Editorial

A change is as good as...

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It is a truism to say that we live in a time of change. Many people with learning disabilities, and their families, are grateful for this. Some of my first encounters with people with learning disabilities were in large institutions and it remains important that we remember that, only 30 or so years ago, more than 40,000 people in England lived in such places. The article by Fionnola Kelly and Roy Mc Conkey, together with Agnes Turnpenny’s commentary, provides both a reminder of this and draws attention to the continuing process of deinstitutionalisation in Ireland and many other countries. They also alert us to the importance of information in both the driving and monitoring of change. Very unusually, Ireland has a national system of monitoring the placement of people with learning disabilities, providing data that can be compared over time and used to inform evaluations of progress and policies. Information is fundamental to change both on a grand scale (think global warming) and in the more personal business of providing social care. Getting a measure, or feedback, on what’s being provided is crucial to monitoring the impact of change on individual lives.

But information on its own is not usually enough to produce change. Change also requires deliberate, skilled effort. The article by Carol Riddington provides good examples of areas in which UK-based services have become much more skilled over the last several years. While Carol draws attention to some of the limitations of Partnership Boards it is important to remember that the whole notion of having professionals, family carers and people with learning disabilities sitting down together to deliver change would have been considered completely ridiculous not that long ago. 30 years ago, in the above-mentioned institutions, it was still radical for different kinds of professionals to work together in this way. It would have been unthinkable to include patients or their relatives.

So this is a remarkable change. To produce such changes, people need new skills and both Carol’s paper and Richard Parrott’s commentary draw attention to some of these. Partnership working requires a whole range of skills that many will not have practiced in the past. We need to learn how to run meetings in more inclusive ways, to support people with learning disabilities to take on new roles, to develop structures that are inherently more inclusive and to engage all stakeholders in the whole task – planning as well as participating in the partnership process. As Carol notes, we have not got this completely right yet. But there are sufficient good examples to suggest that some of these skills are beginning to become embedded in some places.

Even skilled effort, the effects of which we know, depends upon a clear set of values underpinning what we are trying to achieve. Caroline Tomlinson’s article provides a particularly explicit statement of such values. Put simply, she wants her son to have a good life and for this to continue when she’s no longer able to fight his corner. By extension she wants the same for other families and notes powerfully how difficult this often is to achieve. Many of the changes we have seen in services for people with learning disabilities have sprung from individuals, often family members sometimes not, who have advocated initially for one person and later for people more generally. As Val Williams notes in her commentary, however, this should not be seen as an excuse by public authorities to abandon their responsibilities. Not all individuals have families or other advocates. Not all families have the skills or the desire to advocate in this way. So, while the leadership for change should appropriately come from people with learning disabilities themselves, from their families and other
advocates it will remain the job of public authorities to engage effectively with all individuals, and all families, and deliver universal change.