

Chapter 45

Mental Health Issues, Wellbeing, and Related Issues Among Caregivers of Individuals With Intellectual Disability

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ABSTRACT

Caregivers are the important and integral part in the lives of people with intellectual disability. As caregiving is extensive and mostly lifelong for this population, the associated burden, stigma, and also wellbeing of the caregivers are also equally important as these are often very directly correlated with the wellbeing of the individuals with intellectual disability. The chapter focused on the issues and impacts of caregiving, mental health problems, wellbeing, and related issues of caregivers. The authors also discuss the various facets of stigma caregivers do face and ways to deal with the stigma.

INTRODUCTION

Care giving to individuals with disability is laborious and associated with many mental health issues and related problems. In a longitudinal study on the well-being of parents of individuals included in the Australian Rett Syndrome Database over the period from 2002 to 2011, Mori, Downs, Wong, & Leonard (2019) reported that poorer parental physical well-being was related with residential remoteness, the child being a teenager at baseline, having frequent sleep disturbances or behavioural problems, and being a single parent or on a low income was associated with later poorer physical well-being, while the child having enteral feeding was associated with later poorer emotional well-being. Laurvick, Msall, Silburn, Bower, de Klerk, & Leonard (2006) reported in a study on mothers ($n = 135$, age ranged from 21 to 60 years) of children with Rett syndrome (age between 3 and 27 years) that the most important predictors of maternal physical and emotional health are child behavior, caregiver demands, and family function. The scenario is not much different with caregivers of individual with intellectual disability.

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Many researches focused on the management of individuals with intellectual disability, the mental health issues, stress and burden of the care givers of intellectually disabled individuals are equally important as indicated by the recent researches. In some cases, family members neglect the disabled individuals. Enoch, Mprah, Isaac & Joseph (2018) have reported in a study from Ghana that most parents refuse to visit their children with intellectual disability in school. However, due to deinstitutionalization and perspective of inclusion in to society, most of the intellectually disabled children, adults and older adults are taken care at home and at least one of the family members to be the primary care taker. Such scenario gives importance for the needs and difficulties for the caregiver. The chapter focused on the issues and impacts of care giving, mental health problems, wellbeing and related issues of caregiver.

Care giving and Mental Health Issues

The negative impact of caregiving on the mental health of caregivers is well documented in the literature. In a population based study, Schofield et al., (1998) found less life satisfaction, less positive affect, and more negative affect among caregivers compared with non caregivers regardless of age or marital status. Caregivers experienced depression, anxiety and stress symptoms and these symptoms were found to be significantly higher among caregivers of individuals with intellectual disability than those with Psychiatric illness (Panicker & Ramesh, 2019). Similar findings were reported in other studies too. For example, in a study on family burden in people with intellectual disability with or without mental disorders, higher levels of family burden were related to higher functional disability in all the areas, lower intelligence quotient, diagnosis of ID with mental disorders and presence of organic, affective, psychotic and behavioral disorders. Stepwise multiple regression showed that behavioral problems, affective and psychotic disorder, disability in participation in society, disability in personal care and presence of ID-MD explained more than 61% of the variance in family burden (Irazábal, Marsà, García, Gutiérrez-Recacha, Martorell, Salvador-Carulla, & Ochoa, 2012). In another study, higher family impact was found between caregivers to people with mental health disorders - intellectual disability. The interaction of both conditions (ID and mental health problems) results in a higher degree of burden on families (Martorell, Gutiérrez-Recacha, Irazábal, Marsà, & García, 2011).

Maternal depression in families having a child with a disability has been the subject of considerable research over four decades. Bailey, Golden, Roberts, Ford (2007) reviewed 42 articles on maternal depression and found that only eight were clinically diagnosed depression; most of them used a scale rating depressive symptoms. Across the studies, mothers of children with disabilities generally exhibited a higher than average rate of depressive symptoms and are more at risk for clinical depression, but the incidence may be lower than reported in previous literature. Child behavior problems, maternal stress, coping style, and support were consistently associated with depressive symptoms. The distinction between clinical depression and depressive symptoms may be important in conceptualizing how a child with a disability can influence family members and the nature of support that may need to be provided.

Many studies on mental health issues of caregivers of intellectually disabled individuals in different cultural settings consistently reported increased maternal distress and burden. Australian Bureau of Statistics (ABS) (1998) reported that, approximately 30% of caregivers reported that their well-being had been affected by caregiving, and that they were often worried or depressed. McConkey, Truesdale-Kennedy, Chang, & Jarrah, Shukri (2008) have studied 206 mothers with intellectually disabled children in three different countries and reported that mothers experienced poor mental health, increased levels of child-related stress and poorer family functioning. Their child's behaviour problems were a major factor

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