

John Grooms Response to the PM Strategy Paper “Improving the Life Chances of Disabled People”

1. Introduction

1.1 John Grooms is a specialist disability charity and housing association. We are committed to an inclusive society, free of discrimination, in which disabled people are empowered to have an equal right to choice, control, opportunity and respect. We operate nationally providing:

- Accessible holiday facilities for disabled people and their families;
- Education and training;
- Residential, respite and nursing care services;
- Rehabilitation for people with brain injuries;
- Wheelchair accessible homes and supported housing solutions for people who are wheelchair users.

1.2 With all our work we aim to treat everyone as an individual. John Grooms believes that people are not disabled by their individual impairments but by physical barriers and those created by people's attitudes. We support the goal of the Disability Rights Commission “*of a society where all disabled people can participate fully as equal citizens.*”

1.3 This response draws on over 138 years of experience of working with disabled people and, in particular, our inquiry into the contemporary and future needs of disabled people. The inquiry was chaired by our President Baroness Howarth and a copy of the resultant report, entitled **Where do you think you are going?**, is enclosed for ease of reference.

1.4 We warmly welcome the Strategy Unit project on improving the life chances of disabled people believing it to be well placed to conduct this much-needed overview due its independence from departmental constraints. The Interim Analytical Report demonstrated that the Unit's unique role permitted a holistic approach to this issue and a copy of our response to it is enclosed.

1.5 Similarly, we welcome the final report and believe that the recommendations made, if successfully implemented, will make a huge contribution towards improving the life chances of many disabled people. However, we do have a number of concerns and they are outlined below.

2. Lack of Accurate and Reliable Data

2.1 The John Grooms Inquiry noted that:

“ Strenuous efforts have been made over the last decade to improve the supply and standard of services in order to expand opportunities for personal development, independence and social integration for disabled people. Policy initiatives are not always achieving these goals because they are undermined

by the lack of reliable information about the number and characteristics of disabled people, their expectations and their current and future needs.“(1)

2.2 We therefore welcome the report’s acknowledgement of the many limitations to data available about the disabled population.(2) We are disappointed, however, that the report did not make specific and comprehensive recommendations on correcting this fundamental deficiency across all age groups.

2.3 The recommendations for data collection and information sharing in the early years section of the report are very welcome. The fact that the Department of Health will be working with local authorities, PCTs and Children’s Trusts to look at ways to co-ordinate data on the number and needs of disabled people in the area, is to be applauded. Similarly, we were pleased to note that the data collected will be used to inform the design and implementation of databases to enable statistics on disabled children to be readily compiled. We would, however, strongly urge the Government to apply these recommendations to the collection of data on disabled people of all ages.

2.4 We do appreciate that several recently published documents relating to disabled people, and those with long-term conditions, have made recommendations to fill the gaps in data mentioned above. Notable examples include the data requirements of the new public authority duty to promote disability equality, and the suggestion in the Green Paper on Adults Social Care that Directors of Adult Social Services carry out regular assessments and forecasts of the numbers and needs of their local disabled populations.

2.5 It is absolutely crucial that the various initiatives to improve data on disabled people, including those mentioned in the previous paragraph, are centrally co-ordinated so that we have a comprehensive picture of the national disabled population. How can the Government possibly hope to improve the life chances of disabled people if they do not know who or where they are, what services they do or do not have access to and whether these services are meeting their needs?

2.5 We would also like to see data co-ordinated between local authorities so that cross-borough solutions can be found to meet regional needs.

3. Independent Living and Residential Care

The Concept of Independent Living

3.1 We welcome the fact that independent living is the centrepiece of the Government’s 20-year vision for disabled people but, given its importance to the political agenda, we consider it crucial that that the concept is broadly defined. It must include the whole spectrum of choices available to disabled people.

3.2 We are particularly concerned that the Government's interpretation of independent living will exclude high quality residential care. Whilst we appreciate the importance of eradicating poor quality residential care, we believe it is vital to recognise the valuable contribution that individually tailored care provided in a modern residential setting can make towards enhancing autonomy, extending choice and increasing opportunities for disabled people with complex needs.

3.3 There have been some encouraging signs recently that the Government does view residential care as a valid option for disabled people seeking to live independently. In particular, Quality Requirement 8 of the NSF on Long Term Neurological Conditions proscribes that:

“ Health and social care services work together to provide care and support to people with long term neurological conditions to achieve maximum choice about living independently at home.”⁽³⁾

3.4 A footnote clarifies what is meant by “living independently at home” as:

“ Where the individual chooses to live, which may be their own accommodation or may be a residential or care home.”⁽⁴⁾

This approach is to be welcomed and it is disappointing that the definition above is not included on the face of the NSF, and all other documents that involve the concept of independent living. The model of care we provide at John Grooms' residential facilities is all about individuals living in their own home and attaining maximum independence.

3.5 Similarly welcome is the acceptance in the NSF that *“ the availability of a wide range of care and support options allows people with long term neurological conditions to make choices and select the services that suit them and will best meet their changing needs.”*⁽⁵⁾ Furthermore, the range of care and support options can include:

“ Longer term care settings (Eg specialised care homes suited to the needs of people with long term neurological conditions and which also meet their individual cultural and person requirements.”⁽⁶⁾

3.6 The NSF goes on to cite supported living options where,

“people are enabled to live in individual accommodation, or with peers in group homes, with support available on site or nearby. Evidence shows these schemes offer good community integration and quality of life for both the person and their family/carers, while avoiding the need for more expensive options.”

3.7 While “longer term care settings” and “supported living options” are considered to be distinct and separate, we would argue that the division is artificial. The deciding factor in classifying a facility as a “care home” or “supported housing” appears to be whether the care is provided onsite or a

few hundred yards away. Modern and innovative models of residential care are challenging these rigid and unnecessary boundaries and we believe that policy makers need to recognise this.

Compulsion

3.7 The report states that:

“Some people are forced into residential care as a direct result of the cost ceilings imposed by the ILF and by Social Services departments.”⁽⁷⁾

3.8 We would certainly agree with this statement and our recent inquiry found that:

“Recent constraints on social service budgets have compromised the ideals behind the shift in emphasis toward community care, personal choice and autonomy. They have resulted in contractions in services, waiting lists for equipment, the prioritising of crisis assessment over ongoing support and review and the imposition of ceilings for expenditure on individual care costs.”⁽⁸⁾

3.9 Our report goes on to conclude that the above has resulted in some people being placed inappropriately in residential care. We would, however, like to sound a note of caution. It is equally important to recognise that placing an individual in the community inappropriately, and without the necessary support, can inhibit their autonomy and independence. We can evidence the consequences of transferring individuals from residential to community care before they are ready and without providing them with the support required to ensure a successful transition.

3.10 It should also be noted that greater flexibility, allowing easy transfer between residential and community care as needs change, would encourage more disabled people in residential care to opt for a trial period of living in the community. It is often the fear of being prevented from returning to a residential setting of their choice, should living in the community fail to meet their needs, that discourages many individuals from exploring new and challenging housing options.

Culture of Dependency

3.11 The report asserts that one of the most significant barriers to enabling disabled people to become full citizens is the culture of dependency in social care structures. Whilst this is undoubtedly true in many cases, we would again argue that new models of residential care are challenging the assumption that all forms of residential care are institutions that automatically engender dependency.

3.12 The Social Exclusion Unit visited one of our residential high dependency units in Colchester on 17 February as part of their project to improve the delivery of mainstream services to disadvantaged adults. They witnessed the

model of care we provide and discussed the benefits of living in good quality residential care with the residents. We would like to extend a similar invitation to the Strategy Unit as we believe that, by seeing the model of care we provide first hand, policy makers will fully appreciate the advantages of individually tailored residential care for those disabled people who choose it.

The Right to Request not to Live in a Residential Setting

3.13 The report seeks views on a “right to request” not to live in a residential setting. John Grooms does not believe that this specific right is needed. The aim of NSF Quality Requirement 8, referred to above in paragraph 3.3, is:

“ To ensure that people with long term neurological conditions are able to choose where and how they live.”⁽⁹⁾

3.14 We strongly support the Department of Health in achieving this laudable aim. We believe that this simple acknowledgement that it is for the individual to choose, if genuinely supported in practice, would make the proposed “right to request” not to live in a residential setting redundant. A simple right to request to live in whichever setting you choose would deliver real choice for disabled people.

4. The Failure of Mainstream Services to Meet the Needs of Disabled People

4.1 We agree with the Strategy Unit’s conclusion that mainstream services often fail to respond to the needs of disabled people and, as mentioned above, we have been working with the Social Exclusion Unit on their project to improve the delivery of mainstream services for disadvantaged adults. As part of their visit to our high dependency unit in Colchester, representatives of the SEU heard presentations from John Grooms staff on two of our projects, both of which are models of good practice on improving access to and the experience of mainstream services for disabled young adults.

John Grooms Disability Specialist Nurse

4.2 Many disabled people spend considerable time in hospital over their lifetime and yet doctors, nurses and other staff are given very little advice about how best to meet their needs. Consequently, disabled patients often leave hospital with more problems than when they arrived and are more likely to be re-admitted at a later date.

4.3 In response to the concerns expressed by the disabled people we work with, John Grooms has collaborated with Colchester Hospital to employ the country’s only Disability Nurse Specialist (DNS). The DNS works with hospital staff to educate them about the needs of disabled people and acts as a spokesperson and advocate for disabled patients. Through her work, the DNS has identified the following problems:

- Nurses were not always alert to the special needs of disabled people and sometimes made unfortunate assumptions about their preferences and capabilities.
- The attitudes of nurses were also seen as crucial with a number of incidents illustrating the lack of experience and awareness.
- There were no written procedures on the care of disabled patients with the medical profession failing to recognise that the structure and function of the body is changed in disabled people and can dictate their care needs.
- Staff shortages were seen to have a considerable impact on patient care with busy nurses often failing to anticipate problems.
- Standards of nursing and personal care were adversely affected by problems with aids and equipment. Nurses were not always aware of the need for aids and, where they were, the equipment was not always available.
- When equipment was available the administrative procedures for supplying it were not always efficient with the result that, in some cases, discharges were delayed while equipment was sought.

4.4 We believe that the experiences of disabled patients at Colchester Hospital, and the problems identified by the Disability Nurse Specialist, are replicated countrywide. The project has already made a considerable impact on the quality of care received by disabled patients and, as a first step, we would like to see funding made available to expand the project to several pilot areas.

John Grooms Lifestyle Choices Project

4.5 John Grooms is undertaking pioneering work to tackle social exclusion in Bedford, Luton and Neath. The Lifestyle Choices Project is a service for adults with physical and sensory disabilities who are living independently in the community. It encourages and supports people to become more involved in social, leisure and educational activities outside their homes.

4.6 The service is primarily one-to-one with a flexible and client focused approach. It is not a befriending service, which tends to encourage dependency, but a process whereby the volunteer supports clients to develop their own social networks and relationships before withdrawing. In this way, the project empowers disabled people to reach their own full social potential.

4.7 We believe that employing a Lifestyle Choices worker in every local authority would be an excellent way for those public bodies to demonstrate their commitment to eradicating disability discrimination and promoting equality of opportunity for disabled people as required by the new public sector duty contained in the Disability Discrimination Bill.

5. Somewhere to Live

5.1 Given the importance the report attaches to the issue of somewhere to live for disabled people, we were disappointed that it did not produce concrete

recommendations designed to tackle the chronic shortage of accessible housing and residential placements for disabled people.

Residential Care

5.2 There is a severe shortage of specialist care home placements for young disabled adults. The expectation of rising standards, coupled with the reluctance of local authorities to meet the true costs of contracted care, exacerbates this situation.

5.3 Around 22,000 physically disabled young adults live in care homes. It is believed that at least 8,000 of these live in care centres designed primarily for a different client group, usually older people. This can mean that the young disabled person has no friends of their own age and lives in circumstances which deny their ability to study, seek a job or socialise with other people their own age.⁽¹⁰⁾

5.4 Laing & Buisson's most recent annual market update predicted a tripling in demand for residential care across all sectors from 444,000 residents in 2004 to 1,200,000 residents by 2051. They commented that:

"Some, if not most, of the expansion in demand will in fact be satisfied by alternatives such as home care and extra care. Nevertheless, we believe it is imperative that commissioners of care services focus on the need to re-build traditional care home capacity as well."⁽¹¹⁾

5.5 As parents and other elderly relatives supporting young people to live at home become older, and less able to care for the disabled family member, more accommodation will be required to meet their needs.

5.5 Where good quality residential care is available, local authorities often refuse to acknowledge and meet the true costs involved. Good quality care cannot be bought at bargain prices. Annual fee negotiations hamper the ability of the voluntary sector to embark on new and pioneering projects and this short-term, shortsighted and inflexible approach to funding must end.

5.6 We recommend that:

- The Government works in partnership with support agencies to increase the supply of specialist care home places for young disabled adults.
- Administratively costly and over bureaucratic annual fee negotiations should stop and voluntary sector providers should be able to achieve full cost recovery.
- Residential care should shift to longer-term funding reflecting best practice in other sectors.
- Tax breaks and financial incentives for the voluntary sector are introduced to encourage service development and innovation.

Individual Budgets

5.7 We broadly welcome the thinking behind individual budgets and believe that most disabled people will benefit from being more in control of the services and support they receive. However, the majority of the disabled people we work with would not be able to participate owing to the level and complexity of their disability and we have reservations regarding the use of agents to extend the budgets to them.

5.8 Agents assisting disabled people to manage individual budgets would have to be highly trained professionals and funding would need to be set aside to pay them accordingly. Given that the proposals are to be funded from current departmental budgets, this would undoubtedly mean less money going to disabled people. Additionally, safeguards would need to be introduced to ensure that agents were scrupulous in their management of clients' money. This would introduce another level of administration and cost to the detriment of the funds available to service users.

5.9 For those disabled people who can and wish to subscribe to individual budgets, there is a national shortage of carers and key therapeutic staff and this could threaten feasibility. What use will control over budgets be if the services needed are not available?

5.10 There are economic arguments both for and against the introduction of individual budgets. While market forced, via controlled spending power, may well shape a more responsive market, we have the following concerns:

- Uncertainty about present or future demand in a more market-based economy can reduce options in the long term and have a deleterious effect on quality. For example, choice between schools has led to over-subscription and overcrowding in classes, while less favoured schools lack the funds to maintain staff and standards.
- Providers may be less willing to experiment or introduce new initiatives if they are uncertain about potential levels of demand, particularly if buildings and capital would be involved.
- The costs of care could rise to reflect increases in market demand. Unit costs may also be raised by organisations guarding against uncertainties and fluctuations in demand.
- Providers might prioritise “big spenders” to the detriment of those requiring less. The disabled people we work with – those with severe and complex disabilities – are in a very small minority. There is a danger that the more specialised services they require are not well distributed or available locally.

5.11 Finally, individual budgets will eradicate the postcode lottery of entitlement. Currently, disabled people with similar support needs receive different levels of funding depending on where they live. A report recently published by the Health Select Committee concluded that the funding arrangements for people in residential and nursing homes are too complex and that urgent reform is needed to ensure that vulnerable people receive a

fair deal regardless of where they live. Individual budgets will do nothing to tackle this very real concern.

Housing

5.12 For many disabled people, especially wheelchair users, their home is a series of barriers which hinder them doing what we all take for granted – making a meal, going to bed or taking a shower. While society slowly recognises the access needs of physically disabled people, with statutory requirements to change the built environment and service provision, they continue to experience problems in their own home.

5.13 In 2003, a John Grooms survey of physically disabled people found that:

- More than 20% of respondents lived in houses in which it is difficult to move around or to get in and out.
- 40% of respondents felt that their housing situation made them unnecessarily dependent on other people.
- 24% of wheelchair users felt that they were prisoners in their own home due to poor access and location.

5.14 John Grooms estimates that the UK needs over 300,000 new wheelchair-accessible houses to meet current and future need. A start has already been made in London where all new housing must meet the Lifetime Home standard with 10% built, or easily adapted to the higher wheelchair standard.

5.15 Bureaucracy compounds housing difficulties. Many local authorities don't know what accessible housing stock is available or the needs and characteristics of disabled people locally. As a result there are thousands of disabled people who wait years before finding a house suitable for their needs. There are also implications for disabled people who want to move with criteria often different from one area to the next.

5.16 John Grooms recommends:

- All new housing should be built to the Lifetime Home standard.
- 10% of all new social housing should be built to, or easily adapted to, the higher wheelchair standard⁷ to recognise the additional needs of wheelchair users.
- All local authorities must have a statutory obligation to establish an accessible housing register.
- Where housing is developed, greater attention should be given to ensuring that local facilities, shops, offices and transport networks are genuinely accessible.

6. Transition from Childhood to Adulthood

6.1 The report states that the benefits of effective early years intervention will be lost if disabled young peoples' transition to adulthood is not managed effectively. We reached precisely this conclusion in our recent inquiry and our report concluded that:

“ The impact of effective children’s services is undermined by the poor support offered to their families and carers and early gains are often lost in the transition to patch and poor co-ordinated adult provision. Badly managed transitions between age and needs-related services have a cumulative effect on the life chances of disabled people.”⁽¹²⁾

6.2 Similarly, we welcome many of the proposals contained in the Strategy Unit report designed to tackle these problems as they give effect to many of the recommendations we made in our inquiry report. In particular, the proposals on improving the provision of advice and information to disabled young people and their families, the focus on person-centred planning, the emphasis on involving young disabled people in the planning and design of services and increasing the provision of advocacy services to this group, will all make a huge difference to disabled young people.

6.3 We do, however, have a few remaining concerns and they are outlined below:

Poor Data

6.4 We are once again pleased to note that the Strategy Unit has grasped the importance of improving the scale and quality of data collected on young disabled people. The report acknowledges that, while there is a great variation in impairment profile, the evidence base for this group is lacking. It goes on to state that:

“ Significant gaps persist in the evidence at both the national and local level, and there is variation in the definitions used. Large-scale longitudinal data sources that follow-up a large and representative sample of disabled young people who transfer from child to adult services need to be developed. Little research has diagnosed what models of intervention work most effectively, for whom, and in what circumstances, and few cost benefit analyses of the impact of interventions with disabled young people have been carried out.”⁽¹³⁾

6.5 We would like to reiterate our recommendation that the Government conduct a thorough review of the statistical deficiencies mentioned above and organise a consistent mechanism for monitoring the number and needs of disabled people of all ages, together with the supply, efficacy and efficiency of services available to them.

Access to Leisure and Independent Living

6.6 The report recommends that the DRC code of practice to accompany the public sector duty to promote disability equality includes local authorities working with a range of stakeholders, including the leisure industry to increase opportunities for participation by disabled people within their area. We would like to reiterate our earlier recommendation that each local authority be encouraged to employ a Lifestyle Choices worker to support local disabled young people to become more involved in social, leisure and educational activities outside their homes.

6.6 We would also like to offer our assistance with the new research to be commissioned by the Department of Health on the range of meaningful adult life options for young people with the highest levels of need. We have over 140 years experience of working with young disabled people and would welcome the opportunity to contribute towards this work.

7. Conclusion

7.1 We would like to reiterate our support for the majority of the proposals contained in *Improving the Life Chances of Disabled People* and our willingness to assist the Strategy Unit in whatever way we can. We hope that you will find the enclosed John Grooms Inquiry Report of interest and, should you wish to discuss it or this response in more detail, please do not hesitate to contact us.

References

- (1) Page 13 of "Where do you think you are going?"
- (2) Page 16 of "Improving the Life Chances of Disabled People."
- (3) Page 5 of the National Service Framework on Long Term Conditions.
- (4) Page 5 of the National Service Framework on Long Term Conditions.
- (5) Page 47 of the National Service Framework on Long Term Conditions.
- (6) Page 47 of the National Service Framework on Long Term Conditions.
- (7) Page 66 of Improving the Life Chances of Disabled People.
- (8) Page 15 of "Where do you think you're going?" – Report of the John Grooms Inquiry into the needs of young disabled people.
- (9) Page 47 of the National Service Framework on Long Term Conditions.
- (10) Page 13 of "Where do you think you're going?" – Report of the John Grooms Inquiry into the needs of young disabled people.
- (11) Laing & Buisson's Domiciliary Care Market Report 2005 - <http://www.laingbuisson.co.uk/domcare05.htm>
- (12) Page 26 of "Where do you think you're going?" – Report of the John Grooms Inquiry into the needs of young disabled people.
- (13) Page 109 of "Improving the Life Chances of Disabled People."