

## **Joint Resolution Establishing a Parents' Bill of Rights for Parents of Individuals with Developmental Disabilities**

### **Issue**

Parents of individuals with intellectual and developmental disabilities dedicate their lives to their sons and daughters and are essential to ultimately ensuring the health, quality of life, and general well-being of their loved one. Parents are often the primary ones looking out for the best interest of their sons and daughters and ensuring they receive quality supports and services. Unfortunately, these parents face enormous barriers to accessing the supports they need and can sometimes feel overwhelmed and worn down by the very systems designed to help them. Parents of individuals with intellectual and developmental disabilities are also often the primary providers of their loved ones' services, typically at extraordinary financial, physical, and emotional costs.

### **Concern**

Parents are the keystone of the developmental disabilities system and it is critical that they are acknowledged as such. Their role is essential and it is important that they feel valued and have appropriate and meaningful influence on the system and with regard to their own loved one's plan of care. For example, parents should have the right to receive return phone calls in a timely manner, and be assured that they will be free from retaliation if a complaint is made. Parents should be given clear, up-to-date, understandable, and honest information about the system of services for people with developmental disabilities in New Jersey. Parents should be able to receive information and correspondence in writing so there is no confusion about expectations. Parents should have a clear method of recourse if they feel their loved one's plan of care is not being implemented or their son or daughter is not receiving adequate care appropriate to his or her needs. And perhaps most importantly, parents should always be treated with respect and consideration by the people and systems designed to help them. Unfortunately, this is not always the case.

### **Recommendation**

Pass a Joint Resolution acknowledging the essential role parents of individuals with developmental disabilities play in New Jersey and outlining a series of "parents' rights" within the developmental disabilities system. This resolution will help to set the tone for how these parents should be treated and hopefully increase sensitivity by state agencies, healthcare professionals, service providers, school personnel, and any other agencies parents rely on to support them and their son or daughter with a developmental disability.