

Characteristics and Etiology of Infants and Young Children with Disabilities

Spina Bifida and Muscular Dystrophy

Sample Syllabus

Course Description

This course is designed for students to learn about motor impairments such as Spina Bifida and Muscular Dystrophy regarding etiology, diagnosis, prevalence, educational supports, and medical and therapeutic treatments for young children with motor impairments and their families. Family -centered practices will also be covered, as families are central to early intervention and early childhood education for children with a diagnosis of Spina Bifida and Muscular Dystrophy. Students will learn strategies for working with families, and their children who have these diagnoses.

Course Learning Objectives

As a result of active participation and successful completion of course requirements, students will be able to:

1. Explain the etiology, diagnosis, prevalence, educational supports, and medical and therapeutic treatments for young children with motor impairments and their families.
2. Explain the possible implications of having a diagnosis of motor impairments for infants and young children and their families.
3. Identify therapeutic and educational supports available for infants and young children with motor impairments with a specific focus on Spina Bifida and Muscular Dystrophy.
4. Explain the importance of family-centered care in early intervention and early childhood special education for infants and young children with Spina Bifida and Muscular Dystrophy.

Readings

Batshaw, M. L., Roizen, N. J., & Pellegrino, L. (Eds.). (2019). *Children with disabilities* (8th Ed). Paul H. Brookes.

Connelly, A. M. (2007). Transitions of families from early intervention to preschool intervention for children with disabilities. *Young Exceptional Children*, 10(3), 10-16.

<https://doi.org/10.1177/109625060701000302>

Copp, A. J., Adzick, N. S., Chitty, L. S., Fletcher, J. M., Holmbeck, G. N., & Shaw, G. M. (2015). Spina bifida. *Nature Reviews Disease Primers*, 1, 15007.

<https://doi.org/10.1038/nrdp.2015.7>

Howard, V. F., Williams, B. F., Miller, D., & Aiken E. (2014). *Very young children with special needs: A foundation for educators, families, and service providers* (5th ed.). Pearson.

Sussman, A. (2002). Duchenne muscular dystrophy. *Journal of the American Academy of Orthopaedic Surgeons*, 10(2), 138-151. <https://doi.org/10.5435/00124635-200203000-00009>

Turnbull, A. P., Turnbull, H. R., Francis, G. L., Burke, M. M., Kyzar, K., Haines, S., Gershwin, T., Shepherd, K., Holdren, N., & Singer, G. H. S. (2021). *Families and professionals: Trusting partnerships in general and special education* (8th ed.). Paul H. Brookes.

Accommodations

Section 504 of the Rehabilitation Act of 1973 and the American with Disabilities Act of 1990 require the institution to provide academic adjustments or accommodations for students with documented disabilities. Students seeking academic adjustments or accommodations must self-identify with the Coordinator of Services for Students with Disabilities on the appropriate campus.

Attendance

Since many of the classes involve activities, videotapes, discussion, etc., regular attendance is vital to gain maximum benefit. Because this is a 15-week course, each class member needs to make every effort to attend each class. Anyone who misses more than one class will lose 5 points for each class missed after the first absence. Significant tardiness or early departure beyond 15 minutes will count as an absence. If you know ahead of time you will not be in class, please contact the instructor the day before the class.

Communicating with the Instructor

All correspondence from the instructor to the students by way of announcements, updates, assignments, and so forth, will be communicated via school email or online learning management system if not verbally in class. It is the student's responsibility to ensure their university e-mail is correct. Failure to do so may result in missing important information that could negatively impact your grade. Please be mindful of professionalism.

Course Outline

The following schedule is subject to change. For any course syllabi posted prior to the beginning of the semester, the course instructor reserves the right to make changes prior to or during the semester. The course instructor will notify students, via e-mail or verbal announcements when changes are made in the requirements and/or grading of this course. ***The course instructor reserves the right to revise the schedule/assignments if needed.***

Course Schedule

Week	Topic	Readings/Assignments	In-Class Activities
1	<p>What is Spina Bifida (SB)?</p> <ul style="list-style-type: none"> • Spina bifida occulta • Myelomeningocele <p>Meningocele What is the etiology and prevalence of SB?</p> <ul style="list-style-type: none"> • A closer look at the neural tube • Genetic & non-genetic risk factors • Population/prevalence statistics • Prevention 	<p>Copp et al., 2015, pp. 1-4</p> <p>Watch the first 8-minutes of the following video on neural tube development and neural tube defects in SB:</p> <p>https://www.youtube.com/watch?v=aYihqiXw2Xk</p> <ul style="list-style-type: none"> • Take notes on the typical neural tube development process and what happens with SB. 	<p>Break into small groups to discuss an assigned topic (neural tube defect in SB; genetic/non-genetic risk factors; prevalence; and prevention). Groups are encouraged to draw images as appropriate to the topic. Then come together, and each group will summarize key points, and engage in Q & A.</p>
2	<p>How and when is SB diagnosed?</p> <ul style="list-style-type: none"> • Prenatal testing: <ul style="list-style-type: none"> ◦ Alpha-fetoprotein screening ◦ Ultrasound ◦ Amniocentesis • Postnatal testing: <ul style="list-style-type: none"> ◦ Visual markers-discrete/explicit ◦ MRI ◦ Chance 	<p>Copp et al., 2015, pp. 7-8, starting at "Diagnosis, treatment and prevention."</p> <p>Second Trimester Testing:</p> <p>https://www.stanfordchildrens.org/en/topic/default?id=second-trimester-prenatal-screening-tests-90-P08956</p> <p>Ultrasound, Mayo Clinic (2021)</p> <p>https://www.mayoclinic.org/tests-procedures/ultrasound/about/pac-20395177</p> <p>Amniocentesis, Mayo Clinic (2021):</p> <p>https://www.mayoclinic.org/tests-procedures/amniocentesis/about/pac-20392914</p>	<p>Review diagnostic procedures for SB.</p> <p>Watch video family reflection in receiving a diagnosis is SB:</p> <p>https://www.youtube.com/watch?v=gwSUxO8ahIU</p>

3	<p>What are the medical interventions following diagnosis of SB?</p> <ul style="list-style-type: none"> • Prenatal fetal surgery • Postnatal/neonatal surgery 	<p>Copp et al., 2015, pp. 9-10, starting at "Management."</p> <p>Watch the following video on prenatal fetal surgery for SB: https://www.youtube.com/watch?v=bLnYzCcTEEA</p>	<p>Watch video about pre/post-natal surgery: https://www.youtube.com/watch?v=xHP-SVDGPCE</p> <p>In class discussion: Consider the emotional impact on families in determining the best course of medical intervention upon diagnosis. Consider disparities in who is able to access prenatal versus postnatal surgery.</p>
4	<p>What is the long-term health trajectory for individuals with SB?</p> <ul style="list-style-type: none"> • Infancy • Early childhood • Childhood and adolescence • Adulthood • Hope and living with SB 	<p>Copp et al., 2015, pp.11-12, starting at "Quality of Life."</p> <p>Read through the "Complications" sited on the following webpage: https://www.mayoclinic.org/diseases-conditions/spina-bifida/symptoms-causes/syc-20377860</p> <p>Watch short video: https://www.youtube.com/watch?v=yqT5fwCi4c</p> <p>Read 2 case studies of your choice from two different ages: https://www.cdc.gov/ncbddd/birthdefects/stories/spinabifida.html</p> <ul style="list-style-type: none"> • Reflect on quality of life for each case study. 	<p>Review health trajectory and medical complications, and medical expenses related to treatment and health maintenance.</p> <p>Class discussion: Considering quality of life and resiliency, what are your thoughts about the case studies you read and watched? What surprised you? What additional questions do you have for the featured families you read about?</p> <p>Assignment due: Spina Bifida complications presentation</p>

		Listen to the 8 minute NPR interview with Riva Lehrer, an adult artist with SB: https://www.npr.org/2020/10/10/922589514/riva-lehrers-on-her-new-memoir-golem-girl	
5	What is Muscular Dystrophy (MD)?	Listen to this podcast that gives an overview of MD: https://www.youtube.com/watch?v=gzPRUmD4ezs	Small group activity: Read assigned section on type of MD, determine what age range is impacted by each type of MD.
6	Prevalence & Etiology of MD	Sussman, 2002, pp. 138-140, until Diagnosis Watch video until 4:30: https://www.youtube.com/watch?v=DGOmN6rnsNk	Kahoot review on prevalence and etiology key concepts.
7	Characteristics & Diagnosis of MD	Sussman, 2002, pp. 140-142, Diagnosis until Medical Management Read Muscular Dystrophy Association website on diagnosis of DMD: https://www.mda.org/disease/duchenne-muscular-dystrophy/diagnosis	Break into 3 groups, review assigned diagnostic tool (family history screening, physical exam, genetic testing).
8	Medical Intervention: MD	Sussman, 2002, pp. 142-144, Medical Management through Stage 1	
9	Long-term health trajectory: MD	Sussman, 2002, pp. 145-150	Small group case study activity.
10	Implications for families	Watch these videos ahead of class and reflect on what it is like to care for a child with uncertain health needs and vulnerability: https://www.youtube.com/watch?v=4Fi-miRqjHs&t=235s https://www.youtube.com/watch?v=ZrPnmgs4rHM	Class discussion: As an early childhood professional consider the many possible complications of SB and MD and reflect on your role in creating hope in children's and their families' lives and being responsive to family needs.

11	Early Intervention	Batshaw et al., 2019, Ch. 32	In class discussion: Defining physical therapy, occupational therapy & speech therapy.
12	Transition from EI to Preschool	Connelly, 2012	Watch transition meeting video and class discussion: https://www.youtube.com/watch?v=MWnbHPMg2EA
13	Preschool services	Howard et al., 2010	Jigsaw readings, Ch. 19-21 & group presentations. Assignment due: Preschool classroom observation
14	Collaboration and teaming	Turnbull et al., 2021, Ch. 1	In class discussion: Working with interdisciplinary teams.
15	How to find reliable information about SB and MD	Review the handout: https://guides.library.illinois.edu/ld.php?content_id=57224653	Find a peer-reviewed article published in the past 5 years on SB or MD in infants or young children.

Instructions for Assignments

1. Spina Bifida Complications Presentation

Each student will be assigned a medical complication commonly associated with Spina Bifida. Students will present a 10-minute PowerPoint presentation including the following information: definition of the assigned medical complication, medical intervention (as applicable), impact on daily life, health maintenance as it relates to the medical intervention, considerations for the classroom and school day.

2. Classroom Observation

Students will assess the classroom they are in for their practicum to evaluate accessibility for a child with Spina Bifida or Muscular Dystrophy. If there are no children in the classroom with either condition, students may use a fictional student based on the classroom environment they are in. To complete the evaluation, students will:

- Review the Environmental Arrangements Checklist 4 and 5 from the Early Childhood Technical Assistance Center (ECTA)
 - https://ectacenter.org/~pdfs/decrp/ENV-2_Env_Arrangements_2018.pdf
 - https://ectacenter.org/~pdfs/decrp/ENV-4_Environmental_Adaptations_2018.pdf
- Bring the checklists with you to your practicum site and complete the checklists.
- For items you marked “some of the time” and “seldom or never,” write a 1-2 sentence reflection on what you could do differently.

Course Grading

Assignments are due by 11:59pm on the indicated date. Late assignments without previous written approval of the instructor will incur a 50% penalty for the first time and lose all points beyond. This instructor and learners are required to adhere to the University's Academic Integrity policy. Any plagiarism will not be tolerated and referred to the Academic Integrity Office. The learner will be given an "F" in the course and be recommended to the Student Conduct Office.

Learners will be evaluated based upon the assignments described below. The plus/minus grading system and scale is as follows:

Letter Grade	Grade Range
A	93 and above
A-	90-92
B+	88-89
B	83-87
B-	80-82
C+	78-79
C	73-77
C-	70-72
D	60-69
F	59 and below

Component	Weight for final grade
Preparation for class; participation in class	20%
Group work/practice activities	30%
Spina Bifida complications presentation	25%
Preschool classroom observation	25%

Resources

Resources to supplement the Syllabus:

Websites

- Muscular Dystrophy Association: <https://www.mda.org>
- Parent Project Muscular Dystrophy: <https://www.parentprojectmd.org>
- Muscular Dystrophy Family Foundation: <https://www.mdff.org>
- Muscular Dystrophy Information Page: <https://www.ninds.nih.gov/Disorders/All-Disorders/Muscular-Dystrophy-Information-Page>

Webinars

- Muscular Dystrophy Association webinars: <https://www.mda.org/care/mda-engage/community-webinars>
- Physical Therapy and Muscular Dystrophy: <https://www.youtube.com/watch?v=E-11wzftLJ4>
- Center for Parent Information and Resources: <https://www.parentcenterhub.org/spinabifida/>
- Spina Bifida Resource Network: <https://www.thesbrn.org/>
- Spina Bifida Association: <https://www.spinabifidaassociation.org/>
- Mayo Clinic: <https://www.mayoclinic.org/diseases-conditions/spina-bifida/symptoms-causes/syc-20377860>
- Centers for Disease Control and Prevention: <https://www.cdc.gov/ncbddd/spinabifida/facts.html>
- Spina bifida (myelomeningocele, meningocele, occulta)- causes, symptoms, treatment: <https://www.youtube.com/watch?v=jlDZA2PNW2o>

Learning Modules

- Assistive Technology: <https://iris.peabody.vanderbilt.edu/module/at/>
- Related Services: Common Supports for Children with Disabilities: <https://iris.peabody.vanderbilt.edu/module/rs/>

Journals in Sensory Impairments and EI/ECSE

Below are examples of journals that publish topics about Sensory Impairments and Early Childhood. Faculty may want to explain how to use articles to support practice and to examine current research. Clarify the difference between practitioner-based journals and research-based journals.

- *American Journal of Intellectual and Developmental Disabilities*
- *Child Development*
- *Exceptional Parent Magazine*
- *Infants and Young Children*
- *International Journal of Early Childhood Special Education*
- *Journal of Developmental and Physical Disabilities*
- *Journal of Developmental & Behavioral Pediatrics*
- *Journal of Early Hearing Detection and Intervention*
- *Journal of Early Intervention*
- *Journal of Intellectual & Developmental Disability*
- *Journal of Neurodevelopmental Disorders*
- *Journal of Pediatrics*
- *Journal of Pediatric Nursing*
- *Journal of Special Education Technology*
- *Pediatric Research*
- *Rural Special Education Quarterly*
- *Teaching Exceptional Children*
- *Topics in Early Childhood Special Education*
- *Young Children*
- *Young Exceptional Children*

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