

The Big Say

Opportunities to have a real say over the future
direction of day services in Jersey



Day Services May – November 2011

A report by Heartfelt Limited



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“I want a future that makes me happy and where I can do different things”

Individual who uses Day Services

Introduction and Background

This report of the recent consultation around the future direction of day services in Jersey aims to build on the innovative work already done by staff in supporting people who use day services and their families to have a real and lasting say over how those services are designed, developed and delivered.

In particular, the consultation aimed to:

- **Build the confidence and strengthen the skills of individuals who attend Day Services to make a genuine contribution to decision and policy making, the way services are provided, where they are provided and how they are provided at all levels across day provision.**

- **Listen to the views and contribution of parents and carers.**

- **To work alongside service providers in helping to shape any change agenda in day services**

- **Support frontline staff and service managers to develop positive and innovative ways to plan alongside individuals and their families, and in particular, individuals with complex and additional support needs.**

A range of events and reviews had already taken place aimed at helping individuals and their families reflect on how services are performing, and to obtain their ideas for real change. Alongside this, there was an intention to bring together individuals and their families, alongside service providers, to look at the future role of day services.

The great success in re-positioning services traditionally based at Le Geyt centre in recent times has shown the enormous potential for real and meaningful engagement. The purpose of this proposal is to look at developing the right kind of skills and the right kind of frameworks to take this forward.

Put simply, our aim is to further enhance day service provision in Jersey so that they become a centre of excellence to be envied and admired across the UK.

How we did it

Finding out - Day Services Consultation

- Work for 3.5 days with people who use day services to look at what works well just now and we should keep/what could be better and we should change/developing ideas for making day service provision better (7 half-day focus groups)
- Provided 2 planning tools for staff to work with individuals over a number of months
- Developed a questionnaire for families carers and parents who have used the service in the past, those who do so just now, or may wish to use the service in the future.
- Brought together common and emerging themes, compared and contrasted them with vision as outlined in position paper by Fiona McLaughlin, identified a shared vision, developed an action plan and agreed a framework for the future re-provisioning of day services

Making it Happen – our findings and what they mean

Heartfelt would then:

- Prepare and facilitate one large stakeholder (individuals. families. staff and others) event presenting all the gathered information and outlining possible ways forward through small and large group work on the day
- Bring together all the work into a report including developing vision and strategy against national policy drivers and other local authorities day service provision in the UK
- Heartfelt will facilitate action learning sets with day service staff and senior managers to develop action and implementation plan based on the report



“Whatever happens, I think the staff that I have met are really good and I will need them to help me lead a good life.

A young person in transition

This report will bring together the results of what was said and the ideas that came.

A great effort was made by all involved, giving up valuable time to take part in a series of events, questionnaires, focus groups and workshops supported by Day Service staff. A vast range of topics, themes and issues were explored meaning that this report would set out, as best we could, to:

- **Identify and group common themes**
- **Examine and list emerging issues and ideas**
- **Make some attempt to inform and advise the future direction of day services in Jersey based on these themes, issues and ideas and map against existing practice elsewhere in the UK**
- **Consider the unique characteristics of current provision in relation to Day Services the available funding mechanisms in place and the overall ability of the wider Special Needs Service to implement a change agenda within existing frameworks**



We could not possibly list every comment made by everyone who contributed to the consultation but have tried to find ways to make this report a *working document* that can be used readily as opposed to a hefty and weighty document that gathers dust on a shelf. We also felt it right and proper that it be reasonably accessible. We have grouped the main findings under a series of headings or clusters of themes. Although the review was an opportunity to reflect on all day service provision, most of the report focused on allowing people with greater communication and additional support needs have a real say about their service.

All of the findings appear on the following pages and it is our genuine regret that we cannot find space for every comment, observation or idea put forward but we have tried to keep within the general themes of what was said. We have at times separated out comments from particular groupings e.g. staff, carers and individuals, in order that the most effective learning from the evaluation takes place.

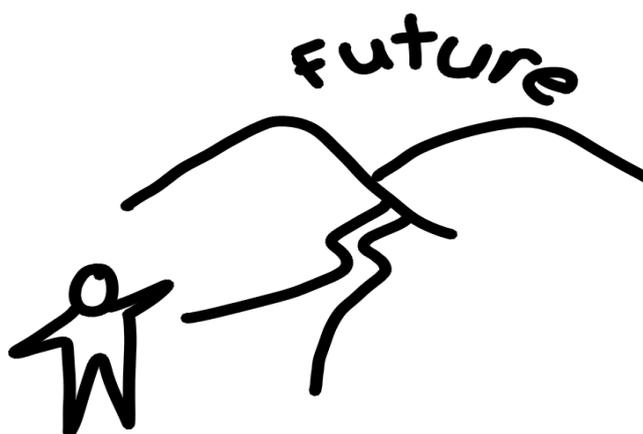
The view from Families – the questionnaire

A short questionnaire was devised for families to help the Special Needs Service get it right in terms of the essential day services it provides to adults with additional needs and their families, but specifically around how it develops day provision historically provided at Le Geyt centre. For the team at Day Services the aim was clear: to provide a range of services that are designed and delivered to meet the unique needs of individuals and their families. The questionnaire, alongside other work with individuals (service users), would go a long way to informing and advising the development of day services in Jersey. Fiona McLaughlin, Team Leader, SNS Day Services, said:

"As you may be aware the team at Le Geyt recently carried out a range of exercises to determine what kind of service we should be offering. It is vital that we hear the views of individuals who use our services and their families; there is a need for wider engagement and consultation with parents of adults with additional support needs and the individuals themselves to find out about the kind of support and services they would find helpful.

As the parent/carer of someone with additional support needs we wanted to include you in this consultation process as your opinions about your child's needs are vital in helping us shape services to meet the needs of families in Jersey".

Clearly, it is not business as usual and there is a commitment to involve individuals and their families as people who can create an agenda for change and actively determine the services they want rather than passively receiving those services.



"I want a good life for my son. I want to know he is safe, happy but is also stretched and challenged so he can be all he possibly can"

A Mother

The view from families – what we wanted to do

- Find out what is currently working well and matches what families want
- Identify what is not working well and could be better
- Gather ideas from families about what could be done to make things better
- Bring together all the emerging themes from the whole consultation and make some sense of them
- Look at ways that a strategy can be devised that is informed, advised and guided by families

The view from families – how we did it

- Families experience of Day Services generally– words that best capture that experience
- Families experience of Day Services – what works well/could be better/ideas for making it better
- Families experience of the Day Service Team – Programmes/Support and Performance of staff/Information and Communication
- What matters most for families in the future design and delivery of services including a scoring system and ranking exercise

The view from families – the response

- 72 questionnaires sent out
- 35 returned
- A response of around 48% - national average is 11%

The view from families – their experience of using services

Families were asked to choose some words that best summed up their experience of using services provided by Day Services.

The most popular answer was **Supportive (67%)** and next most popular was **Helpful** with 23 out of 34 picking this. However, over a third said the service was **Frustrating** and a quarter said the service, at times, was either **Disappointing** or **Unhelpful**. (It is worth noting here that many comments centred on the overall SNS and not specifically the service at Day Services).

The service was described by 39% of families as both **“Professional”** and **“Purposeful”** with over a quarter of families stating the service to be **“Uplifting”**

The view from families – what is working well?



- **A significant number of families highlighted the service as “excellent”**
- **Day Services provides invaluable breaks for families and stimulating, varied “activities for my child”**
- **Many families highlighted the care, passion and on-going support from staff**
- **There was a recognition of how well staff “cope” in difficult times**
- **Families paid tribute to how well support is provided in terms of “behaviour” and “personal care”**
- **Around a fifth of families made reference to the support from the management team**
- **The Sensory Room is a “good facility”**

- **Day Services offers chances to meet new people out with family**
- **Experienced and helpful staff in most services “prepared to do a little extra”**

The view from families – what is not working well?



- **A small but significant number of families felt that Day Services did not suit their child’s needs**
- **A lack of information about what services are available**
- **Families having to constantly “fight” and “struggle” for what they see as a right**
- **Poor and aloof attitudes from some social services and social care staff but not frontline Day Service staff**
- **A perception of a lack of joined-up thinking and joined-up working between services**
- **A lack of urgency in responding to requests**
- **Suspicion, fear and mistrust of some areas of social work**
- **Not enough respite services/ limited choice**
- **Not enough staff**
- **Not enough transport options**
- **A building not “fit-for-purpose”**
- **A perception that some families get more than others**
- **Not enough trained staff e.g. to deal with autism**

- **A sometimes one-dimensional approach with apparent disregard for age, gender or support needs of child**
- **A lack of flexible ways of working e.g. fixed hours**

The view from families – ideas for making things better



- **A more flexible way of working**
- **A guarantee, with agreed timescales, of when things will be responded to**
- **More varied options and programmes**
- **More help to enable parents to stay in work**
- **A settled political will and strong consistent leadership to champion the cause of individuals and their families**
- **The continuation of a building-based facility that offers flexible ways of working**
- **The creation of alternative non building-based short breaks and holidays**
- **Better and more regular contact between social workers and families**
- **The development of breakfast clubs**

“Sometimes it appears a bit boring and repetitive. The staff try their best but it is the same old, same old”

A Father

The view from families – what do they think about the performance of the staff team at Day Services?

The activities and programmes

- ★ 6 people said they felt the activities and programmes on offer was **poor**
- ★ 9 people felt it was **OK**
- ★ 14 people believed it was **good**
- ★ 4 people thought it was **excellent**

Support and performance of staff

- ★ 1 person felt the support from staff and their general performance was **poor**
- ★ 6 felt it to be **OK**
- ★ 16 people felt the staff were **good**
- ★ 10 believed both the support and performance of the staff team was **excellent**

Information and communication

- ★ 3 people felt that information and communication from Day Services and SNS was **poor**
- ★ 8 thought it was **ok**
- ★ 14 highlighted information and communication as **good**
- ★ 8 believed it to be **excellent**

Would families recommend the service to other families?

- **YES** 23 (around two-thirds of participants)
- **NO** 11 (slightly less than a third)

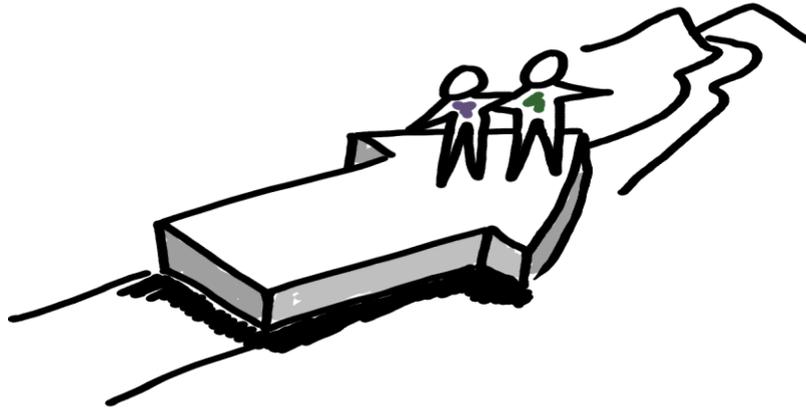
“I think the problems are that agencies and schools and the like just do not communicate with each other and plan together”

A Mother

The view from families – what really matters most

Families were shown a list of 8 statements about the kind of services they may like to see in the future and asked to then rank them in terms of importance, simply putting a **1** next to the statement they thought most important (top priority if you like) then marking second most important statement with a **2** and so on. We then aggregated the findings to produce the following ranking (priorities) order

- ***Better joined-up thinking and joint-up working between agencies e.g. schools, social services, voluntary sector, health service etc. __1__***
- ***A broader range of support providers to choose from __2__***
- ***The use of smaller, localised bases across the island __3__***
- ***Better, clearer information on what is available __4__***
- ***A personal life plan for the person I care for __5__***
- ***Families and Carers having more say and control over how services are run __6__***
- ***A plan/strategy for day services that SNS stick to __7__***
- ***A building based facility situated in Le Geyt at Five Oaks __8__***



The views of individuals – how we did it

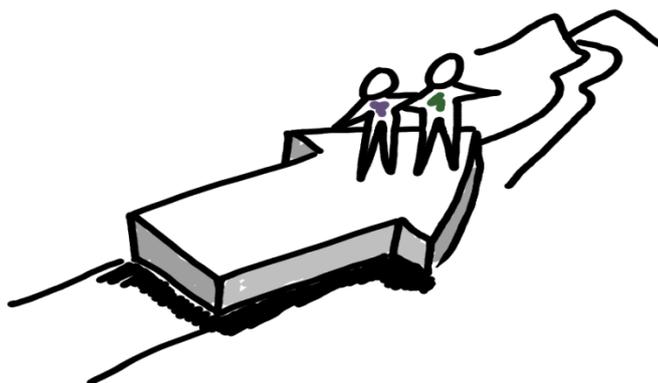
To the great credit of the staff and management at Day Services, there was a quiet determination that any consultation about the future direction of day services in Jersey should have individuals who use those services properly consulted. Staff had spent some time thinking about the challenges in this so that everyone had a chance to have a real contribution and not just the most confident and articulate. Careful thought was given to how this might be done:

- ✦ *Every individual would have the chance to compile a "Who Am I Poster". This a person centred planning tool that allows individuals to record their identity, who they are as people, who is important to them, their skill, talents, hobbies and passions. The emphasis being on people's strength and unique personality. **These posters are available for viewing in one of the rooms at Le Geyt in the form of a gallery.***
- ✦ *Individuals and groups worked on a graphically facilitated record of what individuals like about the service and their lives (that should be kept)/what individuals and groups did not like (that should be stopped)/what individuals would like to do in the future (that should be planned for)/the help and support they need to lead full and meaningful lives (that should determine day services in the future).*
- ✦ *A series of independently facilitated focus groups to discuss the above, develop ideas for making things better and agree some action points*

This work took place over a number of months and a fantastic effort was made by the staff team at Le Geyt to enable this to happen and in a real, inclusive way.



The view from individuals – what works well and should be kept



- ✓ Staff who are friendly and who care
- ✓ The move to smaller bases across the island
- ✓ Chances to do the same things as everyone else
- ✓ A range of staff and enough of them
- ✓ Feeling safe and staying healthy
- ✓ Being with friends and the chance to make new ones
- ✓ Achieving things
- ✓ A life full of promise



The view from individuals – what works well and should be kept



- ✓ Going out
- ✓ Learning to be more independent
- ✓ Gaining in confidence
- ✓ Good support with personal care
- ✓ Staff taking my opinions seriously
- ✓ A fun and happy place to be
- ✓ People listening to me
- ✓ Chances to do sports
- ✓ Learn things to get a job
- ✓ A flexible service



The view from individuals – what does not work well and should be changed



- ✓ Stuck in one room
- ✓ Transport is rotten – not enough options
- ✓ Not being able to choose who supports me or who I do things with
- ✓ Everybody lumped together
- ✓ Too much noise
- ✓ Too many arguments
- ✓ Transitions can be scary
- ✓ Staff assuming things about me
- ✓ Going out all the time
- ✓ Getting bored
- ✓ The Methodist Church – want to go more often

- ✓ St. John – want to go more often
- ✓ The building is not nice
- ✓ Not having enough say
- ✓ Too much red tape

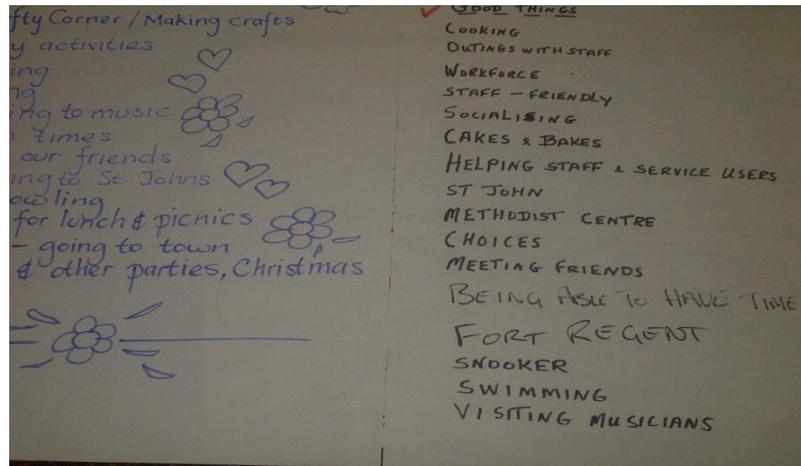


The view from individuals – ideas for the future



- ✓ Flexible transport
- ✓ Individual plans
- ✓ Choosing who supports me and when
- ✓ Attend the service when I want
- ✓ Weekend and night-time support
- ✓ Smaller groups
- ✓ Individual timetables
- ✓ Using all the smaller bases around Jersey
- ✓ A plan for the future just for me

- ✓ Separate services that respect my needs (autism) and my age
- ✓ Staff being properly trained to meet my particular needs



The view from individuals – ideas for the future



- ★ More staff and being able to choose when, how and by who I am supported – staff of different ages
- ★ Somewhere that I feel safe, secure and supported with all my needs
- ★ More help to do practical things like cooking and ironing
- ★ More fun activities that we can invite people to
- ★ Access to a different activities and more choices of what to do
- ★ More say over things
- ★ Help to keep friendships and make new ones



The Big Ideas

Many varied and sometimes competing ideas emerged during this consultation. One of the challenges for the development of day services will be to find ways to promote “individualised”, “personalised” and “person centred” approaches that mean something to individuals and their families and that can be properly funded, staffed and resourced. We have tried to capture some of the main ideas for change; ideas that have some general agreement, fit with current management thinking at Day Services and are realistic and achievable. We have also mapped this against good practice in the UK.

A flexible service

One of the biggest themes to emerge was the idea of flexible services. Again, this meant different things to different people but there was general agreement that we need to move some way towards this.

Any future provision could consider the following:



- ★ Offering services out with traditional day service hours e.g. at evenings and at weekends
- ★ A variety of support options that take account of the wishes of individuals e.g. workers matched to individuals in terms of age, gender and interest
- ★ A "menu" of activities that individuals can choose from and not always linked to one particular place
- ★ A separate service for individuals on the autistic spectrum
- ★ An accessible and flexible transport service

A community resource

Much debate took place around where people should go to receive any service. Many individuals, parents and workers were keen to use the same places as the wider community – be it community centres, colleges, workplaces, sports centres etc. However, an equal number expressed concern about whether facilities and venues in the community were welcoming for people with learning disabilities either in terms of physical access or the attitudes of host groups from within the wider community. Many others recognised both views and felt that somewhere in the middle may be the best way forward i.e. somewhere that is not exclusively for the use of people with learning disabilities but does have a "base" or "hub" that can be used exclusively by them, at certain times of the day. The recent success in using smaller bases across the island has been an outstanding example of this being done well.

Any future provision could consider the following:



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- ★ A feasibility study bringing together individuals, families and staff alongside managers and planners from social work, community planning, leisure and recreation, further and higher education and the local business community to develop a strategy for working together and sharing premises, finance, resources and expertise. Day Service management have been very proactive in thinking innovatively about this through their business plan.
- ★ Individuals, families and staff from Day Services, alongside other planners and policy makers, to visit and report on how local authorities and agencies in the UK have re-developed day provision
- ★ Using the Speak Out group at JET to help develop more positive attitudes across the community.

Involving individuals and their families as equal partners

The process built on the recent good work done by Day Services in helping individuals and their families in becoming genuinely involved as decision makers and planners; the process was a real attempt to find ways that individuals and their families could meaningfully contribute and have their views at the heart of any decisions that are taken. However, there was universal agreement that this needs to continue and structures and frameworks put in place to guarantee that any involvement remains real and sustained.

Any future provision could consider the following:



- ★ A reference group could be established to lead the changes in day services as well as monitor and evaluate progress – this group should have that active involvement of individuals and their families
- ★ Learning and training opportunities should be provided to build the confidence and capacity of individuals and their families.
- ★ More opportunities for joint training with staff and service users.
- ★ A set of new person centred plans should be put in place for all service users at Day Services.

Keeping staff on board

Throughout the review process, great praise was given to the staff at Day Services; in particular, the quality of relationships that have been built between staff and service user and the development of innovative practice across the new bases. However, there was some anxiety among frontline staff as to what any changes in provision may mean; highlighting concerns about things being tried before but not backed at a strategic level.

Any future provision should consider the following:



- ★ A review of terms and conditions of centre staff in the future to reflect changing work practices
- ★ A development plan for the service that includes the roles and responsibilities of staff, job specifications and job descriptions
- ★ New training offered around community bridge building, citizen leadership and person centred planning
- ★ Some work around working with autism
- ★ Some work with staff around managing behaviour

Joined-up thinking and joined-up working

Another area identified as being of great importance to getting things right was the need for a more planned and co-ordinated approach between departments and between agencies. Special reference was made for the need for plans that follow individuals around and a "seamless" transition at vital times in an individual's life. It was also stated that the way people are assessed and the planning tools used in Day Services need to be further developed. In particular, there were a number of comments made that school, colleges, services and employers need to work together and to make a "plan that everyone sticks to". Alongside this, was the idea that Day Services continues to play a full role in the PCP network being developed across the island..

Any future provision should consider the following:



- ★ A planned approach and shared allocation of resources between agencies and departments
- ★ A shared and consistent person centred planning approach used throughout Jersey backed by access to person centred planning training
- ★ Better sharing of talents between centre staff and crossover with other agencies

Creating welcoming communities

Much of the findings of the review were underpinned by the belief that people with learning disabilities had a right to use and share the same facilities as anyone else in Jersey. However, not everyone agreed that the communities within Jersey, or some of the provision, clubs and groups within it, were always ready or able to welcome people with learning disabilities. This meant that some participants (mostly family carers but some workers supporting individuals with complex needs) felt that the retention of a centre exclusively for people with learning disabilities was the right thing to do. Some of these views were expressed from within the carer and service user groups at Day Services so require careful but immediate consideration. The need therefore to support host groups from within the wider community develop more welcoming attitudes and to build the confidence and capacity of workers to engage and work with them, is paramount. Many individuals who use services often talked about what makes a full and meaningful life and the need to be seen as citizens as opposed to service users.

Any future provision should consider the following:



- ★ Training for frontline staff in the skills of community bridge building
- ★ Training for host groups e.g. sports centre staff, leisure and recreation staff etc to be provided by Speak Out
- ★ A small, targeted public education campaign promoting the gifts, talents and potential contribution of people with learning disabilities throughout Jersey in partnership with other agencies such as Speak Out, Jersey Mencap etc.

A working chance

A small group of individuals who use services were particularly keen to find some kind of meaningful work. Many wanted a full or part time job whilst others wanted to try some kind of voluntary work. There was clear evidence of some success in this already but a sense that any look at day services should have some examination of what else can be done to support work for individuals with a learning disability as one of its outcomes. The external factors of the “benefits trap” and the unique funding arrangements on the island were identified as challenges but not reasons not to push for the employability of individuals much more strongly.

Any future provision should consider the following:



- The States of Jersey looking to actively employ more people with learning disabilities.
- Links made with local volunteer agencies to develop new, innovative voluntary activity
- Finding a small group of business “champions” willing to get on board

Conclusion

Professionalism and passion

It was the intention of the management team at Day Services that this look at Day Services and the way it was done was a demonstration that it is not business as usual. This is only a part of a new way of thinking and a new way of doing things – in particular building on the contribution of individuals and families by continuing to involve them as planners, policy and decision makers. The process was also a way of making sure that the current good practice taking place within Day Services, and the passion and motivation of workers is identified and held on to. Clearly, much good practice is taking place and any change is more likely to be along the lines of gentle reform than radical revolution.

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It is not within the remit of this report to provide details and outlines of the next stages nor to provide a critique of what day services currently offer; it was our job in putting this report together to capture what people said, make some sense of it all and signpost the way ahead as determined by the participants. The task facing everyone can be challenging in terms of providing something that everyone gets something out of. For example, individuals who currently use the day service differed greatly in what they wanted – some a centre, some no centre at all, some a service in one place, some a service in various places. However, there is a growing recognition that the need to involve, genuinely involve, individuals and their families in what decisions are made is almost non-negotiable. The staff at Day Services has been simply tremendous in holding on to this ideal.

Pride and purpose

It reflects well on the Special Needs Service and, in particular, those that are responsible for leading its day services that they openly invited an external agency in to facilitate this review and provided a real platform for individuals and their families to give their view on the service. It is our belief that the SNS did so to make things better for the people who use their services and their families and again they deserve the highest praise for this.

Throughout the review an enormous effort was made by everyone involved - by staff, individuals and parents. It is the belief of the author of this report that very rarely have we seen such an honest, open and inclusive attempt to really involve people as genuine and equal partners. Day Services can get many things better but has managed to become a service that gives real and genuine hope to families and great support and care for individuals. The service gets the small things right every day leading to a huge difference in the lives of the people who go there.

“I long to accomplish a great and noble task, but it is my chief duty to accomplish small tasks as if they great and noble”

Helen Keller



David Douglas

Director

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