

Autism Commission
Employment and 14-22 year old Sub-Committee Meeting
October 19, 2016 11:00 a.m. – 1:00 p.m.
500 Harrison Avenue

Present were Chair Kasper Goshgarian, Michelle Brait, Carolyn Kain, Dianne Lescinskas, Kathy Stern, Michael Weiner, Vanda Khadem, Madeline Wenzel, Kathleen Kelly, Jeff Gentry, Todd Garvin, Amy Weinstock, Ilse Levine, Kevin Barrett, Debbie Muldoon, Lea Hill, Dian Bohannon, Brittany Collins, Michael Stepansky, Sarah Geldart, Julia Landau, Sowmya Sundarajan , Maura Sullivan, and Roberta Lewonis.

Remote access: Carrie Breaux, Leslie O'Brien, Ann Guay, Sue Banks, Tersea Schirmer, Amanda Green, Michael Plansky, Melanie Chandonnet, Christina Fitanides, Elana Aubrey, Carly Sebastian, 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 by all members present.

Carolyn welcomed all to this first combined meeting of these two sub-committees and explained that the combined meetings were decided because a lot of the same issues were coming up at both committee meetings. She asked that everyone introduce themselves, describe their work with individuals with ASD and what they would like to achieve through this process.

Carolyn discussed past meetings and hearing from folks that starting services at or before the age of 14 is critical for success in employment and independence after the age of 22. Amanda Greene, in a past meeting, reviewed the work that DESE is doing around transition but it has not translated down to all of the public school districts. There is a disconnect with the IEP transition planning form (TPF) and goals around transition. The question is how we make sure that newly eligible, when they are leaving school, can get their needs addressed and get access to services. JVS and Triangle only have a limited reach – we need to scale these kinds of programs. Schools need more Professional Development to reach students statewide. The underserved need more support.

Jeff from Triangle described an array of services that they offer and they are designed for career and safety. Included in the programs is Career Pathway – focused on workforce development and can provide some 1:1 support for job coaching and work in the community. Last year they secured 234 paid jobs. They also run Impact Ability which is an abuse prevention program. Epic is a yearlong service leadership program with 12 community service days and 6 leadership development days. They are located in Salem, Malden, Boston and Brockton. The plan moving forward is to be community based and they will sell their Malden office to serve people where they live. The next Epic Community Service

event will be at the McKay School in East Boston on November 5th – Carolyn will send out a flyer for the group.

Julia said that while this is important work it only is a small percentage of what students need and we are not getting to the underserved communities.

Vanda told the group about the Paralegal Assistant Program. Pairing students with the probate courts for internships and then to hire. She would like to see every high school partner with a court for this program. The internship also teaches soft skills that are necessary to maintain the job. Vanda asked what is happening after the students turn 22. She has reached out to DDS and wants them to commit external resources for 1:1 support for this program. She met with Commissioner Howe and she is very interested. This program will start in the 10th grade working on the job readiness skills and we also need to train the educators on transition and what it means for students. We need buy in at the top. Currently there are 17 students in this program. She has appealed directly to law firms and will vet out courts to ensure a good fit for the students.

Madeline from JVS told the group about the Transition to Work Program for ages 16-35 but there is a real focus on the 18-22 year olds. They partner with employers and they host a 12 week training. The students do the classroom work for job readiness and then move into an unpaid internship at the employer site. They also match the person with a mentor. JVS is on site to ensure the success of the individual. Once they graduate from the program they are placed in a job in their community and provide ongoing support to both the individual and employer. They are very focused on inclusion and want the job to match the skills of the individual. They try to educate the community on disability and dispel myths around disability.

Lea asked how people are finding out and getting to DDS. The group replied that some districts refer through the 688 process but that is not happening statewide because the districts don't understand the process. Once they are found eligible they are assigned to an Autism Service Coordinator and they do an intake. DDS is focused on Person Centered Planning. They also offer a coaching service to address individual needs. This is a new concept for DDS. DMH and DDS are collaborating on all levels – they have a new two way release form – this is a huge change for both organizations.

Julia asked about the budget issues with DDS. Carolyn stated that there are no new additional funds for the newly eligible in FY17 is remains at the \$12.4million dollar level. Jane Ryder is gathering information to inform the process for the FY18 State Budget. For now, DDS area offices are encouraging the newly eligible to still apply and start the process, so they can identify individuals who are eligible, what services they are requesting and the costs of those services. DDS is also going through a utilization of services review so that if services that were requested an approved are not being used then, those funds can be utilized for another individual requesting services. DDS is also referring individuals to MRC for services and the Autism Support Centers.

Julia asked if the Commission should talk about the budget concerns at the December meeting and should this be a priority for the Commission. Her office is getting a lot of calls about this issue. She also inquired about how many newly eligible we have that are not getting services. Carolyn said she had requested and will follow up with DDS on the number of individuals who have requested services but for whom funding is currently unavailable.

Vanda agreed about the concern and stated that members of the sub-committee should be advocating for more funding. She wanted to know a timeline for when they could get services through DDS. She stated that families are going to their IEP meetings and the service coordinators are telling the families that there is “no money”. What should they do?

Carolyn said she understands members’ concerns about the recent funding issue, and she suggested that they get more specific information from DDS. Carolyn said that the newly eligible were not tracked prior to the Omnibus Law by DDS because eligibility was tied to having an intellectual disability and that once people were deemed eligible with an ID whether they had ASD or another comorbid diagnosis was not tracked for any specific disability. DDS is doing a service scan for all newly eligible now and they are collecting this data for the future. Carolyn said that the sub-committee was looking at the unmet needs of individuals for employment and higher education and to develop recommendations for the Commission on policies, legislation, and regulatory changes needed to provide or improve such services.

Julia asked when funds become available to DDS how are decisions being made on its’ use? Lea Hill responded that DDS has been processing applications for individuals applying for services and allocating funding based on the services that have been requested, and it wasn’t until recently that the issue of funding arose and they were examining the utilization of funds allocated and any un-used funds for newer applicants. Roberta said that DDS staff are trained to work on these issues, and to provide information to individuals and families and they involve Central office for any emergency needs.

Maura asked about collecting stories from families on these issues of people asking for services and being unable to obtain a funding allocation. Maura said these stories are helpful as the ARC prepares its legislative ask to help inform Legislators about the needs and the funding required to meet these needs. Julia asked if they had a script on how to talk to families about the cuts. Lea said they do have a script but that it is very basic that people are encouraged to apply that funding has been fully allocated but DDS is working to identify any un-used funds.

Amy W. said that as a Commission member she felt the Commission should make the lack of funding issue more visible. She said that we talk about all of the good services and the need to bring those services up to scale, but if the money is not available to make this happen then it cannot happen.

Julia said if this sub-committee thinks this is a major issue and priority then we should make a recommendation to the Commission – it could be the perfect time to raise these issues. Vanda agreed and said there is an economic impact on our underserved families. This lack of funding for adults could cause them to have to leave their jobs to take care of their kids/young adults. It’s unacceptable.

Carolyn stated that more factual information on the number of individuals waiting would better inform the group about the scope of the issue. She said she will share the information gathered with this group prior to the next meeting before presenting to the Commission. Carolyn said that the need for funding is on-going and that we know from recent news that the revenues have been lower than expected and the state was looking at spending cuts.

Jeff agreed that it is not just Turning 22 being affected it is affecting folks throughout their lifetime. We need to be proactive by using other resources like those available through MRC.

Amy said that if this is an important issue and we need to have an “ask” for the Commission, not just data.

Michael W. talked about the importance of empowering families. MRC has funding and maybe it can be used to create training for families to understand their rights. The pressure should be put on schools – it is their legal obligation to prepare the students. Budget deficits will occur again and we may not have all the support right now but the students need their needs met while in school.

Debbie discussed training employers for more natural supports. Employees are more successful if they have a mentor to work with them. Carolyn and Dianne met with Craig Welton from Best Buddies last week and Best Buddies continues support after MRC falls off– and they achieve this through private fundraising.

Kasper said that a lot of work has gone into the area of training employers. They just had their conference with more than 240 employers in attendance and they will follow up with all of them. They will break down the barriers and will work with on putting natural supports in place.

Sowmya talked about the MRC counselors that are assigned to each high school. She covers part of Boston and they do career exploration and assist the students while they are still attending high school. They also have workshops at their area offices on developing soft skills and host coffee hours with parents. Kasper said they are required to spend 7.5 hours per month in the schools. He also said that not all students should be 688 referrals and could be better off just using MRC. MRC can guarantee a service. They have increased their collaboration with DDS – it is not always complimentary but can be compatible. They are figuring out how best to maximize services and not compete with each other. They just hired a full time Transition Director – Jennifer Stewart – she currently works for the Federation. She will look at the barriers on the school level.

Julia asked if this group could follow up with a recommendation about working with families so parents and students know and understand their rights. Carolyn agreed that a lot of training needs to be done with parents and also school personnel around transition. Carolyn asked Sarah Geldart from DESE about how she felt they could best get information down to the district level, like DESE’s recent technical advisory on transition. Carolyn said it is very good information but it is not making down to the Team

level and school districts do not inform families about its existence. Sarah said that Amanda Greene has been working on getting information to the schools and they offer professional development. They have the Technical Advisory on Transition Services – they are prioritizing transition. DESE works with the Federation and they provide direct training for families and schools. Maura discussed a webinar that the ARC has done around transition, and that it is an additional resource for families.

The group discussed the need for more parent training – it needs to get to them in multiple ways and communicated as much as possible. Dianne is working on a “fact sheet” for families to be given out at the IEP meeting. This is part of the Workforce Development and Mass. Advocates initiative. It is Boston based but could be used statewide.

Sarah agreed that resources should be provided to parents but they cannot mandate school districts to do so.

It was discussed that it could be part of a public service announcement or possibly a radio/tv ad directing people to services.

Amy W. said that the Autism Support Centers should be a good resource for all information. Carolyn agreed and told the group that she and Dianne are visiting all of the ASC’s and will be looking at how they are getting information out to families.

Michael discussed having MRC do a presentation at the Federations Conference – it could be a combined presentation with Carolyn and Kasper. Michael also stated that some parents did not feel like they have had a good experience with MRC and they didn’t get the support they needed from the agency. Parents need to know that there are good changes happening at MRC.

Kevin stated that he felt very frustrated at this meeting because the focus was more on transition and not on employment for older adults. Todd asked if it would make sense to identify folks from the group that were more interested in post-transition and employment and start a working group.

Carolyn said she would be willing to host other meetings and that she wanted to ensure that DESE was in the room for both 14-22 and employment. We can have a separate meeting for both if needed.

Carolyn said for the next meeting she will work with Kasper to develop the agenda. Todd again stated the need for a working group for the folks interested in post 22. Carolyn will follow up with an email polling the group on their interest in the working group.

Carolyn apologized for the technical difficulties with conferencing in to the meeting.

There being no further business, upon motion duly made, seconded and approved, Kasper adjourned the meeting at about 1:00pm.

