

# Inclusive ECD for parents of children with disabilities

Over the past year, Ilifa Labantwana, along with its partners on the ground, has worked towards the inclusion of children with disabilities in ECD centres in KwaZulu Natal and the creation of support systems for the parents of these children. SUE PHILPOTT and BONGI ZUMA discuss the lessons learned from the parents they worked with

The Essential Package of ECD Services has made it possible to identify specific factors that support the learning and healthy development of all young children, from the period of conception until age five.

In South Africa, however, high levels of poverty, particularly in urban informal settlements and rural areas, create environments that threaten children's growth. Conditions associated with low socio-economic status, such as overcrowding, poor sanitation and a greater exposure to environmental hazards, such as fire, increase the vulnerability of

young children and contribute to compromised development.

Conditions of poverty also contribute to higher levels of disability<sup>1</sup>, through exposure to hazardous environments, for example, or poor maternal care during pregnancy and childbirth, while the costs associated with disability only serve to deepen poverty.

However, research<sup>2</sup> shows that although poverty can have a negative impact on a young child's development, this impact can be mediated by the caregiver-child relationship, thus confirming the critical importance of this interaction.

In mid-2014, Ilifa commissioned a

pilot project to develop an approach to inclusion of children with disabilities in ECD services in the remote and mostly rural Ugu district of KwaZulu Natal. In addition to the training of ECD practitioners from nine **inclusive hubs** in the district, a key component of the project was the running of workshops for parents of children with disabilities in each of the six local municipalities.

The aim was to strengthen the role of parents of children with disabilities to support their own child's development and as advocates of the rights of their children. Each workshop was attended by approximately 20 parents and took place over three consecutive days. Day one focused on sharing childcare experiences, as well as learning about disability rights and cultural beliefs about disability; the second day focused on ECD; and the third looked at inclusion in ECD, as well as the advocacy messages of parents regarding the rights of their children.

This article explores the social milieu of parents of children with disabilities, as related by the parents who participated in these workshops, and it reflects on how this social environment serves to undermine and even "poison" the relationship between mothers and their children. Drawing on the parent support programme piloted in Ugu district, this article shares lessons on the actions which can foster an environment in which every parent finds the affirmation they need to provide a nurturing and loving relationship with their child.

## The need for intervention

The need for support for parents of children with disabilities is perhaps best described by contrasting a selection of their main shared

## 5 Components of the Essential Package



**Nutritional support**



**Maternal and child primary health interventions**



**Stimulation for early learning**



**Social services**



**Support for primary caregivers**



**“The birth of a disabled child is often perceived as a curse or a punishment for the perceived sins of the mother and a source of great shame and disgrace.”**

**“I am not able to leave my child with my neighbours because they say they are scared of him. How can I leave him with people who are scared of him? So I cannot go out and leave him behind.”**

– Grandmother of Kuhle, child with cerebral palsy

experiences with those of parents of able-bodied children. These experiences are based on accounts related by parents during the workshops in Ugu district.

The birth of a baby is usually greeted with joy, with family members talking about it with great pride – a child is seen as a blessing and a gift from God. In contrast, the birth of a disabled child is often perceived as a curse or a punishment for the perceived sins of the mother and a source of great shame and disgrace. In her association with the child, the mother is “disabled by proxy”.

It is common in rural areas for young children to be raised by a number of different family members or adults in the neighbourhood, as per the maxim: “your child is my child”. Even if the father of the child is not involved, other extended family members such as aunts, uncles and grandparents assist with caring for and raising of the child.

In the case of children with disabilities, however, the approach is “your child is your child” and the mother typically receives very



little support from the family or her neighbours. If she takes the child to therapy, for example, there is no one who is willing to go with her. If she asks for support, it is assumed she will have to pay for it.

The attitudes of community members and their actions towards disabled children and their mothers are frequently legitimated by cultural beliefs about disability.

Disabilities associated with behavioural problems, such as autism or Attention Deficit Hyperactivity Disorder, are seen to be manifestations of ancestral spirits, which need to be exorcised. A parent may be pressurised to spend the little money they have on the purchase and sacrificing of animals to appease the ancestors, instead of seeking medical or therapeutic interventions.

What is the impact of this hostile social environment on the mother of a disabled child and how does it undermine her relationship with her young child?

In the first instance, such attitudes contribute to the social isolation of the mother – she is alone, with no one to turn to. Those on whom she would typically rely (mother, mother-in-law) are angry and blame her for the disgrace they believe she has brought to the family. Even where she is trying to respond to the needs of her child, she does not get their support or affirmation. In this situation, is it surprising that a mother would try to hide her child from community scrutiny? Is it surprising that she would be reluctant to acknowledge her concerns about her child or to seek help?

The attitudes of community members contribute to the mother’s feelings of helplessness and uselessness – she is being blamed for something she cannot “undo” and which is beyond her control. She may turn her anger and frustration on to the child, whom she perceives as being the source of the stress in the family dynamic.

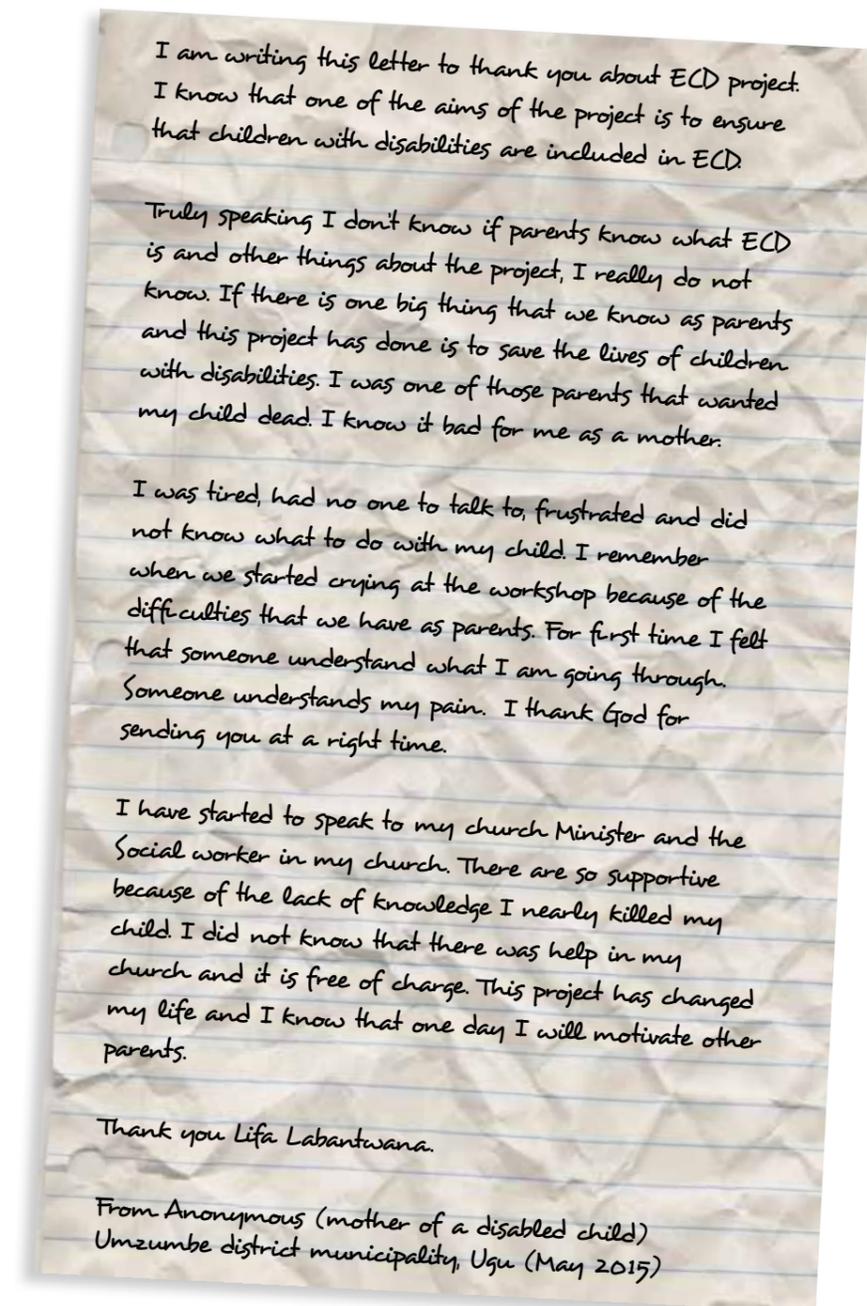
**Opportunities and lessons**

How can this external environment be challenged and the critical role of mothers of young disabled children be supported? Reflections on the Ugu Inclusive ECD project suggests three levels of intervention:

**1. Raising awareness about the causes of disability**

There is a need for wide-spread

information about the causes of disability to be disseminated at community level. Traditional healers and leaders need to understand the role of genetics and other medical factors in causing disability. Armed with understanding, healers and leaders would assist parents to get access to the necessary services, rather than exacting from them appeasement for the ancestors.



**2. Support groups and collective action of parents**

Mothers of disabled children need counselling and psycho-social support, to assist them to accept their children, and to subsequently move from being passive recipients of the disgrace or charity to a position in which they are able to contribute to shaping the future of their child. One mechanism to facilitate collective action is through representation of parents on community structures.

**3. Service providers to ensure services are accessible and appropriate for all children**

Finally, there is an urgent need for service providers (social workers, therapists, school principals and non-governmental organisations) to identify and remove barriers which prevent access for children with disabilities. These could be physical barriers, attitudinal barriers or barriers to information.

Instead of saying "any child is welcome to use our services", the focus needs to be on "how can we make sure that children with disabilities can benefit from our services?" thus actively addressing factors which may hinder access.

The support programme run for parents in Ugu district has begun to address each of these elements. There has been engagement with community leadership, through municipal structures, on information about causes of disability.

In addition, within each local municipality of the district, parent representatives have been elected to represent the concerns and priorities

of their peers on the local Disability Forums.

Further, the involvement of various service providers, such as social workers, therapists, ECD practitioners, among others, in the parent workshops, has contributed to growing awareness of the need for their services to be more accessible and appropriate for parents of children with disabilities.

Sustainability and expansion will require ongoing support from the Special Programmes manager and Focal Persons throughout the municipality, as well as from government and non-governmental service providers in both the ECD and disability sectors.

In a context of vulnerability deepened not only by poverty but also by disability, the parent-child relationship is one of the most precious and influential elements to the well-being of a child.

Supporting and affirming this relationship is critical for the future of children with disabilities.

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**Sue Philpott** is a disability activist, who has been involved in a wide range of disability-related action research studies. She currently co-ordinates the Ugu Inclusive ECD Project.



Implementing ELRU's Family & Community Motivator programme as a key component of Ilifa's partnership with the Department of Social Development in North West over the past four years has been an evolutionary process. FIONA BURTT outlines recent shifts in practice and learning gained from responding to the needs of caregivers through an ECD home visiting programme with a changing focus.

## Circles of support for caregivers in North West province

The Early Learning Resource Unit (ELRU) has been working in partnership with Ilifa and the North West Department of Social Development (NWSD) since 2011, demonstrating the importance of home visiting as part of a continuum of approaches to ECD support for young children and their caregivers. ELRU worked

initially in two local municipalities in two North West districts, targeting children under the age of six years from vulnerable families who were not already in an ECD centre. This presented particular challenges. The families frequently reside in remote villages, which are far from services and where poverty is extreme; and there are high incidences of teenage

1. Emmett, T. 2006. Disability, poverty, gender and race in Watermeyer B., Swartz L., Lorenzo T., Schneider M. & Priestly M. (eds). *Disability and social change: a South African agenda*. Cape Town: HSRC.
2. Graham L., Selipsky, L., Moodley J., Maina, J. & Rowland, W. 2006. Understanding poverty and disability in Johannesburg. Centre for Social Development in Africa, University of Johannesburg & UK Department for International Development.
3. Loeb M., Eide, A., Jelsma J., Toni, M., & Maart S. 2008. Poverty and disability in Eastern and Western Cape Provinces, South Africa. *Disability and Society*, 23(4), pp311-321.
4. See for example, Morgan, B. 2013. Biological embedding of early childhood adversity: Toxic stress and the vicious cycle of poverty in South Africa. Ilifa Labantwana Research and Policy.