

# Estimated number of potential users of Changing Places Toilets in Ireland

June 2021

## Background

The Department of Housing, Local Government and Heritage asked the National Disability Authority to provide advice on the estimated number of potential users of Changing Places Toilets in Ireland. This request arose from a review of Part M of the building regulations to provide for Changing Places Toilets. According to the Changing Places Ireland website, there are currently 14 Changing Places Toilets in Ireland.<sup>1</sup>

A Changing Places Toilet is a toilet facility that provides space for assistance to be provided and equipment, including a hoist and changing bench, to address the needs of people who cannot use standard accessible toilets.

## Calculation of potential users of Changing Places Toilet in Ireland

Four different approaches to estimating the numbers of potential users of Changing Places Toilets in Ireland are outlined below, followed by a summary analysis. The four approaches are:

- Calculation based on UK estimate
- Numbers of wheelchair users and users of hoists
- Persons unable to toilet independently
- Estimate of potential users based on condition/status specific Irish data

### **A: Calculation based on UK estimate**

The number of potential users of changing places in the UK is estimated to be circa 250,000. Users include people with severe and profound intellectual disabilities and people with a range of other disabilities including Cerebral Palsy, Motor Neurone disease, Multiple Sclerosis, stroke, some older people and other specific disabilities.

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<sup>1</sup> <https://changingplaces.ie/>. Accessed on 20<sup>th</sup> May 2021.

The estimate of 250,000 potential users of Changing Places is widely referenced. The source is a report prepared by Professor James Hogg in 2009.<sup>2</sup> The report estimates the number of potential users of changing places to be in the region of 223,800-230,300.<sup>3</sup> The variation arises due to uncertainty regarding the appropriate prevalence rate for profound and multiple intellectual disabilities.<sup>4</sup>

The estimates in the report generally relate to data for 2007-2008. The report uses a UK population estimate of 60.6 M. The UK population in April 2021 is estimated to be 68.2 M;<sup>5</sup> 12.5% higher than the estimated population in 2007-2008. If the number of potential users of changing places is increased to reflect the increase in population between 2008 and 2021 we arrive at a revised estimate of 251,800-259,100. However, the number of older persons resident in nursing and residential care homes in the UK has increased at a faster rate than the general population. Hogg’s calculations were based on a nursing and residential care population of 323,255. In 2021 the UK nursing and residential care population is estimated to be 400,000. This is approximately 24% higher than the estimate used by Hogg in 2009.<sup>6</sup> Accordingly, the estimate of potential users of Changing Places from within the population of persons in nursing and residential care homes has been increased by 24%. Table 1 below sets out an estimate of **265,100** potential users of Changing Places in 2021.

**Table 1: Estimate of Changing Places Users in the UK: 2009 and 2021**

| <b>Condition</b>                          | <b>Year: 2009</b> | <b>Year: 2021</b> |
|---|-------------------|-------------------|
| Severe/profound Intellectual Disabilities | 30,300            | 34,100            |
| Cerebral Palsy                            | 30,900            | 34,800            |
| Spina Bifida                              | 8,000             | 9,000             |
| MS/Motor Neurone                          | 9,000             | 10,100            |

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<sup>2</sup> Hogg, 2009.

<sup>3</sup> All estimates are rounded to the nearest 100.

<sup>4</sup> The higher estimate was based on higher rates of profound ID among certain ethnic groups in the UK. The Irish population does not include any significant cohort of the specific ethnic groups affected.

<sup>5</sup> <https://www.worldometers.info/world-population/uk-population/>

<sup>6</sup> UK Government 2021. The number of residents in UK nursing and care homes is estimated to be 400,000.

| <b>Condition</b>               | <b>Year: 2009</b> | <b>Year: 2021</b> |
|--------------------------------|-------------------|-------------------|
| ABI                            | 13,400            | 15,100            |
| Older persons in Nursing Homes | 116,700           | 144,700           |
| Older persons at home          | 15,400            | 17,300            |
| <b>Total</b>                   | <b>223,700</b>    | <b>265,100</b>    |

If it is assumed that the proportion of potential users of changing places in Ireland mirrors that in the UK we would anticipate that around **19,400** persons might use a Changing Place in Ireland.<sup>7</sup>

### **B: Numbers of wheelchair users and users of hoists**

Many potential users of Changing Places are wheelchair users. The 2006 National Disability Survey (NDS) indicates that 31,342 people were users of manual or electric wheelchairs.<sup>8</sup> A further 8,923 people indicated an unmet need for a wheelchair. However, it should be remembered that many wheelchair users will be able to toilet independently. Also, some people use their wheelchairs intermittently rather than constantly.

The number of people who use hoists is likely to be a better indicator of the potential number of users of Changing Places than the number of wheelchair users. It is acknowledged that a proportion of persons who use hoists, and who are resident in nursing homes or in other communal establishments may be too frail to use community based Changing Place facilities.<sup>9</sup> The 2006 NDS indicates that **15,512** persons with disabilities used hoists and a further **8,918** persons indicated an unmet need for a hoist.<sup>10</sup> The current population of Ireland is estimated to be 4.98 M.<sup>11</sup> This is an increase of 17.7% over the population in 2006.<sup>12</sup> If we apply the same increase to the number of users of hoists in 2006 the

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<sup>7</sup> This calculation is based on the estimated population in Ireland (4.98 M) and the UK (68.2M) in 2021.

<sup>8</sup> CSO 2010.

<sup>9</sup> Communal establishments are comprised of nursing homes, hospitals, children's homes and other.

<sup>10</sup> CSO 2010.

<sup>11</sup> [cso.ie/en/releasesandpublications/er/pme/populationandmigrationestimatesapril2020/](https://www.cso.ie/en/releasesandpublications/er/pme/populationandmigrationestimatesapril2020/)

<sup>12</sup> Census 2006 indicates that the population of Ireland was 4,234,925 in 2006. CSO 2006.

estimated number of users of hoists in 2021 is **18,258**. A further **10,496** are estimated to have an unmet need for a hoist.

However, the Irish population is ageing and the likelihood of requiring a hoist increases with age. During the period from 2006-2016 the proportion of the population aged 65 and over increased from 11% to 13.4%.<sup>13 14</sup> Between 2006 and 2016 the number of persons aged 65 or over increased from 467,926 to 637,567.<sup>15 16</sup> This represents a 36% increase in the number of persons aged 65 or over between 2006 and 2016. In the same ten year period the population of persons aged 85 and over increased by 40.7%. This cohort is especially likely to require a hoist when compared to younger age groups.

In recent years the population of older persons has increased at a much faster rate than the rate of increase in the total population. It is likely that the proportion of the population aged 65 and over and aged 85 and over has continued to grow since 2016. To take account of the increase in the proportion of older people in the population we have assumed that 50% of persons that use a hoist are aged 65 or over.<sup>17</sup> This estimate assumes that mobility and incontinence issues increase with age as can be seen in Table I. The estimate of the number of users of hoists in 2021 has been calculated by applying the normal population increase to 50% of hoist users from the 2006 NDS and applying the rate of increase in the over 65s population to the remaining 50%.<sup>18</sup>

This yields an estimate of the number of users of hoists of **19,700**. The estimate of the unmet need has not been revised.

### **C. Persons unable to toilet independently**

The National Disability Survey presents information regarding the number of persons with disabilities that required assistance with aspects of personal care, including toileting. The survey data indicates that 40% of persons with disabilities living in communal establishments responded 'cannot do at all' to a question

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<sup>13</sup>CSO 2007.

<sup>14</sup> CSO 2017a

<sup>15</sup> CSO 2007.

<sup>16</sup> CSO 2017a.

<sup>17</sup> Almost 6 in ten of the estimated Changing Place users in the UK are comprised of persons aged 65 and over. The estimate of 50% reflects differences in the demographic profile of Ireland and the UK and in particular the smaller proportion of persons aged over 65 in the Irish population compared to the UK.

<sup>18</sup>  $(15,512 \times .5 \times 1.177) + (15,512 \times .5 \times 1.36)$

about going to the toilet by yourself. Just 3% of persons with disabilities living in private homes responded 'cannot do at all' to the same question. It is assumed that all persons that are completely unable to undertake their toileting are potential users of Changing Places.

Census 2016 indicates that 44,531 or 6.9% of persons with disabilities were living in a communal establishment.<sup>19</sup> An estimate of persons unable to undertake toileting has been calculated based on the assumption that the proportion unable to undertake toileting in both communal establishments and private homes has not changed since 2006. The estimate is set out in Table 2 below.

**Table 2: Estimate of persons unable to undertake toileting**

| <b>Living arrangement</b> | <b>No. of persons with disabilities 2016</b> | <b>Est. of Persons unable to undertake toileting 2016</b> | <b>Est. No. of persons with disabilities 2021</b> | <b>Est. of Persons unable to undertake toileting 2021</b> |
|---------------------------|--|---|---|---|
| Communal establishment    | 44,531                                       | 17,800  | 46,900  | 18,800  |
| Private households        | 598,600                                      | 18,000  | 630,900   | 18,900  |
| <b>Total</b>              | <b>643,131</b>                               | <b>35,800</b>   | <b>677,800</b>                                    | <b>37,700</b>   |

#### **D: Estimate of potential users based on condition/status specific Irish data**

Table 3 below sets out details of the cohorts of persons with disabilities that are likely to include potential users of Changing Places.

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<sup>19</sup> CSO 2017b.

**Table 3: Conditions that may indicate a need for a Changing Place**

| <b>Ref</b> | <b>Condition</b>                              | <b>Estimated No. of people with condition</b> | <b>Notes</b>  |
|------------|---|---|---|
| A          | Acquired and inherited neuromuscular diseases | Adults: 2,641 <sup>20</sup><br>Children: 834  | Although not all children with a NMD will survive into adulthood survival rates are improving. Children do not experience all forms of neuromuscular diseases. Estimate has been based on the proportion of children (under 18) in the general population (2641/76*24).   |
| B          | Severe ABI                                    | 700   | Estimate. Total of around 1300-1400 adults aged under 65 are living in nursing homes. <sup>21,22</sup> It is thought that many of these have ABI and many others may have neuromuscular disease/stroke/CP. There are also many people living at home with supports who have an ABI some of whom may benefit from a changing places toilet. In the absence of reliable figures we estimate that 700 (half those <65 living in a nursing home) would benefit from a changing places toilet. |
| C          | Severe/profound intellectual disability       | 5,108   | Taken from the National Intellectual Disability Database Annual Report 2017. <sup>23</sup> Increased by 5.4% in line with increase in population since 2016 (4846*1.054)  |

<sup>20</sup> Lefter, Hardiman and Ryan 2017.

<sup>21</sup> Collins 2019.

<sup>22</sup> Pierce, Kilcullen and Duffy 2018.

<sup>23</sup> Hourigan, Fanagan and Kelly 2018.

| Ref | Condition  | Estimated No. of people with condition | Notes  |
|-----|--|--|--|
|     |  |  | Very high percentage of persons in this cohort likely to be incontinent and to be multiply disabled- will also include people with severe CP.  |
| D   | Nursing home residents   | 23,300                                 | Number of persons funded under the Nursing Home Support Scheme in 2018. As funding is dependent on an assessment of care needs it is likely that persons in receipt of funding would have significant disabilities.  |
| E   | Persons disabled by stroke/dementia living in private households | 65,000                                 | Based on estimate of persons disabled by stroke (circa 30,000) <sup>24</sup> and persons with dementia (circa 60,000). <sup>25</sup> Some of these are likely to be significantly disabled/incontinent. Downward adjustment made on the assumption that some people with these conditions will be resident in nursing homes. |

The proportion of persons with each of these conditions that may need a Changing Place is likely to vary considerably. In the absence of data to evidence the true proportions of individuals requiring a Changing Place in each category a range of estimates is presented below. For persons in categories A, B, and C the estimates range from 100% (high), to 85% (medium) and 75% (low). For persons in category D estimates are informed by UK research, the NDS survey and demographic trends.<sup>26</sup> They range from 40% (high), to 35% (medium) and 30%

<sup>24</sup> <https://irishheart.ie/our-mission/our-policies/stroke/#:~:text=An%20estimated%2030%2C000%20people%20are,biggest%20cause%20of%20acquired%20disability.>

<sup>25</sup> Pierse, Keogh and O'Neill 2020. See also <https://alzheimer.ie/creating-change/awareness-raising/dementia-in-the-media/>

<sup>26</sup> Hogg, 2009. CSO 2010.

(low). For persons in categories E the estimates range from 10% (high), to 7.5% (medium) and 5% (low). As estimates are not underpinned by an evidence base they should be interpreted with caution.

**Table 4: Estimates of potential users of Changing Places from specific cohorts of persons with disabilities**

| <b>Condition</b>  | <b>Total</b> | <b>Low</b>    | <b>Medium</b> | <b>High</b>   |
|---|--------------|---------------|---------------|---------------|
| A: Acquired and inherited neuromuscular diseases                    | 3,475        | 2,600         | 3,000         | 3,500         |
| B: Severe ABI   | 700          | 500           | 600           | 700           |
| C: Severe/profound intellectual disability                          | 5,108        | 3,800         | 4,300         | 5,100         |
| D: Nursing home residents   | 23,300       | 7,000         | 8,200         | 9,300         |
| E: Persons disabled by stroke/dementia living in private households | 65,000       | 3,200         | 4,900         | 6,500         |
| <b>Total</b>  |              | <b>17,100</b> | <b>21,000</b> | <b>25,100</b> |

## Summary

Four different approaches have been explored to arrive at an estimate of the number of potential users of Changing Places Toilets in Ireland. The estimate of users are set out in table 5 below. The estimates range from 17,100 to 37,700 or 1 in 291 to 1 in 132 people<sup>27</sup>.

These numbers do not include the people who will be providing assistance to the users, in the Changing Places Toilet, and who will also be impacted by the provision of the facility, for example family members and carers.

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<sup>27</sup> Based on a current population of 4.98M

The estimates are informed by relevant evidence but are also underpinned by assumptions. It should be borne in mind therefore that estimates are presented as reasonable rather than accurate indicators of the number of potential users of Changing Places.

We note that the provision of Changing Places Toilets in Ireland is at an early stage and it may take some years before a substantial increase in the number of Changing Places Toilets is achieved. Users of Changing Places Toilets are heavily concentrated in the population cohort aged 65 and over. This cohort is projected to grow at a faster rate than the rate of increase in the general population. This has implications for future need for Changing Places Toilets, so planning for the upper end of the range of the estimated number of potential users of Changing Places Toilets is advised.

**Table 5: Summary of estimates**

| Reference  | Estimate   |
|--|--|
| A. Calculation based on UK estimate  | 19,400   |
| B. Numbers of users of hoists  | 30,200 (19,700 plus additional 10,500 with unmet need) |
| C. Persons unable to toilet independently                                    | 37,700   |
| D. Estimate of potential users based on condition/status specific Irish data | 17,100-25,100  |

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