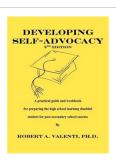
***If You Listen, You Will Hear Us https://www.youtube.com/watch?v=Hp4PW17U h8 focuses on profound and multiple disabilities importance of "communication passport" shows different forms of support

***Inclusion, belonging and disability revolution
https://www.youtube.com/watch?v=VAM9nh8WC-8
13:50 min. - attitudes
19:00 min - labelling
21:20 min - visual labelling
cerebral palsy
communication
possibility more than disability

Let's Talk about intellectual disability: Loretta Claiborne https://www.youtube.com/watch?v=0XXqr_ZSsMg fearlessness - self-advocacy special olympics

Listen Up! Children with disabilities speak out https://www.youtube.com/watch?v=FjhF-pdlJ8M 3:04 clips of students & their dreams

Books of Interest!



Developing Selfadvocacy, Second Edition

This guidebook is a practical, simply written workbook that addresses key issues for students with disabilities planning to

attend a post secondary educational program. It provides students, counselors, and teachers with a wealth of practical strategies, skills and legal accommodations that they can use in assisting the special needs student succeed independently.

by Robert A. Valenti, PH.D., 2005

Ask and Tell



This book aims to help people with autism effectively self-advocate in their pursuit of independent, productive, and fulfilling lives. "Ask and Tell" is unique by being the first book to speak to the twin issues of

self-advocacy and disclosure for people with autism and by consisting exclusively ... of contributions by those on the autism spectrum for persons on the spectrum.

by Temple Grandin & Stephen Shore (editor) 2004

New Voices: Self-Advocacy by People With Disabilities

This book portrays the origins, current status, and future course of the self-advocacy movement by persons with disabilities in the West.

by Brookline Books/Lumen Editions (Author), 1996



Who are we?

Our Centre is one of 6 Centres of Excellence mandated by MELS to provide support, professional development, research activities and provincial expertise to the English sector. We service students who are physically, intellectually or multi-challenged in a school setting. Our team consists of our coordinator, Kymberley Morin and our secretary, Robin Colyer collaborating with Peter Hamilton, Director of Complementary Services and Manon Lessard, Special Needs & French consultant for the ETSB.

Centre of Excellence for the Physically, Intellectually and Multi-Challenged

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