

REMARKABLY ABLE NEWSLETTER

In Behalf of Youth with ASD & Developmental Disabilities

Preventing isolation, reducing vulnerability, and launching individual life outcomes

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All youth with ASD and DD are *remarkably able* when their personal and individualized preferences and rights are acknowledged. The purpose of this newsletter is to raise awareness and lend strength to topics that are most significant to the health and well-being of youth (14 and over) with autism (ASD) and developmental disabilities (DD). Our youth look to us to hear their voice, to acknowledge their challenges, and to see their value as a person. Our acceptance and actions add value to their lives resulting in their continued growth and learning, and making their own contributions to this world.

If you find this newsletter helpful, do something that promotes positive change to help someone with a disability reach goals and dreams. The journey is not easy, but this population is worth it. I welcome your comments. Thank you for taking time out of your busy day to read.

Jackie Marquette

“The world is *not* dangerous because of those who do harm..... but because of those who look at it without doing anything.” *Albert Einstein*

(1) WE ARE ALL EACH OTHER'S BUSINESS

The lives of adolescents and adults with ASD and their families depend on all of us. This population remains invisible from our community and unfortunately has for many years. There is an enormous popularity of autism awareness campaigns, television commercials, and fundraising efforts, with little or no attention to the needs of adolescents and adults with autism. It is costly to everyone to ignore these young adults, who are the very same individuals that early interventions helped as young children.

The Department of Health and Human Services recently reported that one of 91 children has an autism spectrum disorder. For years, an overwhelming social issue facing adolescents and adults with ASD and DD

and their families and occurred *now* it is escalating.

Throughout the literature on disability and inclusion, there is recognition of the importance of societal values to create environments where individuals with disabilities live, work, and contribute along side the rest of us.

Nevertheless, isolation, lack of faith in inclusion, and the practice of traditions that increase sheltered settings, are related to complex cultural patterns. There is a *painfully fine line* between blaming the victim who has autism, then ascribing a role to that person. This often leads the individual to institutional living, whether small or large, but definitely set apart from mainstream society.

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2) ACKNOWLEDGING CHALLENGES –MEET RON

Ron (not his real name) is a 28-year old man with Aspergers who has been hired as a retail clerk in a large discount store for over five years. He worked consistently well, always on time, and dependable. His challenges did exist, but were not a significant issue, because supports provided by the manager facilitated his capabilities. Here are some examples that you may be able to relate to someone you know with autism :

a) At times coworkers remarked that Ron appeared to be rude to a customer. For example he would not recognize a young mother who needed help with groceries or pushing her cart out with young children.

HIS CHALLENGE-- while adhering to a work routine, not noticing a customer needing help.

THE SUPPORT--A coworker or team leader would point out to Ron when a customer needed help, Ron responded positively.

b) Ron did not respond well to three verbal instructions by his supervisor.

HIS CHALLENGE-- holding by memory all three instructions.

THE SUPPORT--With a checklist of tasks, he did much better.

c) Ron lacked the ability to predict results of choices. For example, one day he was asked to work with two coworkers he had never met and unload a truck, a new task. After the truck was unloaded, the two coworkers left the job site.

HIS CHALLENGE-- Ron stood there alone and with no direction. Noticing he had only 15 minutes left on the clock. Ron's logic kicked in and he chose

to walk the circumference of the property for the remainder 15 minutes to fill the time. Afterwards, he entered the store and clocked out. One of the coworkers saw that Ron left the store and reported him. The manager called his parents, and informed them that Ron would not be allowed to return to work for two days as a punishment.

THE SUPPORT--After talking with Ron about the situation, his parents requested to meet with the manager. They explained how Ron's willingness to work in a new area, with a new task, and with new people was growth for him. Ron was challenged to make a prediction of his choice. Although he made a wrong choice, his logic was to fill time. The manager acknowledged Ron's challenge and was able to better provide the supports that Ron needed thereafter.

3) THE REST OF THE STORY--HIDDEN MOTIVES THAT HARM

A new manager took over the store. After a few weeks, the manager called Ron into his office and asked him if he ever smoked marijuana. Being extremely truthful, according to his parents, Ron answered, that he tried marijuana one time a few years ago. The manager then instructed Ron to write three sentences that he had smoked marijuana, and to sign his name. This document was then used to terminate Ron. The story is not over as there is an investigation by corporate office and we are advocating for Ron. Yet what can be learned and passed to others who may encounter similar situations?

It was evident, Ron needed an advocate. The questions presented by the manager as an authority figure seemed straight forward to Ron, yet unsettling. It was quite stressful for Ron to listen to all the questions, quickly absorb the information, and sort through it. We must teach individuals with ASD to take 'next step actions' in their own behalf.

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We must teach them to ask for an advocate, mentor, or parent, when it becomes difficult to interpret what is happening.

4) SEVEN E'S TO BUILDING EMOTIONAL STABILITY AND WELL-BEING

Positive life outcomes NEVER ARRIVE BY ACCIDENT.

There are seven interrelating essential actions needed to evaluate how to positively impact an individual's life. **School personnel, therapists, and parents have reported good results in using the *Capability and Independence Scale*.** Go to this link to preview the scale and learn how it can help you through seven critical pieces. <http://www.independencebound.com/CAIS.htm>

- *exchange* childhood interventions for promising strategies to enter new landscapes of adult life.
- *enlarge* their world by first acknowledging challenges, not over focusing on disability characteristics. Make room for supports and options.
- *examine* closely by measuring the teenager's capabilities, skills, and strengths.
- *expose* the student to plenty of settings and groups to further build strengths and new skills and relationships.
- *entrust* the process by including others to think creatively and brainstorm supports and opportunities.
- *establish* broad creative supports that enable adaptability and capability.
- opt for an *expansive* view of a positive daily life and a good future for our most incredible, genuine citizens.

TO RECEIVE INFORMATION ABOUT

-*SPECIALIZED* services in Crisis and Prevention, Youth Transition, School Personnel, Adult Services, Parent Support, Family Support and Life Planning

-*TRAINING* to use the Capability and Independence Scale to help youth with autism (14 and older) in school or through major life crisis.

-*ONE-ON-ONE* (individual with family) assistance. Prevent isolation, reduce vulnerability, and launch positive outcomes:

CONTACT: Jackie@independencebound.com

TO READ TIPS, RESOURCES, ARTICLES, ETC. or go to www.independencebound.com

5) SEEKING YOUR FEEDBACK

If you used the Capability and Independence Scale, I value your feedback.

Please complete a short survey. Go to this link http://www.independencebound.com/CAIS_survey.rtf, download the survey, complete the survey, and then email to me at Jackie@independencebound.com. If other individuals you know have used the CAIS assessment, I am interested in their input as well. Please guide them to the link to complete online. It is important that I know your opinion because I am writing grants to further test the assessment. Also, your feedback will be a guide to me in developing training for professionals who want to use the CAIS.

6)AUTISM AND ALLELUIAS, A NEW BOOK BY KATHLEEN DEYER BOLDOC

A national report released in October 2009 in the journal *Pediatrics* reveals that one in every 91 children has an autism spectrum disorder. Most everyone knows a family that has been affected. What is the role that faith plays in helping families cope? In Kathleen Deyer Bolduc's new book, *Autism and Alleluias*, God's grace glimmers

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through the shadows as Joel, an intellectually challenged young adult with autism, teaches those who love him that life requires childlike faith, humility, trust, compassion, forgiveness, and an openness to all of God's gifts. Ginny Thornburgh, Program Director, Interfaith Initiative, American Association of People with Disabilities writes, "I was deeply moved by (this) book about (Kathy's) journey with Joel, her son. Most autism resources are either clinical in nature, or deceptively upbeat and sugary sweet. While Kathy acknowledges 'slogging through the wet cement' of her days, her extraordinary book is about valuing, honoring, and enjoying the unexpected gifts of her son." Available in March of 2010, *Autism and Allelulias* can be pre-ordered now from Judson Press at a discount of 10% with free shipping. Judson Press, P.O. Box 851, Valley Forge, PA 194 82-0851. Phone orders 7800-458-3766. Fax 610-768-2107. Kathy's other books are available on her website

www.kathleenbolduc.com. Read her blog at www.kathleenbolduc.com/wp

7) **A BIT ABOUT TRENT** Trent, my son is is a 32 year old man with autism and is doing very well. He is still living with his friend Jason and painting in his studio at Mellwood. He participated in two prestigious Art Avenue art shows this past summer with other artists in Louisville.

He enjoys working at Meijer as a retail clerk. If you ask him about Katie, his Golden Retriever, he smiles, and won't stop talking about her. Katie is one of the loves of his life. To see Trent's art go to www.TrentsStudio.com

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