

Respite care and short breaks for young adults aged 18–40 with complex health-care needs: mixed-methods systematic review and conceptual framework development

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Plain English summary

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Plain English summary

Young adults with life-limiting conditions or complex physical disabilities have complex health-care needs. As more children with complex conditions now survive into adulthood, the number of young adults needing care has risen significantly. Respite care provides essential support for young adults and a break for their families. Lack of respite has a negative impact on the length and quality of life of these young adults, including early death, and physical and emotional strain on ageing parents. Information about what respite care is available after transition to adult services has, to the best of our knowledge, not been gathered nationally.

We looked for evidence about respite care services for young adults aged 18–40 years with complex health-care needs to find out what types of services are available and how well they work for families. We worked with young adults, parents and professionals to identify evidence and understand the findings.

We gathered evidence from lots of sources, including academic papers, reports from organisations and policy documents. We created a ‘knowledge map’ that describes six different categories of respite care currently available: (1) residential, (2) home based, (3) day care, (4) community, leisure and social activities, (5) holidays and (6) emergency respite. None of the documents we found included ratings of how well the services worked or the costs of providing the service, showing that these are areas where future research is needed.

UK government policy had clear intentions on how to provide respite care, including early planning for transition and making respite care available to all those who need it. Young adults, parents and professionals reported that safe, age-appropriate respite care has many benefits for the physical and emotional well-being of all. The biggest barrier to respite after transition to adult services is the lack of appropriate respite services and trained staff. This has a negative effect on the health and well-being of the whole family at a time when they had increasing need for respite care.

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