

Written Evidence submitted by Professor Luke Clements (TRN0006)

Overview comment

I have written widely on the rights of disabled children and disabled adults and their carers. My experience is based on being a solicitor for almost 40 years, as an academic researcher for over 25 years - which for over 10 years was supported by the disabled children's charity Cerebra. I was the legal adviser to the joint Committee that scrutinised the Bill that led to the Care Act 2014 (an Act that incorporated new provisions concerning the transitional process) and my research work has been cited extensively by the Law Commission in its recent investigation into Disabled Children's Social Care Law.

Focus area 1

Although the law has developed innovative approaches in an attempt to regulate the process by which disabled children and their carers move from being the responsibility of Children's Services to being the responsibility of Adult Social Services – these have, in my opinion, been of limited success. The problem stems from the fact that, in practice, the issue is not the adequacy/clarity of the relevant law: the issue is one of 'budgets'.

The relevant institutions (in this case, local authorities and the NHS) operate according to budgets and senior officers' livelihoods often depend upon them staying within their budget ceilings – regardless of how arbitrary the budgets are and regardless of whether adherence to this mandate has a material and adverse impact on the overall financial position of their institution. All too often the question is not whether the resources required are adequate, the question is whether the individual budget is itself adequate and/or sufficiently flexible. In terms of flexibility this invariably concerns the ability to vire money to and from different 'budgets' – against a background of there being a severe lack of incentive to contemplate such action.

Having had 'no hands' on experience of working for a local authority or an NHS body, I am not in a position to explain how services identify those who will need help to transition into adult services. My only comment on this issue, is to observe that (objectively / dispassionately) in many situations it is not in the interests of budget holders to identify individuals who may have call on their resources. In my experience, it is generally only those disabled children and their families who are aware of the need to plan for transitions (and the ability to be sufficiently assertive) that manage to secure timely services and support.

In terms of impact and outcomes, the question concerns 'strength-based' support that focuses on what is positive and possible for the young person. This question avoids the more objectively real and practical issue, namely that in practice the strength-based focus is on the young person's family: a family that may have sacrificed very many things, including paid work, skills development, recreational activities, building up a pension etc. – in order to promote the well-being of the young person. All too often, in my opinion, the transitional

assessment can be characterised as an endeavour to ensure that the family continue in this role: an endeavour to safeguard a specific budget rather than to promote the young person's opportunities and, that of their parents and siblings – and to enable them all to maximise their positive contribution to their community and to the UK PLC.

In terms of appropriateness, in my experience – all too often, transitional planning does not take place unless there has been considerable pressure from the family: all too often there is no plan on the 18th birthday.

In terms of the issue of 'equality and diversity' – disadvantaged families (many with protected characteristics) inevitably find themselves in a profoundly adverse position during the transitional process. If my above premise is correct (concerning the primary role of 'budget protection') then objectively, this reality does not encourage budget holders to take on new responsibilities. If this is so, then only the more 'advantaged' (in terms of wealth, networks and education) will be able to navigate this complex managerial process.

Focus area 2

In terms of the question concerning 'resourcing' – as noted above, I suggest that this is an issue of 'budgets' not 'resources'. The transition process involves the young person's name being entered onto one or more new excel sheets while simultaneously being erased from the Children's Services' excel sheet. This change may not result in the local authority incurring any additional expense – but from an individual budget holder's perspective, it will constitute an additional and unwelcome additional expense. This may then result in new efforts to cut the cost (often a cut to a well-established and effective support plan) and/or an attempt to off-set this 'new cost' by arguing that the young person should be funded from the NHS Continuing Healthcare budget. The net effect, being an additional administrative trauma and uncertainty for the young person and their family. In relation to disabled people and their families finding themselves 'piggy in the middle' of such interagency (budgetary) disputes – it is well established that despite extensive legal obligations on authorities to 'work-together' (dating back to 1948) 'exhortations' of this kind have signally failed.

In terms of 'transitions', there is a strong argument to be made that the Children Act 1989 was a backward step for disabled children – in that it fractured the cradle to the grave social care obligations under the National Assistance Act 1948. Disabled people's needs do not change on their 18th birthday: there is no logic to a system that has the potential to turn upside down, the community care support needs of a disabled young person on their 18th birthday.

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