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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 Fall 2014 issue of the Journal of Nurse Life Care Planning. Our focus is on psych aspects of life care planning. We believe that this issue will offer you insights into this challenging topic, with resources and links. We all know that identifying sources of support and care for persons with long-term psych problems can be difficult; it’s also difficult to explain to carriers and clients why the measures we provide in our plans are as necessary as tangible items like prostheses or architectural modifications. An interesting article on care of a sexual assault victim reminds us that collegial NLCP practice can extend into criminal law, too.

As it would happen, our annual conference will include several sessions on sequelae of brain injury, including a preconference day for CBIS certification. We hope to see you at the conference in the one and only Atlanta on October 24-27, 2014. You will find links to the schedule (Page 708), register for the conference, and find booking information for hotel rooms on the website at the website, www.aanlcp.org. Check it out and see if it excites you as much as it does me!

Cordially,

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

PS: Also check out the list of past Journal issue topics on page 715, added by popular demand!
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.

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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, halftone 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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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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Cheryl Kaufman BScN RN CLCP CNLCP (“Life Care Plan for Victim of Sexual Assault: a case study”) is owner and principal of CK Medical-Legal Consulting Services in Massachusetts. She has more than 25 years of nursing experience to inform her Legal Nurse Consulting and Life Care Planning practice. In addition to her early clinical experience in neonatal intensive care, pediatrics and caring for patients who suffered a stroke, her career path predominantly focused on infectious diseases, oncology and biotechnology and nursing education with emphasis on oncology disease management with specific chemotherapeutics and biological response modifiers, drug-drug interactions, and patient safety issues.

Gordon J. Horn PhD (“A Model of Care for Traumatic Brain Injury Rehabilitation”) is Deputy Director of Clinical Outcomes Systems for NeuroRestorative - National and the Director of Clinical Services for NeuroRestorative - Florida. He has also served as Clinical Neuropsychologist at the Florida Hospital Neuroscience Institute, Rehabilitation and Sports Medicine and Director of Programs and Clinical Services at Communicare in Florida. He directs the behavioral analysis practicum program for the University of South Florida at NeuroRestorative and supervises graduate students in the Behavioral Analysis Department.

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Colleen Manzetti, DNP, RN, CNE, CNLCP (“Role Delineation Study”) is the principal of Prodigy Life Care Planning & Consulting Services, LLC in New Jersey, providing life care planning, legal nurse consulting, medical cost projections, case management, and expert witness services since 2001. Dr. Manzetti has extensive experience as a managed care expert working for Fortune 500 insurance companies. Dr. Manzetti serves as a board member on the CNLCP® Certification Board. She is an assistant professor at Marjorie K. Unterberg School of Nursing and Health Studies at Monmouth University.

April Pettengill, RN, CRRN, CDMS, CNLCP, MSCC (“Role Delineation Study”) has over 27 years of experience as a Registered Nurse. She worked in the hospital setting in geriatrics, pediatrics and orthopedics. For the last 24 years she has been a case manager for work-related injuries and illnesses. Ms. Pettengill has extensive experience with catastrophic injuries and in 2004 she became certified as a Nurse Life Care Planner. Ms. Pettengill became a Medicare Set Aside Consultant Certified in 2005 and began writing MSAs. She currently works per diem for a local Home Health Agency to keep her hands-on clinical skills active.

Martin J. Waalkes PhD (“Determining Need for Protective Supervision in Adults with TBI with Behavioral Disturbance”) is a Psychology Department Supervisor at Hope Network Rehabilitation Specialists in Grand Rapids, MI. He also serves on the Michigan Board of Psychology and the Board of Psychology Disciplinary Subcommittee. He is a member of the American Psychological Association Division of Rehabilitation Psychology and is a Certified Brain Injury Trainer.
Changes in DSM-IV-TR to DSM 5

The American Psychiatric Association has released its 2013 updates to the DSM. A free PDF of highlights (16 pages) is available at http://www.dsm5.org/Documents/changes%20from%20dsms-iv-tr%20to%20dsms-5.pdf with a link to order the full work. Please share this with your readership.

Joan Schofield BSN RN MBA CNLCP
Albuquerque NM

Letters on any topic are welcome and may be sent to the Editor at whowland@howlandhealthconsulting.com. Letters may be edited for brevity.
A new defense attorney client has asked me to review medicals and the plaintiff life care plan as a testifying expert. I assessed the patient, 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 (only the first few weeks post injury) to his physician testifying expert, 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 a 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!

It is not the nurse life care planner’s role to “enlighten” the other expert regarding lack of medical information shared by the retaining attorney. The nurse has already shared his/her concerns with retaining attorney regarding the upcoming deposition and will need to answer all questions truthfully. I expect that the physician expert will not be happy when he/she is deposed and finds out that all medical records were not shared.

Apparently, the defense life care planner discussed these circumstances with the defense attorney at some point because he was not happy. Before deposition, it will be important for the life care planner to recontact the attorney to discuss the intention to communicate with the defense expert to clarify the individual’s current status. If the attorney does not permit contact, the testifying life care planner will have no choice but to discuss the rationale for agreeing with the plaintiff life care planner’s recommendation for a baclofen pump, analgesics, etc. during deposition. The plaintiff’s physician and life care planner should have provided evidence for these recommendations. It is important, as life care planners, to base our future medical recommendations on current treatment and/or expert opinion. Ideally, it would have been preferable for this life care planner to have had a discussion with the referring attorney at the outset of their relationship regarding the need to collaborate with the defense expert in order to obtain physician support for the future medical aspects of care. Relying on current treatment and or collaborating with a medical expert is important PRIOR to any expert testimony.

The crux of the dilemma is, “...my client’s physician expert, who was not given current records and did not see the patient.” I would advise the attorney that I am going to concur with the plaintiff’s recommendations for the

continued next page
baclofen pump and analgesics based on my nursing opinion and assessment that the patient has pain, and because based on the current literature, it is the appropriate treatment for someone with spasticity pain. I would spell out to the attorney the consequences of his expert witness not having current records (gently and diplomatically of course); and offer one last time to discuss the issue with the physician. No one likes looking bad deliberately!

Since the LCP already conveyed her concerns to the attorney, if the disagreement is not resolved, the LCP has a couple of ways to go. One path could be sure the invoicing is caught up, recuse herself from the case, and consider reporting the attorney to the appropriate authority. Since there could be repercussions with that option, another option would be to testify and just tell the truth. The attorney is paying for the LCP’s time, not opinion, and the LCP has been more than honest with regard to her opinion and concern. Perhaps through the process the attorney will come to his senses and the physician expert will get the updated information. Another option would be to involve one’s professional organization such as AANLCP, and seek the advice of the ethics committee for guidance. It is always helpful to have others’ input and professional opinions when faced with such dilemmas.

This is actually a basic nursing ethical issue of protecting yourself through communication and documentation. If your nursing assessment validates your recommendations and research backs that up then your opinion is your opinion….When you advised the attorney of your opinion, and I assume provided your rationales when he expressed discontent, he was placed on notice that he had a problem when the treating physician presented a difference of opinion. This is a situation you never want going forward. It is the attorney’s responsibility, not the nurse LCP to resolve this issue.

It’s not clear if the LCP has asked her attorney client a basic question: “Is there something going on here I need to know?” Her next move might be to say, “Sometimes my clients don’t like what I have to tell them, but they always say they would rather hear it from me than from opposing counsel. If I can learn that your MD expert doesn’t have the full picture when he testifies, they will, too. Shall I call him and fill him in?” If he won’t budge, and you’ve clarified your opinion to him, then you have no choice when called by opposing counsel to testify in deposition.

You’ll probably never get another case from him. However, all is not lost. After they fire him, his senior partner might call you.

For the next issue:

I took a case on short notice for a new client, an expert referral business working for an attorney. He wanted a quick letter regarding standard of care involving a patient fall, and he wanted it in three days. The referral agency sent me a summary they had prepared of the case to work from. It didn’t look too bad until I got the records on day 3 and realized that 1) they were very skimpy and 2) they contradicted some important details in the summary, and 3) the referral principal wanted me to give the attorney the expert opinion he wanted without data to back it up, saying, “We’ll take the responsibility for this.” Your thoughts?

Share your expertise and advice. Send your confidential opinions and recommendations to the editor at whowland@howlandhealthconsulting.com.
In 1988 Claudia Osborn MD, a physician with a thriving academic practice, was leading a charmed life in Detroit. After a busy day she and her partner Marcia went for a bicycle ride in their neighborhood. A car struck her and tossed her over its roof into years of confusion, frustration, and a completely changed life with challenges and losses that continue to this day.

While there are a number of such first-person memoirs on the market, even some written by neurologists or neuropsychologists, none, I think, is as powerfully evocative as this one. Page after page drew me into the bewildering world of disordered function after brain injury with such clarity and power that I carried it with me for weeks. Dr. Osborne says in her introduction that while she cannot remember much of her first nine months post-injury, she has recreated scenes with dialogue from scraps of her own thoughts and help from the friends, colleagues, therapists, and family who worked with her. While she can’t swear that the order of events is perfect, and knows that many of them probably occurred more than once, they are all true.

As a nurse, I feel the value of this book is in its ability to help me work more empathetically with cognitively-affected adults, regardless of cause. How could you not take a second look at someone who seems fine, after reading a vignettes like this?

A few minutes later, Marcia followed me into the bathroom, where I was turning in circles trying to recall what I’d come in for. “How are you going to practice medicine when you can’t brush your teeth without guidance?”

“I don’t need guidance,” I said as I layered the toothbrush with hand lotion from the pump bottle by the sink. “I know medicine.”

And how could you forget family and friends to whom the care of the head-injured falls, after hearing words like Marcia’s, eight months after the accident?

The Claudia I knew was dynamic, articulate, compassionate, and funny. She had a thriving career. She was a

**Over My Head: A Doctor’s Own Story of Head Injury from the Inside Looking Out**  
Andrews McMeel, publ. Kansas City MO, 1998  
E-ISBN 978-0-7407-8663-1

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gifted, empathetic doctor with an analytical mind; a generous, loyal friend; a diplomat; a caring healer whose passion for life was inspiring. This looks like a job recommendation. It feels like an obituary. Surely I have seen flashes of Claudia these last eight months, but, in truth, she is gone. The friend I sent to New York for rehab is an enigma who has lost all. When I talk with others who are close to head-injured people, we discuss the big losses: Claudia can’t be a doctor. Terry will never finish college, Brian cannot support his wife and children.

But it’s the everyday losses that get to you. Claudia is a boring conversationalist. Her language is no longer fluid and she lacks ideas to discuss with me. It doesn’t occur to her to ask me how my day was, and she wouldn’t remember what I told her anyway. Our friendship is now a one-way street of her need.

Dr. Osborne was in rehabilitation for much of the next year, learning a path between the Scylla and Charybdis of adynamia and flooding thoughts and emotions. She was able to move back home, and gradually learned how to be more functional in a world that was more Twilight Zone than Detroit. Traveling to and from home and the rehabilitation program at NYU, she would put notes in her pockets to say what city and airport she was in, so when she left a bathroom at the airport she would know where she was, and how to get to her gate. In such a bathroom once, when she realized she had no such note, she deduced that she must be traveling with someone … but outside the bathroom she found herself in a hallway with people wearing NYU ID badges. Where she belonged. Alone. And feeling, “illogically abandoned.”

While she was never able to resume her previous hospital and medical school teaching duties, 26 years later she is living a full life with daily support from her partner and a nurse case manager. She has adapted to having a very impaired memory and has come to accept the help she needs for tasks we take for granted -- getting dressed with all items of clothing, remembering to eat meals, meeting people. Somebody else keeps her checkbook, shops, and arranges her affairs. She has some duties at the medical school. She has public speaking engagements to describe brain injury, which is where I heard her.

Hers is a story of remarkable persistence in the face of terrible deficits, told without much of the sunny gloss you come to expect from many such books. There’s self-pity, and self-deprecation, and entertaining little scenes from rehab, but there really isn’t a cliché happy ending. She looks like a prosperous physician of middle age should: well-dressed and -coiffed, assured, almost deceptively well-spoken. She communicates living in the baffling world of cognitive damage so well, even while saying how difficult it is to organize her thoughts. It’s not hopeless, it’s just … real. We get an OK ending, and she has made her peace with it.
“The Scout’s name is Peter. He is a 17 year old Life Scout who is right now (literally) working on his Eagle Project.

“The way I became aware of the problem? We were doing a planning meeting for our High Adventure June Trip on a Thursday evening in the Senior Patrol Leader’s basement. There were 6 Scouts and 2 adults on the planning team. Peter had been having some conversations with the other Scouts about how he had to have a recliner because leaning back made his head hurt less, and for awhile he even went over and laid on the floor for a little bit before deciding that wasn’t good either, so he moved back to the recliner.

“At first I just thought he had a bad headache, but as the other adult and I were sitting at the back watching what was going on Peter stood up from a recliner he was sitting in. He swayed back and forth a little bit and I asked him if he was all right. He said something like ‘I get dizzy now if I stand up too quickly,’ to which I replied, ”You are too young to have those kinds of problems,” to which he said, ‘It’s because I had a concussion last weekend,’ as he walked away to the bathroom. The other adult was going to be in charge of the backpacking / caving group for the older Scouts, and he and I exchanged a significant look that said we’d have to seriously discuss this later.

“When he came back from the bathroom he told us that he was supposed to be on brain rest, which he laughed about. One of the other Scouts chimed in with something about how he didn’t use his brain anyway :-).

“It was obvious that he wasn’t quite right, but it was hard to put your finger on exactly what was wrong. It was something about how the responses were just a little too delayed, or they didn’t come out quite the way you would...
have expected them to, or just the look on his face. I’ve been working with this kid for 5 years, and everything about his responses just didn’t quite fit the Peter I knew. Peter is good friends with the other adult’s kid and you could tell the other adult was thinking the exact same thing.

“After the meeting the other adult called Peter’s parents to ask them exactly what had happened. It turns out that Peter had had not one but two concussions, back to back. On Saturday he had gotten one while water skiing when he jumped a wave and did a solid face plant on the water at high speeds. The family hadn’t realized how bad things were until the next day when he was riding in an inner tube behind a boat and again the tube hit a wave and went up in the air, flipped over and came down with him under it and again he smacked the water head first at high speeds. That time he was completely out of it and they took him to an ER where both concussions were diagnosed. Four days later he was at the SPL’s basement, in complete violation of the doctor’s orders.

“After we talked, we worked it out with the parents that for Peter to come with us his doctor must write up a letter explicitly authorizing Peter to take part in backpacking with elevation gains over 500 feet, in 95 degree weather, and to go down into a cave with narrow rocky tunnels, etc., etc., etc. Well, needless to say the doctor not only wouldn’t approve any of that, he specifically told the family that absolutely no way should Peter do any of it, and told them to enforce “brain rest.” So in the end he didn’t go with us.”
Life Care Planning for Victim of Sexual Assault, a case study
Cheryl Kaufman BSN RN CLCP CNLCP

Life care planning for children takes into consideration their future care needs along with many foreseeable changes through their adolescent years as they grow into adulthood and mature into their senior years. Life care planning for a child who has been sexually assaulted by multiple males simultaneously presents more and different challenges for the nurse life care planner, because of the requirements for recommendations to minimize or prevent foreseeable complications as a result of overlapping symptoms of rape trauma syndrome and post traumatic stress syndrome.

Ann Burgess, DNSc, APRN-BC and Sociologist, Lynda Holmstrom first described Rape Trauma Syndrome (RTS) in 1974 as, “the psychological trauma experienced by a rape victim that includes disruptions to normal physical, emotional, cognitive and interpersonal behavior.” RTS is a cluster of psychological and physical signs, symptoms and reactions common to most rape victims immediately following and for months or years after a rape. (J. Sandoval 2002) RTS paved the way for consideration of Complex Post Traumatic Stress Disorder, which can more accurately describe the consequences of serious, protracted trauma. Although the symptoms of RTS and post-traumatic stress syndrome overlap, individually each can have long, devastating effects on rape victims. (Table 1)

G was 13 years old. She and her younger sister were “hanging out together” in a park when they were approached by a male who started talking to her about having a party. There were multiple males in the car; she and her sister were asked if they wanted to accompany them to a party. She was told by one of the males that she recognized that they were going to a party to either celebrate one of their birthdays or “to party,” perhaps meaning to drink and smoke, indicating G’s confusion about their intentions. She entered the car without her sister. Police and psychiatry reports indicated there was drinking in the car; the child became intoxicated after ingest-

Cheryl Kaufman is currently a full time independent Nurse Life Care Planner and Legal Nurse Consultant in Taunton MA. She can be reached at cklegalmed@msn.com
ing half a bottle of gin. Psychiatry records later indicated she trusted somebody because she thought she could always call her aunt or her father for a ride.

The males brought G to a motel, entered a unit through a back door where additional males were waiting, and left her there. Some time later she called her father who picked her up and took her to the emergency room. Examination showed she was alcohol intoxicated and had been sexually assaulted with vaginal, anal, and oral penetration by six different males.

G lived with her mother, younger sister, and younger brother but remained under the partial legal custody of the Department of Children, Youth, and Families (DCYF). The family history was positive for substance abuse and mental illness. Her parents were never married. Her father left her mother when G was 4 years old but she remained in contact with him over the years.

Following the event, her mother reported that on the surface, G seemed “Okay,” but she also acted as if the sexual assault never happened. She showed no emotion. Her mother described her daughter as having a “weird” mood with a distant quality to her interactions. She also reported that G had been “zoning out” with marked episodes of staring off into space during dinner. She had been spending much more time alone in her room.

Despite the rape, G continued to attend school every day. The teachers indicated she had been doing well behaviorally and academically for most of the year, at her own level. They noticed a pronounced change following the rape. The teachers indicated G appeared hopeless, giving up, isolating more, moody, and irritable with aggressive outbursts. She began having behavioral problems at school. She attempted suicide on one occasion. She was admitted to the pediatric inpatient psychiatric unit for nearly four weeks where she treated for acute stress reaction due to the sexual assaults.

She met with a psychiatrist in consultation one month after the sexual assaults. She admitted to actively resisting thinking about the assault, at times, pretending it never happened, avoiding reminders of the people or place associated with the event, preoccupation with

Although the symptoms of RTS and post-traumatic stress syndrome overlap, individually each can have long, devastating effects on rape victims.

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intrusive thoughts of the event during the daytime. She had recurrent dreams about it and marked distress when having to talk about it, irritability, difficulty initiating sleep and inability to recall parts of the trauma. The psychiatrist felt G met full criteria of post traumatic stress disorder (PTSD) and RTS.

The distinguishing characteristic of PTSD is the development of symptoms subsequent to a psychologically traumatic event, typically one that is beyond the range of usual human experience. The extent of impairment in patients diagnosed with PTSD varies. It can be mild or quite severe. Symptoms may begin soon after the trauma. However, it is not unusual for a victim to exhibit a delay in symptom onset. (Edelman 2005)

At the time of the sexual assault, G was receiving medication for bipolar mania symptoms. Her mother indicated that this had helped G stay calm and helped her behavior in general. In the weeks after the assault, her family dynamics and her clinical condition rapidly deteriorated. G’s insight and judgment were poor. Since the sexual assaults by multiple males, her behavior markedly changed and worsened. Her thought process was disorganized. Her mood and affect was euphoric.

Table 1. Common stages of rape-trauma syndrome


**Acute Stage** occurs in the days or weeks after a rape. Durations vary as to the amount of time a survivor may remain in the acute stage. The immediate symptoms may last a few days to a few weeks and may overlap with outward adjustment stage.

**Repression or Outward Adjustment** This stage is characterized by a rationalization of the rape. The victim appears to have “forgotten” it and appears to have resolved the issues. After the immediate issues have been temporarily dealt with, the victim usually returns to her ordinary routine of life. It is during this stage that there is heavy denial and suppression. She denies the rape had a personal impact on her and she concentrates on protecting the feeling of those close to her. However, they simultaneously suffer profound internal turmoil, which may manifest in a variety of ways as the survivor copes with long-term trauma of a rape.

**Reorganization or Integration** This stage begins when the victim develops an inner sense of depression and feels the need to talk about her feelings and the situation. Concerns which have been dealt with superficially or denied successfully reappear for more comprehensive review. In order to resolve her feelings, the victim is encouraged to accept the rape and realize the impact it has had on her feelings and life. During this phase, the victim experiences the reemergence of previous troubling responses, and she may have suicidal thoughts. The victim may appear to be getting worse instead of better. She may experience insomnia, nightmares, and various physical symptoms. It is important that she is encouraged to explore her emotions openly and begin to put an end to the nightmares.

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She became increasingly impulsive with self-endangering promiscuity, acting-out behaviors, and dramatic mood swings. She ran away from home on a number of occasions. During this time, she had an American Psychological Association (APA) Global Assessment of Functioning (GAF) score of 20 to 28. (Table 2)

While hospitalized, she was treated with multiple medications for bipolar disorder in an effort to stabilize her euphoric manic mood and psychotic behaviors. While bipolar disorder is classified by psychotic symptoms, e.g., delusions, hallucinations and disorganized thinking, research indicates that bipolar disorder is likely a result of genetic predisposition combined with environmental influences including stressful traumatic events. (Rush 2003)

In mania, thought processes are accelerated, mood is generally elevated, the need for sleep is greatly reduced or absent, and energy seems limitless. Thinking becomes less critical and is often illogical. Insight into a condition might be missing entirely as is the ability to discriminate between rational and faulty thinking. (Rivas-Vasquez 2002)

As noted above, the symptoms of rape trauma syndrome and PTSD overlap. There are three common stages of RTS posted online by multiple rape crisis centers. (Table 1)

Her behaviors lead to multiple admissions to various residential treatment facilities for adolescents with emotional, behavioral and psychiatric problems. She was admitted to a long-term residential treatment center where she remained for six months. During that admission, she continued to have drastic mood changes while on medications for bipolar disorder and PTSD, ranging from docile and placid to impulsive and argumentative. She continued to run away frequently. She displayed poor judgment, such as eloping without shoes. At one point, she attempted to jump out of a window, naked, hoping to run to safety. During group therapy and while attending classes, she often had a blank, flat affect and did not process incidents. It was felt that until her mood disorder and the PTSD stemming from the rape were addressed and stabilized, G remained at very high risk for relapse of self-endangerment including repeated elopement and sexual acting out due to the fragile and brief recovery she had made thus far.

Over time, G was admitted to several different residential treatment centers, where she attended special schooling and group therapies with other troubled teens but lacked the 1:1 care and guidance she needed. She had multiple recurrent hospitalizations for exacerbations of her manic euphoric symptoms con-
Table 2. Global Assessment of Functioning (GAF) A numeric scoring system (0-100) used by mental health clinicians and doctors to rate the severity of illness in psychiatry and will generally reflect the need for treatment or care. (APA; Endicott, J, et al., 1976) (From DSM-IV-TR, p. 34.)

Consider psychological, social, and occupational functioning on a hypothetical continuum of mental health-illness. Do not include impairment in functioning due to physical (or environmental) limitations.

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<th>Code</th>
<th>Note: use intermediate codes when appropriate, e.g., 45, 68, 72</th>
</tr>
</thead>
<tbody>
<tr>
<td>91-100</td>
<td>Superior functioning in a wide range of activities, life’s problems never seem to get out of hand, is sought out by others because of his or her many positive qualities. No symptoms.</td>
</tr>
<tr>
<td>81-90</td>
<td>Absent or minimal symptoms (e.g., mild anxiety before an exam), good functioning in all areas, interested and involved in a wide range of activities. Socially effective, generally satisfied with life, no more than everyday problems or concerns (e.g., an occasional argument with family members).</td>
</tr>
<tr>
<td>71-80</td>
<td>If symptoms are present, they are transient and expectable reactions to psychosocial stressors (e.g., difficulty concentrating after family argument); no more than slight impairment in social, occupational or school functioning (e.g., temporarily failing behind in schoolwork).</td>
</tr>
<tr>
<td>61-70</td>
<td>Some mild symptoms (e.g., depressed mood and mild insomnia) OR some difficulty in social, occupational, or school functioning (e.g., occasional truancy, or theft within the household), but generally functioning pretty well, has some meaningful interpersonal relationships.</td>
</tr>
<tr>
<td>51-60</td>
<td>Moderate symptoms (e.g., flat affect and circumstantial speech, occasional panic attacks) OR moderate difficulty in social, occupational, or school functioning (e.g., few friends, conflicts with peers or co-workers).</td>
</tr>
<tr>
<td>41-50</td>
<td>Serious symptoms (e.g., suicidal ideation, severe obsessional rituals, frequent shoplifting) OR any serious impairment in social, occupational, or school functioning (e.g., no friends, unable to keep a job).</td>
</tr>
<tr>
<td>31-40</td>
<td>Some impairment in reality testing or communication (e.g., speech is at times illogical, obscure, or irrelevant) OR major impairment in several areas, such as work or school, family relations, judgment, thinking, or mood (e.g., depressed man avoids friends, neglects family, and is unable to work; child frequently beats up younger children, is defiant at home, and is failing at school).</td>
</tr>
<tr>
<td>21-30</td>
<td>Behavior is considerably influenced by delusions or hallucinations OR serious impairment in communication or judgment (e.g., sometimes incoherent, acts grossly inappropriately, suicidal preoccupation) OR inability to function in almost all areas (e.g., stays in bed all day; no job, home, or friends).</td>
</tr>
<tr>
<td>11-20</td>
<td>Some danger of hurting self or others (e.g., suicide attempts without clear expectation of death; frequently violent; manic excitement) OR occasionally fails to maintain minimal personal hygiene (e.g., smears feces) OR gross impairment in communication (e.g., largely incoherent or mute).</td>
</tr>
<tr>
<td>1-10</td>
<td>Persistent danger of severely hurting self or others (e.g., recurrent violence) OR persistent inability to maintain minimal personal hygiene OR serious suicidal act with clear expectation of death.</td>
</tr>
<tr>
<td>0</td>
<td>Inadequate information.</td>
</tr>
</tbody>
</table>
sistent with bipolar disorder. The hospitalizations were often precipitated by periods of refusing to take her medications, running away without leave, and impulsive high risk behaviors of endangerment to self and others. When asked why she refused her medications, she explained it was her way of taking control of her life since she was always being told by others what she can and cannot do and when to do things. Refusing her medications was the one thing she could control.

Her psychiatrist indicated there was no evidence that a specific treatment plan had been developed to address the ongoing effects of bipolar disorder complicated by RTS and PTSD would have on G’s ability to function or keep her safe. There was no speculation on how this would affect her quality of life.

This nurse life care planner was contacted three years after the traumatic event. A review of the medical records and several meetings with G revealed the treatment plan was clearly not meeting current or future needs to allow her to rehabilitate and move forward despite her traumatic experience. In collaboration with the psychiatrist, all parties involved decided to move G out of the region where the trauma took place three years earlier to a different state altogether, primarily for her safety until the matter went to trial. Family members agreed that this was the best option to ensure her safety and try to put the past behind her. Her mother, siblings, father and stepmother were allowed to visit her on weekends and holidays, but she was not to return to the state where the event took place. She needed to feel safe to be a teenager. However, her current environment lacked the opportunity for her to advance and mature mentally, emotionally, vocationally, and socially with individuals her own age.

Therefore, the life care plan’s goal was to provide for an optimal structured environment that permitted her to be part of the decision-making process for her actions while maintaining her safety, as well as to provide recommendations to return her to a normal quality of life as much as possible.

Recommendations were based on shared decision-making with G and set up in consecutive stages: Plan A, Plan B, and Plan C.

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These described provisions for sheltered, semi-independent, and independent living situations, each with close monitoring and both individual and shared responsibilities. They also included vocational opportunities, i.e., 1:1 training or group training depending on milestones accomplished by G from one year to the next. In addition, each plan included a job coach, case management, medical care, medications, and diagnostic testing.

For example, when residential sheltered services in Plan A were no longer applicable when goals were met, semi-independent residential services in Plan B would begin. Plan C was unique in that it provided for her safety but was a less structured family living environment that allowed for more independent living and decision-making. There was no specific timeframe allocated for Plans A, B, or C, as one could not predict with accuracy when G would become more self-sufficient, more independent, and reliable in her living situation and work environment.

One critical challenge was anticipating future services for the relapses that life’s unpredictable events would, inevitably, trigger. Due to poor patient adherence with medications due to side effects or other factors noted above, patients with mental illness are commonly at high risk for relapses or self-endangering beh-

### Table 3. The Plans

| Plan A: Comprehensive treatment and long-term care; staffed 24 hours per day by trained mental health professionals. Daily costs include room/board, multi-disciplinary team for all medication management, psychotherapy with nurses, psychiatrist, social workers, 1:1 counseling, group & family counseling. Community integration and vocational training are encouraged to transition into community based living (Plan B). Transportation for all medical and social events. |
| Plan B: Step down unit: transitional program includes assisted residential living, supportive care, daily vocational rehabilitation with limited work hours, transportation and medication management and psychiatry care. Counseling sessions not included in the daily/weekly rate, based on the G’s functional level and work schedule. |
| Plan C: A psychosocial family model of living together; cooking, cleaning and working as a team in a house on a large homestead. There are 8 residents at any one time; each has a single bedroom. The program involves learning self-help skills, making independent decisions, respect for each other, culinary arts, cooking, along with recreational activities. The program includes a leveling system with 1:1 supervision, depending on personal needs, aspirations and medication management. All psychiatric, medical care and medications are additional to the daily rate. |

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haviors, sometimes requiring hospitalization. Relapses were anticipated, since she remained in a very fragile state. (See Table 1) When these relapses occurred, G became nonfunctional in society and a danger to herself and others. While the degree of complications depended on the severity of illness and the presence of impaired reality (psychoses), these risks were taken very seriously in projecting G’s future needs and long-term associated costs.

The life care planner discussed the goals for each Plan (A, B, C) with G and her psychiatrist; they felt them to be realistic and goal oriented. As is customary with life care planning, there was a beginning and an ending age for her estimated life expectancy, although a specific timeline could not be known. Since regressions and exacerbations could be reasonably expected, e.g., there would probably be times where Plan A (the more restrictive arrangement) would have to replace Plan B.

### Nursing Diagnoses to Consider

NANDA-I Nursing Diagnosis, 2012-2014

- **Ineffective Self-Health Management** (Domain 1, Health Promotion; Class 2, Health Management)
- **Ineffective Impulse Control** (Domain 5, Perception/Cognition; Class 4: Cognition)
- **Readiness for Enhanced Knowledge** (Domain 5, Perception/Cognition; Class 4: Cognition)
- **Disturbed Personal Identity** (Domain 6, Self-Perception; Class 1: Self-Concept)
- **Interrupted Family Processes** (Domain 7, Role Relationships; Class 2: Family Relationships)
- **Impaired Social Interaction** (Domain 7, Role Relationships; Class 3, Role Performance)
- **Ineffective Sexuality Pattern** (Domain 8, Sexuality; Class 2, Sexual Function)
- **Post Trauma Syndrome** (Domain 9, Coping/Stress Tolerance; Class 1: Post Trauma Responses)
- **Rape-Trauma Syndrome** (Domain 9, Coping/Stress Tolerance; Class 1: Post Trauma Responses)
- **Ineffective Coping** (Domain 9, Coping/Stress Tolerance; Class 2, Coping Responses)
- **Readiness for Enhanced Power** (Domain 9, Coping/Stress Tolerance; Class 2: Coping Responses)
- **Risk for Compromised Resilience** (Domain 9: Coping/Stress Tolerance; Class 2: Coping Responses)
- **Decisional Conflict** (Domain 10: Life Principles; Class 3, Value/Belief/Action Congruence)
- **Readiness for Enhanced Decision-Making** (Domain 10, Life Principles; Class 3, Value/Belief/Action congruence)
- **Risk for Self-Directed Violence** (Domain 11: Safety/Protection, Class 3: Violence)

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for some period before Plan B could be safely resumed. Therefore, the life care plan clearly stated that when the services in one Plan were activated, costs related to services in the previous Plan in use no longer applied. The life care planner accomplished this with meticulous collaboration with an economist to prevent duplication errors when calculating costs for services such as medical care, medications, and other services over the long-term.

G continued to treat with the psychiatrist on a weekly basis with recommendations for no changes until she completed high school. At the time of life care plan preparation, she was still having frequent bad dreams and intrusive recollections about the events of the assaults. Reports indicate that despite her improvement over the recent past, her recovery remained fragile.

PTSD is clearly a distressing, even disabling anxiety disorder provoked by exposure to extreme psychological trauma. Individuals diagnosed with PTSD often have problems with attention, working memory and new learning. Such findings have been reported for specific populations of those individuals who have experienced PTSD after childhood sexual abuse and rape. (R. Parslow, et al 2007) A review of G’s school records indicated she was classified with an IQ score of 70, borderline intellectual functioning. Though G had been enrolled in special education programs for many years, when questioned her psychiatrist was unaware of any psychological reports of intelligence or academic testing.

Some of the medical reports indicated that G had cognitive limitations. The course of her bipolar disorder was dramatically worsened by the sexual assault. Psychiatry records indicated that G’s judgment and impulsivity were significantly compromised by her learning disability. Her mood was sometimes destructive and impulsive. But when her mood was stable, she was motivated to do well in school. There was a clear improvement noted in her school performance with improvement in her mental health. Recommendations were made within each of the Plans to include neuropsychological testing to determine whether stabilizing the manic and psychotic features of her bipolar disorder, PTSD, and RTS affected her intellectual functioning.

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A vocational evaluation with testing was included into G’s life care plan. The results of the neuropsychological testing would help determine the most appropriate training method to take her goals, individuality, self esteem, psychological health and future aspirations into account. Collaboration with a vocational consultant proved very helpful to ensure G’s long-term plans included appropriate vocational services and training. G shared with this life care planner that math was her favorite subject because she “liked the challenge.” She really enjoyed choreographing dance moves, which she often did with her free time. She further shared that she liked the “creativity aspects.”

Life care planning for a teenager with mental illness, in particular, is very challenging. Such a plan must truly be a dynamic document. It must be flexible to provide various options to meet her mental health needs as she ages into and through adulthood.

In follow up, G eventually developed a new sense of insight and capacity to deal with her condition but is still haunted by vivid memories of the rape by multiple males. She admitted that in her past she was very impulsive, told people what they wanted to hear, and did not want to do better. Now she is ready “to do better (for herself and her family).” She is finally able to relate her unsafe patterns of behavior to the psychiatrist spontaneously. She also finally recognizes that the medications she is prescribed were more helpful than being without them.

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PATE REHABILITATION

BRAIN INJURY TREATMENT, RESEARCH & ADVOCACY

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- Physical Therapy
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- Animal-assisted Therapy Activities
- Biofeedback
- Occupational Therapy
- Cognitive Rehabilitation
- Vocational Rehabilitation
- Emotional/Psychological Adjustment
- Aquatic Therapy

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- Post-acute Residential
- Supported-living Residential
- Post-acute Day Neuro
- Young Adult (ages 16 – 19)

PATE also provides:
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- Medical Services Provided by a Physical Medicine and Rehabilitation Physician
- Bilingual Services
- Transportation Services

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An estimated 2.4 million adults and children in the United States sustain traumatic brain injury (TBI) each year. Another 795,000 individuals sustain an acquired brain injury (ABI) from non-traumatic causes. Currently more than 5.3 million children and adults in the U.S. live with a lifelong disability as a result of TBI and an estimated 1.1 million have a disability due to stroke (National Center for Injury Prevention and Control, 2003). Many of these individuals with disabilities require supervision supports. Supervision has been defined as “the continuous or intermittent presence of another individual to provide physical care instructions for or setup of daily living tasks, problem solving in case of emergency, or some combination of these.” (Hart, Millis, et al., 2003, p. 221) Describing the Supervision Rating Scale, Boake (1996) defines supervision as “all forms of help that require the caregiver to be in the physical vicinity of the patient.” (p. 765)

Disabilities resulting from TBI or ABI often require supervision to accommodate physical limitations or communication needs, and to provide or monitor medical treatments. Since supervision implies a person’s cognitive, physical, and behavioral challenges, it has long been considered an important measure of outcome in rehabilitation (Condeluci, Ferris, & Bogdan, 1992). Standards for determining care needs for individuals with physical limitations after brain injury are well established. Nurses, occu-
pational therapists, and physicians typically determine need for functional assistance and medical care (Michigan Brain Injury Providers Council (MBIPC), 2011).

However, Glubo et al. (2014) found that of 346 adult patients who had achieved physical independence at discharge from TBI model system acute rehabilitation programs, 215 (62%) remained dependent on others due to cognitive impairments. Where both cognitive and physical needs were present, supervision intensity was better predicted by cognitive factors than by physical needs (Granger, Divan, & Fiedler, 1995). When supervision of an individual is indicated for protection from behavioral risks associated with confusion and cognitive challenges, or from problems of behavioral control, determining specific needs can become complex and subjective. Persons with major and mild neurocognitive disorder, defined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM 5) (American Psychiatric Association, 2013), can display psychotic symptoms, mood disturbance, agitation, apathy, or other behavioral symptoms. This means that individuals with TBI may require measures of protective supervision.

**Syndromes of Risk**

Each individual with brain injury demonstrates unique behavior patterns that reflect pre-morbid characteristics and the specific features of the neurological injury. Despite this individual variability, clinicians can often identify distinctive behavioral and cognitive syndrome patterns that present challenges requiring supervision for protection and safety.

**Executive system dysfunctions** are common in moderate to severe TBI. They are often characterized by overactivation and associated disinhibition, or, conversely, as apathy and with-
drawal (Lezak, Howieson, Bigler, & Tranel, 2012). In both syndromes, the individual has difficulty organizing and executing meaningful and purposeful responses to environmental demands. An individual with executive system injury may not generate the initiative to respond to imminent risks or fulfill necessary routines, or, paradoxically, may also respond too vigorously to opportunity and ideas with stimulus-bound patterns, distractibility, and impulsiveness. The frontal lobe and its reciprocal systems with other parts of the brain are central to judgment, planning, and self-modulation; these are all critical cognitive skills necessary for risk appraisal and safety awareness. Without insight or awareness, individuals with physical limitations may need additional protective supervision to accommodate physical challenges. They may not have the capacity to appreciate the need for assistance with tasks they were formerly able to complete independently, such as assessing fall risk or avoiding accidental self-injury.

The **limbic system** is a complex network of brain structures involved in memory, mood experience, motivation, and drive states. One, the amygdala, processes alarms and sets the tone of threat response, often before the threat is even processed for content. Other limbic structures are implicated in appetite, pleasure/reward, memory development, and mood experience. **Limbic system** damage is associated with explosive reactivity, chronic irritability, anxiety, and depression (McAllister, 2007). Brain injuries that include limbic structures can be marked by strong, inappropriate, and disinhibited emotional reactions (Silver, Yudofsky, and Anderson, 2005). These and other sequelae of limbic injury can require supervisory intervention for safety, self-preservation, or conflict de-escalation.

Confusion, misperception, and memory failures observed in moderate and severe injury present additional dangers in home and community environments. **Unawareness syndromes** such as anosagnosia and neglect, typically associated with right hemisphere cerebral injuries or diffuse severe brain injury, interfere with accurate perception or responses to environments (Flashman, Amador, & McAllister, 2005). Such injuries may be accompanied by disturbance of attention, slow reaction times, sleep pattern disruption, and may include hyper- or hypo-aroused behavior patterns. (Marin & Chakravorty, 2005) The combination of confusion and altered arousal presents unpredictable and often continuous risks.

**Standards of Supervision**

One of the most frequently used research tools to quantify supervision level in TBI is the Supervision Rating Scale (SRS) (Boak, 1996). This scale divides the level of provided supervision continued next page
into 13 ordinal categories from complete independence to physical restraints. The SRS has resulted in a wealth of data on supervision determinants in the TBI model systems longitudinal database (TBIMS). (Table 1)

One challenge is that supervision setting descriptors and staffing ratios are non-standardized: Words such as supervised, structured, and monitored can describe very different conditions depending on setting, program rules, staffing models, and institutional standards. Staffing ratios capture only one dimension of supervision intensity, and the nature of support or level of vigilance implied by these ratios is not necessarily uniform. Even within a single supervised home with a particular staffing ratio, residents may vary substantially on the levels of support and vigilance required for safety.

Predictors of Supervision Requirements
Most of the research on supervision level has been retrospective. While reviewing pre-morbid history, injury severity metrics, and types of cognitive impairments that predict outcome can give important information on related factors, they provide no working assessment strategies or supervision tactics.

Research with 563 participants in the TBIMS identified several pre-morbid factors as predictive of subsequent post-injury supervision needs. Ethnic minority status, lower level of education, and poorer pre-injury productivity were all associated with a higher level of post-injury supervision (Hart et al., 2003). The authors suggest the “cognitive reserve” associated with higher levels of education and productivity contribute to the capacity to adapt to a severe injury.

Hart et al. (2003) also found that although initial Glasgow Coma Scores (GCS) (Teasdale & Jennette, 1974) were not predictive of supervision outcomes, coma length and post-traumatic amnesia duration were. Coma lengths for the moderate and heavily supervised groups were approximately twice the duration of the independent groups.

As an objective indicator of severity, midline shift of > 5mm on computed tomography (CT) imaging was predictive of physical supervision needs for individuals with TBI (Englander, Cifu,
I. Household Services/Replacement Services: Care provided to fulfill ordinary and necessary services unable to be fulfilled due to injury. (The Insurance Code Act of 1956)

II. Medical services: Services of a medical care nature overseen or implemented by nursing under the direction of a physician (MBIPC, 2011).

- Non-skilled services: Basic care such as bathing and oral care that can be provided by Certified Nursing Assistants or attendants.
- Skilled services: Advanced care by licensed RN/LPN nursing providers requiring standard or advanced training such as wound care or ventilator management.

III. Physical Assistance: Physical assistance provided as proxy for personal expression of instrumental and daily living skills for personal needs for an individual with physical impairment. Individuals receiving care may, or may not, be able to direct the assistance or care that is provided. Physical assistance may be provided to fulfill defined tasks and procedures for daily living needs.

IV. Protective supervision: Care interventions and techniques are provided due to safety needs related to capacity, orientation, and judgment (DRC, 2010). Care is provided under the structure of a supervision coverage plan outlining intensity and coverage.

- Dimensions of protective supervision intensity:
  - Proximity: Physical distance from the individual receiving care.
  - General knowledge
  - Ears-on
  - Physical presence/eyes on
  - Arms length

- Standby assistance
- Physical contact
- Control: Endorsed level of physical caregiver intervention in the care and direction of the individual.
- Gestural prompts
- Verbal prompts
- Physical intervention

- Vigilance: Stipulated timeliness and frequency of assessment and responsiveness to manage risk.
- Assessment interval
- Response time

- Dimensions of protective supervision coverage: The degree to which protective supervision applies over the dimensions of time, setting, and context

- Continuous/partial: Protective supervision provided without designated unsupervised times.
- Night supervision/daytime supervision: Protective supervision stipulations aligned with identified characteristic hours of sleep.

- Context stipulations: Features of the setting and inherent controls and responsibilities where protective supervision is provided.

- Supervised: Responsibility for protective supervision coverage is held by the assigned provider.
- Structured: Responsibilities for protective supervision coverage is held by the characteristics of the site or setting in collaboration with the individual.
- Monitored: Protective supervision coverage is non-continuous or intermittent based on time intervals or other specified criteria in a semi-controlled setting.
Wright, & Black, 2003). Although Brown, Malec, and McClelland (2005) did not confirm this finding, they did find other objective measures to distinguish individuals with TBI who need supervision from those who do not. These measures included length of post-traumatic amnesia, age, and physical exam features (including sitting balance and limb strength), but not cranial CT variables, GCS, or gender.

A simple rating score or neuropsychological measure with predictive validity in identifying individuals requiring varying levels of supervision would be very useful. However, such reductionist efforts to predict multiply-determined or low-frequency behaviors from psychometric assessment have many limitations (Lezak, Howieson, Bigler, & Tranel, 2012). While no risk assessment or instrumental measure can replace clinical judgment, there are significant relationships between neuropsychological performance measures and supervision placement. Supervised and non-supervised groups showed differences in nearly all neuropsychological measures in the Hart et al. (2003) TBIMS study. Some measures, such as digit span backward and Trail Making Test-Part B, could even distinguish between moderate and heavy supervision need, as measured by thresholds on the SRS, even after accounting for the influences of pre-morbid moderator variables. Memory measures were not as predictive (Hart et al., 2003).

**Ratings as Predictive of Supervision**

Some rating scales do correlate with supervision needs. The Mayo-Portland Adaptability Index, (MPAI-4) (Maleck, et al., 2003) (sidebar, next page), a rating measure of functional abilities, adjustment features (e.g., mood, awareness, and fatigue), and participation levels, has been broadly adopted as an outcome measure of TBI treatment and outcomes. The MPAI-4 can guide placement and give the probability of progress with rehabilitation. The following studies suggest potential usefulness as a predictive measure of supervision need or to inform guidelines to determine supervision levels.

In a study of the MPAI-4 as a predictor of next level of care for TBI, the MPAI-4 Ability index plus PTA duration measures accounted for nearly 90% of the variance in a decision for inpatient rehabilitation vs. home discharge from acute care (Malec, et al., 2009).

In a study of 604 participants at four different types of rehabilitation settings, the MPAI-4 Adjustment index showed greater adjustment difficulties for participants in intensive rehabilitation placement compared to those in long-term supported community and residential

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placements (Eichner, Murphy, Murphy, & Malec, 2012).

The MPAI-4 total scale score, and particularly the Ability index, were also able to predict progress in rehabilitation for individuals involved in active treatment interventions.

**Risk Assessment**

Risk assessment is central to any supervision determination. This may include a systematic review of typical risk exposures, or may be a review of problem logs of specific behaviors that historically have shown to be risky for individuals (DRC, 2010).

Many institutional settings employ some type of risk assessment tool that guides the process of evaluating supervision needs (Commission on Accreditation of Rehabilitation Facilities, 2012). Such tools function as checklist documentation of historically observed risks. Areas covered in such assessments identify individual risk profile characteristics such as:

- behavioral regulation
- cognitive capacity
- neuropsychiatric stability
- substance abuse
- interpersonal agitation
- history of impulsiveness for high risk behaviors like self-abuse or elopement

The Mayo Portland Adaptability Inventory - 4 (MAPI-4) is a widely used clinical evaluation tool for the post-acute phase of adjustment to brain injury. It is most often used as an outcome measure for program evaluation and in clinical research. It can be completed by the person with the injury, family, or professional providers. It can be used with adults, children, and adolescents.

It includes four Subscales:

- **Ability**: Measures motor and cognitive abilities like use of hands, vision, audition, communication and motor speech, memory, problem-solving, and fund of information.
- **Adjustment**: Measures mood and interpersonal interactions, like anxiety, depression, anger, fatigue, pain, and awareness and sensitivity to symptoms. It also rates family supports, initiation, and social and leisure adjustment.
- **Participation**: Measures social contact, initiation, self-care, activities, residence, transportation, employment, and money management.
- **Pre-existing and associated conditions**: While not scored as part of the composite, these items provide a place to indicate contributing factors, like pre-injury conditions and unrelated disabling conditions like mental illness or addiction.

The MPAI-4 is available for download on the web site (www.tbims.org/combi/mpai) for the Center for Outcome Measurement in Brain Injury (COMBI) sponsored by the National Institute of Disability and Rehabilitation Research (NIDRR) through its TBI Model System Program.

These risk assessment tools also review contextual environment demands, as they can cause problem behaviors. While some risks are universal to any context, there may be

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tasks, time, or settings that present unique challenges or require different levels of supervision for a particular element. For example, an individual may do well in structured group social activities until food is present, then require close protective oversight when consuming a specialized dysphagia diet.

Objective assessment of cognitive features known to correspond to safety risks by a qualified mental health professional will often contribute to predicting protective supervision need. Memory, orientation, and judgment assessment are important parts of a related functionally-oriented neuropsychological evaluation.

Risk assessment also requires considering other factors. Persistent substance abuse, psychiatric co-morbidity, and sensory or physical limitations compounded by unawareness may create risks (e.g., falls or burns) that are worsened by cognitive challenges. Medical conditions like diabetes or pregnancy bring more complex demands for essential safety skills, and they require advanced cognitive skills for active self-monitoring and problem solving which may be impaired. Similarly, there are some settings, such as naturally protective and contained environments or communities, e.g., a residential school environment, that may minimize required supervision.

While supervised individuals differ from those less supervised on several characteristics (Hart et al., 2003), retrospective research does not offer guidance on assigning individuals to particular levels of care. These remain primarily clinical decisions based on clinical judgment and observations of the individual in various settings. There is also no way of reliably knowing, short of trial placement or graded exposure trials, what level of supervision is optimal for a given individual. Since minorities are more likely to receive higher levels of supervision (Hart et al., 2003) influence of covariates or systemic bias in these supervision decisions is possible.

Protective supervision needs are also not static. In a study of 95 injured individuals, 60% required supervision in their first post-injury year; this rate declined to 25% by year 4-5. (Corrigan et al. 1998).

**Alternatives to 24-Hour Supervision**

Continuous direct observation by a single, trained observer who monitors and records behavior and who responds with prescribed interventions is the best tactic to mitigate risk. However, this is often not practical, and in some cases may not be necessary. The most common alternative is some form of supervision in a group environment.

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There are few ways to adapt group efficiencies to an individual or home placement. Monitoring with audio, video, door monitors, and location technology presents some ethical challenges to privacy, but may allow for more efficient oversight, particularly with low-frequency behaviors and context-sensitive risks.

Check-in supervision, group supervision strategies, and scheduled or random supervision intervals may also meet the needs of some individuals with lower intensity challenges, intact emergency skills, or slow-developing risks. While some individuals with broad risks may require continuous supervision, partial supervision, such as stipulating “waking hours only,” may be sufficient for an individual who sleeps predictably without complications, but has trouble with social function. Stipulations of “night hours only” may be appropriate for those vulnerable to wandering or elopement with confusion or sleep disorders confined to the night hours. Such individuals may require such supervision at night while functioning without direct supervision in the context of a structure such as a leisure group or a predictable job where supervision is inherent to the context. There are other examples where employment and social contacts present supervision needs, but the quiet and lower stimulation of the night hours are managed independently or only require on-call assistance. A person with regularly disturbed sleep cycles from psychiatric instability may require more conservative supervision recommendations for nighttime hours (Rao, Rollings, & Spiro, 2005).

Protective Supervision Dimensions

Protective supervision recommendations can be structured around the two related dimensions of intensity and coverage.

Intensity. There are different levels of vigilance, responsiveness, and capacity for control required in response to a risk event. Intensity can range from general knowledge of the individual’s whereabouts to control and contact strategies, such as physical restraint, to protect an individual from imminent self-injury like biting or hair pulling. Intensity can be measured by physical capacity for responsiveness, level of control, or level of vigilance. Locked settings, arms-length proximity, and
auditory monitoring are examples of intensity specification. Practically, the dimension of intensity is typically measured by the ratio of the number of individuals to the staff assigned to their care e.g., 3:1 or 1:1.

Coverage describes how protective supervision applies over time, setting, and context. Coverage ranges widely, from an individual needing intermittent check-in supervision to address specific events or time intervals to someone who needs continuous 24-hour monitoring.

While intensity and coverage can be related (Figure 1), there are examples where high-intensity protective strategies are only necessary intermittently, such as co-attending a medical appointment for a generally reserved individual who may become reactive in a stressful situation. Similarly, some individuals with arousal and apathy patterns who function in well-structured environments and stable routines with little direct support may lack problem-solving skills for intermittent emergencies or abrupt changes in routine, and therefore require a 24-hour protective supervision plan.

### Developing a Protective Supervision Coverage Plan

A coverage plan is an individualized strategy for meeting a disabled individual’s protective supervision needs for all their daily living ac-
tivities and environments. Developing coverage plan requires a careful assessment of individual descriptive factors, environmental risk, cultural standards, available control and support resources, and information compiled from behavior experience tracking.

The resulting coverage plan is the minimum necessary intensity and coverage conditions required to mitigate risks acceptably and sustainably. It should identify coverage and intensity needs for each unique environment anticipated as part of a daily living routine, and specify intervals for reassessment. It should also specify special provisions or strategies that minimize risk in particular contexts, such as controlling access to money or food to neutralize the consequences of impulsivity, or technology systems to monitor location and movements.

**Conclusions**

Individuals with moderate or severe TBI or ABI may need protective supervision, a specific element of care for cognitive and behavioral challenges. Determining supervision level has historically been an exclusively clinical process, and it is unlikely that making such determinations can be reduced to a simple, objective procedure. However, more clinicians support a research-based process that looks at clusters of characteristics and injury severity typically associated with the need for protective supervision for a given individual. The goal is to develop a variety of strategies to fulfill oversight requirements flexibly, with minimal restriction.

**Areas for future research** include developing a standardized structured inventory of supervision risk indicators. This could clarify levels of supervision and indicators of risk, and

---

**Nursing Diagnoses to Consider**

- **Impaired Environmental Interpretation Syndrome**: Consistent lack of orientation to person, place, time, or circumstances over more than 3 to 6 months, necessitating a protective environment (Domain 5, Perception/Cognition; Class 2: Orientation)
- **Impaired Memory**: Inability to remember or recall bits of information or behavioral skills (Domain 5, Perception/Cognition; Class 4: Cognition)
- **Ineffective Impulse Control**: A pattern of performing rapid, unplanned reactions to internal or external stimuli without regard for the negative consequences of these reactions to the impulsive individual or to others (Domain 5, Perception/Cognition; Class 4: Cognition)
- **Ineffective Activity Planning**: Inability to prepare for set of actions fixed in time and under certain conditions (Domain 9, Coping/Stress tolerance; Class 2, Coping Responses)

*continued next page*
could serve as the basis for new lines of research to support safe and consistent decision-making. This has already been attempted in the areas of substance abuse treatment placements (American Association of Community Psychiatrists, 2009), and could be applied to TBI and ABI protective supervision.

Better understanding of the relationship between broad-based measures of disability, such as the World Health Organization Disability Assessment Schedule 2.0 (World Health Organization, 2010), and supervision determination would also be helpful.

Consistent language for levels of intensity and coverage will also be helpful. The Supervision Rating Scale offers some definitions, but reflects clinical practice rather than defining it. Consistent or standardized terminology for levels of care will facilitate research in treatment interventions and protective supervision supports.

Adopting consistent terms, e.g., protective supervision, supervision coverage plan, intensity, and coverage to define the needs unique to the cognitive and behavioral challenges of TBI and ABI will also help objectively specify appropriate recommended supervision supports. This would improve communication between clinicians and providers to specify protective supervision recommendations for this population.

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Corrigan, J. D., Smith-Knapp, K., & Granger, C. V. (1998). Outcomes in the first 5 years after traumatic


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According to the Center for Disease Control (CDC) health statistics (2013) the annual cost of healthcare in the United States has risen steadily since 2000, from $1.2 trillion to $2.3 trillion in 2011 (approximately $7300 per capita), almost doubling in 11 years. For those aged 44-84, the average hospital cost was $12,500 per admission; younger persons averaged $7,000 per event, reflecting increasing costs with aging. Two-thirds of hospitalization costs was spent on persons aged 44 or older.

Some health care costs have decreased. According to the CDC (2012), the death rate for auto related accidents decreased between 2006-2010 by 30-60% across all ages, genders, and races in the United States. According to Caro (2011), automobile accidents may account for up to 60% of traumatic brain injuries. Even with fewer automobile-related injuries, costs for TBI are about $76 billion dollars per year. The Brain Trauma Foundation, The American Association of Neurological Surgeons, Congress of Neurological Surgeons, and the AAN/CNS Joint Section on Neurotrauma and Critical Care (2007) provided guidelines for the acute care of adults with severe brain injury. They concluded that widespread adoption of these guidelines could cause a 50% reduction in deaths, and savings of $288 million in medical and rehabilitation costs. Now it is imperative to develop guidelines related to a neurological rehabilitation to evaluate each level of care, coordinate services, and manage costs.

The CDC reports there were approximately 2.5 million traumatic brain injuries sustained in 2013, approximately 20% of traumatic brain injuries in the moderate to severe category and requiring support post-hospital discharge. This group accounts for the greatest costs in post-hospital care. The purpose of this paper is to describe efficient levels of rehabilitative care.

A Model of Care for Neurological Rehabilitation

Gordon J. Horn PhD and Frank D. Lewis PhD CBIST

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and cost management for moderate to severe traumatic brain injury.

**Traumatic Brain Injury**

Many persons with moderate to severe traumatic brain injury are unable to live independently after inpatient discharge (Langlossis, Rutland-Brown & Wald, 2006). However, with appropriate post-hospital services, they can improve enough to live more independently at home and engage in productive activity, thereby lowering overall health costs. Clinically meaningful improvements (Hayden, Plenger, & Bison, 2013) can be demonstrated any time, not just within the first post-injury year.

Most rehabilitation occurs in inpatient admissions, with average length of stay about two to three months, and with limited funding for care options after discharge. However, much post-injury recovery occurs after the first 6 months. Thereafter, behavioral experiences and interventions drive further recovery (Hayden et al., 2013; Johnson & Lewis, 1991; Lewis & Horn 2013; and Nudo, 2003). Post-hospital services restore independence gradually, using appropriate medical, behavioral, and social supports to sustain and enhance quality of life. The following describes the various elements of hospital and post-hospital care and efficacy, and when these modalities are appropriate for the patient.

**Levels of Care in the Neurologic Rehabilitation Continuum**

1. **Hospital: Intensive Care and Acute Care Step-down**

   The immediate post-trauma period is characterized by life or death decision-making and emergency care to achieve survival. After this, most individuals will spend one to fourteen days (average six days; McElroy, et al., 2013) in critical care or step-down units. This level of care is the most costly due to medical acuity and intensity of medical services (Haddad & Arabi, 2012), approximately $9,700 per day (Pfuntner, Wier & Steiner, 2013), not including physicians, medication, or ancillary costs.

   Acute care step-down length of stay ranges from one to fifteen days, depending upon severity and complexity of patient needs. The overall average length of stay in the acute hospital setting is 6.8 days for all intracranial
injuries (Russo, Owens & Stocks, 2004).

TBI is one of the five most costly conditions, with the aggregate cost of $18,000 per day, nearly double the average daily cost for other conditions (Pfuntner, Wier & Steiner, 2013). For moderate to severe intracranial injury, average length of acute hospital stay was 8.1 days with an average daily cost of $19,300 (Russo & Steiner, 2004).

II. Hospital: Acute Hospital Inpatient Rehabilitation

Inpatient rehabilitation is the second stage of recovery. The individual is mostly medically stable. Length of stay ranges approximately two to three weeks (average = 12.6 days), with an average daily cost of $2,350 not including physicians, medication, or ancillary services (HCUP, 2006).

The goal is to maximize the individual’s potential to return home with family. However, this individual will typically not be ready to use higher level skills and abilities, and in most cases remains dependent on others for supervision and assistance. Hawkins, Lewis, & Medeiros (1996) found that upon discharge from the acute rehabilitation hospital, many TBI patients required physical and/or cognitive assistance in the following areas: 51% with ambulation, 46% with self-care, 55% with communication, and 76% with social cognitive skills. These deficits prevent many TBI survivors from returning to independent, meaningful, and productive activity. As a result, Masel (2009) argued that we should think of TBI as, “a chronic disease rather than a single event or final outcome.” In other words, TBI causes disruptions in neurological systems that require rehabilitation for months or years.

There is a broad spectrum of post-hospital rehabilitative care, described in the next sections, to help move individuals towards less disability and reduced supervision at home and in the community. The continuum is flexible to allow the entry at any level of post-hospital care. Table 1 describes general needs-based admission guidelines for appropriate placement for post-hospital rehabilitation care.

III. Post Hospital Community Neurorehabilitation

The first step after inpatient care is often a community neurorehabilitation (PHCN) program. These residential programs first appeared in 1977 and were referred to as community re-entry or transitional living, and were based on an educational rather than a medical model of care. Costs are determined by treatment intensity and patient needs, but begin at or lower than cost of inpatient rehabilitation programs. As the name implies, they are generally community-based.

This level of care teaches and promotes gen-
continued next page
Table 1  Post-hospital brain injury rehabilitation options: Admission guidelines

<table>
<thead>
<tr>
<th>Admission Guideline</th>
<th>Medical Status</th>
<th>RLA</th>
<th>Volitional Aggression</th>
<th>Inappropriate behaviors</th>
<th>Inappropriate verbalizations</th>
<th>Time since Injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHCN Criteria: neurological injury, disease, or illness</td>
<td>Stable medically including being afebrile, negative for infection, trach capped, bolus G-tube feeding, possibly insulin dependent with appropriate protocols in practice</td>
<td>IV - VII</td>
<td>Not volitionally aggressive; may be mild to moderate involutionally aggressive based on RLA Level</td>
<td>Impulsive, behavior inappropriate for the situation, easily frustrated, attentional deficits,</td>
<td>Mild - easily redirected by staff or loved ones; inappropriate verbalizations may be due to residual confusion</td>
<td>Range = 1 to 24 months since injury and following acute hospital and acute rehabilitation hospital discharge</td>
</tr>
<tr>
<td>NBI Criteria: neurological illness, disease, or injury that results in behavior impairment interfering with social functioning</td>
<td>Stable medically including being afebrile; negative for infection, insulin protocol with medications but no injectables</td>
<td>IV - VIII</td>
<td>Mild to Severe aggressive; may be volitionally aggressive; or may be involutionally aggressive based on the RLA Level</td>
<td>Impulsive, behavior inappropriate for the situation, easily frustrated, attentional deficits, aggressive to others and destructive of property</td>
<td>Mild-Moderate-Severe levels; inappropriate verbalizations require structure, cues, and redirection; verbalization tends to be impulsive, and inappropriate in most contexts</td>
<td>&gt; 8 months since time of injury with minimal residual confusion (e.g., if patient is perpetually in Rancho IV-V due to injury severity)</td>
</tr>
<tr>
<td>* SL Criteria: longer term need for assistance with basic care, access, medical management, daily living needs</td>
<td>Stable medically stable but may include comorbid medical complications associated with other diseases and aging effects</td>
<td>VI-VIII</td>
<td>Mild only but redirected; there are supported living brain injury facilities that can also provide service for the mildly behavioral intense</td>
<td>Need to be easily redirected by staff or loved ones</td>
<td>Easily redirected by staff or others</td>
<td>&gt; 2 years duration of injury, and after neurorehabilitation with residual assistance needed for basic care, daily living activities</td>
</tr>
<tr>
<td>Day Trx Criteria: must live in the community independently or semi-independently</td>
<td>Stable medically stable but may include comorbid medical complications or conditions; aging effects</td>
<td>VI - VII</td>
<td>Mild but redirectable, and minimally socially interfering</td>
<td>Easily redirected by staff, and does not require law enforcement for behavior control</td>
<td>Easily redirected by staff or others</td>
<td>Based on need, could be any time after the hospital where high structure is not required for success</td>
</tr>
<tr>
<td>H&amp;C Criteria: must live in the community either independently or with family but still needs assistance with identified concerns</td>
<td>Stable medically but may include comorbid medical complications or conditions; aging effects</td>
<td>VII - VIII</td>
<td>Mild but redirectable, and minimally socially interfering</td>
<td>Easily redirected by others</td>
<td>Easily redirected by others</td>
<td>Anytime following acute rehabilitation, post-acute rehabilitation, or following outpatient services for skills generalization</td>
</tr>
</tbody>
</table>

PHCN = Neurorehabilitation; NBI = Neurobehavioral Intense; * SL = Supported Living; Day Trx = Day Treatment; H&C = Home and Community. In all program types, ambulation is not a rule out criteria for admission. Those who may be rated as a Rancho Los Amigos (RLA) Level III or lower would be more appropriate for Long-term Acute Care (LTAC) facilities due to the complexity of residual injury and medical needs. With improvement, the patient could re-enter the rehabilitation continuum noted above.

* SL services should only be an option once it has been determined that further neurorehabilitation is no longer showing gains and the emphasis focuses on stability and prevention of decline.

continued next page
eral functional skills (e.g., safe ambulation, problem-solving, compensatory memory strategies, effective interpersonal communication, self-care, and money management) to help prepare patients to return home and resume productive pre-vocational or vocational activities. Though patients are medically stable, a medical director, most often a physiatrist, oversees most of these programs. Services commonly include physical, occupational, and speech therapy, and often psychological counseling (Lewis & Horn, 2013). Treatment focuses on functional return and effective compensatory strategies. Though research indicates that participation in these programs within 3-6 months of injury results in the greatest gains, patients typically enter PHCN six months to one year post-injury, (Hayden et al., 2013; Lewis & Horn, 2013).

Need for PHCN is well-established. In a study of nine PHCN programs, Johnston & Lewis (1991) found that 73% of individuals required day and night supervision and could not be left alone. Similarly Lewis & Horn (2013) found that over 60% of 285 TBI adults at this level of care experienced debilitating problems with basic cognitive skills such as problem-solving, self-awareness, memory, initiation, and attention/concentration.

Effectiveness of PHCN is also well-established. Cope and colleagues (1991) found that 77% of their patients required attendant care at admission, and only 23% required attendant care at one year after discharge. In a comprehensive review of outcomes, Malec & Brasford (1996) observed return to work rates as high as 50% one year post-discharge from PHCN programs. Hayden et al. (2013) studied the outcomes of 1274 patients admitted to PHCN with 5 days per week, 6 hours per day of multidisciplinary intervention. Sixty-nine percent of their sample demonstrated significant functional improvement at the conclusion of treatment. Improvement was greatest for those admitted within three months of injury, but even those admitted five years post injury showed statistically significant clinical improvement. Similar results were found by Lewis & Horn (2013) indicating that a multidisciplinary program providing individualized

77% of PHCN patients required attendant care at admission; only 23% did at one year after discharge.

continued next page
care results in better outcomes (reduced dis-
ability) independent of how soon it begins
post-injury.

IV. Neurobehavioral Intense Programs

Persons with significant behavioral dyscontrol
after TBI require intensive neurobehavioral
rehabilitation from a skilled clinical team, be-
cause the most severe kinds of behaviors can
result in potential danger to self and/or oth-
ers. Behavioral dyscontrol includes:

- Poor impulse control
- Explosive outbursts
- Poor planning and judgment
- Limited or poor self-awareness
- Verbal and physical aggression

Neurobehavioral Intensive (NBI) programs use
applied behavior analysis extensively, to iden-
tify triggers that elicit aggression and, to the
extent possible, eliminate or substantially re-
duce their effect. Staff are proficient in crisis
prevention intervention and de-escalation
techniques. A physician prescribes and over-
sees mood stabilizing medication, and coun-
selors and behavior analysts teach patients to
replace maladaptive behaviors with prosocial
ones.

NBI programming teaches patients how to
use skills in context, using community outings
and productive activities, rather than only tra-
ditional therapies; the physical environment
plays an important role in treatment. These
programs are typically in rural settings or in a
campus model. Residence design maximizes
safety and allows space for reducing stimula-
tion and social complexity simultaneously.
Large open areas create a better line of sight
for nonintrusive supervision. The environment
also has features to control potential for dan-
gers (e.g., few wall fixtures or decorations that
could be missiles).

Some NBI programming is in secured settings
due to patients’ increased risk of elopement,
impulsive behavior, and impaired decision-
making. The short-term goal is to stabilize pa-
tient behavior with repeated learning trials so
that patients can move to less restrictive,
functionally-based setting. The long-term goal
is for patients to achieve socially appropriate
behavior and skills so they can return home or
live in the community with minimal to no su-
 pervision. These patients tend to have been
injured longer than the typical neurorehabili-
tation patients, with time between onset of
injury to admission often averaging over five
years (Lewis & Horn, 2014).

In one of the earliest studies of NBI program
effectiveness, Eames & Wood (1985) ob-
erved that 66% of their participants achieved
behavioral stabilization good enough to allow
discharge to less restrictive treatment set-
tings. In a multicenter study of NBI outcomes,
Worthington and colleagues (2006) reported significant gains in social functioning and reduction in supervision levels that were maintained 18 months post-discharge. Lewis & Horn (2014) studied 70 neurobehavioral patients with moderate to severe symptoms of behavioral dyscontrol. After comprehensive inpatient post-hospital rehabilitation, they achieved statistically significant disability reduction ($p<.01$) in multiple cognitive, behavioral, and functional skills. This was particularly remarkable since they were chronically impaired, averaging 8.3 years post injury at the time of study entry. This study was consistent in showing that time to rehabilitation was not a significant factor in reducing disability.

V. Comprehensive Day Treatment

Comprehensive Day Treatment (CDT) programs offer structured educational activities and therapies from 4-6 hours per day, 3-5 days per week. The multidisciplinary team includes psychologists or mental health counselors, and physical, occupational, and speech therapists. A case manager coordinates treatment and interacts with payers to avoid interruptions in care, allowing seamless transition from more intensive levels of care. Patients typically live at home with family, in supported individual apartments, or in supported living facilities. Patients do not require 24 hour supervision. Treatment builds upon the same functional community reentry activities as in residential rehabilitation. At this point, treatment is largely aimed at improving cognitive skills: initiation, attention, concentration, self-awareness, problem solving, and organization. Higher levels of these skills promote greater home and community safety and vocational success.

Malec & Brasford (1996) reviewed 9 separate CDT outcome studies. They found return to work rates, including part-time, one year after completing CDT programs averaged 60% to 80%. Horn & Lewis (2013) evaluated the outcomes of 12 CDT programs across the United States using the Mayo Portland Adaptability Inventory-4 (MPAI-4). Their data showed statistically significant improvement in MPAI-4 T-scores for Abilities (cogni-

continued next page
tive and physical skills), Adjustment (behavioral and adjustment skills) and Participation (residential and community skills). These improvements were achieved with an average time of onset of injury to program admission of almost 3 years.

VI. Home and Community Programs
These newer additions to the post-hospital continuum provide services that begin in the patient's home but may follow them to work, shopping, or recreational settings. This model is particularly useful for patients who have difficulty transferring the skills they learned in a treatment facility to home, community, and work. These programs teach transition skills using an individualized selection of skilled treatments including PT, OT, SP, cognitive services, behavior analysis, vocational services, and paraprofessional skills for 3-10 hours per week.

Altman et al. (2010) evaluated outcomes of 489 patients averaging 4 months of service within seven post-acute, home and community programs. Using the Mayo Portland Adaptability Inventory-4 (see page 672, Ed.) significant improvement was noted from admission to discharge, even for patients injured longer than one year. Further study is needed, but this model provides an innovative approach to transition individuals to their homes gradually. Cost is based on fee for service.

VII. Supported Living Programs
There is a growing trend toward NBI patients entering Supported Living (SL) programs after stabilization in neurobehavioral programs. More SL programs are adding behavioral management services to maintain positive prosocial behaviors and mitigate periodic behavioral outbursts. Supported Living programs do not typically provide active restorative rehabilitation services unless there is a specific need, e.g., PT, OT, SLP, or counseling. Their focus is threefold:

- Provide a safe living environment
- Maintain the patient’s health and prevent decline by addressing daily health needs
- Involve patients in multiple recreational, leisure, and prevocational activities to improve quality of life

These programs are usually located in the community in shared housing or apartments. Health focus promotes cognitive and physical exercise and challenge.

There are few published studies of their program outcomes. Horn & Lewis (2013) used the MPAI-4 to study outcomes of 70 patients in multiple post-hospital programs, and found that SL patients with an average length of stay of over five years were able to maintain their health and achieve functional gains from admission to discharge.
Cost of the continuum of care
Costs for the programs described above can range from $19,300 per day in critical care (Russo and Steiner, 2007) to $2,350 per day for inpatient rehabilitation (HCUP, 2006). These estimates may vary widely due to unanticipated needs which may arise. Although there have been no systematic studies addressing average post-hospital costs, ranges can be estimated from available data.

Inpatient hospital rehabilitation care averages $2,350 per day, while long-term acute care (LTAC) hospitals/facilities is approximately $1,318 per day. It is reasonable to consider that post-hospital care would begin at either the same cost or lower than for inpatient hospital rehabilitation, and then decrease as the patient’s need for services decreases.

Allocating resources as indicated by clinical needs is important for medical, rehabilitation, and behavioral stability, thus affecting total projected costs. As noted by the Brain Injury Foundation (2007) costs to manage brain injury decrease over time if a proper individualized program continually adjusts with patient status changes. The table below presents a worksheet for clinical cost estimation within post-hospital community rehabilitative care. Relative values (fees) for the services listed can be estimated from sources such as the www.cms.gov for professionals. Other services provided may vary based on each facility. (Table 2)

For example, the cost to care for a neurobehaviorally-intense individual requiring 24-hour 1:1 supervision may be the same or

<table>
<thead>
<tr>
<th>Provision of Service</th>
<th>Cost estimation based on hours per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supervision</td>
<td># hours of direct supervision provided daily x rate</td>
</tr>
<tr>
<td>Medical services</td>
<td># hours of physician, nursing, examination(s) x rate</td>
</tr>
<tr>
<td>Medications</td>
<td>Cost of each (brand vs. generic); daily administration cost</td>
</tr>
<tr>
<td>Rehabilitation services (service x rate = cost)</td>
<td>Physical therapy, occupational therapy, speech therapy, recreation therapy, psychology/counseling, behavior management</td>
</tr>
<tr>
<td>Ancillary services</td>
<td>Community skills and transportation x hourly rate</td>
</tr>
<tr>
<td>Administrative services and overhead</td>
<td>Case management; program director x hourly rate</td>
</tr>
<tr>
<td></td>
<td>Overhead (based on individual facilities)</td>
</tr>
</tbody>
</table>

Table 2 Proposed worksheet, clinical cost estimator

continued next page
similar to cost for a neurorehabilitation individual using a full spectrum of rehabilitation therapy services. The neurorehabilitation case requires more medical and therapeutic services; the NBI case requires more resources for supervision, safety, and behavior management. (Figure 1)

Post-hospital programs involve longer length of time due to the complex needs in this population. Lewis & Horn (2013) reported wide variability with lengths of stay within moderate to severe neurorehabilitation and neurobehavioral samples. Mild brain injury (80% of all injuries) are less costly since they typically do not require facility-based supervision. Services for mild brain injuries are often provided through day treatment, home and community, and/or outpatient programs.

Conclusions
Approximately 5.3 million Americans must live with significant TBI-related disability that precludes return to an independent and productive life. Most TBI treatment currently occurs within a hospital system. Although these therapies stabilize patient condition and improve function as natural recovery progresses, many survivors leave the hospital system needing physical assistance and supervision for their safety. Fortunately, there are now many post-hospital rehabilitative services available to help improve their quality of life.

Significant evidence shows that systematic post-hospital care reduces disability while enhancing independence and productivity, making return to competitive employment possible for some individuals following moderate to severe injury. The most encouraging finding is the emphasis on continuum of care, which, when properly managed, may reduce cost and complications over time.

Traumatic brain injury is a chronic condition best addressed by a flexible system to provide care at any time following injury. Inpatient hos-

Figure 1 Example of allocation of clinical resources for neurobehavioral and neurorehabilitation care

Allocation of Resources = Cost

<table>
<thead>
<tr>
<th>Behavior/psychology Services</th>
<th>Rehabilitation Therapy Services</th>
<th>Medical Services</th>
<th>Team Conferences</th>
<th>Case Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60%</td>
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<td>50%</td>
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</table>

Program Type
- NBI
- PHCN

continued next page
Hospital care may last 15-30 days, with the majority of persons needing additional therapy and 24-hour supervision post discharge. However, for less daily cost, an average of 6 months post-hospital care with 24-hour supervision, therapy, and community integration services may make it possible for them to return home with significantly less supervision. Costs decrease with decreasing level of care as the need for supervision decreases.

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Life care planning is a phrase coined in the mid-1970s by an educational consultant, Paul Deutsch EdD, intended to describe a process to project medical costs for ligation purposes. Registered nurses (RN) expanded their practice to include life care planning and in 1997 the American Association of Nurse Life Care Planning (AANLCP®) was founded by Kelly Lance, MSN, APRN, FNP-C, CNLCP, LNCP-C (Sambucini [Chapter 1], 2013). Since then the Association and certification board has grown considerably, and in 2008 a separate non-profit entity became known as the Certified Nurse Life Care Planner (CNLCP®) Certification Board.

Nurse life care planning is a specialty practice in which an RN uses the nursing process as the foundation for assessing, planning, identifying, implementing and evaluating the medical and other needs of an individual. The RN develops a dynamic document that outlines with reasonable certainty the future healthcare needs of an individual along with the associated costs and frequencies of goods and services necessary to promote quality of life and a safe environment (AANLCP®, 2008). The CNLCP® Certification Board is responsible for the validity of the certification examination as well as ongoing supervision for recertification and quality assurance of nurse life care planners.

Colleen Manzetti, Barbara Bate, and April Pettengill are members of the Certified Nurse Life Care Planner Certification Board. Their biographical information can be found in Contributors to this Issue on page 644.
**Background**

A role delineation study is a tool used to promote content validity of a certification examination by conducting a practice analysis. This results define the tasks of a particular job as well as the knowledge and skill required to perform them competently, and is supported by logical and empirical validity. It allows a testing entity to base test blueprint on best practices using psychometric standards (ABSNC, 2014).

In 2012, the CNLCP® Certification Board launched a role delineation study to ensure that the certification examination continues to be a valid assessment of the knowledge, tasks, and skills required by a nurse life care planner for safe and effective practice. The role delineation study was a joint effort conducted by the Certified Nurse Life Care Planner (CNLCP®) Certification Board, and members of the American Association of Nurse Life Care Planners (AANLCP®) with the assistance of the Professional Testing Corporation (PTC, 2013). The survey was concluded on December 13, 2012.

Members of the role delineation task force included the following registered nurses: April Pettengill, Glenda Evans-Shaw, Mona Yudkoff, Jan Roughan, Janice Skiljo Haris, Jacqueline Morris, Anne Sambucini, Chris Daniel, Jan Klosterman, and Linda G. Dierking. Penelope Caragonne, PhD was asked to participate based on her past experience in developing role delineation studies.

The role delineation study supports the mission of the Certified Nurse Life Care Planner (CNLCP®) Certification Board by identifying and quantifying the necessary knowledge, tasks, and skills needed in today’s practice environment. Consistent with the Certification Board’s mission and the requirement for accreditation through the Accreditation Board for Specialty Nursing Certification (ABNSC), the certification process validates nurse life care planner qualifications through professional education programs, experience in the specialty, and examination. This study data describe current practice in several ways:

(a) Geographic areas of practice throughout the United States
(b) Highest level of education, types of certification and licensure
(c) Age and years of experience
(d) Practice setting including frequency distribution of plans between defense and plaintiff and venues for expert testimony
(e) Patient assessment
(f) Collaboration with others
(g) Life care plan development
(h) Cost research
(i) Life care plan report construction

*continued next page*
(j) Professional activities
(k) Knowledge area rating

This study is a critical component to update and maintain the certification examination and educational requirement process that ensures competency for the specialty practice of nurse life care planning.

**Methodology**

This was the first time a Certified Nurse Life Care Planner (CNLCP®) Certification Board had performed a role delineation study using a psychometrician. The role delineation task force developed the survey in 2012. It consisted of 136 task statements, 16 knowledge areas, and 15 demographic questions. The survey was formatted and administered electronically. AANLCP® members accessed the tool through embedded links in direct email invitation, websites, online boards, or newsletters. To facilitate national participation, the Certified Nurse Life Care Planner (CNLCP®) Certification Board encouraged members to share the link with other nurse life care planners who were not members of AANLCP®. The survey included an introduction and instructions. The tool asked respondents to evaluate the frequency and importance of each task and knowledge statement using a four-point Likert scale. Respondents had an opportunity to enter comments including any tasks that they normally performed that were not addressed in the survey. Professional Testing Corporation (PTC) tabulated, analyzed and summarized the returns and distributed the results to the CNLCP® Certification Board in April 2013.

**Demographic Information**

Overall, 133 respondents (n=133) completed the survey. Ninety-nine percent (n=132) of the respondents identified themselves as Registered Nurses. Using the exclusion criterion requiring any participant to be a Registered Nurse Life Care Planner the data are from 132 respondents (n=132). Not all respondents completed every item.

Thirty-six states were represented in the survey (n= 120) with California having the highest participation rate (n=16, 12%) (Figure 1). Most respondents were currently performing life care plans (n=124, 93.2%) with 36.8% (n=49) completing fewer than 10 life care plans per year on average (Figure 2). The pediatric population represented less than a quarter of all life care plans reportedly performed (PTC, 2013).

Most respondents (n=107) indicated that they are self-employed, in private practice, with 65.4% (n=87) identifying themselves as practice owners. Thirty-nine percent reported their highest degree of education as a baccalaureate degree (BSN) (Figure 3). Only 8.3% (n=11)

continued next page
of the respondents reported that they held no certifications. The average time practicing in the field of life care planning was identified as six to ten years by 33.1% (n=44) of the respondents. The average age of the practitioner was between 50-59 years by 54.9% (n=73) of the respondents. The average number of hours required to complete a Life Care Plan was 26-50 hours (n=66) (PTC, 2013) (Figure 4).

**Task Analysis**
The role delineation survey included 136 tasks divided into six major sections:

- Patient Assessment
- Collaboration with Others
- Life Care Plan Development
- Cost Research
- Life Care Plan Report Construction
- Professional Activities

A four-point Likert scale was used to determine the frequency of performance and how important the task is for competent performance. The scale was slightly modified for Frequency versus Importance.

Frequency Ratings asked the respondent how often the task was performed as part of the job:

- 4 = Regularly
- 3 = Frequently
- 2 = Occasionally
- 1 = Never

The Importance Rating asked the respondent how important is this task for competent performance:

- 4 = Extremely
- 3 = Moderately
- 2 = Slightly
- 1 = Not

The instructions asked respondents to focus specifically on each task as it relates to the day-to-day performance of their jobs. In all cases, respondents rated the importance of the tasks the same as or higher than how often they performed the task. Tasks respondents considered equally important to the frequency for which they are performed were found only in the Patient Assessment category (PTC, 2013). (Figure 5)

**Most Frequently Performed Tasks**
The tasks that are performed most frequently are those that rated higher than 3.5 for frequency of performance by the respondent. This analysis looked at how many highly-rated tasks were found in each section of the survey (PTC, 2013).

Eleven of 25 Patient Assessment tasks (44%) in Patient Assessment were rated high for frequency of performance (PTC, 2013). (Table 1)

Only four of 13 Collaboration with Others tasks (30.7%) were rated high for frequency of performance (PTC, 2013). (Table 2)
### Table 1

<table>
<thead>
<tr>
<th>Patient Assessment Tasks</th>
<th>Rated high for frequency of performance $&gt;3.5$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Document date of birth</td>
<td>4</td>
</tr>
<tr>
<td>Document date of injury/loss</td>
<td>4</td>
</tr>
<tr>
<td>Document current medications</td>
<td>4</td>
</tr>
<tr>
<td>Document gender</td>
<td>3.9</td>
</tr>
<tr>
<td>Document functional abilities pre/post incident</td>
<td>3.9</td>
</tr>
<tr>
<td>Document work/education status</td>
<td>3.8</td>
</tr>
<tr>
<td>Document current address</td>
<td>3.7</td>
</tr>
<tr>
<td>Document marital/relationship status</td>
<td>3.7</td>
</tr>
<tr>
<td>Document daily or routine schedule</td>
<td>3.7</td>
</tr>
<tr>
<td>Document social/environmental profile</td>
<td>3.7</td>
</tr>
<tr>
<td>Document family dynamics</td>
<td>3.6</td>
</tr>
</tbody>
</table>

---

**Figure 5**

Task Statement

Frequency & Importance

- Patient Assessment: 3.3, 3.3
- Collaboration with Others: 3.3, 3.5
- Life Care Plan Development: 3.4, 3.6
- Cost Research: 2.9, 3.1
- Life Care Plan Report Construction: 3.4, 3.5
- Professional Activities: 2.2, 3.3

- Section Average Frequency
- Average Importance
### Table 2

<table>
<thead>
<tr>
<th>Collaboration with Others Tasks</th>
<th>Rated high for frequency of performance &gt;3.5</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the absence of physician or medical provider input, rely upon medical records</td>
<td>3.9</td>
</tr>
<tr>
<td>Request information from treating physicians</td>
<td>3.8</td>
</tr>
<tr>
<td>In the absence of physician or medical provider input, rely upon professional education, training, and experience</td>
<td>3.8</td>
</tr>
<tr>
<td>In the absence of physician or medical provider input, rely upon provider and/or expert report</td>
<td>3.7</td>
</tr>
</tbody>
</table>

### Table 3

<table>
<thead>
<tr>
<th>Life Care Plan Development Tasks</th>
<th>Rated high for frequency of performance &gt;3.5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess need for medications (e.g., pain medications)</td>
<td>3.9</td>
</tr>
<tr>
<td>Review post morbid medical records</td>
<td>3.8</td>
</tr>
<tr>
<td>Assess need for medical care evaluations/services</td>
<td>3.8</td>
</tr>
<tr>
<td>Assess need for therapeutic evaluations/services</td>
<td>3.8</td>
</tr>
<tr>
<td>Assess need for diagnostic testing (e.g., medical labs, radiological studies, neuropsychological, etc.)</td>
<td>3.8</td>
</tr>
<tr>
<td>Assess need for wheelchair/mobility needs</td>
<td>3.8</td>
</tr>
<tr>
<td>Assess need for independent living ability</td>
<td>3.8</td>
</tr>
<tr>
<td>Assess need for home/attendant/facility care</td>
<td>3.8</td>
</tr>
<tr>
<td>Assess need for adaptive equipment</td>
<td>3.8</td>
</tr>
<tr>
<td>Assess need for therapeutic equipment</td>
<td>3.8</td>
</tr>
<tr>
<td>Assess need for orthotics and prosthetics (e.g., braces, ankle/foot orthotics)</td>
<td>3.8</td>
</tr>
<tr>
<td>Assess need for supplies (e.g., bowel/bladder supplies, oxygen, etc.)</td>
<td>3.8</td>
</tr>
<tr>
<td>Review expert reports</td>
<td>3.7</td>
</tr>
<tr>
<td>Assess need for assistive technology</td>
<td>3.7</td>
</tr>
<tr>
<td>Assess need for home furnishing and accessories (e.g., specialty bed, portable ramps, patient lifts)</td>
<td>3.7</td>
</tr>
<tr>
<td>Assess need for transportation (e.g., adapted/modified vehicle, etc.)</td>
<td>3.7</td>
</tr>
<tr>
<td>Assess the need for renovations for accessibility (e.g., widen doorways, installing wheelchair ramp, etc.)</td>
<td>3.7</td>
</tr>
<tr>
<td>Document pre-existing conditions utilizing a Medical Record Summary</td>
<td>3.6</td>
</tr>
<tr>
<td>Assess need for health, strength maintenance</td>
<td>3.6</td>
</tr>
<tr>
<td>Assess need for case management services</td>
<td>3.6</td>
</tr>
<tr>
<td>Assess need for architectural renovations (e.g., wheel-in shower, elevator, etc.)</td>
<td>3.6</td>
</tr>
</tbody>
</table>

*continued next page*
Twenty-one of 36 Life Care Plan Development tasks (58%) were rated as frequently performed (PTC, 2013). (Table 3)

Only three of 23 Cost Research tasks were rated as frequently performed (PTC, 2013). (Table 4)

Nineteen of 34 Life Care Plan Report Construction tasks (56%) were rated as frequently performed. Life Care Plan Report Construction was the second-highest-rated section for frequency of task performance (PTC, 2013). (Table 5)

The psychometrician determined that respondents used tasks scoring greater than 3.5 frequently in the practice of nurse life care planning. Not all professional activities tasks included in the survey met this criterion (> 3.5) for frequency of task performance (PTC, 2013). Those tasks not meeting the criterion included:

- Testifying at trial
- Arbitration
- Mediation
- Settlement conference
- Deposition

- Develop a rebuttal or comparison of opposing counsel’s life care plan expert’s report
- Assist in developing questions for deposition
- Assist in developing questions for cross examination

Tasks that fell between 2.5 and 3.5 are occasionally performed. These tasks included:

- Architectural Renovations (3.4)
- Potential complications (3.4)
- Summary of total lifetime costs (3.4)
- Cost resource list (3.3)
- Home furnishings / accessories (3.3)
- Recreational Needs (3.2)
- Nursing diagnosis (3.1)
- Vocational / Educational service (3.0)
- Articles / literature researched (3.0)
- Clinical practice guidelines (2.9)
- Collateral sources (2.5)

Tasks rated as least frequently performed (<2.5) included the following:

- Physical Assessment: Day in the Life video (1.8)
- Telephone contact only (2.2)
- Photographs of patient (2.2)
- Photographs of home environment (2.4)
- Photographs of equipment (2.4)

Collaboration with Others category rated only one out of 13 tasks identified in the survey as low for frequency of performance: At-

### Table 4

<table>
<thead>
<tr>
<th>Cost Research Tasks</th>
<th>Rated high for frequency of performance &gt;3.5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obtain costs for items and services in a Life Care Plan using provider/vendor contacts</td>
<td>3.7</td>
</tr>
<tr>
<td>Other considerations used in determining Life Care Plan cost: Geographic location</td>
<td>3.7</td>
</tr>
<tr>
<td>Obtain costs for items and services in a Life Care Plan using internet sources</td>
<td>3.6</td>
</tr>
</tbody>
</table>

continued next page
<table>
<thead>
<tr>
<th>Task Description</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Medications</td>
<td>3.9</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Future medical care (MD’s, etc.)</td>
<td>3.9</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Projected therapeutic modalities</td>
<td>3.8</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Durable medical equipment/replacement schedule</td>
<td>3.8</td>
</tr>
<tr>
<td>Include the following components in the Life Care Plan document/report: Narrative component regarding case data</td>
<td>3.8</td>
</tr>
<tr>
<td>Include the following components in the Life Care Plan document/report: List of medical providers/professionals consulted/source of recommendations</td>
<td>3.8</td>
</tr>
<tr>
<td>Include the following components in the Life Care Plan document/report: Medical diagnoses</td>
<td>3.8</td>
</tr>
<tr>
<td>Include the following components in the Life Care Plan document/report: Rationale/purpose for recommendations</td>
<td>3.8</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Projected evaluations</td>
<td>3.7</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Diagnostic/educational testing</td>
<td>3.7</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Mobility (wheelchair/scooter/accessories/maintenance)</td>
<td>3.7</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Aids for independent function</td>
<td>3.7</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Disposable medical supplies</td>
<td>3.7</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Home/facility care</td>
<td>3.7</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Transportation</td>
<td>3.7</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Orthotics/prosthetics</td>
<td>3.6</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Surgical intervention</td>
<td>3.6</td>
</tr>
<tr>
<td>Use standardized categories/tables to list the following recommendation in the Life Care Plan: Case management</td>
<td>3.6</td>
</tr>
<tr>
<td>Include the following components in the Life Care Plan document/report: Summary of total annual costs</td>
<td>3.6</td>
</tr>
</tbody>
</table>

Continued next page
tending independent medical examinations/evaluations (2.1) (PTC, 2013).

The Life Care Plan Development category respondents rated two of the tasks low (<2.5) in frequency of performance, requesting a physician to review without sign-off after completing a Life Care Plan (1.8) and requesting a physician to review with sign-off after completing a Life Care Plan (2.2) (PTC, 2013).

The Cost Research category respondents rated four tasks low (<2.5) in frequency of performance. These included:

- Obtaining costs for items and services in a Life Care Plan using national databases (without geographic adjustment) (2.2)
- Using worker’s compensation fee schedules (2.3)
- Using collateral resources (2.3)
- Using alternative payment sources such as cash pay, private insurance, and Medicaid (2.3).
- Other considerations used in determining life care plan cost included referral source request (2.3) and using Medicare guidelines (2.4) (PTC, 2013).

In the Life Care Plan Report Construction category only three of 34 tasks rated low (<2.5) for frequency of performance. These tasks included video of the patient (1.8), photographs (2.0), and Federal Rule 27 disclosure information (2.4) (PTC, 2013).

Most Important Performed Tasks
Data analysis identified the most important tasks for competent performance whether or not they are frequently performed. These tasks are rated higher than 3.5 (>3.5) for “highly important for competent performance” (PTC, 2013).

Patient Assessment
Respondents rated eleven of 25 tasks in this section highly important (>3.5) for competent performance in the profession. Nine are the same they rated high for performance frequency. These tasks include documenting:

- Functional abilities pre/post incident (4.0)
- Current medications (4.0)
- Date of birth (3.9)
- Date of injury/loss (3.9)
- Gender (3.7)
- Daily or routine schedule (3.7)
- Face to face contact (3.7)
- Home/environment evaluation (3.7)
- Marital/relationship status (3.6)
- Work/education status (3.6)
- Family dynamics (3.6)

Collaboration with Others
Respondents rated six of the tasks in this section high in importance (>3.5) for competent performance, although only four as high for frequency of performance. These tasks included:

- In the absence of physician or medical provider input, rely upon medical records (4.0)
• Request information from treating physicians (3.9)
• In the absence of physician or medical provider input, rely upon professional education, training, and experience (3.9)
• In the absence of physician or medical provider input, rely upon provider and/or expert report (3.8)
• Consult with experts/specialists for a case (3.7)
• In the absence of physician or medical provider input, rely upon clinical or published standard of care guidelines (3.7)

Life Care Plan Development
In this section, respondents rated 26 of the 36 tasks high for importance (>3.5) for competent performance, five more than were rated high for frequency. How to perform life care plan development tasks is clearly important, regardless of frequency. These tasks included assessing need for:
• Medical care evaluations/services (3.9)
• Therapeutic evaluations/services (3.9)
• Wheelchair/mobility needs (3.9)
• Independent living ability (3.9)
• Home/attendant/facility care (3.9)
• Adaptive equipment (3.9)
• Therapeutic equipment (3.9)
• Assistive technology (3.9)
• Home furnishings and accessories (e.g., specialty bed, portable ramps, patient lifts) (3.9)
• Medications (3.9)
• Supplies (e.g., bowel/bladder supplies, oxygen, etc.) (3.9)
• Diagnostic testing (e.g., medical labs, radiological studies, neuropsychological, etc.) (3.8)
• Orthotics and prosthetics (e.g., braces, ankle/foot orthotics) (3.8)
• Transportation (e.g., adapted/modified vehicle, etc.) (3.8)
• Renovations for accessibility (e.g., widen doorways, installing wheelchair ramp, etc.) (3.8)
• Health, strength maintenance (3.8)
• Architectural renovations (e.g., wheel-in shower, elevator, etc.) (3.8)
• Case management services (3.7)
• Nutritional education/support (e.g., weight loss/weight gain) (3.6)

In addition, tasks included:
• Reviewing pre-morbid medical records (3.6)
• Reviewing provider and/or expert depositions (3.6)
• Reviewing expert reports (3.8)
• Reviewing post-morbid medical records (3.9)
• Requesting missing records (3.7)
• Identifying pre-existing conditions utilizing a Medical Record Summary (3.6)
• Using medical experts and/or provider’s opinion for input regarding the content of a life care plan (3.6)

Cost Research
Respondents rated only four of the tasks in this section high for importance for competent performance (3.5>). These tasks included:
• Provider/vendor contact (3.8)
All but recent billing were rated high for performance frequency. The survey suggests that other tasks represented in this section are only moderately necessary for a competent life care planner to know how to perform (PTC, 2013).

**Life Care Plan Report Construction**

Respondents rated performing twenty-one of the tasks in this section competently as highly important (>3.5). These included using standardized categories/tables to list the following recommendations in the Life Care Plan:

- Orthotics/prosthetics (3.9)
- Durable medical equipment/replacement schedule (3.9)
- Aids for independent function (3.9)
- Disposable medical supplies (3.9)
- Medications (3.9)
- Future medical care (MDs, etc.) (3.9)
- Projected evaluations (3.8)
- Projected therapeutic modalities (3.8)
- Diagnostic/educational testing (3.8)
- Mobility (wheelchair/scooter/accessories/maintenance) (3.8)
- Home/facility care (3.8)
- Surgical intervention (3.8)
- Narrative component regarding case data (3.8)

**Knowledge Analysis**

The role delineation task force identified sixteen knowledge areas that a Certified Nurse Life Care Planner should understand. Respondents rated their importance to competent performance. Respondents identified all as essential for the majority of this category. Knowledge of anatomy and physiology was also required for most of the tasks listed in the Life Care Plan Report Construction section of the survey. Table 6 shows the average importance rating of each knowledge area, in descending order.

**Summary**

The 2012 role delineation study of Nurse Life Care Planners in the United States reflects a comprehensive description of the tasks and knowledge used by experienced nurse life care planners. The CNLCP® Certification Board will use these data to maintain the certification examination, including updating the

*continued next page*
test blueprint to reflect current practice and expanding the question data bank. The data will also guide educational preparation for entry into nurse life care planning practice. The study identifies the need to include other weighted components in the certification examination besides the basic six areas of:

- Life Care Planning (35%)
- Spinal Cord Injuries (15%)
- Burns and Amputations (10%)
- Acquired and Traumatic Brain Injuries (15%)
- Neonatal and Pediatric Injuries/Illnesses (15%)
- Chronic Pain (10%)

While the role delineation survey results confirmed the importance of each of these components to underlying individual assessment and the resulting Life Care Plan, the survey also identified that documentation development are the nurse life care planner’s most frequently performed tasks. Hence, we recommend adding a Life Care Plan Construction category to the test blueprint for the CNLCP® certification examination.

This study supports the mission of AANLCP®, which states the RN Nurse Life Care Planner assesses the individual, identifies problems, plans for appropriate interventions, provides for plan implementation, and evaluates the

<table>
<thead>
<tr>
<th>Knowledge Area</th>
<th>Importance Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life care planning process/methodology</td>
<td>4.0</td>
</tr>
<tr>
<td>Brain</td>
<td>4.0</td>
</tr>
<tr>
<td>Nursing process</td>
<td>3.9</td>
</tr>
<tr>
<td>Nursing scope of practice</td>
<td>3.9</td>
</tr>
<tr>
<td>Spine</td>
<td>3.9</td>
</tr>
<tr>
<td>Normal physiology of aging</td>
<td>3.9</td>
</tr>
<tr>
<td>Limb function</td>
<td>3.9</td>
</tr>
<tr>
<td>Integumentary (skin) systems</td>
<td>3.9</td>
</tr>
<tr>
<td>Body organs</td>
<td>3.9</td>
</tr>
<tr>
<td>Pain</td>
<td>3.9</td>
</tr>
<tr>
<td>Mental health</td>
<td>3.8</td>
</tr>
<tr>
<td>Growth and development</td>
<td>3.8</td>
</tr>
<tr>
<td>Expert witness qualifications</td>
<td>3.8</td>
</tr>
<tr>
<td>Venues in which life care planning is applicable</td>
<td>3.7</td>
</tr>
<tr>
<td>Expert witness rules/regulations</td>
<td>3.7</td>
</tr>
<tr>
<td>Nursing diagnoses</td>
<td>3.5</td>
</tr>
</tbody>
</table>

continued next page
plan using the nursing process (AANLCP®, Mission Statement, 2014).

References


Professional Testing Corporation (2013). Role Delineation Survey Results.


Show Them The Evidence

Evidenced-based practice begins with research.
If you write life care plans you already do research.
No fear! Lighten the load!
Strengthen the practice!

Together we can learn the scoop
share knowledge
build a body of evidence
by life care planners
for nurse life care planners

Participate:
email cmanzetti@aol.com
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
</table>
| 8:30 am - 5:00 pm | “CBIS Training and Certification Exam”  
This workshop, presented by Kim Gully, CBIST will help you prepare for the CBIS Certification Exam which will be administered on Monday, October 27th at 2:00 pm (following conference). Member cost is $350 which includes the training and the exam. Kim Gully, MS, CCC, CCM, CBIST |
| 8:30 am - 5:00 pm | “Writing a Quality Life Care Plan: A hands-on approach”  
This all-day class will be limited to 25 participants who will be walked through each stage of drafting a LCP - including assessment of the client, collaboration with providers, medical research, development of LCP recommendations, writing the plan, construction of cost tables, and costing methods. The teaching style will be a hands-on approach with case studies, samples, templates, resources, Q&A, and audience participation. Member cost is $250. Shelene Giles, MS, BSN, BA, RN, CRC, CNLCP, CLCP, MSCC, LNCC |
| 3:00 pm - 4:00 pm | “Test Question Writing Boot Camp”  
To meet criteria for Accreditation by the Board for Specialty Nursing Certification (ABSNC) we are constantly challenged to expand our CNLCP test question bank for certification testing. Attend the Test Question Writing Boot Camp at the 2014 AANLCP® Annual Conference and earn CEU’s for contributing to the test bank. Join us and be part of the challenge. NO CHARGE for this preconference session. Colleen Manzetti, DNP, CNLCP, CNE  
April Pettengill, RN, CRRN, CDMS, CNLCP, MSCC |
| 12:30 pm and 2:30 pm | Shepherd Center Tour  
Pre-registration required (Maximum participants - 10 for each session)  
No Charge |
| 6:30 pm - 8:00 pm | Welcome Reception |

continued next page
### General Session
#### Saturday 25th

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:30 am - 10:00 am</td>
<td>&quot;What's New with Nursing Diagnoses&quot;</td>
</tr>
<tr>
<td></td>
<td>The nursing diagnoses communicates the professional judgments that nurses make every day. Ms Herdman, CEO and Executive Director of NANDA International will discuss the new and deleted nursing diagnoses and how to write one.</td>
</tr>
<tr>
<td></td>
<td>T. Heather Herdman, PhD, RN, FNI</td>
</tr>
<tr>
<td></td>
<td>CEO/Executive Director</td>
</tr>
<tr>
<td></td>
<td>NANDA International Inc</td>
</tr>
<tr>
<td>10:00 am - 10:30 am</td>
<td>Break with Exhibitors</td>
</tr>
<tr>
<td>10:30 am - 12:30 pm</td>
<td>&quot;How Long Will They Live: Where do the numbers come from?&quot;</td>
</tr>
<tr>
<td></td>
<td>Our panel of experts will discuss the the challenge of determining life expectancy and rated age in catastrophic injury or illness cases.</td>
</tr>
<tr>
<td></td>
<td>Kevin Puckett, AALU, ACS</td>
</tr>
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<td></td>
<td>Elizabeth Arias, PhD</td>
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<td>Lead, Statistical Analysis and Research Team</td>
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<td></td>
<td>Centers for Disease Control and Prevention</td>
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<tr>
<td></td>
<td>Robert Shavelle, PhD, FAACPDM</td>
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<tr>
<td>12:30 pm - 1:30 pm</td>
<td>Lunch</td>
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<tr>
<td>1:30 pm - 4:30 pm</td>
<td>&quot;Chronic Traumatic Encephalopathy (CTE)&quot;</td>
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<td>What exactly goes on in the brains of people when they receive repeated blows to the head participating in sports or military service? Hear from an attorney, a physician and several former NFL players about this progressive and debilitating disease.</td>
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<td>John V. Hogan, JD</td>
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<td>Allen I. Levey, MD, PhD</td>
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<tr>
<td>5:00 pm - 6:15 pm</td>
<td>Membership Meeting</td>
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### General Session
#### Sunday 26th

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>8:00 am - 9:30 am</td>
<td>&quot;Using Culture and Language to Reduce Cost and Improve Outcomes&quot;</td>
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<td>Katrina Belen, PsyD, Clinical Neuropsychologist</td>
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<tr>
<td>9:30 am - 10:30 am</td>
<td>&quot;Sacral Neuromodulation for Bladder and Bowel Control&quot;</td>
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<td>Jenelle Foote, MD</td>
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<td>This presentation will include patent selection/criteria, outcomes, failure rate, new research and development, costs, and replacement time frames.</td>
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<td>10:30 am - 11:00 am</td>
<td>Break with Exhibitors</td>
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<tr>
<th>Time</th>
<th>Event</th>
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<tr>
<td>11:00 am - 12:30 pm</td>
<td>“Aging with a TBI”&lt;br&gt;Our distinguished panel will discuss the affects and consequences age has on TBI clients.&lt;br&gt;<strong>Rolf Gainer, PhD</strong>  CEO, Brookhaven Hospital&lt;br&gt;<strong>Thomas Novack, PhD</strong>, Program Director, UAB-TBIMS&lt;br&gt;Life Care Planner</td>
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<tr>
<td>12:30 pm - 1:30 pm</td>
<td>Lunch</td>
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<tr>
<td>1:30 pm - 3:00 pm</td>
<td>“Increasing Evidence Based Practice for Nurse Life Care Planning”&lt;br&gt;In nursing, implementing EBP creates new, state-of-the-science knowledge, summarized into best practice for nurse life care planners. EBP helps to promote the professional practice by a Registered Nurse facilitating a culture of consistent decision making. This important session will review EBP and research guidelines to support collaborative professional practice and decision making addressing the healthcare consumer needs.&lt;br&gt;<strong>Colleen Manzetti, DNP, CNLCP, CNE</strong></td>
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<td>3:30 pm - 5:00 pm</td>
<td>“Are You Prepared for Your Testimony?”&lt;br&gt;Proper planning is necessary to ensure a successful testimony. This panel of legal experts, including a seasoned CNLCP expert witness, will share their tips to navigating the process.&lt;br&gt;<strong>Kelley Simoneaux, JD</strong> &lt;br&gt;<strong>Mike Rosetti, JD</strong> &lt;br&gt;<strong>Victoria Powell, RN, CCM, LNCC, CNLCP, CLCP, MSCC, CEAS</strong></td>
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<td>Dinner and Silent Auction</td>
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<td><strong>General Session</strong>&lt;br&gt;<strong>Monday 27th</strong></td>
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<td>8:30 am - 1:00 pm</td>
<td>On our final day we will travel by bus to Shepherd Center where we will hear lectures on: 1) Long term rehabilitation needs for individuals with complex spinal cord injuries; 2) Utilization of Assistive technology and Augmentative Communication Devices for individuals with physical and cognitive impairments; and 3) Intimate relationships after a Spinal Cord Injury</td>
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<tr>
<td>2:00 pm - 3:00 pm</td>
<td><strong>Shepherd Center Tour</strong>&lt;br&gt;Pre-registration required (Maximum participants - 20)&lt;br&gt;No Charge</td>
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</table>
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

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

CNLCP® HANDBOOK & APPLICATIONS FOR CANDIDATES

Application by Exam: http://www.ptcny.com/PDF/CNLCP.pdf

Application by Reciprocity: http://www.ptcny.com/pdf/CNLCP-Reciprocity.pdf


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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.

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- Choose description length for codes
- Templates can be customized
- Dataflow between LCP, MSA, MCP
- Customize templates by injury for future files
- Set page breaks or change page orientation
- Customize Narrative headings or use default
- Create “options” in LCP, MSA or MCP
- Upload files into template
- Submitter cover letter for MSA
- Calculates “Seed” money
- MSA template for WC and Liability files
- Limited use “User” available for certain sections
- LCP Narrative Section
- LCP Tables Section
- Customize Cover Pages

- Customize Company Logo or Customer Logo
- Footer information
- Admin. section to assign users
- Group files by customer on “Dashboard”
- Custom Data Lists reduces data entry
- Screen lock on “non-usage” for security
- Calculates age
- Calculates life expectancy
- Inflation factor built into template tables
- Calculates tables
- Customize table headings
- Create custom text tables
- Tables Summary with inflation numbers
- End notes section
- Notes section
- LCP Supportive information reference page
- Default templates/tables
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- Select headings by division or customize
- Saves labor cost
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2009
IX.1 MSA
IX.2 SCI
IX.3 Preconference
IX.4 Amputation

2010
X.1 Pediatric LCP
X.2 Elder LCP
X.3 Preconference / Multitrauma
X.4 Tools for NLCP

2011
XI.1 Adaptive Technology
XI.2 Recreation and Voc in NLCP
XI.3 Preconference / Burns
XI.4 Chronic Pain

2012
XII.1 Coding and Costing
XII.2 Electrical Stimulation Technology
XII.3 Preconference / Brain Injury
XII.4 Veterans Administration

2013
XIII.1 LCP for Motor and Developmental Disorders
XIII.2 Ethical Topics in LCP
XIII.3 Preconference / Exemplars in NLCP
XIII.4 Home Modifications

2014
XIV.1 Technology Updates
XIV.2 LCP Across All Ages
XIV.3 Psych topics in LCP
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