

SYSTEMS-BASED PRACTICE DEVELOPMENTAL DISABILITIES SYSTEM

Original (2009) Version Primary Author: Robert L.P. Klaehn, MD, DFAACAP
2020 Updated Version Primary Authors: Robert L.P. Klaehn, MD, DFAACAP &
Kathleen A. Koth, DO, DFAACAP

SYSTEMS-BASED PRACTICE: DEVELOPMENTAL DISABILITIES SYSTEM OBJECTIVES*

Knowledge

The resident will demonstrate an adequate knowledge of:

1. The configuration of services for persons with developmental disabilities in their home state.
2. How to access the local services array for persons with developmental disabilities.
3. Local and state advocacy organizations for persons with developmental disabilities in their home state.
4. The role of the local Developmental Disabilities Service Agency Case Manager within the service delivery system.
5. Eligibility requirements for their state's services for persons with a developmental disability.
6. How to identify and describe the functional limitations that an individual with a developmental disability faces.
7. The use of the Individualized Service Plan (ISP) and the Person Centered Planning (PCP) Process in driving service delivery.
8. The risks to personal safety related to the developmental level of the child with an Intellectual Disability (ID) and the lack of social awareness of a child with an Autism Spectrum Disorder (ASD).
9. The developmental course of autism spectrum disorder and intellectual disability and the changes in the service array that must occur as a person with a developmental disability ages.
10. An understanding of the role of the University Center for Excellence in Developmental Disabilities Education, Research & Service (UCEDD) in their home state.
11. An understanding of the psychotherapeutic interventions for children and adolescents with ID and/or ASD with the child's family.
12. An understanding of the standards of care for psychopharmacological interventions for children and adolescents with ID and/or ASD.
13. An understanding of the principles of cognitive/behavioral interventions for children and adolescent with ID and/or ASD.
14. An understanding of complimentary and integrative medicine in the treatment of neurodevelopmental disabilities.

*Parentheses refer to systems-based practice competencies in the RRC Program Requirements.¹ See Appendix 1.

15. Child and adolescent psychiatrist's role in working with developmental disabilities services and individual children or adolescents and their families regarding their developmental needs.
16. The use of Applied Behavioral Analysis in the treatment of children and adolescents with ASD and/or ID.

Skills

The resident will demonstrate the ability to:

1. Complete a diagnostic assessment of an individual suspected of having a developmental disability.
2. Identify and treat comorbid psychiatric and medical conditions in a person with an Autism Spectrum Disorder or Intellectual Disability.
3. Coordinate care with the child's primary care physician and attending medical specialists.
4. Assist the family of a child with a developmental disability in identifying needed state services.
5. Assist the family of a child with a developmental disability through the application and eligibility process for state services.
6. Coordinate care with a developmental disabilities service agency case manager.
7. Provide needed medical expertise to the PCP process or other interagency planning Process such as a Child and Family Team.
8. Provide the needed expertise to adjust the Individualized Service Plan (ISP) as the individual with a developmental disability ages.
9. Identify the needed level of supervision to achieve safety for a child with a developmental disability.
10. Advocate for the child with a developmental disability and their family in order to obtain needed services.
11. Advocate with other medical professionals for treatment of comorbid psychiatric and medical conditions.
12. Access the technical assistance available to practitioners through their state's UCEDD.
13. Understand when a referral for Applied Behavioral Analysis services is needed for a child or adolescent with a developmental disability.

Attitude

The resident will demonstrate the commitment to:

1. Provide to state agencies the needed documentation to support the child's eligibility for developmental disabilities services.
2. Coordinate care with other medical professionals in order to better serve a child or adolescent with a developmental disability.
3. Avoid "diagnostic overshadowing" (the tendency to attribute medical and psychiatric symptoms to the person's intellectual or developmental disability).
4. Partner with the family of a child with a developmental disability when they are denied access to needed services due to stigma related to their condition.

5. Partner with families and Case Managers for optimal service delivery.
6. Participate in the PCP Process or Child and Family/Wraparound Service Team.
7. See advocacy as an integral part of the work with a child with a developmental disability and their family.
8. Seek out technical assistance from their state’s UCEDD and other local sources of expertise in order to better serve the child with a developmental disability and their family.
9. Provide guidance to families who wish to consider the use of CAM for their child with a developmental disability.
10. Help families with children with developmental disabilities “navigate the system.”

TABLE OF CONTENTS

Overview.....	3-4
Local and State Organizational Structures for Services.....	4-5
Eligibility for State Services.....	5
Service Transitions.....	5-6
The Service Array – Community Based Care.....	6-7
The Service Array – Behavioral Health Services.....	7-8
The Service Array – Psychotherapy.....	8
The Service Array – ABA and Other Related Interventions.....	9-10
Safety Issues.....	10-11
Person Centered Planning Process.....	11
University Centers for Excellence in Developmental Disabilities.....	12
Complementary and Integrative Medicine.....	12-13
Roles of the Child and Adolescent Psychiatrist.....	13-14
Conclusion.....	14

OVERVIEW

This module will provide an introduction to “navigating the system” of services for children and adolescents with a developmental disability. Across the country, there are many different configurations of state-sponsored services that, at times, are a barrier to the identification of the appropriate service agency for a needed service. There are also significant variations in eligibility requirements which also can create a barrier for families seeking care for their child with autism or an intellectual disability.

There are many unique aspects to service planning and delivery in the developmental disability field. The Person Centered Planning (PCP) process is unique to the field of developmental disabilities as a method for futures planning. The child with a developmental disability often requires the coordination of multiple services from a variety of community providers plus needed specialty care from multiple medical providers. As the incidence of mental health conditions is higher for the population with a developmental disability than the typically developing population, the correct diagnosis of co-occurring conditions is essential. The practitioner must ensure that symptoms of a co-occurring psychiatric disorder are not mistaken for behavior due to

their developmental disability. The child with a developmental disability is more likely to have a co-occurring or causative genetic or neurological disorder that contributes to their presentation. Applied Behavioral Analysis has become a frequently employed evidence-based practice for treatment of children and adolescents with developmental disabilities. For many reasons, families of children with developmental disabilities often consider the use of complementary and integrative medicine treatment when other treatments do not result in the hoped-for response.

I. LOCAL AND STATE ORGANIZATIONAL STRUCTURES FOR SERVICES FOR CHILDREN AND ADOLESCENTS WITH DEVELOPMENTAL DISABILITIES

There is significant variation from state to state in the organization of services for persons with developmental disabilities. In many states, services for persons with developmental disabilities are provided by the same agency responsible for public mental health services; for example, in Michigan, the Department of Community Health is responsible for services for persons with developmental disabilities as well as mental health and public health services. However, services for persons with developmental disabilities are not always “housed” in the branch of state government responsible for health-related services; in Arizona, for example, the state’s Division of Developmental Disabilities is part of the Department of Economic Security, which is also home to programs providing unemployment insurance, child support services and food assistance programs.

There are also differences in the way those services are provided. The California Department of Developmental Services’ Regional Centers provide many of the services required by a child with developmental disabilities, including assessment and diagnosis, counseling, individualized service planning, genetic counseling, psychiatric services, and management services. In other states, the local case management functions for persons with developmental disabilities are contracted out to a variety of provider agencies, which in turn may contract with other agencies for needed community-based services. The role of the case manager within agencies for the developmentally disabled is similar to those within behavioral health agencies; the Developmental Disabilities Case Manager will usually be the monitor for the Individualized Service Plan (ISP), “broker” for services, and advocate for the child and family within the system of care. In other states, such as Wisconsin, the services for the developmentally disabled are not administered by the state, but each county is responsible for the services for its residents. In this model even local moves between counties can result in completely different structure of care delivery.

The Web site for the National Association of State Directors of Developmental Disabilities Services (NASDDDS) has an index of all state programs for persons with developmental disabilities which may be accessed at: <http://www.nasddds.org/MemberAgencies/index.shtml>

To be an effective health care provider and advocate for children with developmental disabilities, the child psychiatrist must have a good working knowledge of the organizational structure of services for children with developmental disabilities on the state and local level. The child psychiatrist must be aware of whether the local case managers for services for children

with developmental disabilities are part of the state government or a local, contracted provider agency.

II. ELIGIBILITY FOR STATE SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

There is also variation from state to state in the requirements for eligibility for services for persons with developmental disabilities. Most require the individual to be eligible for Medicaid (Title XIX) in order to receive services. States such as Arizona limit developmental disabilities services to autism spectrum disorder, epilepsy, cerebral palsy and intellectual disability, and provide services to persons who are blind and/or deaf through other state agencies. Other disabling conditions, such as or traumatic brain injury do not have a specific “home” in state government for services. Other states, such as Michigan, more broadly define developmental disabilities and may be more inclusive as to who is able to access services.¹

Several states require that the developmental disability be evident by either age 18 or 21; those, for example, who acquire a traumatic brain injury after age 21 would not be eligible for services. Many states also require documentation of the presence of significant functional limitations in a number of life areas similar to that which is required for the diagnosis of intellectual disability in DSM-5. Though evidence of significant functional limitations in two of seven life areas is required for the DSM-5 diagnosis of intellectual disability, states such as Arizona require evidence of functional limitations in three life areas for eligibility. In DSM-5, these life areas are: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.² Instruments such as the Vineland Adaptive Behavior Scales, Third Edition or the Adaptive Behavior Assessment System (ABAS-3) may be used to determine a child or adolescent’s functional status.

States may also have separate eligibility guidelines for developmental disabilities services and Title XIX Medicaid services. When an individual qualifies for developmental disabilities services, but not for Medicaid, there is typically less access to needed services.

To be an effective health care provider and advocate for children with developmental disabilities, the child psychiatrist must be aware of the eligibility requirements of their state for services and be willing to assist the family in the application process by providing them with the needed documentation of diagnosis and functional limitations.

III. SERVICE TRANSITIONS

There is also variability from state to state in the time of transition from one developmental service to another. Early Intervention Services typically will begin in the first year of life, but the transition to services developmentally appropriate to older children can occur from age three to age six. Eligibility requirements may change with the transition as well; some children who are eligible for Early Intervention Services may not meet the eligibility requirements for services when they are older.

There is also a transition from children's services to adult services; depending on the state, this may occur at either age 18 or 21. It is critical that the need for permanent guardianship be assessed at this transition point. This assessment must be done in a careful and deliberate fashion in order to determine which elements of decision-making an individual will need support for and which elements the individual can manage independently. Different supports will be necessary, for example, for a person with an intellectual disability who is living and working independently versus a person with both a developmental disability and a serious mental illness that is only partially responding to treatment.

To be an effective health care provider and advocate for children with developmental disabilities, the child psychiatrist must be aware of when the transitions in service occur in their state and be willing to provide the needed documentation to ensure continued eligibility. The child psychiatrist must also be willing to provide an individualized assessment of the person's guardianship needs.

IV. THE SERVICE ARRAY: THE MOVEMENT TOWARDS COMMUNITY-BASED SERVICES

Again, there is variability from state to state in the mix of community-based and residential services available to persons with developmental disabilities. Arizona leads the nation with over 85% of individuals enrolled in services for the developmentally disabled living in community settings either in their own homes or group settings of four individuals or less. In other states, there is more of an equal balance between those living in community-based settings and Intermediate Care Facilities for individuals with Intellectual disability (ICF/IID).

Most states show a trend toward a significant increase in the money spent on community-based services for the developmentally disabled in contrast to steady or decreasing funding for those in institutional settings. Most states are actively transitioning individuals from institutional settings and providing an array of community-based services. One such effort to provide community-based services is the Individual Options (I/O) Medicaid Waiver. According to the Ohio Individual Options Waiver Handbook:

The Individual Options Waiver (IO Waiver), is a Medicaid waiver for people who have developmental disabilities. Individuals who are eligible can use a Medicaid waiver to stay in their homes and get support, rather than live in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)...The IO Waiver is for people with developmental disabilities who require the level of care provided in an ICF but who want to live in their family home, or in the community with friends and/or roommates and meet the financial criteria of Medicaid eligibility.³

The trend toward community-based services for persons with developmental disabilities is supported by Medicaid waivers and other state initiatives to support community-based care.

To be an effective health care provider and advocate for children with developmental disabilities, the child psychiatrist must be aware of the array of services designed to support the

child with a developmental disability in their home and community. The child psychiatrist must also be aware of the mix of institutional and community-based services in their state and support the family's choice to keep their child in their home for as long as possible despite severe disabilities.

V. THE SERVICE ARRAY: ACCESS TO BEHAVIORAL HEALTH SERVICES IN COMMUNITY SETTINGS

There is a significant variation from state-to-state in the access for children and adolescents with developmental disabilities. This access is essential due to the higher incidence of behavioral health disorders in persons with developmental disabilities in comparison with the general population.⁴ State organizational structures where services for the developmentally disabled are provided by the same agency or department that provides the mental health services, access may be less of a concern. Access to behavioral health services in states where the organizational structure for services is different may be guaranteed by contract; for example, in Arizona, the Division of Developmental Disabilities contracts with two large managed care companies to provide integrated medical and psychiatric care for its members statewide. In California, behavioral health services for persons with developmental disabilities are provided through their network of Regional Centers. In other states, such as Wisconsin, where there is no formal access to mental health services for persons with developmental disabilities, the family or case manager must search for any available provider who is willing to provide psychiatric care.

Many child psychiatrists feel ill-equipped to identify the presence of co-occurring mental illnesses in persons with developmental disabilities. As an aid to all practitioners who work with persons with both a mental illness and a developmental disability, the National Association for the Dually Diagnosed (NADD) has developed, in association with the American Psychiatric Association, the Diagnostic Manual – Intellectual Disability 2 (DM-ID 2): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability. The DM-ID 2 is intended to be an adaptation of the DSM-5 for persons with an intellectual disability.⁵

For older adolescents and transition-age youth with both a developmental disability and a chronic disabling mental illness, there are increasing options for community-based treatment. Assertive Community Treatment (ACT) Teams, originally did not provide treatment to persons with developmental disabilities. However, there are examples of ACT teams that are now accepting persons with developmental disabilities and chronic mental illness.⁶ The START program, currently being implemented in twelve states, also provides community-based services for persons with developmental disabilities and mental health concerns. From The Center for START Services website:

The Center for START Services, developed in 2009, is a national initiative based at the University of New Hampshire Institute on Disability/UCED that provides educational and capacity building services, promotes and evaluates evidence-informed practices and approaches, and facilitates START model program implementation across the United States with the aim of improving the lives of individuals with IDD and behavioral health needs. START (an acronym for Systemic, Therapeutic, Assessment, Resources, and Treatment) is a tertiary care research-

based model of services and supports. While providing training, assessment and crisis intervention services, START services are implemented in the context of a comprehensive, systems linkage approach, to improve capacity in the system as a whole.⁷

To be an effective health care provider and advocate for children with developmental disabilities, the child psychiatrist must understand how to access to mental health services for children and adolescents with developmental disabilities in their state. In states where there is no formal access to mental health services for persons with developmental disabilities, the child psychiatrist should consider providing the needed psychiatric services out of their office or other community-based setting. The child psychiatrist must also be a strong advocate for access to, and coordination of, services for children and adolescents with developmental disabilities and their families. The child psychiatrist must also advocate for access to the appropriate training for all care providers working with persons with developmental disabilities.

VI. THE SERVICE ARRAY: ACCESS TO PSYCHOTHERAPY

Many child psychiatrists and other community providers remain unaware of the evidence base in support of using psychotherapy in the treatment of persons with developmental disabilities. Usually due to a lack of didactic training and experience, most mental health practitioners feel poorly equipped to provide psychotherapy to this population. However, according to Dr. Robert Fletcher, former Executive Director of the National Association for the Dually Diagnosed, “If you have the skills to work with a child, you can adapt them to working with a person with an Intellectual Disability.” Dr. Robert Fletcher, also states, “The goals of psychotherapy with this group are no different than those used within the general population.”⁸

Multiple forms of psychotherapy have been shown to be effective in the treatment of persons with developmental disabilities. A meta-analysis of 30 years of research on the use of traditional psychotherapy with persons with Intellectual Disability published in 2003 found moderate effectiveness for this intervention.⁹ Lew et. al. adapted Dialectical Behavior Therapy (DBT) for persons with Intellectual Disability and used this intervention to improve mindfulness, distress tolerance, emotional regulation and interpersonal effectiveness.¹⁰ Later work used to DBT to treat persons with Intellectual Disability and challenging behaviors.¹¹ Cognitive Behavioral Therapy has also been shown to be effective in treating children with ASD and Anxiety.¹² Group Therapy is also a useful intervention for persons with Developmental Disabilities, both for role playing difficult social situations¹³ and as part of the treatment of sex offending behavior in this population.¹⁴ Family Therapy, either on an ongoing basis or during a crisis, may also be an effective intervention.

To be an effective health care provider and advocate for children with developmental disabilities, the child psychiatrist must understand the evidence base for the use of psychotherapy in persons with Developmental Disabilities. The Child Psychiatrist must also be able to provide individual, group and family therapy for this population.

VII. THE SERVICE ARRAY: ACCESS TO TREATMENT WITH APPLIED BEHAVIORAL ANALYSIS AND OTHER RELATED INTERVENTIONS

Applied Behavioral Analysis is the most evidence-based intervention for children and adolescents with Autism Spectrum Disorder. The original study by Ivor Lovaas, Ph.D. found that nearly half of the young children (beginning treatment before age four) could be placed in a regular classroom when they reached the first grade.¹⁵ The original study has been replicated many times, with most children receiving between 25 and 40 hours per week of direct intervention by a trained technician, for an average of slightly more than two years.¹⁶ Early Intensive ABA treatment has also shown to be a cost effective intervention, in comparison with standard educational interventions.¹⁷

A more targeted intervention, based on a comprehensive behavioral assessments is used for older children and adolescents, often addressing safety, communication, and self-care goals. According to Granpeesheh and colleagues:

Just as the scope and duration of research studies on ABA for older children with ASD are narrower and shorter-term than those of [Early Intensive ABA] research, service provision programs may often have a narrower focus and emphasize high-priority, short-term goals. Such programs often function on a consultative model, wherein the day-to-day care providers for older children with ASD contact an ABA provider for help when they are at a loss as to how to solve particular problems. In general, the more severe the problem, the more likely a care provider may be to seek outside help from an ABA provider. Such problems include, but are not limited to, particularly destructive behavior, such as aggression, property destruction, elopement, or self-injury.¹⁸

Parent Training, based on ABA principles, is also an evidence-based intervention for children and adolescents with developmental disabilities. Research completed by the Research Units on Pediatric Psychopharmacology (RUPP) Autism Network described a behavioral intervention which is not significantly different from those taught to parents with more typically developing children with psychiatric disorders. The 11 session training:

...covered topics such as prevention strategies, schedules, reinforcement, planned ignoring, compliance training, functional communication training, teaching techniques (task analysis, chaining and prompting) and generalization. Additionally, there were up to four optional sessions including time-out, contingency contracting, imitation training and crisis management...Booster sessions, using previously-introduced parent training strategies...were designed to deal with additional or lingering behavioral concerns.¹⁹

Continued research found that providing Parent Training plus treatment with risperidone for irritable, aggressive behavior in children and adolescents with Autism to be more effective than medication alone. The use of Parent Training along with Risperidone also resulted in the stabilization of individuals at significantly lower doses of medication than those treated with risperidone alone.²⁰ Studies completed later found that treatment for children with Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder with combined treatment with Parent Training and atomoxetine was more effective than medication alone.²¹

As with many other interventions for children with developmental disabilities, access to Applied Behavioral Analysis (ABA) treatment varies from state to state. For example, Arizona has provided Early Intensive ABA to enrolled young children since 2006. Other states began providing ABA services as a result of the settlement of class-action lawsuits. Still other states have specific “Autism Waivers” that children or adolescents must qualify for in order to access ABA services. These waiver programs often have waiting lists due to the limited number of spaces available in the waiver. Many commercial insurances, include the insurance provided to federal government employees provide an Applied Behavioral Analysis benefit. Eligibility requirements for entering state Autism Waivers and accessing commercial ABA benefit are also variable.

Other interventions, such as the Developmental, Individual-differences, Relationship-based/ Floortime Model (DIR/Floortime) Model and the Early Start/Denver Model (ESDM) also have growing evidence bases which demonstrate their effectiveness in treating young children at risk for Autism Spectrum Disorder. The DIR/Floortime Model, developed by Dr. Stanley Greenspan and others, focuses on improving a child’s social and communication skills through a play-based intervention.²² ESDM, using elements of both ABA and DIR/Floortime, has been shown in a recent randomized, multi-site study, to be superior to standard community interventions in improving language skills in 2 - 4 year old children with Autism Spectrum Disorder.²³ It has also been shown to be a cost effective intervention by significantly decreasing annual expenditures for children with ASD that have been treated with these interventions.²⁴ Specific interventions for children at risk for ASD under 1 year old are being developed by the developers of the Early Start/Denver Model.²⁵

To be an effective health care provider and advocate for children with developmental disabilities, the child psychiatrist must understand the evidence base for the use of Applied Behavioral Analysis intensively for very young children with Autism Spectrum Disorder (ASD) and selectively for targeted interventions with older children and adolescents with ASD and/or Intellectual Disability. The Child Psychiatrist must also know the evidence base for the DIR/Floortime and Early Start/Denver Models of early childhood treatment of ASD. The Child Psychiatrist must be able to refer appropriately for these interventions.

VIII. SAFETY ISSUES

Children and adolescents with developmental disabilities are at a higher risk for accidental injury than their typically developing peers. Male children with developmental disabilities are at higher risk for accidental injury than female children with developmental disabilities.²⁶ There is also research to show that children with developmental disabilities are at higher risk for specific injuries; for example, Volkmar and Weisner indicate that children with autism are at an increased risk of injury or death due to drowning or suffocation.²⁷ The higher incidence of epilepsy in persons with developmental disabilities also adds to the risk of accidental injury. Thus, a careful assessment of the child or adolescent’s safety risk, including a suicide assessment, must be done at the beginning of treatment and updated regularly as the child develops.

To be an effective health care provider for children with developmental disabilities, the child psychiatrist must be able to complete an accurate and detailed risk assessment.

IX. THE PERSON CENTERED PLANNING (PCP) PROCESS AND THE INDIVIDUALIZED SERVICE PLAN

The Person Centered Planning (PCP) process is a method for future planning for persons with a developmental disability that is in increasing use across the U.S. The PCP Education Site, managed by the Cornell University School of Industrial and Labor Relations defines Person Centered Planning as:

A process-oriented approach to empowering people with disability labels. It focuses on the people and their needs by putting them in charge of defining the direction for their lives, not on the systems that may or may not be available to serve them. This ultimately leads to greater inclusion as valued members of both community and society. Person-centered planning involves the development of a "toolbox" of methods and resources that enable people with disability labels to choose their own pathways to success; the planners simply help them to figure out where they want to go and how best to get there.²⁸

This approach to future planning is very much in keeping with the self- and family-directed care initiatives that many states are beginning to use to drive service delivery to persons with developmental disabilities. It is a powerful tool for self-determination, particularly for adolescents who are aging out of children's services.

The Individualized Service Plan is developed by a team comprised of both professional and community members to operationalize the futures planning done in the Person Centered Planning Process. According to the Illinois Department of Human Services guidance on The Individual Service Plan Development and Implementation:

The Individualized Service Plan is the written details of the supports, activities, and resources required for the individual to achieve personal goals. The Individual Service Plan is developed to articulate decisions and agreements made during a person-centered process of planning and information gathering. The general welfare and personal preferences of the individual are the key consideration in the development of all plans.²⁹

In most cases, the ISP is updated on an annual or semi-annual basis; regular updating of the ISP is essential in order to meet the child or adolescent's changing needs. In contrast to the Person Center Planning process which focuses on assisting the individual with a developmental disability towards a specific future goal, such as the wish to live independently, the ISP is usually more focused on building on current strengths and meeting current needs.

To be an effective health care provider and advocate for children and adolescents with developmental disabilities, the child psychiatrist must be willing to participate in the PCP process for adolescents with developmental disabilities in their care. The child psychiatrist must also be willing to participate in the development of the Individualized Service Plan (ISP) and advocate for the services identified by the ISP process.

XI. THE ROLE OF THE UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES (UCEDD)

Each state has at least one University Center for Excellence in Developmental Disabilities Education Research and Service (UCEDD) that may provide valuable resources to the practitioner working with individuals with developmental disabilities. According to the Association of University Centers on Disabilities website:

Since 1963, University Centers for Excellence in Developmental Disabilities (UCEDDs) have worked towards a shared vision that foresees a nation in which all Americans, including Americans with disabilities, participate fully in their communities. Independence, productivity, and community inclusion are key components of this vision...

UCEDDs have played key roles in every major disability initiative over the past four decades. Many issues, such as early intervention, health care, community-based services, inclusive and meaningful education, transition from school to work, employment, housing, assistive technology, and transportation have been directly benefited by the services, research, and training provided by UCEDDs.³⁰

The available services and supports from the UCEDD and their impact on state services for the developmentally disabled may vary from state to state.

To be an effective health care provider and advocate for children with developmental disabilities, the child psychiatrist must be able to identify those services and supports available through his or her state UCEDD. The child psychiatrist must also be willing to seek out technical assistance from the state UCEDD and other sources of expertise on developmental disabilities in order to better serve children and adolescents with developmental disabilities.

XI. COMPLEMENTARY AND INTEGRATIVE MEDICINE AND THE TREATMENT OF A CHILD WITH A DEVELOPMENTAL DISABILITY

Complementary and integrative medicine is defined by the National Institute of Health's National Center for Complementary and Integrative Medicine as "a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine."³¹ Parents of children with developmental disabilities are seeking out integrative treatments such as megavitamin therapy, dietary therapy, and supplements for their children in increasing numbers. The reasons for this are many but often come from a wish to help their child's quality of life where there is no medical "cure."

It is part of the medical history to inquire about the use of complementary and integrative medicine approaches that have been tried and their outcomes. It is also important to ask if these were done under the care of an integrative medicine practitioner or the family's own choice.

There was some evidence for a higher prevalence of complementary and alternative medicine use in autism spectrum disorder compared to other psychiatric disorders and the general population. Approximately half of children and adolescents with autism spectrum disorder use

complementary and alternative medicine. Doctors should be aware of this and should discuss complementary and alternative medicine use with patients and their caregivers, especially as the evidence is mixed and some complementary and alternative medicine treatments are potentially harmful.³²

The American Academy of Child and Adolescent Psychiatry's Practice Parameter for the Assessment and Treatment of Children and Adolescents with Autism Spectrum Disorder, provides perhaps further guidance on this issue:

"Dietary and other alternative treatments are not clearly established as being efficacious. Families should be helped to make informed decisions about their use of alternative treatments. Treatments that pose some risk to the child and family should be actively discouraged."³³

In recent years the use of medical tetrahydrocannabinol (THC) and cannabidiol (CBD) have been noted in the popular press to help with many psychiatric and medical conditions including developmental disabilities. The American Academy of Child and Adolescent Psychiatry released a policy statement entitled Use of Medical Marijuana in Children and Adolescents with Autism Spectrum Disorder for Core Autism Symptoms or Co-Occurring Emotional or Behavioral Problems noting that there is no evidence for its effectiveness, but evidence of harm done by use of tetrahydrocannabinol in adolescence and therefore recommends against its use.³⁴

To be an effective health care provider and advocate for children with developmental disabilities, the child psychiatrist must be willing to engage with families concerning the use of integrative treatments and assist them in making the best decision possible.

XII. ROLES OF THE CHILD AND ADOLESCENT PSYCHIATRIST IN PROVIDING SYSTEM-BASED CARE FOR CHILDREN AND ADOLESCENTS WITH DEVELOPMENTAL DISABILITIES

To be an effective health care provider and advocate for children with developmental disabilities, the child psychiatrist must be flexible and be willing to play multiple roles in the community-based care of children and adolescents with developmental disabilities and their families. These roles include:

- System Navigator, to assist families by having a good working knowledge of the organizational structure of services for children with developmental disabilities on the state and local level. The System Navigator must also assist with transition from service array to service array as the child with a developmental disability grows older.
- Medical Case Manager, to assist with access to services or to identify and collaborate with the local case managers of services for persons with a developmental disability. In order to efficiently link a child with a developmental disability to services, the Medical Case Manager must be aware of the mix of institutional and community-based services and supports available in their area. The Medical Case Manager must also be aware of the resources that may be available through that state's UCEDD.
- A sensitive and thoughtful assessor of guardianship needs for an individual with a developmental disability.

- A sensitive and thoughtful physician that can manage both traditional and complimentary and integrative medicine interventions.
- An Advocate, whether it is as part of a Child and Family Team (ISP process), a PCP process or simply as a member of the community, for access to needed services. The child psychiatrist may also need to be an advocate for the child and their family with the broader medical community to obtain needed medical or psychiatric services, particularly when a behavior or physical symptom is thought to be caused by the developmental disability (“diagnostic overshadowing”).
- The medical member of a Child and Family Team or PCP process. The child psychiatrist can identify those future needs for the team that are dictated by the child’s genetic, neurological or other medical condition.
- Psychopharmacologist, providing treatment for both the comorbid psychiatric conditions that may be present and the behavioral manifestations of the developmental disability and coordinate such treatment with the equally important behavioral and psychotherapeutic interventions for the child.
- Family therapist to the family, supporting them as they grieve their dreams for their child with a developmental disability and cheer with them as the child makes much hoped for developmental progress.
- Individual therapist to the child or adolescent with developmental disabilities: the child psychiatrist must also learn to adapt the skills they have developed working with typically developing children and adolescents in order to provide psychotherapy to an individual with an intellectual disability.

CONCLUSION

The developmental disabilities system is a complicated system with different configurations in states throughout the US. There are also differences in the services offered and eligibility requirements. With the knowledge provided in this module you will be able to investigate these requirements and services in your state, along with the support of your local University Center for Excellence in Developmental Disabilities. Your advocacy for your patients will help identify these services, as well as barriers and provide an avenue for further advocacy.

APPENDIX 1*

Residents must demonstrate an awareness of and responsiveness to the larger context and system of health care, as well as the ability to call effectively on other resources in the system to provide optimal health care. Residents are expected to:

IV.B.1.f) Systems-based Practice. Fellows must demonstrate an awareness of and responsiveness to the larger context and system of health care, including the social determinants of health, as well as the ability to call effectively on other resources to provide optimal health care. (Core)

* Accreditation Council for Graduate Medical Education. Program Requirements for Residency Education in Child and Adolescent Psychiatry.

https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/405_ChildAdolescentPsychiatry_2019_TCC.pdf?ver=2019-03-28-161025-277. July 1, 2019.

REFERENCES

1. MDHHS Adult & Children's Services Children & Families Developmental Delays – Early On (n.d.) https://www.michigan.gov/mdhhs/0,5885,7-339-73971_4911_68717---00.html. Accessed October 16, 2019.
2. *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*. Washington (D.C.): American Psychiatric Publishing; 2013.
3. Ohio Department of Developmental Disabilities. Individual Options Waiver Handbook: A Guide to Services and Eligibility. <http://thearcofohio.org/wp-content/uploads/2019/03/IO-Waiver-Handbook.pdf> September 1, 2019.
4. Harris JC. *Intellectual Disability: A Guide for Families and Professionals*. Oxford University Press; 2010.
5. Fletcher RJ. *Diagnostic Manual - Intellectual Disability: a Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability: DM-ID-2*. Kingston N.Y.: NADD Press; 2016.
6. Burge, P. Assertive Community Treatment Teams and Adults with Intellectual Disabilities. *Journal on Developmental Disabilities*, 2009 (15)3, 96-102.
7. The Center for START Services. Center for START Services. <https://www.centerforstartservices.org/>. Published March 26, 2019. Accessed September 1, 2019.
8. Fletcher R.J. Introduction to Therapy Approaches for Persons with Mental Retardation. In: Fletcher R.J. & Gardner W.I., ed. *Therapy Approaches for Persons with Mental Retardation*. Kingston, NY: NADD Press 2000: p. ix.
9. Prout HT, Nowak-Drabik KM. Psychotherapy with Persons Who Have Mental Retardation: An Evaluation of Effectiveness. *American Journal on Mental Retardation*. 2003;108(2):82.
10. Lew M, Matta C, Tripp-Tebo C, Watts D. Dialectical Behavior Therapy (DBT) for individuals with intellectual disabilities: A program description. *Mental Health Aspects of Developmental Disabilities*. 2006;9(1):1-13.
11. Brown, J. F., Brown, M. Z., & Dibiasio, P. Treating individuals with intellectual disabilities and challenging behaviors with adapted dialectical behavior therapy. *Journal of Mental Health Research in Intellectual Disabilities*. 2013;6(4), 280-303.
12. Storch EA, Arnold EB, Lewin AB, et al. The Effect of Cognitive-Behavioral Therapy Versus Treatment as Usual for Anxiety in Children With Autism Spectrum Disorders: A Randomized, Controlled Trial. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2013;52(2).
13. Tomasulo D.J. Group Therapy for People with Mental Retardation. In: Fletcher R.J. & Gardner W.I.,ed. *Therapy Approaches for Persons with Mental Retardation*. Kingston, NY: NADD Press; 2000, p.67-68.
14. Lindsay WR. *The Treatment of Sex Offenders with Developmental Disabilities: a Practice Workbook*. Chichester: Wiley-Blackwell; 2009. p. 57-66.

15. Lovaas OI.. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*. 1987;55(1):3-9.
16. Howlin P, Magiati I, Charman T. Systematic Review of Early Intensive Behavioral Interventions for Children with Autism. *American Journal on Intellectual and Developmental Disabilities*. 2009;114(1):23
17. Chasson GS, Harris GE, Neely WJ. Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism. *Journal of Child and Family Studies*. 2007;16(3):401-413.
18. Granpeesheh D, Tarbox J, Dixon DR. Applied behavior analytic interventions for children with autism: A description and review of treatment research. *Annals of Clinical Psychiatry*. 2009;21(3):162-173.
19. Parent training for children with pervasive developmental disorders: a multi-site feasibility trial. *Behavioral Interventions*. 2007;22(3):179-199.
20. Aman MG, McDougle CJ, Scahill L, et al. Medication and Parent Training in Children with Pervasive Developmental Disorders and Serious Behavior Problems: Results From a Randomized Clinical Trial. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2009;48(12):1143-1154.
21. Silverman L, Hollway JA, Smith T, et al. A multisite trial of atomoxetine and parent training in children with autism spectrum disorders: Rationale and design challenges. *Research in Autism Spectrum Disorders*. 2014;8(7):899-907.
22. Mercer J. Examining DIR/Floortime™ as a Treatment for Children with Autism Spectrum Disorders. *Research on Social Work Practice*. 2015;27(5):625-635. doi:10.1177/1049731515583062.
23. Rogers SJ, Estes A, Lord C, et al. A Multisite Randomized Controlled Two-Phase Trial of the Early Start Denver Model Compared to Treatment as Usual. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2019;58(9):853-865.
24. Cidav Z, Munson J, Estes A, Dawson G, Rogers S, Mandell D. Cost Offset Associated With Early Start Denver Model for Children With Autism. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2017;56(9):777-783.
25. Rogers SJ, Vismara L, Wagner AL, McCormick C, Young G, Ozonoff S. Autism Treatment in the First Year of Life: A Pilot Study of Infant Start, a Parent-Implemented Intervention for Symptomatic Infants. *Journal of Autism and Developmental Disorders*. 2014;44(12):2981-2995.
26. Shi X, Shi J, Wheeler KK, et al. Unintentional injuries in children with disabilities: a systematic review and meta-analysis. *Injury Epidemiology*. 2015;2(1).
27. Volkmar F, Weisner L. Safety and your child. In: Volkmar F. & Weisner L, ed. *Health Care for Children on the Autistic Spectrum: A Guide to Medical, Nutritional and Behavioral Issues*. Bethesda, MD: Woodbine House, Inc; 2004.
28. Person Centered Planning Education Site. The Person-Centered Planning Education Site. <http://www.personcenteredplanning.org/>. Accessed September 16, 2019.

29. Illinois Department of Human Services Module 5 DSP Notebook: Individual Service Plan Development & Implementation. https://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/DirectSupportPerson/Module5NotebookIndividualServicePlan.pdf. Accessed September 1, 2019.
30. Association on University Centers on Disability. <https://www.aucd.org/template/page.cfm?id=667> Accessed September 1, 2019.
31. National Center for Complimentary and Integrative Health, National Institutes of Health, U.S. Department of Health and Human Services. <https://nccih.nih.gov/health/integrative-health> Accessed July 17, 2019.
32. Höfer J, Hoffmann F, Bachmann C. Use of complementary and alternative medicine in children and adolescents with autism spectrum disorder: A systematic review. *Autism*. 2016;21(4):387-402.
33. Volkmar. F., Seigel M., Woodbury-Smith M., King B., McCracken J., State M., Practice Parameter for the Assessment and Treatment of Children and Adolescents with Autism Spectrum Disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2014; 53(2):237-257.
34. AACAP. Use of Medical Marijuana in Children and Adolescents with Autism Spectrum Disorder for Core Autism. https://www.aacap.org/AACAP/Policy_Statements/2019/Use_of_Medical_Marijuana_in_Children_and_Adolescents_with_Autism_Spectrum_Disorder_for_Core_Autism_S.aspx?utm_source=Informz&utm_medium=email&utm_campaign=Annual Meeting. Accessed October 6, 2019.

SUGGESTED READING

Adams N & Grieder DM, eds. *Treatment Planning for Person-Centered Care: Shared Decision Making for Whole Health*, 2nd Edition. Cambridge, MA: The Academic Press; 2013

Brown, J. F. *The emotion regulation skills system for cognitively challenged clients: A DBT-informed approach*. New York: Guilford Press; 2016

David L. Braddock, DL, Hemp RE, Tanis ES, Wu J and Haffer L. *State of the States in Intellectual and Developmental Disabilities*, 11th Edition. Washington, DC: American Association on Intellectual and Developmental Disabilities. 2017

Fletcher RJ, ed. *Therapy Approaches for Persons with Mental Retardation*. Kingston, NY: National Association for the Dually Diagnosed (NADD) Press; 2000

Höfer J, Hoffmann F, Bachmann C. Use of complementary and alternative medicine in children and adolescents with autism spectrum disorder: A systematic review. *Autism*. 2016;21(4):387-402

Schalock, R.L., Thompson, J.R., Tasse, M.J. *Changes in the Field Regarding Personal Support Plans*. American Association on Intellectual and Developmental Disabilities, March 2018.

Volkmar. F., Seigel M., Woodbury-Smith M., King B., McCracken J., State M., *Practice Parameter for the Assessment and Treatment of Children and Adolescents with Autism Spectrum Disorder*. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2014; 53(2):237-257.

Watson SL & Griffiths D, eds. *Demystifying Syndromes II: Clinical and educational implications of common syndromes associated with persons with intellectual disabilities*. Kingston NY: National Association for the Dually Diagnosed (NADD) Press; 2016

Developmental Disabilities System – Discussion Vignette I – Trainee Version

You have been asked to participate in the child and family team for Michael, an eight-year-old boy whom you are treating for attention-deficit/hyperactivity disorder. The school has recently identified him as having a mild Intellectual Disability and Autism Spectrum Disorder. His mother tells you that Michael has several cousins with learning problems and one uncle who has been diagnosed with autism and wonders if Michael's problem "runs in the family." Michael has also been treated with Tegretol for several years for a seizure disorder but has not seen a neurologist since his diagnosis. The prescription has been refilled by his pediatrician, but Michael has recently started to have "staring spells" again.

1. As "Medical Care Manager" for the team, what consultations would you arrange?
2. The Genetics consultation resulted in a diagnosis of Fragile X syndrome. How does this change your treatment plan?

The child and family team is working on an Individualized Service Plan for Michael and his family.

- a. Who is on the team?
- b. What is the purpose of the ISP?
3. What is the role of Michael's CAP?
4. What manual could help guide the CAP in his/her work with Michael?
5. Michael's CAP could receive training or technical assistance from what state resource?
6. What is the focus of the UCEDD?

Developmental Disabilities System – Discussion Vignette II – Trainee Version

Garrett was diagnosed several years ago with autism spectrum disorder and his family is looking desperately for ways to increase his sociability and improve his language skills. Several medication trials have not improved his symptoms as much as his parents would have liked. The last medication trial with Risperdal caused Garrett to gain 20 pounds, which greatly alarmed his mother and father.

Garrett's parents come to you seeking guidance about the use of complementary and integrative medicine. They have heard about special diets, megavitamin treatment, and even CBD oil, but are unsure how to proceed.

1. What advice do you give them?
2. The parents tell you that people on the autism blogs are recommending CBD oil and ask if you recommend its use. What do you reply?
3. Parents finally ask if there any interventions that are effective to increase his socialization and peer interactions. Looking at the evidence base, what do you discuss?

Developmental Disabilities System – Discussion Vignette III – Trainee Version

Linda is a twelve-year-old girl who moved with her family to your state during the summer. She had been failing in her regular class room for the past three years and had been called a “slow learner.” She has been in school for four weeks and already the teacher has noticed that Linda is not keeping up with the other students academically. You are a child psychiatric consultant to a pediatrics practice and Linda’s mother has voiced her concerns about her problems at school. She also reports that Linda’s developmental milestones were delayed in comparison to her other children. You suspect that Linda may have a mild intellectual disability. Her pediatrician has asked you to help develop a plan for Linda.

1. What suggestions do you have for the pediatrician?
2. During your interview, Linda expresses sadness as she has begun to have some awareness of the differences between herself and the other children academically and feels “left out” from some activities by her classmates. What are your next steps?

It is now eight years later and Linda is graduating from high school and looking forward to starting full time work at the veterinarian’s office where she has been working part-time over the last two years through a vocational program at school. Linda has successfully traveled from school to work and then home on public transit without problems for over a year. She is hoping to share an apartment with a friend from school once she has saved up enough money for her portion of the security deposit.

3. Her parents express their concerns about Linda living on her own and are asking you whether or not they should pursue guardianship for her. What is your assessment of the issue?
4. What is Person Centered Planning process?
5. What has Linda already identified as a specific future goal that could be addressed with a PCP process?