

P10

A Parent Empowerment and Knowledge Translation Program Supports Caregivers in an Early Intervention Program in Rural South India

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Introduction:Family-centred care is an integral component of early intervention services for children with developmental disabilities. Sharing information, providing respectful and supportive care and developing partnerships with families contribute to parental well-being. Family-centred programs have positive impacts on caregiver engagement & empowerment and satisfaction with care.

Objectives:To purpose of this program was to: (1) provide a unique opportunity for the parents to meet and network with each other and serve as the platform for experiential sharing amongst themselves, and (2) improve knowledge about childhood disability and the importance of early intervention of developmental delays in children in 0 to 6 year age group.

Participants/Setting:This program was developed and conducted at Amar Seva Sangam (ASSA), an Indian non-government organization in the District of Tirunelveli, State of Tamil Nadu in South India. Children aged 0-6 years and their families/caregivers, followed through the ASSAs Early Intervention (EI) program (centre- and home-based) were invited to participate.

Method:Parent empowerment consultation and knowledge translation programs were developed as full-day events and conducted every 6 months, from September 2017 to December 2019. This program was designed to address elements of family empowerment and parental education. Program included children cultural activities (dancing, singing, acting, wearing fancy dresses), parent cultural programs and sport activities, motivational and empowerment speeches by parents. The knowledge translation component focussed on the understanding of early intervention, life roles (spousal and parent-child relationship) and addressed issues of financial burden on the family. Individual and group parent psychological counselling were also provided to address parents stress and caregiver burden.

Results:Between September 2017 to December 2019, a total of 6 Parent Empowerment Consultation and Knowledge Translation Programs were conducted. Overall, a total of 1545 children and 2180 parent & family members participated. The program consisted of experience sharing sessions which generated positive energy among the parents. The opportunity for parents to meet & network served as the platform for experiential sharing and mutual support. The children demonstrated their talents and potential through the cultural fest, acting on stage. Prizes and small gifts were distributed to all children to motivate and praise achievements. Positive

parental feedback and gratefulness were expressed for support and services provided from the EI program.

Conclusion: Parent empowerment and knowledge translation are both key elements of family-centred care. Providing programs that meets family's need to network, share knowledge and engage with other parents, influences families' ability to engage in the programme and influences parent's ability to provide care for children for developmental disabilities.