

ARLINGTON COUNTY COMMUNITY SERVICES BOARD
Developmental Disability Committee
Monthly Meeting – November 2017
Department of Human Services
2100 Washington Boulevard
Sequoia Building 1/Conference Room D
Arlington VA 22204

DATE/TIME: November 1, 2017 at 6:45 pm

CHAIR: Carol Skelly

MEMBERS (in attendance): Carol Skelly, Cherie Takemoto, Alex Yellin, Atima Omara, Casey Youman, Nancy Tishman, Alex Soroko, Chuck Adkins-Blanch, Lucia Claster, Donna Budway, Moira Saucedo, Ann Kelly, Barbara Jones, Lynne Kozma

MEMBERS (absent): None

ATTENDEES: Maria Aray; Lucy Beadnell (The Arc of Northern Virginia); Staff representatives of service providers: Quinta Akemgu (Community Residences), Khadija Jalloh (Community Residences), Caroline Gingerth (Community Residences), Kenan Aden (M/LE), Pat Vinson (JDI), Jennifer Cordoza-Kellet (ServiceSource), Jan Williams (ServiceSource), Jacquelyn Scholl (ServiceSource), Brenda Richardson (ServiceSource), Bethany Barr (Linden Resources), Susan Keenan (CLA), Deanna Mason (Volunteers of America), and Danielle Warner (CSD); Representatives of Arlington Public Schools: Christina Eagle; and County staff: Elizabeth Cannon (DHS) and La Joyce Reid (DHS)

RECORDER: La Joyce B. Reid and Elizabeth Cannon

Call to Order: Carol Skelly, Committee Chair, called the meeting to order at 7:00 pm (Note: prior to the “business” meeting of the DD Committee, members and attendees were presented with an overview of the Commonwealth Coordinated Care (CCC) Plus, Medicaid’s new Managed Care program that goes into effect in Northern Virginia on 12/01/2017. Ms. Carme Ryan, DHS VICAP Coordinator, presented the overview and also responded to a series of questions and answers. The attachments from the presentation may be obtained by contacting La Joyce Reid at Lreid@arlingtonva.us).

Minutes: October 4, 2017 minutes approved by the Committee with one correction to page 9: the last sentence of the Chair’s updates should read, “to follow staff updates.”

TOPIC	DISCUSSION	RECOMMENDATIONS/ ACTION	RESPONSIBLE PARTY	F/U/P DATE
Public Comments	In this month's "Citizen" (page 5) there is a promotion for "Made in Arlington," which is featuring the Arlington Weaves, Etc. program, its' participants, and their products. Product samples include yoga mats and yoga straps.	N/A	N/A	N/A
The Arc of NOVA	Ms. Lucy Beadnell distributed and reviewed a handout entitled, "The Arc of Northern Virginia's November 2017 Legislative Update" (Attached).			
Therapeutic Recreation	Handout was distributed with activity highlights for November	None	April Rosenthal	N/A
Projected Cost for Employment Initiative	<p>C. Skelly and L. Reid recapped the Committee's October 2017 request for staff to explore cost projections for a customized employment program.</p> <p>L. Reid presented a summary of preliminary cost projections based on potential numbers to be served (see attachment)</p> <p>Four Individuals – \$120,000 12 Individuals – \$267,000 20 Individuals – \$413,000</p> <p><u>Discussion highlights/questions/conversation topics included:</u></p> <ul style="list-style-type: none"> • Cost savings – What costs, if any, could be saved (i.e., shaved off)? • Under this model, expenses appear to be higher in the beginning, but taper off over time 			

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	<ul style="list-style-type: none"> • Does it make more sense to “pitch” this to the Board as a Pilot? A pilot might demonstrate what can be achieved in Arlington using this model. • What data is available to show the success of this model? (Staff from ServiceSource offered that they have been doing customized employed under the Source America grant for two years and thus data is limited to this time frame. The Committee would need to reach out directly to Source America for release of the data. It was noted that Utah has been doing customized employment for 5 years and may have more data showing the overall success of the model. • Recommendation made that the Committee approved moving forward based on the lowest cost estimate presented by staff. 	<p>The following recommendation was approved by the full Committee:</p> <p>Recommend to the full CSB to approve as a recommendation to the County FY19 budget to fund a customized employment pilot for competitive, integrated employment located in Arlington County in the public and private, sectors</p> <p>This recommendation as carried with a unanimous vote of all members present.</p>		
FY18 Legislative Priorities	<p>C. Skelly initiated a conversation about the legislative initiatives and distributed a document (attached) outlining proposed initiatives:</p> <ol style="list-style-type: none"> 1. Support for more DD Waiver slots 2. Funding for DD Waiver “Reserve” slots (allow individuals to move from one Waiver to another. 	<p>The Committee agreed on the legislative issues as presented by C. Skelly.</p>		

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	<ul style="list-style-type: none"> • With Waiver redesign the process of moving between slots is more difficult than anticipated • There is no appeal process • The General Assembly has not funded slots for FY18 • Slots are allocated on a first come first serve basis. <p>3. C Skelly expressed some concern about the future status of Arlington's group supported employment enclaves for auto detailing and facilities cleaning. However, since there is no immediate plan to eliminate these programs, it was decided not to bring the issue to the attention of the legislators.</p> <p>4. Autism/Mental Health – C. Skelly shared that some CSB members and staff are looking into services for people who have both autism and severe mental health conditions. The mental health side of the CSB is experiencing challenges addressing the needs of this population. In 2005, the General Assembly conducted a survey, but since this time the issue has turned into a crisis. Many individuals that fall in this category do not have access to the resources they need.</p>			

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	<p>Q1: Is Medicaid expansion a legislative issue.</p> <p>A1: "Arlington State legislators are supportive of Medicaid expansion, C. Skelly shared, and thus there is no need to advocate on behalf of this issue.</p>			
<p>Staff Updates:</p>	<p>L. Reid shared an overview of the State's (DBHDS) dental program</p> <p>Highlights:</p> <ul style="list-style-type: none"> • Program is for all individuals in the DOJ Settlement Agreement population • Two dental Clinics in NOVA; referrals must be submitted through the assigned Support Coordinator • Includes a range of anesthesia options • General anesthesia is available, but only in Petersburg, VA <p>L. Reid shared Information about a new housing development (Columbia Hills Apartments) for which the Arlington County Housing Authority has ten slots set aside for reduced housing under its Permanent Supportive Housing program. To qualify for these slots, an individual must be open to the Arlington CSB/DDS Bureau for DD Case Management/Support Coordination. It is anticipated that there will mostly be one and two bedrooms and at least one "three" bedroom unit. It is further anticipated that</p>			

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	the units will be available for move-in during the fall of 2018.			
Committee Chair Update(s)	C. Skelly introduced the topic for next month's meeting: Self-Directed Services funding	None	C. Skelly	N/A
Vendor Updates	D. Budway shared that the SPARC ribbon cutting ceremony is scheduled for Thursday, November 30 th from 12:30 – 2:00 pm at the Langston Brown Recreation Center. The actual "Ribbon Cutting" will occur at 1:00 pm. Q1: How many people attend SPARC? A1: As many as eight individuals depending on the day of the week Q2: Do individuals attending SPARC need an Aide? A2: Yes			
New Business	Q1: Is the DD Committee involved with P.I.E. (Parent Infant Education)? (There is interest for at least one member to discuss P.I.E. at the next meeting. A1: It was recommended that this topic be discussed at the full CSB meeting			

The next regular DD Committee Meeting is scheduled for Wednesday, December 6, 2017 at 6:30 pm
2100 Washington Blvd., Conference Room D, Arlington, VA

MADE IN ARLINGTON

Arlington Weaves, etc., a signature program of The Department of Human Services, is among the artisan vendors featured in this pop-up retail market at the Plaza Library Shop. Visit the Weaves studio at 2110 Washington Blvd, Sequoia 2, Suite 301 to learn more about this program.

DATE and TIME:

Nov. 1 – Dec. 22, M – F, 8:00 a.m. – 5:00 p.m.

PLACE:

Plaza Library Shop

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Don't miss the weekly *Made in Arlington* pop-ups in the Courthouse Plaza lobby. More Arlington vendors who will be on hand.

WEEKLY NOVEMBER LOBBY VENDORS:

Thursdays, 11:00 a.m. – 2:00 p.m.

- **Nov. 2:** Livin' the Pie Life — Pie samples, sales and holiday orders
- **Nov. 9:** Georges' Botanique Aromatique — Hand crafted skin care products and custom soaps
- **Nov. 16:** Commonwealth Joe — Pour over samples, coffee sales
- **Nov. 30:** Jules Jewels — Jules Jernigan crafts, wearable art



The Arc of Northern Virginia's November 2017 Legislative Update

General Assembly

- Elections for Governor, Lt. Governor, Attorney General, and State Delegates will be held on November 7, 2017. The Arc of NOVA has worked with our advocacy partners on a disability policy survey. You can see submitted responses here- <https://thearcofnova.org/advocacy/the-ability-blogspot/>
- The Arc's annual DD Advocacy Day will be January 17, 2018 in Richmond. Email Lucy (lucy.beadnell@thearcofnova.org to RSVP)
 - Charter bus is reserved and we will have a meeting space for the day

Department of Behavioral Health and Developmental Services

- IFSP funding application is online (<https://ifsponline.dbhds.virginia.gov/>) and can be completed between now and 5 PM on November 17, 2017
 - Lots of glitches with applications (e.g., told not on waiting list or receipts not submitted), so email IFSPsupport@dbhds.virginia.gov to have it sorted out, but your place in the que is saved
 - Recording of the presentation on this is at <https://www.dropbox.com/s/a1kis3d5zsa12fu/IFSP%20Training%209%2025%2017.mp4?dl=0>
- Three delayed Waiver services will be written up and open for public comment soon
 - Non-medical Transportation
 - Community Guide
 - Benefits Planning
- CCC Plus Letters should have arrived. These managed care plans will oversee/approve all non-Waiver services for DD Waiver users and all services (including Waiver) for other Waiver users.
 - Call each provider (including hospitals) you need to ensure they take the plan to help decide which is best
 - If you're enrolled in HIPP, you will not be enrolled in CCC+
 - Brief video on HIPP- <https://www.dropbox.com/s/tqzr5sngq1108a8/HIPP%20in%203%20Minutes.mp4?dl=0>
 - HIPP website http://www.dmas.virginia.gov/Content_pgs/rcp-hipp.aspx

Local News

- A few local housing subsidies and flexible funds are still available for people with DD Waivers or on the waiting list
- Housing for individuals in the DOJ target population and over 62 coming online in Summer 2018

Arc Updates

- Annual Meeting November 16th, 7-9 PM at the Columbus Club in Arlington <https://thearcofnova.org/upcoming/annual-meeting/>
- Self-Directed Services presentation and other updated webinars at (<https://www.youtube.com/user/VideosatTheArcofNoVA>)

Arlington County Department of Parks and Recreation

Therapeutic Recreation (TR) Office

ASEAC November 2017

Come
Play
With Us!

How to Contact TR

Unit Manager

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TTY: Relay 711

facebook

Do you like TR? Then please
Like Arlington County
Therapeutic Recreation. We
post our most current program
information.

Looking Ahead

Enjoy Arlington Winter Catalogs will be in homes the week of Thanksgiving. Winter Class registration will begin Wednesday December 6th at 7am, Classes begin January 15th.

Family Fun Night

TR Programmer: Kristin Wilcox
Next Event is 11/3/17 from 6:30-8pm
Theme: Carnival!

This drop-in program will be offered on 1st Fridays of the month October-May. Ages 4-17. Join us on Friday, November 3 from 6:30-8:00pm for a Carnival event! It is drop and \$1.50/person.

Social Clubs

TR Programmer: Katie Salyers

Each social club offers 2-3 activities per month ranging from social gatherings to community trips, volunteer experiences, performances and more. Please contact the TR Office at TRinfo@arlingtonva.us or 703-228-4740 to schedule an intake interview. Annual Membership Fee: \$45. Trip Fees are additional.

- Teens Going Places (ages 12-17)
- Young Adults Going Places (ages 18-29)
- Adults Going Places (ages 30+)

Inclusion Supports for Enjoy Arlington Classes

TR Programmer: Cat Trovato and Robyn Mitchell

Modification requests can be made in advance to enable us to plan for the best type of support or assistance. Based on requests, demonstrated need and available resources, we can provide various inclusion support for participants with disabilities enrolled in a general recreation programs offered in the Enjoy Arlington Class Catalogue (EACC). We can also offer consulting support for contracted programs offered in the EACC. We do not have access to rosters when contractors do their own registrations (camps and some classes). Please make sure to contact the contractor directly with any modification requests you have and then let us know once you have signed up. With your written permission we can send along any modification support plans we have on file at your request.

Visit our website for more programs and information:
<http://parks.arlingtonva.us/therapeutic-recreation/>

Draft DD Items for State Legislators

November 1, 2017

Reserve DD Waiver Slots –

Reserve waiver slots are needed to allow individuals who need higher levels of support to “upgrade” from the Family and Individual Supports (FISP) Waiver to the Community Living (CL) Waiver. These are usually individuals who need congregate (group home) residential care.

For the last biennium, the Governor’s budget included 40 reserve slots Statewide for 2016 and 40 for 2017. The reserve slots for 2016 were approved by the legislature, but the 40 for 2017 were struck in the budget negotiations at the last minute. This had the effect of “freezing” service levels for people whose circumstances have changed and need higher levels of support. Arlington currently has two such individuals.

There are also procedural issues associated with changes in waiver status. There is currently no appeal process for individuals whose requests to upgrade are denied. Also, the State appears to be filling the requests on a first-come, first-served basis, rather than acuity of need. It is not sharing information about position on the waiting list, which makes it difficult to plan.

Group Supported Employment –

Arlington may experience difficulty renewing the license for two group supported employment (“enclave”) programs – one crew services county police cars and the other cleans county facilities. This is due to the new, more stringent federal standards for “competitive integrated employment” (CIE), which require that individuals with DD work alongside non-disabled individuals and receive the same pay. We have 11 individuals working in these programs.

Autism/MH Issue – see attached.

Summary of Unmet Needs
Individuals with Autism and Severe Mental Health Issues
Arlington Community Services Board
November 2017

The CSB is working at the local level to appropriately respond to an emerging and urgent issue.

- CSB staff are grappling with providing appropriate services for individuals with an autism diagnosis experiencing acute mental health issues, especially anxiety and depression. Calls to county services for help with this type of case are averaging 1-2 per month.
- The new cases are almost exclusively young adults and intervention is needed to put them on a path to a meaningful adult life in the community.
- These individuals often do not qualify under either developmental disabilities or mental illness because of their profiles do not fit the traditional CSB diagnostic silos.
- Treatment for the most acute cases is challenging, requiring both behavioral and psychiatric support. CSB does not have a current capacity to appropriately serve individuals with the combined autism and MH profile.
- The increase reflects the rising incidence of autism in the general population. Individuals with autism are at increased risk for mental health problems. Some individuals may need crisis placements or residential placements to stabilize and improve.
- Attached is a National Public Radio (NPR) feature related to this topic.

Many Young Adults With Autism Also Have Mental Health Issues

October 1, 2017 5:00 AM ET

TARA HAELLE

College involved "many anxiety attacks and many trips home" for Daniel Share-Strom, an autistic 27-year-old motivational speaker in Bradford, Ontario. It wasn't just the challenge of organizing his assignments and fighting the disability office for the extra time he needed for tests. It was also managing all the aspects of daily life that most people not on the autism spectrum take for granted.

"Relationships are so much harder to understand or initiate when by default you don't really know what certain facial expressions mean or what certain actions mean," Share-Strom says.

Kyle Echakowitz repeated 12th grade, but he still found the first year of college overwhelming.

Courtesy of Kyle Echakowitz

Young adults on the autism spectrum are more likely to also have been diagnosed with a psychiatric condition, such as depression, anxiety and attention deficit hyperactivity disorder (ADHD) than are typically developing people or those with other developmental disabilities, a study finds. And managing those multiple conditions can make the transition to young adulthood especially difficult.

It's not clear how much biological factors may contribute to the higher rates, but Share-Strom definitely sees environmental factors playing a major role.

"People with autism aren't immediately born anxious or with depression," Share-Strom says. "The world is fundamentally not built for us, and people are always judging and trying to change you, whether they have the best intentions or not," he says. "Of course that's going to cause a higher rate of anxiety and depression and even suicide rates. I'd be surprised if it didn't."

That makes providing resources for these young adults all the more important during that transitional period.

"When it comes to mental health diagnoses and use of psychiatric services, there's a really strong need for the entire developmental disabilities community, but it's an even bigger need for folks on the autism spectrum," says Yona Lunsky, a senior scientist at the Centre for Addiction and Mental Health in Toronto and coauthor of the study. "I think sometimes people will dismiss something as being part of autism when, in fact, it's not," she adds. "There are people with autism who don't have psychiatric issues." Lunsky's study is not the first to find a higher prevalence of mental health conditions among those on the spectrum compared to those with typical development. But it is the first to compare autistic young adults to those with other developmental disabilities. It also uses a standard method of gathering data, relying on diagnostic codes in administrative health data instead of using surveys.

Their data came from two groups of young adults, ages 18-24, in Ontario, Canada.

One group included 5,095 young adults with an autism diagnosis and 10,487 people with another developmental disability diagnosis and no autism diagnosis. (Those with both were excluded.) The other group was a random selection of 20 percent of young adults in Ontario without a developmental disability diagnosis.

They chose age 18 as a starting place because that's when people switch from child to adult social and mental services in Canada; they ended at age 24 because Canadians with developmental disabilities usually remain in school until age 22, providing two years of follow-up data. In the U.S., public special education services continue until high school graduation or until age 21 in most states, 22 in some others.

NPR ED

Getting Students With Autism Through High School, To College And Beyond

Those on the spectrum were more than five times more likely to have a psychiatric diagnosis than typically developing individuals and nearly twice as likely compared to others with developmental disabilities, the study found.

While 52 percent of autistic young adults had a psychiatric diagnosis, 39 percent of those with other developmental disabilities did and 20 percent of typically developing people did. Those with an autism diagnosis were also more likely to visit the emergency department for psychiatric reasons (8 percent) than those with other developmental disabilities (7 percent) or typically developing (2 percent).

By contrast, non-psychiatric ER visits were similar between autistic and typically developing young adults: 26 percent of those on the spectrum and 25 percent of typically developing adults, compared to 34 percent of those with other disabilities. Those on the spectrum were also less likely to have asthma, high blood pressure or addiction disorders than those with other developmental disabilities.

"We weren't doing the study to look at mental health," Lunsky says. "It's just what emerged. Unmet needs have a social cost, so we want to be able to recognize both physical and mental health needs for everyone and get them the right care."

That means recognizing that symptoms and behaviors of depression and anxiety may look different in those with an autism diagnosis than in those without, she adds, and caregivers and providers need to understand that.

Indeed, it is especially important to individualize care for youth on the spectrum, according to Lynn Davidson, a pediatrician and member of the American Academy of Pediatrics executive committee on disabilities.

"Transition for youth with autism is a very challenging process," Davidson says. "It is doable, but it takes a lot of preparation and a lot of time on the part of the families, on the part of the patient and on the part of the providers. The earlier one starts, the better."

Research literature suggests that it's good to start learning daily living skills, such as laundry, cooking, bathing alone and similar chores, around 12 to 14 years old, Davidson says. But she believes that should start as early as possible, depending on a child's intellectual, social and mental health disabilities.

"Youth on the autism spectrum may need repetitive modeling and experiences so that they get those skills down and become as independent as possible," Davidson says. Too many families, she says, do tasks for their adolescents long past when the teen could do them on their own. Other youth continue to need support for what might seem like basic tasks, so parents and care providers have to work to learn the boundaries and abilities for each person on the spectrum.

Even more important is for parents to ensure their children have the proper diagnosis, says Jodi Echakowitz, a mother in the Toronto suburbs whose 20-year-old son Kyle was initially misdiagnosed

with social anxiety disorder. He received a correct diagnosis of Asperger's (now included under the autism diagnosis umbrella) in first grade. Diagnoses of generalized anxiety disorder, ADHD, a learning disability and depression followed over time.

"A lot of parents with younger kids remain in denial and feel it's a detriment to put a label on their child, but that does a disservice to their child," Echakowitz says. "I say, embrace your child, embrace their differences — it's not necessarily a negative thing — and once you understand the clinical diagnosis, then you can actually provide them with the support and services they need."

Kyle stayed in school for a second 12th grade before college to ensure he had the support he needed, which included social workers, social skills coaches and the school board psychologist. But the transition was still rough.

"In high school, I was given a lot of accommodations and leeway, and in college, I didn't get that," Kyle says. "In high school, I'd never failed a class, and I failed two classes in my first semester of college, easy ones, because the sheer thought of just how much work there was in other classes prevented me from even thinking about work in the easy classes."

Kyle agrees that getting his diagnoses early on, which opened up access to support and services, was crucial to transitioning to college at all. Just as crucial, however, is listening to what autistic young adults say they need, he says.

"Oftentimes parents, psychologists and experts who are not on the spectrum are the ones consulted, but it's really important that the message becomes 'nothing about us without us,'" Kyle says. "For those who are nonverbal, that's also important — giving a platform to those who don't speak."

That platform could take various forms depending on each child's needs, but that's part of planning for transition to adulthood, determining what those needs and supports are.

In the US, formal transition planning through the school system is required, starting with an Individualized Education Plan (IEP) at age 14. By age 16, the IEP legally must include information on transition services, such as postsecondary agencies and other community services, the student needs to successfully move into adulthood. But those are rarely plentiful. Resources such as Interactive Autism Network, GotTransition, The Arc, the National Collaborative on Workforce and Disability/Youth, Wrightslaw, the National Center on Secondary Education and Transition and AAP resources can help.

"It is very hard to get services when patients turn to the adult world because there's not the funding nor the orientation toward youth [with ASD]," Davidson says. She noted that subspecialties in pediatrics, such as neurodevelopmental disabilities, lack parallels in adult care fields. But the numbers of autistic people reaching adulthood is only going to grow. The CDC has reported a steady increase in autism diagnoses; currently, one in 68 children have the diagnosis.

"There needs to be an effort to train behaviorists, psychologists and psychiatrists to be available and accepting of youth with ASD and to be able to handle them in the offices where they see their patients," Davidson says. "Whether that means funding from a government source or funding to do the training for adult providers, that's essential."

She also highlighted the need to provide young autistic adults with social skills training and support related to the nuances of social hierarchy and work climates that typically developing people tend to pick up on naturally.

"That's something youth with autism don't automatically understand, and it often can cause major disruptions and firing in job situations," Davidson says. "The use of job coaches, who can help those kids with autism adjust to the social stress and milieu of a work environment, and ongoing counseling during the young adult transition, is very, very helpful to youth."

Share-Strom says it took him years to get his current position, a communications coordinator at Community Living Ontario, because so many interviews ended early when he couldn't maintain eye contact or autism came up. He talks about these experiences in his TED talk "Dear Society ... Signed, Autism."

"The thing I found most challenging about autism is that when you're growing up, even people with the best intentions who are trying to help you are always telling you you're wrong, that your basic instincts are incorrect, so you learn not to trust your own judgment," Share-Strom tells NPR. "One of the biggest difficulties with transitioning to adulthood is trying to realize where you've been correct versus where you need to change, where the boundaries are between what you need to do to fit in and what other people need to do to accept certain things that are a part of who you are."

Tara Haelle is the co-author of The Informed Parent: A Science-Based Resource for Your Child's First Four Years. She's on Twitter: @tarahaelle