Poverty and MS: a rapid evidence assessment

Summary report

MS Society summary of finding
from a rapid evidence
assessment by Andrea Finney,
Social Research and Statistics

March 2020

Let's stop MS **together**

The most recent estimates show that almost two fifths of disabled working age adults are in poverty. Compared to around a fifth of non-disabled working age adults.[i] This report uses existing evidence to understand how likely people with or affected by MS are to experience poverty and the reasons for this.

It shows:

- We don't know how many people with or affected by MS experience poverty. But there are higher levels and deeper experiences of poverty among disabled people[ii].
- Lower or lost earnings, extra costs and high social and personal care costs make living with MS difficult financially. And can contribute to poverty and lower standards of living.
- Those who are financially insecure are less likely to access the services and support they need[iii].

Extra costs

- People with MS and their families often have extra costs related to the condition. These costs include items such as food and fuel, transport and special equipment. Fluctuating symptoms can make it more difficult to manage budgets and consumption[iv].
- Estimates for extra costs for people with neurological conditions estimates these are around £800 per month, rising to £1,200 per month for physical impairment[v].
- Benefits to support with the extra costs disabled people face often fall short of the costs people actually have. For example, one study found the average extra costs of disabled adults with the lowest incomes were £507, but only £58 was received in disability benefits[vi]. Another found that extra cost benefits were being used for everyday expenses rather than extra costs of disability[vii].
- Due to the failure of the benefit assessment process to recognise the invisible and fluctuating nature of MS symptoms[viii], people with MS often do not get the level of benefits they are entitled to.
- Both these issues have become worse because of the change from Disability Living Allowance to Personal Independence Payments, and reduced awards under Universal Credit.

Care costs

- Estimates suggest as many as 6 in 10 pay additional costs to meet their social care needs[ix]. The MS Society have estimated that the amount families spend on care could total £110,000 in lifetime costs[x].
- Unmet care needs have been linked to poverty among disabled people in general[xi]. And people with MS who are struggling financially are also more likely to have unmet care needs[xii].
- Looking across the social care and disability benefits system, these limited resources fail to protect the most severely disabled from deep poverty. This is most severe for those who are unaware of, or have difficulty negotiating the systems for claiming care support[xiii].

Disruption to employment

- Fewer people with MS are employed, compared to the general population. More work part-time, or leave work earlier than they would otherwise expect to[xiv].
- Carers also often lose income by reducing or leaving work to provide care. The financial consequences of this can be significant.[xv]
- Support from employers is important, but is often lacking[xvi].
- The out of work benefit Employment Support Allowance is also a gateway to other services. But a significant minority of people with MS are not getting the support they need. Again, the fluctuating and hidden nature of MS can be an issue.[xvii]

Impact on quality of life

- Although there are no poverty estimates specific to MS, financial insecurity is common among people affected by MS. Living in poverty and financial insecurity can have a severe impact on disabled people's quality of life, including a worsening of their physical and mental health[xviii] and social participation[xix].
- Evidence points towards the 'double disadvantage' of MS and poverty, With those who are financially insecure finding it more difficult to access services they need to manage their MS[xx], resulting in unmet needs for care, support, and information[xxi].

Compounding factors

- Early onset[xxii], progressive and more severe forms of MS[xxiii] have greater financial impact. Cognitive impairment[xxiv] and co-morbidity (especially mental health problems)[xxv]are especially high-risk factors for poverty.
- Evidence suggests that in the early days of MS, while income may still be higher than later on, financial insecurity and difficulty in paying bills may be more common[xxvi].
- Financial impacts are likely to be more severe for people of working-age who are more likely to borrow money to invest, while savings and wealth peak in early retirement. Diagnosis of MS, which is common in people's 20s and 30s may cause greater disruption to the ability to earn and save.
- Financial wellbeing is also likely to be influenced by other circumstances. For example, poverty is higher among disabled people renting and living alone. They are also more likely to be paying more on rent, and homes are likely to be unsuitable or unsatisfactory[xxvii].

To find out what we are currently recommending to Government, read our Policy Positions on welfare and care and support.

---

[i] Social Metric Commission (2019) Measuring Poverty 2019: A report of the Social Metrics Commission
[ii] Cribb et al (2018) Living standards, poverty and inequality in the UK: 2018. Institute of Fiscal Studies
[iii] MS Ireland (2016) MS My Needs Survey
[iv] George et al (2013) The Energy Penalty: disability and fuel poverty. Centre for Consumers and Essential Services, University of Leicester
[v] Extra Costs Commission (2015) Driving down the extra costs disabled people face
[vi] Touchet et al (2019) The disability price tag: Technical report. Scope
[vii] Snell et al (2014) Fuel Poverty and Disabled People: The impact of policy change. Centre for Housing Policy, University of York
[viii] Erez (2019) PIP fails: How the PIP process betrays people with MS. MS Society
[ix] MS Society (2020) My MS My Needs Survey 2019
[x] MS Society (2019) Government inaction causing catastrophic care costs for people with MS
[xi] Leonard Cheshire (2017) Essential but Unaffordable: Poverty, social care and disability
[xii] MS Society (2020) My MS My Needs Survey 2019
[xiii] Hancock et al (2016) Disability and poverty in later life. Institute of Fiscal Studies
[xiv] MS Society (2020) My MS My Needs Survey 2019
[xv] Carers UK (2019) State of caring 2019
[xvi] APPG for MS (2016) Employment that works: Supporting people with MS in the workplace
[xvii] MS Society (2017) MS Society Policy Position statement: Employment Support Allowance
[xviii] Leonard Cheshire (2017) Essential but Unaffordable: Poverty, social care and disability
[xix] Equality and Human Rights Commission (2019) Is Britain Fairer: The state of equality and human rights 2018
[xx] MS Ireland (2016) MS My Needs Survey
[xxi] MS Society (2020) My MS My Needs Survey 2019
[xxii] Chwastiak et al (2007) Psychiatric Issues in Multiple Sclerosis. PsychiatrClinNorthAm;30(4) 803-817
[xxiii] MS Ireland (2016) MS My Needs Survey
[xxiv] Equality and Human Rights Commission (2019) Is Britain Fairer: The state of equality and human rights 2018
[xxv] Cribb et al (2018) Living standards, poverty and inequality in the UK: 2018. Institute of Fiscal Studies
[xxvi] De Judicibus et al (2007) The impact of the financial costs of multiple sclerosis on quality of life. Springer Link
[xxvii] Equality and Human Rights Commission (2019) Is Britain Fairer: The state of equality and human rights 2018

We're the MS Society.
Our community is here for you
through the highs, lows and
everything in between.
We understand what life's like with MS.

Together, we are strong enough to stop MS.

mssociety.org.uk

Contact us

MS National Centre 020 8438 0700
info@mssociety.org.uk

MS Helpline Freephone 0808 800 8000 (weekdays 9am-9pm)
helpline@mssociety.org.uk

Online
mssociety.org.uk www.
facebook.com/MSSociety
twitter.com/mssocietyuk

MS Society Scotland
0131 335 4050
msscotland@mssociety.org.uk

MS Society Northern Ireland
028 9080 2802
nireception@mssociety.org.uk

MS Society Cymru
mscymru@mssociety.org.uk

Multiple Sclerosis Society.
Registered charity nos. 1139257 / SC041990.
Registered as a limited company by guarantee
in England and Wales 07451571.

Let's stop MS together