

Executive Summary

This paper presents the findings from the Carer Life Course Framework¹, a component of the Carers NSW *Carers Mental Health Project*. The project develops a theoretically and empirically based framework with practical applications for ensuring that carers of people with a mental illness/mental disorder receive appropriate information and support interventions depending upon their place in the caring journey, their life course/life stage, and their relationship to the person with the mental illness/mental disorder. The framework reflects the lived experiences of carers as well as the findings from a comprehensive literature review.

In this paper, we first present a general introduction to carers' issues, then discuss the unique aspects of caring for a person with a mental illness/mental disorder. We introduce the concept behind the Carer Life Course Framework, the theoretical approach we used, and summarise the findings from a comprehensive background paper.

The rest of the paper focuses on the development and applications of the Carer Life Course Framework. It describes the methodology behind a series of nine focus groups we conducted with 53 adult carers and 7 young carers. We used the patterns derived from the experiences of the individual carers to build a framework that identifies six distinct phases that many carers go through on their caring journeys. We focus on those aspects of caring that are constant across phases, then describe each phase in detail. We next incorporate the differential needs and experiences of parents, siblings, children, and partners/spouses with life course/life stage issues into the model. We then move to a discussion of the practical applications of the Carer Life Course Framework, focusing on information, what carers found helpful/unhelpful within the mental health system, potential contacts, and support services (incorporating some of the findings from the *Carers Mental Health Project Evaluation*).

This project is unique in its identification of the six phases, the incorporation of relationship and life course/life stage into the model, and its practical applications:

- For **carers**, it can help normalise what is often a frightening and isolating journey by providing a map of what other carers have gone through, along with links to relevant information and support services.

1. Originally called the Carer Cycle Project, upon further discussion and reflection the Working Party agreed that the term Carer Life Course more accurately represented the project.

- For **policy and government** organisations, it can be used to construct an evidence-based system of carer support, identify current gaps in those supports, and assign responsibilities for ensuring that carers' needs are met.
 - For **service providers** who work with carers and consumers, it can demystify the carer experience and enable service providers to provide the most effective interventions at the most appropriate time.
-