

GROW TESTIMONY ON TRANSFORMATION

Although there are a multitude of issues involved in OPWDD's Transformation Plan I would like to concentrate on two:

Residential Opportunities

Family/Guardian involvement

RESIDENTIAL OPPORTUNITIES:

Grow has long decried the disparity of residential opportunities in certified settings between those still living at home and those coming out of institutions or residential schools. We therefore applaud the legislative mandate of surveying the needs of those living at home as a first step in closing this gap.

The Survey: Regarding the survey, we also applaud the efforts of OPWDD in modifying its original survey after listening to concerns of stakeholders. Unfortunately the survey did not cover all those school age students who were not classified as part of NY Cares. This will result in a much smaller number of those who actually need a residential placement. Also not enough time was given to conduct the survey.

CRO and AROC : Even as the survey is taking place people have been given a priority status . How this is done is a mystery to us. From persons deemed priority "ones", a few are chosen to go before the AROC. How these persons are chosen is another mystery. Then what one GROW a member has termed a "beauty pageant" occurs whereby the parent tries to "sell " her child to the various agencies that make up the committee. Requests to have families with a developmental disabled child sit of each committee have been denied. This denies the parent of a source of much needed empathy and support.

Self Direction and Residential Opportunities: Despite numerous requests going back to last March we have not been able to get the number of people who have actually been able to use self direction to obtain a residence. We were especially concerned about how this could be done for people who require 24/7 services. From everything we have heard the procedure is very complex for all . And once established nothing is said about, if in a shared residence, a person leaves. How is money allocated then? What happens when a parent or guardian tdes, who makes certain that things still run smoothly?

FAMILY/GUARDIAN INVOLVMENT:

As one of many groups who have created OPWDD we have long sought to have a true, meaningful partnership with OPWDD. We find we must constantly push to be heard. This lack of dialogue has frequently extended to our children's direct care services. For that reason we worked our legislators to create a "Family/Guardian Bill of Rights. When we asked for OPWDD support the ultimate response came in an attempt to change the existing guardianship law. No caring family member wants to deprive their loved one of civil liberties, BUT THEY DO WANT TO KEEP THEM SAFE. In the midst of all the changes

that are occurring at OPWDD we are dismayed that you pick this time to throw in this monkey wrench that will effect all our children.

We at GROW have been working to better the lives of people with developmental disabilities for over 30 years. We intend to continue in this ongoing endeavor and would hope that you truly listen and work to address these concern.

Respectfully submitted,

Barbara Masur

GROW President