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Family Centered Care in a Child Development Center in India: Implications for Low- And Middle-Income Countries

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Purpose-To identify the family centeredness of services for children with disabilities at not-forprofit child development center in India.

Methods-Participatory action research (PAR) with mixed methods was used. Caregivers and researchers co-designed tools co-facilitated focus groups, and co-interpreted data. In 3months, caregivers of children who received >1 service and were in contact with center >6months were recruited consecutively. Data provided by caregivers of children <or equal to 6 years of age was analyzed.Caregivers and service providers completed the Measure of Processes of Care 20(MPOC-20) and the MPOC Service Provider (SP) questionnaires respectively. An open-ended questionnaire and focus groups provided qualitative data.

Results-Out of 154 caregivers meeting the inclusion criteria, 81 caregivers had children under the age of 6 years. Most of the respondents from amongst the 81 caregivers were mothers (85%), 35% had up to high school,21% up to graduation and 29% postgraduation level education. Scale score means ranged from 0 (needs never met), to 7 (needs met to a great extent). MPOC-20 subscale mean scores (Sd) were 6.04 (0.9), 6.2 (0.8), and 6.3 (0.7) for the subscales Enabling Partnership, Coordinated and Comprehensive Care, Respectful Care; and 5.1 (1.3), and 5.9(1.1) for Providing General, and Specific Information respectively. On MPOC SP, completed by 42 service providers, subscale scores were 6.1 (0.5), 5.3 (0.7), 5.3 (1.5) and 4.7(1.1) for Treating People Respectfully, Showing Interpersonal Sensitivity, Providing Specific Information and General Information. Fifteen caregivers participated in focus groups where two themes emerged: service strengths/weaknesses, and caregivers' roles. Access to respectful, coordinated, contextualized care, mental health support and subsidized services when needed were identified as strengths. Long wait times, lack of control over service duration/frequency,limited access to information on children's disabilities, schooling and opportunities for connecting with other caregivers were identified as weaknesses. Caregivers acknowledged limitations in staffing and were keen to co-create solutions.

Conclusions-Family centeredness of services in an Indian not-for-profit child development center was similar to those reported from high-income countries. The qualitative data highlighted caregivers' willingness to partner with providers to build resources and increase access to services.