Ágrip

Tilgangur rannsóknarinnar var að kanna hvernig innflytjendafjölskyldur sem eiga fötluð börn takast á við daglegt líf hér á landi, samskipti þeirra við nærsamfélagið og þjónustukerfið sem ætlað er að styðja fjölskyldur fatlaðra barna. Rannsóknarsniðið var eigindlegt og byggðist á viðtölum við foreldra og þátttökuathugunum. Tólf innflytjendafjölskyldur tóku þátt í rannsókninni. Þær höfðu þær dvalið á Íslandi frá 18 mánuðum að 20 árum og áttu samtals 16 fötluð börn. Reynsla fólks var margþætt og breytileg en staða margra fjölskyldna var erfið, þær stóðu einar og höfðu lítið stuðningsnet. Þótt samanburðurinn við upprunalandið væri hugsanlega hagstæður áttu margir erfitt með að takast á við og samþætta viðfangsefni daglegs lífs. Óvissa í húsnæðismálum, atvinnumálum og fjármálum mótaði líf margra. Tungumálakunnátta, tryggur fjárhagur, öruggt húsnæði og viðeigandi stuðningur réð mestu um það hvernig fólki farnaðist í nýju landi. Mikilvægt er að huga að samþættingu og menningarhæfni í þjónustu við innflytjendafjölskyldur með fötluð börn.

Lykilorð: Innflytjendafjölskyldur, fötluð börn, daglegt líf, þjónusta og stuðningur

Abstract

This qualitative study focused on the daily lives, reflections and experiences of migrant families (first generation) who had disabled children. Twelve families who had altogether 16 disabled children participated in the study. The children were of age 2–17, seven were in preschool, eight in elementary or middle school and one in secondary school. Most of the children had autism spectrum disorder, often combined with intellectual disability or other health-related conditions. Five families were single-parent and seven two-parent families of diverse countries of origin in Southern and Eastern Europe, Central America and Asia with families from Eastern Europe in majority. Data were gathered through semi-structured interviews and participant observations. The interviews were conducted in Icelandic, English or with the help of a professional interpreter, in line with the wishes of parents.

The families in this study were not a homogeneous group with respect to language abilities and other characteristics. Some had lived in Iceland for a long time and had formed social networks either within their ethnic community or within the larger, Icelandic society. Other families did not have these networks. Comparison with the opportunities available in their country of origin were essential when people described their lives. Although parents talked about strenuous days, hard work and struggles with combining roles in employment with care of their children, most of them nevertheless appreciated living in Iceland compared with what the situation would be in their country of origin.

Parents received various types of social, educational and health services for their children. In general, they were pleased with the services provided, particularly those received during the preschool years. In contrast, the transition to elementary school was often demanding and overall parents of children of elementary and middle school age held more mixed views about their experiences with services. A range of barriers related to accessing information about their entitlement to support and services were described. Typically parents had not known where to look for information, whom to ask or what to ask about. Intensifying the challenges were problems connected to language and communication which influenced parent’s ability to receive and understand information about their child’s impairment and about the welfare system. Much of the information was only available in Icelandic.

Overall, the migrant parents faced many of the same challenges that have been described among Icelandic families of disabled children. Nevertheless, these families typically described additional challenges in juggling and balancing work and family care than seen among families of Icelandic origin. There were, however, notable exceptions as a few families were overall content with their living situation and economically well off. Typically, these families had stayed in Iceland for a long time, had formed supportive networks, spoke Icelandic relatively well, knew the system and strongly appreciated what they could get here in comparison with their country of origin. Drawing upon their cultural capital these families had managed to build social and economic capital, using citizenship and knowledge gained from having stayed in Iceland for a long time.

It is important that the service system accommodates the diverse needs of migrant families with disabled children, by showing more flexibility and providing better channels to facilitate communication.

Key words: Migrant families, disabled children, daily life, services and supports