

Learning disabilities and the value of unpaid carer

People with learning disabilities draw on different types of support to enable them to live rich and fulfilling lives. But the support given by unpaid carers is often overlooked and undervalued. We surveyed unpaid carers of adults with a learning disability and found that:

- On average, the support delivered by each unpaid carer in our sample would have cost the taxpayer £114,000 per year to deliver equivalent care. The provision of unpaid personal care alone delivered the taxpayer an annual saving of £55,000 for each carer in our sample.
- Total hours of unpaid care provided per day ranged from 8 to 16 hours for those cohabiting with the person they provide care for, and 5.5 to 8.5 hours for those who provide unpaid care for an adult with learning disabilities that lives elsewhere.
- Unpaid caring roles for adults with learning disabilities differ from what might be expected. Personal care, such as support washing, dressing and eating, comprised only part of the care delivered. Not to be overlooked is the impact of providing other essential care, such as supervision to ensure safety, assisting with leisure activities, providing transport, ordering medications, and liaising with health and social care staff. This means that the unpaid carers in our sample got little genuine downtime.
- Caring responsibilities limit unpaid carers' opportunity to earn income through employment, leaving them more reliant on the social security system for support, which is often insufficient. Just over half the unpaid carers in our sample had household income below or around the poverty line.
- The unpaid carers in our sample generally scored far lower than the national average on wellbeing measures. This was particularly notable for measures of loneliness and burnout.
- Because learning disabilities are by definition lifelong, the impact of caring responsibilities for family members (especially parents) can differ from other caring roles, such as caring for an elderly relative. The lifelong caring commitment creates a loss of agency and limits the long term choices unpaid carers can make.
- When asked for their priorities for better support, all but one of the unpaid carers in our sample demanded more respite and services for the person they care for. This points to a social care system that is not doing enough to support people with learning disabilities and their families.
- During the Covid-19 pandemic, unpaid carers have filled in the gaps left by the care system, leaving many exhausted. None of the unpaid carers in our sample have seen support return to pre-pandemic levels, even as Scotland moves "beyond level 0". With no clear plan for a return to normality, unpaid carers are facing an uncertain future.

The findings in this report demonstrate the vital role that unpaid carers of adults with a learning disability play, but also the pressure that is placed on them due to a lack of support from society's network of support systems. It is clear that the status quo is not sustainable. Support needs are likely to increase for adults with learning disabilities and unpaid carers. As we emerge from the pandemic and begin a new parliament, many will be looking to policy makers for a deliverable plan to meet those needs.