

Health Care Appropriations Subcommittee

October 6, 2015 1:00 – 3:00 PM Webster Hall (212 Knott)

Action Packet

Health Care Appropriations Subcommittee 10/6/2015 1:00:00PM

Location: Webster Hall (212 Knott)

Summary: No Bills Considered

Health Care Appropriations Subcommittee

10/6/2015 1:00:00PM

Location: Webster Hall (212 Knott)

Attendance:

	Present	Absent	Excused
Matt Hudson (Chair)	X		
Michael Bileca	X		
Jason Brodeur	X		
Janet Cruz			Х
W. Travis Cummings	X		
Gayle Harrell	X		
Shawn Harrison	X		
MaryLynn Magar	X		
Jared Moskowitz			Х
Amanda Murphy	X		
Cary Pigman	X		
David Richardson	X		
Kenneth Roberson	X		
Totals:	11	0	2

Health Care Appropriations Subcommittee

10/6/2015 1:00:00PM

Location: Webster Hall (212 Knott)

Presentation/Workshop/Other Business Appearances:

Triay, Cindy (General Public) - Information Only Representing her son Scott Triay Parent 1919 Medinah Lane Green Cove Springs FL 32043 Phone: (904) 284-2660

Pierce, Jeannie (General Public) - Information Only Representing her son Landon Pierce House Wife and Mother 115 Walton Road East palatka FL 32131 Phone: (386) 328-2204

APD Budget Request

Sewell, Suzanne (Lobbyist) - Information Only Florida Association of Rehabilitation Facilities, Inc President & CEO/Florida Association of Rehabilitation Facilities 2475 Apalachee Pky Ste 205 Tallahassee FL 32301 Phone: (850) 251-7925

Legislative Budget Request

Palmer, Barbara (Lobbyist) (State Employee) - Information Only Agency for Persons with Disabilities Agency Director 4030 Esplanade Way Ste 380 Tallahassee FL 32399 Phone: 850)488-1559

Legislative Budget Request

Phone: (850) 245-4454

Dobbs, David (State Employee) (At Request Of Chair) - Information Only Agency for Persons with Disabilities
Deputy Director for Budget and Planning
4030 Esplanade Way
Tallahassee FL 32399
Phone: (850) 414-6058

Legislative Budget Request and Schedule VIII-B

Tallent, Michele (State Employee) (At Request Of Chair) - Information Only Department of Health Director of the Office of Budget & Revenue Management 4052 Bald Cypress Way Tallahassee FL 32399

Health Care Appropriations Subcommittee

10/6/2015 1:00:00PM

Location: Webster Hall (212 Knott)

Presentation/Workshop/Other Business Appearances: (continued)

Legislative Budget Requests and Schedule VIII-B Reductions
Manalo, Jon (Lobbyist) (State Employee) (At Request Of Chair) - Information Only
Department of Elder Affairs
Chief Financial Officer
4040 Esplanade Way
Tallahassee FL 32399-700

Phone: (850) 414-2077



Hello, my name is Cindy Triay and I would like to tell you our son Scott's story. Scott is 34 years old and was born with Down Syndrome. Ten years ago we moved back to Jacksonville from Pittsburgh because of a job transfer. Before taking the transfer we called the Agency for Persons with Disabilities to find out what we needed to do to get Scott services. We were told that there was a 5 to 7 year wait. We were prepared for that, but then we were told it was closer to 10 years. About 2 years ago we learned the rules had changed and they were using a tiered method. He went from almost getting off to back to the bottom. Scott has been on the Medicaid Waitlist now for 10 years as of October 1. We have done everything we can to support him.

Scott has worked at our local Winn Dixie for almost 10 years. Unfortunately, because of some behaviors he was cut from 4 days a week to 1 day for 3 hours. We got him a job coach (through APD, one service they would help us with) in the hope that he would get some of his hours back. This was over 5 years ago, and his employer says that he will get no additional hours. Part of his job description is retrieving grocery carts. As hard as we have all tried, Scott still does not look both ways for cars. He also disappears at times and they cannot find him. This is a health and safety issue.

We have watched a real regression in Scotts life skills. His brother who sees him once or twice a year gets very upset about this. Scott used to talk very carefully in sentences and now he sometimes "baby talks" or repeats himself over and over again. The longer that he is on the wait list, the more supports he is going to need. What Scott is currently needing is funded job coaching for health and safety reasons, three days of Life Skills training to get him back to where he was ten years ago. Respite care at least four times a year so he can be more independent to prepare for the future without us.

Ten years is a long time to patiently wait, added the regression that has occurred. It is time that he gets the services that he so desperately needs.

Dear Committee,

My name is Jeannie Pierce. I am here, as a voice, for my son Landon Pierce. Landon is 21 years old with Trisomy 9 Mosaic, diagnosed at birth. Landon is non-ambulatory; wheelchair bound, wears a diaper, non-verbal and requires total care. He currently attends public school, but his eligibility will end when he turns 22.

Anticipating that he would require services through APD, I enrolled him as a client in the fall of 2003. He qualified for the wait list on December 1, 2003. I have enclosed a copy of his wait list eligibility. I am very worried about the impending conclusion of his public school career. He is very social and thrives in that environment. Not only has his school participation meet his emotional needs but he has also learned valuable skills such as feeding himself, some wheelchair use although safety concerns remain, and using an iPad for communication. We fear he will digress and these skills and others will be lost if he cannot continue to access training and stimulation of a training program.

We love Landon and want him to remain in our home. We have tried to play by the rules and have waited patiently for services for almost 12 years. We only need the limited amount of support required to provide an ongoing training and social opportunity for Landon, which would greatly enhance, our ability to keep him in his family home.

Thank you for giving me the opportunity to be here today and time to hear my concerns. I am asking to have Landon placed on the waver to insure he has a

chance to continue the vital training he requires and that will give him the benefit of a social environment outside of our family home. He needs this and so do we.







agency for persons with disabilities

State of Florida

June 29, 2009

Charlie Crist,

Jeannie Pierce 115 Walton rd

Governor (

E. Palatka, Fl. 32131

Jim DeBeaugrine,

Dear Mrs. Pierce:

Director

1010 Feelmondo

This is in response to your request to the Agency for Persons with Disabilities for your son's status on the waitlist for waiver services.

4030 Esplanade

Way, Suite 380 Delivering services to people on the waitlist continues to be one of the primary goals for the agency. Each year, the number of individuals who can be added to the waiver is contingent upon funding.

Tallahassee.

Florida

32399-0950

Landon Pierce's waitlist eligibility date is 12/01/2003. As funding becomes available, the Agency will enroll people from the waitlist. To date, we have served individuals with a waitlist eligibility date of February 13, 2003.

(850) 488-4257

Please keep the agency informed of any changes in address or telephone number so that you may be contacted immediately if the agency has any questions or if services become available.

F3X:

(850) 922-6456

Toll Free:

If you feel your son's situation is a crisis, I urge you to contact your area office and request that a Crisis Identification Tool be completed. Should you have any questions, please contact your local APD Office at (888) 665-4955.

(866) APD CARES

(866-273-2273)

Sincerely.

Vicki Draubinon

V Draughor

Agency for Persons with Disabilities

cc. Area 3 Office

Dr. Shirley Leadem Dr. Paul Leadem

Pediatric and Adolescent Medicine 1746 TREE BOBLEVARO, SUITE 113 ST AUGUSTINE, 11.0800A 32084 191 (1001) 829 6391 • TAX (1001) 824 8856

9-24-11

I have had the pleasure of treating Landon

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Taylor Pierre. He has been diagnized as

Mosaic Trisomy 9 with associated Severe

Mosaic Trisomy 9 with associated Carditions

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to his mather's meticular care that he has

survived to this age. His condition is permanent

and as such will need a quardien to take care of

his educational and health decisions as he is

incapable of carrying out there responsibilities

Sincerely

far flet Africante, M.D.

fart To Leader To, M.D.

October 5, 2015

To Whom It May Concern,

Landon Pierce has been a full time student in my self-contained ESE class for the past 12 years. He is very social and enjoys being around his peers and adults. He has a contagious laugh and a great sense of humor. I'm writing this letter to outline his level of care during the typical day.

Mobility:

Landon is a ron-ambulatory wheelchair bound student. He is able to maneuver his chair in small areas, however he cannot go anywhere, even around the classroom without continual supervision and physical assistance as needed. He is not always safety conscious and can be a hazard to himself or others if not supervised. He needs to be pushed by an adult for even short distances. (ie. classroom to cafeteria) He needs time out of his wheelchair during the school day, to relieve possible pressure points. We place him in a specially designed beanbag chair provided through his physical therapy plan of care. Because of Landon's physical disability, his current weight and his inability to assist you when lifting him, it takes 2 adults to lift him safely from his wheelchair for repositioning in the beanbag chair. (or 1 adult male can usually lift him when available)

Functional Academics:

Landon requires assistance with manipulation of materials, communication devices and/or positioning for accessibility to given assignments for all learning activities.

Mealtimes:

Landon's meals must be prepared for him and cut into small bite size pieces. He can feed himself with a spoon or small pronged fork (most often a spork) and drinks through a straw in a container with a lid. He can chew soft foods. We don't give him any hard foods or foods that have a high risk of choking.

Toileting:

Landon wears a diaper and needs to be changed at least twice during the school day. Sometimes more if he has a BM. He is transferred from the wheelchair to a changing table in the bathroom. He cannot be left unattended at anytime, as he is not able to lay flat on his back and even a slight startle or shift in his weight could cause him to roll/fall off the changing table. He requires total physical assistance with dressing/undressing.

Communication:

Landon will sometimes use a picture exchange, or his own personal I-pad with a communication program on it to communicate with others. However, Landon primarily depends on non-verbal vocalizations and broad hand gestures as that is his preferred method and he is not always cooperative when presented with the more academic modes of communicating.

sincerety

Linda Becker

ESE Teacher