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Impact of Research on Family Centered Services at a Child Development Center in Urban India

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Background: Very few studies have evaluated Family Centered Services (FCS) in Low- and Middle-Income Countries (LMIC) let alone describe changes in service delivery brought about as a result of such research. Changes in service delivery based on findings of a study on FCS in a non-governmental organization in Mumbai are described in this abstract .

Objective–To describe the process of reorganization of services for children with disabilities and their caregivers based on mixed method study findings on FCS.

Method–Strengths, weaknesses, barriers and facilitators to FCS were identified and jointly analyzed by key stakeholders- caregivers of children under 6 years of age, service providers and managers.

Results- Providers ability to offer respectful care, enable partnerships with caregivers and provide comprehensive and coordinated care were identified as strengths. Long wait time for services, limited access to information, support for stigma and other stressors were gaps in FCS. Service providers acknowledged these gaps, identified shortage of time, human resources as reasons for the gaps. They also acknowledged that interdisciplinary collaboration as being less than optimal. The key stakeholders jointly identified the following strategies to address the gaps in and barriers to implementation of FCS.

Skill building in providers- Upskilling of providers to meet the information needs of caregivers was done through induction and internal training programs for new and experienced providers. Annual performance reviews for providers included evaluation of knowledge and skills about Family Centered Care. Caregivers were involved in curriculum development and cofacilitated training for providers within and outside the organization to enhance understanding about FCS in provider community.

Information- Information needs were met through posters in local languages and online video-based content on disabilities to make it accessible to caregivers with varying literacy levels.

Support –Caregivers’ need for support was addressed through a monthly walk -in Parent Support Group. Increased access and reduced wait times for services- Electronic Medical Records to update providers on caregivers’ progress, needs and predict wait times for services was planned. Caregiver training programs assisted the caregivers in supporting their child’s development while they waited for therapy services.

Conclusion- LMICs have unique challenges related to availability of resources, poverty and low caregiver literacy. These impact caregiver perceptions about family centeredness of services. Innovative solutions are needed to address contextual challenges.