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Provision of Powered Communication aids in the United Kingdom

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### Abstract

AAC service provision in the United Kingdom (UK) has evolved since the first service dedicated to the provision of communication aids opened in 1986. Within the UK, many health and care services are provided via government funding. However, the assessment and provision of AAC and specifically of speech-generating devices (SGDs) is inconsistent and inequitable. The study reported in this paper aimed to collect information on levels of current provision of powered communication aids (the term used in the study to refer to SGDs) by UK service providers in 2013 with the intention of improving future estimates for need of services. A questionnaire survey was designed and data were obtained from 98 AAC services across the UK. Service providers reported the number of individuals known to be using powered communication aids and the mean value reported was 0.0155% of the services' catchment populations. However levels of service provision reported were highly variable. Although the data reported must be treated with caution, it adds to the sparse literature on the topic, informs AAC service design and delivery in the UK, and acts as an indicative baseline measure for future service development.

*Keywords:* AAC service delivery; United Kingdom, Incidence; Prevalence; Caseload; Powered communication aids; Speech-generating devices.

### Provision of Powered Communication Aids in the United Kingdom

The first dedicated AAC service in the United Kingdom (UK) was opened in 1986, and since that time services have been commissioned and developed in many different ways. This ad-hoc approach to service development has led to significant variations in the model of AAC provision in the UK. The aim of the current study was to address the lack of information about the population in receipt of AAC services that had grown out of this lack of strategic commissioning.

In 2007, the UK government commissioned an investigation into the system for providing support to children and young people with speech, language, and communication needs in England. The Bercow Report (2008) concluded that “Children and young people who require alternative or augmentative communication aids (AAC) face a particular struggle to have their needs met under the current commissioning arrangements” (p. 40). The authors of the report also concluded that there was no consistent or equitable system (locally, regionally, or nationally) for ensuring that those who needed communication aids received them and that responsibility for this should rest with the NHS. These conclusions were corroborated by Gross (2010), who also highlighted the complex picture within the UK relating to provision of speech-generating devices (SGDs), referred to by Gross as high-technology AAC. AAC service provision can be contrasted to other services (e.g., environmental control) for similar populations, in that these services originated in the UK National Health Service (NHS) in the 1960s and have since been commissioned solely by the NHS.

AAC includes approaches that require little or no technology as well as communication aids with an output of synthesized or recorded speech. These communication aids are known by a range of terms, including high-tech communication aids, voice-output communication aids and

SGDs. There is little epidemiological evidence available regarding the prevalence of need for AAC or SGDs, making it difficult to determine the extent of inequity in provision and the degree of unmet need in the UK. Gross (2010) and Creer, Enderby, Judge, and John (2016) suggested a level of 0.5% of the population may need AAC, and Gross proposed that “0.05% of children and young people in the UK need high technology AAC” (p.1).

Although other researchers have examined rates of provision and use of AAC in the UK, there is a paucity of these studies or data sets and all have limited applicability. Clarke et al. (2007) provided an analysis of data from a national education initiative that funded and provided communication aids, and reported referrals to the project over the 2-year period as 0.22% of the population of pupils with special educational needs. A 1991 survey by Murphy, Markova, Moodie, Scott, and Boa (1995) revealed that 225 individuals with cerebral palsy living in Scotland used some form of AAC. More recently, Cockerill et al. (2014) reported that a total-population-registry study of children with bilateral cerebral palsy reflected that 32% of the children were provided with one or more types of AAC, and 15% were provided with an SGD, while 30% of the children were reported as mostly or wholly unintelligible even to familiar adults.

Matching epidemiological information with data reflecting actual provision via services is important for informing the commissioning and delivery of services (Chappel, Miller, Parkin, and Thomson, 1999). Such data allows commissioners and service providers to identify geographical and etiological areas of variation in provision and to effectively target resources. Therefore, the aim of this study was to collect and match information on the levels of current provision of SGDs by UK service providers with geographical information, so as to improve future estimates of need and demand for services.

## Method

Ethical approval for this study was provided by the human research ethics review committee of the University of Sheffield, School of Health and Related Research.

### Development of the Questionnaire

A questionnaire survey was developed to address the aims of the research and provide information about the levels of provision of SGDs in the UK and also to provide descriptive information about the characteristics and resources of services. The questionnaire (Supplemental materials) was initially informed by a literature review relating to SGDs conducted by Baxter, Enderby, Evans, and Judge (2012). From prior focus group work by Enderby, Judge, Creer, and John (2013) it was clear that practitioners did not consistently interpret terms describing AAC provision and interventions currently in use within the UK, and that this could lead to unreliable data collection. Thus, all terms used in the questionnaire were defined through a Delphi approach with a separate group of 11 AAC expert stakeholders (Enderby et al., 2013). A glossary was attached to the questionnaire, and the term *powered communication aids* was used and defined as devices that have a power system and usually display written text or speech output (e.g., voice-output communication aids).

The first draft of the questionnaire was reviewed by six UK AAC researchers and clinicians considered by the authors to be AAC experts. On the basis of the experts' review, revisions were made to the questionnaire prior to piloting the questionnaire. In addition to asking respondents to provide total figures for levels of provision, respondents were also asked to provide any anonymized extracts from service databases that would allow independent compilation of the figures from source. The questionnaire was piloted by 19 service providers who responded to a request via Communication Matters – the UK chapter of the International

Society of Augmentative and Alternative Communication. The aim of the pilot was to review the understandability and practicality of the survey. On this basis, the questionnaire was deemed to be understandable, and only one amendment was made to increase its practicality: respondents were asked to return the questionnaire even if only partially completed as it was clear that not all of the service providers would be able to complete all aspects of the survey (e.g., if they did not collect or were unable to access the appropriate data). The final questionnaire was produced in a number of formats: paper, electronic documents (Word and PDF forms), and an online form (using LimeSurvey<sup>TM1</sup> software) to increase the likelihood of it being returned.

### **Data Collection**

Eligibility for inclusion was restricted to those services, teams, or departments that provide specialist or dedicated AAC services related to powered communication aids in the UK. Services were identified through a number of channels: (a) those known to Communication Matters and the Royal College of Speech and Language Therapists (RCSLT); (b) self identification, following marketing of the questionnaire through Communication Matters and RCSLT publications; and (c) “snowball sampling” – where each respondent was asked to identify other potential respondents (Atkinson & Flint, 2001). In 2012, representatives from services identified as meeting the inclusion criteria were approached and followed up with over a 12-month period, ending February 2013, during which data were collected and checked.

### **Analysis**

Respondents were asked to describe the geographical area covered by their service and also the age groups of those to whom they provided services. This information was processed in order to establish accurate figures for the catchment population of each service. To that end, each service coverage description was coded according to a UK government coding system

representing geographical boundaries of UK local authority districts (LAD) codes (Office for National Statistics, 2017). Population data were then collated, by reference to UK census data in 2013, to determine the population figure for each age group and LAD code. These figures were then summed to obtain a total catchment population for each service. SPSS<sup>TM2</sup> scripts were used for this data processing and also to produce the descriptive statistics reported in the sections that follow. The third author completed the coding and matched this data to UK census data, and this coding was verified by the first author.

## Results

### Response Rate and Data Quality

Questionnaires (see Appendix) were distributed to 155 services and 98 of these were returned, reflecting a response rate of 63%. In four of the questionnaires, respondents indicated their service did not offer powered communication aid services and these were not included in the analysis. This left a total of 94 questionnaires for inclusion in the analysis.

Asked how they obtained information about client caseloads ( $n = 51$ ), 61% of respondents selected “Estimates from my experience”, 28% selected “Extracted from a database”, and 12% selected “Estimates based on having previously extracted this data”. Extracts from nine service databases were received and of these, seven could be used to validate the caseload data and increase confidence in the results. Responses were received from across the UK, and Figure 1 shows the service catchment areas represented in the data.

Insert Figure 1 About Here

### Type of Organization

Of the 94 questionnaires analysed, health sector organizations made up the majority of respondents (64%), with 19% from the education sector, 7% from charitable organizations, 3%



from private practice, and 6% being returned from “other” services. The majority of respondents reported that their service covered an area equivalent to a local authority (78%), and the remainder reporting covering wider regional areas.

### **Caseload**

Respondents were asked to describe the age range of their service catchment populations, and the data were categorized into age groups ( $n = 94$ ): 31% of services worked with children only (<16 years); 10% with children and young people (<19 years or end of further education); 29% with adults, and 30% with all age groups. Combining responses, it was apparent that 71% of the services reported working with children or young people and 59% reported working with adults.

### **Referrals for Powered Communication Aids**

Many respondents were not able to provide accurate data on the number of referrals per year and noted that they did not collect or store referral information by type of referral or outcome. Of the 62 responses to this question, the mean number of reported referrals for powered communication aids per team per year was 31, or 0.0058% of the services catchment populations (Table 1). The range and standard deviation of these statistics was high.

Insert Table 1 About Here

### **Caseload of Powered Communication Aid Users**

The questionnaire sought information on (a) the number of individuals known to the service who used powered communication aids, and (b) the active caseload of the service. The majority of respondents (74.3% of  $n=76$ ) reported the same values for their caseload as the total number known to the service. Table 2 shows the full descriptive statistics for these variables. Calculating the total as a percentage of service catchment populations resulted in a mean of

0.0155% and a maximum of 0.08%. Figure 2 shows the distribution of the statistic. The range and standard deviation of all these statistics are very high. Respondents reported the numbers of individuals known to the service by aetiology against a list of 15 conditions and an “other” category. As can be seen in Table 3, the highest mean number of individuals reported was for other conditions, followed by cerebral palsy, amyotrophic lateral sclerosis or motor neurone disease, other learning difficulties, and stroke.

Insert Tables 2 and 3 and Figure 2 About Here

### **Discussion**

The data reported from this survey provided information about annual referrals, service caseloads, and the total number of individuals known to each service as using powered communication aids. Although the data cannot be used to indicate level of need, it contributes towards a better understanding of possible service need in the future. The findings suggest that the prevalence of need for SGDs is at least 0.0155% of the population. The figure proposed by Gross (2010) for the prevalence of “children and young people needing high technology AAC” (p. 11) of 0.05% is within the range of the data reported in this study. As the study was conducted prior to changes in the commissioning and delivery of AAC services within the UK (NHS England, 2016), the findings could be seen as a benchmark measure of need in 2012/13.

The return rate of the survey would be considered high at 63% and this is likely due to the method of data collection – in following up responses from identified services over an extended period. There was a high standard deviation in the statistics reported by services. The maximum figure reported for the total number of individuals known to be using powered communication aids was 0.08% of one service’s catchment population, with five services reporting over 0.05%. This variation could be caused by a genuine disparity in levels of need or

AAC provision; however, it could also be attributed to a number of other factors, including issues with data collection, data recording, and data quality.

### **Limitations**

The findings of this research reflect that there are significant challenges in investigating AAC service provision in the UK. Follow up with respondents and checking their responses required significant effort over an extended period of time. In addition, there was significant variation in the datasets collected by different services and how details were recorded. Even basic information (e.g., the numbers of individuals being referred and geographic boundary) often could not be reported. Most information provided was on the basis of the respondents' best recollection and 15% of respondents reported information on the basis of written case notes rather than electronic notes or databases. Therefore, it was difficult for services to provide data on referral, caseload, and known usage of powered communication aids. This and the poor return rate of database extracts highlighted challenges for the majority of services in storing and/or being able to access this information.

During the data collection period there was no coherent or consistent model of provision of AAC services in the UK, and little consistency for services related to SGDs. The convenience sampling and distribution method reflected this heterogeneity in service provision. It can be seen from Figure 1 that the geographical coverage of the survey was good. However, eligibility criteria applied by services was not accounted for in this mapping (i.e., it indicates only that there is a service available --possibly for one or more specific client groups -- in the mapped area).

### **Implications for Service Provision**

The collection of these data highlights a challenge for service providers, who are increasingly required to report process, performance, and outcomes-based data for

commissioning purposes. Consistent terms and data collection forms need to be developed and reported against national benchmarks if accurate data on the provision of powered communication aids and other AAC interventions is to be obtained. Collecting this information would aid the design of effective commissioning and planning of services in the future and assist in identifying unmet need and promoting equity of AAC service provision across the UK.

Significant recent changes to the commissioning process across the UK (NHS England, 2016) have resulted in national service specifications for specialized AAC services, as well as national commissioning of regional specialized AAC services to provide a significant proportion of SGDs in the future. These changes offer not only the potential to address the possible inequities in levels of provision identified, but also the potential to collect and report accurate statistics on this cohort of individuals who use AAC.

There is no nationally agreed service specification for provision of local, non-specialized, AAC services, and despite national service specifications there is likely to be significant variation across localities within the UK. Local AAC services provide non-specialized AAC interventions and it is likely that the challenges of data collection and quality identified in the current study will remain so for these services. It is important that both specialized and non-specialized local services and commissioners adopt improved data collection methods and processes for ensuring data quality when collecting information related to AAC service delivery.

There will remain a significant challenge in understanding the whole picture of AAC provision within the UK. NHS commissioners have the potential to define national data standards and collection methods. Thus, future research should focus on further developing tools to improve data collection and quality of reporting. Research is also needed to investigate alternative methods for determining the prevalence and variance of use of SGDs and other AAC.

### **Conclusion**

This was the first national survey of its type in the UK and responses were received from 98 service providers. The data reported can be considered an opportunity and judgement sample of services providing SGDs within the UK. The mean value of the number of individuals that service providers reported were known to be using powered communication aids was 0.0155% of the services' catchment populations. There were a number of significant challenges and possible limitations in the process of acquiring these data, and which limit confidence in the results. Although limited in their scope, these figures add empirical data to the literature relating to the level of use and need for communication aids. The authors intend that the information contained in this paper will support service development and commissioning and contribute to the development of future studies investigating the need for or use of communication aids in the UK.

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End Notes

<sup>1</sup>. LimeSurvey™ is a trademark of Fa. Carsten Schmitz, Germany. <https://www.limesurvey.org/>

<sup>2</sup>. SPSS™ is a registered trademark of International Business Machines Corporation, NY.

<http://www.ibm.com/analytics/us/en/technology/spss/>



Table 1

*Referrals for Individuals Using Powered Communication Aids Reported*

Variable	N	Range	Min	Max	Sum	M	SD
Referrals received	62	176	0	176	1896	30.58	39.158
Referrals as % of catchment population	54	.0320	0.0000	.0320	.3127	.0058	.0074

*Note.* Min = Minimum; Max=Maximum; Sum = Summation

Table 2

*Caseload and Total Number of Known Individuals using Powered Communication Aids Reported*

Variable	N	Range	Min	Max	Sum	M	SD
Size of caseload	70	349	1	350	3151	45.01	62.836
Total known to service	76	3626	1	3627	10258	134.97	504.688
Caseload as % catchment population	62	.08	.00	.08	.83	.0135	.01826
Total known as % catchment population	67	.08	.00004	.08	1.04	.0155	.02023

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*Note.* Min = Minimum; Max=Maximum; Sum = Summation

Table 3

*Descriptive Statistics of the Number of Individuals Reported by Services as Known by Them to be Using Powered Communication Aids, by Aetiology*

Aetiology	N	Minimum	Maximum	M	SD
Other	30	0.0	1350.0	99.100	331.0971
Cerebral palsy	52	0.0	1314.0	56.308	206.6322
Motor neuron disease	29	0.0	316.0	18.276	57.8921
Other learning difficulties	35	0.0	124.0	15.857	25.9413
Stroke	31	0.0	239.0	14.677	43.3400
Multiple sclerosis	20	0.0	189.0	14.200	42.1359
Profound and multiple learning difficulties	29	0.0	50.0	10.724	14.4343
Autistic spectrum disorder	41	0.0	112.0	10.537	23.9156
Developmental delay	25	0.0	126.0	7.160	24.8641
Head injury	39	0.0	62.0	6.051	12.2988
Parkinson's disease	25	0.0	32.0	5.120	8.5845
Muscular dystrophy	22	0.0	23.0	2.091	5.2364
Head and neck cancer	22	0.0	15.0	1.773	3.2357
Cleft palate and craniofacial malformations	19	0.0	13.0	1.105	2.9981
Dementia	16	0.0	3.0	.438	.8921

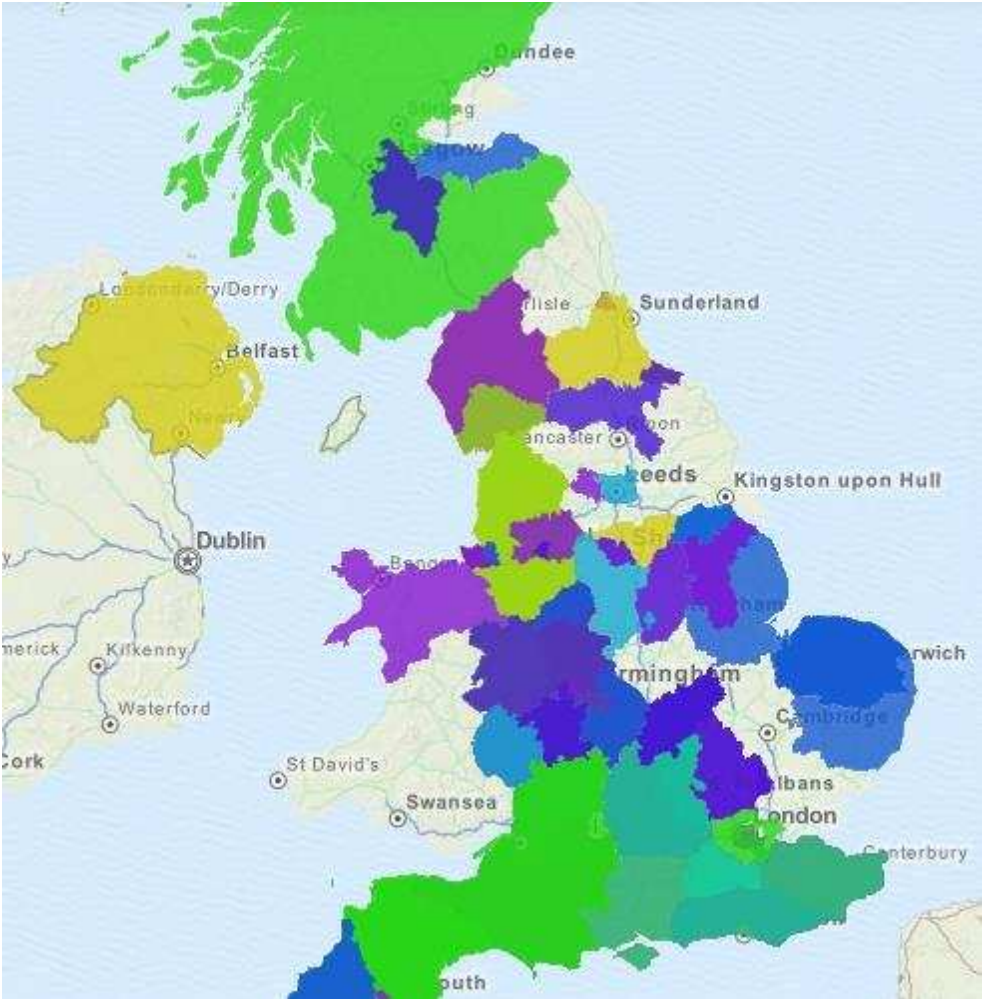


Figure 1. Geographical coverage area reported by respondents

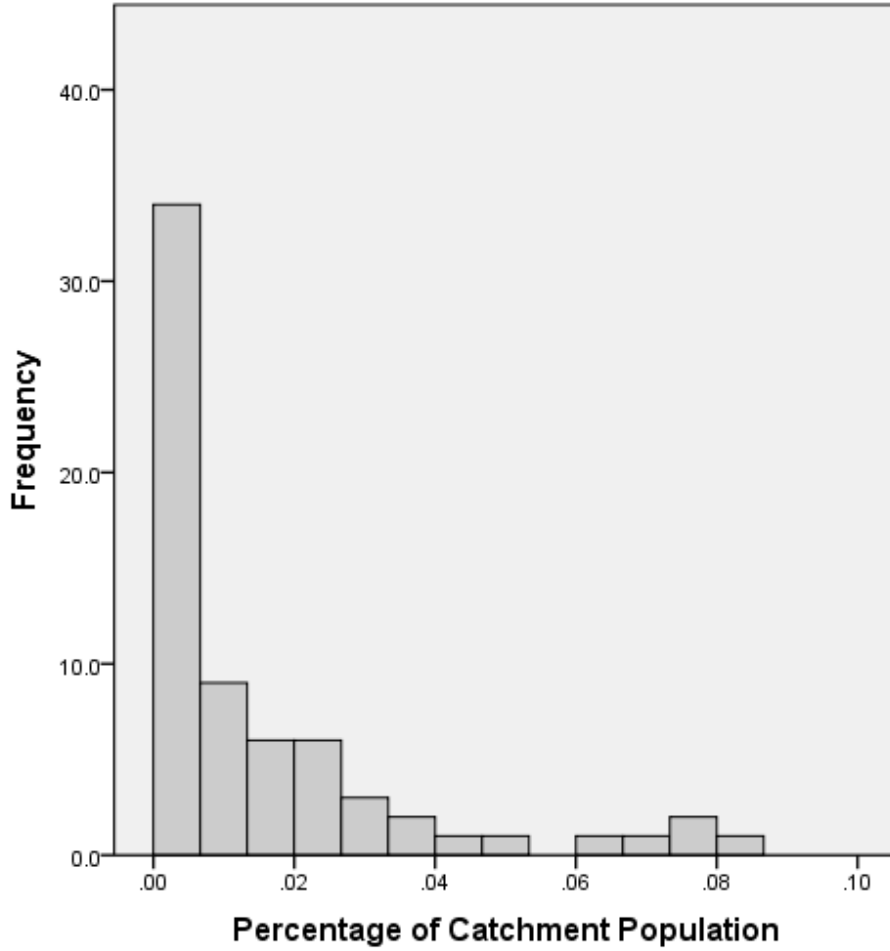


Figure 2. Histogram of number of individuals reported by respondents as known by them to be using powered communication aids, as a percentage of the service’s catchment population.