



Children and Disability Dialogue

25 September 2014

Notes for Working Group

What kinds services do children living with disabilities need to thrive? What kinds of support mechanisms can be put in place for parents of these children? What are some of the myths and societal barriers to service delivery? Will a heightened awareness raising campaign help to reduce stigmatisation, discrimination and ostracisation of children with disabilities?

On the 25th of September 2014, Ilifa in partnership with the Department of Social Development hosted a dialogue on children and disability. The dialogue brought together various stakeholders from government and civil society to explore opportunities for deepening collaboration and acting on various agendas, policies and position papers that have sought to add impetus to enabling access to services for young children and their primary caregivers who are living with or affected by disability or developmental delays.

A draft framework for action was tabled and presented at the meeting. During a group break away, session participants were asked to engage with the draft and to make recommendations on what they thought needed to be the critical focus as well as what they felt were priority areas for engagement. From the level of discussion, it was evident that there is a lot happening at the moment, that there are pockets of good practice emerging across the country but the 'disability sector' operates in isolation of many key stakeholders and that it is deeply fragmented.

A key challenge noted in this regard is a lack of coordinated endeavour as well as a significant policy implementation gap. What follows are bullet points of the key issues raised during the meeting, with particular focus on recommendation and action.

- **MAPPING**
Drawing together those critical and primary elements under consideration, this part of the process is an attempt to join the dots and create a structural analysis of a process flow which will form the basis of the plan to take forward

- Clear picture of gaps and networks, draw on existing services and current work being done by different entities
 - Framework should critically look at what is needed, followed by a core plan of action before funding can be sought
 - Identify the different departments that should be talking to each other and broaden the conversation on children living with disability
 - The framework should go beyond disability, and should have a multi-sectoral response with actions and timeframes for delivery, integrating various key policies and legislation
 - Integrate good practice and legislation related to children – identify priorities
 - Align funding with resources, look at the number of health workers and strengthen capacity
- **DISABILITY PREVENTION**
What are some the services that can be put in place to prevent disability?
 - Spread services to other areas, for use by ECD practitioners, community support, midwifery support, bring midwives into the community
 - Care and training of midwives in community services
 - Care and training and support to parents
 - Accredited centre-based respite care (flexible)
 - Community based respite care
- **INCLUSION**
How can we accommodate children and families affected by disability, ensuring that those barriers to social inclusion and acceptance are not seen as a favour but a right?
 - Participation (inclusion to enhance participation by families)
 - Family care and protection
 - Access to quality inclusive services
 - ECD centres should be inclusive
 - Build consensus on mainstreaming and/versus inclusion
 - Translate disability into mainstream to push integration
- **TRAINING**
We know that training is a critical component if we are to see real and positive changes in ECD service delivery. What are the immediate steps that need to be taken?
 - NQF Level 5 training as career pathing
 - Accredited training of ECD practitioners
 - Training of community workers and practitioners (we need creative practitioners who are not afraid to problem-solve)
 - Train and empower parents
- **AWARENESS TRAINING**
What do parents experience when they are first informed that their child has a disability? What support can be provided? Creating and raising disability awareness throughout society will not only help to increase knowledge and clarify myths but also foster social inclusion and initiate further dialogue on disability

- Information sharing
 - End fear of disabled children
 - End myth that children with disability bring bad luck and should be avoided in public spaces
 - Education to reduce barriers
- **INTEGRATED SERVICES**
We need to develop a less fragmented picture of the nodes of support available to practitioners, with stronger, clearer, workable systems...
 - Active referral system (with reliable database)
 - Continuity of care
 - Practitioners need to know where they can go to for support
 - Quality inclusive ECD and open market place
- **SUPPORT**
What other forms of support can be rendered?
 - Assistive devices (on hygiene/ care) for carers
 - Counseling for parents
 - Specialist services
 - Integration and social inclusion
 - Information on education services
 - Accessibility to services and activities
 - Sensitization to diversity and differences
 - Progress on policy development should be filtered down to the ground, i.e. to parents
- **MONITORING & EVALUATION**
What are the milestones to success? How will they be measured?
 - Good information centres
 - Monitor change around inclusion

At the end of the meeting, a group of volunteers offered consider a way forward for the group and to come back with recommendations.

The task team will undertake the following;

- Input to the *framework for action* that was tabled so that it can be completed,
- Identify initiatives underway which could be ‘tapped into’ to build cohesion and common purpose and impetus to the *framework for action*,
- Take the opportunity presented by the Policy and Programme document for ECD which highlights disability but does not provide a comprehensive plan in this regard and to fill this gap,
- Make recommendations on what next (guided by the above), and Consult with the broader network on the above.