



November 2001

DSA Press

Down Syndrome Association
of West Michigan

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website: www.DSAWM.org e-mail: DSAWM@iserv.net

Calendar

DSAWM meets the 2nd Monday of each month from September through May at First Reformed Church of Grandville unless otherwise noted in the newsletter.

DIRECTIONS TO MEETINGS - First Reformed Church of Grandville, 3060 Wilson Ave. SW, approximately one half mile south of 28th Street in Grandville.

Nov. 11-13 - Learning Disabilities Assoc. of MI *Annual Conference for Parents & Professionals*, East Lansing, MI, call (517) 485-8160 for registration form.

Mon., Nov. 12 - DSAWM general meeting, *Sensory Integration & Processing*, Al Hansberry, OTR, MOTL, 7pm.

Tues., Nov. 13 - *Raising Student Achievement through Discipline & Responsibility with Love & Logic*, 8:30am-2:30pm. Call (800) 338-4065 to register. Fee required.

Sun., Dec. 9 - DSAWM Holiday Party, 1-4pm. Watch your mail for separate invitation.

Mon., Jan. 14 - DSAWM general meeting, *Independent Living - A Presentation on the Issues & Concerns*, Michelle Bryk, Executive Director, Guardian Angel House, 7pm.



ADDRESS CHANGES - Each issue of the DSA Press is sent bulk mail. If you are planning a move, please note that the bulk mailing system will **NOT** forward the DSA Press to your new address. Please call Char Hill at (616) 957-4934 with address changes.

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President's Points

The Turtle and the Hare,

As I watch our daughter's growth and development, I'm reminded of the parable about the turtle and the hare with the ultimate lesson "slow and steady wins the race". While I'm relatively certain Kate's not going to win too many races, I have to remember that she is making slow and steady progress. This seems to be the case with kids with DS. The problem is we are an instant gratification culture and slow and steady doesn't fit our style. Not many people go to a track meet to watch the marathon, they want to see the 100 yard dash, even the 1500 meter race can be kind of boring until the last 200 meters.

As parents of children with DS, we are forced to watch the whole marathon, step by step, stride by stride. And not just one marathon but many marathons. From learning to walk, to saying their first words, to potty training. We are the new marathon crowd. Never having watched a marathon, I would guess that the crowd consists mostly of people who can appreciate the monumental efforts that are being put forth by the runners, overcoming mental and physical pain to push on to the finish. The crowd is there to appreciate and encourage the runners.

What's my point? I want to encourage everyone to keep trying and never give up on our kids. They are running a marathon and they need our support or they may quit. Every day we face the pace of our children's development and we are frustrated and sometimes bored with the lack of progress. We must find ways to overcome these feelings and turn them into support. We must continue to challenge our children. I sometime think of the turtle and the hare. It helps me, I hope it might help you.

Timothy Hill, President

PS: Many thanks to all who participated and supported this year's Buddy Walk.

SENSORY INTEGRATION & PROCESSING

What is it? How does it affect cognitive development? What happens when it goes wrong? Can it be corrected?

Mr. Al Hansberry, OTR, MOTL

Monday, November 12, 7pm

BUDDY WALK 2001 - THE BEST EVER!!!

THANKS FOR YOUR SUPPORT



Pictures omitted

THANKS TO YOU WE RAISED OVER \$16,000

Pictures omitted

We would like to thank the following committee members for their work on this year's walk: Lois Roelse, Brenda Hall, Linda Bueche, Cheryl Kaletka, MaryAnn Tyczynski, Don VanOeveren & Char Hill. Thank you!!!!

Family Feature

Nicole Heydens

Hello everyone! I'd like you to meet Nicole Savannah Heydens. Weighing in at 8lbs., 9oz., Nicole is almost 6 months old. Before Nicole was born, we had no idea that she had Down syndrome or a heart defect. I must admit we were shocked, sad and worried when we found out. At birth, she was immediately taken to the NICU in Grand Rapids, and spent her first 10 days there. We didn't get to meet or hold her until the next day. When we finally got to hold and meet our daughter, I knew immediately that she was a fighter and would be OK. She weighed only 4lbs., 12oz. but was so strong.

Nicole is our first and only child so it was very intimidating bringing home this little baby. Not only was she our first, but we also had feeding tubes, medications and oxygen to contend with. All we could do was bring her home and love her the best way we knew.

She went back into the hospital at 4 weeks with the diagnosis of congenital chylothorax, a leak in her lymphatic system. She had more pokes, procedures and tests performed on her than I could have ever imagined. It was really hard on our family seeing her go through all of this. She was in the hospital for 4 1/2 weeks and was finally released on May 30. She has been home ever since and for the most part has been healthy.

We are preparing for her heart surgery which is tentatively scheduled for October 31. Our biggest challenge at the moment is feeding her and trying to get her to gain weight.

Nicole has been such a joy in our lives. She is so happy, there are days that you can't get her to stop smiling no matter how hard you try. (She has quite a temper at times too!) Sure there are moments

when I am still sad and frustrated, but all I have to do to make the sadness go away is hug my daughter and watch her smile at me. I can tell that Nicole's love for life and others will be huge and what more could I ask? I want to give her every possible opportunity to help her develop to the best of her potential. But for right now, as long as she can smile at us, I'm happy.

So far, everyone has been extremely supportive and helpful. Trying to handle all of her different doctors and therapists can be frustrating. I sometimes feel as though I'm treated more like Nicole's nurse rather than her mom.

If any one has any comments or suggestions, we would love to hear from you. We look forward to meeting all of you and thanks for the support!

Sincerely, Nicole's parents,
Heather and Jason, & Nicole too!
(e-mail: heawil2000@yahoo.com
or telephone (616) 392-8230).



*HAPPY
THANKSGIVING*

DSAWM Board

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Disclaimer Policy Statement

DSAWM is a volunteer group consisting of parents & caregivers of individuals with Down syndrome. The *DSA Press* is written on a volunteer, nonprofessional basis. This newsletter reports items of interest relating to DS in an attempt to create an optimistic outlook and attitude. DSAWM does not support or endorse any particular regimen, treatment, political or religious view and does not endorse any individuals or organizations referred to herein. DSAWM is an affiliate of National Down Syndrome Society.

DSA Press is published by the Down Syndrome Association of West Michigan. Editor: Char Hill, Phone (616) 957-4934, Fax (616) 974-9612.

Note: Please call Sue Lenhardt if you know of a child with Down syndrome that is being hospitalized.

Legislative Update

Congress Approves Negative IDEA Amendments Ask Your President & Conferees to Drop Amendments from Report

House and Senate conferees have begun work to resolve the differences between their versions of the reauthorization of the Elementary and Secondary Education Act (ESEA), S.1 and H.R.1. Both versions contain dangerous amendments that would repeal key components of the Individuals with Disabilities Education Act (IDEA). The Senate bill, but not the House bill, includes the Hagel (R-Neb.)-



Harkin (D-Iowa) amendment to fully fund Part B of IDEA in 6 years through a mandatory funding formula.

The Senate bill contains the Sessions (R-Ala.) amendment that would allow school authorities to cease educational services or segregate students for violations of the school code of conduct. For example, a child with Down Syndrome could be removed from the regular class for hugging a teacher or other student if a school code prohibits unwanted touching. The House bill contains the Norwood (R-Ga.) amendment that allows for the cessation of educational services if a student with a disability violates the school code regarding use and possession of a weapon, illegal drugs or commits "aggravated assault and battery", which states would define.

These amendments will essentially repeal the following vital provisions of IDEA: Free, Appropriate Public Education (FAPE), Least Restrictive Environment (LRE), Individual Education Program (IEP), parent/educator partnership, and due process protections/safeguards.

ACTION NEEDED

Both the White House and the Congress will play key roles in the final IDEA decisions.

President Bush

1. Urge the President to convince the Conferees to remove the Sessions and Norwood amendments from the ESEA bill. 2. Tell the President that his pledge to "leave no child behind" will evaporate if the ESEA bill he signs into law includes either the Sessions or Norwood IDEA amendments. 3. Ask the President to remind the Conferees that IDEA reauthorization is scheduled for next year and that a thoughtful review of IDEA discipline provisions should be considered at that time. 4. Urge the President to press for the IDEA full funding amendment.

House and Senate Conferees

1. Tell them that the Sessions/Norwood amendments repeal vital protections for students with disabilities and should not be in the final bill. 2. Explain that expelling students does not guarantee school safety. Troubled children with disabilities out on the street with no services or supervision is bad public policy, leaving schools, shopping malls and everybody at risk. 3. Show them how Sessions/Norwood will further exclude and segregate students with disabilities. These amendments are about exclusion and segregation, not school discipline. 4. Urge the Conferees to adopt the IDEA full funding amendment.

Contact the White House and Committee Conferees. You can reach any Conferee by calling the U.S. Capitol Switchboard at (202) 224-3121 and asking for them by name. The number for the White House is (202) 456-1414.

Sample letters to the Conferees and President Bush follow. The Conferee from Michigan is Rep. Dale Kildee (D). His addresses are website: www.house.gov/kildee, E-mail: dkildee@mail.house.gov, phone: (202) 225-3611, fax: (202) 225-6393, Hill Address: 2107 Rayburn House Office Building, Washington, D.C. 20515-2209).

SAMPLE LETTERS

President Bush

President George W. Bush
The White House
1600 Pennsylvania Avenue, NW
Washington, D.C. 20500

Dear President Bush,

On behalf of the quarter million students with mental retardation, I write to you in regard to the Administration's role in developing the conference report on the reauthorization of the Elementary and Secondary Education Act (ESEA). In particular, we urge your involvement in two issues in ESEA that affect the Individuals with Disabilities Education Act (IDEA) and the six million children with disabilities in our nation's schools. Your strong commitment to improving educational opportunities for every child in America and to "leave no child behind" has resonated with all Americans. The ESEA reauthorization is the first opportunity for your goals and America's dreams to be realized.

As you are aware, the IDEA amendments address the full funding of IDEA and the discipline of students with disabilities. As a member of The Arc of the United States, I am a vigorous proponent of achieving full funding for IDEA, a goal that was promised by the U.S. Congress over a quarter century ago but has yet to be realized. The Hagel Amendment to ESEA would achieve full funding for IDEA in a reasonable amount of time. It is critical that your Administration do its utmost to convince the House and Senate conferees to support mandatory full funding of IDEA in the ESEA reauthorization.



In regard to discipline and IDEA, the Sessions Amendment in the Senate bill and the Norwood Amendment in the House bill would do grave harm to students with disabilities if enacted into law. Both of these amendments were added to the ESEA bills without any hearings, without sufficient consultation with the disability community, and without reference to meaningful data regarding students with disabilities and discipline. If enacted into law, each of these amendments will have the net effect of leaving children behind by excluding them from educational opportunities, possibly for the rest of their school-age years. I strongly believe that these

amendments are bad public policy for children with disabilities and bad public policy for all Americans. It makes no sense to exclude troubled students from school, leaving them to their own devices on our streets. No one is safer under this scenario. We strongly urge you to have your Administration weigh in with the conferees to remove the Sessions/Norwood amendments in the ESEA conference. There will be ample opportunity in next year's reauthorization of IDEA to review IDEA's current discipline policies.

I thank you for your leadership to improve our nation's schools. I am very hopeful that you and your Administration will achieve the goal of leaving no child behind as well as full funding of IDEA within the ESEA legislation.

ESEA Conferees

Dear ESEA Conferee:

As a member of The Arc of the United States, I urge you to reject the discipline amendments related to students with disabilities. I also urge you to meet the federal promise to funding 40 percent of the excess cost of educating students with disabilities and to ensure that students with disabilities are part of any accountability mechanisms adopted by the conferees.

I urge you to oppose the Norwood and Sessions Amendments. They must not be included in the final bill. Rather, the issue of disciplining students with disabilities is expected to be considered as part of next year's reauthorization of IDEA.

I also ask you to support mandatory full funding of the Individuals with Disabilities Education Act (IDEA). We request the opportunity to work with you to develop final conference language that will ensure that special education services are adequately funded.

The Arc is our country's largest and leading organization which advocates for the 7 million children and adults with mental retardation. Over 250,000 of our constituency are receiving special education under IDEA.

Thank you for considering my views.

* * * * *

Family Opportunity Act Action Must Happen Before Congress Adjourns

The Family Opportunity Act (FOA) – now called the Dylan Lee James Act – is important legislation designed to help families of children with disabilities. The goal of the bill is to give more children with disabilities access to a broad range of needed health care services and supports. The bill would allow states to offer middle-income families of children with disabilities (up to 300 percent of poverty, which is \$51,150 for a family of four in most places) — the option of buying into Medicaid. Currently, these children are ineligible because their families make too much money. Because of this restriction, they are often uninsured or underinsured because insurance is not available through an employer, is too expensive, or has a very limited benefit package. In addition, parents are forced to remain in dead-end jobs to keep some health insurance or forced to turn down jobs in order to access federal health benefits.



Giving parents the option of buying into Medicaid and paying on a sliding scale basis would give children with disabilities in these families access to the full range of Medicaid services. This is very important because Medicaid is designed to offer a very broad range of services, including those provided through the Early Periodic Screening, Diagnosis and Treatment program. This broad range of services is not available through typical State Children's Health Insurance Programs unless a state has built their SCHIP program on Medicaid.

The bill includes a demonstration program that would allow states to cover children with "potentially severe disabilities." This program promises improved overall health, the prevention of future disabilities, and a better chance for

children to live full and healthy lives with their families in their home communities.

Other provisions would allow children receiving inpatient psychiatric services to now be eligible for home and community-based waiver services; restore presumptive eligibility for Medicaid for children born with severe disabilities; and provide funds for Family-to-Family Health Information Centers to help families with children make informed choices about treatment needs.

After the terrorist attacks on the nation on Sept. 11, it was expected that the Administration and Congress would only concentrate — in the short term — on how to deal with national defense and terrorism issues. More recently it appears that a number of health issues could be addressed before Congress adjourns. Congress is looking for issues on which there is strong bipartisan consensus and the Family Opportunity Act (S.321/H.R.600) fits that bill. There is also a set-aside in the FY 2002 budget resolution to fund the FOA. Given the rapidly changing fiscal priorities of the nation, the rapidly dwindling surplus, and new spending initiatives aimed at stimulating our economy and protecting our people, future major federal expenditures — like FOA — are unlikely — **THUS THE TIME IS NOW OR IT POSSIBLY MAY NEVER HAPPEN.**

Call Sen. Daschle (Senate Majority Leader) at 202-224-5556 and ask him to bring the FOA up for a vote. Tell him how important it is to families of children with disabilities. Also call: Sen. Reid (Senate Majority Whip) at 202-224-2158. Sen. Baucus (Chairman of the Senate Finance Committee) at 202-224-4515, Rep. Hastert (Speaker of the House) at 202-225-0600, Rep. Gephardt (House Minority Leader) at 202-225-0100, and Rep. Tauzin (Chairman of the House Energy and Commerce Committee) at 202-225-2927.

(From The Arc's Action Center at www.capwiz.com/thearc/home).

Education

Beware the Retarding Environment

By Kathie Snow

In 1984, a report entitled, *“Surviving in the System: Mental Retardation and the Retarding Environment,”* detailed how placing individuals with cognitive disabilities in institutions or congregate settings put them in “retarding environments.” Today, “retarding environments” can be found at home, in school, and in other settings. But how can typical environments be “retarding?” Because many individuals with a disability do not have the tools and accommodations they need, which causes their social, emotional, and intellectual growth to be slowed down, or retarded.

Sara, a three year old with an orthopedic disability, is not crawling or walking. She’s positioned properly in a manual wheelchair, but she must always be pushed by someone. As a result, Sara isn’t able to experience the vast amounts of learning that occurs when three-year-olds explore their world: going where and when she wants in her own home, learning she can “run away” from mom and return, achieving a new level of independence, and more. Her intellectual and social development are significantly impacted, and Sara is learning dependence in retarding environments at home, in preschool, and in other settings.

Her parents and therapists are focused on getting Sara to walk. That, they believe, is the “problem” that needs to be remedied. While focusing on one ability (walking), other-and more important-aspects of Sara’s development are in jeopardy. But what if Sara had independent mobility (a power wheel-chair) so she could explore and learn, acquire typical social skills and develop independence? Which is more important: walking or mastering her world in whatever way works best for her?

Brian, a nine-year-old with a cognitive disability, is said to “function at the level of a six-year-old”. Because he can’t yet read, educators (and his parents) don’t feel he could be successful in a regular class, so Brian has spent three years in the special ed room, where teachers have focused on teaching him to read.

This placement has produced extremely negative outcomes for Brian. Being in the “retard room” makes him feel bad about himself. His struggles against these feelings is leading adults to presume he has “behavior problems.” Also because he’s in the special room he is not exposed to the typical classroom curriculum, which causes him to fall further and further behind.

Sadly, he’ll probably spend the remainder of his school career in special classes, and he’ll leave the public school system uneducated and unprepared for work or post-secondary education, after spending twelve years in retarding environments.

While educators and Brian’s parents focused on one skill (reading), Brian lost countless opportunities to learn from the typical activities in



regular ed classes. There are many ways of learning; through hands-on activities, using computer programs and videos, listening, and more. The inability to read need not be a barrier to learning and academic success! Overall, which is more important: reading or learning in any way you can?

Mary Ann has spent years in a sheltered workshop being “prepared” for a real job. She hates making widgets all day, and staff thinks she’s incapable of anything more. Like Brian, Mary Ann rebels against the insults to her dignity, using the only power she has left: resistance. According to staff, her behavior “proves” Mary Ann is not ready for a real job.

Retarding environments are not limited to segregated or congregate settings. They can exist anywhere individuals with disabilities are prevented from living ordinary, natural lives and having power over their environment. How can we prevent retarding environments? First, by understanding that people with disabilities need the same experiences for growth and development as people without disabilities. To meet that goal, children and adults with disabilities must be in age-appropriate, typical, ordinary, inclusive settings.

Next, people with disabilities must have the tools, accommodations, and supports they need to be successful in ordinary, inclusive environments. Few people without disabilities would be successful if they didn’t have appropriate tools and accommodations (computers, cell phones, support from peers, and so forth), so why is it OK for people with disabilities to go without the tools and support they need?

And, finally, we must look at people with disabilities and presume competence. The language and labels we use, along with programs, which attempt to fix a person’s “problems,” reflect the paradigm that people with disability are incompetent and unable. But they’re not! When we operate from the “presume competence” paradigm, we’ll ensure the Saras, Brians and Mary Anns of this world are in natural, ordinary and inclusive, environments, with the tools, accommodations, and support they need for success.

Copyright 2001 – Kathie Snow, website www.disabilityisnatural.com. Katie is the parent of a child with a disability and the author of *“Disability is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities.”*

Gift Idea!!!

Believe it or not the winter holidays are just around the corner.

Get a head start on your shopping for those hard to buy for people in your child's life - teachers, therapists, paraprofessionals. Purchase sweatshirts from the DSAWM! These high quality shirts display the association's logo and positive information about our kids.



A member recently purchased sweatshirts for her daughter's team at school and the shirts were a great hit!

Contact Char Hill (616) 957-4934 to order.

Don't forget, family members also would love these shirts!!

In-Home Child Care Providers

Calvin College has compiled a listing of students who are interested in providing child care services on fixed or flexible schedules to families with special needs children. Schedule and fees are negotiated with each student.

Contact Lois Roelse at (616) 554-5410 if interested in receiving the list. It will also be available at the future monthly meetings.

New Parent Coffee

The new parent coffee will be held Thurs., November 8, at 7pm at the home of Char Hill. The coffee is an informal gathering where parents of children 3 and younger can seek support, ask questions, and learn from other parents. Children are welcome. Call Char at (616) 957-4934 for directions.



CELEBRATE THE POSSIBILITIES - West Michigan Inclusion Network's 2nd Annual Conference on Inclusive Education

Date: Friday, December 7
Time: 8:30am - 3:30pm
Cost: \$35.00
Location: Grand Valley State University's Eberhard Center, Grand Rapids, MI

To register call Lauri Stein at (616) 954-9424

Sample Topics-

- Curriculum Adaptations & Accommodations for Elementary Students
- Responding versus Reacting
- Legal Updates on Inclusion
- Young Adult Transition to a University Location
- Assistive Technology Options for Inclusive Settings

Web Resources

The Arc Michigan has a software program "State Capital Wiz" that will allow people to communicate more efficiently with the governor and State Legislature.



Coupled with the new Arc US Legislative Action Center, communication with state and federal official

has never been easier. Connect to www.arcmi.org, then click on the **TAKE ACTION** icon and you are there.

Watch Your Mail for Questionnaire

The Board is currently developing ideas for programs for next year. Such programs include Saturday morning drop-in day care, group and/or individual speech sessions, therapeutic play sessions, and recreational activities for individuals 8-14 and 15-older.

-WE NEED YOUR INPUT-

Please respond timely to the questionnaire when you receive it in the next few weeks.

THANK YOU!!!!!!

Birthday Banns

November

1	Matthew Scott	15
2	Anneke Minnema	3
4	Madeline Lenhardt	3
5	Andrew Glerum	12
5	Ashley Bennett	3
9	Samuel Wiley	2
9	Dominic Mastrouito	16
10	Charles Cater	10
10	Tyler Hays	10
11	Elizabeth Bajema	18
15	Michael Wjutowycz	37
20	Derek Knapp	7
25	Michael Barwacz	12
27	Jensen Knapp	12
28	Landon Hoskinson	1



HAPPY BIRTHDAY!

.....
"Most of the important things in the world have been accomplished by people who have kept on trying when there seemed to be no hope at all."

-Dale Carnegie

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Fundraising Opportunities

SPARTAN STORES

Spartan Stores is sponsoring a program to raise money for nonprofit organizations.

Customers can designate up to 2 percent of their monthly shopping bill to their favorite charity.

Please take the time to enroll in this program and designate the DSAWM as your charity. On your application form, be sure to include our code **#34039**.



**THANK YOU FOR
DESIGNATING THE DSAWM
AS YOUR SPARTAN
CHARITY!!!!!!**

HUNTINGTON NIGHT OF GIVING November 18, 7-10pm Rivertown Crossing Mall

For just \$5.00 a ticket, ticket holders are entitled to a private night a shopping at Rivertown Crossing Mall. The merchants & mall will offer special discounts and prizes. All proceeds from the ticket sales stay with the Association.



Contact Char Hill (616) 957-4934 to obtain tickets to sell or to purchase tickets for yourself. Tickets will also be available at the November meeting.

**THANK YOU FOR SUPPORTING
THE DSAWM!!!!!!**

Thank You!!!!

We would like to thank Deanna Cowden for her past contributions as the New Parent Coordinator and wish her continued success as she becomes involved in Early On. Your work on this very important program has been greatly appreciated.

THANK YOU!!!!!!



Welcome Family and Friends

We would like to extend a warm welcome to Tate Farber and her mother who attended their first general meeting. We hope you can join us again for future meetings and events.