



<http://www.growny.org/>

email: info@grow-ny.org

Phone: 914-493-1318

POSITION PAPER ON THE FAMILY/GUARDIAN BILL OF RIGHTS

GROW fully and enthusiastically supports the “Family Bill of Rights and Privileges” which has been introduced in the Assembly (Bill No.: A05482) and in the Senate (Bill No.: S01157).

For over 30 years GROW has fought to have people with IDD live as fully as possible in the community, and we applaud and encourage those who are able to do so with minimal assistance.

However, throughout that period of time we have come to realize that living as fully as possible in the community requires a different set of supports for each individual. In addition each individual’s ability to express themselves varies tremendously. It is for those individuals whose needs are more complex that we created this legislation.

We have long sought to have a meaningful partnership with our children’s direct care services. However, in many cases we find that instead there is a lack of dialogue that results in situations injurious to their health and safety. Accordingly GROW has expressed the need for families and caregivers to access the information that is needed to make informed decisions about their care and have meaningful input in making those decisions for those individuals who cannot adequately advocate for themselves.

For that reason we worked with our legislators to create a “Family/Guardian Bill of Rights.”

The bill provides the following protections:

- Right to information regarding fire safety, medical treatment and appointments and immediate notification of emergency room admission;
- Right to choose a care coordinator;
- Right to financial information regarding the individual’s care;
- Right to unannounced visits to programs and services and the right to be informed of staffing changes.

We note that the legislation provides that those developmentally disabled individuals who are able can limit access to their information and does not violate any existing confidentiality protections.

We would like to thank Assemblyman Abinanti and his staff for their hard work in crafting the language of this bill, and meeting with OPWDD to effectuate revisions where deemed necessary. Our gratitude extends to Assemblymembers Aileen Gunther, Shelley Mayer, Steve Otis, and David Buchwald for co-sponsoring this legislation thereby assuring its unanimous passage in the Assembly in 2015 and again in 2016. We hope the same will occur in this legislative session.

We appreciate that Senator Ortt has sponsored the legislation in the Senate and we strongly urge our Senators to co-sponsor the bill and assist in its passage.

We had hoped that OPWDD would reconsider supporting the legislation and join us in promoting its passage. OPWDD has also proposed summarizing the principles embodied in the bill of rights in a palm card. We think the current draft of the palm card fails to capture the rights set forth in the proposed legislation and we continue to work with OPWDD to improve the content and scope of the palm card.

The Family/Guardian Bill of Rights expresses our families' wish to have access to the information needed to keep their loved ones safe and free from abuse. We therefore urge its passage by the Legislature and approval by the Governor.

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