

**Special Problems in Counseling and Human Development Services:
Teaching and/or Counseling Children With Chronic Illness or Chronic Medical Conditions
ECHD 4000
Spring 2003
Thursdays, 5:00-7:45pm**

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Office Hours: Mondays 9-11 a.m. (others by appointment)

Course Description:

Psychological, physical, environmental, and sociological aspects of chronic illness and chronic medical conditions in children. This course provides an overview of chronic illnesses and chronic medical conditions in children with emphases placed on advocacy, teaching strategies, counseling interventions, accommodations, multicultural issues, adjustment factors, community attitudes, legislation, barrier removal, and strategies for working with children with these conditions and their parents as well as school systems, the medical community, and community agencies.

Course Objectives:

1. Understand the physical, psychological, environmental, and social impact of chronic illness and disability in children.
2. Understand how attitudes of society and professionals impact children with chronic illness and/or disabilities and their families.
3. Be able to identify and discuss legislation that protects children with chronic illness and/or disabilities.
4. Understand the impact stressful events such as chronic illness and disability has on the child and the child's family.
5. Understand multi cultural and gender issues as they impact children with chronic illness and/or disabilities.
6. Understand and identify specific teaching strategies and counseling interventions that may be beneficial to use when working with children with chronic illness and/or disabilities and their families.
7. Become familiar with Individualized Health Plans, 504 Plans, and Medical CARE Plans for children with chronic illness and/or disabilities and their families.
8. Discuss transition, support services, and family supports as they relate to children with chronic illness and/or disabilities.
9. Understand advocacy and its role in working with children with chronic illness and/or disabilities and their families.
10. Become familiar with adjustment and transition models that facilitate intervention planning for children with chronic illness and/or disabilities and their families.
11. Become knowledgeable about existing resources and how to locate additional resources for children with chronic illness and/or disabilities and their families.

Texts:

Bowe, F. (2000). *Physical, sensory, and health disabilities: An introduction*. Upper Saddle River, NJ: Prentice-Hall.

Supplemental Texts and Materials:

Bleil, M.E., Ramesh, S., Miller, B. D., & Wood, B. L. (2000). The influence of parent-child relatedness on depressive symptoms in children with asthma: Tests of Moderator and mediator models. *Journal of Pediatric Psychology*, 25(7), 481-491.

- Boekaerts, M. & Roder, I. (1999). Stress, coping, and adjustment in children with a chronic disease: A review of the literature. Disability and Rehabilitation, 21(7), 311-337.
- Heller, K. W., Forney, P. E., Alberto, P. A., Schwartzman, M. N., & Goeckel, T. M. (2000). Meeting physical and health needs of children with disabilities: Teaching student participation and management. Toronto: Wadsworth/Thomson Learning.
- Klennert, M. D., McQuaid, E. L., McCormick, D., Adinoff, A. D., & Bryant, N. E. (2000). A multimethod assessment of behavioral and emotional adjustment in children with asthma. Journal of Pediatric Psychology, 25(1), 35-46.
- Kromer, M. E., Prihoda, T. J., Hidalgo, H. A., & Wood, P. R. (2000). Assessing quality of life in Mexican-American children with asthma: Impact on family and functional status. Journal of Pediatric Psychology, 25(6), 415-426.
- Livneh, H. & Antonak, R.F. (1997). Psychosocial adaptation to chronic illness and disability. Gaithersbury, MD: Aspen Publishers, Inc.
- Mackelprang, R. & Salsgiver, R. (1999). Disability: A diversity approach in human service practice. Pacific Grove, CA: Brooks/Cole Publishing Company.
- Marshak, L.E. & Seligman, M. (1993). Counseling persons with physical disabilities. Austin, TX: Pro-Ed.
- Marinelli, R. & Del Orto, A.(Eds.) (1991). The psychological and social impact of disability (3rd ed). New York: Springer Publishing Company.
- Miller, J.F. (2000). Coping with chronic illness: Overcoming powerlessness (3rd ed.). Philadelphia, PA: F.A. Davis Company.
- Nagler, M (Ed.)(1993). Perspectives on Disability (2nd ed.). Palo Alto, CA: Health Markets Research.
- Seagull, E. A. (2000). Beyond mothers and children: Finding the family in pediatric psychology. Journal of Pediatric Psychology, 25(3), 161-169.
- Veach, T.A., Nicholas, D. R., & Barton, M. A. (2002). Cancer and the family life cycle: A practitioner's guide. New York: Brunner-Routledge.
- Zimet, G. D., Cutler, M., Litvene, M., Dahms, W., Owens, R., & Cuttler, L. (1995). Psychological Adjustment of children evaluated for short stature: A preliminary report. Developmental And Behavioral Pediatrics, 16(4), 264-269.

Course Format:

The daily format of the class will vary depending on the topic to be covered. This course includes didactic content, personal reflection, and experiential elements. Lecture, guest speakers, discussion, group activities, and in-class presentations are learning strategies that will be used in this course. Therefore, your personal and active involvement in the process is essential for your successful completion of this course.

Accommodation Needs:

The University of Georgia Department of Counseling and Human Development Services is committed to providing access to all persons with disabilities and will provide accommodation if notified. If you have a documented disability or any other special needs and wish to discuss academic accommodations, please contact me as soon as possible. Necessary academic accommodations will be made for you based on the recommendations received from Disability Services. You must be registered with Disability Services to receive academic accommodations.

Academic Honesty and Integrity:

The University of Georgia's Honor code states: "I will be academically honest in all of my academic work and will not tolerate academic dishonesty of others."

1. All students are responsible for maintaining the highest standards of honesty and integrity in every phase of their academic careers. The penalties for academic dishonesty are severe and ignorance is not an acceptable defense.
2. Academic honesty means performing all academic work without plagiarism, cheating, lying, tampering, stealing, receiving unauthorized or illegitimate assistance from any other person, or using any source of information that is not common knowledge.

Suspensions of dishonesty will be reported to the Office of the Vice President for Instruction for resolution according to the UGA academic honesty policy, *A Culture of Honesty*. Students are responsible for reading and abiding by the honesty policy, which is found at: <http://www.uga.edu/ovpi>.

In addition to the University policy, students in the Department of Counseling and Human Development Services found in violation of the University's academic honesty policies or codes of professional ethics are subject to review and possible permanent expulsion from the programs offered in the Department.

Evaluation:

1. Quiz #1	15%
2. Quiz #2	15%
3. Development of a resource list for a specific medical condition	10%
4. Interviews or a visit to a camp or hospital	10%
5. Development of a Medical CARE Plan, 504 Plan, or IHP	15%
6. Final Intervention Project & Poster Presentation	25%
7. Class Participation	10%

Grading Scale:

A = 93-100	D = 70-77
B = 86-92	F = 69 and below
C = 78-85	

The grading scale is elevated due to the natural break in grades noted by the professor in previous semesters teaching the course. The grading scale is not meant to be seen as overly harsh or high, but rather reflects the high quality of the students who typically select this course. If you are concerned or confused regarding the grading scale, please discuss your concerns with the instructor.

Course Requirements:

Students are expected to **attend class and be prepared** to discuss the assigned readings. Additional readings may be assigned during the semester and students are expected to read these as well. Articles will be made available for photocopying and procedures for doing this will be explained in class.

Participation:

100 points (10%) of your grade is determined through class participation and contribution. Active participation is essential to your learning and contributes to the learning of others. A class roll will be sent around every class period for students to sign. It is **your responsibility to sign the roll sheet** before you leave class.

Students are expected to notify the instructor about absences and it is the student's responsibility to obtain the information missed. An excused absence will not adversely impact your participation grade. An excused absence may include illness or death of an immediate family member. Participation will be evaluated in the following way:

- Excellent – Proactive participation through leading, originating, informing, as well as asking questions that are thought provoking and indicate that you have **read** the material and reflected upon the readings and discussions. Participation does not mean dominating the discussion, making comments merely to make comments, or taking up class time with personal issues or tangential items. [93-100 points]
- Satisfactory – Reactive participation with supportive, follow-up contributions that are relevant and of value, but rely on the leadership and study of others. Active participation in group activities. [86 – 92 points]
- Minimally acceptable – Passive participation including being present, awake, alert, attentive, but not actively involved. I call it the “seat warmer”. While you may be learning, you are not contributing to other's learning nor are you assisting in producing discussions that engage others in learning. [78 - 85 points]
- Unsatisfactory – Uninvolved including being absent, **late**, leaving early, present but not attentive, sleeping, asking questions that clearly indicate you have not kept up with the readings or class discussions, and making irrelevant contributions that inhibit the progress of the discussion. [77 points or less]

Assignment Descriptions:

CARE Plans, IHPs, and 504 plans:

You will learn how to assist teachers, parents, and service providers in the development of a CARE Plan, IHP, or 504 plan. As one of your assignments, you will be expected to develop one of the following (a) a CARE plan for a child and his/her family, (b) an IHP, or (c) a 504 Plan. A care plan will be presented in class. Examples of IHPs and 504 Plans will also be presented in class. You are expected to develop a complete and accurate plan. The most effective way to develop a complete and accurate plan is to work with a parent, teacher, school nurse, etc..

Exams:

There will be two exams during the Semester. The format may include short answer, multiple choice, matching, and short essay. The midterm exam is tentatively scheduled but may be moved due to guest speaker schedules. The exact date of the midterm will be announced at least one week prior to the date indicated on the syllabus. The midterm will be given the first part of class and class will resume after the exam is completed. Note: there may be take home parts to the exams.

Interview, camp visit, or hospital visit:

You will be required to interview a child with a chronic illness/medical condition and their family (usually a parent and the child) or the parent of a child with a chronic illness/medical condition or visit a children's hospital or a camp for children with chronic illness and interview a staff member (nurse, coordinator, social worker, child life worker, etc.) and interview the nursing staff, social worker, child life worker, etc. You must turn in a written summary of your interview **without any identifying information regarding the child and family you interviewed**. In the summary you must include your thoughts, reflections, what you learned from the experience, and any insight you gained from the experience. You can utilize this information to develop the CARE Plan, IHP, or 504 Plan. If you visit a children's hospital you must have a tour and be able to interview at least one staff member involved with providing services to children and their families.

Intervention Project and Poster Presentation:

During the semester you are to develop some type of intervention that will assist a child with a chronic illness/medical condition and his/her family. You may develop a social skill intervention, a Medical CARE Plan with the development of community and school supports, a support group intervention, classroom teaching modules for a specific age group, or a specific counseling strategy, etc to use with the individual that will facilitate adjustment to disability, acceptance of disability, enhancement of abilities, development of community and familial support systems, etc. You could also choose to develop a sequence of lesson plans devoted to teaching a unit to children about a specific chronic illness/medical condition. This is an individual project that will be shared during final exam time as a final project. In some instances students may work in pairs. However, prior permission is required to work in pairs and a clear description of the project must be relayed to the instructor.

The project should be outlined in detail and include strategies to facilitate involvement, potential problems, potential benefits, and possible negative consequences. A poster presentation session will be scheduled for you present your final project. Examples of posters from a previous class will be available to you. Simply providing information on a specific condition does not constitute an intervention. The intervention must be deliverable to a specific target audience. Posters will

be evaluated based upon the quality and creativeness of the intervention, a clearly articulated rationale for the intervention, the target population and mode of delivery should be clearly stated, and neatness counts as well. A rubric will be provided.

Resource List:

You are required to develop a resource list with at least 10 resources that are beneficial to a child with a chronic illness and or their families, teachers, etc. The list should be e-mailed to the instructor by the date due so the resources can be compiled and shared with the entire class. The resources should be described and complete contact or reference information should be listed. You are also to specify who may benefit from the resources.

Course Outline:

Although every effort will be made to follow the course schedule, unforeseen circumstances may require that we deviate from the proposed schedule. If this should occur, the instructor will inform the students (in class) of the changes. **Note:** *Not all the readings are listed on the outline below. Given the nature of the course new material may become available and students will be notified regarding additional required readings.*

Topical Outline:

- January 9** **Introduction and Overview of Children with Chronic Illness**
The population of children with chronic illness/medical conditions
Legislation: Section 504, ADA, and IDEA
Legislation protecting children with chronic illness/medical conditions
(Bowe) Chapters 1 & 2
DeBettencourt, L. U. (2002). Understanding the differences between IDEA and Section 504.
TEACHING Exceptional Children, 34(3), 16-23.
- January 16** **504 Plans, IHPs, and Medical Care Plans**
(Bowe) Chapter 3;
(Heller et al, Chapters 1 & 4) This book will be placed on reserve in the Curriculum and Materials Center on the 2nd floor of Aderhold or copies will be made available in the folder.
- Special Readings:** **Blazer, B. (1999). Developing 504 classroom accommodation plans: A Collaborative, systematic parent-student-teacher approach.**
TEACHING Exceptional Children, 32(2), 28-33.
- Guest Speaker:** **Ms. Krudop "School Nutrition Issues for Children with Chronic Illness"**
- January 23** ***Guest Speaker: Dan Mathew: Project Director, Camp Twin Lakes**
Read pp. 3-34 in Livneh, H. & Antonak, R.F. (1997). Psychosocial Adaptation to Chronic Illness and Disability, Gaithersbury, MD: Aspen Publishers, Inc.
Read chapter 1, pp. 1-22 in Falvo, D. R. (1999). Psychosocial and functional aspects of chronic illness and disability. Gaithersbury, MD: Aspen Publishers, Inc
Read ch. 2 in Miller, J. F.(2000). Coping with chronic illness: Overcoming powerlessness (3rd ed.). Philadelphia, PA: F.A. Davis Company
- January 30** **Children with Asthma and Allergies**
(Bowe) ch. 9 pp. 203-207 & 222-226; (Heller) review ch.4 pp. 79-84
***Cohen, S. Y. & Wamboldt, F. S. (2000). The parent-physician relationship in Pediatric asthma care. . Journal of Pediatric Psychology, 25(2), 69-77.**
Getch, Y. Q., & Neuharth-Pritchett, S. (1999). Children with asthma: Strategies for educators. TEACHING Exceptional Children, 31(3), 30-36.

- *Markson, S. F. & Fiese, B. (2000). Family rituals as a protective factor for children with asthma. *Journal of Pediatric Psychology*, 25(7), 471-479.
- Neuharth-Pritchett, S., & Getch, Y. Q. (2001). Asthma and the school teacher: The status of teacher preparedness and training. *Journal of School Nursing*, 17(6), 323-328.
- Neuharth-Pritchett, S., & Getch, Y. Q. (2001). Entering school with chronic illness: Advocating for children with asthma. *Focus on Pre-K and K*, 14(1), 1-6.
- Guest Speakers:** 10 year old with asthma will demonstrate a computer based asthma game, how to use a peak flow meter, and talk about having asthma.
5 year old with asthma and food allergies will demonstrate use of a nebulizer and talk about his food allergies
- February 6** Children with Cystic Fibrosis (CF)
Heller et al. chapter 14
Bowe ch. 9 pp. 222-226
*Schmitt, G. M. (1993). Perception of illness and coping in adolescents and young Adults suffering from cystic fibrosis.
Zeitschrift fuer Klinische Psychologie. Forschung und Praxis, 22(2), 153-159.
- ***Guest Speaker:** Roberta Watson, mother of a 10 year old who has asthma
- February 13** Children with Diabetes
Guest speaker: Patti Coiner, mother of a 11 year old with diabetes
****Patti may speak on the 20th or the 27th****
(Bowe) ch.9 , 227-232
Wysocki, T. Educating kids about their diabetes. *Diabetes Health Monitor*, 5.
Telling your class about diabetes. *Kids Corner*
Siminerio, L. (1992). Childhood development: What's normal and what's not. *Diabetes Self-Management*, 43-45.
Bearman, K. J. & La Greca, A. M. (2002). Assising friend support of adolescents' diabetes care: The Diabetes Social Support Questionnaire-Friends Version. *Society of Pediatric Psychology*, 27(5), 417-428.
- February 20** Children with Heart Conditions
Children with Blood Disorders or Auto Immune Diseases: Sickle-Cell Anemia; Hemophilia; HIV/AIDS
(Bowe) CH. 8, pp. 237-242
Read ch. 8 pp. 177-191 & 195-200 in Falvo, D. R. (1999). *Psychosocial and functional aspects of chronic illness and disability*. Gaithersbury, MD: Aspen Publishers, Inc.
Graham, L.M. (2002). Sickle Cell Disease: Presents a roll call of respiratory complications. *Advance for Managers of Respiratory Care*, 40-42 & 80.
- February 27** Exam 1
Children with Spina Bifida, Muscular Dystrophy, Amputation, or Arthritis
Bowe pp. 170-186; Heller et al., Chapter 7.
- Special Readings:** Read ch. 11 pp. 265-288.in Miller, J.F. (2000). *Coping with chronic illness: Overcoming powerlessness* (3rd ed.). Philadelphia, PA: F.A. Davis Company
Read ch, 4 in Miller, J.F. (1992). *Coping with chronic illness: Overcoming*

- powerlessness** (2nd ed.). Philadelphia, PA: F.A. Davis Company von Weiss, R. T., Rapoff, M. A., Varni, J. W., Lindsley, C. B., Olson, N. Y., Madson, K. L., & Bernstein, B. H. (2002).
- Daily hassles and social support as predictors of adjustment in children with pediatric rheumatic disease. *Society of Pediatric Psychology*, 27(2), 155-165.
- March 6** **Children with Gastro-Intestinal Disorders, Crohn's; Colitis, Inflammatory Bowel Disease**
****Guest Speaker: Robin Sosbee, Mother of a preteen who has Crohn's.**
 Heller et al., Chapter 12
 *Wood, B. Watkins, J. B., Boyle, J. T., & Nogueira, J. (1987). Psychological Functioning in children with Crohn's disease and ulcerative colitis: Implications for models of psychobiological interaction. *Journal of the American Academy of Child & Adolescent Psychiatry*, 26(5), 774-781.
 Thomsen, H. A., Compas, B. E., Colletti, R. B., Stranger, C. Boyer, M. C., & Konik, B. S. (2002). Parent reports of coping and stress responses in children with recurrent abdominal Pain. *Journal of Pediatric Psychology*, 27(3), 216-226.
- Videotape:** Expressive Art Therapy use with children with Crohn's Disease
- March 13** **Children with Epilepsy**
 Bove Ch. 9 pp. 213-217 & 158-166
- Video:** No Label required: Teens talk straight about epilepsy
 Connelly, C. & Swyberius, S. J. (2001). Catastrophic epilepsy in infancy and childhood. *Living with epilepsy*, 2(3), 9-10.
- Let's hear from the schools:** Panel of educators
 Realities of working with children with chronic medical conditions
 *Panel Discussion led by Dr. Stacey Neuharth-Pritchett
 Sexson, S. Madan-Swain, A. (1995). The chronically ill child in the school. *School Psychology Quarterly*, 10(4), 359-368.
- March 20** **SPRING BREAK**
- March 27** **Interviews Due**
The impact of chronic illness on the Family System
 Canning, R. D., Harris, E. S., & Kelleher, K. J. (1996). Factors predicting distress among caregivers to children with chronic medical conditions. *Journal of Pediatric Psychology*, 21(5), 735-749.
 Gartstein, M. A., Short, A. D., Vannatta, K. & Noll, R. B. (1999). Psychosocial adjustment of children with chronic illness: An evaluation of three models. *Developmental and behavioral Pediatrics*, 20(3), 157-163.
- Guest Speaker:** **Dr. Ronald Blount**
- April 3** **Children with Cancer**
 (Bowe) pp. 196-202 & 207-213; Miller chapter 14
 Eiser, C. (1998). Long-term consequences of childhood cancer. *The Journal of Child Psychology and Psychiatry and Allied Disciplines*, 39(5) 621-633.
 Kazak, A., Barakat, L., Meeske, K., Christakis, D., Meadows, A., Casey, R., Penati, B., Stuber, M. (1997) Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. *Journal of Consulting and Clinical Psychology*, 65(1), 120-129.

- *Guest Speaker:** Suzanne Kilgore, 4th grade teacher who has several students with health conditions in her class and also has a niece with cancer.
- April 10** Careplan/504 plan/ OR IHP Due
***Expressive Arts Therapy with children who have chronic medical conditions: Dr. Pam Paisley (5-6:30)**
Readings to be assigned.
Children with burns (6:40-7:45) (Panel Discussion led by Dr. Nancy Williams)
- April 17** **Children with Growth Disorders and children whose growth has been impacted by chronic illness**
Heller et al., ch. 9
- MAGIC Foundation Web Site:** **Review all disorders listed**
<http://www.magicfoundation.org>
 (Bowe) pp. 187-192
 *Sandberg, D. E., Ognibene, T. C., Brook, A. E., & Barrick, C. (1998). Academic Outcomes among children and adolescents receiving growth hormone Therapy. *Children's Health Care, 27*(4), 265-282.
- *April 24** **School Re-entry for children with chronic illness Dr. Deryl Bailey**
 Sexson, S. Madan-Swain, A. (1993). School reentry for the child with chronic illness. *Journal of Learning Disabilities, 26*(2), 115-125.
- May 1** **Intervention Project Poster Presentations**
Course Evaluations
- Final Exam:** **Monday, May 5th 7-10 pm or Thursday May 8th 5-8pm.**