

***Changing Places Toilets:
Estimates of potential users***

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Summary

Changing Places toilets have been developed in recent years with a specific view to enabling people with profound intellectual and multiple disabilities and their carers to access the wider community, thus contributing to fulfilling the goal of improved community inclusion and participation. Underlying the demand for such facilities is the high level of need of people with profound intellectual and multiple disabilities with respect to mobility and transfer as well as significant continence needs.

It is apparent, however, that those with profound intellectual and multiple disabilities and their carers are not alone in requiring support with respect to activities of daily living relevant to toilet use. The present project set out to provide estimates of the number of people with disabilities with similar support needs with respect to toileting who *potentially* might use *Changing Places* toilets. To derive such estimates a wide range of databases were explored, including national and international governmental and health agency statistics, websites of voluntary organisations and literature searches of a wide range of electronic research databases. Where the report draws on such material this is cited in footnotes. The quality and scope of the information available was highly variable. Some estimates could be made with confidence; in others the best that could be offered was an informed guess.

The groups considered included people with intellectual disabilities (section 2), those with physical disabilities (section 3) and older people (section 4). These groups have been further subdivided and the estimates for the sub-groups are presented in Table 1, below.

Table 1: Total estimate of potential users of *Changing Places* toilets

Condition	Report Section	Sub category	Estimated number of <i>Changing Places</i> toilets users
Intellectual disability	2		30,328-36,782
Physical disabilities	3		
	3.1	Cerebral palsy	30,947
	3.2	Spina Bifida	8,000
	3.2.1	Motor Neurone disease	500
	3.2.2	Parkinson disease	*
	3.2.3	Multiple sclerosis	8,500
	3.3.1	Stroke/ chronic heart failure	*
	3.3.2	Arthritis	*
	3.3.3	Traumatic brain injury	13,437
Older people	4		
	4.1	Nursing & residential homes	116,695
	4.2	Older people in private accommodation	15,391
		Total	223,798-230,252

* **Figures for these conditions subsumed under older people**

It is emphasised that this estimate of 223,798-230,252 of potential users has to be considered in the wider context of the development and use of such facilities. Availability and increased awareness among caregivers and care recipients will progressively narrow the gap between potential and actual users. This will be dependent on information on *Changing Places* toilets being made available and their use actively promoted. Nor is the context in which such a development will occur a static one. For some groups the prevalence of individuals will increase, e.g. people with intellectual disabilities and people of advanced age, increasing the need for and relevance of *Changing Places* toilets.

It is also noted that the report does not identify a heterogeneous group of younger and middle aged people who contract diseases associated with older age at a much earlier stage of their life, as in the case of arthritis or stroke. No estimate of this figure was possible, but we note that: in our view it would not be unreasonable to state that “*Up to a quarter of a million people with disabilities could potentially benefit from the availability of Changing Places toilets.*”

Finally, with respect to the promotion of *Changing Places* toilets and use of the present estimates, we suggest that a series of case studies of individuals in the various groups discussed in this report actually using and benefitting from use of *Changing Places* toilets would provide a very convincing demonstration of their value. To identify such potential users and support them and their carers and organisations to use the facilities and document the benefits would provide a powerful argument demonstrating how *Changing Places* toilets enable society to fulfil its aspiration for community inclusion and participation.

1 Introduction

The objective of the present study is to provide an estimate of the potential number of users of *Changing Places* toilets. The ideal strategy for arriving at such an estimate would be to undertake extensive surveys across a wide range of client groups whose functional abilities may preclude the use in the community of convention toilets or toilets for people with disabilities. Here, however, we analyse a wide range of databases and publications to extrapolate figures that give an indication of the potential number of people in the United Kingdom for whom *Changing Places* toilets may facilitate community access.

The impetus to develop *Changing Places* toilets came from the extreme difficulties carers of people with profound intellectual and multiple disabilities (PIMD) have in using conventional toilets for people with disabilities. People with PIMD typically have extreme limitations in mobility including the ability to self-transfer from one position to another, a functional ability essential to transfer from a wheelchair to a toilet. In addition, they are highly likely to be doubly incontinent and require assistance with respect to all aspects of toileting including changing and care in relation to hygiene. *Changing Places* toilets provide a hoist and a height adjustable changing bench as well as the toilet itself to enable carers, whether family or paid, to meet the full toileting needs of their relative or service users. The full specification for *Changing Places* toilets will be found in British Standard BS300 2009 while they are fully illustrated at: www.changing-places.org. They are relevant to the needs of children and adults, though very small children may also be catered for using conventional baby changing facilities.

While *Changing Places* toilets potentially benefit people with restricted mobility who *are* continent, severe restriction of mobility and continence difficulties are highly correlated. This results from the common neurogenic basis of both impairments to functional abilities in a wide variety of conditions

(Pellatt 2008)¹. In identifying information relevant to the present estimates, we have explored data in which individuals have both mobility and continence restrictions, though where the latter is lacking it is mobility that has determined inclusion in our figures.

In arriving at the present estimates we have been aware of a number of limitations in the available databases and studies, as well as factors that may lead to overestimates. We discuss these fully in our conclusion, but to illustrate this point here we note that a number of populations will overlap significantly. For example people with physical disabilities and intellectual disabilities (other than those with PIMD) will predominantly have cerebral palsy or spina bifida and be included in our estimates for those populations, while the population of older people will include a wide range of age-related physical conditions that impair activities of daily living such as stroke and arthritis.

We have therefore systematically sought information for groups of people for whom we know that there is a high probability of an association between limited activities of daily living abilities including self-transfer and continence needs. Some of these groups are clearly referred to in more general reviews of continence² as may be seen in Figure 1.

Figure 1: Continence: Consequences and associated conditions

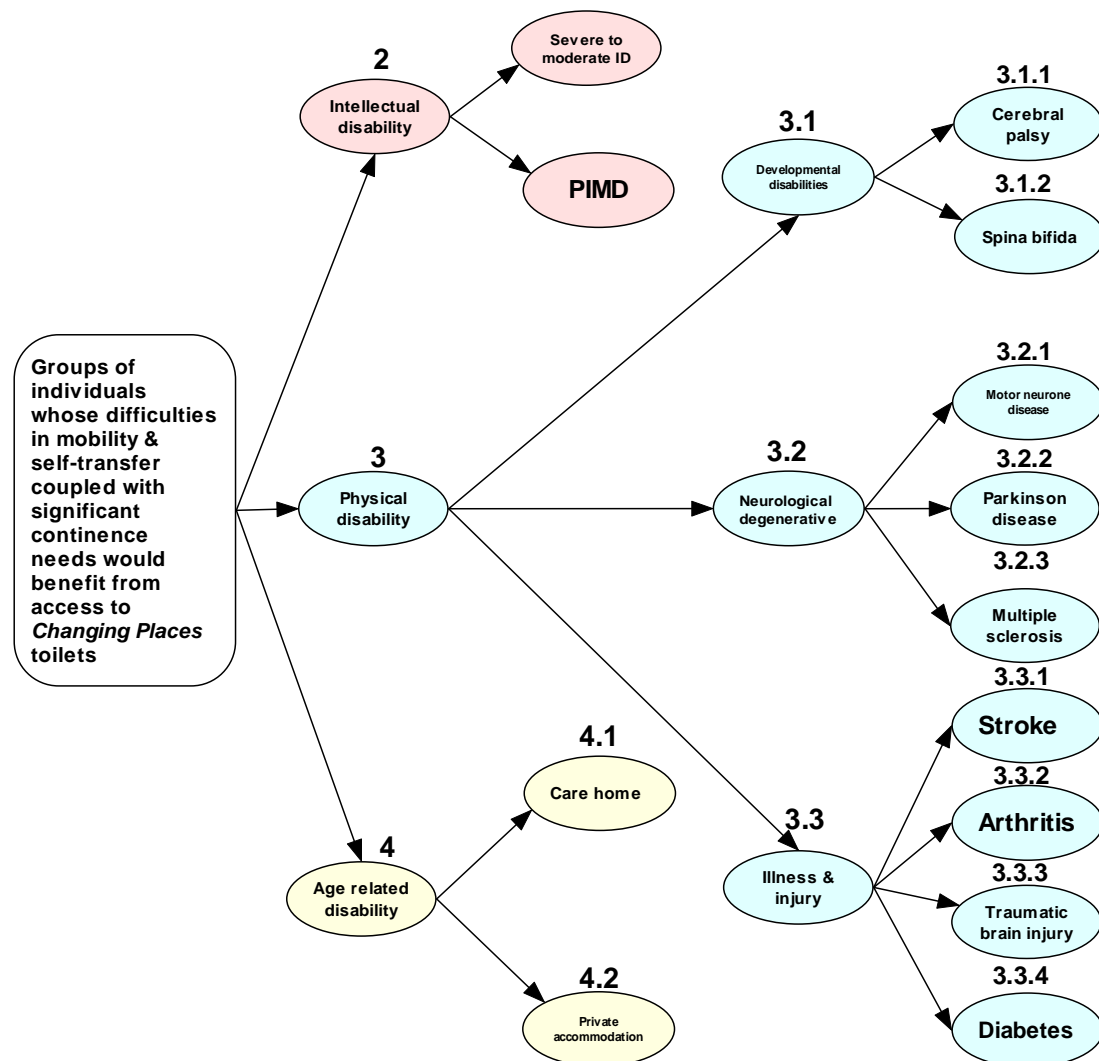
- | | |
|--|--|
| <p>Incontinence can be associated with the following:</p> <ul style="list-style-type: none">▶ Falls▶ Depression▶ Pressure ulcers▶ Bowel problems▶ Skin infection▶ Isolation▶ Impaired quality of life▶ Increased likelihood of institutional care | <p>Incontinence is also a consequence of the following:</p> <ul style="list-style-type: none">▶ Lower urinary tract disease▶ Musculoskeletal disease (arthritis/contractures)▶ Peripheral vascular disease▶ Stroke▶ Parkinson's disease▶ The dementias▶ Diabetes mellitus▶ Venous insufficiency▶ Chronic lung disease▶ Congestive heart failure▶ Neurological disorders, for example: multiple sclerosis, spinal cord injury and motor neurone disease |
|--|--|

¹ Pellatt, G. C. (2008) Neurogenic continence. Part 1: Pathophysiology and quality of life. *British journal of Nursing*, 17, 836-841.

² Wragg, A. (2008) Urinary continence Management in Older People. London:RCN Publishing Company.

Some of these principal conditions are unpacked and illustrated in Figure 2 which provides the basis for this report. Report section numbers are indicated on the figure.

Figure 2: Principal groups which will potentially benefit from *Changing Places* toilets (report section numbers indicated)



1.1 Sources of information

As is so often the case when seeking out very basic information, the expectation that it is readily available is very quickly disappointed. The answer to the simple question “*How many people in such and such a population require significant help to self-transfer and have serious difficulties*

in toileting” requires considerable probing and in some cases the willingness to accept an estimate which is not clearly derived. However, in some studies this information is forthcoming, and extrapolation from a local study to national figures is reasonably firm. This is particularly the case when a standardised assessment tool is used. Some reports, for example, make such criteria related to mobility and continence explicit by using scales which provided information specifically on these activities of daily living, as in the use of the *Barthel Activities of Daily Living Index* in some studies of a wide range of disabled and older populations.

We have consulted a wide range of national and international disability databases in undertaking this work. However these often lack the precision and/or the coverage to provide detailed information. For example, the massive US *National Centre for Health Statistics* makes no mention of conditions such as cerebral palsy or spina bifida. The US *Behavioral Risk Factor Surveillance System* also has limited disability data. As noted, we comment on limitations imposed on the present estimates in our conclusion. UK databases which contain information on social and health care such as the NHS websites deal at a relatively broad level with respect to activities of daily living and need.

We will now consider each of the three areas noted in Figure 2, i.e. intellectual disability (Section 2), physical disability (Section 3) and age related functional impairment in older people (Section 4). Because, as noted above, these broad groupings are far from mutually exclusive, where we place a particular condition can be somewhat arbitrary. Section 2 is limited to people with PIMD. Other people with intellectual disabilities are effectively considered in Section 3 with respect to cerebral palsy and spina bifida because of the high overlap between these conditions and intellectual disability. Figures for older people in Section 4 will include individuals with arthritis and stroke, though we have also considered these conditions in Section 3 on physical disability.

1.3 Presentation of estimates

The overall estimates arising from the estimates in these sections and their subsections appear in section 5 of the report in Table 1. The figures summarised in this table appear in **red** in the main body of the report.

2 People with intellectual disabilities

Definitions of intellectual disability are as variable as are the criteria used to define this classification. Similarly the available information on the prevalence of intellectual disability is limited and of questionable reliability (Emerson & Hatton 2008)³. These problems are further felt when we attempt to identify sub-groups within the population, referred to by the traditional adjectives, *mild*, *moderate*, *severe* and *profound*. What is clear, however, is that functional limitations affecting mobility and the ability to self transfer, as well as continence difficulties, increase as we move from a consideration of people with mild disabilities to those with profound disabilities. Though people across the intellectual disability range may have mobility and continence difficulties, it is in the profound intellectual disability area that we find the majority of people with complex needs who have significant continence difficulties *and* are limited in mobility and self-transfer (Hogg et al. 2007)⁴. It is people with profound intellectual and multiple disabilities for whom *Changing Places* toilets were originally specifically designed and which we will focus on to determine the prevalence of potential users with intellectual disabilities.

Two studies using somewhat different criteria and undertaken in separate countries have yielded remarkable similar estimates of the prevalence of people with profound intellectual and multiple disabilities. A Finnish study found that the prevalence of people with profound intellectual disabilities was

³ Emerson, E. & Hatton, C. (2008) *People with Learning Disabilities in England*. Lancaster: Centre for Disability Research.

⁴ Hogg, J., Juhlberg, K. & Lambe, L. (2007) Policy, service pathways and mortality: A 10-year longitudinal study of people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, **51**, 366-376.

0.06% of the population (Arvio & Sillanpää 2003)⁵. A Scottish study which included specific criteria related to both profound intellectual disability *and* multiple physical and sensory abilities yield a prevalence rate of 0.04% (Hogg et al. 2007)⁶. This lower figure is to be expected because the criteria excluded individuals without additional and physical and sensory impairments as well as excluding infants younger than five years, while the Finnish study included one year olds and upwards.

The influence of births to British citizens of Bangladeshi and Pakistani South Asian origin also needs to be taken into account with respect to the final estimate. Attention has been drawn to the increased prevalence of complex disabilities in this population (Corry 2002⁷; Emerson & Hatton 2004⁸), with this influence being considered one of a number contributing to a modest growth in prevalence of intellectual disability in the coming decades. The prevalence of members of these ethnic communities in Scotland is significantly lower than in England and may have depressed the overall prevalence estimate.

For purposes of the present estimates, therefore, we take a prevalence of 0.05% (the figure intermediate to the two prevalences) on which to base population estimates. Based on the 2007-2008 figures for the population of the UK of 60,656,448, this yields an overall prevalence for profound intellectual and multiple disabilities of **30,328**. In an as yet unpublished study using figures provided by the Department of Children, Schools and Families (DCSF) and a single city register, the author estimates a figure for people with profound intellectual and multiple disabilities in England of 30,328⁹. Extrapolated to include Scotland, Wales and Northern Ireland, this yields a UK estimate of **36,782**. The discrepancy between the figures reflects differing inclusion criteria and the higher frequency of individuals from Pakistani and

⁵ Arvio, M. & Sillanpää, M. (2003) Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland. *Journal of Intellectual Disability Research*, **47**, 108-111.

⁶ Hogg, J., Juhlberg, K. & Lambe, L. (2007) Policy, service pathways and mortality: A 10-year longitudinal study of people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, **51**, 366-376.

⁷ Corry, P.C. (2002) Intellectual disability and cerebral palsy in a UK community. *Community Genetics*, **5**, 201-204.

⁸ Emerson, E. & Hatton, C. (2004) *Estimating future needs/demand for supports for adults with learning disabilities in England*. Lancaster: Institute for Health Research, Lancaster University.

⁹ Emerson, E. Personal communication. April 11 2009.

Bangladeshi communities (see again footnote 9). With respect to the former, the DCSF criteria would include children without physical or sensory disabilities but with a severe medical condition. In Hogg et al. (2007)¹⁰ absence of such disabilities even with a severe medical condition would have led to exclusion from their sample. With regard to the latter point, it should also be noted that the figure of 36,782 would be lower if account was taken of the much lower proportion of communities from south Asia in Scotland and Northern Ireland relative to England. For present purpose, however, we suggest a range of potential users with profound intellectual and multiple disabilities of *Changing Places* toilets of **30,328-36,782**.

As noted above, the number of people with intellectual disabilities with mild to severe intellectual disabilities who are potential users is included in the figures for cerebral palsy and spina bifida.

¹⁰ Hogg, J., Juhlberg, K. & Lambe, L. (2007) Policy, service pathways and mortality: A 10-year longitudinal study of people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, **51**, 366-376.

3 Physical disabilities

This very diverse group is made up of individuals with long term developmental disabilities, notably spina bifida, and physical disabilities acquired through conditions such as arthritis and multiple sclerosis.

3.1 Developmental disabilities

3.2 Cerebral Palsy

Depending on its severity, cerebral palsy may have significant effects on mobility, manual abilities and continence. Information on continence is limited, though it has been argued that if continence has not been achieved by eight years of age for a person with cerebral palsy, attempts at toilet training should not be pursued (Singh et al. 2006)¹¹. There is also a high probability that significant impairment to mobility (including self-transfer) and manual ability will be associated with continence problems. Based on prevalence figures provided in a review of the needs of people with cerebral palsy, we estimate that the number of children and adults in the UK with this condition is between 117,500 and 147,000 (Parkes 2001)¹². For ease of presentation of the present estimate, we take the average of these figures, i.e. 132,250. Severity of the condition among these individuals will vary from very mild causing no significant impairment in activities of everyday living through to people with profound intellectual and multiple disabilities whom we considered in section 2.

In a study which considered the abilities of people with cerebral palsy, 33.4% had no independent walking, while 23.7% had severe manual disability and were incapable of feeding or dressing unaided, while 23.1% had severe intellectual disability (defined as an intelligence quotient of < 50) (Pharoah et

¹¹ Singh B.K., Masey, H. & Morton, R. (2006) *Paediatric Nursing*, **18**, 23-6.

¹² Parkes, J., Donnelly, M. & Hill, N. (2001) *Focusing on Cerebral Palsy: reviewing and communicating needs for services*. London: Scope.

al. 1998)¹³. Composite scores of adaptive abilities are assessed through use of the *Gross Motor Function Classification System*, the two most severe levels of cerebral palsy being levels IV and V which indicate that about 30% of the population are at these levels (Bockung & Hagberg 2002)¹⁴. Eighty five percent of this group predominantly have intellectual disabilities, though these range from mild to profound intellectual disability, while the remaining 15% do not have intellectual disabilities (figures calculated by the author from published figures (Donnelly et al. 2007)¹⁵. Though no specific information is provided on toilet needs, we are taking this 30% figure as defining potential users of Changing Places toilets, though correcting this for the inclusion of people with profound intellectual and multiple disabilities dealt with in section 2. Thirty percent of the total number of individuals with CP noted above, 132,250, yields a figure of 39,675. On the basis of the figures reported above (Donnelly et al. 2007) we estimate that 22% will have profound intellectual and multiple disabilities, reducing the estimate to **30,947** potential users with cerebral palsy of *Changing Places* toilets.

There is one caveat with respect to this figure which is based on children and adults up to the age of 25 years. Since mortality before the age of 30 years is high in people with severe motor and cognitive ability, the proportion of this population over 30 years may overall be more able than the sample on which we have based the estimate (Hutton & Pharoah 2006)¹⁶. Whether this may be off-set by physical decline in people with cerebral palsy later in life we do not know. As yet we have not identified data to make this adjustment and the caution needs to be born in mind.

¹³ Pharoah, P.O.D., Cooke, T., Johnson, M A. King, R and Mutch, L. (1998) Epidemiology of cerebral palsy in England and Scotland, 1984-9. *Archives of . Disease in Childhood. [Fetal Neonatal Edition]*, 7,F21 - F25.

¹⁴ Bockung, E. & Hapberg, G. (2002) Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Developmental Medicine and Child Neurology*, 44, 302-316.

¹⁵ Donnelly, C., Parkes, J., McDowell, B. & Duffy, C. (2007) Lifestyle limitations of children and young people with severe cerebral palsy: a population study protocol. *Journal of Advanced Nursing*, 61, 577-768.

¹⁶ Hutton, J. L. & Pharoah, P. O. D. (2006) Life expectancy in severe cerebral palsy. *Archives of . Disease in Childhood.*, 91, 254 - 258.

3.2 Spina Bifida

There has been a dramatic decrease in the incidence and prevalence of spina bifida in the UK in recent decades with 0.15 cases per 1000 live births in 1998 reported (Lissauer & Clayden 2003)¹⁷, though other sources continue to report higher figures than this with 1 case per 1000 live births also noted¹⁸. The overall prevalence of spina bifida is extremely difficult to determine given the changing incidence of the condition and high mortality, with only just under half of people with spina bifida surviving to 35 years old. Estimates of the prevalence of spina bifida in the UK are lacking in the research literature, disability databases and on the websites of UK and USA voluntary organisations. Here we have taken a US estimate of prevalence and adjust this to the UK population yielding a figure of 38,000. An alternative calculation based on an incidence of 1:1000 live births adjusted for mortality yielded 44,000 individuals with spina bifida in the UK. In the absence of any alternative figures, we have taken 40,000 people with spina bifida in the UK. The basis for this calculation is noted below¹⁹.

A proportion of this 40,000 will be severely disabled and need daily help (principally from an older parent in their 50s to 70s) or partner or from social services (Hunt & Oakeshott 2003)²⁰. Of those in this study 80% were incontinent. The combination of incontinence and inability to walk is reported to be an important factor in the lives of people with spina bifida leading to social isolation (Pit-ten Cate, Kennedy & Stevenson (2002)²¹ and negative feelings of dependency. Indeed, Long-term survival has been suggested to be dependent on adherence to appropriate bowel and bladder regimens and careful management of urinary complications to prevent renal failure. The precise proportion, however, is again difficult to determine in the absence of formal surveys of the functional abilities of people with spina bifida at different

¹⁷ Lissauer, T. & Clayden, G.. (2003) Illustrated Textbook of Paediatrics (Second Edition). Mosby.

¹⁸ <http://emedicine.medscape.com/article/1266529-overview>.

¹⁹ Basis for calculations: US report of just under 200,000 people in US with spina bifida. US population 308 million with UK population of 58 million - 19% of 200,000 gives 38,000. 1:1000 on UK population yields 58,789. With 50% mortality before 35 we have corrected this by 25% giving 44,092.

²⁰ Hunt & Oakeshott (2003)

²¹ Pit-ten Cate, I. M., Kennedy, C. & Stevenson, J. (2002) Disability and quality of life in spina bifida and hydrocephalus. *Developmental Medicine & Child Neurology*, **44** 317-322.

ages. In one survey 33% were assessed as requiring daily support, though this does not necessarily involve the degree of support that would make the use of *Changing Places* toilets beneficial. The majority of these individuals will have intellectual disabilities (as 70% of people with spina bifida are reported to have intellectual disabilities²² and a small proportion will have been included in our section 2 intellectual disability estimate).

Until firm data based on functional assessments is available, therefore, we are basing our figure on a reduction of the 33% requiring daily support to 20% of the population of people with spina bifida. This also takes into account the proportion of children for whom alternative toileting facilities are available. This yields a figure of **8,000** people with spina bifida who would potentially benefit from availability of Changing Places toilets.

3.2 People with Neurological degenerative conditions

3.2.1 Motor neurone disease

Motor neurone disease is essentially a disease that affects middle aged and older people, resulting in increasing loss of motor function and consequent deterioration in activities of daily living (e-medicine)²³ including mobility, though usually individuals remain continent, (UK Motor Neurone Disease Professional Network²⁴) at least until lack of mobility creates difficulty in the later staged of the disease (Patient UK)²⁵. Mortality is high. Within a few years of the on-set of the disease, though some individuals do live well beyond this. Approximately 4,266 people suffer from the disease in the UK at any time (UK Motor Neurone Disease Professional Network)²⁶. There is no available breakdown of where people live, though the UK MND Professional Network suggests most live at home cared for by families with some in residential accommodation. We have not found a database to determine the

²² <http://emedicine.medscape.com/article/1266529-overview>

²³ Shaw, P. J. (1999) Motor neurone disease. *British Medical Journal*, **318**, 1118-1121.

²⁴ <http://www.uk-mnd-professional-network.com/what-is-mnd.html>

²⁵ <http://www.patient.co.uk/showdoc/23069193/>

²⁶ <http://www.uk-mnd-professional-network.com/what-is-mnd.html>

number of people with motor neurone disease who would potentially use *Changing Places* toilets. However, there will clearly be some individuals for whom their use is a possibility and here we settle on a guesstimate of **500** people.

3.2.2 Parkinson disease

There are around 120,000 individuals with Parkinson disease in the UK, with the first appearance of symptoms occurring on average after the age of 50 years, with only one in 20 of those diagnosed each year under 40 years²⁷. The time course of the disease is highly variable, but it is to be anticipated that a majority of individuals who are at an advanced stage of deterioration will be older people, i.e. 65 years plus. For this reason we assume that the majority so incapacitated that they would potentially use *Changing Places* toilets have already been included in the estimates for older people.

3.2.3 Multiple Sclerosis

In the UK functional abilities of multiple sclerosis sufferers are assessed on the Expanded Standard Disability Status Scale (EDSS), a scale running from 0 - 10 where 10 is death. The *Multiple Sclerosis Society* has estimated that on the basis of information using EDSS data, the point on this scale where someone would potentially use *Changing Places* toilets indicates that 10% of the 85,000 UK MS sufferers would require need a changing places toilet, i.e. **8,500** people with MS in the UK²⁸.

3.3 Physical disabilities arising from illness and injury

A very wide range of illnesses and traumas can result in significant conditions that disable the individual and impair activities of daily living including, obviously, motor abilities. Many of these conditions do not result in continued deterioration, and indeed as in the case of stroke appreciable improvement is

²⁷ <http://www.parkinsons.org.uk/about-parkinsons/what-is-parkinsons/how-many-people-have-parkinson.aspx>

²⁸ Personal communication. March 15 2009.

possible. This observation is applicable to both gross motor behaviour and continence. Only a minority of individuals will be sufficiently impaired to require the very high level of support associated with use of *Changing Places* toilets.

3.3.1 Stroke chronic heart failure

Stroke occurs most frequently in the 55 years plus age range²⁹ with risk increasing with advancing age³⁰. Incontinence is a frequent consequence of stroke with high levels of disability and discharge from hospital to institutional care, though it has been reported that prevalence is similar to the general older population and fecal incontinence is the result of lack of mobility rather than neurogenic factors (Brocklehurst et al. 1985)³¹. Data from the *National Sentinel Audits of Stroke for England, Wales and Northern Ireland* of 1998, 1999, 2001-2002 and 2004 were used as the basis for determining the prevalence of urinary incontinence in stroke patients (Wilson et al 2008)³². Prevalence of urinary incontinence varies as both a function of the time elapsed since the stroke and quality of medical care following the stroke. At hospital discharge, 15-20% of stroke patients suffered from urinary incontinence. (As with the ageing data presented above, Barthel Index ADL scores were used in this study.)

Both care recipients and family caregivers experience profound difficulties arising from urinary incontinence. Isolation in the home is compounded by many carers not going out with their relative because the care recipient's incontinence is considered to be better managed at home (Brittain & Shaw 2008)³³.

With respect to chronic heart failure a large scale Scandinavian study of older people found that most were independent with respect to personal activities of

²⁹ Welch, R. (2008) Stroke and old age. *British Journal of Healthcare Assistants*, **2**, 427- 429.

³⁰ <http://www.statistics.gov.uk/STATBASE/xsdataset.asp?vlnk=2656>

³¹ Brocklehurst, J.C., Andrews, K., Richards, B. & Laycock, P.J. (1985) Incidence and correlates of incontinence in stroke patients. *Journal Of The American Geriatrics Society*, **33** 540-2.

³² Wilson et al (2008)

³³ Brittain, K.R. and Shaw, C. (2007) The social consequences of living with and dealing with incontinence--a carers perspective. *Social Science Medicine*, **65**,: 1274-88.

daily living, though some dependency was reported (particularly with respect to shopping) (Norberg et al. 2008)³⁴ .

Clearly people who have had a stroke or chronic heart failure may have long term, serious restrictions to mobility and additional continence difficulties. Both conditions are age-related, and in the absence of specific information on the functional abilities of individuals who have suffered these conditions, we make the conservative estimate that those over 65 years requiring significant support will have been included in the estimates for older people in both family homes and residential accommodation. This leaves a proportion younger than 65 years who may benefit from the use of *Changing Places* toilets but on whom we cannot find data. Nevertheless it is worthwhile highlighting such people who are seriously affected by stroke and chronic heart conditions. Information can be provided to them, their carers and their associations regarding the availability and use of *Changing Places* toilets.

3.3.2 Types of Arthritis - Rheumatic Diseases - Related Conditions

Depending on which source you consider, there are 100 to 200 types of arthritis, rheumatic diseases and related disorders. Here we will consider them all as “arthritis” from the point of view of their gross motor consequences as it affects the activities of everyday life. While the disease can affect a person of any age, the prevalence and severity increase with age. There are 400,000 individuals in the UK with rheumatic diseases, though we can find no breakdown as to their types of accommodation. However, it is to be anticipated that most live at home, with a proportion of older persons resident in care homes. If we applied the estimate of 6.7% requiring assistance with toilet needs in the family home (Brouwer et al. 2004)³⁵ to this entire figure, then 26,800 require support with toilet use. However, it is clear from that paper that most individuals do not require the level of support provided in the

³⁴ Norberg, E-B., Boman, K. & Lofgren, B. (2008) Activities of daily living for older persons in primary health care with chronic heart failure. *Scandinavian Journal of Caring Sciences*, **22**, 203-210.

³⁵ Brouwer, W.B.F., van Exel, N. J. A., van de Berg, B., Dinant, H.J., Koopmanschap, M.A., & den Bos, J.A.M. (2004) Burden of caregiving: Evidence of objective burden, subjective burden, and quality of life impacts on informal caregivers of patients with rheumatoid arthritis. *Arthritis Care & Research*, **51**, 570-577.

use of *Changing Places* toilets. Many of the most severe cases who may require such support will be older people living in care settings who will already have been accounted for in our estimates of older people in section 4. We are left, therefore, with an indeterminate but relatively small number of people across the age range who might benefit from access to *Changing Places* toilets. No estimate of this figure is possible.

3.3.3 *Acquired brain injury through trauma*

Acquired brain injury can arise from a wide range of causes including stroke, trauma, lack of oxygen to the brain, brain infections, tumours and exposure to toxic substances. Here we focus on acquired brain injury through trauma, principally because a younger section of the population is affected in comparison to other conditions closely associated with ageing. This fact provides the opportunity to identify a group of potential users of *Changing Places* toilets for whom access to the community merits particular attention.

The impact of acquired brain injury on the individual's ability to perform the self-help tasks necessary for independent toilet use will depend upon the extent and site of the injury, regardless of the cause. With respect to traumatic brain injury the prevalence of urinary incontinence is reported to be 62% after trauma and 18% at six months after trauma, with the comparable figure for faecal incontinence 62% and 5% at 12 months (Leary et al 2006)³⁶.

The consequences of traumatic brain injury are classified in a variety of ways. For present purposes the distinction between *good recovery*, *moderate disability*, *severe disability* and *vegetative survival* is the most helpful, with a focus on the last two. Here we make no assumptions about the feasibility of people in a coma or persistent vegetative state accessing community facilities, and individuals in both states are implicitly included in the data we utilise. Of the 73,133 individuals surviving traumatic brain damage in the UK, 16% will have severe disability and 6% will be in a vegetative state, respectively 11,701 and 4,388 people (The Institute of Neuropalliative

³⁶ Leary, S.M., Liu, C., Cheesman, A.L., Ritter, A. & Thompson, S. (2006) Incontinence after brain injury: prevalence, outcome and multidisciplinary management on a neurological rehabilitation unit. *Clinical Rehabilitation*, **20**, 1094-1099.

Rehabilitation³⁷). On the available data it is not possible to distinguish those with severe disability requiring very high levels of support with respect to activities of daily living related to toileting from those with ability for more independent skills. Given the rising population of people with acquired traumatic brain injury we therefore take these figures together as our estimate of people in this group who could potentially use *Changing Places* toilets, i.e. 16,089. This figure however requires some correction. A minority of this figure will be elderly and are accounted for in our figures for older people. If therefore we limit our consideration of people with traumatic brain injury to those under 55 years (we do not have any breakdown for the over 55s) (The Institute of Neuropalliative Rehabilitation)³⁸, we would reduce the figure of 16,089 by a further 11%, i.e. by 1,770 bringing the figure to 14,319. Some of this group will already have been accounted for in our estimate of people with profound intellectual and multiple disabilities. Of the latter, 3% will be disabled because of acquired brain injury (Hogg & Lambe 1988)³⁹. i.e. 882, reducing the figure **13,437**.

3.3.4 *Diabetes mellitus (Type 2 diabetes)*

Diabetes mellitus (Type 2) affects 1.44 million people in the UK with incidence increasing with age and 10-15% of people over 70 having the disease (Department for Work & Pensions)⁴⁰. Deterioration in activities of daily living relevant to use of *Changing Places* toilets as the result of diabetes has been found to be associated with ability to transfer (Brookes 2002)⁴¹ as well as with respect to fecal (Schiller et al 1982)⁴² and urinary incontinence (Yerkes 1998)⁴³. However, high dependency, particularly with respect to mobility (Barthel Index), has been found in only 4% of people with diabetes mellitus

³⁷ <http://www.rhn.org.uk/institute/doc.asp?catid=1267&docid=312>

³⁸ <http://www.rhn.org.uk/institute/doc.asp?catid=1267&docid=312>

³⁹ Hogg, J. & Lambe, L. (1988) Sons and daughters with profound retardation and multiple handicaps attending schools and social education centres. Manchester: Mencap.

⁴⁰ http://www.dwp.gov.uk/medical/med_conditions/diabetes/prevalence_diabetes.asp

⁴¹ Brookes, G.S. (2002) Relationship between instrumental activities of daily living and blood glucose control in elderly subjects with type 2 diabetes. Paper delivered at the 130th Annual Meeting of APHA, November 11 2002.

⁴² Schiller, L.R., Santa Ana, C.A., Schmulen, A.C., Hender, R.S., Harford, W.V. & Fordtran, J.S. (1982) Pathogenesis of fecal incontinence in diabetes mellitus: evidence for internal-anal-sphincter dysfunction. *New England Journal of Medicine*, 30, 307(27),1666-71.

⁴³ Yerkes, A. M. (1998) Urinary incontinence in individuals with diabetes mellitus. *Diabetes Spectrum*, 11, 241-247.

over the age of 65 years (Sinclair et al 2007). It is anticipated that individuals with this degree of impairment will be accounted for in the estimates of older people to be presented in section 4 and we do not therefore provide a separate estimate for those with diabetes mellitus. However, in publicising the availability of *Changing Places* toilets, this group merit consideration as potential users.

4 Older people

The percentage of people socially and personally affected by incontinence is relatively low. A large scale epidemiological study reported that 2% of individuals over 40 living in the community experienced symptoms of urinary incontinence that were “...*clinically significant, bothersome and socially disabling...*” (Perry et al. 2000, p. 433). Such consequences increase with age, and these authors argue for targeting older people who have the greatest need. In determining the present estimates we follow this suggestion, though it worth noting that this 2% would cover 500,000 people over 40 years in England, Wales and Scotland who experience bothersome and socially disabling consequences of urinary incontinence.

In a US study, 7.2% of women had faecal incontinence, the proportion increasing with age (Melvill et al. 2005)⁴⁴. Importantly from the perspective of the value of *Changing Places* toilets to those with mobility and transfer difficulties, this condition significantly affected their life style and functional abilities and was associated with depression.

Incontinence can affect individuals of any age, particularly those with a specific disabling condition. While age does not cause incontinence (Roe & Doll 2000)⁴⁵, both urinary and faecal incontinence are associated with older age. Among the over 65s as many as 40% of women and 20% of men have urinary incontinence (Hunnskaar et al 2002)⁴⁶, while as many as 11% have faecal incontinence (Norton et al 2002)⁴⁷. Urinary and faecal incontinence co-occur in 60% of women and 51% of men (Roberts et al. 1999)⁴⁸, though as

⁴⁴ Melville, J., Fan, M-Y., Newton, K. & Fenner, D. (2005) Fecal incontinence in US women: a population-based study. *American Journal of Obstetrics & Gynecology*, **193**, 2071-2076.

⁴⁵ Roe B. & Doll H. (2000) Prevalence of urinary incontinence and its relationship with health status. *Journal of Clinical Nursing*, **9**, 178–187.

⁴⁶ Hunnskaar S., Burgio K., Diokno A.C., Herzog A.R., Hjalmas K. & Lapitan M. (2002) Epidemiology and the natural history of urinary incontinence. In *Incontinence: Second International Consultation on Incontinence – Paris, 2001*. (Abrams P., Cardozo L., Khoury S. & Wein A., Health Publication, Plymouth, pp. 165–201.)

⁴⁷ Norton C., Christiansen J., Butler U., Harai D., Nelson R.L., Pemberton J. et al. (2002) Anal incontinence. In *Incontinence: Second International Consultation on Incontinence – Paris, 2001*. (Abrams P., Cardozo L., Khoury S. & Wein A., Health Publication Ltd, Plymouth, pp. 987-1043.

we shall show, the figure is appreciably higher for those in supported accommodation.

Older people live predominantly in family homes with a minority in nursing and residential homes. Since those in institutional settings have the most significant care needs, including management of continence, we will begin by considering the potential of *Changing Places* toilets to improve their community access and quality of life. In addition, a recent review of continence issues suggests that older people suffering from incontinence are more likely to be institutionalised than their continent peers (Wagg 2008)⁴⁹.

4.1 Nursing & Residential Homes

Reporting on nursing homes, residential homes and those with dual registration, (Rodriguez et al. 2007)⁵⁰ note that 80% of nursing home residents and 49% of residential home residents were reported to be incontinent. Double incontinence is three times more prevalent in nursing homes than residential homes (48% Vs 16%). This comprehensive survey (n=1165) undertaken by the University of Birmingham employed the *Barthel Activities of Daily Living Index* to assess (among other abilities) support need to transfer, toilet needs and continence. The original dataset, generously made available to the present author for further analysis, shows that those unable to transfer or requiring major help to transfer and with high dependency for toilet use totalled 421/1165, i.e. 36.1%. We would define this as the group most likely to benefit from accessing *Changing Places* toilets with their carers.

The total number of supported residents funded by *Councils with Adult Social Services Responsibilities (CASSRs)* in residential and nursing homes in

⁴⁹ Wagg, A. (2008) *Urinary Continence Management in Older People*. London: Royal College of Nursing.

⁵⁰ Rodriguez, N.A., Sackley, C.M. & Badger, F.J. (2007) Exploring the facets of continence care: a continence survey of care homes for older people in Birmingham. *Journal of Nursing Care*, **16**, 954-962.

England was reported in 2008 to be 236,100⁵¹. Employing our calculation of the potential proportion of such residents who will benefit from access to *Changing Places* toilets, this yields a figure of 85,232 residents. The equivalent figure for people in residential and nursing homes in Scotland is 44,857 residents (as of March 2009), yielding 16,193 potential users. Comparable Welsh figures for projected users are 9554 and for Northern Ireland 5716.

The UK total of potential older users of *Changing Places* toilets now living in residential or nursing home accommodation is at present therefore **116,695**.

However, the population of residential and nursing homes has consistently fallen since 2004 due to the national policy of supporting people in their homes. This has led to a concomitant increase in older people living at home with support to whom we now turn.

4.2 Older people living with their family

One consequence of the effect of this policy is that there is an increasing number of people living in family homes with high continence needs and high degrees of dependency on others for support (Akpan et al. 2006)⁵². This support may be provided by family members alone, paid home support, or a combination of both. Their family carers have been well studied, though there has only been limited consideration of the impact of mobility difficulties and incontinence on caregiving. It is known, however, that incontinence is a major challenge and predictor of caregiver burden and institutional placement (Cassels & Watt 2003⁵³). Among the many significant consequences of incontinence is increasing social isolation of the older person and his/her relative and may be a significant caregiver stressor.

⁵¹ NHS Information Centre (2008) *Community Care Statistics 2008: Supported residents (adults), England*. London: Government Statistical Service.

⁵² Akpan, A., Gosney, M. & Barrett, J. (2006) Privacy for defecation and fecal incontinence in older adults. *Journal of Wound, Ostomy & Continence Nursing*, **33**, 536-540.

⁵³ Cassels, C. & Watt, E. (2003) The impact of incontinence on older spousal caregivers. *Journal of Advanced Nursing*, **42**, 607-616.

There has been no comparable study in family homes to that undertaken in Birmingham in residential accommodation (Rodriguez et al. 2007) from which estimates of *Changing Places* toilet use may be extrapolated. Our starting point, therefore, is the *Public Service Agreement Target (PSA)*, aimed at improving the quality of life and independence of older people so they can live at home, which set a target for March 2008 of 34% living at home of the total of people receiving social service support at home or in residential care. In the event this figure was exceeded, the percentage being 37% at that date, a figure that had increased steadily over the previous six years. Based on the total number of people in residential and nursing homes in England given above, 236,100, this would yield an additional figure of 138,661 people over 65 years of age living at home of the total receiving social service support. (This is not, it should be noted, the total of over 65 year olds receiving some measure of home support which is considerably larger than this figure.⁵⁴) However, it is to be anticipated that overall the level of disability will be appreciably less than those cared for in residential settings, particularly nursing homes. Simply to extrapolate the number of potential users of potential *Changing Places* toilet users from the above figures would lead to a considerable overestimate. If, however, we extrapolate from the relevant figures for residential homes from the Birmingham study where impairment of activities of daily living is considerably less than for nursing homes and will be closer to that of those receiving support in the home, we can derive an estimate. Based on the criteria of inability to transfer with no sitting balance or requiring major help to transfer *and* complete dependency in toileting, 11.1% of older people in the Birmingham study require this level of support. Applied to the above figure, we arrive at an estimate of **15,391** who would be potential users of *Changing Places* toilets.

⁵⁴ NHS Information Centre (2008) Community Care Statistics 2007 – 2008: Referrals, Assessments and Packages of Care for Adults, England – Provisional Council Data. London: NHS Information Centre.

5 Discussion and conclusion

Table 1 shows that the overall figure of potential users of *Changing Places* toilets, based on the above estimates is a range of **223,798-230,252**. There is one heterogeneous group of people who have been excluded from these figures because of lack of sufficiently detailed age breakdowns in the data reviewed. This is people who develop a condition associated with older age in their early or middle years. This includes conditions such as arthritis, Parkinson disease, motor neurone disease etc. The omission of these people will stretch the above total towards 250,000, though precisely how close to that figure is not possible to say. However, in our view it would not be unreasonable to state that *“Up to a quarter of a million people with disabilities could potentially benefit from the availability of Changing Places toilets.”*

Table 1: Total estimate of potential users of *Changing Places* toilets

Condition	Report Section	Sub category	Estimated number of <i>Changing Places</i> toilets users
Intellectual disability	2		30,328-36,782
Physical disabilities	3		
	3.1	Cerebral palsy	30,947
	3.2	Spina Bifida	8,000
	3.2.1	Motor Neurone disease	500
	3.2.2	Parkinson disease	*
	3.2.3	Multiple sclerosis	8,500
	3.3.1	Stroke/ chronic heart failure	*
	3.3.2	Arthritis	*
	3.3.3	Traumatic brain injury	13,437
Older people	4		
	4.1	Nursing & residential homes	116,695
	4.2	Older people in private accommodation	15,391
Total			223,798-230,252

* **Figures for these conditions subsumed under older people**

It is important to emphasise that there is no simple one-to-one correspondence between the estimates we have presented and actual use of *Changing Places* toilets. There are several reasons why this is the case:

- (i) at the outset, actual users will inevitably fall well short of the present estimates of potential users. While *Changing Places* toilets are becoming increasingly familiar to caregivers of people with intellectual and multiple disabilities, carers and care recipients with other disabilities are far less likely to know of the availability of such facilities
- (ii) the very availability of *Changing Places* toilets will progressively increase their use and we would anticipate that the gap between our present estimates and eventual usage will continue to narrow. This will depend in part on the extent to which local authorities, health services and the voluntary sector increase and publicise their availability to groups beyond those with intellectual disabilities.
- (iii) the present estimates are based on contemporary or very recent figures. These populations are far from static. The “very old” population of the UK will increase (Office of Health Economics 2007)⁵⁵ with concomitant increases in functional impairment including mobility and continence needs. The population of people with intellectual disabilities is also progressively rising (Emerson & Hatton 2008)⁵⁶ as is that of people with cerebral palsy (Surman et al 2006)⁵⁷. We would anticipate that the need for facilities that improve access to the community and reduce social isolation will increase in the coming years and decades. *Changing Places* toilets will become even more relevant to the lives of UK citizens.

⁵⁵ Office of Health Economics (2007) www.ohe.org/page/knowledge/schools/appendix/aging_population.cfm

⁵⁶ Emerson, E. & Hatton, C. (2008) *People with Learning Disabilities in England*. Lancaster: Centre for Disability Research.

⁵⁷ Surman, G., Bonellie, S., Chalmers, J., Colver, A., Dolk, H., Hemming, K., King, A., Kurinczuk, J., Parkes, J. & Platt, M.J. (2006) UKCP: a collaborative network of cerebral palsy registers in the United Kingdom. *Journal of Public Health*, **28**, 148-156.

- (iv) In contrast, the incidence and prevalence of some conditions will reduce. As has been the case with spina bifida. Improved medical care and rehabilitation techniques will also lead to improvements in or maintenance of activities of daily living.

While the present estimates will contribute to the argument and pressure for *Changing Places* toilets as standard facilities across the UK, we would like to conclude with a recommendation to reinforce this strategy. The estimates combined with a demonstration of the value of these facilities to members of the groups considered in this report would add appreciably to the argument. A series of case studies of individuals in the various groups discussed here actually using and benefitting from use of *Changing Places* toilets would provide a very convincing demonstration of their value. To identify such potential users and support them and their carers and organisations to use the facilities and document the benefits would provide a powerful argument demonstrating how *Changing Places* toilets enable society to fulfil its aspiration for community inclusion and participation.