



# Serving the Underserved: Primary Progressive Aphasia Services in the Life Participation Model

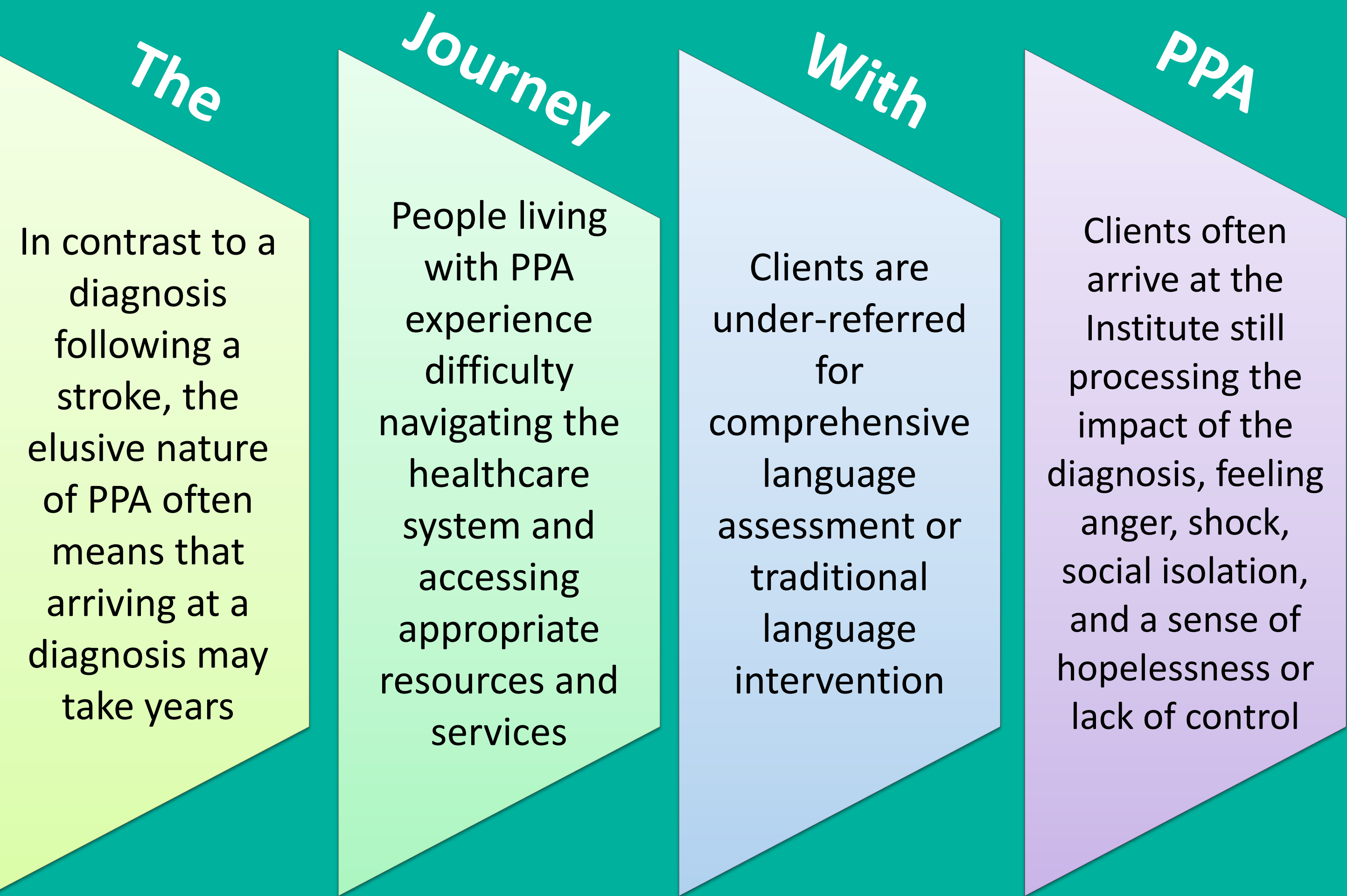
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### What is PPA

- Primary Progressive Aphasia (PPA) is an uncommon type of frontotemporal dementia marked by language loss
- Symptoms of aphasia initially present in isolation but lead to progressive changes in other cognitive skills
- By the time diagnosis is confirmed, the journey of dread and changing identity has already occurred

### The Aphasia Institute's Contribution

- The Aphasia Institute, at its roots and core values, has been providing hope, and access to life participation for people with stroke based aphasia
- The challenge in offering service for people with PPA and their families is to be creative and expand current offerings to this vulnerable minority population
- There is added value in recognizing that providing hope and access to life participation goals must be approached very differently



### A-FROM in Action

- PPA services at the Aphasia Institute are driven by the principles of the Life Participation Approach to Aphasia (LPAA) and the Living with Aphasia: Framework for Outcome Measurement (A-FROM) model
- A-FROM is used to distinguish the language impairment from other domains
- Clients *and* families are entitled to services that lessen the *impact* of aphasia on relationships and participation in meaningful activities
- Reframed hope, and maximized life participation are explicit goals of all services offered to those living with PPA while the aphasia remains the dominant concern
- Although individuals with PPA are encouraged to participate in various AI programs, one program is designated specifically for PPA - *Living Your Best Life*

### References and Acknowledgements

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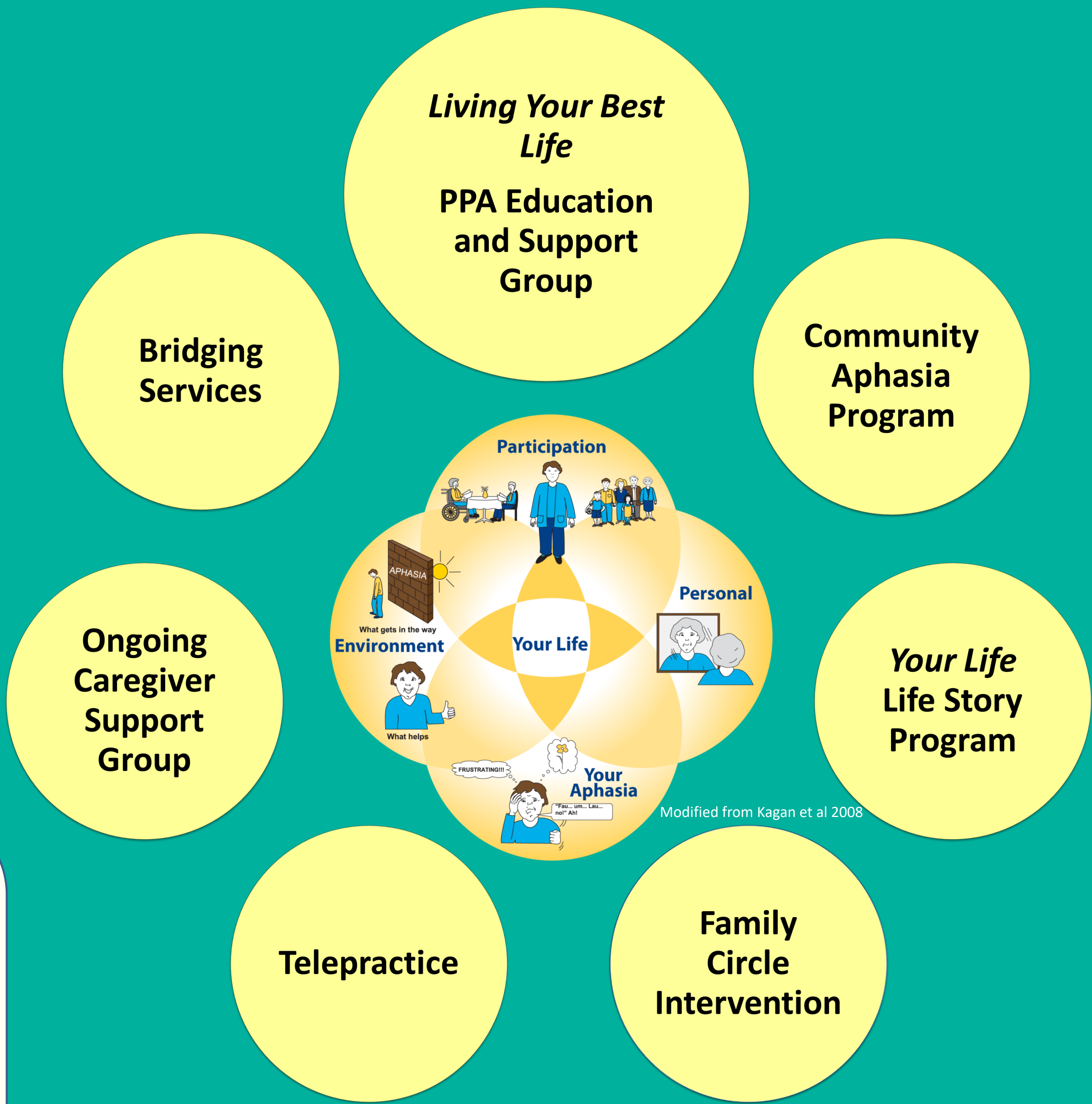
### Keeping Conversations Alive:

#### Living Your Best Life Programs for People Living with PPA

In order to be inclusive of all PPA members and address the unique needs of caregivers, program offerings have been re-evaluated to accommodate individuals on a case-by-case basis

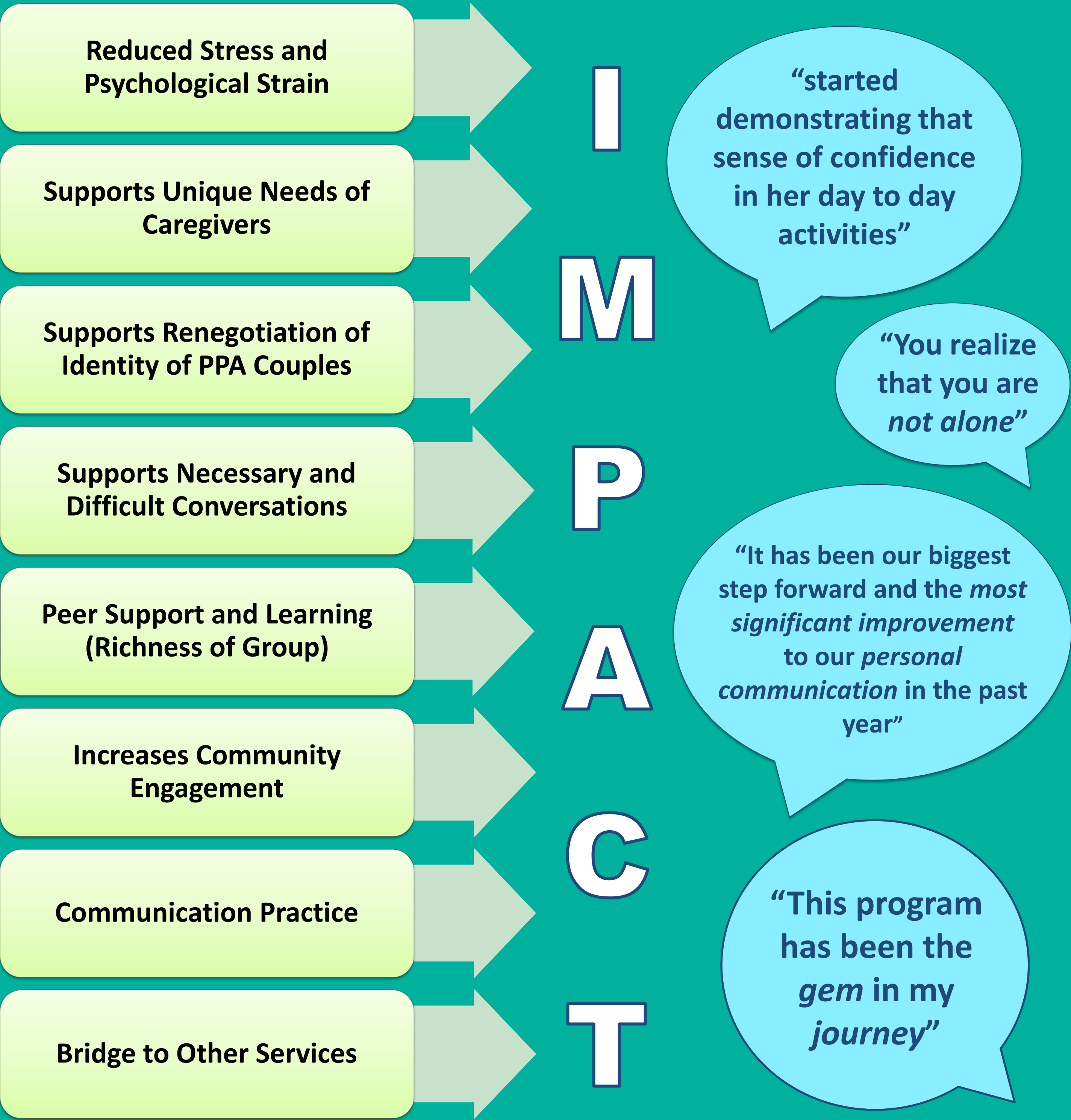
Service to clients with PPA and their families is more intensive, requiring flexibility and careful clinical judgement related to the nuanced and changing needs of this population and their families.

This service model restores relationships by fostering the skills and confidence needed to have and 'keep conversations alive' for as long as possible (e.g. End of Life decisions, and future care planning)

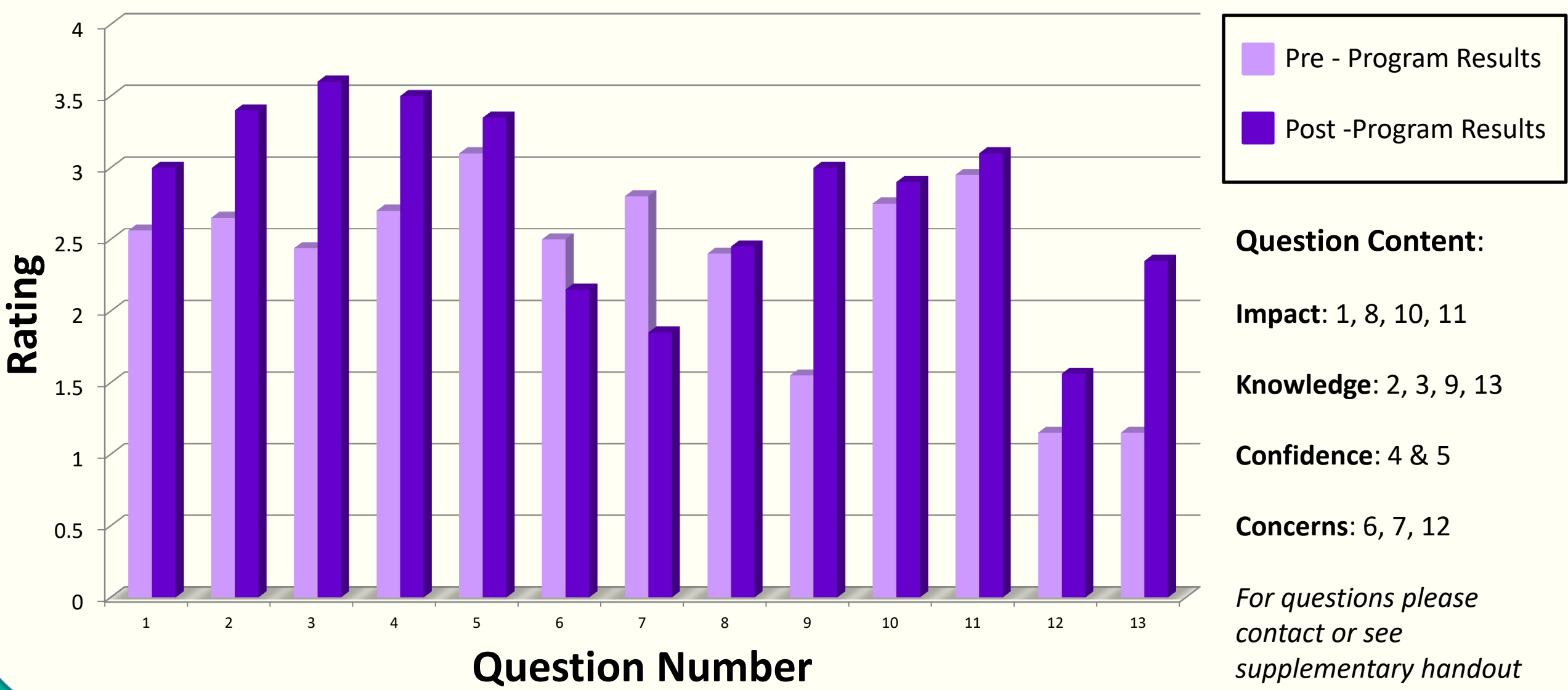


### Living Your Best Life PPA Education and Support Group

- The Living Your Best Life Education and Support group is the signature service offered for families impacted by PPA
- Running for a total of seven weeks, the program is divided into two major components: education and training, and emotional support
- Content is delivered through formal instruction, and collaborative learning is enriched by peer interaction
- PPA-specific support groups ensure that caregivers feel empowered to adapt to the evolving care and relationship dynamic
- Participation expectations are contracted which include 'check-ins' with staff every six weeks
- Discharge occurs when the clients' needs extend beyond the capacity of direct services offered at the Aphasia Institute



### Living Your Best Life Education and Support Group Survey



### Future Development

- Generate Aphasia Friendly resources around topics such as;
  - End of life decisions
  - Renegotiation of future care and planning
- Further explore integration of people with PPA within the larger Aphasia Community
  - Anxiety about future changes
  - Difficulty identifying with those who have stroke-based aphasia
- Continue to examine timing of services throughout the course of PPA and program suitability
- Expand partnerships with relevant agencies and other clinical professionals to create bridging of services on the continuum of care