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Prevention: wrestling with new economic realities

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Abstract

Purpose: To discuss the economic pressures on long-term care systems, and describe how an economic case might be made for better care, support and preventive strategies.

Design: Discussion of recent developments and research responses, with illustrations from previous studies.

Findings: Economics evidence is highly relevant to decision-makers in health, social care and related systems. When resources are especially tight, economics evidence can sometimes persuade uncertain commissioners and others to adopt courses of action that improve the wellbeing of individuals, families and communities.

Originality: This paper uses long-established approaches in economic evaluation to discuss preventive and other strategies in today's challenging context.

Keywords

economics, intellectual disability, mental health issues, research design, modelling, cost-effectiveness, prevention.

Unprecedented challenges

Decision-makers in health, social care, housing and many other systems are facing new and daunting economic realities: needs and aspirations continue to grow while both public and private resources continue to shrink. Not surprisingly, as they wrestle with this new reality, many decision-makers are looking at *prevention* as one possible solution.

Today's challenges stem in part from yesterday's successes. Population ageing is one of the greatest achievements of the past 100 years, due in large measure to public health investments and treatment breakthroughs. More people are staying alive for longer, and enjoying better wellbeing, including many people with physical and intellectual disabilities. But in most countries these achievements also have a downside, since current health, social care and other arrangements to support

¹ This views expressed in this paper are those solely of the author, and do not necessarily represent the views of any bodies that fund or support the author's research, nor of the NIHR School for Social Care Research, the Department of Health, NIHR or NHS.

people with long-term needs and to pay for that support are generally seen to be unaffordable if left unchanged for the future. For example, in the 20-year period between 2010 and 2030, it is projected that there will be a 51% increase in the number of people aged over 64, and a 101% increase in the number aged over 84 (House of Lords 2013). If arrangements for long-term care remained unaltered, these demographic trends will hugely increase the costs of care, both in absolute terms and as a proportion of total national income (Dilnot Commission, 2011). The costs of care and support for people with dementia, the prevalence of which is very much higher in older age groups, will grow especially fast (Comas *et al.*, 2007).

The ageing of the population is a cause for celebration. Another such trend that warrants celebration but also raises challenges is the major shift away from institution-based care to services that are more likely to be community-based. Of course, deinstitutionalisation is more rhetoric than reality in many countries and, even where it has occurred, replacement arrangements are often woefully inadequate. Nevertheless, one consequence is that older and disabled people today have different expectations compared to previous generations: they are much more likely to demand and expect access to the same opportunities as those available to any other citizen. This manifests itself in, for example, higher aspirations for participation in further and higher education, paid employment, social participation, e-inclusion, friendships and family roles, and generally for greater control over decisions that affect their lives. But these positive aspirations have not always been fully met, and one reason is again the concern about affordability.

Accompanying the growth in needs and the changes in aspirations – both of which will surely continue for the foreseeable future – are national and international economic difficulties that are unprecedented in modern history. That is why many budget-holders might feel as if they are caught in a 'perfect storm'. Governments in many countries have responded by introducing austerity measures that are not merely biting, but swallowing too. For example, Sully and Bowen (2012) describe widespread cuts in learning disability services (now more than a year ago: the situation will surely have got worse since). At the same time, many individuals are losing their jobs, many families are facing real falls in household income, and many claimants are seeing benefit entitlements withdrawn or reduced.

A third of the almost 3 million people currently unemployed in the UK have been out of work for more than a year. About one in five households are 'income-poor' (defined as having income below 60% of the median after housing costs have been paid). Household debt is high and rising. But we know that debt is a risk factor for mental illness (Fitch *et al.*, 2011), while poverty and deprivation more generally are risk factors for intellectual disabilities (Emerson *et al.*, 2011).

A perennial issue is that all resources are scarce, whether it is the time of skilled staff, places in formal care settings, public budgets, access to therapeutic environments, or the availability of unpaid care from family and friends. Difficult decisions have to be taken, therefore, about how to use available resources to achieve the best possible outcomes, whether those are gauged in terms of improvements in quality of life, better access to everyday activities, greater efficiency in the delivery of support, or a more egalitarian distribution of available resources. And all the while the economic prospects for the UK continue to suggest that things will get worse before they start to get better, the challenge of scarcity becomes all the more acute.

Economic consequences

Before turning to the question of preventive initiatives, it is helpful to take a short diversion to understand some of the economic consequences of some long-term needs.

Intellectual disabilities have consequences across many life domains, leading to potentially wide-ranging needs for support from many systems (health, social care, housing, employment, criminal justice, income support, social security). The direct costs of care and support for many people are high, but the indirect costs of intellectual disabilities – those that fall to families and to the wider society – can be high too.

For example, a study that my group carried out a little while ago estimated that the lifetime cost in the UK for someone with autism and intellectual disability was £1.2 million at 2005/06 price levels (Knapp *et al.*, 2009); broadly speaking, these are the *additional* costs associated with these disabilities. For someone with autism but *without* intellectual disability the lifetime cost was around £800,000. These costs include treatments delivered by the NHS, accommodation funded by housing departments, support funded by local authority social care budgets, special education, out-of-pocket payments by families for treatment or care, and the personal and societal losses associated with disrupted employment. The economic impacts falling on families are often overlooked in policy discussions.

A second example can be given: Strydom *et al.* (2010) estimated that it cost £42,000 per year (again in 2005/06 prices) to support a single older person with intellectual disability, drawing their data on the population of people with intellectual disabilities aged 60 years and over in five London boroughs (and including those living in residential care settings). One of the conclusions from this study was that 'Older adults with intellectual disability are a growing population who consume a significant, disproportionate and increasing proportion of resources, although perhaps less than their morbidity levels would suggest is equitable according to need' (p.137).

This last clause is important because even though the costs just quoted might look high, they actually measure only what society has been prepared to spend, and not what some observers might think *should* be spent in order to meet care needs, satisfy personal preferences or promote quality of life. But while there can be no doubt that the needs, preferences and quality of life of people with intellectual disabilities warrant much greater attention, it is an uphill task to argue for diverting substantially more resources to this area at a time when the national economy is in recession and when public expenditure is particularly under pressure. This absolutely does not mean that the case should not be made – on professional, moral, social and other grounds – but it may be necessary to take a different tack.

It is at times like these that (well-judged, robust) economic evidence can often make a difference.

Making the economic case

Examining the economic case for prevention – in any field – ought to be straightforward, for the underlying principle is simplicity itself – spend now to save later – and one just needs to compare the two. But it is not always easy to populate that simple statement with convincing evidence. One reason why it is difficult is that some preventive initiatives are universal, which can make them quite expensive to launch. Others might be targeted on specific groups of people, but the identification of those people is itself a rather costly process. A second reason is that the eventual savings that flow from a successful preventive strategy might be a long way down the road, whereas policy makers want (and, when it comes around to re-election time, feel they desperately need) the evidence now. The data required to provide 'proof' of successful prevention are quite demanding too, for the main impact that one is (by definition) trying to measure is the *absence* of something, and measuring something that is not there can be tricky. In the intellectual disability field the argument is also going to have to span a number of systems (health, social care, housing, employment and so on) to gauge the full impact, and then to explore what 'horse-trading' would be needed to get concerted action.

Economists do not have a box of tricks to magic away these practical difficulties, but what they can offer is a framework that has the potential to generate evidence that might connect with the concerns of hard-pressed decision makers. There are five elements to that framework:

- a. cost-effectiveness;
- b. costs;
- c. outcomes;
- d. equity; and
- e. design.

a. Cost-effectiveness: A cost-effectiveness analysis does exactly what it says: for two or more interventions or strategies it compares the resources used by each (the costs) with the outcomes achieved by each (the effectiveness). If one intervention (which could be a preventive strategy) was simultaneously less costly and more effective than another (which could be the option of 'doing nothing'), then it would look pretty attractive to the hard-pressed budget-holder. After all, it improves health or wellbeing while saving money. If, however, one intervention achieves better outcomes than the other, but only at a relatively higher cost, the decision-maker will need to decide whether the better health, wellbeing or other outcomes are *worth* the greater expenditure. There is no simple way to judge such 'worth': it is in the eye of the beholder, and different beholders could well reach different judgements. The crucial point is that someone has to look at the trade-off between better outcome and higher costs, and then make the call. Politicians are elected to do these kinds of things, and at a different level senior commissioners are entrusted with tasks of this kind.

b. Costs: Intellectual disabilities are different from many other conditions in that they have personal, familial and societal impacts that can span many systems and budgets. When examining the economic case for prevention, it might therefore be necessary to reflect on the impacts on health, social care, housing, education and

employment-related costs, on social security benefits received, and on individuals and families. This in turn makes it necessary to tackle the age-old problem of coordinated action across agencies – and coordinated calls on budgets – to ensure, in the first place, that agencies work together to invest in preventive strategies, and second, that the economic pay-offs from such strategies are shared out appropriately. It is often the case that action by one service or system has its greatest impact elsewhere, but many things can get in the way of good coordination, including professional rivalry, narrowly framed performance measures and simply the slow churn of bureaucracy.

c. Outcomes: If an economic case is to be made then it needs to look beyond costs, and this is why my first subsection above concentrated on cost-*effectiveness*. The conceptualisation of effectiveness or outcome also needs to be credible. Preventive strategies are not mooted or initiated primarily with the aim of saving money, or at least one hopes not, but because they have the potential to save or improve lives. Any economic evidence should therefore include adequate (better still, *excellent*) information on what a preventive strategy would achieve in terms of, for example, better health, improved personal functioning, greater and more meaningful social participation, and enhanced quality of life.

d. Equity: Any policy shift or practice change will affect different groups in society in different ways. This applies as much to preventive strategies as to any other effort. A government-funded programme to open up access to sport and leisure facilities to older or disabled people could considerably improve the physical and mental health of potentially thousands of individuals, but at a cost to taxpayers. Offering respite services to provide some relief to family carers will certainly benefit them, but it might not necessarily be enthusiastically welcomed by the individuals being cared for. In assessing a preventive strategy, information is needed on who wins and who loses.

e. Design: Lastly, and this is very much a research issue, there is a need for ingenuity in designing the collection, analysis and interpretation of evidence. To gather data on the costs and outcomes of preventive strategies – what they are and how they are distributed – the researcher is unlikely to be able or perhaps want to use a randomised control design. There is nothing wrong with the randomised design, for it is undoubtedly the best approach to adopt in order to answer a range of questions, but it might not be a feasible design in evaluating whether a preventive strategy works or is cost-effective.

Thus, while certain types of question need the robustness that comes from a randomised trial, such as when deciding which medication is better for the treatment of a particular illness, there are also questions that need evidence that a randomised design cannot easily provide. It would be infeasible, and quite possibly unethical, to ask people to remain in their 'randomised groups' for many years while the research team sought to gather data to assess the long-term consequences of different treatments or care approaches. Moreover, decision-makers today are quite likely to be urging the research community to deliver evidence somewhat faster than would normally be associated with a design such as a randomised trial which will be setting out to collect new ('primary') data. In these circumstances there is a good

case for looking to alternative approaches to generate insights that could inform commissioning and other decisions.

Modelling

An approach that we have found to be helpful is to use some form of mathematical modelling (such as a simple decision tree approach), populated with data that have been collected previously in trials, observational studies or routine management information systems ('secondary data'). Models are representations of what might happen in reality, for example tracing pathways through care for individuals with particular characteristics or needs. It is then possible to model the pathways for two or more different care arrangements or approaches, calculate the associated outcomes and costs, and then compare in order to gauge whether one is more effective, cheaper or more cost-effective than the other. Models are more generalisable and flexible than studies that collect primary data, and they can also generate findings much earlier. But they are clearly simplifications of reality, and they are only as good as the data available to populate them, so that their limitations do need to be borne in mind.

Some examples can be offered. There has been extensive research on parenting programmes where there is a child in the family with a conduct disorder, including almost two dozen randomised control trials. Bonin *et al.* (2011) modelled the economic pay-offs from such parenting programmes over a 25-year time span by tracing through the consequences for service use (health, social care, special education), contacts with the criminal justice system (particularly in adolescence and early adulthood), and patterns of employment. The cost of a parenting programme averaged around £1,200 in 2008/09 prices, but the economic return over a 25-year period was found to be somewhere between 2.8 and 6.1 greater than this intervention cost (the position on that range depending on the assumptions made in the model). Bonin and colleagues also found that the economic case for this intervention would be much greater if the drop-out rate from the programmes could be reduced.

Another study using modelling of this kind found that there could be savings to the public purse in quite a short time period when investing in relatively low-cost community capital-building initiatives. A community navigator scheme focused on offering housing advice to individuals cost around £600 per year per individual supported, and generated benefits to communities and individuals by preventing homelessness and use of crisis services, and resolved some housing issues without further involvement from the statutory sector. The net economic value of this community navigator service was more than £1,900 per person (at 2010 prices) over the course of a year (Knapp *et al.,* 2013). Other modelling analyses as part of the same study found that time banks, where volunteers contribute their skills and practical help in return for services provided by fellow participants, could deliver savings of £1,300 per person, and befriending schemes had a net economic value of just over £400.

We also used the same analytical approach to good effect in investigating the economic case for 15 mental health promotion and mental illness prevention initiatives for which there was already robust evidence of effectiveness. The work on

parenting programmes by Bonin *et al.* (2011) summarised above was one of those 15 analyses. Our report, giving the details of the economic case for each of these prevention and promotion initiatives was published by the Department of Health (Knapp *et al.*, 2011) and has proved quite helpful in discussions of policy and commissioning decisions.

Modelling methods of this kind are currently being used to explore whether there is an economic case for some new interventions for young people with intellectual disabilities whose behaviour is said to be challenging, and also in a study of interventions for people with autism, linked in part to an earlier study by Felce *et al.* (2008). The findings from these studies will be available soon.

Making connections

Economics evidence should not dominate decision-making in health, social care or other systems, but it really does need to be stirred into the mix along with evidence on what needs are being met (or *not* being met), what other outcomes are achieved, and how well care and support arrangements match up to the preferences of the individuals being supported and of their families. In periods when resources are especially tight, economics evidence can sometimes persuade uncertain commissioners and win over reluctant strategic decision-makers. Exploring whether preventive strategies have the potential to be cost-effective and then broadcasting that message loud and wide would be quite a useful way to wrestle with today's reality.

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