

Technology and time: home care regimes and technology-dependent children

Advances in medical technologies have allowed an estimated 60,000 technology-dependent children in the UK to be cared for at home with their families. This study focused on the experiences of 36 families of children who used one or more medical devices, including dialysis, feeding pumps or breathing aids on a daily basis. It examined the daily care routines of the children and how this affected their lives and those of their parents and siblings. It has several messages for policymakers including the need for more flexible respite services, increased funding for hospices and better co-ordination of social services and healthcare professionals.

Key findings

- Routines relating to the devices varied from family to family depending on what types of devices were used, the children's age and medical diagnosis, and the fluctuations in their health.
- Family routines were variously structured around the children's use of the devices, monitoring of the children's condition, the time taken for the devices to perform their function, and school or work schedules.
- Technical care was provided mainly by the children's parents, particularly mothers, with varying degrees of involvement from other family members and service providers.
- Some children relied on technical care from trained staff to enable them to attend nursery or school.
- One third of the families had help from services in the home and a third received respite care away from the home where the child or the whole family were looked after; however, over half the sample received neither of these services.
- In general, the children's use of medical devices was recognised to have benefited their health and quality of life, and made lives easier for their parents because the children's medical condition was generally more stable.
- Families highlighted problems with: availability of appropriate respite care both away from the home and inside the home; difficulties combining caring and working; sleep disruption; social isolation; and children's and siblings relatively limited or disrupted participation at school and in social activities.
- The priority for health and social care policymakers is to ease the time-demands of caring for a technology-dependent child by providing more technically trained carers and suitable respite care for families.

- Hospital appointments, work schedules and school timetables could be better coordinated to reflect the children's care routines and minimise disruption to parents, children and siblings.
- Assessment of children and families' needs should take account of the impacts on siblings and consider what support is needed for them.
- There may be scope for improving the design of medical devices to minimise sleep disruption.

About the study

The findings are based on the experience of 46 parents, 13 technology dependent children, 15 siblings and one grandparent from 36 families. The data was based on face-to-face semi-structured interviews in the home, time-line drawings and diaries kept over a week.

Further details

The project was part of the ESRC Innovative Health Technology Programme <http://www.york.ac.uk/res/ihl> which examines how people and society will be affected by, and in turn affect a wide range of developments in genetics, imaging technologies, cloning and stem cell research, which continue to challenge people's traditional concepts of the NHS.

Further details

The full report is available at www.esrc.ac.uk

Key words

Home care, respite, medical technology