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Participation

Optimising Outcomes in Childhood-Onset Neurodisability

Edited by **Christine Imms and Dido Green**

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Preface

WHAT THIS BOOK IS ABOUT

Why this Book?

Participation: Optimising Outcomes in Childhood-Onset Neurodisability comes nearly 20 years after the publication of the International Classification of Functioning, Disability and Health (ICF; World Health Organization 2001) which proved a catalyst for an altered focus in health and education, for those with lifelong impairments. We have seen a major shift in thinking from the focus of disability on the child and associated impairments to a broader understanding of the roles and opportunities that are available for meaningful participation in life irrespective of measurable impairments. This is the right time to reflect on and explore the crucial notion of participation. Participation is what people do every day – but how we support, promote, maximise or otherwise enable participation will depend entirely on how we understand what it is, and how we value who is able to take part in the multitude of life situations. Society's attitudes towards impairment, disability and participation have evolved over time, and will – and should – continue to change. However, while we aim to consign exclusion and segregation of those with impairments to the pages of history, we are not there yet.

A central goal of this book is: to gather the experiences and knowledge of participation of those with childhood onset neurodisabilty from around the world; to identify and highlight the salient features of participation from multiple perspectives and across varying cultures and contexts; and to endeavour to identify key methods for enabling positive health-promoting participation.

What is it About?

The focus of this book is *participation.* Participation is conceptualised as both attendance and involvement in life situations; by attendance, we mean having a physical or virtual presence, by involvement we mean the experience of participation while attending (Imms et al. 2017). Participation is considered distinct from the ability of an individual to be independent, to have the skills and attributes to perform activities as expected, and is distinct from the ability to make choices or be self-determined. Although competence and autonomy are key issues, and strongly related to participation outcomes, they are not the same as participation. Autonomy does contribute importantly to ensuring an individual is involved, not just present in a situation. In this book the reader is encouraged to consider how to enable individuals to attend the varied life situations that are part of their personal, familial and cultural world, and once there, to be involved – to be 'part of it'. This might include connecting emotionally, or cognitively, or in the doing, in ways that are meaningful and satisfying to those in the situation.

Who is Our Intended Audience?

We wrote this book for practitioners and researchers who work in the field of childhood-onset neurodisability; in health, community and educational settings. This is a complex field that involves engagement with individuals, and their families, whose conditions arise early in life and impact the central nervous system; including those with diagnoses such as cerebral palsy, autism, intellectual impairment and a myriad of other conditions that present in childhood. Practitioners will be working with individuals and their families, as well as those in their communities, to enable increased opportunities and better outcomes. The book takes a non-categorical approach – we are not focused on the 'diagnosis': participation is for all, across contexts irrespective of diagnostic labels. There are scenarios and vignettes that provide stories and exemplars to engage and challenge the reader. These vignettes aim to bring life to underlying concepts and contexts and provide applications for assessment and intervention.

This book may also help those with childhood onset impairments, their parents and other interested community members to develop their own ideas and methods for goal-setting and collaboration with professionals, as well as with day-to-day participation. There are a variety of 'voices' in the book – we have sought contributions from around the world – and each continent is represented to some degree. We have sought stories from children and about children, and from families and from professionals. Some of the stories are so challenging they are heartbreaking. We hope that the reader will use these to drive an agenda for fundamental change in our communities towards attendance and involvement for all. A paradigm shift is required in our thinking; participation must be placed at the forefront of our ambitions as both means and outcomes in the way we work and live.

How is the Book Structured?

The five parts of the book are sequenced to deliver and illustrate:

i) Information that aids understanding of the concept of participation;
ii) Where participation occurs and how contexts and settings influence participation;
iii) How to measure the changing levels of participation;
iv) What we know about interventions that promote participation; and
v) Considerations for future directions.

Each part of the book contains several chapters by authors known for their expertise in the field and who bring research and practice knowledge to the topic.

In addition, each part contains several vignettes. This compilation of 'stories' are contributions from authors from across the world. They were asked to give vivid expression to the participatory experiences of those with childhood-onset disability from within their own country or cultural setting. The vignettes are linked to the chapters by connecting statements within the text and by a brief introduction at the beginning of the vignette to draw your attention to key ideas in the chapter that are exemplified in the vignette. The intent of the vignettes is to provide food for thought and to support the reader's future actions. Some stories may describe experiences novel to the reader and thus bring alternative perspectives to prompt one's creativity in developing solutions to any barriers to participation. Some stories may strike a chord and make for uncomfortable reading, and these too can be used to prompt a reconsideration of *how* and *what* we do in practice.

The book can be read either sequentially – as we have considered carefully how the information builds across the parts and chapters – or each part and each chapter can be read in isolation if a particular element is of interest or concern. The aim of this book is to both challenge and motivate the reader and thereby encourage a change in our approach and attitude to childhood onset neurodisability. There is much work to be done together to realise everyone's rights, hopes and dreams.

At the end of the book we will look again at where we are, where we hope the field is going and how we may progress understanding and developments to optimise opportunities for participation.

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Christine Imms and Dido Green
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Cultural and Contextual Challenges in Resource-Poor Countries: The Case of Sub-Saharan Africa

Joseph K Gona, Karen Bunning and Charles R Newton

This chapter explores participation for children with neurodisability in sub-Saharan Africa. It focuses on disability as a socio-cultural construct, with the interplay between the person and their environment. Factors associated with traditional beliefs, poverty and scarce resources compound the challenges of participation; for not only the child, but also the caregiver. Finally, there is a review of some approaches designed to promote community participation.

INTRODUCTION

The greatest number of children with disabilities live in low- and middle-income countries, with sub-Saharan Africa contributing about 45% (Bitta et al. 2017). Culture influences the place that children with disabilities and their families occupy in society. It affects how the individual with a disability is perceived and responded to by other people. It determines the formation of attitudes and the behaviours that externalise those inner feelings and judgements. Ultimately, culture impacts on the range and types of opportunities that develop social relationships, receive an education, acquire employment and a sustainable livelihood. Made up of the values, beliefs, attitudes and behaviours shared by a group of people, culture is not static, it is dynamic, continuously changing. The same is true of living with a disability as disability is a socio-cultural construct. Bidirectional influences are present between the developing child and the changing environment, which may affect the extent to which participation is achieved.

CHALLENGES

Cultural Beliefs

In many sub-Saharan Africa countries, where there is limited understanding of childhood-onset neurodisability and inadequate coverage of health, educational and social services (Bunning et al. 2014). Traditional beliefs and actions have persisted (Bunning et al. 2017). Representations of disability have tended to be negative and typically associated with an undesirable condition (Gona et al. 2011), although variations have been reported. For example, people with physical disabilities are seen as pacifiers of evil spirits (Gona et al. 2011), while autistic spectrum disorders (ASDs) are attributed to evil spirits, witchcraft and curses (Gona et al. 2015). Some of the distaste associated with disability in sub-Saharan Africa may lie in the cultural explanations that imply breach of social conventions, such as in Botswana (Shumba and Abosi 2011), Ghana (Anthony 2011) and Kenya (Bunning et al. 2017); and external, preternatural forces, for example, in Kenya (Gona et al. 2015), Malawi (McKenzie et al. 2013) and Namibia (Souza Tedrus et al. 2013). Another explanation concerns the will of God (Stone-MacDonald and Butera 2012). These explanations may imply that disability is a punishment from a celestial being, or indeed linked to fate, which may be associated with some form of acceptance.

LINK TO VIGNETTE 20.2
'My Child is Possessed by Evil Spirits', p. 238.

Fearful images and dehumanising language associated with disability, may not only hinder acceptance of the child who has a disability, but undermine possibilities and opportunities for that child. Vignette 21.1, 'When Ben Smiled', illustrates the challenges associated with explaining and understanding disability and the influence on expectations for outcomes. Research in Kenya revealed that children with disabilities are viewed as both a burden to the community and sub-human beings, as exemplified by the lifeless ki-vi class of nouns in Swahili language used to refer to them (Gona et al. 2018).

LINK TO VIGNETTE 21.1
'When Ben Smiled', p. 245.

Poverty

Culture, however, is not a single determining factor in the lives and participation of children with neurodevelopmental disabilities. Poverty is an ever-present challenge. In sub-Saharan Africa, the majority of citizens experience a reduced standard of living compared to people in high-income countries (Ingstad and Whyte 2007). Thus, the challenges encountered by children with disabilities and their families are shared by all (Mitra et al. 2011). This includes poor access to health provision (Peters et al. 2008), low school attendance (Kuper et al. 2014), limited employment rates and low wages (Muzunoya and Mitra 2012). Persons with disabilities in resource-poor countries encounter lower educational and labour market outcomes and are more likely to be poor than those without disabilities (Trani 2010). In Africa alone, less than 10% of children with disability were reported as attending school (UNESCO 2015). It is often the case that families of children with disabilities spend relatively more on healthcare than those without disabled members (Mitra et al. 2011). In Sierra Leone, families with a child with severe disabilities spend an average of 1.3 times more on healthcare than families without a person with a disability (Trani 2010). Disability and poverty are integrally connected (Department for International Development 2004) and families face many daily struggles.

Disability and poverty are integrally connected.

Stigma and Discrimination

In a context of poverty and limited resources, fuelled by traditional beliefs about disability causation, social relations, community attitudes and actions may be affected (Eide and Ingstad 2013). Stigma describes the negative attitudes evinced towards a particular group of people who are viewed as displaying certain characteristics that both discredit and discount the person (Goffman 1963). Stereotypes of what a member of the group is like are generated. This leads to prejudicial treatment by others whenever a person is associated with that stereotype (Werner et al. 2012), as illustrated by Mama Shuku's experience in Vignette 4.1, 'I Will Not Kill My Child'. The disabled child's perceived lack of fit within the local community, and the 'affiliate' stigma experienced by those closest to the child, are major factors in their participation. In the face of aversive responses from others, caregivers and families may adopt a protective stance towards the child (Gona et al. 2018). However, the urge to keep the child safe may come at the cost of inclusion.

LINK TO VIGNETTE 4.1
'I Will Not Kill My Child', p. 46.

The child's social participation frequently depends on the support of the primary caregiver, typically the mother. The time and energies associated with care and support in everyday living activities affects the extent to which participation opportunities may be taken up (Bunning et al. 2017). In particular, the physical burden of supporting a child with disability has repercussions for movement within and beyond the community. With inadequate transport systems in sub-Saharan Africa, unmade roads with rough or unstable surfaces, and a lack of physical aids and adaptations (e.g. wheelchairs), mobility becomes a problem, particularly for those children with multiple disabilities. The sheer difficulty of movement becomes a barrier to not only the child's social participation, but also that of the caregiver.

PARTICIPATION

There is limited information on the meaning of participation to children and their caregivers in sub-Saharan Africa. Nelson et al. (2017), examining the views of children, caregivers and community members in Malawi, identified seven main spheres of participation. These included household work that contributed to family life; social interaction and being with other people (e.g. chatting with neighbours, sharing family stories); social activities, such as unstructured play (e.g. ball games, skipping); organised activities with a definite purpose (e.g. church service, football match); activities of daily living (e.g. bathing, eating meals with the family); education and schooling (travel to school, reading, writing); and entertainment (e.g. watching television, listening to the radio). It appears that with regard to participation, both children with and without disabilities want similar opportunities to take part across varied life situations (Nelson et al. 2017). However, children growing up with disabilities tend to experience a narrower existence with fewer prospects for social participation and engagement in daily activities; for example, household, educational and recreational activities (Bedell et al. 2013; Hansen et al. 2014). Investigating Canadian children with physical disabilities, Law et al. (2006) attributed improved patterns of participation to underlying values and cohesion in the family unit, as well as supportive and 'resource-ready' environments that were considered accessible, non-discriminatory and socially responsive (Law et al. 2006). This is echoed by Bedell et al. (2013) who highlighted the importance of community action to support participation (Bedell et al. 2013).

In sub-Saharan Africa the challenges of participation for children with developmental neurodisability are compounded by limited home resources, inadequate transport (Hansen et al. 2014) and cultural stigma associated with disability (Bunning et al. 2017); inadequate information and poor availability of support (Bunning et al. 2014). The mothers interviewed in Hansen et al.'s study (2014) in Zambia, identified other family members and members of the local community as alternately facilitating, and impeding, their child's social participation (Hansen et al. 2014). Invited and supported participation appeared to be associated with general acceptance of the child's condition. Respondents identified their local church particularly as a place of inclusion, where children could take part in services. However, where the family becomes fragmented, adversely affected by the stresses of caring for a child with disabilities in a context of limited resources and community stigma, participation may be affected. As a result, many children and their caregivers experience social deprivation and isolation (Bunning et al. 2017; Gona et al. 2014).

Participation challenges are amplified by limited resources, cultural stigma and inadequate supports.

Involving caregivers in home-based interventions is linked to positive participation outcomes for children.

Focused and improved attention to the child at home was viewed as providing a model of positive practice to others and therefore linked to improved participation for the child (Nelson et al. 2017). In particular, the chance to improve the child's mobility through therapy exercises as part of community-based rehabilitation was identified as positive help (Hansen et al. 2014). Furthermore, the active involvement of caregivers in home-based interventions appears to be important, not only to the child's development, but to the caregiver's perception of the child and uptake of participation opportunities (Bunning et al. 2014; Gona et al. 2014).

Beyond the homestead, intervention targeted at the community may support improved acceptance and participation. A key feature of the 'resource-ready' environment (Law et al. 2006) and critical to acceptance, participation and inclusion, is the understanding and support of neighbours, friends and members of the community (Hansen et al. 2014). Disability awareness initiatives, as included in community-based rehabilitation and inclusive development guidelines, support the notion of 'empowerment' (WHO 2011). Through activities that encourage people to question their views of disability, while also increasing their contact with people with disabilities, previous beliefs and stereotypes may be challenged (Moore and Nettelbeck 2013). Gona et al. (2018) reported how adults with disabilities, as experts-by-experience, shared their personal narratives with community groups in a rural part of Kenya, which triggered a reassessment of how disability was understood. Learning from people with disabilities underpins Allport's (1954) early 'contact hypothesis' whereby increased interactions between the devalued group and others promotes more positive attitudes and decreases prejudice (Armstrong et al. 2017). In this way, the environment is rendered 'resource ready' (Law et al. 2006).

Of course, achieving participation for children growing up with disabilities is not simply a matter of engineering more positive attitudes and responses in the community; actions are needed to alleviate the stresses within the family; for example, financial, psychosocial and physical (Hansen et al. 2014). Self-help groups are used as a vehicle to promote the wellbeing and livelihoods of a range of users and involve a variety of activities. Self-help groups bring together people with something in common, providing opportunities for sharing experiences and insights, exchanging information and developing self-esteem. Project SEEK is concerned with the development and maintenance of self-help groups for caregivers of children with developmental disabilities (https://www.uea.ac.uk/health-sciences/research/projects/seek). Through empowering activities focused on income generation, mutual psychosocial support, and access to education and health services, the membership moves collectively to improve their home situation and to promote the presence of their child in the community. The activation of caregivers and families as agents for change offers a route to improving the participation of children with neurodisability.

Activating caregivers and families as agents for change is powerful.

CONCLUSIONS

Participation of children with neurodisability is challenged by poverty, scarcity of information giving rise to ignorance about the causes, inadequate coverage of services, and the stigma associated with such conditions. Certain traditional explanations of disability associate it with negative images or undesirable events. The stigmatising of individuals who share specific characteristics and who are perceived as different, can lead others to discriminate against them. In short, they become a discounted group. Some caregivers may assume a protective stance towards the child to minimise the risk to the child and family, or alternatively conceal the child because of shame. Both courses of action may result in separation from the surrounding community and low uptake of participation opportunities. Initiatives exist that are designed to help circumnavigate the negative and frequently isolating consequences of childhood-onset neurodisability, for the child, caregiver and family. However, real and lasting change requires a deliberate, comprehensive and enduring approach that tackles the constructs associated with traditional beliefs and empowers caregivers, and the children themselves in finding a place in their own communities.

SUMMARY OF KEY IDEAS

- Caring for a child with neurodisability in income/resource-poor regions brings many challenges.
- The role of the local community is crucial to participation.
- Experts-by-experience can help the shaping of attitudes.
- Change is most effectively achieved through community-based solutions.

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