Autism Commission

Employment and 14-22 year old Sub-Committee Meeting

November 17, 2016 - 12:00p.m. –2:00 p.m.

500 Harrison Avenue

Present: Carolyn Kain, Dianne Lescinskas, Michael Weiner, Kathleen Kelly, Jeff Gentry, Kasper Goshgarian, Michelle Brait, Amy Weinstock, Lea Hill, Julia Landau, Sowmya Sundarajan, Judith Ursetti, Michael Plansky, Jennifer Stewart, Marisa McCarthy, Leslie O’Brien and Carrie Breaux

Remote access: Amanda Green, Ilyse Levine, Elana Aubrey, Maura Sullivan, Alexis Henry, David Tack and Laura Gillis.

Carolyn Kain stated that the meeting was subject to the Open Meeting Law and that the Sub-Committee members present would need to vote to approve the remote participation of some members because of their geographic location, whenever any members were utilizing video and/or tele-conferencing. Remote access was approved unanimously.

Carolyn welcomed all to this meeting and asked that everyone introduce themselves. The minutes from the last meeting, on October 19th were reviewed and approved unanimously.

Carolyn had previously sent out section 29 of the Omnibus Law which is focused on Higher Education and employment. She felt that it would be helpful for this committee to review and see the language. Higher Education has not been discussed at length in this committee. We are looking for data on individuals that are asking for accommodations in college and are they getting the support. These could be some of the individuals that have yet to be identified with autism.

There was some discussion around DESE and the work that they have done around transition services for students but it hasn’t permeated down to the school level. We need to identify the unmet needs so we can get a full picture.

Carolyn asked Lea if she knew of any barriers to Higher Education. She said that this is a multilayered issue. Some individuals are not self-identifying. Services can be limited to note takers and small modifications. Lea discussed the need for a campus liaison that could connect the students to DDS. The liaison could do “check-ins” with the individual and help them with time management and navigating the campus. Some individuals with ASD become very isolated and drop out of college – it is a social issue and not academic. People are asking for this service. Judith talked about the need for supportive decision making when the individuals go off to college – parents like to be in the loop to give the support when needed. Lea said that this is why a service coordinator would be helpful.

Sowmya discussed services through MRC that could help with some of these issues. They can provide assistive technology evaluation and a neuropsychology evaluation which MRC will pay for in some cases.

Judith from Autism Speaks asked that we keep the focus only on individuals with ASD. Carolyn agreed with Judith and stated that the focus is on autism and would continue to be. Carolyn would like to focus on the adults who didn’t receive services in their school and are now struggling. One of the recommendations should be addressing the needs of older adults and how we can be proactive so we don’t have a continual flow of service needs as the population ages.

Judith asked if MRC had numbers on how may neuro-psych. evaluations they do each year and how many are for individuals with Autism. **Kasper said the number of referrals of individuals with Autism from public schools has increased and he will gather the data.**

Carrie discussed how she had met with undergraduates from Tufts University and that they had formed a small alliance – a community of people that identify with autism. They meet monthly in the Academic Resource Center and talk about autism with pride. Discussions range from time management, scheduling to executive functioning. Their needs are subtle but they overcome barriers by continuing a conversation. Carolyn asked how this group was formed. It was through one young man who identified as being gay but then also identified with ASD. The group started with just two, and they were roommates, and has grown to 8 or 9 participants.

**It was discussed that a recommendation should be that Higher Education should include the built in natural supports**. Michael Plansky discussed his work with Northeastern University and the BCBA Department – they are working with the students from “You’re With Us” and doing assessments and data collection. There is also discussion around doing this at Endicott College and then Simmons. He wants to create a toolbox and is working with DDS to finalize the details. He finds that the students from NU, that are supporting the post-secondary students, are very motivated to do this work.

Carolyn asked that folks from this committee email Dianne Lescinskas (Dianne.Lescinskas@state.ma.us) with their experience with Higher Education. As we move towards recommendations, we want to be able to replicate the successes, identify what is working and be respectful of individual needs.

Michael Plansky asked if someone is not eligible for DDS but eligible for MRC – **Kasper responded, yes and he will send out clarification about eligibility.** Michael responded that it would be helpful for families to understand where to apply for supports.

Judith asked about the 15% allocation from MRC that is supposed to go directly to individuals with ASD. Kasper said they tracked their expenditures last year and this year they are on target to spend 7.4-8 million on transition. Kasper also commented that some individuals on the spectrum do not need DDS – the message needs to translate to the schools on who needs 688 referral, DDS or MRC. They are working on the language for the school districts.

Julia said that the message to families can be confusing. We need to differentiate what is available to students with disabilities while they are still in school and what’s available for services when school ends.

Amanda said that there is no training for districts on the 688 referral process. Carolyn responded that it is important this information on the different agencies and the support they provide gets out and asked if it could be through a Technical Advisory. Amanda said that DESE defers to MRC and DDS but they do work collaboratively. They have had conversations about the need to provide information on agencies and expect it to happen – MRC is working on this now. It was mentioned that it would be comforting to families to have MRC at the table during the IEP meetings giving examples of their offerings. Michael W. discussed the need for MRC to schedule a time to meet with the families and educate them on the services. Families don’t always know that they have to be the driving force to get services. Carolyn said from a parents’ perspective, there is a lot of good information but it can be overwhelming for families to navigate**. A recommendation could be to have agencies give information to families that is straight forward and in multiple languages.** Amy W. said that in particular with students with ASD – if you get services from DDS starting at age 22, prior to age 22, MRC could provide services while still in school. The schools can help by having families apply to the agencies.

Kasper commented that collaboration with DESE is better than ever. It will take some time to get to every school. MRC also offers meetings for parents in the evening – there is a lot of good work in this area and Jennifer Stewart was hired to help this advance this work. **Carolyn said that it may not have to be a recommendation to the full commission – we could move forward with a streamlined way to get information to parents with the agencies helping to coordinate this effort.**

Julia made a point to say that parents are given information but they still run into roadblocks. **Do we want to think about a recommendation to MRC to cover those with IDD and autism?** It is important for us to think about this issue.

Amanda asked if she was advocating increasing funding – Julia responded that she would like to see services that are being offered to meet all the needs of our ASD population. It was said that MRC has expanded and may need more time to catch up with all of the needs. Julia said that in everything that we are discussing; employment, higher education, vocation, we should include everyone who is on the spectrum.

Carolyn discussed that a lot of individuals with ASD gravitate to community colleges and this is an entry way to higher education. She will ask Pat Gentile about CC and self-disclosure and how they create a pathway from community college on to a 4 year college and employment. What are lacking are supports for success – it’s not in the schools, not in higher education and not in employment. How can we grantee supports throughout life. **Amy W. said this is the framework for this committee – we should take this and come up with a recommendation**.

Leslie said that college co-ops are connected to career centers and they have a lot of students who need support. This could be a bridge for the colleges.

Carrie asked what is the buy in for private colleges to provide this support. What is working and who are the leaders in the technology and coding world – can we bridge that gap? The internship piece is important – it is where they will practice their skills.

Michael P. said that he is having a positive experience with private colleges and universities and that they have been very supportive. You’re With Us is focused around inclusion on the college campus and they have supports built into their campus’.

Marisa talked about a Saturday program at MIT – it involves students with autism mentoring younger individuals with autism. **She will gather more information**.

Kasper said that MRC would not support students going to private colleges unless it is a specialized college, for example, hearing impaired. They could recommend to higher education institutes to add additional support – they have a responsibility to provide more supports.

Jeff said there could be a Disability Pride and Identity training. This is important for self-identification and transition - a good way for individuals to take pride and help them continue on to college and get supports. **How could we put this in as a recommendation**?

Michael P. said they are looking at Massasoit College for their next step and are getting funding from DDS. **Maybe they could pilot an advocacy program there and build out a template.**

Jennifer asked if youth groups were a part of this Commission – they could help drive the direction and importance of self-advocacy. Carolyn commented that she does not know of any specific group but ANE might know of one. Carrie said that they have a youth group that is part of their Spotlight Program. Julia said it would be good to have more representatives that have autism on the working groups. Carolyn said that we have two self-advocates but they both are on the 22+ sub-committee.

It was mentioned that it could be important to put together a focus group in response to the newly eligible and lack of funding.

Michael W. asked for clarification on what MRC does in the high schools – Kasper responded that an MRC representative spends at least one day per week in each high school with the Special Education Director and they do referrals. They meet with students, but cannot meet with all of the students, in the individual schools. MRC depends on the Sped. Directors to identify the students that need their services.

**Michael suggested a recommendation to target families – get the message to the families on the importance of signing up with MRC.**

Jeff said we could highlight education and the range of services that DDS provides – a one sheet to parents to point them in the direction of services. Carolyn said that it should be part of the team process. Dianne talked about B-Set for Career, College and Community Living – a project of Massachusetts Advocates for Children. She is the lead for the Community and Family Group and one of their priorities is to have information related to Transition Services presented to families during the IEP meetings. This is Boston specific and they are working with Cindie Nielson (Executive Director of Special Education) from BPS to have this implemented. They have discussed using the Family Guide to Transition Services (Federation) as a guide for families and have the special education coordinators review the content. They are also looking to have workshops for families and teachers at individual schools - these workshops will include Understanding Transition and the services that go along with Transition.

Julia asked how many newly eligible are waiting for funding – Carolyn responded that there are 269 that are eligible but there is no funding for them. There are 929 that are receiving services as part of the newly eligible and 269 are on a wait list (since July). Julia also asked for data on numbers of individuals turning 22 with ID.

MRC reviewed some of their services – starting at age 16 in schools. It was discussed that these services are not being given in a timely fashion. It was mentioned that it would be helpful to pull DDS and other agencies into team meetings starting at age 14. Carolyn commented that the district has access to the families and the state agencies but do not know how to get the information to the families.

Jennifer talked about the new IEP that is being developed with DESE and Mass. Advocates for Children – there is a piece in the form on how parents get informed about transition.

Julia said this is about changing the system – it goes back to the schools. **She asked what recommendation could be made for systematic change – what is feasible?** Carolyn said it is a breakdown in communication from DESE to school districts. Do we change 71B? It is ongoing failure and families cannot access what they don’t know - Districts need to be held accountable. Should we build on the current recommendation – **Amy said we should start the next meeting with a discussion around a game plan.**

Kathy said what she is taking away from this meeting are guidelines:

1. Pride in Autism - self advocacy.
2. Recommendation to Higher Education to provide more supports and possible liaison.
3. Professional Development for district schools and families.

Carolyn said this is a process – we need to look at both short term and long term goals.

It was asked that we bring easel paper to capture notes for our discussion.

Meeting was adjourned at 2:00pm.