

John Grooms Response to the PM Strategy Unit Interim Report on 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 We warmly welcome the Strategy Unit's project on improving the life chances of disabled people. We believe that the Unit is well placed to conduct this much-needed overview due to its independence from department constraints. The interim analytical report, and the conclusions reached so far, demonstrates that the Unit's unique role has permitted a holistic approach to the life chances of disabled people.

1.4 This response draws on over 138 years of experience of working with disabled people and, in particular, our recent inquiry into the contemporary and future needs of disabled people.

The resultant report from the inquiry, which was chaired by John Grooms' President Baroness Howarth, is entitled "Where do you think you're going?". A copy is enclosed for ease of reference.

1.5 The findings of the above inquiry, and the recommendations made in the published report, will be referred to throughout this response.

2. Lack of Reliable and Accurate 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. “

2.2 We are pleased to note that the Interim Analytical Report has recognised the paucity of accurate and reliable data relating to disabled people. In the section on the Early Years, the report identifies limited collection of data on disabled children as a key barrier to progress. We concur with this assessment and believe that it is a failure that extends across all sections of the disabled population, regardless of age.

2.3 The Early Years section goes on to outline the consequences poor data collection and collation as the inability to identify and plan for those most in need of support. One of the key findings of the John Grooms inquiry is that:

“ The needs of disabled people are complex, various and subject to change. The information we have about them is deficient and hampers the planning of future initiatives and the ability of existing services to anticipate or adapt to new demands.”

2.4 The above point is reiterated in the section of the Interim Report dedicated to the transition from child to adult services. Lack of data is identified as a key barrier to progress in this area along with the related problem of forward planning. Other issues arising out of the Unit’s analysis of the transition from child to adult services are dealt with separately in the next section of this response.

2.5 In response to the findings on the severe shortage of information about disabled people, the John Grooms inquiry made 3 key recommendations:

- The Government needs to review the statistical deficiencies outlined above and organise a consistent mechanism for monitoring the numbers and needs of disabled people, together with the supply, efficacy and efficiency of services.
- A central database is needed to collate data across the spectrum to make planning possible, both for individuals and for group needs.
- The inquiry recognised the importance of the Commission for Social Care Inspection in collecting data and disseminating information but also referred to its limitations in terms of wider demographic information or NHS statistics. The latter information will come from the Healthcare Commission and the inquiry calls on the Government to ensure that both these vital sources of data are co-ordinated and made widely available.

2.6 We appreciate that the Strategy Unit has acknowledged the lack of accurate and reliable data but argue that the issue needs to be given greater weight. How can the Government improve the life chances of disabled people if they do not know who they are, what services they do or do not have access to and whether these services are meeting their needs. Consequently, we urge the Unit to examine the above recommendations with a view to including them in the final report outlining policy options for Government.

3. Housing

Somewhere to live?

3.1 Whilst we are pleased to note that the Interim Report identifies poor supply and quality of suitable housing as one of the barriers faced by disabled people, we are disappointed that the issue has not been given more prominence nor does it specifically link poor housing to poor health.

The John Grooms Inquiry identified acute problems with accessible housing shortages and a survey of new tenants moving into John Grooms Housing Association (JGHA) found that:

- 67% of them had been living in an unsuitable home for more than 3 year and 41% of these people for more than 5 years.
- 27% of new tenants had moved from homes that were not adapted to take wheelchairs
- 29% came from homes that could not be adapted in which they had been unable to access some areas.
- 50% of all new tenants had been dependent on others to help with their personal care because of unsuitable housing.

3.2 JGHA estimate that there is a need for another 300,000 homes, either built to or suitably adapted to wheelchair accessible standards, in the UK. The John Grooms Inquiry recommended that the Government devise and implement a strategy for meeting the huge demand among all groups for wheelchair accessible housing.

The importance of Housing Design

“The kitchen is not suitable for my wheelchair. I can’t go into the kitchen. I’ve not been into the kitchen for eight years.”

(A.L., Talking about the flat he used to live in before becoming a JGHA Tenant)

3.3 As the Interim Report notes, *‘Housing provision, and independent living are key life chances, but the quality of provision and support is often unacceptable.’* It is a comment that John Grooms strongly supports. We are therefore disappointed that the analysis that follows is so limited on the need to think ahead with respect to all forms of accommodation including registered properties and housing design for disabled people.

3.4 As the report states, and John Grooms would agree, the right support mechanisms can be delivered through Supporting People and adaptations funded through the Disabled Facilities Grant budget. However, they do not go far enough and are not the complete answer.

A more radical approach is required which acknowledges the needs of disabled people from the planning stage, particularly in the social housing sector. In this way, the complex and changing needs of disabled people would be anticipated and expertly accommodated.

3.5 Too often adaptations are trying to alter the environment when, if a holistic approach was taken from the start which included disabled people, such changes would be unnecessary. This would lead to budget savings and a more efficient use of resources.

With the projected step increase in housing numbers outlined in the Barker Report and other Government reports, now is an opportunity to build a future which includes disabled people.

3.6 For our tenants who are wheelchair users, the design of their house is very important in allowing them to live there as flexibly and reasonably as a non-disabled person. Unfortunately this is rarely the case outside of JGHA stock. Few architects or builders consider the particular needs of disabled people or those who do not meet the criteria of the 'average person' (ie some one who is male, aged between 18 and 40, non disabled and right handed).

3.7 This means that many people are more disabled by their home than by the limitation of their impairments. As a result the disabled person - either as a resident or visitor - is socially excluded by housing design and consequently discriminated against in housing provision. Targets such as the one in the London Plan, which state that 10% of all new social housing must be built to be fully accessible for people who are wheelchair users, should be replicated across the country.

What is efficient?

3.8 With increased pressures on land use, it is important that all available land is used efficiently to maximise housing numbers. However; when drawing up plans there needs to be careful consideration of what is meant by efficient from the perspective of a wheelchair user. A house that is fully wheelchair accessible will generally have a larger footprint than a speculatively built general needs house.

3.9 This is due to the necessity of incorporating extra space standards within the house for the wheelchair user to allow for adequate internal turning space and convenience of use. Most wheelchair accessible houses should also have at least two bedrooms to allow for use by family or a single person with a live in carer.

House Design Standards

3.10 JGHA recognises the progress with design criteria such as Part M of the Building Regulations in ensuring that disabled people are not excluded from new houses. We have concerns that too often the standards required by Part M are not achieved in newly built units due to a lack of understanding by building control officers and builders.

3.11 A lack of understanding can also be shown by developers who feel that, if the individual houses within the housing scheme meet the requirements of Part M, it will also achieve the wheelchair standard. However, Part M only guarantees access to the ground floor and is not sufficient to allow a wheelchair user to live there as reasonably and comfortably as a non-wheelchair user.

Lifetime Homes

3.12 A similar scenario applies with respect to the Lifetime Home standard. John Grooms welcomes the Government's endorsement of the design standard. However, it needs to be recognised that the standard will not necessarily allow a wheelchair user to move into the house straight away and live there as flexibly/reasonably as a non-disabled person without substantial adaptations.

3.13 A lifetime home only guarantees access to the ground floor for the person using a wheelchair. Even then, access may only be on the basis that turning around in the entrance hallway involves going into a room off the hallway to do so. Within a house designed to lifetime home standards, door widths may not accommodate an electric wheelchair user, there may not be an internal area suitable for charging batteries or entrances will not have a long enough run up area.

'It seems that if you are in a wheelchair, people don't think you should get married and have children'.

Claire Dixon, Cleveland

3.14 A house designed to the higher wheelchair standard will fully accommodate the needs of a wheelchair user and will allow them to participate in all aspects of family life (ie putting children into bed, preparing meals, etc) with the minimum of personal inconvenience. Design features such as a through the floor lift and/or the provision of bathing/toileting facilities on both floors of the house (if more than one storey) are incorporated into a wheelchair standard home.

Designing for the car - An equality issue for disabled people

3.15 While John Grooms supports the general requirement that communities should be designed to minimise car use; it cannot be totally excluded. For many disabled people the car is their only realistic means of transport and therefore independence.

This means designing new housing schemes with a dedicated car space within a short distance of the front door, with level access, which is lit and covered.

New Housing Schemes

3.16 Although the car is very important, design considerations need to go beyond this. For new housing schemes, the design of the site layout should keep circulation distances and changes of level to a minimum. Outside paths should provide unobstructed links to public places with minimal gradients and gradual bends. The location and layout of units should assist the integration of disabled people into the community as a whole.

3.17 Housing schemes should be designed with realistic access to shops, health centres/GP surgeries, primary schools, parks, places of worship and the local community/leisure centre. Where ever possible sites with steep hills and busy main roads to cross to reach amenities should be avoided.

3.18 John Grooms urges the Strategy Unit to give greater priority to housing in the next stage of the project. All the policy initiatives designed to improve the life chances of disabled people, such as

4. The Transition from Child to Adult Services

4.1 John Grooms service users and managers frequently experience problems accessing services at the right time and these difficulties become acute when people want to move from one type of service to another. Our experiences led us to focus part of our inquiry on the barriers to lifetime planning and flexible service deliveries. John Grooms works with many disabled young adults and as a result the inquiry examined the transition from child to adult services.

4.2 The John Grooms Inquiry noted with concern that:

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

Statements of Special Educational Need

4.3 The Interim Report identifies a variation in the use of Statements of Special Education Need (SEN), linked to local decision making and differing capacities to include children with additional needs. The John Grooms Inquiry identified a similar variation in assessments and noted that they are unlikely to focus on individual needs. The person undergoing assessment is usually categorised as “physical” or “learning” disability at an early stage and assigned to a specialist team. This fails to recognise the growth in the number

of children and young people with continuing health needs caused by a range of physical, sensory and cognitive impairments.

4.4 The process that follows the above categorisation of a child or young person is service-led as opposed to needs led. It is generally designed to match the person undergoing assessment with an existing service by comparing levels of disability and eligibility criteria. The process is far more about what people can do at the time of the assessment than it is about what they might achieve given appropriate support. The entrenched rigidity of service boundaries leads to services being imposed upon, rather than designed for, individuals. It is a very clear case of the tail wagging the dog.

The Move into Inappropriate Services or Activities

4.5 The Interim Analytical Report identifies the move into the inappropriate services or activities as a frequent consequence of poorly planned transition services. The John Grooms inquiry was disturbed to discover that as many as 8,000 younger disabled people are living in inappropriate care homes designed for an entirely different client group, primarily frail older people.

There is a serious shortage of appropriate care home placements for young disabled adults and, unless Government addresses this, many will remain condemned to live in an environment that fails to meet their particular need.

4.6 The impact on a disabled young person of being placed in inappropriate care is severe. Access to the right services at the right time is key to how well individuals cope with disability, recover or maintain their lifestyle, benefit from health improvements and adjust to new conditions.

For many young adults entry into inappropriate residential care is effectively “warehousing”. Their opportunities to make friends or get involved in their local community may be severely curtailed and the scope for any further personal development may effectively cease.

4.7 The consequences of entering into an unsuitable care setting are well illustrated by a case we encountered during the John Grooms inquiry. Matthew was 23 and at the start of his life when, one week after he graduated, he had a brain haemorrhage. He spent 11 months in a coma and a further 2 months in hospital. Despite being in considerable pain, Matthew worked incredibly hard at physio and speech therapy. As a result of his efforts he learnt to talk and feed himself. Delighted with his progress, the hospital sent him home to continue his rehabilitation. However, after Matthew’s discharge he received no further assistance and his mother was shocked by the lack of options available to her son:

“They said he’d have to go into an old people’s home. Even now when I think about it I can’t believe it. That was the only option. I could not believe that this was the truth – that there was nothing for a 23 year old. There should be something to get him back to his full potential.”

4.8 Despite all of Matthew's hard work and effort in hospital, and the huge financial investment made in his recovery so far by the NHS, the only option for this 23 year old young man was life in a home designed for and populated by older people.

4.9 A key recommendation of the John Grooms inquiry is that all those involved in any way with the provision of services for younger disabled people should adopt an inviolate principle: ***that people requiring long-term residential or nursing care will be found places that are appropriate to their age and needs.***

Service Distribution and Budgetary Ceilings

4.10 The vision section of the Interim Report refers to the "postcode lottery" of service provision and this is an issue that was identified in the John Grooms Inquiry. The inquiry found that, while services for disabled young adults are many and varied, their supply and quality varies according to where people live. The inquiry noted that more equitable and better-distributed services would emerge if what is available and where is thoroughly analysed.

4.11 Furthermore, the supply and quality of services is also arbitrarily affected by past history, local authority policies on provision and imposed budgetary ceilings. John Grooms agrees with the emphasis that the Interim Report places on tailoring services to individual needs and is concerned regarding the practice of most local authorities whereby they compare the costs of community and residential care before offering services to disabled people.

This inevitably limits the choices open to them and means that a less appropriate form of care is often imposed. As the Interim Report notes, this represents a "vicious circle of funding where early intervention is not available leading to later more expensive and intrusive interventions at a later stage.

Information About Services and Support

4.12 The Interim Report notes that disabled young people have to engage with multiple sources of advice and support. Access to information about services and benefits is crucial for people who are trying to secure continuity of care as it allows them to make informed choices about their future.

4.13 The John Grooms Inquiry found that, while the availability of information has improved in recent years, the onus is still on disabled people to search for it. Many disabled people, their families and carers are not aware of services or financial offers that could assist them or where to apply for details. A shift in emphasis is needed so that the onus is on service or funding suppliers to alert disabled people to the relevant information.

4.14 The John Grooms Inquiry proposed that funding be made available from the Government to research and implement a properly funded, comprehensive and accessible information database and support service to enabled disabled people and their carers to make informed choices about funding and services.

Consultation, Communication and Personal Representation

4.15 Consultation, communication and personal representation are well-recognised barriers to a smooth transition between child and adult services. Most of the respondents to a study conducted by Dr Jenny Morris, entitled "Hurtling into a Void: Transition to Adulthood for Young people with Complex Health Needs", had very clear views about what organisations and professionals could do to improve their situation.

Furthermore, the local authorities studied by Dr Morris agreed that the area of consultation and communication needed development. These findings are corroborated by the 2001 Joseph Rowntree Report "Consulting with Disabled Children and Young People".

4.16 The John Grooms Inquiry noted with concern that there is no right to representation at the strategic level of service planning or at the personal level where services are sought. Accordingly, it recommended that the Government should formalise the arrangements for consultation with service user groups at the strategic planning level.

Additionally, they should also introduce formally constituted and legal empowered groups at the local level to which service users could refer issues affecting needs assessment or service delivery. It would be important to ensure that there was a guarantee of investigation and subsequent action.

4.17 We warmly welcome the emphasis that the Strategy Unit has placed on giving disabled people a voice to influence policy design and delivery. This should ensure that resultant policy takes account of disabled people of all ages and across the spectrum of disability including those in residential settings. Our hope is that the Unit will give serious consideration to the recommendations made in paragraph 4.15 with a view to including them in the final report.

5. Healthcare

Access to Information

5.1 We welcome the Interim Reports recognition that disabling barriers to accessing essential services are not only physical – information and attitudes can also be crucial in excluding disabled people. We would like to reiterate the importance of establishing an accessible information database as outlined in paragraph 4.14.

Attitudes of Healthcare Professionals

"There is no point going into hospital. I felt written off. I was safer out of there."

(A John Grooms Tenant explaining her stay in hospital)

5.2 This is not an isolated incident. Social and health services do not fully understand and respond to the needs of disabled people. There is a shortage of services that provide emotional support, mentoring and advocacy.

5.3 John Grooms found that hospitals cater in the main for the general public, not those with high or specific needs. There is a lack of awareness amongst doctors and nurses about disability, and how disabled people should be treated.

Despite their medical training, hospital staff often miss the simplest things about disabled patients: they often cannot get themselves in and out of bed, reach for a glass of water or emergency call button without help.

5.4 John Grooms employs the only nurse in the country looking after the specific needs of disabled people admitted to hospital. The impact she has made by is well illustrated by the quote below from a patient who benefited from her help and assistance:

"She visited me every day and within hours things would get done, her priority was me. All of a sudden I was listened to. I felt safe. I could relax and concentrate on getting better."

5.5 We recommend that every Primary Healthcare Trust should employ a disability specialist nurse to ensure that the needs of disabled people are fully considered and urge the Strategy Unit to consider this as a policy recommendation in the next stage of the project.

5.4 Work with disabled people calls for a comprehensive and detailed range of skills and experience. The current training of clinical staff does not reflect the complexity of individual disabilities. The level of disability awareness is poor.

5.5 We welcome the initiative of the RCN designed to address these issues but we believe that more can be done to improve the situation in the future. In particular, the John Grooms Inquiry recommended that the Government review the training opportunities available to nurses. It should work with service providers towards appropriately structured, consistently assessed and recognised courses and levels of qualification.

6. Conclusion

6.1 We would like to reiterate our support for this project 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 John Grooms.