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The Care Act (UK Government, 2014) specifies the current arrangements applying in England for the assessment and meeting of eligible care and support needs for adults with learning disabilities (as well as all other groups with similar needs). While, previously, eligibility for support was determined at local level, there are now national eligibility criteria that relate to the person's ability to achieve the following outcomes:

- Managing and maintaining nutrition
- Maintaining personal hygiene
- Managing toilet needs
- Being appropriately clothed
- Being able to make use of the adult's home safely
- Maintaining a habitable home environment
- Developing and maintaining family or other personal relationships
- Accessing and engaging in work, training, education or volunteering
- Making use of necessary facilities or services in the local community, including public transport, and recreational facilities or services
- Carrying out any caring responsibilities the adult has for a child.

I recently attended a care plan review for a young man with learning disabilities in a supported living setting. In many respects the review was exemplary. It was clearly conducted with attention to Care Act requirements and all the above outcomes were considered at least in passing. The revised "Care and Support Plan" detailed Tom's (not his real name) needs in self-care, nutrition, domestic support, work and travel. Associated goals were set in all these areas, the needs were noted as being eligible for Local Authority assistance and support arrangements were identified. At the end of the review we came, however, to a need deemed "ineligible" for such assistance and it was here that Tom's anxiety, depression and sometimes self-destructive behaviours were discussed.

Why should such needs be deemed ineligible? Of course it might well be argued that they should be, and, in some circumstances, would be regarded as eligible since maintaining emotional or mental wellbeing is very likely to have an impact on many of the outcomes listed above. But it is notable that the maintenance of emotional wellbeing is not one of the outcomes identified in the Care Act and the social worker involved would have argued that responsibility for such a need belonged primarily with the National Health Service (NHS) rather than the Social Services Department. In other words, this was a *health* need rather than a *social care* need.

This distinction has plagued the provision of services for people with learning disabilities for what seems like forever (e.g., Glasby, 2016). In the UK, health needs are met free at the point of delivery, social care needs are not free unless the person passes the necessary means test. Health needs are to be met by relatively well-paid Doctors, Nurses, Psychologists and other healthcare professionals. Social care needs are (while sometimes assessed by qualified social workers) usually met by unqualified and poorly paid support workers. British governments pay great attention to the funding of the NHS and it is typically a key issue in national elections. Social care funding remains in crisis with no clear future plan to address this (Malli *et al.*, 2019).

However, people with learning disabilities and their families report very mixed experiences of NHS healthcare. Outside of specialist provision, the NHS has a poor record when it comes to meeting the needs of children and adults with learning disabilities as reflected in the difficulty of accessing routine treatment, the apparent discrimination experienced and sometimes highly negative outcomes such as unnecessary death and disability (see, for example, Heslop *et al.*, 2014). However, children and adults with the most significant disabilities may (after a lengthy assessment process) be

deemed to have continuing healthcare needs and have these funded (free, of course) through the NHS. Yet such arrangements are regarded as being implemented in very inconsistent ways in different parts of the country and with different individuals (House of Commons Committee of Public Accounts, 2018). And, despite the sometimes pragmatic benefits for individuals, there remains concern as to the appropriateness of meeting lifelong needs associated with learning disability through a health lens.

Andrew Jahoda's article shows, however, some of the benefits of a health focus on depression. Research on social care remains very limited but healthcare research has demonstrated very clearly that depression can be treated successfully by a range of psychological therapies. In more recent years, this research has extended to consider the application of such treatments to depression of adults with learning disabilities. Jahoda describes some of these treatments and notes the extent to which they have been successful. At the same time, however, Jahoda notes that "social care has a primary role to play in supporting the therapy process and promoting the wellbeing of people with learning disabilities". Of course this brings us full circle, how can social care play this "primary role" if emotional wellbeing is not one of the key outcomes being considered by social care staff?

As noted by Jahoda, depression (and, it can be argued, poor emotional wellbeing more generally) is at least in part a result of the extent to which people with learning disabilities are leading meaningful lives. And such lives would typically be associated with the Care Act outcomes outlined above. To promote the role of social care in maintaining emotional wellbeing we should perhaps start then by showing how these outcomes are centrally relevant – that it is in the interest of achieving such outcomes that social care should be promoting wellbeing more generally. There isn't space to consider all of them here but it may be useful to consider two in more detail – one where the links with emotional wellbeing are clear and already identified, one where more work is required to explore the connections.

Maintaining family or other personal relationships is an outcome we all value. People rate such relationships as one of the most important factors for their wellbeing (Evans, 2011). The breakdown of such relationships contributes to the development of depression (Teo, Choi and Valenstein, 2013). Good relationships with people you can confide in and that provide emotional support are also crucial to recovery. Adults with learning disabilities also greatly value relationships but, beyond their families, they are much less likely to have close friends or partners and will often struggle to find opportunities to meet others and develop such relationships (see, for example, McMahon, Bowring and Hatton, 2019). In such a context, adults living in social care settings rely heavily on social care staff for emotional support. Yet, staff turnover rates are very high and people who struggle to develop close relationships anyway are often required to form many new relationships every year. The quality of such relationships is often problematic and, as a result, people don't receive the emotional support they need or receive it only inconsistently. In any case such relationships, even when very supportive, only exist because they are paid for and will inevitably lack the balance and mutuality inherent in freely given friendship or partnership. Achievement of better family and personal relationships is also likely to be endangered by problems of wellbeing given, for example, the extent to which someone who is depressed may avoid social situations or be socially unresponsive. The social care task here, then, is relatively clear, albeit not easy. Family and other relationships should be supported as much as possible. Recent initiatives in this area include the Supported Loving network (Bates, 2019) and social inclusion activities of various kinds. Attention is also required regarding the skills of social care staff to be emotionally supportive and to develop and maintain good quality relationships with those they support, while being aware of the inevitable

boundaries to such relationships. These activities address an important social care outcome area as well as promoting emotional and mental wellbeing.

Managing and maintaining nutrition is an important social care outcome whose links to emotional wellbeing are also significant but less explored. Good nutrition is essential to good physical health and there are clear links between physical and mental health. Depression, in particular, is a frequent concomitant of physical health problems especially where these are chronic and have painful or restrictive effects on individuals and their lifestyles (Pilling *et al.*, 2009). People whose emotional wellbeing is impaired are also likely to need more support to manage and maintain good levels of nutrition being both more likely to eat unhealthily and to have trouble bothering to attend to their nutritional needs. Problems of nutrition have been increasingly recognised in recent years with clear evidence of people with learning disabilities experiencing, for example, higher levels of obesity and associated health problems (such as diabetes), and needing the support of social care staff to participate effectively in weight management programmes (see, for example, Adolfsson, Ek and Carlsson, 2019).

Similar analyses could be presented for the remaining Care Act outcomes. Ultimately, peoples' needs are not divisible into neat categories of social care and health (or for that matter education or housing etc.) Bureaucratic regimes that rest on such divisions will always struggle to meet peoples' needs in a holistic and effective way.

To return to the example described earlier, Tom is lucky enough to be supported in a setting where, despite his emotional wellbeing needs not being regarded as eligible from a social care perspective, their links to other needs are recognised and the social care provider has been able to both support emotional wellbeing directly and make arrangements for additional specialist support. Just don't tell the social worker!

References

Adofsson, P., Ek, P. and Carlsson, O.U. (2019), "Dietitians' challenges when consulting to adults with intellectual disabilities", *Tizard Learning Disability Review*, Vol. 24 No. 4, pp. 153-62.

Bates, C. (2019), "Supported Loving—developing a national network to support positive intimate relationships for people with learning disabilities", *Tizard Learning Disability Review*, Vol. 24 No. 1, pp. 13-19.

Evans, J. (2011), Findings from the National Well-being Debate, Office for National Statistics, London.

Glasby J. (2016), "If integration Is the answer, what was the question? What next for English Health and Social Care Partnerships?", International Journal of Integrated Care, Vol. 16 No. 4, p. 11.

Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A. and Russ, L. (2014), "The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study", *Lancet*, Vol. 383 No. 9920, pp. 889–95.

House of Commons Committee of Public Accounts (2018), "NHS continuing healthcare funding", available at: https://publications.parliament.uk/pa/cm201719/cmselect/cmpubacc/455/455.pdf (accessed 13 December 2019).

McMahon, M., Bowring, D.L. and Hatton, C. (2019), "Not such an ordinary life: a comparison of employment, marital status and housing profiles of adults with and without intellectual disabilities", *Tizard Learning Disability Review*, Vol. 24 No. 4, pp. 213-221.

Malli, M.A., Sams, L., Forrester-Jones, R., Murphy, G. and Henwood, M. (2018), "Austerity and the lives of people with learning disabilities. A thematic synthesis of current literature", *Disability & Society*, Vol. 33 No. 9, pp. 1412-1435.

Pilling, S., Anderson, I., Goldberg, D., Meader, N. and Taylor, C. (2009), "Guidelines: Depression in adults, including those with a chronic physical health problem: Summary of NICE guidance". *BMJ (Clinical research ed.)*, Vol. 339, b4108.

Teo, A.R., Choi, H. and Valenstein, M. (2013), "Social relationships and depression: ten-year follow-up from a nationally representative study", *PloS one*, Vol. 8 No. 4, e62396.

UK Government (2014), The Care Act.