



Disability & Development. Caring for Children with Disabilities in Ecuador
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SUMMARY

Most research on how families cope with a child having a possible disability tells roughly the same story. When parents suspect there is something wrong with their baby they want a clear diagnosis. They hope and expect that diagnosis will be followed by appropriate medical treatment and support. It should also help them adjust their expectations for the future: to enable them 'to regain predictability and control in life'. The birth of a child with a disability requires a family to make material, psychological and social adaptations. Despite economic growth in recent years, Ecuador is much poorer than Western Europe. There is considerable inequality. About 25% of the population is estimated to live in poverty. Many people lack access to formal health services, with the result that disabilities are often diagnosed very late, this is despite the fact that many new policies were implemented. Nor can it be taken for granted that a child with a disability or developmental deficit will grow up in a stable two-parent household and a caring, sympathetic environment. Despite the fact that Ecuador promotes the biopsychosocial model of disability in its laws and programs, there is no continuous, consistently funded and organized system of care for children and adolescents with disabilities and their families that offers them a good quality of life. The actual practice of disability care is based in a medical approach to disability that focuses on its organic causes (such as malnutrition, illnesses, physical traumas and others) and leaves aside the psychosocial context. With the medical model, we try to cure or rehabilitate the damaged body, so we do not work on prevention and social determinants. There are no state development care programs that detect children with developmental problems and refer them to specialized centers. The few rehabilitation services for functional deficiencies that exist are overstretched due to the massive need for the service. As a result many children remain without professional care. They may be confined in the house and excluded from participation. There are also no programs that support the families of children with disabilities.

Central to this thesis is the hypothesis that both the risk of giving birth to a child with a disability and families' experiences in trying to cope depend on the services available in, and the attitudes and socio-economic structure characteristic of, the society in which they live. The thesis focusses on the distinctive socio-cultural context of Ecuador's Azuay province, in which the city of Cuenca is located. It is a multicultural area in which faith plays an important part in many people's lives, and an area which is marked by very large socio-economic inequalities. How do families experience the birth of a child with a disability? When and how are they informed of the diagnosis? How do they then cope, and what support do they receive from social services and from social networks? How are these experiences influenced by socio-economic status, by culture, and by faith? How are the risks of disability, and of developmental delay more generally, influenced by the nutritional quality of the food consumed in a household? These are the questions to be addressed here.

The researches on which the thesis is based make use both qualitative and quantitative approaches, though principally of the former. Qualitative Interviews with parents or guardians of deaf and hearing-impaired children, and of children with Down Syndrome (DS), were the major method employed. The quantitative study, a cross-sectional study based on clinical observation and measurement, focused on the development, nutritional status, and complementary feeding of 214 children aged 12- to 23-months in Cuenca. Findings were compared with data from Latin America and the Caribbean (LAC), and from low-lower-middle- and upper-middle-income countries more broadly.

The qualitative chapters of the thesis are concerned with families' experiences of coping with a child with a disability, in the specific context of the Ecuadorian province of Azuay. They explore their experiences of the services available to them; effects on family life; their experiences of stigma, and hopes and fears for the future. For many Ecuadorian families their religion is a vital source of support in coping with the presence of a child with a disability. From their faith in God they draw strength, consolation, resignation and spiritual shelter. They can accept that they have been singled out to receive a special gift: an angel from heaven.

In accordance with the social model of disability, chapter II starts from the assumption that parents' experiences of a child's hearing impairment reflect the circumstances of their lives rather than anything innate in the impairment itself. The study shows how inequality – and in particular the experience of poverty – shapes families' experiences of acquiring a diagnosis and of trying to accommodate a child with special needs.

Chapter III uses the same interview data to address a distinctive set of questions. Despite progress in addressing the needs of people with disabilities (PWDS) in Ecuador, many carers are found to be critical of the way in which new measures have been implemented, and (perhaps in particular) of the schooling available to their child. They are also worried by their child's vulnerability, the likelihood of discrimination, and the possibility of abuse.

Chapter IV presents the experiences of parents of children with Down syndrome (DS). This study sought to analyse the influence of distinctive features of Ecuadorian society on the communication of a diagnosis of Down syndrome, and on families' adaptations to having a child with DS. The study shows that, reflecting the effects of status differences and lack of appropriate training, professionals rarely communicate a DS diagnosis in an appropriate manner. Further, it is shown that lack of social support, and the widespread stigmatization confronting children with DS and their families, hinder development of the positive and empowering adjustments that would best serve the child's and the family's interest

Chapter V discusses how under-registration makes children with developmental problems invisible in the state priorities in the planning and allocation of resources. For this reason, through the cross sectional quantitative study carried out in children from 12 to 23 months of age, the prevalence of "possible developmental delay " is discussed in relation to biological (nutrition:

stunting, overweight, complementary feeding) and sociocultural factors (type of family, urban residence or rural, migration), and to characteristics of the caregiver (type of caregiver, level of instruction of the mother). The results indicate the prevalence of developmental delay and the prevalence of malnutrition. They show that Ecuador has many objectives and goals to achieve in relation to child development and in the prevention of disability

Finally, in Chapter VI, the principal results of the research are summarized, some recent developments in policy and practice are presented, and the implications of the present study for policy and practice are briefly discussed. The conclusions sketch a route to improving the quality of life of people with disabilities in Cuenca- Ecuador, based on the laws that protect them, and involving the organizations of people with disabilities and their families.