

Aging Workshop
Family weekend
May 7, 2023

Following is a quick summary of Aging Committee reports, results of the aging survey, and the two workshop sessions at the Family Weekend. Approximately 60 people participated in the two break out sessions. Their comments are in *italics*.

Note: comments related to needs, roles, and responsibilities of families should in most cases be assumed to include parents, siblings, and guardians. Therefore, the use of the term "families" should be viewed as an inclusive term and not a limiting term.

Develop a strategic plan. Representing a hybrid approach

- Approach is to serve all individuals to end-of-life, determine what this means in terms of facility and cost.
- Maintain facilities as they are and transfer residents when no longer able to support.

Encourage all families to apply for DDS funding, while recognizing that DDS is not likely to fund individuals from out of state.

Survey respondents were equally divided with family members in the 21 to 29, 30 to 39, 40 to 49, and 50 to 59, age groups.

- Encourage families of individuals between 21 and 40 to plan for long-term needs
- By age 40 many families, including families of individuals with down syndrome, will be in the execution mode of increased medical Care.
- Beginning at age 50 most individuals will see increasingly complex medical needs requiring different types of care.

Survey results

- Almost 60% of respondents said their family has formal written plans to provide for the future support of their LIFE participant.
 - Importance recognized
 - What can the LIFE community do to assist families in making formal plans?
 - *The term "plans" mean written plans, and may include plans that describe the authorities and capabilities, as well a care plans that provide qualitative direction on how the family would like care to be provided.*
 - *Families want a 411 capability for questions*
 - *Plans should identify guardians, if appointed, as well as alternate guardians.*
 - *Plans involving guardians should contemplate need for changes especially as it relates to duties performed by the guardians and those performed by LIFE staff.*

- *Plans should include health and safety plans, with a local LIFE point of contact (POC) who out of area families can contact to verify health and safety, and who could be contacted by the LIFE participant if they have questions or concerns.*
- *Plans should address transition issues, both for the changing needs of the LIFE participant and for family.*
- *Plans may include instruments like advance directives and powers of attorney.*
- *Plan should include financial plans.*
- *Plan may include guidance on conditions under which current support may be changed in response to emergent needs.*
- *Plans may include tiered approaches (shared living, group home, assisted living, skilled nursing). Where possible the family may want to include how other parts of the overall plan may be informed or affected by financial planning.*
- *There is a need for medical management planning, to set out a clear agreement between the family and LIFE that describes who “owns” overall responsibility as well as responsibility for various medical care related duties (e.g., medication management, transportation to medical appointments, reporting back results of visits including plans for follow on care*
- Only 17% indicated that their family has reviewed the formal plans with the LIFE staff.
 - What should this formal review look like?
 - *Should include participation by a LIFE benefit specialist, life coaches, and families. Add specialized staff as appropriate (e.g., medical, clinical).*
 - *Should not normally include DDS service coordinator participation.*
 - *May include the LIFE participant.*
 - *Should be based on a review model but with flexibility to adapt to specific needs.*
 - *In the absence of a family request to conduct a meeting LIFE staff should initiate requests for meeting on an agreed schedule.*
 - *LIFE and families should develop a standard framework or checklist for meetings with a goal to establish a uniform baseline approach, as well as flexibility to tailor the plan to meet individual needs.*
 - *Families would benefit from a standard plan that meets 80% of the needs of a typical LIFE participant. Families understand the benefit of plan development and periodic review to assess and manage risks and to prepare for uncertainty.*
 - How often should it take place?
 - *It should begin at admission and be repeated regularly or as changed circumstances may require.*
 - *Should be regularly scheduled*
 - *May be scheduled to take place at the same time frame as annual DDS ISP reviews or similar reviews for private pay participants.*
 - *LIFE staff should be empowered to initiate a request for a family meeting at any time, but especially in response to changing or emerging needs.*
 - *Younger participants with no complicating factors could be on a longer periodicity for plan meetings (2, 3, 5 years). Older or more medically*

complex individuals may require much more frequent meetings (monthly, weekly), as required.

- 75% said their family is relying on LIFE to provide for all of the participants needs after they are no longer physically able or mentally capable of providing the current level of care.
 - Consistent with respondent comments that generally desire that the loved one remain at LIFE and receive the care and guidance needed as they age, with increased support from LIFE.
 - Families value kindness and support and continuity
 - Some families may rely on LIFE to provide advocacy and loco parentis care when family is unable to perform parent functions

- 75% said that their family has not yet developed a written plan to address the normal but important aspects of aging on their LIFE participant and they're seeking assistance from the LIFE team to move forward
 - Need for assistance to navigate state and government systems such as DDS, and Medicare, to attain the best level of funding and support their loved one may need.
 - Provide a clear roadmap that includes agencies to identify what state and federal assistance could be available as their loved one ages.
 - Designate an individual at LIFE who is conversant in and up-to-date on these matters.
 - Provide on-site nurse, nurse practitioner, or physical physician's assistant to supervise and to recognize medical needs as they emerge.
 - *Families desire that a "family-to-family" network be established, that may include certain individuals serving as mentors.*
 - *Families are interested to learn how LIFE may develop strategic relationships or partnerships with organizations that provide complimentary services.*