Regional Center Early Start Services

By definition *every child age birth to three years who has received a diagnosis of Prader-Willi syndrome is eligible to receive early intervention services* provided by the State of California through the Regional Center system's Early Start Program. Additionally, it continues to be successfully argued that *all individuals with PWS are eligible to receive Regional Center services for the remainder of their lives through the Lanterman Act.*

As soon as your child receives a diagnosis of Prader-Willi syndrome you should contact or be contacted by your local Regional Center office to begin an Intake Assessment. You and your caseworker will develop a plan for your child, called an Individual & Family Services Plan (IFSP) which will list the types, amount, and duration of early intervention therapies and services your child will receive.

Early Intervention Services should include at a minimum occupational therapy, physical therapy, and speech therapy. Other therapies, such as assistance with feeding, music therapy or aqua therapy (physical therapy performed while in water), hippotherapy or therapeutic horseback therapy may also be fun and helpful, though your Regional Center may not always be able to provide these services. Social skills therapy will be helpful when your child reaches age three to four years. Though outside the purview of services provided by your Regional Center, don't forget to look into your local community classes such as Mommy & Me, Gymboree, My Gym, etc. for more exploration and fun with your child!

Prior to your child's third birthday, your Regional Center caseworker should coordinate an assessment of your child to determine whether he or she is eligible to continue to receive services though the Lanterman Act. People often mistakenly believe that Regional Center services terminate when the child turns three years old. While it is true that the *Early Start Program* ends at age 3 years when the school district is then charged with the responsibility to provide services that relate to the child's *educational* needs**, individuals with PWS may be made eligible to receive ongoing Regional Center services whenever they might need them *for the remainder of their lives*** through the Lanterman Act.

While the diagnosis of Prader-Willi syndrome is not specifically named in the Lanterman Act, an individual with Prader-Willi syndrome can be made eligible for services if they are also diagnosed with a seizure disorder and/or autism and/or intellectual disability. Individuals with PWS without these additional diagnoses may be eligible under the "Fifth Category" which provides services for "a condition closely related to intellectual disabilities or requiring treatment similar to that needed by people with intellectual disabilities." Please take note that some Regional Centers fail to inform families that they may apply, or about how their child may receive continued Regional Center eligibility, particularly under the "Fifth Category."

Prader-Willi California Foundation strongly advises families to appeal any decision to terminate eligibility or services, and to contact the PWCF office for information and advocacy assistance.