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The Prevalence of People Who Could Benefit from Augmentative and Alternative Communication (AAC) in the UK: Determining the need

Abstract

Background: commissioners and providers require information relating to the number of people requiring a service in order to ensure provision is appropriate and equitable. There is little epidemiological evidence available regarding the prevalence of need for Augmentative and Alternative Communication (AAC).

Aim: to determine the prevalence of people who could benefit from AAC in the UK.

Method: An epidemiological approach was taken to create a new estimate of need: the prevalence of the main medical conditions and specific symptoms leading to the requirement for AAC were identified from the literature and AAC specialists were consulted to create an estimate of the numbers who may require AAC.

Results: 97.8% of the total number of people who could benefit from AAC have nine medical conditions: dementia, Parkinson's disease, autism, learning disability, stroke, cerebral palsy, head injury, multiple sclerosis and motor neurone disease. The total expectation is that 536 people per 100,000 of the population (approximately 0.5%) could benefit from AAC.

Keywords: Augmentative and Alternative Communication; Prevalence; Epidemiology; service delivery; commissioning.

What the paper adds:

There is little epidemiological evidence available regarding the prevalence of need for Augmentative and Alternative Communication (AAC), estimates have been provided at 0.5-1% of the population. Commissioners and providers require accurate information relating to the numbers of people requiring a service in order to ensure provision is appropriate and equitable. This epidemiological study provides evidence that 0.5% of the population could benefit from AAC.

The Number of People Who Could Benefit from Augmentative and Alternative Communication (AAC) in the UK: Understanding the need

Introduction

This paper reports a process of data collection and data validation that has taken place to address the question 'how many people could benefit from Augmentative and Alternative Communication (AAC) in the UK?'.

Policy context

There is significant variation in levels of AAC service provision and coverage in the UK due to the different approaches to commissioning and developing these services. The lack of consistency and inequity in provision of AAC in the UK has been captured in national reports (Bercow 2008; Gross 2010). A systematic review (Baxter et al. 2012a) has highlighted a paucity of research into best practice regarding AAC and which models of provision meet the needs of a person with communication impairments, by not identifying any papers that described or evaluated different models of service provision, standardised methods for describing services or any standardised audit or reporting tools.

Changes to the provision of public services in the UK in 2011 (Delamothe and Godlee 2011) required more explicit commissioning, particularly of specialised services and improved integration of services for those with complex health and social care needs. Specialised

services, including specialised AAC services, were brought under the direct commissioning remit of NHS England (NHS England 2015).

Having an estimate of the numbers of individuals who may require a service not only assists in planning and commissioning of that service but is also important in order to identify unmet need and inequity of provision.

Background of study

The work reported in this paper was commissioned and led by Communication Matters, the UK charity for AAC, and funded by the BIG Lottery fund (Big Lottery Fund UK 2015). It was carried out as part of the `Communication Matters – Research Matters: an Augmentative and Alternative Communication evidence base' project which had three main research outcomes:

1. Increased awareness relating to the prevalence of need for AAC in the UK
2. Increased understanding of the current provision of AAC in the UK
3. Improved access to best practice evidence to support early identification and intervention for people of all ages who need AAC.

This paper discusses work completed as part of the first research outcome, specifically determining the prevalence of need for AAC in the UK using an epidemiological approach. Whilst it is acknowledged that describing people who use AAC by their condition is not reflective of how they should be viewed (World Health Organization 2001), this method enables researchers to attempt to quantify in the absence of more specific or relevant data.

There is little epidemiological evidence available regarding the prevalence of need for AAC. Previous estimates for the number of people who could benefit from AAC in the UK have

been provided at 1% (Scope 2008) or 0.5% (Gross 2010) of the population. Searches of the General Practice Research Database (GPRD) (now the Clinical Practice Research Datalink) (Clinical Practice Research Datalink 2015) and the Health Survey for England (Health and Social Care Information Centre 2015) provided estimates of the population who could potentially benefit from AAC of 0.0001% and 0.4-0.6% respectively. There is little international prevalence data based on data rather than estimates, with figures from the USA being suggested at 0.8-1.2% of the population who cannot use natural speech to communicate (Beukelman and Ansel 1995).

This paper examines this cohort further and aims to provide a robust methodology for quantifying the prevalence of people who could benefit from AAC.

It is hypothesised that figures used in the past to estimate AAC need are likely to be an underestimation and that figures need to be reviewed on a regular basis because of changing contexts including increasing:

- prevalence of disabled children surviving longer;
- prevalence of individuals living with complex neurological conditions;
- longevity;
- availability of sophisticated AAC strategies and equipment which can be accessed by people with a greater range of difficulties;
- expectations of individuals and their families.

For example, Parrot, Tilley and Wolstenholme (2008) reported that the prevalence of young people aged 15-19 years who had severe or complex needs had increased by 70% in the period 1998 to 2008 (Parrott et al. 2008).

Aims

The work reported here aims to determine the prevalence of people who could benefit from AAC. Augmentative and Alternative Communication (AAC) covers a range of strategies, equipment, systems, methods and techniques used by people who have impairments of speech, language or communication. It includes technology such as dedicated computerised systems and voice output communication aids and non-technological systems such as symbols and picture charts. Within this work we define prevalence as the number of people who have a particular condition at one point in time. People who could benefit from AAC is defined as `AAC would extend or support their ability to communicate effectively'. Where required this has been defined as those with moderate to severe speech, language or communication impairment.

Methods and Procedures

This research examined information from several different sources and attempted to ask the following questions in order to determine the prevalence of people who could benefit from AAC:

1. What medical impairments/disorders do people have who could benefit from AAC?
2. How many people are there with each of these medical impairments/disorders?
3. How many of those people with the listed medical impairments/disorders have speech, language and communication needs?

4. How many of those people with speech, language and communication needs with the listed medical impairments/disorders could benefit from AAC?

Data collection was also done in order to investigate specialist AAC service providers' perspectives on which client groups need AAC and compare the results to the figures from the epidemiological study.

Epidemiological Data Collection

What medical impairments/disorders do people have who could benefit from AAC?

An initial list of medical disorders was extracted from a systematic literature review previously conducted by members of the research team (Baxter et al. 2012a; Baxter et al. 2012b), which identified studies relating to use of powered AAC.

The list of disorders was then expanded using data from a survey distributed to UK AAC practitioners as part of the second research outcome of the wider project (see Introduction). The survey was distributed to UK AAC practitioners to gain information about their current service provision and their current and past service population. It included a question which requested information on the numbers and underlying disorders of individuals on their caseload using powered AAC. A request was made for the services to indicate any other aetiologies not listed. The final list of conditions can be found in Table 1.

INSERT TABLE 1 HERE

How many people are there with each of these medical impairments/disorders?

Literature searches were conducted to provide the prevalence figures for each of the identified conditions. Published literature was identified using the following databases:

CINAHL, MEDLINE, PsychINFO and Web of Science. The Health and Social Care Information Centre provided links to other literature not accessed through the databases. Search terms were primarily the identified conditions (e.g. Cerebral palsy, Parkinson's disease etc.), secondly the terms relevant to quantifying the prevalence (e.g. prevalence, epidemiology) and also terms relating to the equipment or strategies (e.g. AAC, communication aids). In addition to searching using the electronic databases, reference lists taken from the identified papers were inspected for any potential additional relevant references. Searches were not restricted by year due to the paucity of literature on this subject for some of these conditions, particularly those that are relatively rare. The language of the text was restricted to those papers published in English. Numbers based on research for the UK population or those more relevant to the UK population were used where possible.

How many of those people with the listed medical impairments/disorders have speech, language and communication needs?

The literature search as defined above was also used to extract numbers of people who have speech, language and communication needs where possible. Where this number could not be ascertained from literature, speech and language therapists were consulted as detailed in the section below.

How many of those people with speech, language and communication needs with the listed medical impairments/disorders could benefit from AAC?

Between four and six experienced and specialist speech and language therapists with particular expertise with each specific client group and AAC were then consulted to provide estimates of percentages of people with the specified condition who would require or

benefit from using AAC and, where required, the number of people with that condition who would have speech, language or communication needs. The phrase `benefit from' was defined as `AAC would extend or support their ability to communicate effectively'. These professionals were identified through special interest groups, Communication Matters[1] and snowballing, where further professionals with the required expertise were identified by the initial participant. This method was used because of the relatively small community of AAC professionals. The professionals were shown the figures identified for prevalence of their specific client group and asked to contribute their opinions on who would benefit from AAC within that client group. Where possible the professionals were consulted as part of group discussions to allow for differences of opinion to be managed and a final figure to be agreed upon. Where this was not possible, an average figure was obtained. The staged process to collecting this data is summarised in Figure 1.

INSERT FIGURE 1 HERE

What are the perspectives of specialist service providers on the need for AAC?

To examine these figures in terms of the perspectives of individuals involved in the provision and use of AAC, further data were gathered during a national AAC conference presentation of the epidemiological approach to determining the prevalence of those who could benefit from AAC (*Catching up with the numbers*, 16 September 2012, Communication Matters Conference). The aim was to provide an indication of whether there were any discrepancies between the epidemiological data collection figures and the perspectives of specialist service providers on the prevalence of need for AAC.

[1] www.communicationmatters.org.uk

The session detailed the method taken to establish the prevalence of those who could benefit from AAC including how the final figures were being determined. The final figures for each condition had not yet been completed and were not presented. After the initial presentation of the method of determining prevalence, an interactive session was introduced in which the attendees were able to indicate electronically their responses to questions. The Turning Point[TM1] electronic voting system was used which facilitated voting using handheld keypads and then (once voting was closed) presentation of the results back to the audience. An initial unrelated question was asked which allowed the participants to gain familiarity with the electronic voting system.

A list of nine conditions identified by the initial results of the epidemiological study as common conditions per 100,000 population and predicted to be high in the list of those who use AAC from the epidemiological study were provided in a random order for the attendees to rank (1-5) as answers to the following question:

- "What are the top 5 main conditions of people who could benefit from AAC?"
    - Choice of: autistic spectrum disorder, learning difficulties, profound and multiple learning difficulties, cerebral palsy, motor neurone disease, multiple sclerosis, Parkinson's disease, stroke/CVA, Alzheimer's/dementia.

Choosing the top five conditions was for pragmatic reasons, wanting to include as many conditions as possible but also taking into account the time available during the presentation for people to identify their ordering and the ability to accurately estimate a ranking beyond a relatively small number of items. These results were then compared to the figures gathered from the epidemiological study.

Outcomes and Results

Epidemiological Data Collection

The data collected across all conditions is displayed in Table 2. The prevalence of those with the condition is shown in column (a), the percentage of that population with speech, language or communication needs is shown in column (b), calculated into a number per 100,000 population in column (c). The percentage of those individuals with that condition who have speech, language or communication needs and who could benefit from AAC is shown in column (d), calculated into a number per 100,000 population for column (e). The results show the list of the most common conditions that people have who could benefit from AAC, with Alzheimer's/dementia being the most prevalent. The table shows that a total of 4681.5 people per 100,000 have one of these conditions. The results show that there are 3464.125 people per 100,000 who have speech, language or communication needs that are associated with these conditions and there are 535.9 people per 100,000 population in the UK who could benefit from AAC.

INSERT TABLE 2 HERE

The following sections provide more detail on the prevalence figures for each condition. The results are presented by condition in order of prevalence of those who could benefit from AAC and therefore represent the most common conditions identified for people who use AAC. There are a large number of other more rare conditions (for example, Leigh disease, myoclonic epilepsy with ragged red fibres syndrome, Möbius syndrome), which may result in people having AAC needs but for which we have insufficient information to arrive at a

reliable estimate. It should also be noted that people often have co-morbidities, for example cerebral palsy with learning disabilities.

Alzheimer's/dementia

Over 1000 people per 100,000 have been identified as having dementia in the UK (Neurological Alliance 2003), more recently confirmed by part of the Cognitive Functioning and Ageing Study defining the number across England as 670,000 (approximately 1260 per 100,000 using ONS mid-2011 population estimates) (Matthews et al. 2013). The midpoint of the two results has been taken for table 2.

Using expert input, it was determined that 123 people per 100,000 have Alzheimer's disease or dementia with speech, language or communication needs and could benefit from AAC.

Parkinson's disease

The prevalence figures suggest there are 200 people per 100,000 population with Parkinson's disease with 160 of those developing a communication impairment (Neurological Alliance 2003; Whiston et al. 2009).

Using expert input, it was determined that 120 people per 100,000 have Parkinson's disease with speech, language or communication needs and could benefit from AAC.

Autistic spectrum disorder (ASD)

Approximately 1000 people per 100,000 in the UK population have some form of autistic spectrum disorder (Baird et al. 2006; Baron-Cohen et al. 2009).

Using expert input, it was determined that 100 people per 100,000 have autistic spectrum disorder with speech, language or communication needs and could benefit from AAC.

Learning disabilities

Emerson and McGrother (2011) calculated the numbers of people with learning disabilities by extracting data from local registers of learning disabilities from different parts of the UK (Sheffield, Sefton, Greenwich, Bexley, Lambeth, Harrow, Leicestershire, Sutton and Merton) placing the number at 469.9 per 100,000 population.

Experts felt that all of this cohort will have some restricted communication, many in line with their intellectual and cognitive abilities, however, some will show intellectual and cognitive abilities which are in advance of their ability to communicate.

Using expert input, it was determined that 70.5 people per 100,000 have learning disabilities with speech, language or communication needs and could benefit from AAC.

Stroke/Cerebrovascular accident (CVA)

Numbers have been estimated for UK stroke-related disability (rather than the prevalence of surviving a stroke, estimated at 1766 per 100,000 (Townsend et al. 2012)), with 58% of people discharged from hospital not able to live independently (Intercollegiate Stroke Working Party 2012), equivalent to 1024 per 100,000. 30% of people who have had a stroke will remain severely affected in the long term (Department of Health 2005).

Experts felt that as this cohort is generally older and dysarthria is often associated with those who have had several strokes, this could be a barrier to accessing services. Experts also suggested that there is a growing number of individuals with dysphasia who can benefit from more recently developing technologies which can facilitate word finding.

Using expert input, it was determined that 61.4 people per 100,000 having had a stroke with speech, language or communication needs could benefit from AAC.

Cerebral palsy

The number of people in the UK with cerebral palsy is estimated at approximately 200 per 100,000 (Neurological Alliance 2003; Enderby and Philipp 1986; Whiston et al. 2009). 120 of those will have some speech, language or communication needs (Enderby and Philipp 1986; Beukelman and Mirenda 1998).

Using expert input, it was determined that 24 people per 100,000 have cerebral palsy with speech, language or communication needs and could benefit from AAC.

Head/brain injury

300 people per 100,000 are estimated to have a head/brain injury (Neurological Alliance 2003) with an estimated 60 of those 300 affected having a problem with speech, language or communication (Enderby and Philipp 1986). The majority of those with severe brain injury will have communication impairments including a complex mix of cognitive, language and motoric deficits.

Using expert input, it was determined that 12 people per 100,000 have head/brain injury with speech, language or communication needs and could benefit from AAC.

Profound and multiple learning disabilities (PMLD)

The number of people with PMLD was extracted from figures from the Lambeth register of learning disabilities (81 people from a total of 220,800) and applied to the wider population, resulting in 36.7 people per 100,000 (Emerson and Hatton 2004; Emerson and Hatton 2008;

Emerson 2009; Mencap 2010). All of this client group were estimated to have speech, language or communication needs.

Experts felt that many of the individuals have communication which is below that expected of their retained intellectual/cognitive abilities because of the severe physical and other sensory deficits. Experts suggested that this group is particularly disadvantaged and that individuals in this client group do not always get assessed for AAC.

Using expert input, it was determined that 9.2 people per 100,000 have profound and multiple learning disabilities with speech, language or communication needs and could benefit from AAC.

Motor neurone disease (MND)/Amyotrophic lateral sclerosis (ALS)/Pseudo bulbar palsy (PBP)

Prevalence figures for MND suggest 8 per 100,000 population (Neurological Alliance 2003; Enderby and Philipp 1986; Whiston et al. 2009; Hula and Zivkovic 2009), with the majority eventually developing dysarthria and losing the ability to communicate (Ball et al. 2007).

Using expert input, it was determined that 5.5 people per 100,000 have motor neurone disease with speech, language or communication needs and could benefit from AAC.

Prader-Willi

Prevalence figures for Prader-Willi are estimated at 10 in 100,000 (Whittington et al. 2001), with the majority having speech, language or communication needs (Lewis et al. 2002).

Using expert input, it was determined that 4.6 people per 100,000 have Prader-Willi with speech, language or communication needs and could benefit from AAC.

Huntington's disease

The estimate for the number of people with Huntington's disease is approximately 7 per 100,000 population (Enderby and Philipp 1986; Enderby 2009a; Driver-Dunckley and Caviness 2007; Walker 2007). 4.2 of those will have their speech and language affected (Enderby and Philipp 1986) and most individuals will lose the ability to communicate during the course of the disorder.

Using expert input, it was determined that 2.1 people per 100,000 have Huntington's disease with speech, language or communication needs and could benefit from AAC.

Williams syndrome

The number of people with Williams syndrome is approximately 13 in 100,000 (Stromme et al. 2002).

Using expert input, it was determined that 2 people per 100,000 have Williams syndrome with speech, language or communication needs and could benefit from AAC.

Multiple sclerosis (MS)

The prevalence of people with Multiple Sclerosis has been identified as 150 per 100,000 population (Mackenzie et al. 2014; Neurological Alliance 2003; Whiston et al. 2009).

The expert group suggested that the proportion of people who could benefit from AAC will have increased with the development of AAC and awareness of potential use by practitioners and the client group.

Using expert input, it was determined that 0.4 people per 100,000 have multiple sclerosis with speech, language or communication needs and could benefit from AAC.

Muscular dystrophy

The estimate of prevalence of muscular dystrophy ranges between 1 in every 3500-5000 males (Enderby and Philipp 1986; Pohlschmidt and Meadowcroft 2010), equivalent to 12.5 people per 100,000 population with 3.125 of those people with the condition having speech, language and communication problems (Enderby and Philipp 1986).

Experts felt that there is a small proportion of people with muscular dystrophy who could benefit from AAC, that their AAC requirements will rely on the severity of the condition and that they may change with the progression of the condition.

Using expert input, it was determined that 0.3 people per 100,000 have muscular dystrophy with speech, language or communication needs and could benefit from AAC.

Locked-in syndrome

The figures for Locked-in syndrome are not well established and the estimate here is based on adapting numbers from the Association du Locked-in Syndrome. Between 1997-2004 there were 367 people registered in France with locked-in syndrome although these figures were generally considered to be an underestimate of the total number (Laureys et al. 2005). These figures suggest a prevalence of 2 per 100,000 in the UK. The nature of the condition means that all of the cohort will have communication needs.

Using expert input, it was determined that 0.3 people per 100,000 have locked-in syndrome with speech, language or communication needs and could benefit from AAC.

Myasthenia gravis

There are an estimated 8 people per 100,000 in the UK with myasthenia gravis (Enderby 2009b; Enderby and Philipp 1986). Many will experience problems with dysphonia and/or dysarthria which may vary during the day, with 2 of those people having their speech and language affected (Enderby and Philipp 1986).

Using expert input, it was determined that 0.2 people per 100,000 have myasthenia gravis with speech, language or communication needs and could benefit from AAC.

Rett syndrome

Approximately 0.4 people per 100,000 have Rett syndrome, almost exclusively affecting females (Neurological Alliance 2003; Fombonne et al. 2001). All of the people affected by this condition will have severe communication impairments and, in addition to severe dysarthria, there may be difficulties with initiation of communication by the individuals.

Using expert input, it was determined that 0.2 people per 100,000 have Rett syndrome with speech, language or communication needs and could benefit from AAC.

Angelman's syndrome

The prevalence figures for this rare syndrome are estimated from Danish figures (Petersen et al. 1995) at 10 per 100,000 population.

Using expert input, it was determined that 0.2 people per 100,000 have Angelman's syndrome with speech, language or communication needs and could benefit from AAC.

Total people who could benefit from AAC

By combining the data above, the total expectation is that 536 people per 100,000 of the population (approximately 0.5%) could benefit from AAC.

Figure 2 & 3 display these results. Figure 2 shows the number of people who could benefit from AAC per condition per 100,000 of the population and
Figure 3 shows the aetiological profile of the total cohort of people who could benefit from AAC.

INSERT FIGURE 2 & FIGURE 3 HERE

Perspectives of specialist service providers on the need for AAC

The results of the data collection from the specialist service providers showed the overall ranking by the participants of the conditions of those who could benefit from AAC. From their perspectives, the most common conditions of people who could benefit from AAC were:

1. cerebral palsy,
2. motor neurone disease,
3. stroke/CVA,
4. learning difficulties,
5. autistic spectrum,
6. profound and multiple learning difficulties,
7. multiple sclerosis,
8. Parkinson's disease,
9. Alzheimer's/dementia.

This exercise showed that there was some difference between the perception of AAC need and the estimated need determined from the epidemiological study. The main disparities are the results for Alzheimer's/dementia and Parkinson's disease with the highest expected

number of people who could use AAC in the epidemiological study but neither features highly in the list of conditions as ranked in the exercise on the views of the specialists. Alzheimer's/dementia features ninth and Parkinson's appears eighth. The other obvious disparity in this data is the ranking of cerebral palsy and motor neurone disease – these were placed first and second compared to sixth and eighth from the epidemiological data.

Discussion

The new estimate provided in this paper of 0.5% of the UK population who could benefit from AAC or 536 per 100,000 population compares well with the data gathered by the Health Survey for England and the previous UK reports. This methodology could be used to provide robust estimates for prevalence of need for AAC in the UK and internationally which currently do not exist.

Looking at the epidemiological analysis, the 2 conditions that represent 45.2% of that cohort consist of Alzheimer's/dementia and Parkinson's disease, conditions associated with an ageing demographic of the population. The next sizeable cohorts of people who could benefit from AAC were those with Parkinson's disease, autistic spectrum conditions, learning disabilities, stroke/CVA, cerebral palsy, head/brain injury, profound and multiple learning difficulties and motor neurone disease. 97.8% of the total number of people who could benefit from AAC have nine conditions.

The results of the specialist perspective data if taken as a potential reflection of current use of AAC (i.e. people who the AAC specialists see as their client base) could suggest that there may be a large unmet need for AAC within the cohort of people with Parkinson's disease

and Alzheimer's disease/dementia. However, the authors suggest that this variation is more likely to be due to the cohort completing the exercise being biased towards services providing powered aided communication and/or a paediatric population. The data thus suggests that the epidemiology and/or provision of services to this population may be significantly different to those who need AAC more generally.

The epidemiological approach taken to calculate these numbers provides an evidence-based method to predict need for AAC that has otherwise been estimated. It determines need rather than predicts use, which is needed as a prerequisite to establishing figures for unmet need and therefore address any inequity of provision and ensure all those who could benefit from AAC have an opportunity to do so. Determining need can help to estimate funding requirements for a full service covering all potential clients who could benefit from AAC nationally. Current figures for use of AAC do not fully represent the national picture as data collection relies on what is currently inconsistent record-keeping, for example the Clinical Practice Research Datalink. Having an accurate UK estimate can also help to inform estimates internationally and encourage other countries to adopt the methodology and record-keeping that this approach requires.

The epidemiological approach allows breakdown of the data into condition cohorts. This means that the data can be used to target particular cohorts where the need for AAC is not being met by comparing predicted need for AAC and current use of AAC. However, the whole method relies on accurate and up to date literature and specialist AAC experts. To establish unmet need from the figures and therefore determine which client groups are not accessing services, accurate and consistent data on use of AAC must be collected including

the condition of the individual. This study suggests that a reasonably accurate picture could be obtained from using a subset of nine conditions that people have who could benefit from AAC due to the high percentage of coverage that offers.

Limitations

The data could be considered an under-estimate of need as it relies on having identified the full set of conditions that may result in the potential need for AAC. The list of conditions was based in part on data relating to people who used powered AAC rather than people who used any AAC. However it is suggested that the majority of the cohorts have been covered in this analysis (as validated against the data collected from services reported in Judge and Johnson (2014)) and that any additional conditions are likely to add only marginally to the total estimate.

Other possible limitations with the data may arise from 'double counting' within the conditions where cohorts of people with secondary conditions are included in both of the epidemiology statistics. However, the data reported above is for primary diagnosis so this effect should be minimal.

The estimates of the percentages of the cohorts that may benefit from AAC are based on expert professional opinion. This may be subject to a level of error. For the high incidence cohorts, such as Alzheimer's or autistic spectrum disorder, small variations in this estimate can have relatively large effects on the total estimate.

Many of the estimates for the proportion of the cohort with a condition that may have a speech, language or communication need are based solely on Enderby and Philipp (1986)

because of a lack of other sources. Some of the prevalence data has been based on studies which were conducted between 10-20 years previously, e.g. Angelman syndrome (1995), Rett syndrome (1996) or Williams syndrome (2002), which are likely to have changed since then due to the reasons listed in the Introduction section of this paper. This method for determining prevalence of need relies on accurate and up to date literature and figures and where this does not exist it will affect the accuracy of the final calculations.

Conclusions and Implications

The current best estimate of need for AAC in the UK population is 0.5% of the population or 536 per 100,000 population. This estimate was constructed using an epidemiological approach to identifying the cohort of the population who could benefit from AAC. This is the same as the estimate previously published by the Communication Champion (Gross 2010) and is consistent with data from the Health Survey for England.

Accurate figures on the prevalence of need are required for service planning and commissioning. Determining the prevalence of need is also a prerequisite to identifying unmet need in comparison with use figures. Currently these figures, or an established process of determining them, do not exist. If accurate figures on the potential need for and use of AAC are to be achieved and examined in relation to each other, data needs to be consistently and accurately recorded at a community level. We would suggest that GPs and other primary services should collect and report this data, including data on primary condition of the individual. Questions surrounding AAC could also be added to the Health Survey for England or Clinical Practice Research Datalink as it is disappointing that these

important databases do not collect credible information on communication disabilities - rendering them unhelpful for service planning.

The estimate reported here may be an under-estimate as the Health Survey for England data also suggested a level of 'moderate communication disability' of up to 0.9% of the population.

The changing prevalence of disability along with the changing nature of technology and its accessibility are likely to result in the need to review figures of need on a regular basis. The existing data suggests an urgent need for more accurate and up to date information to be captured about the need for AAC in the UK to provide better services and allow all the people that could benefit from these strategies, equipment and support access to resources to benefit their communication and therefore social inclusion and quality of life.

Bibliography

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D. and Charman, T., 2006. Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet*, 368(9531), 210–215.

Ball, L.J., Anderson, E., Bilyeu, D.V., Pattee, G.L., Beukelman, D.R., and Robertson, J., 2007. Duration of AAC Technology Use by Persons with ALS. *Journal of Medical Speech-Language Pathology*, 15(4), 371-381.

Baron-Cohen, S., Scott, F., Allison, C., Williams, J., Bolton, P., Matthews, F. and Brayne, C., 2009. Prevalence of autism-spectrum conditions: UK school-based population study. *The British Journal of Psychiatry : the journal of mental science*, 194(6), 500–509.

Baxter, S., Enderby, P., Evans, P. and Judge, S., 2012a. Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: a systematic review and qualitative synthesis. *International Journal of Language and Communication Disorders*, 47(2), 115–129.

Baxter, S., Enderby, P., Evans, P. and Judge, S., 2012b. Interventions Using High-Technology Communication Devices: A State of the Art Review. *Folia phoniatrica et logopaedica*, 64(3), 137–144.

Beukelman, D. and Ansel, B., 1995 Research priorities in augmentative and alternative communication, *Augmentative and Alternative Communication*, 11, 131-134.

Beukelman, D.R. and Mirenda, P., 1998. *Augmentative and Alternative Communication: management of severe communication disorders in children and adults,* 2nd ed., (Baltimore, MD: P. H. Brookes).

Delamothe, T. and Godlee, F., 2011. Dr Lansley's monster. *British Medical Journal*, 342, d408.

Department of Health, 2005. *Department of Health - Reducing Brain Damage: Faster access to better stroke care.* (London: National Audit Office).

Driver-Dunckley, E. and Caviness, J.N., 2007. Huntington's Disease. *Neurology and Clinical Neuroscience*, 67, 879-885.

Emerson, E., 2009. *Estimating Future Numbers of Adults with Profound Multiple Learning Disabilities in England: CeDR Research Report 2009(1)*. http://eprints.lancs.ac.uk/26131/1/CeDR_2009-1_Adults_with_PMLD_in_England.pdf [accessed June 4 2013].

Emerson, E. and Hatton, C., 2004. *Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England*, Lancaster University. http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7008_Estimating_Current_Need_Emerson_and_Hatton_2004.pdf [accessed June 4 2013].

Emerson, E. and Hatton, C., 2008. *Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England*, Lancaster University. http://eprints.lancs.ac.uk/21049/1/CeDR_2008-6_Estimating_Future_Needs_for_Adult_Social_Care_Services_for_People_with_Learning_Disabilities_in_England.pdf [accessed June 4 2013].

Emerson, E. and McGrother, C., 2011. *The Use of Pooled Data from Learning Disabilities Registers: a Scoping Review*, Improving Health and Lives Learning Observatory. http://www.nepho.org.uk/uploads/doc/vid_9057_IHAL2011-01Registers.pdf [accessed June 4 2013].

Enderby, P., 2009a. Huntington's disease. *In:* M.R. McNeil, ed. *Clinical Management of Sensorimotor Speech Disorders*. (New York: Thieme), pp. 291-292.

Enderby, P., 2009b. Myasthenia Gravis. *In:* M.R. McNeil, ed. *Clinical Management of Sensorimotor Speech Disorders*. (New York: Thieme), pp. 351-352.

Enderby, P. and Philipp, R., 1986. Speech and language handicap: towards knowing the size of the problem. *International Journal of Language and Communication Disorders*, 21(2), 151-165.

Fombonne, E., Simmons, H., Ford, T., Meltzer, H. and Goodman, R., 2001. Prevalence of Pervasive Developmental Disorders in the British Nationwide Survey of Child Mental Health. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40(7), 820-827.

Gross, J., 2010. *Augmentative and alternative communication: a report on provision for children and young people in England, September 2010*. http://www.thecommunicationtrust.org.uk/commissioners/reports.aspx [accessed August 23 2013].

Hula, W.D. and Zivkovic, S.A., 2009. Amyotrophic Lateral Sclerosis. *In:* M.R. McNeil, ed. *Clinical Management of Sensorimotor Speech Disorders*. (New York: Thieme), pp. 291-292.

Intercollegiate Stroke Working Party, 2012. *National Sentinel Stroke Clinical Audit 2010 Round 7: Public Report for England, Wales and Northern Ireland.* www.rcplondon.ac.uk/sites/default/files/national-sentinel-stroke-audit-2010-public-report-and-appendices_0.pdf [accessed December 9 2014].

Judge, S. and Johnson, V., 2014. Provision of AAC and Communication Aids by Local Services In England – A Survey. *Augmentative and Alternative Communication*, SUBMITTED.

Laureys, S., Pellas, F., Van Eeckhout, P. Ghorbel, S., Schnakers, C., Perrin, F., Berre, J., Faymonville, M., Pantke, K., Damas, F., Lamy, M., Moonen, G. and Goldman, S., 2005. The locked-in syndrome: what is it like to be conscious but paralyzed and voiceless? *Progress in Brain Research*, 150, 495–511.

Lewis, B.A., Freebairn, L., Heeger, S. and Cassidy, S.B., 2002. Speech and Language Skills of Individuals with Prader-Willi Syndrome. *American Journal of Speech-Language Pathology,* 11, 285-294.

Mackenzie, I.S., Morant, S.V., Bloomfield, G.A., MacDonald, T.M. and O'Riordan, J., 2014. Incidence and prevalence of multiple sclerosis in the UK 1990-2010: a descriptive study in the General Practice Research Database. *Journal of Neurology, Neurosurgery and Psychiatry*, 85(1), 76-84.

Matthews, F.E., Arthur, A., Barnes, L., Bond, J., Jagger, C., Robinson, L. and Brayne, C., 2013. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *Lancet*, 382(9902), 1405-1412.

Mencap, 2010. *Lambeth PMLD project: Understanding the lives and needs of people with profound and multiple learning disabilities in Lambeth*, (London: Mencap).

Neurological Alliance, 2003. *Neuro numbers: a brief review of the numbers of people in the UK with a neurological condition*. (London: Neurological Alliance).

Parrott, R., Tilley, N. and Wolstenholme, J., 2008. Changes in demography and demand for services from people with complex needs and profound and multiple learning disabilities. *Tizard Learning Disability Review*, 13(3), 26–34.

Petersen, M.B., Brøndum-Nielsen, K., Hansen, L.K. and Wulff, K., 1995. Clinical, cytogenetic, and molecular diagnosis of Angelman syndrome: estimated prevalence rate in a Danish county. *American Journal of Medical Genetics*, 60(3), 261–262.

Pohlschmidt, M. and Meadowcroft, R., 2010. *Muscle disease: the impact*. (London: Muscular Dystrophy Campaign).

Scope, 2008. *No Voice, No Choice: Professional experiences of the provision and support of alternative and augmentative communication (AAC)*. (London: Scope).

Strømme, P., Bjørnstad, P.G. and Ramstad, K., 2002. Prevalence estimate of Williams syndrome. *Journal of Child Neurology*, 17(4), 269-271.

Townsend, N., Wickramasinghe, K., Bhatnagar, P., Smolina, K., Nichols, M., Leal, J., Luengo-Fernandez, R. and Rayner, M., 2012. *Coronary heart disease statistics: a compendium of health statistics*, (London: British Heart Foundation).

Walker, F.O., 2007. Huntington's disease. *Lancet,* 369, 218-228.

Whiston, S., Coyle, C. and Chappel, D., 2009. Health Needs Assessment for Long Term Neurological Conditions in North East England. (Durham: North East Public Health Observatory).

Whittington, J.E., Holland, A.J., Webb, T., Butler, J., Clarke, D. and Boer, H., 2001. Population prevalence and estimated birth incidence and mortality rate for people with Prader-Willi syndrome in one UK Health Region, *Journal of Medical Genetics,* 38, 792-798.

World Health Organization, 2001. *International Classification of Functioning, Disability and Health.* (Geneva: WHO).

Notes:

1. Turning Point™ is a registered trademark of Turning Technologies.

TABLES

Table 1: Full list of conditions searched for

Acquired	Acquired neurological	Acquired neurological non-progressive	Stroke/CVA Head/brain injury
		Other acquired neurological non-progressive	Locked in syndrome
		Acquired neurological progressive	Multiple sclerosis Motor Neurone Disease (MND/ALS/PSP) Parkinson's disease Dementia/Alzheimer's
		Other acquired neurological progressive	Friedreich's ataxia Multiple systems atrophy
	Other acquired (non-neurological)		Head and neck cancer Guillain-Barre Syndrome
Developmental	Developmental non-progressive	Physical Disability	Cleft palate Craniofacial abnormalities
		Sensory impairment	Vision impairment Hearing impairment Multisensory impairment
		Learning disabilities	PMLD Autistic Spectrum Disorder (ASD) Developmental delay Other learning disabilities Down syndrome
		Genetic disorders	Angelman syndrome Huntington's disease Prader-Willi Rett syndrome Williams syndrome
	Other developmental non-progressive disorders		Cerebral palsy Specific language impairment (including dyspraxia)
	Developmental progressive	Developmental progressive neuromuscular	Muscular dystrophy Myasthenia Gravis Other developmental progressive neuromuscular
		Developmental progressive genetic disorders	Leigh's disease
Other recorded conditions	Absence epilepsy Adducted thumb syndrome (cleft palate) Arthrogryposis (developmental non-progressive) Burns Cerebellar ataxia (head/brain injury) Chromasomal mosaicism (developmental non-progressive genetic) Congestive Cardiac Failure and Renal Failure Diplegia Dissection of vertebral artery Dystonia		

	Extensive Pontine infarction (stroke) Foix Chavany Marie Syndrome (brain injury) Functional Muscle Tension Dysphonia Glutaric aciduria Hemiplegia Langerhans Histiocytosis X Language disorder Laryngectomy Laryngotracheitis Meningo-encephalitis Merrf syndrome Mitochondrial Cytopathy Mobius syndrome Multi Systems Atrophy Schizencephaly Supra Glottic Tension Vocal cord palsy Voice disorder Voice

Table 2: prevalence of conditions associated with use of AAC

Condition	Per 100,000 population **(a)**	Speech, language or communication needs (%) **(b)**	Speech, language or communication needs (per 100,000 population) **(c)**	Who could benefit from AAC (%) **(d)**	Who could benefit from AAC (per 100,000 population) **(e)**
Alzheimer's/ dementia	1230	100	1230	10	123
Parkinson's disease	200	80	160	75	120
Autistic spectrum disorder	1000	100	1000	10	100
Learning disabilities	469.9	100	469.9	15	70.5
Stroke	1024	30	307.2	20	61.4
Cerebral palsy	200	60	120	20	24
Head/brain injury	300	20	60	20	12
Profound and multiple learning disabilities (PMLD)	36.7	100	36.7	25	9.2
Motor neurone disease	8	95	7.6	72	5.5
Prader-Willi	10	91	9.1	50	4.6
Huntington's disease	7	60	4.2	50	2.1

Williams syndrome	13	60	7.8	25	2
Multiple sclerosis	150	23	34.5	1	0.4
Muscular dystrophy	12.5	25	3.125	10	0.3
Locked-in Syndrome	2	100	2	16	0.3
Myasthenia gravis	8	25	2	8	0.2
Rett syndrome	0.4	100	0.4	50	0.2
Angelman syndrome	10	100	10	2	0.2
Total	4681.5		3464.125		535.9
% of UK population				0.5%	

Figures

Figure 1*:* the staged process to determine the figures for the prevalence of people who could benefit from AAC. Questions for each stage are shown in bold type, the method is shown in italic type and the output is boxed.

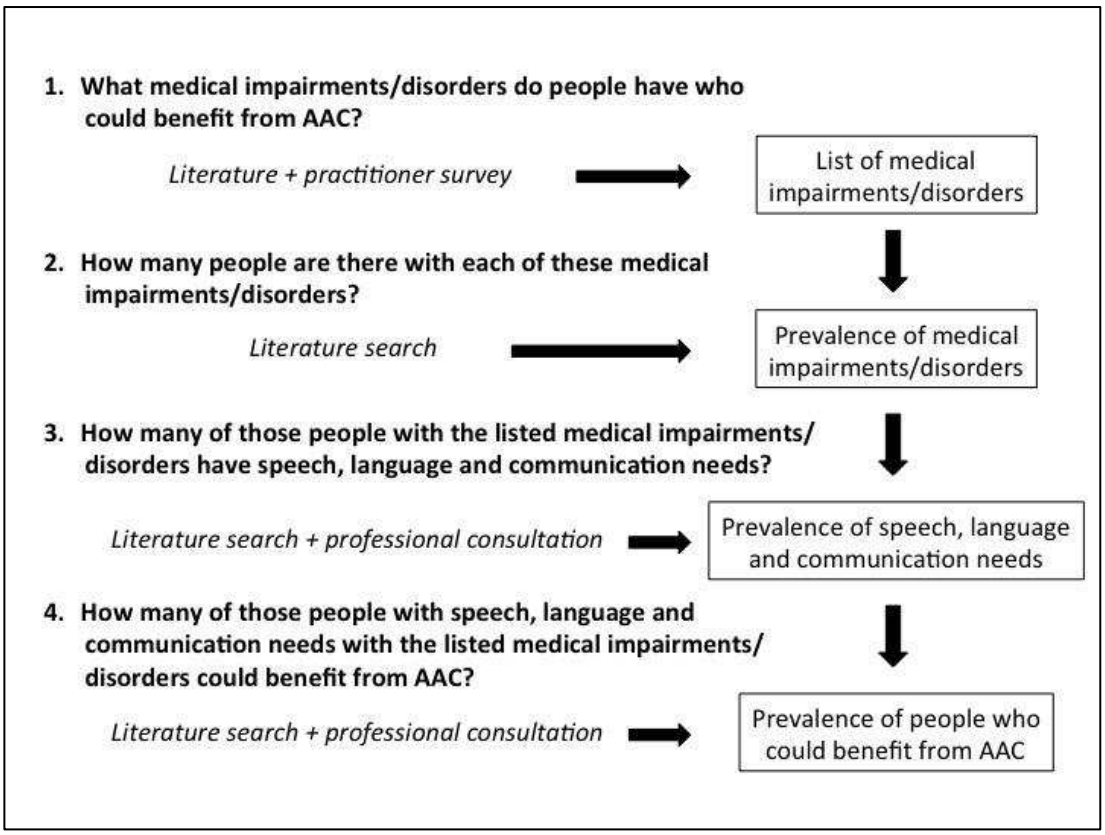


Figure 2: The number of people identified through epidemiological data collection who could benefit from AAC per condition per 100,000 population.

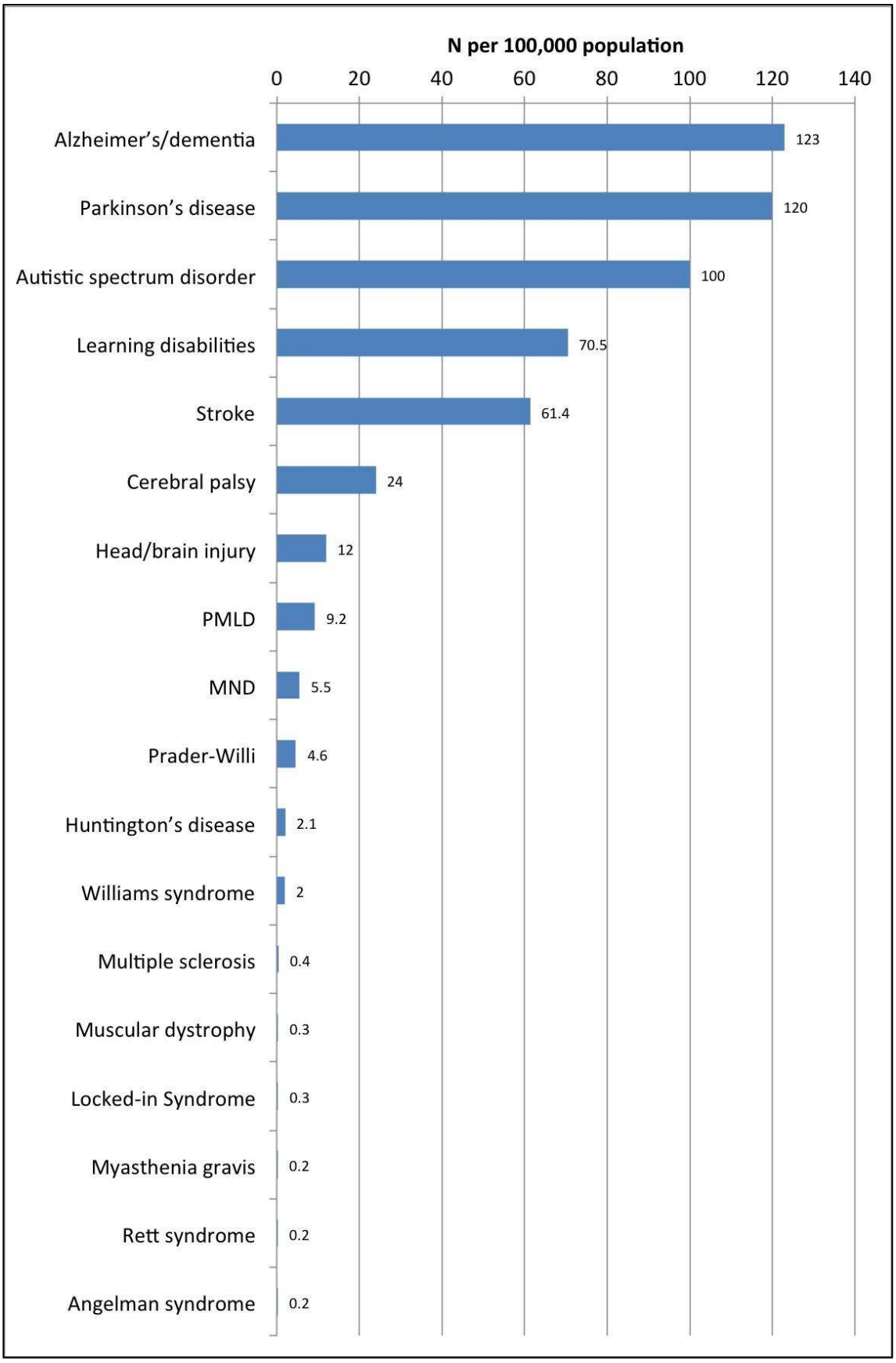
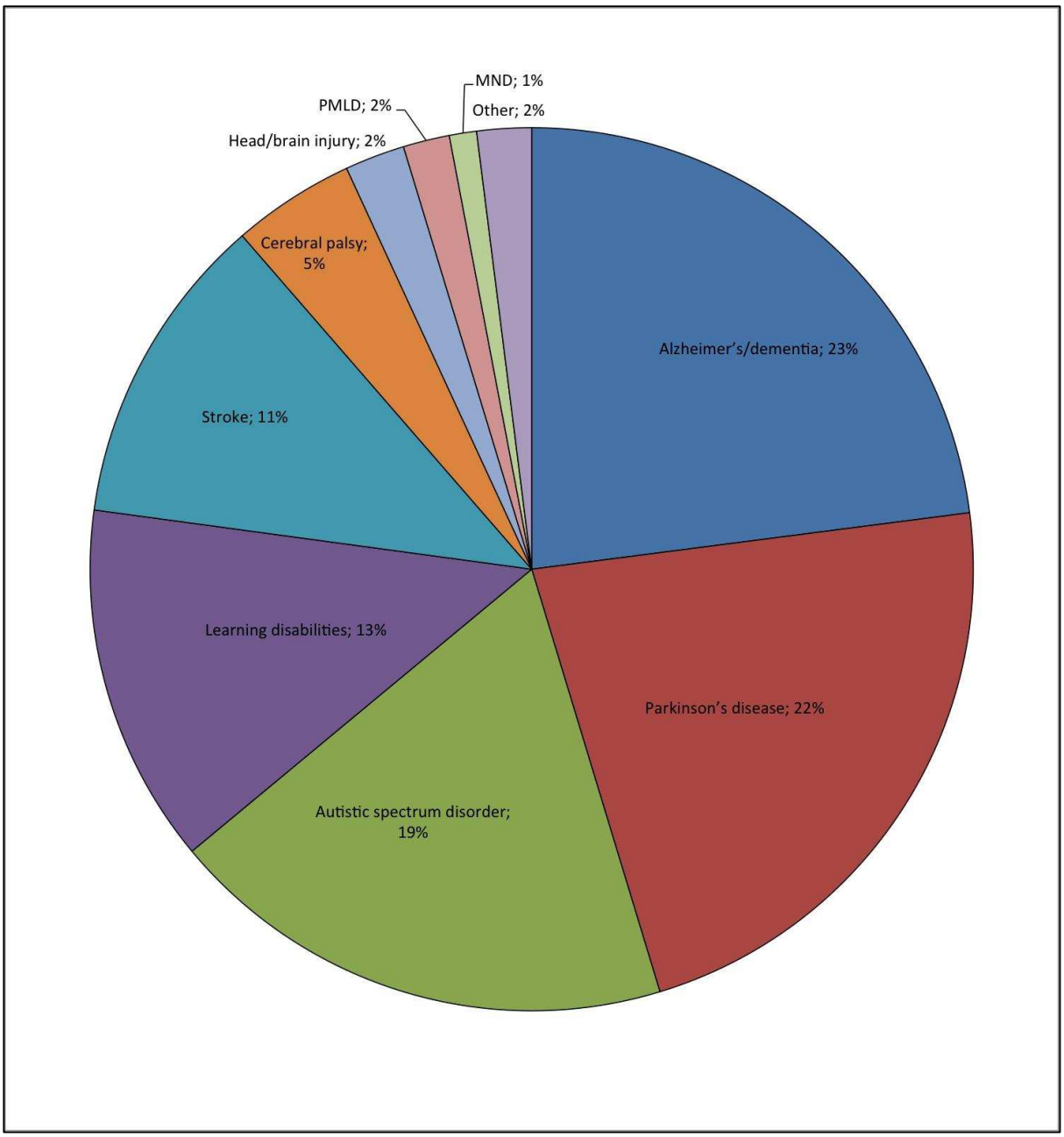

N per 100,000 population
0
20
40
60
80
100
120
140
Alzheimer's/dementia
123
Parkinson's disease
120
Autistic spectrum disorder
100
Learning disabilities
70.5
Stroke
61.4
Cerebral palsy
24
Head/brain injury
12
PMLD
9.2
MND
5.5
Prader-Willi
4.6
Huntington's disease
2.1
Williams syndrome
2
Multiple sclerosis
0.4
Muscular dystrophy
0.3
Locked-in Syndrome
0.3
Myasthenia gravis
0.2
Rett syndrome
0.2
Angelman syndrome
0.2

Figure 3: the percentage of the total number of people who could benefit from AAC in terms of the individual conditions.



Conditions comprising "other" are: Prader-Willi, Huntington's disease, Williams syndrome, multiple sclerosis, locked-in syndrome, muscular dystrophy, Angelman syndrome, myasthenia gravis, Rett syndrome.