

Feb. 18, 2015 – NYC FAIR hosted a presentation by

Peter Pierri, Executive Director of the IAC, Inter Agency Council

The Inter Agency Council is a consortium of about 150 non-profit agencies from NYC, Long Island and Westchester that offer services from Pre-School through end of life for people with ID/DD. They lobby for these agencies, and do staff training as well

Pete introduced himself by explaining that he started as a Social Worker at an Agency upstate, stayed in the field and eventually became Exec. Director of Ulster ARC for 25 years.

He moved back downstate and worked at DDI on Long Island for 8 years from there he came to IAC as Executive Director. He has been in that position for 6 years. He does not have a family member. He knew nothing about people with disabilities but it took only about 3 days to fall in love with the field.

**Pete Pierri:**

We are now in budget season. The budget year starts April 1. The Governor published his recommendations for the budget in January and between then and April 1 the Legislature debates the budget, makes changes and by April 1 is supposed to pass the budget. This is what is supposed to happen when NY State is working well. This didn't happen in the past many times budgets weren't passed until much later, sometimes as late as September.

**This is important to us because** – the budget is the road map that shows the State Agencies like OPWDD and State Education what they need to do, what they are supposed to do.

The budget tells them not only how much money they have but also what kind of services they are supposed to provide, what they need to do more of, what they need to do less of. That has a direct affect on the kind of services your family member will receive,

I'll talk about what is in this year's budget; what changes and what the impact could be on you as family members. We will also talk about what isn't in there that needs to be there.

Sometimes the State has control over the money and sometimes they don't. Almost all the money that pays for supports is Medicaid money. Medicaid money originates from Federal Govt, and then it comes down to the state. So the money is Federal money and state money- usually half and half but all of it is your tax dollars.

For that reason the Federal govt. will tell them what they can and cannot do with the money.

This year in the budget for OPW, there is a pot of money that is reserved specifically for new or additional services. I can tell you it's \$30 million. Out of that, there are certain things that the state must do, must pay for.

For example, New York State is generally committed to the idea that whenever a student graduates from special education that student will have some kind of day service or there will be support for that individual; Day Habilitation, Vocational or whatever might be appropriate for them. New York State also has quite a number of special education students who have been placed out of state because they have very unique educational needs. They have been placed in residential schools and live outside NY State. When those students turn 21, they come back to NY State. In the budget there is some money put aside for a place for those students to live, and some kind of day service for when they come back. This is the same pot of money used for families who are looking for additional services or for families who are looking for some sort of residential support.

We have been very concerned that in the past couple of years the amount of money that is available for additional supports for families is much less money than had been available four or five years ago. We are seeing and hearing that there are more and more families looking for residential services and there is not to be enough money available for that.

**There is a huge concern in NY State that the waiting lists are growing. This issue is particularly acute downstate, here in NYC, Long Island and Westchester –**

New York State changed its policy a number of years ago moving away from creating group homes, to having many less buildings for residential services. They are hoping that that there are those who are capable of living on their own and they don't have to create residences. Because this is their goal they have allocated less money.

We know that there is a growing waiting list that is not being addressed in the state budget. That's why we must be trying to change this year's budget- we must try to get additional money put into this year's budget for people who are looking for residential placement. This is the largest issue that we are aware of, unaddressed needs for people whose families are getting older, as well as for people whose disabilities are quite complex, or who might have some behavior issues or medical issues. The state has been trying to provide as many supports for people living at home, trying to delay having to move them out of that home. There is a general consensus that there is only so much one can do going about it that way.

There are a couple of other topics that are certainly not as urgent. There is something that is good, some additional money to give to Direct Support Staff who have are currently working with your family members.

The other thing that we are concerned about is that the state has embarked on a policy of trying to give people more and more employment opportunities, to create that as an option. They state that this what they want to achieve. The concern is that there is no extra money in the budget to do this.

## THESE ARE THE THINGS THAT NEED TO BE CHANGED

Q. Is there money for people who are finishing their education but are living at home? Is there money set aside for them for residential or only for day supports

There is supposed to be some money for that, but the reality is there isn't enough money for that.

In terms of money matching the need - far and away there is not enough money matching the residential need. The budget allocation for Day supports for people living at home, while not perfect, is proportionally much closer. There is not as large a waiting list of people wanting day services.

NY State also has this practice of allowing families to personally direct how money is spent. You can sign up with an agency and they spend it based upon your plan. Or there is a process called self-direction and based upon an assessment of your family member's needs they will give you a budget and you can direct that budget and buy services yourself. Many families find that to their liking, they like having more control. State talks policy but when it comes to implementing it, the procedures very lengthy and difficult but you do have the option

Q. Is there a pathway to making a difference with this residential issue?

I think the pathway is your advocacy as family members. You need to convince your legislators of your need because all I can do is to tell you that the state is not doing it. Let me give you a small example - up until about 4 to 5 years ago the state would have a big plan of what they wanted to achieve that year and in that plan there were numbers that would identify what the needs were, so we would talk about how many people in each part of the state were looking for a residential service, who needed it immediately and who needed it in 2 years or so. Then the plan would be 'here's what we are going to do for this group of people'. About 4 or 5 years ago they stopped publishing the needs data so they no longer make it very easy to see how many people are looking for residential services, how many have an immediate need, how many looking for 2 or 3 years for now. I think it is urgent that the Legislature insist that the state once again keep this data, keep a waiting list and publicize it because without this list how can a state figure out how to meet the most urgent needs.

Pete reiterated that it is absolutely clear that you as a family member when you talk to your legislator, I can guarantee that that is worth 10 of me going to talk to them