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Local Service Provision of Augmentative and Alternative Communication and
Communication Aids In England

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Declaration of Interests Statement

The authors disclose they have no financial or other interest in objects or entities
mentioned in this paper.

Abstract

BACKGROUND: Provision of Augmentative and Alternative Communication (AAC) interventions have been acknowledged to be highly variable in England and elsewhere.

OBJECTIVE: The aim of the project described in this paper was to provide data to inform service planning and delivery of services delivering AAC including communication aids.

METHODS: A survey was developed by an expert group and administered by telephone interview to service managers of primary and secondary services providing AAC interventions at a local level in England and data were included from two hundred and twenty respondents.

RESULTS: Services included had mean caseload sizes of 0.09% of the catchment population for AAC provision, with a mean of 0.017% of the catchment population for high tech communication aids. Significantly higher levels of caseload and spend were reported for services working with children and young people as compared to those working with adults. Mean levels of unmet need for AAC equating to approximately one in every eight individuals on services' caseloads were reported.

CONCLUSIONS: Although these data should be treated with caution, they suggest a significant level of variation of provision of AAC by local services.

Keywords: Incidence, prevalence, caseload, service delivery, communication aids,
AAC

Local Service Provision Of Augmentative and Alternative Communication and Communication Aids In England

Augmentative and Alternative Communication (AAC) is a key intervention for children and adults who are unable to communicate through speech. AAC interventions include strategies and therapy involving no equipment, those involving paper and other low tech resources and those involving powered ‘high tech’ communication aids. In their state of the art literature review of ‘high-technology communication devices’ Baxter et al (1) report that “the literature describes custom-made communication aids which provide voice output (VOCAs), also referred to as speech-generating devices (SGDs). In addition, there is software which can be used on standard personal computers or laptops which provide a voice output.” Light and McNaughton (2) also describe the more recent ‘mobile technology revolution’ that has impacted on the AAC field.

A number of authors have identified that AAC services have been inconsistently and inequitably provided in the United Kingdom (UK). A review by John Bercow, a UK Member of Parliament, found no consistent or equitable system locally, regionally or nationally for ensuring that those who needed communication aids received them (3) and concluded that the needs of many children and young people were still not being met and that “*children and young people who require AAC face a particular struggle to have their needs met under the current commissioning arrangements*” (p. 40). A further report completed by Gross following a two year UK government role also highlighted significant variation in the makeup, quality and level of provision (4).

Both local (primary and secondary) services and regional (specialised) services are involved in the provision of AAC and aided communication in the UK and at the time of this project there was no standard model of provision of services providing AAC in the UK. Although in most localities services providing AAC were hosted as part of the National

Health Service (NHS), a variety of different sectors were also involved in some areas including education and social care. AAC services were also delivered from varying departments (e.g. speech and language therapy or disability services) and trusts (e.g. community or acute). Funding of communication aid provision was also highlighted by Gross and others as varying significantly throughout the UK both in its availability and the source of funding (e.g. from health, education or charitable sources).

There is little epidemiological evidence available about the provision of AAC or communication aids. A systematic review (5) highlighted some limited investigation into aspects of service provision but did not identify any papers that described or evaluated different models of service provision, standardised methods for describing services or any standard audit or reporting tools. Both Gross (4) and Creer et al. (6) estimate that 0.5% of the population may benefit from AAC strategies.

Other studies have examined rates of provision and use of AAC in the UK; however, there is an apparent paucity of these studies or data sets and all have limited applicability: Clarke et al. (7) provide an analysis of data from a national education initiative that funded and provided communication aids and reported referrals to the project over the two year period as 0.22% of the population of pupils with special educational needs; Murphy et al. (8) report a survey in 1991 of all those who had cerebral palsy living within Scotland using AAC systems, this identified 225 individuals; more recently Cockerill et al. (9) provide data from the a total population registry study of children with bilateral cerebral palsy and report that 32% were provided with one or more types of AAC.

The literature on the use of AAC from outside of the UK also appears limited. Data reported refers to specific populations (particularly children and young people) or environments, for example: survey data of pre-schoolers within special education services in Pennsylvania, USA (10); survey data including reported use of AAC and powered

communication aids within the population of children and young people with complex communication needs in New Zealand (11); the uptake of aided AAC by individuals with ‘intellectual disability’ in 26 US states (12); and registry data on the uptake of AAC by children with Cerebral Palsy in Norway (13).

Given this lack of information, the overall aim of the project in which this work was carried out was to gather data that could inform AAC service commissioning and design in the UK.

Method

The survey was developed over a two-month period. Initially, the tool was referenced against the Communication Matters AAC Service Standards (14) and prior work surveying tertiary services (15). The tool was then developed further through consultation with a group of six expert AAC practitioners nominated by consortia representing each of four regions of England. The group was involved in a group critique and edit of the initial draft survey and then in providing Delphi style email feedback on twelve further rounds of revisions. Finally, the survey was piloted with seven participants to check the understanding of the questions and to check the feasibility and acceptability of the survey to the participants. A small number of questions required further explanation at the piloting stage and so supplementary guidance and an interviewers’ script was developed. The survey was designed to provide nominal, ordinal and discrete data, rather than free text data that would require coding or interpretation. A set of definitions was developed to cover every term used in the survey.

Identification

In order to identify appropriate services within the available resources, a snowballing approach was used based on a national listing of more specialised services. Each service on this list was contacted and a list of all local (primary or secondary) services with an AAC

remit known to them was requested. These services were then contacted and the process was repeated until no further services could be identified.

Inclusion and Exclusion Criteria

Inclusion criteria were defined as: services with a remit across a defined geographical area or across a defined population and area; and that are involved in the provision of AAC services, equipment or support or have a caseload including people with speech, language and communication needs where it would be expected that there would be an AAC need.

Exclusion criteria were defined as services without a remit across a defined geographical area or population (e.g. private consultancies or some charitable organisations).

Protocol

Interviewers were trained by the authors in administering the survey and in the definitions used. An interviewer from each region followed an agreed protocol in gathering data in their region. Interviewers contacted the service manager for each identified service and arranged a telephone interview. Some respondents requested to be able to look up some data (particularly caseload data) and so in some cases respondents were sent supplementary data collection forms.

The decision to administer the survey was made for a number of reasons: this was the first time a survey such as this had been carried out and thus there was no familiarity with the content, terms or format of the survey; consultation with the expert group identified that terms and definitions used within the field of AAC are interpreted differently; and models of service delivery are also known to be different as well as being differently described.

Analysis

The data were collected using an online data collection tool developed by an independent contractor (Document Capture Co. - DCC) designed for secure online data collection and hosted on DCC's secure servers. An online dashboard of simple descriptive

statistics of the collected data per region was also implemented by DCC using Qlikview^{TM 1} software. On completion of the surveying, the data were exported as a CSV file.

The complete data set was imported into SPSS^{TM 2} software to allow manipulation of the data. The following steps were undertaken to create a complete, processed, data set: firstly, the geographical areas reported by each respondent were coded into Local Authority District (LAD) codes; corresponding population and geographical area data were calculated by looking up the LAD code area against the corresponding UK population estimates using Excel^{TM 3}. Population data were then calculated for the age groups reported by the service and an SPSS script was used to calculate appropriate values as a percentage of the services' catchment populations and to generate descriptive statistics.

Results

In total, respondents from 264 services across England (population 52 million) were surveyed. All respondents were service managers. Only those services meeting the inclusion criteria were included (n=220). The 44 responses excluded did not report covering a defined geographical catchment population. These respondents reported either covering a non geographical catchment such as a school, an in-patient or acute ward, or had selective national or regional coverage, such as a private practitioner. Of those services included, 66% reported they were commissioned (funded) by the NHS, 13% by education, 29% from mixed sources, 16% from other sources and none reported being commissioned via social care or charity sources. Fifty seven percent of respondents reported that the data provided were sourced from "estimates based on my own experience.", 22% of respondents provided data which had been extracted from a database.

Caseload Information

Respondents reported the age ranges of individuals that their services were provided to by choosing the appropriate group(s): all ages; pre-school; primary school; secondary

school; further education; adults; other. These data were then coded into either adult only (adults and/or further education groups), children only (pre-, primary or secondary school groups) or all ages (all ages or where one or more child groups and the adult group were reported). As can be seen in Figure 1, 50% of respondents reported providing services to adults only and 42% reporting providing services to children and young people only (n=220). Only five percent reported providing to a service to all ages.

INSERT FIGURE 1 HERE

The aetiologies of individuals most frequently seen in the service were ranked by respondents for their caseload of individuals using AAC and also using aided AAC. The distribution of the mean values is shown in Figure 2 (ordered by the mean rank for aided AAC). Cerebral palsy, other learning disabilities and autistic spectrum disorder were ranked as most frequently seen within services for both AAC and aided AAC.

INSERT FIGURE 2 HERE

Caseload Data

Respondents reported the total number of individuals on the service's current caseload; the number seen in the last 12 months and the unmet need. These data were requested to be broken down by the unaided AAC caseload, the low tech and the high tech aided communication caseloads (see Table 1 for the definitions used). Unmet need was defined as those who "do not use but could benefit from using this type of AAC". Caseload was defined as "The number of people that are currently receiving or have been identified to receive one or more of the service components for AAC listed in the glossary."

INSERT TABLE 2 HERE

Table 2 and Table 3 provide the descriptive statistics for these data. Figure 3 and Figure 4 show histograms of the caseload data for the total AAC caseload and the high-tech communication aid caseload, calculated as a percentage of the service's catchment population. The mean total AAC caseload reported was 0.09% of the catchment populations, $n=180$, $SD = 0.183$. The mean high tech communication aid caseload reported was 0.017% of the catchment populations, $n=151$, $SD = 0.027$.

INSERT TABLES 3 and FIGURES 3&4 HERE

A one-way ANOVA test was carried out to test for variations in the provision rate by age groups served. Provision rates to each age group varied significantly for both the high tech communication aid caseload, $F(2, 148) = 15.375$, $p = 0.000$, and for the total AAC caseload, $F(2, 177) = 21.227$, $p = 0.000$. Figure 5 illustrates the disparity in rates of reported caseload for high tech communication aid provision.

No significant difference in provision rates (using one-way ANOVA) was found between the four regions of England $F(3, 147) = 0.584$, $p = 0.627$.

INSERT FIGURE 5 HERE

The mean number of new referrals reported per year was 0.039% of the catchment populations, $SD = 0.110$, $n=158$. The mean yearly referral rate equated to 42% of the mean caseload value reported.

The mean unmet need for AAC reported was 0.0109% of the catchment populations, $SD = 0.02009$, $n=128$. Unmet need reported relating to high tech communication aids was estimated by respondents at 0.0038% of their catchment populations, $SD = 0.00546$, $n=86$.

Communication Aid Provision

Forty four percent of services (n=220) reported providing long term provision of communication aids, with 29% reporting provision being funded from their service budget. Seventeen percent of services responded that they had no access to a loan bank with 40% accessing a loan bank from within their service and 43% accessing it from other sources. Of those who did report having access to a loan bank, 12% reported that it was sufficient for their needs (n=174), whilst 51% felt the loan bank was insufficient for their needs.

Sixty Eight percent of services reported that they did not have “access to funding for equipment for loan bank or library items” via the service budget (n=169). The mean loan bank size was 23 devices, SD=29.1, n = 130 with ‘One to eight message devices’ making up the largest part of this on average (mean=7, SD=12.5, n=130).

Summing the total equipment funding (this could be from any source - i.e. not just services’ budgets) in the previous 12 months gave a total £850,000. The total figure reported for spending on loan bank equipment was £892,000. The loan bank and provision spending was totalled to obtain a total equipment spend per service. 50% of the total spend reported was by health services and 22% of the spend by Local (Education) Authorities (n=130). The mean reported total spend equated to £0.10 per head of the catchment populations, SD=0.20, n=130. Mean spend by services providing to children and young people (only) was significantly higher than that on adults (only) and that by services providing to adults and children (one-way ANOVA $F(2, 123) = 2.988, p = 0.054$). Rates of total equipment spend reported across each of the four regions did not vary (one-way ANOVA, $F(3, 122) = 1.224, p = 0.304$) nor by sector ($F(3, 116) = 0.491, p = 0.689$).

Discussion

The data reported in this paper from primary and secondary AAC services in England should assist with service planning and commissioning of AAC services.

Significantly greater levels of provision and spending by services working with children and young people were found when compared to adults. There could be a number of reasons for this, including the method and nature of this survey, however other reasons could be hypothesised: there may be a greater need for AAC in paediatric populations as a result of the epidemiology of conditions; there may be a paediatric bias in levels of service provision; there may be institutional use of AAC in education that is not supported in adulthood; it may be that AAC is used as an aid to language development; and it may be that there is a high rate of abandonment of AAC in adulthood.

The caseload and referral data collected contributes to the evidence of incidence and prevalence of AAC and high tech communication aid provision and use. The mean caseload levels reported are below the potential levels of need estimated elsewhere (4),(6) however this is to be expected as this survey was not designed to provide a complete population estimate of need. However, it can be seen that the prior estimates are within the range of the data reported here.

Respondents provided an estimate of unmet need within their catchment populations. These data suggest that for approximately every eight individuals on a service's caseload, there may be one individual within the service's catchment population with an identified unmet AAC need and for every four individuals on a service's high tech communication aid caseload there may be one additional individual within the catchment population identified as needing a high tech communication aid who has not been provided with one.

These data were collected prior to significant changes in the organisation of health services within the UK that included AAC services. It is hoped that these data will provide a bench mark that can be used in future studies or audits against which to evaluate these changes. Matching epidemiological information with data reflecting actual provision via services is important for informing the commissioning and delivery of services (16). These

data can be used to influence the commissioning of local and specialised AAC services within the UK and elsewhere as they provide evidence to support the identification of a level of need within a population. National audit can also be a tool for promoting service improvement (17) and it is also hoped that the survey developed for this study can be used to form the basis of a regular audit of AAC service provision.

Although the data presented represents the largest survey of services of this type to date in the UK, the data should be viewed with caution. All the data reported had large standard deviations, although this in itself is an interesting result, potentially highlighting considerable variation in service models and provision as well as challenges in data collection. The sampling method was in essence opportunistic and this may be a biased sample (of the most easily identifiable services). In addition, most of the data were reported by respondents from their memory rather than formal extracts from databases. However, the method used – in administering the survey and carefully defining all terms – was designed to ensure that the quality and comparability of the data was as high as practicable

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Notes

1. QlikviewTM is a registered trademark of QlikTech International, PA.
2. SPSSTM is a registered trademark of International Business Machines Corporation, NY.
3. ExcelTM is a registered trademark of Microsoft Corporation, WA.
4. Tableau Public Software is software by Tableau Software, Inc, WA.

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Tables

Table 1

AAC Definitions Used

Aided Communication	Aided communication is a subset of AAC which refers to those methods of communication which involve using additional equipment, such as picture, letter or word boards or books and technology based systems such as voice output communication aids.
Low-tech aided communication:	These systems are those which do not require power to function such as picture, letter or word boards or books.
High-tech aided communication	These systems require some power to function, ranging from systems such as single recorded message output devices to more complex systems which take text or symbol input and produce a synthesised speech output.

Table 2

Absolute Caseload and Unmet Need Reported

Variable	N	Min	Max	Sum	Mean	SD
Caseload						
Unaided AAC	111	0	1420	7093	63.90	169.210
Low tech aided AAC	157	0	958	9035	57.55	105.089
High tech aided AAC	154	0	210	3359	21.81	31.044
Total: all AAC	184	0	2443	19938	108.36	230.303
Unmet need						
Unaided AAC	64	0	80	373	5.83	14.240
Low tech aided AAC	93	0	100	785	8.44	14.463
High tech aided AAC	88	0	40	503	5.72	7.532
Total: all AAC	132	0	130	1919	14.54	22.004
Referrals						
Unaided AAC	87	0	1420	3645	41.90	171.338
Low tech aided AAC	126	0	958	5072	40.25	116.155
High tech aided AAC	120	0	600	2192	18.27	57.440
Total: all AAC	162	0	2443	11184	69.04	244.053

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

Table 3

Caseload and unmet need reported per percentage of catchment populations

Variable	N	Min	Max	Sum	Mean	SD
Caseload						
Unaided AAC	111	0	.70	6.1	.055	.121
Low tech aided AAC	154	0	.50	7.6	.049	.088
High tech aided AAC	151	0	.23	2.5	.017	.027
Total: all AAC	180	0	1.22	16.6	.092	.183
Unmet need						
Unaided AAC	64	0	.08	.34	.0054	.01580
Low tech aided AAC	91	0	.07	.60	.0066	.01189
High tech aided AAC	86	0	.03	.33	.0038	.00546
Total: all AAC	128	0	.14	1.39	.0109	.02009
Referrals						
Unaided AAC	87	0	.60	2.08	.024	.086
Low tech aided AAC	123	0	.40	2.72	.022	.052
High tech aided AAC	117	0	.13	1.11	.009	.018
Total: all AAC	158	0	1.03	6.12	.039	.110

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

Figures

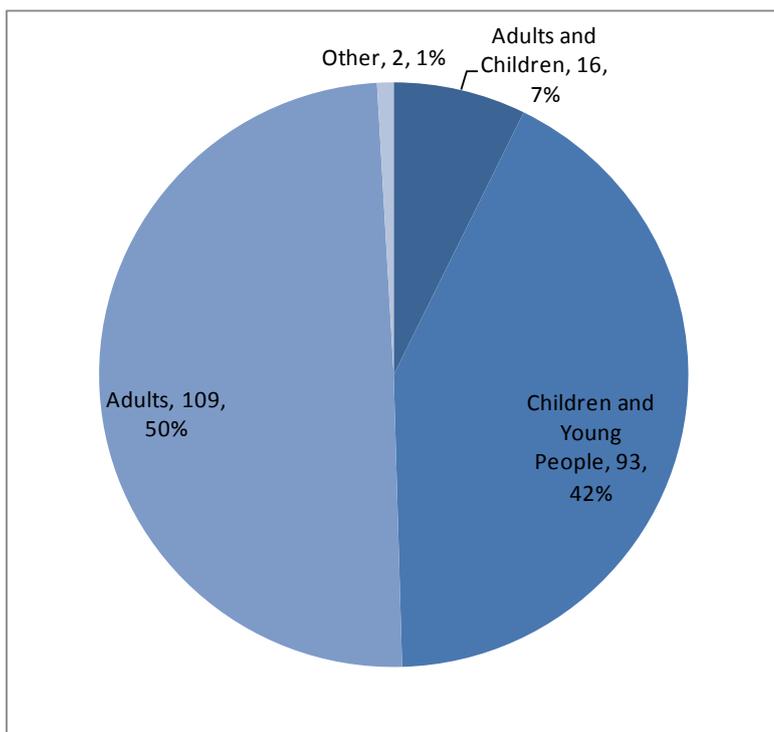
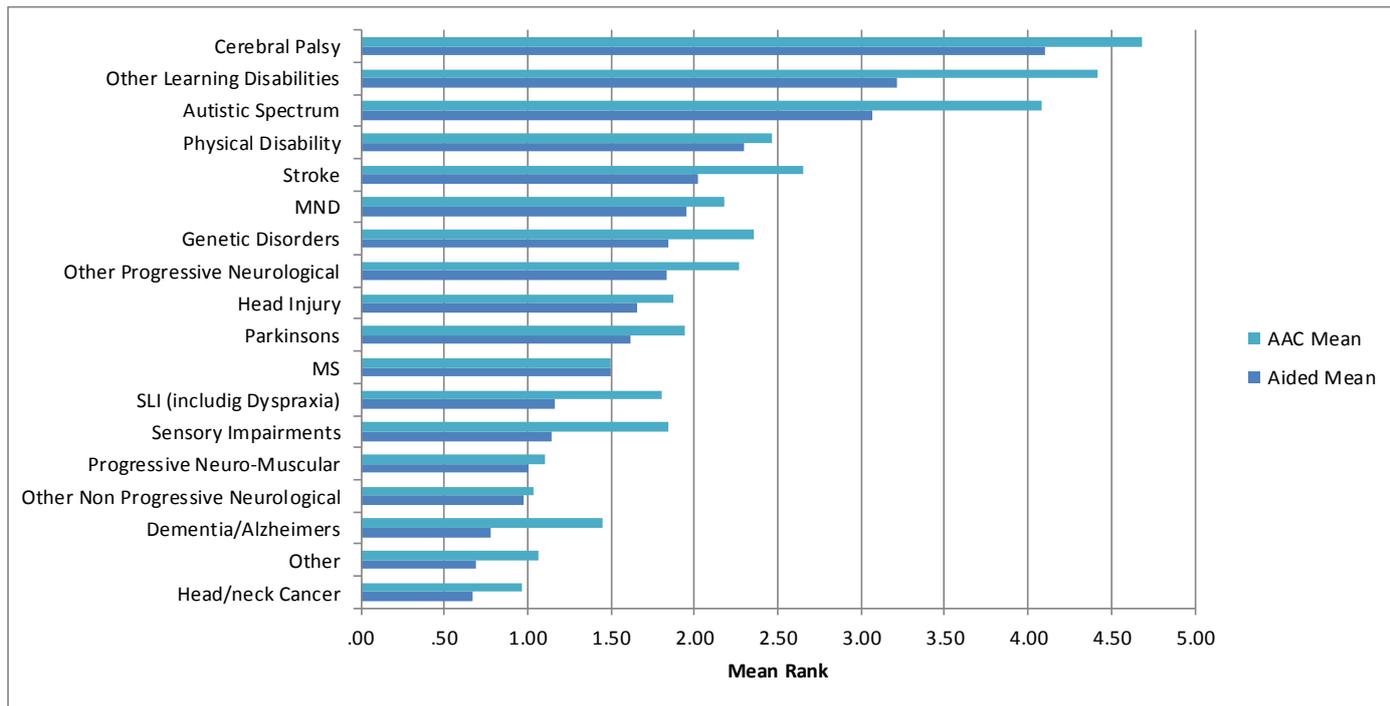


Figure 1. Reported age groups served (coded) – count and percentage



Note: Ranking: 10 = most frequently seen, 1 = least frequent, 0 =null responses

Figure 2. Mean ranking of AAC and Aided AAC Aetiologies (ordered by mean Aided AAC ranking)

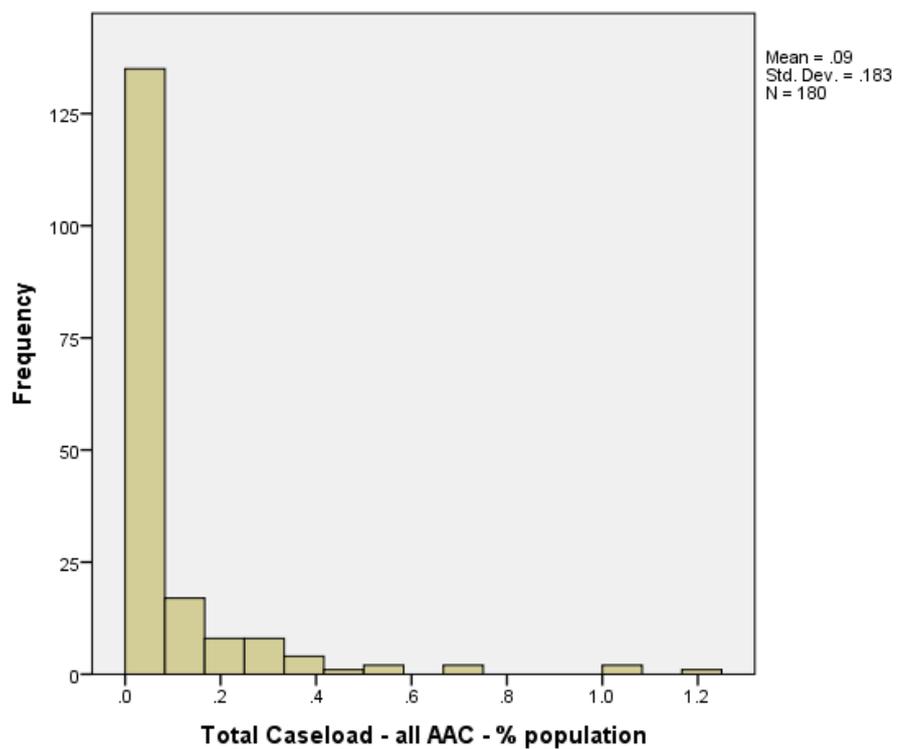


Figure 3. Histogram of AAC caseload reported (per % population)

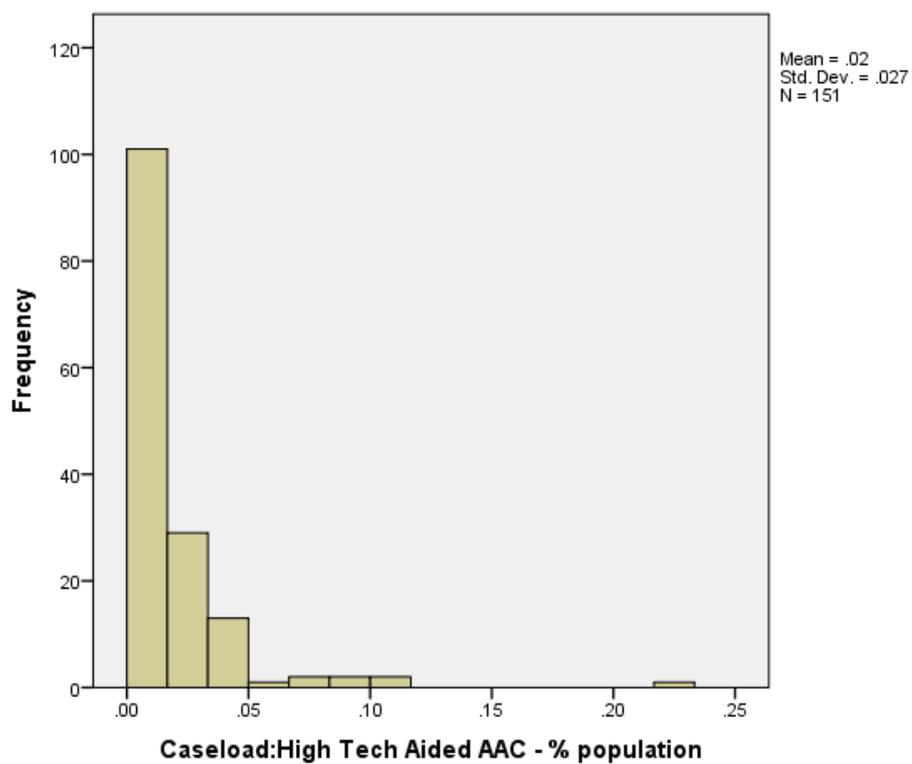


Figure 4. Histogram of High tech communication aid caseload reported (per % population)

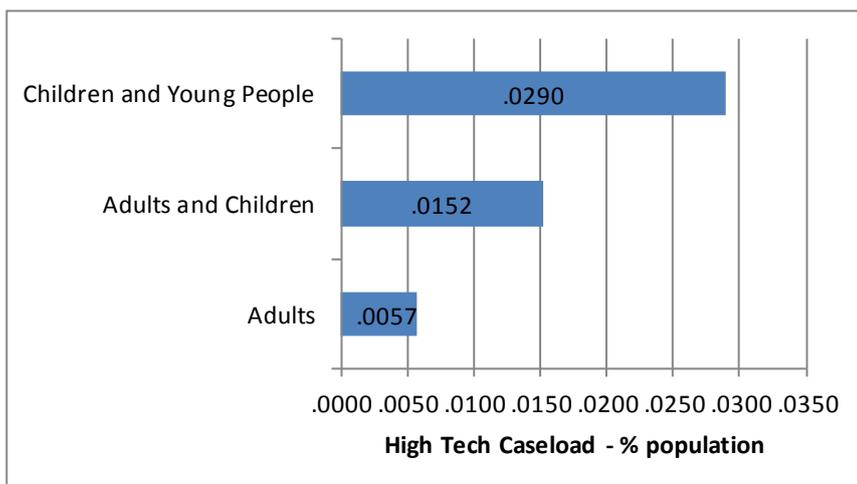


Figure 5. Caseload of High Tech Aided AAC as % population by age group