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## **Growing up Caring**

**Chris Dearden and Saul Becker**

**Young Carers Research Group, Loughborough University**

Karen is 22 and cares for her mother, who has rheumatoid arthritis, and her grandmother who has had a stroke. Karen has been assisting her mother since she was 12 and her grandmother since she was 18. She has never entered the labour market and is a full-time carer, receiving invalid care allowance. She feels unable to leave home while her family needs her support, and experiences stress, tiredness and depression.

Karen is one of 60 young people interviewed as part of a Joseph Rowntree Foundation study on young carers' transitions to adulthood. Although research has documented young carers' experiences, little is known about how caring during childhood affects young people's *transitions* into adulthood. This study, published today, examines the experiences of young people aged 16-25 who have been caring for a parent with a long-term illness or disability.

How has caring influenced young people's own development and transitions into adulthood?

Areas investigated included family structure and the nature of parental illness/disability; education, training and employment; income and benefits; receipt of and experiences of services; housing, leaving home and family separations; and becoming an adult. Data were collected through in-depth interviews with young people.

## **Context of the study**

Community care policy assumes that family members will provide much of the care and support required by relatives, with health and social care agencies and others stepping in to fill the gaps. While adults are therefore conforming to social norms by adopting caring roles, children transgress them, since childhood is viewed as a distinct and protected phase, with children protected, in theory, by the Children Act (1989) and the UN Convention on the Rights of the Child. Younger disabled or ill adults who have dependent children often lack the necessary social care provision and financial resources, resulting in their children sometimes adopting inappropriate caring roles.

Some young people are also 'pushed' into inappropriate caring roles because of changes in the labour market and the adverse effects of other social policies. For example, the collapse of the youth labour market led to the introduction of training schemes and vocationalism within education. Most 16 and 17 year olds are no longer entitled to social security benefits and those under 25 receive reduced benefits. Student grants have been eroded and loans and tuition fees introduced. Young people have become increasingly financially dependent on their families for longer periods of time. For some, staying at home makes economic sense in the absence of alternatives that would provide young people with secure and stable independence.

Ill or disabled parents may have to rely on their children to provide care and support in the absence of adequate external support services, while children may rely on their parents for financial support. Poverty and social exclusion exacerbate this mutual dependency.

## **The study**

The majority of families in this new study lived in rented accommodation and none of the parents with illness or disability were in employment. Their previous occupations had been predominantly manual, retail or clerical. In two parent families, only a third of second parents were in employment, all except one in manual, retail or clerical jobs. As a consequence, all but two of the families were in receipt of some form of welfare or disability benefits and most had long-term experience of living on low incomes.

Two thirds of the young people were helping to support mothers and seven were caring for more than one person. Most of the parents had physical health problems or disabilities, ten had mental health problems and five had problems with alcohol or drugs. The young people were involved in a range of caring and supportive tasks including domestic chores; general caring tasks such as giving medication, assisting with mobility and nursing-type tasks; personal, intimate care; and the provision of emotional support. Family structure, the severity and nature of parental illness, and the availability of other avenues of support largely determined the level and type of support provided by the young people.

## **Summary of main findings**

- A large proportion of young carers had educational problems and missed school. Many failed to attain any educational qualifications. This, combined with ongoing caring responsibilities, served to exclude some young carers from the labour market.
- Leaving home was problematic for many young carers, particularly if they had a parent who required considerable help and support. As a result, some young people delayed moving out.

- Where a parent had a severe and enduring mental health problem, some young people reached crisis point and left home prematurely, sometimes to be taken into care.
- Young carers matured quickly and gained practical skills that aided independence. However, these gains were easily outweighed by decreased educational, social and employment opportunities.
- Many families received no or inadequate social care services. Where services were provided they were sometimes inappropriate, intrusive, or too costly. There was no evidence of any specific services that supported disabled adults in their parenting role.
- Services need to focus on the whole family and be quick to respond to the needs of disabled and ill parents if their children are to be prevented from taking on inappropriate caring roles and from suffering the attendant problems in managing their own transitions to adulthood.

## **Conclusions**

Children and young people who adopt inappropriate caring responsibilities can be affected not only during childhood, but also as they make the transition to adulthood. The absence of family-focussed, positive and supportive interventions by many professionals, combined with inadequate income, result in negative outcomes for young people and their parents. Parental illness or disability is usually an indirect influence on young carers' transitions. The more direct influences are the lack of appropriate, affordable social care services, educational difficulties, poverty, social exclusion and stress.

Policies and services that identify and respond to the needs of all family members, but in particular those that support ill or disabled parents to enable them to prevent inappropriate caring roles from developing, will offer the best way forward. This requires a critical re-think about how services to ill or disabled parents and to existing young carers should be structured. A fundamental change to the existing structures for young carers' services and new and empowering services for ill and disabled parents are required.

*Growing up Caring: Vulnerability and Transition to Adulthood – Young Carers' Experiences* by Chris Dearden and Saul Becker is available from the National Youth Agency Tel: 0116 285 3700 £12.95 ISBN 0 86155 233 4

Chris Dearden is a Research Fellow and Saul Becker is Director, Young Carers Research Group, Loughborough University.