

Research Summary and Seminal Peer-Reviewed Research-based Journal Articles on Parents with ID and Their Children.

Compiled by Dr. Maurice Feldman

Compiled by Dr. Maurice Feldman, this includes a research summary and list of seminal peer-reviewed journal articles on parents with learning difficulties and their children. Dr. Feldman notes the list of 32 articles is by no means exhaustive and does not include influential books and book chapters. Nonetheless, looking at the list of articles, several key themes emerge, as well as areas where more research is needed.

1. Teaching Parenting Skills

What we know: Many people still assume that parents with learning difficulties cannot benefit from parent education. Research since the 1980s show support for an effective parent training approach to teaching child-care skills and parent-child interaction skills to parents with learning difficulties, including those with intellectual disabilities. Effective instruction includes breaking down the skill into small steps, using simple verbal instructions and modeling, allowing the parent to practice with the child in the setting in which they need to use the skill, and providing positive and correct feedback. Group instruction in artificial (e.g., classroom) settings is not as effective as in-home parent training.

What we need to find out: More research is needed on strategies that encourage parents to use the skills whenever and wherever they are needed (generalization). We need to find out more about the long-term benefits of early parent education for the family and children, and how to teach parents to promote the wellbeing of older children. Interventions need to move past just training parenting skills and should include teaching parents how to develop and manage a social support network, promote self-advocacy and protection skills and resolve any mental health issues.

2. Context Matters

What we know: For years (and still today), many people assume that any difficulties seen in parents with learning difficulties are due to their cognitive impairment. Recent research with large numbers of research participants now shows that other factors need to be considered when predicting the abilities of parents with learning difficulties, child protection decisions and child outcomes. One overriding factor is that many of the concerns noted in families led by parents with learning difficulties is more a function of poverty than their cognitive impairments. Parents with learning difficulties are more likely to have poverty-related physical and mental health issues, be highly stressed and socially isolated, all of which may affect their ability to parent. The parents own upbringing, exposure to traumatic events and ongoing stigmatization and discrimination may also make it more difficult to parent and increase the chances of them having their children taken away.

What we need to find out: Much of the research has focused on what factors predict failure. Researchers should be looking at what factors predict success and resilience in the face of difficult situations that many families led by parents with learning difficulties encounter on a daily basis.

3. Child Protection Services Need to Step Up

What we know: Research in several developed countries, including the U.S., UK and Australia, show systemic discrimination in child protection and the court systems against parents with learning difficulties. The characteristics, experience and training of child protection workers, psychologists, lawyers and judges play a role in predicting whether parents with learning difficulties get to keep their children. The current parenting capacity assessment process appears to be flawed and biased. There is a great need for a national strategy, such as Healthy Start in Australia, to help support and train professionals involved working with these families.

What we need to find out: Do worker and professional attitudes, perceptions, practice and decisions change with more training? Will a systematic, large-scale effort to support and train professionals working with families headed by parents with learning difficulties make a meaningful difference in retention of families and the wellbeing of the parents and children?

Seminal Peer-Reviewed Research-based Journal Articles on Parents with ID and Their Children

Teaching Parenting Skills

1. Bakken, J., Miltenberger, R. G., & Schauss, S. (1993). Teaching parents with mental retardation: Knowledge vs. skills. *American Journal of Mental Retardation*, 97, 405-417.
2. Booth, T., & Booth, W. (2003). Self-advocacy and supported learning for mothers with learning difficulties. *Journal of Learning Disabilities*, 7(2), 165-193.
3. Feldman, M.A. (1994). Parenting education for parents with intellectual disabilities: A review of outcome studies. *Research in Developmental Disabilities*, 15, 299-332.
4. Feldman, M.A. (1998). Preventing child neglect: Child-care training for parents with intellectual disabilities. *Infants & Young Children*, 11, 1-11.
5. Feldman, M.A. (2004). Self-directed learning of child-care skills by parents with intellectual disabilities. *Infants & Young Children*, 17, 17-31.
6. Feldman, M.A., Sparks, B., & Case, L. (1993). Effectiveness of home-based early intervention on the language development of children of parents with mental retardation. *Research in Developmental Disabilities*, 14, 387-408.
7. Llewellyn, G., McConnell, D., Honey, A., Mayes, R., & Russo, D. (2003). Promoting health and home safety for children of parents with intellectual disability: A randomized controlled trial. *Research in Developmental Disabilities*, 24(6), 405-431.

8. Wade, C., Llewellyn, G., & Matthews, J. (2008). Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disability*, 21, 351-366.

Context Matters

9. Aunos, M., Feldman, M. & Goupil, G. (2008). Mothering with intellectual disabilities: Relationships between social support, health and wellbeing, parenting and child behaviour outcomes. *Journal of Applied Research in Intellectual Disabilities*, 21, 320-330.
10. Aunos, M., Goupil, G., & Feldman, M.A. (2003). Mothers with an intellectual disability who do and not have custody of their children. *Journal on Developmental Disabilities*, 10, 65-79.
11. Booth, T., & Booth, W. (2000). Against the odds: Growing up with parents who have learning difficulties. *Mental Retardation*, 38(1), 1-14.
12. Emerson, E., & Brigham, P. (2013). Health behaviours and mental health status of parents with intellectual disabilities: cross sectional study. *Public Health*, 127(12), 1111-1116.
13. Feldman, M.A., McConnell, D., Aunos, M. (2012). Parental cognitive impairment, mental health and child outcomes in a child protection population. *Journal of Mental Health Research in Intellectual Disabilities*, 5, 66-90.
<http://dx.doi.org/10.1080/19315864.2011.587632>
14. Feldman, M. A., Varghese, J., Ramsay, J., & Rajska, D. (2002). Relationship between social support, stress and mother-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disability*, 15, 314-323.
15. Feldman, M.A., & Walton-Allen, N. (1997). Effects of maternal mental retardation and poverty on intellectual, academic, and behavioral status of school-age children. *American Journal on Mental Retardation*, 101, 352-364.
16. Granqvist, P., Forslund, T., Fransson, L., Springer, L., & Lindberg, L. (2014) Mothers with intellectual disability, their experiences of maltreatment, and their children's attachment representations: a small-group matched comparison study. *Attachment & Human Development*, 16, 417-436. DOI: 10.1080/14616734.2014.926946.
17. Hindmarsh, G., Llewellyn, G., & Emerson, E. (2017). The social-emotional well-being of children of mothers with intellectual impairment: a population-based analysis. *Journal of Applied Research in Intellectual Disabilities*, 30, 469–481. DOI: 10.1111/jar.12306
18. McConnell, D., Llewellyn, G., Mayes, R., Russo, D., & Honey, A. (2003). Developmental profiles of children born to mothers with intellectual disability. *Journal of Intellectual & Developmental Disability*, 28(2), 122-134.
19. McConnell, D., Mayes, R., & Llewellyn, G. (2008). Women with intellectual disability at risk of adverse pregnancy and birth outcomes. *Journal of Intellectual Disability Research*, 52, 529-535.

20. McGaw, Scully, T., & Pritchard, C. (2010). Predicting the unpredictable? Identifying high-risk versus low-risk parents with intellectual disabilities. *Child Abuse & Neglect*, *34*, 699-710.
21. Parish, S. L., Mitra, M., Son, E., Bonardi, A., & Swoboda, P. (2014). A national profile of deliveries by women with intellectual disabilities in the US: Maternal characteristics and pregnancy outcomes. In *Journal of Applied Research in Intellectual Disabilities*, *27*, 323-323.
22. Powell, R.M., Parish, S.L., & Akobirshoev, I. (2017). The health and economic well-being of US mothers with intellectual impairments. *Journal of Applied Research in Intellectual Disabilities*, *30*, 456-468. DOI: 10.1111/jar.12308
23. Wade, C., Llewellyn, G., & Matthews, J. (2011). Modeling contextual influences on parents with intellectual disability and their children. *American Journal on Intellectual and Developmental Disabilities*, *116*, 419-437.

Child Protection Services Need to Step Up

24. Azar, S. T., Lauretti, A. F., & Loding, B. V. (1998). The evaluation of parental fitness in termination of parental rights cases: A functional-contextual perspective. *Clinical Child and Family Psychology Review*, *1*(2), 77-100.
25. Budd, K. S. (2005). Assessing parenting capacity in a child welfare context. *Children and Youth Services Review*, *27*(4), 429-444.
26. Budd, K. S., & Holdsworth, M. J. (1996). Issues in clinical assessment of minimal parenting competence. *Journal of clinical child psychology*, *25*(1), 2-14.
27. LaLiberte, T., Piescher, K., Mickelson, N., & Lee, M.H. (2017). Child protection services and parents with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, *30*, 521-532. DOI: 10.1111/jar.12323
28. McConnell, D. (2008). Parents labelled with intellectual disabilities: Position of the IASSID SIRG on parents and parenting with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *21*, 296-307.
29. McConnell, D., & Llewellyn, G. (2000). Disability and discrimination in statutory child protection proceedings. *Disability & Society*, *15*(6), 883-895.
30. McConnell, D., Llewellyn, G., & Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse & Neglect*, *27*, 235-251.
31. McConnell, D., Matthews, J., Llewellyn, G., Mildon, R., & Hindmarsh, G. (2008). "Healthy Start". A national strategy for parents with intellectual disabilities and their children. *Journal of Policy and Practice Intellectual Disabilities*, *5*, 194-202
32. Sigurjonsdottir, H.B., & Rice, J. G. (2017). 'Framed': Terminating the parenting rights of parents with intellectual disability in Iceland. *Journal of Applied Research in Intellectual Disabilities*, *30*, 543-552. DOI: 10.1111/jar.12301