

Valuing People, 15 years old – destination reached, stalled or derailed?

When it was launched there was cross-party support for the Valuing People White Paper (DoH, 2001) which set out a new strategy for learning disability for the 21st century to improve the lives of people with learning disabilities.

Valuing People said: “People with learning disabilities are amongst the most vulnerable and socially excluded in our society. Very few have jobs, live in their own homes or have choice over who cares for them. This needs to change: people with learning disabilities must no longer be marginalised or excluded. Valuing People sets out how the Government will provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their communities.”

Using the Valuing People categories a team from Paradigm asked self advocates, advocates, families, commissioners, support providers, health/social care workers, and policy makers what has changed over the last 15 years.

Report by Sue Livett and Sally Warren of Paradigm.

Quote (p.13) “I am in constant fear of having a reduction in services”.

Quote (p.14) “As the aims of Valuing People become more distant, they are dismissed and crowded out by other agendas”.

In our survey we were struck by the many statements and stories shared. People talked about their direct experience, some of it positive, often due to individuals in key positions, like head teachers, and good new models of support. However, nearly every positive comment was qualified with a ‘but’... and for families the story is overwhelmingly one of fear, stress and uncertainty due to battles they’ve had, and expect to continue, in the future.

A patchy picture has emerged – some glimmers of hope, some changes in culture – against a backdrop of huge pressure on the system. People talked of links to hostile stereotypes which support the Government’s austerity policies, resulting in support and services being reduced, removed or under threat.

The results

The graph opposite illustrates what we found. We offered a sliding scale of 0 (no change), 3 (making good progress), to 6 (big improvements, we’ve cracked it!). We would hope after 15 years the responses would be clustered around

making good progress (the spotty purple bar).

The league table

Between 40 – 50% of people felt that the areas of Control, Housing, Fulfilment and Partnerships are making good progress and heading towards big improvements. The areas where people felt least change has been made are Employment and Transition.

Some strong themes emerged throughout the survey:-

- **People with complex needs and people with autism** experience difficulties in being part of local communities, getting information, support and joined up approaches from places many of us use, including schools and the NHS.

“More needs to be done in terms of making community spaces fully accessible for all. Fully accessible hoist- assisted toilets (or lack of) is a good example.”

People are still ending up in segregated settings such as prisons, residential settings and ATUs. Despite

reports such as ‘Death by Indifference’ (Mencap 2012) there appears to be a lack of understanding of the health needs of people with learning disabilities:-

“There is still a tendency to assume that symptoms are caused by someone’s learning disabilities... and miss other conditions, also to not offer treatment because the client would not be able to cope due to their learning disabilities, rather than seeking support from the appropriate health services to support them to have treatment”.

- **Theory and practice need to meet:** some aspects of reform have been experienced as positive, eg, the Education, Health and Care Plan (EHCP) process and Special Educational Needs Disability (SEND) reforms, as they introduced a framework that enables a focus on delivering outcomes and preparing children for adulthood. Some NHS initiatives are welcome but there is a need for ongoing investment and promotion. The majority of responses on Education Health and Care Plans and Person Centred Plans said they were insufficiently used to make action happen. People com-

mented on the need for greater joined up working between education, health and social care.

Comments included: “Roles like acute liaison officers in hospitals are helping people with their ‘journeys’ through hospital and improving their experiences. Paid annual health checks have helped to highlight people with learning disabilities on doctors’ registers, as well as igniting a better monitoring of care.” (Advocate)

“Have seen creation of acute liaison nurses in hospitals and doctors’ surgeries, automatic booking of double appointments and use of hospital passports and health action plans”.

“The primary care learning disability liaison/screening nurses have been a huge step in the right direction”.

“Yellow health books and annual health checks are good”.

“GP surgeries are clueless – they are unable to deal with people with complex needs, are frightened of them and have no training in providing a proper healthcare service for them”.

- **There are enormous pressures on families and carers,** financially and emotionally.

“Things are much harder for carers.

I am 65 and still looking after my 22 year old daughter... carers’ supporters are now not able to offer carers free coffee and we have to buy our own – how’s that for being valued?”

Families talked about being frightened of the future, dreading their children moving into adulthood and losing services.

“I am in constant fear of having a reduction in services”.

“Talking with families, they find it as hard now as they always have.. If you are able to cope you are left to it.. they may not be able to cope but the alternatives aren’t suitable so the family just keep quiet and put up with the minimal support or limited respite”.

Examples were given of considerable delays across social care services and lack of opportunities for people to spend time away from their families in community settings.

- **We’re still not giving people information** despite the 2014 Care Act’s requirements. People referred to some good examples where advocacy had worked and of carers support services working hard for them - but others talked about struggling to access advocacy and support.

As noted above, families and social

workers talked about the lack of planning for adulthood. Families were dreading this challenge and experienced a culture shock moving from children’s to adult services, with different funding and eligibility for support.

“It’s like dropping off a cliff.”

A number of people commented on power and control still sitting with local authorities. This suggests little progress with personal budgets – they were rarely mentioned.

“Individual budgets can add to family responsibilities... partly due to benefit cuts and reductions in professional support and services”.

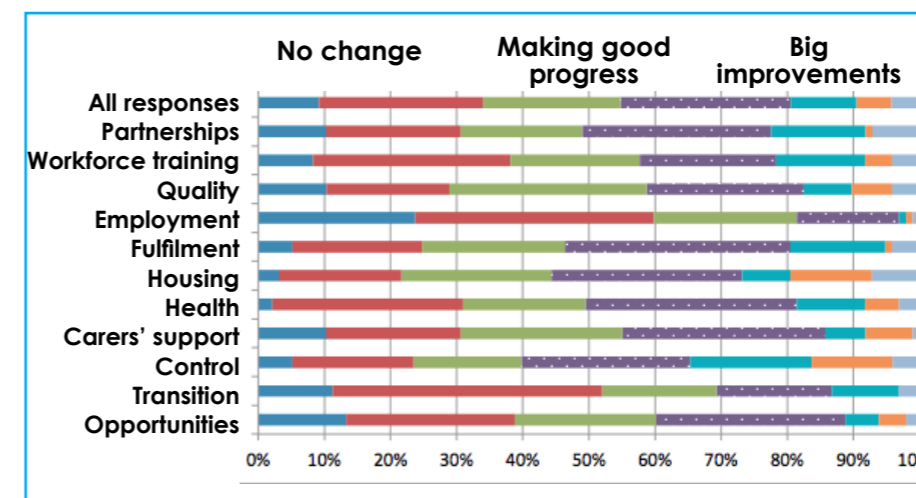
“I am often infuriated by the lack of support available for the individual and their family during transition.” (Social worker)

“.....the support for carers has gradually decreased despite the implementation of the Care Act. Carers are assessed in their own right now but it has not improved the quality or type of support given to them. If anything it has increased the amount of signposting to services that either are unaffordable or have huge waiting lists.” (Carer)

“We have been totally let down. Because our son has high/complex needs we were told as he was turning 18 that things would be in place as he was ‘flagged’ up. The exact opposite was true and we could never have imagined how stressful the next two years would be. The lack of support, information and lack of people with experience who could help us was frightening.”

There were many comments about housing. Again, some examples were given about successes: “My daughter moved into her own shared ownership home eight years ago and has never looked back...” But most of the feedback expressed frustration on lack of information, advice and access to housing.

“Housing information is really complicated to understand”.



The league table. Note: We did not offer a ‘worse’ option, which some people wanted to use as a rating. From the comments made, this is likely to have resulted in a shift towards ‘no change’.

“We feel palmed off.. we want to be able to talk face to face about important issues like housing but we are often told to use the phone or computer”.

“We had a nightmare! It took six and a half years to get our son housed. We had to climb to the highest people in charge at the county council – the people who write the glossy brochures and compile the statistics – to be told all their rhetoric was ‘aspirational’ and they were not able to provide or deliver housing other than residential care. We had to do it for ourselves.” (Family carer)

People talked about real challenges in navigating systems. There was some support for contract monitoring with a hope that this would bring improvements but there was little evidence of this happening.

“Perhaps we have made simple things complicated”.

• **Austerity is being felt**, with examples of cuts to support, across agencies, such as legal aid, the courts, college funding, short breaks. People talked about planning models being used more but as a paper exercise rather than in real life.

“Powers have to be constantly reminded about the person at the centre.” (Relative and social worker)

“We provide employment coaching and support in partnership with job centre+ but funding has been cut, putting additional pressure on people to move swiftly into work... the Government is putting in additional barriers to people preparing for and gaining paid employment. Government support and funding is not readily available”.

People talked about cost considerations overriding quality.

“Providers have been squeezed to the bone and are falling like flies. In Cornwall legal challenges from providers are pending. Contracts have

been given back as they can't provide the service for the reduced contract. One provider gave 14 days notice of eviction to 12 people with learning disabilities”.

“Quality doesn't come into it – it's all down to cost, like Ebay but for the lowest bidder”.

“With the budget cuts, quality is less of a driving force. If you can provide the cheapest service you win the business. I was told in a professional meeting that it is 70/30 cost v quality”.

• **Hate crime** was referred to, sometimes linked to people spending more time in their communities and being ‘visible’. Being able to go out and meet people and go to ordinary places is restricted. “There is still a sense that people want something for nothing and shouldn't need support to care for their family rather than recognising that most people only ask for help when they are desperate or in a crisis”.

“Social media seems primarily to blame – or at least to fan the flames. There is definitely a lot of anxiety now about community safety which I did not see or feel when my son was younger”.

“A lot of clients are still isolated and unable to go out at night. They need more social activities and opportunities in the community, support with travel training, befrienders, and support to get to activities”.

“I have to comment on the inexorable rise of hate crime. We have experienced it – a fire which would have had dire consequences if we had not installed telecare and a surveillance system.”

“I once took my daughter to a local employment event – first it wasn't accessible, second the majority of employers did not understand that my daughter might want to work. It was a very depressing experience”.

There were many comments about people feeling isolated and that



people with learning disabilities should be at the centre of initiatives to be part of their communities, eg. by developing and being involved in social enterprises.

“The community resource should be promoted to the wider public rather than to marginalised groups, so that barriers to inclusion are broken down. When people with learning disabilities are co-ordinating and working at the resource, customer and community members from disadvantaged and marginalised groups feel more comfortable and welcomed giving them opportunities to make friends and contribute to their community”.

Our conclusion is that progress has stalled. We have heard about some areas where improvements have been made but we need to see these continue and become much more widespread so they become the norm, the standard which people with learning disabilities and their families should expect. There is a danger that as the aims of Valuing People become more distant, they are dismissed and crowded out by other agendas. We must not let this happen.

What next?

We must push the bar higher and address these challenges. We are sending the results of our survey to Penny Mordaunt, the Minister of State for Disabled People and other ministers – we want to know what plans and commitment the Government has to make real progress. We invite readers to contact their MP to show them what life is like for thousands of people.

References

Valuing People, DoH 2001
Death by Indifference, Mencap 2012

If you would like fuller details of the survey e-mail Sally Warren at sallyw@paradigm-uk.org or go to their website www.paradigm-uk.org