Course description

This course will examine the role of families in raising children with disabilities, how families have influenced the development of policies and programs for children with disabilities, and how they interact with these policies and programs to improve their children’s well-being and outcomes. As a secondary topic the course will also examine the experiences of families led by parents with disabilities. The course will be anchored on Andrew Solomon’s book *Far from the Tree*, as well as the lived experiences of children/youth with disabilities and their families as depicted in various types of “vignettes”. We will also read articles and policy reports from various disciplines that examine disability issues. Timely and thorough completion of required readings and assignments is an essential part of the course.

We will start by understanding the uniqueness of families that raise children with disabilities including how disability affects families’ identities, resources and relationships, as well as the unique responsibilities, tasks and skills these families have/require to successfully raise their children. We will use the World Health Organization’s framework of functioning and disability; we will look at how the interplay of environmental factors, policies and family agency influence functioning (both that of the individual with a disability and that of his/her family). We will critically examine characterizations of these families as “stressed”/“coping” with disability, and will provide alternative frameworks that emphasize expertise, leadership and agency.

Children with disabilities often have worse access to quality services and worse outcomes than other children. Often disability results in increased expenses and reduced paid work for parents/caregivers, which puts these families at an additional disadvantage. Among children with disabilities and their families, children from racial/ethnic minority groups face additional challenges. Therefore, we will also consider how issues of equity, discrimination and intersectionality affect families of children with disabilities, as well as the policy/legal frameworks that address these issues.

We will review the historical evolution in the United States of societal expectations and family supports, with an emphasis on the expected role of families and a trend towards devolving responsibility for children with disabilities to families. We will critically examine seemingly positive notions such as “family-centered” service systems, and their implications for families.

We will then focus on four policy areas: education, family life, work/income, and health. For each policy area, we will examine:
(1) How program/policy supports may enhance both functioning (per the WHO framework) and participation,

(2) Assumptions, content and adequacy of program/policy supports,

(3) The historical evolution of the rights of people with disabilities and their families in that policy area, and the role played by families in advancing those rights,

(4) The frontier of disability rights and policy supports in that policy area.

Course Objectives
At the completion of the course, you will be able to:

1) Demonstrate a basic understanding of the life course and functioning perspectives on disability and how they can help us understand the role of public policy in supporting families of children with disabilities;

2) Describe the evolution of U.S. public policy in the last 50 years in supporting families of children with disabilities in the following areas: education, family life, work and income, and health.

3) Describe how policies and programs can affect family functioning and participation of children with disabilities.

4) Describe some of the frontier issues in the area of rights of children with disabilities and U.S. policies to support their families.

Course Requirements
Class Participation: Active learning through class participation and discussion are an essential component of the course. Students are expected to attend and participate in all classes. Class participation should be informed by the required readings for each session.

Attendance policy: You should attend at least 85% of all the class sessions. Please let me know via e-mail if you will be missing class.

Assignments will require that you apply concepts and tools covered in the class. For example, in one of the exercises, you will use life course concepts to analyze a vignette about a child with a specific type of disability and her family. In another exercise, you will participate in a mock special education team meeting to address the needs of a child with a specific type of disability (we will use child/family vignettes for these exercises).

Mid-term exam: in-class (Tuesday March 7, 11am-12:20pm).

Final exam: in-class (Friday, May 5, 9:15am-12:15pm)

Grading Criteria
Your final grade will be based on:
Regular class participation including engaged attendance, active participation in class discussions informed by the assigned readings, and class exercises: 25%

Assignments: 25%

Mid-term exam: 25%

Final exam: 25%

**Late assignments:** The grade on any assignment will be reduced by ten points (out of 100) for each day the assignment is late, unless an extension based on a well justified need for additional time has been agreed upon between the student and the instructor.

**Attendance:** The final grade will be reduced by five points for each unjustified absence.

**Additional Information:** Please note that there is a minimum attendance requirement (24 sessions). Please limit in-class use of laptops to note taking, and use of cell phones to class breaks.

**Course Evaluations:** Please complete the course evaluation. Your feedback is very important.

**Course format:** Class sessions will include both lectures by the instructor, in-class, seminar-like discussions, and in-class hands on exercise. Please do the required readings so that we can have informed and lively class discussions. The instructor will provide questions/discussion topics to guide the reading and discussion.

**Provisions for Feedback:** Written feedback will be provided after each assignment including the in-class mid-term and final exams. The feedback will follow a grading rubric provided for each assignment and will also include comments regarding whether the student is making progress towards a solid understanding of the course content. Students are welcome to see the instructor during office hours to clarify written feedback or request additional feedback.

**Academic Integrity:** You are expected to be honest in all of your academic work. Please consult Brandeis University *Rights and Responsibilities* for all policies and procedures related to academic integrity. Students may be required to submit work to TurnItIn.com software to verify originality. Allegations of alleged academic dishonesty will be forwarded to the Director of Academic Integrity. Sanctions for academic dishonesty can include failing grades and/or suspension from the university. Citation and research assistance can be found at LTS - Library guides.

**Notice:** If you are a student with a documented disability on record at Brandeis University and wish to have a reasonable accommodation made for you in this class, please see me immediately.

**Communications:** All course materials (e.g., syllabus, readings, instructional materials, assignments, and grading rubrics) will be posted on Latte. I will also use Latte to communicate with you about routine class matters such as discussion questions for the following class, as well as to alert you to any changes such as class cancellations/make up due to inclement weather.

**Course plan**
<table>
<thead>
<tr>
<th>Date</th>
<th>Session, objectives and readings</th>
<th>Assignments</th>
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<tbody>
<tr>
<td>Tuesday January 17, 2017</td>
<td><strong>Session 1: Introduction</strong></td>
<td>One paragraph (250-300 words) about why you are interested in disability.</td>
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<td>Objective: To introduce ourselves and describe the plan and expectations for the course</td>
<td>Before class: Write one paragraph (250-300 words) about why you are interested in disability.</td>
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<td></td>
<td>Watch Stella Young’s TED Talk <em>I am not your inspiration, thank you very much</em></td>
<td><strong>Required readings:</strong> None</td>
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<td>Friday January 20, 2017</td>
<td><strong>Session 2: “Parenting is no sport for perfectionists”</strong></td>
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<td>Objective: To discuss the identity issues involved in raising a child with a disability (or any child who is “different”)</td>
<td><strong>Required readings:</strong> Chapter 1 (Son) in <em>Solomon 2012</em> (Adams 2013) (a critique of Solomon’s book)</td>
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<td>Before class, watch Andrew Solomon’s TED talk <em>Love no matter what</em></td>
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<td>Tuesday January 24, 2017</td>
<td><strong>Session 3: The socioecological model of child development</strong></td>
<td><strong>New assignment: Life course concepts (due in class two weeks from this date)</strong></td>
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<td>Objective: To discuss how the socioecological model helps us understand the role of caregivers, families and policies in the development of children with disabilities</td>
<td><strong>Readings:</strong> (Bronfenbrenner 1993)</td>
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<td>Before class: Watch this short video about Bronfenbrenner’s ecological theory</td>
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<td>Friday January 27, 2017</td>
<td><strong>Session 4: Life course and disability</strong></td>
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<td>Objective: To review how a life course perspective helps us understand disability</td>
<td><strong>Readings:</strong> Introduction and Chapter 1 (Concepts) in <em>Priestley 2003</em> (Gee, Walsemann et al. 2012)</td>
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<tr>
<td>Tuesday January 31, 2017</td>
<td><strong>Session 5: The medical and social models of disability; critique of the social model of</strong></td>
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Objective: To review the key elements of the medical and social models of disability, as well as the critique of the social model of disability

Required reading:
(Wasserman, Asch et al. 2016) (read #1 “Definitions of Disability” and #2 “Models” of Disability) (Shakespeare 2002)

Friday February 3, 2017
Session 6: How unique are families of children with disabilities?

Objective: To discuss the uniqueness of parenting children with disabilities and its implications for policies and programs

Required reading:
Read:
(Turnbull, Beegle et al. 2001) Chapter 4 (Down Syndrome) in (Solomon 2012)
Skim:
(Green 2007), OR (McKeever and Miller 2004)

Tuesday February 7, 2017
Session 7: Disability, functioning and participation

Objective: To review the World Health Organization’s framework on functioning and disability (ICF)

Readings:
Read: (Simeonsson, Leonardi et al. 2003)

Guest speaker: Dr. Jessica Kramer, Boston University

Friday February 10, 2017
Session 8: Families versus professionals

Objective: To review the collaboration and conflict between families and professionals in raising and supporting children with disabilities

Required reading:
(Leiter 2004)
<table>
<thead>
<tr>
<th>Date</th>
<th>Session Title</th>
<th>Summary</th>
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<tbody>
<tr>
<td>Tuesday February 14, 2017</td>
<td><strong>Session 9: Historical perspective on the right to education</strong></td>
<td>Objective: To discuss the evolution of the right to education for children with disabilities in the U.S.</td>
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<td>Required reading: (Martin, Martin et al. 1996)</td>
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<td>Friday February 17, 2017</td>
<td><strong>Session 10: The role of family advocates in shaping the right to education</strong></td>
<td>Objective: To discuss the role that families had in policy advocacy and litigation that led to the right to education</td>
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<tr>
<td>Tuesday February 21, 2017</td>
<td>***** NO CLASS *****</td>
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<tr>
<td>Friday February 24, 2017</td>
<td>***** NO CLASS *****</td>
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<tr>
<td>Tuesday February 28, 2017</td>
<td><strong>Session 11: The frontier of the right to education</strong></td>
<td>Objectives: To discuss new directions in strengthening and expanding the right to education, e.g., inclusive college education</td>
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<td>Assignment: ICF concepts DUE</td>
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<td>New assignment: Prepare for in-class simulation of an IEP meeting (in class on Friday March 3)</td>
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<td>Required reading: (Grigal, Hart et al. 2013)</td>
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<td><strong>Guest speaker: Dr. Tom Sannicandro, former</strong></td>
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<tr>
<td>Date</td>
<td>Session Title</td>
<td>Objective</td>
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<tr>
<td>Friday March 3, 2017</td>
<td><strong>Session 12: How do families exercise and defend the right to education?</strong></td>
<td>Objective: To discuss the involvement of families in special education process and advocacy, and the demands that it places on them.</td>
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<tr>
<td>Tuesday March 7, 2017</td>
<td><strong>Mid-term exam</strong></td>
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<tr>
<td>Friday March 10, 2017</td>
<td><strong>Session 13: Family life and disability: A historical perspective</strong></td>
<td>Objective: To review critical changes in the laws/policies that influence the life of families of children with disabilities</td>
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<tr>
<td>Tuesday March 14, 2017</td>
<td><strong>Session 14: Parents with disabilities</strong></td>
<td>Objective: To discuss parents with disabilities and the ability and limitations of public policies and programs to support them</td>
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<tr>
<td>Friday March 17, 2017</td>
<td><strong>Session 15: Reproductive rights</strong></td>
<td>Objective: To discuss the tension between</td>
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<tr>
<td>Date</td>
<td>Session Title</td>
<td>Details</td>
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<td>Tuesday March 21, 2017</td>
<td><strong>Session 16: Reproductive/birth rights of and information/supports for families of children with disabilities</strong></td>
<td>Objective: To discuss the evolving reproductive/birth rights, and genetic information and technology available to families of children with disabilities; we will use as an example the case of families of children with Down Syndrome</td>
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<td>Friday March 24, 2017</td>
<td><strong>Session 17: Transition to adulthood</strong></td>
<td>Objective: To discuss the process and policy framework of the transition to adulthood (e.g., post-secondary education, employment, housing), and its implications for families</td>
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<td>Required reading:</td>
<td>(Cobb, Lipscomb et al. 2013) (Harmon 2011) (Additional readings TBD)</td>
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<td>Tuesday March 28, 2017</td>
<td><strong>Session 18: Selected Frontier Issue: Supports for siblings in their future planning/caregiving role</strong></td>
<td>Before class, watch this video about &quot;Where is Molly?&quot; Also explore the website Sibling Leadership Network on Employment and on policy advocacy.</td>
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<td>Required reading:</td>
<td>(Meltzer and Kramer 2016) (Stoneman 2005)</td>
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<td>Optional reading:</td>
<td>(Kramer, Hall et al. 2013) (Coyle, Kramer et al. 2014)</td>
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### INCOME AND WORK

**Friday March 31, 2017**  
**Session 19: How can income and work support policies help children with disabilities and their families?**  
Objective: To discuss the economic impact of raising a child with disabilities  
Required reading:  
(Stabile and Allin 2012)  
Chapter 7 (Disability) in (Solomon 2012)

**Tuesday April 4, 2017**  
**Session 20: Supplemental Security Income for children with disabilities**  
Objective: To discuss the role of the Supplemental Security Income in supporting children with disabilities and their families  
Required reading:  
TBD

### HEALTH

**Friday April 7, 2017**  
**Session 21: The health of children with disabilities**  
Objective: To describe the rise in chronic health conditions and disability among U.S. children and the implications for families  
Required reading:  
(Perrin, Anderson et al. 2014)

**Tuesday April 11, 2017**  
***** NO CLASS *****

**Friday April 14, 2017**  
***** NO CLASS *****

**Tuesday April 18, 2017**  
***** NO CLASS *****

**Friday April 21, 2017**  
**Session 22: Meeting the needs of children with special health care needs (CSHCN): Health insurance**  
Objective: To describe the health insurance programs that help families meet the needs of (CSHCN)  
Required reading:  
(Berry, Hall et al. 2014)

**Tuesday April 25, 2017**  
**Session 23: Meeting the needs of children with special health care needs (CSHCN): family and medical leave**  
Objective: To describe the family and medical
<table>
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<tr>
<th>Date</th>
<th>Session</th>
<th>Topic</th>
<th>Objective</th>
<th>Required reading</th>
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<tbody>
<tr>
<td>Friday April 28, 2017</td>
<td>Session 24</td>
<td>Frontier issues in meeting the needs of children with special health care needs (CSHCN)</td>
<td>To describe the frontier issues in improving the supports for families of (CSHCN), e.g., expansion of family and medical leave</td>
<td>TBD</td>
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<tr>
<td>Tuesday May 2, 2017</td>
<td>Session 25</td>
<td>What have we learned? How do we hope that the life of families of children with disabilities and the policies that support them will be like in 10/20 years from now? What role would you like to play in making that happen?</td>
<td>To discuss what we envision as new frontiers for families of children with disabilities, and what legal, policy and social changes are required to reach them</td>
<td>TBD</td>
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<tr>
<td>Friday May 5, 2017</td>
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<td><strong>FINAL EXAM</strong></td>
<td><strong>9:15am-12:15pm</strong></td>
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Readings:


Legal documents