

STATES OF JERSEY



DRAFT ANNUAL BUSINESS PLAN 2010 (P.117/2009): THIRD AMENDMENT

**Lodged au Greffe on 7th September 2009
by Senator B.E. Shenton**

STATES GREFFE

1 PAGE 3, PARAGRAPH (b) –

After the words “withdrawn from the consolidated fund in 2010”, insert the words –

“except that the net revenue expenditure of the Health and Social Services Department shall be increased by £475,000 to provide funding for adult respite care.”

2 PAGE 3, PARAGRAPH (f) –

After the words “Summary Table C, page 96, for the period 2011 to 2014”, insert the words –

“except that total indicative net revenue expenditure of the Health and Social Services Department shall be increased by £487,000 in 2011 and by £499,000 in 2012 and by a similar sum (increased in accordance with the appropriate non-staff inflation figure) for 2013 and 2014 to provide funding for adult respite care”.

SENATOR B.E. SHENTON

REPORT

Introduction

The need for respite and crisis care continues to grow. As the trend towards deinstitutionalisation continues more and more families are caring for members with disabilities and chronic health care conditions at home. As the costs of long-term care continue to rise, respite and crisis care services are increasingly recognised as a cost effective way to help preserve families and protect children and dependent adults at risk of abuse or neglect.

Health and Social Services – Special Needs Service

Background

There are a number of component parts to the short break respite services that have been developed to support clients and their families. These include the provision of short breaks for either the individual or for their family. Clients covered by these services include adults with learning disabilities and/or those on the autistic spectrum living within the family home. The respite can be provided as either a residential stay away from home, or on an outreach basis, through support provided to maintain the individual in the family home.

Children's provision

At present children with special needs are catered for at a number of centres. These are Maison Allo, Oakwell and Aviemore/Eden House.

Maison Allo, which is run by Jersey Mencap, supports families with children with a mild to moderate learning disability and has capacity to provide 5 beds per night.

Oakwell, which is run by H&SS Special Needs Service, supports families with children with profound multiple disabilities and with associated complex health issues. Currently 4 beds per night are provided.

Aviemore/Eden House, which is also run by H&SS Special Needs Service, supports families with children on the autistic spectrum with complex needs, including challenging behaviour. Currently 2 beds per night and an outreach service are provided.

Adult provision

At present provision is made at Les Amis – funded by H&SS – to support adults with a mild to moderate learning disability where 5 beds per night are available. There are, however, only limited respite facilities available for adults with more complex needs such as people with severe learning disabilities, physical disabilities and brain injury. It is estimated that there are approximately 12-15 young people in this category.

What is required?

Evidence from the U.K., which featured very largely in the work already undertaken in developing the Carers' Strategy here in Jersey, indicates that there are a range of measures that can be taken to support carers in maintaining loved ones in the community wherever possible. This research, undertaken by the Audit Commission, the London School of Economics and the University of Kent identified that there were four key priorities to be addressed. These were increases in the provision of Daycare

facilities, Home help care, Institutional respite care and access to Social work counselling. In Jersey, whilst partnership working with a range of community care service providers is already underway, it is evident that more could be done.

Institutional respite care

The development of a 'bed based' residential service that can respond to people with more complex support needs, including those people with multiple profound disabilities, associated complex health issues, severe learning disabilities, acute autism, challenging behaviour is an early priority.

Provision for the majority of these clients might be secured through the block purchase of up to 4 beds per night, from an appropriate residential provider, at a maximum cost of £1300 per bed per week. This would be a very significant investment indeed with projected full year costs in the region £270k, but would have the capacity to respond to both regular planned residential respite short breaks, and to supporting planned holiday breaks. It would also have the potential to respond to those individuals who do not have a learning disability but have, instead, a physical disability, where there is also a service need.

A smaller group, however, would require more specialist and intensive short break support and it is estimated that this would cost £140k per annum, on a recurring basis.

Outreach Service

Another service required is to develop an outreach service that would provide tailored support to individuals in their place of care to enable their carers to have 'time out' without the disruption of admitting the client into an institutional facility. It is estimated that the establishment of a community based team to provide this service could cost approximately £75k per annum. This model has the potential for the co-ordinator / supervisor to develop both the professional community support service and a volunteer support service at the same time, thus benefiting a much wider development than just the respite short break service.

Meeting the needs of those with complex needs and challenging behaviour

This is likely to be the most difficult to establish and to cost. During a 'service development' workshop held last summer, involving almost all care providers active in Jersey, there was recognition that potential existed for partnership working in the provision of flexible services for this client group. This could obviate the need for H&SS to provide this service directly, electing instead to contract with an experienced operator for the provision of the same. Much more detailed analysis of the financial implications of such an initiative would be required, but it is likely to cost at least £150k on a recurring basis, without reference to potential capital costs.

Conclusion

Taken together these developments could cost well in excess of £500k per annum. There are not the funds available within the H&SS Budget at present to deliver this vital service.

In times of financial constraint it is important that we squeeze the last drop of value out of everything we do. Furthermore we must concentrate on the 'must have services' rather than the 'nice to have' facilities.

Adult respite is, in my opinion, a must have service – and it is the duty of a morally responsible Government to provide the funding. The figure applied for, £475,000, will be sufficient to provide a very good service to this very valued, but somewhat neglected, part of society. It will enable H&SS to move forward in an area that requires investment and shall provide a quality of life to many people that is far superior to that currently attained.

I ask for the support of this Assembly.

Financial and manpower implications

The financial implications are laid out in the Proposition. In terms of manpower this will depend on the final plan as devised by H&SS once funds have been allocated. We live in a chicken and egg environment – you cannot plan anything without knowing what funds are available, but you cannot get funding without detailed plans.

Report by the Christian charity Livability

TEENAGERS who are disabled suffer from a sudden and nightmare-like drop in support once they become adults, a report by the Christian charity Livability says.

Things will not get better until health professionals are legally required to help plan the transition from children's to adult services for these young people, says the report, *Freedom to Live*, from the charity, formed last year by a merger of the charities John Grooms and the Shaftesbury Society. They believe that real and lasting change will only happen when doing nothing is no longer an option, it says. Some families described the struggle to find support, once the young person becomes an adult, as a "nightmare". They were "full of anger" at the sense that services they had fought for "simply disappeared at transition to adulthood", the charity reports.

Lack of planning and too few facilities mean that many teenagers are treated like disabled pensioners rather than young adults, it says. "The services that are offered to disabled people are often designed with much older clients in mind." One mother said her young son had respite care in a unit with 70 year olds.

"The disabled young person can end up feeling that they have moved not from childhood to adulthood, but from adolescence to retirement," the report says. By the age of 25, young disabled people are four times less likely to be in work than their able-bodied contemporaries, and 40 per cent have nowhere to live suitable for their age and needs, Livability says. To give them choice, one in ten of all new social housing units should have wheelchair access. They should have sufficient places in special schools, and an individually tailored and balanced curriculum. They should also have advocates.

Case Study

Note; I have used a case study from the UK because, quite frankly, on a small Island it is too easy to identify people even if you change their names.

Ged is a carer for his son, Shaun, now aged 26, who was diagnosed with Cerebral palsy when he was 18 months-old.

“We were told that Shaun would probably not crawl and would never walk. He would often lie on the floor on his back or his front playing.

Then one day he just got up and crawled without anyone’s help. I can’t describe in words how proud I was, and cried tears of joy. As with any child with a disability, each small step and achievement is magnified ten times over and gives a real sense of progress.”

Daily tasks

Ged explained the day-to-day caring tasks he helps with: “The daily tasks for Shaun and me are getting breakfast ready which is Weetabix, Shaun’s favourite – which he has in bed! Then it’s a quick crawl for Shaun to the bathroom for a wash, shave and a teeth brush. Then it’s time to get dressed, down the stairs and out the door. I then drop Shaun off at his learning centre for the day or we go out somewhere if it’s the weekend. Shaun loves going to the shops or watching his beloved Everton football team- he’s a season ticket holder.

“Shaun will never be totally independent, but can do some things on his own. I prepare his meals for him, although his fine motor skills mean he can feed himself, provided you cut up his food for him.

Shaun needs help with his personal hygiene. He cannot bath himself or clean himself after he’s been to the toilet.

He cannot walk unaided so I have to help him by taking his weight, I put my arms under his arms and walk behind him. Now he is 26 that is getting harder, as is lifting him in and out of the bath.”

Despite Shaun’s condition, Ged has still been able to pursue a career. He said: “I have had a great career in the police service, but there have been periods where I have had to stay in the comfort zone and not move into jobs that would otherwise have been a challenge to me. However, with the support of others I’ve not done too bad... I’ve no complaints.”

Help and support

Ged described some of the help Shaun has received over the years: “Disabled facilities for children are widespread, and there is a lot of help and support available.

Ged described how Shaun’s condition has affected both him and Shaun emotionally: “Not being able to do things for himself sometimes frustrates Shaun, but he never moans about it, and gets on with the cards he’s been dealt with.

“There isn’t a day that goes by that I don’t wish Shaun was a normal 26 year old. However that would take away the character and the lovely young man Shaun has become – he is the apple of my eye. Looking after Shaun has not been ‘a walk in the

park'. There are a lot of sacrifices to be made. However, despite all Shaun's problems he lives life with a smile on his face and is truly an inspiration to me and many other people."

Too often Government gives to those that shout the loudest and neglects those that selflessly dedicate their lives to those they love, but chose not to speak out. They deserve Government help far more than those that selfishly play the system for their own benefit. This proposition puts the funding for adult respite services in place and will provide a welcome facility for many dedicated carers.

Many Islanders do not see the good work that their taxes pay for – the facilities for the elderly, the sick, the disabled, those with mental health problems. Often because they do not want to see or help. We must take responsibility for others and must not judge need on the basis of who can shout the loudest.

I am pleased to have the full support of Senator Perchard in respect of this amendment. As Assistant Minister, and then Minister of Health, Senator Perchard did much good work examining the needs of the community and identifying weaknesses.

In addition Senator Paul Routier, Deputy Montfort Tadier, and Deputy Sean Power have an understanding of the failures in this area and are in agreement that action is required to alleviate the burden we place unfairly on sections of our community.