

PUNS - Prioritization of Unmet Need for Services Victory and Confusion

Two years ago, advocates celebrated a historic victory when a bill was passed by the Illinois General Assembly creating a cross-disability database or waiting list for services for people with disabilities in Illinois.

Now, for the first time, disability advocates can anticipate having real and accurate information about the needs, met and unmet, of people with disabilities in Illinois. Last November, the State began officially gathering that information for persons with developmental disabilities using a survey tool called the **Prioritization of Urgency of Need for Service (PUNS)**. The name is an unfortunate acronym because, for us, **PUNS is no joke.**

- PUNS will allow us to have accurate information to use as advocates as we talk to our policymakers.
- PUNS will be the tool the state uses as it decides who will receive services on an individual basis.
- PUNS will be the tool the state uses as new programs and services are being developed.

The PUNS Survey is the result of a year and a half of planning and design by Celia Feinstein of Temple University in Pennsylvania and the Illinois Division of Developmental Disabilities. Ms. Feinstein was brought to Illinois by the Illinois Council on Developmental Disabilities after developing a similar survey in Pennsylvania. **Based on that survey, Pennsylvania increased funding for disability services by \$835 million!** History tells us that this is an important effort!

THE PUNS SURVEY IS A FAMILY SUPPORT ISSUE.

As with any new project, there has been plenty of confusion. Many people perceive the PUNS survey as being **ONLY** for people anticipating the need for residential services. Others perceive the survey as being only for adults. The survey is for **ANYONE** or the family of anyone anticipating the need for services in the next five years. The person with a disability must have a developmental disability as defined by the Division of Developmental Disabilities. For families of minor children the need may mean respite or after school care. It may mean access to therapies or equipment or home modifications. Do not think about available services or specific programs; think about what your need is. Think about what you haven't been able to get, either because it doesn't exist or because it is not available to you. If you do not anticipate having a need in the next five years, the PAS agent is not supposed to complete the survey! So be thoughtful about your needs! This is your chance! Families which include members with disabilities have a hard time acknowledging their needs. Our need to be self-sufficient and competent is vital. Our need to present ourselves to the world as "normal" is powerful. All we want to do is lead a typical life. We bury our struggles.

THIS IS NOT THE TIME TO BE PROUD. NOW IS THE TIME FOR YOU TO STEP UP AND BE COUNTED.

This is the time to think critically about what our loved one with a disability needs to be successful, either in your home or his home in the community. Your willingness to complete the survey will allow us to advocate for family support programs! Currently just over 6,700 individuals have completed the survey. Demographics lead us to believe that as many as 14,000 could eventually be included in the database.

THIS IS HOW TO DO IT.

Call your local Pre-Admission Screening (PAS) Agency (ISC Agency). They must fill out the survey for you with your input. You can identify your PAS agency on the web at <http://www.dhs.state.il.us/OfficeLocator/> or through Illinois Life Span on the web, www.illinoislifespan.org, or by phone, 800-588-7002. We have also included a list in this newsletter. Your PAS agency representative will make an appointment to meet with you, probably in your home, or possibly in their office. The process of filling out the form involves a face-to-face conversation between the PAS agent and the person with a disability, a family member or a guardian, and any other person the individual with a disability wishes to include. The survey represents the combined perception of all these parties.

The PUNS survey must be updated on an annual basis.

At twelve months, a notice will be issued to all parties of the need to update the form. If not updated, an additional warning will be submitted of the intent to close the PUNS record. **Some people report being told that they don't qualify or that they're not eligible.** Others report being told that if they don't have a need within five years that they don't need to complete the PUNS. Everybody with a developmental disability who anticipates a need within the next five years should complete the PUNS form. Think critically about your needs. Even if it is "just" respite or "just" after school supports, or "just" transportation. If you are not satisfied with the survey, feel it has been filled out inadequately or if you feel you have been inaccurately turned down in your request to fill out the survey, you should contact your DHS Network Facilitator at 217-524-2521 or 312-814-2735. Please also contact Mike Kaminsky at the Life Span Project at 800-588-7002. We are trying to understand how well things are going and Mike is racking questions and concerns. **Also, please remember that inclusion in the database does not assume eligibility for services or guarantee the receipt of services.**

WHAT DOES THE FORM LOOK LIKE?

The PUNS form first categorizes need by three levels of urgency.

- **Emergency:** the individual or caregiver needs support immediately;
- **Critical:** the individual or caregiver needs support within one year;

- Planning: the individual or caregiver needs support within 1-5 years or their caregiver is aged 60+.

Then it asks you to identify supports and services you or your loved one with a disability need or will need in the future. Even if you are doing well now, you need to think about what you need to continue doing well! Our families should not have to become dysfunctional to access help! Think carefully about the choices being presented. Most will be obvious. **The PUNS Survey is a new and exciting opportunity for Illinois advocates.** But it is frustrating. As with any new project we are learning. Some question if the PUNS survey is asking the questions we want to answer. Do we really have the opportunity to share our needs? Others wonder if we shouldn't be asking for information for more than five years out. Maybe. Probably. As this process goes forward we will have opportunities to ask for changes to the survey. But, we must step up and use it to understand it! **Please take this opportunity to contact your PAS/ISC Agency and ask for an appointment today!**

DD Definition for Eligibility of Services

Following is the definition of developmental disabilities used by DHS. You must meet this definition for state-funded services and to be included in the PUNS database.

A person is determined to have a developmental disability if the person has Mental Retardation or a Related Condition. Mental Retardation refers to significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested before the age of 22 years. Significantly sub-average is defined as an IQ of 70 or below. A related condition refers means the individual has a severe, chronic disability that meets all of the following conditions: It is attributable to Cerebral Palsy or epilepsy or any other condition other than mental illness, found to be closely related to mental retardation because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with mental retardation and requires treatment or services similar to those required for these persons. It is manifested before the person reaches age 22. It is likely to continue indefinitely. It results in substantial functional limitations in three or more of the following areas of major life activity: self-care, understanding and use of language, learning, mobility, self-direction, capacity for independent living.