Governor's Commission on Disabilities
Legislation Committee
Healthcare/Support Working Group Minutes
October 16, 2012 12:30 pm

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Meeting graphic

Attendees: Meredith Sheehan, Steve Florio, Deb Garneau
Staff: Gabrielle Mele-Algus, Mary Brennan Public Policy Fellow

Action Items:

Public forum graphic

1. Public Forums on the Concerns of People with Disabilities and their Families

Purpose/Goal: To review the testimony from the public forums, identify common concerns and develop recommendations

Meeting Notes:

On Pages	Concerns	Recommendations
Meeting Notes: a. Legislation was introduced last session – Lou DiPalma was senator b. Related to Autism and people that make too much money for son to get SSI benefits, yet out of pocket expenses for therapy bring down their costs c. Bill changed eligibility requirements and income levels d. Should support legislation to be introduced e. Women unable to get Katie Beckett - State says haven't changed the eligibility, but parents feel that it has changed f. Should be legislation that private insurance pay for autism services g. last year corrected legislation to behavior specialist and/or psychologist		
56	Individuals with Autism are having trouble accessing healthcare	Continue to work on prior legislative intitiatives on restoring the 2008 Katie Beckett and children with autism specturm disorders eligibility rules and to provide transition for young adults with autism spectrum disorders to adult services providers.
Meeting Notes: a. Overlap between the many concerns b. AA meetings and the 12 step program tend to be paid by insurance or the healthcare provider, in addition do they provide communication access – who would pay for that c. Bridgemark – looks for money to pay for interpreters, but work very hard to do that		

d. Massachusetts has a system in place to pay for interpreters who are deaf and hard of hearing
e. Colorado has law that requires any person who is ordered by court to go to AA meeting is required to have interpreting services paid for
    i. If not court ordered or on voluntary basis, not sure how that is paid or if there is a system
f. Want to have a similar system to look into system wide issues for who could pay for these services
    ii. Department of Health
g. Systematic problem
    iii. Provider needs to know how to pay for services
h. Steve Florio happy to look into it
i. Need to have expanded definition of what is medical services
j. AA meetings, consumer education programs
k. Issue is who is going to pay for it
l. Which category of insurance should pay for it?
m. Already a federal law that requires that service providers make accommodations, but then becomes a payment issues
n. Pretty low incidence so often put aside for larger priorities
o. Should figure out what is the best system for this small state

need investigation to find the underlying problem

15, 16, 18	Interpreters at ancillary healthcare programs for individuals who are deaf and hard of hearing	Provide interpreter services for ancillary healthcare programs or supports and the Commission on the Deaf and Hard of Hearing will assist with these services including Alocoholic Anonymous meetings.
46, 47, 62	Services for the uninsured	Make information on how to access charity care (The Point, United Way, etc.) more accessible.
62	Customer Service for Medicaid is inadequate	Have continuing professional development, specifically with disability sensitivity.

Meeting Notes:

a. Not receiving medication because didn't receive the 20% better
b. Good for the Governor's Commission on Disabilities to collect some of the stories and to help have a voice for the need for the health reform
c. Rhode Island will move forward with health reform regardless of election

	The disability community does not have a say in healthcare reform	As Healthcare Reform unfolds, make sure disability community has voice at the discussions. Prior legislative package has looked at maintaining developmental disability service funding.

Meeting Notes:

2. Affordable Care Act
    a. Not anything that could be done on our end
    b. Concern was having trouble getting Medicaid in Florida to close out paperwork
    c. Was having issues transferring to Rhode Island

d. Call someone at a federal level for assistance with that

3. Blue Cross/Blue Shield
    a. Not covering the medication needed to stay out of the wheel chair
    b. Not necessarily subject to state rules since is a Medicare and private insurance company
    c. Many are regulation concerns instead of legislative action
4. Confidentiality
    a. Issue with limit on how much she can earn with working and still receive her benefits
5. Donut Hole
    a. Not too much that can be done about this
6. Family Opportunity Act
    a. About the Medicaid buy-in legislation
    b. Gives the states the ability for the Medicaid buy-in act
7. Medicaid
    a. Medicaid transfer issue – contact the state legislators
    b. Are provisions around charity care that provide access to people who are adults with children at home
    c. Not well publicized
    d. Felt that Medicaid wasn't customer friendly
8. Physicians
    a. Physicians do not have the knowledge necessary for rare disorder
    b. Do have medical transition program at RI hospital for med/peds group
        i. Certified pediatric and adult medicine
        ii. Does try to find resources and link people up
    c. Concern about finding specialists in the area
        i. How to find the appropriate physicians?
    d. Already giving out information at secondary IEPs and at pediatrician offices
9. Post Operation
    a. Up to hospital to decide if going to rehab facilities/post-op plans
10. Social Security
    a. Question on what is the criteria to get social security
11. Social Security Disability Income
    a. How to reapply for SSDI
12. Supplemental Security Income
    a. First person was referred to the Sherlock Center
    b. Medicaid-buy in

☑ voting check off graphic	MOTION: To propose the concerns and recommendations above MS/SF/DG passed unanimously
alarm clock graphic	**2. Adjournment**
	Meeting adjourned at 1:45 pm