

Autism Community Connection

Autismcc Yahoo Group Responds!

Our group is comprised of parents, educators and professionals in the autism community. We welcome parents to ask questions so that together we may share our wealth of collected knowledge and insight. www.autismcommunityconnection.com - <http://health.groups.yahoo.com/group/autismcc/>

Subject: What is PUNS

Information on signing up for PUNS - <http://ww.dd.illinois.gov/SignUp.cfm>

Many people have heard the word PUNS used and that they should be on this PUNS list. But there has been much confusion about what it is and why is it important for families with ASD children/teens/adults to be included. Laurie sums it all up:

Prioritization of Unmet Needs (PUNS) is Illinois' database designed to COUNT and DOCUMENT what are the UNMET service needs of families in Illinois who have children with developmental disabilities. Not just autism, but any developmental disability. You register by calling the PAS agency for your county, and in many cases you need to go in for a face-to-face meeting. It's a bit of a pain.

Now we parents know that the numbers of kids with autism have grown dramatically. Trouble is, our numbers as reflected in this PUNS database don't show that. As of several months ago, there were less than 400 people TOTAL in the whole state of Illinois who have autism spectrum disorder who are registered with this database. Less than 400. That, by the way, includes all age groups. Does that sound accurate?

Meanwhile, people with other diagnoses are signing up in relative droves! :) If we ever hope to get the state to agree with us that there's a CRISIS here with these incidence rates sky-rocketing, we need to register with this blasted database.

Shall we? First I'll post a list from the State of Wisconsin website of services available for funding under their General Childhood Waiver. Then I'll post the Autism Waiver, too. Just to give everyone some idea of what UNMET NEEDS we might talk about with a PAS agent. :) And remember, in the survey they'll ask you not just about what you need today, but also to project out by 1 and 5 years from now. OK, here's the Wisconsin info -- read it and weep:

Description of Services Under the Children's Waivers (services available next door in Wisconsin)

A variety of services are available under the children's waivers. If a child is receiving intensive in-home services, this will be the only waiver service delivered.

If the child is in the ongoing waiver, the federal Centers for Medicare and Medicaid Services (CMS) has approved the following types of services: adaptive equipment,

counseling and therapeutic resources, respite, home modifications, specialized transportation, family-directed services, family-centered services, and day services related to supported employment as well as child care.

The rest of this document provides descriptions of these services:

Adaptive Aids

Adaptive Aids are devices, controls or appliances which enable children to increase their abilities to perform activities of daily living, participate in typical home and community activities or control the environment in which the child lives or frequents on a regular basis. Adaptive aids facilitate self-reliance; independence and community participation may decrease the need for paid care and may reduce the risk of institutionalization. Adaptive aids consist of any device that achieves any of the objectives specified in this definition.

Communication Aids

Communication Aids are devices or services necessary to assist children with hearing, speech, or vision impairments to effectively communicate with service providers, family, friends, and the general public. Communication Aids consist of the devices listed below and, to permit efficient and effective responses to new technologies, any other device even if it is not listed below so long as the device achieves the objective of this service. This list is not intended to be all-inclusive. Other Communication Aids including new devices or technologies not included on the list should be approved and funded by the waiver if the need is assessed, and the Communication Aid addresses the objectives of this service. The cost of installation repair, maintenance and support of any covered communication aid are also covered by this service.

Consumer Education and Training

The provision of services to help a child with a disability develop self-advocacy skills, exercise civil rights, and acquire skill needed to exercise control and responsibility over other support services. Education may also include individualized tutoring, individual instruction, and educational related services to the extent which they are not permitted under a program funded by the Individuals with Disabilities Education Act (IDEA). Expenses for this service may include enrollment fees, materials, and transportation related to participation in conferences, courses and other events related to the objective of Consumer Education and Training.

Consumer and Family-Directed Supports

Consumer and Family Directed Supports are designed to assist children and their families to build, strengthen, or maintain informal networks of community supports. Consumer and Family Directed Supports include the activities and supports at the request and direction of the child and/or the family. The types of services and supports provided through consumer and family directed supports are the same as other waiver allowable services, however, the method of arranging for the provision of services and the supervision of these services is directed by the family.

Counseling and Therapeutic Resources

The provision of professional habilitation services to people with personal, social, behavioral, mental, alcohol or drug abuse, cognitive, developmental, or medical needs. The intent of these services are to maintain or improve health, welfare, or effective functioning in the community. This service may consist of, but is not limited to counseling, psychotherapy, music therapy, recreational therapy, music therapy or nutritional counseling.

Counseling and Therapeutic Resources includes the following requirements for providers of this service:

The individual providing counseling services, except in the areas of medical and legal counseling, shall have the skills and knowledge that would be typically acquired through a course of study leading to a master's degree in one of the behavioral sciences and one year of training or experience in the specific area in which counseling is being offered. Medical counseling shall be provided by a licensed physician or a registered professional nurse in accord with the Professional Practice Act, and legal counseling shall be provided by a licensed attorney. Other counselors or therapists shall be professionally licensed and certified in the appropriate field. Or other appropriately trained persons under the supervision of qualified individuals as identified in a. and c.

Daily Living Skills Training

The provision of services to children who need instruction and guidance to successfully complete routine daily living tasks. Services are intended to improve the child's ability to perform routine daily living tasks and utilize community resources more independently. Services are focused on skill development and are not designed to provide substitute task performance. Daily Living Skills Training includes skill development in the following areas:

Parenting;
Money management;
Home upkeep and maintenance;
Food preparation;
Accessing and using community resources;
Community mobility training; and
Personal hygiene.

The major distinction between Daily Living Skills Training and Supportive Home Care services is Daily Living Skills Training is intended to teach children to perform activities with greater independence.

Day Services

The provision of services that provide children with regularly scheduled activities for part of the day. Services include training, coordination and intervention directed at skill development and maintenance, physical health promotion and maintenance, language development, cognitive development, socialization, social and community integration and domestic and economic management. This includes services not otherwise

available through public education programs that provide after school supervision, daytime services when school is not in session, and services to pre-school age children. Services are typically provided up to five days per week in a non-residential setting and may occur in a single physical environment or in multiple environments, including natural settings in the community. Training activities may involve children and their families. Coordination activities may involve the implementation of components of the child's the family-centered and individualized service plans and may involve family, professionals, and others involved with the child as directed by the child's plan. Day Services for children also include the provision of supplementary staffing necessary to meet the child's exceptional care needs.

Home Modifications

Home modifications are additions or alterations to a child/family's primary residence that address needs associated with accessibility, health, safety, or life in the community. Home modifications may include materials and services that assist in the assessment of need for a modification, as well as the actual construction of the modification.

Personal Emergency Response System

A Personal Emergency Response System provides immediate assistance in the event of a physical, emotional or environmental emergency through a community-based electronic communications device. This service can provide a direct link to health professionals to secure immediate assistance by the activation of an electronic communications unit in the child's home.

Respite Care

Respite care is the provision of services to children, on a short term basis, in a number of different settings. Services are provided to the child and are also intended to benefit the child's family and/or other primary caregiver(s). Respite care provided in regulated residential settings is called "Residential Respite Care." The allowed regulated settings include licensed or certified Adult Family Homes, Children's Foster Homes including treatment foster homes, Community Based Residential Facilities (size limit of 8 applies) or Children's Group Homes. Respite care that is provided in a certified Medicaid funded institutional setting is called "Institutional Respite Care." The allowed institutional settings include hospitals, nursing homes or Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). Respite care provided in the child's home is called "Home-based Respite Care." Respite care provided outside the child's home, in the home of someone unrelated to the child where the setting is not licensed or certified by the state or county agencies or, for children, in a licensed or certified child day care setting is called "Respite Care-Other."

Specialized Medical and Therapeutic Supplies

The provision of items and devices necessary to maintain the child's health, manage a medical or physical condition, improve functioning or enhance independence. Items or devices needed must be of direct therapeutic or habilitative benefit to the child. The following is an illustrative list of therapeutic items or devices that may be included in this service: nutritional supplements, therapy aids, incontinence materials, over the counter

medications and books and literature relevant to the child's medical condition.

Specialized Transportation

Specialized Transportation is the provision of services to permit children access to destinations in the community to obtain services, use needed community resources, and participate in community life. Specialized Transportation Services may consist of material benefits such as tickets or other fare medium or a payment covering all costs associated with the conveyance of the child using the waiver and their attendants.

Specialized transportation services include those services which assist in improving the child's general mobility in the community, increase independence and participation and prevent institutionalization. Payments for this service may be based on the provider's cost of operating the vehicle and driver costs and may be charged on a per-trip or per-mile basis.

Support and Service Coordination

The provision of services to facilitate all the services and supports, both formal and informal, needed by the child and family to meet identified outcomes. This includes locating, managing, coordinating and monitoring all services and informal supports needed by the child using the waiver and assure that services are provided in accordance with program requirements and assessed support needs. This also includes an assessment of family's needs so they may adequately support their minor child in the family home. Support and Service Coordination may also be directed at assisting connecting the child and family to natural supports. The intent of this service is to enable the child using the waiver to receive a full range of appropriate services consistent with their needs in a planned, coordinated, efficient and effective manner. Support and Service Coordination facilitates establishing and maintaining the child and family's individualized support system.

Support and Service Coordination includes assistance with establishing Medicaid financial and functional eligibility, assisting children and their families to gain access to waiver supports and services; Medicaid covered services; medical, social, and educational assessments and services; and any other services and resources; regardless of the funding source and to identify the supports necessary to insure the child's health and safety. This service includes writing to individual service plan; coordinating, updating and assuring the effective implementation of the child and family's support plan; developing, implementing, and updating a family-centered transition plan; and coordinating across systems with all necessary supports and services needed by the child.

Supported Employment

Supported Employment is paid employment; in an integrated and competitive work setting in a business or industry which primarily employs people without disabilities; and is for people with disabilities who need on-going support to maintain employment in such settings.

Services include assessment, job development, supervision, training, and

transportation. Other support services, not specifically related to job skill training, may also be provided to support a person with disabilities in employment.

Supportive Home Care

Supportive Home Care (SHC) is the provision of a range of services for children who require assistance to meet their daily living needs, ensure adequate functioning in their home, and permit safe access to the community. Supportive Home Care services include:

Personal Services

Assistance with activities of daily living such as eating, bathing, grooming, personal hygiene, dressing, exercising, transferring and ambulating; Assistance in the use of adaptive equipment, mobility, and communication aids;

Accompaniment of a person to community activities;

Assistance with medications that are ordinarily self-administered;

Provision of attendant care;

Supervision and monitoring of children in their homes; during transportation, if not provided by the transportation provider; and in community settings;

Reporting observed changes in the person's condition and needs; and

Providing an extension of therapy services.

Extension of therapy services means activities by the SHC worker that assist the person with a PT or OT treatment plan. These include assistance with exercise routines, range of motion exercises, standing by during therapies for safety reasons, having the SHC worker read the therapist's directions, helping the person remember and follow the steps of the exercise plan or hands on assistance with equipment/devices used in the therapy routine. It does not include the actual service the therapist provides.

Household Services

Performance of household tasks and home maintenance activities, such as meal preparation, shopping, laundry, house cleaning, simple home repairs, snow shoveling, lawn mowing and running errands; and Assistance with packing and general house cleaning when a person moves.

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