



Socialstyrelsen

Litteraturliste til temaet
Søskende til børn og
unge med
funktionsnedsættelse

august 2020

Viden til gavn

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Baggrund for søgning

År for søgning

Maj/juni 2016 (Søskende til børn med erhvervet hjerneskade + opdatering i 2017 (emnet udvidet til: Søskende til børn og unge med handicap generelt)).

Tidsafgrænsning

For den første søgning: 2011-2016, tidsafgrænsning for opdatering: 2007-2017.

Geografisk afgrænsning

Dansk, nordisk, internationalt

Den samlede litteraturliste

Belling, M.H. et al (2008). Risk and Protective Influences in the Lives of Siblings of Youth with Spina Bifida. *Health and Social Work*, 33 (3): 199-209.

Brody, G. H. (1998). Sibling relationship quality: Its causes and consequences. *Annual review of psychology*, Vol. 49(1): 1-24.

Buhrmester, D. & Furman, W. (1990). Perceptions of sibling relationships during middle childhood and adolescence. *Child development*, Vol. 61(5): 1387-1398.

Burke, P. (2010). Brothers and sisters of Disabled Children: The Experience of Disability by Association. *British Journal of Social Work*, Vol. 40 (6): 1681-1699.

Carr, J. (1988). Six Weeks to twenty one years old: A longitudinal study of children with Downs syndrome and their families. *Child Psychology & Psychiatry & Allied Disciplines*, Vol. 29(4): 407-431.

Carr, J. (2005). Families of 30-35-Year Olds with Down's Syndrome. *Journal of Applied Research in Intellectual Disabilities*, Vol. 18(1): 75-84.

Constantino, J. N. et al. (2006). Autistic social impairment in the siblings of children with pervasive developmental disorders. *The American Journal of Psychiatry*, Vol. 163(2): 294-296.

Cuskelly, M. & Gunn, P. (2003). Sibling relationships of children with Down syndrome: Perspectives of mothers, fathers, and siblings. *American Journal on Mental Retardation*, Vol. 108(4): 234-244.

Dellve, L. (2004). *Syskonprojekt inom forskningsprojektet: Familjen runt barn med funktionshinder. Betydelsen av skyddande faktorer och intervention för familjens livskvalitet*. Göteborg: Sahlgrenska Universitetssjukhuset.

Fisman, S., et al. (2000). A longitudinal study of children with chronic disabilities. *Canadian Journal of Psychiatry*, Vol. 45(4): 399-410.

Fjelseth, K. P. & Owren, S. K. (2016). *Emotional communication in support groups: An explorative study of youth and therapist assessments of communication in support groups for siblings of children with chronic illness or disability*. Master thesis, University of Oslo.

- Giallo, R. et al. (2012). Siblings voices: The self-reported mental health of siblings of children with a disability. *Clinical Psychologist*, Vol. 16(1): 36-43.
- Giallo, R., & Gavidia-Payne, S. (2006). Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research*, Vol. 50(12): 937-948.
- Giallo, Rebecca & Gavidia-Payne, Susana (2008). Evaluation of a family-based intervention for siblings of children with a disability or chronic illness. *Australian E-Journal For The Advancement Of Mental Health*, Vol. 7 (2): 1-13.
- Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders*, Vol. 23(1): 147–163.
- Goodman, R. (1997). The Strengths and Difficulties Questionnaire: a research note. *Child Psychology & Psychiatry & Allied Disciplines*. Vol. 38(5):581-586.
- Granat, T. et al. (2006). *Att ge syskon utrymme: Om utveckling av hälso-främjande stöd till syskon i familjer som har barn med funktionshinder*. Uppsala län: Barn- och ungdomshabiliteringen.
- Granat, T. et al. (2008). *Ökad kunskap och förändrade relationer: Utbildning för syskon till barn med olika funktionshinder. Slutrapport från projektet "Att ge syskon utrymme"*. Uppsala län: Barn- och ungdomshabiliteringen.
- Granat, T. et al. (2012). Group intervention for siblings with disabilities: A pilot study in a clinical setting. *Disability and Rehabilitation*. Vol. 34(1):69-75.
- Greenberg, J. S. et al. (1999). Siblings of adults with mental illness or mental retardation: Current involvement and expectation of future caregiving. *Psychiatric Services*, Vol. 50(9), 1214–1219.
- Habilitering & Hälsa (2013). *Syskonkärlek eller i skuggan av ett syskon: Ett idéhäfte om grupper för små syskon med parallell föräldragrupp*. Stockholms läns landsting.
- Hales, K. (2015). *Exploring the Impact of Childhood Chronic Health Conditions on Siblings: A Systematic Review and Qualitative Study*. Thesis. University of Queensland.
- Hames, A. (1998). Do the younger siblings of learning disabled children see them as similar or different? *Child: Care, Health and Development*, Vol. 24(2): 157-168.
- Hartling, L. et al. (2010). A systematic review of interventions to support siblings of children with chronic illness or disability. *Journal of Pediatrics and Child Health*, Vol. 50(10): E26-E38.
- Hastings, R. P. (2003a). Behavioral adjustment of siblings of children with autism engaged in applied behavior analysis early intervention programs: The moderating role of social support. *Journal of Autism and Developmental Disorders*, Vol. 33(2): 141–150.
- Haugland, B. S. M. (2006). Barn som omsorgsgivere: Adaptiv versus destruktiv parentifisering. *Tidsskrift for Norsk Psykologforening*, Vol. 43(3): 211-220.
- Haukeland, Y.B. et al. (2015). Emotional Experiences Among Siblings of Children With Rare Disorders. *Journal of Pediatric Psychology*. Vol. 40(7): 712–720.
- Hodapp, R.M. & Urbano, R.C (2007). Adult siblings of individuals with Down syndrome versus with autism: findings from a large-scale US survey. *Journal of Intellectual Disability Research*, Vol. 51(12): 1081-1029.
- Jansbøl, Kåre et al. (2015). *Kortlægning af evidensbaserede programmer og lovende indsatser i forhold til forældre og søskende til børn med handicap*. Kbh: KORA.

- Kate Strohm (2008). Too important to ignore: Siblings of children with special needs. *Australian e-journal for the Advancement of Mental Health*, Vol. 7(2): 1-6.
- Lobato, D.J. & Kao, B.T. (2002). Integrated Sibling-Parent Group Intervention to improve Sibling Knowledge and Adjustment to Chronic Illness and Disability. *Journal of Pediatric Psychology*, Vol. 27(8): 711-716.
- Lobato, D.J. & Kao B.T. (2005). Brief report: Family-based group intervention for young siblings of children with chronic illness and developmental disability. *Journal of Pediatric Psychology*, Vol. 30(8): 678-682.
- McCubbin, H.I. & Patterson, J.M. (1983). The family stress process: The double ABCX model of family adjustment and adaptation. I: McCubbin H.I. et al. (Red.), *Social stress and the family: Advances and developments in family stress theory and research* (s. 7-37). New York: Haworth.
- Metcalfe, A. et al. (2008). Family communication between children and their parents about inherited genetic conditions: A meta-synthesis of the research. *European Journal of Human Genetics*, Vol. 16(10): 1193–1200.
- Meyer, K. A. et al. (2011). Factors influencing adjustment in siblings of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, Vol. 5(4): 1413–1420.
- Moshier, M.S. et al. (2012). Siblings of individuals with Smith–Magenis syndrome: an investigation of the correlates of positive and negative behavioural traits. *Journal of Intellectual Disability Research*, Vol.56(10): 996–1007.
- Nordgren, I. et al. (2006). *Att ge syskon utrymme: Manual för syskonprogrammet*. Uppsala: Habilitering och hjälpmedel, Landstinget i Uppsala Län.
- NTNU Samfunnsforskning (2012). *Som alle andre? Søsknen til barn og unge med funksjonsnedsettelser*. Trondheim: NTNU Samfunnsforskning, Mangfold og inkludering.
- Osborne, L. A., & Reed, P. (2009). The relationship between parenting stress and behavior problems of children with autistic spectrum disorders. *Exceptional Children*, Vol. 76(1): 54–73.
- Renlund, Christina (2009). *Litet syskon: Om att vara liten och ha en syster eller bror med sjukdom eller funktionsnedsättning*. Stockholm: Gothia.
- Roberts, R.M. et al. (2015). A controlled trial of the SibworkS group program for siblings of children with special needs. *Research in Developmental Disability*, Vol. 43-44(Aug-Sep): 21-31.
- Roberts, R.M. et al. (2016). Support group programme for siblings of children with special needs: Predictors of improved emotional and behavioural functioning. *Disability and Rehabilitation*, Vol.38(21): 2063-2072.
- Rodrigue, J. R. (1993). Perceived competence and behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, Vol. 23(4): 665–674
- Rossiter, L. & Sharpe, D. (2001). The Siblings of Individuals with Mental Retardation: A qualitative Integration of the literature. *Journal of Child and Family Studies*, Vol. 10(1): 65-84.
- Seltzer, M. M. et al. (2005). Life course studies of siblings of individuals with developmental disabilities. *Mental Retardation*, Vol. 43(5): 354–359.
- Skotko, B.G. & Levine, S.P. (2006). What the Other Children are Thinking: Brothers and Sisters of Persons With Down Syndrome. *American Journal of Medical Genetics Part C-Seminars in Medical Genetics*, 142C(3): 180-186.
- Socialstyrelsen (2016, 24. november). *Erfaringer med søskendegrupper fra Københavns Kommune*. Tilgængelig fra: <https://socialstyrelsen.dk/tvaergaende-områder/born-med->

funktionsnedsættelser/inspirationsmateriale-en-hel-familie/inspirationsmateriale-en-hel-familie-1/tidlige-og-forebyggende-indsatster/soskendegrupper/erfaringer-fra-kobenhavns-kommune [Lokaliseret 08-06-2017].

Stiftelsen Allmänna Barnhuset (2009). *Jag finns också! Om att vara syskon till en bror eller syster med svår sjukdom eller funktionsnedsättning*. Stockholm: Stiftelsen allmänna barnhuset.

Strohm K. (2008). Too important to ignore: Siblings of children with special needs. *Australian e-Journal for the Advancement of Mental Health*, Vol. 7(2): 1–6.

Strohm, K. & Nesa, M. (2010). *SibworkS facilitator manual: Groups for siblings of children with special needs* (2. udgave). Siblings Australia Inc.

Tomeny, T. S. et al. (2014). Birth order rank as a moderator of the relation between behavior problems among children with an autism spectrum disorder and their siblings. *Autism*, Vol. 18(2): 199-202.

Tudor, Megan E. & Lerner, Mathew D. (2014). Intervention and support for siblings of youth with developmental disabilities: A systematic review. *Clinical Child and Family Psychology Review*, Vol. 18(1): 1-23.

Vatne, T. M. & Zahl, E. (2017): Emotional communication in support groups for siblings of children with disabilities. *Patient Education and Counseling*, Vol. 100(11): 2106-2108.

Vatne, T.M. et al (2014). "She Came out of mum's Tummy the Wrong way" (Mis) Conceptions Among Siblings of Children with Rare Disorders. *Journal of Genetic Counseling*, Vol. 24(2): 247–258.

Vermaes, I. P et al. (2012). Psychological functioning of siblings in families of children with chronic health conditions: A meta-analytics. *Journal of Pediatric Psychology*, Vol. 37(2): 166-184.

Verte, S. et al. (2003). Behavioral problems, social competence, and self-concept in siblings of children with autism. *Child: Care, Health and Development*, Vol. 29(3): 193–205.

Williams, P.D. (1997). Siblings and pediatric chronic illness: A review of the literature. *International Journal of Nursing Studies*, Vol. 34(4): 312-323.

Wolf, L., et al. (1998). Effect of Sibling Perception of Differential Treatment in Sibling Dyads With One Disabled Child. *Journal of the American Academy of Child & Adolescent Psychiatry*, Vol. 37(12): 1317-25.

Zahl, E. (2015). *Fremstår støttegrupper støttende? Samtale om emosjonelle tema i støttegrupper med friske søskener til barn med sjeldne diagnoser*. Master Thesis, University of Oslo.

Aalborg Universitetshospital (2017, 23. januar). *Nyt tilbud skal støtte søskende til handicappede børn*. Tilgængelig fra: <https://aalborghu.rn.dk/Forskning/Forskning-Nyhedsliste-Aalborg/Nyhed?id=1900d876-e7c3-4a4d-8a5d-998b2c007902>

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Barnes, H. & Olson, D. (1985). Parent-adolescent communication and the circumplex model. *Child Development*, Vol. 56(2): 438-447.

Cuskelly, M. & Gunn, P. (2003). Sibling relationships of children with Down syndrome: Perspectives of mothers, fathers, and siblings. *American Journal of Mental Retardation*, Vol. 108(4): 234-44.

- Greenberg, J.S. et al. (1999). Siblings of adults with mental illness or mental retardation: Current involvement and expectation of future caregiving. *Psychiatric Services*, Vol. 50(9): 1214–1219.
- Haugland, B.S.M. (2006). Barn som omsorgsgivere: Adaptiv versus destruktiv parentifisering. *Tidsskrift for Norsk Psykologforening*, Vol. 43(3): 211.
- Haukeland, Y. B. et al. (2020). Evaluation of “SIBS”: An intervention for siblings and parents of children with chronic disorders. *Journal of Child and Family Studies*, Vol. 29(8): 2201-2217.
- Haukeland, Y., psykolog, Frambu. (2020). *Mailkorrespondance*. Frambu. Siggerud. August 2020.
- Incledon, E. et al. (2015). A review of factors associated with mental health in siblings of children with chronic illness. *Journal of Child Health Care*, Vol. 19(2): 182-194.
- Jackson, S. et al. (1998). Adolescents' perceptions of communication with parents relative to specific aspects of relationships with parents and personal development. *Journal of Adolescence*, Vol. 21(3): 305-322.
- Lobato, D. J. & Kao, B. T. (2002). Integrated sibling-parent group intervention to improve sibling knowledge and adjustment to chronic illness and disability. *Journal of Pediatric Psychology*, Vol. 27(8): 711-716.
- Long, K. A. et al. (2013). Perceptions of emotion expression and sibling-parent emotion communication in Latino and non-Latino white siblings of children with intellectual disabilities. *Journal of Pediatric Psychology*, Vol. 38(5): 551-562.
- Mendlowitz, S. L. et al. (1999). Cognitive-behavioral group treatments in childhood anxiety disorders: The role of parental involvement. *Journal of the American Adademy of Child & Adolescent Psychiatry*, Vol. 38(10): 1223-1229.
- Mulroy, S. et al. (2008). The impact of having a sibling with an intellectual disability: Parental perspectives in two disorders. *Journal of Intellectual Disability Research*, Vol. 52(3): 216-229.
- Murphy, L.K. et al. (2017). Topical review: Integrating findings on direct observation of family communication in studies comparing pediatric chronic illness and typically developing samples. *Journal of Pediatric Psychology*, Vol. 42(1): 85-94.
- O'Brien, I. et al. (2009). Impact of childhood chronic illnesses on siblings: a literature review. *British Journal of nursing*, Vol. 18(22): 1358-1365.
- Scholten, L. et al. (2013). Efficacy of psychosocial group intervention for children with chronic illness and their parents. *Pediatrics*, Vol. 131(4): e1196-e1203.
- Taylor, V. et al. (2001). Well sibling psychological adjustment to chronic physical disorder in a sibling: how important is maternal awareness of their illness attitudes and perceptions? *The Journal of Child Psychology and Psychiatry*, Vol. 42(7): 953-962.
- Tudor, M. & Lerner, M. (2015). Intervention and support for siblings of youth with developmental disabilities: A systematic review. *Clinical Child and Family Psychology Review*, Vol. 18(1): 1-23.
- Vatne, T. (2018). *SIBS-manual*. Siggerud: Frambu.
- Vatne, T. M. (2014). Et annerledes søskenliv? I: Talseth, Randi (ansv. Redaktør) et al., *Barn i Norge 2014: Når barn er pårørende* (s. 8-21). Oslo: Voksne for Barn.
- Vatne, T. M. et al. (2019). The development of a joint parent-child intervention for siblings of children with chronic disorders. *Fokus på Familien*, Vol. 47(1): 20-35.

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- Vatne, T. ph.d., Frambu (2019). *Mailkorrespondance*. Frambu. Siggerud. 2019.
- Vatne, T. ph.d., Frambu (2020). *Mailkorrespondance*. Frambu. Siggerud. 2020.
- Vermaes, I.P. et al. (2012). Psychological functioning of siblings in families of children with chronic health conditions: A meta-analysis. *Journal of Pediatric Psychology*, Vol. 37(2): 166-184.



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