

## **Prenatally & Postnatally Diagnosed Conditions Awareness Act**

### **Section 3 -**

Amends the Public Health Service Act to require the Secretary of Health and Human Services, acting through either the Director of the National Institutes of Health (NIH), the Director of the Centers for Disease Control and Prevention (CDC), or the Administrator of the Health Resources and Services Administration (HRSA), to authorize and oversee certain activities relating to Down syndrome or other prenatally or postnatally diagnosed conditions. Includes among such activities the awarding of grants, contracts or cooperative agreements to eligible entities to: (1) collect, synthesize, and disseminate current evidence-based information relating to such conditions; and (2) coordinate the provision of, and access to, new or existing supportive services for patients receiving a positive diagnosis for such conditions. Includes within such supportive services: (1) the establishment of a resource telephone hotline; (2) the expansion of the National Dissemination Center for Children with Disabilities; (3) the expansion of national and local peer-support programs; (4) the establishment of a national registry, or network of local registries, of families willing to adopt newborns with such conditions; and (5) the establishment of awareness and education programs for health care providers who provide, interpret, or inform parents of the results of prenatal tests for such conditions. Requires the Secretary to place an emphasis on funding partnerships between health care professional groups and disability advocacy organizations in distributing funds.

Requires a grantee under this Act to make available to health care providers of parents who receive a prenatal or postnatal diagnosis: (1) up-to-date, evidence-based, written information concerning the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes; and (2) contact information regarding support services, including information hotlines, resource centers or clearinghouses, national and local peer support groups, and other educational and support programs. Requires information provided to be culturally and linguistically appropriate and to be approved by the Secretary.

Requires the Government Accountability Office (GAO) to report to Congress concerning the effectiveness of current health care and family support programs serving as resources for the families of children with disabilities.