Symposium: Family Needs

Expected unmet needs of families of individuals with ID in Switzerland

M.T. Wicki (mosoka.wicki@th.ch) & J. Adler
Research and Development, University of Applied Sciences of Special Needs Education, Zürich, Switzerland

Aim: Many families of individuals with ID provide lifelong family-based care. Growing old, future planning is particularly important to these families. Research indicates that many families have not made concrete plans. The aim is to analyze expert’s expected unmet needs of ageing care-giving parents in Switzerland for the purpose of starting future planning. Method: Structured interviews with 30 service providers from agencies helping adults with ID and their families. Results: Future planning is a major issue for adults with ID living at home. Experts suspect increasing emergency placements but do not exactly know which unmet needs ageing care-giving parents have. Conclusion: The results indicate a strong need for improved investigation of unmet service needs, case management and staff and family training for future planning. A possible adaptation of the future planning curriculum to the Swiss context might be helpful.

Are separate policies for carers and for adults with ID serving all family members?

C. Fyffe (mdfysf@grimwood.net.au), G. Pierce, B. Isley & P. Paul
Policy, Carers Victoria, Melbourne, Australia

Aim: To explore whether and how current policy directions and services can be improved for family carers and adults with ID. The immediate impetus for this work is the growing evidence of shortfalls in Australia in the amount, nature and funding of service responses for carers and people with disabilities. Method: A conceptual discussion of the key issues derived from a thematic review of the literature about family carers and people with disabilities. Results: The paper asserts that the creation of two discrete groups, carers and adults with disabilities, with separate discourses and little reference to each other, has occurred despite the interrelationships in daily life and over the life course between many individuals with ID and their family and friends. Final thoughts, unrealistically, as part of gaining recognition, the separation of the two groups has meant that if the viewpoints of one group are promoted, the other group’s view is perceived to be automatically disadvantaged or at least invisible. The aim of this study is to bring together the two perspectives, so as to encourage a more collaborative approach. The paper concludes with some suggestions for future studies. Conclusion: This paper is an initial review of the issues and makes it easier to obtain tailor-made support.

Migrant families with disabled children

A.M. Kittelsaa (anja.kittelsaa@ycmdk.no) & B. Berg
Centre for Diversity and Inclusion, NTNU Social Research, Trondheim, Norway

Aim: One aim was to gather more knowledge about how minority ethnic families in Norwegian society understand disability and how they cope with their daily situation with regard to information, practical and emotional stress and the stresses with the service system. Another aim was to study how the service system responded to these families. Method: Qualitative interviews with 50 families from 8 municipalities were performed together with observations of their children in kindergartens and schools and qualitative interviews with teachers and other professionals. Results: The study is not completed but results so far indicate that the situation of migrant families with disabled children is both similar to and different from families in the majority population. Special challenges include: problems with language and communication, lack of information about disability and the service system, being met with prejudice or discrimination and having practical problems defined as culture. Conclusion: Further analysis is required but, so far, we see great need for improving the service system so that professionals are able to meet the needs of these families. Improvements have to be made with regard to: written information in the preferred language of the families, systematic use of interpreters, better co-ordination of services and greater awareness among professionals about how these families both are similar to and differ from other families.

Symposium: Interaction and Education in Families

Dyadic interactions between Chinese mothers and their children with autism

P. Wang (pawang@qc.cuny.edu)
Educational and Community Programs, Queens College, City University of New York, Flushing, USA

Aim: To examine the interactions between Chinese mothers and their children with autism. Specifically, this study is guided by three research questions: (a) how do Chinese parents interact with their children with autism? (b) how do Chinese parents interact with their typically developing children and (c) are there differences between these interaction styles? Method: Forty-one mothers and their young children participated in this study. A 30-minute videotaped interaction was collected for each parent-child dyad in a clinic setting with a set of toys provided by the researcher. Parents’ and children’s behaviours were coded separately using the Dyadic Parent-Child Interaction Coding System. Results: Analysis of this data set is underway at this time. Group comparisons will be presented regarding parents’ and children’s behaviour. Conclusion: Implications of findings from the current study will be discussed.

Interaction and education for parents and their child with mild ID

A. Boom, J. Luijten & L. Joukes
Acertanueva, Zonnehuizen, Zutphn, Netherlands

Aim: Many parents and children have an insufficient understanding of the consequences of ID in their daily life. This can lead to feelings of incompetence. In conjoint psycho-educational sessions, parents and children learn to talk to each other about ID. Together they develop a shared concept of the child’s specific disabilities and the vulnerabilities they create, and increase coping strategies for daily living. Method: In structured sessions involving parents, their children and parent and child therapists, information is exchanged about the child’s functioning in the treatment group, at school and at home. An interactive method with visual tools is developed to help the child understand his or her own functioning and the problems s/he encounters. The same goes for parents. Results: The family develops a shared concept of the disability and a common language with which to talk about ID and its implications for daily living. Awareness and self-understanding become integral to the family narrative about ID, helping parents and the child alike to integrate and cope with other life-events in the future. Increased understanding of the disability and its impact makes it easier to obtain tailor-made support. Conclusion: This new method of individualized psycho-education for parents and their child with ID increases resilience and restores a sense of self-worth and competence while diminishing feelings of guilt.

Parents’ role in developing early mathematical concepts with their children with Down syndrome

T.M. Shellahshear (theresa.shellahshear@acu.edu.au) & R. Faragher
School of Education, Australian Catholic University, Canberra Campus, Canberra, Australia

Aim: To identify the nature of the role parents undertake in supporting the development of early mathematical concepts and to identify possible factors that may impact on the variation in the nature of this role among parents and for each individual parent over time. The focus for this research is the parent-child interaction in the home environment. This paper announces the study and will provide initial findings. Method: Multiple case studies will be undertaken with two groups of parents based in the south-eastern region of Australia, one based in Sydney and the other in Canberra. Data will be collected through surveys/questionnaires, participant group sessions, parent workshop, semi-structured one-on-one interviews and participant journals. Results: Literature in this field would suggest that parents may identify their role as teaching early concepts such as counting and recognizing numerals while ignoring the many opportunities within play activities and games. This paper will present findings to date and will raise issues for further clarification. Conclusion: Parents are eager to be involved in this research project and are willing to discuss and report on their interactions. The findings will identify the parents’ current roles and how this may be enhanced through proactive involvement in relevant workshops and through ongoing discussion.

© 2010 Blackwell Publishing Ltd, 23, 458–466