

The Keys To Life Briefing

Scottish Parliament Debate, Tuesday 24th September

Learning Disability Alliance Scotland

The Learning Disability Alliance Scotland welcomes the Keys To Life, the new strategy on support and services to people with learning disabilities. It is now over 13 years since the Same As You was written and it was creaking at its edges. Many people felt that it no longer covered the key issues that affected people with learning disabilities and their families.

The Keys to Life is a long document with 52 separate recommendations that cover many different areas of support and help. These recommendations are very helpful for many of the services and organisations that support people with learning disabilities helping to give clear indication of what they should be doing.

People with learning disabilities want 3 things

1. A safe and secure place to stay
2. Meaningful things to do with their time
3. Friends and family to have in their life

These are really just the same thing that everyone else wants. However sometimes the way they are supported prevents them from achieving these.

The reason that we need a Scottish Government learning disability strategy is about balancing the different pressures that exist for those authorities charged with supporting and helping people with learning disabilities. From “best value” to resource management, from “statutory duties” to a simple shortage of resources, local authorities, health boards, the government itself and even the voluntary sector have to make difficult decisions about what they do and what priority it has.

A strategy is really a guide for these bodies to prioritise their actions in relation to a particular group of people.

A defining theme – The Keys to Life states it has Human Rights at the centre. But it has a feel of being put together from a number of different reports and interests. There are strong sections on health, criminal justice, independent living and people with profound and complex disabilities. But often the recommendations feel like a checklist, for example have we got something on dental health and have we got something on employability? This means that many things are covered in the report but leaves the danger that when unforeseen issues arise the strategy may not be able to guide an approach.

It could have been strengthened from the start by re-emphasising the phrase “Nothing About Us, Without Us.” This key message for the disability community is that people themselves should be at the heart of their own support.

Over the last 13 years, it has become clearer to many people, agencies and organisations that an individual approach to support for people with learning disabilities was both in demand by the individuals themselves and also the best way of helping people to meet the outcomes that they wanted. Whether it is in the growth of Person Centred Planning, the take up of Self Directed Support or in the recruitment of their own support staff, people with learning disabilities want to be at the centre of their own support.

We have found the Keys To Life hard to explain to groups of people with learning disabilities. Every individual recommendation can be explained but to go through 52 recommendations leaves most people dazed.

With an overall strategy or theme of people with learning disabilities becoming the centre of the improvement of the quality of their lives, much of what is included in the report could have been more easily understood.

Instead some of it is about increasing the role of organisations such as the NHS in people's lives but not about making sure that people with learning disabilities are better placed to control the intervention of the NHS in their lives.

Coproduction needs to be everywhere within this strategy. Not just in words but in deeds. Some local authorities have now started paying the support costs and other expenses of those who attend consultations and planning groups, recognising their input in a professional way as equals. This approach needs to be taken up by more public authorities to make sure that people can really get involved in the transformation of public services

Outcomes

The word "outcomes" is mentioned 80 times in the strategy but except for a specific mention in the Joint Commissioning sections, these outcomes and the method of working out if they have been achieved are omitted. It is taken for granted that everyone is working in the same direction. Given that eligibility criteria for social care in Scotland is tightening and resources are being squeezed there are inevitable conflicts over the outcomes that people want and how they are to be achieved.

The Scottish Government's Joint Improvement Team has spent a lot of time in developing the Talking Points outcomes approach for people with learning disabilities. This involves a set of outcomes measures designed by consultation with people themselves and is measured by skilled professionals having conversations with individuals about the difference that their support makes for them.

Given the £670 million from local authorities, the £110 million from the NHS and the £50 million from the Independent Living Fund spent on care and support for people with learning disabilities having a systematic approach to working out what difference this support makes to people with learning disabilities and their families would be helpful.

Welfare Reform – The Keys to Life is a Scottish Government document and can only cover matters that the Scottish Government can have control over. The changes to welfare benefits that have been introduced and that are coming over the next few years will have a major impact on people with learning disabilities. The bedroom tax affects many people with learning disabilities who were given 2 bedroom houses when they moved into supported accommodation.

Some have already moved into smaller houses. Albert from Edinburgh who was given a two bedroom house when he had to leave his previous housing because of neighbour harassment has had to move a further time to escape the bedroom tax.

Others are struggling with managing to pay their rent with difficulty and are accumulating arrears. This week, Barry from Ayrshire told us this week about a series of letters he has had from his council threatening him with further action if he does not pay off his £60 in rent arrears. The “Same As You” has taken on a more ominous meaning with the introduction of the bedroom tax.

Further changes to the benefits system such as the introduction of Personal Independence Payment will bring new challenges. The new benefit will see the ending of the lower rate of the Daily Living Element and many people with mild and moderate learning disabilities will lose out as a result. Ewan from Argyll is a person who needs consistent amounts of support but who is unlikely to score enough points in the new PIP assessment to qualify for the benefit. Already living in a rural situation, the loss of this benefit will make his life much more difficult and narrow his horizons.

Improving Health – This is the area that the Keys To Life is strongest on. 26 of the recommendations relate to NHS, hospital and other health issues. This is quite right. There is an unacceptable gap of 20 years between life expectancy for people with learning disabilities and the main population. The life expectancy of smokers in the most deprived areas of Scotland is still 5 years more than for people with learning disabilities.

This section is the most coherent of the Keys To Life. It starts with a plan to identify the reasons for the gap in life expectancy and for other health inequalities. Then it proposes action on each of the main issues that are already known about, making it clear who has responsibility and what needs to be done about it.

A new Scottish Learning Disabilities Observatory will be set up to keep an eye on what is happening in hospitals and doctors’ surgeries to people with learning disabilities. NHS Boards are given specific responsibilities to make sure there is better care for particular conditions such as epilepsy and more

Real Life Challenges - Sadie – Aberdeen. “I used to have two bedrooms in my old house. I had a lot of anti social neighbours and when they got really loud, I could move into the spare room to get peace and some sleep.

I now have a new house that also has two bedrooms in it. This was what I was offered by my local council.

I want to use this bedroom for my art work, painting and collages. I have a learning disability and this is the one thing that I am really good at. There used to be a number of arts projects that I could use for my art but most of them have shut because of spending cuts. I have nowhere else to go to do my art now.

Also when I am upset and low, I can have a friend over to offer me support. This helps me not need to much support and stops me being in crisis.”

general duties to ensure a dedicated primary care liaison resource in each area. Better cooperation will be encouraged between local authorities and NHS staff to make sure no one falls out of the net when they go into or leave hospital.

There will be a new register of people with a learning disability with their NHS number is used to identify people when they use either social work or health services.

If the work and cooperation outlined can help increase the length of people's lives, this will be worth it alone. If these recommendations are put into effect then we can look to improvements. Two things need to be done.

1. The research and pilot projects that are being commissioned should lead to change in policy and long term interventions. The lives of people with learning disabilities are often helped by short term interventions which promise people change but are then stopped when funding ends.
2. Secondly there needs to be clear and proper accounting for the interventions that have been promised. – how many NHS staff have been trained in the use of Talking Mats – how many Learning Disability Liaison Nurses are there – and so on. Previous research we carried out on the employment of Learning Disability Liaison Nurses recommended by “Tackling Indifference” found significant gaps. We cannot allow these recommendations to disappear under the radar.

An annual report by the Minister on progress might be one way of ensuring proper monitoring takes place.

Self Directed Support

Self Directed Support poses the greatest opportunities and challenges in making the Keys to Life a reality. This major strategy depends on the willing participation of local authorities in the process. Some developments over the last couple of years have raised great concerns over how much self directed support is likely to be linked with service reductions.

Real Life Challenges – Rhona – Glasgow

I have to feed Peter through a tube twice a day. All his medicine has to be fed through the tube too. I grind down the tablets and dissolve them in water and then feed them through.

For the last 10 years, I have been given disposable syringes from the health board. They were “one use” and then discard. This reduced the danger of infection. However last month instead of the usual supply of 200 they only sent 4. I phoned up and was told this was the new policy and there was nothing I could do about it.

Eventually I got a senior member of staff. None of the others had thought to explain to me that they were reusable and could be safely washed. Why don't they take the time to explain things to us. I don't want to have to worry unnecessarily.

Real Life Challenges - Margret – Glasgow.

Margret cares for her 24 year old son, Billy at home. He has profound learning disabilities and suffers from severe epilepsy. Her husband has been disabled since being knocked down by a car, ten years ago. She herself suffers from a damaged hip.

Billy currently attends a day centre and his SDS package will allow this to continue. His respite break, which Margret depends on “to get some sleep” was initially to be cut by 50% because the budget wasn't enough. Instead Margret has let go the care company who came in to put Billy to bed at night and to take him out at the weekend. As a result she has managed to keep her respite but will put Billy to bed herself in order to fund this out of the SDS budget.

For many people with learning disabilities, a reducing input of resources is welcomed as it is matched with growing skills in living independently. For these people the removal of staff resources is another opportunity to stretch themselves and to take more responsibility for their own lives.

For others the reduction of resources has seen an increased dependence on family to provide additional care to maintain their skills. In some cases where support has been reduced people have begun to lose skills that they had gained from their external support.

For many others guardianship orders have been taken out on them by family members thus losing their rights to make decisions for themselves. For many families this is the only way they can continue to be involved in the care of their loved ones. However we know the Mental Welfare Commission in Scotland has heard concerns that some of these guardianship orders include powers to decide what clothes individuals wear, possibly a step too far.

It is too early yet to determine which direction SDS will go in Scotland. So far it has been those with the greatest capacity to decide for themselves or for those with good support structures that have made the most of Self Directed Support. The case study in the Keys to Life of Jane was someone with a lot of capacity to decide for herself. She was even able to take a course at the University of the West of Scotland, a rare course of action for people with learning disabilities. It is impossible to generalise from Jane's case to other people with learning disabilities.

Day Opportunities

One of the biggest public challenges in learning disabilities support over the last few years has been over what people with learning disabilities will be able to do during the day. All four Scottish cities, Aberdeen, Dundee, Edinburgh and Glasgow have seen public campaigns over the provision of day opportunities. More private concerns have been raised in other regional areas about the future of day opportunities.

Much of the driver for this is the continuing stress on local authority funding. Local authority run building based services are significantly more expensive than voluntary sector building based services. This is not just a wage differential but is also linked to different staff ratios meaning that overall less people may be employed.

This motivation is rarely as simple as spending less money. There is a continuing demand for new service as young people leave school and the health and life expectancy of current users continues to improve. Money saved in one area is likely to be, though not always, reinvested in spending elsewhere.

So far none of the local authorities involved have been able to provide a compelling vision of the alternatives to win over service users and families convincingly. This is partly due to the changes that have already taken place within day services.

One former Local Authority Director of Social Work put it as "Day Centres have changed. There is hardly a centre in Scotland that you can go into during the day and find anyone in it. Usually people are out doing things in the community."

5 day a week users at day centres can spend as little as 44% of their time in the actual centre including time for arrival and departure.

ESAY statistics, the information collected by SCLD on support for people with learning disabilities, doesn't yet recognise the changes that have taken place. The numbers of people attending day centres simply reflect those attending local authority building based services. In Glasgow alone, there are 18 voluntary sector building based day services. In addition there are a further 33 voluntary sector outreach day services.

As a result when the Keys To Life says on page 72 that it is expected that more people will stop using day centres, it really means local authority day centres. We have no information on how many use voluntary sector building based services, how long they attend and what community alternatives that they can take part in.

The Keys to Life has not addressed this directly but proposed a 5 year period in which a wide range of stakeholders can come together to review and further develop day opportunities. As part of this it needs to collect much more complex information about the real experience of people with learning disabilities and what they do during the day.

The Edinburgh campaign about day opportunities was different from the rest. It did not concern day centres but was about the alternatives that people who did not attend day centres would be able to access to support them into volunteering or employment. A real concern emerged about a "one model" approach to people who have widely varied needs.

If coproduction is to be at the heart of the Keys To Life, then it has to make sure that people themselves are at the heart of planning and not simply asked leading questions that are interpreted to fit pre-existing attitudes. This will involve skilled facilitators to make this happen.

Facilitation

One of the biggest challenges for the Keys to Life will be making sure that people can take part in coproducing their own lives. Most people with learning disabilities who need support in their daily lives will also need independent support to take part in these processes.

However many face a harder challenge to secure such support. Increasingly Advocacy services are tied up with statutory representation work in mental health and court work. Where advocacy is provided for special events it can often be very short term with little space to build working

Real Life Challenges - Michael – Edinburgh

I have been at the Engine Shed for two years. It's really good, you make new friends. You get to do new stuff every day. Like new recipes. And chopping up vegetables.

A lot of people think cutting of vegetables is easy. But it's not. You can cut yourself easily and do a lot of damage. It's a skill. I do everything that needs to be done in the café and its kitchen. I did some work in the hospitality kitchen.

I have learned a lot since I came here. I used to go to Stevenson. I never knew this place existed before they told me. Now I am part of a team. If you are part of a team, other people can help you. If you are on your own you are struggling to do different stuff.

I did a couple of work placement first at Hendersons, then at the Zoo and then MacDonald's. I'm looking forward to the future and I'm hoping to get a good part time job. But if they shut the Engine Shed then I'll lose my support.

relationships with vulnerable people. It is more of a “McKenzie’s Friend” than an independent advocate – some one who knows and advises on the legal process but very little about the individual.

Conclusion

Some might say that the document is weakest on the key question that faces people with learning disabilities –that of cuts in spending and welfare reform. Over the next few years, the Centre for Welfare Reform estimate that the 2% of the population with severe disabilities will face 15% of the overall cuts. Overall they will see an average real terms cut in income or support of £8,832 per person since 2008.

We think that is too strong. The Scottish Government cannot do everything and at the start of the Keys of Life it sets out that the new strategy should be based on a Human Rights approach. People with learning disabilities are part of the wider community and share its challenges with everyone else.

Of course, people with learning disabilities do have a range of special needs that require to be respected. We look forward to implementation of the very first recommendation – an expectation on all local authorities in Scotland to carry out Equality Impact Assessments on their policies for supporting people with learning disabilities to make sure that the rights of people with learning disabilities to dignity, respect and equality are upheld.