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PE1545/B

Dear Petitions Committee

Thank you for the opportunity to contribute to the discussion over Petition PE1545 on residential care for severely learning disabled children, young people and adults. Research suggests that there are about 2,000 people in Scotland that have profound and multiple learning disabilities. They have severely limited understanding, multiple disabilities, which may include impairments of vision, hearing and movement as well as other problems like epilepsy and autism. Most people in this group are unable to walk unaided and many people have complex health needs requiring extensive help. It is small, easily identifiable group with undeniable needs for support which should have made improving services easier. There has been some improvement for some people but for many others there is still more to do. A national organisation, PAMIS, has been campaigning on behalf of people with profound learning disabilities and their families and they are very knowledgeable in this area.

It seems to us that the issue described by Mrs Maxwell in her presentation go well beyond the question of residential care for people with profound learning disabilities. We would like to touch on these issues first and then come back to the core question raised in the petition.

There are 4 issues that she covers

1. Quality of statistical information
2. The Changing Nature of social work
3. Eligibility criteria for social care support
4. Challenging transitions from children's to adults' services

1. There is a shortage of information on how many people have a profound learning disability and what their support needs are. This is because it is clear at one end of the spectrum who has a profound learning disability but as those needs gradually lessen as we move up the spectrum, there is no clear dividing line. We do not think there should be. Instead everyone should be treated as an individual and given support based on a Personal Support Plan. But nonetheless for planning purposes, we need to have some idea of the range of needs and how many may be affected. There are three key data sets for people with learning disabilities in Scotland.

The Scottish Consortium of Learning Disability produces an annual set of statistics called ESay. This is based on a lengthy return completed by local authorities using information they record on their computerised case files. The returns are only made for adults "known" to the social work department, meaning that if an adult has not had contact with social work or received a service for 3 years then they become "unknown" and drop off the list. There is no record kept in these statistics of unmet or partially met need as local authorities are not required to keep this information There is a current proposal to link up local authority, health board data and GP records to create a more comprehensive data base that can track health and other outcomes for people with learning disabilities. It will allow a much better understanding of the needs of everyone with learning disabilities including those with the most profound disabilities. When this is established it will be a very useful planning tool.

There is a further set of data produced on school pupils that identifies a range of different disabilities such as learning disabilities, epilepsy and this could be correlated with information on which of those people needed active intervention from social work and health professional to give us an indication of how many young people leave school each year with profound disabilities. Unfortunately this is not routinely done.

2. Since the Community Care Act was introduced in 1993, there has been a clear shift away from an interventionist model of social work practice to a Care Manager model. In the first, the social worker got to know the family, provided advice and practical support and guided them to additional support. In the second the social worker carries out high level tasks such as assessment and then arranges support for the family. This is a more distant arrangement but one, it is argued, that allows social workers to use their skills to help more and more people.

Few people today enjoy the type of relationship that Mrs Maxwell does with her social worker and she is right to be worried about this for others. A number of families we have spoken to describe being "left on the clipboard." This is a literal clipboard on the wall of the social work office with details of every client which all social workers have access to. It doesn't take much to see how the quality of service might vary or deteriorate under such circumstances.

3. People with profound learning disabilities will be eligible for support in every local authority in Scotland. All have criteria which recognise the needs of people who need significant amounts of support. Actual access to particular services will depend on a combination of assessed need and how serious their need is on a scale ranging from Critical to Low.

But in Scotland, there is no clear guidance on how social workers should take into account existing unpaid support for an adult. After a person reaches adulthood (usually 18), parents no longer have responsibility for them and continue to care for them on a voluntary basis. Few parents would want to sever all relationship with an

adult disabled child but may wish to see that relationship change and for them to reduce their caring role.

Currently some local authorities expect family carers to continue to care and take this into account in the assessment and eligibility processes. This can mean adults with profound learning disabilities can get significantly less help than they did as a child or that families are expected to maintain their caring role indefinitely.

The new Carers Bill is seeking to address this problem by ensuring that a carers assessment takes place at the same time as the assessment of the disabled person. Some time will be needed to see if this solves the problem.

4. Transitions remain an enduring problem for many families of children with special needs in Scotland. Education authorities have strict rules on how they must ensure that all children receive an education and the problems of coordination within a school setting are better understood. Moving into adult services, means that many people with special needs no longer get a service and those that do may get less than they used to. The issue that Mrs Maxwell addresses here is a real one that a number of organisations and the Scottish Government are working on. However that does not make the individual problems any less and we are sympathetic to the idea that there is a need for more to be done.

Turning now to the key question raised by Mrs Maxwell the question of residential care homes.

There has been a shortage of specialise accommodation for adults with profound disabilities for a long time. Many groups such as SHARE and Inclusion Alliance have been set up to specifically develop support services and supported living for people with profound disabilities. Other organisations throughout Scotland have developed their own service provision.

Few of these services are now residential care. Instead many of them are described as Housing Support services where the tenants have an individual or a joint tenancy of the house. There is no reason why people with profound learning disabilities should not be able to enjoy the same rights and protections that other people enjoy. There is still oversight from the Care Inspectorate as to the quality of care provided. One example of good quality care is in the Tayside area, where two young people with profound learning disabilities live in neighbouring houses. Each has their own tenancy and their own support plan and staff but are able to share staff for tasks that need more than one member of staff. This helps to keep costs down while allowing each to live independently.

Residential care homes are business and residents may have to put up with unpleasant living circumstances when there are problems. Residents do not enjoy tenancy rights and can be asked to leave at any time for any reason. While this may

rarely happen and many care home owners or providers work hard to help people remain, the final loyalty is to “the home”.

There are other reasons why we would prefer people with profound learning disabilities to live in a range of support living situations. The key to good support is Person Centred Planning which builds future support arrangements around the unique needs of individuals.

We don’t think it would be right to be prescriptive of the choice that people should make. The introduction of the Self Directed Support Act by the Scottish Government is about supporting individual choice and making person centred planning a key part of the social care structure.

We ran a short consultation exercise to prepare this response and asked people with learning disabilities to give us their opinion on care homes. When asked what care home they would choose many people said they would rather live in the smallest possible care home, but others people said they would rather live in a 5 -1- bedded care home because they would have more opportunities to make friends and didn’t want to be lonely.

As an organisation we do not think people with learning disabilities flourish in large care homes. Small care homes for 4 or 5 people can be indistinguishable from many ordinary houses in the community and can allow individual many more opportunities to be part of the local society. Small care homes also offer their residents regular opportunities for social interactions which may be hard for them in other situations. We asked our focus groups to identify the three biggest problems with care homes.

They chose

1. Not enough staff
2. Having to wait for help
3. Being rushed to do something.

They also identified three key things that could help to make care homes better.

1. Being treated with respect by staff.
2. Homely and personalised surroundings.
3. Enough staff to attend to my needs.
4. Support to get out and about

Scot Excel, the Scottish procurement body has already taken on comments like this and is currently finalising a framework agreement to improve the quality of care services that are purchased by local authorities to meet the needs to people with learning disabilities that they are responsible for. This will only apply to new arrangements.

However similar levels of care and quality of service can be provided in lots of other ways too and as a society we should be careful about saying there is only one way to provide care for any segment of our community and our focus groups were very worried about discriminating against people with more profound disabilities by denying their rights to make choices.

Finally many local authorities are setting a maximum rate for individual Self Directed Support Budgets at the level of the local residential care home rate. We think this means that there will be more pressure on people with greater needs to move into residential care homes.

While the numbers who stay in care homes for people with learning disabilities fell by about 20% in the 3 years up to 2012, many other people with learning disabilities ended up in large homes registered for older people. Currently there are 250 large homes registered for older people (over 20 residents) supporting up to 1,000 adults with learning disabilities.

Unless we properly plan for the needs of all people with learning disabilities by understanding more about their needs and numbers and ensure that these needs are being met, there may indeed be an increase in the number of people with profound disabilities in residential care. But there is a danger it will not be the specialist care that Mrs Maxwell and many others would like.

We think the committee would be well served if it were to invite, Jenny Miller, the CEO of PAMIS to provide supporting evidence on the needs of people with profound disabilities in Scotland and how they might be best met.

Yours Sincerely

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