

Lieke van Heumen, PhD

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EDUCATION

- 2015 PhD Disability Studies
University of Illinois at Chicago, USA
- 2008 MS Psychology cum laude (specialization gerontology)
Radboud University Nijmegen, the Netherlands
- 2006 BS Psychology (specialization gerontology)
Radboud University Nijmegen, the Netherlands

EMPLOYMENT

Current

- 2019-present Clinical assistant professor
Department of Disability and Human Development, University of Illinois at Chicago, USA
- 2018-2019 Visiting clinical assistant professor
Department of Disability and Human Development, University of Illinois at Chicago, USA
- 2015-2018 Postdoctoral research associate
Institute for Disability and Human Development, University of Illinois at Chicago, USA

Previous

- 2014-2015 Research assistant
Ligas Evaluation study
Institute for Disability and Human Development, University of Illinois at Chicago, USA
- 2013 Interviewer
Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham, UK
- 2012-2013 Co-Principal Investigator
Disability Studies in the Netherlands
- 2008-2014 Research assistant
Consumer-Directed Support: Impact of Hiring Practices and Training in “Learning to Direct your own Supports” on Adults with I/DD and Families
Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago, USA

AREAS OF RESEARCH

- Content** Aging with intellectual disabilities; Autism; Dementia
- Theory** Critical Disability Theory; Critical social gerontology; Life course perspectives
- Method** Interdisciplinary research; Participatory Research; Qualitative research

GRANTS AND FELLOWSHIPS

Health and Aging Policy Fellowship, 2019-2020

Special Olympics International, *Special Olympics Research and Evaluation Translation and Dissemination Project*, 2019, \$31,000. Principal Investigator.

Retirement Research Foundation, *Building community capacity for person centered planning for people aging with ID*, 2018, \$99,026. Principal Investigator. Co-PIs Haleigh Scott and Tamar Heller.

Individual Advocacy Group, Envision Unlimited through Illinois Department of Human Services, Division of Developmental Disabilities, *Short-term Stabilization Homes Evaluation*, 2017, \$80,000. Co-Principal Investigator with Tamar Heller, PhD

Envision Unlimited, University of Illinois at Chicago, *Life Like Any Other*, 2015, \$12,500. Co-Principal Investigator with Tamar Heller, PhD

PUBLICATIONS

Peer Reviewed Journal Articles

Williamson, H., **van Heumen, L.**, & Schwartz, A. (under review). Photovoice with Individuals with Intellectual and/or Developmental Disabilities: Lessons Learned from Inclusive Research Efforts.

van Heumen, L., & Koneczny, N. (2019). Flexibility and Accessibility: Promoting Inclusive Teaching Strategies in a Large Enrollment Disability Studies College Course. *Journal of Teaching Disability Studies*, 1.

van Heumen, L., & Schippers, A. (2016). Quality of Life for Young Adults with Intellectual Disabilities Following Individualized Support: Individual and Family Responses. *Journal of Intellectual and Developmental Disability*, 41(4), 1-13. doi:10.3109/13668250.2016.1213797.

Schippers, A. & **van Heumen, L.** (2014). The inclusive city through the lens of quality of life. *International Public Health Journal*, 6(4), 311-322.

Heller, T., Arnold, C.K., **van Heumen, L.**, McBride, E., & Factor, A. (2012). Consumer-Directed Support: Impact of Hiring Practices on Adults with Intellectual and Developmental Disabilities and Families. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 464-477. doi: 10.1352/1944-7558-117.6.464.

Book chapters

van Heumen, L. (in press). Aging with lifelong disability: individual meanings and experiences over time. In M. Putnam & C. Bigby (Eds). *Handbook of Aging with Disability*. New York, NY: Taylor & Francis/Routledge.

Heller, T., & **van Heumen, L.**, (in press). Aging in Individuals with Intellectual and Developmental Disabilities. APA Handbook of Intellectual and Developmental Disabilities, American Psychological Association.

Perkins, E. A., & **van Heumen, L.** (2017). When the journey ends: Parental caregiving and later life planning. In B. S. Goff, & N. P. Springer (Eds). *Families and Disabilities: A Guide for Helping Professionals*. New York, NY: Taylor & Francis/Routledge.

- van Heumen, L.** & Heller, T. (2017). Aging. In K. Shogren, M. Wehmeyer & N. Singh (Eds.) *Handbook of positive psychology in intellectual and developmental disabilities: translating research into practice* (pp. 357-372). New York, NY: Springer.
- Schippers, A. & **van Heumen, L.** (2014). The inclusive city through the lens of quality of life. In R. I. Brown & R. Faragher (Eds.). *Challenges for Quality of Life: Applications in Education and other Social Contexts* (169-184). Hauppauge NY: Nova Science Publishers
- Heller, T. & **van Heumen, L.** (2013). Aging with disability. In M. Wehmeyer (Ed.) *Oxford handbook of positive psychology and disability* (pp.409-423). Oxford, U.K.: Oxford University Press.
- Parker, S., Heller, T., Schindler, A., & **van Heumen, L.** (2012). Problems, controversies and solutions. In T. Heller & S. Parker (Eds.). *Disability through the Lifecourse* (pp.39-102). Volume 1 for Sage Reference Series on Disability. Sage Publications.
- van Heumen, L.** (2012). Challenging the way we think about dementia. In *Zie meer Kijk anders. Tien jonge wetenschappers over disability studies (See more by looking in a different way. Ten young scientists on disability studies)* (pp. 101-114). Utrecht: ZonMw.

Encyclopedia entries

- van Heumen, L.** (2018). Aging and disability. In Heller, T., Harris, S. P., Gill, C., & Gould, R. (Eds.). (2018). *Disability in American Life: An Encyclopedia of Concepts, Policies, and Controversies* [2 volumes]. ABC-CLIO.

Book reviews

- van Heumen, L.** (2016). Illuminating the black hole: aging with autism spectrum disorder. *The Gerontologist*, 56(6), 1180-1181, doi: 10.1093/geront/gnw160

Policy briefs and reports

- Heller, T., **van Heumen, L.**, Lee, M., Xiong, S. & Fedoris, A. (2016). *Ligas evaluation final report*. Chicago: Institute on Disability and Human Development.
- van Heumen, L.**, Heller, T., Lee, M., & Xiong, S. (2016). *Evaluation of the Ligas consent decree: Family members/guardian's experiences in the transition from an ICF/DD*. Chicago: Institute on Disability and Human Development.
- van Heumen, L.**, Caldwell, K., Xiong, S., & Heller, T. (2015). *The Ligas Consent Decree: An Evaluation of the Preferences and Experiences of Persons with Disabilities on the Waiting List*. Chicago: Institute on Disability and Human Development.
- Heller, T., **van Heumen, L.**, Caldwell, K., Wei, Y., Xiong, S., & Burke, M. (2015). *Ligas evaluation annual report: year 2 report*. Chicago: Institute on Disability and Human Development.

AWARDS AND HONORS

University

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| 2017 | Excalibur Award for Teaching Excellence, College of Applied Health Sciences (student nominated) |
| 2016 | Student Achievement Award for the Program in Disability Studies |
| 2014 | Rue Bucher memorial award for qualitative studies in social processes |

- 2014 Paul D. Doolen Graduate Scholarship for the Study of Aging
- 2013, 2014 Chancellor's Graduate Research Fellowship
- 2012 10th Ann & Edward Page-El, M.D. Scholarship
- 2011 Chicago Consular Corps Scholarship

National

- 2016 Student and Early Career Professionals Special Interest Group Scholarship
American Association on Intellectual and Developmental Disabilities, AAIDD
- 2016 Gerontology Division Student Scholarship (AAIDD)
- 2015 Student Award (in recognition of exceptional accomplishments, AAIDD)

International

- 2012 Best essay award (Disability Studies in the Netherlands, essay published in book, see: van Heumen, 2012)
- 2009 Cultuurfondsbeurs (Prins Bernhard Cultuur Fonds, Dutch award for students pursuing graduate education abroad)
- 2008 VSB Beurs (VSB fonds, Dutch award for students pursuing graduate education abroad)

TRAVEL GRANTS

Gerontological Society of America/National Center on Gerontological Social Work Excellence

- 2014 Accelerating Translation of Knowledge to Community Practices for Older Adults – Washington, DC

International Association of the Scientific Study of Intellectual and Developmental Disabilities

- 2010, 2013 Aging Special Interest Research Group scholarship – Boston, MA; Prato, Italy
- 2009 Health Special Interest Research Group scholarship – Kingston, Canada

ALTER European Association on Disability Research and Disability Studies in the Netherlands

- 2012 DisABILITY MUNDUS: European summerschool in Disability Studies – Paris, France

SELECTED INVITED TALKS

- 2019 Postnote: inclusive research with older adults with IDD: implications for practice. Aging with Developmental Disabilities Conference, St. Louis, MO, USA
- 2017 Introduction to disability from a life course perspective. DePaul University, Chicago, Illinois
- 2017 Social support networks of aging persons with intellectual disabilities. The Arc, national webinar, USA
- 2017 Creative interventions when caring for our IDD geriatric population. Texas Health and Human Services Commission, Austin, Texas
- 2017 How to support older adults with intellectual and developmental disabilities to age well. 15th Annual QIDP leadership conference, the Arc, Alsip, Illinois
- 2016 How to support older adults with intellectual and developmental disabilities to age well

- University of Texas at Austin, School of Nursing, USA
- 2015 Research with people with intellectual disabilities: an example of the use of photo voice
University of Texas at Austin, School of Nursing, USA
- 2015 Aging with intellectual and developmental disabilities
Easter Seals, two part national webinar, USA
- 2014 Lived experience of people aging with intellectual and developmental disabilities:
the use of inclusive research methods
Symposium Disability Studies preceding inaugural lecture Prof. Dr. Geert van Hove
VU University Amsterdam, the Netherlands
- 2014 Lived experience of people aging with intellectual and developmental disabilities:
the use of inclusive research methods
Pre-conference workshop 'New perspectives in Community Based Participatory
Research on Aging and Developmental Disabilities' with Tamar Heller, PhD, Joseph
Caldwell, PhD, Susan Fox, MA, MS, and Tia Nelis
Association of University Centers on Disabilities, Washington DC, USA
- 2014 Aging with an intellectual disability
Anixter Center, Chicago, USA
- 2013 Aging with an intellectual disability
Lambs Farm, Libertyville, USA
- 2013 Aging and intellectual disability in the US: Context, challenges, & opportunities
with Brian Grossman, PhD, Sc.M.
Leadership Education in Neurodevelopmental and related Disabilities (LEND)
Interdisciplinary Training Program, University of Illinois at Chicago, USA
- 2013 Aging Well across the Lifespan of Adults with Intellectual Disabilities
Illinois Association for Rehabilitation Facilities conference
Springfield, IL, USA
- 2013 Aging Well across the Lifespan of Adults with Intellectual Disabilities
Network of Psychologists working with Aging people with intellectual disabilities, the
Netherlands
- 2013 Social Relations of Older Adults with Intellectual Disabilities from a Life Course
Perspective
American Public Health Association, Disability Section Student webinar, USA
- 2011 Aging with an intellectual disability
LEND Interdisciplinary Training Program, University of Illinois at Chicago, USA

CONFERENCE ACTIVITY

Panels Organized

- van Heumen, L.** (2016). *Aging experiences of individuals with intellectual and developmental disabilities and families*. Gerontological Society of America annual scientific meeting, New Orleans, LA, USA.
- Dexter, J., Peters-Beumer, L., & **van Heumen, L.** (2016). *Bridging Aging and Disability in a New Policy, Research and Practice Paradigm*. Aging in America Conference of the American Society on Aging, Washington DC, USA.
- Peters-Beumer, L. & **van Heumen, L.** (2016). *Aging and Disability Peer Group*. Aging in America Conference of the American Society on Aging, Washington DC, USA.

Papers Presented

- van Heumen, L.** Scott, H., Xiong, S., & Heller, T. (2018). *Building community capacity for person centered planning for people aging with intellectual disability*. Oral presentation at the Annual Scientific Meeting of the Gerontological Society of America, Boston, MA, USA.
- van Heumen, L.** (2018). *Building community capacity for person centered planning for people aging with intellectual disability*. Oral presentation at the Annual Meeting of the American Association on Intellectual and Developmental Disabilities, St. Louis, MO, USA.
- van Heumen, L.** (2018). *Improving Accessibility of Applied Research Methods to Promote Inclusive Research with People with ID*. Oral presentation at the Annual Meeting of the American Association on Intellectual and Developmental Disabilities, St. Louis, MO, USA.
- van Heumen, L.,** Ennis, D., Hsu, C., Zalka, A., Gill, J., Killingsworth, A., & Winn, S. (2017). *Enhancing community collaboration: experiences of people with intellectual and developmental disabilities*. Arc of Illinois Annual Convention, Lisle, IL, USA.
- Ennis, D., **van Heumen, L.,** Hsu, C., Zalka, A., & Gill, J. (2016). *Envision: Life Like Any Other. Enhancing community collaboration*. Illinois Council on Developmental Disabilities Retreat, Bloomington, IL, USA
- van Heumen, L.,** (2016). *Retirement for adults with intellectual disabilities: Critical review and future research needs*. Paper presentation at the Gerontological Society of America annual scientific meeting, New Orleans, LA, USA.
- van Heumen, L.,** (2016). *Bridging Aging and Disability in a New Policy, Research and Practice Paradigm: Perspectives on Research*. Oral presentation at the Aging in America Conference of the American Society on Aging, Washington DC, USA.
- Jordan Sheth, A., & **van Heumen, L.** (2016). *The experience of living with intellectual disability and dementia: A literature review and implications for practitioners and research*. Oral presentation At the Annual Conference of the American Academy of Developmental Medicine and Dentistry, Chicago, IL, USA.
- van Heumen, L.** (2016). *Social relations of older adults with intellectual disability from a life course perspective*. Oral presentation at the Annual Meeting of the American Association on Intellectual and Developmental Disabilities, Atlanta, GA, USA.
- van Heumen, L.,** Heller, T., Xiong, S., & Lee, M. (2016). *Impact of the Ligas consent decree in Illinois on individuals with intellectual and developmental disabilities moving off the waiting list for community based services*. Oral presentation at the Annual Meeting of the American Association on Intellectual and Developmental Disabilities, Atlanta, GA, USA.
- van Heumen, L.** (2016). *Life Story Research with People Aging with Intellectual Disabilities: An Application of the Life Line Interview Method*. Oral presentation at the International Congress of Qualitative Inquiry, University of Illinois at Urbana-Champaign, USA.
- van Heumen, L.** (2015). *Aging with Intellectual Disabilities: Selfhood and the Renegotiation of Familial Relationships*. Paper presentation at the Gerontological Society of America annual scientific meeting, Orlando, FL, USA.
- van Heumen, L.** & Schippers, A. (2014). *Evaluation of Family Quality of Life after Family-Oriented Support with Young Adults with Intellectual Disabilities and Families*. Paper presentation at the Annual Meeting of the American Association on Intellectual and Developmental Disabilities, Orlando, FL, USA.
- van Heumen, L.** & Schippers, A. (2013). *Quality of Life Effects of Individual Support for Families*. Paper presentation at Roundtable of the Quality of Life Special Research Interest Group (SIRG), International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), Amsterdam, the Netherlands.

- van Heumen, L.**, Schippers, A., Kleine, J., Steinbach, Z. & Adel Nikkhooij, A. (2013). *Evaluation of Family Quality of Life after Family-Oriented Support with Young Adults with Intellectual Disabilities and Families*. Paper presentation at “The Art of Belonging”, 2nd International Conference Disability Studies in the Netherlands, Amsterdam, the Netherlands.
- van Heumen, L.** (2011). *Disability studies and aging*. Paper presentation at ‘Beyond Access: From Disability Rights to Disability Justice’, Society for Disability Studies Conference, San Jose, California, USA.
- van Heumen, L.** (2010). *Disability studies and aging*. Paper presentation at ‘Diversity in Quality of Life’ International Conference of Disability Studies in the Netherlands and VU University around World Disability Day, Amsterdam, the Netherlands.
- Heller, T., **van Heumen, L.**, McBride, E., Keiling, C. & Factor, A. (2011). *Consumer-Direction: Impact of Hiring Practices on Adults with ID/DD*. Paper presentation at Festival of International Conferences on Caregiving, Disability, Aging and Technology, Growing Older With a Disability, Toronto, Canada.
- Heller, T., Arnold, C.K., **van Heumen, L.**, McBride, E. & Factor, A. (2011). *Consumer-directed support: impact of hiring practice on adults with I/DD and families*. Paper presentation at State of Science Conference on Lifespan Health and Function of Adults with Intellectual and Developmental Disabilities: Translating Research into Practice, Bethesda, MD, USA.
- Heller, T., **van Heumen, L.**, Caldwell, K., McBride, E., Arnold, C. K. & Factor, A. (2010). *Consumer-directed support: impact of hiring practices on families of adults with I/DD*. Paper presentation at IASSIDD Europe Congress, Rome, Italy.

Posters Presented

- van Heumen, L.**, DuBois, L., & Xiong, S. (2019). Inclusive Translation and Dissemination of Special Olympics International Health Data. Poster presentation at the Annual Meeting of the American Association on Intellectual and Developmental Disabilities, Minneapolis, MN, USA.
- van Heumen, L.** Scott, H., Xiong, S., & Heller, T. (2018). *Building community capacity for person centered planning for people aging with intellectual disability*. Poster presentation at the Annual Meeting of the American Association on Intellectual and Developmental Disabilities, St. Louis, MO, USA.
- van Heumen, L.**, Hsu, C., Ennis, D., Lilley, V., Zalka, A., Gill, J., Killingsworth, A., & Winn, S. (2017). *Experiences of adults with intellectual disabilities with community participation: results from a photo voice study*. Poster presentation at the Annual Meeting of the American Association on Intellectual and Developmental Disabilities, Hartford, Connecticut, USA.
- van Heumen, L.** (2016). *Life story research with people aging with intellectual disability: an application of the lifeline interview method*. Poster presentation at the Annual Meeting of the American Association on Intellectual and Developmental Disabilities, Atlanta, GA, USA.
- van Heumen, L.** (2014). *Social Relationships of Older Adults with Intellectual Disabilities from a Life Course Perspective*. Poster presentation at the Annual Scientific Meeting of the Gerontological Society of America, Washington DC, USA.
- van Heumen, L.** (2014). *Social relations of older adults with intellectual disabilities from a life course perspective*. Poster presentation at the Annual Meeting of the American Association on Intellectual and Developmental Disabilities, Orlando, FL, USA.
- Burke, M. B., Arnold, K., Xiong, S., **van Heumen, L.**, McBride, E., & Heller, T. (2014). *Comparing Caregiver Experiences of Parents and Siblings of Individuals with Intellectual and Developmental Disabilities*. Poster presentation at the 47th Annual Gatlinburg Conference, Chicago, USA.
- van Heumen, L.**, Heller, T., McBride, E. & Arnold, C.K. (2013). *Satisfaction with personal support workers and well-being of aging family caregivers of adults with I/DD*. Poster presentation at the

Roundtable of the Aging Special Research Interest Group (SIRG), International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), Boston, MA, USA.

Heller, T., McBride, E., **van Heumen, L.**, Arnold, C.K., Factor, A. (2012). *Consumer-Direction: Impact of Hiring Practices on Adults with ID/DD*. Poster presentation at the American Association of Intellectual and Developmental Disabilities, Charlotte, NC, USA.

van Heumen, L. (2010) 'Social Relations of Ageing People with Intellectual Disabilities'. Poster presentation at the Joint Roundtable of the Aging and Health Issues SIRG's, IASSIDD, Prato, Italy.

TEACHING EXPERIENCE

Department of Disability and Human Development, University of Illinois at Chicago, USA

Curriculum development and sole instructor

Disability in U.S. society (undergraduate 170 students)	Fall 2017-present
Disability through the life course (joint undergraduate and graduate, 10 students)	Spring 2017

Courses taught as sole instructor

Independent Research (graduate, 1 PhD student)	Fall 2016
Disability in U.S. society (undergraduate, 124 students)	Spring 2016

Courses taught as co-instructor

Foundations of Disability and Human Development (graduate, 7 students)	Fall 2012
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Student mentorship

Independent Research (undergraduate and graduate); Honors college mentor and fellow, Supervisor for Bachelor of Rehabilitation Science AHS393 Field Experience	Fall 2016-present
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Teaching assistantships

Disability in U.S. society (undergraduate, 130 students)	Fall 2014
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Radboud University, the Netherlands

Teaching assistantships

Developmental psychology, clinical psychology and gerontology (undergraduate, 20 students per course)	2007-2009
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SERVICE TO PROFESSION

Leadership

2018-present	Member of the Editorial Board of Alter, the European Journal of Disability Research
2018-present	Board member Arc of Illinois
2018-present	Chair Gerontology Division American Association on Intellectual and Developmental Disabilities

2015-2017 Co-convener Lifelong Disabilities Special Interest Group
Gerontological Society of America
2015 Participant Aging Strand (invitation only)
National Goals in Research, Policy and Practice for and with People with Intellectual
and Developmental Disabilities Working Meeting
Washington, DC

Reviewer

2015-present *Disability Studies Quarterly*
Intellectual and Developmental Disabilities
Journal of Intellectual and Developmental Disability
Journal of Policy and Practice in Intellectual Disabilities
Research on Aging
Scandinavian Journal of Occupational Therapy
2019 AAIDD Annual meeting
2014 IASSIDD Europe Regional Congress

CLINICAL EXPERIENCE

2002-2009 Direct support professional
Cello (organization for persons with intellectual disabilities), the Netherlands
2007-2008 Psychologist
Stichting Pergamijn (organization for persons with intellectual disabilities), the
Netherlands

LANGUAGES

Dutch (native); English (near-native); German (good receptive skill, basic expressive skill); French (basic
receptive skill, basic expressive skill)

PROFESSIONAL MEMBERSHIPS

American Association on Intellectual and Developmental Disabilities
Gerontological Society of America