



September 26, 2013

Dear JRC Families:

Thank you for the July 10th letter where you expressed your shared concerns about your family members leaving JRC and receiving adult services in New York State. I am very sympathetic to your concerns and I understand that many of you have had difficulties in the past getting the needed care for your family members. I want to assure you that OPWDD only wants the best for your family members, only wants to help them live rich full lives in the community.

Currently, your family members are at a school. The school is intended to serve students until they are 21 years old. OPWDD doesn't have the long term authority to fund individuals in school settings. Your children, as all children, should be afforded the opportunity to receive age appropriate services and move on to their adult lives. The services offered by New York State providers are far more varied than those offered in school settings and are individually developed based on the choices and interests of the individuals and their families. Each service plan is tailored to the individual and is revised as the individual's interests and needs change.

I would like to take this opportunity to discuss some of the concerns shared in your letter and to assure you that OPWDD clinical staff will be reviewing each adult services plan developed by a provider to ensure the provider can meet your family member's needs.

A concern mentioned in the letter is that families will be responsible for searching out services on their own. This is not the case. OPWDD has identified providers and will continue to identify providers that can serve your family members; OPWDD will do its best to provide families with a choice of providers. Another important concern mentioned in your letter is that many of you didn't have success with providers in New York State in the past and that New York State providers are ill equipped to serve individuals with severe behavior disorders. Many OPWDD funded agencies serve individuals with challenging behaviors that are very similar to those of your family members and serve them successfully. These agencies have behavior intervention specialists (many of whom are nationally certified behavior analysts), licensed psychologists, psychiatrists, medical doctors, and nurses on their staff. They have staff with the skill and experience to work with individuals with challenging behaviors. In addition, OPWDD will not approve an agency to provide services unless our clinicians believe that the agency can provide the appropriate services. Prior to OPWDD making an official adult services offer, OPWDD clinical staff review a preliminary service plan for each individual to ensure the agency has the appropriate staffing in place, that the agency has a behavior support plan in place, and

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We help people with developmental disabilities live richer lives

that the services described will meet the individual's needs and interests. This plan is sent to the family with the formal adult services offer so that the family can review it before giving consent to the service offer.

I understand that many of you remain concerned about the use of psychotropic medication with your loved ones. OPWDD has a rigorous process for approving the use of such medications, and absent an emergency, such medications cannot be used without your consent or a court order. A number of our provider agencies that have been serving former JRC individuals for more than a year have not used psychotropic medications for these individuals. Although OPWDD cannot guarantee that psychotropic medication will never be used for a particular individual, we can assure you that you will be consulted if it is being considered, and that the provider will discuss with you the reasons why it is believed the medication is necessary. In addition, medication when used effectively does not impair a person's ability to function but instead, increases the individual's ability to integrate into the community and to fully participate in his/her own life.

I know many of you hear rumors about individuals returning from JRC with ill consequences but contrary to these rumors, these individuals are living full lives in the community.

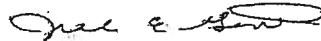
Once again, I encourage you to participate in the planning process. OPWDD has many opportunities available for your family members and you can play an integral role in developing the services that will best meet your family members' needs.

- You can choose to have your family member come home and receive the services needed to support him/her at home.
- You and your family member can self-direct the services and hire your own staff to provide them.
- Your family member can live in a small community residence, in a shared apartment or in his/her own apartment with supports. In some cases, you can help determine the location of the residence.
- You can work with a provider agency to help identify the supports your family member will need.

So, I ask for your cooperation; please work with OPWDD and our provider partners to develop services for your family members. It is important that you make and keep appointments to see the types of services these agencies provide. You may also ask to talk with other parents/grandparents of individuals served by these agencies. You are encouraged to share any concerns you may have as the services are developed for your family members. OPWDD would like both you and your family member to be satisfied with the services provided.

OPWDD cannot continue to provide funding for individuals after they complete their schooling. Please work with OPWDD to help shape the services your family members will receive and to help shape your family members' future. If you have any questions, please contact your DDRO representative. Attached is a list of coordinators for each county. Thank you.

Sincerely,



Jill E. Gentile
Associate Deputy Commissioner

cc: Senator David Carlucci
Assemblywoman Eileen M. Gunther
Assemblywoman Donna A. Lupardo
Senator Simcha Felder
Ms. Laurie Kelley, Commissioner
Ms. Glenda Crookes, Executive Director JRC
DDRO Directors
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