

# CONNECTIONS

## Buddy Walk 2011



By Gena Mitchell  
President  
gena@dsnmc.org

This year's Buddy Walk was a BIG SUCCESS despite the weather and pouring rain! The day began with looming clouds, which ultimately opened up just as the event was underway, but neither the rain nor the frigid temperatures could keep our membership away! Unfortunately we were unable to put up the inflatable play structures, which everyone loves, but we had tents filled with activities like face painting, karaoke, pizza,

popcorn, cotton candy and the dj continued to play the music which brought a whole new meaning of dancing and singing in the rain. The event was kicked off with a few local speakers who brought the house down in both tears of admiration and shouts of joy.

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## DECEMBER 2011

Buddy Walk 2011

Post-secondary Education

The Power of Words

Miracle League

Book Review:  
*Out of my Mind*

Swimming with Dolphins

Techniques for Success &  
Education Resource Guide

## Maryland Down Syndrome Advocacy Coalition Begins Postsecondary Education Initiative



By Heather Sachs  
heather@dsnmc.org

The Maryland Down Syndrome Advocacy Coalition (MDAC) held a retreat focusing on Postsecondary Education (PSE) on July 10, 2011 at The Arc of Prince George's County that was attended by advocates from across the State of Maryland. MDAC, whose members include advocates from Anne Arundel, Baltimore, Caroline, Frederick, Montgomery, Prince George's and Queen Anne's counties, has designated Postsecondary Education as one of its top priorities (along with Universal Design for Learning and Self-Determination issues).

Madeleine Will, NDSS Vice President of Public Policy, kicked off the MDAC PSE Retreat by explaining the National Down Syndrome Society's strong and ongoing effort to help develop PSE programs in many states, and she provided advice to MDAC about creating new PSE programs in Maryland. Nancy Forsythe, DSNMC Board Member and MDAC Co-Chair, gave a presentation about the current status of PSE options in Maryland and provided helpful suggestions for MDAC's future PSE initiatives. In the immediate future, MDAC will be reaching out to potential stakeholders to begin a discussion about plans to develop substantial and high-quality PSE options in Maryland.

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# Welcome to our New VP

Cynthia Smith, a recent addition to the Board of Directors and our new Board Vice President, is a licensed attorney who has lived and worked in the Washington area for 16 years. Cynthia currently works on migration and refugee policy issues, engaging frequently with both Congress and the Administration. Prior to her current policy work, Cynthia practiced law at a Washington, D.C.-based firm. Cynthia has also held positions at several non-governmental organizations in the region, working on a range of issues, from human rights in Guatemala to designing and directing international development programs in Latin America which focused on strengthening local governments, rule of law, and building civil society. Cynthia lives with her husband, Matthew Quick, and daughter, Emma, in Bethesda, Maryland. Emma is 13 months old and has Down syndrome.

## DSNMC Membership Survey

DSNMC is conduct a survey to better understand the needs of our members. Your input is important to us. Once you have completed the survey, you can enter to win a FREE NOOK COLOR! To complete the survey, go to [www.surveymonkey.com/s/HJWTVVQ](http://www.surveymonkey.com/s/HJWTVVQ) Deadline is December 31, 2010.

## **DSNMC EDUCATION RESOURCE GUIDE NOW AVAILABLE ON WEBSITE!**

The DSNMC Education Committee has worked for over a year to compile a guide that contains information about Down syndrome, curriculum modification, inclusion, behavior strategies, Universal Design for Learning, and useful reading, writing and math programs. We will be giving one printed and bound guide to every elementary school in MCPS. We have also made this guide available as a PDF for you to download on our website, at [www.dsnmc.org](http://www.dsnmc.org). We encourage you to download it for your personal use, as well as to provide individual copies to your child's educator.

<http://www.dsnmc.org/resources/teachers/>

## **FAMILY EXPERIENCES HELP EDUCATE FUTURE MEDICAL PROVIDERS**

The Uniformed Services University for the Health Sciences (USUHS) is looking for more parent volunteers to speak during their Ethics and Advocacy courses for medical students. If you would like to help in the training of these future medical professionals by sharing your family's experience in raising a child with Down syndrome, please contact me at [mimi@dsnmc.org](mailto:mimi@dsnmc.org)



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## HELP WANTED!

### Board Treasurer & Secretary

The DSNMC Board of Directors is actively seeking a Secretary and Treasurer. If you are interested or know of someone who is interested, please contact Kathy Myers at [kathy@dsnmc.org](mailto:kathy@dsnmc.org). *Please note that is not necessary to have a child with Down syndrome to serve on the Board.*

### Advocacy Committee Chairperson

The DSNMC Advocacy Committee strives to enhance the lives of people with Down syndrome in Montgomery County and statewide, with a particular focus on educational and recreational opportunities. We provide education and support opportunities to parents to effectively advocate for their children, and work with other Down syndrome groups to achieve local and national policy objectives. Contact Heather Sachs for more information.

### Spanish Speaking Community

DSNMC is participating in a national initiative of the Down Syndrome Affiliates in Action to increase the involvement of Spanish-speaking families in the activities and programs of the Down syndrome community. If you are interested in helping in our area, or if you have questions, please contact Nancy Forsythe at 301.779.3462 or [nancy@dsnmc.org](mailto:nancy@dsnmc.org).

### Professional Outreach Committee

If you are interested in reaching out to the medical community and other healthcare professionals, contact Mimi Gehres at [mimi@dsnmc.org](mailto:mimi@dsnmc.org)

### Newsletter Contributions

Do have an idea for an article? Knowledge to share? Can you review a movie, book or conference? If you are interested in submitting a piece or helping with the newsletter, contact Elizabeth Totah ([elizabethwt@dnmc.org](mailto:elizabethwt@dnmc.org))

## Jim Begg

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## Kennedy Krieger

Seeks individuals with Down syndrome ages 7 – 17 to be involved in a 2 hour computer study. They will be coming to Montgomery County to conduct the study, and need multiple families. Planned for the January/February 2012 timeframe. Please email [gena@dsnmc.org](mailto:gena@dsnmc.org) if you are interested.

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## EVENTS

### DSNMC

#### Annual Membership Meeting

Sunday, January 22, 2012

2:30am – 4:30pm

Potomac Community Resource Center, Falls Road, Potomac, MD  
Discussion includes membership survey results, where DSNMC is headed, and open elections for the Board of Directors

#### Coffee and Conversation

2<sup>nd</sup> Tuesday of each month

9:30am – 11:30am

Montgomery Mall - Caribou Coffee (1st floor near Crate and Barrel)

Contact Karen O'Connor at 301-972-5138 or [tkrbmo@verizon.net](mailto:tkrbmo@verizon.net)

#### Board Meeting

3<sup>rd</sup> Wednesday of each month

7:30pm -9:30pm

Contact Gena at [gena@dsnmc.org](mailto:gena@dsnmc.org)

#### Play Groups

If you would like to join a playgroup, please email [info@dsnmc.org](mailto:info@dsnmc.org), or you can call (301) 979-1112 which is our general number.

For the latest  
information and details  
on all DSNMC events  
and news

[dsnmc.org](http://dsnmc.org)

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We salute DSNMC's mission to empower individuals with Down syndrome and their families, and to educate the community through awareness and advocacy programs.

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# The Power of Words

By Allison Wohl

The DSNMC co-sponsored a panel discussion focusing on the power of everyday language to create opportunities for those with disabilities. The program, entitled “The Power of Words: the Impact of Labels” took place on October 5<sup>th</sup> at the Universities at Shady Grove. A journey that began as one Maryland family’s battle for respect and acceptance for their daughter and sister, Rosa, became a significant milestone in the ongoing battle for dignity, inclusion and respect of all people with intellectual disabilities when United

States President Barack Obama signed bill S.2781 into federal law on October 5, 2010. Known as “Rosa’s Law,” the law removes

the terms "mental retardation" and "mentally retarded" from federal health, education and labor policy and replaces them with people first language “individual with an intellectual disability” and “intellectual



disability.” A staff member from Congressman Van Hollen’s office came to grant the Marcellino family a citation for their efforts on behalf of people with intellectual disabilities.

A robust panel discussion took place as our panelists, Nina Marcellino, Madeleine Will, Director of the National Policy Center at the National Down Syndrome Society, and Sal Campo, a social worker and “People-First” language trainer at the National Children’s center, talked about the negative impact that labels cast on children with disabilities. The panelists talked about labels from a parent perspective, a policy perspective and a service provider’s perspective. The discussion was rich and interesting, and it sparked some very thoughtful questions from the audience. It was an opportunity for educators, students, administrators, therapists and parents to come together to address the importance of language in our community.



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BUDDY WALK 2011

Continued from front page

In years past DSNMC has brought in a self-advocate speaker from across the country, but this year we decided to highlight those local self advocates and mentors that inspire us who live in Montgomery County. These are people that are living our mission, to empower and support people with Down syndrome and their families. Our speaking panel included: Eli is a proud member of DSNMC, Special Olympics and KEEN. He met his teacher Mr. Mark McKeel in 2009 after he graduated from Walter Johnson & began at CCC Career Community Connections. Mark McKeel supports Eli & other transition students to learn critical life skills to achieve independence at the Mid County CCC site at Rockville HS. Devin, who is also a member of DSNMC, Special Olympics and KEEN. She will be speaking with Darby. Together



they formed a lasting friendship when Darby was assigned to be Devin's safety patrol two years ago and still do things together at least once a month. Finally, Delaney, who is also a member of DSNMC, Special Olympics and Destiny Cheerleading. Delaney was 5 and Micaela was 8 when they met on the sidewalk in their neighborhood. Their friendship began immediately and has continued to grow over the past nine years even as they are now in different neighborhoods.

hearts. As I listened, I wasn't thinking about therapy or how to get my daughter to memorize her math facts, or how to teach her to use the microwave. I was only smiling. Smiling because I was overcome with appreciation for what all six of these children and adults had to say. I knew there was happiness and friendship and our DSNMC members standing on the stage were beaming with pride to introduce us to their buddy. This was my reminder of what the Buddy Walk is all about. At its core, the Buddy Walk is about bringing our community together to celebrate what we have and let everyone know there is so much to appreciate about each other. I think this is what makes this community so special. That is why so many people came out in the rain to participate and celebrate together! Congrats DSNMC - we did it again - another wonderful Buddy Walk to remember.

These speakers, Mark, Darby and Micaela, announced with such pride and warmth that they were inspired by their, Buddies, Eli, Devin and Delaney, and their stories warmed our



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These businesses provided in-kind contributions to the 2011 Buddy Walk.



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Thank you.

# Techniques for Success Conference

by Julie Ryan-Silva  
Parent and TFS Planning Committee Member

On November 5, 2011, the 3<sup>rd</sup> Techniques for Success (TFS) conference for educators was held at the Frederick Fairgrounds in Frederick, Maryland. TFS is held each school year and focuses on classroom strategies for educating students with Down syndrome and those with other special needs. The specific topics and speakers change each time. The conference is a joint effort between DSNMC and F.R.I.E.N.D.S., a Down syndrome advocacy group in Frederick County.

DSNMC and F.R.I.E.N.D.S. developed TFS to help students with Down syndrome and their families by building positive partnerships with schools. Educators attend TFS free of charge (thanks to those Buddy Walk donations!) and MCPS staff receive 8 hours toward a continuing education unit (CEU). Based on the positive feedback received from participants, educators return to their schools with renewed energy and creative ideas for teaching and including students with Down syndrome and other special needs.

The number of registrants for TFS continues to increase. Approximately 200 people attended on November 5 including included general educators, special educators, paraprofessionals, therapists, counselors and parents. (Parents were invited on a space available basis.) This year, three key administrators also participated: Chrisandra Richardson, MCPS Associate Superintendent for Special Education and Student Services, Gwendolyn Mason, MCPS Director of Special Education Services, and Donna Crook, Vice President of the Frederick County Board of Education.

## Conference Highlights

- **Moving Towards Independence** by Bridget Murphy, President of the Down Syndrome Guild of Greater Kansas City, one of the most dynamic Down syndrome groups in the country. Bridget's 20-year old son, Jack, has Down syndrome and now attends the University of Iowa's REACH program. Bridget emphasized the need for parents to create a vision of where they want their child to be at age 21 and to work collaboratively with educators toward this goal. Being guided by a long-term vision can reduce conflict that arises from focusing on the short term and adhering to rigid principles.
- **Successful IEPs** by Michael Remus, the Director of Special Education for Deer Valley Schools in Phoenix, Arizona. Michael's talk discussed approaches for writing IEPs to maximize inclusion, reduce conflict and increase chances for student and teacher comfort and success. He discussed the importance of developing IEP goals that make sense to the student, are a natural part of their day and connected to the general education curriculum. He encouraged educators and parents to think broadly about school personnel who can be called upon to assist students with special needs, including peers, and to not limit themselves to the idea that one-to-one aides are always necessary.

- **Self-Advocate Success Stories** by Sara Wolff and Adrian Forsythe Korzeniewicz. Sara, from Moscow, PA, is a 28-year old, nationally-know self-advocate who has worked as a law clerk for more than 10 years. Sara was successfully included in general education classes, with support, from preschool through high school. Sara explained that, "Every September began with much doubt on [the teachers' part] but, by June, they were believers."



Adrian, from University Park, MD, is a third-year student in George Mason's LIFE Program, a post-secondary program for students with intellectual disabilities. Adrian is also an intern with Congressman Steny Hoyer's office and an aspiring actor. Adrian emphasized the value of post-secondary programs for students with Down syndrome, particularly to enhance employment options.

- **Creating an Effective Teaching Team** by Melissa Desmond, Charlotte Landahl and Beth Olsen of Deer Crossing Elementary School in New Market, MD, a school that has created a culture of inclusion through successful collaboration practices among staff. This teaching team discussed the why, what and how of inclusion at their school. They also gave participants a chance to interact with a variety of tools used for positive behavior management.
- **Classroom Implementation of Universal Design for Learning (UDL)** by Bill McGrath, Assistive Technology and UDL consultant for MCPS. Bill defined UDL as “a scientifically valid framework for guiding the design of curriculum goals, teaching methods, instructional materials and assessments” to provide flexibility and reduce barriers in instruction, thereby creating high achievement expectations for all students. Using UDL techniques, teachers offer options to all students in a class allowing them to meet diverse needs without significantly more work and reducing stigmas for those with identifiable disabilities. Bill led participants through a process of identifying simple actions they could take to immediately incorporate UDL principles in their classrooms.

### Participant Quotes

A fabulous conference. Thank you for providing such a powerfully rich resource.

-

Great strategies that can be used in any classroom.

-

I feel better equipped to address inclusion and independence within my school and with my students.... I already see things I am going to change come Monday morning!

-

Inspirational - refuels my passion for working with families of students with special needs.

-

Beneficial for both special educators and general educators.

-

The variety of presenters and topics made the day slip by.

-

Gave me a new perspective on the abilities of my students and all they can accomplish when we work together and trust and believe in their path to success.

Continued on next page



### ***Next TFS Conference***

Based on the success of TFS, DSNMC and F.R.I.E.N.D.S. have made it an annual event with the location alternating between Montgomery County and Frederick County. The next TFS conference will be held in the fall of 2012 in Montgomery County.

Parents play a key role in spreading the word about TFS. (Thanks to all those who helped publicize TFS this year!) Please plan to invite staff at your child's school next fall. This is a wonderful way to support your child's teaching team and to contribute to improvements in the education of all students with Down syndrome in our county. If staff at your school have attended in the past, remind them that topics and speakers change each time so it is definitely worthwhile to attend TFS every year.

### ***Getting Involved***

DSNMC welcomes volunteers for the TFS Planning Committee. This year's committee included four parents from DSNMC (Co-Chair Heather Sachs, Gena Mitchell, Kirsten Jones and Julie Ryan-Silva), five parents from F.R.I.E.N.D.S. (Co-Chair Katie Routzahn, Denny Weikert, Bob Walsh and Shane Buckland) and a member of the Civitan Club of Frederick (Doug Silvern). If you have an interest, we can find a task for you, large or small. The majority of work for the conference occurs between August and November. To get involved or learn more, contact Heather Sachs at [heather@dsnmc.org](mailto:heather@dsnmc.org).

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# Join DSNMC and the National Down Syndrome Society for the Buddy Walk® on Washington

February 29th and March 1st 2012

The Buddy Walk on Washington is an annual two-day advocacy experience that brings the Down syndrome community together to advocate for public policies that impact the lives of people with Down syndrome and their families. Advocates come face to face with Members of Congress and their staff on Capitol Hill to advance education, research and healthcare for people with Down syndrome. Attendees will participate in an interactive advocacy training, attend a celebration and advocacy awards dinner and spend a day on Capitol Hill. The experience is perfectly suited for self-advocates, family members, professionals, affiliate leaders and members and anyone else who wants to make a difference for people with Down syndrome.

## Registration Information

You can register on your own through the NDSS website ([www.ndss.org](http://www.ndss.org)), or we can register for you. The fee for registration, which includes a ticket to the dinner reception, is \$25. ***DSNMC has a limited amount of funds available to cover the cost of registration for our members. Please email Heather Sachs ([heather@dsnmc.org](mailto:heather@dsnmc.org)) if you would like to take advantage of this option, or if you would like someone from DSNMC to complete the registration process for you.*** The deadline for registration is January 27th.

Everyone that registers to attend the conference will receive additional information and resources (including a webinar presentation to attend before you come to Washington) that will prepare participants to schedule and attend meetings, and fully experience Capitol Hill.

## Preliminary Conference Schedule

*Wednesday, Feb. 29<sup>th</sup>*

Registration	1:00 PM – 3:00 PM
Buddy Walk on Washington Advocacy Training	3:00 PM – 6:00 PM
NDSS Awards Reception & Dinner	7:00 PM - 9:00 PM

*Thursday, March 1<sup>st</sup>*

Capitol Hill Visits	9:00 – 5:00 PM
Down Syndrome Caucus Lunch Briefing	1:00 – 2:00 PM
Joint NDSS/DSAIA Reception Evening	

## Resources for Conference Attendees

As the Buddy Walk on Washington approaches, registered attendees will begin to receive detailed information about:

- How to obtain a meeting with a Senator or member of Congress
- What to expect and how to prepare for meetings with elected officials
- Conference activities and details
- Getting around in D.C.
- Policy issues and priorities
- How to connect with other advocates in your state who will be attending the conference

Please check back periodically at [www.ndss.org](http://www.ndss.org) for updated information.

## Frequently Asked Questions

- *Why is it called a Buddy Walk on Washington if there is no walk involved?*

While we don't want to disappoint anyone who may be expecting a mile loop to walk, we have chosen to call the advocacy conference the Buddy Walk® on Washington to help send a cohesive message about Down syndrome awareness and inclusion. Further, one of the things many advocates will ask the legislators for during the meetings will be to attend a local walk. Using this name for the conference will help the elected official connect local and national Down syndrome awareness activities with the local advocates with whom they are building a relationship.

- *Will there be help for me to set up meetings on Capitol Hill? Will there be training and assistance on how to best approach and meet with elected officials?*

Absolutely! We suggest that you begin to start setting up meetings in early February, and advise that you plan to have all of your meetings scheduled at least week or two before you come to Washington.

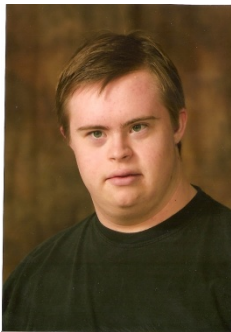
- *Who should attend this conference? What about self-advocates?*

Whether you aren't sure who your local elected representatives are or you are a seasoned advocate, if you are interested in advocating for people with Down syndrome or meeting legislators on the Hill, you are encouraged to attend...and we're sure you'll have an amazing experience!

Self-advocates are of course the best candidates to attend the Buddy Walk on Washington and are strongly encouraged to attend, however, self-advocates that attend should be over the age of 18.



## OUT OF MY MIND by Sharon M. Draper



**Reviewed By**  
**Adrian Forsythe**  
Self-Advocate

This book follows the life of a girl named Melody whom has Cerebral Palsy. She is also 11 years old. She is in fifth grade. In the beginning of the book, she started in a special education class. Then the school board decided to let the kids with disabilities to mainstream into

regular classes. Melody was very nervous because she didn't want to act up in class. Fortunately for her, she didn't. Every day she goes to

Special Ed class then goes into Mainstream classes. She encounters bullies and friends. She even got to be in a "Whack your brain team". She also got a machine that talks for her. All she has to do is type what she wants to say and the machine speaks. How cool is that!

I'm going to explain how Melody got a machine that can talk. Before she got the machine, the only way for Melody to express what she wants is by having a tantrum. Rather than having people looking at her as if she is crazy, Melody wants to talk like everybody else. Melody wants to share her thoughts, telling others who she is, and what she wants. Both her aide and Melody decided to look up on the Internet on machine that talks. They found a machine that was suitable for Melody. Melody finally found a way to express what she wants without having a tantrum.

These are several issues contained in this book: The first issue is how much can a person with a disability mainstream into regular classes. The second issue is being involved in extracurricular activities. The very last thing is learning to speak up for yourself.

I would recommend this book to people who might be interested, even though the character is fictional. She is an inspirational.



Image courtesy of: [www.goodereads.com](http://www.goodereads.com)

*Are you a self-advocate? Would like to write a book or film review? Would you like to submit a poem, photograph, etc. the newsletter?*

*Please send submissions to [elizabethwt@dsnmc.org](mailto:elizabethwt@dsnmc.org)*





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## 21 Act Package Introduced in U.S. House of Representatives to Establish Down Syndrome Research Centers and Increase Funding for Research

*From the National Down Syndrome Society Policy Center:*

Representatives and Congressional Down Syndrome Caucus Co-Chairs, Cathy McMorris Rodgers (R-WA), Pete Sessions (R-TX), and Chris Van Hollen (D-MD) introduced the **Trisomy 21 Act of 2011** or “**21 Acts**” package. The 21 Act package includes two important pieces of legislation, the **Trisomy 21 Research Resource Act of 2011 (H.R. 2696)** and **Trisomy 21 Research Centers of Excellence Act of 2011 (H.R.2695)**. The **21 Act** would establish an infrastructure within the Department of Health and Human Services (HHS) to facilitate results-oriented research, forge new partnerships between academic institutions and clinics to work together to conduct translational research, produce targeted-funding opportunities, and help stimulate steps in the discovery and development pipeline for Down syndrome.

The 21 Act, first introduced as one bill in 2009, attempted to incorporate Down syndrome as an area of permissible research and surveillance at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) to foster a better understanding of Down syndrome. The Children's Health Act of 2000 (Public Law 106-310) amended the Public Health Service Act and included a number of provisions that addressed the research and surveillance needs of many disabilities (e.g., autism, juvenile diabetes, asthma and many others). However, this landmark legislation did not address the significant research, surveillance, and clinical care needs of Down syndrome and thus has been an impediment to progress in the Down syndrome research community over the last decade.

**The 21 Research Resource Act** will expand and intensify Down syndrome programs of the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) to create an infrastructure of Down syndrome tools, including a Down syndrome contract registry, Down syndrome research database, and Down syndrome biobank. These research resources will further strengthen the research being conducted on Down syndrome across the country. This bill also establishes a Down Syndrome Consortium with NIH to facilitate the exchange of information and make research efforts more efficient by integrating the perspectives of key stakeholders.

**The 21 Research Centers of Excellence Act** will create at least six *Down Syndrome Translational Research Centers of Excellence* that provide an optimal venue and infrastructure for more translational research on Down syndrome. The bill requires NIH to publish a research plan on Down syndrome, and update the plan every five years.

**Please contact your U.S. Representative to encourage him or her to support these bills (you can go to the following [link](http://capwiz.com/ndss/issues/alert/?alertid=52080836&PROCESS=Take+Action) for instructions and talking points:**

**If your Representative is Chris Van Hollen, please take a moment to email or call his office to thank him for co-sponsoring these important bills (Phone: (202) 225-5341 or email at <http://vanhollen.house.gov/Contact/>)**





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## SELF-ADVOCACY: WORKSHOP RESULTS



By **Mary Ann Dawedeit**  
Self-Advocacy Committee

Last night my son went to dinner with his friends. He chose the restaurant and got together his posse.

They ordered what they wanted, paid for it and let their rides know when to pick them up. This might not sound too remarkable, but Eli is a young man with Down Syndrome. He gained these skills and others through his attendance at Self Advocacy classes held this spring.

Self-advocacy is defined as the ability to make choices, understand one’s strengths and needs, identify one’s personal goals and how to act on those goals, understand the advantages and disadvantages of disclosure of one’s disability communicate one’s support needs in a variety of settings including school (both in classroom settings and social settings), IEP meetings, social and community outings, and at work.

Led by the Self-Advocacy Leadership Network of the Down Syndrome Network of Montgomery County, a group of young adults were welcomed to attend Self-Advocacy Workshops designed by Maryland Coalition for Inclusive Education. The Maryland Coalition for Inclusive Education (MCIE), a nonprofit organization, provides advocacy and legal representation for families of children with disabilities, and technical assistance and training for schools.

Carol Quirk, Ed.D. Co-Executive Director of MCIE devised a 4 part curriculum. The first session took place on March 17th from 4:30 to 6:30. First, the participants were assessed to determine the appropriate curriculum for our group of self-advocates. Questions were asked of families:

- Do you want your son or daughter to learn about the advantages and disadvantages of asking for necessary accommodation?

- Do you want your son or daughter to learn about understanding one’s strengths and needs during the coaching sessions?
- Do you want your son or daughter to learn about understanding one’s strengths and needs during the coaching sessions?
- Do you want your son or daughter to learn about identify one's personal goals and how to act on those goals?

These young adults then attended four sessions. First they listed their skills, dreams, and challenges. Their dreams for the future were matched with supports that may be needed to achieve them.

Carol was assisted in these sessions by Nancy Forsythe, DSNMC board member and other MCIE staff. The participants used flip charts to express themselves within the program. Questions asked included:

- What is something about me you should know?
- Where do I want to live in my future?
- What kinds of work do I want to do?
- A personal goal that I have is?

These members of the SA group of DSNMC were asked to state one good thing about themselves, and then to start to choose for themselves a choice for the future and alternatives for work. The group met at The Arc in Rockville and ate dinner together and enjoyed door prizes along with Carol’s valuable instruction. After dinner the group would get together for review to share their thoughts with their peers.

These young adults are forever enriched by the Self Advocacy training and they all want to thank the membership of DSNMC for their support of this project.

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# POST-SECONDARY EDUCATION FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES

By Nancy Forsythe  
Self-Advocacy Chairperson  
nancy@dsnmc.org

Until recently, when individuals with Down syndrome finished high school, they almost certainly terminated their formal education as well. This is changing slowly but surely across the US as more and more institutions of high education (IHE) offer opportunities for people with intellectual disabilities (ID) to attend. Nevertheless, national research on post-school outcomes demonstrates that while only 30% of students with any type of disability take post-secondary classes, an even smaller percentage—2%-- of students with ID take post-secondary classes.

Over the next several issues of *Connections*, we will discuss post-secondary education for individuals with ID. We will look at what is currently happening across the US; what is happening in Maryland; different program models and quality indicators; the benefits to students who attend; public policy dimensions; financial considerations; and other issues that arise from your feedback and questions.

## Higher Education Opportunity Act

In 2008, for the first time, the Higher Education Opportunity Act (HEOA) defined PSE programming, indicating that it should be designed to support students with intellectual disabilities who are seeking to continue academic, career and technical, and independent living instruction in order to prepare for gainful employment. The connection between PSE and employment is important: IHE faculty/staff, policymakers, and families agree that PSE should support students in their individual employment goals and include program elements that lead to the skills that are critical to successful employment, including the 'soft skills' – teamwork, problem-solving, and communications-- that

## TYPES OF PROGRAMS

There are now over 200 programs for individuals with ID offered at 2-year, 4-year and technical post-secondary schools in the US. These programs differ widely in their programming and in how students interact with the rest of the campus; we can broadly distinguish three models of post-secondary education.

- **Substantially separate programs** in which students participate on campus only in classes/activities with other students with ID. Students may have access to campus for activities with students without disabilities, and/or may have work experiences on campus through the program.
- **Aninclusive individual support model** in which there is no program base on campus. Through the IHE's disability support services office, students receive individualized services and supports for classes, activities, work.
- **Amixed/hybrid model** in which students participate in separate classes/activities but may also access classes/activities with students without disabilities. Students' employment experience may be more or less inclusive.

Many students enroll in what are called dual-enrollment programs where high-school students still eligible for funding through the Individuals with Disabilities Education Act (IDEA) attend programs on college campuses for one or two years. Maryland has several of these programs.

Admission to PSE programs is very competitive because of the high demand among prospective students and the limited number of programs. Attesting to the demand, 6 students from Maryland are included among the 30 students currently enrolled in the George Mason LIFE Program nearby in Fairfax, VA.

## Further Information

The premier source of information and resources regarding PSE is ThinkCollege <http://www.thinkcollege.net>. On this website, you will find a database of programs; useful information about what to expect from programs; testimonials from program participants; information on public policy, financial aid, and the benefits of programs for students; and more. As we review considerations that families in Maryland face in thinking about post-secondary options for their transitioning youth, visit this site to learn more about PSE programs.

As noted elsewhere in this issue of *Connections*, the Maryland Down Syndrome Advocacy Coalition has included PSE as a priority for our state. We will keep you informed as we move ahead with this initiative. If you'd like to join in this effort, please contact Heather Sachs at [heather@dsnmc.org](mailto:heather@dsnmc.org).



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I was at the Grand Opening Day of the Miracle League in Germantown. I felt moved and inspired. There was a ribbon-cutting ceremony along with a short game. Owners, executives and players from the Nationals participated in the event along with the Lt. Governor of Maryland Anthony Brown and the Montgomery County Councilmember Craig Rice. The Miracle Field has a cushioned turf and other features that allow players who use wheelchairs to circle the bases.

**By Gena Mitchell  
President  
gena@dsnmc.org**

There are only two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle.

-Albert Einstein



# MIRACLE LEAGUE

## Swimming with the Dolphins

By Jen Duran

We had a dream for Isabelle – we’ve had it for a few years now. We wanted her to swim with the Dolphins. Fortunately our dream did not require a trip to the Bahamas or even to Sea World; the Dolphins are just a few blocks away at our community pool. But when we first had our dream, it seemed like it would be a long journey.

Since we moved to this neighborhood when Isabelle was 8 months old, we have always loved the pool. For the first three summers she was not yet walking. It was hard to imagine making friends. While the other 2 year olds were running around, talking, and using their water wings in the big pool we were still holding Isabelle up in the baby pool. That first year a brochure came in the mail. It talked about the Dolphins swim team – the history, coaches, cost to join – the regular stuff. Except this brochure went out of its way to share the team’s ‘all are welcome’ philosophy, and it mentioned children with Special Needs. Part of me felt like that brochure was written just for us; but the cynical side thought: ‘They didn’t mean kids like Isabelle when they said that.’ Nonetheless that was where the Dream of Swimming with the Dolphins started. After all, that brochure did say ‘Special Needs welcomed.’

In those first few years we met many wonderful neighbors who were welcoming and very, very kind to Isabelle, but their kids just seemed to be in a stratosphere that Isabelle couldn’t reach. Nonetheless, several families went out of their way to introduce their sometimes reluctant kids to our daughter. It pretty much started and ended there. The kids would say ‘Hi’ and then run to the playground or hop in the pool – totally normal things for them - but things Isabelle really couldn’t do on her own yet.



At the end of the third summer one of my neighbors, Claire, said ‘Isabelle should join the team next year.’ I said ‘Thanks’ but thought that this seemed like an impossible idea. Isabelle had just started walking, was nowhere near being potty trained, could have an ear infection at any moment... No, it wasn’t a good idea. And the coach, Terry, she looked pretty intimidating at swim practice even though she was nice to Isabelle when we ran into her on the weekends. ‘But,’ said a little voice in my head, ‘Isabelle is starting to use her water wings, and she’s blowing bubbles in the water...’ Could she poke at that stratosphere where the other kids dwelled? It made me pause. And of course I had that Dream.

The year following that fourth summer was when Isabelle blossomed. She was walking well, even running a little, she was talking more, and she had grown a couple of inches. She also welcomed baby brother Jonas home that winter. By that Spring I decided to take a chance and email Coach Terry about some swimming lessons for Isabelle. I was intimidated but figured perhaps we could start to make a connection here, and maybe that connection could turn into Isabelle joining the team in a few years. We probably talked for an hour when I called, during which time I shared all the possible challenges of working with Isabelle. Thankfully Terry was enthusiastic and did not let my hang-ups get in the way. We had a number of great lessons that spring; Isabelle improved. Terry even said to Isabelle ‘Someday maybe you’ll be a Dolphin.’ I smiled inside. Well, Terry said it. Now nothing can stop the Dream.

*Continued on page 26*



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Last summer it was still a bit too early to join the team, but we knew the Dream was real and it was going to happen. So we let our guard down a little and began to go out of our way to learn more about those nice families who had always said ‘Hi.’ We got better about encouraging Isabelle to play with the other kids. We tried very hard to let Isabelle be herself around them; we stopped always apologizing for her and trying to manipulate every situation to show only her ‘best’ side. She was able to start using her natural magnetism to find friends because her parents weren’t hovering quite as much. She was invited to some of the swim team kids’ birthday parties. More connections; an unexpected Dream.

Fast-forward a year. Isabelle is shy in school but her blossoming continued in other ways. She had basically finished potty training when summer arrived and with some strong advocating we had gotten her placed in our neighborhood school where there are no Special Ed classrooms or dedicated aides. During her IEP, the Special Ed coordinator for the school stated that our ‘community involvement’, which stemmed from our connection with the pool, helped influence the recommendation that Isabelle be placed in the school. She said that Isabelle was part of the community already, and she deserved to be given the chance to go to school here. Wow, who knew?

I had been prompting Isabelle all spring about the team. ‘Isabelle do you want to join the swim team?’ ‘I’d say. ‘Yeah, swim team!’ she would yell as she jumped up and down. Imagine our delight when, on the first day of practice this past June, after just a little prompting to get in line, Isabelle checked herself in to the swim team by responding to Developmental Coach Joanna’s questions. It went something like this:

Joanna: Are you here for the swim team?  
 Isabelle: Yes.  
 Joanna: Great, what’s your name?  
 Isabelle: Belle.  
 Joanna: Okay Belle. You can sit on the edge of the pool with the other kids.  
 And there it was – the Dream had happened! Isabelle was a Dolphin.

Actually, the Dream was just beginning. The team’s Developmental coaches, Joanna, Sarah and Lilan, were amazing with Isabelle. They treated her just like any other kid but somehow knew how to accommodate for the extra help she needed. Isabelle blew away our expectations by her willingness to come to every practice, sit with her teammates, and overcome her apprehensions in the water. She learned to kick, do her ‘freestyle’ arms, and keep blowing those bubbles. She reluctantly tried backstroke, kicked on a kickboard and by far her favorite thing to learn was the racing dive. The team assigns ‘buddies’ for every swimmer, so in addition to the 6 weekly practices she had with her coaches, Isabelle had two practices a week with Winston, an accomplished swimmer who swam in the 13-14 Boys group. Winston was as amazingly patient with Isabelle as the coaches were, and Isabelle loved him.

We participated in just about every swim team event that happened this summer, and as much as we could, we helped. We timed at the meets, we came to the Pasta Parties, the Dolphin Dance; my husband took pictures at as many events as he could. Even though she wasn’t swimming competitively



this year Isabelle learned what it meant to be part of the team – she cheered on her teammates during practice and at the meets. Her buddy Winston made sure she attended the team meetings after practice. The swim team exposure this first year was very good for us too – at the meets we saw that just about every 8 and Under swimmer struggles to get across the pool in the beginning, and we were able to witness how the team pulls together to cheer these kids on to the finish at the wall. It won’t just be Isabelle who struggles at the swim meets; it seems like all the kids do at first. Again, who knew?

Isabelle showed us she had her own Dreams beyond just joining the team this year. She earned Swimmer of the Week

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and the Coaches Award for Most Improved 8 and Under at the awards banquet. And amazingly, while Isabelle was learning new words like 'swim meet' and 'practice' and 'Go, go, go!' we found ourselves losing vocabulary – no longer did every other sentence contain 'Down syndrome', 'speech delay' or 'low tone'. A humbling lesson was one morning when Winston was working with Isabelle on her freestyle – trying to get her to kick, use her arms and blow bubbles all at the same time – it was clearly a struggle for her. When I started to spew something about 'motor planning challenges' he just interrupted me with the kindest smile and said 'Yeah, but at least she's trying.'

And best of all, Isabelle has friends at the pool now. Friends who say 'Hi' even when their parents aren't looking, and slow down to talk to her instead of whizzing by every time. Friends who play with her and also seem to instinctively know when she needs help. We found that we never actually had to 'explain' Isabelle to anyone on the team. Occasionally a kid would ask if she talked much or could she do this or that, but it was always with that kid-like curiosity that is so normal. We would answer the best we can, and wherever possible we'd prompt Isabelle help us with the answer. If she could do something she'd do it; if she couldn't we'd say 'No, she doesn't do that yet.' Holding back the reasons ('Down syndrome', 'speech delay', 'low tone') was so hard, but we tried to bite our tongue and just let it ride. The results were incredible – many of the kids seemed motivated to teach Isabelle something when she couldn't do it – the racing dive, the breathing pattern, swimming to the wall in the Big Lane.

For one of the kids' birthday parties at the pool, the parents had rented a huge moon bounce with a slide in it. A boy named Owen asked us if he could take Isabelle into the moon bounce. I said 'Sure, but you know she can't get up those slippery steps to go down the slide; she can just jump on the flat part, right?' Owen smiled and said 'I know' and led her in. Being 6, Owen soon lost interest in the flat part and was climbing up those slippery stairs, with Isabelle at the bottom trying over and over to get up herself. Owen noticed and tried to help her, first by trying to push her up, and eventually by trying to teach her how to position her feet on the corners of the stairs to avoid slipping. I was thinking 'Oh Owen give it up. She can't do it.' But I bit my tongue. And after what seemed like an eternity the two of them willed Isabelle up those stairs – first with Owen pushing her and positioning her feet for her. And then, after a few times, Isabelle positioned her feet all by herself! Long after Owen had run out of the moon bounce to his next adventure, Isabelle was in there, climbing those slippery steps and flying down that slide.

*When I started to spew something about 'motor planning challenges', he just interrupted me with the kindest smile and said 'Yeah, but at least she's trying.'*

No longer do we hover over Isabelle; her friends let us know when we're needed. By the end of the season it seemed that everyone on the team included Isabelle and just treated her like one of the group. It overwhelmed us that this team and community had found this way to include our family, and our special daughter, in such a 'typical' way. That was the real Dream realized, wasn't it? Oh how I wish we could spend every day at the pool swimming with the Dolphins; sadly that will be ending soon for the season. But Isabelle will be taking so much with her into Kindergarten – several team members are starting as well - and so we now know we'll be playing with the Dolphins long after the swimming season is over. A Dream is realized, 100 times greater than we could have dared to imagine. And the next Dream? Swimming with the Dolphins, in a swim meet, and making it across the pool. And how far will that journey take us? Stay tuned.

*Dedicated to Karen Gaffney and her family, our first very first swimming inspiration and one of our 'model' families, for teaching us the importance of inclusion, athletics, and involvement. We were standing on your shoulders this summer. And to the Strathmore Bel Pre Dolphins swim team, coaches and parents. They are the model for how all communities should embrace every one of their children.*

## Children and Young Adults with Down Syndrome Have a Story to Tell!

Researchers at the NIH are conducting a research study on brain development and learning in children and young adults with Down syndrome.

All procedures (including brain imaging, learning and memory testing) will be completed on an outpatient basis at the NIH Clinical Center and may be completed over 4 visits. Each visit will take between 4-8 hours.

Children and young adults may be eligible to participate if they are between 8 and 30 years old and have a confirmed chromosomal diagnosis of Down syndrome.

Volunteers will be compensated for their participation. Parent or legal guardian, child, and young adult must agree to participation. There is no charge for research procedures and evaluations.

### For more information, contact:

Nancy Raitano Lee, Ph.D. at 301-435-4520

TTY: 1-866-411-1010

email: LNANCY@MAIL.NIH.GOV

<http://patientinfo.nimh.nih.gov>



National Institute of Mental Health, National Institutes of Health,  
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Protocol No. 89-M-0006

Continued from front page

MDAC believes that individuals with intellectual disabilities, including Down syndrome, should be afforded the opportunity to learn, grow and contribute to the well-being and prosperity of our State. To that end, MDAC is committed to: (1) Expanding the availability of, affordability of, and access to meaningful postsecondary education programs that support students through a focus on academic, social, employment and independent living strategies, as outlined in the Higher Education Opportunity Act (HEOA) (PL-110-315); (2) Partnering with members of the business community, state policymakers, higher education institutions, school systems, adult service providers, advocacy groups and other stakeholders to develop and fund such high-quality comprehensive transition and postsecondary education programs; (3) Aligning such high-quality postsecondary education programs with education and workforce development goals in the State; and (4) Increasing public awareness of and support for such high-quality postsecondary education programs.

*If you are interested in joining MDAC and working on its PSE initiatives, please contact Heather Sachs at [heather@dsnmc.org](mailto:heather@dsnmc.org).*



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