

Testimony of Lisa Elias - JFC
March 26, 2015

My brother, Eric Sovde, aged 68, has been intellectually and developmentally disabled since birth. For many people with more severe forms of I/DD, the most important element for a safe and happy life is not the setting in which they live but the human beings at their sides - the Direct Support Professionals.

For a moment, I ask you to imagine this: You are often seized by mental confusion, anxiety and compulsions you are unable to control. You cannot read or write. You are unable to discern others' motives, and you are at times, overly desperate to please. You have an intense desire for attention, and the manner in which you try to seek it alienates you. You have difficulty walking and your balance is poor, so you fall down easily. You are at risk of choking on your food, and it's hard even to keep yourself clean.

This is a glimpse of Eric's reality from the inside, and illustrates the challenges that his caregivers address every single day with kindness and forbearance. When you meet Eric, you will see, on a good day, an engaged, and talkative older gentleman who wants to show you his artwork. Eric is active in the community as a volunteer. For example, he serves on a Human Rights Committee, and is an "official" greeter at his provider agency's functions. He attends a senior program during the week, goes to church on Sundays, and out to dinner with friends. He attends summer camp, and loves musical performance - especially "the blues". All of his involvement in the larger community is made possible with the dedicated assistance of Direct Support Professionals. They provide the sensitive, insightful and understanding support he needs to feel capable and independent. They are with him every step of the way, and sometimes literally keep him on his feet so that he may reach his goals.

I am deeply disturbed by the low wages DSPs earn which require many to take second jobs, and that the turn-over rate is so high. Care-giving needs to become truly validated as a profession. DSPs deserve livable wages, with ongoing education, for a demanding and difficult job. I am concerned for the future of the hopeful new generation of citizens who live with the most challenging forms of intellectual and developmental disabilities. Wherever they live or work, be it fully integrated into the community or in the most appropriate setting for the individual, they will need the intensive assistance provided by Direct Support Professionals.

As you make decisions about funding services for the I/DD citizens who are the most vulnerable, please remember the people key to their quality of life: Committed and caring Direct Support Professionals.

Thank you for listening.

[SCROLL TO READ TESTIMONY OF LIBBY CUSACK]

**Testimony of Libby Cusack
For the Division of Developmental Disabilities Services
Joint Finance Committee meeting on March 26, 2015**

Good afternoon, Representative Smith, Senator McDowell, and the members of the Joint Finance Committee. My name is Libby Cusack, and I am here today advocating for my daughter, Olivia.

Olivia is 22 years old and is diagnosed with a rare and severe form of childhood-onset epilepsy that includes frequent seizures, multiple seizure types, a resistance to medication, behavior disturbances, and moderate to severe cognitive dysfunction. Olivia was first diagnosed with a seizure disorder when she was six months old and continues to have frequent daily seizures and aggressive behaviors. She is at the cognitive level of a first grader – with limited time, money, math, and reading skills.

Olivia likes to stay active and is a hard worker. She attends a community-based day program where she enjoys participating in recreational and volunteer activities and recently started a part-time job where she works six hours a week. Olivia has a one-on-one direct support person with her at her day program and job to ensure her safety and to provide support during her unpredictable seizures and aggressive behaviors.

Olivia continues to live at home with my husband, Chris, and me. One of us is usually within an arm's reach of her to be ready to catch and assist her during a seizure. We help her with her daily living activities, including taking care of her finances, preparing her meals, and assisting with her dressing and bathing. We also take Olivia to social activities that she enjoys, including visits to her sister and extended family members, sports activities with Special Olympics, personal training sessions, and church functions.

Chris and I are very concerned with the current disability movement and Olivia's future. Where will Olivia live? Will options exist in the future to support her specific needs? Who will ensure Olivia's safety and her quality of life? These questions weigh heavily on us every day. We don't see a current living arrangement outside of our home that is suitable for Olivia. But she should have a life and so should we!

My husband and I see Olivia's opportunity for a quality life best being met with her living in an intentional community, where she is treated and respected as an adult. Rather than a setting that isolates, we see a purpose-built, planned community as a safe, supportive, and social environment. This community would complement Olivia's day programming and activities that she currently enjoys participating in out in the community. The lifestyle of the intentional community that we envision for Olivia would encourage independent living to the degree possible for each person. This type of community is being supported and built in many states today. But we are concerned that this will not be an option for Olivia based on Delaware's interpretation of the new Home and Community Based Settings requirements.

I ask that you please support The Arc of Delaware's Top Legislative Priorities that focus on person-centered choice, family support, and appropriate funding to service providers.

Thank you for your time today.

[SCROLL TO READ TESTIMONY OF TEESIE BONK]

Testimony of Teesie Bonk – Joint Finance Committee
3/26/15

Good morning Representative George Smith, Senator McDowell and members of the Joint Finance Committee.

My name is Teesie Bonk and this is my brother, Michael McNesby. I am speaking today on behalf of Families Speaking Up (FSU) and I am also speaking as an advocate for my brother.

FSU is a grassroots movement of people with intellectual and developmental disabilities, their families, and caregivers. We work to ensure that all voices are heard in the debate over the future of community services. We represent a few hundred families advocating for the rights of our loved ones.

A major issue that comes up at our FSU meetings is the state's criteria for placing adults with IDD in group homes. Presently there are nearly 3,000 people with IDD living at home and being cared for by people over the age of 60.

I come from an Irish Catholic family. When Michael was born there were already five of us. Michael was loved and raised by our parents until our dad passed away 11 years ago. My siblings and I made the decision to care for Michael in our own homes. We are very fortunate that we all live locally and are able to share the responsibility of caring for Michael. Our situation is unique – we are the exception, not the norm.

Today's families are smaller. Parents cannot assume that one of their other children will take over as caregiver for their disabled sibling when they are gone. Taking over as caregiver to a disabled sibling can be overwhelming and prove to be too much for them.

As it stands now, the state's criteria for residential placements for adults with IDD living with their families is determined by crisis placement, such as the death of a parent. FSU is asking that Delaware change this criteria. FSU would like families to be given the opportunity to plan for transitions to appropriate residential options before a serious crisis situation develops.

The question begs: Is it fair for persons with IDD to be placed out of their family homes at perhaps the worst possible time in their lives? It is extremely difficult for adults with IDD to lose the one constant in their lives – their parents. Moving them at this time can cause many physical and mental health issues. The greatest worry my parents had was what would happen to Michael when they were gone. This is every parent's greatest concern. We need to work together to ensure that parents are given peace of mind after years of love and care for their adults with IDD. The sacrifices that these parents willingly made to provide a home for their adult children with IDD has saved the state and federal government millions of dollars over the years. Let's honor the choices that parents and family members have made by investing some resources to make more planful transitions instead of waiting for a crisis to occur.

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Another issue of great importance to FSU is the future of center-based day and work programs in Delaware. In January of 2014 the Center for Medicaid and Medicare Services (CMS) issued new regulations defining setting requirements for Home and Community Based Services (HCBS) Waivers. We have received the Delaware Statewide Transition Plan which describes how Delaware will move forward into compliance with the new regulations. Delaware submitted its plan to CMS on March 17, 2015 and now has four years to come into complete compliance with the new regulations.

According to these new CMS regulations, Delaware must seek and revise the Transition Plan based on public comment. A public hearing was held on February 23, 2015 in order for DMMA (Division of Medicaid and Medical Assistance) to receive input from stakeholders regarding this plan.

During this hearing it became abundantly clear that one of the main concerns was the definition of “Prevocational Services.” A person given this service must have employment-related goals with the optimal outcome of competitive employment in the community earning at or above minimum wage. The reality is that not everyone with a disability can find a community job, and center-based workshops offer the option for the MOST APPROPRIATE SETTING for these individuals.

Families are worried that the option to continue receiving prevocational services in a center-based workshop will be eliminated and will be forced to accept “Day Habilitation” services instead. If not properly funded and managed correctly, Day Habilitation will quickly become a Day Care. I have attached a copy of an article entitled, “New Zealand – Road to Hell.” This article describes what happened after they closed their sheltered workshops. It was a disaster.

At the public hearing the majority of families explained to DMMA that their loved one, because of the nature or severity of IDD and physical disabilities, cannot work in the community at this time, but have found their niche in a center-based work program. If closed, their loved one would lose the opportunity to work in a safe and productive environment, socialize with their friends and proudly earn a paycheck.

Michael has worked at Elwyn for 25 years and receives a paycheck every other Friday. Yes, it is small but that is of little interest to him. This paycheck tells Michael that he is important, that he has done a good job. He takes great pride in this and so do we.

FSU is asking that Delaware not limit the choices that are offered now, but instead that residential options be explored and expanded, and that employment options are focused on outcomes with the MOST APPROPRIATE SETTING for the success of the individual. We would ask the Joint Finance Committee to continue their commitment to funding a wide range of service options that meet the needs of individuals, instead of yielding to the pressure of the “one size fits all” philosophy. Thank you very much for your time and attention.

[SCROLL TO READ TESTIMONY OF PAT SWANSON]

Testimony of Pat Swanson - Joint Finance Committee
March 26, 2015

Representative Smith, Senator McDowell and members of the committee:

My name is Pat Swanson and I would like to thank you for allowing me to testify before you today. I am the proud parent of 26 year old identical twin boys. Andrew is an individual with autism. His brother Ben is neuro typical. When Andrew was diagnosed at age 2, we embarked on a pathway of extensive therapies to help him meet the same developmental milestones as his brother. Moving through the grief process, we started to accept that Andrew's life would have limitations and at age 12 made the decision to remove him from an academic track into a functional life skills program. This was an extremely painful decision that made us feel as if we had given up on Andrew. Despite our feelings, we somehow knew that this was best for him. In this environment, Andrew not only flourished and met kids he could finally consider friends, he became a content and happy young boy. It became clear that our choice was in reality ANDREW'S choice and that for us to continue to assist him in making correct choices we had to accept the realities of his disability.

Disabilities of the mind are not concrete or well defined. However, our government has defined these limitations in 42 U.S.C. § 15002 as: resulting in substantial functional limitations in 3 or more areas of major life activity: (a) self-care; (b) receptive and expressive language; (c) learning; (d) mobility; (e) self-direction; (f) capacity for independent living; (g) economic self-sufficiency. Learning of this definition made things clearer for me. My son has limitations in 6 of the 7 areas.

I have parented identical twin boys. Now that they are grown, the least restrictive and most appropriate environment for these two young men is literally worlds apart. Ben lives and works in China and has mastered the language. I would give all that I own to have Andrew capable of this life. But, I have had to accept his limitations and reality: he will need help for the rest of his life. I will never give up on what my son's potential can be. However, have to accept that there are things he will never do. I must accept that despite what I want for him, I can no more change his intellectual capabilities than a parent of a paralyzed child can ask that child to get up out of their wheelchair and walk. This is not the way I think out of fear or for ease of my own life. I am his mother. This is what I know.

There are those with IDD who are not as disabled as my son and they can and should speak for themselves. In developing policies for the future of ALL individuals with IDD we must hear all voices. I am Andrew's voice. Andrew still lives at home with us and has expressed in his own way his desire to be on his own. I can be seduced by the ideal of total inclusion for Andrew. But, I learned the reality of what is best for him years ago and obtaining this dream for him is dependent on the proper supports. As an almost 60 year old parent my obvious questions are: will Andrew be able to find his place before I die and when I am gone, who will know him well enough to truly speak for him?

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I should be and want to be excited about the future for those with IDD. We are in a time of great change that holds unlimited potential for positive movement forward. But, I am extremely concerned about the future of many persons with IDD and their families. The goal of full inclusion for ALL may ultimately isolate and exclude many. The disabilities world mirrors the mainstream in requiring a range of needs and wants and the right to have a full menu of choices to meet these. People should not be shut out because they cannot express themselves. One voice in this community cannot speak for everyone. Since I am Andrew's voice, I can say with great confidence that he thanks you for listening to me today.

[SCROLL TO READ TESTIMONY OF MARY STEPPI]

**Testimony of Mary Steppi – Joint Finance Committee
March 26, 2015**

My name is Mary Steppi and I am here today as a family member to comment on how the underfunding of Disabilities Services has personally affected my family. Last year my older sister Jean turned 60 years old. A milestone for many people – time to reflect on years past and a time to envision the retirement years ahead. But not for Jean. Jean was born in 1954 with a developmental disability – an era when low expectations prevailed for those with a disability like Jean. Each decade has brought new challenges for Jean and for our family. And now at the age of 60, and after all of these years advocating for services, Jean’s employment and housing supports are now in crisis and the future is not hopeful, but instead filled with uncertainty and discontent. In the last month I have learned that new CMS regulations may eventually close Elwyn’s workshop employment program where Jean has been working for over 35 years. I have also learned that the lease at Jean’s group home in Hockessin will not be renewed and that she will be uprooted and displaced from her home.

The housing crisis for those with disabilities is now a very personal issue. Rent caps from DDDS have caused providers to scramble for low cost housing alternatives. The real issue is that safe, affordable, accessible and integrated housing is a challenge for the disability community– it is not consumer driven by choice, nor is it “person-centered”, but instead it is driven by bureaucratic pressure to reduce costs at a time when the demand for housing is escalating. And the reality remains that there is no ‘official’ wait list for housing as in the old days, but instead there is a registry where placement is determined by crisis only. This is a moral outrage. I challenge where the 75 new Community Residential placements will live when my sister’s own housing dilemma is a crisis. Where will Jean live? Will it be safe and accessible and at 60 years old, will she be able to age in place?

Turning now to employment, community job placements are still a challenge here in Delaware. Providers must develop and manage these placements and utilize many resources – time, costs and commitments. There are many success stories, but there are also many disappointments. Our family had great hopes for a community job for Jean, but that was a long time ago. Jean could have worked in a community job; she has a strong work ethic and takes pride in her accomplishments. However she would need one-on-one supports for prompting and direction and extensive job coaching. And the resources to support her would drain the system. So instead of a community placement, Jean has flourished at Elwyn’s workshop as this is the most “appropriate setting” for her – it is her choice and her achievements at Elwyn are always “person-centered”.

After advocating and fighting for services all these years, I am disappointed that the funding gap remains and that the \$37 million underfunding of services has not been addressed in the Governor’s budget. The low funding and underfunding of Disabilities Services over these past years has been the driving force for low disability employment rates and for the community housing crisis.

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But the most profound and the greatest unintentional consequence of this low funding are the issues of neglect and abuse of our most vulnerable citizens.

Last year I met with a number of officials including former Lt. Governor Matt Denn, Secretary Rita Landgraf, Director Jane Gallivan, and Director Frann Anderson of Quality Improvements. Why you may ask? As my sister's guardian and advocate and as driven, as devoted, as passionate, as tenacious as I am, I could not protect Jean nor could I protect her dignity when she became a victim of neglect and abuse. I filed complaints and several incidents were investigated and substantiated as neglect and/or abuse. And specifically one recent incident moved onto an investigation with the Attorney General's Office only to later be dismissed for lack of evidence. For someone with a disability like Jean who has communication issues and could be easily confused, her statement of the incident had no credibility. This is all terribly shameful to talk about, but I am not alone. There are many, many families who have shared experiences. So I put shame aside, and started the dialogue to address quality standards, policies and procedures that should protect the most vulnerable, but in reality aren't even worth the paper they are printed on. And I have come to realize that this is not a provider issue necessarily, but instead a systemic issue of the funding shortfall in the Disabilities Services budget and the mismanagement of the policies of the Division.

A while back I was given the greatest compliment by Kendra Johnson a director at Elwyn; she introduced me at an event as a 'warrior' – a 'warrior' for Jean and a 'warrior' for Elwyn. I have tried my best to live up to that 'warrior' status. Most days I am that 'warrior', but not today. Today I am exhausted and beaten down. Today I am nearly broken. And the system is winning.

Today, I ask for all of you to be warriors for our disability community. Today, I ask of you to make a commitment to families, to address the \$37million funding gap and to add additional funding to the Governor's budget. Today, I ask of you to raise the expectations for employment, for housing and for quality programs where neglect and abuse cannot, will not and should not be tolerated at any level, at any time and for any reason.

I sincerely thank you all collectively and individually for your service, your support and your dedication to Delaware's disability community and to their 'warrior' families.

[SCROLL TO READ TESTIMONY OF GAIL WOMBLE]

Testimony of Gail Womble
Joint Finance Committee Hearing March 26, 2015

Representative George Smith, Senator McDowell and Committee Members,
I would like you to meet Will Womble, my son. If Will was a talker, he would tell you, “Life is good!”

Will thrives in his work life through employment at Delaware Elwyn, separating blue from gray X-Rays. Because of physical issues, Will is not an appropriate candidate to work in the community. He is well challenged making contributions as a citizen employed at Elwyn. Will is happy and content living with three friends in a Mosaic group home. Dedicated Direct Support Professionals orchestrate many activities for the guys’ pleasure. In addition to his work life, Will swims at the YMCA on Saturdays, participates in Bowling Special Olympics as well as the Elwyn Bowling Party, does his banking on Fridays, eats out at various restaurants including Elwyn’s Pancake Breakfast, shops, really enjoys the Dollar Store, goes to Rockford Park, attends Sunday School, and participates in monthly dances at Aldersgate Church. Will attends many Mosaic organized parties, picnics, and barbecues — so many that Will is now a true party animal!

This picture of Will’s life is similar to the lives of many other people with more serious intellectual disabilities who work in sheltered workshops up and down the State of Delaware. Many families gave poignant testimony at recent Medicaid Home and Community Based Transition Plan Hearings.

We expressed the need for our sons, daughters, brothers and sisters to continue working in sheltered workshops that are absolutely necessary for their productivity, positive self regard and peace of mind.

Life dealt serious blows to all of them beginning the day they were born and stretching out their entire lives. No matter how intellectually challenged they may be, our sons and daughters all know they cannot do what their sisters and brothers can do. They know, despite lifelong struggles, they cannot understand a lot of the words people say. They know they do their best to make words come out right, but people still do not understand a lot of what they are saying. They know their bodies will not do things that are ordinary for other people no matter how hard they try to make them work.

They also know the sheltered workshops lift them up by fitting them with jobs they can do. They know Friday is payday, the day they go to the bank. Their jobs mean as much to them as ours do to us. Will would feel devastated if his job was taken away. So would his friends and their families.

Despite serious odds against them, our sons and daughters have fought mightily to get to the place where they can contribute and where their contributions are valued.

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Through the years, this Joint Finance Committee has been the driving force that brought our loved ones out of the shadows and into the workforce of the State of Delaware.

For Will to be where he feels "Life is good", many people, including Will, have dedicated themselves to 44 years of painstaking, meticulous effort. Help us keep what so many have successfully built up.

Thank you for very much for taking Delaware's first step in the SFY 15 budget to erase the \$37M provider deficit. This year we ask you to take the next step by bringing Delaware's group home and employment providers to 80% of benchmark identified in the ICAP Rebasing Report of 2014. Thank you. Gail and Will Womble

[SCROLL TO READ TESTIMONY OF ANDREW EDELSON]

JFC Testimony 3.26.15
Andrew Edelsohn for Homes For Life Foundation

Good morning, Representative Smith, Senator McDowell and members of the Joint Finance Committee.

My name is Andrew Edelsohn and I am the Vice President of Homes For Life Foundation and a member of Families Speaking UP.

I would like to begin by giving you my background and reason for my testimony. I am the older brother of Robert Edelsohn a 42-year-old man with an intellectual disability and the son of Lanny and Micki Edelsohn, the founders of Homes For Life Foundation and Families Speaking UP. As a sibling, I bring a different point of view about my concerns for the future for not only my brother but also the tens of thousands of adults with IDD who will most likely outlive their parents.

I am 31/2 years older than Robert and as far back as I can remember my parents were continually advocating for my brother. Finding the right schools, looking for tutors and always, always including Robert at events with extended family and friends. Their goals for Robert were the same as for me...complete our schooling at the highest level possible, get a job, find a home of our own, and develop interests and relationships that would bring us joy. I am pleased to tell you that Robert and I are both gainfully employed, Robert having passed his 20 year anniversary at Bank of America formerly MBNA. I am now happily married with a number of varied interests and friends, and Robert has one of the more active social lives of the people I know; I can tell you it's not always easy to get on his schedule for a dinner date!

Whether it was in gratitude for our blessings, or a tradition of philanthropy, or a desire to be of public service, my mother did not stop advocating once she secured Robert's future. Rather, she doubled her efforts to help others with intellectual disabilities and their families. I was in college during the early years of her fundraising efforts and when I came home I noticed that my father's office and my old bedroom were slowly becoming my mother's offices. As a result, today 25 neighborhood group homes and two condos at Justison Landing allow 104 Delawareans to live in affordable housing. These homes represent a gift to the people of Delaware of almost 10 million dollars, 2 million from out of state donors. All of this raised by my mother, a volunteer with no paid staff! In my view, from a taxpayer payer perspective, we have built an exemplary model of an affordable housing public-private partnership. I am unaware of any other partnership of similar scope in the state. I am so proud, today, of my parents' philanthropy and volunteer public service to the State of Delaware. I am proud of my brother Robert, and the happy man he has grown to be, successful by his own terms. And I am proud to serve on Home For Life Foundation and be able to offer deserving people in Delaware— vulnerable people who live at the poverty level-- beautiful, safe and affordable housing options.

Today, I want to ask the legislature to partner with us to ensure our work will continue successfully. While there are many things you can do to help, today I ask only for two.

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First: As you all know, developing a skilled and caring workforce for this population is critical. Thanks to all of you, last year JCF added \$1.169 million to the FY15 budget to begin to fill a longstanding \$37 million shortfall. I request that the JFC continue to remedy this shortfall which discourages competent, dedicated people from becoming Direct Support Professionals.

Second: Our foundation's work is predicated on preserving a full range of affordable, safe housing options for a vulnerable population. Please work with us to make safe and affordable housing a priority for this population, driven by consumer—not bureaucratic—choice. It is especially critical for our legislators to be vigilant as our state moves forward with its transition plan under the new CMS Medicaid regulations.

I am grateful for all this committee has done to safeguard the rights and wellbeing of my brother Robert and those like him. I look forward to working with you on many future affordable housing projects.

Thank you.