



CURRICULUM VITAE



Name: Snæfríður Thóra Egilson
Date of birth: October 13, 1956
Academic position: Professor in Disability Studies at University of Iceland,
School of Social Sciences
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Education

2005 PhD degree in Education. University of Iceland, Faculty of Social Sciences.
1994 MSc degree in Occupational Therapy. San Jose State University, San Jose, California, USA.
1981 Diploma in Occupational Therapy. Oslo College of Occupational Therapy, Oslo, Norway.

Professional Experience

2016 – present. Professor and program manager in disability studies. University of Iceland.
2013 – 2016. Professor in disability studies. University of Iceland, Faculty of Social and Human Sciences. Acting program manager 2015.
2009 – 2013. Professor in occupational therapy. University of Akureyri, Faculty of Health Sciences.
2006 – 2009. Associate professor in occupational therapy. University of Akureyri, Faculty of Health Sciences.
1997 – 2006. Assistant professor in occupational therapy. University of Akureyri, Faculty of Health Sciences. One of two founders of the occupational therapy education program.
1987 – 1992 & 1994 – 1997. Senior occupational therapist at the State Diagnostic and Counselling Center, Iceland.
1993-1994 Consultant at CAR, center for families of young disabled children, California, USA
1984-1987 Senior occupational therapist at Styrktarfélag lamaðra og fatlaðra, [SLF therapy center] Reykjavik, Iceland.
1981-1987 Occupational therapist at Hlíðaskóli primary school, Reykjavik, Iceland.

Research Projects

2017-2020 *Life quality and participation of disabled children and youth: A transformative study (LIFE-DCY)*
Principal Investigator. Funded by Rannis: the Icelandic Center for Research (nr. 174299-051) and the University of Iceland Research Fund. Co-investigators: Stefan Hardonk, Ásta Jóhannsdóttir, Linda Björk Ólafsdóttir, Anna Sigrún Ingimarsdóttir og Freyja Haraldsdóttir.

2017-2019 *Migrant families with disabled children.* Funded by MARK and þróunarsjóður innflytjendamála. Together with Unnur Dís Skaptadóttir og Guðbjörg Ottósdóttir.

2012-2016 *Quality of life, participation and environment of children living in Iceland.* Principal Investigator. Funded by the University of Iceland Research Fund and the University of Akureyri Research fund.

2010-2012 *Services to disabled children and their families*. Principal Investigator. Funded by the University of Akureyri Research fund.

2003-2006. Development of the *School Setting Interview (SSI)* Co-Investigator. Translation and research on the SSI in Iceland. Principal Investigator. Funded by the University of Akureyri Research fund.

2000-2005. *School participation - Icelandic students with physical impairments*. Doctoral study. Funded by the University of Akureyri Research fund.

Participation in international projects such as the Nordic Centre of Excellence: Reassessing the Nordic Welfare Model – a virtual research centre funded by NordForsk 2007-2012. Participation in various projects related to the development and translation of measures to be used with disabled children and their families.

Since 2013 Snæfríður is part of the Centre for Disability Studies which engages in extensive international collaboration with scholars and research institutions and has hosted many international research projects.

Current and previous projects include policy analysis and assessment of disability and welfare services, poverty and disability, the disability pension system, social inclusion/exclusion, human rights, disabled children and youth, families and disability, gender and disability, disability and identity, employment, violence against disabled women, and disability and culture.

Selected publications (since 2005)

- 2018 Ólafsdóttir, L.B., Egilson, S.T., Árnadóttir, U. & Hardonk, C. (2018). Child and parent perspectives of life quality of children with physical impairments compared with non-disabled peers. (early online) *Scandinavian Journal of Occupational Therapy*. <https://doi.org/10.1080/11038128.2018.1509371>
- 2018 Egilson, S.T. & Pálmadóttir, G. (2018). Iðjuþjálfun í ljósi gagnrýnna sjónarhorna: Umfjöllun um verk K.W. Hammell og gildi þeirra fyrir iðjuþjálfun á Íslandi. [Occupational therapy in a critical perspective. The work of K.W. Hammell and its relevance for occupational therapy in Iceland.] *Iðjuþjálfinn*, 1, 6-13.
- 2018 Egilson, S.T., Dybbroe, B. & Olsen, T. (2018). Brukermedvirkning og velferdstjenester. *Nordisk Vælfärdsforskning*. 1, 4-6.
- 2018 Ingólfssdóttir, J., Egilson, S. & Traustadóttir, R. (2018). Family-centredness in welfare services in Iceland. *Journal of Intellectual Disabilities*, 24(4)361-377.
- 2018 Jónasdóttir, S.K., Egilson, S. og Polgar, J. (2018). Services, systems and policies affecting community mobility for people with mobility impairments in Northern Iceland: An occupational perspective. *Journal of Occupational Science*, 25, 309-321.
- 2017 Egilson, S. T., Jakobsdóttir, G. & Ólafsdóttir, L. B. (2017). Parent perspectives on home participation of high-functioning children with ASD compared with a matched group of children without ASD. *Autism*, 22, 560-570. doi.org/10.1177/1362361316630881
- 2017 Gunnhildur Jakobsdóttir, Þóra Leósdóttir & Snæfríður Þóra Egilson (2017). Samfélagsþátttaka einhverfra barna: Viðhorf foreldra. *Iðjuþjálfinn*, 6-13.
- 2017 Egilson, S.T., Jakobsdóttir, G., Ólafsson, K. & Leósdóttir, T. (2017). Community participation and environment of children with and without autism spectrum disorder: Parent perspectives. *Scandinavian Journal of Occupational Therapy*, 24(3), 187-196. doi: 10.1080/11038128.2016.1198419
- 2017 Hemmingsson, H., Ólafsdóttir, L.B. & Egilson, S.T. (2017). Agreements and disagreements between children and their parents in health-related assessments. *Disability and Rehabilitation*, 30(11), 1059-1072. doi: 10.1080/09638288.2016.1189603
- 2017 Egilson, S.T., Ólafsdóttir, L.B., Saemundsen, E. & Leósdóttir, S. (2017). Quality of life of high-functioning children and youth with autism spectrum disorders compared with a control group of peers: Self- and proxy-reports. *Autism*. 24(3), 187-196. doi: 10.1080/11038128.2016.1198419. doi: 10.1177/1362361316630881
- 2016 Egilson, S. (2016). Skólabátttaka fatlaðra nemenda. Viðvera tryggir ekki þátttöku [Being present is not enough: School participation of disabled pupils]. In D. Bjarnason, H. Gunnþórsdóttir & Jónsson, Ó.P. (eds). *Skóli margbreytileikans: Menntun og manngildi í kjölfar Salamanca* [The diverse school: Education and human dignity after Salamanca] (pp.117-135). Reykjavík: Háskólaútgáfan.
- 2016 Ingvarsson, I., Egilson, S.T. & Skaptadóttir, U.D. (2016). "I want a normal life like everyone else". Daily life of asylum seekers in Iceland. *Scandinavian Journal of Occupational Therapy*, 23, 416-424. doi: 10.3109/11038128.2016.1144787

- 2016 Einarisdóttir, J. & Egilson, S.T. (2016). Embracing diversity in childhood studies: Methodological and practical considerations. In A. Farrell and I. P. Samuelsson (eds.) *Diversity in the early years: Intercultural learning and teaching* (pp. 35–53). Melbourne: Oxford University Press.
- 2015 Stefánsdóttir, S. & Egilson, S.T. (2015). Diverging perspectives on children's rehabilitation services: A mixed-methods study. *Scandinavian Journal of Occupational Therapy*, 23, 374–382. doi: 10.3109/11038128.2015.1105292
- 2015 Jakobsdóttir, G., Egilson, S.T. & Ólafsson, K. (2015). Skólaþátttaka og umhverfi 8-17 ára getumikilla barna með einhverfu: Mat foreldra. [School participation and environment of high-functioning children with autism spectrum disorders, aged 8-17 years]. *Icelandic Journal of Education*, 24(2), 75–97.
- 2015 Traustadóttir, R., Ytterhus, B., Egilson, S.T., & Berg, B. (eds). (2015). *Childhood and disability in the Nordic countries: Being, becoming, belonging*. Basingstoke: Palgrave.
- 2015 Egilson, S.T. & Traustadóttir, R. (2015). Familier med funksjonshemmede barn: Dagligliv in en sosial kontekst. In P. Kermit, A. Gustavsson, A. Kittelsaa and B. Ytterhus (eds). *Utviklingshemming: Hverdagsliv, levekår og politikk* (pp. 91-104). Oslo: Universitetsforlaget.
- 2014 Ólafsdóttir, L.B., Egilson, S.T. & Ólafsson, K. (2014). Lífsgæði 8-17 ára getumikilla barna með einhverfu: Mat barna og foreldra þeirra. [Quality of life of high-functioning children with autism spectrum disorders, aged between 8-17 years]. *Icelandic Journal of Education*, 23(2), 43–63.
- 2014 Egilson, S.T. (2014). School experiences of pupils with physical impairments over time. *Disability and Society*, 29, 1076–1089. doi: 10.1080/09687599.2014.902363
- 2014 Egilson, S.T. & Stefánsdóttir, S. (2014). Velferðarþjónusta og fötluð börn: Reynsla foreldra af starfi fjölskyldudeildar Akureyrarbæjar. [Welfare services and disabled children: Perspectives of parents in the municipality of Akureyri]. *Icelandic Review of Politics and Administration*, 10(2), 587–610. doi: 10.13177/irpa.a.2014.10.2.19
- 2014 Hemmingsson, H., Egilson, S., Lidström, S. & Kielhofner, G. (2014). *The School Setting Interview (3.1 ed)*. Nacka: The Swedish Association of Occupational Therapists.
- 2014 Hemmingsson, H., Egilson, S., Lidström, S. & Kielhofner, G. (2014). *Bedömning av anpassningar i skolmiljön (3.1 ed)*. Nacka: The Swedish Association of Occupational Therapists.
- 2013 Egilson, S.T. (2013). Editorial. *Scandinavian Journal of Occupational Therapy*, 20, 321–322.
- 2013 Jónsdóttir, G. & Egilson, S.T. (2013). „Við gerum bara eins og við getum“ – Þjónusta við fólk með fjölpættar skerðingar. [“We do as well as we can”. The experiences of staff assisting disabled people in community residential homes]. *Icelandic Review of Politics and Administration*, 9(1), 171–190. doi: 10.13177/irpa.a.2013.9.1.9
- 2013 Egilson, S.T., Ólafsdóttir, L.B., Methúsalemsdóttir, H.F. & Leósdóttir, T. (2013). Þýðingarferli og notkun lífsgæðamatlistans KIDSCREEN á Íslandi. [Translation and use of the KIDSCREEN in Iceland]. *Iðjuþjálfinn*, 1, 28–33.
- 2013 Traustadóttir, R., Sigurjónsdóttir, H.B. & Egilson, S.T. (2013). Disability studies in Iceland: past, present and future. *Scandinavian Journal of Disability Research*, 15(supplement 1), 55–70. doi: 10.1080/15017419.2013.800726
- 2013 Methúsalemsdóttir, H.F., Egilson, S.T., Gudmundsdóttir, R., Valdimarsdóttir, U. & Georgsdóttir, I. (2013). Quality of life of adolescents born with extremely low birth-weight. *Acta Paediatrica*, 102, 597–601. doi: 10.1111/apa.12192
- 2012 Ingólfsdóttir, J., Traustadóttir, R., Egilson, S. & Goodley, D. (2012). Thinking relationally: Disability, families and cultural-historical activity theory. *Barn, Norsk senter for barneforskning*, 4, 13–24.
- 2012 Árnadóttir, U. & Egilson, S. (2012). Evaluation of therapy services with the Measure of Processes of Care (MPOC-20): the perspectives of Icelandic parents of children with physical disability. *Journal of Child Health Care*, 16, 62–74. doi: 10.1177/1367493511423769
- 2012 Stefánsdóttir, S. & Egilson, S.T. (2012). Er markmiðinu náð? Útkoma íhlutunar í endurhæfingu barna metin með Goal attainment scaling aðferðinni. [Outcome of therapy for children assessed by the Goal attainment scaling method]. *Iðjuþjálfinn*, 12–17.
- 2011 Sigurðardóttir, G. & Egilson, S.T. (2011). Aðstæður ungs fólks í Fjölsmiðjunni á Akureyri. [Conditions of young people at Fjölsmidjan in Akureyri]. In Halldór Sig. Guðmundsson (ed.) *Rannsóknir í félagsvísindum 2011* (pp. 18–28). Reykjavík: Félagsráðgjafardeild Háskóla Íslands.
- 2011 Pálmadóttir, G. & Egilson, S.T. (eds). (2011). *Iðja, heilsa og velferð, iðjuþjálfun í íslensku samfélagi [Occupation, health and welfare, occupational therapy within an Icelandic context]*. Akureyri: Háskólinn á Akureyri.

- 2011 Egilson, S.T. (2011). Umhverfi og þátttaka [Environment and participation]: In Guðrún Pálmadóttir & Snæfríður Thóra Egilson (eds). *Iðja, heilsa og velferð, iðjubjálfun í íslensku samfélagi* [Occupation, health and welfare, occupational therapy within an Icelandic context] (pp. 37–65). Akureyri: Háskólinn á Akureyri.
- 2011 Pálmadóttir, G. & Egilson, S.T. (2011). Skjólstæðingsmiðað starf með einstaklingum og fjölskyldum [Client-centred service to individuals and families]. In Guðrún Pálmadóttir & Snæfríður Thóra Egilson (eds). *Iðja, heilsa og velferð, iðjubjálfun í íslensku samfélagi* [Occupation, health and welfare, occupational therapy within an Icelandic context] (pp. 105–120). Akureyri: Háskólinn á Akureyri.
- 2011 Egilson, S.T. (2011). Parent perspectives of therapy services for their children with physical disabilities. *Scandinavian Journal of Caring Sciences*, 25(2), 277–284. doi: 10.1111/j.1471-6712.2010.00823
- 2010 Stefánsdóttir, S. & Egilson, S.T. (2010). Fjölskyldumiðuð þjónusta í endurhæfingu barna. Mat foreldra. [Family-centred care in children's rehabilitation services. Parents' view]. In Gunnar Þór Jóhannesson & Helga Björnsdóttir (eds), *Rannsóknir í félagsvísindum XI* (pp. 252–265). Reykjavík: Félagsvísindastofnun Háskóla Íslands.
- 2009 Egilson, S.T. & Hemmingsson, H. School participation of pupils with physical and psychosocial limitations: A comparison. *British Journal of Occupational Therapy*, 72, 144–152. doi: doi: 10.1177/030802260907200402
- 2009 Egilson, S.T. & Traustadóttir, R. Participation of students with physical impairments within the school environment. *American Journal of Occupational Therapy*, 63, 264–272.
- 2009 Egilson, S.T. & Traustadóttir, R. Theoretical perspectives and childhood participation. *Scandinavian Journal of Disability Research*, 11, 51–63. doi: 10.1080/15017410802461970
- 2009 Egilson, S. T. & Traustadóttir, R. (2009). Assistance to pupils with physical disabilities in regular schools: Promoting inclusion or creating dependency? *European Journal of Special Needs Education*, 24, 21–36
- 2008 Egilson, S.T. (2008). Glíman við daglega lífið: Fjölskyldur barna með hreyfihömlun. [Negotiating daily routines: Families of children with physical impairments] In Gunnar Þór Jóhannesson & Helga Björnsdóttir (eds.) *Rannsóknir í félagsvísindum IX* (pp. 443–452). Reykjavík: Félagsvísindastofnun Háskóla Íslands.
- 2006 Egilson, S.T. & Pálmadóttir, G. (2006). Heilbrigði og fötlun: Alþjóðleg líkön og flokkunarkerfi [Health and disability: International models and taxonomy]. In Rannveig Traustadóttir (ed.) *Fötlun. Hugmyndir og aðferðir á nýju fræðasviði* [Disability: Ideas and methods in a new field of knowledge] (pp. 37–65). Reykjavík: Háskólaútgáfan.
- 2006 Egilson, S.T. (2006). Á heimavelli: Að rannsaka fyrrum starfsvettvang [On the homefront: Doing research on familiar tracks]. In Rannveig Traustadóttir (ed.) *Fötlun. Hugmyndir og aðferðir á nýju fræðasviði* [Disability: Ideas and methods in a new field of knowledge], (pp. 107–121). Reykjavík: Háskólaútgáfan.
- 2006 Egilson, S.T. (2006). Þátttaka í ljósi kennisetninga um heilbrigði og fötlun [Participation in the light of conceptual models of health and disability]. In *Rannsóknir Félagsvísindum VII* (pp. 327–337). Reykjavík: Félagsvísindastofnun Háskóla Íslands.
- 2006 Hemmingsson, H., Egilson, S.T., Hoffman, O. & Kielhofner, G. (2006). *The School Setting Interview (3. ed)*. Nacka: The Swedish Association of Occupational Therapists.
- 2005 Leosdóttir, T., Egilson, S.T. & Georgsdóttir, I. (2005). Performance of extremely low birthweight children at 5 years of age on the Miller Assessment for Preschoolers. *Physical and Occupational Therapy in Pediatrics*. 4, 59–72. doi: 10.1300/J006v25n04_05
- 2005 Egilson, S.T. (2005). *School Participation: Icelandic Students with Physical Impairments*. Doctoral dissertation. University of Iceland, Faculty of Social Sciences.

Selected presentations internationally (since 2007)

- 2018 Life quality and participation of disabled children and youth living in Iceland. Paper presented at the Disability Studies conference in Lancaster, England.
- 2018 Parent perspectives of home participation of high-functioning children with ASD compared to a matched group of children without ASD. Paper presented at the World Congress of Occupational Therapy in Cape Town, South Africa.
- 2017 Quality of life and participation of disabled children and youth in Iceland. Paper presented at the 5th International Conference on Geographies of Children, Youth and Families in Loughborough, England.
- 2017 Methodological and practical considerations in doing research with disabled children. Paper presented at the Nordic Network of Disability Research (NNDR 14th research conference) in Örebro, Sweden.

- 2016 *Quality of life of high-functioning children and youth with autism spectrum disorders compared to a paired control group of peers: self- and proxy reports.* Paper presented at the XI Autism-Europe International Congress in Edinburgh, Scotland.
- 2016 *Eliciting disabled children's voices in research – methodological and practical considerations.* Paper presented at the COTEC & ENOTHE Congress in Galway, Ireland.
- 2016 *Quality of life, participation and environment of children with autism spectrum disorder.* Symposium of three papers presented at the COTEC & ENOTHE Congress in Galway, Ireland.
- 2015 *Participation and environment of high functioning children with autism.* Paper presented at the Nordic Network of Disability Research (NNDR 13th research conference) in Bergen, Norway.
- 2015 *User perspectives on support services provided to disabled children and their families.* Paper presented at the Nordic Network of Disability Research (NNDR 13th research conference) in Berge, Norway.
- 2015 *Quality of life of high-functioning children with autism spectrum disorders, aged between 8-17 years.* Paper presented at the Nordic Network of Disability Research (NNDR 13th research conference) in Bergen, Norway.
- 2014 *School experiences of pupils with physical impairments over time.* Paper presented at the Disability Studies conference in Lancaster, England.
- 2014 *Quality of life of children and youth with autism.* Paper presented at the Disability Studies conference in Lancaster, England.
- 2013 *Assistive devices as promoting independence or creating stigma?* Paper presented at the Nordic Network of Disability Research (NNDR 12th research conference) in Turku, Finland.
- 2013 *Parents' perspectives on support services provided to their disabled children.* Paper presented at the Nordic Network of Disability Research (NNDR 12th research conference) in Turku, Finland.
- 2012 *Parents' experiences of therapy services for their children with disabilities.* Paper presented at the 9th European Congress of Occupational Therapy in Stockholm.
- 2012 *Views and experiences of secondary school students with physical impairments.* Paper presented at the 9th European Congress of Occupational Therapy in Stockholm.
- 2012 *User perspectives on services to disabled children and their families.* Paper presented at the Reassessing the Nordic Welfare Model – Final International Conference, Oslo.
- 2011 *Family-centred service: moving ideas into practice.* Paper presented at the Joint Nordic Conference on Welfare and Professionalism in turbulent times, in Reykjavik, Iceland.
- 2011 *Participation in high school: Views and experiences of students with physical impairments at a time of transition.* Paper presented at the Nordic Network of Disability Research (NNDR 11th research conference) in Reykjavik, Iceland.
- 2010 *Parents' views of therapy services for their children.* Paper presented at the Disability Studies conference in Lancaster, England.
- 2010 *School participation of children with physical and psychosocial disabilities.* Paper presented at the World Federation of Occupational Therapy congress in Santiago, Chile.
- 2010 *Environmental impact on people with spinal cord injury.* Poster presented at the World Federation of Occupational Therapy congress in Santiago, Chile.
- 2010 *Current trends and research in school participation: How to apply the School Setting Interview.* Workshop at the World Federation of Occupational Therapy congress in Santiago, Chile (together with Professor Helena Hemmingsson)
- 2009 *Negotiating daily routines.* Paper presented at the Nordic Network of Disability Research (NNDR 10th research conference) in Nyborg, Denmark.
- 2009 *The environment: how does it affect the daily life of individuals with spinal cord injury?* Poster presented at the Nordic Network of Disability Research (NNDR 10th research conference) in Nyborg, Denmark
- 2008 *Negotiating family routines.* Paper presented at the 8th European Congress of Occupational Therapy in Hamburg
- 2007 *Theoretical perspectives on childhood participation.* Paper presented at the Nordic Network of Disability Research (NNDR 9th research conference) in Gothenburg.
- 2007 *Icelandic students with physical disabilities. Assistance provided in regular schools.* Poster presented at the Nordic Conference on Occupational Therapy, Stockholm.
- 2007 *Theoretical perspectives on school participation.* Paper presented at the Nordic Conference on Occupational Therapy, Stockholm.
- 2006 *School Participation: Icelandic students with physical impairments.* Paper presented at the Disability Studies conference in Lancaster, England

- 2006 *School Participation: Students with physical impairments*. Paper presented at the the World Federation of Occupational Therapy conference in Sidney, Australia.
- 2006 *Assistance to students with physical impairments in general education settings: Alternative support strategies provided by occupational therapists*. Poster at the World Federation of Occupational Therapy conference in Sidney, Australia.
- 2005 *School Participation: Students with physical impairments*. Paper presented at the Nordic Network of Disability Research (NNDR 8 research conference) in Oslo, Norway.

Visiting professor

- November 2015 Toronto University and the University of Alberta, Canada.
- Feb and March 2013 Nordic School of Public Health, Sweden.
- Feb 2013 Linköping University, Sweden.
- April – May 2007 Karolinska Institutet, Sweden.
- Jan – May 2004 Boston University, United States.

Elected or appointed membership in a large number of professional boards and organizations (selected)

- 2013 – 2015 Scientific Committee, Faculty of Social and Human Sciences, University of Iceland.
- 2009 – 2013 Evaluation board of faculty credentials (vice chair), University of Akureyri.
- 2005 – 2009 Committee on accessibility (chair), University of Akureyri.
- 2005 – 2010 Graduate program faculty board (vice chair), School of Health Sciences, University of Akureyri.
- 2009 – 2012 Development of a diploma program in Universal design at the Nordic School of Public Health, Sweden, and a Nordic Charter of Universal Design.
- 2007-2013 Icelandic delegate in the *Nordic Network for Disability Research (NNDR)* board (Secretary 2007-2011).
- 1997 – 2013 Icelandic national editor of the *Scandinavian Journal of Occupational Therapy*.
- From 2016 Icelandic national editor of the *Nordic Welfare Research*.