

Center for Excellence in Disabilities (CED) Trainee Handbook



PROVIDING LEADERSHIP IN THE DEVELOPMENT OF SERVICES AND
SUPPORTS FOR PERSONS WITH DISABILITIES.

THE LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES (LEND) GRANT IS
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2016-2017 CED Trainees

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About the CED

Established in 1978, the Center for Excellence in Disabilities (CED) at West Virginia University (WVU) is a part of a national network of University Centers for Excellence in Developmental Disabilities (UCEDDs). UCEDDs were created in 1963 by the federal government with the enactment of Public Law 88-164 to serve people with intellectual disabilities. Today, there are sixty-seven (67) Centers across the country, authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (PL- 106402), to serve as resources for Americans with a wide range of disabilities. The sixty- seven (67) Centers, at least one in every state and territory, are affiliated with a major research University and serve as a resource for people of all ages. Centers work with people with disabilities, members of their families, state and local government agencies, and community providers in projects that provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to sustain all their citizens.

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. To implement their core functions of providing preservice preparation, services (including technical assistance, community education, and direct services), research, and information dissemination, UCEDDs leverage their core funding to partner with other federal, state, and local resources.

The CED is located in Morgantown, West Virginia and has a satellite office in Big Chimney, West Virginia with staff located in offices across the state to better serve clients in their communities. The West Virginia Center is a unit within West Virginia University (WVU), Health Sciences, and because of the placement within the University, has access and alignment with the Schools of Pharmacy, Public Health, Nursing, Medicine and Dentistry. Reporting authority with WVU supports the opportunity for collaboration, education and training needed to support and strengthen the state's capacity to meet the needs of persons with disabilities. The CED's role is to provide education and training to University students in multiple disciplines; educate direct care providers who serve persons with disabilities; and provide policy makers with objective information about the status of disabilities services in West Virginia. The CED also provides gap-filling direct services and supports in an effort to improve availability and acceptability of services.

West Virginia's Center for Excellence in Disabilities, in partnership with the Developmental Disabilities Council (DDC) and the State Protection and Advocacy agency, West Virginia Advocates (WVA), is engaged in capacity building, advocacy and systems change that promotes the integration and inclusion of people with disabilities in community life.

Graduate Assistants Guidelines

The WVUCED provides graduate assistant trainee opportunities to WVU students pursuing health and human service degrees. Traineeships may include stipends and tuition waivers based upon availability of funding. Internships and practicum opportunities are also available to undergraduate students based on availability and programming.

Trainee Enrollment

Upon being selected as a CED trainee, the student will be notified by the Training Coordinator or program supervisor. Once the student has accepted the offer, Trainee Registration, Student Support Identification, Background Check and Tuition Waiver Memo forms must be completed. Trainee Contracts are signed when the student begins work and discusses roles and responsibilities with supervisors.

As a part of the Robert C. Byrd Health Sciences Center, the CED must also follow policies established by HSC for their students. These include proof of current immunization (TB and Hepatitis B1, 2, and 3) and certification in compliance with the Health Insurance Portability and Accountability Act (HIPAA). Staff at the CED will ensure your opportunity to receive HIPAA certification, which must be completed yearly and may be included on your resume.

Requirements of Training Participants

Long-term Trainees

Long-term trainees are those who will complete over 300 hours of training in one academic year with the CED. Most graduate assistants are expected to work 20 hours per week, meeting all requirements within the 20 hours. Trainees receiving partial assistantships will negotiate hours and duties with program managers and mentors. All long-term trainees must complete the Orientation, a Core Course (DISB 580, Disability and the Family, or DISB 585, Disability and Society), the Professional Development Seminar, and a minimum of 45 hours of interdisciplinary clinical and field experiences. Long-term trainees may also complete DISB 581, Lifespan Disability Policy. The rest of the time will be spent in interdisciplinary clinical and field settings, and meeting other CED requirements. The WVU for-credit courses can be part of graduate students earning a graduate certificate in Disability Studies. For more information, contact Dian Williams, MSW, the Disability Studies Program Coordinator at awilliams@hsc.wvu.edu.

Intermediate-term Trainees

Intermediate-term trainees are defined as those who will complete 40-299 hours of training in one academic year with CED. However, trainees who are funded by another department (for example, Physical Education and Motor Development), who would meet the number of hours to qualify as long-term trainees, will be considered intermediate-term trainees for the purpose of meeting CED training requirements. All intermediate-term trainees must be registered as such by completing and submitting the CED Trainee Registration Form. All intermediate term trainees must attend interdisciplinary clinics, and become familiar with family-centered care.

Short-term Trainees

Short-term trainees are defined as those who will complete less than 40 hours of contact training in one academic year with the CED. These individuals must complete and submit the CED Trainee Registration Form. Minimum requirements for short-term trainees are the observation of an interdisciplinary clinic, and observation and participation in an interdisciplinary staffing.

Other University Students

Other University students are those who are not registered as CED trainees and who meet at least one of the following:

- Enrolled in University courses related to disabilities, taught by CED faculty/staff, and carrying academic credit;
- Enrolled in University courses related to disabilities and carrying academic credit for which CED faculty provide one or more lectures;
- Receiving other structured experiences in the CED which does not otherwise meet the definition of CED Interdisciplinary Trainee;
- Students enrolled in the Undergraduate Disability Certificate or minor or graduate students enrolled in the Graduate Certificate in Disability Services.

Professional Conduct of CED Trainees

Time Commitment

All long-term full-time Graduate Assistants must complete 20 hours per week for the duration of their assistantship. During the 20 hours per week, time will be spent in formalized training, interdisciplinary clinical or field settings and specific CED activities. Trainees must attend a core course for one semester, and the leadership seminar for two semesters.

The CED operates on the WVU faculty calendar and, as such, does not have Christmas or spring breaks. Graduate Assistants are expected to fulfill their obligation of 20 hours per week during breaks. However, in the case of Thanksgiving and Christmas when WVU faculty and staff have a holiday, the hours required will be less than twenty, depending upon the number of days off for faculty and staff. Graduate Assistants are expected to work one-half the number of hours in a week as the faculty and staff. For example, if the faculty is given three days off (24 hours) and working two days (16 hours), then graduate assistants will be expected to work one day (8 hours). Arrangements may be made with the graduate assistant's supervisor to allow time for out-of-town travel by accumulating additional hours. These arrangements must be approved prior to the holiday or break.

Confidentiality

All CED faculty, staff, and trainees may have access to client information for service, training, and/or evaluation purposes. Client information may not be shared with others unless the client or the parent(s)/guardian signs the CED Informed Consent Form to release the information to people or agencies outside CED and the WVU Health Sciences Center. Information gained from talking to community and

state agency personnel should also be handled confidentially and professionally in accordance with the Privacy Practices Policy (See Privacy Practices Policy page). Trainees are expected to behave in ethical, diplomatic, and discreet ways regarding the sharing of information within CED/Health Sciences Center and with outside agencies with which they may deal. All trainees should read, sign, and submit the Confidentiality and Security Agreement to the Trainee and Clinical Services Coordinator.

Data Collection

All trainees are required to submit data regarding their activities to the CED Data Manager. The Data Manager will provide trainees detailed instructions for completing data forms.

Dress Code

In many cases, a trainee's affiliation with CED is the beginning of a career in which he or she will be expected to exhibit professionalism in behavior, as well as appearance. Trainees are expected to dress in a manner that is consistent with appropriate professional attire. Jeans may be worn at the CED and in some field experiences depending upon the situation. For example, mentors may suggest to trainees to "dress down" when going on a home visit. Jeans with holes, shorts, low cut tops, and athletic shoes are not considered professional dress and should not be worn at CED or in clinical settings.

Use of CED Resources

Trainees have access to resources that may be necessary to the fulfillment of their specified duties at CED. These include use of the copy machine, long distance telephone calls, fax machine, job-related travel, and computers. Questions regarding specific uses of these resources should be addressed to the trainee's supervisor or mentor. The CED Resource Center, located in Room 111, is available to students, professionals, community members and people with disabilities to get information on disabilities. The Resource Center includes information on disability law, research and best practice, referral sources, advocacy supports and community living and is located in Room 111.

Evaluation

Trainees will also be asked to complete a program evaluation form of their training with CED at mid-term and at the end of each semester. At the completion of the traineeship, the student will meet again with the Public Relations/Dissemination Manager and complete a Self-Evaluation and an Exit Interview. These evaluations will be submitted to the Trainee and Clinical Services Coordinator and retained in the trainee's permanent file. It is critical that trainees provide an email address at this time that will remain in use throughout the follow-up period.

Follow-up

One year after leaving CED, the trainee will be contacted and asked to complete a follow-up evaluation and information form. Follow-up will be conducted at 1 year, 5 years and 10 years out. Information will be used to evaluate and improve the programs of the CED. Trainees may be contacted for several years after their tenure at the CED so it is important to keep in touch with us for any contact information changes.



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Trainee Registration Form

Disability Studies Certificate Student ☐

Registration Date _____/_____/_____

Name _____ WVU ID# _____

Birth Date _____/_____/_____ Gender ☐ Male ☐ Female

Ethnicity ☐ Hispanic

Race (White, Black, Asian, Am. Indian, Multi-racial, Other)

First Day of Training _____/_____/_____ (month/day/year)

Anticipated Last Day of Training _____/_____/_____ (month/day/year)

*Current Contact Hours _____ Total Hours per Year (20 per wk x 36 wk = 720 hrs)

☐ Long Term (300+ Hrs) ☐ Intermediate Medium 1 (40-149 Hrs) ☐ Intermediate Medium 2 (150-299 Hrs)

☐ Short Term (1-39 Hrs)

Your Discipline _____ Enrollment Status ☐ Full-Time ☐ Part-Time

Current Academic Level _____ Degree Program (BA, MS, PhD

etc) _____ Academic Degree(s) Achieved _____ Year Awarded

Are you a LEND Trainee? ☐ Yes ☐ No

Are you a CED Pre-Service Prep and Continuing Education Trainee? ☐ Yes ☐ No

Position Title at Admission: _____

Position Setting at Admission: _____

(Student, Schools, Post-Secondary, CED/LEND, Government, For-Profit, Non-Profit, Public Health/Title V, Hospital, Private Practice)

Personal Relationship with Disabilities: Is the trainee a

☐ Person with a disability ☐ Person with a special health care need (SHCN)

☐ Parent of a person with a disability ☐ Parent of a person with a SHCN

☐ Family member of a person with a disability ☐ Family member of a person with a SHCN Support Type:

(Core grant funding) ☐ MCH ☐ ADD ☐ OSEP

(Other funding) ☐ Clinical Fees ☐ Academic Dept ☐ Fellowship/Scholarship

☐ Internship ☐ Other ☐ None/Not Applicable

Stipend \$ _____ Tuition & Fees \$ _____ Travel \$ _____ Total \$ _____

Type of Participation: ☐ Didactic ☐ Clinical ☐ Research ☐ Practicum/Field work ☐ Other _____ Which of the following training curricula is the trainee completing (independent of trainee's funding source)

☐ MCH/LEND ☐ CED/ADD ☐ OSEP ☐ Pediatric Residency

☐ Other _____ ☐ Not Applicable

CED Supervisor: _____

Faculty Advisor: _____

Training Site: _____

Informed consent and Confidentiality Statement: I understand that the information disclosed on this form might be used to compile national statistics on training programs such as ours, and that it will not be used for any other purpose without my explicit consent. I also understand that it is incumbent upon all trainees at CED to keep all client information, both written and verbal, in strict confidence during their tenure at CED and thereafter.

Signature: _____ **Date:** _____

Current Address _____
Street _____ City _____ State _____ Zip _____
Phone _____ WVU MIX E-mail address _____

Permanent Address (parents or permanent contact, for follow-up)

Permanent Address _____
Street _____ City _____ State _____ Zip _____
Phone _____ Alternate E-mail address _____



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Student Support Identification Form

Date: _____
Name: _____
Discipline: _____

Fiscal Year: _____
Date of Birth: _____

Funding Source (s): _____

Mentor: _____
Training Coordinator: _____

Period of Support: _____ (# mos.)
_____ (start/end dates)

CED Support Level:

First Year Masters	\$1,378/month	_____
	Second Year Masters	\$1,444/month _____
First Year Doctoral	\$1,511/month	_____
	Second Year Doctoral	\$1,578/month _____
	Third Year Doctoral	\$1,644/month _____

Signatures:

Mentor: _____ Date: _____

Training Coordinator: _____ Date: _____

Director: _____ Date: _____

Note: After completion, submit to Ken Rodeheaver, Assistant Director for Finance and Operations, for processing onto WVU Payroll.



Department of Human Resources

Request for Background Check

☐ Faculty ☐ FEAP ☐ Non-Classified ☐ Classified ☐ Mt Temp ☐ Seasonal
☐ Student ☐ Volunteer ☐ Interim ☐ Re-classification ☐ Re-assignment

☐ Internal ☐ External

Name: _____
First Middle Last

Email: _____

Daytime Phone # (____) _____ Cell Phone # (____) _____

Position Title: _____ # _____

Department Name: _____

West Virginia Institution:

☐ Main Campus
☐ Charleston
☐ Extension
☐ Health Science Center
☐ Institute of Technology
☐ Parkersburg
☐ Potomac

Background Check Type:

☐ Standard 7-yr Background (criminal, crime guard, social security #, national/federal)
☐ DMV Check
☐ Education Check

Authorizing Signature

Date

Confidential

Leadership Education in Neurodevelopmental Disabilities (LEND)

About LEND – From the Association of University Centers on Disability (AUCD) website

Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs provide long-term, graduate level interdisciplinary training as well as interdisciplinary services and care. The purpose of the LEND training program is to improve the health of infants, children, and adolescents with disabilities. They accomplish this by preparing trainees from diverse professional disciplines to assume leadership roles in their respective fields and by insuring high levels of interdisciplinary clinical competence.

LEND programs operate within a university system, usually as part of a University Center for Excellence (UCEDD) or other larger entity, and collaborate with local university hospitals and/or health care centers. This set-up gives them the expert faculty, facilities, and other resources necessary to provide exceptional interdisciplinary training and services.

There are LEND programs located in 42 U.S. states, with an additional six states and two territories reached through program partnerships. Collectively, they form a national network that shares information and resources and maximizes their impact. They work together to address national issues of importance to children with special health care needs and their families, exchange best practices and develop shared products. They also come together regionally to address specific issues and concerns.

While each LEND program is unique, with its own focus and expertise, they all provide interdisciplinary training, have faculty and trainees in a wide range of disciplines, and include parents, persons with disabilities or family members as paid program participants. They also share the following objectives:

1. Advancing the knowledge and skills of all child health professionals to improve health care delivery systems for children with developmental disabilities;
2. Providing high-quality interdisciplinary education that emphasizes the integration of services from state and local agencies and organizations, private providers, and communities;
3. Providing health professionals with skills that foster community-based partnerships; and
4. Promoting innovative practices to enhance cultural competency, family-centered care, and interdisciplinary partnerships.

The LENDs grew from the 1950s efforts of the Children's Bureau (now the Maternal and Child Health Bureau) to identify children with disabilities as a Title V of the Social Security Act program priority. They are currently funded in part under the 2006 Combating Autism Act and are administered by the Health Resources and Service's Administration's (HRSA) Maternal and Child Health Bureau (MCHB).

West Virginia University LEND

The Center for Excellence in Disabilities at West Virginia University receives funding for the Leadership Education in Neurodevelopmental Disabilities (LEND) program from the US Department of Health Resources and Service Administration (HRSA). It has been continuously refunded for over 20 years.

The purpose of the LEND Program is to contribute to the development of clinically competent leaders, skilled in the interdisciplinary process, who make family-centered, coordinated care a reality and improve the health status of infants, children, and adolescents with, or at risk for Autism and related neurodevelopmental disabilities, and their families.

LEND prepares health professionals to assist children and their families in achieving their developmental potential by forging a community-based partnership of health resources and community leadership. Program objectives are to identify, recruit, and select health care professionals who have a demonstrated commitment to children with special health care needs; to prepare MCH/LEND trainees who can participate in interdisciplinary activities with family-centered care; and to develop leaders who are capable of working in rural Appalachian community, hospital and clinic-based health care. To meet these objectives, the Program sponsors interdisciplinary clinics, utilizes various classroom and clinical training methods, and provides leadership and training observation opportunities.

This Interdisciplinary Training Manual outlines the specific opportunities and requirements for long-term trainees who are funded by MCH/LEND. This program is designed to offer the trainee a wide variety of experiences in various clinical, educational, and community settings. In addition, the leadership training opportunities are intended to provide occasions for trainees to gain experience in observing and participating in leadership activities. The following provides guidelines for trainee requirements and responsibilities.

PROGRAM REQUIREMENTS FOR LEND

1. Orientation

The orientation program, conducted at the beginning of each fall semester, introduces trainees to the WVU CED. It provides an overview of the Center's management system and operations, an introduction to the core faculty and staff, and an overview of the goals and objectives. Orientation begins the learning process for trainees to become committed to and involved in delivery of support, within their discipline, to people with disabilities and their families. All trainees are required to attend the orientation.

2. Core Courses

Disability Studies Courses

Graduate students may complete a Certificate in Disability Studies which will include some of the following courses. Contact Diane Williams at awilliams@hsc.wvu.edu for more information.

DISB 580. Disability and the Family. 3 Hours. This course is designed to familiarize students with developmental disabilities and their impact on families. Interdisciplinary, family-centered care is emphasized, along with how to access resources to meet the needs of children and families.

DISB 581. Lifespan Disability Policy. 3 Hours. Overview of health, education, financial and related policies impacting individuals with disabilities across the lifespan and at the federal, state, and local levels.

DISB 585. Disability and Society. 3 Hours. This course provides a global, interdisciplinary overview of issues and policies that are the concern of individuals with disabilities (e.g., public policy, health-related issues, employment, and social benefits).

3. Interdisciplinary Clinics

The Feeding and Swallowing Disorders Clinic meets weekly in the CED clinic space. In conjunction with LEND mentors, trainees participate in assessment, reporting, care coordination and follow-up for children who have neurological, physiological and behavioral difficulties with eating.

The Next Steps Clinic meets for two hours on the second and fourth Thursdays of the month in the CED clinic space. In conjunction with the LEND mentors, trainees participate in assessment, reporting, treatment coordination, and follow-up for children with a variety of disabilities and their families. Particular emphasis is placed on assisting individuals with disabilities as they encounter life transitions. An interdisciplinary, family-centered model is followed. This clinic not only provides a valuable service to children and their families, but also provides clinical, management and leadership opportunities for trainees.

4. The Family Partnership Program

The Family Partnership Program provides trainees the opportunity to learn directly from a family rather than from clinical or didactic experiences alone. This program provides trainees with an in-depth experience with a family of a child with special health care needs. Through this program, trainees will acquire an understanding of the elements of a family-centered approach and will demonstrate a working knowledge of the ways in which existing systems and policies can become more responsive to family concerns and priorities. The Program offers a unique training opportunity that cannot be obtained through reading, attending lectures, or practicum experiences, by allowing the trainee to directly experience what it is like to have and care for a child with special needs on a daily basis.

The coordinator of the program and a parent of a young woman with special health care needs is available to provide resources and support to trainees throughout the academic year and to meet with students as needed during the fall and spring semesters. Activities of the Family Partnership Program should also be reviewed on a regular basis with the Training Coordinator and the trainee's mentor.

The requirements of the program are purposely flexible to allow for the convenience of the family. Trainees should maintain regular contact with the family and should avoid activities that may be intrusive to the family. Through this program, each student will get a "true to life" feeling for what life is like in the home setting, as well as the educational and community setting. Graduates of the program have reported this experience as being one of their most rewarding in the LEND program.

The coordinator is responsible for linking one or two trainees with a family of their choice. The requirements of the program are listed below and trainees will record their experiences with their assigned families in a journal. These activities should include:

- 1) An introduction to the family by visiting with the family during a meal or other time when the family is engaged in a routine family activity;
- 2) A physician's appointment or any other parent-professional meeting;
- 3) Interactions with the family during two additional times convenient to the family; and, 4) An observation of the child in an educational or therapeutic setting.

The requirements listed above are to be completed by the end of the first semester. Students are required at the end of the first semester to contact the coordinator via email with an update on first semester requirements, including their journal notes.

During the spring semester, a special project is required. Together with the family, trainees identify goals and activities for the spring semester. These should be mutually beneficial, considering the learning needs of the trainee and the family's priorities. Trainees decide on a project or major activity that can be completed during the spring semester with the family. Some ideas for special projects for past trainees and families include:

- Developing a "Fun and Care Book" that the family could share with babysitters or respite workers about their child.

- Providing child care for the child and/or siblings.
- Helping a family to apply through WV Medicaid for assistive technology funding.
- Linking families with appropriate financial support systems such as SSI, Medicaid- Home & Community Based Waiver and the WV Family Support Program.
- Making a videotape of the child's functional abilities to be used to apply for medical equipment or an assistance program.
- Spending time observing the child in an educational setting and reporting back to the family (this will require permission from the school.)

At the end of the semester, the student is **required** to write a reaction paper that is concise and descriptive of the experience, detailing what was learned and how the experience compared to other training experiences and forums (readings, lectures, practica). The paper should be typed, double-spaced, and approximately three pages in length. A photograph of the trainee with the child and family should accompany the paper along with a CED Media Consent Form. The paper should be emailed to the coordinator no later than April 30. Contact the coordinator if you have any questions or concerns. The goal is to make this experience one that you will always remember as you head out into the world of work!

Family Partnership Program Mentor

Carrie Cobun-Stark, MA, NCC

Program Coordinator

Klingberg Center for Child Development

(304) 293-2890 or (304) 293-7331

Email: ccobun@hsc.wvu.edu

5. Clinical and Community Observation Experiences

A wide variety of clinics and community settings are available for observational experiences. The observational experiences will be determined with mentors and the LEND Training Coordinator as part of the Individualized Training Plan (ITP). A journal entry describing the experience should be completed for each experience and reviewed by the Training Coordinator. A monthly calendar of observational experiences is also required and will be reviewed by the Training Coordinator. For experiences that conflict with class times, trainees should arrange to observe during semester breaks or make alternate arrangements with the Training Coordinator. CED Clinics, WVU Clinics and Community Clinics are arranged by the Training Coordinator. Jennifer Forester, MSW, arranges clinics at the WVU Physician Office Center. Her phone number is 304-293-1244 and her email is jforester@hsc.wvu.edu.

CED Clinics

Clinic: Feeding and Swallowing Disorders Clinic *

Place: CED, 959 Hartman Run Rd.

Time: Thursdays, 10:00-12:00

Contact: Monica Andis, M.S., R.D., 293-4692 or mandis@hsc.wvu.edu

Description: This clinic is staffed by an interdisciplinary team from the areas of nutrition, psychology, speech pathology, and social work.

Learning Objectives: The student will learn about:

- Feeding problems that occur in children with disabilities
- Complex medical conditions that affect feeding and swallowing
- Behavioral components of feeding problems
- Resources available to help children with feeding problems and their families

Clinic: Next Steps LEND Clinic*

Place: CED, 959 Hartman Run Road, Ground Floor Clinic Time: Second and fourth Thursdays, 1-3 p.m.

Contact: Diane Williams, LEND Training Coordinator, 304-293-4692, awilliams@hsc.wvu.edu

Description: Interdisciplinary clinic for children and adolescents and their families experiencing difficulties with transition or with systems impacting their lives.

Learning Objectives: The student will learn about:

- Types of disabilities that affect children, especially autism
- How children are evaluated and assisted by an interdisciplinary team
- Resources available for assisting children with disabilities and their families.
- Families barriers to obtaining services or issues with systems
- How families can assist the child or teen with disabilities in effective life transitions.

WVU Physician Office Center Clinics

Clinic: Children with Special Health Care Needs (CHSCN) Seizure Disorder Clinic

Place: Physician Office Center, Pediatrics, 2nd Floor

Time: The CHSCN seizure clinic, third Monday afternoon and the fourth Tuesday of each month.

Contact: Jennifer Forester, M.S.W., 293-7331 or jforester@hsc.wvu.edu

Description: The students will observe different neurologic diagnoses and treatments via an interdisciplinary team that includes a social worker, a parent advocate, nursing, and pediatric neurologists. Clinic time ranges from 15 minutes to longer, based on the needs of the child.

Learning Objectives: The student will learn about:

- Differing neurologic diagnoses
- Workings of an interdisciplinary team
- Resources available to families through CHSCN

Clinic: Cleft Lip and Palate Clinic

Place: Physician's Office Center, 1st Floor, Otolaryngology (ENT) Time: Second Wednesday of every month,

1-4 p.m.

Contact: Monica Andis, M.S., R.D., 293-4692, ext 1148 or mandis@hsc.wvu.edu

Description: This clinic provides diagnostic and follow-up services for children of all ages who have cleft lip and palate. Disciplines directly involved in the clinic include speech pathology, dentistry, nursing, nutrition and otolaryngology.

Learning Objectives: The student will learn about:

Causes of Cleft Lip and Palate including genetic syndromes

How a multi-disciplinary team assists children with cleft palate and their families

Resources available for children with cleft palate and their families

Clinic: Genetics Clinic

Place: Physician's Office Center, 2nd Floor, Pediatrics, Special Clinics Suite Time: As arranged

Contact: Jennifer Forester, 304-293-1244.

Description: Children and families with, or suspected of having, genetic disorders are provided services consisting of assessment, service coordination, genetic counseling, and follow-up.

Learning Objectives: The student will learn about:

Causes and treatment of genetic disorders.

Causes of health problems due to exposure before birth to toxic substances.

Resources available to help those with genetic disorders and their families.

Clinic: Genetics Outreach Clinics

Place: Charleston, Martinsburg, Wheeling, Parkersburg, Charleston and Huntington.

Time: As arranged.

Contact: Jennifer Forester, 304-293-1244. Description: Same as above.

Learning Objectives: Same as above.

Clinic: Klingberg Neurodevelopmental Center, Attention Deficit Disorder Clinic

Place: Physician's Office Center, 2nd Floor Pediatrics, Special Clinics Suite Time: Varies.

Contact: Jennifer Forester, M.S.W., at 293-1244 or jforester@hsc.wvu.edu

Description: Through observation, the trainee will learn the diagnostic criteria for a diagnosis of ADD in a medical clinic setting. Clinic time is typically 1 ½ to two hours.

Learning Objectives: The student will learn about:

Diagnosis of ADD and ruling out other diagnostic possibilities

Importance of psycho-educational evaluations and how to interpret them

How to score Hawthorne ADD assessment scales

Treatment and follow-up for ADD

Identifying resources available, through websites, books, to children and families that receive a diagnosis of ADD

The importance of IEPs and 504 Plans

Clinic: Klingberg Neurodevelopmental Center, Neurodevelopmental Clinic

Place: Physician's Office Center, 2nd Floor Pediatrics, Special Clinics Suite Time: Varies.

Contact: Carrie Cobun-Stark, at 293-2890 or ccobun@hsc.wvu.edu

Description: Students will observe a diagnostic assessment for a child typically under that age of 4 with concerns

for an autism spectrum disorder. Clinic sessions typically last 3 hours.

Learning Objectives: The student will learn about:

- Diagnosing an autism spectrum disorder in a medical setting
- Administering and scoring a developmental assessment tool, the DP-3 Scale (GARS) with autism
- Administering and scoring the Gilliam Autism Rating
- Delivering sensitive information to families
- Resources available in the state of WV for assistance

WVU Clinics spectrum disorders.

Clinic: Audiology Clinic

Place: Allen Hall, WVU Evansdale Campus

Time: Monday through Thursday, 9:30-11:30, 1:30-3:30

Contact: Gayle Neldon, gayle.neldon@mail.wvu.edu, 293-4241 Description: Clients of all ages receive outpatient audiology services.

Learning Objective: The student will learn about:

- Hearing screening and evaluation
- The importance of hearing in language development
- Types of hearing problems in children and adults

Clinic: Speech and Language Pathology Clinic

Place: Allen Hall

Time: Monday through Thursday, 9:30-11:30, 1:30-3:30

Contact: Karen Haines, karen.haines@mail.wvu.edu, 293-4241

Description: Clients of all ages receive outpatient speech language therapy.

Learning Objectives: The student will learn about:

- Individual benefits from a speech language evaluation
- Components of a speech evaluation
- Interpreting results from standardized speech language evaluations
- Conducting speech language therapy

Clinic: Augmentative Communication Clinic

Place: Allen Hall, WVU Evansdale Campus

Time: Monday through Thursday, 9:30-11:30, - 1:30-3:30

Contact: Karen Haines, MS, CCC/SLP, karen.haines@mail.wvu.edu

Description: Clients who have severe oral communication problems are seen for assessment.

Each client is evaluated to determine the best possible communication system.

Learning Objectives: The student will learn:

- Augmentative Communication Basics
- Benefits of receiving augmentative communication services
- Low-tech to high-tech augmentative communication services and devices
- Funding sources for augmentative communication devices

Community Observation Experiences

Presbyterian Child Development Center

Place: Spruce & Willey Streets, Morgantown Time: 7:00 AM – 6:00 PM, Monday – Friday
Contact: Sharon Portaro, Director, Presbyterian Child Development Center, 304-292-2194.
Description: PCDC provides daycare and pre-school services to children, birth through five years of age. PCDC also offers a summer program to school age children up to age 12. They serve children with and without disabilities.

Learning Objectives: The student will learn:

- Typical child development in the pre-school population
- Atypical development in the pre-school population
- Structure and learning strategies of the pre-school classroom
- Discipline techniques for preschoolers

Special Education Instruction Settings

Place: Varies
Time: Varies
Contact: Diane Williams, M.S.W., CED Training Coordinator, awilliams@hsc.wvu.edu
Description: Trainees make observations in a special education classroom in a local public school, usually in conjunction with the Family Partnership Program.

Learning Objectives: The student will learn:

- How educational services are provided to children with disabilities
- Supportive services provided such as physical therapy, occupational therapy and speech
- Types of disabilities that children have who receive special education

Observation Room Etiquette

Observing patients during their time in clinic without intruding in their space is a benefit of having the Observation Room. Often there are many people in this setting, and it is important to know what behavior is appropriate and inappropriate. Mentors may wish to instruct by pointing out examples during observations, but lengthy discussions should be held during breaks to allow everyone to participate and learn.

Appropriate:

- Use a low tone of voice when making comment/observation
- Stay out of the way of others trying to see
- Be aware of personal space
- Write down questions for further discussion during break
- Remain in the room during the observation

Inappropriate:

- Don't talk or laugh loudly since the Observation Room is not soundproof
- Don't hold a discussion about other topics, especially personal matters, with others during the observation
- Don't enter and exit the observation room excessively
- Don't have paraphernalia (books, bags, coats, etc.) taking up room in the setting, making it difficult to get to a seat
- Don't stand in front of the mirror, blocking the view of others

6. Leadership Requirements Summary Part-Time (5/9) Trainees

Trainees who are being supported at the 5/9 level of funding will be responsible for completing 11.1 hours per week of LEND activities. Trainees are expected to attend the monthly Journal Club (1 hour per month), the Leadership Seminar (2 Hours) per month and the courses Disability and the Family (3 hours per week, 45/semester) and Life Span Disability Policy (3 hours per week/45 semester) or Disability and Society. It is also recommended that trainees attend the weekly Feeding and Swallowing Clinic (2 hours) and the twice monthly LEND Next Steps Clinic (2 Hours). Other hours may be chosen from the items indicated below. Trainees will develop the ITP (Individual Training Plan) during Orientation in which their own specific schedule will be completed with the assistance of the LEND Training Coordinator.

Leadership Requirements for 2016- 2017 Academic Year

Activity	Required	Number Required
Orientation	X	1 day
Leadership Pre-Survey	X	1
Leadership Portfolio (electronic)	X	1

ITP	X	1
Journal	X	1
Cultural Competency Assignments	X	At least 2
Leadership Development Seminar	X	3 rd Thursday
Feeding and Swallowing Clinic	X	Weekly
Next Steps LEND Clinic	X	Twice monthly 2 nd and 4 th Thurs.
Clinic Observational Experiences	X	At least 6*
Leadership Field Experiences	X	At least 1
Journal Club/Reading Assignments	X	1 st Thursday
Disabilities and the Family, Disability and Society and Life Span (2 of 3)	X	Fall and Spring Semesters
Research activities (including IRB online tutorial)	X	
AUCD Conference	Recommended	1
AUCD Trainee List Serve	X	ongoing
Family Partnership Program	X	recommended
CED Trainee List Serve	X	ongoing
Leadership Post-Survey	X	1

*6 per year. Attendance at LEND Next Steps Clinic and the Feeding and Swallowing Clinic are required unless discipline coursework prohibits it. The other clinical observation experiences should be spread out so that no single clinic is attended more than two times. Additional leadership field experiences will be announced via CED Trainee Listserv; however, if a trainee identifies a leadership or professional development opportunity, please share with the LEND Training Coordinator and/or share via the listserv.

Examples:

- *AUCD Conference
- *AUCD Council meetings
- *Advisory Board Meetings (WVATS, TBI)
- *Statewide trainings, conferences and workshops
- *HSC Grand Rounds
- *Statewide work groups and task forces related to disabilities
- *Community-based clinical experiences
- *Camp Gizmo
- *Poster presentations (completed by trainee)
- *Presentations (conducted by trainee or trainee and mentor)
- *Mentor and other faculty research projects
- *Shadowing Experiences with leaders in the field of disabilities

Monthly calendars will be provided to LEND trainees at orientations to assist with scheduling required activities. The LEND Training Coordinator will discuss calendar activities with trainees monthly.

Leadership Requirements Summary Full-Time Trainees

Trainees who are supported at the full-time (20 hours per week) level of funding will complete the activities listed below as part of the ITP (Individual Training Plan) developed during Orientation with the assistance of the LEND Training Coordinator.

Leadership Requirements for 2015- 2016 Academic Year

Activity	Required	Number Required
Orientation	X	1 day
Leadership Pre-Survey	X	1
Leadership Portfolio (electronic)	X	1
ITP	X	1
Journal	X	1
Cultural Competency Assignments	X	4
Leadership Development Seminar	X	3 rd Thursday
Feeding and Swallowing Clinic	X	weekly
Next Steps LEND Clinic	X	2 nd and 4 th Thurs.
Clinic Observational Experiences	X	10*
Leadership Field Experiences	X	2
Journal Club/Reading Assignments	X	1 st Thursday
Disabilities and the Family and Life Span Disability Policy Courses	X	Fall and Spring Semesters
Research activities (including IRB online tutorial)	X	ongoing
AUCD Conference	Recommended	1
AUCD Trainee List Serve	X	ongoing
Family Partnership Program	X	ongoing
CED Trainee List Serve	X	ongoing
Leadership Post-Survey	X	1

*10 per year. Attendance at LEND Next Steps Clinic and the Feeding and Swallowing Clinic are required unless discipline coursework prohibits it. The other clinical observation experiences should be spread out so that no single clinic is attended more than two times.

Additional leadership field experiences will be announced via CED Trainee Listserv; however, if a trainee identifies a leadership or professional development opportunity, please share with the LEND Training Coordinator and/or share via the listserv.

Examples:

- *AUCD Conference
- *AUCD Council meetings
- *Advisory Board Meetings (WVATS, TBI)
- *Statewide trainings, conferences and workshops
- *HSC Grand Rounds
- *Statewide work groups and task forces related to disabilities
- *Community-based clinical experiences
- *Camp Gizmo
- *Poster presentations (completed by trainee)
- *Presentations (conducted by trainee or trainee and mentor)
- *Mentor and other faculty research projects
- *Shadowing Experiences with leaders in the field of disabilities

Monthly calendars will be provided to LEND trainees at orientations to assist with scheduling required activities. The LEND Training Coordinator will discuss calendar activities with trainees monthly.

7. Mentoring

Trainees receive individual instruction and career guidance from the mentors in their disciplines. Mentoring activities include participation in the MCH/LEND Interdisciplinary Clinic and a combination of other clinical, didactic and consultative instruction as negotiated by the mentor and trainee and detailed in the Individualized Training Program (ITP). Trainees also meet with the MCH/LEND Training Coordinator to monitor progress in the program. The Training Coordinator utilizes the Next Steps LEND Clinic, the Feeding and Swallowing Clinic and individual and group consultation with trainees to assist with integrating the components of the LEND Program into a meaningful whole.

Research

Trainees will complete research related to their disciplines as part of their requirements in the Disabilities and the Family course, as research with their discipline mentors or as part of a discipline course.

8. Data Entry

Trainees will complete data entry monthly. The data collection system is currently under revision and students will be trained when more information is available.

9. Individual Training Plan, or ITP is developed early in the fall semester in conjunction with the trainee's mentor and the LEND Training Coordinator. The ITP should include both broad goals for learning and the specific action steps you will take to meet those goals. For example, a goal might be: Gain clinical experience in working with children with disabilities and their families. Action Steps would include attending the LEND Next Steps Clinic 2 times per month, attend Feeding Clinic weekly, and complete clinic/community observations.

LEND Mentors Contact Information

Monica Andis, MS, RD: Nutrition

mandis@hsc.wvu.edu

304-293-4692, ext 60661

Carrie Cobun-Stark: Family/Pediatrics

ccobun@hsc.wvu.edu

304-293-2890

Anne Cronin, PhD: Occupational Therapy

acronin@hsc.wvu.edu

304-293-0433

Jennifer Forester, MSW: Social Work

jforester@hsc.wvu.edu

304-293-7331, ext 1244

Mary Beth Hummel, MD: Genetics

mhummel@hsc.wvu.edu

304-293-7332

Maggie Jaynes, MD: Pediatric Neurology

mjaynes@hsc.wvu.edu

304-293-4692, ext 60676

Jodi Lindsey, MD: Neurodevelopment/Pediatric Neurologist

Jlink1@hsc.wvu.edu

304-293-7331

Mary Beth Mandich, PhD: Physical Therapy

mmandich@hsc.wvu.edu

304-293-1320

Linda Nield, MD; Medicine

lnield@hsc.wvu.edu

304-293-1217

Susannah Poe, EdD: Educational Psychology

spoe@hsc.wvu.edu

304-293-7331

Karen Haines: Speech Language Pathology

Karen.Haines@mail.wvu.edu

Diane Williams, MSW: Social Work

awilliams@hsc.wvu.edu

304-293-4692, 60678

TIME ALLOCATION

Full-time trainees sign a contract to spend twenty hours per week throughout the academic year on grant activities. Trainees follow the faculty calendar, and may need to plan on working during times when the University is open but class is not in session to meet the requirements of the LEND Program. The trainee's mentor and the LEND Training Coordinator will help plan activities during these times. Trainees should refer to the Training Manual for specific information regarding vacation time and semester breaks. While this is a training position, it is also the trainee's employment and should be treated as such by the trainee. Half-time trainees will work out a schedule with their mentors and the LEND Training Coordinator.

Training activities comprise five to seven hours per week in both the fall and spring semesters, and are described above. Trainees will also meet weekly as a group with the LEND Training Coordinator (approximately 1 hour per week) and with their mentors (1 or more hours per week). Other hours are assigned to clinic, field, or specific project activities.

REQUIRED DOCUMENTATION/REPORTING

Individualized Training Plan:

The Individualized Training Plan (ITP) is established for the trainee to work on his or her individual goals for interdisciplinary training. In conjunction with support from the supervisor and other CED faculty, the trainee works on activities that are geared toward his or her individual skills and interests, as well as meeting the needs of the particular CED project with which he or she is involved. Each trainee is expected to develop, with the Training Coordinator, an ITP during the first month of placement. All ITP's are kept in the permanent file of the trainee in the office of the Public Relations/Dissemination Manager. The ITP form follows on the next page.

Journal: Trainees will also maintain a journal as a means of evaluating progress towards meeting expected competencies. Trainees will record their experiences during clinical and non-clinical activities and the Family Partnership Program and discuss them with the Training Coordinator. The journal will be part of a portfolio of experiences that chronicles the impact of receiving in-depth training in interdisciplinary leadership. The journal should be kept electronically, with de-identified client information and submitted monthly to the Training Coordinator.

Time Log Sheet: Trainees are required to complete the time log sheet. A copy of the log is included under trainee documents in this manual. They should be completed at least monthly and a copy given to the trainee's program mentor. LEND trainees should also give the logs to Diane Williams, LEND Training Coordinator. These may be submitted electronically by emailing them to awilliams@hsc.wvu.edu.

Portfolio Development: In order to showcase the accomplishments of MCH/LEND trainees for prospective employers, an electronic record will be prepared to gather the year's work. Trainees will be given a jump drive to preserve journal entries, reports, projects and presentations, Family Partnership Program activities and other important activities. Trainees will share their endeavors with fellow trainees, new incoming trainees and mentors at the end of the spring semester.

TRAINEE/EMPLOYEE RIGHTS, RESPONSIBILITIES AND GUIDELINES

The WVUCED follows the policies and procedures for WVU as described in the following websites:

<http://bog.wvu.edu/policies>

<http://studentlife.wvu.edu>

(student rights and policies);

<http://diversity.wvu.edu/> (social justice guidelines);

<http://www.hr.wvu.edu/> (WVU Human Resources policies).

In addition, trainees are asked to meet the training requirements of the LEND grant and meet the educational standards of their individual disciplines. The Program Director and Training Coordinator attempt to mediate disputes between mentors and trainees. A plan of action is developed with input from all parties to address any serious concerns that arise (see sample of corrective action plan Appendix F). Should disputes beyond the trainee-mentor level arise, CED administrators may be asked to help mediate. Disputes may also be referred to the appropriate WVU authority.

Local Area Network (LAN) Accounts

LAN accounts have been created for all WVU trainees. These accounts provide you with access to the computers and the printer in our GA Room.

To access your LAN account, you should type in your first name as your User I.D. and your last name spelled backwards as your Password.

Any problems with using your LAN account should be reported to Jack Stewart, CED Assistant Director of Operations, jcstewart@hsc.wvu.edu.

AUCD Trainee Listserv

The Association of University Centers on Disabilities (AUCD) has established an un-moderated discussion list to bring together network trainees. We strongly encourage you to make use of this listserv to get to know trainees from other programs, problem solve together, and provide information about upcoming conferences, leadership opportunities, grant and employment information.

To subscribe to the listserv, send an e-mail to:

http://www.aucd.org/resources/alltrainee_subscription.cfm Include in the subject or body the command “subscribe”. The list administrator will approve and add your address to the list of participants. We hope to make this listserv enhance the training and learning experience and to develop into a useful resource for trainees at UCEDDs and LEND programs throughout the network.

CED Trainee Listserv: Trainees will be updated on upcoming activities such as clinical opportunities, webinars, Journal Club meetings and more by joining the trainee listserv. The list serve is

also used to discuss upcoming clinic clients using de-identified information. To subscribe contact Melina Danko at mdanko@hsc.wvu.edu.

Copying, Making Phone Calls, Sending Mail

As a trainee you are supported by funds allocated by your particular grant. Grants also pay for the day-to-day expenses of running a program. For this reason, when you need to make copies or long distance phone calls, your Program Manager will give you a code to enter into the copy machine or a TID number to enter into the telephone. These numbers track and ensure proper billing to the individual grant account. Likewise, when sending mail via the U.S. Postal Service, a mailing code is needed or stamps must be purchased with a Purchase Order. In these instances, please see your Training Coordinator/ Program Manager for a mailing code or postage stamps. All outgoing mail is placed in bins at the receptionist's desk. The receptionist will direct you to the correct bin.

Phones in the GA Room

There are two phones located in the GA Room. Extension 1169 may be used for incoming and outgoing calls. This is the extension number you should give out to others as it is the only phone currently programmed for voice mail. Extension 1170 should only be used for outgoing phone calls (e.g., when someone is using ext. 1169 and you want to make a phone call).

When there is a voice mail message(s) the red light will blink. For instructions to retrieve the message, contact the LEND administrative assistant in Room 223.

TRAINEE DOCUMENTS DIVIDER



Providing leadership in the development of services and supports for persons with disabilities.

CED Trainee Time Log Sheets

All long-term graduate assistants must complete 20 hours per week for the duration of their assistantship. During the 20 hours per week, time will be spent in formalized training, interdisciplinary clinical or field settings and specific CED activities. The CED operates on the WVU faculty calendar and, as such, does not have Christmas or spring breaks. Graduate assistants are expected to fulfill their obligation of 20 hours per week during breaks. However, in the case of Thanksgiving and Christmas when WVU faculty and staff have a holiday, the hours required will be less than twenty, depending upon the number of days off for faculty and staff. Graduate assistants are expected to work one-half the number of hours in a week as the faculty and staff. For example, if the faculty is given three days off (24 hours) and working two days (16 hours), then graduate assistants will be expected to work one day (8 hours). Arrangements may be made with the graduate assistant's supervisor to allow time for out-of-town travel by accumulating additional hours. These arrangements must be approved prior to the holiday or break.

Approved activities include: Hands on time at CED; Clinical/prep time; DISB 580, 581 & 585 course time; Meetings (community, professional, mentor, families, journal club, leadership, staff meetings, etc.); online activities; participation in other CED opportunities; entering data.

DATE	ACTIVITY	START TIME	END TIME	TOTAL HRS	NOTES

GA Signature

Note: An electronic copy will be sent to you via the CED Trainee Listserv



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MCH/LEND Individual Training Plan

Goal 1:

Action Steps:

Goal 2:

Action Steps:

Goal 3:

Action Steps:

Trainee Signature: _____ Date: _____

Mentor Signature: _____ Date: _____

Note: an electronic version of this document will be provided via the CED Trainee Listserv



PROVIDING LEADERSHIP IN THE DEVELOPMENT OF SERVICES AND
SUPPORTS FOR PERSONS WITH DISABILITIES.

Corrective Action Plan

Date: _____

Trainee Name: _____

Discipline: _____

Mentor: _____

Problems to be addressed:

- 1.
- 2.
- 3.

Actions Steps, Responsible Person(s), Dates

- 1.
- 2.
- 3.

Comments:

Signatures: (Training Coordinator, Trainee, Mentor)



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Student Trainee Evaluation To Be Completed by Mentor

Student: _____

Mentor: _____ **Discipline:** _____

Address: _____

Phone: _____ **E-mail:** _____

Please answer the following:

1. What special professional skills have you observed in this student trainee?

2. What professional skills should this student trainee continue to develop?

3. In what ways do you see this student trainee contributing to his/her field?

Circle the number that best describes the student's performance:

	Expectation:	Exceeds	Meets	Below
1. Was the student prepared to serve as a trainee?	3	2	1	
2. Did the student demonstrate knowledge of his/ her professional field?	3	2	1	
3. Did the student demonstrate skill in time management?	3	2	1	
4. Did the student demonstrate professional attitude/behavior?	3	2	1	
5. Was the student responsive to suggestions/ criticisms?	3	2	1	
6. Did the consumer benefit from contact with the student?	3	2	1	
7. Did the student work cooperatively in an interdisciplinary setting?	3	2	1	

Comments:



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Student Trainee Evaluation To Be Completed by Trainee

Student: _____

Address: _____

Phone: _____ **E-mail:** _____

Mentor: _____ **Discipline:** _____

Please answer the following:

1. What special professional/leadership skills have you developed during this traineeship?

2. What professional skills do you feel you should continue to develop?

3. In what ways do you see yourself contributing to your field?

Circle the number that you think best describes your performance:

	Expectations:	Exceed	Meet	Below
1. Were you prepared to serve as a trainee?	3	2	1	
2. Did you have sufficient background knowledge of your professional field?	3	2	1	
3. Did your time management skills meet the demands of the job?	3	2	1	
4. Did you demonstrate professional attitude/behavior?	3	2	1	
5. Were you responsive to suggestions/criticisms?	3	2	1	
6. Did the consumer benefit from contact with you?	3	2	1	
7. Were you able to work cooperatively in an interdisciplinary setting?	3	2	1	

Comments:



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EXIT INTERVIEWS FOR LONG-TERM TRAINEES

NAME _____ DEGREE _____

MENTOR _____ FUNDED THROUGH _____

DATE OF PARTICIPATION _____ TO _____

Some of these questions apply only to MCH/LEND trainees.

1. What are your plans after WVUCED?
2. What part (s) of your training here was most valuable enjoyable/interesting/informative?
3. What part (s) of your training here do you think will be most helpful in your future training or work? Why?
4. Describe your mentor relationship. Would you change anything about it?
5. Were the courses *Disabilities and the Family*, *Disability and Society* and *Life Span Disability Policy* helpful? Why or why not?
6. Were the Leadership Seminars and Journal Club helpful? Why or why not?

7. Was the Family Partnership Program useful to you? Explain.
8. Describe your clinical experiences. Would you change anything about them?
9. Is there anything additional the training program could offer students?
10. Where do you plan to be in five years? Ten years
11. Do you feel better prepared for professional work because of your WVUCED experience?
Why or why not?
12. Did you make use of the AUCD Trainee Listserv or the AUCD Web Page? In what way?
13. Was the CED Trainee Listserv helpful? Do you have any suggestions?
14. Which of the following best reflects your level of satisfaction with the training that you received at the CED?

_____ Highly satisfied

_____ Satisfied

_____ Satisfied somewhat

_____ Not at all satisfied

Please give us your future contact information so that we can send you a follow-up survey. This is a requirement of trainees and helps us with reporting and securing funding.

Permanent Address (or parent's address)

Permanent Email Address (not WVU)

Facebook or LinkedIn contact information (Please send a link request to Diane Williams)

Names of presentations or publications (including thesis or dissertation)



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CONFIDENTIALITY AND SECURITY AGREEMENT

As an employee, trainee, intern, or practicum student of the Center for Excellence in Disabilities (CED), you may have access to confidential information, including protected health information (PHI), business asset data, secret, proprietary, or private information obtained through your association with the CED. The purpose of this Agreement is to help you understand your personal obligation regarding confidential information.

Confidential information, including protected health information (PHI), business asset data, secret, proprietary, or private information is valuable and sensitive and is protected by law and by strict confidentiality policies. The Health Insurance Portability and Accountability Act of 1996 (HIPAA), establishes standards for the protection of patient information. Inappropriate disclosure of PHI may result in the imposition of fines up to \$250,000 and ten years imprisonment per incident.

Accordingly, as a condition of and in consideration of my access to confidential information, I agree to abide by the following:

I will not access confidential information, including protected health information (PHI), business asset data, secret, proprietary, or private information which I have no legitimate need to know and for which I am not an authorized user.

I will not in any way divulge, disclose, copy, release, sell, loan, review, alter or destroy any confidential information, including protected health information (PHI), business asset data, secret, proprietary, or private information, unless expressly permitted by existing policy except as properly approved in writing by an authorized officer of the CED within the scope of my association with such entity.

I will not utilize another user's password in order to access any system. I will not reveal my computer access code to anyone else unless a confirmed request for access to my password has been made by Information Technology Department and I am able to confirm the legitimacy of the request and the requesters. I accept personal responsibility for all activities occurring under my password.

If I observe or have knowledge of unauthorized access or divulgence of confidential information, including protected health information (PHI), business asset data, secret, proprietary, or private information, I will report it immediately to my supervisor and to the Privacy Officer or designee.

I will not seek personal benefit or permit others to benefit personally by any confidential information, including protected health information (PHI), business asset data, secret, proprietary, or private information that I may have access to or that I access as an unauthorized user.

I understand that all information, regardless of the media on which it is stored (paper, computer, videos, recorders, etc.), the system which processes it (computers, voice mail, telephone systems, faxes, etc.), or the methods by which it is moved (electronic mail, face to face conversation, facsimiles, etc.), is the property of the CED and shall not be used inappropriately or for personal gain and shall not be removed from the premises without prior authorization. I also understand that all electronic communication shall be monitored and subject to internal and external audit.

I understand that discussions regarding patient and/or protected health information shall not take place in the presence of persons not entitled to such confidential information and shall not take place in public places (such as elevators, lobbies, off premises, etc.).

I agree to abide by all rules and regulations as specified in the CED's policies unless specifically altered by a separate contractual agreement. I can request a copy of these policies be provided to me.

I understand that my failure to comply with this Agreement (intentional or unintentional) may result in disciplinary action, which might include, but is not limited to, termination of employment, traineeship, internship, practicum experience and/or loss of my privileges with the CED, dismissal from the premises, and could result in my being held personally liable in a court action by a patient or their family.

I understand that the obligations in this Agreement continue after the end of my association with the CED.

By signing this agreement, I acknowledge that the CED has an active, on-going program to review records and transactions for inappropriate access and I understand that inappropriate access or disclosure of information can result in penalties, including disciplinary action, termination, refusal of access to premises, and /or legal action.

Signature

Date

Printed Name



Providing leadership in the development of services and supports for persons with disabilities.

Notice of Privacy Practices

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION.

PLEASE REVIEW IT
CAREFULLY.

Private medical information includes any past, present, or future health condition you might have, health service you receive, and any record of payment for health service that you make or are made on your behalf. This information is also called ***Protected Health Information (PHI)***.

Your Privacy Rights:

Your right to inspect and copy. You or your legal guardian have the right to inspect and obtain a copy of your protected health information. You may request copies at any time.

Your right to authorize.

- You or your legal guardian have the right to authorize the release of any or all your protected health information to other providers.
- Your authorization is required before your protected health information can be used for marketing or sale.

Your right to opt out of fundraising requests. You have a right to opt out of any fundraising requests we may make of you. An opt-out provision must be included with any fundraising communication or materials.

Your right to request restrictions and make corrections. You or your legal guardian have the right to request certain restrictions and limitations in how your medical information is used. You may also correct and amend information in your medical records. For example:

- **Restrict routine disclosures.** You may ask us not to use or disclose any part of your protected health information (PHI) to others who might otherwise be routinely involved in the provision of services to you. We will comply with such requests but they may limit the services we can offer you.

- **Request confidential communications.** You have the right to request that we contact you and/or send your protected health information to an alternate location other than your home, and that we do not disclose your PHI to specific family members.
- **Request medical record corrections.** You have the right to make amendments to your protected health information. If the health care provider who wrote the entry that you would like to correct agrees with the correction, we will make the appropriate changes to the medical record. If the health care provider who wrote the original entry disagrees with your correction, we will not change the record but will include your corrections in the record to document your disagreement.
- **If you pay out of pocket for a medical service or test:** You have the right to instruct the medical provider of the test to NOT send the results to your medical insurer or health plan.

Your right to a paper copy and/or electronic copy of this notice.

Routine Disclosure of Your Protected Health Information

The law allows us to use and disclose your protected health information in certain routine ways. These are listed below.

In all cases, we will use and disclose the minimum amount of protected information necessary to fulfill each function.

For Treatment and Services. WVU CED providers working within specific programs or collaborating programs may discuss your protected health information (PHI) with other providers in those programs to discuss how to provide you with the best possible services. Students-in-training within those programs may also have access to your PHI. If you have an interdisciplinary treatment team or service coordination team, they may discuss your PHI with one another.

For Payment. Your protected health information could be disclosed to our in house accounting office as needed, in order to process billing claims or distribution of funds.

For Daily Activities and Organizational Operations. We may need to collect and disclose some of your protected health information when we provide service coordination, technical assistance, and treatment services. For example, we may disclose your PHI when referring you to other agencies, when making appointments for you, or when organizing a service coordination team or treatment team for you. In addition, we are obligated to conduct quality assurance activities of our privacy practices. In carrying out these activities, the quality assurance team may have access to your PHI.

If you are a WVU CED Clinic patient, your protected health information may be electronically collected and stored securely in a central WVU CED database. To assure continuity of care among WVU CED services, parts of this database may be viewed by authorized WVU CED personnel.

Research. Some WVU CED Programs conduct research studies. We will not use your protected health information for any research studies without your prior consent and written authorization.

De-identified Information. De-identified information is protected health information from which all personal identification has been removed. This means it can no longer be identified as yours and is no longer considered protected. Our center uses de-identified information for data collection, progress reports, research, and evaluation activities. For example, we might generate a report on the number of hours we spent giving technical assistance, or the number of people with

spinal cord injury we have served, or the number of children with cerebral palsy we have seen who need new wheelchairs.

Non Routine Situations Where We Must Disclose Your Protected Health Information.

The law requires us to disclose your protected health information under certain circumstances. In these cases, we can disclose your protected health information without your permission. Examples of such cases include: subpoenas or other court orders; suspected cases of domestic violence, abuse, or neglect; workers' and veterans' compensation requirements; to avert a serious threat to public health or safety; or to comply with governmental regulations.

In these cases, you have the right to know which individuals or agencies have received or reviewed copies of your protected health information. WVU CED staff will be happy to provide you with this information if you ask for it.

Change of WVU CED Ownership.

If the WVU CED becomes part of another organization in the future, your medical information will become the property of that new organization.

If You Think Your Right To Privacy Has Been Violated.

If you think we have violated your privacy rights, you may submit a written complaint to the West Virginia University School of Medicine Legal Services. You may also file a complaint with the U.S. Department of Health and Human Services (DHHS). All complaints filed with the U.S. DHHS must be filed within 180 days of when you first learned of the incident.

Paper copies of complaint forms are available at our receptionist's desk on the third floor of the WVU CED. If you prefer to contact the departments directly, here is contact information:

To request a complaint form
the WVU School of Medicine,
please call (304) 293-3584

To request a complaint form from
the U.S. Department of HHS,
please call (800) 368-1019
or visit the website

<http://www.hhs.gov/ocr/civilrights/complaints/>

The WVU CED reserves the right to change this notice at any time in the future. The effective date of this notice is at the bottom of page one. You may request a copy of any revised notice of privacy practices. Notices can be requested in person, by contacting your WVU CED staff by phone or email, or by visiting our website <http://www.cedwvu.org/>.

Appendix A

The Maternal and Child Health Bureau

The Leadership Education in Neurodevelopmental Disabilities (LEND) is funded by a federal agency, the Maternal and Child Health Bureau (MCHB). MCHB is part of the Health Resources and Services Administration (HRSA) which in turn is part of the U.S. Department of Health and Human Services (DHHS).

History of MCHB

MCHB grew out of the federal Children's Bureau which was established in 1912. It has operated as a Federal-State partnership for 75 years. When the Social Security Act was passed in 1935, the Federal Government, through Title V of the Act, pledged support of State efforts to extend and improve health and welfare services for mothers and children.

Title V has been amended many times over the years to reflect the expansion of the national interest in maternal and child health. It was converted to a block grant program in 1981. Congress later tried to balance the flexibility of the block grant with greater accountability by the States. In 1989, Congress required States to report on the progress made toward key maternal and child health indicators and performance measure.

Mission of MCHB

MCHB's goal is to improve the health of mothers, children, adolescents and their families. Their vision for the 21st century is that all children, youth, and families will live and thrive in healthy communities served by a quality workforce that helps assure their health and well-being.

Their goals are:

1. Address current and emerging MCH workforce needs by engaging with and providing support to MCH leaders in practice, academics and policy.
2. Prepare and empower MCH leaders from diverse communities to promote health equity, wellness, and reduce disparities in health and health care.
3. Promote interdisciplinary/interprofessional training, practice and interorganizational collaboration to improve quality of care by enhancing systems integration for MCH populations.
4. Generate and translate new knowledge for the MCH field in order to advance science-based practice, innovation, and quality improvement in MCH training, policies and programs.

Discretionary Grant Programs

MCHB has a wide range of programs funded by discretionary grants to target populations within the maternal and child health umbrella. Programs include Child Health and Safety, Oral Health, Children with Special Health Care Needs, Adolescents, Data, Evaluation and Epidemiology, Health Promotion and Disease Prevention, Genetics, Research, Training, Traumatic Brain Injury and Women's Health.

Training

The LEND Program is located in the Training component of MCHB and targets developing quality services for mothers, children and adolescents by preparing professionals who are:

- Attuned to the special needs of children, adolescents and children with special health care needs.
- Trained to provide or assure the provision of interdisciplinary, family-centered and culturally competent services.
- Focused on improving the health of the entire population.

Appendix B

UCEDD Funding and Federal Agencies

Department of Health and Human Services

The Department of Health and Human Services (HHS) has 13 different offices. CED training experiences are most likely funded by programs under HHS. The following offices are strongly linked to training or services for persons with disabilities. www.hhs.gov

The Administration for Children and Families (ACF)

The Administration for Children and Families (ACF), within the Department of Health and Human Services (HHS), is a federal agency funding state, territory, local, and tribal organizations to provide family assistance (welfare), child support, child care, Head Start, child welfare, and other programs relating to children and families. www.acf.hhs.gov

Administration on Community Living (ACL)

The ACL includes the Administration on Aging, the Office on Disability and the Administration on Developmental Disabilities in a single agency. ACL has enhanced policy and program support for both cross-cutting initiatives and efforts focused on the unique needs of individual groups such as children with developmental disabilities, adults with physical disabilities, or seniors, including seniors with Alzheimer's. <http://www.hhs.gov/acl/>

Administration on Intellectual Developmental Disabilities (AIDD)

Within ACF is the Administration on Intellectual Developmental Disabilities (AIDD). AIDD administers the Developmental Disabilities Act. As noted earlier in this chapter, the DD Act establishes UCEDDs that coordinate university training experiences in which you are likely involved. www.acl.gov/Programs/AIDD/Index.aspx

Appendix C

KEY CONCEPTS

Culturally Sensitive Health Care: “A set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency, or those professionals to work effectively in cross-cultural situations.”

<http://www.hrsa.gov/culturalcompetence/healthdlvr.pdf>

Family-Centered Care: Patient- and family-centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers. Patient- and family-centered care applies to patients of all ages, and it may be practiced in any health care setting. (From Institute on Family Centered Care website: <http://www.familycenteredcare.org/faq.html>).

Interdisciplinary Team: Individuals involved in assessment and recommendations for persons with disabilities. The team consists of persons from a wide variety of disciplines including, but not limited to, medical experts, educators, speech language pathologists, occupational therapists, rehabilitation engineers, care providers, psychologist, counselors, and social workers. Website: http://leadership.mchtraining.net/?page_id=132

Medical Home: A medical home is defined as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. (From the American Academy of Pediatrics website: <http://www.medicalhomeinfo.org/>

Appendix D

People First Language

From the West Virginia Developmental Disabilities Council Website

Person First Language

Language is power. Our words have the power to inspire, motivate, and uplift people. They also have the power to hurt, isolate and oppress individuals or entire segments of society. Often times, throughout our history, it has become necessary to change our language and the way in which we refer to individuals and groups to avoid further oppressing those members of society. The time has come to reshape our language once again so that we may refer to people with disabilities and the disability community in a respectful and inclusive manner.

Choosing to Use People First Language

Generally, in choosing words about people with disabilities, the guiding principle is to refer to the person first, not the disability. In place of saying “the disabled,” it is preferable to say “people with disabilities.” This way, the emphasis is placed on the person, not the disability.

It is only important to refer to the person’s disability if it is relevant to the conversation or situation. Disability should not be the primary, defining characteristic of an individual but merely one aspect of the whole person.

Why Should You Use People First Language?

People who have disabilities are present in every aspect of society. They are

- moms and dads
- sons and daughters
- employees and employers
- scientists (Stephen Hawking)
- friends and neighbors
- movie stars (Marlee Matlin)
- students and teachers

Most importantly, they are *people first*.

Examples of People First Language:

Many labels used for disabilities in our society have negative connotations or are misleading. Using labels contributes to negative stereotypes and devalues the person they attempt to describe. Avoid them when speaking to, or about, persons with disabilities.

The following terms should be avoided when speaking to or about people with disabilities:

- invalid
- wheelchair-bound
- mongoloid
- deaf and dumb
- defective
- mute
- victim
- crippled
- special person
- suffers from
- handicapped
- stricken with
- a patient
- retarded
- afflicted with
- handicapped

Making the Change to People First Language:

- “handicapped” or “disabled” should be replaced with “people with disabilities”
- “the handicapped” or “the disabled” should be replaced with “people who have disabilities”
- “he/she is wheelchair bound” or “he/she is confined to a wheelchair” should be replaced with “he/she uses a wheelchair”
- “he/she has a birth defect” should be replaced with “he/she has a congenital disability”
- “handicapped” in reference to parking, bathrooms, rooms etc. should be replaced with “accessible”
- “he/she is retarded or MR” should be replaced with “he/she has a cognitive disability or intellectual disability”

General Guidelines for Talking about Disability:

- Do not refer to a person’s disability unless it is relevant to the conversation
- Use the word “disability” rather than “handicap” to refer to a person’s disability. Never use “cripple/crippled” in any reference to a disability
- When referring to a person’s disability, use “People First Language”
- Avoid referring to people with disabilities as “the disabled, the blind, the epileptics, the retarded.” Descriptive terms should be used as adjectives, not as nouns
- Avoid negative or sensational descriptions of a person’s disability. Don’t say “suffers from, a victim of, or afflicted with.” These portrayals elicit unwanted sympathy, or worse, pity toward individuals with disabilities. Respect and acceptance is what people with disabilities prefer

- Don't use "normal" or "able-bodied" to describe people who do not have disabilities. It is better to say "people without disabilities," if necessary to make comparisons

Appendix E

Related Legislative Acts and Court Decisions Affecting People with Disabilities

As a trainee you will become familiar with a wide range of laws and policies impacting the lives of persons with disabilities. In this section a brief overview of several laws will be presented. You are encouraged to learn more about the legislative process as well as existing laws and policies pertaining to persons with disabilities.

Individuals with Disabilities Education Improvement Act (IDEIA)

Enacted in 1975, this act was initially titled the Education of Handicapped Children Act and is now titled the Individuals with Disabilities Education Improvement Act (IDEIA). Part B of this law enables all children ages three to 22 to be educated in our nation's schools. The law requires schools to conduct nondiscriminatory evaluations to determine eligibility (in fourteen different categories) for services. Every student eligible for Part B special education has an Individualized Education Plan (IEP) that identifies annual goals, objectives and services and parents must approve evaluations, placements, and IEP goals and objectives. When a student is 16 years of age a Transition Plan must be developed that will address specific goals that will prepare students for postsecondary educational and work settings.

Part C of IDEIA outlines required components for states to develop a system of services for eligible infants and toddlers and their families. Participating states identify a lead agency to oversee administration of the Part C system and eligibility for services under two categories: established risk and developmental delay. A service coordinator assists the family in obtaining needed services and supports, and a team develops the Individualized Family Service Plan. Services to eligible children and families are delivered by qualified personnel in the child's natural environment.

The family's role is central in planning and implementing services, and the IFSP is based upon resources and priorities pertaining to the child. Planning for transition from Part C to Part B (preschool services) begins at least six months prior to the child's third birthday. For more information, visit <http://idea.ed.gov/explore/view/p/%2Croot%2Cstatute%2C>

Americans with Disabilities Act (ADA)

The ADA was passed in 1990 and is considered an extension of civil rights protections to individuals with disabilities. It requires equal access for persons with disabilities in employment,

transportation and public facilities and services. All public entities affected by this law must make “reasonable accommodations” that will allow individuals with disabilities to access the workplace . public facilities.

After the ADA was passed in 1990, cases were filed and ended up in courts. Some were appealed all the way to the U.S. Supreme Court, and the ADA began to change. Rulings by the Supreme Court, as well as lower courts, began to narrow the definition of disability. After its first dozen years, the definition of disability had become the focus of most disputes. Congress never intended for it to be that way. The focus of the ADA was supposed to be on access and accommodation, not on whether the person really had a disability. Congress had not foreseen the ways in which the courts would narrowly interpret, and ultimately change, the definition. So on January 1, 2009, the ADAAA became effective. It essentially overturned those Supreme Court cases that narrowed the definition of disability and it made clear that the definition must be “construed in favor of broad coverage of individuals” with disabilities. So rather than this being a “new ADA,” it really is just going back to the way Congress meant the ADA to be when it was first written and passed back in 1990. For more information, visit <http://www.ada.gov/>

Vocational Rehabilitation Act

The legislation that set the stage for ADA was the Vocational Rehabilitation Act of 1973. In this Act, Section 504 stated “No otherwise qualified individual with a disability in the United States, as defined in section 7(20), shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.” Programs receiving federal funding were required to make reasonable accommodations for persons with disabilities. This Act authorizes vocational rehabilitation, supported employment, independent living, and client assistance. Adults with disabilities benefit from the provisions of this law. For more information, visit <http://www2.ed.gov/policy/speced/reg/narrative.html>

Assistive Technology Act

This Act was passed in 1998 and focuses on increasing awareness and use of assistive technology for persons with disabilities in each state. States may apply for funding of activities in their comprehensive state plans. For more information, visit www.section508.gov

Ticket to Work Incentives Improvement Act

This act was passed in 1999, reauthorized in 2004, and enables individuals with disabilities, while employed, to continue receiving financial support through Medicaid and Medicare programs. This legislation recognizes the importance of continued health care so that persons with disabilities can become more independent and productive. For more information, visit www.disabilitypolicycenter.org/twwiia.htm

Olmstead v. L.C.

On June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The court ruled that the Americans with Disabilities Act may require states to provide community-based services rather than institutional placements for individuals with disabilities. This historic pronouncement makes attainable a goal long-sought by people with disabilities and advocates. For more information, visit <https://www.law.cornell.edu/supct/html/98-536.ZS.html>

Appendix E



Providing leadership in the development of services and supports for persons with disabilities.

ACRONYMS

ACL – Administration for Community Living
ADA – Americans with Disability Act
AIDD – Administration on Intellectual and Developmental Disabilities
AUCD – Association of University Centers on Disabilities
BBHFF – Bureau for Behavioral Health and Health Facilities (used to be OBHS)
BCF – Bureau for Children and Families (DHHR)
BMS – Bureau for Medical Services
BOSS – Bureau of Senior Services
BPH – Bureau for Public Health (DHHR)
CDC – Centers for Disease Control and Prevention
CIL – Center for Independent Living
CMS – Centers for Medicare and Medicaid Services
COCA – Council on Community Advocacy
CSHCN – Children with Special Health Care Needs
DDC – Developmental Disabilities Council
DDN – Developmental Disabilities Network (State)
DOE – Department of Education
DHHR – Department of Health and Human Resources
DHHS – Department of Health and Human Services (Federal)
DOL – Department of Labor
DRS – Division of Rehabilitation Service
FSN – Fair Shake Network
HIPAA – Health Insurance Portability and Accountability Act
HRSA – Health Resources and Services Administration

JAN – Job Accommodation Network
MCHB – Maternal and Child Health Bureau (Federal)
MHCA – Mental Health Consumer’s Association
NCIL – National Council on Independent Living
NIDRR – National Institute of Disabilities and Rehabilitation Research
NWVCIL – Northern West Virginia Center for Independent Living
OMCFH – Office of Maternal, Child and Family Health (State)
OSERS – Office of Special Education and Rehabilitative Services (U.S. DOE)
OSP – Office of Sponsored Programs
P&A – Protection & Advocacy
SILC – Statewide Independent Living Council
UCEDD – University Centers for Excellence in Developmental Disabilities
WVA – West Virginia Advocates

Appendix G

RESOURCE DIRECTORY

Taken from the website of the West Virginia Developmental Disabilities Council:

<http://www.ddc.wv.gov/resources/Pages/ForChildrenwithDevelopmentalDisabilities.aspx>

Resources for Children with Disabilities

Family Support, Education and Advocacy

West Virginia Family Support Program, Bureau for Behavioral Health and Health Facilities - Statewide service to assist families in accessing child care, home modifications, transportation and other needed supports. The Family Support Program provides leadership in family-centered and family-driven service coordination and planning.

Phone: (304) 558-0627

Fax: (304) 558-1008

Website: <http://www.dhhr.wv.gov/bhhf/Pages/contact.aspx>

Program Coordinators http://www.wvdhhr.org/bhhftest/pdfs/fs_corrid.pdf

West Virginia Parent Training and Information, Inc. - Consultation and support for parents of children with disabilities. Education and training services on special education policies, preparing for Individual Education Planning meetings and working collaboratively with school personnel.

Phone: (304) 624-1436 or 1-800- 281-1436

Fax: (304) 624-1438

Website: www.wvpti.org

West Virginia Advocates, Inc. - Federally designated protection and advocacy program for West Virginians with disabilities. WVA provides consultation and education services on human and legal rights.

Phone: (304) 346-0847 (V/TTY) or 1(800) 950-5250

Website: www.wvadvocates.org

Parent Network Specialists (PNS), Center for Excellence in Disabilities at West Virginia University - Statewide network of parents who serve as advisors to parents of children with disabilities, administered by the University Center for Excellence in Disabilities, funded by the Office of Maternal Child and Family Health/Title V.

Phone: (304) 293-4692

Toll Free: (888) 829-9426

TTY: (800) 518-1448

Fax: (304) 293-7294

Website: www.cedwvu.org

Parent Educator Resource Centers (WV Department of Education) - Training and support for parents of students with disabilities. Parents and educators work as a team to provide positive collaborative relationships in school districts statewide. PERCs provide current information and resources on a wide variety of topics including parenting skills, education policies and obligations, problem solving, behavior support and other supports to strengthen the home-school partnership.

Phone: (304) 558-2696 (V/TDD) (800) 642-8541

Fax: (304) 558-3741

Website: <http://wvde.state.wv.us>

Governor's Cabinet on Children and Families - Organization that works in partnership with other community programs to support families and children on a wide variety of issues including healthcare, education and social services.

Phone: (304) 347-4890

Website: <http://www.legis.state.wv.us/Joint/PERD/perdrep/govcab.html>

Family Matters - Information and referral hotline with toll-free access to information on programs for children and families throughout West Virginia. Access to financial assistance and support, healthcare, housing, disability services including case management, child care, crisis services, educational programs, emergency services, and entitlement information.

Phone: (304) 745-5065

Website: <http://www.wvfamilymatters.com/>

Mountain State Parents, Children & Adolescent Network (MSPCAN) - Information and referral, emotional support and advocacy training for parents who have children with emotional, psychiatric and/or behavioral support needs.

Phone: (304) 233-5399

Fax: (304) 233-3847

Website: www.mspscan.org

Early Intervention and Pre-school Services

Office of Maternal, Child and Family Health, WV Birth to Three - Statewide, locally administered program to provide supports and services that assist families in meeting the developmental needs of their infant or toddler to age 3 with special needs. All children under the age of three who are found eligible by having a developmental delay, medical condition and/or multiple risk factors are eligible for services. Program provides linkage to specialized therapy services in accordance with Part C of the Individuals with Disabilities Act, U.S. Department of Education.

Telephone: (304) 558-5388

Fax: (304) 558-2183

Toll Free in WV: (800) 642-8522

Website: www.wvdhhr.org/mcfh

WV Department of Education, Office of Instructional Services - Kindergarten, early childhood education and Even Start programs. Programs provide assessment and specialized services for children ages 3 through 5.

Phone: (304) 558-2691 (V/TDD) (800) 642-8541

Website: <http://wvde.state.wv.us>

WV Head Start Association - Lead state agency that oversees 24 Head Start programs in WV. Disability services including individualized programming, inclusive placement, dental, health, nutrition, developmental, family support and social services. Services available to children aged birth to 5 years in low income families.

Phone: 1 (866) 763-6481

Website: <http://wvheadstart.org/about/association/>

The National Information Center for Children and Youth with Disabilities (NICHCY) - National information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals. Focus is on children and youth (birth to age 22).

Phone: 1(800) 695-0285

Website: www.nichcy.org

Education (K-12)

West Virginia Department of Education, Office of Special Education - Responsible for ensuring that appropriate instruction and support are provided to students with disabilities. Statewide management, monitoring and technical support for special education programs. Administration of due process and mediation. Find information about Policy 2419 - Regulations for the Education of Exceptional Students and links to state and federal programs and resources on the website listed below.

Phone: (304) 558-2696
Fax: (304) 558-3741
Website: <http://wvde.state.wv.us/ose/>

West Virginia Advisory Council for the Education of Exceptional Children - State advisory council as mandated under the Individuals with Disabilities Education Act (IDEA). The Council evaluates educational services in West Virginia and advises decision makers regarding the unmet needs of students with disabilities. The Council facilitates public meetings, develops reports, informational materials and works cooperatively with the WV Department of Education. The Council is composed of members appointed by the State Superintendent of Schools.

Phone: (304) 746-2076 or 1 (800) 642-3642 TDD (304) 746-2008
Website: <http://wvde.state.wv.us/osp/advisorycouncil.html>

WV Safe Schools HELPLINE - A 24- hour, toll-free number for all of West Virginia for confidentially reporting information that may be harmful to students, staff or school property. Threats of violence, use of weapons, sexual harassment, drug use or other harmful behavior should be reported.

Phone: 1(866) 723-3982 (1 (866) SAFE-WVA)
Website: <http://wvde.state.wv.us/safeschools/>

Medicaid, Social Security and Other Entitlement Programs

WV Bureau for Medical Services - State medical services program as mandated under the West Virginia Code and Social Security Act. Medicaid, behavioral health, home health and Children with Disabilities Services Program (formerly TEFRA).

Phone: (304) 558-1700
Website: <http://www.dhhr.wv.gov/bms/Pages/default.aspx>

WV Children's Health Insurance Program (CHIP) - Free or low cost health plan for children from birth to age 19 in low income families. Insurance plan covers preventive care, immunizations, prescriptions, hospital visits, dental, vision and mental health services.

Phone: 1(877) 982-2447 (1 (877) WVA CHIP)
Website: <http://www.chip.wv.gov/Pages/default.aspx>

Social Security Administration - Assistance and information about government benefits including Supplemental Security Income (SSI) and Social Security Disability (SSD) programs. Medicaid, CHIP, and other health care services and resources.

Website: www.ssa.gov
Toll Free: 1 (800) 772-1213 (TTY 1 (800) 325-0778)

WV Office of Maternal, Child and Family Health - Early and Periodic Screening Diagnosis and Treatment (EPSDT), care for pregnant women and newborns through the first year of life and children with chronic health conditions through a statewide clinical network. Assistance to families and their children (birth to 21) in accessing benefits and linkage to community services and resources.

Telephone: (304) 558-5388
Fax: (304) 558-2183
Toll Free in WV: (800) 642-9704/8522
Website: www.wvdhhr.org/mcfh

Case Management and Community Services and Supports

Medicaid Title XIX I/DD Home and Community-Based Waiver Program: Service coordination, respite, qualified professional services, residential habilitation, medical/nursing services and other supports. Program manuals are available by contacting the local behavioral center or the MR/DD Waiver Office.

Toll Free: (866) 385-8920
Phone: (304) 380-0617
Fax: (866) 521-6882
Website: <http://www.wvdhhr.org/bhhftest/pdfs/RevisedWaiverManual.PDF>

WV Bureau for Children and Families - Support services for children and families. Protective services, early intervention, foster care, specialized family care, child care, adoption, legal assistance and other supports and services.

Phone: (304) 558-0628 or (304) 356-4521
Fax: (304) 558-4194
Website: <http://www.dhhr.wv.gov/bcf/Pages/default.aspx>

Bureau for Behavioral Health and Health Facilities (DD Services) - Information and linkage to community case management, crisis services, family support, behavior support, and crisis intervention services. Medicaid Title XIX Home and Community Based Waiver Program.

Phone: (304) 356-4811
Fax: (304) 558-1008
Website: <http://www.dhhr.wv.gov/BHHF/Pages/default.aspx>

Bureau for Behavioral Health and Health Facilities, (Children's Mental Health Services) - Serving children diagnosed as Severely Emotionally Disturbed and their families. Linkage to the statewide service system of mental health programs including referral, assessment, inpatient and outpatient services.

Phone: (304) 356-4811

Fax: (304) 558-1008

Website: <http://www.dhhr.wv.gov/BHMF/Pages/default.aspx>

WV University's Center for Excellence in Disabilities - Positive behavior support training, consultation and assistance with public schools. Specialized health care coordination and services.

Phone: (304) 293-4692

Toll Free: (888) 829-9426

TTY: (800) 518-1448

Fax: (304) 293-7294

Website: www.cedwvu.org

The WV Autism Training Center, Marshall University - College of Education and Human Services. Training, information and support for West Virginians with autism, their families, educators, and others.

Toll Free: 1(800) 344-5115 all others: (304) 696-2332

Website: <http://www.marshall.edu/atc/>

Brain Injury Association of West Virginia, Inc. - State chartered organization dedicated to providing education, advocacy and support to persons with brain and spinal cord injuries and their families. Toll-free help line to provide information about support groups, case management, crisis services, health care and psychiatric services in West Virginia and nationwide.

Phone: (304) 766-4892

Toll Free in WV: 1 (800) 356-6443

Fax: (304) 766-4940

Website: <http://www.traumaticbraininjury.com/injury-resources/state-resources-for-tbi/west-virginia/>

WV Commission for the Deaf and Hard of Hearing - Programs for children and youth who are deaf or hard of hearing. Information and referral, family support, educational services, interpreter services and telephonic communication device loan program.

Phone: (304) 558-1675

Toll Free: (866) 461-3578

Fax: (304) 558-0937

Website: www.wvdhhr.org/wvcdhh

Assistive Technology

West Virginia Assistive Technology System (WVATS) - Information and referral, toll free hotline, funding, training and education about AT devices and services. Linkage to regional resource centers, lending libraries and tech teams to assist consumers and families. The WVATS is a project funded by the US Department of Education and coordinated by the WVU Center for Excellence in Disabilities.

Phone: (304) 293-4692
Toll Free: (888) 829-9426
TTY: (800) 518-1448
Fax: (304) 293-7294
Website: wvats.cedwvu.org/

WV Office of Special Education - Information and assistance for accessing appropriate AT equipment for school aged children. Technical assistance to school personnel and programs.

Phone: (304) 558-2696
Website: <http://wvde.state.wv.us/osp/>

ABLEDATA - Information, resources, research, support and training about assistive technology. Publications and consumer product reviews. Nationwide database.

Phone: 1 (800) 227-0216
Website: www.abledata.com

National Institute on Disability and Rehabilitation Research - Information and referral, research projects, public policy advocacy related to assistive technology to increase access to employment, healthcare and independent living.

Phone: 1 (800) 872-5327
Website: <http://www.acl.gov/programs/NIDILRR/>

Information Technology Technical Assistance and Training Center - Organization that promotes the development of accessible electronic and information technology by providing technical assistance, training and educational services. Informational workshops, conferences, and AT related publications.

Phone: 1 (800) 726-9119 (Voice/TTY)
Fax: (404) 894-9320
Website: http://www.icdri.org/legal/ITTATC_state_reportp.htm

National Rehabilitation Information Center - Information and referral service including access to database of more than 70,000 assistive technology products and resources. Education about the Americans with Disabilities Act (ADA), advocacy projects, and funding.

Phone: 1 (800) 346-2742
TTY: (301) 459-5984
Fax: (301) 459-4263
Website: www.naric.com

Recreation

West Virginia Division of Natural Resources - Information and assistance about accessible fishing, hunting and camping areas. Parks and forest information, hunting and fishing licenses for persons with disabilities. Fish stocking schedules, boating and other information.

Phone: (304) 558-2754
Website: <http://www.wvdnr.gov/>

West Virginia Division of Tourism - Lodging, restaurants, attractions and events around the state. Accessibility information for public parks and recreation areas. Information about snow sports, white water rafting, biking and walking trails.

Phone: 1 (800) CALL-WVA
Website: www.callwva.com

National Center on Accessibility - Organization committed to the full participation in parks, recreation and tourism by people with disabilities. Education, technical assistance, research and information and referral services. Information on key legislation including the Architectural Barriers Act, Rehabilitation Act, Americans with Disabilities Act (ADA) and the Uniform Federal Accessibility Standards.

Phone: (812) 856-4422 TTY: (812) 856-4421
Website: www.ncaonline.org

The National Park Service - Federal Bureau in The Department of the Interior responsible for protection of the national parks, monuments, rivers, reservations and other lands. Accessibility resources and assistance.

Phone: (202) 208-6843
Website: www.nps.gov

US Department of the Interior, Coordinating Committee on Accessibility for People with Disabilities - Current programs and information about legal standards for federal lands regarding accessibility. Information about advocacy initiatives and groups, accessible federal parks and monument information.

Phone: (202) 208-3100
Website: <https://www.doi.gov/employees>

Appendix H

Trainee Survey FY 2016 - LEND/UCEDD Trainees

* Response Required

Contact / Background Information

*Name (first, middle, last): _____

Previous Name: _____

*Address: _____

City State Zip

Phone: _____

Primary Email: _____

Secondary Email: _____

*What is the name of your current place of employment: _____

*What is the name of your current job position/title: _____

What year you graduate/complete the MCH Training Program? _____

Degree(s) earned while participating in the MCH Training Program _____

Permanent Contact Information (someone at a different address who will know how to contact you in the future, e.g., parents)

*Name of Contact: _____

Relationship: _____

*Address: _____

City State Zip

Phone: _____

*Race: (choose one)

___ **White** refers to people having origins in any of the original peoples of Europe, the Middle East, or North Africa.

___ **Black or African American** refers to people having origins in any of the Black racial groups of Africa.

___ **American Indian and Alaskan Native** refer to people having origins in any of the original peoples of North and South America (including Central America), and who maintain tribal affiliation or community attachment.
Tribe: _____

___ **Asian** refers to people having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent (e.g. Asian Indian).

___ **Native Hawaiian and Other Pacific Islander** refers to people having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

___ **More than one** race includes individuals who identify with two or more racial designations.

___ **Unrecorded** is included for individuals who are unable to identify with the categories.

*Ethnicity: (choose one)

Hispanic is an ethnic category for people whose origins are in the Spanish-speaking countries of Latin America or

who identify with a Spanish-speaking culture. Individuals who are Hispanic may be of any race.

☐ **Hispanic**

☐ **Non-Hispanic**

☐ **Unrecorded** is included for individuals who are unable to identify with the categories

Please answer the following questions as thoroughly as possible. When you have filled out the entire survey, return it to your Center/Program.

Survey

1. Are you a (check all that apply):

☐ Person with a disability

☐ Person with a special health care need

☐ parent of a person with a disability

☐ Parent of a person with a special health care need

☐ Family member of a person with a disability

☐ Family member of a person with a special health care need

☐ None

☐ Unrecorded

***2. Does your current work relate to Maternal and Child Health (MCH) populations (i.e. women, infants and children, adolescents, and their families including fathers and children and youth with special health care needs)?**

☐ Yes ☐ No

3. Does your current work relate to individuals with disabilities?

☐ Yes ☐ No

***4. Do you currently work in a public health organization or agency (including Title V)?**

☐ Yes ☐ No

***5. Does your current work relate to underserved or vulnerable populations? (i.e, Immigrant Populations Tribal Populations, Migrant Populations, Uninsured Populations, Individuals Who Have Experienced Family Violence, Homeless, Foster Care, HIV/AIDS, health disparities, etc)**

☐ Yes ☐ No

***6. Select your primary type/setting of employment (select what best describes your current employment):**

☐ Student

☐ Schools or school system (includes EI programs, elementary and secondary)

☐ Post-secondary setting

☐ UCEDD/LEND/LEAH/PPC/DBP

☐ Government agency

☐ For-profit

☐ Non-profit

☐ Hospital

- ☐ Private sector
☐ Other: please specify: _____

7. Do you regularly work with other disciplines that work with an MCH population?

- ☐ Yes ☐ No

8. What is the number of individuals with developmental disabilities who are receiving direct services through activities in which you are involved? _____

Leadership Activities

***9. Have you done any of the following activities since completing your training program?**

- ☐ Participated on any of the following as a group leader, initiator, key contributor or in a position of influence/authority: committees of state, national or local organizations; task forces; community boards; advocacy groups; research societies; professional societies; etc.
- ☐ Served in a clinical position of influence (e.g. director, senior therapist, team leader, etc.)
- ☐ Provided consultation or technical assistance in MCH areas
- ☐ Taught/mentored in my discipline or other MCH related field
- ☐ Conducted research or quality improvement on MCH issues
- ☐ Disseminated information on MCH Issues (e.g., Peer reviewed publications, key presentations, training manuals, issue briefs, best practices documents, standards of care)
- ☐ Served as a reviewer (e.g., for a journal, conference abstracts, grant, quality assurance process)
- ☐ Procured grant and other funding in MCH areas
- ☐ Conducted strategic planning or program evaluation
- ☐ Participated in public policy development activities (e.g., Participated in community engagement or coalition building efforts, written policy or guidelines, influenced MCH related legislation (provided testimony, educated legislators, etc)
- ☐ None

***10. If you checked any of the activities above, in which of the following settings or capacities would you say these activities occurred? (check all that apply)**

- ☐ Academic
- ☐ Clinical
- ☐ Public Health
- ☐ Public Policy & Advocacy
- ☐ None

***11. If you are currently in the fields of developmental disabilities, and are participating in leadership activities, please select in which of the following settings or capacities these activities occur:**

☐ Academic

☐ Clinical

☐ Public Health

☐ Public Policy & Advocacy

☐ None

12. Please describe professional achievement(s) that you would attribute to the training program or anything else you'd like us to know about your career

Evaluation of Training Program

13. I would recommend the training program to others.

<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0	No	<input type="checkbox"/>
(Completely agree)	(Mostly agree)	(Partially agree)	(Disagree)		

response

14. Thinking about the professional skills needed by health care professionals in your own field, what suggestions for changing training curriculum would you recommend for our Training Program?

Confidentiality Statement

Thank you for agreeing to provide information that will enable your training program to track your training experience and follow up with you after the completion of your training. Your input on how well the training equips you to provide supports and services to individuals with disabilities and families is critical to our own improvement efforts and our compliance with Federal reporting requirements. You are currently completing the alternate format paper survey.

Please know that your participation in providing information is entirely voluntary. The information you provide will only be used for evaluating your training program. Please also be assured that we take the confidentiality of your personal information very seriously. This website is a secure site and the data entered is stored in a secure database. Only a few select staff at your training program and at the Association of University Centers on Disabilities (AUCD) will have access to this information. Individual records will be kept confidential using the highest professional standards.

As you know, your training program already has similar information and, at your request, viewing of updated information can be restricted from AUCD. None of the information that you provide will be used to individually identify you to any outside agency, such as the Maternal Child Health Bureau (MCHB) or Administration on Developmental Disabilities (ADD). Any information supplied to these or any other federal agencies will be done on an aggregate basis in such a way as to preclude the ability to identify any individual trainee. If you have any questions or concerns, please contact the Director of the Center from which you received your training or Corina Miclea at AUCD (cmiclea@aucd.org) or 301-588-8252.

We very much appreciate your time and assistance in helping your training program, AUCD, and Federal agencies assess the outcomes of the training we provide. We look forward to learning about your academic and professional development.