

The Rt Hon Matt Hancock MP
Secretary of State for Health and Social Care
Department of Health and Social Care
39 Victoria Street
Westminster
London SW1H 0EU

27 October 2020

Dear Secretary of State

We are writing to you as the leaders of organisations representing people living with rare and less common health conditions, many of which require support from both health and social care services. We recognise that as the Government prepares its Comprehensive Spending Review ministers will be considering the resources and policies required to deliver improvements in social care, and we want to stress the importance of effective social care services for people of all ages.

Many of the people that we represent have rare – and sometimes genetic – conditions that they live with from birth or otherwise from a relatively young age. Indeed, many such conditions are those that might have led to an early death in the recent past, but which can now be treated effectively, thus giving people the hope of a longer life expectancy. Nonetheless, people living with these conditions may require ongoing social care support.

Much of the debate about social care reform focuses on care for older people and how it can be paid for. However, in every year since 2015, the number of people of working age requesting social care support has increased at a faster rate than the number of older people requesting such support. Improvements in social care are just as important for these younger people as they are for older people.

We are therefore calling on any package of social care reforms to deliver for people of all ages in five ways.

First, social care services need to be personalised in nature, with the aim of fostering independence and ensuring people are supported to live the life they choose – including being supported to work. People should be given control over the services they receive and who provides them. Where relevant, people also need to experience a seamless handover from child social care services to adult social care services.

Second, assessments of social care support should be aimed at delivering a high quality of life. Arbitrary and repeated assessment processes – which can lead to loss of support, disruption as people are moved between NHS and social care services, and high levels of anxiety – need to be avoided.

Third, social care services need to be closely integrated with both physical and mental health services at both the national and local levels. Future reforms need to strengthen – rather than overlook – the support offered through NHS continuing healthcare services.

Fourth, more specialised social care support is needed for those with particularly complex needs. People living with rare conditions, and who receive specialised care from the NHS which is organised at the national level, typically find that their social care needs are met by services at the local level with relatively little experience of the conditions they live with.

Although important and welcome steps are being taken at the local level to join together NHS and social care – particularly for older people – people with rare health conditions often receive nationally-organised NHS services with underdeveloped links to social care services.

Finally, social care services need to be both properly resourced and financed fairly. This means restoring social care quality and access levels to those last seen in 2009 (which the King's Fund and Health Foundation estimate requires £8 billion a year), and further meeting the growing demands for social care from both younger and older people by investment in more capacity. It also means that reforms which help people meet the costs of social care should be available to all, regardless of their age, and regardless of whether they receive social care in residential care or in their own homes.

We hope that the Government takes the steps we are calling for to deliver effective social care services for people of all ages.

Yours sincerely,

Lord Sharkey, Chair, Specialised Healthcare Alliance
Baroness Wheeler, Vice Chair, Specialised Healthcare Alliance
Baroness Chisholm, Vice Chair, Specialised Healthcare Alliance

Amanda Batten, CEO of Contact and Chair, Disabled Children's Partnership
Amanda Mortensen, Chief Executive, Batten Disease Family Association
Andrea Brown, Chief Executive, National Kidney Federation
Ann Chivers, Chief Executive, Alström Syndrome UK
Anne Keatley Clarke, CEO, Children's Heart Federation
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Bob Stevens, Group Chief Executive, MPS Society
Catherine Woodhead, CEO, Muscular Dystrophy UK
Chris Bradshaw, Chair, The Dystonia Society
Chris James, Director of External Affairs, Motor Neurone Disease Association
Clive Smith, Chair, The Haemophilia Society
Dr Charlotte Augst, Chief Executive, National Voices
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Heidi Travis, CEO, Sue Ryder
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Specialised Healthcare Alliance

FOR EVERYONE WITH RARE AND COMPLEX CONDITIONS

Sara Hunt, Chief Executive Officer, Alex, The Leukodystrophy Charity

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Tara Parker, Director of Programmes, WellChild

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