

Submission of Lesley Bratch received 31st January 2020

For the attention of: The Scrutiny Panel

Firstly, I would like to say I am approaching this review as a mother, and main carer, of a young lady with learning disabilities and complex health needs. Over the years we have used many health and social care services, she is now 25 years old and is in receipt of domiciliary care funded by the LTCB. As I was lucky enough to know my way around the LTC Law, I was able to point out where in the law it allows for payments to be made to the individual or agent, for this reason we have as near as possible to a personalised budget. I would like to suggest at this point, that we should be heading towards this option, were it is wanted and were it is deemed appropriate. Added to this:

Easily accessible information with a clear pathway to access person centred services overseen by openness and transparency will be key to underpinning a successful model for Personalised Social Care (As per p.37)

I have read through the briefing paper on the Jersey Care Model. Unfortunately, I was not able to attend any of the public meetings where I could have listened to debates and ask questions. There are some good ideas, but I would require more information on: How will these initiatives be funded? How will they be staffed? How will you be making sure the patients/ clients and carers have a voice? How will you ensure that safety and person centred care is not compromised whilst balancing costs and budgets?

1) **Complex Needs (should be added to the workstreams p.14)**

Hospital

a) For those with lifelong complex needs such as my daughter I would suggest a cradle to grave service within the entire spectrum of Health and Social Care Services with support for carers including access to residential respite (this is an issue in itself and has been for years)

b) A ward (Possibly a Neurological Ward?) in the hospital should be set aside for patients such as my daughter so that we are guaranteed nursing and care assistant support from people who understand these very specific and sometimes challenging needs, possibly linked to the Paediatric Ward this would assist with continuity of care. These rooms or wards must have the capacity to accommodate carers/families and all the necessary equipment with accessible personal care facilities.

c) Continue and develop (24/7) the services of the Autism Nurse and LD Nurse in the hospital as their work has been invaluable.

d) Look at accessible personal care facilities within the hospital....at present there is no Changing Place facility within the hospital.

e) All staff from first responders through to care assistants and consultants must have training to understand the needs of those with LD/Autism/Mental Health conditions this should include various types of signing. Good communication between the patient and the care provider is so important in the care environment.

f) When planning the Emergency Care Centre don't forget the needs of people with LD/Autism etc.

g) The outpatient service via virtual hubs...would this work for complex needs patients and how would it look??

Community and Domiciliary Care

a) Inevitably informal carers will be used to support loved ones at home, as I do. We need support to do this financially, physically and emotionally. Enhanced support for carers p16. What will this look like?

b) The whole structure of LTC and its relationship with Income Support needs to be addressed. The loss of the Impairment Component when moving to LTC has had a huge impact on already overstretched families. I am aware of several families who have opted for no support due not being able to manage financially without this benefit. Care is not just the physical delivery of care, it comes in many other forms.

The LTC benefit does not take account of people with life long complex conditions, it is aimed at the older person. Where ever my daughter goes she has to have a support worker with her, we have to cover the costs of that support worker's activity ie If she is bowling with my daughter we pay for both, if she goes out for a meal we have to pay for both, if she goes to a Mencap disco we have to pay for 2 tickets. She is lucky that at present we can do this, but what happens if we cant carry on supporting her? I know life is about compromise but these young people have already had huge compromises in their life isolating them because a benefit has not been thought through properly is unnecessary.

c) Moving people through hospital and into the community needs to be done safely and quickly. We need the staff to do this? More Social Workers and or assistants will be needed. More Occupational Therapists, Physiotherapists and Speech and Language Therapists.

d) Once we have been deemed to have the support we need the case is closed. Who fights our corner when we have a problem. We cant always go back to already overstretched Social Workers. We need easily accessible support....An Advocacy Project perhaps?? Government or Third Sector?

e) Equipment and subsidised products: people living with disabilities in the community and/or those coming out of hospital to be cared for at home will need access to the correct equipment and the correct products to support their needs. Their home may need to be adapted to accommodate these needs. How will these issues be funded? Informal carers can not keep taking all the responsibility with little support. There is very little Government support for home adaptations and no support for accessible vehicles.

f) Carers need access to information. At the moment we come across information by chance or word of mouth. Living with someone who has extra needs gives you a very different perspective on life...casually going out for a meal does not happen it has to be planned. If we were to have a website with details of for example: accessibility, disabled toilet facilities, changing place facilities, life needs to be easier and not such an upward struggle.

g) The Children's Service has a CDC, on leaving that service there is nothing to support the individual, carer, family. People who have got used to this hub will have nothing. A hub similar to the CDC could be used as a social meeting place/café/social enterprise or for formal meetings, information centre, therapy centre.

At present formal carers struggle for somewhere to go during a session. A meeting place could provide a useful alternative to driving around the island in circles or going bowling for the 100th time!

Maybe this could be linked to the Closer to Home initiative? p.40

h) Where is the Respite that carers need? And where is the Carers Strategy that has been discussed for years but never acted on?

i) I think it is questionable whether private companies should be providing care in the community. I feel that my experiences have shown that profit can get in the way of care.

j) Expand the LD Community Nursing Team.

2) Education

a) Safeguarding: alongside all Health and Social care reforms there needs to be an island wide awareness campaign on Safeguarding. People in general have no idea how to report an incident or what constitutes abuse. Carers and individuals need to understand this important subject. And how to keep themselves safe. I note Safe Places are mentioned. I would like to mention the Connect Card which would link in well here.

b) Inspections and Regulations: Again people need to know more about this Department and how to access them. I believe the Department needs more 'teeth' and a higher profile.

c) Capacity and Self Determination: information on this should be readily available to people.

3) Staffing

a) How do we develop a well trained highly skilled workforce?

b) How do we encourage our children to return after training off-island? We need to be looking at the Island Plan....population growth, cost of living, housing.

c) We need incentives for the poorly paid and over worked care staff..tax breaks, pensions.

d) I believe we need to be developing our local market by training and recruiting locally as these people have a vested interest in their island. We have had too many interim staff and we are spending far too much on contractors. I believe this is getting out of hand.

e) We need an island wide awareness campaign including going into schools to promote the Health and Social Care Sector.

f) Potential employees need to see a future in this sector.....promotion, personal development and appreciation of this very important role within the island community. N.B Please do not employ people from agencies in the UK to come in and care for vulnerable people for short periods at a time, we need continuity of care.

g) Staff across the board should be trained to communicate in BSL/Makaton

4) Mental Health

1) Please remember that mental health does not sit in isolation it can and often straddles LD and Autism, so services need to link up and learn from each other.

2) The Listening Lounge is a great concept for those able enough to access it. But for those who aren't able there needs to be an easily accessible service that is available 24 hours a day 7 days a week...not 9 to 5.

3) I have visited friends in Orchard House, I am so glad to see it acknowledged here that this is not a suitable environment to aide recovery.

5) Commissioning Service

As a long time user of social care I am very interested in your proposal around commissioning. I am particularly aware of how I feel behaviours may be driven by the funding model.

I have also seen how mistakes can be made unintentionally, however over time these could prove very costly to the LTC pot. It is only by us managing our benefit and checking hours invoiced against hours received that we have been able to highlight errors. I must say to the credit of our provider they have been very few and unintentional but never the less someone sitting in the accounts department settling LTC invoices is not going to know first hand what the client has or hasn't received in hours.

Please do not transplant ideas from the UK and implant them here, learn from the UKs mistakes and only pick up what works and what is achievable.

Finally, we will need all the Government Departments to pull together; this has not always been the case leading to huge financial waste.

We need to see strong partnerships developed with the third sector, and other relevant organisations, both now and going forwards....

And the voice of the user must be heard!

Any questions please do not hesitate to contact me.

Kind Regards

Lesley