TESTIMONY IN SUPPORT OF ADDING FUNDING FOR *MOCO BETTER BEGINNINGS* INITIATIVE

Chair Albornoz and members of the Council:

For the record, my name is Larry Bram. I wear a number of hats, including as Senior Vice President of Innovation for Easterseals, a member of the Montgomery County Commission on People with Disabilities, and the Maryland Commission on Caregiving, but I'm here today to speak in my most important role—as parent of a daughter with developmental disabilities. I'm here to urge you to add funding in the budget for a project manager for the **Moco Better Beginnings** initiative to reach the audacious goal of Montgomery County becoming the first county in America to screen 100% of children for developmental disabilities.

Let me briefly tell you a story about the day that my life took a new trajectory. The moment my daughter was born 28 years ago, we knew something was wrong. She had her first MRI when she was 5 days old and we were told then that she was missing part of her brain and would probably never develop language. As you can imagine, we were devastated. However, the next thing the doctor told us changed everything. He put us in touch with the Montgomery County Infants & Toddlers Program. Sarah began services when she was only 3 months old. Fast forward to today…Sarah has a BS degree in Speech & Hearing Sciences, lives independently (with support from DDA and SEEC) and is obtaining her Speech-Language Pathology Assistant credential. I truly believe in the plasticity of the brain; my daughter has literally been a poster child of how it works. Clearly, Sarah had the privilege of who her parents were. Her mother was able to leave the workforce, we were able to pay for private therapies, etc. In fact it was this feeling of privilege that guided my career choices and had me end up at Easterseals. The system is too hard for people and I made it my life mission to provide access for those who otherwise might not receive it.

In 2018, we formed a coalition of parents, pediatricians, and organizations to figure out how we could best solve a major problem….that so many children enter kindergarten with undiagnosed disabilities. In 2019, Easterseals received a grant from the Washington Area's Women's Foundation on behalf of the coalition to work on the issue. We studied best practice efforts across the country, spoke with concerned stakeholders and came up with recommendations. Then came COVID, which delayed implementation for a couple of years. Now is the time to bring it back. When we started the CDC reported that 1 in 60 children would be diagnosed with autism; then it was 1 in 50; now it is 1 in 44 children. 80% of brain development occurs by the age of 5. Autism can be diagnosed effectively by 18 months, yet most diagnoses happen at around 4-years-old or later. We are losing time that can never be recovered and ends up costing society so much more in special education, medical and other expenses. Earlier is definitely better.

As part of our written testimony, we are including our proposal and 5-year budget to implement our plan. It is a modest investment in transforming the lives of our young children, particularly children from underserved communities in Montgomery County. We re commend beginning by hiring the project manager, either internally or outsourced to a local nonprofit. We could then come back with a request for full project funding. Believe me, I know, this is the best investment you can make. Thank you and I am happy to answer any questions.

Promotion of Early Intervention for Socioeconomically Disadvantaged Infants and Toddlers

We ask the County to do more to link socioeconomically disadvantaged infants and toddlers with developmental/intellectual disabilities with evidence-based early interventions. Currently, at least half of the County's socioeconomically disadvantaged infants and toddlers are not receiving the early interventions they need and are entitled to under the IDEA, which mandates appropriate evidence-based intervention for children under three.

There is a growing body of scientific data establishing that certain types of early interventions can dramatically improve outcomes for children with ASD, and that those interventions are most effective when administered as early in the child's development as possible. Evidence-based early interventions have been developed that capitalize on the malleability and growth-potential of the young child's brain. For instance, controlled and peer reviewed studies have established that properly administered intensive early interventions when administered for a period of a year to children under thirty-six months of age diagnosed with autism lead to either the elimination of the autism diagnosis or a significant change in the severity of the diagnosis for between a quarter and half of participants.

Recognizing the efficacy of evidence-based early interventions and the attendant imperative of early detection of developmental and intellectual disabilities, the American Academy of Pediatricians (AAP) recommends that its members conduct screenings for developmental/intellectual disabilities and autism for all children under three. Further, since 2014, Maryland now requires private insurance to cover habilitative services, including early intervention costs for autism, up to at least 25 hours per week.

Nonetheless, most children with serious developmental disabilities in the County either do not receive appropriate intervention or receive it when they are too old to benefit fully from it. For instance, one study revealed that in MD, while roughly 30,000 children under age 3 are at risk of a developmental disability, only about 15,000 are currently receiving any amount of early intervention services through Part C of IDEA. The most detailed study of early intervention for children with autism in Maryland found that most children with autism are not identified as having autism prior to age 4.

Early intervention rates are low, especially among the socioeconomically disadvantaged, primarily because of problems and delays with screening, diagnosis, and referrals. Providers of pediatric services are not screening when they should because of concerns over reimbursement; difficulties with workflow; the tendency to rely on clinical skills instead of screening tools; lack of training on using screening tools; and apprehension about what to tell parents if a child screens positive. Delays in obtaining diagnosis after a positive screen are caused by various factors, including: lack of information for parents of a child who screens positive; delays in pediatric referrals to MITP; and a dearth of qualified providers of services for diagnosis of developmental/intellectual disabilities. When a child has been diagnosed with autism, the child's parents are often not clearly informed by their trusted provider of medical services that appropriate early intervention should include some type of an intensive evidence-

Improving Outcomes for Infants and Toddlers with Developmental Disabilities in Montgomery County

Project Budget

Expenses	**Year 1**	**Year 2**	**Year 3**	**Year 4**	**Year 5**	**Total**	**Assumptions**
Project Manager Salary (includes benefits)	$ 73,200	$ 75,396	$ 77,658	$ 79,988	$ 82,387	$ 291,200	This budget assumes a $60,000 starting salary, 3% annual increase, and a 22% fringe rate.
Software Subscriptions (CHADIS)	$ 18,000	$ 18,000	$ 18,000	$ 18,000	$ 18,000	$ 90,000	One year's worth of a subscription to CHADIS or comparable softwre for screening/data managment. 40 new pediatricians per year for 5 years @ $1,500 per individual subscription (includes management and screening tools for pediatricians; data analysis and tracking; off-site scoring for screening tool; quality improvement reports; pediatrician training, certifications, and support; and modified version of software for use at County clinics and MCITP. County pays for only one year per private practice pediatrician) .
Local Mileage	$ 2,700	$ 2,700	$ 2,700	$ 2,700	$ 2,700	$ 13,500	local travel visiting doctors' offices and community organizations
Telephone	$ 600	$ 600	$ 600	$ 600	$ 600	$ 3,000	$50/month
Tablets	$ 2,000	$ 2,000	$ 2,000	$ 2,000	$ 2,000	$ 10,000	Tablets for parents and clinicians to access CHADIS or comparable software/screening tool at pediatric practices. 1 tablet per practice. 5 practices per year @ $400. For parents to fill out screening tools in waiting room.
Meetings/Convenings	$ 1,500	$ 1,000	$ 1,000	$ 1,000	$ 1,000	$ 5,500	
Printed Materials	$ 5,000	$ 3,000	$ 3,000	$ 3,000	$ 3,000	$ 17,000	Printed materials not included in the subscription fee for software (includes materials/educational kiosks for waiting rooms at pediatric offices and clinics providing pediatric care, recruitment materials for pediatricians, and printed information about this project).
Miscellaneous	$ 2,500	$ 2,500	$ 2,500	$ 2,500	$ 2,500	$ 12,500	
Total Direct	$ 105,500	$ 105,196	$ 107,458	$ 109,788	$ 112,187	$ 442,700	
Indirect	$ 15,825	$ 15,779	$ 16,119	$ 16,468	$ 16,828	$ 81,019	15% of direct expenses
Total Expenses	**$ 121,325**	**$ 120,975**	**$ 123,577**	**$ 126,256**	**$ 129,015**	**$ 621,148**	

Easterseals DC MD VA

Improving Outcomes for Infants and Toddlers with Developmental Disabilities in Montgomery County

Project Budget

Revenue	Total	Narrative
CHADIS	$ 21,000	In-kind, confirmed
Montgomery County Infants & Toddlers Program	$ 25,200	In-kind, confirmed through a grant from the MSDE
Montgomery County Community Development Block Grant	$ 45,000	Pending
Montgomery County Council Grants	$ 25,000	To be submitted
WAWF ECEFC (this proposal)	***$ 60,000***	
Total Revenue	**$ 176,200**	

Expenses	Total	Narrative	
Salaries			
Project Manager	$ 45,000	1 FTE (100%)	$ 25,000
Regional Director, Early Intervention Services	$ 9,760	10% FTE	
Total Salaries	$ 54,760		
Fringe Benefits	$ 12,237	22.4% fringe benefits	$ 5,000
Total Salaries & Fringe Benefits	$ 66,997		
Consultants			
The Treatment and Learning Centers	$ 10,000	Outreach, recruitment, and training	
Maryland AAP	$ 5,000	Outreach, recruitment, and training	
Total Consultants	$ 15,000		
Office rent/utilities	$ 3,500	$35/SF	
Audit & Accounting	$ 1,500	For A-133 Audit expenses	
Local Mileage	$ 1,620	250 miles/month @ $0.54/mile	$ 1,600
Telephone	$ 600	$50/month	$ 600
Materials (recruitment, training, information)	$ 8,000	Materials in English and Spanish	$ 2,000
Software subscriptions	$ 56,000	40 pediatricians @ 1,400	$ 9,800
Total Direct	$ 153,217		$ 44,000
Indirect (15%)	$ 22,983	15% indirect	$ 6,600
Total Expenses	**$ 176,200**		$ 50,600

based intervention, where and how they can obtain such intervention, and the extent to which the intervention will be paid for by insurance and/or the county.

To address the challenge in those areas of our County suffering the most from this failure to adequately identify and refer infants and toddlers with developmental disabilities to appropriate evidence-based interventions, MoCo Better Beginnings, a coalition of stakeholders interested in improving early intervention in the County, proposes the creation of a new Project Manager position at either Montgomery County Infants and Toddlers Program (MCITP) or the County funding a similar position at an area social service provider already serving the County's socioeconomically disadvantaged residents.

The Project Manager duties would include: (1) identifying current providers of pediatric care to the County's socioeconomically disadvantaged residents, especially those residing in communities adversely impacted by systemic and structural racism; (2) using "the pharmaceutical representative model" to promote screening for developmental disabilities among area providers of pediatric care, including through encouraging providers to adopt an electronic system of care, such as CHADIS, that automates and increases the accuracy of screenings; (3) assisting providers of pediatric care with expeditiously linking parents of/caregivers for infants or toddles who screen positive to evaluations and/or evidence-based interventions; (4) increasing partnerships and collaboration between providers of pediatric care, early interventionists, childcare professionals, educators, and parents/caregivers; and (5) gathering data on the impact of the program.

We also propose a limited subsidy to assist with the promotion of the electronic system of care for pediatric providers focused on serving the area's socioeconomically disadvantaged families. The electronic system of care is a best practice that includes screening, referral, and data management tools, that is being used by a significant percentage of pediatric practices serving the more affluent parts of the County, but is practically unavailable to the County's socioeconomically disadvantaged families. Our proposal would work toward making it equally possible for families in the less affluent parts of the County to access pediatric care that includes this best practice.

To learn more about MoCo Better beginnings and join our coalition to improve early intervention in the County go to: Mo Co Better Beginnings. To learn about a program with similarities to the program we are proposing here that existed in Prince George's County and received funding from the County's Department of Health and Human Services go to: PG County Special Needs identification Phsyician Support Program.

DANIEL G. SHAPIRO, M.D.

DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS

drdanshapiro@gmail.com

4/3/2022

Avner Shapiro
Cochair
MoCo Better Beginnings

Mr. Shapiro,

I am writing to express my support for your initiative to improve early identification and intervention for children with autism in Montgomery County.

As a developmental and behavioral pediatrician practicing in Montgomery County, I care for many children who have been diagnosed with autism and are struggling with behavioral and learning problems. I am aware of the data showing that earlier diagnosis and intervention can make a difference in later social competence. I have encouraged my colleagues in primary care to follow the American Academy of Pediatrics guidelines for screening beginning at 18 months, but it is not universally accepted and there are barriers to implementation on a regular basis and follow-through is particularly lacking.

I have been using an online clinical process support system called CHADIS that helps identify problems in children with developmental disabilities but is particularly valuable for early identification as the founders are also taking the lead in developing new evidence-based approaches to autism identification and have some unique solutions to some of the barriers to addressing this important problem.

Sincerely,

Daniel G. Shapiro, M.D.
Fellow, American Academy of Pediatrics
Member, Society for Behavioral and Developmental Pediatrics
MD license #D0032383

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Dear Montgomery County Council Members:

My name is Giorgio Kulp and I have been a pediatrician in Montgomery County for the past 24 years. I am writing in support of the initiative to better address early identification and intervention for children with potential developmental challenges/disabilities in the county. Early diagnosis and intervention in this cohort of children can significantly improve outcomes in social and other behavioral development. My practice has used an online system called CHADIS for the past 18 years and this has been absolutely indispensible in identifying these children and providing parents with proper guidance. The developers of this platform have partnered with physicians and continue to lead in the development of tools to aid in this effort.

Getting a critical mass of pediatricians in the county to use this system would be a significant step in the County's ability to track the progress of these children in the school system and pinpoint any gaps in services. MoCo Better Beginnings has been leading the effort to implement evidence-based methods like CHADIS to help the county's children, especially the children from socioeconomically disadvantaged/minority communities. Without the support of the Montgomery County Council for this initiative, I fear many children will fall through the cracks, further stressing families and burdening an already fragile system of services that can barely support these complicated developmental delays.

I hope the County will see what so many of us already do....At risk children and adolescents alike are at risk for delayed intervention without comprehensive identification systems and tools. This initiative is a REAL STEP in the right direction and I hope the Council will put resources into this effort.

Thank you sincerely for your consideration in this matter and please feel free to contact me at anytime.

Sincerely,

Giorgio Kulp, MD, FAAP
President, Mid Atlantic Pediatric Partners, LLC (MAPP)
Owner, Metropolitan Pediatrics, a division of Mid Atlantic Pediatric Partners
Former Co-Chair, Montgomery County School Health Council, 2006-2010
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Tamara M. Buckley, M.S.N., P.N.P.

Website: pacaremd.com

Dear Montgomery County Councilmembers,

4/11/2022

I am a pediatrician in Silver Spring Maryland who is part of the coalition MoCo Better Beginnings.
As a group we are trying to make sure that every child in Montgomery County is screened for developmental delays and autism prior to their second birthday. Developmental screenings are part of every well child visit as recommended by the American Academy of Pediatrics. Unfortunately, not all children visit pediatricians and not all pediatricians have the time or ability to make sure that every patient is screened. The most efficient method to make sure that every child is screened is to have the questionnaires easily available and sent to the parents just prior to the visit. This can be facilitated by companies such as CHADIS who send out the forms and score them so that they are available in the patient's chart at the time of their physical examination.

It is also extremely important that once delays are identified that children receive early intervention services as soon as possible. The Montgomery County Infant's and Toddler's program is free for all residents of the county but unfortunately, they do not have enough highly trained individuals who can test for autism. There are long wait lists at the developmental clinics at all of the local children's hospitals and because of this the diagnosis of autism takes more than one year to make. The earlier a diagnosis is made, the earlier that intervention can start. Parents often need help navigating this difficult process.

I fully agree that funding is needed to help facilitate efficient screening of every child at all pediatric practices in the county. Funding is also necessary to make sure that all children have access to testing and appropriate therapies so that they can develop to the best of their abilities.

Thank you for your consideration,

Robin G Witkin MD, FAAP

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disabilityscoop

Delays For Autism Diagnosis And Treatment Grew Even Longer During The Pandemic

by Andy Miller and Jenny Gold, Kaiser Health News | March 30, 2022

Wylie James Prescott, 3, had to wait more than a year after his autism diagnosis to begin behavioral therapy, even though research shows early treatment of autism can be crucial for children's long-term development.

His mother, Brandie Kurtz, said his therapy wasn't approved through Georgia's Medicaid program until recently, despite her continued requests. "I know insurance, so it's even more frustrating," said Kurtz, who works in a doctor's office near her home in rural Wrens, Ga.

Those frustrations are all too familiar to parents who have a child with autism, a complex lifelong disorder. And the pandemic has exacerbated the already difficult process of getting services.

This comes as public awareness of autism and research on it have grown and insurance coverage for treatment is more widespread. In February, Texas became the last state to cover a widely used autism therapy through Medicaid. And all states now have laws requiring private health plans to cover the therapy, applied behavior analysis.

Yet children from Georgia to California often wait months — and in many cases more than a year — to get a diagnosis and then receive specialized treatment services. Therapies that can cost $40,000 or more a year are especially out of reach for families who don't have insurance or have high-deductible health plans. Children from minority communities and those who live in rural areas may face additional barriers to getting help.

"You would never allow a kid with cancer to experience these waits," said Dr. Kristin Sohl, a pediatrician at University of Missouri Health Care and chair of the American Academy of Pediatrics' Council on Children With Disabilities Autism Subcommittee.

During the early months of the COVID-19 pandemic, many families canceled in-home services, fearing infection. Virtual therapy often didn't seem to work, especially for nonverbal and younger children. With fewer clients, some providers laid off staff or shut down entirely.

And treatment services always face high turnover rates among the low-wage workers who do direct, in-home care for autism. But COVID made the staffing problem worse. Companies now struggle to compete with rising wages in other sectors.

The Centers for Disease Control and Prevention estimates that autism affects 1 in 44 U.S. children, a higher prevalence rate than ever before. Autism symptoms can include communication difficulties and repetitive behaviors and can be accompanied by a range of developmental and psychiatric health conditions.

Early diagnosis of autism can make a difference, Sohl said. Symptoms of some kids who begin their therapy by age 2 or 3 can be greatly reduced.

Diagnoses are typically done by developmental-behavioral pediatricians, psychologists, psychiatrists, and neurologists, all of whom are in short supply. The shortage of developmental pediatricians is especially acute. Even though they do three more years of fellowship training than a general pediatrician does, developmental pediatricians typically earn less.

General pediatricians with training can also do assessments, but insurers often require a specialist's diagnosis before paying for services, creating a bottleneck for families.

"If we solely rely on specialists, we're setting ourselves up for failure because there aren't enough of us. We need the insurance companies on board," said Dr. Sharief Taraman, a pediatric neurologist and president of the Orange County, Calif., chapter of the American Academy of Pediatrics.

Even in a metro area, getting a child an appointment can take months. "We cannot get these families in fast enough," said Dr. Alan Weintraub, a developmental pediatrician in suburban Atlanta. "It's heartbreaking."

Some parents pay cash for an evaluation with a private specialist, worsening disparities between kids whose parents can afford to skip the wait and those whose parents cannot.

Once a child has been diagnosed, many face an equal — or longer — wait to get autism therapies, including applied behavior analysis, a process that aims to improve social, communication, and learning skills. These sessions can take more than 20 hours a week and last more than a year. ABA techniques have some critics, but the American Academy of Pediatrics says that most evidence-based autism treatment models are based on ABA principles.

Accessing such treatment largely depends on insurance coverage — and for many families how well Medicaid pays. The Georgia Medicaid program reimburses well for ABA, Georgia doctors said, while Missouri's pay is low, leading to a scarcity of options there, Sohl said.

In California, Medicaid reimbursement rates vary by county, and wait times for ABA range from about three to 12 months. In the rural northern reaches of the state, where few providers work, some families wait years.

During the first year of the pandemic, Claire Hise of Orange County was thrilled with the ABA therapist who worked with her son. But in January 2021, the therapist quit to go back to school. The company she was working with sent others. Hise had to train each new therapist to work with her son, a difficult process that always took more than a month. “It’s a special relationship, and each kid with autism is an individual,” Hise said. “It takes time.”

By then, they were out the door, replaced by another after no more than four to six weeks. Sometimes the family waited weeks for a replacement.

Hise tried switching to another company, but they all had a six-month waitlist. “He’s already so far behind,” Hise said. “It’s really a year I feel we’ve lost.”

The average age of diagnosis in the U.S. is about 4 years old, but Black and Latino children on average are evaluated later than white kids.

“The impact on families having to wait for diagnosis or treatment can be devastating,” said Kristin Jacobson, founder of the Autism Deserves Equal Coverage Foundation, an advocacy group in California. “They know in their gut something is seriously not right and that there is help out there, and yet they are helpless to do anything about it.”

Araceli Barrientos helps run an autism support group in Atlanta for immigrant families, for whom language barriers can cause additional snags. It took her over a year to get her daughter, Lesly, diagnosed and two more years to secure further treatment.

Sabrina Oxford of Dawson, in rural southwestern Georgia, had to take her daughter Jamelyn more than 150 miles to the Marcus Autism Center in Atlanta to get her diagnosed. “You don’t have any resources around here,” Oxford said.

Dr. Michelle Zeanah, a behavioral pediatrician, draws families from 60 mostly rural counties to her clinic in Statesboro, Ga. “There’s a massive shortage of people willing and able to do an autism diagnosis,” she said.

Getting insurance to pay for autism treatment can be another frustrating process for families. Therapy denials can be triggered by clerical errors or missed paperwork. Insurer approvals can be especially difficult for older children, who can be less likely to get treatment services than younger ones, said Dr. Donna Londino, a child and adolescent psychiatrist at Augusta University in Georgia.

Many children with autism also need speech, occupational, and physical therapy, all of which are generally easier to secure than behavioral therapy. But even then, Weintraub said, the insurers push back: “They really dictate how many services you can have. These families, literally, meet obstacles at every turn.”

David Allen, a spokesperson for AHIP, an insurance industry trade group formerly known as America’s Health Insurance Plans, said insurers often require prior authorization to ensure that autism services are “medically necessary and evidence-based” and that patients are treated by “providers with appropriate education and training in treating autism.”

Tracy-Ann Samuels of New York said she paid out-of-pocket for speech and occupational therapy for her son, Trey, now 15. Two years ago, after 18 months on a waiting list, he finally got ABA services covered by insurance.

“He’s doing so great,” she said. “My son was nonverbal. Now he’s talking my ear off.”

This story was produced by KHN (Kaiser Health News), a national newsroom that produces in-depth journalism about health issues. Together with Policy Analysis and Polling, KHN is one of the three major operating programs at KFF (Kaiser Family Foundation). KFF is an endowed nonprofit organization providing information on health issues to the nation.

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