

98 Sibling Study, DBHDD Advocates Mtg, Restraint & Seclusion forum and an Autism Race!

Dearest Advocates:

Below is information regarding a sibling study that is currently being conducted at GSU, and the Race for Autism event this weekend. I've also attached information on a Restraint and Seclusion public forum being held in Macon on October 15, 2009.

In addition, the Developmental Disabilities Advocates meeting was held on September 30, 2009. Below are the meeting minutes from that meeting that maybe helpful regarding the difficulties families and providers are facing regarding the implementation of the home and community based NOW/COMP Waivers.

I have been told that training sessions are going to be announced for those families that are self participated under the NOW/COMP waivers starting Mid-October. Registration is necessary but I have not received any information from DBHDD to give you at this time. Stay tuned.

Also wanted you to be aware of the following website for upcoming information on activities from Disability Link. <http://disabilitylink.org/docs/adapt.html>

Please note: I will not be distributing a newsletter next week due to personal commitments so please be patient.

Have a great weekend!

“UNITED – WE WILL MAKE A DIFFERENCE!”

Sincerely,

Heidi

(Proud Mother to Jacob - 9 yrs old with Down syndrome and Jared - 7 yrs old)

“Help the Children Now, So They Can Help Themselves Later!”

www.heidijmoore.com

Sibling Study:

From: Stacey Ramirez, Director of Individual and Family Supports, Center for Leadership in Disability
Georgia State University

I'm trying to help out a GSU psychology student working on her Ph.D. She is doing her dissertation on sibling interaction and communication. I had her come out to our home to observe Ryan and his big brother, Rico, cook dinner together. Win - win for me. The boys actually cooked dinner that night!! The other win is that Ashlyn is delightful. We had a great time.

This is what she is looking for:

1. Do you have a child 6-18 years of age with a diagnosed developmental disability?
2. Does the child with a disability have an older sibling 10-18 years of age?

If so, your and the two of your children may be able to participate in a project that will help us learn more about communication skills and siblings.

What will happen:

-one approx 2 hour visit in your home to:

- assess language for your child with a disability
- have typically developing older sibling complete a short questionnaire
- 10 min observation between your child with a disability and their sibling

If you are interested, please contact:

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Oct. 15th Macon Public Forum- Restraint and Seclusion:

The Georgia Advocacy Office, in collaboration with The Georgia Council on Developmental Disabilities, the Center for Leadership in Disability at Georgia State University, and the Institute on Human Development and Disability at the University of Georgia, urges the Georgia State Board of Education to promulgate a rule that protects all Georgia students from restraint and seclusion and which encourages the proactive use of Positive Behavior Supports in Georgia public schools.

The Department of Education has heeded the call of advocates to regulate the State's dangerous practice of restraint and seclusion by preparing for rule initiation sometime in the late fall or early spring. Early draft versions of the rule have outlawed the use of seclusion and have limited the use of restraint to those situations involving risk of serious bodily injury to self or others. Additionally, prone restraint, chemical restraint, and the practice of restraint used as a punitive measure have been prohibited.

We applaud the Department's decision to address this issue through the development of a rule. This is a good start, but more work is needed. The coalition urges the public to join us in insisting that the rule prohibits the use of adversives, clarifies and strengthens the training requirements for school personnel, provides enhanced safeguards for students who experience prolonged restraint, and creates enforcement and reporting mechanisms.

We invite members of the community to come hear about the State Board of Education rule promulgation process and how they can become involved through public comment. Please join us as we discuss this exciting opportunity at the Georgia Council on Developmental Disabilities public forum on Thursday, October 15, 2009 at 5:30 p.m. at the Pilot International Foundation located at 102 Preston Ct, Macon, 31210."

Stonemill Race for Autism:
this Saturday, October 3rd

Don't Miss the FUN this Saturday at The Stonemill Race for Autism and Family Fun Day.

The Stonemill Race for Autism is a standard 5K Road Race (approx. 3.1 miles). There will also be a One Mile Fun Run/Walk and a Tot Trot. Runners and walkers are both welcome. On-line pre-registration ends Thursday 10/1 at 3:00pm. Walk-ups are welcome the day of the race!

Following the race is a Family Fun Day with lots of fun activities for the whole family!

*Pony Rides

*Toothpick the Clown

*Inflatables (including moonwalks, giant slides, & obstacle courses)

*Petting Zoo

*Concessions

*Face Painting

*Cupcake Walk

*Hay Rides

*Vendors

*Silent Auction

and MORE!

Race and Family Fun Day Schedule

- 6:30 On-Site Registration Opens
- 7:00 Runner Check-in Opens
- 8:00 5K Race Start
- 8:30 Family Fun Day Begins
- 9:30 5K Awards Presentation
- 10:00 Tot Trot
- 10:30 1 mile Fun Run/Walk

Family Fun Day Events end at Noon

Stonemill Church

855 Northbrook Parkway

Suwanee, GA 30024

Advocate's Meeting Minutes for DBHDD
September 30, 2009

Welcome Dr. Garland

Dr. Garland has been spending a lot of time in the community meeting with providers, parents and advocates to discuss issues

1. Acumen:

CLS- caregivers can only bill 8 hours per day with a limit of 40 hour work week

Acumen has been working on this for a month

For the time being- if a support worker works 4-10 hour days, put only 8 per day and the rest on the 5th day

If this is a billing issue with DCH, Dr Garland will work with DCH to resolve the issue

Maximum Hourly rate- families should be able to negotiate, but the rates are affected by the tax burden.

Division will post minimum and the maximums are already posted, families can then decide

Timely Payments- Acumen has been responsive and the system is working better now. There is a system in place to catch the late payments. Acumen COO has been very responsive. A second fiscal agent company should be on board January 1st 2010

2. Self Direction:

Who can be a paid caregiver? Only exclusions, parent of minor child, spouse or legal guardian. Other family members can serve IF they are approved by the regional board as extenuating circumstance.

Need to follow this rule or they will be in a payback situation for all wages paid without approval.

October 14 will begin a series of training over 3 months to include- family members, representative from Acumen, participants, support coordination, - starting from scratch so everybody gets same information.

Support Coordination- lots of inconsistencies going on- there are four agencies with lots of misinformation- need a manual

3. Pa's

Use the ones the Beverly Rollins has been given as investigation training tool- get in a room, figure out the issues- if PA is a problem, provider needs to take it to Beverly, Beverly then takes it to the region.

Training will be done

No OTs or PTs enrolled? 2 agencies have applied; waiting on approval from Division- self directed can hire OT, PT as vendor

4. Rollover \$- from July 1-birthday rolls over, from birthday, start over with new allocation for 12 months. Allocation presented to families providers looks to see if they can provide services.

5. Support Coordination Fee- is NOT taken from individual's budget- completely separate

Peer Support is not being offered, only community guide training.

6. Manuals – NOW/COMP self-directed will be out by October 15th- correction/edits are done

7. Cost- Based Study- Start in November and will take 6 months. Company will do field study, talk to parents, providers, participants etc.

Once rate structure study is done, may need advocacy in legislature to support enhanced rate structure

8. Documentation-Self-Directed- Need to develop manual. Karen Addams volunteered to work with division to get that done

9. Other

Coordinated public transportation system, Fitzgerald/Ben Hill- braided funding – local state and federal monies

Rate is not sufficient to pay for trips

Brunswick and surrounding counties purchased 64 accessible vans- still DD folks not using as they do not have enough \$ for trips

Unified transportation still being paid for MOU between Departments – need to triage transportation \$
Parent spoke re daughter leaving Katie Beckett. Dr Garland and others already aware and working on issue

Dr Garland's priorities

-choice

-Portal- unified single data systems

-Quality Improvement process

-Quality Improvement plan monitored on a regular basis

-1500 new services- especially short term

-provider development

Dr. Shelp has held 5% back just in case there are budget cuts to BHDD

-transitioning kids

-DD experts in regions- will hire with existing funds

Thanks to GCDD for hosting the meeting and providing phone for people to call in.

Thanks to Pat Nobbie for taking notes of meeting

Thanks to Dr. Garland and her staff for attending and informing families