

Challenges of Complexity:

Issues from People with a Learning Disability and
Complex Needs, Their Carers and Those Who
Work Closely with Them

CHALLENGES OF COMPLEXITY

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Who are we?

As a group of professionals working with adults who have a range of learning disabilities, we have consulted with service users, families, staff and other advocates, and have highlighted some specific issues relevant to people with a learning disability and complex needs and their families. We would like these views to be considered as part of the review.

The group of adults we have consulted with have limited formal communication skills. Communication skills range from; eye contact, facial expression, sounds/noises, and whole body actions. In many cases individuals can only be understood by people very familiar to them. Each of the individuals has a communication schedule established with assistance from the Speech and Language Therapist and these were used whilst compiling the information.

It is not possible to gain direct information on all issues being considered by the review from individuals, so therefore a questionnaire was formulated to be completed by family and carers in Day Care.

A Social Education Centre was chosen for the consultation. Expressions of interest were gathered from families and the families were then visited by one of the consultation group. The consultation group members were; 2 Occupational Therapist and 2 Speech and Language Therapists, who work with the individuals on a regular basis.

The interviews took place; in the family home and in day care, along with evidence from many years working with these individuals.

Carers were consulted with on the specific areas addressed by the review with specific consideration given to those with complex needs:

- children and families
- accommodation and support
- physical health
- mental health
- day opportunities ‘a full life’
- ageing issues.

Questions were designed to elicit responses around Citizenship, Empowerment, Inclusion, Support at Transitions and Partnership Working.

Thank you

We would like to thank all those who helped us to compile the information for this report. In particular, service users and their families and the day care staff. Many families wished to remain anonymous.

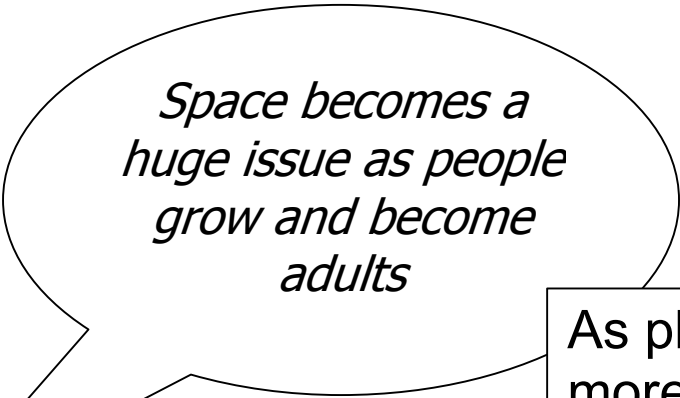
Why have we written this report?

The Learning Disability Review Committee agreed that the specific issues that affect those with a learning disability and more complex needs were not necessarily addressed by those who made it to the Equal Lives meetings. Due to difficulties with communication, only people familiar to those with complex needs can identify issues that are relevant and important to this unique group of individuals.

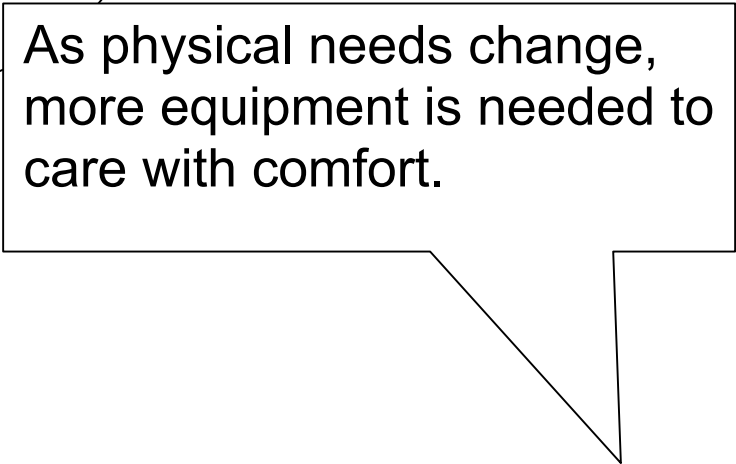
Our home

All of the people we met live at home with their parents and other family members. At present everyone is happy and content to be at home and enjoy family life and activities. This has been evidenced through people's individual means of communication.

Carers have, however, highlighted a number of specific issues which affect how the individual is cared for at home.



Space becomes a huge issue as people grow and become adults



As physical needs change, more equipment is needed to care with comfort.

Building changes are too complicated, take too long and are too expensive

Financial assistance is not available if you are building your own house

Day opportunities/having a full life

All of the individuals we met with, attend day care daily. Families were able to demonstrate how enjoyable this part of the day is for each individual.

He squeals and laughs when he hears the noise of the bus.

He goes crackers when he see the bus.

Families did state that they felt it would be more beneficial for their son/daughter if more appropriate activities took place. This was echoed by familiar staff who feel that on occasions they can only meet personal care needs fully. Staff and family members were able to identify more interesting activities that they have evidenced

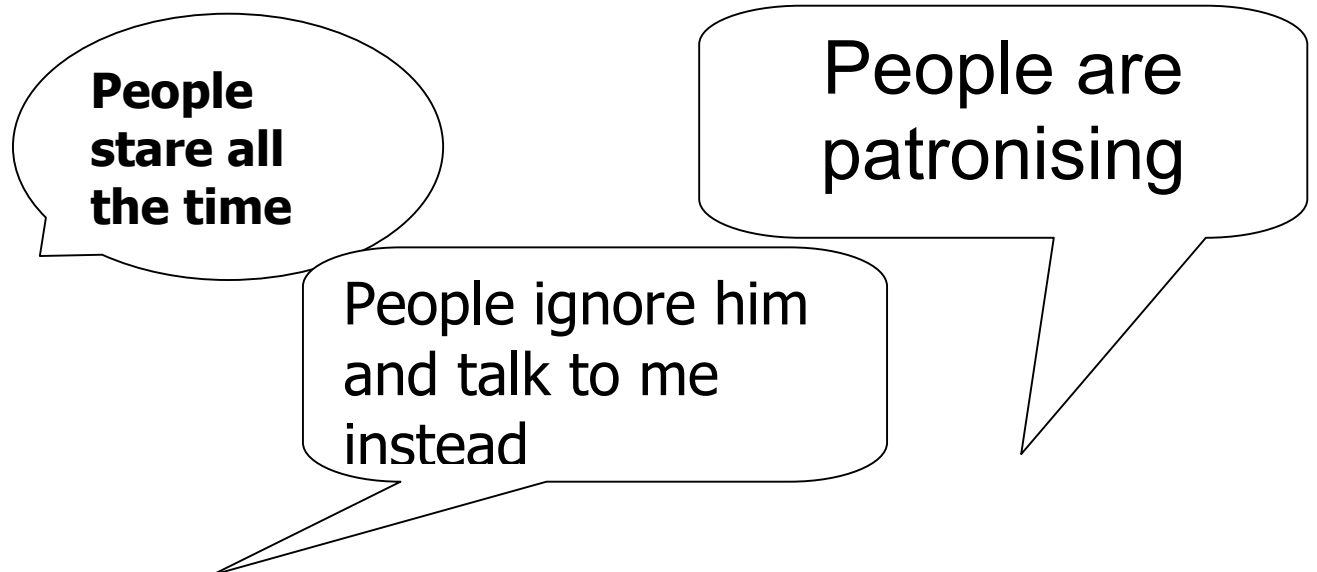
individuals respond positively to. If there were more staff and space resources, these are the things people would be happy being involved in:

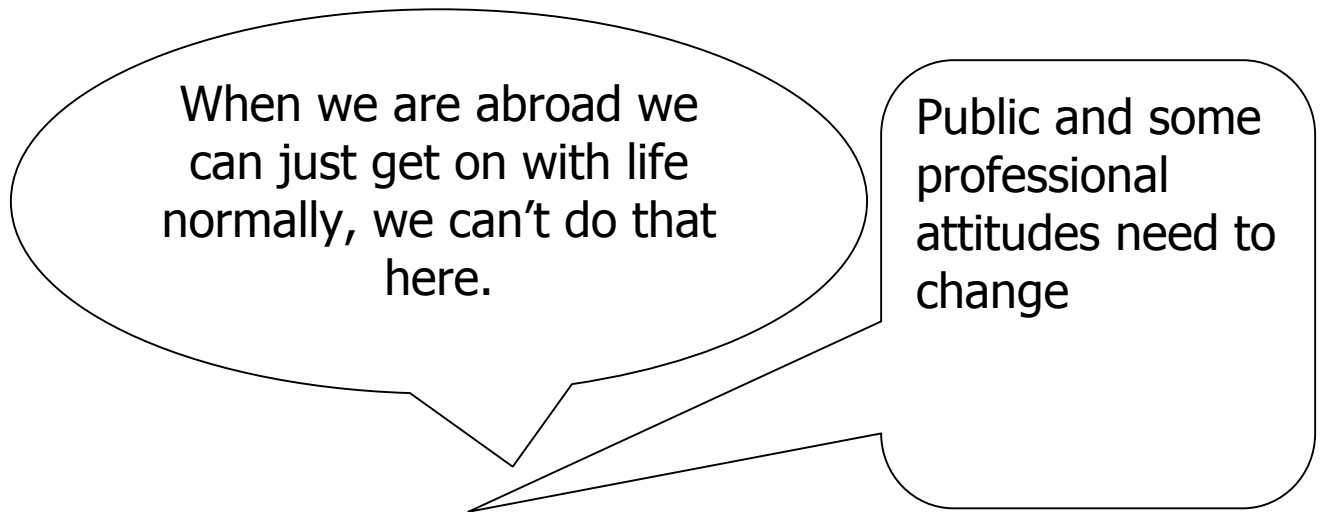
- music therapy
- aromatherapy
- multi-sensory rooms
- sensory cookery
- appropriate outings
- meal time opportunities
- 1:1 communication development
- hydrotherapy
- social interaction with other groups
- sensory based activities were often echoed.

All other life experiences outside of day care are planned and carried out by parents and close family members. There are no planned social outlets in the local area for this group of people.

All the people we talked to highlighted that full involvement in community life is restricted by the few facilities which are accessible. Even those facilities which have access for disabled people do not have suitable facilities for these individuals.

Most of the people we talked to were adamant that full citizenship and inclusion are not yet possible for this group of individuals. Comments included:





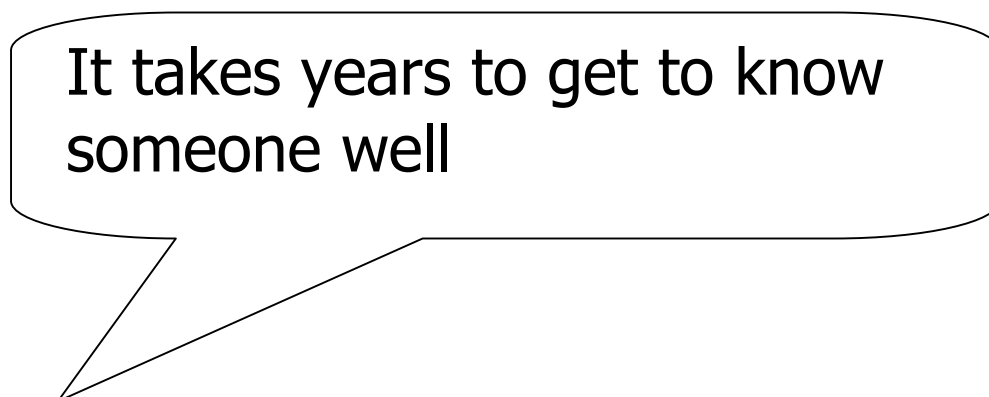
Transport issues were highlighted by many of the families. All agreed that it was beneficial for their son/daughter to travel with their work mates on transport which was suitable. For home life, however, all found the cost of purchase of an appropriate vehicle was prohibitive.

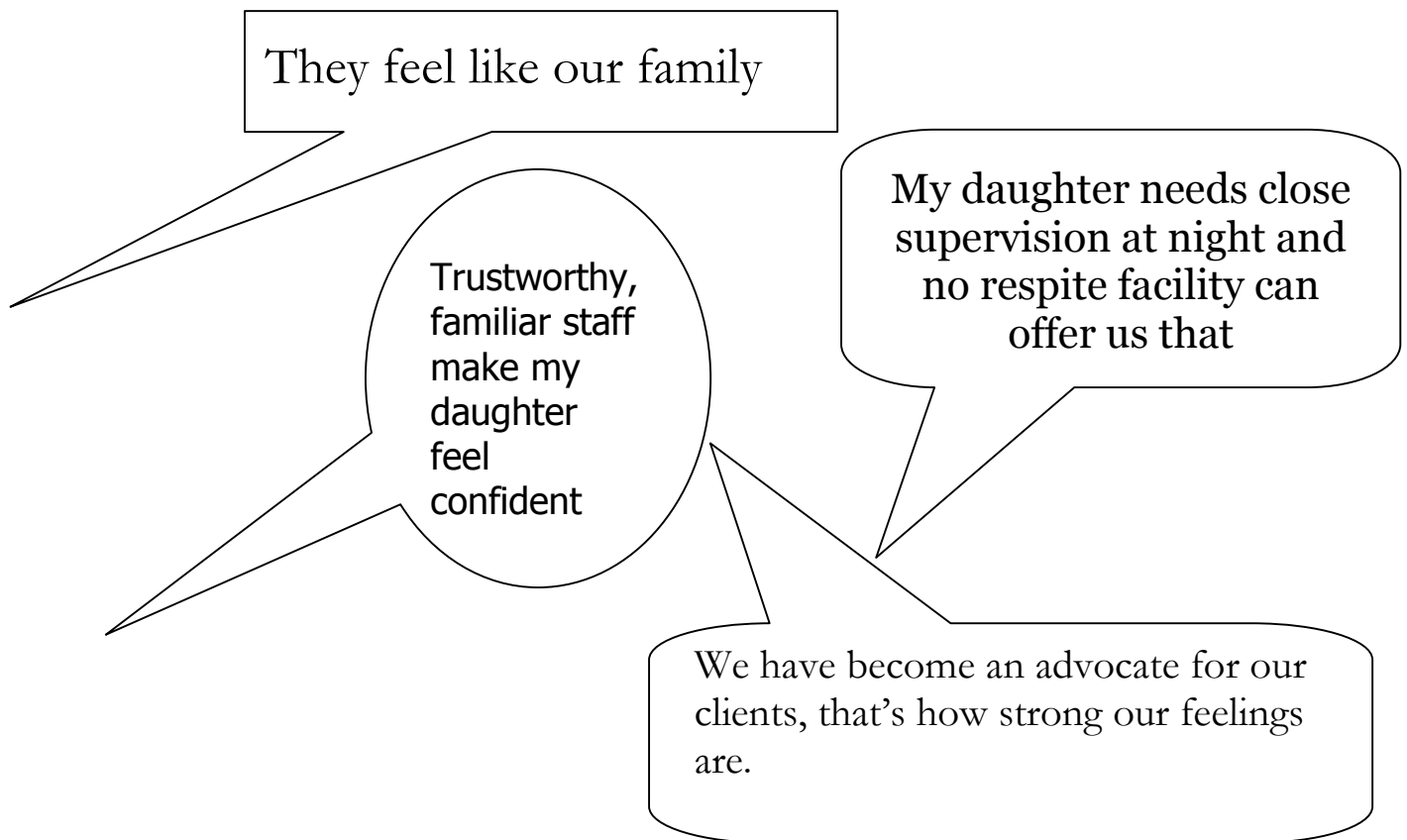
Support from staff

The right staff support was highlighted by all the people we spoke with as being a crucial element of care. All advocated that familiar, consistent staff/carers are essential. Due to complex health needs, very specific communication methods and vulnerability, care can only be provided properly by experienced, familiar people.

Some people did not feel they would be happy using respite services out of the home environment. Most felt that respite would be better for them and the individual if it was local and flexible, so that it could be used in emergencies.

Some comments on staff support...





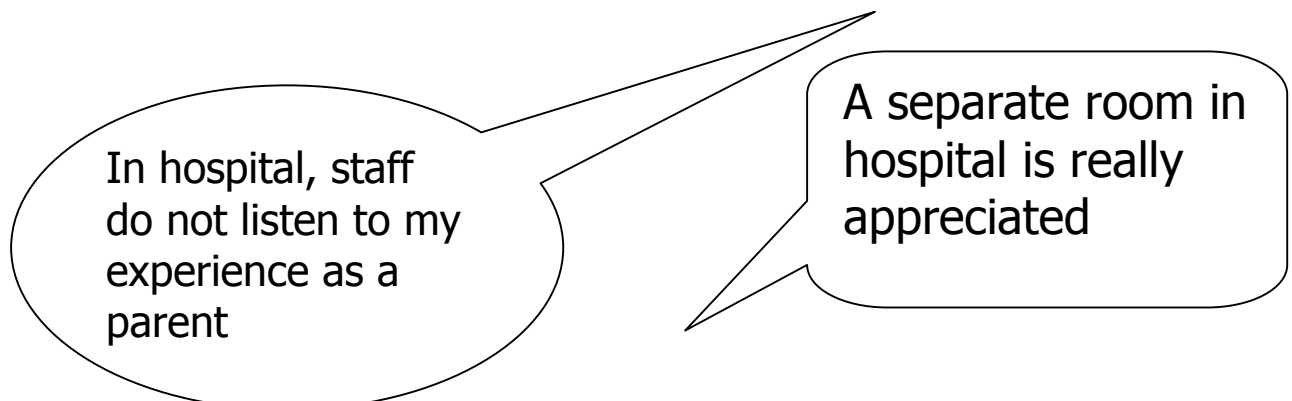
It was evident that family members and staff have become very skilled in caring, but there is little formal recognition of these skills.

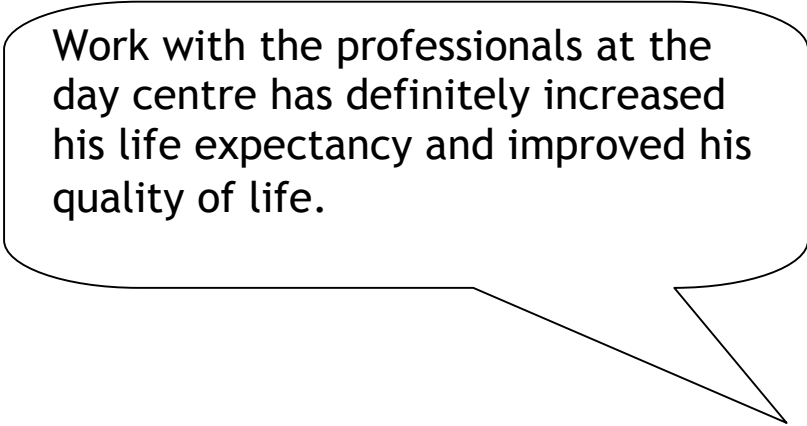
Health matters

All of the parents we spoke to felt it was essential to be with their son/daughter, around the clock when they were admitted for treatment to a general hospital.

Most did not expect regular health screening eg for eyesight and hearing checks, as standard facilities did not often suit the individual's needs.

Parents and staff emphasised the high standard of healthcare available through day care from: dental hygienists, dieticians, nurses, occupational therapists, physiotherapists, podiatrists and speech and language therapists.





Work with the professionals at the day centre has definitely increased his life expectancy and improved his quality of life.

What the Review should do?

- Appropriate financial assistance needs to be made available to improve the accommodation needs of people with a learning disability and more complex needs.
- Day Care is an important and enjoyable part of people's day. It could further be improved with increased resources to enable sensory based activities with professional input.
- Specific and regular Communication training is essential for staff working with this group of people.
- There needs to be a recognised framework of standards that staff can achieve when working with people with complex needs.
- Appropriate financial assistance needs to be made available to enable families to purchase a suitable vehicle.
- Respite facilities need to be small, local and offer flexible services.
- A change in attitudes is required from all people to ensure all those with a learning disability, including those with very complex needs, can enjoy a full and meaningful life in their community.