

Mental Hygiene Budget Hearing 2/6/171

Testimony of Patrick J. Curran on behalf of ENYDDA & SWAN; Steering Committees

- Chairs, Hon. Members, Staff: Thank you for your work on this portion of the State's budget, for the opportunity to appear before this evening, and for staying to listen at the end of a long day. I will be brief.
- My name is Patrick Curran. I am the Father of Katie Curran, a beautiful, profoundly disabled 28 year old woman. It is my privilege to serve on the Steering Committees of both the Eastern NY Developmental Disability Advocates (we pronounce the acronym "any day"), and the State-wide umbrella organization of similar groups from around State, of which ENYDDA is a member, SWAN, the StateWide Advocacy Network. These are independent, all volunteer organizations of the parents and families of the developmentally disabled. Our sole purpose is to educate policy makers, the media and the public on the issues impacting our disabled children. We have no stake in the process other than their well-being. The membership and contact lists of our combined organization represents thousands of families in NYS and we fairly believe we are representative of 10s of thousands more.
- SWAN & ENYDDA endorses virtually everything you have heard today in support of funding for increasing the salaries of the Direct Care Workers

(the Direct Service Providers), with the exception that we genuinely believe that the \$45 million request is too little by half to get those workers back to the then barely adequate salary level they had relative to the minimum wage more than 10 years ago (I won't go into that now but we would be happy to follow up with the data to support our position). For the sake of time we will not reiterate all the points which you heard earlier.

- What we will try to do is offer the perspective of and give a voice to our children, tens of thousands of them, most of whom cannot speak for themselves, but who are the ultimately the focus and object of everything you are doing here, and for their families.
- I believe If our children could speak to you this evening, they would try to leave you with two thoughts: Toothpicks and Continuity.
- [Toothpicks] - If we envisioned all of the wonderful services, programs, resources that have been developed and set aside over the years, by both the State and Federal level, to aid and serve the needs of our disabled citizens - residences, respite, day-hab, physical and occupational therapy, transportation, educational and community integration, the beaurocracy to support them, everything, and the billions of dollars that has been dedicated to these purposes, all of it and envision it as a single great structure that, a vast edifice that represents the best impulses of our society ... It is sitting on a foundation of toothpicks, thousands of toothpicks, who are the direct care workers;

because virtually every single program, every service, every resource every dollar set aside to meet the needs of our developmentally disabled citizens, is ultimately delivered through the hands and hearts and minds, the skills and training, of a direct care worker. Without them that building will collapse and become a very expensive, useless, shell.

- Yet every day more and more of those dedicated, critically needed workers find they must leave their jobs because we, as a State, refuse to provide them with a professional wage, or a living wage, or even minimum wage, to support themselves and their families, much less thrive in their careers as nurturers and caregivers.
- [Continuity] - The other word my daughter Katie and her peers would want you to remember is continuity. In no other form of service from one human being to another, does continuity of caregivers matter more , in almost every way, than it does in the services provided by the direct care workers to the developmentally disabled. The number, breadth, variability, complexity and often subtlety of needs for just one developmental disabled person can be extraordinary, just to provide for their basic health, safety and welfare.
- As a parent, just to deal with just one DD child is life changing - and NOT just in the esoteric sense of how you view the world, but in the mechanical everyday sense of how you function, what you must do physically and deal with emotionally, every day, no matter what else is going on in your life or the larger world (even if you're conducting or staffing a legislative hearing, and its running late; I know because I've been in exactly that

position, more than once); only as parents can we appreciate that it is exponentially harder to care for 3 - 6 such individuals at once; it is literally one of the most demanding occupations in society, requiring patience, strength (emotional and physical), compassion, skill, and a working familiarity of various aspects of nursing, psychology, pharmacology, orthopedics, nutrition, communications, and countless other skills.

- And these are just the things needed to deal with the “mechanics”, the basic physical needs of care-giving. It doesn't speak to what we all aspire to - to break through to those trapped in bodies with which they cannot communicate, and to begin to reach them emotionally and deal with all of the human needs that each of us has: the need for contact, connection with others, understanding, emotional as well as physical support, which is so much harder for so many of the DD community.
- Coupled with this is the difficulty people like my daughter often have dealing with change, even very small changes (because the scope of their world is really very small). We all struggle with change; we depend on routine and familiarity to help us cope. Imagine how much harder, how much more frustrating that is for the DD; when your understanding and ability to cope is limited, when you are completely dependent on others for even your most basic needs, when you can't communicate what you want or need or feel, and it may have taken years for another individual to begin to understand what those needs, simple or profound, might be, to breakthrough and reach the human being in the disabled shell; to reach

them emotionally, personally. But those people, those caregivers, are rarely ever there for years, or even months, or even weeks because that continuity is exactly what is being undermined by our failure to provide those workers with a living professional wage (much less one equal to that of a person who stacks boxes or flips burgers).

- We appreciate that virtually every member of the legislature we have approached understands these issues and has been supportive, at least in principle, of the need to fund a substantial increase in the wages of direct care workers going forward. We are grateful for that and for all your efforts on behalf of our children.
- But it is not enough. We are all familiar with how the process works here. There is a finite pool of resources to meet seemingly infinite set of needs. Unless you and a critical mass of your colleagues go to your Leadership and say: we know there is limited number of things that can be prioritized, on which we as members can expend our limited political capital and this funding is something that we must have, for the direct care workers and the developmentally disabled they serve - they must have a living, professional wage and we are willing to pay for it.
- And you must then insist that your Leaders go to the Governor and make the same demand: that this increase must be part of any budget and that Legislature is willing to pay for it (it would seem to us that \$90 million we believe necessary to make this happen should be easy for a Governor who, earlier last month, when discussing another matter related to this

budget, publicly referred to a difference of some \$160 million as a “rounding error”).

- You know, and we know, that THAT is what it is going to take to get this done. That is what we take your support to mean, and what we humbly and respectfully ask that you do. And we are willing to use every resource at our disposal to support you in that effort. Thank you.