

## GDA focus group on Health & Social Care in Guernsey

The GDA invited members (individual, groups and carers), Health and Social Care (HSC) staff, service users, the CareWatch team and other partners to join us for a focus group around the priorities in Health and Social Care in relation to disability and carers. This took place on 12<sup>th</sup> September 2017 at Beau Sejour, 41 people were present.

This document summarises the evening's discussions, extra notes were provided by group unable to attend including CF Cystic Fibrosis. It is hoped other gaps ie MIND and mental health group will also be added in due course. The notes are available for those unable to attend and or HSC CareWatch and HSC team to progress further as necessary.

### GAPs (these were summarised at the end but moved to the front here)

The following gaps and priorities were noted by the tables:

- Joining up services in HSC and other departments to form a coherent and effective individualise service to meet complex needs
  - Joined up SC/SS: nobody seems to know what services are available (2)
  - Communication from HSC and ESS to make people aware of services they are entitled to (2)
  - Social security to put a package together of things people are entitled to when diagnosed with debilitating illness
  - A co-ordination of services and information: where do we go, what are we entitled to
  - Mixed messages to families, e.g. information gap from strategies to coal face
  - Communication and co-ordination
- Lack respite care /facilities suitable for the person needing it (5)
  - More respite than current 4 weeks per person, Carers need more of a break (6), including emotional support
  - Respite: need information to service users and States funding between Hospital and Residential
  - People unaware that they can access this service (respice)
  - Working respite care for children & young people; one size doesn't fit all
  - A 24/7 service for parents of children with mental health issues who may reach crisis when CAMHS is not open!!
  - Full time care for working parents for young adults leaving education which is not resource led
  - Support for the carer when loved one needs to access private services once children's services finish e.g. dentist
- Legislation: the rights of disabled people need to be enshrined in law (4)Future care / accommodation / living for young adults / adult / elderly for moderate to severe special needs
- Lack of community services = AHP/packages of care/ appropriate respite / support for carers (2)
  - Lack of care in the community, not even able to provide 1 hour per week
  - More carers in the community
- Implement the Disability & Inclusion strategy legislation (2)

- Lack of employment opportunities (2)
- Lack of access to educational opportunities
- Lack of Social Inclusion
- Lack of data on 5-18 year olds
  - Lack of data is a disgrace; how can you run a service when you don't know who you are serving
  - Data Management
- Lack of Wheelchair access in the community (3)
  - On Bridge and in Town (2)
- More physiotherapists to allow for consistency and to reduce waiting lists
  - Physio: Recognition that this is very cost effective for recovery
- Dedicated wheelchair posture and seating person on Island (2)
- States of Guernsey action: Lots of talk about analysis but no action, it's taking too long!!
- Gap in service for people with Autism but without learning disability (LD) (2)
  - Don't fit into any category – no help!
- Access to buildings
- Acute staff awareness of hidden & learning disabilities in a hospital & community setting.
- Personal budgets, e.g. Autism
- Idea – execution of initiatives. TAC *should* be transformative but issues with families understanding what it is
- Co-ordinated accessible transport (2)
  - More options at low cost – co-ordinating etc.
- No continuity of support in school holidays – access to play schemes for social contact
- Development of activities – wider access
- Bed blocking linked to paucity of beds, poor domiciliary care provision and unaffordability of private beds

## **Introduction by Karen Blanchford**

GDA umbrella, assist gov't in policy making and influencing policy and practices. Bring together diverse range of people with disabilities. 42 member charities (new youth commission and spotlight); also individual members and partners. When there are key themes we pull everyone together before feeding in. We also do considerable amounts of research to influence policy seeking to be effective and positive influence on gov't.

How many have disabilities? About 13,000 (14,000 in the Bailiwick). About 4,000 carers. 1 in 4 mental health, plus dementia, plus hidden disabilities. Everyone is somewhere on the disability spectrum. Our work benefits all.

New campaign has been launched "Think Differently about Disability"; mostly on social media, but also with JKT tomorrow. Do you know how many people, do you know how broad, do you know how to talk about it, or to people with disabilities? Social media in September, visiting businesses in October to encourage corporate involvement. [#Endthe awkward campaign by Scope. Encourage people to talk openly.]

Karen introduced Roger Allsopp OBE (CareWatch chair and also on the Board of HSC). Karen, Tanya, Catherine, Rick, also members, please accept apologies from the rest of the team. Today, focus only on HSC, but not just on how it looks now, but also aspirations for the future. Where are the gaps?

Pull out gaps in constructive way, so GDA can take it away.

## **CareWatch Introduction by Roger Allsop, OBE**

"The primary purpose of the CareWatch is to provide advice to the HSC on Strategy, Health and Social Care Services and reviews, Health & Social Care Programmes, and proposed Service Developments and Disinvestments from a Servia User perspective."

I am here to listen. One of longest serving members of present Board. New board under Paul Luxon, came in as Lay Member. Volunteered to stay on after new election. Only continuity except also Heidi Soulsby. Has learned a lot. Believes a lot of structural change has taken place. Believes the Board is now well constructed. Heidi has great vision, great compassion and great courage. Proud to remain on Board. Believe Mark de Garis is talented and also his assistant Matt. With nurse professor and medical director? Very talented core.

Number of people contributing tax is diminishing, while need is increasing. There is no choice but to change. Looks like Board has turned the corner in terms of gaining control of expense. Very difficult to recruit and retain nurses and social workers. Problems facing board same as problems facing a country. Want to reassure you that I have great faith in their ability and commitment to getting things right and seeing through the changes.

Frightening, but also exciting. These are the essentials, these are the places where money needs to be spent, these are the things we can improve, and these are the things that we can dispense with.

We want to talk to the GDA forum first of all, because of your diversity and commitment. I am proud to be able to listen. I can go tomorrow and knock on the Chief Exec's door, and give your message.

## **Feedback from Round Table Discussions**

### **1. Works Well**

- Grow Ltd. But concerns about handover from health to employment (who do not understand the needs of the people inside)
- Mixed independent residential homes work well (e.g. Grands Courtils and Nouvelle Maritaine overdue steps forward)
- Headway and HSC joint post means more joined up
- Rehab garden at HSC (but now infection control is upset)
- Foster care support
- Autism care under various services
- Supported living and crown support to keep people in community
- Greater outreach to help people stay at home
- Speech therapy is great (access is still an issue)
- School dental service
- Diabetes support for children
- Team around the child lead training: there is potential
- Ron Short support
- Organic links between HSC and third sector (but tight)
- Website info
- Gov't seems more open to improvement and taking on ideas
- Wheelchair service evolved positively (but more to do; funding in place, but recruitment)
- Sports for disabled people are improved (but by volunteers and sponsors)

### **2. Issues and ideas for change**

- Physiotherapists; long waiting list [four or five week sessions, then stopping is awful; improvement is then lost and that has a spin off effect on mental health]
- Lack of respite facilities, choice of days and times
- Poor wheelchair access in town and on the Bridge
- Lack of regulation in terms of care home standards
- Disability legislation still below standard; people need rights that give HSC and other providers clear responsibilities
- Lack of commissioning – third sector left on a knife edge
- Bed locking in hospitals (again lack of domiciliary care)

- People in wrong places because they have to fit into empty beds (e.g. lucid stroke patient housed on a dementia ward)
- Poor social housing for young individuals (or adapted housing) to live independently (or with support) at home
- Reducing cost of new builds by adapting people's homes
- Increase level of domiciliary care (care packages and staffing)
- Third sector gov't partnerships more rhetoric than action
- Difficult to coordinate Social Security and HSC (and education)
- Availability of transport for wheelchair users.
- Wheelchair servicing is very limited and quite expensive
- Employment for physically disabled people is very difficult still
- Lack of coordination of services (public, private and third sector, but also within HSC)
- Picking up issues sooner, before crisis point (autism, diabetes).
- Need more supported employment.
- Need more service level agreements with third sector (like Headway)
- UN Charter on rights of disabled still not signed.
- Primary legislation still missing, so disabled people have no rights.
- Speed of service delivery is insufficient (and leads to escalation of issues).
- Need better evidence based pathways; better equity with private treatment.
- Continuity of care (too many changes are hard on those receiving care).
- Timing of appointments has to be more flexible so it doesn't cut into the limited available activities for some people.
- Suitable respite.
- Care homes are not old people's homes.
- Disability and inclusion strategy still not completed.
- Proper resources and motivation to actualise agreed strategies (rather than endless meetings about how they might be actioned)
- Legislation
- waiting times (with inequity in health) Until we get rid of it, we haven't got a health service

## **GAPs**

These were completed last but placed at the beginning of the document for quick reference

## **Closing response by Roger Allsop**

We cannot do all these things tomorrow. Some we know about. Some are new. It is a great honour that you told them to us. Get them all in order, and we can take it back to the government. We certainly cannot do any harm by raising our voice.

## Appendix

### Agenda

GDA focus group on Health and Social Care in Guernsey

Tuesday 12th September 2017, Beau Sejour, Delancey and Saumarez rooms (upstairs)

Thank you for taking the time to attend and represent yourselves, charities, service areas in this session with Health and Social Care (HSC) and the CareWatch team. The objective of the focus group is to hear your views and ideas on the future of HSC, to raise the CareWatch team and HSC board's knowledge of issues and priorities around Health & Social Care in relation to disability and present possible solutions or ideas for change.

#### Agenda

6:30pm Registration, refreshments and table allocations

6:45pm Brief introduction by Karen Blanchford, Executive Director GDA

6:50pm CareWatch introduction by Roger Allsop OBE, Chair of CareWatch & HSC board member

7:00pm Round Table discussions on accessing Health & Social Care:

- What works well? Current issues and ideas for change?
- Prioritisation of your tables and individual needs

7:45pm Feedback from the groups

8:00pm Summary

8:15pm Next steps, if required and close

Notes: CareWatch: 'The primary purpose of the CareWatch is to provide advice to the HSC on Strategy, Health and Social Care Services and reviews, Health & Social Care Programmes, and proposed Service Developments and Disinvestments from a Service User perspective'

#### CareWatch team

- Roger Allsop, HSC Board Member, Chair
- David Inglis, Age Concern Representative
- Charlie Cox, Youth Commission

Guernsey Youth Forum Representative together with Guernsey Youth Commission

- Katherine Adam, Citizen's Advice Representative
- Karen Blanchford, Guernsey Disability Alliance Representative
- Anita Kilby
- Peter Neville
- Rick Lowe
- Tracey O'Neill
- Tanya Martinson
- Graham McInley, States of Alderney Representative
- Martin Gavet, Change and Performance Manager, HSC (non- voting /administrative/ advisory)

**Attendees:**

We had 41 people attend, with representation from:

- Guernsey Disability Alliance (GDA) members
- Health & Social Care (HSC) CareWatch team
- Health & Social Care (HSC) staff and service users
- Guernsey Cheshire Home
- Headway
- Access for All
- Wigwam
- NAS /Autism Guernsey
- Guernsey Down Syndrome Group
- Guernsey Community Foundation, representing Carers Guernsey
- Aging Well in the Bailiwick
- Association of Guernsey Charites, AGC – Health Sector
- Dementia Friendly Guernsey / Alzheimer's Society Guernsey
- Citizens Advice Bureau (CAB)
- Mencap
- Employment, Social Security (ESS) staff
- Guernsey Ron Short Centre

**Attachments/to follow**

- Cystic Fibrosis feedback below by email
- Mental Health feedback –to follow

## Cystic Fibrosis CF - H&SC

There are some very clear guidelines provided by the States through the Disability Officer and Signpost.gg in this area that those with CF, in my opinion, are failed by or at best ignored because they don't fit easily into the model.

The 'Transition Forum', which I know nothing about, sounds exactly like the place where are CF youngsters (14yrs onwards) should be being discussed to achieve co-ordination and a support plan, for their transition to adult services. The big area where it all falls down is that 'on transition' the child/young adult's lead professional ceases to be locally based and ties with MSG and the other services are essentially cut (communication problems back to the Gsy services providers multiply exponentially) because we pay for Southampton Gen Host (SGH) to provide adult services for CF. Adult services at SGH mean health services only. The 'Transition Forum' specifically include Education, Health, Social Security, Housing, Community and Disability Services. Adult services at SGH take no account of other practical needs required to be a productive part of our community.

### what works well

- paediatric care for CF
- I note that we have a new respiratory specialist in the form of Dr Clare Betteridge, who I met. I am pleased to say that she has good CF experience and thus would expect that local paediatric CF care would remain at least as is, which is managing the condition from Guernsey, overseen from Southampton. When treatment is required such as antibiotic IVs, it is usually managed locally.

### what doesn't work well

- local care of adults with CF, example as above. this is only going to become a bigger issue as more and more of the children with CF start transitioning to adult care.
- For CF patients, I think one of the biggest issues has to be the transition from paediatric care, which involves 'the full service' in the Frossard Ward to adult care, which mostly seems to be 'we want nothing to do with you here – go to Southampton'.
- As a quick recap, the incident which really highlights the problem was C eventually having to go to the local A&E to be medevac'd to Southampton before she could access IV antibiotic treatment. The treatment required is routinely given to kids with CF in the Frossard Ward – so why the same treatment cannot be given to adults locally should be considered.
- Our children/young adults/adults all need support from multiple services, they certainly have complex needs. Whilst these are unlikely to involve a learning disability their mental and emotional well being is likely to be fragile.
- Their transition through Education should be monitored more closely, particularly from 14-19. Post 16 education and life long learning support needs integration as does assistance with careers in Guernsey. Emotional wellbeing and mental health are not tackled actively by education or health for those with CF despite the organisations and frame work being there.
- mental health; at a fragile and stressful time in their lives the States add even more stress by abandoning their care to the UK. And this is happening whilst they are not yet legally considered to be adults!
- the cut off for the transition to adult care occurs at 16. So once the child reaches 16, instead of having the two weeks course of IVs in Frossard ward they will have to go to Southampton – pretty well cut off from friends and family, unless the family can afford to be out of work regularly and unexpectedly for two weeks at a time. It is quite common for children with CF to have two to four courses of IVs a year – so that could take them off island for a total of two months in a given year – years that include the most important parts of their education (GCSE exam year and then the A level years).
- the "move from child to adult services", our biggest emerging issue for the coming years
- In the past those with CF didn't normally make adult services, so have been discounted by the system. The support system needs to adapt and include those with CF even if the MSG and their medical protocols can't adapt at this time.