

**Avner Shapiro's Remarks to Montgomery County Council
on the Need to Increase the rate at which children with
Developmental Disabilities Receive Early Intervention Services**

Good afternoon, my name is Avner Shapiro, I am cochair of MoCo Better Beginnings, a coalition of parent advocates, pediatricians, service providers, and professional advocates for people with developmental disabilities. In our proposal, we ask for modest investments to improve the rate at which children with DD receive early intervention.

Our County is failing to meet its obligation under the IDEA. Currently, only about half of the County's children with DD receive the early intervention they need and are entitled to. While this is a Countywide problem, a disproportionately high percentage of those children are from our low income, historically discriminated against communities.

Whenever we fail to provide early intervention to an individual with DD, it's a tragedy. That's because an ever-growing body of scientific evidence establishes that by capitalizing on the malleability of the *toddler's* brain, these interventions change the very trajectory of a person's development for the better.

Unless and until we help families find their way to early intervention, we will be consigning many of our residents to restrictive environments, and unnecessary torment and misery. And the County and State will also continue paying a steep price as well. They will have to continue spending enormous sums on individuals who could have lived relatively independent lives if they had received early intervention.

With a small investment, we can create a different future for many by simply ensuring two things occur *throughout* our County: First, that our providers of pediatric services screen all of our infants and toddlers in accordance with the

guidelines of the American Academy of Pediatrics; and second, that those who screen positive for DD, are both promptly diagnosed for conditions like autism and expeditiously referred to our County's I&TP and other service providers to receive early intervention by no later than age two.

We CAN do this. We MUST do this.

Thank you.

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 Pediatrics (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-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 toddlers 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 Physician Support Program](#).

Montgomery County Needs to Lead on Early Intervention

Now is the time for Montgomery County to lead on the issue of early intervention services. As with most counties in the country, Montgomery County is not yet taking advantage of new breakthroughs in brain-science and technological advances to provide appropriate interventions for infants and toddlers with significant intellectual and developmental disabilities (IDDs). The failure to do so comes at great cost to affected individuals, their families, and the broader community. It is a failure born most heavily by those from our socioeconomically disadvantaged and historically discriminated against communities.

A growing body of scientific evidence establishes that evidence-based interventions administered between the ages of zero to three can dramatically change and improve outcomes for children with IDD. These early interventions redirect the trajectory of a person's development by capitalizing on the malleability and growth-potential of the young child's brain.

For instance, studies show that the most effective interventions for autism—a condition now affecting one in 50 children in Maryland—can be reliably diagnosed at as early as 14 months (JAMA Pediatrics, April 2019) and bettered with a number of incredibly effective intensive, evidence-based, early interventions, involving a combination of developmental and behavioral approaches (Pediatrics, 2015, Vol. 136:S60). These interventions, most of which have been developed within the last 20 years—when administered early in a child's life at the appropriate dosage level—routinely result in dramatic and permanent gains in cognitive functioning, social communication, and other domains affected by autism (Id.; Pediatrics, 2010, Vol. 125; JAMA Pediatrics, 2019)

Despite the compelling need for zero-to-three, early intervention, best estimates indicate that Montgomery County's early intervention service, the Montgomery County Infants and Toddlers Program (MCITP), currently provides services to only half of those who would qualify for the service (*Make the First Five Count, Easter Seals Disability Services, 2018*). Moreover, a significant percentage of those who do receive early intervention treatment, receive treatment that is not evidence-based or effective because of a failure to properly identify the characteristics of their disability.

The reason for this breakdown in the provision of services is that most children with IDDs are not identified as having disabilities and linked up with appropriate evidence-based interventions quickly enough. For instance, the most detailed study of early intervention for children with autism in Maryland found that most are neither identified as having autism or provided with early intervention services prior to age four (MD, ADDM, 2018).

Working together, Montgomery County government and area foundations and non-profits can eliminate the delay in the provision of appropriate intervention services by moving forward with a proposal championed by MoCo Better Beginnings, a diverse coalition of stakeholders, consisting of parents of children with developmental disabilities, area pediatricians, leaders of the non-profits in the County providing services to young children with IDD, professional advocates for people with IDD, and leaders of County Commissions charged with advocating on behalf of persons with IDD and young children.

The elements of the initiative include: First, ensuring that County government partners with area stakeholders to engage in sustained, consistent outreach and coordination with pediatric practices within the County, both to increase compliance with universal screening protocols and to improve care coordination between pediatricians and service providers; second, selecting and

promoting adoption of an electronic system of care that includes screening, referral, and data management tools for use by area pediatricians.

In sum, our County – home to the National Institute of Health – should follow the science and lead on this issue for the sake of our children, families, and community. We should set ourselves the ambitious goal of linking all of our toddlers with IDD with the evidence-based interventions they need by no later than 24 months. We can do this, and when we do, the lives of so many of our County’s most vulnerable residents will be transformed for the better.

DANIEL G. SHAPIRO, M.D.

DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS

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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

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Dear Montgomery County Council Members:

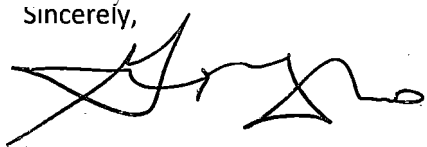
My name is Giorgio Kulp and I have been a pediatrician in Montgomery County for the past 24 years. I am writing in support of the initiative to better address early identification and intervention for children with potential developmental challenges/disabilities in the county. Early diagnosis and intervention 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 indispensable 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,
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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,

A handwritten signature in black ink, appearing to read "Robin G. Witkin". The signature is fluid and cursive, written over a light grey rectangular background.

Robin G Witkin MD, FAAP

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