

Case Study – Luke

Background

Luke is 41 years old and has been severely disabled almost since birth; he has quadriplegic cerebral palsy, contractures of hips and knees, hip dislocation, very little trunk control, stretched bowel and hypersensitivity to touch. He cannot bear weight and is dependent on a wheelchair. He has severe visual impairment and is registered blind, although he has some low-vision sight. In the past he has been recorded as having depression, persistent low mood and anxiety.

For around 20 years Luke has lived in an adapted, purpose built bungalow in a complex for disabled people. Luke needs help with all intimate personal care, all domiciliary tasks and activities of daily living, including accessing the community. During his time in the bungalow, Luke has had the same team of seven carers, some of whom are his family members. With the exception of Luke's mother, all carers are paid.

Luke has received funded support from his council for many years. Until June 2015, Luke's paid-for care costs were £1651 per week (mostly publicly funded with a small contribution from Luke). Changes to the Independent Living Fund (ILF) caused the council to reconsider Luke's package.

The council reviewed Luke's needs, revised the care plan, and gave notice of its intention to significantly reduce his personal budget (PB) to £950 per week - a reduction of over 42%. The reduced budget would mean Luke was alone for 6.5 hours per day, in 3 periods of 2 hours (largely to manage toileting). The council gave two primary reasons for the reduction in PB:

1. Luke could spend more time alone without the benefit of personal assistants (PA) being present
2. Luke could and should reduce the amount he pays his PAs (in line with national minimum wage)

Luke complained, and then issued proceedings for Judicial Review. Luke claimed (broadly):

- The council is in breach of its duties under the Care Act - it has failed to properly assess his needs, to consider the impact on his wellbeing of the anxiety caused by spending unwanted time alone, and the risk of losing his established team of carers
- The council is in breach of its public law duties – its decision is so unreasonable that no reasonable council could have reached it. The council had set a budget and revised its view of his needs to fit that budget
- The council has failed to consider CRPD (Art 19: right to live independently and be included in the community)

Questions

You are the judge hearing Luke's application for judicial review;

1. What are the implications of the Convention on the Rights of Persons with Disabilities?
2. Do you think the council has sufficiently "had regard to" Luke's wellbeing (the impact of spending more time alone, a potential change of carers, a reduction in social activities, his toileting needs etc)?
3. Do you think the council has taken "reasonable steps" to reach agreement with Luke/ his family (as required by the Care Act s27(5))?
4. Has the council evidenced to your satisfaction that the proposed rates for PAs are reasonable?
5. Would you decide in Luke's favour, or in the council's? Why?

Outcome:

- There are no ambiguities in the Care Act in respect of which Article 19 might serve as an interpretative tool
- The assessment duty is an objective duty on the local authority acting via its social workers or OTs (s9(1))
- There is no duty to achieve the outcomes which the adult wishes to achieve; rather there is a duty to assess whether the provision of care and support could contribute to those outcomes (s9(4))
- If no assessment of the matters specified in s9(4) (including the impact on wellbeing of the matters set out in s.1(2)), then there is a breach of the statutory duty – but there was no such breach here
- Luke would still have opportunities to engage in social activity “very limited curtailment does not amount to a breach of s.1 of the Act”
- No evidence that changes to pay/ conditions would result in a break-up of Luke’s team; the issue of a different team being a positive move for Luke’s independence therefore didn’t arise
- “The Claimant is in effect saying to the Council “(a) some of my carers are not prepared to work for the local going rate; (b) therefore, in order to maintain the continuity which I value, you must set my personal budget at a level which enables me to pay them more than that rate”. I do not consider that it is unlawful for the Council to decline to do so”
- Wellbeing has clearly been considered; “It does seem counterintuitive to me, at least if one is referring to a complete or substantial break-up of the team who have looked after the Claimant for so long; but I am not an expert in the field, and I cannot possibly say that the view expressed by Ms Lovelock is irrational”
- “One must always bear in mind the context of an assessment of this kind. It is an assessment prepared by a social worker for his or her employers. It is not a final determination of a legal dispute by a lawyer which may be subject to overzealous textual analysis. Courts must be wary [.....] of expecting so much of hard pressed social workers that we risk taking them away unnecessarily from their front line duties”

Luke’s perspective

- The 3 most important things in my life are:
 - Continuing to have the same carers as “they are my community.”
 - “Familiarity of my team who knows me well” and
 - “My family” (*NB Luke’s father, sister and sister in law all act as paid carers; his mother is an unpaid carer – so there is a significant cross over between carers and family*)
- The outcomes that matter most to me are:
 - Independence
 - the ability to make my own decisions
 - social interaction with my different carers
 - being able to attend a variety of activities in the community (e.g. meals, disabled person’s club)
- If I pay my carers any less, they may leave; they have all been supporting me for between 17 and 20 years. To pay minimum wage to carers of that quality and experience would offer them poor reward
- I don’t want to consider a live-in carer, because although this would be cheaper, I would lose some of the variety and flexibility I have currently. My carers take me to lots of activities and I have them on a 1:1 basis
- I don’t want to try assistive technology because I don’t think it will help

- Historically I have had 2 hours on my own every Tuesday afternoon; I wasn't willing to consider any more time on my own, but by the time of the court case I had agreed to two additional two hour slots on my own (2 x 2 hours). I get very anxious when I need the loo but I have a large button phone if I need emergency help when alone
- I commissioned an independent OT report, which concluded I couldn't be left alone for more than 2 hours a day due to my toileting needs
- Neither me nor any member of my family (including those paid to deliver care) want there to be any change in current arrangements

The council's perspective

- Luke has consistently identified independence as being important to him; for example, an OT assessment noted the importance of reducing Luke's anxiety in order to develop his independence
- Luke and his mother were involved in redeveloping Luke's care plan (although the revision resulted in Luke's formal complaint)
- When we received Luke's complaint, he and his mother were offered a further meeting to discuss his care plan with us; the offer was declined
- Further assessments (e.g. OT) were arranged for Luke, but he and his family have said they're unwilling to continue with meetings, placing their faith in the JR process instead. This was a barrier to progress
- Luke/ his family have refused to consider live in care, although such would meet Luke's needs
- Luke's revised package would continue to offer regular support (although less than 24 hour care: initially 19 hours per day, reducing to 17.5 hours per day) and still allow him support to get out and about
- Luke has only need to use his emergency telephone once; this suggests the risks to him are minimal
- Luke has become dependent on his carers/ family to meet his needs; a change of team could be positive as the current team are inhibiting his independence – it would be unsettling in the short term, but of benefit in the longer term
- Luke's social worker is firmly of the view that more time alone would be beneficial to him
- We gave Luke notice of our intention to reduce the budget, and reduced it gradually over several months to give him some time to get used to it
- Although Luke's carers are being asked to reduce what they earn, the rates offered are still comparable with rates many other service users are paying locally. There is no evidence the existing carers will leave