

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.

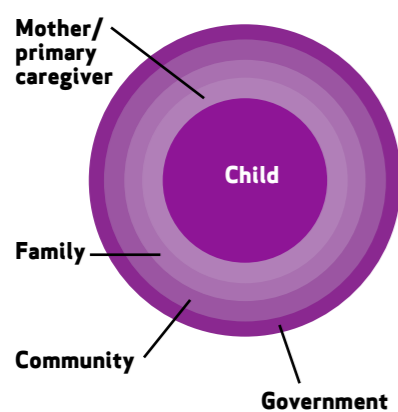
pregnancy and child stunting.

The signing of a new Memorandum of Understanding between Ilifa and NWSD in 2014 determined an expansion of the programme to defined areas in all four districts in the province, doubling the number of home visitors. At the same time, a growing focus globally, and in South Africa¹, on the importance of the first 1 000 days of a child's life and the critical role of the primary caregiver, led Ilifa and ELRU to shift the focus of the North West home visiting programme to offer more explicit support for this period.

Circles of support

ELRU's programme is founded on the understanding that the caring environment around a vulnerable young child and parent or caregiver is critical to the child's development and wellbeing. The environment can be seen as a series of concentric circles of support, with the child at the centre, from conception onwards. Direct care for that child is provided by the mother/primary caregiver, who becomes the child's immediate support. Providing support for that caregiver and child is a family/household. That household is based in a community, which provides the next layer of support and, even in the most impoverished or remote communities, many means of support may be found, such as a church, community groups and structures

Support around the child



or just by neighbours helping neighbours.

The last circle of support is provided by government services – local, provincial and national. So, for this model to be effective, government services should support the community to support the household to support the caregiver to support the child.

The importance of encouraging every circle to work is the major impetus behind the original naming of ELRU's home visitors as Family & Community Motivators (FCMs) and lies at the heart of ELRU's recognition of such programmes being not just about early childhood development, but a process of community and, ultimately, systemic development.

From doing to encouraging

At the core of the FCM intervention is a year-long programme of fortnightly home visits and monthly cluster workshops for caregivers, the latter providing both education and information and an invaluable opportunity to share with other caregivers. While the programme places a strong focus on early stimulation and nurturing parenting, caregivers and children are also linked through referrals and support to health and social services, such as grants.

In ELRU's 0-5 home visiting programme, the FCM would spend a major part of each visit undertaking play activities with young children and demonstrating these to the caregiver. A stronger spotlight on pregnancy and babyhood, since the commencement of the third phase of the North West FCM intervention, in April 2015, has, however, led to a subtle shift in the training and practice of FCMs. It has also resulted in new understanding about the support required by pregnant women and caregivers of very young children.

FCMs are now trained to work more alongside the caregiver, to encourage her to engage with her child and observe and check her child's

progressive development, during pregnancy and beyond. But, according to ELRU's FCM programme manager, Bernie Dawood, in some households, the mother may have no idea how to do that, so it may be necessary for the FCM to model and invite the mother to practice while the FCM is present.

Recognising that the relationship between mother or caregiver and child is the critical factor in all aspects of a young child's development and well-being (as discussed elsewhere in this issue of *Ilifa Insights*), FCMs have discovered that the support they need to offer can be as basic as showing a caregiver how to hold, talk to or smile at her baby. As Bernie Dawood explains, "some mothers immediately respond, but others take time. We encountered a very young mother, who looked very depressed, unkempt, absolutely absent, not relating to her baby. The FCM had to show her how to smile and laugh with her baby and, eventually, she was able to do it. But, if there had been no home visitor offering support, it would have been terrible for that mother and child."

It's all about relationship

As ELRU staff always affirm, the key to the success of any home visiting programme is the positive relationship built between the home visitor and the caregiver. Simply stated: "For good outcomes, the relationship between participant and programme staff needs to be stable, warm, supportive and uncritical."² How the perhaps intangible notion of relationship and support for the caregiver translates into positive outcomes for the child can be difficult to quantify, but Bernie



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significant community resources, this would emphasise the role of FCMs as part of the outer circle of support described above. The qualitative learning about the needs of young children and their caregivers, and the best approaches developed by FCMs for responding to these needs, informs the deepening of FCM's practice and the increasing impact of the programme.

Of concern, therefore, is that the current, multi-layered DSD reporting structure – from the ground via NWSD to national DSD – is entirely about numbers. As systemic change gradually happens and home visiting becomes more embedded in DSD ECD programmes, where will all this learning go?

Fiona Burt is a development consultant, who has been researching aspects of ELRU's FCM programme in North West province for Ilifa.

Dawood is clear that it does make a real difference: "Especially for an isolated, vulnerable caregiver, when someone visits, it's really important. Home visits lift your spirit. You're sitting bottled with all this hardship, now there's someone to share it with and immediately it's released. As soon as it's released, there's a space for something better to come in. Home visits bring trust, motivation, encouragement, moral support. Women naturally learn from each other and sharing helps."

ELRU has often seen this as a very female space, but, since April, has welcomed four men into the programme as FCMs, recruited by NWSD. All are fathers and are proving to have a positive effect

in demonstrating the role of men as caregivers of young children. And in one area, the male FCM has successfully enrolled pregnant women and gained the trust of their families, thus challenging the commonly-held assumption that men in South Africa cannot undertake home-based work with pregnant women or new mothers.

Sharing learning with the outer circle

A major goal of the North West FCM programme has been not only to model the intervention on the ground, but to see it scaled up and sustained over the long term by integrating it into NWSD systems. Ultimately, while still acknowledged as

1. As highlighted in the 2012 *Diagnostic Review of Early Childhood Development in South Africa*, commissioned by the Department of Performance Monitoring and Evaluation in the Presidency and the Inter-Departmental Steering Committee on Early Childhood Development, and the draft South African National ECD Policy, awaiting adoption.

2. Dawes, A., Biersteker, L. & Hendricks, L. 2012. *Home visiting for households with children not in formal ECD: Evidence from the Sobambisana Initiative*. Ilifa Labantwana Learning Brief 5.