

Delivering the Promise of An Ordinary Life.



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In our thought piece (see <u>Re connecting Heart and Mind</u>) Sally Warren introduced Paradigm's national initiative to reconnect hearts, minds and hands so as to ensure disabled people get the support they need to live their lives as they wish. Now **David Towell** links this initiative to the 'An Ordinary Life' movement which drove reform in an earlier generation and brings this up-to-date.

SEPTEMBER 2012

In the final sentence of the first article in this series, Sally Warren asks 'If we accept that the foundation of our work in providing good support is (as John O'Brien puts this) to see me as I am, as I am becoming and what I potentially can be, we have to ask how something so simple has become so complicated and then what we can do to make it simple again?'

In now launching this national initiative, Paradigm has borrowed a title from an earlier era *An Ordinary Life For All* which seeks to reflect this simplicity. I try here to recall something of this history of our movement and renew its message for new times.

The 1980s: Closing institutions

Thatcher came to power in 1979 and quickly embarked on economic policies which put millions out of work and destroyed many traditional communities. (Sound familiar?) But paradoxically this was the occasion for progressive reform in learning disability services, not a reason to avoid it. The series of scandals in institutional care over the previous two decades had drawn public attention to the human rights abuses in state i.e. mostly NHS, care and generated momentum for policy change – initially focused unfortunately on capital investment in 'community units' and other buildings which were certainly units but had little to do with community.

Faced with this opportunity for change and using the status of the King's Fund, I and my colleagues were able to bring together allies to advance an alternative philosophy. We defined the goal of good support as that of enabling people with learning disabilities to live An Ordinary Life in all its richness and diversity.

We want to see people with learning disabilities 'in the mainstream of life, living in ordinary houses and ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other membersof their own community'

(An Ordinary Life, 1988)

The An Ordinary Life initiative was nationally important not

just in

setting out a clear philosophy and producing an extensive guide to practical action, but also in providing inspiration for a wide network of local leaders and a common currency for their efforts to do better with and for people with learning disabilities and their families - always recognising that families were and remain the main source of support to their disabled children well into adulthood if not for life. Indeed within a few years there had been sufficient local progress for the 1988 publication An Ordinary Life In Practice. Paradigm is launching this new initiative to coincide with this book's 25th anniversary!

21st Century renewal

Of course, there have been newer formulations of this goal since the 1980s. The An Ordinary Life philosophy informed the 2001 Valuing People White Paper and its core principles of 'Rights, Independence, Choice and Inclusion'. Simon Duffy has reworked these ideas in his influential book Keys to Citizenship (2003). And practice has moved on as we have recognised the limitations of the small group homes which dominated community living arrangements in the 1980s to favour supported living and helping people gain more control though self-directed support and individual budgets.

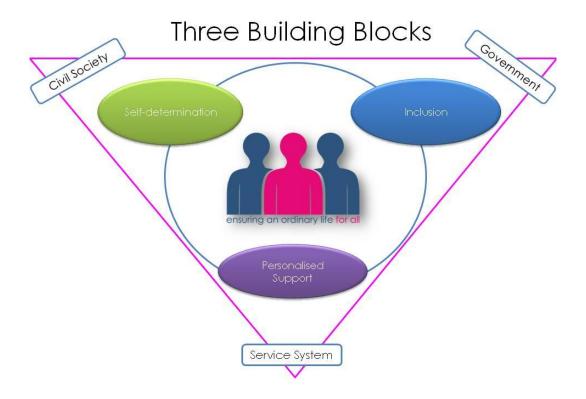
Most importantly, these values have recently been restated comprehensively in the United Nations Convention on the Rights of Persons with Disabilities (ratified by the U.K. in 2009), especially Article 19 Living Independently and Being Included in the Community.

'UN speak' is complex but this Article makes the unequivocal commitment that,

'State Parties....recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community'

This Convention is much more than a statement of rights: it is also a broad route map for their implementation. Looking across different aspects of life in the community it suggests three main building blocks for advancing equal citizenship which I summarise as:

- Self- determination: 'I can say what matters to me and how I want to live'.
- Personalised support: 'I get the assistance I need to live as I want'.
- Inclusion: 'I'm included in my community and benefit from its services'.



Contemporary challenges

Advancing the Convention's radical agenda faces three great challenges. The first of these is not new at all. Despite better support to families, this frequently remains inadequate for them to live ordinary lives like other families. Second, for many people with learning disabilities, presence in the community has not equated to full participation, for example in education, employment and leisure opportunities – and many still report lifetimes of loneliness and discrimination. Third, these weaknesses are now being magnified as the government's response to the global financial crisis leads to cuts in public expenditure on both services and welfare benefits. Moreover, this chilly climate may also be weakening the capacity of local communities as sources of mutual support, including for their disadvantaged members.

What next?

If the earlier An Ordinary Life initiative ended the reliance on traditional institutions, the challenge for a new generation is to ensure that good support

Delivering the Promise of An Ordinary Life. May 2012

delivers on the UNCRPD goals of autonomy and genuine community inclusion for people with learning disabilities in the face of these challenges.

No-one says that this is going to be easy but in the classic words of Robert Frost, we have promises to keep.

Stopping by Woods on a Snowy Evening

Whose woods these are I think I know. His house is in the village, though; He will not see me stopping here To watch his woods fill up with snow.

My little horse must think it queer To stop without a farmhouse near Between the woods and frozen lake The darkest evening of the year.

He gives his harness bells a shake To ask if there is some mistake. The only other sound's the sweep Of easy wind and downy flake.

The woods are lovely, dark, and deep, But I have promises to keep, And miles to go before I sleep, And miles to go before I sleep.

Robert Frost

David Towell directs the Centre for Inclusive Futures. He is currently helping Inclusion International with its global report on implementation of Article 19 of the UN Convention, to be launched in Washington this October.

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