



Moms In Motion Empowering One Family at a Time! February 2017

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Division 4 Team Meeting!

Greetings!

Hi there! We hope this newsletter finds you healthy and happy. Moms In Motion is excited to let you know we have a new phone number. If you have had difficulty getting through our phone system in the past, try us again! We just installed a state of the art system to expand our capabilities to answer calls. Our new number is **844-828-5591**.

Please be sure to check out a new section in <u>Spotlight On</u>. We will be featuring a new family in each newsletter that has inspired us and will be sure to inspire you! Family Highlights is meant to raise awareness, have a positive impact, and connect our community. Moms In Motion is honored to serve all families! We hope you enjoy and are enlightened by our featured family.

Find it Quick

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What You and Your Service Facilitator Should be Discussing

1. New for this period:

- If you are on the EDCD Waiver, are you ALSO on the wait list for any of the three Waivers? - Building Independence, Family and Individual Supports or Community Living? Read more about these Waivers.
- 2. Review Mobility and Behavior/Orientation levels as noted on our reports. Are they accurately reflecting your reality?

2. At Every Visit:

- 1. Are you enrolled in <u>Commonwealth Coordinated Care (CCC)</u>? If so, which Managed Care Organization (MCO) are you using?
- 2. Any medical and/or functional changes.
- 3. Who are your attendants and are they getting paid?
- 4. Have there been any recent hospitalizations?
- 5. Turning 18 We have an amazing resource page for young adults on our website.
- 6. Reviewing time sheets filed by your attendants.

Waivers

Choice of Providers

Due to Virginia Waiver Redesign you should be aware of changes happening at your local Community Service Board (CSB).

If you receive a Family & Individual Supports Waiver, you will be offered provider choice. This

means that you have the right to choose from (1) a case manager at your local CSB, (2) a partnering CSB with a memorandum of agreement or (3) a private provider which the CSB has chosen to contract with for these services. Each CSB has contracted with at least one private provider.

If you choose a private provider that does not have a contract with your CSB, the CSB Support Coordinator will make note of that on the Provider Choice Form, detailing your preference and why it was not able to be met. We encourage you to advocate for the provider you want. While Moms In Motion is not contracted with every CSB, we are hopeful that enough documentation of choice will eventually open up our ability to support all of those that choose us.

For those on the waiting list for the Family & Individual Supports Waiver and Community Living Waiver, the Individual Family Support Program is available every year to support you while you wait for the waiver. To date, this program has been primarily a financial support for needed services, however it is currently undergoing revision to meet the state's requirement for comprehensive services for those on the wait list. The Family & Individual Supports and the Community Living Waivers are based on need and so it is necessary for each individual to be prioritized based on their needs when added to the wait list. There are more than 11,000 people on the list currently. Please check with your CSB about your status on the wait list and inform them if your needs or circumstances change, as this may change your priority on the wait list.

Feel free to contact our Family Resource Specialists for more information at 1-844-828-5591.

Supports Intensity Scale in the News

"The SIS, as it's called, is a tool the state has used for years to determine how much support disabled Virginians need, but this is the first year it has been tied to how much money is paid to caretakers for certain services. The change in funding models was part of a sweeping redesign of the Medicaid waiver system in Virginia, which was implemented in large part last year. Kim Goodloe and several other parents and advocates have voiced concerns that the SIS assessment is not accurately capturing the needs of disabled Virginians and resulting in detrimental cuts that could lead to people with disabilities being placed in more institutional settings." Read the entire Richmond Times-Dispatch January 22, 2017 news article.

Statewide Transition Plan Update

On January 16, 2014, the Centers for Medicare and Medicaid Services (CMS) published in the Federal Register a <u>Final Rule</u> on Home and Community Based Services (HCBS). The statewide transition plan for six 1915(c) home and community based waivers, which brought on <u>Waiver Redesign</u>.

The Virginia Departments of Medical Assistance Services and Behavioral Health and Developmental Services submitted a revised Statewide Transition Plan (STP) to the U.S. Centers for Medicare & Medicaid Services (CMS) on April 29, 2016. After reviewing the April 2016 STP, CMS provided verbal feedback and technical assistance to the Commonwealth in June 2016 and additional written feedback in September 2016. CMS requested several clarifications and technical corrections in order for Virginia to receive initial approval. These changes did not necessitate another public comment period. The Commonwealth addressed all issues and resubmitted an updated STP on December 2, 2016. CMS granted initial approval of the Commonwealth's STP on December 9, 2017. The CMS VA STP Initial Approval Letter and updated STP.

Waiver System Implementation Call Schedule - March 2017

My Life My Community Stakeholder Calls began in January and have been scheduled every other week through March. The next scheduled calls will be on March 1st, 15th, and 29th.

Participation on these calls, continues and has assisted in understanding and addressing many issues as they implement My Life My Community. These calls primarily focus on Waiver Redesign and System Implementation. Families and individuals, providers, and other stakeholders are all invited to join these calls. Staff from both Department of Behavioral Health and Developmental Services (DBHDS) and the Department of Medical Assistance Services (DMAS) will be available to answer questions. Call in numbers and times.

Maximizing Your Benefits

ABLE Accounts Now Available

As of December 19, 2016 individuals with disabilities or their parents/guardians can now sign up for an <u>ABLE account!</u> Virginia has launched its version of the ABLE savings program, which lets people with disabilities and their families save money for disability-related expenses without jeopardizing eligibility for other assistance programs. ABLEnow is a tax-advantaged account that allows eligible people to save up to \$14,000 a year.

Virginia is one of the first states in the nation to offer an ABLE savings account program. ABLE accounts are tax-advantaged savings accounts that can be used for a wide array of disability-related expenses, including doctors' visits, basic living expenses, and more. The accounts are administered like college savings accounts, health savings accounts and individual retirement accounts. The Virginia ABLEnow program includes a debit card that can be used to pay for qualified disability expenses directly from the account. The program has no enrollment fee and no minimum contribution. You can also take an eligibility quiz, see examples of qualified expenses, and more at ABLEnow.

Slideshow Packed With Resources

In case you missed this Breakout Session at last summer's The Arc of Virginia Annual Convention, Moms In Motion has it here for you! This slideshow was created and presented by Elise May Gladding, the President of The Arc of Southern Virginia.

Little Things Mean a Lot: Support Outside of Virginia DD Waivers

- What you're eligible for if you have a waiver
- What you can apply for while on a waiver waiting list
- and much more!

PPL - Waiver Fiscal Agent/"Payroll"



Check out Moms In Motion's:

PPL & Aides Resource Page

Check out PPL's:

- Consumer Directed Service Resource Page
- Online Timesheet Tutorial

Payroll Schedules for 2016 - March 2017

- A Central VA & Tidewater
- B Northern VA, Piedmont & Southwest

Hiring a New Attendant?

Use PPL's attendant application to get a pre-populated hire packet sent to you.

Advocacy

Partners in Policymaking

The Virginia Board is now accepting applications for the next session of Partners in Policymaking. The '17-'18 class will consist of seven two-day sessions beginning September of 2017 and lasting through April of 2018. Eligible participants are people with developmental disabilities and/or parents of young children with developmental disabilities. Individuals participating in the program will attend advocacy training and skill-building workshops. Completion of the application and selection for the PIP program requires substantial commitment of time, motivation, and energy. More than four hundred Virginia Partner in Policymaking alumni, and thousands who have graduated from PIP programs across the country, have learned how to make a difference every day for themselves, their families, and communities. Applications are due March 31, 2017 by 5pm.

First Call Program

The <u>First Call Program</u> is a volunteer group of experienced parents who make themselves available to parents of children newly diagnosed with Down syndrome. Whether a parent has received a diagnosis prenatally or after the birth of your child, volunteers are here to help. They will answer your questions honestly and do their best to describe the joys and challenges we have experienced in our own personal journeys.

The volunteers of the First Call Program are here as a shoulder to lean on, a voice of experience, and a source of current information. If they don't have the answers to your questions, they'll direct you to someone who may. They are also there to listen with compassion, never judgment. Not every parent in First Call has the same story or has found the same solution, but they have all had the same concerns at one time or another. No family should feel alone.

World Down Syndrome Day (WDSD) is on March 21, 2017!

The Functional and Access Needs Support (FANS) Team Program

<u>The Functional and Access Needs Support (FANS) Team Program</u> trains volunteers to assist residents with functional and access needs in emergency shelters. FANS Team volunteers provide critical non-medical personal care and assistance during emergencies.

Nursing students, personal care assistants (PCAs), registered nurses (RNs), licensed practical nurses (LPNs), occupational and physical therapists, hospice volunteers, and others with training and experience in providing personal care assistance interested in volunteering during a disaster will receive training to join Virginia's Functional and Access Needs Support (FANS) Team.

"Having a force of trained, response-ready volunteers is a critical component of disaster recovery, especially in assisting those with functional and access needs. With winter approaching and Virginia's recovery from Hurricane Matthew ongoing, preparedness is a top priority for us, and we

are actively recruiting for our FANS team," said Chris Rini, MRC coordinator for the Thomas Jefferson Health District.

 Frederick-Winchester Health Department 10 Baker Street, Winchester, VA 22601 Wed, Feb 22nd, 6 pm-8:30 pm Sat, Feb 25th 9:30 am-12:30 pm

Spotlight On...





Bryant's Mom -

In June 2015, I accepted a new job and moved from Philadelphia to Richmond, along with my four boys -- Quentin (13), Trevor (10), Bryant (8) and Austin (6). As a recently divorced single mom starting a new job, I envisioned the move to an unfamiliar city where I had no friends and family as an adventure, a new start. Those feelings of hope and promise lasted about six months before my typically developing second-grader, Bryant, got very ill. Bryant came home from school one day in December 2015 with a fever and complaining of a headache. Two days later, Bryant still had the fever and I took him to the emergency room, where the doctors discovered he had swelling, inflammation and fluid in his brain. Throughout the course of that day, Bryant's condition quickly deteriorated. By that same night, the doctors placed Bryant on a ventilator and inserted an external ventricular drain in his brain to relieve the elevated intracranial pressure. The doctors eventually determined that Bryant had a rare neurological disorder called acute disseminated encephalomyelitis (ADEM). Read more from Bryant's mother, Robyn.

Katie Webb -

One of my most favorite people that I have had the opportunity of working with this past year was Bryant. I never would have thought that an eight year old would motivate me to be a better person, but he has. Upon meeting this family I was very unfamiliar with his diagnosis, and probably would have misdiagnosed him if I did not know better. When I initially met with Robyn I was amazed by her strength, openness and her extreme optimism to what would be a very difficult situation for most. Every time that I see Bryant I see tremendous gains in his development. When I first met him he would give me a halfway smile and could barely grab my hand. Now he can give me a full smile and has quite the grip! Also, I cannot fail to mention how sweet and accepting his three other brothers have been. Read more from Moms In Motion's Katie Webb, Regional Manager, Richmond, Va.

Caroline Raker Advocates for Virginians with Disabilities

Caroline Raker is our Division 1 Manager for Northern Virginia. We are featuring her, because in LESS THAN A DAY Caroline got a response from her Senator's office! This is an awesome example of how advocating is so powerful! One voice can speak for many. If we all joined in, just imagine the combined power our voices can have. We congratulate Caroline and hope this will encourage our Newsletter readers to advocate.

(Caroline recently created a Moms In Motion's <u>Northern Virginia</u> <u>Facebook Page</u>.)



Tue, Dec 13, 2016 at 8:31 AM, Caroline Raker's email wrote:

Good morning,

I am writing as a mother with two children who have severe disabilities, including both being medically fragile. One child is on an EDCD waiver and wait-listed for the CL waiver, while my other son currently has a CL waiver and is being negatively impacted by the recent changes that have taken place through waiver redesign.

My son who has an EDCD waiver is currently permitted to have respite, which is defined as a service to give relief to the primary unpaid caregiver, me. Under EDCD services, I can employ my Read more here.

The reply:

Tue, Dec 13, 2016 at 2:42 PM,

From: "senate district27" < district27@senate.virginia.gov>

Date: Dec 13, 2016 2:41 PM

Subject: Re: Medicaid waiver redesign

To: "Caroline Raker's email"

Cc:

Dear Ms. Raker:

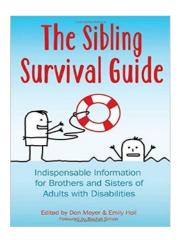
It is distressing to learn that there has been such a serious negative consequence of a redesign of a program that is supposed to be making things a little bit easier for families such as yours. Senator Vogel's office would be pleased to add our voice to yours by communicating directly with the DBHDS Policy Director and the Director of Legislative Affairs about this situation

which is, clearly, not specific to just your family. We will encourage them to develop a solution for this significant problem.

Best wishes to you and your family. Thank you for making us aware of this issue and thank you for your work with Moms in Motion.

Regards,

Tricia Stiles Legislative Assistant Senator Jill H. Vogel



Sibling Resources & Support

The role of a sibling in the life of a person with an intellectual and developmental disability (I/DD) is as complex as it is meaningful. Siblings can often be forgotten about. The future of a person with a disability can possibly hinge on a sibling. While parents need to be informed so do adult siblings. Siblings of people with disabilities can find support and knowledge from others in a similar situation which is why reaching out to sibling support groups is important. The Arc of the Untied States has an amazing webpage with email subscription lists, support groups, and more.

Alison Barkoff

Alison Barkoff is Director of Advocacy, Center for Public Representation, Washington, D.C. office. She works on policy and litigation related to community integration and inclusion, including Olmstead, Medicaid, employment, housing, and education. From 2010 to 2014, she served as Special Counsel for Olmstead Enforcement in the Civil Rights Division of the Department of Justice, leading efforts to enforce the right of individuals with disabilities to live, work and receive services in the community. Her passions have also driven her to be published in Impact Magazine. Read the issue of this magazine with her article, The Revolution (Re)Starts Now: Federal Policies Driving Toward Person-Centered, Individualized and Inclusive Practices.



Moms In Motion in the Community Thank you for believing in us!

Moms In Motion would like to express our appreciation to the following organizations and individuals who have shared Moms as a resource with families they know. Thank you to:



New Horizons Professional ABA Services

 Located in Winchester Virginia, they provide Applied Behavior Analysis (ABA) therapy services to children with developmental disabilities to include Autism Spectrum and Intellectual Disorders through the age of twenty-one. Which improves an individual's adaptive, social, behavioral, and communicative functioning to improve the functioning of the family unit.

BreakThru Autism Services

 Located in Nokesville Virginia, they provide in-home behavior therapy. They are also an EPSDT provider to children on the spectrum. They are dedicated to working diligently to improving the autism community one child at a time.

Buzz about Moms In Motion

What people have been saying about us:

"I have exhausted all avenues I know of to get my daughter the help she needs. I wrote a letter to my delegate, he forwarded it to DBDHS (Virginia Department of Behavioral Health and Developmental Services), they forwarded me to you (Moms In Motion)."

"Hope you (x) and your family are doing well these days. I just wanted to let you know that although we do miss our old Facilitator (x), we really like our newly assigned Facilitator, (x) as well! She has taken the time on several occasions to answer our questions, she always gets back with me quickly, and is very patient! She went the extra mile to work with us this month, in October. While conferencing with us and checking in on (x), she helped us resolve some challenges we were having with PPL regarding some time sheets and payroll. Those issues are now resolved! :-) I just wanted to let you know that we are very pleased with Moms In Motion and all of you who help us! Thanks so much for all you do."

Events



Intro to Virginia Medicaid Waivers Video by Moms In Motion.

Special Needs Tax Planning Workshop Review tax benefits such as the Livable Homes Tax Credit Regarding Consumer Directed Services by and Deduction of Tuition as a Medical Expense. There will also be an update on the taxadvantaged ABLE Accounts. Feb 23, 7pm Fairfax, How to Fill Out a Hire Packet Va.

Medicaid Waiver Social Workshop with **Moms In** Motion! Learn a lot about information on the application process for the Medicaid Waiver (in home supports for people of all ages with disabilities). Feb 23, 6pm Chesapeake, Va.

Virginia Victory Games For children and adolescents (ages 6-22) with medically diagnosed physical, visual and/or hearing disabilities that are not eligible to participate in the Special Olympics because they do not have any Intellectual

Frequently Asked Questions

Tools You Can Use

Moms In Motion.

Video by Moms In Motion.

Guide to a Better Future for Youth and Adults with Disabilities by The Arc of Northern Virginia

Why, When, and How Can I Get the IEP Revised? Consenting to an IEP does not mean you are stuck with it - or that it will be appropriate for an entire year.

Searchable Resource List

Disability. Mar 4, 8am Richmond, Va.

Speak to an Advocate or Attorney from disAILITY Law Center of Virginia A dLCV advocate or attorney will talk to you, by appointment, about issues related to discrimination as it relates to your disability. Mar 16, 11am Norfolk, Va.

Adapted Sports Recreation and Travel Fair

Resources from 20 other agencies and teams from fifteen adapted sports and recreation categories. This fair will provide information on adapted sports, recreation and travel opportunities for all individuals with disabilities living in Northern Virginia, including adapted summer programs and camps. Mar 18, 1pm Falls Church, Va.

Free Dental Clinic Adults will be seen and each person is medically triaged (health history, BP, glucose, INR) before evaluation by dental professionals. Registration and ancillary volunteers are also needed. Mar 25, 6:30am Yorktown, Va.

<u>IEP Boot Camp</u> Two session workshop series will empower parents / caregivers to understand and become effective partners in the I.E.P. process. Mar 31 - Apl 1, Richmond, Va.

These events and others can be accessed at Moms In Motion's <u>Calendar</u>.

Waivers

- Moms In Motion's Waiver Facebook Group Discuss and ask questions about Virginia's Medicaid Waivers. (must have Facebook account)
- <u>VaWaivers</u> is used to discuss and share news about Virginia Medicaid Waivers.
- www.VaMedicaidWaivers.org The Medicaid Waiver Information Center provides information, materials, workshops, and advocacy meetings about Virginia Medicaid Home and Community-Based Waiver Services.
- Sign up for updates on Virginia's
 Waiver Redesign Initiative. Send an
 email to
 waiverupdates@dbhds.virginia.gov
 and provide your email address in the
 body of the email (it is not required,
 but feel free to also briefly note if
 you/a family member is on the ID or
 DD Waiver, on a waitlist for the ID or
 DD Waiver, etc).

Finding Attendants

A Virginia Statewide Directory is now available for people who would like to become a Consumer-Directed Assistant and for people who need a Consumer-Directed Assistant. People wanting to become assistants can list their skills, availability, location, and contact information. People with disabilities that need assistants can search for a person to work with them that matches their needs.

The Arc of Northern Virginia has put together an incredible document to introduce individuals to consumer direction. Starting on page 8 of the document, there are very valuable insights into finding and managing qualified care providers. (Remember they are located in Northern Virginia so the reimbursement rate is only relevant to Northern Virginia.)

Other strategies to find attendants:

- Relevant departments of local colleges.
- Your local department of social services likely has a list of people interested in working as attendants.
- Ask your school's paraprofessionals.
- Virginia Employment Commission
- Utilize sites such as:
 - Care.com
 - o Craig's List
 - MySupport
 - SitterCity



Moms in Motion is a Service Facilitation provider for Medicaid EDCD, CL & FIS Waiver enrollees and a Case Management provider for FIS Waiver enrollees.

MomsInMotion.net