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Great leap backwards

The UK's austerity programme has disproportionately affected children and people with disabilities

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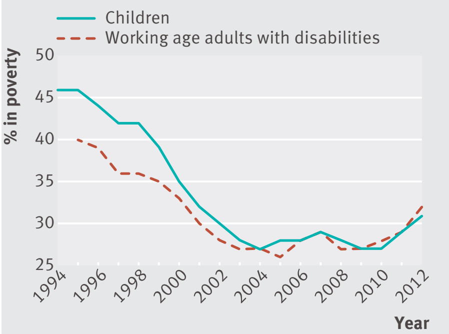
Many health outcomes for children and people with disabilities in the UK remain poor. More children and young people are dying in this country than in comparable countries in northern and western Europe.[5 6] Within the UK there are striking inequalities in the life chances of children based on the social circumstances into which they are born—a baby girl in Manchester can expect to live 15 fewer years in good health than a baby girl in Richmond.[7] There are more than 10 million people in the UK with a disability, with people living in the most deprived areas twice as likely to report a disability as people in the most affluent parts of the country.[8] People with learning disabilities and mental health problems in the UK are also more likely to experience serious illnesses at a younger age and die sooner as a consequence.[9]

But policies can make a difference. The levels of poverty experienced by children and people with disabilities fell substantially in the decade before the global financial crisis (figure).[10] Changes to the tax and benefits system and the targeted provision of preschool education through Sure Start children's centres contributed to the decline in child poverty.[11] Policies in social care, employment, social security, transport, and housing also supported disabled people's right to independent living,[12] with the employment of people with disabilities increasing from 38% in 1998 to 47% in 2009.[13] Now we see clear signs that this progress is being undone.

Child health and wellbeing has taken "a great leap backwards" in many countries in the Organisation for Economic Cooperation and Development (OECD) according to Unicef,[14] with the UK one of the most affected. Poverty is now rising for families with children and adults with disabilities, and we face a decade of rising absolute child poverty, unprecedented since records began in the 1960s.[15] This has important implications for health. It is likely to harm child health now, as well as casting a long shadow forward, damaging health in adulthood. Rising poverty among people with disabilities is likely to cause greater social exclusion and increase health inequalities.



Proportion of children and adults with disabilities living in poverty in the UK (below 60% of median income for 2010-11 held constant in real terms after housing costs[10])

Although the financial crash had serious consequences for public health,[16] the programme of austerity is equally concerning because people with disabilities and children are being disproportionately affected. Changes to welfare have disproportionately reduced the income of the most disadvantaged families with children.[17 18] Food poverty has risen exponentially in the UK over the past few years,[19] with well over half a million children living in families who cannot afford to feed them properly.[20]

Low incomes and benefit sanctions

This has been driven by low incomes and benefit sanctions according to the All-Party Parliamentary Inquiry into Hunger in the United Kingdom.[21] Severe cuts to funding for local government have hit the poorest places hardest.[22] As a consequence funding for children's centres is falling, with large numbers facing closure[23] and funding of children's social care is being cut in the places that need it most.[24] Given the wealth of evidence indicating that we need greater investment in the early years of life to reduce health inequalities, doing the opposite is of great concern.

People with disabilities claiming benefits because they are unable to work have been subjected to more stringent medical assessments. Concerns have been raised about the effectiveness and fairness of these assessments,[25 26] in addition to the potential for adverse mental health consequences.[27 28] Similar changes are being applied to benefits that contribute towards the additional care and mobility related costs faced by people with disabilities,[29] and changes to housing benefit and council tax also disproportionately affect people with disabilities.[30] Overall people with disabilities are set to lose £28bn (€35bn; $44bn) of support from 2010 to 2018,[31] exacerbated by pressures on local authority budgets.[12]

But the worse is yet to come.[32 33] The prescription in the Chancellor's autumn budget is for faster, deeper cuts to welfare and public services, with public spending falling to the lowest level as a proportion of national income since before the last war. The Institute for Fiscal Studies has described these as "colossal cuts," raising the question, "Is this a fundamental re-imagining of the role of the state?"[32]

How have we let this situation arise? We suggest that these policies represent a collective failure to protect the rights of children and people with disabilities. The Joint Parliamentary Committee on Human Rights has expressed concern that the cumulative effect of welfare reform will constitute a contravention of the government's obligations to protect the rights of people with disabilities.[34] The children's commissioner has further warned that the government's welfare reforms pose real risks to the rights of children and that the imposition of a benefit cap would contravene the UN convention on the rights of the child.[35]

As part of Due North, *The Inquiry on Health Equity for the North of England*, we highlight key actions needed to reduce health inequalities. These include embedding a rights based approach to children's health across government and a cumulative assessment of the effect of welfare reform and cuts to public services on children and people with disabilities. We recommend that Public Health England should lead this, assessing the impact of these policies on health inequalities and developing a charter to protect the rights of children to the best possible health.[7] These arguments are not just about the evidence. Protecting the rights of the most vulnerable groups in society, including children and people with disabilities, is morally and legally the right thing to do.

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- Find out more about evidence based medicine in *The BMJ* at http://www.bmj.com/content/evidence-based-medicine
- Editorial: Evidence based policy for illicit drugs (*BMJ* 2010;341:c3374)
- Views & Reviews: It's time for the UK government to fully review drug policy (*BMJ* 2011;343:d5235)

What would an evidence based drug policy be like?

Policy must move beyond evidence based to evidence infused to produce public good

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In their foreword to the UK Home Office's comparison of drug policies in various countries, government ministers stated that "the UK will continue to advocate a balanced, evidence-based approach to the misuse of drugs internationally."[1] In a subsequent Commons debate there was cross party support for the motion that "this House…believes that an evidence-based approach is required in order for…the Government to pursue the most effective drugs policy."[2] This flurry of attention raises the question: what would an evidence-based drug policy look like?

Although the prohibitionist legislative framework is the main focus of calls for reform, it is just one element of policy. Most countries have drug policies that include activities to reduce the demand for drugs, the harms associated with their use, and their supply. Evidence-based policy suggests a neat menu of well evidenced interventions from which a government can select the right mix for its circumstances. However, in common with many areas of social policy, drug use is multifaceted and "what works" is rarely clear cut and often contested. Both the nature and patterns of use, and the responses to these, vary between countries and over time; the interventions that will be appropriate and effective will therefore also vary. Nevertheless, it is important that the available evidence is considered if policies are to be effective, provide value for money, and avoid unintended consequences.

Several recent publications have sought to pull together the current evidence, both positive and negative, for drug policy.[3 4] These, and the Home Office's study, highlight the evidence of benefit from a range of interventions, particularly treatments and programmes of harm reduction for people with problematic opiate use.[1] Unfortunately, the evidence base for many other common interventions, in particular in law enforcement and drug education, is weak and some may even do harm.

Evidence infused

These reports also highlight several other important challenges for evidence based policy making. Firstly, whether something can be considered successful depends on the goal. For example, strong evidence exists for the effectiveness of heroin assisted treatment in reducing the harms associated with heroin use among people with entrenched problems for whom other forms of treatment have failed.[5] However, other interventions will be required to support people addicted to other drugs or seeking to maintain abstinence.

Secondly, what has been shown to work in one context may not readily transfer to another. This is shown by the varying success of drug courts. Although the evidence is largely positive in the US, the picture is mixed and much less positive elsewhere, including in the UK.[6] This underlines the importance of continuing to review effectiveness and develop robust indicators of outcomes once policies have been implemented. The same is true for innovative programmes where the evidence is promising but as yet limited, as in the case of take-home naloxone.[7] Public policy and criminal justice interventions should be studied and trialled using scientific methods familiar in health[8 9]; this will generate tomorrow's better evidence.

Openness to negative evidence

A common theme from recent reports is that approaches that view drug problems as a public health rather than a criminal justice concern tend to be more effective. The negative consequences arising from the criminalisation and imprisonment of drug users have been well documented,[10] and, as the international comparator report points out, the evidence from countries with different approaches suggests no massive upsurge of harms.[1] Nevertheless, concerns about possible negative consequences persist, and calls for change are often dismissed out of hand. The results from individual studies should rightly be scrutinised and tested.

However, if the UK government is serious about having evidence based policies, then there must be the political will to accept the evidence even if it is at odds with prior beliefs. The unwillingness to accept the evidence from independent bodies such as the National Institute of Health and Care Excellence (NICE) and the Advisory Council on the Misuse of Drugs suggests a failure of process.

We are seeing new drugs emerge alongside new patterns of use, supply routes, and opportunities for intervention. Consequently, new approaches need to be developed and the evidence base must continue to grow and be updated to reflect the new realities. As circumstances and contexts change, interventions may not always work as expected, so regular reviews of effectiveness are needed and policy revised to optimise benefits.

An evidence based drug policy, therefore, might be better conceived as evidence infused policy. Such a policy would have clear, achievable objectives but would recognise the inevitability of changes as a result of the drug policies themselves and changes in the wider social context.[4 11] Evidence infused policy would monitor the change in harms and benefits over time and makes changes in response. Part of such an approach would be the discontinuation of interventions shown to be no longer effective or with adverse effects.

Similarly, it will be necessary to embark on innovative approaches with only limited evidence. In these circumstances evaluation will be essential, as will be the requirement to act on the results. Stopping a programme should not be viewed as a policy failure but policy maturity, and an example of the dynamic nature of the science-policy relationship.

For such an approach to be successful requires a policy making environment akin to that of a "learning organisation," in which politicians, policy makers, and practitioners are open to and seek out evidence of failure as well as success. In addition, honest and open minded engagement is needed from the public and the media, with an understanding that policy must adapt and change to meet new challenges and changing circumstances.

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LAST WORDS, p 39

Press releases should be treated as a part of the scientific publication, linked to the paper, referenced directly from the academic paper being promoted, and presented through existing infrastructure as online data appendices, in full view of peers

Preventing bad reporting on health research

Academics should be made accountable for exaggerations in press releases about their own work

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For anyone with medical training, mainstream media coverage of science can be an uncomfortable read. It is common to find correlational findings misrepresented as denoting causation, for example, or findings in animal studies confidently exaggerated to make claims about treatment for humans. But who is responsible for these misrepresentations?

In the linked paper Sumner and colleagues found that much of the exaggeration in mainstream media coverage of health research was already present in the press release sent out to journalists by the academic institution itself.[1]

Sumner and colleagues identified all 462 press releases on health research from 20 leading UK universities over one year. They traced 668 associated news stories and the original academic papers that reported the scientific findings. Finally, they assessed the press releases and the news articles for exaggeration, defined as claims going beyond those in the peer reviewed paper.

Since coding for exaggeration could be subjective, the authors' structured appraisal focused on three areas: making causal claims from correlational findings in observational data, making inference about humans from studies on other animals, and giving direct advice to readers about behaviour change. This allowed an assessment of where each exaggeration first appeared. If a news story claimed a new treatment for humans, for example, but the study was on mice—and the academic paper made no claim about humans—then did the exaggeration first appear in the press release, or the newspaper article?

Over a third of press releases contained exaggerated advice, causal claims, or inference to humans. When press releases contained exaggeration, 58% to 86% of derived news stories contained similar exaggeration, compared with exaggeration rates of 10% to 18% in news articles when the press releases were not exaggerated. This was an onerous piece of research, with coding done by a large team of students, but the high concordance in exaggeration scores between blinded raters is reassuringly high.

Considerable quantitative research has already been done on the misrepresentation of medical research in mainstream media. The HealthNewsReview website in the United States offers ongoing critical appraisal of mainstream media coverage on treatments and tests. A published summary of its first 500 appraisals[2] found that most news articles failed to satisfactorily discuss the quality of the evidence or to quantify the absolute magnitude of benefits and harms.

Projects in Canada[3] and Australia[4] reported similar findings, and an analysis of all coverage for trastuzumab (Herceptin) found uncritically positive reporting.[5] In terms of story selection, evidence suggests that the media are more inclined to report exceptional causes of death[6 7]; that bad news generates more coverage than good news and that observational studies are more likely to be covered than trials[8] (perhaps because observational research more often reflects the kinds of lifestyle choices that patients can make themselves).

Press releases have also been studied: 58% from US research institutions failed to include caveats about important methodological shortcomings in the research that was being promoted[9]; and a cohort study of five major medical journals found that lower quality press releases were associated with lower quality news coverage.[10]

This is not a peripheral matter. Evidence suggests that media coverage can affect the uptake of treatments and services[11 12]; and even subsequent academic citations.[13] Because of this, it is useful to think about practical positive steps. Improving standards among journalists has long been tried; best practice guidelines already exist for academics, journals,[14] and institutional press officers,[15] but these are routinely ignored. In addition to these strategies, it might be useful to build on the features of academic journals that improve standards and earn trust in science: accountability, transparency, and feedback.

Accountability is straightforward: all academic press releases should have named authors, including both the press officers and the academics from the original academic paper. This would create professional reputational consequences for misrepresenting scientific findings in a press release, which would parallel the risks around misrepresenting science in an academic paper.

Transparency is similarly straightforward. Press releases are a crucial part of communicating science, often more impactful than the paper, but they are often only sent privately to journalists and are rarely linked from academic papers. Instead, press releases should be treated as a part of the scientific publication, linked to the paper, referenced directly from the academic paper being promoted, and presented through existing infrastructure as online data appendices, in full view of peers.

Feedback requires a modest extension of current norms. At present, researchers who exaggerate in an academic paper are publicly corrected—and held to account—in commentaries and letters to the publishing journal, through the process of post-publication peer review. This could be extended. Press releases are a key part of the publication of the science: journals should reflect this and publish commentary and letters about misrepresentations in the press release, just as they publish commentary on the academic paper itself.

Information trail and accountability

Collectively this would produce an information trail and accountability among peers and the public. An immediate—albeit mischievous—opportunity also exists. Sumner and colleagues were good enough to share 462 individual coding sheets online and were generous enough to avoid naming and shaming the worst offenders. A motivated student with a spare afternoon could write the analytical code needed to extract data on those academics and institutions associated with the worst exaggerations and publish their names online, along with details of the transgressions. If funding could be found, then extending this project for a further two years would offer a much larger prize: the discovery of whether an ongoing ranking, prominently presented in public, might change academic behaviour and create an environment where researchers finally act to prevent patients and the public being routinely misled.

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RESEARCH, p13

- Personal view: Improving the use of IT in the NHS (*BMJ* 2009;339:b3922)
- News: New e-records system leads to 20% drop in emergency department performance at Addenbrooke's (*BMJ* 2014;349:g7537)

An alternative viewpoint is that healthcare is not primarily a consumer transaction but a complex physical, emotional, and social experience. Technology can provide, at best, only part of the solution

"Personalising" NHS information technology in England

The latest framework for action has learnt few lessons from recent failures

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The remit of England's National Information Board is to set strategy and commission informatics services for health and social care.[1] The new board recently released its first major publication, *Personalised Health and Care 2020*.[2]

Described as a policy framework and resting heavily on unpublished "research" from the management consultancy McKinsey, the 66 page document paints a futuristic picture of an NHS in which information flows freely between citizens, general practitioners, and other care providers, and staff are freed up from inefficient and repetitive data entry to engage in more productive work.

Patients, the framework predicts, will regularly access and annotate their online health record, order repeat prescriptions, and book hospital appointments through a personal portal. They will use "kitemarked" mobile applications (apps) and wearable monitoring devices to manage their illnesses and support healthy lifestyles.

This vision is depicted as dependent on three things: a high degree of technical interoperability between systems; consistently excellent data quality; and "activated" (that is, informed, skilled, and motivated) patients and staff. An ambitious timetable promises that by March 2015, for example, all NHS patients will have online access to their general practice record and later in the year there will be clear guidance on interoperability standards for linking systems (including smartphones, apps, and sensors).

Reassuringly, some important lessons have been learnt from England's failed National Programme for IT.[3,4] In particular, the board is unlikely to repeat the mistakes of issuing tenders for expensive, centrally procured systems that nobody wants or imposing a policy of ruthless standardisation that is deaf to local contingencies.

Repeated mistakes

But other key lessons do not seem to have been learnt. Firstly, the framework depicts information technology as a driver for organisation and system change, exactly the mindset that precipitated the failed National Programme for IT. In reality, mismatches between technological developments and their uptake in practice are ubiquitous.[5] Most NHS patients, for example, are already registered with general practices in which online access to records is technically possible, but only 4% of practices offer access[2]—presumably because doctors fear security breaches or a tsunami of concerns from the worried well.

Secondly, the framework, like the national programme, assumes that people's informed choices, supported by competition and transparency, will improve efficiency, quality, and health outcomes. It follows from these neoliberal assumptions that the key to success is technology, transparency of information, and activated staff and patients.[6] The framework speculates that people with mental health conditions will use approved "high efficiency" apps to access online cognitive behavioural therapy, which will restore them to economic productivity.[2]

An alternative viewpoint is that healthcare is not primarily a consumer transaction but a complex physical, emotional, and social experience. Technology can provide, at best, only part of the solution.[7] The health professional's role is social and professional as well as rational and technical.[8] Perhaps this is why computerised cognitive behavioural therapy, even in motivated trial volunteers, had only modest effects[9] and why mental health service users did not like treatment apps and did not intend to use them.[10]

A third lesson the board might have gleaned is that concerns about confidentiality and consent are unlikely to be resolved by a "task and finish" group working to a looming deadline. Every decision to share data requires a situational trade-off between the benefits of making data accessible and the risk to confidentiality.[11] Ideally, people's preferences must be ascertained and acted on in real time, not pre-programmed into a rigid system.

Fourthly, although the board has strongly endorsed local innovation, it is unclear how this will mesh with the national vision. For example, citizens accessing and annotating their records assumes a two-way flow of information, in and out of current record systems. This cuts across current developments in several localities, where moves are being made towards one-way access (for example, when hospital doctors and other clinicians may view someone's GP record but not amend it directly). One-way access may be less empowering, but it follows an important rule of data quality—that only the designated controller of the record should be able to amend it.[12] There is a danger that the politically appealing offer to give citizens the ability to write in their care records will fail as similar initiatives have done in the past.[4,13]

Fifthly, the new framework is coy on who will pick up the bill. Local health and social care organisations will be expected to fund at least some of the initial technology investment along with its ongoing costs. The board may be assuming that personal health information is commercially valuable and that its sale will raise money—but the subject is not mentioned in the new framework. This is surprising, given that the care.data debacle[14] and the Partridge review[15] revealed that NHS data have been sold to commercial clients without due regard for confidentiality.

Worryingly, the framework is highly selective in its use of evidence. For example, it advocates greater use of telehealth and illustrates this with briefly described (and mostly unreferenced) case examples, all of which are positive. But it fails to mention the large Whole System Demonstrator trial, funded by the Department of Health, which cast doubt on the cost effectiveness of telehealth.[16] Neither was there mention of systematic reviews of telehealth that have highlighted the poor methodological quality of primary studies and documented its low uptake, high rate of abandonment, variable efficacy, and high cost compared with usual care.[17-21]

We should be concerned about the lack of evidence for these proposals, and sceptical about the intentions of those who support them.

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