

# Commonwealth of Massachusetts

Executive Office of Health and  
Human Services



Executive Director Update  
Autism Commission  
December 13, 2016

Sub-committee Work  
May 2016-December 2016



# Sub-Committees (8)



	No. Of Meetings
Birth to Three Year Olds	(2)
3-14 Year Olds	(6)
14-22 year Olds, Employment & Higher Ed.	(5)
Employment Age 22+	(1)
Adults	(4)
Data	(2)
Housing	(2)
Workforce Development	(5)



# Birth to Three



Commission Members: Ron Benham (DPH), Chair, Vincent Strully President and CEO NECC, Ann Neumeyer, M.D.

Non-Commission Members: Cynthia Berkowitz, M.D. (DMH), Rafael Castro, Ph.D., Joan Rafferty (DPH), Robert Polsinelli (DDS), Sarah Richmann (DDS), Nancy Lunden (May Institute), Kristy Murphy, Shari King (BMC)

## Issues discussed

Early diagnosis and access to services. Research evidences that the earlier children start receiving services the better the outcomes and lessened need for services as they age. *MacDonald et al. (2014) Over 90% of one year olds were close to their typical age-matched peers after 13 months of treatment.*

Investing more in services earlier at DPH Early Intervention level and MassHealth.

Average age of children diagnosed with ASD is 2.5, early intervention ends at age 3. Diagnosis is impacted by lack of trained clinicians to diagnose ASD and available workforce of ABA therapists and BCBAs.

Language barriers exist for non-English speaking families for both diagnosis and treatment.

Training is needed for DCF workforce on ASD

Examine expanding coverage up to age 5



# 3-14 Year Olds



Commission Members: Carolyn Kain, Chair, Laura Conrad (MassHealth).

Non-Commission Members: Sarah Geldart (DESE), Julie Kelley, Teresita Ramos, Esq., Zachary Houston, B.C.B.A, Sue McCarthy, Dr. Beth Jerskey, Laurie Gobeil (DMH), Janice LeBel (DMH), Christina Fitanides Esq., Lee Robinson M.D., Dianne Lescinskas

## Issues discussed

Language access issues for families in understanding their legal rights and obtaining interpreters and interpreted documents from public school systems

Role of DESE in overseeing public school systems' compliance with state law and DESE's August 2006 technical advisory on autism.

Connecting with families in homeless shelters, and overall expanded to access of information for parents through the Federation for Children with Special needs

Expansion of Autism Endorsement to general education teachers

Quality of ABA services by paraprofessionals, there is no standard for training. DESE's trainings for paraprofessionals are not mandatory. Registered Behavior Technician training is 40 hours. Autism Project in Rhode Island trains school personnel and parents.

Examine ways to connect families to the (7) DDS funded Autism support centers.



# 14-22 Year Olds/Employment and Higher Education



Commission Members: Kasper Goshgarian, Chair (MRC), Carolyn Kain Co-Chair, Michelle Brait, Deidre Phillips, Amy Weinstock, Laura Conrad (MassHealth), Teresa Schirmer, Danielle Ferrier (DCF), Julia Landau, Esq., Judith Ursitti

Non-Commission Members: Amanda Green (DESE), Kathleen Kelly (MRC), Sowyma Sundarajan (MRC), Michael Plansky, Maura Sullivan, Jeff Gentry, Amy Nazaire, Kristen O'Melia, Roberta Lewonis (DDS), Melissa Guyer (DDS), Melanie Chandonnet, Carrie Breau, David Tack (DMH), Carly Sebastian (DMH), Kathy Reilly, Laura Gillis Esq., Ilyse Levine, Cheryl Ryan, Leslie O'Brien, Coleman Nee, Alexis Henry, Madeline Wenzel, Ann Guay Esq., Vanda Khadem Esq., Lea Hill (DDS), Margaret Van Gelder (DDS), Sue Banks (DDS), Lisa Borges, Michael Weiner, Dianne Lescinskas

## Issues discussed

Lack of appropriate transition services for students ages 14-22, impact is the need for more adults requiring services for skills that should have been begun at age 14 and taught during their educational career. Oversight by DESE on public school transition services.

Need to replicate and bring to scale effective pre-employment services such as Triangle, JVS, Aspire, Best Buddies, Autism Higher Education Foundation Paralegal Assistant Training or PLAT program, which actively work with students on employment skills, job, coaching, travel training, resume writing, interviewing.

Need for multi-disciplinary Team approach to services by public schools, MRC and DDS, and earlier waiting for 688 referral process is too late. Need to inform parents about transition services.

More work and training needs to occur with the public school systems on transition services, change of culture so that students are going into the community to work on these services, which is the natural environment and where they will need to apply skills.

More opportunities need to exist for higher education, ICEI has limited capacity and higher functioning students only receive support where they request accommodations.



# 14-22 Year Olds/Employment and Higher Education continued



## Issues discussed

Need for schools to recognize mental health issues and provide access to counseling and mental health services. Many adolescents are presenting with mental health needs that go unaddressed during high school years.

Need to train employers on ASD and how to provide support with peers in the workplace, some agencies have made connections with certain businesses but expanded opportunities and training of the workplace is needed.

Examine dissemination of information to families to prepare them for the transition process beginning at age 14.

Parents need basic and direct information on the steps to prepare and advocate for their children and to focus the services on their interests for employment or higher education, it should not be based on what the public schools have available (recycling, custodian work, cooking)

Many of the same issues were discussed by the 14-22 and the employment and Higher education sub-committees so they were combined after a few months with a separate working group created for adults over 22 on employment.



# Employment for 22+ Years



Commission Members: Carolyn Kain, Chair, Todd Garvin

Non-Commission Members: Kevin Barrett, Kay Murray, Lea Hill (DDS), Debra Dunn (DDS), Dian Bohannon, Michael Stepansky (DMH), Dianne Lescinskas

## Issues Discussed

This working group wanted to focus on employment issues for individuals over 22 years old. Many individuals with ASD have sought employment and were unsuccessful or remain under employed.

Need to identify supports and services to help people with ASD maintain employment and advance in their careers.

Transportation issues are a barrier for many in finding and staying employed

Connecting individuals with Career Centers, DMH clubhouses, DDS and services through MRC

MRC can also assist individuals with obtaining a diagnosis when it is related to their employment goals



# Housing



Commission Members: Dan Burke, Chair, Carolyn Kain, Cathy Boyle, Michelle Brait, Janet George (DDS), Ayana Gonzalez (DHCD), Patti Jennings, Chris Supple Esq., Judith Ursitti, Jane Ryder (DDS)

Non-Commission Members: Amit Basak, Albert Rex, Nan Leonard, Kevin Barrett, Lea Hill (DDS), Kelly Lawless(DDS), Victor Hernandez (DDS), Karen Mariscal, Dafna Krouk-Gordon, Leo Sarkissian, Michelle Harris (DMH), Joseph Valley (DMH), Dianne Lescinskas

## Issues discussed

Types of housing available and types of services required to enable an individual to live in affordable housing. Type of housing is based on the programs (Section 8, FCF, set-asides, etc.) support services can be tailored to the individual. Most housing options are impacted by the individual's income.

After first sub-committee meeting the group agreed to reconvene after Housing think tank in September 2016, most subcommittee members participated, Cathy Boyle is in the process of writing up a more detailed report of the outcomes from the Housing think tank.

Two Motions by Sub-committee regarding housing survey and supplemental budget increase for DDS (\$12.4 mil in funding for newly eligible has been fully allocated) (1) "That the Governor's Commission on Autism adopt a motion that the *administration release funds for a Massachusetts survey which would identify the housing and related support needs for people with ASD.*" *Second motion: (2) That the Governor's Commission on Autism adopt a motion that Governor Baker request a supplemental budget for DDS 5920-3020, Adult Omnibus, of \$2,000,000 for a total of \$14,434,095."*

Different types of housing options were discussed and some of the issues to review are: 1) affordability, 2) zoning, 3) expanding use, 4) technology and 5) design. Possible recommendation regarding zoning laws, locals defer to state building code.



# Adults



Commission Members: Janet George Ed.D. (DDS) Chair, Dr. Kathy Sanders (DMH) Co-Chair, Todd Garvin, Dania Jekel, Sue Loring, Rita Gardner, Carolyn Kain

Non-Commission Members: Mike Moloney, Lea Hill (DDS), Mark Dumas (DDS), Maria Stefano (DDS), Elizabeth Duffy, Melissa Guyer (DDS), David Tobin (DDS), Deb Johnson, Gail Gillespie (DDS), Sandy Honig (DDS), Tim Cahill (DDS), Lisa Saba (DDS), Michelle Mayer, Casey Seaman (DDS), John Townsend (DDS), Nancy Marticio, Tara Callahan (DMH), Cynthia Berkowitz M.D. (DMH)

## Issues discussed

Understanding of services available through DDS, services available through DMH and how the agencies have been working together to meet the needs of individuals with ASD.

Need to identify current service gaps for adult population; Agreement between DDS and DMH has provided access to fellowships and consultative services.

Need for more training of staff at Emergency Room and EMS. Mobile Crisis Teams need more training about autism through MassHealth. DDS is trialing OCALI training for direct providers.

Lack of experienced mental health providers for ASD population. Anxiety, depression and OCD are common mental health issues, treatments for someone with ASD may not be the same as general population.

Issue that most mental health providers do not take private insurance or MassHealth and this greatly limits access for treatment/therapy.

Adults needing services need to know how to apply, who to contact, service options that are not program based and transportation is a barrier to accessing services.



# Data



Commission Members: Jane Ryder (DDS) Chair, Dan Burke, Roccio Calvo, Janet George (DDS), Christine Hubbard, Amy Weinstock, Carolyn Kain

Non- Commission Members: Julia O'Rourke Ph.D., Dr. Deidre Donaldson, Kathy Phillips (DDS), Tim Fife (DDS), Beth Ferguson (DDS), Ashley Montgomery (DMH), Carly Sebastian (DMH), Elaine Gabovitch, Emily Lauer

## Issues discussed

Review of current data available from state agencies; DESE, DPH (early intervention data), DDS on newly eligible, (DCF does not have any available). DESE provided more extensive data after its presentation to the Commission. Numbers for ASD are available from 2003-2016 from Pre-K through 12<sup>th</sup> + grade. An increase in numbers is evident wherein 2003 number of students with ASD reported as 4,986, and in 2016 that number is reported as 18, 572.

UMass is processing a report from their study for review by the commission, which has some data available and recommendations. Draft report was available at the end of October report should be finalized by the end of 2016.

MassHealth has provided recent data as of June 2016; total of 22, 977 individuals with ASD (including 6,004 over 22 years old) compared to 14,755 total of individuals in 2012.

Adults without ID were not eligible for service prior to the Omnibus Law, DDS has begun tracking for new applicants.



# Workforce Development



Commission Members: Dr. Pat Gentile, Co-Chair, Dr. Pat Marshall, Co-Chair, Dr. Carolyn Langer (MassHealth), Carolyn Kain

Non-Commission Members: Mike Moloney, Steve Sullivan, Katherine Johnson, Susan Senator, Jeff Keilson, Liz Martineau, Sue Houle, Maryann Dezieck (DMH), Dianne Lescinskas

## Issues discussed

There are major workforce needs for the positions of BCBA's (Board Certified Behavior Analyst), BCaBA's (Board Certified assistant Behavior Analyst), ABA (Applied Behavior Analyst) therapists, paraprofessionals, direct care staff in adult programs, life coaches, RBT (registered behavior technician) certification and that this was an area of high turnover. The need for respite was also raised, given the daily demands placed on families in raising and caring for individuals with ASD.

More bilingual staff are needed in the workforce, this creates a barrier to families getting ABA services, in addition to current waiting lists.

Need to examine how to combine certifications and bundle trainings and courses toward a degree and making it into a career pathway. Connecting the jobs on the lattices people could see how they can expand and grow their career and not feel that a direct care position has no opportunity for advancement.

How to make community and state colleges understand the need for pathways to work in this human services field. Possibly approaching University and College advisory boards to get the word out.



# Expectations



Timelines for recommendation(s) to be submitted to the Commission by the respective sub-committees for review and discussion by the Commission. 2017 quarterly meetings of the Commission; March 6<sup>th</sup>, June 5<sup>th</sup>, September 12<sup>th</sup> and December 4<sup>th</sup>. First annual report was filed October 24, 2016.

Charge of the Commission is to make recommendations on policies, any regulatory or statutory action necessary to provide or improve services for individual with ASD and Smith-Magenis syndrome, outline any unmet needs, monitor its recommendations and update recommendations. . .

Investigate and study the higher education opportunities, employment training and employment opportunities available to persons with ASD and make recommendation in regard thereto. Review the rise and prevalence of ASD in past 30 years, make estimates of the number of children aged 21 or younger and resulting needs for employment training and employment opportunities and recommend a plan of action for the Commonwealth.

Statewide housing survey to determine the current status of affordable housing stock for adults with ASD and make recommendations in regard thereto.

Investigate and study the present and anticipated future statewide affordable supportive housing needs for the commonwealth's population of persons with ASD. Review the rise and prevalence of ASD in past 30 years, make estimates of the number of children aged 21 or younger and resulting needs for affordable supportive housing and recommend a plan of action for the Commonwealth.