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JOURNAL OF NURSE LIFE CARE PLANNING
Summer 2014

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In order to make safe and effective judgments using NANDA-I nursing diagnoses it is essential that nurses refer to the definitions and defining characteristics of the diagnoses listed in this work.
Editor’s Note

Welcome to the Spring 2014 issue of the Journal of Nurse Life Care Planning. You will notice our new look, congruent with the new colors and fonts for all AANLCP online and print offerings. Sharp-eyed readers will also notice a change in our header to reflect the fact that our Journal has been peer-reviewed since 1998, with thanks to the home-grown archivists who documented this with issues from that year. Our current Issue numbering system will remain unchanged, however; issues before 2008 are not available for sale.

Please take a minute to check our updated website at www.aanlcp.org, especially the sections on new and exciting member benefits to support your research and networking activities.

Cordially,

Wendie Howland
Editor, Journal of Nurse Life Care Planning
whowland@howlandhealthconsulting.com

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Information for Authors

AANLCP® invites interested nurses and allied professionals to submit article queries or manuscripts that educate and inform the Nurse Life Care Planner about current clinical practice methods, professional development, and the promotion of Nurse Life Care Planning within the medical-legal community. Submitted material must be original. Manuscripts and queries may be addressed to the Editorial Committee. Authors should use the following guidelines for articles to be considered for publication. Please note capitalization of Nurse Life Care Plan, Planning, etc.

Text
Manuscript length: 1500 – 3000 words
• Use Word© format (.doc, .docx) or Pages (.pages)
• Submit only original manuscript not under consideration by other publications
• Put the title and page number in a header on each page (using the Header feature in Word)
• Use Times, Times New Roman, or Arial font, 12 point
• Place author name, contact information, and article title on a separate title page, so author name can be blinded for editorial review
• Use APA style (Publication Manual of the American Psychological Association)

Art, Figures, Links
All photos, figures, and artwork should be in JPG or PDF format (JPG preferred for photos). Line art should have a minimum resolution of 1000 dpi, half-tone art (photos) a minimum of 300 dpi, and combination art (line/tone) a minimum of 500 dpi.
Each table, figure, photo, or art should be on a separate page, labeled to match its reference in text, with credits if needed (e.g., Table 1, Common nursing diagnoses in SCI; Figure 3, Time to endpoints by intervention, American Cancer Society, 2003)
Live links are encouraged. Please include the full URL for each.

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All accepted manuscripts are subject to editing, which may involve only minor changes of grammar, punctuation, paragraphing, etc. However, some editing may involve condensing or restructuring the narrative. Authors will be notified of extensive editing. Authors will approve the final revision for submission.
The author, not the Journal, is responsible for the views and conclusions of a published manuscript.
Submit your article as an email attachment, with document title articlename.doc, e.g., wheelchairs.doc
All manuscripts published become the property of the Journal. Manuscripts not published will be returned to the author.
Queries may be addressed to the care of the Editor at: whowland@howlandhealthconsulting.com

Manuscript Review Process
Submitted articles are peer reviewed by Nurse Life Care Planners with diverse backgrounds in life care planning, case management, rehabilitation, and the nursing profession. Acceptance is based on manuscript content, originality, suitability for the intended audience, relevance to Nurse Life Care Planning, and quality of the submitted material. If you would like to review articles for this journal, please contact the Editor.

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Susan Smith DNP RN CEN CCRN
Contributing To This Issue

Becky Czarnik MS, RN, CNLC, LNCP-C, CMSP (“Elder Care Life Care Planning”) is the owner of Sierra Nurse Consultants. Her business comprises nurse life planning, legal nurse consulting, medical cost projection and healthcare consulting. She has a special interest in elder care issues. As a lifelong learner, she enjoys networking and being an active member of AANCLP and other nursing organizations.

Liz Holakiewicz (“Creating a New Long Term Living Model for Adults with Autism Spectrum Disorder”) is in full time private practice as a life care planner in San Diego, California. She has 25 years of experience as a life care planner.

Melinda Nylund RN, LNCP-C (“Subcontracting in Life Care Planning”) is the owner of Nylund Life Care Planning, providing subcontracting services for life care planners, legal nurse consultants, and case managers. She has more than 20 years of experience in home health, rehabilitation, cardiology, telemetry, orthopedics, neurology, medical/surgical, oncology, behavioral health and hospice. Her background includes quality assurance and auditing medical charts.

Eileen Sheehan (“Equine-assisted Therapies in Rehabilitation: an overview”) is a Certified Life Planner and owner of Due Diligence Life Care Planning, Inc. in the Boston area. She graduated from Suffolk University Magna Cum Laude with a degree in Paralegal Studies. She also holds Graduate Certificates in Conflict Resolution, Life Care Planning, and Medicare Set-Asides. She is currently working towards her Master’s Degree in Psychology. She has almost 20 years of experience working in the medicolegal field.

Keith Sofka (“Technology Corner”) is a principal of Caragonne and Associates, Ajijic, Jalisco, MX. He has practiced the provision of assistive technology services for the past 30 years. Mr. Sofka provides consultation to hundreds of companies, schools, Government Agencies and individuals. A major focus of Mr. Sofka’s work has been to provide recommendations for and implementation of school and workplace reasonable accommodation recommendations for individuals and organizations. He has also taken training and practiced in other areas of assistive technology including custom seating and positioning for individuals with severe orthopedic involvement. His work has always been focused on ways to use technology to increase the independence of the individual.

Hal Wright (“Life Care Planning for Intellectual Disability”) is a Certified Financial Planner® and an expert on comprehensive special needs planning. He is a parent of an adult daughter with Down syndrome. He has developed concepts, techniques, and tools for holistic planning over an individual’s entire lifetime, including how to fund and manage a special needs trust, planning for supported independence, and planning for the lifetime care of a child who may significantly outlive his or her parents. He is the author of The Complete Guide to Creating a Special Needs Life Plan: a Comprehensive Approach Integrating Life, Resource, Financial and Legal Planning to Ensure a Brighter Future for a Person with a Disability.
Letters to the Editor

Scrambler therapy
Great Journal this quarter (XIV.2, Spring 2014)! Lots of good stuff! I shared it with a relative who has chronic neuropathic pain issues, as well as Parkinson’s, and is considering DBS. I am not sure if he would be interested in Scrambler therapy, or even a candidate, but any new information is always welcomed by him.

anonymous member via the Internet

I have had occasion to recommend Scrambler therapy evaluations to two clients since reading your article on Scrambler Therapy (Sparadeo & D’Amato, XIV.2, p.19). Many thanks to JNLCP and AANLCP for impacting lives in such a meaningful way.

anonymous member via the Internet

Standing Wheelchairs
David Dillard, our research guru, sends along this list of related articles for your information and further background.

• Monitoring standing wheelchair use after spinal cord injury: A case report
  Author: Shields, Richard K
  Journal: Disability and rehabilitation
  ISSN: 0963-8288 Date: 01/2005
  Volume: 27 Issue: 3 Page: 142 - 146
  DOI:10.1080/09638280400009337

• Standing frames and standing wheelchairs: Implications for standing.
  Topics in spinal cord injury rehabilitation, 5, 24-28.

• Orthostatic hypotension following spinal cord injury: impact on the use of standing apparatus
  Author: Chelvarajah, R
  Journal: NeuroRehabilitation (Reading, Mass.)
  ISSN: 1053-8135 Date: 2009
  Volume: 24 Issue: 3 Page: 237

• Are wheelchair-skills assessment and training relevant for long-standing wheelchair users? Two case reports
  Author: Mountain, Anita D.
  Journal: Disability and rehabilitation: Assistive technology
  ISSN: 1748-3107 Date: 05/2010
  Volume: 5 Issue: 3 Page: 230 - 233
  DOI:10.3109/17483100903391145

  Realization of an FPGA-based Motion control system for electric standing wheelchairs.
  In Industrial Electronics and Applications (ISIEA), 2011 IEEE Symposium on (pp. 47-52). IEEE.

  The psychosocial impact on standing devices.
  Disability and Rehabilitation: Assistive Technology, (0), 1-8.

continued next page
• Bone mineral status in paraplegic patients who do or do not perform standing
Author: Goemaere, S.
Journal: Osteoporosis international
ISSN: 0937-941X Date: 05/1994
Volume: 4 Issue: 3 Page: 138 - 143
DOI: 10.1007/BF01623058

• Treatments for Osteoporosis in People With a Disability
Author: Smith, Éimear M.
Journal: PM & R
ISSN: 1934-1482 Date: 02/2011
Volume: 3 Issue: 2 Page: 143 - 152
DOI: 10.1016/j.pmrj.2010.10.001

• Follow-up Assessment of Standing Mobility Device Users
Author: Dunn, Robert B.
Journal: Assistive technology
ISSN: 1040-0435 Date: 12/1998
Volume: 10 Issue: 2 Page: 84 - 93
DOI:10.1080/10400435.1998.10131966

• State of the science on wheeled mobility and seating measuring the health, activity and participation of wheelchair users
Author: Sprigle, Stephen
Journal: Disability and rehabilitation: Assistive technology
ISSN: 1748-3107 Date: 01/2007
Volume: 2 Issue: 3 Page: 133 - 135
DOI: 10.1080/17483100701396507

• Ambulation in children and youth with spinal cord injuries
Author: Vogel, LC
Journal: The journal of spinal cord medicine
ISSN: 1079-0268 Date: 2007
Volume: 30 Issue: suppl 1 Page: S158

• Does standing protect bone density in patients with chronic spinal cord injury?
Author: Goktepe, AS
Journal: The journal of spinal cord medicine
ISSN: 1079-0268 Date: 2008
Volume: 31 Issue: 2 Page: 197

Annual Readership Survey
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Tell us what you think!
Fixed-rate life care plans, a conflict?

This scenario came from a life care planner. The comments are from a group of nurse life care planners who were asked to share their opinions. Nothing in this column is to be taken as legal advice or as the official position of the AANLCP, its board, or the JNLCP.

Q. What does your panel think about this? I have recently been asked to review some really bad life care plans produced at a fixed price. Our standards of practice require that we develop comprehensive plan that identifies all needs and includes peer-reviewed, evidence-based research, and personal assessment (when possible, as allowed) or record review on which to base our opinions. When an expert prices LCP work at a fixed rate in order to attract a larger volume of attorney clients, isn’t this in conflict with the needs of the patient, when the methods used to produce the plan meet few if any professional LCP standards?

A. Charging a fixed rate in order to attract a larger volume of attorney clients does not in and of itself violate business ethics. What is at issue here is the quality of the plans. What is a “really bad life care plan” and, more importantly, what is a “quality” plan, and who decides? Quality can be judged only if there is a standard to judge it by. Does the AANLCP have a model life care plan (template/outline/key elements) for LCPs to use? [Ed. note: There is a Scope and Standard of Practice for what should be included in the planning process. Formatting is always at the discretion of the planner.) If so, then the attorneys hiring LCPs obviously need to be educated on what is standard for inclusion in a life care plan. If the AANLCP or other organization does not have a model for life care plans, then there is no way for an LCP or an attorney client to know what is needed.

In my experience in other arenas, the client gets what the client asks for in the contract and in other discussions about their expectations. This does not necessarily result in a product that meets an established standard, but it satisfies the client. Were the attorneys satisfied with the life care plans initially because these plans met their expectations, only to find out later that there were significant gaps in the plan? If so, did they ask the LCPs to revise the plans as needed? If not, (and the client has every right to seek other LCPs to revise plans they decide are inadequate), then the LCPs will not be able to grow in their understanding of what is needed in a life care plan, and the cycle goes on.

I agree that each life care plan is developed for the individual needs of the injured person. A fixed rate would tend to standardize LCP and possibly add unneeded services and equipment and possibly miss needed services and equipment. This does not meet the ultimate goal of the life care plan, to create an individualized plan of care based on needs.

I am finding a consistent pattern where physician life care planners, some nurses and others who want to secure a bigger practice, consis-
tently underbid the market costs for a life care plan, and, on top of it, using a fixed cost to do so. I contend that their decision to place their business interests over the interests of the person for whom the plan is being designed as they cut corners to ensure greater profit. The issue being: with a fixed cost arrangement, the fewer hours your work, the greater your profit. So in service of their profit, they eliminate a home visit, they eliminate collaborating with providers, they eliminate collecting individualized data because each of these tasks takes time and cuts into their profits. Hence the fiduciary profit. And conflict of interest.

I would think that the price is immaterial if the work product demonstrably doesn’t meet standards. When they come up against somebody better in a case, the difference will become obvious. Word will get around.

The people who do that will end up like the guys that opened a seafood chain restaurant across the street from a well-established family seafood restaurant, Shaw’s, in our area a few years back, with cut-rate prices and fairly decent food. Shaw’s had a pretty lean year, as the tourists saw the familiar chain logo and went there, and the locals all tried it. Once. Then come winter, the locals went back to Shaw’s, happy to pay for a better chowder, and never went back to the chain store. The chain store couldn’t live on just the summer tourist trade and folded.

In marketing there’s the Walmart vs. Starbucks phenomenon. You can have big volume with low prices, few choices, and low quality, or smaller volume with higher prices, more choices, and higher quality. Interestingly, research indicates that people who are willing to pay the lower prices expect, understand, and accept the associated lower quality; others are willing to pay $4.50 for a cup of coffee if it’s made just the way they like it with many different options.

So this may not be an ethical issue per se, but more a cautionary tale about marketing and buying strategy. Caveat emptor.

For the next issue:

A new attorney has asked me to review medicals and the plaintiff life care plan for a defense case as a testifying expert. I assessed the client, a young person with severe head injuries resulting in spasticity, with tracheostomy and G-tube feeding, presently cared for at her parent’s home. While she was comatose for some weeks post injury, she is now aware and appears to have pain from the spasticity and other reasons. The plaintiff life care plan included a baclofen pump and pain medicine consult, and I informed the attorney that I felt it was reasonable, even conservative.

The attorney was not happy with my opinion and sent the initial medical records (first few weeks post injury) to a physician, telling him that the patient was comatose and unresponsive. The physician then opined that she would not feel pain and that therefore baclofen and analgesics would not be necessary. Now I am in the uncomfortable position of being the testifying expert at deposition who disagrees with my client’s physician expert, who was not given current records and did not see the patient. I have already expressed my concerns to the attorney. Should I call the physician? Deposition is on the calendar!

Share your expertise and advice. Send your confidential opinions and recommendations to the editor at whowland@howlandhealthconsulting.com.
Since our profession is based on the nursing process, when I received a gift copy of a medical textbook I hesitated to review it in this space. However, for those who develop plans for children who suffer the effects of birth abnormalities it’s sometimes useful to have a good idea of the standards of care for the maternal-fetal dyad and neonate during the puerperal and neonatal period. This book does not disappoint.

This latest edition of the classic text offers many excellent tables, drawings, photos, and diagnostic images. Probably of most use to a nurse life care planner are the extensive images and descriptions of fetal and perinatal abnormalities of every kind. To name a few:

- central nervous system: cephalocele, ventricular abnormalities, spinal abnormalities
- face and neck: cleft lip and palate, micro- and retrognathia
- thoracic: congenital diaphragmatic hernia, cystic lung conditions
- cardiac: fetal cardiac malformations, arrhythmias, heart failure
- abdominal: ascites, gastrochisis, intestinal atresias, omphalocele
- urogenital: bladder extrophy, renal abnormalities, genital malformations
- skeletal: arthrogryposis, clubfoot, neural tube defects, the many skeletal dysplasias, achondroplasia

In addition, for each condition there is an extensive list of possible associated abnormalities and conditions, descriptions of antenatal and obstetric management, neonatal diagnostics and management, and neonatal prognosis including mortality, developmental disability, and complications later in life.

This hefty volume of nearly 1300 pages also includes online access to an extensive list of resources, e.g., more imaging and an immense bibliography, that the nurse will find useful for further reference.

Creasy & Resnik’s Maternal-Fetal Medicine, Principles and Practice, 7th ed.
http://aanlcp.site-ym.com/?page=01

Wendie Howland is the Editor of the Journal of Nurse Life Care Planning. She is the owner and principal of Howland Health Consulting, Inc., providing life care planning, legal nurse consulting, case management, Medicare set-asides, and editing for health professionals. She may be reached at whowland@howlandhealthconsulting.com
The population of individuals with disabilities in the United States is larger than many realize. There are 37.3 million Americans with disabilities (12.1% of the total population) living in a non-institutional setting according to the US Census Bureau’s 2011 American Community Survey (Erikson, Lee, and Von Schrader, 2013). This includes those with a cognitive impairment or intellectual disability, mental illness, or a limiting physical disability. In part because of chronic underfunding of disability services by Federal and state governments, 16% of American families (20.9 million) care for someone with a disability (US Census Bureau Report, 2005).

Life planning for someone with a cognitive impairment is especially challenging. There is detailed demographic data for this population (Braddock, Hemp, Rizzolo, et al., 2013). Of the 4.9 million individuals with IDD, 71.5% (3,514,211) live with a family caregiver. Twenty-five percent of those (891,783) live with family caregivers older than 60. Thirty-five percent (1,232,785) live with caregivers between 41 and 59 years old (Braddock, Hemp, Rizzolo, et al., 2013). As a society, we haven’t fully appreciated the significance of this demographic but it has enormous implications for families and cost implications for Federal and state governments.

Because of advances in health care and increased emphasis on socialization, it is likely

Hal Wright is a Certified Financial Planner, an expert on comprehensive special needs planning, and a parent of an adult daughter with Down syndrome. He is the author of The Complete Guide to Creating a Special Needs Life Plan: a Comprehensive Approach Integrating Life, Resource, Financial and Legal Planning to Ensure a Brighter Future for a Person with a Disability. He can be contacted at hwwright@earthlink.net.
that many, if not most, children with an intellectual disability will outlive their parents. The life expectancy of someone with autism is not significantly less than that of the overall population. The biochemistry of Down syndrome shortens life expectancy but an individual who survives the first year of life has a life expectancy of more than 60 years, and this continues to improve (Patterson, D. and Costa, A. 2005). Consequently, there is an important and sometimes overlooked dimension in life planning for those with IDD. The planning horizon must span the person’s entire lifetime including the period after his or her parents pass away.

The Rights of a Person with a Disability

A person with a disability has a right to a good life, the right to an appropriate place in the community, and the right to determine the nature and quality of his or her own life to the extent capable. I’m not naïve about the right of self-determination. Persons with moderate or more severe cognitive impairment will require help making decisions or will require having decisions made for them, especially those involving personal safety and protection. But implicit in the right of self-determination is their right to be heard and to be listened to respectfully and supportively in the language with which they can communicate.

Logically following from the right of self-determination is the importance of person-centered planning (PCP). This is both a philosophy and a practical process to assist people in planning their own lives and the necessary system of supports. (One can find extensive materials on www.inclusion.com.) The concept was initially used to help people with learning or intellectual disabilities but it is now a widely used model for many other disempowered or vulnerable populations.

My passionate advocacy of person-centered planning is not solely grounded in the belief of an individual’s right of self-determination. The ultimate reason is to create the best possible life. I have found from years of professional practice that we should not focus exclusively or even primarily on the disability (although such needs must be met); we must focus on the person’s capabilities. We need to enable these people to take their rightful places in the community and enhance their potential for independence and employment. We must address the necessaries for a life of dignity, pride and self-esteem.

What is Special Needs Planning?

Let’s start with its purpose: To assure adults with disabilities a place in the community ap-
propriate to their needs and capabilities and the resources available, respecting what they want for themselves. Comprehensive special needs planning integrates life, resource, financial and legal planning into a practical plan of action. Figure 1 illustrates the architecture.

Life planning envisions a desired quality of life. It includes social life; a job or business; a place to live, possibly a home of one’s own; and supports to alleviate, mitigate or overcome the effects of the disability. Resource planning addresses what is needed to make the life plan possible. Resources include government assistance to the extent the individual is eligible, and private pay resources to the extent the individual or family can afford.

Financial planning addresses how to pay for the private resources while maintaining eligibility for government assistance. It includes estimating lifetime financial support and how the needed support will be provided. Legal planning is about ensuring the individual’s protection and family estate planning.

Life Planning, as I define it as a parent of someone with an intellectual disability, is more than Life Care Planning as defined by the American Association of Nurse Life Care Planners. The AANLCP position statement defines it as the “practice in which the nurse life care planner utilizes the nursing process in the collection and analysis of comprehensive, client specific data in the preparation of... an organized, concise plan that estimates the rea-

continued next page
sonable and necessary...current and future healthcare (my italics) needs with the associated costs and frequencies of goods and services. The nurse life care plan is developed for individuals who have experienced injury or chronic health issues (again my italics).”

For someone with a cognitive impairment, life planning requires a more holistic approach to make possible a quality of life. When people ask my wife and me what we want for our daughter, we tell them, “After her needs are met, we want Meg to have friends, a job and a home. We want her to have the life she wants for herself. And we want her to be safe and happy when we are not here to protect and support her.” This is what life planning is all about.

Life planning is the sine qua non of special needs planning; the rest is implementation. Certainly a life plan must address one’s physical, emotional and medical needs. But there is so much more for someone with IDD. If we are to create the best possible life for someone, something that person has a right to, we need a holistic plan that addresses all aspects of a good life. This includes one’s social life – friends, maybe lifelong partners, and social and continued next page

Table 1. Components of a Life Plan

<table>
<thead>
<tr>
<th>Social Life and Community Access</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Family, friends, companions</td>
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<tr>
<td>• Life skills</td>
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<tr>
<td>• Spiritual life</td>
</tr>
<tr>
<td>• Weekly and monthly routines</td>
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<tr>
<td>• Entertainment, recreation, hobbies</td>
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<tr>
<td>• Participation in organizational activities</td>
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<td>• Travel</td>
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<td>• Pets</td>
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<tr>
<td>• Transportation</td>
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<td>• Circles of support</td>
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<tr>
<th>Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Type of residence</td>
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<tr>
<td>• Housemates and in-residence caregivers</td>
</tr>
<tr>
<td>• Location</td>
</tr>
<tr>
<td>• Property management</td>
</tr>
<tr>
<td>• Furnishings, amenities</td>
</tr>
<tr>
<td>• Independence or semi-independence</td>
</tr>
<tr>
<td>• Cost of rent, mortgage, taxes, maintenance, insurance</td>
</tr>
<tr>
<td>• Human supports</td>
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<tr>
<td>• Assistive technology</td>
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<tr>
<td>• Home modifications</td>
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<td>• Transportation</td>
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<table>
<thead>
<tr>
<th>Vocation</th>
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</thead>
<tbody>
<tr>
<td>• Employment, personal business or volunteer position</td>
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<tr>
<td>• Skills coaching, vocational training or secondary education</td>
</tr>
<tr>
<td>• On-the-job training and assistance</td>
</tr>
<tr>
<td>• Earnings and employee benefits</td>
</tr>
<tr>
<td>• Transportation</td>
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<tr>
<td>• Social Security TTW*, TWP†, PASS‡</td>
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*Ticket to Work, † Trial Work Period, ‡ Plan for Achieving Self-Support

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<tr>
<th>Special Needs</th>
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<tbody>
<tr>
<td>• Medical, vision, dental, medication</td>
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<tr>
<td>• Speech, occupational or physical therapy</td>
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<tr>
<td>• Psychological or behavioral coaching</td>
</tr>
<tr>
<td>• Guardianship or other protections</td>
</tr>
<tr>
<td>• Government programs for income, healthcare and disability services</td>
</tr>
<tr>
<td>• Care management, case management</td>
</tr>
<tr>
<td>• Dietary needs</td>
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<tr>
<td>• Hygiene</td>
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<tr>
<td>• Personal fitness</td>
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<tr>
<td>• Day programs</td>
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<td>• Respite care</td>
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<tr>
<td>• Management of medical, financial, and legal affairs</td>
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recreational activities. We should consider one’s spiritual needs and participation in a faith community. A plan should support independence to the extent of one’s capabilities, a job to be proud of, and a place to call one’s own, perhaps a home. It must include establishing the circles of support to sustain a plan over a lifetime. Table 1 lists factors that one might consider in developing a life plan.

As a financial planner experienced with long-term care planning and long-term care insurance, I have worked with planners who develop plans of care to keep an elderly person in their home. The approaches used in elder care planning are similar to those in life planning for people with disabilities including those with an intellectual disability. I also encounter care planners in litigation or legal settlements in the field of personal injury (for economic damages) and divorce (for child support). I have seen plans in litigation that address only care needs. Estimating economic claims in a legal action must be derived from a plan that addresses all human needs.

The scope and depth of a life planning will depend on the age of the individual. At an early age, foreseeing the person’s life as an adult may be a guess at best. A life plan for a preschooler will likely be primarily a contingency plan in case of the death or disability of one or both parents. Planning for adulthood will take shape with increasing specificity through middle school, high school and the transitions program.

Planning for a Child’s Transition from School to Adulthood

The Individuals with Disabilities Education Improvement Act (IDEIA) mandates that children with disabilities have a right to a “free and appropriate public education.” This act was originally passed in 1975 as the Education for All Handicapped Children’s Act (Public Law 94-142). Thus, children born in 1970 or later have been “mainstreamed” in schools. Their life spans are lengthening and closing the gap with the typical population. There are expectations that they will have a place in the community as adults.

The entitlement to a free and appropriate public education under IDEIA ends at the twenty-first birthday. The school system personalizes the child’s education using an annual Individualized Education Plan (IEP) through high school and an Individualized Transitions Plan (ITP) after high school until the 21st birthday. The focus of the IEP and ITP from middle school through transitions should be on child’s life after aging out of school. The emphasis is usually on life skills and employment (if the child is deemed capable of holding a job). Although planning for independence or a residential placement should theoretically be a

continued next page
part of an IEP or ITP, in practice the scope is usually more immediate and shorter term.

Parents often don’t appreciate the importance of longer term planning while the child is in the school system and are often surprised and dismayed when the need for full life planning becomes apparent after the child ages out. They may rely too much on the staff of the school system whose primary goal is to get the child through school. Parents with inadequate knowledge and resources must catch up to take control of planning for their child’s future. The urgency of the problem is compounded when the child won’t receive state disability services upon leaving school system, landing on a wait list for IDD or MI (mental illness) services. The concern becomes more acute as the years pass by without services and the prospects for a good life narrow or vanish.

The IEP or ITP meeting is crucial. Often parents take too passive a role by relying on the school professionals to develop the annual goals and the education plan. I would advise parents to come into the meeting with a life plan to guide the creation of the education plan. They can also enhance the chances of success by consulting with professionals in their circles of support. They have a right under IDEIA to have advisors of their choosing attend the meeting with them. A nurse life care planner who has assisted in preparing the life plan could be an important member of the parents’ team. With the necessary privacy waivers, the NLCP can interact directly with school staff as part of ongoing plan monitoring. (Ed. note: For more information on IEP and related topics, see also Cosby and Cosby, Pediatric Life Care Development, JNLC 13.1)

Planning for the transition from the school system to adulthood should begin no later than middle school; earlier is better. If one waits until the teen years, there will be catching up to do.

From an early age the focus must be on life skills. The most important set of life skills are those I call empowerment skills. These are:

- personal management skills
- social skills
- assertiveness
- self-advocacy
- safety awareness

continued next page
• decision-making
• personal care
• hygiene
• physical fitness

By adolescence, teaching healthy sexuality including personal safety is absolutely essential.

Ideally, the life skills coach will be mentoring the parents to teach these skills to their child. However, it is difficult to find life skills coaches with a holistic, empowerment approach. Too often the emphasis is on task skills, which alone are insufficient to enable a life in the community.

By the early teens preparation for employment should be a major element of a life plan. By the mid-teens, planning should expand to include life in the community. It is particularly important to plan for the transition out of the school system in states that have a wait list for disability services (which is most of them). If there is no access to Home and Community Based Services (HCBS) when the child ages out of school, what then? There must be plan to cover this possibility. You can’t put persons with cognitive impairment in a hold pattern for long. Either they continue to grow and progress or they regress.

Once a plan for life as an adult takes shape, planning should address the sustainability of the plan over the lifetime with attention to the circles of support to take over when the parents pass away.

A Letter of Intent (LOI)
As a parent of a child with Down syndrome who could outlive me by two decades, I am acutely aware of the importance of writing a letter of intent (LOI) describing my spouse’s and my wishes for our daughter and her wishes for herself. An LOI documents a life plan. It is not a legal document; it is guidance for successor guardians, advocates, care planners, care managers, caregivers, and professional fiduciaries such as trustees.

Many people have seen a printed form called a letter of intent distributed by funeral homes, life insurance companies, estate planning attorneys, financial planners and non-profit organizations. The form summarizes arrangements for personal care, government services, financial matters and legal documents.

As useful as this form may be, I strongly advocate that parents write a family narrative. This is a personal letter describing the family members, the circles of support, what parents want others to know about their child with special needs, what the parents want for the child, what the child wants. It should include a narrative “week in the life” of the child including those who play a part in it, the schedule of activities and events, and the care that the continued next page
parents and others provide. Most importantly, it should describe the immediate actions that must be taken to stabilize a situation if the parents die unexpectedly or become unable to continue parental support. An outline of a family narrative is shown in Table 2.

Those that assist parents in life planning should strongly encourage parents to write a letter of intent.

Table 2. The Wright Family Narrative

<table>
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<tr>
<th>About our family</th>
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<tbody>
<tr>
<td>• Mom – Eleanor</td>
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<td>• Dad – Hal</td>
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<tr>
<td>• Brother – David</td>
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<td>• Sister - Rebecca</td>
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<tr>
<td>• And Meg</td>
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<tr>
<th>What we want you to know about Meg</th>
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<tr>
<td>• Personality</td>
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<td>• Abilities</td>
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<tr>
<td>• Likes, dislikes, and fears</td>
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<tr>
<td>• Care needs</td>
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<tr>
<td>• Her Circle of Friends</td>
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<tr>
<th>What we want for Meg’s future, and what she wants for herself</th>
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<tr>
<td>• Independence</td>
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<tr>
<td>• Social life</td>
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<tr>
<td>• Job</td>
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<tr>
<td>• A good home</td>
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<td>• Care</td>
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<tr>
<th>A week in the life of Meg</th>
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<tr>
<td>• Daily routine</td>
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<td>• Personal care and care providers</td>
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<td>• Social activities</td>
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<tr>
<td>• Job</td>
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<td>• Programs outside the home</td>
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<th>If something happens to us</th>
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<tr>
<td>• Notifications</td>
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<td>• Immediate needs for intervention</td>
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A Team Approach  Comprehensive special needs planning requires a team approach. It crosses many professional disciplines. An important role a nurse life care planner can play is helping parents understand the team they will need, help identifying team members and managing and coordinating everyone’s efforts. Life planning is like putting together a complicated jigsaw puzzle. How do you put a jigsaw puzzle together? You start with the picture on the box as a guide. You find and identify the major pieces – corner pieces, border pieces and pieces that make up prominent features. Gradually, you fill in the puzzle. Someone who can help parents see how to do this will make an immeasurable impact on the life of one precious human being.

It is impossible to predict or control the future. Developing a life plan and the writing of a letter of intent is not a one-time exercise. The plan and letter must be reviewed periodically and updated as things change and as life unfolds. Stability is never achieved; it is only managed. And for many people with a disability, it may need to be managed over a period of decades.

References


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**Nursing Diagnoses to Consider**

NANDA-I Nursing Diagnosis, 2012-2014

- **Ineffective Health Maintenance:** Inability to identify, manage, and/or seek out help to maintain health (Domain 1, Health Promotion; Class 2, Health Management)

- **Risk for Compromised Human Dignity:** At risk for perceived loss of respect and honor (Domain 6, Self-Perception; Class 1: Self-Concept)

- **Risk for Caregiver Role Strain:** Caregiver is vulnerable for felt difficulty in performing the family caregiver role (Domain 7, Role Relationships; Class 1: Caregiving Roles)

- **Risk for powerlessness:** At risk for perceived lack of control over a situation and/or one’s ability to significantly affect an outcome (Domain 6, Self-Perception; Class 1: Self-Concept)

- **Interrupted Family Processes:** Change in family relationships or functioning (Domain 7, Role Relationships; Class 2: Family Relationships)

- **Ineffective Denial:** Conscious or unconscious attempt to disavow the knowledge or meaning of an event to reduce anxiety/fear, but leading to the detriment of health (Domain 9: Coping/Stress Tolerance; Class 2: Coping Responses)

- **Risk for Ineffective Activity Planning** Risk of inability to prepare for set of actions fixed in time and under certain conditions (Domain 9, Coping/Stress tolerance; Class 2, Coping Responses)
Winston Churchill once wrote, “There is something about the outside of a horse that is good for the inside of man.” For many years humans have held emotional bonds with animals, especially horses, perhaps because they represent freedom, spirit, adventure, perseverance, and drive. This is particularly true for those with disabilities, for whom horses can provide a vehicle (no pun intended) to pursue and achieve these goals.

The term “hippotherapy” is derived from the Greek hippos (horse), and the modern Latin eohippus. Interestingly enough, the term hippus refers to a medical condition, characterized by spasmodic, rhythmical dilation and constriction of the pupil, independent of illumination, convergence, or psychic stimuli. It was possibly so named due to the rhythm of the contractions, representing a galloping horse. Hippotherapy is defined as treatment with the help of a horse. Used in conjunction with conventional physical, occupational, and speech therapies, hippotherapy can be a unique and enjoyable way for improving functional outcomes for patients with neuromuscular dysfunction, psychiatric issues, receptive or expressive language disorders, and behavioral issues (American Hippotherapy Association, 2007).

The concept of using horses for one’s wellbeing goes back to 460 B.C. when Hippocrates (whose Latinized name comes from the Classic Greek name Hippokrates, meaning “horse power”) wrote about the benefits of improving one’s health through horseback riding. In 1875, the French neurologist Chassaignac conducted many case studies on the effects of therapeutic riding. He concluded that this exercise regimen helped with improving a patient’s muscle tone and emotional condition, and he recommended this type of therapy for paraplegics and others with neurological conditions. Shortly after World War I, a British physiotherapist, Olive Sands, allowed Oxford Hospital to use horses in an experiment involv-
ing the use of animal therapy to help war veterans.

However, the most inspiring event involving horses and rehabilitation occurred when Lis Hartel, a 23 year old Danish woman equestrian athlete paralyzed from polio, went on to be the first woman to win a Silver Medal in a men’s dominated sport during the 1952 Olympics. Henri St. Cyr, the gold medal winner, was so moved by her accomplishments that he rushed to her side and then carried her to the victory platform for the medal presentation. This very emotional and respectful action demonstrated her determination to overcome her disability to the world.

Lis Hartel and her therapist later founded Europe’s first riding center in the 1960s, which is believed to be the beginning of modern therapeutic riding. Shortly after the opening of the first therapeutic riding center, it became a widely acceptable alternative form of therapy throughout Europe (www.equi-search.com). However, it was not until 1987 that the first program was established in the United States by the American Hippotherapy Association.

Researchers compare the rhythmical movement of horseback riding to human gait and found that rehabilitative riders overall showed improvements with flexibility, balance, and muscle strength. The principle concept is to use the horse’s movement to improve the patient’s neuromotor function by positioning the patient on the horse facing forward, backward, sitting sideways, lying prone or supine. Participants in this type of therapy have included those with cerebral palsy, multiple sclerosis, spina bifida, spinal cord injuries (SCI), traumatic brain injuries (TBI), stroke, ADD, ADHD, PTSD, Down syndrome, and autism spectrum disorders including Asperger’s syndrome.

The American Physical Therapy Association has recognized and endorsed hippotherapy as a physical therapy intervention that can be incorporated as an integrated part of a patient’s physical therapy program for improving impaired balance, strength, and flexibility (American Hippotherapy Association, 2007).

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Therapeutic riding and equine assisted psychotherapy are two other horse-related rehabilitation activities that many people often confuse with hippotherapy.

Therapeutic riding is a recreational activity, provided by a trained horse professional, which focuses on teaching people with various disabilities about horsemanship, carriage riding, and vaulting. Therapeutic riding also incorporates grooming and caring for the horse. Similar to hippotherapy, the horse's movements are used to facilitate postural control, balance, and multi-sensory awareness, but sessions are led by a certified therapeutic riding instructor. This recreational program has yet not been generally recognized or accepted by all practitioners to be part of an integrated physical, occupational, or speech therapy regimen. However, equine-assisted activities have been gaining in popularity with families of children and adults with a variety of disabilities, and particularly with disabled veterans who have suffered TBI, PTSD, and limb loss.

Equine-assisted psychotherapy involves using horses to assist people with psychological and psychiatric disorders, through psychotherapy sessions with a licensed clinical psychologist or psychotherapist. Horses are integrated into the counseling or psychotherapy session in a variety of ways, such as riding, grooming, saddling, and other interactions. Since horses respond directly to human behaviors, participants receive immediate feedback.

A major premise of equine-assisted psychotherapy is that a person with an emotional or psychiatric disorder who wants to develop and maintain a relationship with a horse must act in ways that the horse can accept. In addition, a horse's size in relationship to the human engenders immediate respect, thus promoting positive behaviors. Success in horsemanship is reported to result in greater confidence, self-esteem, and increased social skills for children and adults (Equine Assisted Growth and Learning Association, 2009).

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With respect to equine-assisted programs in general, the Department of Veterans Affairs has recently begun to provide grant support and funding to educational centers across the country, in order to offer therapeutic riding programs to wounded veterans. For example, the Walter Reed National Military Medical Center has founded the Caisson Platoon Equine Assisted Program for wounded military and veterans who have suffered TBI, PTSD, or physical wounds. Anecdotal evidence reported by riding centers has shown that veterans who have participated in this program showed physical and emotional improvements, involving center of balance, efficiency in use and adaptation to prostheses, improvement in core muscle strength, self-confidence, and decreases in social anxiety and depression.

Since this program for wounded veterans is relatively new, and the medical literature somewhat sparse, there is a need for further research to evaluate its efficacy on quality of life for treated patients. Such studies should be possible, although any study design would have to be sufficiently sensitive to detect measurable changes and to ascertain the effects of equine assisted activities for patients with different severities or different types of disabilities.

Of the articles noted in the suggested reading below, one test had only 15 participants with a pre-test and post-test comparison group study (Benda W, McGibbon NH, Grant KL, 2003). Another study used a repeated measures with to pre-test and two post-test studies involving 10 children with cerebral palsy (Casady RL, Nichols-Larsen DS, 2004). Another study implemented a repeat measures design involving 11 children with moderate to severe spastic cerebral palsy. Studies with such small numbers of subjects may not be sufficient to justify drawing firm conclusions about the utility of hippotherapy.

Also, other social skill sets need to be studied for patients having impaired social functioning, such as problems with empathy, sense of belonging, and development of social language, as well as measuring improvements in personal qualities such as self esteem, confidence, and self efficacy.

Success in horsemanship is reported to result in greater confidence, self-esteem, and increased social skills for children and adults.
It would seem very probable that in view of the hundreds of centers offering such equine related services and with the strong national and international support they have received, more studies should be forthcoming in the near future.

References
http://www.new.americanhippotherapyassociation.org/
Suggested Additional Reading


Nursing Diagnoses to Consider NANDA-I Nursing Diagnosis, 2012-2014

- **Impaired Physical Mobility** Limitation in independent purposeful physical movement of one or more extremities (Domain 4, Activity/Rest; Class 2: Activity/Exercise)
- **Impaired Walking**: Limitation of independent movement within the environment on foot (Domain 4, Activity/Rest; Class 2: Activity/Exercise)
- **Risk for compromised human dignity** (Domain 6, Self Perception: Class 1 Self Concept)
- **Situational Low Self-Esteem**: Development of a negative perception of self-worth in response to a current situation (specify) (Domain 6, Self-Perception; Class 2: Self-Esteem)
- **Impaired social interaction** (Domain 7, Role Relationships; Class 3, Role Performance)
- **Impaired Individual Resilience**: Decreased ability to sustain a pattern of positive responses to an adverse situation or crisis (Domain 9: Coping/Stress Tolerance; Class 2: Coping Responses)
- **Delayed Growth and Development**: Deviation from age group norms (Domain 13: Growth/Development, Class 2: Development)
The CDC reports that 1 in 88 children have been identified with an autism spectrum disorder based on 2008 data; crossing all racial, ethnic and socioeconomic groups. These children are rapidly growing into adulthood. Adults with autism have, until now, had limited long-term living options: live with aging parents / other family members or move into a group home. Sweetwater Spectrum in Sonoma, California offers a paradigm shift: housing and supportive living services for adults with autism no longer need to be one and the same.

Traditionally, individuals who need support to live outside a family home need a group home environment that provides required living services within a specific “home” or environment. In California, these homes are licensed by the state, but privately owned. Owners provide room, board, and supportive services based on the care level of the resident. The owner’s charges are paid based on a fee schedule set by the state, and funded by a combination of the resident’s Social Security income and supplemental payments through a Regional Center. Finding a high-quality living environment with the needed supportive services often involves wait lists of up to ten years. Often aging parents do not have the luxury of time.

Sweetwater Spectrum was formed by a group of families with autistic family members collaborating with professionals and community leaders to create a residential community specifically for adults with autism. Rather than isolating these individuals, the goal was to give each resident “choices and the ability to live a productive, independent and fulfilling life.”

Creating a New Long Term Living Model for Adults with Autism Spectrum Disorder: An interview

Liz Holakiewicz BSN RN CCM CNLCP

The nonprofit organization purchased a prop-

Liz Holakiewicz is a certified nurse life care planner in full-time private practice in the San Diego area. She has 25 years of experience in life care planning. She may be reached at liz@lcpnurse.com
erty near downtown Sonoma and hired an architect, Leddy, Maytum, Stacy of San Francisco, to design their project. The resulting design was an environment specifically created to minimize the visual distraction, ambient sound, lighting, and odors that are problematic for residents with autism, while promoting a sense of community. The design was influenced by a report entitled Advancing Full Spectrum Housing “Designing for Adults with Autism Syndrome Disorders” by the Arizona State University Stardust Center and School of Architecture.

Sweetwater Spectrum Founding Principles are:

- Celebrate and support the full range of autism spectrum disorders
- Encourage active resident involvement in their home, neighborhood and surrounding communities.
- Provide access to productive enriching choices that support life with a purpose
- Offer the potential for life time residency
- Utilize autism specific design which addresses both safety and sensory issues
- Nurture long term, high value relationships between residents and support staff
- Accommodate a broad financial spectrum
- Create and foster a model that can be replicated nationwide.

Though individuals with autism have social skills deficits, early evidence seems to indicate that social interaction in this community is satisfying to the residents. The community has a mix of residents with varying abilities: some are non-verbal or barely verbal. All have a variety of interests to contribute to community.

The property acquired by the organization is located a short walking distance from the downtown plaza of Sonoma. It is approximately 3 acres and is comprised of four, 4 bedroom homes, a 2,300 square foot community center, a 1.2 acre farm, a greenhouse and a therapy pool.

I interviewed the executive director of the Sweetwater Spectrum, Deirdre Sheerin, to learn a bit more about Sweetwater Spectrum.

**Entry and Placement**

Liz: Please tell me a little bit about the criteria for entry into your program.

Deirdre: Sweetwater Spectrum is not an autism treatment program. We are a housing alternative for individuals with autism. The model is that of a landlord and tenant.

LH: What are the criteria for entry into Sweetwater Spectrum?

DS: Just as you would fill out an application to rent an apartment, we have prospective residents fill out an application. I tour the prospective tenants and their families through the unit and the grounds and in the process learn something about them: how their autism affects them and what type of supportive services they require, etc. We also assess how they might fit

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in with residents already living in the home. For instance, if we have a resident who is really bothered by cords that show from the TV in the entertainment system, but the prospective resident needed to have the cords visible or they are distracted, this would be a living situation that wouldn’t work.

We don’t place people. There is no waiting list. If a prospective resident looks like a possible fit for Sweetwater, he is encouraged to get a plan of care and meet the other residents to decide about living with one another. We do look at finances. We want to have this be a long term solution for the residents and their families. If their circumstances don’t fit that goal, then this is likely not the right option.

Regional Centers were created by the Lanterman Act in the State of California (1969). This act says individuals with disabilities have the right to services and support needed to live like people without disabilities and defines an IPP (Individual Program Plan) on how to get them. To be eligible a person must have a disability that begins before their 18th birthday and is expected to continue indefinitely, and must present a substantial disability as defined in 4512 Welfare code. Regional Center determines eligibility. They provide diagnosis and assessment of eligibility and help plan access, coordinate and monitor the services and supports that are needed because of a developmental disability. There is no charge for the assessment. Once eligible, a case manager or service coordinator is assigned to help develop a plan for services, locate services and help one obtain services. Most services are free regardless of age or income. There is a share of cost while the child is under 18. Some services offered by Regional Centers include:

- Information and referral
- Assessment and diagnosis
- Counseling
- Life long individualized planning and service coordination
- Purchase of necessary services in the IPP
- Resource development
- Outreach
- Assistance with community and other resources
- Advocacy for protection of legal, civil and service rights
- Early intervention for at risk infants and families
- Genetic counseling
- Family support
- Planning, placement and monitoring for 24 hour out of home care
- Training and educational opportunities for individuals and families
- Community education about developmental disabilities
Sweetwater Spectrum requires a plan of care from the family or outside agencies because we don’t provide direct support. We work together with vendored organizations (through Regional Center) and with individual caregivers. We may interface with the Regional Center case manager. The common goal is that the resident is living a life with purpose. Everyone who works with the resident, family, and Regional Center can be invited into the planning meetings. Everyone comes to the table to support the resident.

**Costs**

LH: Is this similar to evaluating a tenant to rent an apartment, in that you want to know whether his income and credit are the right fit for the unit you are renting?

DS: Yes. As you can imagine, it is expensive to do this type of construction and own land and run a business in this area.

LH: Right, you need to cover your payments. What are the fees involved for a prospective resident?

DS: You can do the research on this. We make it a practice not to discuss the rent except on a private basis with families. There are two fees: the rent and the community fee. We require a minimum of a one year lease.


DS: We do have discounts for residents based on need, since one of our founding principles is to accommodate a broad financial spectrum.

LH: What is discounted based on need-- the rent or the annual community fee?

DS: The community fee.

**Covered Activities**

LH: So, other than the facilities, what does the $2,600 community fee cover?

DS: Similar to a homeowner’s association, we have certain capital investments...
that need to be maintained, like the pool and the gym, as well as the landscape and buildings. Additionally, to support life with purpose, we have an enrichment coordinator, a farm manager/steward, and a volunteer coordinator. Finally, my administrative assistant and I, as onsite executive director, run the organization and support the residents and their families.

The enrichment coordinator coordinates engagement into the community of Sonoma, as well as the on campus community. The founders wanted lives with engagement for the residents – with one another and with the community. Group and individual events are facilitated, e.g., an artist resident is supported with environment that allows her expression of art. The enrichment coordinator lets residents know about community activities and events with family, other residents and service providers. There is also the availability of the farmers market every Tuesday night, and regular Friday “hangout.” Residents can come or not as they like.

Several of the girls are now getting together for weekly dinner. They cook together and eat together. They coordinated this themselves.

LH: Is farm work part of each of the residents’ experience?

DS: Weekly on Wednesday nights there is a farm activity. Just last week, they got veggies from the farm and made vegetable soup together. They worked together to collect the vegetables, to make the meal and then had a meal together. The purpose of the farm is to provide opportunity for healthy eating and activity. It is not required to work in the farm, but it is an option available for participation should they choose. There is also a weekly Farmers Stand.

LH: If a resident’s IPP goals included learning how to manage cash, they could work at the farm stand as part of their plan?

DS: The farm stand is available for that whether or not they have it as part of their plan. The founders wanted farming to be part of the experience at Sweetwater Spectrum. It’s not required but it’s available if they are

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interested. They can also collect eggs and take care of the chickens.

Author’s note: There are other choices: exercise, watching a movie, swimming, quiet time in the library, hanging out in the common areas with other residents or being alone in one’s own room. There is a teaching kitchen and a movement studio where volunteers from the community assist residents in integration vs. isolation.

Functional level
LH: It sounds like a prospective resident needs to be relatively high-functioning to live here.

DS: Again, that’s not really the case. The tenant comes with an IPP or plan of care and coordinated supportive living services (SLS). The environment here is ADA accessible and we are committed to reasonable accommodation based on need.

LH: Is there room for a live-in attendant in any of the 4 homes?

DS: Yes, each of the four residences has a “staff office” available with a bed and separate bathroom for live-in support, if needed.

LH: Are there transportation services available into the community?

DS: Transportation arrangements are made along with other supportive living services through the IPP process. The campus is close enough to the community that most residents can walk into Sonoma or use public transportation.

A Unique Environment
LH: What about this new model of housing for autism makes it unique?

DS: Separating housing from the supportive living service provider is part of what makes us unique. If the housing doesn’t work, then the individual doesn’t need to dispense with the service providers; if the service providers are problematic, residents don’t need to lose their housing.

The sense of community is also unique for this population. There is a natural connection to downtown, within walking distance. Another innovative factor is the active role Sweetwater Spectrum staff plays in the lives of residents to develop and sustain community.

LH: How does this environment contribute to residents’ socialization and sense of community?

DS: There are 4 buildings around a central community building. There are natural engagements in the way an individual navigates the community, e.g., she passes the community center and the same house on the way to her car each day. Each house is designed in

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the same way so it minimizes the anxiety associated with change in housing and creates familiarity in another person’s space.

**Replicating This Model**

LH: Your website mentions this as a unique model that is replicable to other parts of the state and country. Do you have a council that aids others in replicating this model?

DS: We are still working on this and haven’t formalized that process yet. It is our goal to share knowledge and help others create living options for persons with autism. Those who are interested in the model can feel free to contact us through info@sweetwaterspectrum.org.

**Summary**

Sweetwater Spectrum offers a model of living specific for adults with autism. It is different from the traditional group home model, where provision of meals, support for ADL's and medication management are built in to the residential model. At Sweetwater, care delivery and living environment are no longer inextricably linked.

Group homes are traditionally not environments that are rich with thought for residents they house. The architectural design of this housing community was specifically created for adults with autism. The design itself promotes a natural interaction between residents and facilitates community with fellow residents and with the greater community, while also allowing for private spaces.

It is the design of the community and residences that make this model unique, not service delivery. Residents need to bring with them the supportive services they need. If a live-in attendant is required for a resident, the facilities are available to accommodate this care.

**Nursing Diagnoses to Consider**

- **Impaired environmental interpretation syndrome** (Domain 5, Perception/Cognition; Class 3, Sensation/Perception)
- **Impaired verbal communication** (Domain 5: Perception/Cognition; Class 5 Communication)
- **Risk for compromised human dignity** (Domain 6, Self Perception: Class 1 Self Concept)
- **Impaired social interaction** (Domain 7, Role Relationships; Class 3, Role Performance)
- **Risk for relocation stress syndrome** (Domain 9, Coping/stress tolerance; Class 2, Coping responses – managing environmental stress)
- **Readiness for enhanced community coping** (Domain 9, Coping/Stress Tolerance; Class 2, Coping Responses)
- **Readiness for enhanced resilience** (Domain 9: Coping/Stress Tolerance; Class 2: Coping Responses)

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need, e.g., a separate living space, but Sweetwater Spectrum does not provide or manage the attendant. The resident, family and Regional Center maintain responsibility for delivery of a plan of care. As a result, Sweetwater Spectrum residents can choose to have a quality living environment and experience continuity and community in that living environment regardless of the nature of their care needs or disability.

Footnotes


2 http://sweetwaterspectrum.org/faq.aspx
3 http://sweetwaterspectrum.org/home0.aspx
4 http://stardust.asu.edu/project-archive/advancing-full-spectrum-housing/
5 http://sweetwaterspectrum.org/home0.aspx
6 http://www.dds.ca.gov/RC/RCSvs.cfm
7 http://www.nytimes.com/2013/10/10/garden/the-architecture-of-autism.html?_r=0

Dogwood, Washington College
Liz Holakiewicz
Clarifying “Aging in Place”

Ashley Krapacs, National Aging in Place Council

What is “aging in place”? A term of art, a nuanced phrase, but what is it really?

At its simplest, aging in place is choice. Aging in place comes in many different flavors, but choice is at its core - the choices of aging Americans to remain in their family homes, downsize and move into smaller residences, or join retirement communities. The aging in place movement helps seniors become aware of what options are available to them, to appreciate them, and receive the support and resources to exercise them. It’s important to understand each aspect of what often becomes an overwhelming maze. Thinking holistically is critical to thorough understanding.

The Big Picture
Aging in place represents the coming together of businesses, federal and local government, and the for-profit and non-profit sectors to provide a better life for more people. It is an acknowledgment that, by ourselves, we cannot make as much of a difference in anyone’s life as we can together. This involves housing, healthcare and wellness, personal finance, transportation, academia, community involvement, and social interaction, as well as the organization of one’s everyday affairs. It includes advice, education, socialization, empathy, and mutual support.

Almost 90 percent of people over 65 say they want to live in their homes and communities as long as possible, according to a report by the AARP Public Policy Institute and the National Conference of State Legislatures. A whopping 80 percent believe they will stay in their home until they die. For some, friends and a familiar setting are the main draw, and for others, it’s an emotional attachment to the house and neighborhood. But all too often, support and home-based services to make this possible aren’t easily accessible, especially for those caught in the middle - neither quali-

NAIPC is a 501©6 trade association comprised of senior service providers, businesses of all sizes, government agencies and consumer advocate organizations, all concerned with the aging population and how to provide needed services to them in their own homes. NAIPC has been in existence for ten years and currently has local chapters in 17 cities, plus individual members throughout the country. Contact them at http://www.ageinplace.org/
fying for public entitlements nor able to pay for themselves.

The National Aging in Place Council (NAIPC) spearheads a movement to provide aging Americans with the services, security, support, resources, and comfort to remain in the home of their choice as they grow older. Our mission is to organize aging in place and to transform it from an abstract idea into a lifestyle supported on many fronts. Our goals are

- to increase awareness of the choices available to seniors
- to develop useful solutions and tools to help boomers and seniors plan and facilitate their choices
- to explore the role of the private sector and small businesses to further the aging in place agenda through economic growth, job generation, and creation of products and services
- to stimulate a public policy approach that will benefit individual citizens, families, and our society as a whole

Increasingly, policymakers and local leaders are recognizing the benefits of providing such services. They are recognizing that costs are far lower and social benefits much higher when we help someone remain at home rather than go into a care facility.

Until recently, there was no national approach to aging in place, no federal policy agenda, and no national outcry to expand participation. In 2013, NAIPC began to change that. We gathered our membership at an annual meeting, followed by a coming together of policy experts for an Aging in Place Summit to discuss and strategize the process of filling these voids and figuring out the aging in place maze.

Members of NAIPC understand the maze and work every day to help their clients navigate it. Our members are providers in fields that cover the spectrum of services that seniors may need to age in place: nurses and caregivers, financial planners, geriatric care managers, non-profit stakeholders, home modifiers, elder law attorneys, and reverse mortgage professionals, to name but a few. Our members are not only experts in their respective fields, but are also well-versed in the scope of aging in place services. Organized into chapters nationwide, NAIPC members form local senior support networks. They learn about other chapter members’ businesses and services so that they are better able to serve their own clients and can confidently make referrals to other trusted, vetted professionals. They both advocate and educate. They set themselves apart by striving to understand as much as possible

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Late breaking news: A group headed by a nurse researcher has been doing excellent research on using video games and simulations to look at functional decline in elders and ways to prevent it. Here are some links to their work.

Contact: Marilyn Rantz, PhD, RN, FAAN
Curators’ Professor, MU Sinclair School of Nursing, Associate Director, Missouri University Interdisciplinary Center on Aging, (573) 882-0258


www.eldertech.missouri.edu
Explanations of technology and RN monitoring for change in health status; early detection of functional decline leading to interventions that slow rate of decline.

http://www.eldertech.missouri.edu/papers.php
Free access to full-text PDFs of all research papers from this group
about every corner of the maze in their local communities.

In that, we share a similar mission to that of nurse life care planners, understanding the value of taking a broad approach. Your work includes not just the basic functions that nurses perform, but a holistic methodology to identify needs, both present and potential, and develop case-by-case plans to ensure that the scope of seniors' needs are met. In the same way that nurse life care planning is a niche practice, NAIPC members are niche experts, specializing in their respective fields while furthering and expanding the aging in place movement.

It comes down to the same common goal: assisting seniors with navigating the maze; making sure they understand the options available to them; positioning communities to better handle the diverse needs of the growing aging population; and ultimately, improving their quality of life of aging Americans through each turn in the maze.
A presentation at the 2012 AANLCP conference motivated me to look at elder life care plans in a new light and focus on an underserved market niche. Traditionally, life care plans are done for catastrophic injury or illness. As a case manager and home health care nurse, I often see the impact of the lack of planning and its toll on the financial plans of my elderly (and not so elderly) clients. What if we took the cost projection portion of the plan to help elders plan for the future?

A nurse life care planner (NLCP) is the ideal professional to help develop a plan to address health, safety and housing needs based on the individuals’ requirements, preferences, and financial situation. What makes elder life care planning different is that finding the best solution is a bit like searching for buried treasure. There are many financial and legal professionals who assist clients in developing retirement portfolios, some who advertise their services (such as estate planning) and others who have their services marketed to elders through other services. Some elders can be approached directly. However, unless they have significant chronic health issues and understand the need for planning, they can be quite suspicious of the NLCP’s intentions.

You can network with professional groups such as bank trust officers, estate planning organizations, CPA firms, and wealth management professionals. As with any networking, focus on “What issues have you come up across as you work with elder clients? How can I help you help them?” Taking this approach, I often hear about medical conditions (and the latest hospital horror story) and a knowledge deficit on how to plan effectively. That’s the perfect opportunity to ask if they would be interested in any assistance with projecting the client’s future medical needs to help maintain the portfolio.

Here are two representative examples where elderly couples benefited from life care planning expertise.

**Acute Illness in Both Spouses**

I received an urgent call from a family attorney who wanted to know if I could help sort...
through a medical crisis and provide some direction about John V., a 73-year-old male with a permanent tracheostomy and multiple thoracic and lumbar compression fractures. John was admitted to the hospital for an acute myocardial infarction, congestive heart failure and pacemaker insertion. His 70-year-old wife, Charlotte V., is his primary caregiver and in generally good health. Charlotte regularly visited John during his hospitalization until one day she did not arrive at her usual time. John became concerned and notified his neighbors, who found Charlotte unresponsive in her car in a grocery store parking lot. She was admitted to the same hospital with an acute left thalamic intracranial hemorrhage, right sided hemiplegia, and aphasia.

John and Charlotte have a long term care policy, some savings, and a Medicare Advantage policy. In collaboration with the hospital case managers, I identified a skilled nursing facility where John and Charlotte could receive the appropriate level of care needed for rehabilitation while remaining together. The long term care policy required no prior authorization and would pay a maximum benefit of $300,000 per person. The Medicare Advantage policy dictated which skilled nursing facility was within their network and covered 10 days of skilled nursing with a 20% copay. Knowing this information, we were able to plan for at least 10 days of skilled nursing care, skilled home health care upon discharge, and paid caregivers for four hours a day. A “lady from the church” moved in with them to provide on-site oversight. We estimated that this plan would be effective and affordable for the next 6 months. As a result of the couple’s financial and physical fragility, we also made a referral to the area’s Elder Protective Services.

The next levels of planning options were entirely financially driven. We determined that they could afford 13 months of homemaking/attendant care ($2250/month) or to sell their home and move into a group home (for about $2500/month) and have some residual income and qualify for Medicaid assistance. The second choice was more secure, and has worked out well for them.

A “Healthy” Older Couple

A trust officer asked me to review a case regarding a “healthy older” couple, Jan and
Clare E. They were doing their annual review and wanted to make sure their finances would support their current needs. Armed with a file of medical bills and a brief health history from the couple, I prepared a medical cost projection.

Jan is an 80-year-old white female whose primary medical concern is pulmonary hypertension status post pulmonary emboli in 2010. She sees a pulmonologist twice a year and has her anticoagulation status monitored monthly by the community hospital Coumadin Clinic. She uses supplemental oxygen, performs activities of daily living independently, and participates in outpatient pulmonary rehabilitation three times a week.

Clare is an 86-year-old white male whose primary medical concern, wet macular degeneration, was diagnosed in 2013. He receives intraocular injections every 4-8 weeks as indicated by examination findings. He can perform most activities of daily living independently, requiring assistance only those activities requiring detailed work, such as bookkeeping activities like writing checks and reviewing financial statements.

Jan and Clare own their one-story home in a small town in Ohio. Jan is a retired RN and Clare a retired MD; they are active in their church and community. They have five adult children, one living two hours away and the rest scattered across the country. They obtain their health care from their community hospital and the metropolitan hospitals located one hour away. They hire help for home repair, lawn mowing, and snow removal, and do the general housekeeping themselves. They need frequent rest periods for housekeeping and activities of daily living. Jan drives locally and has help from neighbors for additional transportation. To cover their medical expenses they both have Medicare coverage (Part A, B and D), a Medi-gap supplemental insurance policy, and some private funds.

Based upon the interview and review of current expenses the following services may be warranted:

• Transportation for MD appointments and therapy (Jan and Clare)
• Housekeeping services (Jan and Clare)
• Referral to a Low vision therapy team (OT, low vision therapist, Vision Rehabilitation therapist) (Clare)
• Self-help ADL vision related devices (Clare)

As with traditional medical cost projections, I reviewed the couple’s insurance expense coverage and then identified current and anticipated life time needs. The following tables show the results.

continued next page
### Insurance expenses:

<table>
<thead>
<tr>
<th>Insurance Cost</th>
<th>Medicare A &amp; B</th>
<th>Medicare D</th>
<th>Medi-Gap</th>
<th>Annual Total cost</th>
<th>Expected lifetime *</th>
<th>Expected Lifetime cost</th>
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<tbody>
<tr>
<td>Jan</td>
<td>$847.20</td>
<td>$4,189</td>
<td></td>
<td>$5,036.20</td>
<td>10 years</td>
<td>$50,362.00</td>
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<td>Clare</td>
<td>$847.20</td>
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<td>$5,229.20</td>
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<td><strong>Combined total cost</strong></td>
<td><strong>$10,265.40</strong></td>
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<td></td>
<td></td>
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<td><strong>$76,508.00</strong></td>
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* Life expectancy and costs are based on the US Life Table, National Vital Statistics Reports, Volume 61, Number 3 dated 9/24/2012 the “US Life Tables, 2008” published by the US Department of Health and Human Services, Center for Disease Control, current at the time of the plan. These are not rated ages.

### Lifetime Medical Cost projections:

Costs have not been adjusted for inflation or growth. * Duration (Years) is life expectancy.

<table>
<thead>
<tr>
<th>Jan E</th>
<th>ITEM</th>
<th>Duration (Years)*</th>
<th>Avg # per year</th>
<th># per lifetime</th>
<th>Avg. unit cost</th>
<th>Routine Annual $ per year</th>
<th>Routine $ for lifetime</th>
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<tr>
<td></td>
<td>Physician</td>
<td>10</td>
<td>2</td>
<td>20</td>
<td>$106</td>
<td>$212</td>
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<td></td>
<td>Coumadin Clinic</td>
<td>10</td>
<td>12</td>
<td>120</td>
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<td></td>
<td><strong>Subtotal</strong></td>
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<td></td>
<td><strong>$9,812</strong></td>
<td><strong>$10,240</strong></td>
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<td></td>
<td>Current Medication</td>
<td>10</td>
<td>365</td>
<td>3650</td>
<td>$0.70</td>
<td><strong>$248</strong></td>
<td><strong>$4107.50</strong></td>
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<tr>
<td></td>
<td>Oxygen</td>
<td>10</td>
<td>3.5</td>
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<td>$465 every 36 months</td>
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<td><strong>Subtotal</strong></td>
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<td><strong>$248</strong></td>
<td><strong>$4107.50</strong></td>
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<td></td>
<td>Therapy</td>
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<td>156</td>
<td>1560</td>
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<td></td>
<td><strong>$28,080</strong></td>
<td><strong>$280,800</strong></td>
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<td>Transportation</td>
<td>Taxi for in town appointments</td>
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<td></td>
<td></td>
<td><strong>$80</strong></td>
<td><strong>$800</strong></td>
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<td>Housekeeping services</td>
<td>General cleaning, grocery shopping, errands</td>
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<td>6</td>
<td>60</td>
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<td>$600</td>
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<td><strong>$6,000</strong></td>
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<td><strong>Totals</strong></td>
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<td><strong>$38,820</strong></td>
<td><strong>$388,200</strong></td>
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<table>
<thead>
<tr>
<th>Clare E</th>
<th>ITEM</th>
<th>Duration (Years)*</th>
<th>Avg # per year</th>
<th># per lifetime</th>
<th>Avg. unit cost</th>
<th>Routine Annual $ per year</th>
<th>Routine $ for lifetime</th>
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<tbody>
<tr>
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continued next page
## Procedure

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<tr>
<th>Procedure</th>
<th>Ocular injection</th>
<th>Diagnostic studies</th>
<th>Medication</th>
<th>Low Vision Devices</th>
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<tr>
<td></td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>1</td>
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<td></td>
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<td>$260</td>
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<td></td>
<td>$1,820</td>
<td>$434</td>
<td>$19,250</td>
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<td></td>
<td>$9,100</td>
<td>$2,170</td>
<td>$96,250</td>
<td>$4,000</td>
</tr>
</tbody>
</table>

### Annual Total

- **Ocular injection**: $260
- **Diagnostic studies**: $62
- **Medication**: $2,750
- **Low Vision Devices**: $4000

**Annual Total**: **$26,344**

### Lifetime Total

- **Ocular injection**: $1,820
- **Diagnostic studies**: $434
- **Medication**: $19,250
- **Low Vision Devices**: $4,000

**Lifetime Total**: **$115,720**

As a result of expert financial planning and foresight, this couple will require approximately $10,000 to pay for their annual insurance premiums. Their out-of-pocket expense are anticipated to be less than 1% of projected costs. Therefore, their trust officer made the recommendation to set aside $1000 for medical expenses with an annual 1.5% buffer for the cost of inflation.

### Summary

Preparing an elder life care plan can be simple or complex. The NLCP must work with a mix of projected and current focused health care needs, and must consider the desires and resources of the elder client in concert with the financial expert or trust officer who will use the plan to manage the client funds to meet them. This underappreciated niche can be an excellent area in which to apply nurse life care planning skills for the benefit of a vulnerable population.
Part I of this article described the basic needs for an accessible home for a person with mobility impairments. Part II will describe the aspects to look for in a home to determine if it can readily be made accessible.

In this author’s experience, people who are newly injured generally want to stay in the homes where they lived at the time of injury. Three factors contribute to this desire.

1) After the medical and rehabilitation expenses stemming from injury and the corresponding loss of income, they do not have the means to consider moving and making a new home accessible.

2) We all feel some connection to where we live. The strength of this connection usually increases the longer people live in their homes.

3) Most people are still adjusting to the changes forced upon them by the injury; further changes, like moving, may seem beyond their adaptive capacity. As a life care planner or case manager, however, you may have to convince someone that moving is the right decision for himself, his family, and for overall safety.

Sometimes it is possible to “make do” for a time. In some circumstances, though, an existing home may present barriers that would require large expenditures for elevators and lifts. However, unmodified barriers and many work-arounds may present danger to the individual using the wheelchair or to other family members.

For example, carrying a person seated in a wheelchair, even if that person consents to be carried, should always be avoided. The chance of a fall is too great, because the center of gravity is high and the person and chair can rotate, spilling the individual onto the ground head-first.

Temporary ramps are useful but can also be dangerous, particularly two-part ramps. When using any portable ramp, be careful never to exceed the height that the ramp was designed to access. A ten-foot ramp is safe to a height of 10 inches. Keep in mind that the average stair rise should be about 8.25 inches. So a ten-foot ramp is useful for a single...
step and a small doorway threshold. Using it to go higher can result in the ramp sliding backwards off the step or, in the case of two-part ramps, could cause one of the ramps to twist out from under the wheels of the chair. In either case, misuse presents a serious fall risk.

Larger cities may have an equipment vendor who has temporary ramps to rent. For someone first returning home, before access modifications have been completed, this service can be very helpful. Reputable vendors will visit the location, decide on the ramps needed and return with the ramps to complete the installation. Using this service, one can be sure that the ramps have been placed securely and will be serviceable for the user.

In cases where an existing home cannot be made accessible, you must try to find a home that is easy to modify for access. The general principles for this type of readily-accessible housing are called Universal Design, pioneered in the 1990s at North Carolina State University. For those who wish more in-depth information a simple Internet search for the term “Universal Design” will yield countless hours of reading material. Universal Design principles apply to all types of design, not just architectural accommodations. You probably will not be able to find a truly universal design dwelling but in function, look for the following:

- **One story** A single story dwelling is best. It eliminates complications when developing access to all parts of the home. The home should be as close to grade as possible. If this is the case, it may be possible to remove entry stairs and swale (intersect or slope the land to) the entrance walkway so that the person may enter easily.

- **Open floor plans** lend themselves to wheelchair access. There are generally fewer hallways and door openings to present access problems.

- **Safety exits** Be sure that there will be two wheelchair-accessible doors for safety. In hilly areas this may be more difficult, for example, if the front door is easy to enter but the back door is many feet above grade.

- **Permissions and Permits** Be sure that you can get the permission and permits needed to complete the accessibility modifications. Sometimes local ordinances and building codes may block building within a specified distance of the lot line. Often, that extra space is needed to enlarge a bath or widen a walk or driveway to permit wheelchair passage. Usually, a variance to existing building regulations can be obtained but in some housing developments, the

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**People who are newly injured generally want to stay in the homes where they lived at the time of injury.**

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local board of commissioners or home owners association will resist or even refuse this type of request. This is why it is better to know before the purchase is made if the work can be completed as planned.

**Parking**  Is there room to park a lift-equipped van in the garage or under some shelter? If the garage is not large enough to hold the van and this is an area with large temperature variation summer to winter with snow or severe storms, then a garage is very important. The resources required to modify a garage to fit a van can be very costly and are an additional consideration.

Generally a newer home will meet more of these readily accessible expectations. You may be able to locate a development that has just started construction and housing is being sold based upon one or more model homes. Often, given the right terrain and house design, complete access can be designed into the construction of the home before it is built, with, for example, accessible cabinets, swaled entrances, and wider doors. A larger bathroom with an accessible shower can be incorporated into the design – perhaps taking some space from adjoining rooms to assure that the space will have a sixty-inch turning radius.

Sometimes new apartment/condominium complexes are built with an allotment of accessible units. Even if they are made accessible already, they are often easier to modify than a free-standing home. This type of housing is worth checking into if it is available in an area where the individual wants to live.

If using a multi-story building is unavoidable, is there a closet or other area on the upper floor that’s directly above another on the first floor, and is it of sufficient size that an elevator could be easily installed?

**Power supply**  Determine if the electrical power in the community is reliable. This is most important for individuals who rely on medical equipment, e.g., suction machines and ventilators. Equally important, being able to maintain air conditioning during hot spells in summer months or continuous heat during the winter are absolutely necessary for any individual with a spinal cord injury. If the power is unreliable, it may be easier to find a different location. If that is not an option, then always consider a back-up generator. Be sure to notify the local utilities if the individual relies on powered medical devices. The utility should have a list of people who must have power restored first.

**Universal Design principles apply to all types of design, not just architectural accommodations.**

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More importantly, every situation must include an evacuation plan for all possible emergencies. Fire, storms, power outages, etc. these all must be considered prior to their occurrence. Before any severe storm it is essential to identify a safe place to go. A hospital or even a hotel out of the path of the storm should be identified. Hotel staff should be alerted in advance that the hotel has been selected as a potential refuge for an individual with a particular set of needs.

A “bug-out bag” should also be created for use in emergency departure. It should contain clothes and medical supplies as well as a list of items to be added just before leaving the house. It should contain current medications, a suction machine, extra batteries for the ventilator, etc. Be sure that all emergency procedures are in writing and are reviewed not only at orientation with each new staff member but periodically with all staffers.

Finally, to refine your recommendations further, identify a builder, contractor or architect in the area with demonstrated expertise with accessible dwellings. The cost for the professional’s time will pay for itself by eliminating costly mistakes and missteps. This person should be able to give you a good idea of the overall cost and potential difficulties entailed in modifying a particular property based upon a walk-through. Complete plans, permits, and estimates, etc. will have to be completed and represent additional costs. This person you select as a consultant should be able to tell you approximately how much this planning stage will cost before you begin.
The author interviewed several life care planners and subcontractors via e-mail and used their answers and information from articles on subcontracting for this article. The majority of the interviewees wished to remain anonymous. The author extends sincere thanks to all the life care planners and subcontractors who shared their experiences and expertise for this article.

Consider the following scenario: You own a successful life care planning business. You work hard and your company is growing, but you are still working by yourself. The amount of work fluctuates; there are times when you have either too much or too little work. How do you handle this? If you are too busy, do you refer your next case to someone else or do you decline it altogether? In both situations, you risk losing a client and you could be aiding a competitor. Could hiring more employees provide a solution to handling your increasing workload? Perhaps, but hiring a full-time employee means a substantial financial investment, and paying an employee when there is not enough work is unprofitable. If you try to do it all yourself, you may get overwhelmed and stressed. Your work quality may suffer. What to do? Consider subcontracting.

A subcontractor/independent contractor is hired to do a single job, is not an employee, and does not have employee benefits, rights, or obligations. Subcontractors own their own businesses and are usually responsible for their own expenses, except as arranged (US Small Business Administration, n.d.). They have their own websites and are paid by the job. They set their own rules and hours, may work at separate locations, and generally provide their own supplies and equipment.

There are legal definitions distinguishing employees from subcontractors. According to the IRS (Internal Revenue Service, 2014), whether a person is an employee or an independent contractor depends on:

- Behavioral factors: who controls how the job is done

Melinda Nylund provides subcontracting services for life care planners, legal nurse consultants, and case managers. She has more than 20 years of experience in healthcare ranging from clinical care to administrative responsibility. She may be reached at msnylund@gmail.com.
• Financial factors: who controls the business aspects (expenses, supplies, equipment)
• Contractual relationship: Are there written contracts or benefits, and is the relationship episodic or ongoing

Subcontractors should present themselves as being in business for the purpose of making a profit and should not be prohibited from working simultaneously with other clients. (Encyclopedia of Business, n.d.)

What can subcontractors do for you?
Life care planners use subcontractors in different ways. Some have the subcontractor prepare a complete life care plan (LCP) independently, sign the document, and give testimony. Other life care planners subcontract out only portions of the LCP. The majority of the life care planners interviewed find it essential to do home visits and patient assessments personally, since they take full responsibility for creating the LCP and give testimony. They may subcontractors for parts of the LCP process, e.g., preparing a medical history/chronology, conducting literature searches, obtaining pricing, conducting phone interviews with the patient, conducting collateral interviews with treating team and people who know the patient, or attending independent medical examinations. Some life care planners use subcontractors to prepare medical cost estimates and Medicare Set-Asides and critique opposing LCPs.

One important question was how or whether subcontracting affects testimony. None of the life care planners felt that subcontracting did. They explained that they take full responsibility for the LCP and they have final approval for the information provided by subcontractors.

As for letting the client know about subcontractor arrangements, responses varied. Some planners were never asked about subcontractors; others, if asked, provided the subcontractor’s resume to the client.

Why do subcontracting?
Subcontractors subcontract for several reasons. Subcontracting allows them to use skills they have acquired during their nursing careers. Cecilia Ryan of Illuminant Medical Legal Consulting LLC, says, “Subcontracting allows me to apply my nursing, research and writing skills and knowledge.” (personal communication, 2014) Other reasons include flexible schedules, opportunities to work for more than one contractor, and gaining work experience if one is new to the field (Anonymous, personal communication, 2014). Subcontracting can provide experience before the subcontractor is ready to start an independent business, although some subcontractors are

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content with remaining as subcontractors. Becky Czarnik, the owner of Sierra Nurse Consultants, finds subcontracting a great way to learn specific aspects of the LCP process (personal communication, 2014). Some life care planners have independent businesses, but subcontract as a way to earn additional income.

**Advantages and disadvantages for the business owner**

**Productivity and efficiency:** Using subcontractors allows busy life care planners to take on larger projects, increase the number of cases they accept, and avoid having to turn down business. They are able to meet deadlines more easily and professionally. Subcontractors provide additional resources, bring in specialty expertise and may be able to help educate the life care planners in unfamiliar specialty areas. All this allows the business to grow and be more profitable.

**Costs:** Using subcontractors allows a company to save on labor costs, as they do not have to provide common employer-provided benefits, such as Social Security, health and liability insurance, worker’s compensation insurance, and unemployment. The company saves money by avoiding the high cost of hiring and training a full-time employee. It also saves on the cost of office space and equipment.

**Administrative burden:** Subcontractors are not covered under the clients’ workers compensation benefits or Equal Employment Opportunity laws, and they are not entitled to receive employee benefits or have taxes withheld by the client (US Small Business Administration (n.d.). This decreases demands on the business owner, as there are fewer administrative tasks, less paperwork, no payroll processing, less reporting to the IRS, and no withholding.

**Time:** Subcontracting frees up management time and resources to focus on more important issues, thus allowing business owners to concentrate on growing their businesses. On the other hand, some life care planners find contracting and coordinating work time consuming.

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Flexibility: Hiring a subcontractor for only a specific task and paying for only work performed makes workflow more flexible. According to some life care planners, subcontracting allows them to take a vacation or a day off, attend a conference or marketing event, or be out of the office while still producing billable hours. Subcontracting provides additional help during busy times without obligation if you are not busy. If the client is in another state, some life care planners consider it an advantage to have a subcontractor licensed in that state.

Control: “No one is ever going to take care of my business like I take care of my business,” says Victoria Powell, owner of VP Medical Consulting (personal communication, 2014). Using a subcontractor means that a business owner has less control over a project and workers. Most life care planners interviewed considered the main disadvantage was related to quality: work not being done exactly the way they want it. In the worst-case scenario, the subcontractor does not complete the assignment or uses minimal critical thinking, leading to incomplete, substandard, or erroneous work. In these situations, the life care planner would need to juggle other work to finish the project, perhaps resulting in delayed deliverables. This can cause problems with clients. It is critical to have a trustworthy subcontractor who will produce good work timely. Subcontractors must assure their life care planner clients that they will maintain reliability and quality services even if they have several customers simultaneously.

Advantages and disadvantages for the subcontractor

Independence and flexibility: Subcontractors decide how many hours they work, where they work, and what kind of work they want to do. However, work is not guaranteed work and may be irregular and unsteady. There is a tendency for subcontractors to work more hours than regular employees (Lines, 2013).

Control: Although subcontractors have much independence over the work they do, the contractor has the control over the project. The subcontractor may differ in opinion about how to conduct business, and the contractor has the final say.

Variety: Subcontractors get work from different sources, such as life care planning, case management, and legal nurse consulting. All subcontractors interviewed enjoy the different types of assignments they get. The variety of work guarantees them opportunities for continual learning and professional growth. As one subcontractor observes, “It keeps me
“sharper in all areas and adds to my skills.” (Anonymous, personal communication, 2014)

**Income:** Subcontractors control their earnings by setting their own fees; however, these may be limited by the contractors’ negotiated agreements with their clients. If the subcontractor is paid after the contractor receives payment, this can mean delayed reimbursement. Subcontractors should discuss and resolve these arrangements frankly at the beginning (see below). Subcontractors can be eligible for certain tax deductions, such as home office, travel, and work-related expenses if not reimbursed by their clients.

**Marketing:** The contractor does the marketing, finding the work, negotiating the projects, and building the relationships with the referral base of attorneys and insurance carriers. The subcontractor will need to do some marketing to establish a client base.

**Testimony:** Subcontractors rarely testify, although subcontractors who prepare complete LCPs for some companies may expect to testify.

**Other:** Some subcontractors who were interviewed considered it a disadvantage to have many different report formats and company preferences to learn. Some companies require subcontractors to read e-mails and submit work through a company Internet connection (VPN), which can be very time-consuming, as subcontractors may be required to go through several Internet pages in order to sign in.

**Keys To a Successful Contracting-Subcontracting Relationship**

**Connect:** The life care planners and subcontractors who were interviewed reported finding each other through professional association networking, AANLCP member list, conferences, workshops, and references from others. What qualities do life care planners look for in a subcontractor? A subcontractor should:

- be professional and articulate
- possess varied background of experience in healthcare (often specialty unit care, rehabilitation nursing, case management, or home care).
- have good critical thinking, writing, and communication skills
- be self-motivated
- be interested in expanding working knowledge base: attends conferences and workshops, participates in online professional community lists
- be flexible with time and work flow
- have access to resources such as equipment and reference materials.

**Manage expectations:** One life care planner conducts a detailed interview with the potential subcontractor. This provides a clear under-
standing of expectations and process and identifies and assesses the subcontractor’s knowledge base and areas of expertise (Anonymous, personal communication, 2014). Many life care planners request writing samples.

According to the Encyclopedia of Small Business, interview questions should assess the subcontractor’s intentions and expectations of the relationship. “Overall, the questions should establish whether the subcontractor will provide a good fit with the small business client.” (Encyclopedia of Business, n.d.)

One important theme to address in the interview is the company’s philosophy. Some life care planners look for a subcontractor with all the skills needed to do the work independently. Some recognize that everyone has different skills and provide coaching, believe that this can improve their own skills as well. Some life care planners view the subcontractor as a subordinate; others view the relationship as collegial. Some life care planners include the name of the subcontractor on the report; others do not.

**Contracting**

The contract defines all work, responsibilities, pay and, performance criteria. The contract should state that work is performed by an independent contractor but should not specify details such as working hours or materials. Include the following:

- **Outline expectations and duties:** The project deadline should be clearly defined. Time for revisions should be clear, including whether revisions can be done after the deadline or whether they are included within the deadline (in which case it would be a good idea to do reviews before the deadline). Renewal, cancellation, and termination should also be specified.

- **Compensation:** Pay rates vary depending upon the assignment and expertise and experience of the subcontractor. Subcontractors typically earn half of the contractor’s billable rate; some get a lower provisional rate. One life care planner reported that subcontractors earn an hourly rate of $50 to $100 (Anonymous, personal communication, 2014).

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*Subcontractors are not covered under the clients’ workers compensation benefits or Equal Employment Opportunity laws*
Payment arrangements vary; you must specify yours. Some contractors pay upon completion of the assignment; others pay after the contractor receives payment from the client. Specify rates for travel, waiting time, and mileage if applicable. Discuss deposition/trial compensation in situations where the subcontractor can be expected to testify.

**Confidentiality, privacy and HIPAA compliance issues:** Use the AANLCP Code of Ethics as a guide. Noncompete and nondisclosure of trade secrets, customer lists, and other proprietary information clauses will give the business owner peace of mind. Address any situations where the subcontractor may testify against the contractor. This is less of an issue if the subcontractor is located in another state and not an issue if the subcontractor does not testify.

**Copyright:** In cases where a subcontractor does work that can be copyrighted, the contractor may not be considered the owner of the work. If this is the case, the contract should specify transfer of copyright to the contractor. (Forbes Magazine Online, 2006)

**Other:** The Encyclopedia of Small Business suggests “including tangible measures of job performance, as well as financial incentives to encourage the subcontractor to meet deadlines and control costs.” (Encyclopedia of Small Business, n.d.)

The contract should cover anything the subcontractor needs to know to represent the contractor well and to be a credit to the company, so that the relationship between the contractor, subcontractor, and client will be successful. (Little, 2011)

*(A sample contract is attached at the end of this article).*

**Communication**

Excellent communication is at the core of a successful contracting-subcontracting relationship. All parties – contractor, subcontractor, and client – benefit. To have a successful outcome, it is vital that the hiring party takes the time to fully explain the project. The contractor or designee should answer all questions regarding the assignment and assist in solving any problems with the case. The subcontractor should never be afraid to ask to clarify questions. A good understanding of the project is crucial and saves everyone time and money. Expecting anyone to “figure it out” instead of getting a clear understanding leads to problems.

Discuss problems when they arise so that they can be solved before they escalate. For example, the subcontractor should inform the

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contractor immediately if information is missing or if the job cannot be finished by the deadline.

Communication is even more important if the contractor and subcontractor are in different states and working online and by telephone. Good communication is also essential to supervision of subcontractors. Life care planners who mentor their subcontractors communicate with them frequently. Others review the project regularly while the subcontractor is working to ensure it’s on the right track. Both parties should share feedback after the first assignment is completed and periodically thereafter. It is a good idea to have a quality assurance program to evaluate non-medical components of a report as well (Anonymous, personal communication, 2014).

**Conclusion**

A smoothly-functioning relationship with a subcontractor can make a company prosperous and thrive; a problematic relationship can do the opposite. Excellent communication and a well-written contract are the key elements to forming a successful, rewarding business relationship.

**References**


A. SUBCONTRACTOR NAME is a professional registered nurse consultant offering the services of life care planning and case management, and is licensed to do business in STATE. The principal place of business is ADDRESS.

B. Each party warrants to the other that it has full power and authority to enter into and perform this Agreement.

C. The Customer desires to engage the services of ABC Consulting, Inc. for the purpose of (specify, e.g., developing a life care plan, researching standards of care, researching pricing) for PT NAME, DOB, and ABC Consulting agrees to provide such services subject to the following terms and conditions:

AGREEMENT

1. Upon receipt of retainer and continuing thereafter until this Agreement is terminated as provided below, Subcontractor agrees to (specified activity) for PT NAME. (If a LCP: A Life Care Plan is a tool used for the purpose of estimating medical and non-medical needs of a person with a catastrophic injury or chronic illness over an estimated life span. It is a dynamic document based upon published standards of practice, comprehensive assessment, data analysis and research. A Plan may include medical needs and costs, future projections, and a vocational assessment. The contents may be comprehensive or modified, based on the needs of the party making the request. This LCP will not include a vocational assessment or detailed architectural modifications as requested by the Customer.)

2. The Customer agrees to make payment to ABC Consulting in the amount of $XXX (XX dollars) per billed hour, payable upon receipt of the invoice. The retainer is applied to the final balance.

3. Reasonable and necessary travel and other expenses incurred by ABC Consulting during the course of (specified activity) will be reimbursed by the Customer. Mileage will be reimbursed at the current rate allowed by the IRS. Travel time will be billed at $XX (XX dollars) per hour rate. Travel will be prorated when appropriate.

4. Finance charge of 2% will be billed on all undisputed balances not paid within 30 days, with a minimum charge of $10.00 (ten dollars) per month.

5. Nothing in this Agreement is intended nor will be construed to create a partnership relationship, an employer-employee relationship, a principal-agent relationship, or a joint-venture relationship between...
parties, or to allow the Customer to have or exercise control, direction, or supervision over the professional judgment, manner, means, or methods by which ABC Consulting performs the services which are the subject matter of this Agreement. It is mutually understood and agreed that the representatives of ABC Consulting at all times while performing services for the hourly fee under this agreement shall be in the capacity of an independent contractor, provided, however, that the services to be provided hereunder by ABC Consulting shall be completed in a manner consistent with the standards governing such services and the provision of this Agreement.

6. This agreement contains the entire understanding between two parties and supersedes any and all written and oral communication and it shall remain in effect until a written notice of termination is received by either party from the other.

7. ABC Consulting shall comply with all applicable laws and regulations relating to its services under this Agreement, and will obtain, maintain, and, upon request, provide Customer with proof of any and all necessary certifications, licenses and regulatory approvals. ABC Consulting shall immediately notify Customer of any laws or regulations that may affect ABC Consulting’s or Subcontractor’s ability to satisfy its obligations hereunder.

8. Customer and ABC Consulting acknowledge that Workers Compensation is a highly regulated industry and that ABC Consulting and its employees’ performance of its obligations under this Agreement may give rise to certain duties imposed under laws, rules and regulations that govern insurance companies, agents and suppliers of insurance services and functions. Customer and ABC Consulting further acknowledge that nonpublic personally identifiable personal, financial and medical information about Customer’s customers, former customers, applicants and claimants may be disclosed to ABC Consulting or its employees during the course of, and as necessary for, the performance of this Agreement. ABC Consulting and its employees agree that it will maintain the confidentiality and privacy of such information and comply with all applicable laws, rules and regulations concerning the maintenance of the privacy of such information. ABC Consulting and its employees will limit access to such information to only those individuals that require access to such information for performance of this Agreement and will not disclose such information to a third party unless otherwise permitted by law and then only after requiring the third party to execute a similar confidentiality and privacy clause and with prior writ-
ten consent of Customer. The obligations under this paragraph shall survive the termination of this Agreement.

9. ABC Consulting agrees to carry the following insurance coverage during the term of this Agreement or any Supplemental Agreement:

   a. Worker’s compensation as required by the laws of the state in which the work is being performed.
   b. Automobile liability for both hired and non-owned company automobiles of one million and 00/100 ($1,000,000.00) dollars for bodily injury and property damage.
   c. Professional liability for an aggregate coverage of two million and 00/100 ($2,000,000.00) dollars.

10. ABC Consulting shall indemnify, defend and hold harmless Customer and its officers, directors, partners, agents, members and employees from and against any and all demands, claims, damages to persons or property, losses and liabilities, including reasonable attorneys fees (collectively “Claims”) arising out of or caused by ABC Consulting, its nurses, and/or its members’, agents’, employees’, or independent contractors’ negligence in connection with the performance of services hereunder.

IN WITNESS THEREOF, parties have executed this Agreement on the day and year first written above, and it shall remain in effect until one or both parties terminate the agreement as stipulated in the contract.

(signature)
Requestor of Services/Customer
Life Care Planner
Date: Xxx x, 20xx  Date: ____________________________

11.
Candidates must meet the following eligibility criteria per the application deadline as indicated in the CNLCP® Handbook and Website: [http://cnlcp.org/certification-by-examination.htm](http://cnlcp.org/certification-by-examination.htm)

Candidates for reciprocity must meet the following eligibility criteria per the application as indicated in the CNLCP® Handbook and Website: [http://cnlcp.org/certification-by-reciprocity.htm](http://cnlcp.org/certification-by-reciprocity.htm)

**Certified Nurse Life Care Planner (CNLCP®) Certification Board Position Statement**

As healthcare has become more complex, it is increasingly vital to assure the public that healthcare professionals are competent. Individual State Registered Nurse (RN) licensure measures entry-level competence only; and, in so doing, provides the legal authority for an individual to practice nursing. It is the minimum professional practice standard.

Certification, on the other hand, is a formal recognition that validates knowledge, experience, skills and clinical judgment within a specific nursing specialty; and, as such, is reflective of a more stringent professional practice standard. It reflects achievement of proficiency beyond basic licensure.

The CNLCP® Certification Board is a separately incorporated entity that facilitates consumer health and safety through credentialing/certification of nurse life care planners. It ensures that their practice is consistent with established standards of excellence in the development and defense of the life care planning document.

Similar to consumers knowing to seek out certification status within other professions (e.g., dentists, pharmacists, etc.), certification within the field of nurse life care planning has become an important indicator that a certified nurse not only holds state licensure to practice nursing, but is qualified, competent and has met rigorous requirements in the achievement of the CNLCP® credential.

**FOR MORE INFORMATION PLEASE VISIT [WWW.CNLCP.ORG](http://www.cnlcp.org) AND/OR CONTACT:**

Glenda Evans-Shaw, Chairperson  
[glenda@suttercreek.com](mailto:glenda@suttercreek.com) /phone: (209) 267-0890

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