ECiDC Early Childhood Intervention Doctoral Consortium

Creating Leaders in Intensive Interventions for Infants, Young Children and Their Families

Etiology and Characteristics of Infants and Young Children with Disabilities

Prader-Willi Syndrome and Angelman Syndrome

Sample Syllabus

Course Description

This course is designed to provide students with a broad range of topics on both Prader-Willi syndrome (PWS) and Angelman syndrome (AS). The course begins with general background information on genetics so that students can understand the etiological causes of the conditions and continues into signs and symptoms and co-occurring conditions. Aspects of the lives of individuals with PWS and AS will be examined, including, but not limited to, early intervention and special education. Family impacts/dynamics will also be explored as well as current and emerging treatment options.

Required Texts

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

Wehmeyer, M. L., Brown, I., Percy, M., Shogren, K. A., & Fung, W. L. A. (Eds.) (2017). *A comprehensive guide to intellectual and developmental disabilities (*2nd ed.). Paul H. Brookes.

Course Learning Objectives

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

1. Describe the genetics of imprinting disorders.
2. Identify the etiological causes of Prader-Willi and Angelman syndromes.
3. Provide an overview of Prader-Willi syndrome and Angelman syndrome and including diagnosis, primary features, and co-occurring for each condition.
4. Compare and contrast the similarities and differences between PWS and AS.
5. Identify early signs of each disorder and how they are diagnosed.
6. Identify the roles and services of direct support professionals, early intervention specialists, and special education teachers.
7. Describe current evidence-based interventions and emerging treatments for each condition. Identify resources available to children with PWS and AS, as well as their families and care providers.

Readings

Grieco, J., Ciarlone, S., Gierone-Korthals, M., Schoenberg, M., Smith, A., & Philpot, R. (2014). An open-label pilot trial of minocycline in children as a treatment for Angelman syndrome. *BMC Neurology (14)*, 1-9. https://doi.org/10.1186/s12883-014-0232-x

Hayden, N., McCaffrey, M., Fraser-Lim, C., & Hastings, R. (2019). Supporting siblings of children with a special educational need or disability: An evaluation of Sibs Talk, a one-to-one intervention delivered by staff in mainstream schools. *Support for Learning*, *34*(4), 405–420. https://doi.org/10.1111/1467-9604.12275

Kayadjanian, N., Schwartz, L., Farrar, E., & Strong, T. (2018). High levels of caregiver burden in Prader-Willi syndrome. *PLOS ONE*, 1–15. https://doi.org/10.1371/journal.pone.0194655

Mahomoud, R., Leonenko, A., Butler, M., Flodman, P., & Gold, J. A. (2021). Influence of molecular classes and growth hormone treatment on growth and dysmorphology in Prader-Willi syndrome: A multicenter study. *Clinical Genetics*, *100*(1), 29–39. https://doi.org/10.1111/cge.13947

Miller, E., Buys, L., & Woodbridge, S. (2012). Impact of disability on families: Grandparents' perspectives. *Journal of Intellectual Disability Research*, *56*(1), 102–110. https://doi.org/10.1111/j.1365-2788.2011.01403.x

National Institute of Health. (2020, August 8). *Chromosome 15*. Medline Plus. https://medlineplus.gov/genetics/chromosome/15/#conditions

Poser, H., & Trutia, A. (2015). Treatment of a Prader-Willi patient with recurrent catatonia. *Case Reports in Psychiatry*, *2015*, 1–4. https://doi.org/10.1155/2015/697428

Pullen, L., Pullen, C., Picone, M., Litjen, T., Johnston, C., & Stark, H. (2019). Cognitive improvements in children with Prader-Willi syndrome following pitolisant treatment. *The Journal of Pediatric Pharmacology and Therapeutics*, *24*(2), 166–171. https://doi.org/10.5863/1551-6776-24.2.166

Shaaya, E., Grocott, O., Laing, O., & Thibert, R. (2016). Seizure treatment in Angelman syndrome. *Epilepsy and Behavior*, *60*, 138–141. https://doi.org/10.1016/j.yebeh.2016.04.030

Trute, B., Hiebert-Murphy, D., & Levine, K. (2007). Parental appraisal of the family impact of childhood developmental disability: Times of sadness and times of joy. *Journal of Intellectual and Developmental Disability*, *32*(1), 1–9. https://doi.org/10.1080/13668250601146753

U.S. Department of Health and Human Services. (n.d.). *Angelman syndrome*. Genetic and Rare Disease Information Center. https://rarediseases.info.nih.gov/diseases/5810/angelman-syndrome

U.S. Department of Health and Human Services. (n.d.). *Prader-Willi syndrome*. Genetic and Rare Disease Information Center. https://rarediseases.info.nih.gov/diseases/5575/prader-willi-syndrome

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 is 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	Reading	Activities
1	Genetics	Batshaw et al., 2019, Chapter 1 Wehmeyer et al., 2017, Chapter 10	**Discussion Prompt**: Pose a question you have on the basics of genetics. Respond to at least one question from a classmate. Provide your source.
2	Chromosome 15	NIH Medline Plus: Chromosome 15	**Assignment: PowerPoint: Chromosome 15**
3	Prader-Willi Syndrome: Overview, Signs and Symptoms	NIH: Genetic and Rare Diseases Information Center (GARD): Prader-Willi Syndrome	**Discussion Prompt**: Develop a list of the signs and symptoms of PWS. Reflect on how the presence of these can lead to additional hardships for the child.
4	Prader-Willi Syndrome: Diagnosis	Batshaw et al., 2019, Chapter 12	**Discussion Prompt**: Explain your thoughts on the sequence of events that may take place during the diagnostic process for a child displaying the signs and symptoms of PWS.
5	Prader-Willi Syndrome: Early Intervention and Special Education	Batshaw et al., 2019, Chapters 30, 31, 33 Wehmeyer et al., 2017, Chapter 25, 34, 36	**Assignment: Reflection: PWS Early Intervention and Special Education** **Discussion Prompt**: Both PWS and AS result from deletions on chromosome 15, yet they present very differently. Why?
6	Angelman Syndrome: Overview, Signs and Symptoms	NIH: Genetic and Rare Diseases Information Center (GARD): Angelman Syndrome Mayo Clinic: Angelman Syndrome	**Discussion Prompt**: Describe two of the common comorbid/co-occurring conditions in children with AS. How may these impact the daily life of a child with AS?

Week	Topic	Reading	Activities
7	Angelman Syndrome: Diagnosis, Early Intervention and Special Education	Batshaw et al., 2019, Chapters 12, 30, 21 Wehmeyer et al., 2017, Chapter 26, 34, 36	Discussion: Compare and contrast the diagnostic processes for PWS and AS. Compare and contrast the role of the interdisciplinary team and the interventions for a child with PWS and a child with AS.
8	Family Impacts and Considerations	Batshaw et al., 2019, Chapter 37 Wehmeyer et al., 2017, Chapter 40 Hayden et al., 2019; Kayadjanian et al., 2018; Miller et al., 2012; Trute et al., 2007	**Assignment: Reflection: In a Family's Shoes**
9	Treatment of PWS & Common Co-Occurring Conditions	Mahomoud et al., 2021; Pullen et al., 2019; Poser & Trutia, 2015	**Discussion Prompt**: Comment on the readings and treatment options that are new to you.
10	Treatment of AS & Common Co-Occurring Conditions	Greico et al., 2014; Shaaya et al., 2016	In-Class Activity: **Jigsaw Reading Groups** **Instructions:** 1. Divide the class into two groups: o **Group A** reads and discusses **Shaaya et al. (2016)**. o **Group B** reads and discusses **Grieco et al. (2014)**. 2. Each group answers: o What treatment is discussed? o What are the outcomes or challenges? o How might this affect a child's behavior or learning in early childhood settings?

Week	Topic	Reading	Activities
11	Transitioning to Adulthood	Batshaw et al., 2019, Chapter 40 Wehmeyer et al., 2017, Chapters 37, 38, 39	Discussion: Find at least one external resource for families with children with PWS and AS related to post-secondary transition. Discuss how this resource can be useful for families and professionals.
12	Case Studies		**Assignment: Case Study** **In-Class Activity:** Ask students to create a "resource binder" for families of children with AS based on the case studies and readings, including: • A summary of seizure treatments • Questions to ask doctors • Tips for classroom accommodations • Communication strategies
13	PWS and AS	Professional Development Guide: PWS and AS	**In-Class Activity:** In small groups, fill out a chart comparing: Feature / Prader-Willi Syndrome / Angelman Syndrome Genetic Cause Developmental Features Behavioral Traits Educational Needs **Assignment: Venn Diagram**
14	Final Presentations		**Assignment: Final Presentations: Treatment Option**
15	Finals week		

Instructions for Assignments

1. **Assignment: PowerPoint: Chromosome 15**: Choose one of the following: genomic imprinting, translocation, uniparental disomy, or gene mutation. Using at least 2 external sources, create a 10-minute PowerPoint presentation on the topic. Prepare to present to classmates.
2. **Assignment: Reflection: PWS Early Intervention and Special Education:** Reflect on the possible members of an interdisciplinary team supporting a child and family with PWS. Include a justification for each team member. During class you will discuss your reflection with a peer and compare your teams and justifications.
3. **Assignment: Reflection: In a Family's Shoes:** Put yourself in the shoes of a family member that has a child with PWS or AS. Write a 2–3-page paper on a day in the life from their perspective. What emotions do you experience? What support do you provide? Be sure to include the family membership and syndrome that you have chosen.
4. **Assignment: Case Study:** Develop a 1-2 page case study of a child and family with either PWS or AS. Case studies need to include: history, signs and symptoms, diagnostic process, and functional and behavioral characteristics.
5. **Assignment: Venn Diagram:** Complete the Venn diagram on the similarities and differences between PWS and AS. Be sure to include: chromosomes/genetics, history, prevalence, early signs, diagnosis, characteristics, and treatments.
6. **Assignment: Final Presentations: Treatment Option**: Conduct a literature review (at least 5 external sources) on a treatment option for either PWS or AS. Develop a 15-minute PowerPoint presentation on the treatment option. Prepare to give the presentation during week 14.

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

Graded Assignments	**Points toward final grade**
7 Discussion posts and responses to peers' discussions	70
PowerPoint: Chromosome 15	20
Reflection: PWS Early Intervention and Special Education	40
Reflection: In a Family's Shoes	40
Case Study	20
Venn diagram	10
Final assignment: Treatment option	100
Total Possible Points	300

Resources

Resources to supplement the Syllabus:

Title	Key Content	Link
Prader-Willi Syndrome	Overview of PWS including information on genetic imprinting.	View
PWS Video	A video describing what it is like to live with PWS from individuals with PWS	View
PWS with Dr. Michalec	A podcast interview with Dr. Michalec on PWS and how caregivers and practitioners can help.	View
PWS	A podcast of experts on PWD who provide an in-depth look at PWD including diagnosis, treatment, and PWS in the community.	View
A Parent's Early Perspective on PWS	A podcast series of parents sharing their story of having a child with PWS.	View
A Son with PWS	A podcast interview of a mother on raising her son with PWS.	View
PWS Behavior Challenges and Solutions	Behavior tips for teachers.	View
Comparison of Prader-Willi and Angelman Syndrome	Coursera video overview of PWS and AS.	View
Genetic Comparison of PWS and AS	An in-depth comparison of the genetics of PWS and AS.	View
An Inside Look at Angelman Syndrome Rare Disease: An Interview with Amanda Moore	A podcast interview with Amanda Moore, mother of a child with AS and CEO of the Angelman Syndrome Foundation, on her experiences raising a child with AS.	View
RARE Diagnosis: Angelman Syndrome	A podcast interview series of parents of children with AS.	View
Angelman Syndrome	A podcast of experts who discuss AS in-depth including diagnosis, treatment, and the strength of the AS community.	View
Angelman UK video collection	A collection of videos including communication, behavior, epilepsy, transition, siblings, challenging behaviors, and conferences talks.	View

Journals in EI/ECSE

Below are examples of journals that publish topics about motor disabilities and EI/ECSE. 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.

- *Exceptional Parent Magazine*
- *Infants and Young Children*
- *International Journal of Early Childhood Special Education*
- *Intervention in School and Clinic*
- *Journal of Early Hearing Detection and Intervention*
- *Journal of Early Intervention*
- *Journal of Pediatrics*
- *Journal of Special Education Technology*
- *Rural Special Education Quarterly*
- *Teaching Exceptional Children*
- *Topics in Early Childhood Special Education*
- *Young Children*
- *Young Exceptional Children*

This is a product of the Early Childhood Intervention Doctoral Consortium (ECiDC), a project of the A.J. Pappanikou Center for Excellence in Developmental Disabilities at UConn Health. The Center is funded through cooperative agreement number H325H190004 from the Office of Special Education Programs, U.S. Department of Education. Materials and opinions expressed herein do not necessarily represent the Department of Education's position or policy.