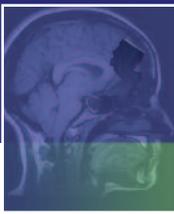


# The New Jersey Aphasia Study Commission

## Final Report

May, 2015





# The New Jersey Aphasia Study Commission Final Report

## Members of the Aphasia Study Commission

**Mary Jo Santo Pietro, Chair;** Person with Aphasia Expertise

**Karen Tucker, Co-Chair;** Person who Provides Services to Persons with Aphasia

**Wendy Greenspan, Member;** Person who Provides services to Persons with Aphasia

**Nancy King, Member;** Person with Aphasia

**Mike Adler, Member;** Person with Aphasia

**Joseph Amoroso, Ex-officio member;** NJ Dept. of Human Services, Division of Disabilities

**Steven Green, Ex-officio member;** NJ Dept. of Banking and Insurance

**Abate Mammo, Ex-officio member;** NJ Dept. of Health

*The Commission would like to thank all of those who helped in the development of this report, especially the hard-working participants of the two subcommittees.*

## Contributing Sub-Committee Participants:

**Andrew Gomory,** Lingraphica, inc.

**Shirley Morganstein,** Speaking of Aphasia

**Barbara Schwerin-Bohus,** Hackensack University Medical Center

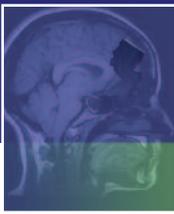
**Rachel Hammond,** NJ Dept. of Health

**Debra Virgilio,** NJ Dept. of Health

**Emmanuel Noggoh,** NJ Dept. of Health

**Elaine Adler,** Family Member

**John King,** Family Member



# The New Jersey Aphasia Study Commission Final Report

## Statement from the Chairperson

The Aphasia Study Commission would like to thank the New Jersey State Legislature and Governor Christie for passing PL 2010, c.117 that created this much needed Commission. The law came into being as a result of urgent pleas from a large group of New Jerseyans who came together from all walks of life to let the legislature know that they have not received their fair share of attention. This group of people came from all age groups, all cultures and all geographical areas of New Jersey. Their campaign was remarkable because this diverse group of people was united by only one common factor-- they all have serious difficulty speaking for themselves. They all have aphasia.

I have been teaching a course in Aphasia to graduate students in speech-language pathology for thirty-five years, first at Rutgers University and now at Kean University's School of Communication Disorders and Deafness. I have come to know hundreds of brave and extraordinary people and their families who live with aphasia. I am honored to be given the opportunity to make their voices heard through the work of this Commission.

Here is what I have learned and taught about aphasia over the last three-and-a-half decades: Many thousands of New Jerseyans live with aphasia for many years, even decades after a stroke or head injury. The inability to communicate is devastating in every way to both the persons with aphasia and their families. Untreated aphasia is costly to families, communities, and the long-term healthcare system. Studies in neuroplasticity show that with treatment and support, persons with aphasia continue to improve and regain life skills and independence for a lifetime. However, for a confluence of reasons which this Commission explored, persons with aphasia and their families do not receive adequate support and treatment. In fact, the general public, most medical professionals and even some families living with aphasia know little about aphasia.

The work of this Commission, then, was to try to figure out how many persons with aphasia who can't speak for themselves are living in New Jersey; what are the unmet needs of these persons and their families, and how the services they need can best be provided.

I would like to thank all the members of the Aphasia Study Commission and its volunteer subcommittees, and all aphasia advocates, who worked so hard to gather the information and formulate the recommendations in this report. I would also like to thank the ex-officio members from the Departments of Health, Human Services and Banking and Finance, who took our cause to heart and contributed enormously.

I sincerely hope that we have lived up to the expectations of that original group of voices of aphasia who worked so hard to get PL 2010, c.117 passed. And I hope that our recommendations, broad in scope but modest in cost, can be implemented as soon as possible.

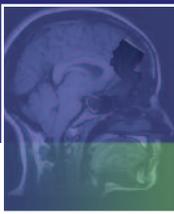
**Mary Jo Santo Pietro, Ph.D. CCC-SLP**  
Chair, Aphasia Study Commission



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## Executive Summary

Aphasia is an acquired language disorder caused by localized brain damage resulting from a cerebrovascular accident (stroke), traumatic brain injury, brain tumors or other neurological conditions. People with aphasia suddenly find they have difficulty with language in all forms--understanding, speaking, reading and writing. While many younger people are afflicted with aphasia, most persons with aphasia are over the age of 50. Current research shows that due to neuroplasticity, people with aphasia can make significant improvements in communication and quality of life for years after the onset of aphasia when provided with treatment and support. Health insurance covers the costs of speech-language therapy and support services in the first few months after onset (acute stage), but more than half of survivors live for years beyond onset (chronic stage). Despite the fact that people with aphasia are better able to adapt and learn in the chronic stage, few services and supports are available to them after the first few months.

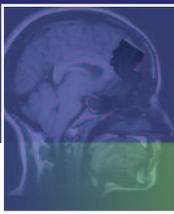
This document is the result of a year-long endeavor to carry out the mandates of P.L.2010, c.117 calling for an Aphasia Study Commission under the auspices of the New Jersey Department of Health to:

- (1) establish a mechanism to ascertain the prevalence of aphasia in New Jersey, and the unmet needs of persons with aphasia and those of their families;
- (2) study model aphasia support programs in the State; and
- (3) provide recommendations for additional support programs and resources to address the unmet needs of persons with aphasia and their families.

The eight members of the Commission met officially four times between April 2013 and April 2014. They created two subcommittees that included invited experts as well as Commission members. Subcommittee One tackled the problem of establishing the prevalence of aphasia in New Jersey, while Subcommittee Two sought information on the unmet needs of persons with aphasia and the currently existing programs and resources attempting to meet those needs.

### **1a. Prevalence**

Because there are no valid prevalence figures for the state of New Jersey, nor for the nation at large, the Commission sought to estimate prevalence in two ways: First, by examining existing related data bases in New Jersey, (e.g. The NJ Hospital Discharge Data Collection System (NJDDCS) which documents diagnoses at discharge from general acute care hospitals; and the Minimum Data Set (MDS) which tracks diagnoses of residents in longterm-care). And second, by employing statistical methods such as a “capture-recapture” methodology as well as using multiple estimates derived from the National Institutes of Health (NIH) study and the 2011 CDC Behavioral Risk Factor Surveillance System (BRFSS). Based on statistical approaches, the Commission arrived at an estimate of 55,603 persons with aphasia in New Jersey as probably the most reliable estimate. This number is significantly greater than the numbers of persons with better-known disabilities like Parkinson’s disease or Multiple Sclerosis. However, due



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to the limitations of the prevalence estimates, the Commission stated that there is an urgent need for a careful study to arrive at a reliable aphasia prevalence estimate.

## 1b. Unmet needs

The Commission found that in the acute stage of aphasia (1-3 months post onset), the needs of persons with aphasia and their families are largely being met through insured medical settings. Once discharged from acute rehabilitation, however, persons with aphasia and their families have very few options for treatment and support. The Commission examined unmet needs reported in the research literature and in a recent survey of New Jersey speech-language pathologists. They found repeated voicing of common themes:

- the need for **awareness** among the public, medical and support personnel, and even patients and families themselves;
- the need for **resources**, especially accessible information about the disorder and available services; Caregivers report
- the need for **services** for persons with aphasia and their families, especially their caregivers. There are very few community-based services suitable for persons with aphasia in the chronic stage, and almost no psychological/counseling services available for persons with aphasia or their caregivers.

## 2. Model Aphasia Support Programs

The Commission identified and studied seven model aphasia support programs in the state: The private non-profit Adler Aphasia Center; the Kean University Institute for Adults Living with Communication Disabilities; a hospital/rehabilitation outreach; an aphasia-based private speech therapy practice, Speaking of Aphasia; a New Jersey-based technology company with an internet virtual community, Lingraphica; and two additional non-profit community-based programs, the Jersey City Programs of All-Inclusive Care for the Elderly (PACE) program sponsored by Lutheran Social Ministries, and the Opportunity Project, Inc. which provides a “clubhouse” model of community service. While all of these models provide excellent programs for persons with aphasia and their caregivers, each is limited by financial need, personnel shortages, etc. The commission estimates that less than 2% of persons with aphasia have access to such programs statewide.

## 3. Recommendations for Additional Support Programs and Resources

The first recommendation of the Aphasia Study Commission asks the legislature to create a permanent **Task Force on Aphasia** housed in the New Jersey Department of Health. This task force comprised of professionals, caregivers, volunteers and persons with aphasia could assume responsibility for implementing the Commission’s twelve other recommendations both for establishing the true prevalence of aphasia, and for creating additional support programs and resources for persons with aphasia.



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## **Prevalence:**

1. Continue to gather data through current systems;
2. Collect data by piggy-backing aphasia questions to the New Jersey Behavioral Risk Factor Survey (NJBRFS) which is based on CDC's BRFSS.

## **Support Programs:**

3. Encourage and establish new aphasia community support groups in senior centers, county offices of the disabled, libraries, etc.;
4. Coordinate support groups within the State.

## **Resources to address unmet needs:**

5. Create focus groups to highlight regional needs;
6. Establish an informational website;
7. Create an aphasia-friendly quarterly e-newsletter;
8. Encourage distribution of aphasia information at hospital discharge;
9. Compile a registry of counselors and psychologists available to work with persons and families with aphasia;
10. Explore and document funding sources for post-acute services for persons with aphasia (PWA) in the chronic phase;
11. Coordinate listings with Area Agencies on Aging (County AOAs);
12. Enlist and assist persons with chronic aphasia who wish to instruct first responders, medical personnel, vendors, and others in their communities on the needs and abilities of persons with aphasia.

## **Conclusions:**

***Aphasia is a serious problem.***

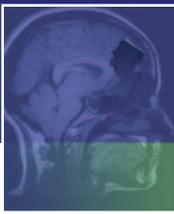
***Aphasia is a widespread problem.***

***Aphasia is a family problem.***

***Aphasia is a public health problem.***

***Aphasia is a costly problem for individuals, for society, for government.***

This Commission concludes that with awareness, treatment and support, quality of life for persons with aphasia and their families and their caregivers can be significantly improved, and that the State of New Jersey can be instrumental in making this a reality for a large number of people affected by aphasia.



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## Background



### Legislation and Charge

P.L. 2010, c.117 (Appendix IV) begins by citing the realities of living with aphasia in twenty-first century New Jersey. It notes that aphasia, which “occurs, most commonly after a stroke or traumatic brain injury” results in “difficulty speaking, and sometimes, difficulty with reading, writing, and understanding what other people are saying”. However, the law points out that “the condition does not affect a person’s intellect.”

The law describes the four most common types of aphasia (expressive, receptive, anomic and global), and notes that “many persons with aphasia are prone to depression, hopelessness, and isolation. . .”, but also notes that “persons with aphasia usually experience improvement over time, aided by speech therapy, rehabilitation services, and counseling.” Further, P.L.2010, c.117 estimated that “one million people in the United States have aphasia, more than the number of people suffering from Parkinson’s disease, muscular dystrophy, multiple sclerosis or cerebral palsy.” Considering the seriousness of the disorder and the size of the population, P.L. 2010, c.117 concludes: “It is, therefore, in the public interest for the State to establish a commission to study the prevalence and impact of aphasia on residents of the State and to review model support programs for persons with aphasia and their families.”

An eleven-member Aphasia Study Commission was established and given a three-part purpose:

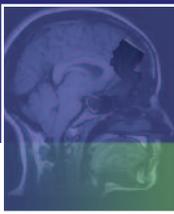
- (1) establish a mechanism in order to ascertain the prevalence of aphasia in New Jersey and the unmet needs of persons with aphasia and their families;
- (2) study model aphasia support programs, such as, the Kean University Institute for Adults Living with Communication Disabilities and the Adler Aphasia Center; and
- (3) provide recommendations for additional support programs and resources to meet the unmet needs of persons with aphasia and their families.

### Defining Aphasia

#### **An operational definition of aphasia:**

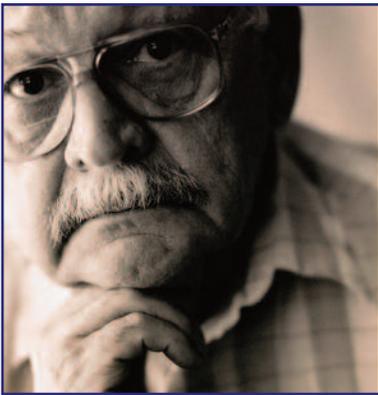
*Aphasia is an acquired selective impairment of language modalities and functions resulting from a focal brain lesion in the language-dominant hemisphere that affects the person’s communicative and social functioning, quality of life and the quality of life of his or her relatives and caregivers.*

Aphasia characteristics vary from person to person and can range from mild (occasional difficulty thinking of a word) to severe (little to no ability to speak), based on location and severity of the damage. While young Americans increasingly experience CVAs (cerebrovascular accidents/strokes) and other brain injuries, the majority of persons with aphasia are over the age of 50.



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The onset of aphasia is sudden and unimaginably traumatic. However, recent research shows that due to neuroplasticity, people with aphasia make significant improvements in communication and quality of life for years after the onset of aphasia when provided with treatment and support. The health professional with advanced training in the identification, evaluation and treatment of persons with aphasia is the certified speech-language pathologist (SLP). Speech-language pathologists are licensed by the State of New Jersey and certified nationally by the American Speech-Language-Hearing Association. Studies have shown that unfortunately physicians and other medical personnel know little about chronic aphasia and are unaware of its long-term effects including the capacity for chronic aphasia to improve over time. (McClenahan, et al., 1992). Many persons with aphasia do not themselves know that their communication difficulties stem from a disorder called aphasia, perhaps because so many health care professionals are unfamiliar with the condition.



Health insurance generally covers the costs of speech-language therapy and support services in the first few months after onset (acute stage), but more than half of survivors live for years and decades beyond onset (chronic stage). Despite the fact that people with aphasia are better able to adapt and learn in the chronic stage, few services and support programs are available to them after the first few months.

Reliable, precise numbers for the prevalence of aphasia do not currently exist for New Jersey nor for the United States as a whole. This Commission examined all available data from State and Federal records, and used a complex statistical approach and estimated that between 50,000 and 70,000 New Jerseyans and their families live with aphasia (see Appendix I); between one in 90 and one in 130 persons. Communication disabilities are as numerous in only two other populations—persons with autism and persons with Alzheimer dementia.

## **Impact of Aphasia**

Aphasia profoundly affects a person's communicative and social functioning, employability, and quality of life. The cost of the large scale loss of productivity and independence and the increase in long-term medical care expenses in this population is enormous. The CDC estimates that stroke alone, the primary cause of aphasia, "costs the United States an estimated \$35.5 billion each year. This total includes the cost of health care services, medications to treat stroke and missed days of work" (Go, et al., 2014; Greenberg, et al., 2003; Le Dorze & Brassard, 1995).

Aphasia places an enormous financial, professional, psychological, physical, and emotional burden on family caregivers. Divorce rates for married persons with aphasia are high, and early admission to long term care is common. Persons with aphasia are prone to depression, hopelessness and isolation. It is estimated that over 90% of stroke survivors experience clinical depression; yet counseling services for



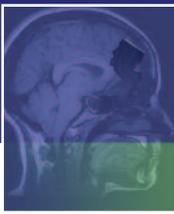
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persons with aphasia who have difficulty communicating are all but non-existent in the State (Townend, et al., 2010; Astrom, et al., 1993).

## **Hope for Aphasia**

Evidence-based treatments exist that result in significant improvements in the communication skills of persons with aphasia for many years post-onset due to neuroplasticity. (Lyon, 2009; Robey, 1998). Persons with chronic aphasia who participate in the few model programs that currently exist in New Jersey show remarkable gains, not only in communication skills, but in general health, independence, productivity and overall quality of life (See Avi's Story on p.17).

Support for persons with aphasia and their families can, and does, reduce their level of disability and the overall cost of their care (Hilari, et al., 2003).



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## Study Commission Charge 1: Ascertain Prevalence of Aphasia and Unmet Needs



The first charge of P.L. 2010, c.117 called for the Commission to “Establish a mechanism in order to ascertain the prevalence of aphasia in New Jersey and the unmet needs of persons with aphasia and those of their families.” The Commission considered this charge in two parts as follows: **A) a mechanism to ascertain prevalence of aphasia in New Jersey; B) ascertaining the unmet needs of aphasia and those of their families.**

### **A: A Mechanism to Ascertain Prevalence of Aphasia in New Jersey**

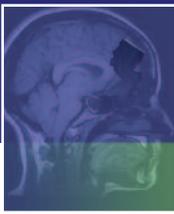
An extensive search by members of this Commission revealed that there are no reliable statistics on the prevalence of aphasia in New Jersey. What was even more surprising to the Commission was that there were no reliable national aphasia prevalence estimates or statistics. The few available prevalence estimates were based either on extremely small samples or were bold extrapolations from clinical findings. Some estimates had no sources at all for their prevalence estimates to allow the Commission to evaluate their reliability. It was against this background that this Commission began a process to arrive at an estimate that would lead to a reasonable starting point for further assessment of the aphasia problem in the State. First, the Commission created a “Prevalence Study Subcommittee” as one of two subcommittees that explored ways to arrive at a reasonable starting point for estimating aphasia prevalence. The prevalence study subcommittee created its prevalence estimate in two ways: examining existing data bases in New Jersey, and using statistical methods.

### **Examination of existing data bases in New Jersey<sup>1</sup>**

- The subcommittee examined sources of data currently available in the State including those maintained by the New Jersey Department of Health. One such source is the NJ Discharge Data Collection System (NJDDCS), also known as the Uniform Billing (UB) database, which contains Aphasia status of a patient who had hospital encounters and reported as diagnosis codes. For this analysis, the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) codes of 784.3 or 438.11 reported as primary or secondary diagnoses were used. The first 13 diagnosis codes out of a possible 25 for aphasia mention were examined in the databases for this analysis. The analysis started with discharges in 2011 which contained 2,650,

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1 In January 2014, the New Jersey Department of Health (NJDOH), consistent with CDC’s Paul Coverdell Acute Stroke Registry, added “aphasia” as a data element in its New Jersey Acute Stroke Registry (NJASR). Because aphasia cases come about predominantly from strokes, this addition will provide a better idea of the number of acute aphasia cases, provided that patients are adequately evaluated for it. This recent addition of aphasia in NJASR is a step forward, however, it will not provide sufficient information on overall aphasia prevalence, nor will it provide useful information about the need for chronic aphasia treatment.



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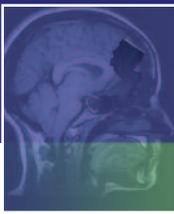
322 patients (including Emergency Department cases). In 2011, 3,848 (0.15%) were reported as having a diagnosis of aphasia at discharge.

- In addition to NJDDCS, the subcommittee explored other sources of data. Among the sources explored were the Minimum Data Set (MDS) which is a standardized uniform comprehensive assessment of all residents in Medicare or Medicaid certified long-term care facilities mandated by federal law (P.L.100-203: Omnibus Budget Reconciliation Act of 1987). In 2012, aphasia diagnoses were reported on 2,043 (4.7%) of 43,571 of long-term residents in the MDS (See Appendix II).

## Estimation of prevalence

After exploring several other options to obtain an aphasia prevalence estimate, the subcommittee arrived at a consensus to implement a synthetic statistical estimation procedure known as “capture-recapture methodology” (Bishop, Feinberg and Holland, 1975). This procedure used data from two hospital discharge years (2011 and 2012 for this analysis) to create estimates. A complete explanation of the capture-recapture methodology used for this estimate is provided in Appendix I.

- In order for the capture-recapture approach to work, certain assumptions had to be made. For example, patients discharged in 2011 must have a chance to be re-hospitalized so that they can be identified or “recaptured” within the following year, in this case 2012. We also made a bold assumption that none of those discharged alive would have died prior to having a chance for re-hospitalization in 2012 or would have moved out of state.
- According to capture-recapture methodology, the total number of people in the state with aphasia in the 2011-2012 period would have been 119,126 (with a 95% confidence interval of 98,884-139,368). This estimate included aphasia cases that would have resolved following discharge as well as those with ongoing chronic aphasia. Since the focus of this Commission was to identify the need and demand for ongoing aphasia treatment, correcting for resolved cases became an important factor.
- An adjustment for resolved cases was implemented using an NIH study by Maas, Lew, Ay et al. (2012) who found that 74% of Aphasia cases identified at discharge could have resolved within six months. Applying that correction to the prevalence estimate yielded a prevalence of chronic aphasia cases of 30,973 (95% confidence: 25,710 - 36,236). Thus, according to the capture-recapture estimate, the prevalence of aphasia cases in the state could be as high as 119,126, but the number with chronic aphasia was estimated at 30,973 (See Appendix I).
- As a validation exercise for the capture-recapture methodology, several additional independent statistical estimates of aphasia



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prevalence were made for New Jersey. One such estimate projected lifetime stroke prevalence in New Jersey obtained from the NJ Behavioral Risk Factor Survey (NJBRFS) based on the 2011 New Jersey population and then applied a “commonly accepted” percentage (i.e. 30% of stroke patients as having aphasia) to get aphasia prevalence numbers (See Appendix I).

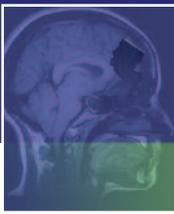


- After pulling multiple estimates derived from the different sources and projecting them onto the State’s population, the subcommittee concluded that the number of persons over 18 with aphasia in the State of New Jersey ranges from 30,973 to 73,858 with a .05 confidence level. Based on this prevalence estimate, the likelihood of an adult in New Jersey having chronic aphasia (subsequent to stroke) lies somewhere between 1 in 90 and 1 in 130, significantly higher than the rates of more commonly recognized conditions like Parkinson’s disease (1 in 350 as currently reported by the Parkinson’s Disease Foundation, [www.pdf.org](http://www.pdf.org)) and Multiple Sclerosis (1 in 875 as currently reported by the National Multiple Sclerosis Society, [www.nationalmssociety.org](http://www.nationalmssociety.org))
- Because each of the estimates, including the capture-recapture estimate, had its own limitations the Commission decided to compute the median and mean of all the estimates derived from the various sources after correcting for resolved cases as a rough approximation for prevalence. Adopting this approach, the median number of people with chronic aphasia would be 55,603 while the mean would be 51,458. The committee adopted **55,603** as probably the most reliable prevalence number to use in this report.

## Limitations of the Prevalence Estimates

Several of the studies upon which the statistical measures were based were small studies with unclear or questionable designs and procedures. For example:

- The NIH study that determined the number of aphasia cases claimed that 74% of aphasia cases resolved in the first six months. This figure was based on one short question contained in a five-minute exam conducted by a non-expert. Research shows that speech and language behavior collected by nurses and physicians as opposed to speech-language pathologists is unreliable (McClenahan, et al., 1992).
- Most of the statistics referenced above reported on persons with aphasia only in the “acute” stage immediately after diagnosis. Treatment and support needs of persons in the acute stage are significantly different from those of persons with “chronic” aphasia.



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## Conclusions and Recommendations for Establishing Prevalence

According to the Commission's findings, there are probably more than 55,000 persons (families) living with aphasia in New Jersey today. With the increases in strokes, head injuries and brain cancer, that number could soon be significantly higher. The limitations of the prevalence estimates in this report make it clear that there is an urgent need for a careful study to arrive at reliable or true aphasia prevalence estimate.

In order to establish a mechanism to ascertain the prevalence of aphasia in New Jersey, the Aphasia Study Commission recommends:

### 1. Continue to gather available data

The Department of Health should continue to collect and monitor the diagnoses codes for aphasia in the hospital discharge databases as well as the Minimum Data Set (MDS) for Long Term Care, and continue to collect data on aphasia in the New Jersey Acute Stroke Registry (NJASR). These data should be provided to the New Jersey Aphasia Task Force proposed later in this report.

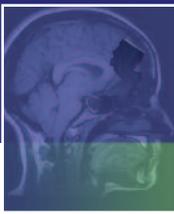
*Cost estimate: Little to no additional cost*

### 2. Survey the public at large

A short survey concerning aphasia prevalence and knowledge of available services could be "piggy-backed" onto the annual NJBRFS telephone survey. This too could be managed within the current NJDOH. While persons with aphasia who live alone might not be able to personally respond to a phone survey, significant information might be obtained from family members. The questions should solicit the following information:

1. During the last 12 months, have you or anyone in your household had aphasia, i.e. difficulty speaking or understanding speech due to a stroke or other brain injury that was diagnosed in the last 12 months?  yes  no
2. If yes, have you (or the person with aphasia) received any of the following treatments or services for the aphasia problem during the last 12 months:
  - speech-language therapy?
  - stroke or aphasia support group?
  - psychological/emotional treatment or support?
  - financial or insurance counseling?
3. What treatments or support services would you seek now if they were available?
  - speech-language therapy
  - stroke or aphasia support group

*continued*

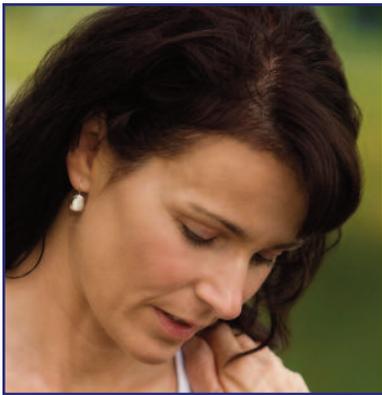


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- psychological treatment or support
- financial or insurance counseling
- none

**Cost estimate: Approximately \$3,000/question for a total of \$18,000.**

## **B: Ascertain the unmet needs of persons with Aphasia and those of their families**



Part of the first charge for the Commission was to “ascertain the unmet needs of persons with aphasia and their families.” In order to assess the unmet needs of persons with aphasia and their families, it was important for the Commission to explore services that are currently available in the State for persons with aphasia (i.e., during its acute and chronic phases) and then review the unmet needs.

### **What services currently exist for persons with aphasia in New Jersey?**

**In the acute phase** (1-3 months post onset), it appears that needs of persons with aphasia and their families are largely being met through clinical settings. In addition to medical and physical rehabilitation services, most persons with aphasia are evaluated and treated by speech- language pathologists in sub-acute or out-patient settings immediately post-onset of brain injury; they receive a maximum of about 20 sessions of speech therapy covered by Medicare<sup>2</sup> or other health insurance. While many family members and caregivers report that they do not receive the information and/or support they need, in general they do have access to available services.

**In the chronic phase** (one year to decades post-onset), high quality, successful treatment and support programs do exist for persons with aphasia and families. Model programs in New Jersey include a non-profit center (Adler Aphasia Center); university clinic programs (e.g. Kean University Institute for Adults Living with Communication Disabilities); speech-language pathology private practices (e.g. Speaking of Aphasia); medically-based support group (e.g. JFK-Johnson Rehabilitation) and “telepractice communities” (e.g. Lingraphica, see page 22 in this report ). However, current programs are estimated to reach less than 2% of persons with aphasia due to limitations in resources.

### **What are the Unmet Needs of Persons with Aphasia in New Jersey?**

Unmet needs of persons with aphasia may be classified into unmet needs for services during the acute phase of aphasia and unmet needs for services during the chronic phase of aphasia.

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<sup>2</sup> The current Medicare “cap” is \$1,950 divided between speech therapy and physical therapy, giving some patients a choice between learning to walk and learning to talk.



# The New Jersey Aphasia Study Commission Final Report

- **Unmet needs of persons in the acute phase of aphasia**

Stroke and head injury are sudden catastrophic events that end lives or drastically change lives in an instant. Victims begin their treatment journeys in the emergency room and those who survive typically move through the intensive care unit (ICU) to acute care in a matter of days; then they proceed to rehabilitation facilities or outpatient treatment for as long as insurance allows – anywhere from 30 to 90 days. Outside of the need for information and counseling, up to the end of the rehabilitation phase, few people complain about receiving inadequate services— medical treatment, physical therapy, occupational therapy, speech therapy, case management are built into the system. During this acute phase of recovery, consistent with the NIH study, most stroke and brain injury patients also make significant spontaneous recovery. Families are fearful because everything has changed radically, but they remain hopeful and stay engaged.

- **Unmet needs of persons in the chronic phase of aphasia**

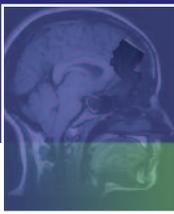
Once discharged from rehabilitation, however, treatment options for persons with aphasia (PWA) become fewer and more expensive, despite the fact that most stroke and head injury survivors make the greatest progress after discharge from acute rehabilitation (Barthel, et al., 2008). The Commission first reviewed the research literature to examine previous attempts to determine the unmet needs of PWA, and then drew from the experiences of professionals working with persons with aphasia.

## **Unmet needs described in previous research**

One way of ascertaining the unmet needs of New Jerseyans with aphasia is to review previous research examining the issue. Unfortunately, little such research exists.

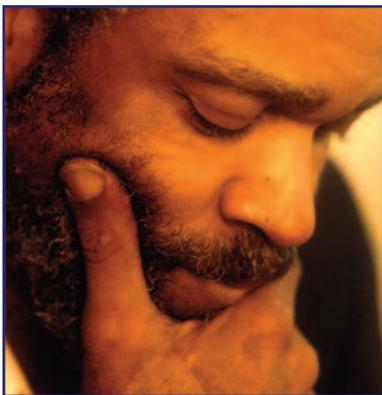
A recent systematic review in the *American Journal of Speech Language Pathology* (Hinckley, et al., 2013) sought to “gather the perceptions of consumers living with chronic aphasia about resource availability and information needs.” The study polled 302 persons with aphasia and/or caregivers who had previously contacted the National Aphasia Association ([www.aphasia.org](http://www.aphasia.org)) for information. The survey was conducted online and that over half the respondents were under the age of 60 (probably not a truly representative sample of the aphasic population at large). Even though none of the respondents was from New Jersey, the results are notable for the information the survey provided on the question of “unmet needs”. The younger, more assertive, technology savvy individuals who responded to this survey unequivocally and universally identified the following four experiences reflecting unmet needs:

- a. Difficulty in locating resources**
- b. Need for support and social interaction**
- c. Need for adequate insurance funding for speech therapy**
- d. Need for public awareness of aphasia**



# The New Jersey Aphasia Study Commission Final Report

A systematic review of the literature (Hafsteinsdottir, et al., 2011) indicated that stroke patients often do not receive all the information they need. This lack of information, they noted, results from both failures on the part of medical professionals to provide adequate information and from the patients' difficulty in understanding the information provided. Stroke patients with aphasia have obvious problems in terms of access to information. They need new information at several points over time as their needs change and as they progress from the acute to chronic stages of the disorder, and they report the information was difficult to obtain.



## Unmet needs revealed by a recent survey of practicing speech-language pathologists in New Jersey

A second approach to investigating the unmet needs of persons with aphasia in the State is to evaluate the amount of services currently being provided to persons with chronic aphasia and compare it to the identified needs.

### *Addendum for Speech-language Pathologists Practicing in New Jersey:*

*The Legislature of the State of New Jersey and the Governor's office recently created an **Aphasia Study Commission** to determine the prevalence of aphasia in the State and the extent to which the needs of persons with aphasia are being met. Your answers below will help gather these data.*

*1. How many persons with aphasia would you estimate you treat in a typical week? \_\_\_\_\_ (Please answer 0 if you do not work with persons with aphasia.)*

*2. In what setting(s) do you work with persons with aphasia?  
Acute care \_\_\_\_\_, Sub-acute \_\_\_\_\_, Nursing home \_\_\_\_\_,  
Home/Community \_\_\_\_\_, Other? \_\_\_\_\_.*

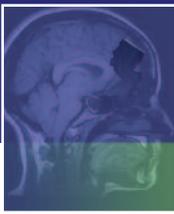
*3. Are you aware of any community services in your area that support or work with persons with aphasia and/or their families? Please list:*

\_\_\_\_\_

1. *Comments?*

School of Communication Disorders and Deafness;  
Kean University, 2013

A 2013 survey conducted by the School of Communication Disorders and Deafness at Kean University asked all 4,104 certified speech-language pathologists in the State of New Jersey a set of questions about their work with persons with aphasia. The primary purpose of the survey was to determine the level of interest in a proposed Ph.D. degree program. With the consent of the University, a three-question aphasia addendum was included (see below). As of December 31, 2013, the "aphasia addendum" was completed by 591 of the 655 surveys returned by New Jersey residents, or about 90% of the returns.



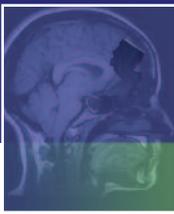
# The New Jersey Aphasia Study Commission Final Report

## Survey Results:

- 1. Number of aphasia cases treated in a week:** Of the 591 speech-language pathologists (SLPs) who responded to the aphasia survey, only 127 (21%) reported that they currently treat persons with aphasia. Of those 127, only 69 SLPs (54%) reported treating more than one or two aphasic persons per week.
- 2. Treatment settings:** Twenty-five percent of those who treated aphasic persons worked in acute care hospitals; 31% in sub-acute settings, 22% in nursing homes, and 13% in home health care immediately following hospital release. In short, 91% of treatment provided occurred within the first couple of months following onset. Treatment in other community settings that are more supportive of persons with chronic aphasia was reported much less frequently, accounting for only about 9% of treatments identified broken down as follows: Outpatient rehabilitation, 3.4%; Private practice, 2.3%; High school, 2.3%; and “Other“, including support groups, <01%.
- 3. Awareness of Community Services:** When asked if they were aware of any community services in their area that supported or worked with persons with aphasia and/or their families, only 16.4% reported knowing of any community services. Only 57 speech-language pathologists (<10%) reported being familiar with the Adler Aphasia Center in Maywood, NJ, and no other programs were as well-known. Eleven people knew that the Robert Wood Johnson Rehabilitation Center at JFK Hospital had an aphasia group; seven cited Kean’s Institute for Adults with Communication Disabilities, six named Kessler Rehabilitation and five cited Speaking of Aphasia (a private practice in Montclair). Just 11 other programs or support groups were mentioned, primarily in the northern half of the state; none by more than one respondent.

## Selected comments by SLPs responding to the aphasia survey:

- ❖ One respondent wrote, “*That (support groups or ongoing treatment) is something we are lacking in our area—Ocean County—a continuum program for our patients with aphasia so they can get together. None available in immediate area*”
- ❖ A woman from Monmouth County wrote, “. . . *there is an indication that although the older adult population has been growing, there is still a shortage of professional SLPs to work with this population.*”
- ❖ But it isn’t only the southern half of New Jersey. One northern clinician wrote, “*I see a desperate need for therapeutic services as well as family support and education, especially within a multicultural setting, as I have a large Spanish-speaking aphasia population in North Bergen.*”
- ❖ Another said, “*(Programs are) badly needed. None in Jersey City or Hoboken,*”
- ❖ And many added comments like, “*Very important to support caregiving family.*”, “*No support services in my area. . .*”



# The New Jersey Aphasia Study Commission Final Report

## Conclusions of the survey

The Kean University survey showed that despite the fact that aphasia is a high-incidence adult disorder, only about twenty percent of speech-language pathologists work with persons with aphasia, and the vast majority who do, work with them for a relatively short period of time in medical and rehab settings while they are in the acute stage of the disorder. While New Jersey SLPs are aware of the dearth of services, even speech-language pathologists working with persons with aphasia are not well-informed about the few community treatment and support services that are available for persons with chronic aphasia in the State.



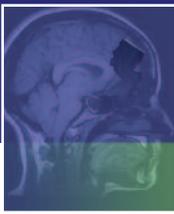
## Unmet mental health needs among persons with aphasia: Aphasia and Depression

Depression is a costly condition. It is generally reported that as many as 90% of persons with aphasia suffer from clinical depression (Townend, et al., 2007). “Depression has human costs that we all know of: sadness, sense of isolation, feeling like a burden, inability to enjoy life, and—for 35,000 people every year—suicide (Joiner, 2010). The cost of depression (lost productivity and increased medical expenses) is \$83 billion each year which exceeds the costs of the war in Afghanistan (Greenberg, et al., 2003). Depression is not a “limited engagement with a fixed endpoint. These costs reoccur each year, every year, for the foreseeable future...” (Leahy, 2010).

In 2009, the National Stroke Association sent the following message to members with aphasia:

***“Socializing with family and friends is an important part of stroke recovery. But as a stroke survivor, you may have trouble doing the very things that allow you to connect with other people – talking on the phone, understanding what people say, writing letters, taking walks, shopping, getting around or eating out. This can make you feel disconnected and alone at a time when you need more social support than ever before...”***

Because of their communication disabilities, very few persons with aphasia receive adequate evaluation and treatment for their depression. This results in increased dependency, loss of function and additional illness. Post-stroke depression results in higher rates of institutionalization and higher overall costs of medical care. To date, no valid evidence-based assessment of depression in persons with chronic aphasia has been developed that can tell us the prevalence of psychological disability (Townend et al., 2007). Worse, an informal search by the Commission could locate only three licensed psychotherapists in New Jersey who felt qualified to counsel individuals given the communication deficits of persons with aphasia. And there are no published guidelines on the use of anti-depressant medication for stroke survivors.



# The New Jersey Aphasia Study Commission Final Report

## Unmet need for family and caregiver support

The burden and strain of caring for stroke patients with aphasia greatly affect primary caregivers. Caring for a person who cannot communicate is physically and psychologically exhausting and costly in terms of loss of work days and financial drain.

Typically, stroke research focuses on the stroke survivor and not the caregiver. An article by Canadian researchers (Rombough, et al., 2010) examined (a) the existing literature on the burden and strain experienced by caregivers of stroke patients, and (b) the relationship between aphasia and caregiver burden and strain.

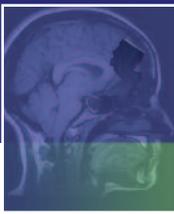
Only 14 professional articles were found to contain valid information about the burden and strain on caregivers of stroke patients, and no articles presented valid information on the effects of survivors' aphasia on caregiving. The authors suggested that there is very limited research in this area and that several key initiatives are needed, including the development of an instrument with psychometric properties appropriate for assessing the burden and strain on caregivers of aphasic persons.

The majority of caregivers described across the studies reviewed were female and they were primarily spouses. They ranged in age from 18 to 91 with a mean of approximately 61 years. The key finding of Rombough's review was that caregiver burden and strain play a major role in the recovery of stroke survivors in the community. In addition, the loss or impairment of the ability to communicate is typically devastating and frustrating to both the stroke survivor and the primary caregiver and can result in fear, feelings of hopelessness, and depression. When the stroke survivor has aphasia, the caregiver often assumes added responsibility for interpreting non-verbal cues and communicating on behalf of the stroke survivor.

In short, the unmet needs of families with aphasia include (but are not limited to) the following: ***Need for awareness, Need for Resources, and Need for Services.***

### **Need for Awareness:**

- a. Medical and allied health professionals and first responders are not sufficiently aware of the diagnosis of aphasia and of available services for persons with aphasia and their families.
- b. Many survivors and families report they did not receive adequate information about aphasia and ongoing services upon hospital discharge.
- c. The public lacks information about what aphasia is; frequently even persons with aphasia do not have a name or diagnosis for their communication problem.
- d. Speech-language pathologists lack information on available programs for persons with chronic aphasia and their families.



# The New Jersey Aphasia Study Commission Final Report

## **Need for Resources:**

- a. Health insurance funding is limited and geared primarily to treatment in the acute stage.
- b. Survivors have difficulty locating resources--finding services and funding available to them after they leave the hospital.
- c. Health insurance coverage for augmentative devices and other reimbursable services is difficult to understand and to negotiate; more so for persons with aphasia and their families.

## **Need for Services:**

- a. Currently, empirical evidence is lacking to demonstrate the known financial, emotional, medical needs of persons with aphasia and their caregivers.
- b. Support services and training for caregivers are limited and not well advertised. Existing programs need to be better advertised.
- c. Survivors report a lack of follow-up beyond the acute stage of aphasia. New Jersey designated stroke centers provide little follow-up evaluation and service.
- d. There is a lack of community-based services for persons with chronic aphasia and their families. Treatment of chronic aphasia does not require hospital- based programs. Community-based services are less expensive and better meet the needs of persons with aphasia and their families to re-integrate into the community in which they live.
- e. There are few psychological/counseling services for persons with aphasia or for their caregivers. There is a need for aphasia awareness programs for clinical psychologists, social workers and other counselors to reduce the incidence of depression and improve independence and quality of life of persons with aphasia and their families.
- f. Persons with aphasia and their caregivers report an ongoing need for support and social interaction during the chronic stage of the disorder. Communities need aphasia-friendly places and activities where persons with aphasia can reintegrate into the community.



## **Conclusions about unmet needs of persons with aphasia**

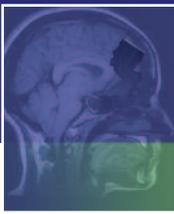
### **Based on the above findings, the Commission concluded that:**

- A large number of persons with chronic aphasia currently live in New Jersey.
- This is a largely neglected population that has difficulty speaking for itself.
- This is a “hidden” population, but a costly one due to lack of independence, loss of livelihood, depression problems, demands on caregivers and early admission to long- term care.
- Because this population has not been studied, it is difficult to say where the underserved PWA live—at home or in long-term care; in urban or rural settings; in what parts of the state.



# The New Jersey Aphasia Study Commission Final Report

- While effective treatments for chronic aphasia and family support exist, only a limited number of persons with aphasia currently take advantage of them. This might be because:
  - a. insurance funding for treatment stops at the end of the acute stage of the disorder and many people are told that they have “plateaued” and no longer seek treatment, or
  - b. survivors are not aware of the availability of professional services nor of the benefits these services can provide in the chronic stage of aphasia, or
  - c. there are geographic disparities in availability of services; fewer services exist in Southern New Jersey, or
  - d. lack of ability to communicate due to the nature of the disorder itself.
- We have no mechanism to determine the number of people with aphasia who need treatment and/or support and would actually seek treatment or support if it were provided or easily available. Such information would require a carefully structured comprehensive study.



# The New Jersey Aphasia Study Commission Final Report

## Study Commission Charge 2: Model Aphasia Programs

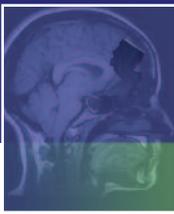
The second charge of P.L. 2010, c.117 called on the Commission to study model aphasia support programs. In order to address that, the Commission sought to study model programs currently serving people with aphasia and their families. This section addresses some of the findings of this effort by the Commission with focus on chronic aphasia programs.

### Model programs currently serving persons with chronic aphasia in New Jersey

The Commission determined that, currently in the State of New Jersey, five working prototypes of programs exist for persons with chronic aphasia and their families: non-profit, university-based, hospital/rehabilitation, private practice, and a virtual website. Non-profit programs are both private and faith-based, and have both formal and “clubhouse” structures. All of these programs attempt to meet both the treatment and support needs of persons with aphasia and their caregivers once they exit the acute medical care system. All the prototype programs serve families with aphasia primarily outside of insurance reimbursement and presently serve a very small segment of the population. Detailed descriptions of the seven representative programs in the State are provided following the list.

1. **Private non-profit:** The Adler Aphasia Center
2. **University-based:** Kean Institute for Adults Living with Communication Disabilities
3. **Hospital/rehabilitation:** JFK Medical Center
4. **Private Practice:** Speaking of Aphasia
5. **Internet Community:** Lingraphica
6. **Faith Based non-profit:** Lutheran Social Ministries (P.A.C.E.)
7. **Clubhouse non-profit:** Opportunity Project, Inc.

**Note:** *The above list and descriptions of the model programs below are the result of an extensive, unbiased search by the Commission. Their presentation here in no way implies an official endorsement of their work.*



# The New Jersey Aphasia Study Commission Final Report

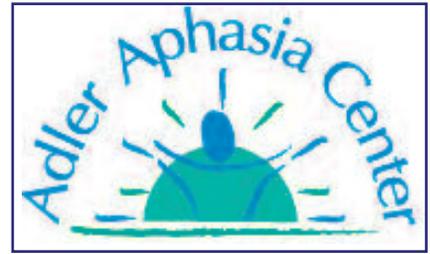
## 1 Private Non-profit: The Adler Aphasia Center

### Avi's Story:



- *Helping others has always been second nature for Avi. At age 33, he was an accomplished paramedical professional working as an EMT and medic. Despite a hectic professional life, he made time for a wide range of volunteer activities. He was also an avid sportsman, and enjoyed skiing, snowboarding, fencing, and rock-climbing.*
- *His active life was interrupted dramatically when he experienced a stroke during cardiac surgery. The stroke left Avi with right-sided paralysis and severe aphasia, upending his life and his dream of going to medical school. While he still has weakness on the right side of his body his greatest*

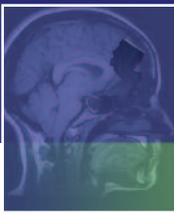
The Adler Aphasia Center was established in Maywood, NJ, in 2003 as the only long-term aphasia therapy center of its kind in the greater New York-New Jersey area, and the only long-term aphasia support center undertaking supervised research. The Center



was founded by Mike Adler, a local business entrepreneur with aphasia, in order to answer a growing need for community-based, long-term therapeutic care for aphasia. With the guidance of a scientific advisory board comprised of leading speech-language pathologists and health care leaders from across the country, the Center has developed a unique program based on the Life Participation Approach to Aphasia, a consumer-driven methodology that places priority on the life concerns of those affected by aphasia and assists them in their efforts to return to active life. The programs and services offered through the Adler model all share the important goals of enhancing the communication skills of the Center members, providing opportunities for social and peer support, and building self-esteem and self-confidence to help persons with aphasia lead productive lives. The program, directed by speech-language pathologists with the support of volunteers, includes group activities in speech, reading, and writing; support groups; and activities such as art, drama, cooking, exercise, and public speaking. The Center offers a regular support group for spouses and caregivers, to help them learn specific techniques that can facilitate their communication with loved ones, and provide them with opportunities to share and learn from each other's experiences. The Center's recent research on the effectiveness of its programs has shown that after just one year in the Center's Life Skills Program, participants had a statistically significant increase in functional language as well as in perceived quality of life.

Center members come from across the socio-economic spectrum and often travel great distances to participate in its programs, including from the five boroughs of New York City. Membership in the center entitles a person with aphasia to participate in the center's activities on a two-day-a-week basis. In May 2012, the program's first regional satellite center was established in West Orange, New Jersey, to serve the population of the New Jersey Metro-West region including Essex, Union, and Morris counties. In 2013, an aphasia support group was formed to reach people with aphasia in the Somerset County area, meeting at the JCC in Bridgewater twice a month. Among its three programs, the Adler Aphasia Center currently serves 87 people with aphasia. Almost all have at least one family member who benefits from caregiver services

*Continued on page 18*



# The New Jersey Aphasia Study Commission Final Report

## **Avi's Story (continued):**

*frustration comes from aphasia. This communication disability prevents him from returning to his career or pursuing a medical degree.*

- *To help himself meet these challenges, Avi joined the Adler Aphasia Center. His participation in group activities has helped improve his speech and restore his confidence. He is now a leading advocate for the Center through visits to local businesses and community centers and helps educate emergency responders about aphasia. He has also been able to resume favorite activities such as snowboarding and rock climbing.*
- *Avi credits the Adler Aphasia Center with enabling him to recognize that his aphasia has not fundamentally changed him. He is still the same sociable, compassionate person he was before the stroke. With the help of the Center, his communication skills continue to improve, allowing him to return to many of his previous endeavors. ■*

## **Organization and Financing**

The average age of Center members is 67; almost all are at a financial disadvantage, as older adults living on fixed incomes and struggling to pay for healthcare supports and therapies. As the programs and services provided at the Adler Aphasia Center are not reimbursed through traditional medical insurance, the Center's activities are funded by philanthropic support from the private sector. The Center has a staff of nineteen – five full-time and fourteen part-time employees -- including an executive director, licensed speech-language pathologists, a wellness coach, a life coach, and administrative and development staff. More than 90 trained volunteers are actively involved in the Center's activities and in helping Center members learn and use technology. The Center also has an extensive volunteer scientific advisory committee of leading researchers and practitioners, as well as a volunteer Board with 27 dedicated community and business leaders who provide governance and leadership to sustain the organization. The Center also houses a vocational gift store program; and provides outreach and training to hundreds of healthcare students and professionals throughout northern NJ in order to optimize their care for aphasia sufferers. In 2010, the Center facilitated the launch of the Aphasia Alliance, a national consortium of long-term therapeutic support programs which meets annually to share best practices.

## **Statement of Caregivers attending the Adler Center:**

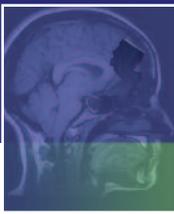
"Aphasia totally changes the lives of the person with aphasia as well as that of the family caregiver. Caregivers feel that "we are now two people living only one life."

- ❖ Many of us have given up our careers.
- ❖ We have very little personal time.
- ❖ Social lives have been drastically changed.

The Adler Aphasia Center provides a loving, cheerful and supportive community for the person with aphasia and the caregiver. The Caregiver Support Group gives us a valuable outlet for our challenges and needs."

## **Shortcomings of the private non-profit model:**

The non-profit aphasia center is dependent on the generosity of foundations and private individuals. The major component of its administration is fund-raising and its continuation relies on the dedication of its workers and patrons.



# The New Jersey Aphasia Study Commission Final Report

## 2 University-based Center:

**Kean Institute for  
Adults Living with  
Communication  
Disabilities;  
Kean University  
Union, NJ**

Kean University's Institute for Adults Living with Communication Disabilities (IALCD) opened in January 2008 and serves approximately 40-50

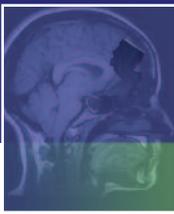


persons with aphasia and their family members each year. The Institute's specialized services include individual and group speech-language therapy, individualized training programs, counseling, client and caregiver support groups, a lending library, special projects and community education. The Institute accepts clients from anywhere, but concentrates its outreach to Union, Essex and Middlesex counties. Current clients range in age from 22 to 87 years with a mean age of 60. Approximately 50% of clients are over 65. Funding for the Institute's operating expenses comes from foundation grants (e.g. the Kessler Foundation), direct donations, Kean University and the nominal semester registration fees paid by each client (approx. \$300)

The Institute for Adults Living with Communication Disabilities (IALCD) operates under the auspices of The Center for Communication Disorders, which has existed for over 50 years at the University. The Center provides assessment and intervention for the communication problems of children and adults in the community. IALCD provides individual therapy programs for adults with aphasia conducted by graduate students supervised by licensed speech-language pathologists, as well as aphasia discussion groups, women's and men's support groups, a caregiver support group, computer instruction for clients, an aphasia choir, a speaker's bureau, and a speaker's series for clients, students and the community. The aphasia groups also participate in special projects each semester, assisting community members and agencies.

The goal of the Institute is to provide innovative, viable, speech-language-communication rehabilitation services at minimal cost to adults in the central New Jersey community. Like the Adler Center, the Institute is based on a Life Participation Approach to Aphasia designed to meet the following four objectives:

- ❖ *To provide speech, language, communication therapy and support services to a growing population of communication-disabled adults in the central New Jersey community whose needs are not being met by the current medical rehabilitation system;*
- ❖ *To enable adults with aphasia to become more self-sufficient and productive within their communities.*
- ❖ *To create a model center for the long-term treatment of adults with communication impairments.*



# The New Jersey Aphasia Study Commission Final Report

- ❖ *To provide much-needed relevant clinical education and practicum experience for Kean University graduate students in speech-language pathology in the treatment of community-based adult and elderly persons, America's most rapidly growing population.*
- ❖ *To provide a site and database to conduct significant clinical research to document the long-term recovery of communication and life skills in adults with impaired nervous systems and to develop new evidence-based therapies for individuals with targeted disorders.*



*“It's a place where we get together. I don't know what I would do if I didn't come here. .. It's learning and fun and all our friends are here and we share things. It's not just learning, learning to read and speak again It's friendly. It's a friendly atmosphere.”*

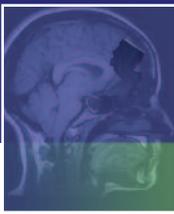
*Mary*

The goal of the Institute's rehabilitation services is to achieve maximum recovery and to assist the individual in progressing to the most independent level of functioning possible. Treatment focuses on regaining lost skills as well as teaching new ways to compensate for lost abilities and to return to the community. Family members are included in the identification of client needs, treatment planning and the ongoing rehabilitation process. Caregiver support is an important component of the program.

While Kean University offers the most comprehensive program in a university setting, other universities such as Montclair State University and William Patterson University provide aphasia therapy in clinics as part of their Master's degree programs.

## **Shortcomings of the University Clinic Model**

The University Institute model is limited by the number of graduate students enrolled in the program in any one semester. Openings vary from semester to semester, and the program only runs when classes are in session (Fall and Spring semesters and Summer session). The full program is also dependent on the ability of the faculty directors to raise additional funds to cover support groups, lending library, speakers, choir, etc.



## **3 Hospital/ Rehabilitation Centers: Medically-based stroke/aphasia support groups (e.g. JFK, Edison, NJ)**

Hospitals housing NJ designated stroke centers focus on the acute stage of aphasia. When indicated, they provide bedside evaluations of aphasia during the first few days following onset of the stroke. Many also provide outpatient speech-language therapy for approximately three or four months. The extent of outpatient therapy is determined by insurance reimbursement. A large percentage of these patients are on Medicare. The Medicare cap for speech-language therapy and physical therapy **combined** is currently \$1950, which translates to about a dozen sessions of either speech OR physical therapy, and the allocation is exhausted well before most patients have reached the chronic stage of aphasia.

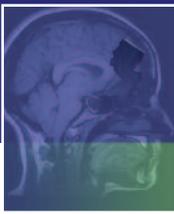


A handful of hospitals offer monthly stroke support groups. The National Stroke Association lists only nine hospitals associated with stroke support groups for survivors, with and without aphasia, and family members in the community: JFK Medical Center, Edison; Englewood Hospital and Medical Center; Hackensack University Medical Center; Morristown Memorial Hospital; Somerset Medical Center, Somerville; Overlook Medical Center, Summit; Inspira Medical Center, Vineland; Cape Regional Medical Center, Cape May Courthouse.

Several Rehabilitation centers also offer stroke support groups ( Kessler--Wellkind, Saddle Brook and West Orange, Robert Wood Johnson Rehab at JFK, R.W. Johnson Medical Centers at Rahway, New Brunswick and Hamilton. St. Lawrence Rehab, Bacharach, Tinton Falls, Health South Tom's River, Virtua Health and Rehab in Mount Holly.), but again, only on a monthly basis for all stroke survivors and only stroke survivors.

### **Shortcomings of the Hospital/Rehab Support Group Model**

All of the hospital programs that were identified met only once a month, and only JFK offered a separate group for caregivers. All were open to persons with and without aphasia. Unfortunately, people with aphasia are frequently unable to participate fully because conversations are dominated by those without aphasia. People with aphasia due to other causes (head injury, cancer) are not included in hospital stroke support groups.



# The New Jersey Aphasia Study Commission Final Report

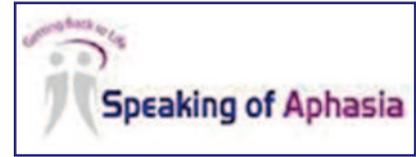
## 4 Private Practice: Speaking of Aphasia, Montclair, NJ

### Story of a businessman:

*“Individual LPAA therapy just means that the person with aphasia defines the goals and chooses the interventions that follow. In one example, a small businessman, urged by his family to seek further services for his aphasia, told us that he really did not want traditional speech therapy. He had “been there, and done that.” Now, with very little effective speech, he was learning to program a hand-held computerized speaking device, for which he desired no help. What disturbed him, however, was the inability of his staff of over 40 people to communicate with him. What he wanted was for us to educate his staff, so that he could continue to work effectively for as long as possible. He advised us on what the content of our education program should be, and we put together a PowerPoint presentation which he reviewed and edited. We then presented it to his staff at his place of business, to overwhelmingly positive effect.” ■*

Although a number of private practitioners in speech-language pathology treat individuals with aphasia, the Commission could find only one private practice devoted exclusively to persons with aphasia.

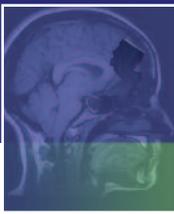
Located on Bloomfield Avenue in Montclair, NJ, Speaking of Aphasia (SOA) is owned and operated by Shirley Morganstein and Marilyn Certner Smith.



As described above, the continuum of care for persons with aphasia typically involves an acute hospital admission, possibly followed by an acute rehab or sub-acute rehab stay. Following this, perhaps home care services will be offered, or a course of out-patient therapy. When third party payments for these services expire, typically within 5-6 months post onset, private practice offers ongoing individual speech-language therapy for which clients pay on a fee-for-service basis. SOA offers: 1. consistency of care, 2. consumer driven goal setting and determination of the length of stay, 3. greater opportunity for targeting not only the impairment- based aspects of aphasia, but the environmental ones as well. Since private practitioners are free to determine the breadth of service without outside determinants, they permit easier access to fulfillment of the desires of the person with aphasia to achieve a better quality of life. Emphasis at Speaking of Aphasia is on the Life Participation Approach (LPAA). To our knowledge, SOA is the only private practice in the State currently offering it. Ms. Morganstein furnished this example (Story of a Businessman) of how the Life Participation Model works

### Shortcomings of the Private Practice Model:

Persons with aphasia who seek treatment and support through private practice can expect a high quality, highly personalized rehabilitation program. Unfortunately, few speech-language pathologists find it profitable and few patients can afford it. Private practice is by far the most costly of treatment alternatives.



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## 5 The Internet Community: Lingraphica

### Meet Rita: The Ultimate Optimist despite Having Aphasia



*One year ago, Rita was settling into her normal routine following a trip to Israel. She was busy unpacking her things, sharing stories of her adventure, and getting ready for a family get-together when she had her stroke. Rita spent two days in the hospital recovering. During her stay she said only a handful of words. While she recognized something was different with her speech, no one officially diagnosed her with aphasia until after she was discharged from the hospital.*

*“I only said four or five words when I was in the hospital,” said Rita. “The therapist didn’t say I had aphasia; it was later that we figured it out.”*

*Continued on page 24*

Lingraphica, based in Princeton, N. J., is a leading provider of speech-generating devices and therapy apps for people whose ability to speak or understand words has been impaired by a stroke or brain injury. Since 1990, Lingraphica has been developing increasingly sophisticated technological /internet approaches to restoring communication. Its most recent products include a lightweight, portable TouchTalk tablet speech-generating device and a supplemental, downloadable SmallTalk Family of Apps for the iPhone, iPad, and iPod touch. Lingraphica conducts online support groups as well as real-time support for the users of its products. They are strong advocates for “TeleSpeech”.

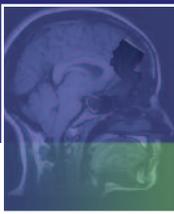


Treatment and support through the “TeleSpeech” has the potential to play a significant role in the rehabilitation of people with aphasia living in New Jersey. People with aphasia are able to improve their speech for as long as they live, but typically receive only a few months of treatment due to limits on insurance coverage and accessibility to care (Weinrich 1995; Aftonomos 1999; Wertz 2004; Steele 2010). TeleSpeech can effectively address both of these issues.

There are a number of ways in which TeleSpeech may address cost. For the portion of the population that is capable of self-help, therapy apps and websites provide unlimited treatment and practice at a fraction of the cost of in-person therapy. Less independent persons with aphasia may be supported at a distance through online audio and video connections, screen sharing and remote computer control, again at a fraction of the cost of in-person support. This sort of distance-based in-person interaction can support a range of activities from the purely social to purely therapeutic.

TeleSpeech also greatly improves access to services. Lack of mobility and transportation often prevent persons with aphasia from receiving care and participating in programs, and many live a significant distance from qualified providers. TeleSpeech requires only an Internet connection and a computer or tablet, so services may be brought into a person’s home or other convenient location.

The technologies involved in TeleSpeech have become widespread, reliable and inexpensive. They are relatively easy to implement, maintain and develop. TeleSpeech supports a wide range of activities and recent studies have demonstrated that they can be as effective as in-person activities. Many persons with aphasia give them high marks for satisfaction. TeleSpeech deserves consideration as a viable service-delivery model for persons with aphasia.



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## **Meet Rita: (continued)**

*Rita's stroke did not slow her determination to live life to the fullest. She got involved with a speech therapy program, a stroke support group, and began practicing her speech with apps on her iPad. When Rita's speech therapy concluded she was looking for another avenue to continue working on her reading, writing, listening, and speaking skills.*

*"Someone at my stroke support group told me about Lingraphica," said Rita. "I looked at TalkPath Online Speech Therapy and immediately started the speech therapy exercises. I like that I can do it at home on my computer."*

*Today, Rita is speaking in full sentences and reading again. She credits TalkPath Online Speech Therapy for supporting her efforts to continue her recovery, even after her formal speech therapy sessions ended. She especially likes the speaking exercises because she can work on common words and phrases. ([www.aphasia.com](http://www.aphasia.com); Lingraphica) ■*

In addition to the online support groups run by Lingraphica, a handful of online aphasia support groups and chat sites have emerged recently. They are directed primarily at caregivers ("Aphasia Online" at [Aphasia.org](http://Aphasia.org)) and younger, more computer-savvy survivors ("ARC – Aphasia Recovery Connection at [Aphasiahope.org](http://Aphasiahope.org)).

## **Shortcomings of Online treatment and support:**

As a treatment tool, telespeech requires that the person with aphasia be technology-savvy, have access to the technology offered, and be connected to a source. When used with persons with more severe aphasia, Telespeech requires the presence of a caregiver who can direct and accommodate the sessions.

The prospects for social media providing both a connection to the world and personal support are excellent. Telespeech promises improved awareness and access.



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## 6 Faith-based Non-profit: The "P.A.C.E." program

The New Jersey Department of Human Services, Division of Aging Services currently oversees four *Programs of All-inclusive Care for the Elderly* (PACE)

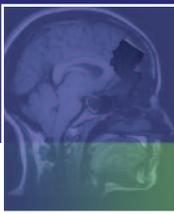


programs like the Lutheran Senior Life at Jersey City. As stated on the Department of Human Services website, ". . . PACE is an innovative Medicare program that provides frail individuals age 55 and older comprehensive medical and social services coordinated and provided by an interdisciplinary team of professionals in a community-based center and in their homes, helping program participants delay or avoid long-term nursing home care. Each PACE participant receives customized care that is planned and delivered by a coordinated, interdisciplinary team of professionals working at the center. The team meets regularly with each participant and his or her representative in order to assess the participant's needs. A participant's care plan usually integrates some home care services from the team with several visits each week to the PACE center, which serves as the hub for medical care, rehabilitation, social activities and dining."

PACE centers can and do provide aphasia treatment and support groups. If the State decides to move forward increasing the number of such centers throughout the state, efforts to keep persons with aphasia in the community would be strengthened. The National PACE Association is currently studying the overall effectiveness of the PACE model, but it looks promising for reaching the target population.

### **Shortcomings of the PACE model:**

PACE serves only the Medicare-Medicaid population. Although a large percentage of persons with aphasia are older Medicare recipients, Many persons with aphasia are younger or do not meet the economic restrictions of PACE eligible clients.



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## 7 Clubhouse Model Non-Profit: The Opportunity Project

The Opportunity Project website describes the clubhouse model this way:

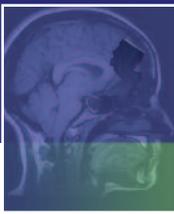


"The National Clubhouse model of service delivery exists in New Jersey in the Opportunity Center for persons with Brain Injury. . . . The Clubhouse Program is a supportive network of members who participate in a work-oriented environment where they develop and engage in practical, functional community work and living skills. The program is designed to address the vocational, cognitive, behavioral, social and emotional difficulties which individuals affected by brain injury frequently experience as they try to resume their lives. . . . Members and staff work together to plan and carry out the wide variety of jobs, tasks, and functions needed each day to operate the Clubhouse. The Clubhouse location, program structure, activities, and staff-member relationship emphasize the important of self-determination and community self-sufficiency following brain injury."

While the needs of persons with aphasia are different overall from those recovering from traumatic brain injury, a community-based all-day model that works toward self-sufficiency might be an excellent alternative to restore independence to persons with chronic aphasia.

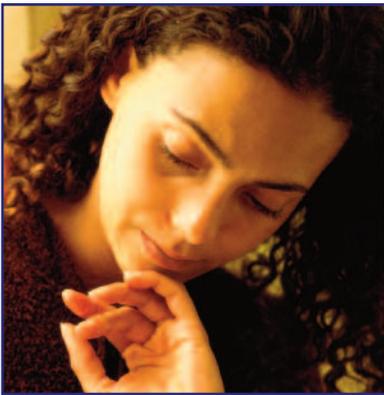
### **Shortcomings of the Clubhouse model:**

Like the Adler Center, the Clubhouse is financed as a non-profit seeking private funds to function.



# The New Jersey Aphasia Study Commission Final Report

## Study Commission Charge 3: Recommendations for Additional Programs and Resources



As the third charge, P.L. 2010, c.117 called on the Commission to provide recommendations for additional support programs and resources to meet the unmet needs of persons with aphasia and their families. The Aphasia Study Commission has concluded that there is a lot of room for improving conditions for persons with aphasia in the State of New Jersey. Meeting their needs makes economic, medical and social sense. This section presents the Commission's recommendations with estimated costs associated with each.

### 1. Enact Legislation to Appoint a Permanent Aphasia Task Force

New Jersey is one of only a handful of states that has five functioning diverse model programs created primarily for the treatment and support of persons with aphasia and their families, (non-profit, university-based, private practice, hospital/rehabilitation and virtual website). The Commission proposes a State Aphasia Task Force with a volunteer member representing each of the five types of programs, plus two persons with aphasia, and additional professional and caregiver members as appropriate. Administration (meeting space, office supplies, telephone and travel expenses) can be supplied by the State. A part-time coordinator could be hired for one day a week to oversee and coordinate the work of the Task Force. The Task Force could enact and coordinate programs recommended below.

#### Cost estimate:

Coordinator salary: \$12,000, office supplies, telephone and travel expenses: \$13,000.

Estimated total cost: \$25,000/year (Meeting space can be provided by DOH).

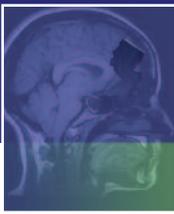
### 2. Encourage or Establish Aphasia Support Programs

- ❖ **Encourage and establish new aphasia support groups** in senior centers, Federally Qualified Health Centers (FQHC)s, county offices of the disabled, and libraries, particularly in areas with large senior and minority populations. Sponsor orientation programs for SLPs and caregivers interested in volunteering to facilitate such groups. Include persons with aphasia as ambassadors to motivate new groups. Encourage all universities with masters-level programs in speech-language pathology to offer aphasia support groups. This will benefit not just people with aphasia, but provide training to future professionals in how to facilitate support groups.

**Cost Estimate:** None (To be mediated by the Aphasia Task Force)

- ❖ **Coordinate support groups within the State** so that there is a vehicle (data base) for shared resources and state-wide coordination of efforts.

**Cost Estimate:** None (To be mediated by the Aphasia Task Force)



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## 3. Facilitate Availability of Resources to Address Unmet Needs

In order to determine more specifically the unmet needs of persons with aphasia in New Jersey, the Commission recommends the following:

- ❖ **Creating Focus Groups to Highlight Regional Needs:** Invite those persons currently participating in the small number (We have identified fewer than 20) of aphasia/stroke/caregiver support groups operating in the State as well as persons with aphasia and caregivers in the community at large to act as focus groups to identify needs of persons with aphasia (PWA) and their families throughout the State. Results would be reported to the Task Force.

**Cost estimate:** Cost of mailing, meeting site and audio-recording

In order to increase awareness of aphasia among medical professionals and the public, the Commission recommends the following:

- ❖ **Provide “Aphasia” listings in “New Jersey Resources”.** Require that the Division of Disability Services in the Department of Human Services add the diagnosis of aphasia to the disabilities included in its annual listing of services available to the disabled in New Jersey, and include current treatment and support services available for persons with aphasia and their families (the word “aphasia” does not currently appear in the 2014 edition). Recommend “New Jersey Resources” to families of PWA and medical professionals as relevant.

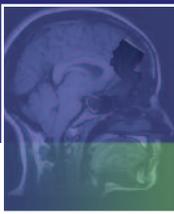
**Cost estimate:** No cost.

- ❖ **Establish an informational website** containing a listing/registry of community services available for people with aphasia in New Jersey administered by the Department of Human Services/Division of Disabilities and monitored by the Aphasia Task Force. This site can connect caregivers to available online information and print forums. Provide a link to the website in all correspondences.

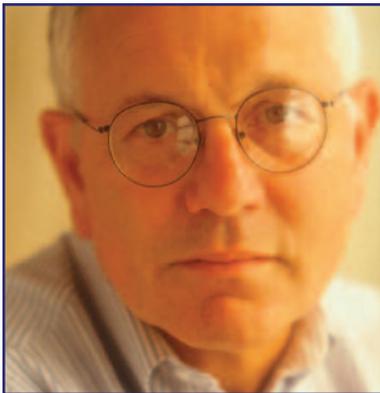
**Cost estimate:** Approximately \$1,500 to design site and \$1,200/year to maintain the website.

- ❖ **Create an aphasia-friendly quarterly e-newsletter** (or print newsletter for those who are not tech savvy) to update PWA, caregivers and professionals to information about new developments in the treatment of aphasia.

**Cost estimate:** No Cost if posted on the website.



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- ❖ **Encourage distribution of aphasia information at hospital discharge.** Pamphlets and information packets, already available from the National Aphasia Association (NAA), American Stroke Association (ASA), American Speech-Language Hearing Association (ASHA), can be made available to the community education departments of designated stroke centers throughout the State and recommend that these pamphlets be distributed to stroke and head injury survivors at discharge.

**Cost estimate:** None. Pamphlets already exist from agencies such as the American Speech-Language-Hearing Association.

- ❖ **Compile a registry of counselors and psychologists** available to work with persons and families with aphasia. Post the listing on the Aphasia website.

**Cost estimate:** None (To be mediated by the Aphasia Task Force)

- ❖ **Explore and document funding sources for post-acute services for PWA in the chronic phase. These resources can be posted on the Aphasia website.**

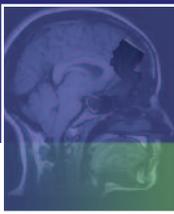
**Cost estimate:** None (To be mediated by the Aphasia Task Force)

- ❖ **Coordinate listings with Area Agencies on Aging** (County AOAs) to provide listings and descriptions of available aphasia services and support groups in their counties.

**Cost estimate:** None (To be mediated by the Aphasia Task Force)

- ❖ **Enlist and assist persons with chronic aphasia** who wish to instruct first responders, medical personnel, vendors, and others in their communities on the needs and abilities of persons with aphasia and the needs of their caregivers.

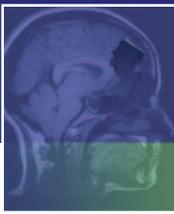
**Cost estimate:** None (To be mediated by the Aphasia Task Force)



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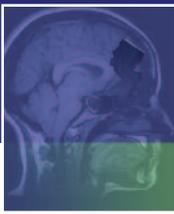
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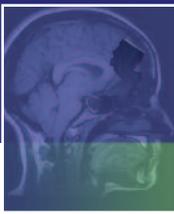
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## Appendix I:

### Estimating the number of people with aphasia in New Jersey

## Potential Scenarios for Aphasia Prevalence Estimation

| Scenario   | Source  | Prevalence | 95% LCL   | 95% UCL |
|--|---|------------|-----------|---------|
| 1  | BRFSS (2012): Has a doctor, nurse, or other health professional EVER told you that you had stroke? 1 = Yes, 2 = No, 7 = Don't Know/ Not sure, 9 = Refused ( <a href="http://www.cdc.gov/brfss/index.htm">http://www.cdc.gov/brfss/index.htm</a> ) | 2.30       | 2.00      | 2.50    |
|  | Estimated Number Ever had Stroke (Ages 18+) -- Lifetime Stroke  | 154,714    | 134,534   | 168,167 |
|  | Estimated Number with Aphasia -- Assuming 30% of aphasia presence in acute stroke patients*   | 46,414     | 40,360    | 50,450  |
| 2  | <b>Captain Maureen Will (National Association of Aphasia): 23-40% of Stroke Survivors Acquire Aphasia</b>   |            |           |         |
|  | 23% of Stroke Patients  | 35,584     |           |         |
|  | 40% of Stroke Patients  | 61,885     |           |         |
| 3  | Engelter et al. (2006)  |            |           |         |
|  | 43/100,000 of First-Ever Ischemic Strokes develop Aphasia   | 3,781      |           |         |
| 4  | New Aphasia cases per year (National Institute of Deafness and other Communication Disorders)   |            |           |         |
|  | Number of Acute Strokes per Year in the Use (AHA)   | 795,000    |           |         |
|  | Percent of New Aphasia Cases resulting from Stroke  | 10.1%      |           |         |
|  | Applying the above incidence rate to the 19,000 discharged alive, 2012 acute stroke Registry, the number of aphasia cases would be (We made a lot of Assumptions to get this estimate):   | 1,911      |           |         |
| Notes: a Population of NJ used for estimation in 2011  |   |            | 8,791,894 |         |
| b Population of NJ in 2011 (18+ years old)   |   |            | 6,726,680 |         |
| * Matthew B. Maas, MD, Michael H. Lew, MD, Hapkan Ay, MD, et. al (2010). "The Prognosis for Aphasia in Stroke," J Stroke Cerebrovasc Dis. 2012 July; 21(5):350-357 |   |            |           |         |

## Aphasia Prevalence Estimation Using the Capture-Recapture Method

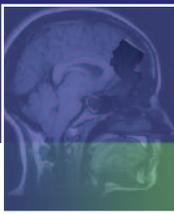
|                         |         | 2012 Aphasia Discharges                     |                     |   |
|-------------------------|---------|---|---------------------|---|
|                         |         | Present                                     | Absent              | Total                                       |
| 2011 Aphasia Discharges | Present | Count <sub>11,12</sub>                      | Count <sub>11</sub> | Count <sub>11,12</sub> +Count <sub>11</sub> |
|                         | Absent  | Count <sub>12</sub>                         | —                   |   |
|                         | Total   | Count <sub>11,12</sub> +Count <sub>11</sub> |                     |   |

**Interest:** Whether or not a hospitalized aphasia patient in 2011 will also be hospitalized in 2012 – aphasia cases in 2011 are considered sample 1, 2012 cases as sample 2.

**Assumptions:**

- 1) The patient's hospitalization in 2011 is independent of that patient's hospitalization in 2012.
- 2) There were no deaths, migrations in or out of the population of aphasia during the study period (i.e., Population was closed).
- 3) Whether a patient was hospitalized in 2011 has not impact on that patient's hospitalization in 2012

**Reference:** Bishop, Feinberg and Holland (1975): Discrete Multivariate Analysis. Cambridge, MA: MIT Press.



# The New Jersey Aphasia Study Commission Final Report

## Prevalence of Aphasia Resulting from the Capture-Recapture Method

| Scenario | Source   | Prevalence | 95% LCL | 95% UCL |
|----------|--|------------|---------|---------|
| 5        | Capture-Recapture Aphasia Prevalence Estimate (all ages), excludes deaths                              | 119,126    | 98,884  | 139,368 |
|          | Capture-Recapture Aphasia Prevalence Estimate (Ages 18+), No deaths                                    | 117,479    | 97,515  | 137,721 |
|          | Capture-Recapture Aphasia Prevalence Estimate (Ages 18+), No deaths & Using <b>Only Primary Stroke</b> | 117,494    | 85,599  | 149,389 |

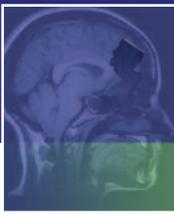
### Notes:

- Population of NJ in 2011 used for estimation 8,791,894
- Adult population of NJ in 2011 (18+ years old) 6,726,680

## Refining Estimates: Assuming 38% of “all” Aphasia Cases resolve by Discharge (5 days)

| Source  | Aphasia Prevalence | 95% LCL | 95% UCL | Aphasia Prevalence, Assuming 38% Resolved * | 95% LCL | 95% UCL |
|---|--------------------|---------|---------|---|---------|---------|
| BRFSS: Estimated Number with Aphasia -- Assuming 30% of aphasia presence in acute stroke patients *                 | 46,414             | 40,360  | 50,450  | 28,777                                      | 25,023  | 31,279  |
| <b>Captain Maureen Will (National Association of Aphasia): 23-40% of Stroke Survivors Acquire Aphasia</b>           |                    |         |         | -   | -       | -       |
| 23% of Stroke Patients  | 35,584             | -       | -       | 22,062                                      | -       | -       |
| 40% of Stroke Patients  | 61,885             | -       | -       | 38,369                                      | -       | -       |
| Engelter et al. (2006): 43/100,000 of First-Ever Ischemic Strokes develop aphasia--Projecting this to Registry data | 3,781              | -       | -       | -   | -       | -       |
| Capture-Recapture Aphasia Prevalence Estimate (all ages), excludes deaths   | 119,126            | 98,884  | 139,368 | 73,858                                      | 61,308  | 86,408  |
| Capture-Recapture Aphasia Prevalence Estimate (Ages 18+), No deaths   | 117,479            | 97,515  | 137,721 | 72,837                                      | 60,459  | 85,387  |
| Capture-Recapture Aphasia Prevalence Estimate (Ages 18+), No deaths & Using <b>Only Primary Stroke</b>              | 117,494            | 85,599  | 149,389 | 72,846                                      | 53,071  | 92,621  |

\* Matthew B. Maas, MD, Michael H. Lew, MD, Hapkan Ay, MD, et. al (2010). "The Prognosis for Aphasia in Stroke," J Stroke Cerebrovasc Dis. 2012 July; 21(5):350-357



## Recommendation

1. May use the Capture-recapture estimate since it is the most “reliable” and defensible of the ones we have at hand
2. Alternatively, I suggest using the mean or median of I estimates after correcting for resolved cases
  - Median = 55,603
  - Mean = 51,458
  - Or Mean = 21,579 if 74% resolve
  - Or Median = 23,317 if 74% resolve

## Demand for Treatment

### Total Demand for Treatment

- \* There is a need to assess the total number of people with Aphasia conditions who would seek treatment if treatment were provided or easily available

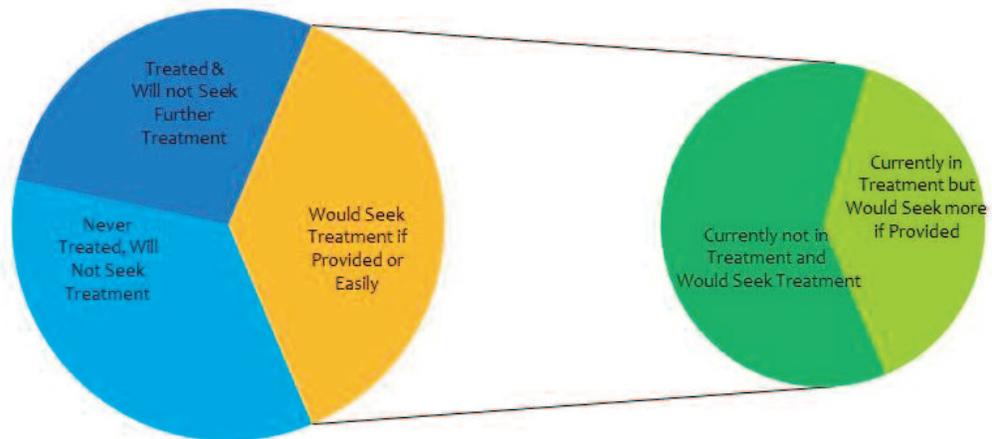
### Met Demand for Treatment

- \* We have to find a mechanism to estimate the total number of people with Aphasia conditions who are currently in treatment or would seek additional treatment if treatment were available



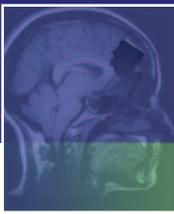
## Unmet Demand (Need) for Aphasia Treatment

Aphasia Prevalence



## Suggestion

- \* Recommend a careful study to arrive at Aphasia prevalence, Aphasia demand for treatment and the met need (demand) for Aphasia treatment to make informed decisions.



# The New Jersey Aphasia Study Commission Final Report

## Appendix II:

### Minimum Data Set (MDS)

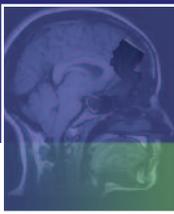
The Minimum Data Set (MDS) is a standardized uniform comprehensive assessment of all residents in Medicare or Medicaid certified long-term care facilities mandated by federal law (P.L.100-203) and is electronically transmitted to the state.

The MDS is used as an assessment tool to identify resident care problems that are addressed in an individualized care plan. Data collected from MDS assessments are used for the Medicare reimbursement system, state Medicaid reimbursement systems and to monitor the quality of care provided to nursing facility residents. The MDS contains items that reflect the treatment level of the resident including diagnoses, treatments and an evaluation of the resident's functional status. The New Jersey Department of Health is the state survey agency responsible for the survey and certification of long-term care facilities (LTCF) and for the implementation of the MDS data system.

### **NJ MDS Aphasia cases reported in 2011 and 2012:**

|   |          |               |
|---|----------|---------------|
| <b>2012-- Clients in N.J. Long-Term Care Facilities</b> | <b>=</b> | <b>43,575</b> |
| <b>Clients with diagnosis of Aphasia (4.69%)</b>        | <b>=</b> | <b>2,043</b>  |
| <b>2011-- Clients in N.J. Long-Term Care Facilities</b> | <b>=</b> | <b>44,051</b> |
| <b>Clients with diagnosis of Aphasia (4.46%)</b>        | <b>=</b> | <b>1,965</b>  |

The total number of persons in Long Term Care each year represents less than ½ of one percent of the State's population (0.49%) and only 3.5% of the state's population over the age of 65.



# The New Jersey Aphasia Study Commission Final Report

## Appendix III:

### New Jersey Acute Stroke Registry (NJASR) Data

New Jersey is one of only a handful of states that now keeps statistics on Stroke. As part of the NJ Stroke Center Act of 2004, the NJ Department of Health designates licensed general hospitals that meet certain standards as either Primary or Comprehensive Stroke Centers. A designated NJ stroke center hospital is required to submit patient-level stroke data to the Department in order to establish a stroke registry. In 2010, the NJ Acute Stroke Registry (NJASR) was launched. The Department is the data repository for stroke data submitted by designated stroke center hospitals on a quarterly basis. The patient-level registry data is analyzed and used to improve patient care and long-term outcomes for stroke patients. Typically, some analysts estimate that about 30-40% of stroke patients develop aphasia. In 2011 and 2012 there was a total of 65 Designated Stroke Center Hospitals in NJ reporting patient-level stroke data. In the past, the NJASR did not collect data on the presence of aphasia in stroke cases, but for 2014 the NJASR has been updated to include a data element for aphasia.

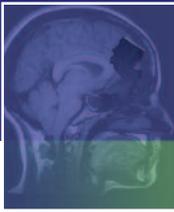
| Total NJASR stroke cases reported for |               |               |
|---------------------------------------|---------------|---------------|
| Type of Stroke                        | Year 2011     | Year 2012     |
| Subarachnoid hemorrhage               | 577           | 602           |
| Intra-cerebral hemorrhage             | 1,915         | 2,003         |
| Ischemic stroke                       | 10,726        | 11,109        |
| Transient ischemic attack (TIA)       | 6,241         | 5,625         |
| Stroke not otherwise specified        | 555           | 486           |
| <b>Total</b>                          | <b>20,014</b> | <b>19,825</b> |

### Shortcomings of current state data bases in predicting the overall prevalence of Aphasia in New Jersey

The MDS reports on only a very small percentage of the total population (1/2 of one percent), and documents primarily older nursing home residents who are already being treated within the health care system. On the other hand, the New Jersey Hospital Discharge Data Collection System (NJDDCS) (also commonly known as the Uniform Billing (UB) System) gives us some indication of actual numbers of persons diagnosed with aphasia among patients who had hospital encounters.

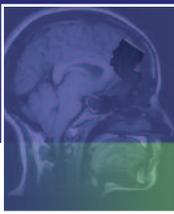
While adding “Aphasia” to the NJASR will be extremely helpful in establishing the prevalence of Aphasia in New Jersey, these measures will--

1. tally numbers of persons with aphasia only as an outcome of stroke; other etiologies will not be counted;



# The New Jersey Aphasia Study Commission Final Report

2. document the incidence of aphasia only in the acute stage at hospital discharge;
3. document aphasia only if the patient was fortunate enough to be examined for aphasia during his/her hospital stay. (For example, now that the DRG for hospital stay for “uncomplicated stroke” has been reduced to four days, we know that many patients are discharged without a speech and language evaluation, therefore, the presence of aphasia in patients discharged after stroke is undoubtedly underestimated.)
4. NJASR documents only persons over 18 years of age where younger victims will not be counted, nor will persons living long-term with chronic aphasia in the community be counted.



# The New Jersey Aphasia Study Commission Final Report

## Appendix IV

### The ACT Establishing the New Jersey Aphasia Study Commission

#### CHAPTER 117

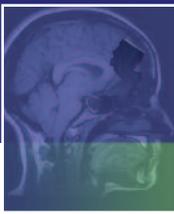
AN ACT establishing the New Jersey Aphasia Study Commission.

BE IT ENACTED by the Senate and General Assembly of the State of New Jersey:

1. The Legislature finds and declares that:
  - a. Aphasia is a disorder of the brain that occurs, most commonly, after a stroke or traumatic brain injury and affects a person's ability to communicate. A person with aphasia typically has difficulty speaking and, sometimes, difficulty with reading, writing, and understanding what other people are saying; however, the condition does not affect a person's intellect;
  - b. Although the condition is most common among older people, aphasia can be acquired by people of all ages following severe head and brain trauma;
  - c. The type and severity of language dysfunction depends on the precise location and extent of damaged brain tissue. Generally, there are four types of aphasia: (1) expressive aphasia involves difficulty in conveying thoughts through speech or writing; (2) receptive aphasia involves difficulty understanding spoken or written language; (3) anomic or amnesia aphasia, the least severe form of aphasia, involves difficulty in using the correct names for particular objects, people, places or events; and (4) global aphasia, the most severe form of aphasia, involves loss of almost all language function, both comprehensive and expression;
  - d. There is no one treatment proven to be effective for all types of aphasia. Persons with aphasia usually experience improvement over time, aided by speech therapy, rehabilitation services, and counseling; however, many persons with aphasia are prone to depression, hopelessness, and isolation, avoiding contact with others in order to pass on social situations that may lead to mutual frustration;
  - e. It is estimated that one million people in the United States have aphasia, more than the number of people suffering from Parkinson's disease, muscular dystrophy, multiple sclerosis, or cerebral palsy; and
  - f. It is, therefore, in the public interest for the State to establish a commission to study the prevalence and impact of aphasia on residents of the State, and to review model support programs for persons with aphasia and their families.
2. a. There is established the New Jersey Aphasia Study Commission in the Department of Health and Senior Services.

The purpose of the commission shall be to:

  - (1) establish a mechanism in order to ascertain the prevalence of aphasia in New Jersey, and the unmet needs of persons with aphasia and those of their families;
  - (2) study model aphasia support programs, such as, the Kean University Institute for Adults Living with Communication Disabilities and the Adler Aphasia Center; and



# The New Jersey Aphasia Study Commission Final Report

## PL.2010, CHAPTER 117

2

- (3) provide recommendations for additional support programs and resources to meet the unmet needs of persons with aphasia and their families.
  - b. The commission shall consist of 11 members as follows:
    - (1) the Commissioners of Health and Senior Services, Banking and Insurance, and Human Services, or their designees, who shall serve ex officio; and
    - (2) eight public members who shall be appointed as follows: two persons appointed by the Senate President, one of whom is a person with aphasia and one of whom provides services to persons with aphasia; two persons appointed by the Speaker of the General Assembly, one of whom is a person with aphasia and one of whom provides services to persons with aphasia; and four persons appointed by the Governor, one of whom is a person with aphasia, one of whom provides services to persons with aphasia, and two of whom are members of the public with demonstrated expertise in issues relating to the work of the commission.

Vacancies in the membership of the commission shall be filled in the same manner provided for the original appointments.
  - c. The commission shall organize within 120 days following the appointment of a majority of its members and shall select a chairperson and vice-chairperson from among the members. The chairperson shall appoint a secretary who need not be a member of the commission.
  - d. The public members shall serve without compensation, but shall be reimbursed for necessary expenses incurred in the performance of their duties and within the limits of funds available to the commission.
  - e. The commission shall be entitled to call to its assistance and avail itself of the services of the employees of any State, county or municipal department, board, bureau, commission or agency as it may require and as may be available to it for its purposes.
  - f. The commission may meet and hold hearings as it deems appropriate.
  - g. The Department of Health and Senior Services shall provide staff support to the commission.
3. The commission shall report its findings and recommendations to the Governor, and to the Legislature pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), along with any legislative bills that it desires to recommend for adoption by the Legislature, no later than 12 months after the initial meeting of the commission.
  4. This act shall take effect immediately and shall expire upon the issuance of the commission report.

*Approved January 5, 2011.*

**The New Jersey Aphasia Study Commission  
Final Report, May, 2015**