

# FitzRoy

transforming lives



## ahead...

**Start by looking inside**

### **A Plan For Life**

The long view of social care for  
adults with learning disabilities

# About this report

**A Plan For Life is an in-depth study of social care planning for adults with learning disabilities, from learning disability charity FitzRoy.**

FitzRoy's research aims to spark debate about how social care decisions are made, and to enable a more informed discussion about long-term planning and wellbeing.

The study reveals the systemic pressures on local government that have led to widespread short-term planning and a subsequent increase in long-term costs.

The report highlights the need for change, from the local authority's perspective, and that of the individual, their family and the professionals that care for them.

FitzRoy is calling on the governments to publish Guidelines alongside the Draft Care and Support Bill 2013-14, to help local authorities interpret, act upon and adjudicate their obligation to promote individual wellbeing.

The study is a positive recognition of local government's desire for change. However, this requires a major overhaul of social care decision-making.

The study is based on opinion research amongst 100 chief executives, heads of adult social care and commissioning managers in local authorities in England.

We would like to thank everyone who participated in the research, and to our partners Man Bites Dog, Coleman Parkes and Pixeldot for their generous donations.

## Introducing... A Plan For Life

**There are around 1.14 million people with learning disabilities in England including 236,000 children, and 908,000 adults<sup>1</sup>. How they will be cared for and supported is an incredibly important decision that will have an impact on their health and wellbeing for the rest of their lives.**

FitzRoy has more than fifty years' heritage in supporting adults with learning disabilities to live healthy and happy lives, and to be more independent. We enable them to have a life – not just an existence – and we work with local authorities nationally to put long-term plans in place.

But caring about these values isn't enough; current pressures on local government mean we needed to raise awareness of the barriers to long-term planning and highlight the benefits of lifelong plans.



The timing of this research is significant: the Draft Care and Support Bill is making its way through Parliament and will govern how local authorities make these social care decisions. Shockingly, almost half of care commissioners are unaware of their impending obligation to promote individual wellbeing, and it appears that this provision alone signifies a significant shift in mindsets and standard practice.

Wellbeing is intrinsically linked to quality of life, and the Draft Care Bill goes some way to define this with examples including “control by the adult over day-to-day life” and “participation in work, education, training or recreation”. However, we strongly believe that this falls short of a sufficiently clear and comprehensive definition.



Local authorities are unlikely to start considering control over everyday tasks such as shopping, cooking and home-based entertainment of their own volition, for example, or know what standards to aim for. Yet, our case studies show that this level of independence can help reduce care needs, reduce care costs and transform lives.

This report provides evidence of the need for long-term planning and the risk that – without further guidance from central government – wellbeing will become an exercise in word play.

Whether you are a care commissioner, a service provider, a care professional or you have or know somebody who has a learning disability, we hope you find the report useful and look forward to developing a plan for life with you.

Anna Galliford  
Chief Executive, FitzRoy

# The short view:

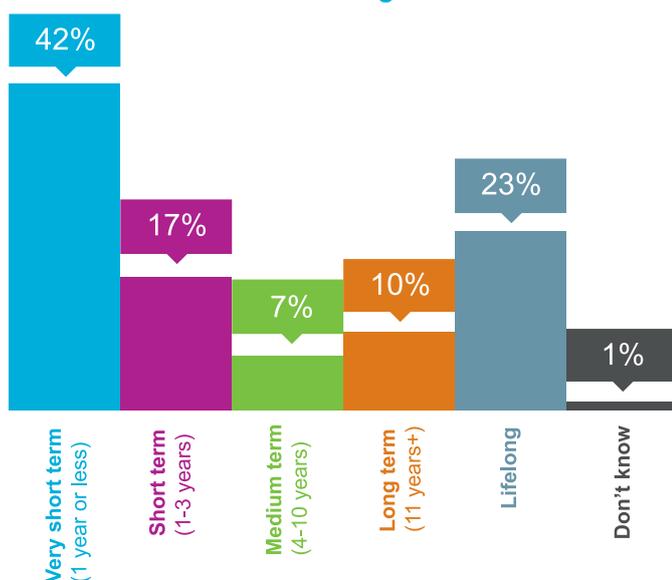
## The prevalence of short-term planning in social care for adults with learning disabilities

One of the greatest and most dangerous challenges facing local authorities is the pressure to make quick decisions. This short-term focus can have undesirable consequences for the local authority and the people affected by the plans they put in place.

FitzRoy's research reveals that short termism is endemic in social care planning for adults with learning disabilities, despite these decisions affecting them for the rest of their lives. Two fifths (42%) of local authorities look just one year ahead or less when making decisions about an individual's care and support plan (See Figure 1).

Figure 1

Future timeframe for making social care decisions for adults with learning disabilities



One fifth (19%) of local authorities admit that quality of life does not influence their assessment of services for adults with learning disabilities. There is also a serious lack of consideration for the whole life of an individual, including critical life stages that have a significant impact on their care and support plan.

Almost a third (29%) of local authorities do not consider the death of a parent to be a significant event, despite this often meaning the loss of a main carer and constant source of support. For the 29,000 adults with learning disabilities living with parents aged 70 or over<sup>2</sup>, this is a real concern.

Parents of adults with learning disabilities often tell FitzRoy that their biggest fear has been what will happen to their child when they are gone. Sometimes they would even hope that their child would die before them - an unthinkable wish for any parent.

FitzRoy hopes that we, and organisations like us, can make this fear a thing of the past. But it will take the collective effort of central and local government and the rest of the care profession to eradicate this issue.

The study reveals the absence of long-term considerations such as placement stability and quality of life beyond just care. However, the vast majority of local authorities believe that they should all measure placement stability (87%) and that this is necessary to protect individual wellbeing (90%).

Currently, two fifths (40%) of local authorities do not have a formal measure of placement stability. Where there is a formal measure, in some cases this is limited to an annual review from the social worker or a proxy measure such as greater collaboration with the service provider.

# The long view: The long-term impact of short-term thinking

**The prevalence of short-term planning has a severely detrimental impact on local authorities – aggravating the very issues that they are trying to overcome.**

Two fifths of local authorities admit that short-term planning leads to higher long-term care costs (**83%**) and greater care needs (**78%**). Two thirds (**62%**) agree that time and cost mean they don't choose the right service first time as often as they should. The average authority gets it right first time in just two thirds (**68%**) of cases, and almost two thirds (**60%**) say short-term planning leads to emergency care decisions.

This mounting cost is unsustainable – especially in the current economic environment – and will continue to grow as long as local authorities are only planning for the next year.

**82% of local authorities say too many adults with learning disabilities are unable to live a happy, independent life**

Four fifths (**82%**) of local authorities agree that too many adults with learning disabilities are currently unable to live a happy, independent life. This is not only a moral right, but can also help to improve health and wellbeing, social integration and opportunities to participate in work, training, education and recreation – and therefore contributions to the local community and wider UK economy.

**83% of local authorities say short-term planning leads to higher long-term care costs**





## Paying the price: The overriding influence of cost

The study reveals that cost is the overriding consideration when local authorities are assessing social care services for adults with learning disabilities. Almost all (94%) local authorities admit that cost is an influencing factor.

Three quarters (73%) go so far as to say that cost is a disproportionately influential consideration, and two thirds (64%) admit that they are often under pressure to save costs at the expense of quality.

Time is also a considerable challenge, with four fifths (82%) of local authorities admitting that this is a main barrier to long-term planning. Three quarters (71%) would like to have more dialogue with service providers – which may be a symptom of the time pressure – and more than half (55%) say they need more guidance from central government on planning for life.

## Time to change

Despite these significant barriers to change, local authorities are adamant that long-term planning is essential and are ready and willing to address these challenges.

The vast majority (94%) of local authorities believe that local government needs to be given the opportunity to make long-term decisions rather than focusing on short-term challenges. The majority (87%) also believe that long-term planning presents the single greatest opportunity to improve quality of life in these cases.

In the current regime, quality of life is far removed from local authorities' key considerations and there is no universal measure in place to ensure that this is consistently measured across the country. However, three quarters (74%) of local authorities believe a consistent measure would improve placement stability, and two thirds believe it would reduce long-term care costs (66%) and improve health (61%).



The majority (87%) of local authorities say long-term planning presents the single greatest opportunity to improve quality of life in adults with learning disabilities





## Looking ahead: Positive steps for all



Recent discussions about health and social care integration, the wellbeing agenda and the resulting Draft Care and Support Bill have all been very welcome, and have gone to great lengths to put in place a framework for a more effective social care system.

However, this is going to require a concerted effort by everyone involved in the delivery and maintenance of social care services to ensure that it works in practice.

Local government is very familiar with the concept of quality of service and service excellence, but this is very different to the quality of life considerations that they now need to factor into their decisions. This creates even further room for confusion if clearer definitions of wellbeing are not put in place.

Unfortunately, local authorities are already on the back foot as a third (36%) are not aware that the Bill requires them to promote individual wellbeing and a quarter (25%) do not feel prepared to fulfil this legal duty.



FitzRoy is calling on the government to publish Guidelines that will help local authorities to quickly understand their obligations to guarantee a better quality of life for adults with learning disabilities. Please also get in touch if you would like to discuss the challenges that you face and how FitzRoy has approached long-term planning in the past, with resounding benefits for everyone involved.

Anna Galliford, Chief Executive of FitzRoy, comments:

“**Local government has reached a “crisis point” in social care for adults with learning disabilities, and can no longer afford to make these financially unviable decisions that simultaneously ignore their impact on the individual’s quality of life and wellbeing.**

**With this resounding acknowledgement from local authorities that the current state of social care planning is illogical and unacceptable, and with a new governing framework due to come into force, there really is no better time for the government to make a change.**”

## Methodology

A Plan For Life is based on opinion research amongst 100 chief executives, heads of adult social care and commissioning managers in local authorities in England. The research was designed by FitzRoy and the interviews were conducted by independent research company Coleman Parkes in October 2013.

## Further information

Please see the accompanying case studies for further information about how FitzRoy is working with local authorities to plan for people’s lives, and enabling adults with learning disabilities to live more independently in a safe and happy environment.

To view these case studies online, and for further information about A Plan For Life including videos and blogs, please visit our website [www.fitzroy.org](http://www.fitzroy.org).

## References

1. People with Learning Disabilities in England 2012; Improving Health and Lives: Learning Disabilities Observatory; <http://bit.ly/19zvDTj>
2. Disability in the United Kingdom 2013: Facts and Figures; Papworth Trust; <http://bit.ly/1bAl4mZ>

# About FitzRoy

FitzRoy is a national charity that helps people with learning disabilities, physical disabilities and autism to live more independently. We provide support to people in their home and in the community, and a range of additional services including supported volunteering, community involvement and assistive technology.

FitzRoy currently work in: Cambridgeshire; Norfolk; Suffolk; Berkshire; East Sussex; Essex; Greater London; Hampshire; Kent; Surrey; Cheshire; East Midlands; Greater Manchester; West Midlands and Worcestershire.

## Get in touch

FitzRoy House  
8 Hylton Road  
Petersfield  
Hampshire  
GU32 3JY

Tel: **01730 711 111**  
Email: **[info@fitzroy.org](mailto:info@fitzroy.org)**  
Web: **[www.fitzroy.org](http://www.fitzroy.org)**

Registered charity number 1011290  
A Company Limited by Guarantee  
Registered in England, number 2699902

## Find us on



FitzRoy UK



FitzRoyUK-TransformingLives

