



# Brandeis University

The Heller School for Social Policy and Management

## Lurie Institute for Disability Policy Annual Report – July 2011

This annual report of the Lurie Institute for Disability Policy summarizes highlights of the fiscal year ending June 30, 2011.

### Personnel

- Susan Parish joined the Lurie Institute for Disability Policy as its inaugural director and Nancy Lurie Marks Professor of Disability Policy.
- Marji Erickson Warfield, PhD '91, concluded her service as interim director of the Lurie Institute. She was appointed Director of the Nathan and Toby Starr Center, which has a longstanding, respected history of conducting research at The Heller School related to people with developmental disabilities and their families.
- The Institute welcomed Michelle Techler as department coordinator.
- Rachel Fichtenbaum, MPP '11, joined the Institute as a part-time research associate.
- Two MPP students, Greg Wheeler and Ellen Tracy Marya worked as graduate research assistants in the Spring 2011 semester.

### Teaching

- Five students were supported as Lurie Doctoral Fellows: Giusi Chiri, Morgan Crossman, Taletha Derrington, Cady Landa, and Maria Timberlake. Their research interests include autism, children with Down Syndrome and their parents, substance-exposed infants and the early intervention system, immigrant children with disabilities, and special education policy. Ms. Derrington is conducting her dissertation research. Ms. Chiri and Ms. Timberlake advanced to candidacy and are preparing their dissertation proposals. Ms. Landa and Ms. Crossman are engaged in coursework.
- Susan Parish was honored with the 2011 Heller School Teaching Award.
- Maria Timberlake provided a guest lecture entitled "Special Education Policy in the United States," for the Heller School's Disability Policy course.

- Both Drs. Parish and Erickson-Warfield actively supported doctoral students who are conducting their dissertations. Both are chairing dissertation committees and serving on additional dissertation committees. In addition, both assisted a Master's student who conducted her Capstone Project (an MPP program requirement) on transportation services for people with disabilities.
- Marji Erickson-Warfield, PhD '91, taught the doctoral seminar for students concentrating in Child, Youth and Family Policy.
- Susan Parish developed and taught a new course, Disability Policy, to Masters' and Doctoral students at the Heller School.
- Maria Timberlake provided a guest lecture in the class "Teaching Students with Special Needs in Regular Classrooms" at Colby College in Waterville, Maine.
- The Starr Center offered a Sociology of Disability course for undergraduate students, taught by Stephen Gulley, PhD '06.

## Research Activities

### *New External Funding*

- Marji Erickson Warfield, PhD '91, began collaborating with the Lurie Family Autism Center at Massachusetts General Hospital on a new project to study transitions to the adult health care system for youth with autism. This study is funded by the Maternal and Child Health Bureau, US Department of Health & Human Services.
- Susan Parish received three new grants to:
  - study health care access of Black and Latino children with autism, with funding from the Maternal & Child Health Bureau, US Department of Health & Human Services;
  - collaborate with the Arc of the United States on the development of its Autism Now! National Information and Resource Center; and
  - investigate the health care access of poor and low-income children with disabilities, with support from the University of Kentucky Center for Poverty Research.
- Susan Parish concluded a study, *State Health Policy and the Health Care Access of Children with Autism*, funded by the Maternal & Child Health Bureau, US Department of Health & Human Services.

## Ongoing Research Projects

- Marji Erickson-Warfield, PhD '91, led research on four ongoing projects:
  - In partnership with Walter Leutz, an evaluation of Massachusetts' participant-directed service system for low-income children with autism, funded by the Maternal & Child Health Bureau, US Department of Health and Human Services;
  - A longitudinal investigation of children with early special needs and their families who participated in an early intervention program and are now 23 years of age. This study, which is also funded by the Maternal & Child Health Bureau, US Department of Health & Human Services, seeks to understand transitions and well-being in early adulthood;
  - Fresh Start: Helping Hands for Infants and their Families, a project designed to support and stabilize families where substance abuse and/or HIV AIDS are putting young children at risk for temporary or permanent removal. The Massachusetts Department of Public Health funds this study.
- Susan Parish continued a study to promote cervical and breast cancer screening for women with developmental disabilities in North Carolina. This study is funded by the National Institute on Disability and Rehabilitation Research, US Department of Education.
- Susan Parish concluded a study to understand the health care access and financial burden of low-income children with special health care needs in the American South. This research was funded by the University of Kentucky Center for Poverty Research, through a grant from the US Department of Health & Human Services.

## Publications

- Chiri, G., & Warfield, M.E. (2011, June). Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Maternal and Child Health Journal* (published online).
- Dababnah, S., **Parish, S.L.**, Brown, L.T., & Hooper, S.R. (2010). Early screening for Autism Spectrum Disorders: A primer for social work practice. *Children and Youth Services Review*, 33, 265-273.
- Derrington, T. (2011). Findings from a Massachusetts Study on Drug-Exposed Infants and Early Intervention Service Use. *Zero to Three Journal*, 31(4), 69.
- Dickens, P., Luken, K., **Parish, S.L.**, & Swaine, J.G. (2011, June). *Women Be Healthy 2: A curriculum to increase cervical and breast cancer screening rates of women with intellectual and developmental disabilities*. Chapel Hill, NC: North Carolina Office on Disability & Health.

- Laws, J., **Parish, S. L.**, Scheyett, A. M., & Egan, C. (2010). Preparation of social workers to support people with intellectual and developmental disabilities. *Journal of Teaching in Social Work, 30*, 317-333.
- Nageswaran, S., **Parish, S.L.**, Rose, R.A., & Grady, M. (2011). Health care access of children with developmental disabilities. *Maternal and Child Health Journal, 15*, 634-641.
- **Parish, S.L.**, Macy, R.J., & Moss, K. (2010, July). Final report on *Standing by Safety* for the Armfield-Reeves Innovation Fund. Chapel Hill, North Carolina: School of Social Work, University of North Carolina at Chapel Hill.
- **Parish, S.L.**, Rose, R.A., & Swaine, J.G. (2010). Financial well-being of US parents caring for coresident children and adults with developmental disabilities: An age-cohort analysis. *Journal of Intellectual & Developmental Disabilities, 35*, 235-243.
- **Parish, S.L.**, Rose, R.A., Yoo, J., & Swaine, J.G. (2011, May). *State Medicaid policies and the health care access of low-income children with special health care needs in the American South*. Final report prepared for the University of Kentucky Center for Poverty Research. Waltham, MA: Lurie Institute for Disability Policy, Brandeis University.
- **Parish, S.L.**, Swaine, J.G., Luken, K., & Moss, K. (2010, July). *Improving cervical and breast cancer screening for women with developmental disabilities in North Carolina*. Report for the North Carolina Division of Mental Health, Developmental Disabilities & Substance Abuse Services. Chapel Hill, North Carolina: School of Social Work, University of North Carolina at Chapel Hill.
- **Parish, S.L.**, Swaine, J.G., Luken, K., Rose, R.A., Dababnah, S., & Fichtenbaum, R. (2011, June). *Increased knowledge of breast and cervical cancer screening needed among women with developmental disabilities*. Waltham, MA: Lurie Institute for Disability Policy, Brandeis University.
- **Parish, S.L.**, Thomas, K., Rose, R.A., Shattuck, P.T., Kilany, M., & Crossman, M. (2011, June). *Financial burden of raising children with autism: Association with state Medicaid spending*. Waltham, MA: Lurie Institute for Disability Policy, Brandeis University.
- **Parish, S. L.**, Whisnant, A. I., & Swaine, J. G. (2010). Policies and programs for children and youth with disabilities. In J. M. Jenson & M. W. Fraser (Eds.), *Social policy for children and families: A risk and resilience perspective, 2nd ed.* Thousand Oaks, CA: Sage.
- Swaine, J.G., **Parish, S.L.**, & Luken, K. (2011, June). *Increasing cervical and breast cancer screening rates for women with developmental disabilities: Interim report to the North Carolina Division of Mental Health, Developmental Disabilities & Substance Abuse Services*. Chapel Hill, North Carolina: University of North Carolina School of Social Work.
- Swaine, J.G., **Parish, S.L.**, Luken, K., & Atkins, L. (2011). Recruitment and consent of women with intellectual disabilities in research studies. *Journal of Intellectual Disability Research, 55*, part 5; 474–483.

- **Timberlake, M.** (2011). Policy fact and policy fiction: Assessment, accountability and inclusive education. *Journal of Maine Education*.

## Public Engagement

### *Lectures and Panels sponsored by the Lurie Institute for Disability Policy*

- Peter Bearman, Cole Professor of Social Science of Columbia University and Director of the Lazarsfeld Center for the Social Sciences, gave a lecture entitled “Understanding the Increased Prevalence of Autism.” This lecture was co-sponsored with the Brandeis Department of Sociology and the Martin Weiner Fund.
- Susan Parish moderated a disability research panel at a national financial literacy conference convened by the Social Security Administration.
- The Joseph P. Kennedy Foundation invited Susan Parish to a policy and planning roundtable regarding the needs of adults with developmental disabilities and their elderly parent-caregivers.

### *Scholarly Presentations*

- **Parish, S.L.** (November 2010). Panel moderator; Research panel on Supplemental Security Income. *New insights and advances in financial literacy: Translation, dissemination, change*. Sponsored by the Social Security Administration’s Financial Literacy Research Consortium.
- **Derrington, TM** (December, 2010). *Using Linked, Population-Level Administrative Data to Identify Prenatal “Illicit” Drug Exposure and Referral to Early Intervention*. 16th Annual Maternal and Child Health Epidemiology Conference, San Antonio, TX.
- **Warfield, M.E., & Leutz, W.** (January, 2011). “Implementing participant direction for services for low income children with autism.” Roundtable Discussion at the Combating Autism Act Initiatives (CAAI) Conference. Washington, DC.
- **Parish, S.L** (January 2011). Panelist, disability research: *Ethics, logistics and methods*. Panel moderator: E. Lightfoot. Presentation at the annual conference of the Society for Social Work Research; Tampa.
- **Derrington, T.M.** (February 2011). *Using Linked, Population-Level Administrative Data to Identify Prenatal “Illicit” Drug Exposure and Referral to Early Intervention*. Massachusetts Early Intervention Program, Boston, MA.
- **Parish, S. L., Magaña, S., Rose, R., Timberlake, M., & Swaine, J.G.** (February 2011). *Racial and ethnic disparities in health care access of children with autism*. Paper presented at the 43rd Annual Gatlinburg Conference on Research & Theory in Intellectual and Developmental Disabilities; San Antonio.

- Plummer K., **Derrington, T.M.**, Kotelchuck, M., Cabral, H., Belanoff, C., Shin, M., Grosse, S., & Correa, A. (February 2011). *Patterns of Hospital Use among Children with Down Syndrome in Massachusetts, 1999-2005*. National Birth Defects Prevention Network Annual Meeting, Orlando, FL.
- **Parish, S.L.** (April 2011). *Reproductive health care access of women with developmental disabilities*. Paper presented at the Medicine and Culture Symposium, Department of Anthropology, Brandeis University, Waltham, MA.
- **Parish, S.L.** (May 2011). *State policy and the health care access and financial burden of children with special health care needs in the South*. University of Kentucky Center for Poverty Research annual research conference, Lexington, KY.
- **Parish, S.L.** (June 2011). *Financial well-being of children and adults with disabilities in the United States*. Invited address for the International Conference on Disability Economics. Sponsored by the University of Tokyo and the Burton Blatt Institute, Syracuse University. Syracuse, NY.
- **Parish, S.L.** (June 2011). *Problems with the US disability service system: Can Japan learn from our mistakes?* Invited presentation for the International Conference on Disability Economics. Sponsored by the University of Tokyo and the Burton Blatt Institute, Syracuse University, Syracuse, NY.
- **Parish, S. L.**, Magaña, S., Rose, R., Timberlake, M., & Swaine, J.G. (June 2011). *Racial and ethnic disparities in health care access of children with autism and other developmental disabilities*. Poster presented at the annual conference of the American Association on Intellectual & Developmental Disabilities; St Paul, MN.

### *Engagement with Editorial Boards and Review Panels*

- Marji Erickson Warfield serves on the Deborah Munroe Noonan Memorial Fund review panel, which supports innovative and collaborative clinical research, demonstration projects, and pilot studies in the Boston area designed to improve the quality of life for children with disabilities.
- Lurie Doctoral fellow Taletha Derringer serves on the review board for the *Review of Disability Studies*.
- Susan Parish guest edited a special section on poverty for the *Journal of Intellectual & Developmental Disabilities*, with Eric Emerson of Lancaster University in the UK.
- Marji Erickson Warfield PhD '91, is serving on a national review panel for the Maternal and Child Health Bureau of the National Institutes of Health.
- Susan Parish was appointed to the editorial boards of the journals *Health & Social Work* and *Research on Social Work Practice*.

- Marji Erickson Warfield PhD '91, and Susan Parish serve as editors of *Intellectual and Developmental Disabilities*.

## *Engagement with Community Organizations and Government Agencies*

- Taletha Derrington joined the Mass Health Policy Forum.
- Susan Parish was appointed to the board of directors of the Arc of Massachusetts and the Advisory Board of the Health Surveillance Task Force for People with Intellectual Disabilities.
- Maria Timberlake was elected to serve on the Board of WCI, Work, Community and Independence, a non-profit organization providing residential, employment, and other supports for adults with intellectual developmental disabilities.
- Marji Erickson Warfield PhD '91, began partnering with Autism Housing Pathways by helping them connect with a student to conduct a survey of the housing needs and resources of families with children with autism and of adults with autism in Massachusetts.
- Susan Parish was appointed to the Health Surveillance Task Force for People with Intellectual Disabilities, Shriver Center, Waltham, MA.
- Susan Parish conducted grant reviews for the National Institute on Disability and Rehabilitation Research, US Department of Education.
- The Starr Center provides space and refreshments for quarterly meetings of the Department of Developmental Services' (DDS) State Advisory Committee.

## **Financial Statement<sup>1</sup>**

### *Revenues*

Research grants	\$136,877
Lurie Institute fund	\$179,914
<b>Total revenues</b>	<b>\$316,791</b>

### *Expenses*

Personnel	\$192,740
Operating Expenses	\$67,063
Overhead	\$56,988
<b>Total expenses</b>	<b>\$316,791</b>

<sup>1</sup>*does not include Starr Center*