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## **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 intellectual and developmental disabilities 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. This lack of dialogue frequently results in situations injurious to their very health and safety. Accordingly GROW has expressed the need to: access the information that is needed to make informed decisions as well as guaranteed 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 individuals with developmental disabilities who are able can limit access to their information and thus 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 that were deemed necessary. Our gratitude extends to Assembly members 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.

Lastly we hope that OPWDD will join us in promoting its passage.

No caring family member wants to deprive their loved one of civil liberties, **BUT THEY DO WANT TO KEEP THEM HEALTHY AND SAFE!**

**SUPPORT: A 5482**

**S 1157**