pennsylvania
DEPARTMENT OF HUMAN SERVICES

DHS BULLETIN

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SUBJECT:

Referring Children to the County Intellectual Disability and Autism Programs

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SCOPE:

County Children and Youth Social Service Agencies
Private Children and Youth Social Service Agencies
County Mental Health/Behavioral Health (MH/BH) Programs
County Intellectual Disability and Autism Programs
Physical Health Managed Care Organizations – Special Needs Units
Service/Supports Coordination Organizations and Agencies
Infant Toddler and Preschool Early Intervention (EI) Programs

COMMENTS AND QUESTIONS REGARDING THIS BULLETIN SHOULD BE DIRECTED TO:

The Appropriate Developmental Programs Regional Office

Visit the Office of Developmental Programs Website

PURPOSE:

The purpose of this bulletin is to provide guidance to the county and private children and youth social service agencies, county MH/BH programs, EI programs, and managed care organizations on the process for referring children to the county intellectual disability and autism (ID/A)[1] program when a child has a diagnosis of an intellectual disability, developmental disability, and/or autism (ID/DD/A) (see Attachment 1 for information regarding eligibility and diagnostic criteria) or when it is suspected that a child may have one of these diagnoses. Referring the child to the county ID/A program can provide eligible children and their families with access to information, services, and supports in the community, as well as assistance with preparing for life's transitions through childhood into adulthood.

BACKGROUND:

The Department of Human Services (DHS) wants to improve services and supports to all children and their families or legal guardians[2] so that children can grow to adulthood living in a home with loving adults. The Office of Developmental Programs (ODP), the Office of Child Development and Early Learning (OCDEL), the Office of Children, Youth, and Families (OCYF), the Office of Mental Health and Substance Abuse Services (OMHSAS), and the Office of Medical Assistance Programs (OMAP) work closely together to ensure children with ID/DD/A and their families have access to high quality services that support the child's growth and development. Please see Attachment 2 for further information about each DHS Office addressed in this bulletin.

DISCUSSION:

There are many benefits for children with ID/DD/A to be registered with the county ID/A program. The county ID/A program can help identify supports and services needed for the child and family to live an everyday life. For this reason, when county and private children and youth social service agencies, county MH/BH programs, EI programs, and managed care organizations become aware of a child who has a diagnosis of ID/DD/A or is suspected of having a diagnosis of ID/DD/A (as outlined in Attachment 1), the child and family should be informed that there are services through the county ID/A program that may be beneficial to the child and family. In addition, Attachment 3 should be shared with the child and family to help them understand the importance of registering with the county ID/A program. Along with sharing Attachment 3, it is also recommended that the following talking points be shared with the child and family:

- Enrolling in the county ID/A program can provide access to information and a connection to a network of family support.
- Enrolling in the county ID/A program can provide access to a range of non-medical in home and community services and other services, such as services through the Medical Assistance (MA) or the educational system.
- Enrolling in the county ID/A program is not required; it is optional and can occur at any time during an individual's life.

[1] For the purpose of this bulletin, the county ID/A program is addressed separately from the county MH/BH program to explain the different responsibilities of each program.

[2] Throughout this bulletin, where "family" is referenced this also includes legal guardians.

- Enrolling in the county ID/A program during childhood will support the child's transition from existing services to other appropriate services. When the child reaches the age of 21, services through the school district end and some services through the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit of MA will be discontinued (see Attachments 2 and 3).

If the child and family are interested in services through the county ID/A program, the county and private children and youth social service agency, the county MH/BH program, EI program, or managed care organization should refer that child and family to their local county ID/A program, and as necessary, assist the child and family in making contact with the local county ID/A program (see Attachment 2 for county ID/A program contact information). If the referring agency has information about the child relating to diagnosis, adaptive skills testing, or any information that could help the county ID/A program in determining eligibility for services and permission is granted to share the information, this information should be shared with the county ID/A program to assist with a smooth transition (see Attachment 1 regarding eligibility and diagnostic criteria).

EI Referral Process

An infant, toddler, or preschooler who is eligible to receive EI services will be assigned a service coordinator. The service coordinator is responsible for coordinating and monitoring needed services and supports for the child and the child's family. If the child has a diagnosis of ID/DD/A or is suspected of having a diagnosis of ID/DD/A, the EI service coordinator should discuss with the family the potential services and supports available through the county ID/A program and the benefit of registering the child with the county ID/A program. With the family's consent, the EI service coordinator or lead will refer the child to the county ID/A program by contacting the ID/A program and following the referral process. When a child does not have a diagnosis of ID/DD/A, but a diagnosis of ID/DD/A is suspected, the EI service coordinator should refer the child to the county ID/A program, which will provide a list of resources that can assist the child and family with obtaining the necessary test and/or assessment to determine whether the child has a diagnosis of ID/DD/A.

Children may receive Targeted Support Management (TSM) through ODP to complete the following activities listed below, even if the child is receiving service coordination services through OCDEL:

- Completion of the Prioritization of Urgency of Need for Services (PUNS) instrument; and
- Planning for transitions from congregate settings.

OCYF County Referral Process

Child development screenings and subsequent referrals to the county ID/A program will benefit children and youth by resulting in appropriate intervention and services for children who are in the early stages of development. OCYF recommends that county and private children and youth social service agencies refer all children age 5 and a half years of age and older (if the child and family are interested in services) to the child's local county ID/A program when it is evident or suspected that the child may have a diagnosis of ID/DD/A.

Children may also be eligible to receive EI services. County and private children and youth social service agencies are required to assess all children under the age of three, who have been a subject of a substantiated report of child abuse or neglect, and refer eligible children to the EI program, when the EI program is not currently involved with the child (34 C.F.R.§303.321). DHS strongly recommends that this requirement be extended up to and including age five and one-half for all children who are served by the child welfare system.

This includes children the county or private children and youth social service agency have identified as having a diagnosis or ID/DD/A or are suspected of having a diagnosis of ID/DD/A as a result of the Ages & Stages Questionnaires® (ASQ™) and Ages & Stages Questionnaires®: Social-Emotional (ASQ:SE™) screenings, as well as children who may not have the ASQ™ and ASQ:SE™ completed but it is evident or suspected by the agency that the child may has a diagnosis of ID/DD/A (see Attachment 2 for more information).

Eligible children under the age of three should be referred directly to the EI program in a timely manner, but no later than two working days after the child has been identified (55 Pa. Code §4226.24(e)(2)). For children ages three to 5.5 years of age, the county or private children and youth social service agency should refer that child to the Preschool EI program. If at any time the county or private children and youth social service agency cannot determine after reviewing Attachment 2 whom to contact to refer the child, the county should also contact CONNECT. When a referral is made to EI or EI is already involved with the child and family, a referral to the county ID/A program is not required because the EI program should refer the child to the county ID/A program.

County MH/BH Referral Process

Children may receive services from both the county MH/BH program and the county ID/A program. When a county MH/BH program becomes aware of a child that could benefit from services through the county ID/A program and the child and family are interested in receiving services through the county ID/A program, a referral should be made to the county ID/A program.

When a child has a diagnosis of ID/DD/A or is suspected of having a diagnosis, of ID/DD/A, the designated county MH/BH program staff[3] should inform the child and family of the potential to receive services and supports through the county ID/A program and the benefit of the referral with the child and family (see bulleted list in the Discussion section and Attachment 3).

If the child and family are interested in receiving services through the county ID/A program, the designated county MH/BH staff should contact the county ID/A program. When a child does not have a diagnosis of ID/DD/A, but a diagnosis of ID/DD/A is suspected, the county MH/BH staff should refer the child to the county ID/A program, which will provide a list of resources that can assist them with obtaining the necessary test and/or assessment to determine whether the child has a diagnosis of ID/DD/A.

Special Needs Unit (SNU) Referral Process

Any child or family member with a child enrolled with a Physical Health–Managed Care Organization (PH-MCO) may self-refer to the PH-MCO's SNU. The PH-MCO's SNU should discuss the benefits of enrolling with the county ID/A program with the member and family (Attachment 3 should be given to the family) and offer to provide assistance with the referral to the county ID/A program.

County ID/A Program Registration and Eligibility Process

[3] For example: the Child and Adolescent Social Service Program (CASSP) coordinator, children specialist, a behavioral health specialist, etc.

After a referral has been made to the county ID/A program and the child and family have expressed interest in receiving services, the county ID/A program will determine eligibility for services, which includes confirming a diagnosis of:

- an intellectual disability,
- an autism spectrum disorder, or
- developmental disability.

If the child does not have the documentation needed to assess eligibility, the county ID/A program will provide a list of resources that can assist the child and family with obtaining the necessary documents. The county ID/A program can also work with the county MH/BH program to assist with resources for additional services for the child and family.

During the registration and eligibility process for services, the county ID/A program or TSM provider should offer families information about the Charting the LifeCourse framework and tools that were developed by the UMKC Institute for Human Development, UCEDD (see Attachment 3). The Charting the LifeCourse framework has core principles and values that assist people to envision a good life and have high expectations for the future (see Attachment 3). In order to support the child and the child's family, the county ID/A program will offer an array of resources that support the important role of the family as well as enhance the child's quality of life throughout the child's lifespan. From the moment a child and family reach out for assistance, applying the values and principles from the Chartering the LifeCourse framework ensures a more positive experience and improved outcomes as the child and the family begin to navigate through the service system.

Targeted Support Management (TSM):

TSM services will help a child gain access to needed medical, social, educational, and other services that align with the vision and expectations for the child in having a good everyday life (please reference https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Everyday-Lives.aspx). When a child is determined eligible for TSM services, the county ID/A program is responsible for informing the child and family of their right to choose any willing and qualified TSM provider. The child's information will be given to the chosen TSM provider. Within 45 days of accepting the referral, the TSM provider will complete a PUNS instrument (which is a tool used to promote discussions with children and their families about their needs), if needed. Once the child is determined eligible for TSM services, the child will receive a Supports Coordinator who will assist with accessing supports and services for the child that are consistent with the child's and family's vision and expectation for the child.

Please note:

When a child is already registered and receiving case management through the county EI program, the child may also receive TSM to complete the following activities:

- completion of the PUNS instrument, and
- planning for transitions from congregate settings.

Base Funding:

Base Funding is state funding that is given to the county ID/A program. The county ID/A program has the discretion to choose how to use these funds when other funding and capacity is not available through one of

ODP's waivers. If Base Funds are available and the child is eligible for these funds, the county ID/A program will assist the child and family with needed services and supports that are available through Base Funding.

Intellectual Disability, Developmental Disability and Autism Waivers:

If the child is found to be eligible for waiver services, the county ID/A program will offer the individual and the family the application (DP 457) for the Medicaid Home and Community Based Waiver Program. The county ID/A program will also complete a PUNS assessment, if appropriate. If there are immediate needs for waiver services as indicated on the PUNS, and capacity is available, the child will be enrolled in a waiver for ODP services. If waiver capacity is not available, the child will be put on a waiting list to receive services in the future once capacity becomes available. During the time the child is waiting for ODP waiver services, the individual will be assisted in enrolling in TSM, if applicable and appropriate.

Attachments:

- Attachment 1 - Diagnostic and Eligibility Information for Services Through the County ID/A Program
- Attachment 2 - Department of Human Services: Office Overview and Resources
- Attachment 3 - Understanding the Importance of Registering with the County Intellectual Disability/Autism (ID/A) Program