

**Indiana University
School of Social Work**

**S600: Children with Special Health Care Needs
3 credit hours**

Room Assignment: RI 5931
Spring Semester, 2010

Instructor: Stephan Viehweg, ACSW, LCSW
Telephone contact: 317-274-0361

I. Course Description

This course will focus on the development of professional expertise relevant to children with special health care needs and their families. It is designed to provide nursing and 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.

II. Text and Required Readings

Batshaw, M., Pellegrino, L., & Roizen, N. (2007). *Children with disabilities*. (6th ed.). Baltimore, MD: Paul H. Brookes Publishing Company.

Other reading materials will be assigned throughout the course.

III. Course Competencies

As a result of successfully completing this course, the student will be able to:

1. Incorporate new knowledge and understanding of the developmental, historical, cultural, policy, treatment and research paradigms that define practice with children with special health care needs.
2. Incorporate new knowledge and understanding about various childhood disabilities and their diagnosis and treatment.
3. Demonstrate a conceptualization of disability practice which builds upon a strengths-based patient-centered approach.
4. Demonstrate a conceptualization of consumer driven strategies of disability advocacy and practice.
5. Critique professional peer reviewed articles and apply relevant findings to professional practice.

6. Describe unique factors that should be considered when engaged in professional practice with disenfranchised groups.
7. Describe ethical issues that need to be considered and analyzed when engaged in professional practice with children with special health care needs and their families.
8. Identify disability related service delivery gaps and contradictions within the medical and social service delivery systems.
9. To explore and analyze their personal perceptions and attitudes regarding children with special health care needs and their families.
10. Appreciate and understand parental perspectives on raising a child with special health care needs.
11. Recognize the professional values, ethics, awareness and sensitivities related to working with children with special health care needs and their families.
12. Apply critical thinking skills to evaluate disability related information and apply these to their own professional judgments and decisions.

IV. Instructional Approach/Class Format/Responsibilities

The instructional approach for this course will include lecture, class discussion, small group work, videos, guest presentations and assigned discussion question from Ocourse. Students are expected to actively participate in all assignments and class discussions.

Instructor's Responsibilities:

1. Provide empirically based knowledge.
2. Provide clear and concise directions to all assignments.
3. Provide clear and concise written feedback on all graded assignments.
4. Provide clear and concise verbal feedback during class exercises and discussions.
5. Provide individualized clarification on lecture materials and assignments per request of student.
6. Provide a professional classroom environment which fosters learning.

Student's Responsibilities:

1. Attend all classes in a timely manner.
2. Complete all written assignments by due date.
3. Complete all reading assignments by due date.

4. Complete the mid-term and final examination on assigned date.
5. Act professionally to the instructor and all fellow students.
6. Actively participate in classroom discussions and assignments.
7. Respect differences of opinion of other students, the instructor and guest presenters.

V. Class Assignments and Grading Procedures

- A. Attendance and active participation is required in this course. Both will increase the student's ability to understand and apply course content. Content related to this course will be presented in class with some materials posted on Oncourse.
- B. Oncourse Discussion Questions – Will comprise of 10% of the Course Grade
Discussion Questions on assigned articles will be posted on Oncourse. Students will be required to read all assigned articles and to submit the completed discussion questions to the instructor.
Due Date: Articles will be assigned throughout the course.
- C. Midterm and Final Examinations – Each will comprise of 25% of the Course Grade
In-class mid-term and final examinations will be given. The examinations will include objective questions, and short answer questions. A study guide will be provided to students prior to each examination and will be posted on Oncourse.
Mid-term Examination Date: TBA
Final Examination Date: TBA
- D. Ethnographic Research Paper – Will comprise of 30% of the Course Grade
Students are required to complete an ethnographic research paper. The format and instructions for this paper is located in Section VIII of this Syllabus and will be posted on Oncourse.
Due Date: TBA

***Details for this class assignment can be found in Section VIII of this Syllabus.**

- E. Paper Presentation – Will comprise of 10% of the Course Grade
Each student will present orally their ethnographic research paper to the class. The format and instructions for this paper presentation is located in Section VIII of this Syllabus and will be posted on Oncourse.
Date of Presentation: TBA

***Details for this class assignment can be found in Section VIII of this Syllabus.**

VI. Class Schedule

Week One

Overview of Course;
The Context of Disability Practice;
Disability Theory;
Disability Demographics.

Week One Assigned Readings:

Batshaw Text – Chapter 16: Epidemiology of Developmental Disabilities.

Gilson, S. & DePoy, E. (2002). Theoretical approaches to disability content in social work education. *Journal of Social Work Education*, 38(1), 153-165.

Mackelprang, R. (2008). Disability overview. In T. Mizarahi & L. Davis, Eds., *Encyclopedia of Social Work*, (20th ed.). New York, NY: Oxford University Press.

Week Two

Historical Treatment of Persons with Disabilities;
Stigma, Ableism, and Social Justice;
Disabilities Culture;
Person-First Language.

Week Two Assigned Readings:

Asch, A. (2001). Critical race theory, feminism, and disability: Reflections on social justice and personal identity. *Ohio State Law Review*, 62, 1-17.

Burnes, D., Antle, B., Williams, C. & Cook, L. (2008). Mothers raising children with sickle cell disease at the intersection of race, gender, and illness stigma. *Health and Social Work*, 33(3), 211-220.

Week Three

Human Development;
Genes and Chromosomes;
Genetic and Metabolic Birth Defects;
Environmental Toxins;
Prenatal Infections;
Premature Birth;

Brain Trauma.

Week Three Assigned Readings:

Batshaw Text – Chapter 1: Genetics and Developmental Disabilities; Chapter 2: Development before Birth; Chapter 3: Having a Baby: The Birth Process; Chapter 4: The First Weeks of Life; Chapter 5: Environmental Toxins; Chapter 6: Infections and the Fetus; Chapter 9: Premature and Small-for-Dates Infants; Chapter 30: Traumatic Brain Injury.

Attia, J., Ioannidis, J., Thakkinstian, A., McEvoy, M., Scott, R., Minelli, C., Thompson, J., Infante-Rivard, C. & Guyatt, G. (2009). How to use an article about genetic association. *JAMA*, 301(1), 74-81.

Laino, C. (2007, March/April). The hunt for genes and cures. *Neurology Today*, 20-27.

Week Four

Prenatal Diagnosis;
Newborn Screening;
Developmental Assessment.

Tour and Class Discussion: Riley Children's Hospital

Week Four Assigned Readings:

Batshaw Text – Chapter 7: Birth Defects and Prenatal Diagnosis; Chapter 8: Newborn Screenings: Opportunities for Prevention of Developmental Disabilities; Chapter 10: Nutrition and Children with Disabilities; Chapter 11: Vision: Our Window to the World; Chapter 12: Hearing: Sounds and Silences; Chapter 13: The Brain and Nervous System; Chapter 14: Muscles, Bones and Nerves; Chapter 15: Patterns in Development and Disability.

Marlow, N. (2004). Neurocognitive outcome after very preterm birth. *Archives of Disease in Childhood – Fetal and Neonatal Edition*, 89, 224-228.

Weiss, J. (2008). Genetics. In T. Mizarahi & L. Davis (Eds.) *Encyclopedia of Social Work*, (20th ed.). New York, NY: Oxford University Press.

Week Five

Developmental Disabilities;
Neurocognitive Disabilities;
Physical Disabilities;
Psychiatric Disabilities.

Guest Presentaion: Genetics Counselor and/or Pediatrician from Riley Children's Hospital

Week Five Assigned Readings:

Batshaw Text – Chapter 17: Developmental Delay and Intellectual Disability; Chapter 18: Down Syndrome; Chapter 19: X-Linked Syndromes Causing Intellectual Disability; Chapter 20: Inborn Errors of Metabolism; Chapter 21: Behavioral and Psychiatric Disorders in Children with Disabilities; Chapter 22: Communication Disorders; Chapter 23: Autism Spectrum Disorders; Chapter 24: Attention Deficits and Hyperactivity; Chapter 25: Specific Learning Disabilities; Chapter 26: Cerebral Palsy; Chapter 27: Movement Disorders; Chapter 28: Neural Tube Defects; Chapter 29: Epilepsy.

Clute, M. A. (2008). Physical disabilities. In T. Mizrahi & L. Davis (Eds.) *Encyclopedia of Social Work*, (20th ed.). New York, NY: Oxford University Press.

Patchner, L. & DeWeaver, K. (2008). Neurocognitive disabilities. In T. Mizrahi & L. Davis (Eds.) *Encyclopedia of Social Work*, (20th ed.). New York, NY: Oxford University Press.

Week Six

Family and Child System;
Family Stress;
Social/Educational Supports;
Spiritual Supports;
Government Policy/Programs.

Guest Presentation: Drs. Michael and Lisa Patchner, Indiana University School of Social Work

Week Six Assigned Readings:

Batshaw Text – Chapter 40: Caring and Coping: Helping the Family of a Child with a Disability; Chapter 42: Health Care Delivery Systems and Financing Issues.

Head, L. & Abbeduto, L. (2007). Recognizing the role of parents in developmental outcomes: A systems approach to evaluating the child with developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 293-301.

Singer, G., Biegel, D. & Ethridge, B. (2009). Toward a cross disability view of family support for caregiving families. *Journal of Family Social Work*, 12(2), 97-118.

Week Seven

Infancy and Early Childhood;
 Pre-school;
 Elementary School Aged;
 Middle School Aged;
 High School Aged;
 Mid-term Examination Review.

Week Seven Assigned Readings:

Batshaw Text – Chapter 31: Feeding; Chapter 32: Dental Care: Promoting Health and Preventing Disease; Chapter 33: Early Intervention; Chapter 34: Special Education Services; Chapter 35: Behavioral Principles, Assessment, and Therapy; Chapter 36: Technological Assistance; Chapter 37: Physical Therapy and Occupational Therapy; Chapter 38: Exercise, Sports, and Recreation.

Cook, B. & Schirmer, B. (2003). What is special about special education? Overview and analysis. *The Journal of Special Education*, 37(3), 200-205.

Harrington, D. & Castellanos-Brown, K. (2008). Early childhood and preschool. In T. Mizrahi & L. Davis (Eds.). *Encyclopedia of Social Work*, (20th ed.). New York, NY: Oxford University Press.

Week Eight

Mid-term Examination
 Individual Instructor Review on status of Ethnographic Paper

Week Nine

Young Adulthood;
 Transition to Independence;
 Occupational Preparation.

Guest Presentation: Center for Youth and Adults with Conditions of Childhood (CYACC) Riley Hospital

Week Nine Assigned Readings:

Batshaw Text – Chapter 41: Future Expectations: Transition from Adolescence to Adulthood.

Antle, B. (2004). Factors associated with self-worth in young people with physical disabilities. *Health and Social Work*, 29(3), 167-175.

Kim, K & Turnbull, A. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research and Practice for Persons with Severe Disabilities*, 29(1), 53-57.

Week Ten

Interdependence within the larger community;
 Navigating a complex system of care;
 Residential Care outside the family home;
 Residential Care in the family home.

Guest Presentation: Agency Provider Panel

Week Ten Assigned Readings:

Darnell, J. (2007). Patient navigation: A call to action. *Social Work*, 52(1), 81-84.

Parish, S. & Lutwick, Z. (2005). A critical analysis of the emerging crisis in long-term care for people with developmental disabilities. *Social Work*, 50(4), 345-354.

Week Eleven

Community Development Issues;
 Grassroots Advocacy;
 University Affiliated Programs (UAP);
 Developmental Disabilities (DD) Planning Councils;
 Protection and Advocacy Agencies (P&A).

Guest Presentation: Family Panel with Consumers

Week Eleven Assigned Readings:

Galambos, C. (2004). Social work practice with people with disabilities: Are we doing enough? *Health and Social Work*, 29(3), 163-165.

Itzhaky, H. & Schwartz, C. (2000). Empowerment of parents of children with disabilities: The effect of community and personal variables. *Journal of Family Social Work*, 5(1), 21-36.

Week Twelve

Person-Centered (Family-Centered) Care;
 Consumer Driven Health Care;
 Medical Home;

Advocacy, Policy and Politics.

Week Twelve Assigned Readings:

Dunst, C., Trivette, C. & Hamby, D. (2007). Meta-analysis of family-centered helpgiving practices research. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 370-378.

Patchner, L. (2005). Social work practice and people with disabilities: Our future selves. *Advances in Social Work*, 6(1), 109-120.

Week Thirteen

Ethical Decision Making;
Guardianship;
Advance Directives;
Ethics Committees.

Week Thirteen Assigned Readings:

Batshaw Text – Chapter 39: Ethical Dilemmas.

Vourlekis, B., Ell, K. & Padgett, D. (2001). Educating social workers for health care's brave new world. *Journal of Social Work Education*, 37(1), 177-191.

Miller, V. & Martin, A. (2008). The human genome project: Implications for families. *Health and Social Work*, 33(1), 73-76.

Week Fourteen

Professional Practice;
Settings, Roles and Services;
Standards, Values and Ethics;
Interdisciplinary Collaboration;
Political and Cultural Impact on Practice;
Future Practice Implications.

Guest Presentation: Riley Hospital MSW and Nurse

Week Fourteen Assigned Readings:

Holliman, D., Dziegielewski, S. & Teare, R. (2003). Differences and similarities between social work and nurse discharge planners. *Health and Social Work*, 28(3), 224-231.

Schneiderman, J., Waugaman, W. & Flynn, M. (2008). Nurse social work practitioner: A new professional for health care settings. *Health and Social Work*, 33(2), 149-154.

Week Fifteen

Student Ethnographic Research Paper Presentation;
Course Evaluation.

Week Sixteen

Final Examination.

VII. Course PoliciesAttendance Policy

Students are expected to attend all scheduled classes. If a class needs to be missed due to an extreme situation please contact the instructor as soon as possible. The instructor may request documentation regarding absences.

Assignment Policy

All assignments are due on the date assigned by the instructor. Assignments cannot be turned in late without prior permission from the instructor. True emergencies may require an incomplete.

Cell Phone Policy

Cell phone should be turned to silent mode unless prior arrangements are made with the instructor for emergency calls. Pagers are to be set on vibration mode.

Professional Writing Standards

The assigned paper will comply with the Publication Manual of the American Psychological Association (5th ed.). Information on APA format can be found at: <http://www.apastyle.org/faqs.html>

Indiana University Policy on Plagiarism

Plagiarism is defined as presenting someone else's work, including the work of other students, as one's own. Any ideas or materials taken from another source for either written or oral use must be fully acknowledged, unless the information is common knowledge. What is considered "common knowledge" may differ from course to course.

- a. A student must not adopt or reproduce ideas, opinions, theories, formulas, graphics, or pictures of another person without acknowledgment.
- b. A student must give credit to the originality of others and acknowledge indebtedness whenever:
 1. Directly quoting another person's actual words, whether oral or written;

2. Using another person's ideas, opinions, or theories;
3. Paraphrasing the works, ideas, opinions, or theories of others, whether oral or written;
4. Borrowing facts, statistics, or illustrative material; or
5. Offering materials assembled or collected by others in the form of projects or collections without acknowledgment.

Code of Student Rights, Responsibilities, and Conduct. Indiana University.

<http://www.iupui.edu/code/>

IU School of Social Work Addendum to Indiana University Policy on Plagiarism

In addition to the university statement on plagiarism which is published in the IU Student Code of Student Rights, Responsibilities, and Conduct, the IU School of Social Work defines plagiarism as including:

- The intentional or *unintentional* use of information from another person without full acknowledgment. Such use, even when unintended, causes the work to appear to be the student's own work and thus the student, not the original author, benefits from the omission of proper acknowledgment.
- Copying or using information from websites without appropriately documenting the internet source.
- Buying or using a document written by another person.
- Submitting any part of the student's own work which has been previously submitted, unless one's own prior work is fully acknowledged and appropriately cited.

Right to Accommodation for Individuals with Disabilities

Indiana University is committed to creating a learning environment and academic community that promotes educational opportunities for all individuals, including those with disabilities. Course directors are asked to make reasonable accommodations, upon request by the student or the university, for such disabilities. It is the responsibility of students with documented physical or learning disabilities seeking accommodation to notify their course directors and the relevant campus office that deals with such cases in a timely manner concerning the need for such accommodation. Indiana University will make reasonable accommodations for access to programs, services, and facilities as outlined by applicable state and federal laws.

Campus support offices:

Bloomington: Disability Services for Students www.indiana.edu/~iubdss

East: Student Support Services www.iue.edu/stuserv

Indianapolis: Adaptive Educational Services life.iupui.edu/aes/index.asp

Kokomo: Affirmative Action www.iuk.edu/ADMINFIN/affirmative-action

Northwest: Student Support Services www.iun.edu/~supportn

Southeast: Disability Services www.ius.edu/UD/DisabilityServices

South Bend: Office of Disabled Student Services www.iusb.edu/~sbdss

Grading Rubric -- New for 2009

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.

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

A+	96%	Exceptional
A	93%	Excellent 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
D+	67%	Unsatisfactory Quality
D	63%	Unsatisfactory Quality
D-	60%	Unsatisfactory Quality
F	<60%	Unsatisfactory Quality

VIII. Detailed Description of Class Assignments

Format for 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. Class presentation of the paper must be done utilizing PowerPoint and will be scheduled for the last class prior to the final examination. A copy of the PowerPoint presentation is to be included with the paper submission.

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. Select an informant who is the parent of a child who is currently experiencing a chronic illness or disability. The parent and child should not be related to you.
2. The major objective of the 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 their 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:
 - (1) The meaning of the illness or disability to the child, parent and family;
 - (2) The types of strategies used by the child and/or parent to live with the illness or disability;
 - (3) 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. Confidentiality must be upheld and discussed with the informant before the interview occurs. A release of information form will be provided by the instructor prior to the interview.
5. 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 parents 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.

6. Summarize your interview in five (5) double-spaced, typed pages (removing all identifying information), including at least three (3) direct quotes from the consumer.
7. Provide a five (5) page critique of your interview, addressing the following:
 - How well do you think you elicited information from the informant about their child's illness or disability experience?
 - Name two things that you might have done differently during the interview and explain why.
 - What areas do you wish you had covered in the interview but did not? Please explain.
 - How "connected" did you feel to the informant and why?
 - What part of the interview was most difficult for you and why?
 - 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) peer reviewed journal articles.
9. Briefly discuss any possible social service programs and/or services that might be helpful to the child and parent.
10. Attach a copy of your interview guide.
11. Attach a hard copy of your PowerPoint presentation.

Paper Presentation

1. All students are to be respectful and attentive toward other presenters. Attendance for the presentation class is expected.
2. The presentation is to be done using Power-Point. Handouts can be provided to other class members if you desire.
3. You will have 20 minutes to present your paper to the class. Please keep your presentation to within this allocated time so that other students will have time to present their papers.
4. The following is to be covered in your PowerPoint presentation. (Please present a brief presentation of the following. Do not read from your paper.)

- Describe the parent informant that was the focus of your interview.
- Share questions from your interview guide with the class.
- From your literature review, describe the primary illness or disability of the child.
- Describe how the parent and child organize their daily lives within the context of the illness or disability.
- Describe any challenges that you faced in completing the Ethnographic Research Paper.
- Discuss what you learned by doing this assignment.

IX. Bibliography

- Antle, B. (2004). Factors associated with self-worth in young people with physical disabilities. *Health and Social Work, 29*(3), 167-175.
- Asch, A. (2001). Critical race theory, feminism, and disability: Reflections on social justice and personal identity. *Ohio State Law Review, 62*, 1-17.
- Attia, J., Ioannidis, J., Thakkinstian, A., McEvoy, M., Scott, R., Minelli, C., Thompson, J., Infante-Rivard, C. & Guyatt, G. (2009). How to use an article about genetic association. *JAMA, 301*(1), 74-81.
- Batshaw, M., Pellegrino, L., & Roizen, N. (2007). *Children with disabilities*. 6th ed. Baltimore, MD: Paul H. Brookes Publishing Company.
- Burnes, D., Antle, B., Williams, C. & Cook, L. (2008). Mothers raising children with sickle cell disease at the intersection of race, gender, and illness stigma. *Health and Social Work, 33*(3), 211-220.
- Centers for Disease Control and Prevention. (2009). CDC statement on autism data, *CDC Data and Statistics, October 5, 2009*. from <http://www.cdc.gov/ncbddd/autism/data.html>
- Clute, M. A. (2008). Physical disabilities. In T. Mizrahi & L. Davis (Eds.) *Encyclopedia of Social Work*, (20th ed.). New York, NY: Oxford University Press.
- Coates, H. (2009). Autism spectrum disorders: Wading through the controversies on the web. *Medical Reference Services Quarterly, 28*, 259-267.
- Cook, B. & Schirmer, B. (2003). What is special about special education? Overview and analysis. *The Journal of Special Education, 37*(3), 200-205.
- Corrigan, P. (2007). How clinical diagnosis might exacerbate the stigma of mental illness. *Social Work, 52*(1), 31-39.
- Darnell, J. (2007). Patient navigation: A call to action. *Social Work, 52*(1), 81-84.

- Dunst, C., Trivette, C. & Hamby, D. (2007). Meta-analysis of family-centered helpgiving practices research. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 370-378.
- Ell, K. & Vourlekis, B. (2005). Social work in health care in 2025: The landscape and paths to transformation. *Advances in Social Work*, 6(1), 182-192.
- Galambos, C. (2004). Social work practice with people with disabilities: Are we doing enough? *Health and Social Work*, 29,(3), 163-165.
- Gilson, S. & DePoy, E. (2002). Theoretical approaches to disability content in social work education. *Journal of Social Work Education*, 38(1), 153-165.
- Gordon, D. (2009). Early intervention in autism. *Neurology Now*, September/October 2009, 23-26.
- Harrington, D. & Castellanos-Brown, K. (2008). Early childhood and preschool. In T. Mizrahi & L. Davis (Eds.) *Encyclopedia of Social Work*, 20th ed., New York, NY: Oxford University Press.
- Holliman, D., Dziegielewski, S. & Teare, R. (2003). Differences and similarities between social work and nurse discharge planners. *Health and Social Work*, 28(3), 224-231.
- Hardiman, E., Theriot, M. & Hodges, J. (2005). Evidence-based practice in consumer-run programs. *Best Practices in Mental Health*, 1(1), 105-122.
- Head, L. & Abbeduto, L. (2007). Recognizing the role of parents in developmental outcomes: A systems approach to evaluating the child with developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 293-301.
- Itzhaky, H. & Schwartz, C. (2000). Empowerment of parents of children with disabilities: The effect of community and personal variables. *Journal of Family Social Work*, 5(1), 21-36.
- Johnson, V., Edwards, K., Sherman, S., Stephens, L., Williams, W., Adair, A. & Deer-Smith, M. (2009). Decisions to participate in Fragile X and other genomics-related research: Native American and African American voices. *Journal of Cultural Diversity*, 16(3), 127-135.
- Kim, K & Turnbull, A. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research and Practice for Persons with Severe Disabilities*, 29(1), 53-57.
- Laino, C. (2007, March/April). The hunt for genes and cures. *Neurology Today*, 20-27.

- Mackelprang, R. (2008). Disability overview. In T. Mizarahi & L. Davis (Eds.) *Encyclopedia of Social Work*, (20th ed.). New York, NY: Oxford University Press.
- Mattox, R. & Harder, J. (2007). Attention deficit hyperactivity disorder. *Child and Adolescent Social Work Journal*, 24(2), 101-207.
- Marlow, N. (2004). Neurocognitive outcome after very preterm birth. *Archives of Disease in Childhood – Fetal and Neonatal Edition*, 89, 224-228.
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X. Suggested Websites

American Academy of Neurology Foundation	www.aan.com/go/foundation
About Special Kids (ASK)	www.ipin.org
The ARC of the United States	www.thearc.org
The ARC of Indiana	www.arcind.org
Autism Society of America	www.autism-society.org/
Autism Society of Indiana	www.autismindiana.org
Autism Speaks, Inc.	www.autismspeaks.org
Beach Center on Families and Disability	www.beachcenter.org
BenefitsCheckUp – Federal and State Program eligibility information	www.benefitscheckup.org
Brain Injury Association of America	www.biausa.org
Children’s Brain Tumor Foundation	www.abta.org
Children’s Hydrocephalus Support Group	www.hydrosupport.org
Children’s Special Healthcare Services	www.in.gov/isdh/programs/cshcs/
Centers for Disease Control and Prevention	www.cdc.gov
Epilepsy Foundation	www.edilepsyfoundation.org
Family Voices	www.familyvoices.org
Federal Government Programs	www.FirstGov.gov
Global and Regional Asperger	

Syndrome Partnership	www.grasp.org
Hereditary Disease Foundation	www.hdfoundation.org
IMPACT: Transition to Empowered Lifestyles Project Person-Centered Project	www.ptimpact.com
Indiana Department of Education, Division of Exceptional Learners	www.doe.state.in.us/exceptional/welcome.html
Indiana Department of Family and Social Services Administration Division of Disability Services	www.in.gov/fssa/disability
Indiana Governor's Council for People with Disabilities	www.in.gov/gpcpd/
Indiana Institute on Disability And Community	www.iidc.indiana.edu/
Indiana Protection and Advocacy Services	www.in.gov/ipas/
Individuals with Disabilities Education Improvement Act	www.ed.gov/policy/speced/guid/idea/idea2004.html
IN*SOURCE (Resource Center for Families with Special Needs)	www.incource.org
Institute for Independent Living	www.independentliving.org
Kidscount – Annie E. Casey Foundation	www.aecf.org/kidscount
Library Service for Disabled	www.loc.gov/nls
Maternal and Child Health Bureau	www.mchb.hrsa.gov
Medicaid and People with Disabilities	www.kff.org/medicaid/4017.cfm
Medline 24 Hour Consumer Health	

Information	www.MEDLINEplus.gov
MetDESK – MetLife’s Division of Estate Planning for Special Kids	www.metlife.com/desk
Muscular Dystrophy Association	www.mda.org
National Association of Social Workers – Social Workers Help Starts Here: Disabilities	www.helpstartshere.org/health_and_wellness/disabilities
The National Caregivers Association	www.nfcacares.org
National Center for Health Statistics	www.cdc.gov/nchswww/
National Center on Secondary Education and Transition	www.ncset.org/
National Dissemination Center for Children with Disabilities	www.nichy.org
National Institute of Health	www.nih.gov
National Institute of Mental Health	www.nimh.gov
National Library of Medicine	www.nlm.nih.gov
National Mental Health Information Center	www.mentalhealth.org
National Women’s Health Information	www.4woman.gov
Office of Minority Health Resource Center	www.healthgap.omhrc.gov
Social Security Administration	www.ssa.gov
Society for Disability Studies	www.uic.edu/orgs/sds/links.html
Supplemental Security Income	www.ssa.gov/work
Tourette Syndrome Association	www.tsa-usa.org
United Cerebral Palsy	www.ucp.org

United Nations ENABLE – Rights
And Dignity of Persons with
Disabilities

www.un.org/disabilities/

U. S. Dept. of Health and
Human Services

www.os.dhhs.gov/

Women, Infants and Children
(WIC) Supplemental Nutrition
Program

www.fns.usda.gov/wic

World Institute on Disability

www.wid.org

World Health Organization

www.who.ch/