

Mr R.A. & Mrs D Rees

07 March 2005

RESPONSE TO STRATEGY UNIT
'Improving the Life Chances of Disabled People'

These are just a few comments we have regarding the report. We hope they can be of use and in some small way play a part in the development and changes needed to enable disabled people to take a more inclusive role in Britain and its future.

1.1.2 Disabled Adults Living In Residential Settings

It appears that this issue has been sidestepped by the Government and health providers. Once again a backdoor method of NHS privatization by stealth and redirection has been covertly implemented under the guise of Modernizing service provision, ultimately having an internecine effect on this service. This has enabled the private health providers to grow rapidly (they only do it for profit) and raises several questions:

Where have these private providers suddenly sprung from?

Who will be responsible for inspection and monitoring when the Goal posts have been moved?

Who owns them?

Who financed them?

When and how, were they made aware of the expulsion of these people from the public sector institutions, at a rate and quantity that they knew would sustain their capital investment and would enable them to grow into a lucrative sustainable business venture?

It appears that this group of people with complex needs and a labour intensive approach to their integration into mainstream society are being pushed out of sight by our representatives purely for financial considerations. As is evident by the reports stating that, "**Since Valuing People** a PCT can be **penalized** for keeping someone long-term in a NHS facility, however, the same rules **do not apply** to keeping someone in a **private hospital.**"

It begs the questions, how was the definition of the terminology **Valuing people** interpreted. Which people were being **valued** and what sort of **valuation** was being put on the group of people to be transferred?

How can these individuals feel valued or represented in a way that enables them to be included in society when they have been passed from one institution to another by the accountancy driven mentality that is prevalent in to-days Modern Britain. It comes from the top i.e. Government, this then feeds through our public services down to local provision. **Which is the next target group for Private Service provision?**

1.2.2 People with learning disabilities, high support and multiple needs:

The comments and observations that follow are in no way meant to undermine and criticize the individuals working for the service but rather the working practices that are imposed and the institutional snobbery that has developed, which has stifled the services ability to act and view each person as an individual with rights and a voice that should be heard and taken into account.

From our own first hand knowledge and experiences over the past 25 years up to and including 2005. It is obvious that whilst the conclusions and key barriers in the report have been correctly identified, it is interesting to observe that the practical steps necessary to make the changes are taken from a **Social Services Inspectorate Report**. Although the report displays a knowledge of the issues, it is common practice for Social Services to give the impression of correct terminology and awareness (they can always say the right things) while constantly finding ways out, of providing from their own policy guidelines and mandatory obligations. The needs and wishes of the individual are rarely taken into account. These needs are **invariably overruled** by financial consideration i.e. the need for managers to protect individual budgets. The philosophy being if we allow one person to have **freedom of choice**, and advocacy, everyone else will want **equality** and the same rights and consideration. Where will it end? Heaven forbid. People would be able to demand their **rights**. Our family has found this to be the attitude in both children and into adult services. Our family's experiences of this Service have been ones of great stress, humiliation, total failure to provide or the desire to change. It is an organization driven by secrecy and fear and a ridiculous lack of funding for the ever increasing demands put on them. How is this service provider going to co-operate fully with the other agencies to enable the changes to be made that are necessary for **society** to change? **Our!** minds, ears, and eyes are open to new challenges and ideas. We wish you luck in getting this service to adopt the same attitude.

Carers:

There does not appear to be much information with regards to the role of **carers**. Where **do they fit in** to this report? There needs to be a significant change in the attitudes of the "professionals" towards the family members who care for their dependents and indeed each other when they are dealing with the Public sector **money is God mentality**. From our own experiences, **fact**, carers are treated with contempt by the whole benefits system and penalized for trying to look after their family members while trying to engage in meaningful employment. **Who cares for the carers?** We have raised this question many times with various individuals and organizations; We have yet to receive a reply that would give a glimmer of hope for the future for carers and **their needs**. Even the introduction of the carers assessment plan has little effect if they are perceived as being of little value and their needs and wishes are overruled because of financial restraints.

Transport:

This is the one issue that affects people with disabilities/ learning difficulties the most. It is no use improving services and choices while providing better access into buildings, if

you cannot get to them in the first place. We feel the Government's way of limiting an individual's right to access was by omitting transport from the Disability Discrimination Act when it came into force in October 2004. If **disabled people** are to truly gel into the vision of the opportunity society, transport **must not** be used as a mechanism to discriminate and limit their choices. This is the method that is currently employed by our **elected representatives** and **public servants**. **Local and County Councils etc**, e.g. If, after an assessment of needs is completed an individual cared for at home wishes to exercise their right to choose a suitable placement in a Day Centre appropriate to their needs. Their choice is obstructed by the authority's policy on limiting the transport provided (as part of the care package) to and from the day centre, to individuals of the authority's choice. This then forces people into a limited scope of the opportunity provided or no provision and support at all.

Control! Instead of valuing people.

If this transport barrier is overcome the authority will then demand that the parent /carer transports the cared for or will demand an unreasonable amount in payment for transport, if they are asked to provide, thus minimizing their choice.

How is this going to fit in with the reports overall programme of action, of support, inclusion and provision of services? If, as we are led to believe. The provision of Day Centre services is going to evolve into a community based provision, whereby people will access a broad spectrum of community based activities and services, also employment prospects. How will they get to all these different places in the communities and areas of their choice? Who will provide the transport and what will be the cost to the **service provider** and to the **individuals** and **carers** involved? We feel on past performance and experiences that it will be the person trying to access the service and their carers/relatives who will bear the brunt of any costs and personal time incurred in this area. Which will at a stroke negate the principal of 'Improving the life Chances of Disabled People' whilst limiting and destroying most peoples aspirations of inclusion and freedom of opportunity in society. It will also place an even greater strain on the family of the cared for, while reducing the providers. **Once again, who cares for the carers?**

Day Service Provision

It may be that Day Centre provision is the best way for people with certain disabilities using a central base as a focal point of activities and to meet their personal needs whilst also accessing community based projects.

Are these centers in danger of being closed to meet the requirements and vision of the report?

Improving support and incentives for getting and staying in employment:

We feel this is a commendable strategy which **should**, offer people (**where appropriate**) the chance of feeling more valued and part of society whilst giving individuals higher expectations and scope to broaden their social boundaries and encourage involvement.

If, as a result of expected implementation of this strategy across the whole spectrum of Service Providers, money is targeted towards this common goal and a multi agency partnership of co-operation and vision is achieved. What are the plans for people who through varying degrees of disability and learning difficulty are unable to achieve the goal of **meaningful** employment? Are resources going to be targeted at an ever increasing rate towards one group to the detriment of another? Who, through no fault of their own will be unable to participate in the vision of this strategy and subsequently marginalized as is now the modus operandum used by our service providers when called upon to facilitate new initiatives. Or will there be a complete **mind wipe?** of people in senior managerial positions and an **equal** balance drawn between social rights and the need to focus on the accountants figures. This would enable all to benefit from freedom to choose, support in their choice also full and equal participation of carers/parents in the cared for persons current and future life and role in society in modern Britain.

Where public sector services are involved in the changes envisaged. They should be the **benchmark** for all other sectors of society. If they then take a leading role in the training and assessment process to enable people with disabilities/learning difficulties to prepare themselves for a work based life, this process must be carefully independently monitored. e.g.

N V Q s: **People with Disabilities/ learning Difficulties**

Where vocational qualifications are used as a means to provide training for work in the environment of a service provider that previously did not use this method. Would there be pressure to make the person being assessed appear more able in their achievement than is fact? To enable the service provider to look as if it is meeting its government monitored targets. Will an in house assessment be true and correct? Or, will an individuals progress appear to be more than they can truly achieve themselves thus giving a false impression of an individuals ability if they then try to move on into other areas of work outside of this environment.

Service Providers Concepts of their roles towards Service Users:

The whole principle of the report ‘ Improving the Life Chances of **Disabled People**’, has focused on **disabled people** in Britain having full opportunities and choices to improve their quality of life, to enable them to be respected and included as equal members of society. There is one aspect of attitude within all Service providers that is in danger of negating this reports vision:

The separation of services for the disabled into child and adult services.

As long as this continues a cohesive and continuous person centered approach cannot be maintained as the funding allowed for each area will always remain unequal. The staff employed will always have a separatist attitude towards their work and perceptions of service users and their abilities and value will be limited. If **all**, Service Providers could have a change in mindset to **work together** in the common aim of seeing each service

user as a **person**, instead of a child/adult then we may see a continuous development and support programme to enable every **person** to fulfill their potential.

Sincerely *Ray and Denise Rees*
Parents & Carers of *Adam and Sarah Rees*