

The Scottish Allied Health Professions Lifecurve™ Survey: Report on Respondents with Communication Support Needs

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This report presents a provisional analysis of findings from a major survey of clients of Scottish Allied Health Professionals (AHPs), focused on survey respondents who reported having communication support needs. It thereby contributes data and evidence relevant to the legal duty of Scottish Ministers to “provide or secure the provision of (a) communication equipment, and (b) support in using that equipment, to any person who has lost their voice or has difficulty speaking”¹; and to the Scottish Government’s ‘See Hear’ Strategy for people with sensory impairment².

Key Findings

- **Communication support needs:** approximately one fifth of survey respondents reported having communication support needs. These needs could reflect loss of voice or difficulty speaking, but also wider sensory needs such as vision or hearing loss.
- **Age profile:** survey respondents with communication support needs were older on average than those without.
- **Functional ability:** survey respondents with communication support needs reported a greater loss of functional ability compared with those without, possibly reflecting their older age profile.
- **AHP professions seen:** people with communication support needs were accessing a wide range of AHP services; around half were seeing an occupational therapist or a physiotherapist. This suggests potential value in providing relevant training and education to all AHP groups.

1. Introduction

The purpose of this report is to contribute data and evidence relevant to the legal duty of Scottish Ministers to “provide or secure the provision of (a) communication equipment, and (b) support in using that equipment, to any person who has lost their voice or has difficulty speaking”¹; and to the Scottish Government’s ‘See Hear’ Strategy² for people with sensory impairment.

Communication Equipment and Support is often referred to as Augmentative and Alternative Communication (AAC)³. Since the Scottish Parliament passed the legal duty¹ in 2016, and its subsequent commencement in March 2018, the Scottish Government’s Assisted Communication policy team has been working to collect data and evidence about the population in Scotland who need communication equipment and support and to whom the duty applies. As part of this work they secured the inclusion of a question about communication support needs in the AHP survey; and commissioned this report, having secured funding for a three month internship.

2. Survey Background

AHPs comprise a range of fourteen professional groups, including Occupational Therapists, Physiotherapists and Speech and Language Therapists. They support people of all ages, providing preventative interventions in such areas as supported self-management, diagnostic, therapeutic, rehabilitation and enablement services⁴.

The Active and Independent Living Programme (AILP) is a Scottish Government programme led by the Chief Health Professions Officer, within the Chief Nursing Officer Directorate. It is intended to drive significant culture change in how people can access and receive AHP support for self-management, prevention, early intervention, rehabilitation and enablement services.⁵

In 2017, AILP requested all AHPs in Scotland to participate in ‘The AHP LifeCurve™ Survey’, whose purpose was to develop a better understanding of where in people’s lives the AHP workforce is intervening. AHPs were asked to identify at least two clients typical of those using their service, and to invite them to complete the survey questionnaire⁶. This sought to gather information on the range of clients being seen by AHPs, and to map their functional abilities against the ADL LifeCurve™ tool, developed by ADL Research and Newcastle University’s Institute for Ageing. The tool is a model of “Compression of Functional Decline” (CFD), based on evidence that there is a hierarchical order to the loss of functional ability⁷. Figure 1 below shows the LifeCurve™ model, including ‘pre-curve’ items (hiking, brisk walking, getting up from the floor and walking a mile) and then the fifteen LifeCurve™ items. People are considered to enter the LifeCurve™ when they begin to have difficulty independently completing the first item on the LifeCurve™, ‘Cutting Toenails’.

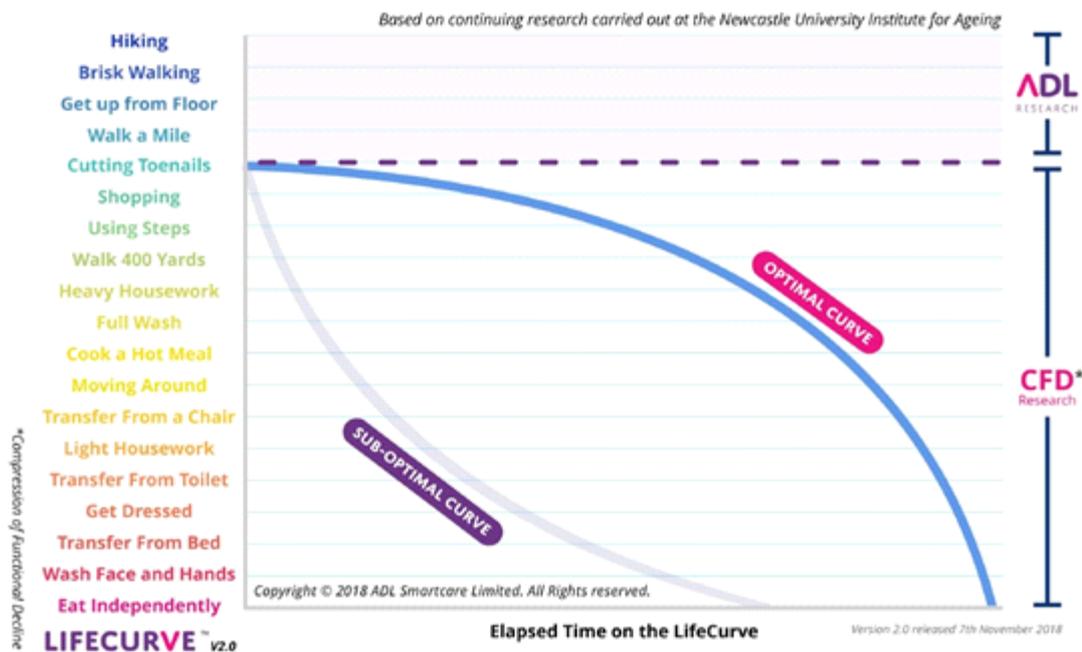


Figure 1: The University of Newcastle LifeCurve™ Model⁸.

The survey data is intended to provide evidence of the need for earlier, preventative interventions by AHPs, to support people to improve and maintain skills and reduce functional dependence.

3. Survey Content

The survey questionnaire was presented in two parts. The first part asked respondents to provide information on the activities of daily living (ADLs) and instrumental activities of daily living (IADLs) that they could and could not complete without help from either a person or by using equipment. It also asked for background information on the person’s domestic situation and their attendance at their AHP appointment. The second part asked the AHP to complete the questionnaire by providing information on their profession, band / grade, the NHS board and the Health and Social Care Partnership (HSCP; referred to as ‘partnership’ from this point) area where the respondent was seen.

Following consideration of a submission from SG’s Assisted Communication policy team, one overarching question about communication support needs was included in part one of the questionnaire:

‘Do you have any communication support needs? E.g. hearing or low vision aid, interpreter, large print, easy read, communication aid’.

The total responses to the questionnaire (n=13345) were filtered by those who had answered ‘yes’ (n=2883) and ‘no’ (n=10462) to this question. Respondents who answered ‘yes’ are the primary focus of this report. As this was a yes/no question the responses cannot be further broken down by type of communication needs. Rather, they provide a high level overview of people with a wide range of communication and sensory needs across Scotland, though potentially excluding people with very severe communication needs who might have been unable to respond to the survey.

4. Data Analysis and Limitations

This analysis was undertaken during the period January – April 2019, when an intern recruited from the Scottish Graduate School of Social Science was available to undertake a three-month internship. In order to take advantage of her availability, and to accelerate the provision of the survey findings, this analysis was completed before the definitive cleaning and analysis of the whole dataset. The findings are therefore provisional and may be superseded by later published reports from the main survey data controllers.

A number of other specific data and analysis limitations are shown below.

- a) The survey did not set out to reach a random sample of the population, but was completed by people who happened to see an AHP on the day of the survey, and whom the AHP considered to be typical clients. Therefore, the data has not been weighted or otherwise adjusted, and the results have not been tested statistically.
- b) The questionnaires were completed in written format and there was some variation in the information provided and the completeness of responses received.
- c) Each survey response relates to one AHP appointment only, and does not capture information about the respondent's other appointments with AHPs or other health and social care needs.
- d) Data for respondents who answered 'yes' to the communication question has been 'cleaned'; however data for the other survey respondents has not been cleaned. So comparisons with that group are provisional but are provided for information.
- e) Some data which was submitted late has not yet been incorporated into the dataset. While it is considered unlikely that the profile of the missing data will vary significantly from the data which has been analysed, this cannot be ruled out.
- f) Information about respondent gender was not requested, so male vs female breakdowns are not possible.

5. Main Findings

- **Communication support needs:** approximately one fifth of survey respondents reported having communication support needs. These needs could reflect loss of voice or difficulty speaking, but also wider sensory needs such as vision or hearing loss.
- **Age Profile:**
 - survey respondents were on average older when compared with the population of Scotland;
 - survey respondents with communication support needs were older on average than those without;
 - 75% of respondents with such needs were aged over 65.
 - 57% of the respondents without such needs were aged over 65.
- **LifeCurve™ profile:** a higher proportion of respondents with communication support needs were in the 'late-curve', reflecting a greater loss of functional ability, while respondents without communication support needs were more likely to be 'pre-curve'.
- **Appointment location:** respondents with communication support needs were more likely to be seen as in-patients or at home, while respondents without communication support needs were more likely to be seen as out-patients.
- **Travel to appointment:** respondents with communication support needs were more likely to select N/A (not applicable) from the travel options presented, probably reflecting their appointment location profile.
- **Living arrangements:** slightly more respondents with communication support needs lived alone, whereas respondents without communication support needs were slightly more likely to live with others. A relatively small proportion of both groups lived in sheltered accommodation or care homes.
- **Home suitability:** respondents with communication support needs were less likely to be able to manage their daily activities and more likely to report difficulties, compared with respondents without communication support needs.
- **Emotional wellbeing:** the profiles of respondents with and without communication support needs were similar, with a clear majority in both groups reporting their wellbeing positively or neutrally.
- **Referral source:** the majority of respondents with and without communication support needs were referred to an AHP by another healthcare staff member.
- **AHP professions seen:** people with communication support needs were accessing a wide range of AHP services. Around half of those respondents were seeing an occupational therapist or a physiotherapist. Only 8% of this group were seeing a speech and language therapist or support worker. This suggests potential value in providing training and education to all AHP groups around communication support needs, and about onward referral to speech and language therapy where appropriate.

6. Conclusion

This report has been prepared to inform the Scottish Government Assisted Communications Policy Team, who are working to better understand the profile of people in Scotland with communication support needs. It demonstrates that people with communication support needs across Scotland are accessing a range of AHP services and across a variety of settings. The profile of AHP services accessed highlights potential opportunities to provide training and education to all AHPs around communication support needs and supportive communication strategies, and guidance for onward referral to speech and language therapists where appropriate.

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