

FINAL REPORT ON THE SOCIAL SECURITY ADMINISTRATION'S DISABILITY DETERMINATION PROCESS SMALL GRANT PROGRAM, 2012 - 2017

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Disability Determination Process Small Grant Program Overview

Through an extensive network of local field offices, the Social Security Administration (SSA) makes decisions on over two million Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) applications annually. In 2008, SSA began implementing measures to improve the efficiency of this disability determination process (DDP) and reduce the initial claims backlog. SSA's strategy included objectives to increase staff at the DDSs, including the use of Extended Service Teams (ESTs); improve efficiency through automation with tools, such as the Electronic Claims Analysis Tool (eCAT); expand the use of screening tools, such as Compassionate Allowances (CAL) and Quick Disability Determinations (QDD); and refine policies and business processes.¹ By 2011, the agency had reduced the average wait for a disability hearing from 18 months to 12 months.² Building on this momentum, SSA launched the Disability Determination Process Small Grant Program in that same year. Administered by Policy Research, Inc. (PRI), the small grant program provided \$10,000 stipends to support approved graduate-level research that could inform and improve the DDP.

Between 2012 and 2017, 36 Masters and PhD-level students, partnered with mentoring faculty at 27 colleges and universities. Participants represented a range of academic disciplines, including Sociology, Psychology, Medicine, Public Health, Economics, and Social Work. Fifty-five proposals were accepted resulting in 49 successfully completed research projects

with topics ranging from the impact of stigma on claims application rates of Veterans to the development of a database that will help DDP staff identify appropriate jobs for SSDI claimants.

SCHOLAR SELECTION PROCESS

Program participants were recruited through graduate program list-servs, forums, professional organizations, and research publications. At the beginning of each program year, PRI staff compiled a summary of all proposals for submission to SSA. Once an initial list of viable proposals was selected, teams of expert reviewers from around the country, evaluated proposals using three criteria—proposal quality, SSA's priorities, and potential usefulness to the disability field. Through multiple reviewing rounds culminating in a virtual meeting of all reviewers, a final ranking was determined and submitted back to SSA for final approval decisions.

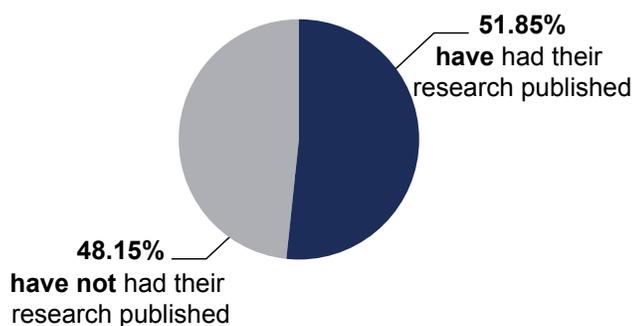
PROJECT COMPLETION PROCESS

With final SSA approval completed, awarded students officially began what was, for most, a year-long research project. While their mentors supervised most of the participant's day-to-day work, PRI staff administered the financial aspects of the program and created the administrative structure that monitored and supported each participant's progress through an annual kick-off call, required submission of quarterly reports and participation on quarterly calls, and the occasional provision of methodological assistance when necessary.

“My DDP grant was like a seed funding that allowed me to focus all my attention on the disability benefits systems. Without the DDP, I doubt that I would have [gone] on to do a dissertation in the topic let alone to become an Assistant Professor who is focused on conducting research to improve our disability support system.”

- Zachary Morris, 2014 and 2016 Cohorts

PUBLISHED RESEARCH



Participants published the following articles related to their DDP research:

- Burke, S. & Maramaldi, P. (2016). *Smith-Magenis Syndrome and the Compassionate Allowances Program*. Intellectual and Developmental Disabilities.
- Burke, S. & Maramaldi, P. (2017). *Variability in Clinical and Anatomical Manifestation of Velocardiofacial Syndrome Presents Diagnostic and Policy Uncertainty*. Fetal and Pediatric Pathology.

- Burke, S. & Maramaldi, P. (2017). *An Evaluative Review of the Evidence Supporting Idiopathic Basal Ganglia Calcification for Inclusion in the Compassionate Allowances Program*. Basal Ganglia
- Burke, S. & Maramaldi, P. (2017). *The Social Security Administration's Compassionate Allowances Initiative: Condition Spotlight: Rubinstein-Taybi Syndrome*. Health & Social Work.
- Hooyer, K. (2017). *The "Trauma Pitch": Stigma in the PTSD Diagnostic and Disability Determination Process for Iraq and Afghanistan Veterans*. Psychiatric Services.
- Keesler, J. M. (2015). *Applying for Supplemental Security Income (SSI) for individuals with intellectual and developmental disabilities: Service coordinator and family experiences*. Intellectual and Developmental Disabilities.
- Li, C. & Arthur, P. et al. (2017). *An empirical approach to link the ICFS Model and job demand classification*. Archives of Physical Medicine and Rehabilitation.
- Lowder, E. et al. (2017). *SSI/SSDI Outreach, Access, and Recovery Program (SOAR) Application Outcomes in Homeless Adults*. Psychiatric Services.
- McCauley, E. & Samples, L. (2017). *Navigating the Disability Determination Process from the Perspective of Incarcerated Adults with Serious Mental Illness*. Community Mental Health Journal.
- Morris, Z. (2015) *Disability benefit reform in Great Britain from the Perspective of the United States*. International Social Security Review.
- Pulcini, C. et al. (2015). *Examining Trends and Coexisting Conditions Among Children Qualifying for SSI under ADHD, ASD, and ID*. Academic Pediatrics.
- Sogar, C. (2016). *The Relationship between Parents' Physical and Mental Health Symptoms and Parenting and Material Limitations*. American International Journal of Humanities and Social Sciences.

Participants have also presented posters and papers on their DDP research at a wide range of annual conferences and events including the following:

- American Association of Intellectual and Developmental Disabilities
- American Public Health Association
- American Sociological Society
- Association of Higher Education and Disability
- Association for Public Policy Analysis and Management
- Assumption College Graduate Symposium
- Cambridge Health Alliance
- Correctional Health Conference
- Harvard Medical School Psychiatry Research Day
- International Association of Forensic Mental Health Services
- International Conference on Educational, Cultural, and Disability Studies
- International Neuropsychological Society
- National Association for Welfare Research and Statistics
- Northeastern Educational Research Association
- Occupational Therapy Association
- Pediatric Academic Societies Meeting
- Pennsylvania Psychological Association
- Pennsylvania Rehabilitation Studies
- Society for Community Research and Action
- Society for Social Work and Research
- Society of the Study of Social Problems
- St. Francis House
- Trauma Conference for Military Veterans and Populations

OPPORTUNITIES AND IMPACT

At the end of the DDP program's sixth and final cohort, PRI reached out to all former participants to learn what subsequent steps they had taken with their research. Sixty-eight (68) percent of participants responded. Their responses illuminate the program's extensive influence. Fifty-two (52) percent of respondents had published their research and 67 percent had presented their research at academic conferences, professional organizations, and community events.

TRANSITION TO THE ARDRAW SMALL GRANT PROGRAM

The successes of the DDP Small Grant Program gave rise to a new SSA initiative – the Analyzing Relationships between Disability, Rehabilitation and Work Small Grant Program (ARDRAW). This new program builds on the DDP Small Grant Program structure, but with a new prioritization of research on SSA's work incentives and employment supports.

Small Grant Program Projects

DDP Small Grant Program projects were reviewed by SSA program, policy and research staff, mentors and PRI to ensure rigorous academic and methodological standards. The resulting reports offer valuable information and insights on a breadth of DDP-related topics. The full text of published reports is available on the [DDP website](#).

SCHOLARS	YEAR	SMALL GRANT PROGRAM PROJECTS
Maggie Butler	2017	Social Security Benefits Eligibility at the Intersection of Disability, Advanced Age, Homelessness, and the Labor Market
Karino Barro	2017	School Professionals' Knowledge of the Disability Determination Process for Children Applying for Supplemental Security Income
Evan Lowder	2017	Implementing the SSI/DDI Outreach, Access, and Recovery (SOAR) Model with Justice-Involved Populations: A Survey of Practitioners
Elda Zeko-Underwood	2017	Phenomenological Study of Six Translated Materials as Completed by Foreign-Born Applicants
Alex Fixler	2017	Considering Early Intervention Programming for Major Depressive Disorder
Zachary Glendenning and Erin McCauley	2017	Public Assistance, Self-Sufficiency, and Housing Stability Among Families with Disabilities Experiencing Homelessness
Lindsay Berkowitz	2017	An Exploratory Study to Assess the Evaluation of Chronic Pain in the Social Security Administration Disability Determination Process Phase II: Investigating Institutional Interaction between Legal, State, and Medical Institutions
Rajan A. Sonik	2017	Changes in Material Hardship Preceding Entry into the Supplemental Security Income Program: Evidence from the Survey of Income and Program Participation
Elda Zeko-Underwood	2016	Emerging Challenge on Access: Phenomenological Study on non-US Citizens experience during SSI Application Process
Katherine Aquino	2016	Higher Education and the Disability Determination Process: Accessing SSI/SSDI in Postsecondary education
Lindsay Berkowitz	2016	An Exploratory Study to Assess the Evaluation of Chronic Pain in the SSA Disability Determination Process
Evan Lowder	2016	Application-level and State level Predictors of SSI/SSDI Outcomes in a National Sample of Adults at Risk of Homelessness
Erin McCauley and Leah Samples	2016	Qualitative and Quantitative Study of SOAR in the CJ Setting
Zachary Morris	2016	How to Intervene Early with SSDI Applicants: Lessons From a New Return to Work Program in Denmark
Megan Stanley	2016	Fresh Perspectives: How Claimants Understand the Adult Disability and Function Reports
Sarah Prenovitz	2016	Effects of DI on Health and Financial Well-Being
Adrianna Bagnall-Munson	2016	SSI in Transition: Benefits Application and Transition Planning for Youth in Special Education
Amber Davis	2016	Systematic Review of the Age-18 Redetermination Process Impacting the Transition of Youth to Adulthood: Recommendations for Social Security Administration
Rajan Sonik	2016	Review of Sickle Cell Disease, as Experienced by Children and Adults, for Possible Inclusion in the Social Security Administration's List of Compassionate Allowances
Paul Arthur	2015	ICF-AM/O*NET System: A Web-Based Application Linking Claimant Ability to Employment Possibility
Adrianna Bagnall	2015	Don't Step in the Cracks: Individuals with Autism and Their Parents in the Disability Determination Process
Mackenzie Dezieck	2015	Enhanced Claimant Participation for Veterans with Mental Health Disabilities in Evaluating Functional Limitations and Severity
Evan Lowder	2015	The Role of the SOAR Model in Successful Community Reintegration
Dana Olzenak	2015	Adding to Motor Assessment to the Disability Determination Process in School-Aged Children with ASD: Implications for Participation
Sarina Sechrist	2015	A Conceptual Harmonization between the SSA Disability Determination Process and ICCF and DOT Frameworks: A Guide to Assessing the Mental Residual Functional Capacity of Individuals with Autism Spectrum Disorders
Anne Skenzich	2015	A Full Research Study Formally Analyzing and Objective, Functional Measurement of Pain with the use of a Validated Visual Analog Scale for Chronic Pain Patients for the Purposes of a Disability Determination Program

SCHOLARS	YEAR	SMALL GRANT PROGRAM PROJECTS
Shanna Burke	2015	A Systematic Review of Idiopathic Basal Ganglia Calcification for Possible Inclusion in the Social Security Administration's Compassionate Allowances Program
Angela VanDerwerken	2014	Effect of New Psychotropic Pharmaceuticals on Disability Insurance Applications: Evidence from Matched SIPP/Administrative Data
Anna Johnson	2014	Homelessness and SSI: Comparing SSI Applications for Individuals Accepted and Denied Disability Income
Lea Vella	2014	Cognitive Impairment and Disability Determination in the Sheltered Homeless
Mary Ellen Stone	2014	Making the Transition: Influence of Self-Reported Work Disability on Labor Force Careers
Anne Skenzich	2014	A Proposal to Measure Chronic Pain: From Subjective or non-measurement to Objective and Scientific Measurement of Chronic Pain for Purposes of Disability Evaluation
Sarina Sechrist	2014	Incorporating ICF and Employment Concepts and Terminology in Residual Mental Functional Capacity Ratings: A Proposed Modification for Autism Spectrum Disorder
Zachary Morris	2014	Measuring Capabilities and Requiring Work: Comparing the Work Capability Assessment in Great Britain with the United States Disability Process
John Keesler	2014	The Application Process for Supplemental Security Income for Individuals with Intellectual and Developmental Disabilities: A National Survey of Service Coordinator and Family Experiences
Paul Arthur	2014	Empirical Approach to Linking the ICF to the Dictionary of Occupational Titles
Christian Pulcini	2014	Identifying and Explaining Co-morbid Conditions among Children and Adolescents Qualifying for SSI under the Mental Health Impairment Category
Shanna Burke	2013	A Systematic Review of Three Conditions for Possible Inclusion in the Social Security Administration's Compassionate Allowances Program
Katinka Hooyer	2013	The "Trauma Pitch": How Stigma Emerges for Iraq and Afghanistan Veterans in the PTSD Claims Process
Sharon Jung	2013	Ecological Validity of Neuropsychological Tests: Role of Memory and Executive Skills in Predicting Functional Ability in a Clinical Population
Allyssa Lanza	2013	The WISC-IV and Children and Adolescents with Intellectual Disability: Evaluating for Hidden Floor Effects in the US Version
Rose Nevill	2013	Improving Knowledge Transfer to Families of People with Disabilities on the SSI Application Process
Kathy Wu	2013	The "Lived Experiences" of a Chronically Homeless, Urban Population: Systemic Challenges to Achieving Their Vocational and Rehabilitation Dreams
Christian Pulcini	2013	Explaining Growth of Mental Impairments Among Children and Adolescents Receiving SSI
John Keesler	2013	A Pilot Study of Service Coordinator and Family Experiences in Applying for Supplemental Security Income for Individuals with Intellectual and Developmental Disabilities: Identifying Strengths, Obstacles and Recommendations for Improvement
Tamara Peace	2013	Refining the QDD Process to Assist Adolescents with Mental Health Disorders in Applying for SSI in Philadelphia: A Preliminary Study
Katie McIntyre-Reece	2013	Defined as a Disability: An Institutional Ethnography on Disability Determination for People with HIV/AIDS
Robin Telford	2012	Justice-Involved Adults with Serious Mental Illness and the Disability Determination Process
Sharon Jung	2012	The Impact of the DSM-5's Dimensional Classification System on SSDI and SSI Rolls
Kate Brown	2012	Disability Determination Process: Compassionate Allowance List
Mary Ellen Stone	2012	The Rising Visibility of the Work-Disabled Population: Influence of Self-Reported Work Disability in Applying for SSDI
Christina Sogar	2012	The TANF-SSI Transition
Casey MacGregor	2012	Case Study of a Program to Help Clients of a Homeless Shelter and Supportive Housing Residents with SSI/SSDI Applications
Kathleen Chiarantona	2012	Providing for Our Heroes: Understanding Social Security Disability Benefits for Wounded Warriors
Joseph Bocanegra	2012	A Forecasting Model for Disability Enrollment

The quality of research and scholarship achieved by the following ten participants stood out across the six cohorts and far exceeded program expectations. PRI would like to acknowledge and highlight these scholar's accomplishments.

PAUL ARTHUR, PHD 2014 COHORT

Mentor: Craig Velozo, Medical University of South Carolina

Dr. Paul Arthur developed a database connection between the International Classification of Functioning, Disability and Health (ICF) and the Dictionary of Occupational Titles. The result of this technological innovation is the ability to use self-reported measure of physical abilities to identify appropriate job choices for SSDI claimants. Arthur published this research in the Archives of Physical Medicine and Rehabilitation (2017) and presented a poster at the American Occupational Therapy Association's (2015). Dr. Arthur is currently an Assistant Professor and Regional Lead at St. Catherine University.

SHANNA BURKE, PHD, 2013 AND 2014 COHORTS

Mentor: Dr. Peter Maramaldi, Simmons College School of Social Work

Dr. Shanna Burke completed two small grant program research projects. The initial project studied the appropriateness of inclusion of a diagnosis of Idiopathic Basal Ganglia Calcification into SSA's Compassionate Allowances List (CAL). Her second research project studied the potential inclusion of Rubinstein-Taybi Syndrome, Smith-Magenis Syndrome and Velocardiofacial Syndrome into the CAL. Her work has been published in Health and Social Work, (2017), Basal Ganglia (2017),

Intellectual and Developmental Disabilities (2016), and Fetal and Pediatric Pathology (2016). In 2015, she presented this research at the Society for Social Work and Research. Dr. Burke is currently an Assistant Professor at Florida International University's Robert Stemple College of Public Health and Social Work.

KATINKA HOOYER, PHD 2013 COHORT

Mentor: Paul Brodwin, University of Wisconsin, Milwaukee, Anthropology

Dr. Katinka Hooyer conducted a longitudinal qualitative study of Iraq and Afghanistan Veteran's disability claims to determine if and where stigma became a variable and the effects of linking a PTSD diagnosis to compensation. This research is forthcoming in Psychiatric Services. The research was also translated into a performance ethnography titled "Tracings of Trauma," which was highlighted in a documentary about PTSD and moral injury titled "Almost Sunrise." The documentary has been shown at professional and community screenings around the country. Dr. Hooyer is currently a research fellow at the Medical College of Wisconsin.

SHARON JUNG, PSYD, 2013 COHORT

Mentor: Dr. David LaPorte, Indiana University of Pennsylvania, Department of Psychology

Dr. Sharon Jung's research explored the potentialities and limitations of using neuroimaging data in the Disability Determination Process. She presented her research at Cambridge Health Alliance (2016), the Harvard Medical School Psychiatry Research Day (2016), the International Neuropsychological Society (2015), and the Pennsylvania Psychological

Association (2014). Dr. Jung is currently on staff at the Cambridge Health Alliance/Harvard Medical School.

JOHN M. KEESLER, PH.D. 2014 COHORT

Mentor: Dr. Thomas Nochajski, University at Buffalo, School of Social Work

Dr. John Keesler surveyed hundreds of service coordinators and family members to understand their experiences applying for SSI for individuals with intellectual and development disabilities.

He subsequently published his findings in *Intellectual and Developmental Disabilities* (2015). He presented posters on his research at the Society for Social Work Research Annual (2016) and the American Association of Intellectual and Developmental Disabilities. (2013 and 2014). Dr. Keesler is currently an Assistant Professor in the School of Social Work at Indiana University. Current Affiliation: Indiana University of Bloomington, School of Social Work

EVAN MARIE LOWDER, PHD, 2014, 2015, 2016 COHORTS

Mentor: Dr. Sarah Desmarais, North Carolina State University, Department of Psychology

Dr. Evan Marie Lowder conducted three studies as part of the DDP Small Grant Program. The first research project studied the impact of the SSI/SSDI Outreach, Access and Recovery (SOAR) model on recidivism rates of adults experiencing homelessness in Miami-Dade County Florida. Building on this research, Lowder then conducted a second study of the

predictors of successful state-level SSI/SSDI applications. Lowder's final project studied the implementation and effectiveness of the SOAR model in justice settings. Dr. Lowder has published this research in *Psychiatric Services* and presented papers at the American Public Health Association (2016) and the International Association of Forensic Mental Health Services (2015). Dr. Lowder is currently at the School of Public and Environmental Affairs at Indiana University.

ERIN MCCAULEY, MED, 2016 AND 2017 COHORTS

Mentor: Dr. Beth Shinn, Vanderbilt University, Peabody College of Education and Human Development

Erin McCauley's first DDP research study, completed with Leah Samples, evaluated the effectiveness of the SOAR model in working with incarcerated adults with serious mental illness in a mid-sized city in Tennessee. McCauley's second project, completed with Zachary Glendenning, investigated the relationship between the receipt of disability income by families entering emergency shelters and later housing and self-sufficiency outcomes. McCauley and Samples published their research in *Community Health Journal* (2015). They presented their research at the 2015 and 2016 Correctional Health conferences. Both research studies were presented at the Society for Community Research and Action Biennial Conference (2017). McCauley is currently a doctoral student at the Cornell University College of Human Ecology.

ZACHARY MORRIS, PHD, 2014 AND 2016 COHORTS

Mentor: Neil Gilbert, University of California-Berkeley, Social Welfare

Dr. Zachary Morris conducted two comparative policy analyses as part of the DDP Small Grant Program. The first study examined 2008 reforms to Great Britain's disability determination process as potential consideration for U.S. reforms. Morris's second study explored work-capacity reforms (reforms that seek a person's remaining ability to work as opposed to their inability to work) in Denmark, Great Britain and Netherlands. Morris's research was nominated for the Best Comparative Policy Paper Award at the 2016 Association for Public Policy Analysis and Management conference and is under consideration for that award. He has presented his research at the Society for Social Work Research (2016) and at the Association for Public Policy Analysis and Management (2016). Dr. Morris is currently an Assistant Professor at the Stony Brook University School of Social Welfare.

CHRISTIAN PULCINI, MD, 2013 AND 2014 COHORTS

Mentor: Dr. Karen Kuhlthau, Pediatric Service, Massachusetts General Hospital

Dr. Christian Pulcini conducted two research studies as a DDP Small Grant Program scholar. His initial study compared the rise in mental health diagnosis in the general population of children to the increase in such diagnosis for recipients of the children's SSI program. Pulcini's second study examined the rise in the number of children qualifying for SSI under the mental health impairment category and the rates of co-morbid conditions among this population. This

research was published in *Academic Pediatrics* (2015). The initial study was also presented at the Pediatric Academic Societies Meeting (2013). Dr. Pulcini is currently on staff the Children's Hospital of Philadelphia.

MEGAN STANLEY, MPPA, 2016 COHORT

Mentor: William Lester, Northwestern University, School of Professional Studies

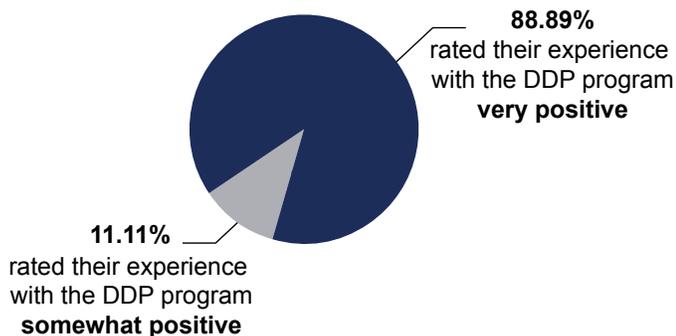
Megan Stanley conducted a mixed methods study to explore ways to improve the SSA 3368 and 3373 forms, two key forms in the disability determination process. She presented a poster on this research at the Association for Public Policy Analysis and Management (2016). In 2017, Montgomery County, Maryland awarded Stanly additional funding to continue her research and expand the size and scope of the research participants. Megan Stanley is currently traveling and conducting freelance research.

DDP Small Grant Program Participant Feedback

For many participants, the program served as their entrance into serious academic and/or scientific research. Supported by faculty mentors, participants developed and refined their substantive and process-based research skills including attaining approval from their university's Institutional Review Board and meeting funder reporting and product obligations. Of the 68 percent of participants who responded to PRI's feedback request, the overwhelming majority—89 percent—ranked their experiences as very positive. The program experience has also likely had a career-long impact on many participants, 67 percent of respondents expressing that the experience continues to inform their future research and/or work.

Their words best describe their experience as a program participant.

OVERALL EXPERIENCE



PARTICIPANT QUOTES

“From my participation in the DDP Small Grant Program I have been able to focus on crucial topics, gain experience using difficult data, and learn the research process. I anticipate many papers growing out of this nourishing beginning.”

- **Angela VanDerwerken, 2014 Cohort**

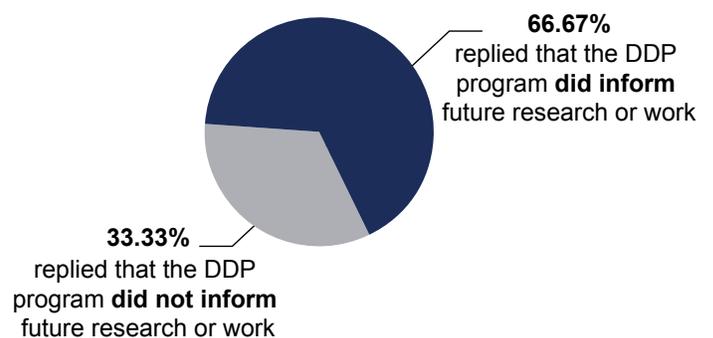
“This program has provided me with first-hand experience in applying for and managing research grants. This experience will be instrumental as I apply for additional grants to grow my program of research as a research scientist. Further, through this program, I gained both knowledge and experience in a new area of research (i.e. disability research) that helped me diversify my interests and expertise as a graduate student. I hope to bring this knowledge and skillset to my postdoctoral research career.”

- **Evan Marie Lowder, 2015 and 2016 Cohorts**

“My participation in the DDP program in the first year gave me a good understanding of the nuanced changes and issues in our diagnostic manual from DSM-IV to DSM-5. My participation in the second year in my researching the ecological validity of neuropsychological tests has significantly shaped my understanding of how to interpret tests results and the potential relation/prediction to a patient's real world functioning. I tend to focus my recommendations to patients in terms of day-to-day functioning versus simply their performances on cognitive tests. I am constantly asking myself, ‘What does this mean to the patient?’”

- **Sharon Jung, 2012 and 2013 Cohorts**

DDP PROGRAM INFORMED FUTURE RESEARCH OR WORK



“It was a wonderful experience! It was run by intelligent and supportive individuals and allowed me to learn a great deal about research in general and specifically the Social Security Administration’s services for individuals with disabilities.”

- **Sarina Sechrist, 2014 and 2015 Cohorts**

The participants also offered constructive criticism that included requests for additional communication at the proposal phase of the project, opportunities to present research to SSA, the addition of levels for post-doctoral researchers and early stage investigators, and the recruitment of past participants as mentors.

DDP Small Grant Program Mentor Feedback

Faculty mentors were a key component of the DDP Small Grant Program. Throughout the program, 39 mentors volunteered countless hours to guide students through the development and implementation of complex research projects. They partnered as problem-solvers when research issues arose, assisted with Institutional Review Board processes, reviewed and edited drafts, participated in quarterly calls, and signed-off on quarterly reports. Fifty-four percent of mentors provided feedback on the program. Of those mentors who responded, 90 percent felt that the program had benefitted their students. In addition, 91 percent of respondents felt that they had benefited from being a mentor with the program. The mentors’ constructive comments for program improvement included requests for increased involvement in the initial proposal approval process, the implementation of virtual meetings between mentors, and organized interactions between funded students.

MENTOR QUOTES

“The awards (she received two consecutive awards) enabled the student to engage in scholarship at the national level. She has since completed her PhD and is launching an academic career. The award set her on a trajectory that will include participation in policy on the national level. In sum, the award taught this newly minted PhD that through rigorous science and collaboration with funding sources, she has a great deal to offer the populations and the policy makers.”

- **Peter Maramaldi, Simmons College, Mentee Shanna Burke**

“I became aware of the projects that other students had done and were currently doing. I enjoyed mentoring the student as she went through the process of designing and carrying out the research project. The people at PRI were efficient, clear in their expectations, and a pleasure to work with.”

- **Deborah Oliveira, Tulane University, Mentee Alex Fixler**

“Across the three projects, our students learned a great deal and were supported by the outstanding staff at DDP. They were both challenged as well as encouraged to present their own professional opinions. I believe that our students, at all times, felt that they were colleagues in this very important element of SSA, under the guidance of DDP.

- **William Sanchez, Northeastern University, Mentees Kathy Wu and Elda Zeko-Underwood**

Summary of Digital DDP Resources Available

The DDP Small Grant Program has resulted in the centralization of dozens of studies on the DDP in a digital space easily accessed by professionals and the public. A catalogue of each of the program's approved research papers is available at the end of this report; and the full text of the papers are available online at ddp.policyresearchinc.org. This website also contains links to the SSA's webpages specifically relevant to the DDP including direct links to information on SSI and SSDI benefits, the disability determination process, a PowerPoint presentation on the sequential evaluation process SSA uses to assess disability, and SSA's publicly available data on topics ranging from application rates to processing times to state workload data. The website also houses a disability education and awareness initiative titled "The Faces and Facts of Disability." This website seeks to educate the public about disabilities while debunking commonly held myths.

Implementation Lessons for Moving Forward

Overall, the DDP Small Grant Program was very successful. It created opportunities for graduate students to engage in and potentially publish funded research while providing potentially valuable information to an essential federal process. During the program's six years of operation, PRI made some adjustments to improve the student experience. Based on lessons learned on the application timing of the first cohort, PRI adjusted subsequent program application and selection timelines to better align with the typical timetables for graduate

research awards. During the initial cohorts PRI also clarified the role and responsibilities of the program mentors, stressing the importance of their participation throughout the entire research process, from participating on quarterly calls to reviewing drafts and final papers prior to submission. Over the course of the program, PRI staff became increasingly aware of the importance of access to data for the successful completion of projects. The quarterly report form was modified to include comments from the mentors on their students' progress during the previous quarter. To ensure clarity among all participants, PRI implemented two informational webinars prior to the application deadline to provide an opportunity for potential students and their mentors to learn more about the DDP program and its expectations. As part of its outreach efforts, PRI staff also increased its use of social media and reached out to other organizations working in the field of disability. PRI also began monthly calls with the federal project officer and staff.

Moving forward with SSA's successor program, ARDRAW, PRI staff will continue to stress the importance of the role of the mentor from the beginning, as well as ongoing communication with students, mentors and the federal project officer. In addition, PRI learned from DDP that access to required data was essential in the successful completion of projects. Accordingly, this will be stressed in the application process and in the review of applications, and as much as possible, use of publicly available data will be encouraged. Taking the lessons learned from DDP, PRI is confident that ARDRAW will continue to provide the research opportunities and valuable insights of its predecessor.

SUPPORTER ACKNOWLEDGMENTS

SSA and PRI extend their sincerest thanks and gratitude to the DDP reviewers, mentors, and staff of SSA and PRI who have offered their time and expertise to the program.

Disability Determination Process Small Grant Program Application Reviewers

- Michelle Ballan, Columbia University
- Roger Boothroyd, University of Southern Florida
- Isaac Brown, Baltic Street
- Allison Carey, Shippensburg University for Disability Studies
- Marty Deane, New York State Troopers
- Sarah Desmarais, North Carolina State University
- Debra Dwyer, SUNY at Stony Brook
- Patrick Ferrel, Nathan Kline Institute
- Thomas Golden, Cornell University
- Daniel Hazen, Voices of the Heart
- Devva Kasnitz, City University of NY
- Jessica Kelley-Moore, Case Western University
- Kajal Lahiri, University of Albany
- Paul Luken, University of West Georgia
- Jane Mauldon, University of California Berkeley
- Eileen McGinn, City University of NY
- Brian McGregor, Morehouse School of Medicine
- Susan M. Nochajski, University of Buffalo
- Thomas Nochajski, University at Buffalo
- Noam Ostrander, DePaul University
- Susan Parish, Brandeis University
- Kim Rutledge, United Domestic Workers AFSCME Local 3930

- Alan Sager, Boston University
- Mark Salzer, Temple University
- William Sanchez, Northeastern University
- Richard Scotch, University of Texas at Dallas
- Beth Shinn, Vanderbilt University
- Steven Taylor, Syracuse University

Disability Determination Process Small Grant Program Mentors

- Michelle Ballan, Columbia University
- Paul Brodwin, University of Wisconsin-Milwaukee
- Sarah Desmarais, North Carolina State University
- Ron Dumont, Fairleigh Dickinson University
- Gil Eyal, Columbia University
- Vivian Gadsden, University of Pennsylvania
- Neil Gilbert, University of California, Berkeley
- Ruby Gourdine, Howard University
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- Zeke Hasenfeld, University of California, Los Angeles
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Frequently Encountered Acronyms

- DDP: Disability Determination Process
- DI: Social Security Disability Insurance
- PTSD: Posttraumatic Stress Disorder
- SOAR: SSI/SSDI Outreach, Access and Recovery
- SSA: Social Security Administration
- SSDI: Social Security Disability Insurance
- SSI: Supplemental Security Income

Endnotes

1 Office of the Inspector General – Social Security Administration. (2014). The Social Security Administration’s Progress in Reducing the Initial Disability Claims Backlog, Evaluation Report. A-07-13-13073. Washington DC: Author

2 Social Security. (n.d.). Retrieved from https://www.ssa.gov/legislation/testimony_032012.html

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2017 COHORT

Maggie Butler

Social Security Benefits Eligibility at the Intersection of Disability, Advanced Age, Homelessness, and the Labor Market

Older adults with disabilities who are experiencing homelessness and are between the ages of 50 and 64 continually fall between the cracks when pursuing safety-net programs due to limited awareness and access to governmental resources for which they may qualify. Despite this fact, homelessness scholarship has generally focused on both the demographics and the etiology of the phenomenon with minimal attention to access to support services that can benefit the population by providing financial resources. The current study identified barriers that impede quality of life, access to resources, and social integration among older adults with disabilities experiencing homelessness using social dominance theory to frame the research. The current study is a qualitative exploration of older adults with disabilities who are experiencing homelessness as they recount their experiences applying for and securing SSA benefits as a result of their chronically inconsistent and limited work histories. Fifteen women and men utilizing a rural emergency shelter in the Midwest participated in face to face semi-structured interviews. The participants provided insight into barriers within the application process for SSA benefits, homelessness across their lifespan, and reported barriers related to their age and the labor market. Emergent themes from the participant

interviews related to securing SSA benefits are provided. Implications for policy and professional addressing homelessness are discussed.

Karina Barro

School Professionals' Knowledge of the Disability Determination Process for Children Applying for Supplemental Security Income

Children with disabilities may be entitled to financial benefits that could help supplement their needs with financial aid and potentially bridge a large gap in learning for which they may be susceptible to. Through the Individuals with Disabilities Education Act (IDEA) Child Find mandate, school professionals are legally required to identify children with disabilities. However, there are no laws that mandate advocating for or informing families about social services programs, such as SSI despite there being ethical standards for most school professionals to do so. The current study examined the knowledge school professionals had on Supplemental Security Income (SSI) and the disability determination process of applicant children. More specifically, this study analyzed their knowledge of SSI through a questionnaire examining school professionals that work with children. This investigation used a quantitative approach through descriptive and inferential statistical analyses to understand the knowledge school professionals have on SSI and the disability determination process. Professionals involved in submitting medical evidence to SSI on behalf of a claimant do not usually get special training on the application process (Noblitt & Noblitt, 2010). The findings of the investigation suggested that school professionals need more training on SSI as a large percentage of participants had no knowledge of SSI or the disability determination process for SSI.

Lindsay Berkowitz

An Exploratory Study to Assess the Evaluation of Chronic Pain in the Social Security Administration Disability Determination Process Phase II: Investigating Institutional Interaction between Legal, State, and Medical Institutions

This study is the second phase of a two-part study to analyze how chronic pain is evaluated comprehensively across institutions in the SSA DDP. Chronic pain is noted as one of the most problematic areas of disability determination. Those who seek disability benefits on account for their chronic pain have among the lowest initial allowance rates yet the highest reversal rates in the appeals process. Medical uncertainty and cultural bias about the subjectivity of pain has manifested in conflicting changes in SSA, legal and Congressional rulings on the evaluation of chronic pain, and resulted in inconsistent implementation from medical adjudicators across DDP institutions. Though recent Social Security Rulings on the evaluation of symptoms (including pain) have provided more detailed and inclusive factors to consider in evaluation, this adds to the complexity of decision-making. This study seeks to improve methods for efficient and reliable complex decision-making in the evaluation of chronic pain. Phase I analyzed interview data from claimants, treating physicians, and Consultative Examiners, and highlighted specific problem areas in the evaluation of chronic pain in medical and state institutions. Phase II investigates legal institutional processes of disability evaluation through interviews with legal representatives, judicial clerks, Administrative Law Judges, and a Disability Examiner. The discussion and recommendation sections integrate findings across both phases to provide comprehensive analysis.

Alex Fixler

Considering Early Intervention Programming for Major Depressive Disorder

Major depressive disorder is the most prevalent global disability (WHO, 2015) and accounts for nearly half of lost workplace productivity in America (Stewart, Ricci, Chee, Hahn, & Morganstein, 2003). It is also exceptionally treatable (NIMH, 2013), which makes it a strong candidate for an early intervention program run by the Social Security Administration in the interest of reducing reliance on disability benefits and facilitating personal independence for sufferers of depression. This research examines the importance of early intervention models in dealing with mental health disabilities, since vocational rehabilitation intervention is not shown to be effective in re-integrating individuals who have already left the workforce. This research develops a set of recommendations for a potential early intervention program geared toward individuals with major depressive disorder. Semi-structured interviews were conducted with clients from permanent supportive housing agencies in New Orleans, developing themes and suggestions based on reports of their lived experiences with depression and the workforce.

Zachary Glendenning and Erin McCauley

Public Assistance, Self-Sufficiency, and Housing Stability Among Families with Disabilities Experiencing Homelessness

This study investigated the relationship between disabilities and SSA disability income reported by families entering emergency shelter and later housing and self-sufficiency outcomes. It also examined how housing interventions affect SSI and SSDI receipt. Participating families (N = 1,857) responded to two waves of interviews

as part of the Family Options Study, a random assignment housing evaluation. Families entering emergency shelter were surveyed and randomly offered priority access to one of three housing interventions or assigned to usual care (i.e., not referred to housing interventions beyond emergency shelter). Families were re-interviewed 20 months later. We used logistic and linear regression to analyze housing, self-sufficiency, and disability benefit outcomes. At shelter entry, 34% of participating families reported a disability. SSI/SSDI coverage of families reporting disabilities increased from 25-30% at shelter entry to no more than 40% 20 months later. About 87% of families reporting coverage at shelter entry retained it 20 months later. Disabilities indicated greater housing instability, food insecurity, and economic stress and less work and income. Among families reporting disabilities, SSI/SSDI receipt was related to fewer returns to emergency shelter and more income despite less work. Offers of long-term housing subsidies increased SSI/SSDI receipt. Long-term rental subsidies, increased attention to disabilities, and assistance in securing disability income for families experiencing homelessness could yield public health benefits.

Evan Marie Lowder

Implementing the SSI/DDI Outreach, Access, and Recovery (SOAR) Model with Justice-Involved Populations: A Survey of Practitioners

Under the leadership of the Substance Abuse and Mental Health Services Administration (SAMHSA), the SSI/SSDI Outreach, Access, and Recovery (SOAR) program was developed as a national model to improve disability application outcomes for adults experiencing homelessness. Although SOAR has been increasingly implemented in criminal justice

settings, the model remains underutilized in this setting. Insights from SOAR practitioners may inform facilitators and barriers to implementing SOAR in just-involved populations. The purpose of this study was to describe how SOAR has been implemented in justice settings (Aim 1), to identify facilitators and challenges to the use of SOAR for justice-involved adults (Aim 2), and to evaluate the success of the SOAR model in this population (Aim 3). The survey was designed consistent with a mixed-methods approach and administered in an online format. Although most agencies completed applications for justice-involved adults, only a third reported collaboration with a criminal justice agency. The most commonly cited barriers to a successful SOAR application included gaps in care for justice-involved populations and incomplete and unavailable medical records. Facilitators included strong agency leadership, communication and relationship building with criminal justice agencies, and access to medical staff at correctional agencies or in the community. The average reported approval rate (58.3%) was comparable to the SOAR model more broadly and most study participants rated the SOAR model as successful in facilitating access to benefits for justice-involved adults. Overall, despite obstacles to serving this high-risk population, practitioners have developed strategies to facilitate the successful use of the SOAR model in this population.

Rajan A. Sonik

Changes in Material Hardship Preceding Entry into the Supplemental Security Income Program: Evidence from the Survey of Income and Program Participation

Not all eligible individuals seek benefits from means-tested social welfare programs, but the reasons behind this phenomenon are poorly

understood. Evidence from studies of the Supplemental Nutrition Assistance Program suggests that beneficiaries may be those whose hardship levels rise shortly before applying for benefits. In this project, I embarked on a preliminary investigation into whether similar patterns exist for the SSI program through use of data from the nationally representative Survey of Income and Program Participation. I found preliminary evidence to suggest that uninsurance and food insecurity rise for eventual SSI recipients as compared to eligible non-recipients prior to program entry. The information provided here may help in the development of policies that can alleviate vulnerabilities for people before they have a need for SSI benefits.

For centuries, the United States has attracted immigrants from all continents, many of whom, on arrival, have brought with them not only different cultures and customs, but above all a language, semantically, and grammatically different from English. Today, one in five Americans speaks a different language from English at home. As a result, many government institutions and non-profit organizations have increased their efforts to translate documents into some of the more commonly used languages in the US. The Social Security Administration has created and maintains The Translation and Priority Workload Unit (TPWU), to guarantee quality translations of documents generated by SSA and foreign documents presented by applicants. The purpose of this study is to determine the level of perceived accuracy of translated documents in three languages: Italian, Portuguese, and Russian. Research participants are native speakers of these languages, who do not have translator-level training. The functional-pragmatic model of translation evaluation will be used as the bases for the evaluative feedback. This model

stresses the importance of using a “cultural filter” in translation. Using phenomenological research and thematic analysis, the researcher will give voice to immigrants in narrating their understanding of SSA documentation in their native language and gather suggestions on how the forms can be improved, as seen from the eyes of those directly engaged with these crucial materials.

Elda Zeko-Underwood

Phenomenological Study of Six Translated Materials as Completed by Foreign-Born Applicants

For centuries, the United States has attracted immigrants from all continents, many of whom, on arrival, have brought with them not only different cultures and customs, but above all a language, semantically, and grammatically different from English. Today, one in five Americans speaks a different language from English at home. As a result, many government institutions and non-profit organizations have increased their efforts to translate documents into some of the more commonly used languages in the US. The Social Security Administration has created and maintains The Translation and Priority Workload Unit (TPWU), to guarantee quality translations of documents generated by SSA and foreign documents presented by applicants. The purpose of this study is to determine the level of perceived accuracy of translated documents in three languages: Italian, Portuguese, and Russian. Research participants are native speakers of these languages, who do not have translator-level training. The functional-pragmatic model of translation evaluation will be used as the bases for the evaluative feedback. This model stresses the importance of using a “cultural filter” in translation. Using phenomenological

research and thematic analysis, the researcher will give voice to immigrants in narrating their understanding of SSA documentation in their native language and gather suggestions on how the forms can be improved, as seen from the eyes of those directly engaged with these crucial materials.

2016 COHORT

Katherine Aquino

Higher Education and the Disability Determination Process: Accessing SSI/SSDI in Postsecondary Education

Limited research has explored the demographic characteristics and enrollment patterns of students receiving SSI/SSDI within the postsecondary education environment. Utilizing the Beginning Postsecondary Students longitudinal survey, nationally representative data from the National Center for Education Statistics, descriptive analyses were performed to investigate key characteristics and enrollment trends of students receiving SSI/SSDI benefits at the postsecondary level. Additionally, binary logistic regressions were performed to predict eventual job attainment for students receiving and not receiving SSI/SSDI. Findings indicate that students receiving SSI/SSDI who are enrolled in higher education are more likely to be older, first generation, low income, and attend two-year institutions. Moreover, for students receiving SSI/SSDI, the odds of eventual employment decrease if a student identified as non-White, low income, or enrolled in a public institution. Overall, receiving SSI/SSDI decreased the odds of eventual job attainment in the six years following initial postsecondary enrollment.

Adrianna Bagnall-Munson

SSI in Transition: Benefits Application and Transition Planning for Youth in Special Education

For families of children with developmental disabilities, preparing for life after high school is a monumental task. The transition process involves a wide selection of tasks from applying for public benefits like SSI and Medicaid, to finding employment and learning the skills for independent living. For each student, the individual tasks associated with transition are interdependent and embedded in the larger project of moving into adulthood. This paper argues that the application for SSI benefits should be considered as part of the process of transition. To make this argument, the study investigates the formal process of transition out of high school in order to better understand the ways in which families prepare for their child's post-secondary life. While the data shows that parents find the transition process to be unhelpful in understanding the specificities of SSI benefits and post-secondary options for their children, there are things that they like about their transition experiences. In particular, parents experience schools to be most supportive in the transition process in their role as an understanding and empathetic institution. This paper elaborates on the ways in which transition services are experienced as helpful by both parents and students in order to make suggestions for how we should understand the application process for SSI benefits for youth who are transitioning out of high school.

Lindsay Berkowitz

An Exploratory Study to Assess the Evaluation of Chronic Pain in the SSA Disability Determination Process

This study uses interview data with claimants, treating physicians and consultative examiners (CEs) to assess how chronic pain is evaluated in the SSA DDP. Various legislative rulings, codes, and regulations, have attempted to create standardized rules for the evaluation of chronic pain; however, legal evidence proves the existence of inconsistency and institutional non-compliance with such regulation. The most central finding of this study is that the interaction of chronic pain with other conditions, or multimorbidity is a root cause of the complexity and inconsistency in chronic pain evaluation in the DDP. Current medical models of chronic pain and multimorbidity are not robustly implemented in biomedical or SSA institutions, and physician biases against the controversial nature of these new models results in dismissal of patients and DDP non-compliance with SSA rulings. Therefore, the main recommendation of this study is to create a committee of experts on pain and multimorbidity to evaluate the SSA's current rulings, listings, and guidebooks and to propose recommendations in line with the most current models of pain and multimorbidity. Recommendations to mitigate current downstream issues pertaining to the topics are also made.

Evan Lowder

Application-level and State level Predictors of SSI/SSDI Outcomes in a National Sample of Adults at Risk of Homelessness

Homelessness affects nearly one-sixth of the U.S. population over the course of a lifetime. Even greater numbers of U.S. adults are at

risk for homelessness, including Veterans, justice-involved adults, and adults with mental illnesses. A growing body of research suggests disability income, including Supplemental Security Income and Social Security Disability Insurance, may promote community integration in this broader population. However, adults at risk of homelessness experience difficulty accessing disability benefits. The SOAR program was developed to improve disability application outcomes in this population. However, few studies have investigated factors associated with successful disability application outcomes for SOAR-assisted applications or among homeless populations. To that end, this study investigated factors associated with the receipt of disability benefits and the efficient processing of disability applications in a national sample of 6,361 adult applicants applying for benefits through the SOAR model from 2006 to 2015. Multi-level modeling was used to explore application- and state-level predictors of application outcome (approved, not approved) and application processing time (days). Results identified several applicant characteristics associated with more successful applications, including male gender, older age, and living in an institutional setting. SOAR critical components, including collection and submission of medical records, preparation of a medical summary report, and a co-signed application, additionally predicted application success. In contrast, consultative exams predicted longer processing times and lower likelihood of application approval. Although state-level characteristics were not associated with application outcome or processing time, states with high SSI/SSDI award rates had more pronounced effects of application characteristics on application outcome and processing time.

Erin McCauley and Leah Samples

Qualitative and Quantitative Study of SOAR in the CJ Setting

The criminal justice system has become one of the largest providers of mental healthcare in the United States. While resources exist to support people suffering from serious mental illnesses, incarcerated people often suffer from reduced access. One such resource is the Social Security Administration's disability benefit program. Incarcerated adults with serious mental illnesses face numerous barriers in navigating the disability determination process to receive SSI/SSDI disability benefits. This research project is a case study of SOAR InReach program in a mid-sized city in Tennessee. The aims of this study are to document the process of program implementation, evaluate the effectiveness of the program, and explore the disability determination process from the perspective of incarcerated adults with serious mental illnesses. Interviews were conducted with employees (n=4) and clients (n=25) in the SOAR InReach program, and quantitative data was collected from internal administrative databases and publically available databases. We identified facilitators and barriers to program implementation, identified areas of difficulty for this population in navigating the disability determination process, and found evidence the support the effectiveness of the program. Interviews highlighted the importance of community reentry in stabilizing this population for continued success and desistance from crime. Implications for practice, policy, and inquiry are discussed.

Zachary Morris

How to Intervene Early with SSDI Applicants: Lessons From a New Return to Work Program in Denmark

The traditional model for determining eligibility for disability benefits is based on the premises that an individual must be totally unable to work and that the disability can be medically determined. With a focus on US disability policy, this paper examines an alternative model that has been described as the work-capacity approach. This approach departs from the traditional binary/medical model of disability determination by seeking to identify a person's remaining work-abilities, as opposed to an individual's inability to work. This paper appraises whether work-capacity reforms in three countries – Denmark, Great Britain, and the Netherlands – have resulted in improvements in the accuracy of the disability determination process and in the employment of people with disabilities. The analysis draws on an examination of a harmonized cross-national panel data set that provides a nationally representative sample of older adults in each country before and after the respective reforms. The pre-post reform analysis suggests that the reforms improved the targeting of benefits towards those with more severe health conditions but the analysis provides no indication of improvements in employment. There is evidence, however, of the replacing of disability benefits with unemployment benefits.

Sarah Prenovitz

Effects of DI on Health and Financial Well-Being

Individuals who apply for DI receive initial decisions within a few months but often appeal or reapply following a denial, resulting in substantially longer waits. Applicants waiting in the determination process face strong incentives

to remain out of the labor force and receive no benefits from the program. A substantial literature in economics has considered the effects of DI on workforce participation and earnings, but the effects of the determination process have received much less attention. This study uses linked survey and administrative data and construct instruments that reflect average or expected waits to identify the effect of time spent waiting for a decision on health and financial well-being. A longer wait decreases the likelihood of requesting a reconsideration, decreases the likelihood of having had benefits terminated at the time of survey, decreases subjective health, and decreases the likelihood of having forgone needed mental health care due to cost.

Megan Stanley

Fresh Perspectives: How Claimants Understand the Adult Disability and Function Reports

The initial claims process for Social Security disability benefits is complex and often misunderstood by applicants. Claimants for both SSI and SSDI benefits have to fill out numerous forms and recall detailed medical information in order to complete the claims process. This research used both qualitative and quantitative data to explore ways to improve two important forms: SSA 3368, the Adult Disability Report, and SSA 3373, the Adult Function Report. Using focus group data and feedback, this study proposes revisions to language on both forms based on measured changes in participant understanding. Changes were made to make the forms easier to understand and more inclusive of non-physical disabilities, while encouraging an increase in accurate form completion.

Elda Zeko-Underwood

Emerging Challenge on Access: Phenomenological Study on non-US Citizens experience during SSI Application Process

Immigrants, who reside legally in the US, are eligible for a number of federally mandated benefits, among which are included SSI and SSDI. While there are detailed eligibility criteria based on the country of origin, method of immigration to the US and employment, the information is complex and only available in a limited number of languages, other than English. This study examines the lived experiences of forty Latino and Albanian immigrants in an urban setting, identified as purposive sampling, as they explain their understanding of the eligibility criteria, and the application process. A series of semi-structured questions were used in conducting interviews and focus groups, giving the participants an opportunity to address interaction with SSA field offices, the easiness of access to materials, and support received from community members. Thematic data analysis was used to understand the responses to the research questions. Using feminist/ecological framework researchers explored the interaction between participants with larger structural forces, as well as their relations with state and federal institutions. Participants reported the need to access the application and other documentation in their native language, need for interpreters when interacting with SSA employees, differences in the quality of service obtained, and unclear eligibility criteria. Diversification of SSA workforce to mirror the population they serve, as well as close collaboration with local community organizations, were two of recommendations made by participants. Study limitations include generalizability of findings and ethnic differences among participants.

2015 COHORT

Shanna Burke

A Systematic Review of Idiopathic Basal Ganglia Calcification for Possible Inclusion in the Social Security Administration's Compassionate Allowances Program

The SSA launched the Compassionate Allowances List in 2008. This initiative created a mechanism for identifying diseases and other medical conditions that meet the Social Security Administration's standards for expedited review and delivery of disability benefits. Idiopathic basal ganglia calcification or Fahr's disease was selected for review in this study. Using guidance from the Cochrane methodology, a systematic review of the literature was undertaken. This study demonstrated that Idiopathic Basal Ganglia Calcification does not invariably meet the criteria for inclusion in the Compassionate Allowance List. While some experience this condition in a severe form, the presentation of the condition is too variable to universally recommend its inclusion. Some remain asymptomatic and are diagnosed through CT scans. For these people, disability benefits would be unnecessary. For those who are clinically symptomatic, however, inclusion is recommended.

Mackenzie Dezieck

Enhanced Claimant Participation for Veterans with Mental Health Disabilities in Evaluating Functional Limitations and Severity

This research will report on a qualitative examination of the real experiences of veterans with mental health disabilities and their interactions with the SSA disability determination process. Semi-structured interviews will be conducted at the Veterans Inc. location in Worcester, Massachusetts with a total of twenty-

two veterans who have applied for social security benefits for a mental disability within the last five years. The interviews will focus on the participants' experience in applying for Social Security Benefits, what they found to be most challenging in expressing how their disability has impacted their lives. The aim of these interviews will be to gain an understanding on these veteran's views of how the systematic assessment of severity of a mental disability is carried out during the disability determination process, and how accurate the claimants feel the severity of their disability is presented in this evaluation. A pilot self-report instrument will also be distributed to participants after the initial interview for them to fill out and discuss during a second interview administered a couple weeks later. Implications for improving the validity and efficiency of this evaluation process will also be discussed.

Evan Lowder

The Role of the SOAR Model in Successful Community Reintegration

Justice-involved adults with serious mental illnesses face significant barriers to successful community reintegration, contributing to cycles of repeat offending termed "the revolving door" of the criminal justice system. The SOAR model was implemented in Miami-Dade County, Florida's mental health diversion programs to increase receipt of disability benefits in this population to promote successful community reintegration. However, little is known about the effectiveness of disability benefit receipt in decreasing recidivism for this population, or about how or for whom receipt of disability benefits may facilitate successful community reintegration. The present study addressed these limitations. Aim 1 involved a systematic literature review on associations between disability benefit

receipt and community integration outcomes. Findings provided very limited evidence on community integration outcomes following receipt of disability benefits, particularly among justice-involved adults with mental illnesses. Findings from similar populations (e.g., adults with mental illnesses more generally) suggested disability benefit receipt may have a positive impact on outcomes such as housing status, mental health treatment, employment, and well-being. Aim 2 involved an empirical investigation of the effectiveness of disability benefit receipt on 1-year recidivism in a sample of 227 SOAR clients participating in Miami-Dade County's mental health jail diversion programs. Results showed some evidence of the impact of disability benefit receipt on jail days following disability determination. Importantly, participants who had both moderate-to-high levels of criminogenic risk and co-morbid substance use (i.e., high-risk, high-needs participants) experienced fewer jail days and new charges following disability benefit receipt relative to lower-risk, lower-needs participants.. Findings suggest receipt of disability benefits may be a promising intervention for justice-involved adults with mental illnesses to aid community reintegration.

Dana Olzenak

Adding to Motor Assessment to the Disability Determination Process in School-Aged Children with ASD: Implications for Participation

This project examines the prevalence of motor impairments in children with autism spectrum disorder (ASD) to determine the association of motor skill proficiency and participation in a variety of activities. Although ASD is not considered a syndrome with obvious motor deficits, emerging evidence suggests the presence of motor impairments and that coordination and motor planning deficits are

regularly recognized clinically in children with ASD. In addition to impaired social skills for the child with ASD, motor deficits may be an important contributor to poor motivation for activities involving peer interaction, decreased participation, and increased inactivity. Researchers conducted a cross-sectional study with school-aged children diagnosed with ASD recruited from Upstate NY. The Bruininks-Oseretsky Test of Motor Proficiency-2 Short Form was used to objectively assess motor skill proficiency; the Children's Assessment of Participation and Enjoyment was completed together by children and parents to measure overall participation in a variety of activities. Researchers analyzed the associations of motor proficiency and participation through multiple linear regression models to adjust for demographic variables. Sixty-eight children with an average age of 9.4 years and IQ score of 98 participated in the study. Motor proficiency scores were in the below average range, one standard deviation below the mean. The association between motor proficiency and participation was statistically significant. This study supports the position that an effective and relevant clinical evaluation of a child with ASD should include the measurement of motor performance. Findings of motor skill deficiencies provide a fuller picture of the functional status of the child with ASD and add necessary information to the disability determination process.

Sarina Sechrist

A Conceptual Harmonization between the SSA Disability Determination Process and ICCF and DOT Frameworks: A Guide to Assessing the Mental Residual Functional Capacity of Individuals with Autism Spectrum Disorders

The aim of the current project is to create a useful product that cross-walks the Social Security Administration's (SSA) Mental Residual Functional Capacity Assessment (MRFCA) with the International Classification of Functioning (ICF) and the Dictionary of Occupational Titles (DOT) applied to a population of individuals with Autism Spectrum Disorders (ASD). SSA's MRFCA was previously cross-walked with the ICF in order to allow for a more in depth and functional breakdown of the purposefully more generic categories of the MRFCA. The current project expands upon that methodology by adding Worker Functions derived from the DOT to the previous SSA/ICF crosswalk in order to better operationalize the functional manifestations associated with disability states as they occur in a natural (work) environment. A decision tree was developed from the crosswalk to increase the ease of use of the product, titled the MRFCA Decision Tree. The outcomes are the following: (a) A MRFCA Decision Tree that will allow a disability adjudicator to derive a more reliable disability decision when assessing individuals with ASD, and (b) A narrative review of how coordinating the DOT with the ICF can provide a deeper understanding of how functional manifestations of a disability relate to job demands.

Anne Skenzich

A Full Research Study Formally Analyzing and Objective, Functional Measurement of Pain with the use of a Validated Visual Analog Scale for Chronic Pain Patients for the Purposes of a Disability Determination Program

Measuring pain is important, but considering pain as a primary disabling disorder is a secondary objective of this study. To show that pain can be measured functionally, repetitively, and transparently, and that the effect pain has on the life of the individual can be enumerated in a predictable manner is primary. This writer hopes to make it so that pain is not merely mentioned in a report as 'contributing to disability' but the effect of pain on the life of an individual applying for disability is front of mind for the adjudicator in the DDP process. There were two questions to be finalized in this case-control, full panel research study: can pain be objectively and functionally measured so as to be included within an evaluation such as in that of a DDP, or within a clinical setting? The unqualified answer to this, from this study, is a yes. Second, is it possible to validate a visual analog scale [VAS], a 10-point pain scale, for use with the chronic pain population, to improve their communication of pain? The validation process would make the pain ratings comparable both intra- and inter-personally, as well as converting the pain ratings from an ordinal to a cardinal scale. Could these results and changes then be use within a DDP, as well as in a clinical setting? The answer the validation question, from this research study, is also an unqualified yes.

2014 COHORT

Paul Arthur

Empirical Approach to Linking the ICF to the Dictionary of Occupational Titles

The purpose of this pilot/demonstration project is to link the International Classification of Functioning, Disability and Health (ICF) to the Dictionary of Occupational Titles (DOT) using an ICF-based computer adaptive self-report measure and the Occupational Information Network (O*NET) database. The ICF provides a logical structure and classification of physical abilities that are often associated with various jobs. The O*NET database provides a connection between DOT job classifications and O*NET job classification. This project highlights a connection between the self-report ICF Activity Measure (ICF-AM) to the DOT through the O*NET database. The resulting database connection allows ICF based self-reported measures of physical ability to produce listings of appropriate job choices for Social Security Disability Insurance (SSDI) claimants.

Anna Johnson

Homelessness and SSI: Comparing SSI Applications for Individuals Accepted and Denied Disability Income

On any given night, over 600,000 individuals are homeless in America (National Alliance to End Homelessness). Among these homeless individuals, nearly 37% have significant physical or mental health issues (2010 Annual Homeless Assessment Report). Given that only 19% of non-institutionalized adults have a disability (US Census, 2010), it is clear that those with disabilities are overrepresented in the homeless population. Working age people with disabilities are more likely to be in poverty than working

age people without disabilities (Disability and Employment Status Report, 2011), and because of their inability to work many apply for SSI, or SSDI. The process of applying for SSI/SSDI can be lengthy (Stapleton, et al., 2006), and many applicants are denied. The goal of this research is to gain a better understanding of the differences between applicants that are accepted and those that are denied in the SSI/SSDI process. Understanding these differences will help clients- and workers who assist these clients- better understand the application process, and how to make it more efficient and effective. The results from this study could be used to develop a training curriculum for caseworkers and other facilitators of the SSI and SSDI application process among the homeless population.

John Keesler

The Application Process for Supplemental Security Income for Individuals with Intellectual and Developmental Disabilities: A National Survey of Service Coordinator and Family Experiences

SSI began in 1974 as a critical source of financial support for many individuals with intellectual and developmental disabilities (IDD), enabling them to live in the community while reducing the impact of poverty and providing access to various supports and services. Although anecdotal evidence highlights the challenging nature of the application process for SSI, there is a dearth of research regarding the experiential component of the process. The present research sought to understand the experiences of service coordinators (SCs) and family members with the application process for SSI benefits for individuals with IDD. The study focused on the parts of the application process that facilitated success, barriers that

hindered the procurement of benefits, and elicited suggestions for improvement of the process. Respondents to the online survey included 96 SCs and 483 family members from across the United States. Analyses considered respondent role, time (i.e. length of time as an SC, when families applied for SSI) and region of the US. Findings highlight systemic deficiencies (e.g. SSA's understanding of SC role, privacy and sensitivity to IDD); positive and negative emergent trends (e.g. increased use of phone interviews and decreased training attendance); and, recommendations for improvement (e.g. simplification of application process and increased transparency). This study provides preliminary insight into a difficult process to secure a much needed resource, however, additional research remains warranted.

Zachary Morris

Measuring Capabilities and Requiring Work: Comparing the Work Capability Assessment in Great Britain with the United States Disability Process

In 2008, Great Britain overhauled its disability benefit program by introducing a new disability determination process called the Work Capability Assessment (WCA) and a new earnings replacement program called Employment Support Allowance (ESA). This paper examines the British reforms from the perspective of the United States, which may consider changes to the Social Security Disability Insurance (SSDI) program in the near future. The paper provides an overview of the steps leading to the reform in Britain, details how the new system operates, and reviews research on its initial implementation and effects. The paper concludes by identifying lessons for the reform of the SSDI program in the United States.

Christian Pulcini

Identifying and Explaining Co-morbid Conditions among Children and Adolescents Qualifying for SSI under the Mental Health Impairment Category

There has been extensive political and media scrutiny of the children's SSI program, culminating in an ongoing Institute of Medicine study. Many individuals are specifically concerned with the large increase in the number of children and adolescents with a mental health impairment qualifying for SSI benefits in recent years. We sought to examine if the rise in the number of children who qualify for SSI under the mental health impairment category is comparable to the general population, and further if recipients of SSI have a greater burden of co-morbid conditions as compared to the general population. Our hypotheses are that the changes in mental health impairments are at least partially explained by co-morbid conditions which either in sum or individually qualify them for SSI funds. Further, the rates of co-morbidities among children receiving SSI are higher than the general population.

Sarina Sechrist

Incorporating ICF and Employment Concepts and Terminology in Residual Mental Functional Capacity Ratings: A Proposed Modification for Autism Spectrum Disorder

The aim of the current project is to create a conceptual crosswalk between SSA's Mental Residual Functional Capacity Assessment (MRFCA) and the International Classification of Functioning (ICF) in terms of a population with Autism Spectrum Disorders (ASD). SSA's MRFCA is cross-walked with the ICF in order to allow for a more in depth and functional breakdown of the purposefully more generic

categories of the MRFCA. The SSA/ICF crosswalk will create a stepwise process for a disability examiner to operationalize the items of the MRFCA in order to better understand the functional manifestations associated with the disability state as they occur in a natural (work) environment. For this reason, the crosswalk will act as a supplemental guidance document to employ the MRFCA. ASD was chosen as an exemplar to test this process. A literature review was conducted before the creation of the crosswalk on the symptoms and presentations of ASD, the concepts and terminology of the ICF, and the background of the current disability determination process (DDP). This information was used to inform the content of the crosswalk and to determine implementation strategies and benefits of incorporating the crosswalk into the DDP. The outcomes are the following: (a) A MRFCA supplemental guidance document that will allow a disability examiner to derive a more reliable disability decision when assessing individuals with ASD, and (b) A breakdown of the current DDP process including problem areas and improvement suggestions based on the implementation of the crosswalk. Plans for future research aimed at improving the SSA/ICF crosswalk are also discussed.

Anne Skenzich

A Proposal to Measure Chronic Pain: From Subjective or non-measurement to Objective and Scientific Measurement of Chronic Pain for Purposes of Disability Evaluation

This is effectively two studies that merge in the results: The first study looks at the functional testing of chronic pain patients to determine if their pain can be measured objectively. The second study is the validation of a visual analog scale [VAS], a 10-point pain measurement tool for use with the chronic pain population. There

were two questions to be answered in this case-control pilot study: can pain be objectively and functionally measured so as to be included within an evaluation in a DDP and is it possible to validate a visual analog scale [VAS], a 10-point pain scale, of self-reported pain for use with the chronic pain population to improve the communication of their pain throughout the DDP, as well make the pain comparable across episodes within the patient, and across patients, both in DDP and in clinical settings. The answers to both questions are a qualified yes: It is possible to objectively measure pain, and it is possible to validate a VAS for use with a chronic pain population. In both cases there are data limitations because this was only a pilot study to test the feasibility of the concepts. A much larger, full study must be done to confirm all results found here and make them generalizable to the full population. A full study will also determine if the theory of chronic pain measurement is valid, and if the newly validated VAS is effective for communication of pain in that setting.

Mary Ellen Stone

Making the Transition: Influence of Self-Reported Work Disability on Labor Force Careers

To date, much of what we know about labor force transitions and the likelihood of applying for SSDI has been based on a person's first labor force exit. Given the fact that workers can experience a number of labor force transitions in mid-life and that persons with health problems and disability tend to be even more varied in their labor force careers (Cahill, Giandrea, and Quinn 2006; Maestas 2004; Warner and Hoffmeister 2006), it is critical to account for these diverse careers when examining the likelihood of workers entering into the disability determination process. Studies that limit their analyses to first labor force exits are missing a

proportion of the work disabled population that attempt to avoid applying for SSDI by retiring first only to later apply, for example, and the factors that account for variable labor force careers. The purpose of this study is to further explore the relative importance of self-identified work disability, personal resources, health and employer characteristics in labor force careers. Three specific aims are examined using five waves (10 years) of the Health and Retirement Study, a nationally-representative panel study of adults ages 50 and older. Results indicate six dominant labor force transition patterns, a majority of which do not contain a one-time (crisp) labor force exit. Results also indicate that self-identified work disability, personal resources and labor force transition types are significant predictors of application for SSDI.

Angela VanDerwerken

Effect of New Psychotropic Pharmaceuticals on Disability Insurance Applications: Evidence from Matched SIPP/Administrative Data

Considerable growth of the DI rolls during the last several decades has prompted research investigating various topics relating to DI applications. Medical innovation should hypothetically be contributing to the long-term decline in disability, but measuring this impact can be challenging. This paper focuses on the relationship between pharmaceutical innovation of mental health drugs and federal disability insurance applications. Using data from the Survey of Income and Program Participation (SIPP) merged with administrative records from the SSA, I employ an econometric model of disability application behavior and examine the relationship between a measure of psychotropic pharmaceutical innovation and the decision to apply for DI benefits. I find a significant inverse relationship between the availability

of psychotropic drugs and DI applications. In the absence of any post-1995 increase in psychotropic pharmaceutical innovation, there would be a predicted 2.8% increase in applications for disability insurance. This translates to an estimated reduction of 950,000 DI applications, or approximately 380,000 DI awards over the period from 1996-2012; a relatively small impact on the over 33 million total applications during this time.

Lea Vella

Cognitive Impairment and Disability Determination in the Sheltered Homeless

With lifetime prevalence as high as 7% in the United States, homelessness continues to be a major social and financial problem. In the context of a homeless shelter, homeless individuals who are also cognitively impaired may be at a disadvantage when navigating the application process for SSI and SSDI. While successful application for such benefits may be affected by cognitive abilities, the relationship between cognitive impairment and application for SSI/SSDI benefits has not been formally examined. To address this gap in the research literature, the following hypothesis is proposed: of those who have previously applied for SSI, those with cognitive or functional capacity impairments will be more likely to have been denied benefits in the past than those without cognitive or functional capacity impairments. We also explored the demographic, homelessness history, cognitive, psychiatric and physical disability profiles of homeless shelter residents with and without SSI/SSDI benefits at the time of entry to the shelter, as well as those who stated an intention of applying for benefits after entering the shelter.

2013 COHORT

Shanna Burke

A Systematic Review of Three Conditions for Possible Inclusion in the Social Security Administration's Compassionate Allowances Program

Exploratory research methods were employed to analyze a number of systems and protocols in place at the SSA, regarding the provision of the Compassionate Allowances List. Literature available in academic databases was reviewed and reported on and was used as empirical evidence demonstrating whether or not a condition invariably met the disability criteria set forth by the Social Security Administration. Based on this systematic review, it was determined that Rubinstein-Taybi syndrome and Smith-Magenis syndrome 'invariably' meet the criteria for disability as specified by the Social Security Administration. 22q11 deletion syndrome results in a highly variable disease presentation and individual cases fluctuate widely. Given this, it is suggested that those with 22q11 deletion syndrome proceed through the standard claims process if the individual case warrants disability consideration and benefits.

Katinka Hooyer

The "Trauma Pitch": How Stigma Emerges for Iraq and Afghanistan Veterans in the PTSD Disability Claims Process

PTSD continues to be a highly stigmatized disorder for the veteran population and stigma continues to be identified as the main deterrent in treatment seeking. PTSD also remains the highest compensable mental health disorder in the Veterans Affairs disability system. The author conducted a formative longitudinal qualitative study of Iraq and Afghanistan veterans, veterans'

disability claims officers and Veterans Affairs mental health providers to identify if and where stigma became a variable in the disability claims process and the effects of linking a PTSD diagnosis to compensation in relation to stigma. Data was gathered through semi-structured in-depth interviews and participant observation over 10 months. Stigma was identified in four inter-related areas: the structural level in the VA disability claims process, the individual level in interactions with VA service providers, and a social level in the public's negative perceptions of mental illness diagnosis and government aid. Results based on veterans' narratives suggest that the bureaucratic nature of the disability claims process requiring multiple repetitions of personal trauma, coupled with an institutional stigma of malingering, exacerbated PTSD symptoms. This influenced first time users of the VA by deterring treatment--seeking but was not found to affect veterans who had already initiated treatment. Ancillary to this, treatment seeking was negatively affected by public stigma surrounding new gun ownership laws that required background mental health checks. Despite the stigma experienced in everyday public life and at the VA veterans separated from military service still sought disability compensation. Veterans viewed this compensation as acknowledgment of their loss and validation of their sacrifice.

Sharon Jung

Ecological Validity of Neuropsychological Tests: Role of Memory and Executive Skills in Predicting Functional Ability in a Clinical Population

While neuroimaging data are useful in assessing brain-injury outcomes, these data do not provide information regarding how a patient will function in their everyday environment (Bigler, 2001).

Consequently, neuropsychological evaluations are often conducted in order to obtain information regarding the extent of cognitive impairment, which is often used to make predictions about functional capacity (Lezak, Howieson, & Loring, 2004). Neuropsychology may be an appropriate arena in the prediction of resuming everyday activities for those who have experienced a brain injury or a neurodegenerative disorder. Past research that has examined the ecological validity of neuropsychological tests for predicting functional outcome has resulted in mixed findings. Therefore, the question addressed is whether ecological validity exists for traditional neuropsychological tests in the prediction of everyday skills. To answer these research questions, data were collected and analyzed on 39 outpatients referred for a neuropsychological evaluation at Allegheny General Hospital. Examined areas included measures of executive functioning and memory. Functional ability was assessed using the Independent Living Scales (ILS), which assesses cognition as it affects daily functioning (i.e., instrumental activities of daily living [IADL]). Using multiple regression analyses, the role of tests of memory and executive functioning in predicting everyday skills suggests that traditional neuropsychological tests can demonstrate acceptable levels of ecological validity within the population investigated in the current study. Specifically, although the pattern of explained variance in IADL functioning increased with the inclusion of executive functioning measures, memory was still a significant predictor in the final model, suggesting that both domains provide a unique contribution in accounting for the variance in functional impairment.

John Keesler

A Pilot Study of Service Coordinator and Family Experiences in Applying for Supplemental Security Income for Individuals with Intellectual and Developmental Disabilities: Identifying Strengths, Obstacles and Recommendations for Improvement

The Social Security Administration provides financial benefits through SSI to many individuals with intellectual and developmental disabilities (IDD). However, despite its many implications and significance, there remains a dearth of research investigating its impact and complexities. Through the use of focus groups and interviews with service coordinators (SCs) and family members, surveys were developed and piloted to understand their respective experiences with applying for SSI for individuals with IDD and to identify successful components and challenges, as well as recommendations for improvement. Survey participants included 122 SCs and 122 family members in the western region of New York State. Findings regarding experiences with the various steps of applying for SSI, including initial applications, interviews, and assessment processes, as well as quality of interactions with SSA personnel are presented. At times, significant differences were noted between SCs and family members, most notably in the quality of interactions with SSA personnel, general experiences and challenges, as well as in their recommendations for improvement between SSA and disability organizations. In addition, it was found that SCs provided integral support for families in obtaining SSI, often serving as a mediator with SSA; however, SCs expressed difficulty with SSA personnel understanding the SC role. Despite the limitations of the present study, numerous recommendations are offered and

endorsed by those most critically involved in applying for SSI for individuals with IDD, namely, SCs and family members. Furthermore, the study provides a preliminary evaluation of an often difficult process to secure much needed financial support integral to the quality of life for individuals with IDD.

Allysa Lanza

The WISC-IV and Children and Adolescents with Intellectual Disability: Evaluating for Hidden Floor Effects in the US Version

This study is a recreation of research by Whitaker and Gordon (2012) that assesses for possible floor effects in the Wechsler Intelligence Scale for Children, Fourth Edition (WISC-IV). Their study suggested that the Index and Full Scale IQ (FSIQ) scores of low IQ adolescents taking the WISC-IV (UK version) were significantly inflated because of low raw scores being converted to scaled scores of 1. Since the WISC-IV is the most commonly used intelligence test in school settings in the United States (Riccio, Houston, & Harrison, 1998), this author assessed for similar findings in the US version of the WISC-IV by completing a pilot replication of their study. Additionally, this author created her own adjusted scoring system that more modestly alters WISC-IV scaled scores. Results of this study suggest that Index and FSIQ are not significantly affected by the alternative scoring systems. The author concludes that this area warrants further research.

Rose Nevill

Improving Knowledge Transfer to Families of People with Disabilities on the SSI Application Process

This project studies the difficulties that families of transition-aged youth with developmental disabilities and mental disorders experience

in gaining independence-maximizing supports through SSA's DDP and the receipt of SSI payments. This paper addresses the following questions: 1) what options for employment and educational support are available for transition-aged youth with disabilities transitioning out of child SSI eligibility? 2) what information is needed for families to improve the accuracy with which they complete the adult SSI application? and 3) what information would prepare families for their transition-age youth's progression out of child SSI eligibility and facing adult SSI redetermination? Many youth with developmental and mental disorders receive child SSI prior to turning 18, but the changed criteria for adult SSI leaves many families confused and with incomplete or incorrect information in their application. Due to the high health care and social support needs of youth with developmental and mental disorders, this paper seeks to understand what their experiences are in learning about and applying for SSI. This paper reviews SSI and the disability determination process. It then reviews predictors of SSI ineligibility findings, why this population needs extra support in navigating this process, and then alternative options that the SSA has provided to support adults with disabilities who are found ineligible, specifically vocational rehabilitation programs. A three-fold methodology examined these questions these questions: 1) a detailed literature review on transition-aged youth's experiences with SSI and vocational rehabilitation programs, 2) an online survey asking families more specific questions about their experiences with the SSA, and 3) in-depth interviews with survey participants.

Christian Pulcini

Explaining Growth of Mental Impairments among Children and Adolescents receiving SSI

Given the current economic climate, there has been extensive political and media scrutiny of federal benefit programs, including the children's SSI program. Lawmakers (among others) are specifically concerned with the large increase in the number of children and adolescents with a mental health impairment qualifying for SSI benefits. Little research has evaluated the claim that the increase in childhood mental health diagnoses in the general population accounts for the dramatic increase in these conditions in the SSI population over any given period of time. Given the current economic climate, there has been extensive political and media scrutiny of federal benefit programs, including the children's SSI (SSI) program. Lawmakers (among others) are specifically concerned with the large increase in the number of children and adolescents with a mental health impairment qualifying for SSI benefits. Little research has evaluated the claim that the increase in childhood mental health diagnoses in the general population accounts for the dramatic increase in these conditions in the SSI population over any given period of time. We sought to examine the rise in mental health diagnosis in the general population of children, and then compare the increases in the general population to the SSI population.

Kathy Wu

The "Lived Experiences" of a Chronically Homeless, Urban Population: Systemic Challenges to Achieving Their Vocational and Rehabilitation Dreams

This paper reports on a qualitative examination of the lived experiences of individuals undergoing chronic homelessness in an urban

setting, along with their interactions with the SSA DDP. Semi-structured interviews were conducted in a day-time shelter with a total of 20 women and men who either self-identified or were identified by their case managers as chronically homeless. The participants provided their definition of chronic homelessness, what they believed to be systems-level challenges to achieving their vocational and rehabilitation dreams, and their recommendations to service providers. Thematic elements related to overall experience of being chronically homeless while applying for disability benefits are provided. Implications for public policy, practice and research are also discussed.

2012 COHORT

Kate Brown

DDP Grant Compassionate Allowance List

Expanding the Compassionate Allowances List (CAL) is an efficient and effective way of improving the Social Security Administrations (SSA) disability determination process. In this paper, traumatic brain injuries (TBIs) and fatal familial insomnia (FFI) are evaluated and their qualification for the CAL is assessed. Upon researching TBIs and FFI, two models were created that can be used as a framework to add additional conditions. The first model is based on FFI and can be used when there is little variability in a patient's condition. The second model is based on TBIs and can be used when there is significant variability among patients. This framework will potentially improve the ease and efficiency of the disability determination process for both the patients as well as the SSA.

Sharon Jung

The Impact of the DSM-5's Dimensional Classification System on SSDI and SSI Rolls

The publication of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is expected in May 2013. Preliminary information from DSM work groups indicates that there will be substantial changes in the criteria for some diagnoses, reorganization of old and introduction of new diagnoses, and inclusion of dimensional severity ratings for most diagnoses. These changes may represent a critical challenge to disability evaluation for several reasons. First, some argue that base rates of mental disorders will concomitantly increase because individuals with less severe disorders can receive a diagnosis. Second, the reorganization of disorders, such as the neurocognitive disorders, will change the meaning and perception of functioning that we might attach to a diagnosis. Third, the proposed addition of dimensional severity ratings will provide information that was not included before and how that information is used can impact the disability determination process. The current study examines various mental disorders representative of nine broad categories based on the Social Security Administration's "Disability Evaluation Under Social Security". In order to address the question of the impact of DSM-5 on SSA's disability determination, a systematic literature review was performed. The specific changes in diagnostic criteria reveals that some disorders will have limited impact on base rates whereas others may significantly impact prevalence rates as well as conceptualizations of some disorders. Furthermore, dimensional severity ratings can provide important information regarding the extent of an individual's

functional impairment and, in some cases, can significantly predict morbidity score better than the categorical diagnosis alone.

Casey MacGregor

Case Study of a Program to Help Clients of a Homeless Shelter and Supportive Housing Residents with SSI/SSDI Applications

The social service sector has increased efforts to obtain SSI and SSDI for homeless and insecurely-housed disabled individuals. This case study profiled and analyzed the implementation of a program offered by a public interest law center (the Program) to process SSI and SSDI claims for selected clients of local nonprofit organizations. In-depth interviews were conducted with employees of the Program, stakeholder organizations and the Social Security Administration. A content analysis was conducted using Atlas.ti to identify emerging themes. The Program had more success when their program goal narrowed to processing SSI / SSDI applications only. Barriers to program implementation included the drop-in shelter setting which could not accommodate the needs of Program. A lack of connection to a medical provider or service was also identified as a barrier.

Christina Sogar

The TANF-SSI Transition

Parents who turn to the Temporary Assistance for Needy Families (TANF) program for cash aid experience a higher rate of physical, mental health and/or learning disabilities than that found in the general population. For a small number of these parents each year, their disabilities are severe enough to qualify them for the SSI program. This descriptive study reports findings from interviews with 83 parents who transitioned from TANF to SSI. Sixty-five

percent of the SSI-receiving parents in this study relied on professional help from doctors, attorneys or social workers when completing the SSI application. Parents with professional help applied more times for SSI, and had longer waits for approval on average than parents who applied on their own or with help from family and friends. This research suggests that there are differences between parents who turn to attorneys, doctors or social workers for help with the SSI application and those who complete the application independently or with family or friends and these differences influence how quickly parents' transition from TANF to SSI.

Mary Ellen Stone

The Rising Visibility of the Work-Disabled Population: Influence of Self-Reported Work Disability in Applying for SSDI

Traditionally, the pension-based retirement system and employer-based health care served as the primary vehicles for leaving the labor force prior to full retirement age. Those workers experiencing health problems could retire and have sufficient income and medical insurance prior to full retirement age (FRA). Yet with the recent erosion of these employment benefits in many occupational sectors, an increasing number of workers are no longer able to “retire early” in the face of significant physical health problems that limit the ability to work. This has contributed to the increase in SSDI applications in the past 15 years and is expected to lead to even greater swells in the future. Given these sweeping changes in the availability of employer-based retirement and medical benefits, as well as changes in the labor force structure, health-mandated early exits from the labor force have become a critically important line of inquiry. To better understand these health-mandated early exits, I examine the interaction of self-perceived

work disability with the availability of personal resources and health status in labor force exits and application for and receipt of SSDI using waves 5 through 10 of the Health and Retirement Study. The findings from this study suggest that self-identified work disability is a key predictor of first labor force exit and SSDI receipt. Further, personal resources are also found to be a strong predictor of first labor force exit, application for and receipt of SSDI. This study helps distinguish the “invisible” work-disabled older adults who are able to retire early from the “visible” work-disabled older adults who enter into the SSDI application process.

Robin Telford

Justice-Involved Adults with Serious Mental Illness and Disability Determination Process

Applying for disability benefits, like SSI and SSDI is difficult for justice-involved adults with serious mental illness (SMI). To help increase approvals of SSI and SSDI applications, the SOAR program was developed. The SOAR program provides guidance on the application process for case managers who work with individuals who are homeless, and was recently adapted to work with justice-involved adults with SMI. Open-ended semi-structured qualitative interviews were conducted with SOAR-trained case managers (N=10). Data from SOAR applications (N=176) were matched to aggregate data from the Social Security Administration to examine SSI and SSDI approval and denial rates, and factors that impact these rates.

The main emergent themes were the SOAR-trained case manager's belief that a standardized approach to applying for SSI and SSDI benefits would improve the time-to-decision and the application success for justice-involved adults with SMI. The SOAR program that was evaluated had 88.1% of their

applications approved and the mean months to approval was 1.6. Applications for both SSI/SSDI were more likely to be approved if the claimant had criminal justice involvement anytime throughout the application process. Preliminary evidence indicates that SOAR is an effective way to increase access to disability benefits for this vulnerable population. Although, in these data there was little evidence that the receipt of SSI/SSDI benefits directly reduced the risk of post-decision jail bookings, the combined effect of these benefits, housing, and treatment suggested in this sample deserves further study. cohort that were required for both students and mentors. PRI staff also increased its use of social media to expand the audience of potential program applicants. As the DDP Small Grant Program concluded, SSA expanded the focus of a successor program, Analyzing Relationships between Disability, Rehabilitation, and Work (ARDRAW).