Special Needs Life Care Planning

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What is Life Care Planning?

• Comprehensive legal, financial, and care planning for changes and challenges associated with aging and disability

• Initially developed for elder clients and their families

• More complex version is appropriate for families that include individuals with special needs – accounts for aging of parents/caregivers and complements future planning for lifelong needs of the person with special needs
The Elder Care Continuum

- Tool used to plan for aging
- For families including individuals with special needs, situation is more complex – may need to start earlier
When to start planning: major life transitions

• Person with special needs becoming an adult (18)
• Aging out of school system (22)
• Changes in residence
• Changes in family financial situation
• Marriage, divorce, birth, or adoption of a child
• Retirement
• Illness, incapacity, or death of caregivers/family members
Components of a Special Needs Life Care Plan

Legal

Financial

Care Planning/Coordination

Person with special needs

Caregivers (generally parents)

Other family members (e.g. siblings or grandparents)
Intersection of the whole family’s needs and resources

Parent/Family

- Health & Ability
- Living Situation
- Cost of Care
- Public Benefits

Person with Special Needs

- Health & Ability
- Living Situation
- Cost of Care
- Public Benefits

Resources
Legal considerations

- Estate planning
- Incapacity planning
- Advance directives for healthcare
- Conservatorship/guardianship
- Special needs trusts
- ABLE accounts
- Public benefits (SSI, TennCare, MSPs, SNAP, Section 8, Waivers, VA)
Financial considerations

- Financial planning
- Risk planning
- Retirement planning
- Tax and estate tax planning
- Business planning
- Budgeting and projections of lifetime costs
- Engage other qualified professionals, Trustee, CFP, CPA, etc.
Financial considerations (con’t.)

• Benefit programs to help pay for care:
  • TennCare – special rules permit transfers of assets to a disabled child; how should such transfers be structured for the benefit of the family unit?
  • Veterans benefits
    • Pension with Aid and Attendance - for veteran, surviving spouse, dependent child with permanent and total disability prior to 18, or dependent parent
    • Service Connected Disability and Dependency and Indemnity Compensation for Surviving Spouse and Disabled Child where veteran died in active duty or was 100% service connected disabled for 10 years before death
Care planning, coordination & advocacy

• Contingency plans
  • Short-term options if caregiver is temporarily unavailable
  • Long-term options if caregiver is permanently incapacitated or unable to provide care

• Engage special needs professionals/care providers

• Evaluate family’s health history and likely direction of long-term health needs
  • Long-term care options for parents/family
  • Long-term care options for person with special needs
Case study: meet the Browns

• Parents, Jim and Susan, ages 46 and 44
  • Jim works full-time at Verizon as a regional manager and Susan works part-time as a decorator; she provides substantial care for their daughter, Diane
  • Both are healthy at this time; Jim has high stress at work
  • Susan’s parents live nearby and are experiencing health declines; her mother (70) has dementia

• Daughter, Diane, age 17
  • Outgoing, trusting, born with an intellectual disability
  • Currently attends West High School

• Son, Keith, age 20
  • Currently enrolled in college at UT Chattanooga, studying mathematics
  • Wants to work this summer and save for a trip abroad next year

Problem: no cohesive plans in place
Immediate need: legal planning for the whole family

- Goal is to protect the family unit and the status quo; begin visioning for the long-term plan that addresses intersection of Diane’s needs and abilities with Jim and Susan’s needs and resources
- Key issues: incapacity, death, resources
  - POAs/Advance Directives for Jim, Susan & Keith
  - Estate plan with SNT components
  - Identify guardians/Trustee for Diane
  - Plan for Susan’s parents
  - Financial planner for Jim and Susan
  - Plan for retirement
  - Cover risk of Jim and Susan’s death with life insurance to provide for family and fund SNT
The Special Needs Life Care Plan should …

• Address each major life transition for both the parent and the child
• Involve person with special needs, caregivers, family members, professionals, friends, and others who are supportive and knowledgeable
• Ensure family’s resources are structured to ensure best possible care for person with special needs AND family
Transition #1: Diane turns 18

- Parental decision-making authority for Diane evaporates
  - Pursue conservatorship or powers of attorney
  - Consider milestones: residence, employment, changing care needs, changing level of ability/independence
  - Develop integral relationships that support Diane’s plan and quality of life

- Structure family assets for Diane’s lifetime care needs:
  - Create a stand-alone third party special needs trust
  - Identify key fiduciaries in tiers
  - Apply for SSI and TennCare/Medicaid
  - Use ABLE accounts
  - Project resource needs for Diane’s lifetime
Transition #2: Diane graduates from high school at 22

• Plan for Diane’s increased independence; consider:
  • Group living/Section 8 housing options/waiting lists
  • SNAP if she moves out of the homeplace
  • TennCare Employment and Community First Waiver program for employment opportunities and community living
  • ABLE accounts

• Jim and Susan’s retirement – stay on track, maximize retirement contributions

• Include Keith in planning; gauge his support
Consider Diane’s evolving needs and available resources

• Estimate lifetime support needs
  • Healthcare/therapy
  • Personal assistance/supervision
  • Community access programs
  • Education and employment training/assistance
  • Residential services and home modifications
  • Assistive technologies/devices and vehicle modifications
  • Family respite care

• Identify possible sources of income
  • Social Security/government income assistance
  • Court ordered or contractual payments
  • Personal income
  • Support from others
Transition #3: Susan’s mother needs 24/7 care & Susan needs help managing

- Use elder care continuum as a planning tool
- Elder care coordinators assist with residential placement in memory care or long-term nursing home care
- Elder care coordinators provide advocacy in care setting & assess Susan’s father’s emotional, financial, and physical needs and health
- Goal is to get good care for Susan’s mother and prevent impoverishment of Susan’s father
- Identify and access resources to provide care for mother
- Public benefits shore up private funds
Transition #4: Jim and Susan at or near retirement age

- Consider purchase of long term care insurance
- Review financial plan for Jim, Susan, and Diane
  - Make Medicare selections
  - Make Social Security elections
  - Consider and pursue asset protection strategies
  - Evaluate effect of retirement on Diane’s SSI benefits
- Continue to involve Keith and his wife, Kathy, with the idea that they can confidently and respectfully manage care for Diane at some point in the future
Transition #5: Jim and Susan can no longer care for Diane

• Jim has had several strokes; Susan is frail with early signs of memory loss
• Where will Jim and Susan receive care? Will one care for the other? What if both need substantial daily assistance?
• Anticipate needs of surviving spouse at first spouse’s death
• Keith and Kathy follow Diane’s changing care needs
• Life Care Plan offers solutions for Keith and Kathy as they now care, manage, and advocate for Jim, Susan and Diane
Resources

• Resources: Life Care Planning Law Firms Association, www.lcplfa.org
• Special Needs Alliance, www.specialneedsalliance.org
• The ARC’s Center for Future Planning, www.futureplanning.thearc.org
• Sharon Davis, Ph.D., Editor, A Family Handbook on Future Planning, The Arc of The Unites States and University of Illinois, 2003.
• Planning Alternative Tomorrows with Hope (P.A.T.H.)
Thank you. We have time for questions.