



**Governor's Commission on Disabilities
Legislation Committee Revised Agenda
Monday October 21, 2013 3:00 PM - 4:30 PM**

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Attendees: Linda Ward (Chair.); Angelina Stabile(Vice Chair.); Sharon Brinkworth; Regina Connor; Timothy Flynn; Casey Gartland; William R. Inlow; Arthur M. Plitt; & Meredith Sheehan

Absentees: Rosemary C. Carmody; Joseph Cirillo; Heather Daglieri; Julie DeRosa; Linda Deschenes; Elaina Goldstein; Kathleen Heren; Paula Parker; Msgr. Gerard O. Sabourin & Dawn Wardyga

Guests:

Jack Ringlane?

Staff:

Bob Cooper



3:00 Call to Order and Acceptance of the Minutes, Linda Ward, Chair

Chair calls the meeting to order at 3:05 PM
Introductions of Commissioners and guests



MOTION: To accept the minutes of the previous meeting as presented
Motion moved by AP, seconded by TF, *passed abstained SB*

Action Items:



3:05 Status of the Commission's 2013 Legislative Package, Bob Cooper, Executive Secretary

Purpose/Goal: To decide which items the 2013 Legislative Package should be recommend for inclusion in the 2014 Legislative Package

Governor's Commission on Disabilities – Legislative Process

Chapter N General Operating Rules

V. Method of Operation

E. Permanent Committees

2. Legislation Committee

- a) The Legislation Committee shall review and comment on local, state, and federal legislation concerning persons with disabilities. A quorum for committee meetings shall be three (3) members, at least two (2) of who shall be commission members.
- b) The Legislation Committee shall conduct public hearings to elicit public comments prior to the development of the Commission's Legislative Package.
- c) The committee shall prepare and mail to all commissioners, at least two (2) weeks prior to the Commission's Fall Legislative Meeting:
 - (1) Proposed a Legislative Package for the commission to review; and
 - (2) A Scope of Review, that outlines the areas of general assembly legislation that the committee should

be empowered to review and comment on during the upcoming legislative session.

d) The Legislation Committee shall prepare and disseminate statements as to the impact of legislation being considered by the RI General Assembly, on the quality of life of individuals. The committee is authorized to:

(1) Review all legislation, introduced into the General Assembly, within the approved scope of review;

(2) Send a statement concerning the impact (beneficial or harmful) of bills, along with reasons, to the appropriate General Assembly committees, legislative leaders and the Governor;

(3) Include comments on the need for amendments to those bills; and

(4) Provide statement of impact on any legislation which the Governor's Office or the General Assembly request, even if outside the approved scope of review.

e) Only the Commission or the Executive Committee is authorized to announce support or opposition to bills.

f) Any legislation outside the committee's approved scope of review that in the committee's judgment would have a dangerous impact on the mission of the Commission may be referred to the Commission or Executive Committee along with the committee's comments.

g) All other reports, statements, etc. of the committee, except for those mentioned in subsection d) above, shall be submitted to the commission for its review, modification, and adoption.

The 2013 Legislative Package

1. Transportation to Employment, job training, education, health care, etc.

a. Maintain the existing RIPTA/RIde service areas;

b. Adequate funding/new & stable funding source;

c. Expand the RIPTA/RIde service areas/hours beyond the existing service/hours

2. Global Medicaid Consumer Choice Waiver; making sure the 2008 level of services stay in place for persons with severe disabilities:

a. Restore the 2008 Katie Beckett and children with autism spectrum disorders eligibility rules¹;

b. Restore the right to medically necessary brand name drugs without requiring two generic failures before allowing brand name

c. Improve services for adults with autism spectrum disorders;

d. Retain multiple behavioral healthcare service delivery models; and

e. Maintain developmental disability service funding.

f. Post-Global Medicaid Consumer Choice Waiver Transition Plan

3. Housing Supports and other services for people with behavioral health concerns:

a. Restore the Neighborhood Opportunities Program funding; and

b. Create a supportive housing program; and

c. Expansion of Affordable Housing - require at least 2 additional affordable housing units for cities and towns that have not met the affordable housing goals

4. Require Health Insurance Plans to cover specialty drug (Tier 4 Drug Category) in Tier 3

5. Refocusing State and Municipal Disability Pension Systems to become Reemployment

6. Accessibility to Services:

a. Provide interpreter services for ancillary healthcare programs or supports (including peer supports)²; and

¹ Adopted Resolution 13 H 5099 Sub A JOINT RESOLUTION CREATING A SPECIAL JOINT COMMISSION TO STUDY THE QUALITY OF LIFE AND CREATE POSITIVE OUTCOMES FOR INDIVIDUALS WITH AUTISM IN THE STATE OF RHODE ISLAND

² Enacted into law: 13 H 5127 Article 17 Sub A AN ARTICLE RELATING TO EMERGENCY AND PUBLIC COMMUNICATION ACCESS FUND would (create a new restricted receipt account in the Commission of the Deaf and Hard of Hearing and provides funding in the sum of \$80,000 dollars) for technology required to provide

b. Provide closed captions of all Capitol Television programming.



Motion: To recommend the Commission retain the following items to it's the 2014 Legislative Package:

1. Transportation to Employment, job training, education, health care, etc.
 - a. Maintain the existing RIPTA/RIde service areas;
 - b. Adequate funding/new & stable funding source;
 - c. Expand the RIPTA/RIde service areas/hours beyond the existing service/hours
2. Global Medicaid Consumer Choice Waiver; making sure the 2008 level of services stay in place for persons with severe disabilities:
 - a. Restore the 2008 Katie Beckett and children with autism spectrum disorders eligibility rules³;
 - b. Restore the right to medically necessary brand name drugs without requiring two generic failures before allowing brand name
 - c. Improve services for adults with autism spectrum disorders;
 - d. Retain multiple behavioral healthcare service delivery models; and
 - e. Maintain developmental disability service funding.
 - f. Post-Global Medicaid Consumer Choice Waiver Transition Plan
3. Housing Supports and other services for people with behavioral health concerns:
 - a. Restore the Neighborhood Opportunities Program funding; and
 - b. Create a supportive housing program; and
 - c. Expansion of Affordable Housing - require at least 2 additional affordable housing units for cities and towns that have not met the affordable housing goals
4. Accessibility to Services:
 - a. Provide interpreter services for ancillary healthcare programs or supports (including peer supports)⁴; and
 - b. Provide closed captions of all Capitol Television programming.

Motion moved by TF, seconded by AP, passed unanimously

The Committee will monitor progress on two items from the 2013 legislative package:

- *Require Health Insurance Plans to cover specialty drug (Tier 4 Drug Category) in Tier 3 - determine impact of Affordable Care Act*
- *Refocusing State and Municipal Disability Pension Systems to become Reemployment - shift to Employment Cmte.*



3:35 Recommendations from the Public Forums on the Concerns of

communication access for the deaf and hard of hearing population during periods of emergencies or in other necessary situations.)

³ Adopted Resolution 13 H 5099 Sub A JOINT RESOLUTION CREATING A SPECIAL JOINT COMMISSION TO STUDY THE QUALITY OF LIFE AND CREATE POSITIVE OUTCOMES FOR INDIVIDUALS WITH AUTISM IN THE STATE OF RHODE ISLAND

⁴ Enacted into law: 13 H 5127 Article 17 Sub A AN ARTICLE RELATING TO EMERGENCY AND PUBLIC COMMUNICATION ACCESS FUND would (create a new restricted receipt account in the Commission of the Deaf and Hard of Hearing and provides funding in the sum of \$80,000 dollars) for technology required to provide communication access for the deaf and hard of hearing population during periods of emergencies or in other necessary situations.)

	<p><i>People with Disabilities and their Families, Linda Ward</i></p> <p>Purpose/Goal: To decide which items from the 2013 Public Forums to recommend be included in the 2014 Legislative Package</p> <p>Discussion: Reports from the Working Groups Chairperson:</p>
	<ul style="list-style-type: none"> • Transportation and Accessibility Working Group Chairperson, Casey Gartland <p>Concern: Taking away accessibility to Ride when people fail to be at the scheduled pick up. Recommendation: GCD Legislation committee should look at another solution such as levying a fine</p> <p>Concern: Access to an accessible minivan Recommendation: GCD should refer the person to OSCIL.</p> <p>Concern: High cost of Ride Recommendation: GCD legislation committee should consider submitting legislation that implements a sliding scale</p> <p>Concern: Person (son) needing an assistant while taking Ride Recommendation: GCD should follow up with family to let them know they can ride the bus with them</p> <p>Concern: Public events not having enforced accessible parking & seating Recommendation: GCD legislation committee should propose legislation requiring those holding public events have the ADA required parking and seats as well as a way to enforce it (i.e. police) Referred to Accessibility Cmte</p> <p>Concern: Non-accessibility of state college campuses when construction is being done Recommendation: GCD legislation committee should propose legislation requiring the state colleges ensure accessibility to all buildings. Walkways, etc., as well as the ratio of handicapped parking spaces, whenever a construction project is undertaken. Referred to Accessibility Cmte</p> <p>Concern: Transportation Recommendation: GCD should propose a task force that develops a multi-faceted plan to expand transportation resources (such as using school buses top assist transporting people with disabilities) Get copy of the plan</p>
	<ul style="list-style-type: none"> • Healthcare and Supports Working Group Chairperson <p>Concern: Inaccuracy in Supports Intensity Scale Evaluations and lack of funding Recommendation: GCD Legislation committee should reevaluate using the Supports Intensity Scale as an assessment tool and make a distinction between BHDDH vs. nursing home.</p> <p>Concern: Funding/ Lacking of Quality Recommendation: GCD Legislation committee should check the laws that already exist for example "Perry Sullivan" The payment of state and private workers needs to be reviewed.</p> <p>Concern: Lack of accessible housing for individuals who are trying to stay in their homes for as long as possible Recommendation: _____ should provide affordable housing and maintain people independently in housing.</p> <p>Concern: The lack of knowledge on autism from health care providers Recommendation: GCD Legislation committee should be collaborations between health services for families, medical providers and patients/consumers. Providers need to be educated.</p> <p>Concern: The lack of supports and funding for children transitioning into adult services Recommendation: GCD Legislation committee should need more supports for children into adult services.</p>
	<ul style="list-style-type: none"> • Employment Working Group Chairperson, Angeline Stabile <p>Concern: Lack of funding and miscalculations on how much funding needed for each individual. Recommendation: GCD legislative committee should review the eligibility category under</p>

	<p>Medicaid and the Sherlock Plan to better access the Education Plans for individuals with disabilities.</p> <p>Concern: Supports Intensity Scale evaluations attempting to fit all individuals into one category because one size does not fit all</p> <p>Recommendation: GCD legislative committee should review a different assessment product for Employment First or modify the Supports Intensity Scale evaluation.</p> <p>Concern: The lack of training for staff working with individuals on employment opportunities</p> <p>Recommendation: GCD legislative committee should look into increasing training for staff of Developmental Disability employment.</p> <p>Concern: Support Intensity Scale inaccurate Support Intensity Scale inaccurate rate structure and tier packages</p> <p>Recommendation: GCD legislative committee should review how Supports Intensity Scale is determined and look into different tools. Funds are needed to provide different types of assessments for different needs. Funds are needed to provide different types of assessments for different needs.</p> <p>Concern: With the cuts in shelter workshops, there are uncertainties about what individuals will do without them.</p> <p>Recommendation: GCD legislative committee should develop a plan for Developmentally Disabled and older individuals that cannot work into competitive employment. There needs to be an alternative to the shelter workshops.</p>
	<ul style="list-style-type: none"> • Housing Working Group Chairperson, Sharon Brinkworth <p>Concern: Accessible affordable housing during transition stage and the years long waiting lists into these establishments</p> <p>Recommendation: GCD legislative committee should review this information to check for discrimination.</p> <p>Concern: The barriers for people with disabilities and trying to obtain affordable housing</p> <p>Recommendation: GCD legislative committee should explore the idea of having a separate list of affordable housing for people with disabilities.</p> <p>Concern: Accessibility to funding for home modifications for families of individuals in wheelchairs</p> <p>Recommendation: GCD legislative committee should review housing accessibility funding and make sure the money is being distributed properly.</p> <p>Concern: Affordable housing is accessible for all individuals</p> <p>Recommendation: GCD legislative committee should look into making legislation for all new public housing should use universally (accessible) design.</p>
	<ul style="list-style-type: none"> • Education <p>Concern: The increase in the number of students being dropped from IEPs (individual education plans).</p> <p>Concern: Lack of screening in the early school years to pick up language based learning disabilities.</p> <p>Concern: Lack of information on the transition from school to adult services/career supports for parents and students in high school.</p> <p>Concern: Lack of information on the range of services that should be included in an IEP</p>

Education Testimony

Children IEPs Services, 51

I also attend a lot of IEP meetings for children in South Kingstown, Barrington, Burrillville, word has spread. I'm alarmed at the amount of children that are being dropped from IEP, and the Parents don't realize really what's going on and are able to look at the testing. I know there's a 10th grader here at South Kingstown high school, obviously the testing shown there was definitely some things going on with language based learning disabilities, and requested more testing. The child is now getting a one-on-one program next year. That parent did not have me at that meeting that child would be exited as a 10th Grader from an IEP, and this girl has high goals and now being addressed at the school department. I think our school

departments are exiting kids from IEPs. I see it. I'm seeing the praises of Kathy Sanford in that group that put two bills together for children with dyslexia, and I really thought there would have been more work done on those bills. I think that the committee was sent up. I think there was the second piece of the bill that I thought really should have gone further, so the schools would be able to recognize children with dyslexia is a disability. So tied in with that is the language based learning disability

Screenings, 52

We really do need screenings from the early school years to pick up on language based learning disabilities, and we need to train our teachers. right now the biggest person that has the most amount of knowledge with language based learning disability is speech language therapist, and they're not allowed In some school districts, and I will say South Kingstown is one of them, that they will not allow speech and language therapists who have reading backgrounds to work with children with reading disabilities. I think that that is a real loss. We're not capitalizing on the strengths of our speech language pathologists working with the reading teachers to get the gaps closed for children.

Recommendation, 53

I really think education to parents; I know that when my daughter left the high school there was very little knowledge. I know there's a lot of parents that have kids involved in independent transition academy. I get the call, what's going to happen? When does DDD, or when does ORS get involved? She graduated in 2007. They held her diploma until 21. She's 24. The school department said to me, we're going to go through this process together. We're going to learn. Even from that point on, what has been learned is not being implemented in the school department. My biggest concern for my daughter, you know, I have a large family, and after my husband and I are gone, we do have family members that will come in. But transportation is a big issue. She's the type of kid where she's got a hundred things on her agenda. She does a lot of volunteer work. (laughter) [51-53 is one testimony]

IEP Compliance, 78 [Healthcare?]

. For the most part in our town we get good services but we just went through this experience where my son's IEP one of his services was not addressed and we said what about this? And it was sort of, oh yeah, what about that? Hoping you would ignore that. So I don't know how much there is over sight on the city or town level. I often feel and my husband and I are fortunate because we are college educated, professionals, I have a sister who is a special needs teacher, I worry about those parents who don't know that and I sometimes see and I don't think it's just in my town because I have talked to parents in other towns, is it just what they don't know they don't know and we'll just try to move things along so that is a little bit of a frustration and I would like to see that more equitably distributed.

Transition, 132 (this could go into employment)

Remember the people eligible for support through BHDDH-DDD, by definition, have cognitive and often multiple disabilities and their families are frequently responsible for the day to day details of their care as well as for planning their supports within this new and confusing system. In spite of applying to BHDDH-DDD in a timely manner, many transitioning students never get to the planning stage with BHDDH –DDD before finishing school (which had been their major support system) and so never get connected to services. We have met many 24 and 25 year olds who have been sitting at home, with only the tenuous support that their stressed and often misinformed families can muster, who got lost in this transition gap in spite of having applied to BHDDH well before exiting school. The result for some of these young adults is loss of hard won skills, sometimes loss of employment due to lack of necessary employment supports, increasing isolations and sometimes the onset of depression. BHDDH makes no effort to find or identify these individuals who have applied, and maybe even been assessed, but have not accessed service. Many others have begun and continue the process of planning, but experience a gap of months to even years after exiting school while they continue through BHDDH bureaucratic maze trying to get their ISPs approved and services authorized to start.

	<p>MOTION: To recommend the Commission add the following items to it's the 2014 Legislative Package:</p> <ul style="list-style-type: none">A. Ride fare - mandating a sliding scale (add to # 1 d)B. Reevaluate using the Supports Intensity Scale as an assessment tool (add to # 2 g)C. Funding of disability services (expand #2e)D. Increase affordable & accessible housing (already in #3a & b)
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	<p>E. Clarify eligibility for Medicaid/Sherlock services (add to # 2 h) F. Create Employment category: a. Improve school to adult transitional services b. Transition from education to adult services/employment/post-secondary education c. Maintain non-competitive employment options G. Increase funding of home modifications (add to # 3 d) Motion moved by SB, seconded by CG, passed unanimously The Committee tabled for next Legislation Cmte discussion on Education: a. Parent information on transition & range of services b. Standard for leaving special education invite RIPIN and the parent⁵</p>
	<p><i>4:15 Recommendations for the Legislation Committee's 2014 Scope of Review, Linda Ward</i></p> <p>Purpose/Goal: To decide which categories of bills to recommend be included in the 2014 Legislative Committee's Scope of Review</p> <p>Discussion: 2013 Legislation Committee's Scope of Review: Civil Rights; Disability Prevention; Employment; Health Insurance; Housing; Human Services; Medicaid; Professional Standards; Special Education; Transportation, and to make recommendations to the Executive Committee in regard to budget articles. Categories no included in the 2013 Scope of Review were: appropriations; education; financial assistance; government operations; motor vehicle insurance / registration; & taxes</p>
	<p>MOTION: To recommend the following categories of bills in the Committee's 2014 Scope of Review: Civil Rights; Disability Prevention; Employment; Health Insurance; Housing; Human Services; Medicaid; Special Education; Transportation, and to make recommendations to the Executive Committee in regard to budget articles. Motion moved by TF, seconded by AP, passed unanimously</p>
	<p><i>4:20 Election of the Vice Chairperson, Linda Ward</i></p> <p>Chapter N General Operating Rules V. Method of Operation G. Membership and Officers of Permanent and Other Committees 1. Each committee chairperson shall appoint members from the public to his/her committee for a one (1) year term following the annual meeting. These appointees shall be associate members of the commission. 2. Each committee shall elect a vice-chairperson at its first meeting after the annual</p>

⁵ Invite Diana Kriner kriner@ripin.org to the next meeting

	<p>meeting who shall serve as chairperson pro-tempore, in the absence of the chairperson.</p> <p>3. Any Commissioner present may participate and vote on any matter pending before a Committee (except the Executive Committee, State Coordinating Committee on Disability Rights, and Disability Business Enterprise Committee).</p>
	<p>MOTION: To elect Jack Ringland, the Vice Chairperson Motion moved by TF, seconded by AP, <i>passed abstained JR</i></p>
	<p>4:25 Agenda for the Next Meeting, Linda Ward</p> <p>Purpose/Goal: To set the agenda for the next meeting.</p> <p>Discussion: The Legislation Committee meets the 2nd Monday 3 - 4:30 PM. The remaining scheduled meetings 12/09.</p> <ol style="list-style-type: none"> Drafting bills for introduction in the 2014 General Assembly
	<p>4:30 Adjournment, Linda Ward</p>
	<p>MOTION: To adjourn at 4:21 PM Motion moved by CG, seconded by AP, <i>passed unanimously</i></p>