



Special Needs Advisory Panel

Representing Adults & Children with Learning Disabilities & Autism

The Scrutiny Officer,

Morier House,

Halkett Place,

St Helier

JE1 1DD

8th February 2015

Dear Madam,

Review into Respite Care for Adults 2015

Firstly, on behalf of SNAP may I thank you for following up on our suggestion to look in to this much needed and under resourced service. I know you are all aware how important respite is to both the carer and the person receiving the care. If nothing changes it is quite valid to question what the inevitable cost of doing nothing will be!

Residential respite should provide quality, person centred care in a safe and easily accessible age appropriate environment; giving the carer a much needed break knowing that their loved one is receiving appropriate stimulation and care to meet his/her needs.

I believe that under investment in the Adult Residential Respite provision has lead to the problems that families have faced recently. There has been a lack of joined up thinking compounded by a lack of understanding of the client group requiring this service. I feel that H&SS need to be working with the families, the individuals and the community and voluntary sector to provide a fit for purpose service that meets the needs of those it is intended to support. To underpin this work it is imperative that the States Departments work together to look at the level of need both now and in to the future.

Transition has always thrown up problems for families and this still remains the case. Again, the Department seems to leave everything to the last minute in the hope that the necessary support packages will fall in to place; inevitably families spend months worrying about how their young person will be supported in the adult world. The department will normally say that families have been cocooned in the Children's Service and that moving to the adult world is a shock...it is only a shock because of the lack of investment in its services.

There is a lack of all therapies across physiotherapy, occupational therapy and speech and language. The support and advice offered by way of the Child Development Centre and Complex Needs Clinics are not replaced; access to equipment once in the Adult Service is nonexistent, so much so that families are advised to claim anything that they might need before leaving the Children's Service.

Why does the department constantly seem surprised that these children grow up? And why do these young people suddenly at the age of eighteen not require the support and input that they did prior to their eighteenth birthday? They still have autism or a learning disability; they do not grow out of their condition!

At this point, I would respectfully suggest that as part of this review you look in to how the Children's Respite provisions are functioning with a view to joint and creative working.

Looking at the Day Service provisions one can see how the lack of investment has affected this service. The building at Five Oaks is tired and out of date having an institutional feeling. There is a lack of up to date equipment and not enough accessible vehicles to allow wheelchair bound individuals the ability to access the wider community. There are smaller hubs around the island...the one within the old St John's telephone exchange is a prime example of how this service has been offered the most rundown of buildings.

There are other hubs in better locations for example the one at Fort Regent where there is an accessible changing and personal care room; however access to this building is limited due to the lack of transport.

On leaving school these young people deserve the chance to achieve their full potential whatever that might be; they have been given that chance within the school environment due to investment in buildings, staff, equipment and the therapies. This needs to continue as these children grow in to adulthood otherwise our island is letting down its most vulnerable residents.

Recently, there has been an increase in outreach provisions. This service has enabled individuals to access the wider community with appropriate support and has proved very successful. I believe this service could be used to support daily activities, employment and leisure pursuits that would enhance people's quality of life.

It must be said that despite the shortfalls within the Adult Service there are many caring and highly motivated staff who want to do the best they can for the people they support. However, they need support to do their job by way of investment in the services.

It is therefore important that when approaching this review you look at how to maintain these staff and how, looking to the future, you can encourage new people in to this field. I believe that they need to feel proud of the service they provide and valued in the work they do, while being able to see a clear career path ahead of them.

Finally, on behalf of the people I represent I would like to say thank you for looking in to Adult Respite. These families need your support! They have been caring for their children since birth; it is a role that the vast majority of families take on without a second thought however, it is tiring and all consuming!

I look forward to reading the outcome of your review in due course, should you require any further information please do not hesitate to contact me.