Parents with Intellectual Disabilities: Past, Present and Futures

Book Reviews

‘Parents With Intellectual Disabilities: Past, Present and Futures is thought provoking worth reading for those working with families with intellectual disabilities’.
—PsycCRITIQUES, February 2011

‘Parents with Intellectual Disabilities: Past, Present and Futures is essential reading for anyone interested in the lives of parents with intellectual disabilities, and it is recommended reading for everyone in the broader field of developmental disabilities. It provides a synthesis of current research and practice, along with clear picture of the challenges ahead. Its contents are both comprehensive and compassionate. The international authorship provides an important global perspective.’
—Dr Dick Sobsey, University of Alberta, Canada

‘This is a unique exploration – from an international and multi-disciplinary perspective – of the lives and experiences of parents with intellectual disabilities, their children and the services that both enable and disable them in their parenting. Its combination of scholarly research and "insider" accounts makes it essential reading for researchers and practitioners around the world.’
—Professor Dorothy Atkinson, The Open University, UK

‘Parents with Intellectual Disabilities is a thoughtful and comprehensive collection by an international team that blazes new trails for inclusion and equality for adults with intellectual disabilities. By asserting that forming a family and parenting are pathways both to social value and personal fulfilment, it challenges us to question our own values and assumptions about adults with intellectual disabilities as parents. An essential text for a full understanding of disability in the world of today and tomorrow.’
—Ivan Brown, Ph.D., Centre of Excellence for Child Welfare, University of Toronto, Canada

‘A rare achievement, this book integrates clear-eyed analyses of the social circumstances faced by people with intellectual disability who parent or long to parent, strong research on critical aspects of this neglected human rights issue, and creative guidelines for improved practice. We may believe that Eugenics is over, long discredited. But what is its legacy in the lives of people with intellectual disability in relationships, pregnancy, decisions about parenting, and actual parenting? What do their children say? And how can we overcome the remaining barriers of history? ‘This must-read book explores the experiences of mothers and fathers with intellectual disability and their children, contextualized within their communities. It investigates the systems and services that do or do not support successful parenting, and explores modern complexities of gender, terminology, citizenship, public policy, and human rights.’
—Ruth Luckasson, Professor of Education, University of New Mexico, US
Parents with Intellectual Disabilities: Past, Present and Futures

Book Reviews

Jan Walmsley

For anyone concerned with parents with intellectual disabilities, this will be a very valuable resource. It is an international collection of chapters and provides (almost) comprehensive coverage of research and practice in relation to the topic. The book’s focus is on the experiences of parents with intellectual disabilities and how they can be supported to be successful in the role. One of its principal virtues is that many chapters feature the ‘voice’, both of parents and of their children. Each chapter includes Principles for Practice, which translates the research messages into practical implications. It is rooted in a human rights perspective, drawing on the 2006 United Nations Convention on Human Rights, which calls on states to eliminate discrimination and to provide disabled people with the support they need to rear children (p. xiv). The book builds on the pioneering work of Tim and Wendy Booth to whom the volume is dedicated.

Parents with intellectual disabilities are a disadvantaged group. The book notes that they are drawn from three principal groups in high-income countries where most research has been conducted:

- People once institutionalised who now live in the community
- People who have continuously received services for people with intellectual disabilities
- The ‘hidden majority’, people who may have been labelled at school as having learning difficulties but who live with few supports until they come to the attention of services when they have children and whose cognitive abilities are then questioned. (p.244)

There is here a circular argument – many parents who struggle with bringing up children will tend to be described as having cognitive impairment, and this perceived impairment will make it more probable that they will be subject to professional intervention and – frequently – losing custody of their children. Because of problems of definition, numbers are hard to come by, but the book’s editors present data which indicate that around 50% of such parents lose custody of their children (p.249–50); though, this varies in different countries. When there is a label of intellectual disabilities two factors make it more likely that children will be removed, first that intellectual disability is of itself evidence of parental incapacity and secondly that any shortcomings cannot be overcome.
The book takes a resolutely positive view of the capability of most (if not all) parents with intellectual disabilities to parent if given support. Several chapters note that most parents would struggle if lacking money, positive experience of being parented themselves, supportive networks and sympathetic professional help. One Chapter in particular stands out the contrasting stories told by two women – Nicky whose family gave her wholehearted support in bringing up her daughter and Suzanne who lacked such support. Unsurprisingly, Nicky succeeded and Suzanne lost custody (Mirfin-Veitch Chapter 6).

The book features a range of positive interventions from around the world, which demonstrably support people’s parenting capabilities, shared decision making, parenting education, parental advocacy and readaptation centres. There is plenty here for any imaginative practitioner to draw on. There is also much that is depressing in the response of mainstream services to perceptions of risk to children, something that is exacerbated by child protection scandals such as Baby Peter, a challenge the book does not fully address save by advocating positive intervention.

There are omissions. In his Foreword, Steven J Taylor notes that no longer is the question ‘should people with intellectual disabilities have children?’ – we have moved on from that – rather it is whether they can be effective parents. Having said that he notes that in effect many people are prevented or discouraged from having children through subtle and less subtle means. It is in this area that the book is in my view lacking. There are a group of people with intellectual disabilities who have children, mostly with mild impairments and many who, until they become parents, muddle along without a label. It is important to get things right for them, certainly, and the book deals comprehensively with this. There are many people with more substantial impairments fully embedded in the service system who are discouraged or prevented from becoming parents at all. Whether they could or should be similarly supported to be parents is a question the book does not address.

Finally, this is a book very much about western research and experience. The editors acknowledge this, because of lack of research and naming of this as a problem in low and middle income countries. Less readily forgivable perhaps is the relative absence of data about the experiences of minority groups in western countries, a gap which cannot be laid at the editors’ door, but one which points to the direction for future studies. Overall, this is a comprehensive and practical book that will undoubtedly become the standard reference point in the important area of parents with intellectual disabilities.

Jan Walmsley
Jan Walmsley Associates Ltd
E-mail: Janwalmsleyassociates@googlemail.com

Parents with Intellectual Disabilities: Past, Present and Futures

Book Reviews
Geraldine Cassidy

Although it is known that there are 2.1 million disabled parents in the UK, the actual numbers of parents with intellectual disabilities (ID) are unknown, which means there is a lack of concrete information on which to base the development and planning of services to support them (Stickland 2003). Parents with ID include three groups: those who previously lived in institutions and are now living in the community, those who have always lived in the community and in receipt of ID services and the largest group, entitled the 'hidden majority' (Edgerton 2001), who had learning difficulties or identified ID at school, but have not gone on to receive support from ID services in adult life, and whose ability is questioned only when they become parents. Historically, concern that permitting those with an ID to become parents would be harmful to society resulted in the introduction of preventative measures, such as the provision of institutional care segregated by gender and the adoption of legislation to permit involuntary sterilization of women with ID in many countries. People with ID are no longer prevented from becoming parents; however, they face many barriers as they strive to be good parents with the substantial risk of their child being placed away from home.

The barriers to successful parenting include the opposition of others before and after the birth, which may include pressure to terminate the pregnancy and involvement of child welfare agencies with the persistent fear that the child may be removed. Parents with ID are more likely than any other group to have their children removed by child welfare authorities and permanently placed away from home. In their dealings with such agencies, they may face discrimination whereby their ID is accepted as prima facie evidence of parental incapacity or risk of harm to the child. After the birth, the parent with ID is more likely than other parents to experience poor mental health and may face unemployment, poverty, the lack of suitable housing and social isolation. Factors which have been found to be associated with successful parenting outcomes by parents with ID include the availability of formal and informal support, the absence of co-morbid mental illness and physical disability in the parents, having had a happy childhood and exposure to positive parenting role models. Other factors include the presence of a supportive and healthy partner, parental IQ over 60, having fewer children and children who have no significant special needs.

This is as far as I am aware of the first international publication that brings together research findings from several countries and across a number of professional disciplines. The international perspective is novel and enables the reader to learn about good practice in other countries. The contributors are all committed to the human rights of people with ID and their equal participation in society, as enshrined in the 2006 United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006), which requires countries to remove discriminatory practices against people with disabilities with regard to marriage and parenthood and to provide the necessary support with child rearing.
Part 1 of the book, entitled Family and Community Life, includes chapters on the perspectives of parents with ID and their children documenting their experiences within the wider network of family, community and the various agencies that support them. Each chapter includes a review of the literature on the topic before going on to present the authors’ qualitative research. Studies on the experiences of fathers with ID are included, a group who have been much less well represented in the literature on parenting with ID to date.

Part 11 focuses on how to support parents with ID and their children, with chapters on parent education programmes, supporting parents on informed decision making, child protection processes and the use of independent advocates to support parents in encounters with child protection services. Research evidence is presented, which shows that parents with ID can learn and apply parenting skills, providing the training is tailored to their individual needs and delivered in the place where it will be used. Practical advice is included on how to deliver support programmes from the authors’ experiences in several countries. The final chapter includes the position statement developed by the Special Interest Research Group on Parents and Parenting with Intellectual Disabilities of the International Association for the Scientific Study of Intellectual Disabilities (2008). These recommendations aim to assist parents with ID to overcome the barriers they face in caring for their children. They stress the need for long-term support, as it is acknowledged that the intensity of support required will vary as the child develops and parents’ circumstances change.

Much of the research on parent education to date relates to support given in the first few years of the child’s life. There is a lack of randomised control trials in this field that will compare outcomes of one intervention with another or with a control group where no intervention takes place. Outcome measurement must focus on all relevant outcomes, that is, development in parenting skills, improvement in parent–child interaction, social inclusion for the child and family and child development through into adolescence/early adulthood. I would recommend this book for all students, clinicians and researchers involved in supporting parents with ID and their children. It is well written and provides an excellent introduction to the topic. It should serve as a wake-up call to us all and a reminder of what can be achieved if parents with ID and their children receive the flexible and targeted support they rightly deserve.

Geraldine Cassidy  
Coventry and Warwickshire Partnership Trust, Psychiatry of Learning Disability, Birmingham, UK