SWK-S 695 Practice with Children with Special Healthcare Needs & Their Families (3 cr.)

Course Information
Semester: XXXXXX  Instructor: XXXXXX
Section: XXXXXX  Office: XXXXXX
Location: XXXXXX  Email: XXXXXX
Day: XXXXXX  Phone: XXXXXX
Time: XXXXXX  Office Hours: XXXXXX

Course Description
This course will focus on the development of professional expertise relevant to children with special health care needs (CSHCN) and their families. It is designed to provide social work students with an overview of disability within the developmental, historical, cultural, policy, treatment and research paradigms. Special emphasis on assessment of the impact of illness and disability on children with special health care needs and their families will be addressed. This course also aims to socialize students to their professional role(s) utilizing patient-centered and consumer driven strategies of disability advocacy and practice. This course is an elective in the health care concentration however is open to all concentrations for students interested in focusing on children with special health care needs.

Course Competencies
Council on Social Work Education (CWSE) 2015 EPAS Competencies addressed by this course.

Primary
- 7: Assess individuals, families, groups, organizations and communities
  Social workers understand that assessment is an ongoing component of the interactive process of social work practice with individuals, families, groups, organizations, and communities. They understand methods of assessment with diverse clients and develop mutually agreed-on intervention goals based on critical assessment of strengths, needs, and challenges within clients and constituencies (CSWE, 2015 EPAS, p.9).
- 8: Intervene with individuals, families, groups, organizations and communities
  Social workers understand and implement evidence-informed interventions to achieve the goals of clients and constituencies. They negotiate, mediate, and advocate with and on behalf of diverse clients and use inter-professional collaboration as appropriate to advance mutually agreed-on goals. (CSWE, 2015 EPAS, p. 9).

Secondary
- 4: Engage in practice-informed research and research-informed practice
- 5: Engage in policy practice
Course Objectives

**S695-01** Understand and apply new knowledge and understanding of the developmental, historical, cultural, policy, treatment and research paradigms that define practice with children with special health care needs and their families.

**S695-02** Demonstrate a conceptualization of disability practice which builds upon strengths-based person-centered and family-centered approaches.

**S695-03** Apply relevant findings from peer-reviewed articles to professional practice with children with special health care needs and their families.

**S695-04** Evaluate disability related service delivery gaps and contradictions within the medical and social service delivery systems and construct a conceptualization of consumer driven strategies of disability advocacy and practice.

**S695-05** Explore and analyze competing personal and professional perceptions, values and attitudes regarding practice with children with special health care needs and their families.

Required Texts


Other reading materials will be assigned throughout the course.

Course Content

This course will focus on the development of professional expertise relevant to CSHCN and their families. It is designed to provide social work students with an overview of disability within the developmental, historical, cultural, policy, treatment and research paradigms. Special emphasis on assessment of the impact of illness and disability on children with special health care needs and their families will be addressed. This course also aims to socialize students to their professional role(s) utilizing patient-centered and consumer driven strategies of disability advocacy and practice.

Course Outline

Module 1: Overview of course; Context of Disability Practice

*Overview*

A. Overview of class, review of syllabus and course expectations
B. Jason Baker and the Catie B Fellowship for Family Centered Care and this course
C. Developmental Disabilities Overview and Introduction

Module 2:

**Historical Treatment of Persons with Disabilities; Stigma, Ableism, and Social Justice; Disabilities Culture; Person-First Language; Political and Cultural Impact on Practice**
Overview
A. People first language
B. DD History
C. DD Culture
D. Medical Home

Assignments
Readings

Module 3:
**Defining Disability; Professional Practice; Settings, Roles and Services; Standards, Values and Ethics; Inter-disciplinary Collaboration; Future Practice Implications; Disability Theory; Disability Demographics**

Overview
A. Defining Disability
B. Child Development
C. Interdisciplinary Practice
D. Professional Practice with CYSHCN and Families

Assignments
Readings
Required Readings for this Week
1. Batshaw Text – Chapter 14: Patterns in Development and Disability

Module 4:
**Autism and Other Neuro-developmental Disorders; Human Development; Birth Defects; Environmental Toxins; Prenatal Infections; Premature Birth**

Overview
A. Autism Spectrum Disorders
B. Typical and Atypical Development
C. Environmental Influences
D. Life Course Theory
Assignments

Readings
1. Batshaw Text – Chapter 21: Autism Spectrum Disorders
3. Website resource: CDC Website

Individual Assignment
1. Self Reflection on Disability Paper

Module 5:
**Person-Centered (Family-Centered) Care; Consumer Driven Health Care; Advocacy, Policy and Politics; Resources for CYSHCN and Their Families**

Overview
A. The Family Perspective
B. Resources for CYSHCN and Their Families—The Funding Maze
C. Family Centered Care (Theory vs. Application)

Assignments

Readings

Module 6:
**Newborn Screening; Developmental Assessment; Brain Development; Physical Development (Vision, Hearing, Nutrition)**

Overview
A. Screening and Assessment
B. Brain Development
C. Physical Development

Assignments

Readings
2. Batshaw Text Additional Relevant Resources: Chapter 5: Newborn Screening: Opportunities for Prevention of Developmental Disabilities; Chapter 8: Nutrition and Children with Disabilities; Chapter 9: Feeding and its Disorders; Chapter 10: Hearing and Deafness;
Module 7: Interdisciplinary Teams; Navigating a Complex System of Care

**Overview**
A. The Role of Nursing for Children with Special Health Care and Complex Care Needs

**Assignments**
**Readings:**
1. Week 7 Readings TBD

**Assignment**
1. Specific Disability Topic Phase I – Research

Module 8: Early Intervention, Special Education

**Overview**
A. Early intervention
B. Special Education

**Assignments**
**Readings**
1. Batshaw Text – Chapter 30: Early Intervention: Chapter 31: Special Education Services

**Assignment**
1. Status check of Ethnographic Paper (interviews with families should be completed by this time)

Module 9:
Young Adulthood; Transition to Independence; Guardianship; Advance Directives; Occupational Preparation; Medical Home

**Overview**
A. Transition from Childhood to Adulthood

**Assignments**
**Readings**

Module 10:
Residential Care outside the family home; Residential Care in the family; Community Development Issues; Government Policy/ Programs
Overview
A. Therapies and Interventions

Assignments
Readings
1. Batshaw text – Chapter 32: Behavior Principles, Assessment, and Therapy; Chapter 36: Assistive Technology; Chapter 38: Complementary and Alternative Therapies.

Assignment
1. Specific Disability Topic Phase II – Document

Module 11: Intervention and Treatment; State and National Resources; Advocacy

Overview
A. Community-Based Services and Supports Systems
B. State and National Resources
C. Building a Professional Network

Assignments
Readings
1. Review Website resources: Association of University Centers of Excellence at AUCD Website, Governor’s Council for People with Disabilities at Indiana Government Website, Indiana Institute on Disability and Community at Indiana Institute on Disability and Community, Indiana Protection and Advocacy at Indiana Government Website.

Assignment
1. Ethnographic Research Paper

Module 12: Specific Disability Areas

Overview
A. Class Presentations

Assignments
1. Specific Disability Topic Phase III – TED Talk

Module 13: Specific Disability Areas

Overview
A. Class Presentations

Assignments
1. Specific Disability Topic Phase III – TED Talk

Module 14: Ethical Decision Making; Ethics Committees

Overview
B. Shared Decision Making (Privacy Management Theory)
C. Exploring Ethical Dilemmas
Assignments

Readings
1. Batshaw Text – Chapter 39: Ethical Considerations.

Module 15: Reflecting on the Ethnographic Paper; Future Plans; Professional Development

Overview
A. Reflective Practice
B. Lifelong Learning
C. Family Perspective/Family-Centered Care
D. Course Wrap-Up
E. In-Class Activity: Ethnographic Research Paper Presentation/Reflective Activity

Assignments and Grading
More specific instructions for each assignment will be posted on Canvas. Instructor also will discuss details or answer any questions related to assignment during the class and office hours.

All assignments should be produced on a wordprocessor (or typed), double spaced, with one-inch margins on all sides, carefully edited and proofed, using no smaller than a 12 point font, and conforming to APA style (6th ed.)

Assignments

Self-Reflection on Disability ...............................................................25 points
Disability Topic Phase I – Research ......................................................75 points
Disability Topic Phase II – Create a Document: .................................75 points
Disability Topic Phase III – Presentation/TED Talk: .............................50 points
Ethnographic Research Paper: ..........................................................75 points

TOTAL ............................................  ............................................ 300 points

Ethnographic Research Paper
Students are required to complete an ethnographic interview paper and present this paper in class. You are required to complete this paper and presentation independently. The completed paper must be typed, include a title page, cite all contacts and sources, and completed in APA format. You will present/discuss your experience during an in class session as part of this assignment. Details of this presentation will be discussed in class.

The objective of this assignment is to understand what it means to live with a chronic illness or disability from the primary caregiver (the parent) who can give an “expert perspective.” One way to adopt an expert perspective is to conduct an ethnographic interview.
Instructions:

1. Contact the assigned parent of a child who is currently experiencing a chronic illness or disability. Contact information will be provided. Initial contact with the family should be made by XXXXXXX to schedule an appointment for as early as possible in order to accommodate for any possible needs on the family’s part to reschedule. Interviews with families should be completed by XXXXXXXX. Final paper due XXXXXXXX.

2. The major objective of the face to face interview is to gain an insider’s view of the informant’s experience of living with a chronic illness or disability. Since informants are living day-to-day with the disability, they are considered the “experts,” and you should approach them with a posture of naïve ignorance. You should assume the role of the student-learner and ask the informant to teach you about their experience and identify what they think is important for you to learn about the daily life functioning with their child’s illness or disability.

3. The ethnographic interview approach focuses on three main dimensions:
   A. The meaning of the illness or disability to the child, parent and family;
   B. The types of strategies used by the child and/or parent to live with the illness or disability;
   C. The way in which the child and/or parent organizes their life within the context of the child’s illness or disability.

4. Interviews should be approximately 60 minutes long and may be tape-recorded (with the informant’s permission) or recorded by taking detailed handwritten notes during the interview. The interview questions should be fairly open, yet focused on topic areas of importance. Confidentially must be upheld and discussed with the informant before the interview occurs.

In preparation for the interview develop a series of questions that you can refer to during the interview process. The following are suggestions for what you might cover:

- When the parent first suspected an illness or developmental delay in their child;
- Initial feelings or responses to the suspected illness or developmental delay and what it meant for the parent;
- What brought the parent to seek assistance for their child and what were the primary concerns, fears and worries about seeking assistance;
- How the parent made sense of their child’s illness or disability (i.e., what kinds or explanations and/or theories about “why my child?”);
- How the parent’s family history, culture, ethnicity and philosophical or religious beliefs have affected their experience;
- How the parent and child function with the illness or disability on a daily basis;
- What is the impact of the illness or disability on the parent, family, career, social relationships, etc.;
- What is the parent’s experience in accessing health care and their interactions with health care providers.

It is important to note that deeply probing questions can illicit an emotional response from the informant. Students must take great care in creating an interview setting that is private and
comfortable for the informant. To maintain an appropriate comfort level during the interview, students may suggest a break or move onto another topic area.

5. Summarize your interview in five (5) double-spaced, typed pages (removing all identifying information), including at least three (3) direct quotes from the parent.

6. Provide a five (5) page critique of your interview, addressing the following:
   A. How well do you think you elicited information from the informant about their child’s illness or disability experience?
   B. Name two things that you might have done differently during the interview and explain why.
   C. What areas do you wish you had covered in the interview but did not? Please explain.
   D. How “connected” you felt to the informant and why?
   E. What part of the interview was most difficult for you and why?

7. What was the most compelling thing that you learned from the informant?

8. Complete a brief literature review on the child’s primary illness or disability. This should include at least five (5) relevant peer reviewed journal articles and juried resources.

9. Outline a list of possible social service programs and/or services that might be helpful to the child and parent and briefly describe them.

Attach a copy of your interview guide (the list of questions you plan to ask).

Related EPAS Competencies: 5, 6, 7, 8

Disability Topic Assignment Guidelines
The overarching goal of this assignment is to 1) become expert with a specific disability area through research of the topic from multiple perspectives, 2) summarize your research into a 2 to 4 page document that speaks to the general public/families with the knowledge and information they need to be introduced to the disability topic, 3) present your knowledge in a TED talk style presentation to share pertinent information with your colleagues, and 4) access the knowledge and expertise of your colleagues’ work through their documents and presentations.

Phase I – Research your assigned topic
Worth: 75 points

Provide a summary of your research on this topic that includes:
Definition/Description:
Etiology, Assessment, Diagnosis:
Evidence based Treatment/Services:
Effects on family:
Effects on individual and Interactions with community:
Resources (including local, state, national support groups, financial, community based, education, employment, etc.):
Web-based Resources (local, state, national, including social media):
Evidence based Sources, Research articles, Additional Information: NOTE there are likely many journal articles and resources so your task is to select the most relevant three to five that you believe are the most useful.

Phase II – Create a document
Worth: 75 points

Next you will create a 2-4 page(ish) document to present the technical information one should know about the condition or disability in a manner and using language that a family member and colleague unfamiliar with the condition could understand and appreciate. You should take the technical information you encounter and translate it into language understandable by all.

Creativity is welcome however remember that people will want to print your document for future reference (including your classmates) so pay attention to format, font, color, graphics, and printability. It is also suggested to ask families and individuals with disabilities what information they might like to know and how they best might receive it; you might ask a family member to comment on your document as you prepare it.

Documents will be shared in either print or electronic format (class decision) so everyone has access to each other’s research and information.

Phase III – Share your info with the class in a TED talk format
Worth: 50 points

Goal: To share with your classmates the highlights and salient points you learned from your research in creating the disability specific document. Please think about this from the perspective of:

1. Colleagues – what do we need to know about this disability or condition to help prepare us for our work with children with special health care needs and their families?
2. Families – what do families want to know about this disability/condition to best understand what it is and what to do?

Specifically we might want to know about:

A. The disability/condition – what is it called?
B. How is it described both in the literature and in the community?
C. How is it recognized? How is it diagnosed? By whom? By what process?
D. How is it treated? Are there evidence based treatments/services? Are there emerging treatments? Are there controversial treatments? What are the potential effects on the family? On the child? On the community?
E. What resources are available at the local, state, and national level to learn more about this disability/condition? To receive services/treatment/financial support/community support? For families? How are these resources/services accessible?
F. What was the most surprising thing you learned?
G. What is the most important message you want your colleagues to know about this disability/condition?

NOTE:
YOU ONLY GET 10 MINUTES MAXIMUM.
Presenting your information in a creative (even fun) way is encouraged to maximize our learning.

NO PowerPoint is necessary.

You may show an online resource to highlight your presentation if you would like, however you must keep within the 10 minute limit so everyone has equal chance to share their information. If you want to use PPT or other media to enhance your presentation of course you may. The point is that the traditional PPT presentation is not necessary, please.

Related EPAS Competencies: 5, 6, 7, 8

Self-Reflection on Disability Paper

Write a 6-7 page reflection paper about your views and experiences with disability. This can be from a personal viewpoint, about a family member, or about others with disability in your life experience. Talk about feelings that you or your loved one experienced. How does this experience impact your future practice as a health care social worker? No references are necessary for this paper unless you choose to incorporate them. Additional guidelines to be discussed in class.

Related EPAS Competencies: 5, 6, 7, 8, 9

Grading Standards

Papers are graded on the quality of the final product not on the effort you extended completing them. The grade of A is reserved for truly outstanding work that goes beyond basic requirements.

In the Indiana University School of Social Work MSW program, grades of B are the expected norm. Reflecting competency and proficiency, grades of B reflect good or high quality work typical of graduate students in professional schools. Indeed, professors typically evaluate students’ work in such a way that B is the average grade. Grades in both the A and the C range are relatively uncommon and reflect work that is significantly superior to or significantly inferior, respectively, to the average, high quality, professional work conducted by most IU MSW students. Because of this approach to grading, students who routinely earned A grades in their undergraduate studies may conclude that a B grade reflects a decrease in their academic performance. Such is not the case. Grades of B in the IU MSW program reflect the average, highly competent, proficient quality of our students. In a sense, a B grade in graduate school is analogous to an A grade in undergraduate studies. MSW students must work extremely hard to achieve a B grade. If you are fortunate enough receive a B, prize it as evidence of the professional quality of your work.

Grades of A reflect Excellence. Excellent scholarly products and academic or professional performances are substantially superior to the “good,” “the high quality,” “the competent,” or the “satisfactory.” They are unusual, exceptional, and extraordinary. Criteria for assignments are not only met, they are exceeded by a significant margin. Excellence is a rare phenomenon. As a result, relatively few MSW students earn A grades.

Grades of B signify good or high quality scholarly products and academic or professional performance. Grades in the B range reflect work expected of a conscientious graduate student in a professional program. Criteria for assignments are met in a competent, thoughtful, and professional manner. However, the criteria are not exceeded and the quality is not substantially superior to other good quality products or performances. There is a clear distinction between the good and the excellent. We expect that most MSW
students will earn grades in the B range—reflecting the good or high quality work expected of competent future helping professionals.

Grades of C and C+ signify work that is marginal in nature. The scholarly products or professional performances meet many but not all of the expected criteria. The work approaches but does not quite meet the standards of quality expected of a graduate student in a professional school. Satisfactory in many respects, its quality is not consistently so and cannot be considered of good or high quality. We anticipate that a minority of MSW students will earn C and C+ grades.

Grades of C- and lower reflect work that is unsatisfactory. The products or performances do not meet several, many, or most of the criteria. The work fails to approach the standards of quality expected of a graduate student and a future MSW-level professional. We anticipate that a small percentage of MSW students will earn unsatisfactory grades of C-, D, and F.

**Grading scale**

Grade minimums are as follows [Note: grades below C are Unsatisfactory in the MSW Program]:

- A  93%   Excellent, Exceptional Quality
- A-  90%   Superior Quality
- B+  87%   Very Good, Slightly Higher Quality
- B   83%   Good, High Quality (expected of most MSW students)
- B-  80%   Satisfactory Quality
- C+  77%   Marginal, Modestly Acceptable Quality
- C   73%   Marginal, Minimally Acceptable Quality
- C-  70%   Unsatisfactory Quality

**Course Policies**

**Assignment**

Students are expected to submit all assignments on time. If you need to extend a deadline you MUST speak to me in advance of the due date to get an approval and an agreement will be reached. Late submission (except by prior agreement) will be marked down 5% per day late. IU has a subscription with the Turnitin plagiarism detection service, and faculty members have the right to submit student papers to the service to check for originality. Turnitin.com service will be used for all student papers in this course.

**Attendance and participation**

Students are expected to attend and participate in all class sessions. Students should complete readings and homework as assigned and come to class prepared for discussion and questions. Because of the nature of this course and group assignments, regular attendance is required and extremely important. Class attendance and active participation in class activities are considered essential for the satisfactory completion of the course objectives. If you are absent, it is your responsibility to get notes from other students regarding materials covered during your absence. If you are absent on the day when an assignment is due, you need to submit
your assignment before the beginning of the class. Missing more than 2 of the scheduled classes will result in a letter-grade deduction for the course. Late arrivals and early departures will also lead to course point deductions. It’s up to instructor’s discretion to decide the deduction points. If you miss five or more classes you will fail the course.

Suggested Websites

American Academy of Neurology Foundation ..............................................aan.com/go/foundation
About Special Kids (ASK) ...........................................................................aboutspecialkids.org
The ARC of the United States.................................................................thearc.org
The ARC of Indiana ..................................................................................arcind.org
Autism Society of America .......................................................................autism-society.org/
Autism Society of Indiana .......................................................................autismsocietyofindiana.org/
Autism Speaks, Inc. ....................................................................................autismspeaks.org
Beach Center on Families and Disability ...................................................beachcenter.org
Benefits CheckUp – Federal & State Program eligibility .........................benefitscheckup.org
Brain Injury Association of America .........................................................biausa.org
Children’s Brain Tumor Foundation ..........................................................abta.org
Children’s Hydrocephalus Support Group ..................................................hydrosupport.org
Children’s Special Healthcare Services ....................................................in.gov/isdh/19613.htm
Centers for Disease Control and Prevention ..........................................cdc.gov
Epilepsy Foundation ...................................................................................epilepsy.com/
Family Voices Indiana ...............................................................................fvindiana.org
Family Voices (national) ..............................................................................familyvoices.org
Federal Government Programs ...............................................................FirstGov.gov
Global and Regional Asperger Syndrome Partnership ............................grasp.org
Hereditary Disease Foundation ...................................................................hdfoundation.org
Indiana Department of Education, Office of Special Educ .......................doe.in.gov/specialed
Indiana Department of Family and Social Services Administration ...........
Division of Disability Services ...................................................................in.gov/fssa/2328.htm
Indiana Governor’s Council for People with Disabilities .........................in.gov/gpcpd/
Indiana Institute on Disability and Community ...........................................iiddc.indiana.edu/
Indiana Disability Rights .............................................................................in.gov/ipas/
Infancy Onward (infant mental health association) ....................................iaitmh.org
IN*SOURCE (Resource Center for Families with Special Needs) ..............insource.org
Institute for Independent Living ...............................................................independentliving.org
Kaiser Family Foundation (info on national health issues) .......................kff.org/
Kids Count – Annie E. Casey Foundation ..................................................aecf.org/kidscount
Learn the Signs Act Early .........................................................................cdc.gov/actearly
Library Service for Disabled ................................................................. .loc.gov/nls
Maternal and Child Health Bureau .................................................. mchb.hrsa.gov
Medline 24 Hour Consumer Health Information ............................. MEDLINEplus.gov
Mental Health America of Indiana ................................................... mhai.net
Muscular Dystrophy Association ...................................................... mda.org
NASW Social Workers Help Starts Here: Disabilities........................ helpstartshere.org/health_and_wellness/disabilities
The National Caregivers Association ............................................. nfcacares.org
National Center for Health Statistics .............................................. cdc.gov/nchs/
National Center on Secondary Education and Transition ............... ncset.org/
National Institute of Health .............................................................. nih.gov
National Institute of Mental Health ................................................... nimh.nih.gov/
National Library of Medicine ........................................................ nlm.nih.gov/
National Women’s Health Information .......................................... womenshealth.gov/
Office of Minority Health Resource Center ................................ minorityhealth.hhs.gov/
Social Security Administration ......................................................... ssa.gov
Society for Disability Studies ......................................................... disstudies.org/
Supplemental Security Income ....................................................... ssa.gov/work
Tourette Syndrome Association ....................................................... tsa-usa.org
United Cerebral Palsy ................................................................. ucp.org
United Nations ENABLE – Rights And Dignity of Persons with Disabilities ............................................. un.org/development/desa/disabilities/
U.S. Dept. of Health and Human Services ..................................... hhs.gov/
Women, Infants & Children (WIC) Supplemental Nutrition .............. fns.usda.gov/wic
World Institute on Disability ............................................................ wid.org
World Health Organization ............................................................ who.ch/
World Association for Infant Mental Health ................................... waimh.org

Weblinks active/accurate as of January 8, 2017