

Young carers' transitions into adulthood

Little is known about how caring during childhood affects young people as they move into adulthood. Chris Dearden and Saul Becker of Loughborough University examined the experiences of 60 young people caring for a parent with a long-term illness or disability. They investigated the extent to which caring influenced young people's decisions and activities in relation to education, training and employment, leaving home and becoming an adult. The study also looked at the impact of community care policies and services on these young people.

- f** 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.
- f** 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.
- f** 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.
- f** Young carers matured quickly and gained practical skills that aided independence. However, these gains were easily outweighed by decreased educational, social and employment opportunities.
- f** Virtually all the young carers' parents were in receipt of welfare benefits and were outside the paid labour market. Experience of poverty and social exclusion was common.
- f** 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.
- f** The researchers conclude that 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 suffering the attendant problems as they move into adulthood.

Background

This study examined the experiences of 60 young people (aged 16-25 years) who were, or had been, carers for their ill or disabled parents. The focus of the research was on the ways in which caring influenced the young people as they moved into adulthood. Areas investigated were: 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.

Young carers are defined as children and young people under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult.

Policy context

Some young people are pushed into inappropriate caring roles because of changes in the labour market and the adverse effects of other social policies:

- Community care policy assumes that family members will provide much of the care and support required by relatives, with the State stepping in to fill the gaps. Younger disabled or ill adults with dependent children often lack the necessary social care provision and financial resources; as a result their children sometimes take on caring for their parents. This conflicts with a view of childhood as a distinct phase, protected by the Children Act (1989) and the UN Convention on the Rights of the Child. In recognition of this, there has been a growth in specialist support services for young carers in recent years. However, services that support disabled parents have not developed as extensively.
- Most 16- and 17-year-olds are no longer eligible for benefits and 18- to 25-year-olds receive reduced benefit payments. Student grants have been eroded and loans and tuition fees introduced. With youth unemployment high, young people have become increasingly financially dependent on their families for longer periods of time.
- In families where there is long-term illness or disability, poverty is common. Children may be

required to provide care and support in the absence of adequate external support services. These young people may be increasingly financially reliant on families already living with poverty, ill health and social exclusion.

Family circumstances and parental illness

Half of the young carers were living in lone-parent families. Family structure is significant since, in lone-parent families where a parent becomes ill or disabled and requires support, there is usually no other adult available in the home to adopt that role. However, the presence of a second adult does not necessarily preclude children and young people from caring. Some second parents were in employment and in many cases the severity of parental illness meant that all family members, including children, were involved in providing support, care or supervision.

The majority of families 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 positions. 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 determined the level and type of support provided by the young people.

Education, training and employment

Half of the sample had missed some school and a quarter had no GCSEs. The majority confirmed that missed schooling was related to caring. This was because they were reluctant to leave ill parents alone, because they felt they were needed at home or, in a small number of cases, because parents did not want them to go to school. In some cases, teachers and

education welfare staff had colluded in these absences, perhaps in the belief that this was a supportive course of action.

"I missed school a lot because he [dad] wasn't well and I didn't like leaving him in case he fell over and he couldn't reach a phone or pull the cords." (Mark, age 16)

Despite the evidence of educational difficulties, many had continued into further education. However, this was often due to a lack of viable alternatives and, with the absence of maintenance allowances, continued study brought financial hardship. Caring responsibilities in the home made it difficult for some of the respondents to seek part-time work while studying, often compounding financial difficulties.

Of those no longer in education, a small number were in, or about to start, youth training schemes or were employed under the New Deal arrangements. Only a quarter of the sample was employed. Three young women were full-time carers and in receipt of invalid care allowance – two of these had never had a job.

The move from school to employment was complex and was influenced by many factors, including caring responsibilities. Previous missed school and poor educational qualifications placed many of the respondents at a disadvantage in the labour market. Changes to social security law, which effectively exclude 16- to 18-year-olds and pay lower rates to under-25s, made them more reliant on their families for financial support, despite the fact that many of the families were reliant on benefits.

Benefits and services

Only two of the respondents had parents who were not receiving some form of welfare or disability benefits. The most common payment was disability living allowance, sometimes in combination with income support. Few families were therefore able to purchase alternative care services and most relied on services provided by social services departments. Long-term illness/disability coupled with unemployment left many families poor and some respondents spoke about the extreme and enduring financial difficulties they faced.

"I just don't eat healthy food, we ain't got the money to eat healthy food." (Gill, age 17)

A third of the respondents' parents received ongoing social care or mental health services, but another

third had no support at all. It was more common for families to refuse or cancel services than for social services to refuse to provide support. Families cancelled services for a variety of reasons, but the most common ones were the perceived intrusive nature of services, poor quality services and the prohibitive costs of such services.

"We had home help for ages but suddenly they just stopped. They wanted my mum to pay but she couldn't 'cause she had no money, so they stopped. [I felt] gutted. I was, like, 'Oh no, not again'." (Judy, age 16)

None of the parents appeared to receive services to support them in their parenting roles. Where services were provided sensitively and were acceptable to families they reduced the level of support provided by young people and were greatly appreciated.

Leaving home

Seven of the respondents had left the parental home or were living independently, but in five cases this had not been a positive or planned choice. Parental mental ill health had forced some young people into leaving home earlier than they would have chosen. Other respondents felt that they were unable to leave because their parents needed their support. Two had begun to live alone following the death or institutionalisation of their parents. The research suggests that caring can lead young people to leave home earlier or later than they would have chosen.

"Things had been going bad for about ten months with my mum's health problems. I was getting to the stage where I knew if I stayed there I would end up ending my life, never mind hers." (Clare, age 20)

Three young people had been in care at some point, another had been made a Ward of Court and cared for by relatives, and in two other cases social services had informally arranged alternative care by neighbours. In five out of six of these cases, the parent concerned had mental health difficulties. Young people whose parents have mental health difficulties can find moving into adulthood traumatic or can have disruptive lives which can lead to them being separated from their parents.

Becoming an adult

Caring appeared to have both positive and negative impacts on young people's lives. The positive impacts included maturity, responsibility, life skills and a

close and loving relationship with parents. Some young people viewed the practical skills acquired through caring as important and useful for independence and adulthood.

"I think I sort of become an adult when I were fifteen in that way ... like a woman might be running a house, I were doing all the things maybe a twenty-two- or -three-year-old would be doing. I think I become mature when I were fifteen." (Sandra, age 19)

However, providing significant support to a parent in the absence of appropriate family-centred services had both immediate and long-term negative consequences for young people. These included stress and depression, restricted social, educational and career opportunities and impaired psychosocial development.

Young people's choices were both influenced and restricted by caring. The most important choices influenced appeared to be leaving home and choosing a career. Although career and job choice were sometimes influenced by the skills gained through caring, for example a desire to enter the 'caring professions', they were often restricted by a lack of formal qualifications as a result of missed school and poor educational performance.

Conclusions

The researchers conclude that children and young people who adopt inappropriate caring responsibilities can be affected not only during childhood, but also as they become adults. The absence of family-focused, positive and supportive interventions by professionals, combined with inadequate income, have negative effects for young people and their parents. Parental illness or disability is usually an indirect influence. The more direct influences are the lack of appropriate, affordable social care services, educational difficulties, poverty, social exclusion and stress.

About the study

The study was conducted between 1998 and 1999. Sixty young people were interviewed from across England, 36 aged 16-18 and 24 aged 19-25. All of the young people were either caring at the time of interview, or had cared during their childhood, for a parent with a long-term illness or disability. The

young people were contacted via carers' and young carers' support services throughout England.

The interviews were semi-structured and the voice of the young people was paramount. All interviews were recorded and fully transcribed. They were analysed thematically and the words of the young people are used throughout the full report. All quotes are verbatim but names have been changed to preserve anonymity.

How to get further information

The full report, **Growing up caring: Vulnerability and transition to adulthood – young carers' experiences** by Chris Dearden and Saul Becker, is published for the Foundation by the National Youth Agency (ISBN 0 86155 233 4, price £12.95 incl. p&p).