

# Lieke van Heumen, PhD

lvheumen@uic.edu

## EDUCATION

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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

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### Current

2015-present	Postdoctoral research associate Institute for Disability and Human Development, University of Illinois at Chicago, USA
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### 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	Research project coordinator 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

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<b>Content</b>	Aging with intellectual disabilities Autism Dementia
<b>Theory</b>	Disability Studies Critical social gerontology Life course perspectives
<b>Method</b>	Interdisciplinary research Inclusive research Life story research

## GRANTS

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

## PUBLICATIONS

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### Peer Reviewed Journal Articles

- 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

- Perkins, E. A., & **van Heumen, L.** (forthcoming). 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. (forthcoming). Aging. In K. Shogren, M. Wehmeyer & N. Singh (Eds.) *Handbook of positive psychology in intellectual and developmental disabilities: translating research into practice*. 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.** (forthcoming). Aging and disability. In T. Heller, S. Parker-Harris, C. Gill and R. P. Gould (Eds.). *Disability in American Life: An Encyclopedia of Concepts, Policies, and Controversies* Framework for Table of Contents. Santa Barbara, CA: ABC-CLIO

## Book reviews

**van Heumen, L.** (forthcoming). Illuminating the black hole: aging with autism spectrum disorder. *The Gerontologist*.

## 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.

## Manuscripts in preparation

**van Heumen, L.** (in preparation). Social relations of older adults with intellectual disabilities from a life course perspective.

**van Heumen, L.** (in preparation). Life story research with people aging with intellectual disabilities: an application of the lifeline interview method.

## AWARDS AND HONORS

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### University

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	10 <sup>th</sup> 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**

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### **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**

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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

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### 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.** (2016). *Social relations in older adults with intellectual disabilities: Applying the social convoy model*. Paper presentation at the Gerontological Society of America annual scientific meeting, New Orleans, LA, 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.** (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 47<sup>th</sup> 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

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

#### *Curriculum development*

Disability through the life course (graduate, 10-30 students)	Spring 2017
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#### *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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#### *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

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### Leadership

2015-present	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     *Intellectual and Developmental Disabilities*  
                      *Journal of Intellectual and Developmental Disability*  
                      *Journal of Policy and Practice in Intellectual Disabilities*  
                      *Research on Aging*  
2014                IASSIDD Europe Regional Congress

## **CLINICAL EXPERIENCE**

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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**

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Dutch (native)  
English (near-native)  
German (good)

## **PROFESSIONAL MEMBERSHIPS**

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American Association on Intellectual and Developmental Disabilities  
Gerontological Society of America  
International Association of the Scientific Study of Intellectual and Developmental Disabilities

## **REFERENCES**

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References available upon request.