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Developments in the application of Intensive Comprehensive Aphasia Programs: An international survey of practice

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Developments in the application of Intensive Comprehensive Aphasia Programs: An international survey of practice

Purpose: Intensive comprehensive aphasia programs (ICAPs) were first described in 2013 with an international survey documenting 12 unique programs. ICAPs involve high dose intervention delivered in both group and individual settings, targeting communication across impairment, functioning, participation, and contextual domains. In this study we aimed to investigate international growth in ICAPs.

Materials and methods: We developed a 43-item questionnaire expanding on the original 2013 version to investigate program modifications, activities, protocolised therapies, computer and therapy apps, and family involvement. The survey was disseminated to aphasia clinicians and researchers internationally (Nov 2019 - Feb 2020).

Results: Thirty-nine unique respondents completed the survey from nine countries. Twenty-one met the criteria for an ICAP or modified ICAP (mICAP): 14 ICAPs; 7 mICAPs, 13 of these new programs. ICAPs differed from mICAPs with greater emphasis on group sessions, use of technology, total communication, advocacy, and art activities. A large range of protocolised therapies were used across programs. An increased focus on mood and psychosocial well-being was observed compared to the 2013 survey.

Conclusions: The number and comprehensiveness of ICAPs has grown since 2013 with development of modified versions. Future research should focus on comparative efficacy of ICAPs/mICAPs and other forms of aphasia interventions and factors underpinning growth and sustainability.

Keywords: aphasia, rehabilitation, stroke, intensity, intensive comprehensive aphasia program

Introduction

Aphasia is an acquired communication disability caused by damage to the language

processing networks of the brain. Aphasia results in difficulty speaking, understanding speech, reading, and writing with the amount and type of communication difficulty varying with the extent and location of the brain injury. Aphasia most commonly results from stroke, with approximately 30% of first-time stroke survivors experiencing aphasia [1,2] but aphasia can also result from traumatic brain injury, brain tumor, and some infectious neurological diseases. Aphasia is usually a lifelong communication disability [3], with approximately 50% of those with aphasia immediately after stroke still experiencing the disability at 12 months follow up [4] and beyond [3]. Given that communication is central to almost all activities of daily living, it is not surprising that aphasia impacts a wide range of psychosocial domains. People with aphasia have four times the rate of depression compared to the general population and double the rate of their stroke peers without aphasia [5,6], poorer rates of return to work than non-aphasic stroke peers [7], significantly reduced numbers of friends [8], high rates of social isolation [9], and overall low quality of life [10,11]. The negative sequelae of aphasia not only impact the individual with aphasia but also their family and friends, with third party disability well documented [12]. Therefore, finding effective interventions for aphasia is important for people living with aphasia and their wider communities.

High level evidence for the effectiveness of speech and language pathology interventions for individuals with aphasia beyond six months post-stroke has been documented in the most recent Cochrane Collaboration systematic review of 57 aphasia therapy trials [13]. Statistically significant treatment effects were found following a range of different aphasia interventions targeting functional communication, reading, writing, and expressive language outcomes. Additional benefits were found for high intensity and high dose interventions despite increased attrition for these intensive aphasia programs. Higher intensity treatment, coupled with strategically implemented principles of neuroplasticity, has

been demonstrated to promote functional neural reorganization of language function [14, 15].

Given the broad communication and psychosocial impacts of aphasia, clinicians frequently utilise the International Classification of Functioning, Disability and Health (ICF) [16] as a framework to underpin goal setting and intervention targets in aphasia rehabilitation beyond a narrower focus on reducing the aphasic language impairment. These broader targets include communication activity (e.g., ordering a coffee in a café), communication participation, (e.g., conversation at a party), personal factors (e.g., negotiating altered identity while living with aphasia) and environmental factors (e.g., conversation partner training) [17].

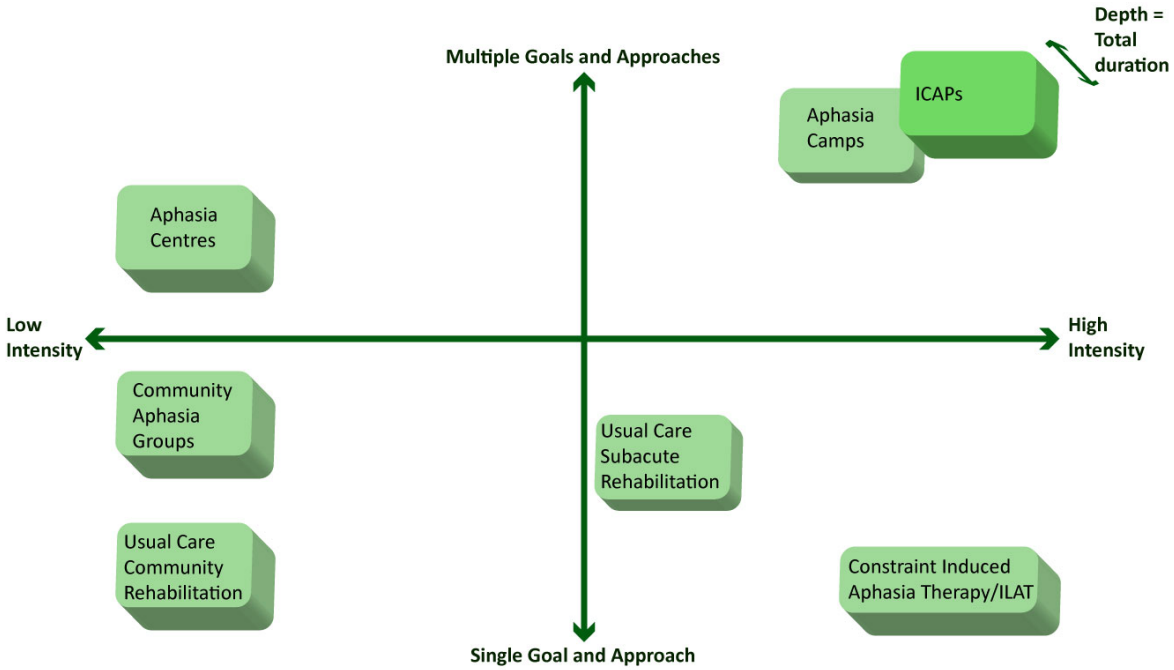
In 2013, we became aware of an emerging aphasia rehabilitation practice that infused the philosophical foundation of the ICF [16] with principles of neuroplasticity [15]. Subsequently, we described and labelled a group of integrated aphasia rehabilitation programs delivered to cohorts of individuals with aphasia utilising both group and individual sessions, with an intensive treatment schedule. We referred to these programs as Intensive Comprehensive Aphasia Programs (ICAPs) [18,19] and provided the following definition:

(1) Provides a minimum of 3 hours of daily treatment over a period of at least 2 weeks
(2) Uses a variety of different treatment approaches and formats including individual and group therapy
(3) Directly targets both the impairment and the activity/participation levels of language and communication functioning
(4) Includes patient and/or family education; and
(5) Has a definable start and end date, with a cohort of participants entering and leaving the program at the same time [19, p.380].

The ICAP model marries the ICF and patient-centred care [16] with principles of neuroplasticity [14] to provide comprehensive intensive aphasia treatment to a

cohort of participants. ICAPs can be conceptualised as a specific service delivery option within a continuum of therapeutic approaches and treatment intensity dimensions. Figure 1 illustrates this continuum.

[Insert figure 1 about here]



To assess early global interest and implementation of the emerging ICAP service delivery model, a 32-item survey of international ICAP practice was conducted from May to August 2012. Results revealed 12 ICAPs were being implemented across the USA (8), Canada (2), Australia (1) and the United Kingdom (1). Most of these programs were newly established with the exception of one program that had been running for over 12 years. On average, the ICAPs included cohorts of 6 individuals with aphasia at a time (range 3-10), ran for 4.5 days per week for 21 days, and provided 101 hours of intervention. These ICAPs were predominantly staffed by speech language pathologists, with the minority of programs including part time volunteers, recreational therapists, physical therapists, and music therapists. All the ICAPs included individual, group, and computer-based therapy sessions, with family involvement a key feature. One limitation of the 2013 survey was that it did not

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seek precise detail concerning the use of specific therapeutic interventions within ICAP sessions.

A growing number of empirical studies have investigated the feasibility and efficacy of ICAPs since the 2013 survey and have revealed improvements following the intervention. Babbitt et al. [20] (*n* =74) reported statistically significant improvements in naming skills and overall language severity (medium to large effect sizes), communication participation (large effects size) and communication confidence (medium effect size), with no significant impact of aphasia type, severity, or time post onset (up to 7 years post-stroke) on outcomes. Following the Aphasia LIFT ICAP, Dignam et al. [21] (*n* =34) found significant group effects immediately post ICAP and at 1 month follow up for naming, communication participation and communication related quality of life. More recently, Hoover et al. [22] (*n* =20) integrated iPad use into their ICAP intervention and demonstrated significant pre-post change in a range of language tasks, stroke impact, and communication related quality of life measures. In a residential ICAP (PIRATE) delivered across four weeks, Winans-Mitrik et al. [23] (*n* =73) reported positive group level change on aphasia severity, use of language in discourse, and client- and family-reported communication functioning immediately following and at one month follow up, greater than that measured during the baseline period. Importantly, Winans-Mitrik et al. explored individual variability in treatment response and noted a minority of cases where no improvement occurred following intervention. Recently, Griffin-Musick and colleagues [24] (*n* =37) expanded ICAP research beyond linguistic-based measures and found that ICAPs also have the potential to facilitate positive change in psychosocial well-being including decreased depression and increased quality of life. To complement the behavioural evidence emerging for the ICAP model, Baliki and colleagues [25] (*n* =8) showed that ICAPs have the potential to facilitate experience-dependent neuroplasticity, resulting in functional neural reorganization.

The first publications about the ICAP service delivery model emerged in 2013 with the special edition of Topics in Stroke Rehabilitation [18] which included the data from the original 2013 survey, two Phase I proof-of-concept studies [26,27], and a commentary paper regarding a future research agenda for ICAPs [28]. Since this 2013 special issue, the number of ICAP publications has been steadily increasing. In a literature search we conducted, eight articles were published between 2014 and 2016 and 19 articles were published between 2017 and 2019 (Appendix One lists the search strategy for the literature review and all social media data collection). These scientific publications are complemented by an increase in conference presentations and an increase in public visibility as seen on social media and websites dedicated to the ICAP service delivery model. Social media platforms provide a different lens for the recognition of intensive aphasia therapy programs. The first posts on Twitter for "intensive comprehensive aphasia program(s)" emerged in 2015, linked to the announcement of the publication of early ICAP data following the original survey [19]. From 2015-2017, a handful of ICAP-related tweets were posted to Twitter, with a recent increase of posts associated with the new Twitter handle "@ICAPcommunity" established in 2018 from researchers in the United Kingdom. Using the @ICAPcommunity handle, 53 tweets were posted in 2019 and 194 tweets were posted through October of 2020. Posts typically originate from clinics and research labs who offer intensive and comprehensive aphasia therapy options. This increased social media presence likely reflects an interest in and application of the ICAP intervention approach although published data is not available to confirm such growth.

Further, we have observed through social media (Facebook, Twitter) that research groups and clinicians are reporting modifications and innovations to the original concepts and definitions of ICAPs but there is limited formal reporting of the nature of these modifications and how well the original definition holds to current practice. Understanding the current

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scope and range of activities within ICAPs and conceptualizing the emerging modified versions from the original model is important for reporting of therapeutic approaches and evidence generation, and to gauge utility of these novel intervention programs. Therefore, the purpose of this prospective observational study was to investigate the growth in number and scope of ICAPs that has occurred internationally during the seven years since the 2013 survey. Further, we aimed to monitor the utility of our original ICAP definition [19] and to describe any reported program modifications.

Materials and Methods

Ethics approval for this study was obtained from La Trobe University Low Risk Human Ethics Committee in October 2019 (HEC #19421). The study design and reporting are consistent with the STROBE statement for observational studies [29]. We developed a 43-item questionnaire expanding on the 32-item version used in the original 2013 study [19] (survey can be found in supplementary materials). The survey provided the original definition of an ICAP along with an option for respondents to indicate if their program incorporated a programmatic modification to the original definition in intensity or comprehensiveness. For this survey we coined the term modified ICAP (mICAP) to refer to a program which met all ICAP definition elements except one (see Appendix Two for a full description); that is, a mICAP could have a modification to either intensity or programming but not both. Figure 1 shows that a modification to both programming and intensity would render the program to be entirely beyond the domain of ICAPs and more consistent with usual sub-acute or community rehabilitation programs.

The updated survey contained both closed and open-ended questions with newly developed questions to address (1) program modifications to ICAPs identifying them as modified ICAPs or mICAPs, (2) specific activities included in each ICAP/mICAP, and (3) details of the use of protocolised therapies, computer and therapy apps, and family

involvement. The survey was open on the Qualtrics platform from November 2019-end February 2020.

Several recruitment methods were employed to maximise the reach to potential participants across the world and included: advertising in the Speech Language Pathology professional association newsletters in specific countries; emailing participants from aphasia conference lists and authors of published aphasia research; contacting aphasia research organisations with a request to send the study advertisement onto relevant persons in their organisation and countries; and posting a call for responses on Twitter and Facebook. The Supplementary Material displays the methods and targeted groups by country.

Data Analysis

At study close, the Qualtrics data was downloaded and collated into an Excel database. Data was screened to eliminate possible duplicate responses and reviewed for valid responses for each question, and complete questionnaires for individual participants. Descriptive statistics (means, medians, ranges) were used to describe the data. All responses to the open-ended questions were downloaded to an Excel database and analysed using qualitative content analysis methods to describe and quantify responses [30]. Two members of the research team independently coded the open-ended responses and then came together to reach consensus about themes [31]. A third member of the research team coded, reviewed, and confirmed these themes.

Results

Respondents

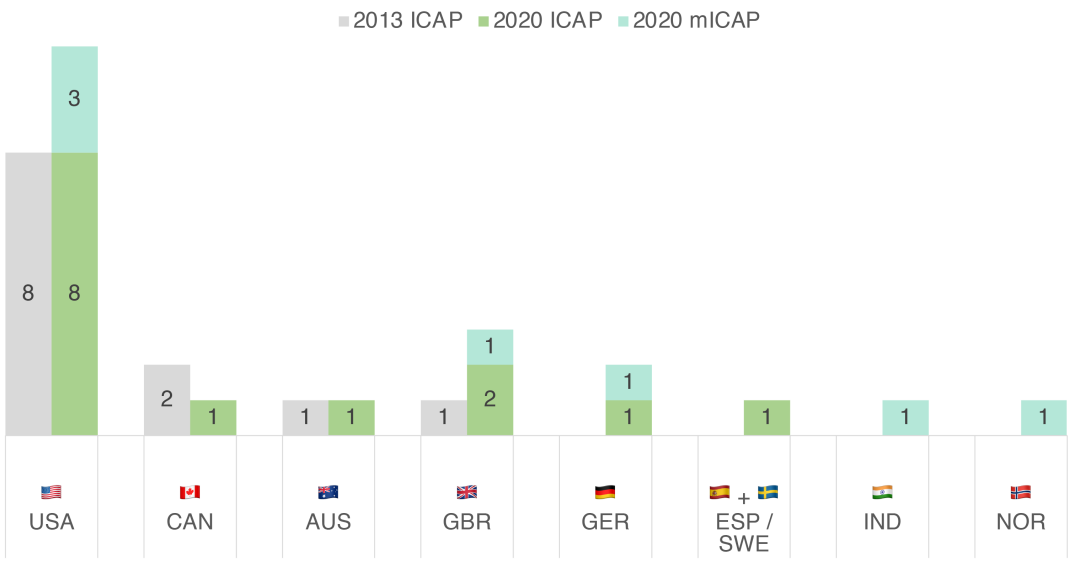
A total of 48 respondents completed the 2020 survey. Once duplicate entries from repeated attempts from the same programs were removed, 39 unique surveys remained. Of these 39

surveys, 10 self-identified as not meeting the criteria for an ICAP or mICAP and a further 8 were excluded by the authors as not meeting criteria (e.g., more than one programmatic modification identified). Of the 21 remaining responses meeting criteria, 14 were classified as ICAPs and 7 as mICAPs (see Appendix Three for full description of the categorisation process). Eight respondents answered both the 2013 and the current survey, with 13 new respondents included in the current survey.

Location, funding, and growth

Figure 2 shows the location by country and the growth in number of ICAPs from the 2013 survey (12) compared to ICAPs (14) and mICAPs (7) in the current 2020 survey. Appendix four contains details on sources of funding by program and country.

[Insert figure 2 about here]

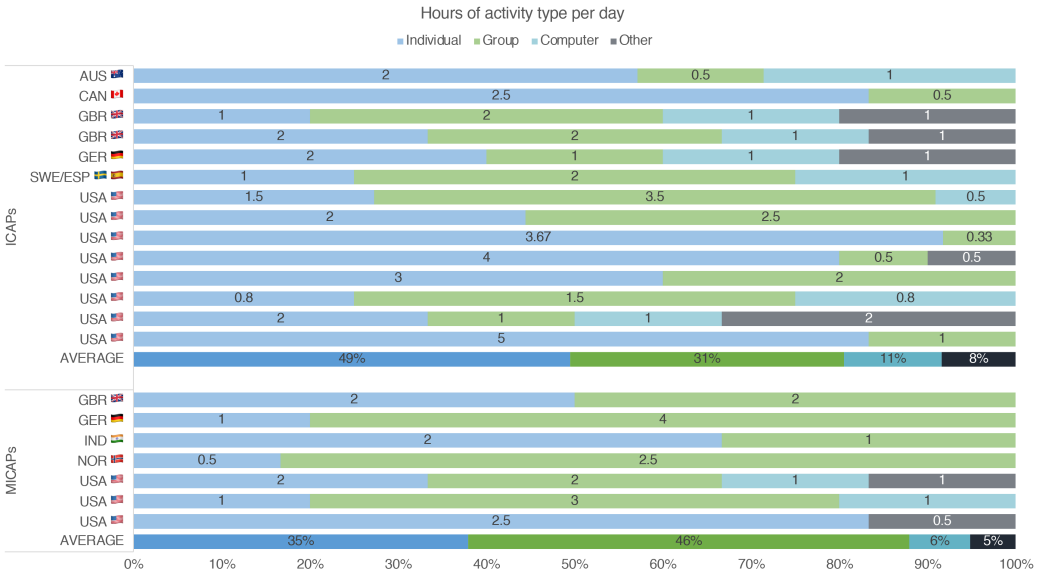


Number, hours, duration, and size

Respondents reported implementing between 1-18 programs per year (ICAP mode: 2; mICAP mode: 2) with 2-12 attendees per program (ICAP mode: 4; mICAP mode: 5), running

for a total number of 10-56 days (ICAP mode:15; mICAP mode: 15) at 3-5 days per week (ICAP mode: 5; mICAP mode: 5) and at a rate of 6.25-37.5 hours per week (ICAP mode: 25; mICAP mode: 12). On average, the ICAPs had been running for 8.9 years and the mICAPs for 7.0 years. Figure 3 displays the hours of different activities per day included in the programs. On average, approximately 50% of time in ICAPs is spent in individual sessions, 30% in group sessions, and 11% in technology-based sessions. This contrasts with 35% individual sessions, 46% group sessions, and 6% computer sessions in mICAPs.

[Insert figure 3 about here]



Philosophy, values, and mission

While only 4 of 13 ICAPs reported having a mission statement in the 2013 survey, a greater number of programs reported having a mission statement in the current survey: 8 of 14 ICAPs and 1 of 7 mICAPs. An additional 9 ICAPs and 4 mICAPs reported core values and principles. Thematic analysis [31] of the 2020 survey core values and principles responses indicated a focus on: (1) patient-centered care (including individualized and collaboratively developed goal setting and treatment, the patient as the expert of their own condition, and self-directed learning); (2) principles of neuroplasticity used to inform treatment delivery; (3)

the use of evidence-based treatment approaches; and (4) a detailed description of "comprehensive treatment" including philosophies stemming from the WHO-ICF [16], the Life Participation Approach to Aphasia (LPAA) [32], the use of multi-modality communication, and a variety of treatment session types. Additional themes included the supportive community of the ICAP model, an overarching philosophy of the possibility of ongoing recovery across the phases of rehabilitation, family inclusion in the ICAP, and the advantages of training student clinicians in the context of the ICAP model. Table 1 summarises core values and principles across the 2013 and 2020 surveys.

[Insert table 1 about here]

Admission criteria

Table 2 shows that all ICAPs and 5 of 7 mICAPs reported specific admission criteria. Consistent with the 2013 survey, some programs in the 2020 survey had admission criteria that included time post onset and severity of the aphasia. However, of greater importance for admission was the need for participants to have a primary diagnosis of aphasia without associated cognitive deficits. Age continued to be a criterion for admission for 9 of 14 ICAPs and 3 of 7 mICAPs compared with 6 of 13 ICAPs in 2013.

Some ICAPs and mICAPs required that participants be medically stable to join the program. While endurance tended to be a more important factor in 2013 for 9 of 13 ICAPs, it was a less important admission criteria for programs in the current survey with only 3 of 14 ICAPs and 4 of 7 mICAPS including endurance as an admission criterion. However, when specifically questioned in the survey about endurance and program participation, ICAP respondents listed adequate stamina to remain alert, ability to sit for four hours per day, or the ability to participate in treatment for the duration of the program (i.e., 3-7 hours each day for multiple days) as considerations. mICAP programs required similar endurance criteria. Importantly, 10 of the 14 ICAPs indicated that participants must be independent or have

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caregiver support for activities of daily living (ADLs), especially toileting. None of the 2020 programs indicated that ambulation was a requirement compared to 2 out of 13 programs in 2013.

[Insert table 2 about here]

Staffing

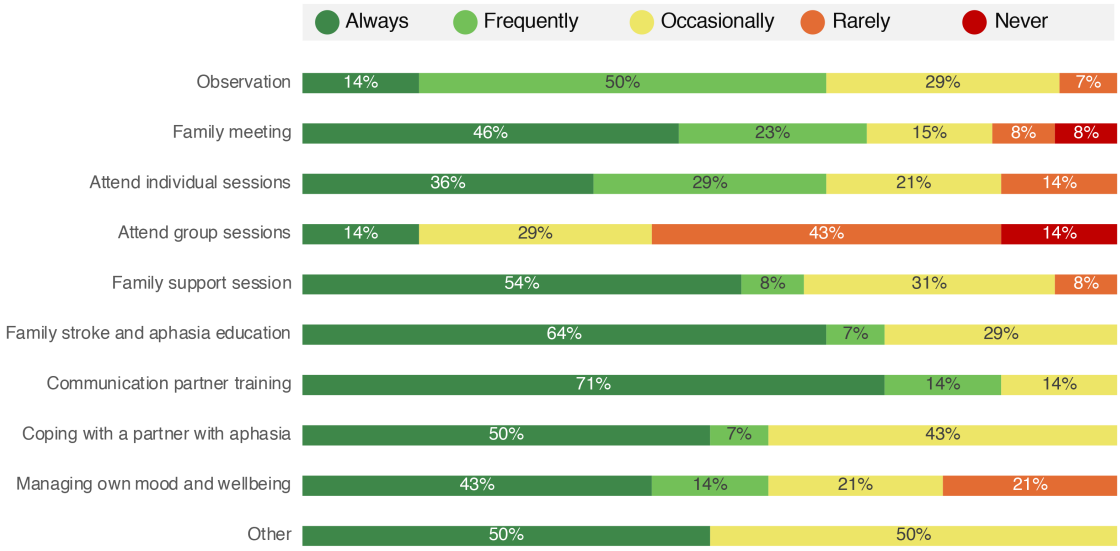
Speech language pathologists remained the majority staff members in ICAPs and mICAPs. The vast majority of other staff, including mental health practitioners and other allied health staff, were employed at a fractional rate. Table 3 details the staff types and numbers for each program type.

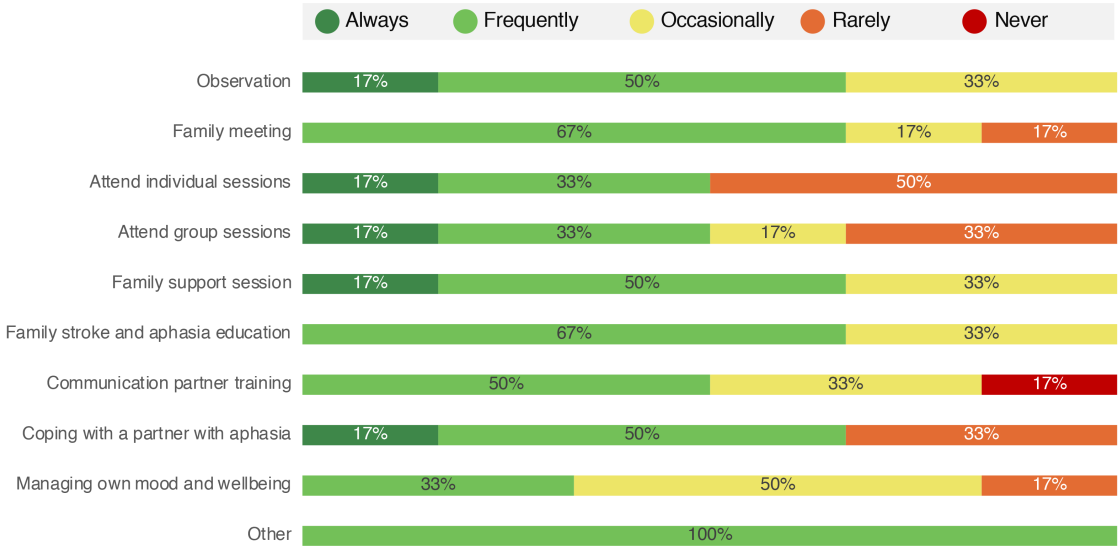
[Insert table 3 about here]

Family involvement

Figure 4a and 4b displays the percentage of ICAPs and mICAPs reporting family involvement across various program activities. Overall, results suggested a greater emphasis on family involvement in 2020 as compared to the 2013 survey. For example, the percentage of ICAPs reporting they always or frequently include a family meeting was 69% in 2020 and 50% in 2013, while for family support sessions it was 62% in 2020 and 50% in 2013. ICAPs consistently reported always including family across various activities at a higher rate than mICAPS. One particular finding of note is that 71% of ICAPS reported always including communication partner training programs. This inclusion of communication partner training was markedly higher for ICAPS than for mICAPS where only 50% reported frequently and none reporting always including it.

[Insert figures 4a. and 4b. about here]





Program therapies and activities

Table 4 lists the percentage of various activities that programs include. ICAPs and mICAPs differed in that ICAPs appeared to implement various activities as standard (i.e., 100% of programs included the activity). mICAPs also overall included fewer activities concerning total communication, mental health and wellbeing, advocacy, and the arts. Respondents provided responses to the "other" option and reported community outings, a communication

challenge day, adaptive sports, and arranging guest speakers and activities.

A range of protocolised aphasia therapies were reported as part of the ICAPs and mICAPs. Table 5 details these therapies according to the dropdown menu options provided in the survey. Several other protocolised therapies were listed by ≤2 programs and these are listed in Appendix five.

[Insert tables 4 and 5 about here]

Technologies utilised: apps and software

The use of technology was considered to be an essential element of an ICAP but was not necessarily essential to a mICAP. The majority of the ICAPs used therapy apps and software both during their individual treatment sessions (10/14) and for home-based practice (12/14). Six of the ICAPs used the technology within their group sessions, whereas only three provided separate computer sessions within the daily schedule. In contrast to the extensive use of technology within the ICAPs, only 4 out of 7 mICAPs used therapy apps and software during their individual therapy sessions and only 2 out of 7 mICAPs provided technology-based home practice. We note that the 2013 survey did not include questions about technology and therefore changes about the use of technology from 2013 to 2020 can only be inferred. Nevertheless, there has been growth in the number of therapy apps and software programs over the last 5-10 years with the development of suites of apps designed specifically for people with aphasia (see The Aphasia Software Finder for descriptions of these; https://www.aphasiasoftwarefinder.org).

Appendix six shows the specific apps and computer programs that respondents reported using. Several ICAPs indicated that in addition to using aphasia-specific programs, they trained use of applications that are available on any smartphone as well as trained the

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use of social media. Respondents also mentioned that they referred to the Aphasia Software Finder (https://www.aphasiasoftwarefinder.org) for information about available apps and software for people with aphasia.

Outcome measurements

All of the programs reported measuring participant outcomes, as shown in Table 6. Areas of outcome assessment were generally consistent with the survey results from 2013 and included linguistic and cognitive tests, ratings of communication, quality of life, and client and family satisfaction. The 2020 survey results showed an increased emphasis on measuring mood, including stress and anxiety, with almost half of the ICAPs and mICAPs reporting that they now assessed this area. Another notable change was the use of goal-attainment scaling (GAS) [33]. Half of the ICAPs and almost a third of the mICAPs responding to the 2020 survey used GAS as compared to only one ICAP in the 2013 survey. Some programs used attendance as an outcome measure and also considered the financial impact of the program by tracking revenue and expenses. Appendix seven includes a list of specific outcome measures that programs listed that they used to assess outcomes.

[Table 6 about here]

Discussion

Results from this international survey demonstrated growth in the implementation of ICAPs across the world. These data can be used to support the development of research grants and future projects focusing on the ICAP model. Modifications to program components and dose/schedule parameters with respect to the original 2013 definition of ICAP were also found.

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Growth and modification to ICAPs

Growth connected to the implementation of the ICAP model and underlying ICAP philosophy is demonstrated by an increase in respondents to the 2020 survey compared to the 2013 survey. The 2020 survey provided options for programs to describe modifications made to one of the core elements of the ICAP model. Common modifications included a variation in the intensity of the therapeutic dose (e.g., less than the 30-hour minimum dose over two weeks), a reduction in programmatic offerings (e.g., no dedicated family education, computer time, or group therapy), and programs that do not include a cohort of participants beginning and ending the program at the same time. The overall increase in respondents demonstrates a clear international interest in the ICAP model of service delivery and includes several respondents who indicated a plan to expand their mICAP program offerings to meet the ICAP definition. Other programs described specific barriers to meeting the formal ICAP definition such as limited clinical staff, time constraints imposed by the clinical setting, or a rolling admission process.

ICAP dose and schedule

ICAPs by definition are delivered intensively and provide a high overall dose of intervention but research regarding appropriate dosing of therapy highlights complexity when attempting to describe and compare therapies. Baker [34] identified that optimal intensity of therapy is a complex notion that is comprised of multiple variables with several current description methods. Warren, Fey, and Yoder [35] described how the cumulative intervention intensity is dependent on the main ingredients in the therapy tasks, the duration and frequency of sessions, and total intervention duration. A cumulative intensity is the calculation of the total number of specified speech tasks. Another metric to assess the "intensiveness" of a treatment is to consider a Therapeutic Intensity Ratio (TIR) [20]. Therapeutic Intensity Ratio divides the number of hours of therapy delivered in a week by a 40-hour work week to calculate a

percentage. The TIR provides a basis to compare therapeutic intensity between programs.

In the definition of an ICAP, the TIR of a program providing three hours of therapy a day, five days a week would equal 37.5%. The maximal intensity reported for an ICAP in the 2020 survey provided six hours of therapy a day, five days a week for a TIR equal to 75%. At present, there are no agreed upon standards in the field for reporting dose and therapeutic intensity (see recent review by Harvey et al. [36] for an overview), however a TIR of 75% is at the upper limit of most current reports of aphasia treatment intensity. TIR may be a consistent way to compare doses across intensive programs. It remains unclear whether intensive aphasia therapies are superior to more distributed doses overall, or whether there may be subgroups of people with aphasia for whom different doses are differentially effective, with several research trials in progress addressing these questions (see recent reviews by Cherney et al. [37]; Pierce et al. [38]). What is clear from the results of this survey is that an increasing number of programs across the globe are prioritising the delivery of aphasia services in high and intense doses, presumably with the belief that they confer added benefit to the ICAP participants.

ICAP comprehensiveness

In addition to overall program dose and intensity, the breadth of the treatment targets and formats by which the treatments are delivered, including individual, group, and computer-based interventions, are hallmark features of an ICAP. This comprehensiveness differentiates an ICAP from other intensive aphasia programs that provide a single treatment such as group treatment or Intensive Language-Action Therapy (ILAT/CIAT; [39]; (see figure 1). The 14 ICAPs in the 2020 survey continue to target all areas of the WHO-ICF, providing a variety of both impairment based and functional communication interventions that focus on activity limitations and participation restrictions. These ICAPs address environmental and personal

factors of the WHO-ICF, incorporating family education, communication partner training, and wellness strategies into their programs.

Not all programs are able to provide this broad array of activities and the modifications that resulted in seven programs being classified as mICAPs included omission of family education, computer time, or group therapy. Eight programs responded to the 2020 survey but did not meet criteria for either an ICAP or mICAP even though the survey instructions defined core ICAP and mICAP characteristics. These programs were classified as "other" because of multiple changes to core components including modifications of both comprehensiveness and intensity of services or the lack of a cohort of participants that start and end the program at the same time. It is essential that programs are clear about whether or not they meet the criteria of an ICAP or mICAP so that consumers are informed about the various treatment options that are available and the evidence supporting them.

ICAP costs and sustainability

While preliminary feasibility of implementing ICAPs is documented [20], and our survey results highlight the growth of this service delivery model, it is important to address issues regarding program sustainability. Of the 2013 survey respondents, 25% of the programs did not respond in 2020 and upon further investigation it was found that these programs were no longer operating. Three of these former programs were university programs and one program was hospital-based. Several factors may account for their closure, but two factors that are applicable to our discussion on the sustainability of ICAPs are the importance of having a leader who is committed to the program and issues related to financial stability.

In both the 2013 and the 2020 survey, respondents commented on the importance of having a leader who was passionate about the ICAP as a service delivery model for people with aphasia. We argue that the successful implementation of an ICAP is dependent on its leadership who must advocate for and promote the program, especially when the ICAP is an

optional service offered only a few times a year and not yet a mainstream service. The leader must address issues such as budget, facilities, and staffing. The leader must also oversee the day-to-day administration of the treatments ensuring the quality of the services and the satisfaction of the participants and their family members. When a leader retires without a succession plan or when a leader changes his or her priorities, the sustainability of the ICAP may be impacted.

With regard to finances, a recent study showed that the first-time costs of running a month long hospital-based ICAP in the USA for a cohort of eight participants with aphasia was $133,644 [40]. If the provider is not able to recoup the costs of running the ICAP, the program may not be sustainable. Notably, the major contributor to the provider costs was clinician salary. Some university ICAP programs have been able to mitigate these costs by utilizing speech-language pathology graduate students who provide the intervention under supervision [24]. This serves a twofold purpose of addressing the therapy needs of the person with aphasia while at the same time providing training to the students. Faculty costs associated with the supervision of students during the ICAP program are then covered in part by student tuition dollars.

In most countries, participation in an ICAP is not reimbursed by insurance or covered by the national health service. In some cases, the cost to the provider of running the ICAP may be covered by philanthropic funds or research grants. When these are not available, it is the person with aphasia who must pay for the ICAP services. For hospital and clinic-based ICAPs particularly, these out-of-pocket expenses may be high, making the program unaffordable to many which further impacts the sustainability of the ICAP.

Recent international focus group research explored the barriers and enablers to implementation of intensive aphasia services including ICAPs [41]. This research identified cultural, collaborative, advocacy, and innovation factors that were seen to be modifiable, to

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increase delivery of intensive aphasia programs. Future research should qualitatively investigate the challenges and barriers behind discontinued ICAPs and the development of aphasia programs that have yet to meet the criteria of an ICAP or mICAP. Future research also needs to explore the practical issues associated with sustaining the ICAP service delivery model over long periods of time.

COVID-19 Implications for ICAPs

Since the completion of the 2020 survey and in response to the onset of the COVID-19 pandemic, and the reduced ability for families living with aphasia to access post-acute rehabilitation services, several clinical sites have rapidly developed telehealth-based ICAPs (verbal communication with CA Off and LR Cherney; unreferenced). While telehealth services may increase the access to rehabilitation, virtual platforms present new and different challenges for those implementing the ICAP service delivery model. Some challenges may include: (1) assessing telehealth readiness (i.e., access to internet and hardware, availability of e-helper, technological literacy) for each family, (2) appropriately and legally adapting diagnostic and outcomes-based assessments for delivery via a telehealth platform, (3) organizing the logistics of multiple virtual meetings/overlapping sessions, (4) adapting the treatment model to adequately support the more severely impaired individuals with aphasia, and (5) adhering to state and interstate telehealth provision rules and regulations. Significant effort is required to maintain the comprehensive nature of the ICAP service delivery model when delivering services via telehealth – for example the virtual modality is likely to reduce the amount of time that patients and care-partners spend with each other in social communication contexts, potentially limiting the bonding and friendship building that occurs spontaneously during the in-person ICAP.

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ICAP research agenda and reporting standards: Where are we now and where should we go next?

With an increase in the number of ICAPs and mICAPs being clinically implemented across the globe and the increased number of respondents to the 2020 survey, it is important to revisit the developing research base supporting the ICAP model. Thus far, these Phase I investigations have provided evidence of *proof-of-concept***,** describing a number of distinct ICAPs while demonstrating desired treatment effects under a range of conditions [20,22-24,26,42-44]. While each of these studies have provided clear descriptions of the outcome measures used to measure the desired treatment effect, comparing patient outcomes across ICAPs remains challenging as a result of inconsistency of outcome measures used across studies. Moving forward, ICAP researchers should minimally include the core outcome set for aphasia treatment research that reached international consensus in 2019 [45]. Furthermore, while these publications provide clear descriptions of programmatic aspects of the ICAP (e.g., session types implemented), details about the specific treatment approaches implemented during individual sessions have not been clearly reported. Our survey revealed a large number of diverse protocolized therapies being utilized across programs. In addition to following the Template for Intervention Description and Replication (TIDieR) checklist and guide [46], we recommend that ICAP publications include the following details to allow for improved comparison and replication across ICAPs: hours per day, days per week, total weeks, total number of hours (i.e., total intervention duration), hours of session types per day (i.e., individual, group, technology), and treatment intensity ratio [20]. We also recommend that ICAP publications more clearly describe session types (e.g., individual, group, technology, patient education/counseling, family education/counseling) and the types and hours of individual aphasia treatment approaches (i.e., protocolized therapies or levels of impairment treated) applied to each participant. Descriptions of staff preparation and training also seem important to better understand implementation issues of this complex intervention

approach.

Phase I studies have also provided evidence to demonstrate that the ICAP service delivery model is broadly *feasible* and can be implemented across a variety of healthcare contexts. These feasibility and acceptability studies have described the perspectives of clinicians implementing the ICAP model [27], the feasibility of using graduate student speech-pathology clinicians to implement ICAP treatment sessions [24], the feasibility and acceptability of implementing family caregiver interventions in the context of the ICAP model [47], the use of iPad technology in the context of the ICAP model [42], and the feasibility of infusing occupational therapy [44] and occupational therapy graduate students in the ICAP model [48].

To date, only one study [21] meets the definition of a Phase II research protocol [28]. In a nonrandomized, parallel-group, pre-post design, Dignam and colleagues [21] compared the efficacy of a massed versus distributed model of intensive and comprehensive aphasia treatment, with both programs achieving the same "*total intervention duration*" [35]. To date, no Phase II study has compared an ICAP to usual care or directly with other intensively delivered treatments such as ILAT/CIAT [39]. Therefore, to date no evidence has been provided to support the efficacy of the ICAP model as compared to other models and this is an important research goal.

In summary, while the evidence base demonstrates preliminary efficacy and feasibility, additional research is needed to (1) compare the efficacy of ICAPs to other intensively delivered programs and (2) document the issues of sustainability and the lack of widespread ICAP implementation around the globe.

Summary

In summary, ICAPs continue to be provided in many countries across the globe and at a

higher rate than in 2013. It appears that the original ICAP definition [19] has retained its utility as evidenced by the 14 programs in this survey whose programs match that definition. One major finding of this survey was the documentation of programs that we term mICAPs, that have modified a single major element of the ICAP program, often for pragmatic implementation reasons. Some significant differences between ICAP and mICAP programming include a greater focus on total communication, the use of technology, advocacy activities, and the arts in ICAPs. While the original ICAP definition has retained utility, there have been notable developments in program elements including: an increased emphasis on intervening and outcome measurement in participant and family mental health and wellbeing, accompanied by a greater number of programs employing mental health professionals; greater employment of goal attainment scaling as a key goal setting and outcome measurement tool. Future research should focus on the comparative efficacy of ICAPs/mICAPs and other forms of aphasia interventions and obtaining a deeper understanding of the factors underpinning growth and sustainability in provision of this service delivery option.

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Figure Captions

Figure 1. Schematic of various service delivery options for aphasia. Horizontal continuum represents intensity; vertical continuum represents goals and approaches; depth represents total duration.

Figure 2. Number of ICAPs in 2013 compared to the number of ICAPs and mICAPs in the 2020 survey.

Figure 3. Hours of activity type per treatment day

Figure 4. Percentage of ICAPs (4a) and mICAPs (4b) showing frequency of family involvement in various activities. (Other responses included education, reading/writing class, recreation/relaxation, paired treatment, and interdisciplinary sessions such as Physiotherapy.)

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Tables

Table 1. Thematic analysis of number of ICAPs and mICAPs reporting core values and principles

Core Values and Principles	**2013 ICAPs (n=13)**	**2020 ICAPs (n=9)**	**2020 mICAPs (n=3)**
Patient-Centered Care		9	2
Principles of Neuroplasticity	5	7	1
Comprehensive Treatment including WHO-ICF and LPAA		5	2
Philosophy of Ongoing Recovery		4	1
Supportive Community	4	4	0
Evidence-Based Practice	4	3	1
Family Caregiver Education		3	1
Context of Clinical Training		1	1
Individualized Treatment Goals	6		
Aim to Enhance Life Participation	3		
Focus on Family and Friends	3		
Involving Peer Volunteers	1		
Daily Feedback	1		
Education about Stroke and Aphasia	1		

Note: ICAPs = intensive comprehensive aphasia programs; mICAPs = modified intensive comprehensive aphasia programs; WHO-ICF = World Health Organization International Classification of Functioning and Disability, LPAA = Life Participation Approach to Aphasia

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Table 2. Admission criteria reported for ICAPs and mICAPs

Admission Criteria	2013 ICAPs (n=13)	2020 ICAPs (n=14)	mICAPs (n=7)
Endurance	9	3	4
Time post onset	8	5	4
Age	6	9	3
Severity of aphasia	4	3	1
Motivation	4	2	1
Independent or caregiver supported ADLs (toileting)	3	11	
Medically stable	3	2	2
No history of dementia or cognitive impairment/pass a cognitive screening	3	4	2
Ambulate/transfer	2		
Auditory comprehension	1	1	1
Must attend with communication partner	1		1
Knowledge of English	1	1	1
Ability to function in group setting		1	1
Ability to say/repeat words		1	1
Matching within cohort on similar clinical characteristics		1	
Own transportation		2	
Primary aphasia with no concurrent diagnoses		4	1

Note: ICAPs = intensive comprehensive aphasia programs; mICAPs = modified intensive comprehensive aphasia programs

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Table 3. Number of ICAPs and mICAPs employing staff at full-time equivalent (FTE) fractions

	2013 ICAPs	2020 ICAPs	2020 mICAPs
Roles in 2013 Survey			
Speech Language Pathologists	11	14	7
Students	5	6	5*
Administrative Staff**	4	7	2
Volunteers	3	3	1
Recreation Coordinators	2	1	1
Physical Therapists	2	2	3
Music Therapists	1	1	0
Roles Added to 2020 Survey			
Social Workers		1	0
Psychologists		4***	3
Physicians		2	1
Art Therapists		0	0
Occupational Therapists		0	2
Exercise Coordinators		1	1
Other		4	

Note: *Students include 1 additional response from free-text box: roughly 25 students per term, each do half day per week; **Administrative Assistant in 2013; Administrators/Clerical assistants in 2020 ; ***Psychologists includes 3 additional responses from free-text box: Family Counselor, Counsellor/supportive listener, Mental Health Counselors; ICAP Other Textbox: 1 program reported 4 Faculty or research support staff each part time, 1 reported a Clinical Manager, 1 reported an Allied health assistant, and 1 reported Rehab assistants

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Table 4. Percentage of programs reporting typical activities (from survey provided option)

Activity/Task	ICAP (n=14)	mICAP (n=7)
Education about stroke and aphasia	100%	86%
Discourse/conversation	100%	71%
Reading	100%	71%
Sentence Construction	100%	71%
Word Retrieval	100%	71%
Comprehension	100%	57%
Computer apps	100%	57%
Conversation partner training	93%	71%
Writing	93%	71%
Total communication strategies	93%	57%
Telephone use	86%	43%
Speech production tasks (e.g. for apraxia of speech; dysarthria)	79%	71%
Internet browsing	79%	29%
Arranging additional/follow up activities and services	71%	57%
Managing mood and wellbeing	71%	57%
Advocacy activities	57%	29%
Identity (e.g., biographic narrative)	43%	0%
Life booking	43%	43%
Music	43%	14%
Singing	36%	14%
Meditation	29%	0%
Physical exercise	21%	43%
Painting	14%	0%

Yoga	14%	0%
Drama	0%	0%
Fundraising	0%	0%

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Table 5. Number of ICAPs and mICAPs reporting use of protocolised therapies

Commonly Used Protocols	ICAP (n=14)	mICAP (n=7)
Semantic Feature Analysis (SFA)	13	4
Script Training	12	4
Verb Network Strengthening Treatment (VNeST)	12	4
Melodic Intonation Therapy (MIT)	9	3
Phonological Components Analysis (PCA)	9	3
Multi-Modality Aphasia Therapy (M-MAT)	9	2
Oral Reading for Language in Aphasia (ORLA)	8	4
Biographic narrative	8	3
Phonomotor Therapy	8	3
Response Elaboration Training (RET)	8	3
Promoting Aphasics' Communication Effectiveness (PACE)	8	2
Constraint-induced Aphasia Therapy (CIAT)	7	4
Copy and Recall Treatment (CART) (including T-CART)	8	3
Story telling	7	3
Treatment of Underlying Forms (TUF)	7	1
Anagram and Copy Therapy (ACT)	6	1
Sentence Production Program for Aphasia (SPPA)	6	1
Intensive Auditory Comprehension Treatment	4	

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Table 6. Updated number of outcome areas measured by ICAPs (tick boxes)

	2013 ICAPS (n=12, %)		**2020 ICAPs (n=14, %)**		**2020 mICAPs (n=7, %)**	
Outcome areas 2013 survey						
Linguistic and cognitive tests	12	100%	11	79%	5	71%
Ratings of communication	12	100%	10	71%	5	71%
Quality of life, well-being	9	75%	8	57%	5	71%
Mood	1	8%	6	43%	3	43%
Client satisfaction with ICAP	9	75%	10	71%	5	71%
Family satisfaction with ICAP	7	58%	6	43%	3	43%
Goal attainment scaling	1	8%	7	50%	2	29%
Options added to 2020 Survey						
Family ratings			4	29%	2	29%
Stress or Anxiety			4	29%	3	43%
Costs/economic			3	21%	1	14%
Dropouts/attendance			7	50%	3	43%

Appendices

Appendix One

Database search strategies

Database Search Strategy Development

Search strings executed in databases (excluding social search) were searched with double quotes to indicate an exact phrase search (no word variants). To ensure plurals were included, the Boolean OR operator was used to broaden the search, e.g., "intensive comprehensive aphasia program" OR "intensive comprehensive aphasia ***programs***." The acronym ICAP has other meanings in disciplines outside of speech language pathology. Therefore, a Boolean AND operator was used to ensure records also contained the word "aphasia" (or the plural "aphasias"). Parentheses were used to clarify the order of operation for these Boolean operators. The query produced by these considerations is: ((ICAP OR ICAPS) AND (aphasia OR aphasias)).

Social Search Strategy Development

Twitter search was performed in a newly created account in which no other accounts were followed, and no tweets were posted. The "advanced search" functionality was used in Twitter to construct the search. The search was conducted in Incognito mode in Chrome.

Facebook search was performed in a dormant Facebook account associated with the university library where only four other university librarians had been "friended" and no textual posts had been posted.

Result counts are not provided for Facebook or Twitter searches. To ensure accurate hand-counted results and prevent search results from being truncated or cut-off, searches were subdivided into individual years.

Appendix Two

Definitions for the survey

ICAPs

ICAPs are defined (Rose et al., 2013) as a service delivery model that optimizes recovery by: a) Providing an **intensive dose** (with a specific start and end date) of **a minimum of 3 hours of daily treatment** over a **period of at least 2 weeks (minimum 30 hours) AND** b) Being **comprehensive** in scope, utilizing **individual therapy** and **group therapy** and **patient/family education** and **technological advances** (e.g. apps, computer therapy) **AND** c) Targeting **both** the **impairment** and the **activity/participation** levels of **language and communication functioning.** The overarching goal of an ICAP is to maximize communication potential with the goal of enhanced life participation. Note: Constraint Induced Aphasia Therapy/Intensive Language Action Therapy when delivered as a standalone treatment does not fulfill the above definition. CIAT/ILAT may be delivered with additional components that allow it to meet the definition of a modified ICAP (mICAP).

mICAPs:

Since the 2013 definition, a variety of ICAPs have been developed with modifications to the original definition, which we are calling modified ICAPs (mICAPs). mICAPs may include all of the above features but have a modification to **one** core feature (intensity, treatment modes, or ICF level). For example, providing the minimum overall amount of therapy (30 hours) over 3 rather than 2 weeks, **or** not providing family education whilst providing intensive individual, group, and app-based therapies.

Appendix Three

Description of response categorisation

The survey yielded a total of 48 respondents. Following the procedure to address the duplicate and partial respondents, 18 entries self-rated as meeting the ICAP definition. Further, 11 entries indicated at least one modification to the core components of an ICAP and self-rated as a mICAP. Two members of the research team independently reviewed the responses and then met to discuss the correspondence of the self-ratings to the ICAP and mICAP definitions. Of the 18 ICAP responses, 14 were confirmed and recommendations were made to the full research team to reconsider the self-rating for four entries. After the full team discussion, two programs were changed to mICAPs due to a single modification of one core feature from the ICAP definition, and two programs were classified as “Other” because they did not meet the criteria for either an ICAP or a mICAP. After an extensive review of the program responses that self-rated as mICAPs, seven programs were confirmed to meet the criteria of only a single modification to one of the core ICAP elements. Six programs were classified as “Other” because the responses clearly indicated at least two deviations from the core ICAP elements. The final classifications for the 29 program responses included 14 ICAPs, 7 mICAPs, and 8 responses that were classified as “Other”.

Appendix Four

Sources of ICAP funding by country

	Country	Self Pay	Insurance	Research Funds	Government (non-research) Grants	Donations	Other	Not reported
ICAPs	AUS			✓				
	CAN	✓	✓			✓		
	GBR					✓	✓	
	GBR			✓		✓		
	GER		✓					
	SWE/ESP	✓	✓					
	USA							✓
	USA	✓	✓			✓		
	USA	✓						
	USA	✓						
	USA	✓				✓		
	USA	✓				✓		
	USA			✓	✓			
	USA		✓				✓	
mICAPs	GBR					✓	✓	
	GER			✓				
	IND	✓						
	NOR				✓		✓	
	USA						✓	
	USA						✓	
	USA	✓				✓		

Appendix Five

List of therapy applications and software

Apps/Software	Type of Program	ICAP (n=14)	mICAP (n=7)
Tactus Therapy	Company	10	1
Constant Therapy	Application	6	1
ORLA Software	Software	4	1
Phone apps (calendar, notes, text, voice memos, photos, videos, etc.)	Application	4	2
Other		3	3
Social Media	Other	2	1
Speech Sounds on Cue	Application	2	1
Attention Process Training (APT-3)	Software	1	1
React	Application	1	1

Note: ICAPs = intensive comprehensive aphasia programs; M-ICAPs = modified intensive comprehensive aphasia programs
*= program is still in a clinical trial and is not yet available to the public
Note: Other software reported by single ICAP or mICAP only included AAC/AT lab, AphasiaScripts, Co-Writer, eSALT, FreshMinder, iReadMore, iTALKbetter, Lexia, Lingraphica, Listen In, Neolexon, Penfriend, Pictello, Predictable, Proloquo, StepbyStep and Touch Chat Aphasia Pages.

Appendix Six

Additional infrequently reported therapy protocols

Other Protocols	ICAP (n=14)	M-ICAP (n=7)
Combined Aphasia and Apraxia of Speech Treatment (CAAST)	2	1
Semantic Priming to Improve Comprehension and Expression of Sentences (SPICES)	1	1
Abstract Semantic Associative Network Training (AbSANT)	1	
Attentive Reading and Constrained Summarization – Written (ARCS-W)	1	
Attentive Reading and Constrained Summarization (ARCS)	1	
Language-Specific Attention Treatment (LSAT)	1	
Mapping therapies (MT)		1
Modalitätenaktiviering in der Aphasietherapie (MODAK)	1	
Multiple Oral Re-Reading (MOR)	1	
Newcastle Aphasia Therapy Programmes e.g., auditory processing		1
Novel Approach to Real-Life communication: Narrative Intervention in Aphasia (NARNIA)	1	
Problem Solving Therapy Program (PSTP)	1	
Singing Intonation Prosody Atmung Rhythm Improvisation (SIPARI)	1	
Speech entrainment	1	
ST-WM Aphasia	1	
TAKTIN/PROMPT	1	
Transcranial Direct Current Stimulation (tDCS)	1	
Treatment for Wernicke's Aphasia (TWA)	1	

Appendix Seven

Reported Outcome Measures used in ICAPs and mICAPs (from free-text boxes)

Lists of Measures Used	Results from 2013 Survey	Added to 2020 Survey ICAPs	Added to 2020 Survey mICAPs
Linguistic and Cognitive Tests	Language samples	Aphasia Bank Discourse Protocol	TRIP
	Western Aphasia Battery	Raven's Coloured Progressive Mat	Test of Everyday Attention
	Comprehensive Aphasia Test	Scale for Language Rehab (Milman, unpub)	Repeatable Battery for the Assessment of Neuropsychological Status
	Verb Naming Test	Apraxia of Speech Rating Scale	Scales of Cognitive and Communicative Ability for Neurorehabilitation
	Boston Naming Test	Test for Apraxia of Speech (TAX)	
	Psycholinguistics Assessment of Language Processing (PALPA)	Nicholas and Brookshire	
	Pyramids and Palm Trees	Reading Comprehension Battery for Aphasia	
	Cognitive Linguistic Quick Test	Boston Diagnostic Aphasia Examination	
		Cookie Theft	
		Story Retell Procedure	
		Philadelphia Naming test	
		Test of Adult Word Finding	
		Communication Activities of Daily Living	

		Apraxia Battery for Adults	
		Discourse Comprehension Test	
		Northwestern Assessment of Verbs and Sentences	
		Obj & Action, Nouns & Verbs	
Ratings of Communication	Assessment of Living with Aphasia	Communication Participation Item Bank	Communication Activities of Daily Living 2
	Communication Effectiveness Index	Communication Outcomes After STroke	Cookie Theft
	MiniCal	Interviews with client and family	Western Aphasia Battery
	Communication Confidence Rating Scale for Aphasia	Discourse – Content Information Unit analysis	Amsterdam-Nijmegen Everyday Language Test
	American Speech-Language-Hearing Association Functional Assessment of Communication Skills for Adults	Western Aphasia Battery	Functional Communcation Therapy Planner
	Aphasia Communication Outcome Measure		Communicative Activities Checklist
			Gesture/drawing
			Social Capital Assessment Tool
			Child and Adolescent Scale of Participation-Youth (participation comm skills)
Quality of Life, Well-being	Supports Intensity Scale	Assessment of Living with Aphasia	EuroQol 5D
	Burden of Stroke Scale	Aphasia Impact Questionnaire	Hilari[a]

		Communication Outcomes After STroke	AQI[b]
		Multicomponent Fatigue Scale	Interview
		Aphasia Communication Outcome Measure	Traumatic Brain Injury Quality of Life - shortforms
		Communication Effectiveness Index	
		Quality of Communication Life scale	
		Patient Reported Outcome Measurement Information System – Satisf w. social activities	
		Assessment of Quality Of Life – 4D	
		Stroke and Aphasia Quality of Life Scale-39	
Mood	Visual Analogue Self-Esteem Scale	Geriatric Depression Scale	General Health Questionnaire-12
		Stroke Aphasic Depression Questionnaire-10	Hamilton
		Mental Fatigue Scale	
		Assessment of Living with Aphasia	
		Burden of Stroke Scale	
		Patient Reported Outcome Measurement Information System – mental health	
		Dynamic Visual Analogue Mood Scales	
		Stroke Aphasic Depression Questionnaire-C21	
Satisfaction with ICAP		Internal rating scale, questionnaire, survey, feedback form	Unstructured
		Focus group	
		Exit / semi-structured interview	

Family Ratings		Stroke Aphasic Depression Questionnaire-10	Communication Outcomes After STroke - Carer
		Communication Effectiveness Index	Child and Adolescent Scale of Participation-Caregiver (partic comm skills)
		Family Assessment Motivation, and Linkage Intervention	
		Perceived Stress Scale	
		Caregiver Rating Scale (American Medical Association)	
		Bakas Caregiving Outcomes Scale	
Goal Attainment Scaling		Likert	Goals setting process & review
		Informal 1-10	Participants generate goal; Goal Attainment Scale
		Questionnaire	
		SPROUT (goal bank and ratings; in-house)	
		Goal Attainment Scale goals	
Stress or Anxiety		Modified Perceived Stress Scale	Hospital and Anxiety Depression Scale
		Perceived Stress Scale (co-survivor)	Traumatic Brain Injury Quality of Life - anxiety
		Mental Fatigue Scale	
Costs/Economic		Total cost vs # of therapy hrs provided	Budget holder

		Track revenue and expenses	
		Tailored assessment	
Dropouts/ Attendance		Nil 100% attendance, no dropouts	Frequency count
		Questionnaire	Database/spreadsheet
		Tracking system	

Note: Others listed but no specific measure recorded: Language skills (picture naming, word retrieval, discourse analysis, treatment/nontreatment baselines), Communication skills (informal measures), Goal Attainment Scaling (set for each client after pre-treatment testing and 1st 3 days of treatment and modifying weekly thereafter or as needed), Confidence rated most days informally.

[a]Sic – likely referring to Stroke and Aphasia Quality of Life Scale-39 by Hilari et al. (2003)

[b]Sic – possibly referring to Aphasia Impact Questionnaire (AIQ)