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## EDITORIAL

### Preventing dependency...supporting independence

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Work on this special issue of *TLDR* started early in 2012. Public services in the UK and elsewhere were already facing unprecedented challenges from the fall out of the international economic crisis. Since then it has become clear that, in the UK and many other countries, the challenge will be even greater and longer lasting than we had feared. The need for solutions becomes ever more pressing.

'Preventive' approaches may offer one potential solution. Such approaches, however, must be rooted in improving people's lives and outcomes, require a robust evidence base, and are likely to demand culture change and consensus across the wider system. This issue of *TLDR* aims to explore these issues by bringing together a wide variety of perspectives – people with learning disabilities, family carers, economics, practice, policy and research.

Putting together this issue has been an illuminating journey. The theme of preventing dependency and supporting independence for people with a learning disability emerges as a 'wicked issue'. Alongside a strong consensus in the articles, there is real debate. Indeed the articles show there is a discussion to be had around our very concepts of 'dependency' and 'independence'. Eric Emerson notes that personal independence is highly valued in most cultures yet, as Rob Greig observes, we do not really have a clear or shared understanding of what it means. Helpfully, in the paper by Steve Chapman and colleagues, people with a learning disability offer us a clear breakdown of what both 'independence' and 'dependence' mean for them. It is a good starting point.

Despite the 'wicked' nature of the subject, there is a strong degree of consensus in the contributions. First, there is general agreement that there is a real issue to be addressed here. Economics and demographic change mean current arrangements are unaffordable in the longer term and we need to work differently together. As Rob Greig notes, the challenge is to do this in positive and creative ways that meet people's rightful expectations of a good life.

This brings us to the next consensus: at its heart, 'preventing dependency and supporting independence' is about achieving good outcomes for people with a learning disability and their families. Cally Ward and Viv Cooper, and Steve Chapman and colleagues tell us such outcomes are 'a good life', where people are genuinely part of their communities, where mainstream society is inclusive, and where services enable rather than limit people's independence. However, as Martin Knapp cautions, such 'positive aspirations for social participation and inclusion have not always been fully met, and one reason is concern about affordability'.

There is consensus, too, on the need for a step change in the relationships between health, social care, housing and wider systems. This also means taking a 'life course' approach. The benefits are well illustrated in the paper by Caroline Reid, Catherine Sholl and Nick Gore. The Ealing Intensive Therapeutic and Short Breaks Service brings health and social care together in a way that makes sense for young people and families, and provides compelling evidence of success in improving people's lives and preventing residential care placements.

Many articles hold out the hope that a more inclusive society has the potential to make a real difference to people's independence. And it is worth noting that when wider society gets it right for people with a learning disability and their families it usually means getting it right for everyone. The dropped kerb or wheelchair accessible ramp is as helpful for parents with buggies as it is essential for people with disabilities. Nowadays the 'easy read' summary is often the 'go to' part of the document for everyone. But there is a question over whether society has become more or less inclusive of people with disabilities. As Rob Grieg notes, recent public dialogue describes older people as a 'burden on society' whilst disabled people are, at least in part, being cast as 'benefit scroungers'. And, if poverty and deprivation are risk factors for intellectual disabilities, what will be the long term impact of Welfare Reform?

What has certainly transformed society over the last 20 years is the level of technology in our everyday lives. Again the hope is often held that Assistive Technology (AT) has the potential to help disabled people achieve greater independence and reduce their dependency on paid support. Stephen Beyer and Jonathan Perry look at the reality and give us a mixed picture. Whilst AT can prevent harm and has the potential to reduce people's dependency on paid support (at least in residential settings), data on its effectiveness for people with learning disabilities is limited, and studies have shown mixed results. They also raise clear concerns, echoed in other articles, over ethical issues including conflicts of interest, privacy, consent, risk and social isolation.

Stephen Beyer and Jonathan Perry's article also highlights a final issue. Empirical evidence on the effectiveness of approaches that prevent or reduce the need for social care for people with a learning disability is scarce. Martin Knapp gives us an example of how such evidence, where available, can influence policy. It is certainly essential if we are to shift investment towards preventing dependency and supporting independence. There are inherent challenges: as noted in several of the articles, evidence of 'prevention' often requires measuring something that has not happened, or interventions so 'upstream' that cause and effect relationships are problematic.

The problem is serious and urgent. We would not pretend that the current issue provides solutions. Finding solutions will demand creativity and collaboration across people who use services, families, researchers, practitioners and policy-makers. We are very grateful to the contributors to this special issue for helping to identify potential directions that will help us all to meet the challenges involved.