Topics in Perinatal and Childhood NLCP
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I’ve just been enjoying the September issue of my state nursing association newsletter, noting information about continuing education and advanced degrees for nurses, and news items of legislative initiatives and awards. Since so much of NLCP involves writing, I can’t help looking at things with an editorial eye. I sent the following to their editor:

Dear Editor: I’d like to make a request, one editor to another, about the language we use to describe nursing and aspects of its practitioners. I’ve learned to look out for these in the work that I edit and produce; I’ve seen the effects of changing language on attitudes towards nurses and by nurses.

First, I’d like to call attention to the use of the word “fortunate,” as in, “I was fortunate to (get a position).” I’m sure that this nurse worked hard to earn that position. She—and we—should own that. Injecting an intimation that luck had something to do with achievement subtly diminishes it. I note that males rarely, if ever, use this language in self-description.

This word is also used in reports of awards for achievement or grants. Award-givers bestow their awards precisely because recipient individuals and groups earn them. See the difference between, “We are proud to have received this grant” and “I was fortunate to receive this award”?

Second is the good old “training,” as in, “…provided training in ….” This subtly harkens back to the old training schools of yore, where aspiring nurses were trained (as handmaidens?) by physicians to serve them. Nowadays, we teach new skills and ideas, we share evidence-based best practices, we educate nurses for enhanced roles. We don’t “train.”

Last, and to my mind the biggest challenge, is the imperative to lose the term “orders” in all care contexts, as in, “signing home care orders.” This is a vestigial organ, another leftover from the nineteenth-century military hospital model, useless in the modern corpus of healthcare writing. It should go without saying that a nurse is no longer an inferior in a hierarchy with the physician on top. So let’s do without saying anything that implies otherwise.

One of the ways I work on this is in my volunteer work on the MA Nurse Practice Advisory Panel. My current nursing practice is as a nurse life care planner and legal nurse consultant. While many of the advisories on which we are asked to opine are related to areas not in my clinical background, I make my contribution by editing for clarity and usage. Making “(doctor’s) order” go away in favor of “medical plan of care” and “provider’s prescription” both recognizes that many parts of the medical plan of care are prescribed by advanced nurse practitioners and subtly removes the assumption that nurses implementing parts of it are somehow subservient, less than collaborators. Every advisory I review leaves my desk with those alterations. They have been well-received.

These archaic usages are so deeply ingrained in the culture that it’s a challenge even to notice them. And like other subtle, culturally-embedded forms of discrimination, the more you see them for what they are, the easier they are to recognize and remediate. Fortunately, as nurse writers and editors, we can make a difference just as subtly and (I hope) as effectively.

All of us are in a position to change attitudes about nurses and their value by how we choose to do our writing. Do you reference “doctor’s orders” in your work? Think about it.

Wendie A. Howland

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Information for Authors

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

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

Art, Figures, Links
All photos, figures, and artwork should be in JPG or PDF format (JPG preferred for photos). Line art should have a minimum resolution of 1000 dpi, 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.

Editing and Permissions
The author must accompany the submission with written release from:
- Any recognizable identified facility for the use of name or image
- Any recognizable person in a photograph, for unrestricted use of the image
- Any copyright holder, for copyrighted materials including illustrations, photographs, tables, etc.

All authors must disclose any relationship with facilities, institutions, organizations, or companies mentioned in their work. All accepted manuscripts are subject to editing, which may involve only minor changes of grammar, punctuation, paragraphing, etc. However, some editing may involve condensing or restructuring the narrative. Authors will be notified of extensive editing. Authors will approve the final revision for submission. The author, not the Journal, is responsible for the views and conclusions of a published manuscript. Submit your article as an email attachment, with document title articlename.doc, e.g., wheelchairs.doc
All manuscripts published become the property of the Journal.

Manuscripts not published will be returned to the author. Queries may be addressed to the care of the Editor at: whowland@howlandhealthconsulting.com

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

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A Message from the President

It is hard to believe my year as AANLCP President is coming to a close. It has been a wonderful and very busy year, as my board member colleagues can attest. It has been my honor to serve alongside these wonderful ladies who have such a passion for our association. I am so very proud of AANLCP and the accomplishments we achieved as a team in supporting our very ambitious Strategic Plan. Thank you to the Executive Board members, committee chairpersons, committee members and volunteers for your hard work and dedication to our mission of achieving excellence in the practice of nurse life care planning.

Upon joining the Executive Board as President-elect and as I transitioned to President, AANLCP was actively engaged and working toward infrastructure development, determining strategies for association growth, continual assessment of current standards of operation, evaluating methods to streamline management duties and workload, and program development. I’m proud to share just a few of our exciting outcomes (Be sure to access our complete “Year in Review,” coming in February 2016, at Aanlcp.org--->resources--->members only --->member only documents--->year in review).

This year we launched our first Mastermind Series, a year-long education series to support life care planners starting, operating, and growing a successful life care planning practice. I am excited that this series will be continued in 2016, even expanded with some new topics. This year we also successfully launched Crash Cart; an information, data, and resource-sharing repository. My pet project this year has been the creation of StudentTrack, an access and discount program specifically targeted at life care planning students that supports continual growth in the life care planning industry.

This year we also made strides in membership. For 2015 we surpassed our Premier membership goal with an astounding 105% increase in Premier memberships over the previous year. This tells us that our members enjoy the member benefits we have to offer and have found them valuable in their practice. We are now looking at adding more valuable resources. In addition, we had an 18% growth in overall membership revenue, especially helpful in a year without a conference.

While serving as President I have had the privilege of representing AANLCP at CMSA, ISLCP, NALA, and The Summit, meeting many nurses from a variety of backgrounds and fields. Through our active participation in professional meetings, AANLCP stays connected with the larger nursing community while spreading the word about nurse life care planning and our mission.

AANLCP has begun strategic planning for a three-year strategic and financial plan, starting in 2016. The goal is to fine-tune the many projects we started in 2015 to create a better experience for our members. We have opened up multiple lines of communication with our members using email campaigns, the AANLCP e-news (blog), our membership survey, members-only documents including our monthly Executive Board meeting minutes, and social media on LinkedIn and Facebook. Check out what your association is doing for you and give us feedback on what you like, what you don’t like, and how we can improve.

While this experience as President of AANLCP has kept me plenty busy it has definitely been a labor of love. Thank you for the opportunity to serve. I will still continue to cheer on each nurse life care planner working in this rewarding field. The future of AANLCP and nurse life care planning is in our hands. I urge each and every one of you to become involved. We have service opportunities lasting only an hour and others for a year or more. Even if you only give a little, many hands make light work, the sum of efforts produces growth and practice excellence, and volunteering is far more rewarding than you can imagine!

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President, AANLCP
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Coming!
Summer 2018

Core Curriculum for Nurse Life Care Planning
2nd edition

To contribute, contact
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801-274-1184
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("Autism spectrum disorder: current trends") is the owner and clinical director of a large private practice for pediatric communication and feeding disorders near Charleston, SC. Her career has focused on autism spectrum disorders (ASD), which she finds enormously rewarding on a daily basis. In addition to clinical treatment, Sally lectures on the sequelae of autism to professional groups, and works with families to develop life care plans.

PATRICIA BROCK
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("Service Dogs for Autistic Children") has been a nurse for thirty years. She began her nursing career as an Associate Degree nurse and after two years of med/surg nursing, she worked exclusively in critical care. In 2004, she left the bedside temporarily to obtain her certifications and grow her business, HTI Legal Nurse Consulting and Life Care Planning. She is an active member of the Orlando chapter of the American Association of Legal Nurse Consultants and frequently testifies as a nursing SOC expert. Ms. Brock is a clinical nurse educator for Daytona State College.

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to this Issue

Husted Life Care Planning, Inc. She has more than 25 years’ experience in rehabilitation, disability management, case management, medical cost projections, and life care planning. As a rehabilitation specialist and nurse case manager, Ms. Husted developed cost-effective case management interventions on high dollar claims for Fortune 500 Companies as well as life care plans and disability assessments from pediatric to geriatric.

She has extensive experience in catastrophic claims involving head injury, spinal cord injury, burns, amputations, multiple trauma, and chronic pain including 18 years of acute care experience in neuro-intensive care, medical surgical nursing, operating room and recovery room. Nine of the 18 years involved work in labor and delivery culminating in the role of clinical nurse specialist in maternal child health.

JANA PRESSLER
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(“Neuro-Optometry, Hidden Visual Problems and Life Care Planning”) has a private practice near Boston limited to the diagnosis of neurological vision problems and treatment with vision rehabilitation. She presents courses in the USA and abroad about acquired brain injury, vision rehabilitation, and working with special needs children. She is a physician mentor for the MIT Health Technology course, teaches the COVD Acquired Brain Injury course and is an instructor for the Neuro Optometric Vision Rehabilitation Curriculum II program.
YOUR INTERNATIONAL LIFE CARE PLANNING EXPERIENCES WANTED

- Have you ever written life care plan incorporating considerations due to:
  - Cultural differences
  - Religious beliefs
  - Spiritual customs
  - Caretaking customs
  - Social customs about the elderly
  - Beliefs about disabilities
  - Differences in pain perception and behaviors
  - Differences in communication
  - Differences in health care practices, providers, or maintenance
  - Different financial resources abroad
- How did these work out? What would you do differently? Why?
- Have you ever done a home assessment for a life care plan considering cultural differences?
- What is the single most important difference to respect when providing LCP services to a person from a different culture?
- What source of information should you review before interviewing a person from a different culture?
- How can you determine you have broken an unknown standard when interviewing a new client internationally?

The JNLCP is planning an issue on life care planning with an international flavor for Fall 2016. We’ll have some article from LCPrs in other lands, and would also like to include your insights on cultural aspects of care anywhere. Please send your experiences, good and bad, examples, opinions, and advice on any of these for a Round Table discussion to the Editor at whowland@howlancareconsulting.com. Anonymity guaranteed if you prefer, and don’t worry about formatting!

On September 25, 2015, a group of life care planners and prosthetists gathered at BiOM’s facility in Bedford MA outside Boston for the second annual day of education on personal bionics in lower extremity prostheses and related topics. Attendees enjoyed a series of videos, discussions, Q&A sessions, experiences, and networking on this very timely topic. Everyone took home a packet and thumb drive with all the slides, handouts, and resources, too. Don’t miss out next year; plan to join us on Friday, September 23, 2016. Mark your calendar!
In preparation for our Annual Educational Conference in 2016 we asked our speakers to share something about themselves that readers may not know. Below are just some of the responses we received. Please be sure to catch our speakers in action at our conference.

WHITNEY CHAPMAN
Becoming a physical therapist was an early calling for me. As a child, I was fortunate enough to volunteer my services with Special Olympics, in-school services for children with intellectual disabilities, and at local hospitals and my church for people with disabilities. All of these experiences helped foster the attitude of service I have, particularly for people with physical challenges who need to interact in their communities. Once in college, I majored in kinesiology with emphasis on the pre-medical track for preparation for physical therapy school. After completing student observations and clinical affiliations in various inpatient and acute settings for people with acquired brain injuries, I found a special interest in understanding and making a difference in the lives of those who experienced various neurological disorders.

DAWN COOK
I entered the field of life care planning after a career-ending illness. I was a very happy and satisfied hospital nurse, enjoying the 12 hour shifts and skiing at least 40 days a year in the Eastern Sierras. Then, in 2011, shortly after enrolling in a life care planning course, I came down with a viral infection in my inner ear with severe vertigo. I was taking the life care planning course at the urging of a nurse-friend who said that I should have an alternative to 12 hour shifts. Boy, was she right!

I was in bed with vertigo for 6 months and couldn’t drive for a year. In 2012, I passed the life care planning course and became certified, all while using my laptop in bed, hoping that I might get well enough to walk without a cane or at least be able to sit long enough to testify. When I got my first cases in 2012, my husband had to drive me to interviews and home visits. In 2013 I could drive for up to 30 minutes so I could do some of my own driving to home visits and I could stand or walk for about 2 hours before I was overwhelmed by sound and movement.

Before 2011, I did not know about nursing jobs that could be done at home. I am grateful that I was guided to a career where I could be productive and continue the great work of nursing despite my illness. My vertigo is my ever-present companion but it is less troubling every year. I can now drive for 3 or 4 hours and I can sit through a 6-hour deposition without flaking out. I have written many life care plans and I have testified many times. I never imagined that I would be doing this kind of work, but I am very grateful that the right person came into my life at the right time. It is an honor and a privilege to work as a nurse life care planner and I truly believe that when one door is closed, another one will open. My advice is to be receptive for your OWN opportunities!

SHELENE GILES
Specializing in Nurse Life Care Planning can be envisioned as growing a garden. How beautiful and tenacious is your garden? That will depend on the quality elements and sweat equity you’ve invested in it.

A thriving garden does not happen by chance or occur swiftly. As in gardening, there is much learning, planting, fertilizing/watering, nurturing, and pruning in Nurse Life Care Planning. Choose your seeds (learning) wisely, invest in rich fertilizer and purified water (AANLCP), and schedule your nurturing and pruning (AANLCP) faithfully to ensure a beautiful bloom. And, be prepared to get your hands into the soil while planting. You’re learning will be enriched and the end result will be a flourishing garden.

Afterwards, you can relax with a manicure & pedicure on your ideal vacation. Mine is a tropical island with luxury amenities (running water, hot water, AC/heat, comfy bed & pillows, prepared meals, onsite spa, infinity pool, & tropical views), no creepy crawling things, no cell phone or Wi-Fi reception, no traffic, and no kids (including mine). My ideal vacation spot would be a time for relaxation, rest, reflection, and rejuvenation – don’t forget the manicure & pedicure!

MICHELE L. TEJADA, AUD, PASC
I became an audiologist by accident. I was a music major and when I decided that was not for me, I took “Introduction to Speech and Hearing Sciences” because speech-language pathologist came up first on an interest test that I had taken. When I took the required audiology course, I realized that hearing was more interesting. I had already applied for graduate school in Speech-Language Pathology but was able to switch to Audiology and even received funding. I knew then that I was meant to be an audiologist.

I wish I knew at age 21 that I don’t need to pretend to be someone that I am not. When I finally learned to accept myself as I am, life became much less stressful and more fun.

GENE A. TREVINO
I entered this business by default. When I graduated the economy was in the toilet and I could not find a job. So I started my own business doing what I learned in school – valuing businesses. Working with attorneys asked me if I could value lost earnings in injury and death cases. That was over 25 years ago. Over time I eventually became an expert in this field.

I find the intellectual challenge most interesting in this field. I am constantly learning new things and improving on the skills I already have. As long as I am growing, I will never get bored or burnt out.

I want to see all the great places we have in American such as the Florida Keys, New York City, and other great attraction here at home.

I would encourage a young person entering this field to commit themselves to learn all they can and find a mentor to teach them what is not in a book or article. New entrants in this filed are fortunate that there are book and journals available. Twenty-five years ago there was very little written in the field on economic damages in personal injury.

When I was 21 I wish I knew that the Bible is the truth. My secret power is my faith in the finished works of Jesus Christ.
ADVOCACY ON TRIAL:
ARE THE NURSE LIFE CARE PLANNER’S ROLES OF ADVOCATE AND EXPERT WITNESS IN CONFLICT?

SARAH SCHOFIELD MSN-COM RN
MELINDA HUNTINGTON-FRAZIER MSN-COM RN

KEY WORDS:
Advocacy, attorney, expert witness, testimony, registered nurse

Abstract
Nurses are ethically obligated by professional licensure to advocate. Registered nurses (RNs) are often used in litigation as expert witnesses (EWs). EWs are specifically instructed not to advocate for the client (party) regarding whom they have been asked to give expert opinions. Therefore, an RN acting as an EW appears to have conflicting requirements on advocacy.

Introduction
We conducted a literature review on “advocacy” and “advocate” in nursing and law and compared the findings. Although instructions from each profession regarding advocacy differ, we found that duties of RN advocacy are not in conflict with legal obligations for EWs. The ethical obligations of the RN to advocate for the client complement the court’s requirement for objectivity. Registered Nurses (RNs) are often used in the litigation process to act as expert witnesses (EWs) when medical issues are involved in, or are the subject of, litigation, e.g., in worker’s compensation, personal injury, or medical malpractice. Registered nurse life care planners (NLCPs) may serve as EWs in these cases.

For example: A male patient in an acute care facility develops an infected pressure ulcer, necessitating amputation of the affected foot. An RN may be retained by counsel to act as an EW in the resulting malpractice case. A NLCP would provide testimony relating to the amount and extent of lifetime care/support this individual would need after lower extremity amputation, with...
associated costs. After a thorough nursing assessment of the individual, his environment, and his history, the NLCP would then make recommendations for:
- medical treatment
- diagnostics
- therapies
- durable medical equipment
- nursing care
- attendant care
- environmental controls
- environmental remodeling (home modification, etc.)
- medications
- care management

RN scope of practice does not include opining on claim validity, injury causation (with some exceptions), or responsibility for damages. The American Nurses Association (ANA) considers advocacy to be a fundamental role of nursing practice. Therefore, all RNs, regardless of specialty, have a professional and ethical obligation to advocate for patients (ANA, 2015).

All EWs are required to practice at the highest level of applicable professional scope and standards, including ethical conduct (Phillips & Stark, 2013). For nursing, this would encompass practicing as a patient advocate, regardless of specialty. Furthermore, the EW is expected to be unbiased and objective, never arguing for the purpose or benefit of the retaining party; rather, their opinions must be based on facts that are appropriately applied to the case (Federal Rules of Evidence, 2015). Advocacy by the EW is highly frowned upon by the courts as the legal field considers it to indicate bias.

Therefore, a nurse acting in the dual roles of RN and EW appear to have conflicting instructions regarding advocacy. This confusion may inappropriately lead NLCPs and other RN-EWs to feel as though they must surrender their nurse advocate role to fulfill expectations set forth by the court. In this article we seek to expand the understanding of advocacy and to clarify how a registered nurse can be an advocate while acting as an impartial expert witness.

**Literature Review**

We conducted a literature review on advocacy and advocate in the fields of law and nursing to gain a better understanding of advocacy and to identify differences between the nursing and legal definitions. The Oxford Dictionary was used to define the general meaning of both advocate (2015b) and advocacy (2015b). We reviewed nursing literature pertaining to RN scope of practice, RN-EWs, and NLCPs for information relating to the role of the advocate and/or the practice of advocacy. We identified characteristics, behaviors, actions, and dynamics of the advocating RN. The ANA Scope and Standards of Nursing Practice (2015) defines both advocate and advocacy for the profession of nursing. Black's Law Dictionary defines advocate (2015a) and advocacy (2015a) for the legal professions. We also reviewed legal literature pertaining to EW practice requirements, EW adversarial bias, EW advocacy, medical EWs, RN-EWs, and NLCPs.

We then compared how nursing and law interpret the role, context, and dynamics of acting as an advocate and the practice of advocacy.

We found that when advocate or advocacy is used to describe a professional practice or role, the general definition is adjusted to fit within the context and scope of that profession (see Table 1). We found no literature that explored this difference of perspectives. This information led us to identify practices within the RN advocacy role that did not conflict with EW role expectations regarding legal advocacy and objectivity.

**Definitions**

**General**

The Oxford Dictionary describes an advocate (2015b) as 1) “a person who publicly supports or recommends a particular cause or policy” 2) “a person who pleads on someone else’s behalf”. Advocacy (2015b) is defined as 1) “public support for or recommendation of a particular cause or policy; 2) “the profession or work of a legal advocate.” Not all dictionaries made this critical distinction.

**Advocacy for Registered Nurses Versus Attorneys**

Table 1 compares these definitions, who can advocate, the professional obligations of an advocate, who is being advocated for, the desired outcomes of advocacy, and who benefits from the advocacy as they differ for registered nurses and attorneys.

The ANA (2015) defines nursing as “the protection, promotion, and optimization of
of health and abilities, prevention of illness and injury, facilitation of healing, alleviation of suffering through diagnosis and treatment of human response, and advocacy in the care of individuals, families, groups, communities, and populations.” Advocacy is used to define nursing and nurses are defined as the advocate.

Black’s Legal Dictionary defines an advocate (2015a) as “one who assists, defends, or pleads, for another; one who renders legal advice and pleads the cause of another before a court. A person learned in the law, and duly admitted to practice, who assists his client with advice, and pleads for him in open court...” This describes the attorney or legal advocate.

The Expert Witness

Courts have used EWs since 1786 to provide objective opinions relevant to the legal case (Rix, 1999). An EW provides expert evidence, in the form of opinion testimony, to aid the court in a decision or judgment. The testimony or statements of the expert’s opinion is based on training and experience in a professional or scientific subject (Expert Evidence, 2015). The EW’s opinions should be based on professional expertise rather than investment in a particular legal party or legal outcome. In application, expectations of EW objectivity are not always met; EWs are prone to many forms of adversarial bias, as seen in Table 2 (Feola & Alcorn, 2009). EWs are specifically instructed not to advocate for the client/party by whom they have been asked to give their opinion. For this reason, EWs testify under a legal oath whereby they agree to abstain from advocacy, bias, and partisanship. Courtroom accusations of advocacy by the EW can carry heavy consequences. The EW who is found to demonstrate any form of adversarial bias, including advocacy, risks being disqualified from testifying, and related work product and testimony are subject to being excluded. EW testimony is expected to be reliable, accurate, and relevant, and to provide a truthful analysis of the data (Federal Rules of Evidence, 2015).

The Registered Nurse as an Expert Witness

US courts have used RNs as EWs since the 1970s (Salmond, 1986). The first RN-EWs were used in medico-legal cases to provide opinions and testimony regarding nursing malpractice, discussing standards of care and breaches in nursing practice standards (Salmond, 1986). In 2009, the RN-EW’s scope of practice broadened to include determination of the cause or mechanism of an injury or illness in some cases (Phillips & Stark, 2015). See Table 3 for reasons an attorney may contract an RN to act in the role of EW.

The American Association for Nurse Life Care Planners (AANLCP) recognizes NLCPs as advocates for the patient in the Core Curriculum for Nurse Life Care Planning (2013). Ideally, when the litigation process is over, the patient receives the means to implement the Life Care Plan (LCP) provisions. In this scenario, the LCP serves as an advocacy tool. NLCPs advocate for interventions that protect the patient’s safety, maintain health, prevent medical complications, and help manage the patient’s condition over a lifetime.

The LCP enables the patient to understand and advocate for the provision of care outlined in the personalized care plan, a detailed list of everything the RN recommends for the patient. In this way, the LCP is applied nursing advocacy. The LCP helps the patient to understand what care is needed, what management strategies are best evidence-based practice, what to expect with disability, and how to prioritize financial allocations to optimize health.

Although the LCP itself is a tool for advocacy, NLCPs themselves act as advocates for both the client and greater health care system during its development. The AANLCP notes that NLCPs advocate for the delivery of dignified and humane care by all members of the care team, social and environmental responsibility, community

<table>
<thead>
<tr>
<th>Deliberate advocacy</th>
<th>Expert intentionally or knowingly tailors the evidence to support the clients arguments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unconscious partisanship</td>
<td>Unintentional, and usually results from situational factors or biases that caused the expert to provide evidence to advocate for clients positions</td>
</tr>
<tr>
<td>Selection bias</td>
<td>Trial lawyers selects persons as their witnesses whose views are known or presumed to support their case</td>
</tr>
<tr>
<td>Hindsight bias/outcome bias</td>
<td>The tendency of an expert equipped with knowledge of an outcome to overstate his or her ability to predict in the inevitability of the outcome</td>
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</table>

Table 2. Types of legal adversarial bias. (Feola and Alcorn, 2009)
engagement, access to high-quality and equitable health care to maximize health outcomes, the minimization of health disparities between groups, and the judicious and appropriate use of products in healthcare (AANLCP, 2015). NLCPs are uniquely concerned with these principles, in contrast to other life care planners, due to their RN obligations regarding advocacy independent of retaining party.

A NLCP may be asked to review a LCP submitted by opposing counsel, and to provide opinions, recommendations, and suggested changes to that document. When reviewing, the NLCP may find the current plan includes unnecessary procedures that could cause harm to the client. In this scenario, the NLCP may demonstrate advocacy by recommending these procedures be removed from the plan of care for client safety and to avoid unnecessary burden to the health care system. In their stead, the NLCP may advocate for providing items not previously considered or removing those that are not evidence-based or effective. All revisions should be based upon the RN's best nursing judgment for that patient; to do otherwise would be to participate in legal advocacy.

In litigation, the NLCP is typically retained by a lawyer who pays for EW services. This financial arrangement has been one of the major ways for adversarial bias to color EW testimony by disreputable EWs and attorneys (Feola & Alcorn, 2009). An EW with adversarial bias works for the retaining party rather than the person in question. Ethically, there can be no financial arrangements between the EW and the lawyer in exchange for supporting findings in the best interest of the hiring attorney (Feola & Alcorn, 2009). This also means the EW cannot ethically be engaged on a contingency basis, e.g., being paid only if the retaining counsel prevails.

### Discussion

#### Dichotomy of Interpretation and Application

Advocacy has multiple definitions in the literature. The Oxford Dictionary definition provides two; nursing uses the first, while the legal system uses the second. Not all dictionaries appreciate the difference.

Both RNs and lawyers have the terms advocate and advocacy in their professional job definitions, and both professions advocate. However, one field's interpretation and application of advocacy can be unrecognizable to the other. The most important differences in the literature are that in law, advocacy implies adversarial bias and partisanship. For nursing, advocacy implies objectivity, nonpartisanship, and commitment to the client's health.

In law, advocacy involves supporting one side in a two-sided legal battle. The advocate is one who supports a legal cause and works in a capacity to further efforts in support of that cause. In contrast, for nurses, including nurses serving as EWs in the legal field, advocacy involves taking action to support what is in the best health interest of an individual, regardless of the two-sided legal battle involved.

The NLCP always works for the patient without regard to who retained her to contribute her expertise, whether the plaintiff or defense counsel. The NLCP needs to make it clear, to all concerned, that the LCP work product would be the same in either case.

### Advocacy Obligations in Conflict

It would be against both the ANA (2015) Scope and Standards of Practice and the ANA (2010) Code of Ethics for an RN to use a professional nursing title and license to participate in legal advocacy in lieu of nursing advocacy. For the NLCP, this is also a violation in the AANLCP (2013) Code of Conduct and EW expectations. It is outside the scope of practice of the RN and against professional ethics to advocate in the legal sense of the word. It is not within the RN’s scope of practice to practice law. Note, however, that RNs working in salaried in-house jobs for law firms do use their nursing expertise in an advisory capacity to support legal advocacy; this practice is not in conflict with the Code of Ethics. They also cannot provide EW opinions in testimony.

EWs are asked to practice to the highest level of their professional scope and standards/code of conduct. For an RN acting as an NLCP, this includes being a patient advocate by practicing behaviors that demonstrate advocacy. It would also be unethical for an RN to refrain from advocating for the best health interests of the patient when asked to provide her expert nursing opinions for care recommendations.

Nursing advocacy does not compromise the two-party objectivity expected of the EW. Furthermore, requirements regarding objectivity in findings and an unbiased practice are already addressed in nursing professional standards for nursing practice regardless of EW role requirements (ANA, 2015).

For example, when an RN performs a nursing assessment of a patient and concludes that the patient is
overestimating condition severity, acting in an untruthful manner, or should be evaluated for conversion or somatization disorder, the RN must advocate for the best interest of the patient. It may be in the patient’s best interest to withhold the provision of unnecessary medical interventions that also pose a danger to this patient. This may not benefit the client’s legal cause; however, the NLCP does not consider this. The RN would instead recommend to retaining counsel, and testify if required, that the patient requires psychological evaluation with interventions as indicated.

Conclusion
This article clarified that RNs and attorneys engage in two different forms of advocacy. RN advocacy is not the same as legal advocacy, even when applied in litigation. It is possible for an RN to advocate within nursing professional expectations while simultaneously not exhibiting bias as an EW.

Although superficially it appears instructions from each profession regarding advocacy conflict, this is not the case. Rather, the RNs ethical obligations to advocate for the patient are complementary to the court’s requirement for objectivity. All RN-EWs are advocates when they make care recommendations. The NLCP is required to provide objective services, opinions, work products, recommendations, and testimony. Demonstrating nursing advocacy does not conflict with these requirements.

Terms such as “working for the plaintiff” or “I’m on defense,” used between EW life care planners themselves, seriously undermine their true role in a legal case. These terms, among others, understandably and reasonably perpetuates the mistaken belief that the NLCPs are being legal advocates, when in reality they are acting as RN advocates.

Nurses and others should mindfully use different words to describe the NLCP’s role in a legal proceeding. A NLCP should never be considered to be working for the plaintiff or defense; the NLCP works for the patient in discussion. The NLCP should self-describe as retained by the plaintiff or defense. The NLCP’s words should be clear to all concerned that LCP work product would be unchanged regardless of retaining client.

RNIs are well-positioned and prepared to act as EWs. As nurses, they can focus on health outcomes by providing an objective opinion for their patients’ health interests. NLCPs should embrace the position of advocacy for patients and explain to the court exactly how their objective, impartial, and unbiased stance epitomizes expert witnessing.

REFERENCES
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BIRTH INJURIES
KNOWLEDGE, KNOWLEDGE GAPS, AND PLANNING FOR THE FUTURE

JANA L. PRESSLER, PhD RN

Abstract
This article provides a brief overview of birth injuries and how knowledge of injuries might affect ongoing planning for caregiving, health care, and further research. It describes selected birth injuries with information on what is known regarding short- and long-term sequelae. It also identifies areas needing clarification and further exploration. The author offers an explanation regarding potential barriers to uncovering pertinent information surrounding birth injuries, and suggests recommendations for prioritizing where to begin to address knowledge gaps relevant to birth injuries and outcomes from these injuries.

Introduction
Childbirth tends to be a joyous occasion, especially after the process of labor and delivery is completed for the mother and her newborn or newborns are deemed healthy and injury-free. Yet events can occur in the perinatal period that result in injuries to the fetus and newborn and lead to long-lasting problems and less healthy outcomes. It is useful to review birth injuries to develop an understanding of what they entail should they occur.

Definition of Birth Injuries
Birth injury to the fetus is typically thought of in terms of injuries grouped around the central nervous system, muscles, and bones. Birth injury antecedents are many, varied, and complex. Timing of what, where, why, when, and how birth injury occurred is difficult and at times nearly impossible to determine precisely. Birth injuries can never be 100% prevented. They require careful diagnostic consideration by caregivers and restorative efforts in order to maximally preserve newborn integrity and well-being. Further, birth injuries contribute significantly to increased neonatal morbidity and mortality.

In this article, the terms birth trauma and birth injury are synonymous, and defined as injury occurring as a result of, and/or in relationship to, labor, delivery, or both. Birth asphyxia, intrauterine asphyxia, and fetal hypoxia are treated and categorized...
as distinctively different conditions from birth injury and will not be included as birth injuries in this article per se.

Some authors reserve birth trauma exclusively for newborn injuries resulting from a mechanical problem during labor and/or delivery, and use birth injury for injuries resulting from intrauterine asphyxia or fetal hypoxia during labor and/or delivery (Demissie, Rhoads, Smulian, et al., 2004). Because the multitude of possible birth injuries would require a small textbook to discuss, this article only reviews select birth injuries (birth trauma) that originate from mechanical injury.

**KNOWN RISKS.** Birth injury can result from umbilical cord abnormalities (e.g., a short cord reducing fetal movement or a long cord entangling the fetus). Yet frequently birth injury is associated with abnormal fetal presentations and their complications, particularly breech presentation (e.g., frank, complete, and footling), and difficult presentations (such as face, brow, and compound) that sometimes require vacuum extractor and/or forceps for vaginal delivery. Asynclitism (with the fetus' head presenting first but tilted to the shoulder) (Asynclitism, 2015) and no longer in line with the birth canal (Types of forceps used in deliveries, 2015) or shoulder dystocia are known to be a major risks for birth injury.

**TRANSIENT RISKS.** While currently unknown, there also may be risks associated with even transient or superficial indicators of birth injury. Since transient indications of birth injury might not always be as easily detected or diagnosed as injuries, underlying morbidities and risks remain uncertain. Such injuries will not be covered in this article.

**Where, Why, When, and How Injuries Occur**

Where. During childbirth, there is always a chance that something will not go as planned and lead to some kind of birth injury. Approximately 2.9% of newborns born in the U.S. suffer some kind of major birth injury during the labor and delivery process (Mortality and burden of disease, 2002). Overall, the U.S. rate of birth injuries is much lower now than in previous decades because of improved prenatal ultrasonography and because cesarean delivery is used and preferred in certain circumstances (Healthy People 2010, 2001). Major birth injury is known to be more common in developing nations located in Africa, Asia, and Latin America (Mortality and burden of disease, 2002).

**WHY.** Birthing instrument use can be improved with simulations and manikins to train caregivers delivering newborns. Yet often birth injury results from misuse of instruments (vacuum extractor or forceps) or improper management or handling of a fetus during the second stage of labor or delivery (Birth Injury Guide, 2015). Birth injury occurs more often among newborns who are large-for-gestational age (LGA), particularly in macrosomic babies, over 4000 grams (8 lbs, 13 oz).

**WHEN.** With LGA fetuses, the size of the fetus may be known to be too large in relation to the mother's pelvis: cephalopelvic disproportion (CPD). When CPD occurs, it may lead to labor and delivery dystocia, causing fetal compression injuries while passing through the birth canal. Parts of the fetus's body can press firmly up against the mother's pelvis repeatedly during difficult deliveries (e.g., fetal head banging), as well as being compressed during rotation and descent. It is possible that neonates who experience longer head-to-body delivery intervals are the ones who suffer from permanent brachial plexus injury due to a longer wait time on the mother's perineum (Allen, Rosenbaum, Ghidini, Boggi, & Spong, 2002).

**HOW.** Delivering larger and heavier fetuses often requires care providers to use their hands or some sort of mechanical device, such as a vacuum extractor or forceps, to guide and ease the passage of the fetus through the birth canal. In deliveries requiring a high level of skill and delivery expertise, birth injuries to the newborn can occur if the care provider exerts too much physical force, or is not highly skilled plus extremely cautious when using the birthing instruments. Infants are more prone to experience birth injuries if the birth involves:

- abnormal fetal presentation (face) or abnormal position (e.g., breech)
- birth before the 37th week of pregnancy
- prolonged labor
- labor dystocia
- unusual maternal pelvic shape (Demissie et al., 2004)

**Major Types of Birth Injuries and Treatment**

Although there is overlap, with injuries falling into more than one category, major birth injuries generally can be grouped into five areas:

- fractures
- dislocations and subluxations
- neurologic damage
- hemorrhages
- tissue damage (Neonatal birth injuries, 2015; Alexander, Leveno, Hauth, et al., 2006; Alexander, Leveno, Rouse, et al., 2007)

Although a certain birth injury or injuries have healed, it's important to recognize that other accompanying problems might remain or develop at a later time. For example, bones affected by a skull fracture might appear to heal without issue. Yet the brain or other nerves injured as a consequence of the initial skull fracture can cause additional problems later.

**FRACTURES.** Examples of major birth injuries involving fractures include:

- fractured clavicle
- fractured femur
- skull fracture
- nasal septum deviation
- fractured humerus,
- orbital fracture
- mandibular fracture
- radial fractures

Fractures tend to result as a complication of fetal descent through the birth canal. They are seen with...
Fractures can be painful and lead to significant functional loss and potential disability. The amount of remaining bone growth provides the basis for fracture remodeling to an anatomic position. Because the greatest remodeling potential in bone occurs with infants, this offers them a great opportunity for successful healing (Behrman, Kliegman, & Jenson, 2007). Further, pediatric fractures tend to heal more quickly than adult fractures due to children having a thicker, more active periosteum (Calmar & Vinci, 2002).

The infant’s periosteum is extremely strong and thick, functioning well in reduction and maintenance of fracture alignment. Infant bone is significantly less dense and more porous, penetrated throughout by capillary channels. Infant bone has less elasticity, lower bending strength, and lower mineral content. The low bending strength puts more strain in an infant’s bone, with low elasticity allowing for greater energy absorption. Infant bone’s increased porosity prevents propagation of fractures, thereby decreasing the incidence of bone splintering into more than two pieces of comminuted fractures.

Nondisplaced newborn clavicular fractures tend to be managed nonoperatively (Staheli, 2015). Although clavicle fractures are relatively common, more likely to occur in the middle of the clavicle, and believed to usually heal regardless of the selected treatment, complications are possible. Clavicular fracture complications warrant careful attention of caregivers to these fractures from birth (Allman, 1967). The significance is not clear and the classification is not perfect, yet attempts have been made to devise a simplistic classification scheme for clavicle fractures. Allman created a well-known classification system in 1967, dividing the clavicle into thirds.

- Group I fractures: Middle third injuries (69-85%)
- Group II fractures: Distal third injuries (12-28%)
- Group III fractures: Medial (proximal) third injuries (3-6%) (Allman, 1967)

However, within this system of categorizing fractures, no mention is made of the time involved in healing, leading to questions concerning the healing process for such injuries to the clavicle.

Another aspect of fracture healing time is that rapid healing predisposes to refractures, another fracture occurring in the same bone. An infant who has experienced a fracture should have qualified followup to evaluate movement of the affected part, and any notable discrepancies or deformity from normal function or appearance. These are likely to be followed with radiographs (x-rays) or advanced imaging, such as a nuclear bone scan, CT, MRI, or PET scan.

DISLOCATIONS AND SUBLUXATIONS. Ligaments are flexible bands of fibrous tissue that connect bones and cartilage (Staheli, 2015). Ligaments bind the bones within a joint together, such as in the hip and shoulder joint. Extreme force on the ligaments within these joints can cause the ball of the bone to partially or completely pop out of the socket. This can occur when extreme force from descent through the birth canal affects a ligament. Examples of major birth injuries involving dislocations and subluxations include:

- subluxation of the shoulder
- nasal septum dislocation
- subluxation of the cervical spine
- dislocated hip
- dislocated knee
- dislocated elbow

When dislocation occurs, the infant experiences severe pain in the affected area upon movement, and difficulty using or moving the injured part normally (Staheli, 2015).

The most common dislocation birth injury is the shoulder (Sudesh, Rangdal, Bali, Kumar, Gahlot, & Patel, 2010). When shoulder dislocation occurs, the infant has severe pain upon upper body movement (Staheli, 2015). There might be swelling in the injured area and deformity of the dislocated area as well; dislocation is diagnosed by x-ray. Dislocations require immediate medical attention that includes either a sling, splint, traction, or cast; possibly medication for pain; surgery; activity restrictions; and/or PT (El-Adl, Elgohary, & Elshennawy, 2014).

Decisions made concerning treatment will involve the infant’s postconceptual age and overall health, dislocation extent and type, the infant’s likely ability to tolerate special therapies, and the care provider’s expectations for the course of the dislocation (El-Adl et al.,...
It is important that the infant’s family adhere to the activity restrictions and/or strengthening rehabilitative PT programs ordered to promote healing and prevent re-injury to the affected area.

Subluxation is sometimes confused with a dislocation; in subluxation, nerves become stretched or twisted, disrupting function.

Anterior subluxation often occurs when the fetus’s arm is outstretched and is forced backwards (Woodring & Lee, 1992). In shoulder subluxation, the humeral head slips out of the glenoid cavity as a result of weakness in the rotator cuff, or in response to a blow to the shoulder area. Notably, the humeral head pops back into its socket.

During the pushing stage of labor during childbirth, the fetus’s cervical spine can be pushed out of natural alignment and injured as the fetus is compressed and descends through the mother’s birth canal (Asynclitism, 2015). Use of a vacuum extractor or forceps can forcefully extend the neonate’s head such that the infant’s vertebrae are pulled out of alignment (Asynclitism, 2015). During a vaginal birth, damage to the fetus can be more severe if the delivery is difficult. Subluxation of the cervical spine can lead to immediate respiratory depression.

The main problem with shoulder subluxation is glenohumeral joint instability. Normal anatomy of this joint permits a large range of movement, but this comes at the price of decreased stability. Shoulder subluxation can lead to soft tissue damage, because traction damage can occur due to gravitational pull and a weak shoulder offers poor protection.

Traditionally supportive devices, in the form of slings or braces, have been used to manage shoulder subluxation in adults. The aim of supportive devices is to support the weight of the arm, thus preventing/minimizing the inferior pull on the humerus and reducing the stretch on the joint capsule. However, a Cochrane Review in 2009 concluded that there is insufficient evidence to conclude whether supportive devices are beneficial (Kaplan, 1995). Parents and caregivers need to be taught why and how to position the affected limb so that the weight of the arm is supported. Judicious passive or active assisted exercises might be started within 24 hours post-delivery with the goal of maintaining shoulder range of motion (Greenfield & Geist, 2011; Magee, 2014).

NEUROLOGIC DAMAGE. Neurologic damage is dependent on the severity and spinal level of the injury. Examples of major birth injuries involving neurologic damage include:

- brachial plexus palsies
- facial nerve injury or palsy
- laryngeal nerve injury
- phrenic nerve injury
- spinal cord injury
- cervical spinal cord injury
- abducens nerve injury
- cerebellar contusions
- spinal cord transection
- hypoglossal nerve injury
- cerebral contusion
- epidural hematoma
- glenohumeral deformity

Brachial plexus injuries are one of the most common neurologic birth injuries, followed by injury to the seventh pair of cranial nerves or facial nerve (Menticoglou, Perlman, & Manning, 1995). Brachial plexus palsy is a result of shoulder dystocia (Zuarez-Easton, Zafra, Garmi, Nachum, & Salim, 2015). There are no known ways to prevent or predict brachial plexus injuries per se (Benjamin, 2005). A favorable finding is that they tend to have a good prognosis, with the more severe injuries aided significantly by reconstructive microsurgery (Pondaag, Gert van Dijk, & Malessy, 2010; Pondaag & Malessy, 2006; Pondaag, Malessy, Van Dijk, & Thomeer, 2004). Brachial plexus injuries can be divided into high and total injuries, with injury to C5, C6, and C7 being high or upper, and total involving the roots from C5 to T1. Total brachial plexus palsy presents with arm paralysis and sometimes, a decreased pupil size, drooping eyelid, and decreased sweating on the affected side of the face (Alfonso, 2011). Brachial plexus injuries that occurred well before delivery might involve the affected arm, including atrophy of the hand and arm muscles, and the pectoralis major muscle, joint contractures, and bone demineralization (ACOG Task Force on Neonatal Brachial Plexus Palsy, April, 2014).

The body part that is presenting at delivery has a direct influence on the severity of the injury (Tada, Tsuyuquchi, & Kawai, 1984). For example, the outcome of severely high cervical lesions is poor. Lower injuries can result in significant morbidity with permanent neurologic
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disability. Although neurologic damage is typically diagnosed using an ultrasound, magnetic resonance imaging (MRI) offers better visualization of the spinal column and is the preferred radiographic test.

Controversy exists regarding management of brachial plexus palsy (Piatt, 2004). A period of PT and observation for signs of recovery is fairly common. Surgical intervention is recommended in cases where functional recovery does not commence within three to nine months. Neurosurgeons disagree on the utility and timing of surgery. One of the most advocated approaches is referring the infant to a neurology center having neurologists with expertise in brachial plexus palsy (Coroneos, Voineskos, Coroneos, et al., 2015; Hoeksma, ter Steeg, Nelissen, van Ouwerkerk, Lankhorst, & de Jong, 2004).

**HEMORRHAGES.** Hemorrhagic damage is dependent on the severity and spinal level of the injury. Examples of major birth injuries involving hemorrhage include:
- subdural hematoma
- intracranial hemorrhage
- retinal hemorrhage
- subgaleal hemorrhage
- adrenal hemorrhage
- hyphema

One significant and worrisome hemorrhage secondary to birth injury is the subgaleal hemorrhage (Chang, Peng, Kao, Hsu, Hung, & Chang, 2007). Subgaleal hemorrhage is frequently associated with instrumental delivery, with close to 30% of affected newborns not surviving, and others suffering from serious complications, such as epilepsy, severe hearing loss, cerebral palsy, and occasionally renal vein thrombosis. The important point about planning when a newborn is suspected as having experienced subgaleal hemorrhage is to monitor the infant closely and transfer the infant to a tertiary level intensive care unit as carefully and as soon as possible. These infants can experience hypotension and other conditions that lead to poor prognosis. If they survive, they likely will require pressors, blood transfusion, ventilatory support, and long term follow-up.

**TISSUE DAMAGE.** Tissue damage is dependent on the severity and spinal level of the injury. Examples of major birth injuries involving tissue damage include:
- ruptured spleen
- torticollis
- renal injury
- ruptured liver
- hematocoele
- corneal abscess
- Purtscher’s retinopathy
- Scalp hematoma with necrosis

Various interventions tailor-made to address the injury are needed depending on the specific tissues injured. Although tissue injuries can be severe at the time of birth, some infants who are affected can recover fully, depending on the injury and interventions available. For example, in a case of a newborn suffering splenic rupture due to birth trauma, a heterotopic splenic auto-transplantation was completed following a splenectomy (Yamataka, Fujwara, Tsuchioka, Kurosu, & Sunagawa, 1996). Follow-up at 7 years showed that the child was healthy, with no increased susceptibility to infections. But not all newborns’ ruptured spleens can be saved using surgical techniques.
Sequelae and restoring function

In general, birth-injured babies need a comprehensive approach managing long-term sequelae of birth injuries (Pillai, Vijayaraghavan, Kishore et al., 2011). Physical therapy (PT) is used to help aid infants experiencing brachial plexus injuries (BelloWS, BuceWSka, Verchere, 2015; Martinez-MorenO, Jimenez-MartIn, AInfonso-Barrera, Espinosa, & Miodovnik, 2013; Ho, Curtis, & Clarke, 2015), as well as fractures, dislocations and subluxations, and nerve injuries (Oktay, Comert, Gokkaya, Ozbudak, & Uysal, 2014). Occupational therapy (OT) can enhance an individual’s activities of daily living effectively by minimizing the effects of disease, injury, disability, or developmental delay (Opp, 2009). An infant or child’s “occupation” can include such things as play, learning, and activities of daily living. In treating birth injuries, OT is considered effective when the infant or child is able to be more independent or efficient in completing functional tasks. Caregivers can assist children having experienced brachial plexus palsy with home exercises (Rasmussen, Justice, Chang, Nelson, & Yang, 2013) and improving from language delays (Chang, Yang, Driver, & Nelson, 2014).

The Individuals with Disabilities Education Act (IDEA) (Education for All Handicapped Children Act of 1975; IDEA, 1997; IDEA, 1998; Katsiyannis, 2001) mandates that early intervention programs provide services in the natural environment and within naturally occurring routines and activities of the family’s day. According to IDEA, natural environments are those that are typical for the child’s peers who have no disabilities. OT practitioners work within the infant or child and family situation. Consultation with other health care providers concerning an infant or child’s situation is used to monitor how well an infant or child is progressing before OT services are discontinued. Direct OT services tend to be phased out over time based on how well the infant or child is progressing and meeting pre-established goals. Occupational therapists work with young infants in early intervention centers or with the infant’s family. Occupational therapists aim to support and encourage parents’ relationships with their infant or child and relationship-centered care delivery (Becerra, Fry, & Rowley, 1991; Felgen, 2004; Tresolini & the Pew-Fetzer Task Force, 1994). This is important to keep in mind for life care planning purposes.

After humerus or femur fractures, the neonatologist or pediatrician might prescribe PT to help the infant regain optimal function as soon as possible. It is likely that a physical therapist will meet with the infant and family prior to discharge or in a follow-up clinic to set up a PT plan. The infant might require a sling or splint to keep the affected area immobilized. The physical therapist will instruct the parents or primary caregivers how to apply and remove the sling. There might be a physician’s prescription for home physical therapy if the family is unable to come to a follow-up clinic. A PT could be involved in helping the infant regain range of motion, strength, flexibility, or motor function.

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After trauma during birth (Sherman, 1984).

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KEY WORDS:
Life care planning, neonatal encephalopathy, intrauterine hypoxia, birth asphyxia, hypoxic-ischemia, neonatal brain injury, cerebral palsy, epilepsy, cognitive impairment, developmental disorder, therapeutic hypothermia, neurologic outcome, long-term follow-up after neonatal encephalopathy, pediatric medical home, aging with cerebral palsy

Abstract:
With advances in prenatal and neonatal care, survival rates for infants with intrauterine hypoxia and birth asphyxia have risen dramatically. This article gives an overview of the current state of research for perinatal brain injury, neonatal encephalopathy (NE), and cerebral palsy, with findings of pertinent studies, reviews, and meta-analyses, with a focus on how research findings translate into life care plan considerations including aging with disability.

Introduction
In 1970, 13 percent of infant deaths were attributed to intrauterine hypoxia and birth asphyxia; and by 2007, only one percent of infant deaths was attributed to these conditions (Singh & van Dyck, 2010).

In 2003, the American College of Obstetricians & Gynecologists (ACOG)
and the American Academy of Pediatrics (AAP) published a task force report on neonatal encephalopathy and cerebral palsy. In 2014, the task force issued an executive summary renaming the report as Neonatal Encephalopathy and Neurologic Outcome (Executive Summary, 2014).

There are many prenatal and perinatal causes and predisposing risks for cerebral palsy (CP), not only hypoxia-ischemia, and other manifestations of brain injury besides CP. Symptoms in newborns range from mild to severe, depending on the nature and timing of the injury.

Neonatal encephalopathy (NE) has emerged as the preferred term for central nervous system dysfunction in the newborn period (Wu, 2015), without implying a specific underlying cause (Executive Summary, 2014; Wu, 2015).

According to the Executive Summary 2014, NE is a clinically defined syndrome of disturbed neurologic function in the earliest days of life in an infant born at or beyond 35 weeks of gestation, manifested by:
- subnormal level of consciousness
- seizures

Table 1. Infant Deaths and Mortality Rates per 100,000 Live Births for Selected (10) Leading Causes of Infant Death: United States, 2007 and 1970 (Singh and vanDyck, 2010)

<table>
<thead>
<tr>
<th>Cause</th>
<th>2007</th>
<th>2007 Rate</th>
<th>1970</th>
<th>1970 Rate</th>
<th>% Change in Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Causes</td>
<td>29,138</td>
<td>674.9</td>
<td>74,667</td>
<td>2001.1</td>
<td>-66.3</td>
</tr>
<tr>
<td>Congenital Malformations (Birth Defects)</td>
<td>5,785</td>
<td>124</td>
<td>11,259</td>
<td>301.7</td>
<td>-58.9</td>
</tr>
<tr>
<td>Short Gestation and Low Birth Weight</td>
<td>4,857</td>
<td>112.5</td>
<td>8,754</td>
<td>234.6</td>
<td>-52.0</td>
</tr>
<tr>
<td>Sudden Infant Death Syndrome (SIDS)</td>
<td>2,453</td>
<td>56.8</td>
<td>3,516</td>
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<td>Maternal Complications of Pregnancy</td>
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<td>4,914</td>
<td>131.7</td>
<td>-68.9</td>
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<td>Unintentional Injuries</td>
<td>1,285</td>
<td>29.8</td>
<td>2,294</td>
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<td>-51.5</td>
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<tr>
<td>Cord and Placental Complications</td>
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<td>26.3</td>
<td>2,736</td>
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<td>Respiratory Distress Syndrome (RDS)</td>
<td>820</td>
<td>19.0</td>
<td>9,763</td>
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<td>Intrauterine Hypoxia and Birth Asphyxia</td>
<td>344</td>
<td>8.1</td>
<td>9,438</td>
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<td>Pneumonia and Influenza</td>
<td>222</td>
<td>5.1</td>
<td>6,303</td>
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<td>All Other Causes</td>
<td>10,468</td>
<td>242.5</td>
<td>15,690</td>
<td>420.5</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>29,138</strong></td>
<td><strong>74,667</strong></td>
<td><strong>29,138</strong></td>
<td><strong>74,667</strong></td>
<td>-</td>
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</tbody>
</table>

No. of live births in 2007 = 4,317,119; no. of live births in 1970 = 3,731,386
The 1970 deaths from symptoms, signs, and ill-defined conditions are assumed to be SIDS Deaths.
RDS in 1970 combines deaths from RDS and Hyaline Membrane disease.
Neuroprotective therapy currently known (Wu, 2015). The pathophysiology of brain injury following hypoxia-ischemia is a cascade of events resulting from excitotoxic and oxidative injury, and culminating in cell death (Shankaran, 2012). According to Shankaran, hypothermia is protective by inhibiting various events in the injury cascade. The interval between the primary and secondary energy failures in NE, the latent phase, offers a therapeutic window for the use of hypothermia (Shankaran, 2012). Therapeutic hypothermia improves survival and reduces major neurodevelopmental disability outcomes at 18 months in neonatal asphyxia and/or NE (Wu, 2015). Treatment effectiveness is limited, however. A 2012 meta-analysis of the major trials of therapeutic hypothermia found that nearly half of all infants treated either died or had major neurodevelopmental disability at 18 months (Wu, 2015). According to McIntyre et al., only one in eight neonates meeting eligibility criteria for therapeutic hypothermia apparently benefits. Therefore, there is a need for additional neuroprotective therapies (Wu, 2015).

Long-Term Follow-Up
After hypoxic ischemic encephalopathy (HIE), problems are often detected at birth or during infancy; however, some problems may take years to detect (Robertson & Perlman, 2006). After newborn HIE diagnosis, timing to identify impairment is important, because early identification results in early treatment. Timelines for detection vary:
- severe motor or sensory losses are identified in the first year
- low developmental quotients are detected in the second year
- fine and gross motor impairments can be identified age 2 to 4
- abnormalities of cognitive function are detected age 4 to 7 years
- learning disabilities can be identified age 7 to 9 years (Robertson & Perlman, 2006)

According to Perez et al., neurodevelopmental outcome depends on the severity of HIE. Adverse
outcomes with mild HIE are rare, more common with moderate HIE, and always present with severe HIE. HIE is not limited to major disability outcomes, such as CP and/or severe cognitive impairment. HIE outcomes may also include:

- intellectual impairments
- specific memory problems
- verbal problems
- difficulties in executive function
- behavior difficulties
- difficulties in social competence (Perez et al., 2013)

The pattern of brain injury may be more predictive than the severity of lesions seen on neonatal cerebral MRI. The basal ganglia/thalamus brain injury pattern has been associated with the most severe motor and cognitive outcomes. The watershed-predominant brain injury pattern has been associated with cognitive impairments that frequently occur without functional motor deficits (Perez et al., 2013).

In a study by Perez et al., long-term developmental outcome after HIE for 68 children aged 8.2 to 15.7 years old who did not have a major disability, eleven had a major disability (CP or mental retardation). Even though the remaining 57 children were without major disability, they still had lower full-scale and performance IQ scores compared to the population norm and were at risk for long-term intellectual, verbal, and motor deficits.

Mandatory long-term follow-up is critical in children with HIE, even in the absence of major disability. These children can have cognitive delays in reading, spelling, and arithmetic. They can have impaired motor skills (adaptive gross and fine motor). Mild to moderate cognitive deficits may not manifest until the children are older. For children who are treated with therapeutic hypothermia, long-term follow-up is particularly important (de Vries & Jongmans, 2010; Perez et al., 2013).

**Mild NE**

Follow-up evaluations of term infants with mild NE show they have a high probability of being normal (Wu, 2015), with consistently positive long-term general cognitive functioning, educational achievement, neuropsychological functioning, and behavior (Handel et al., 2007). In one study, however, school-aged children with mild NE without CP had academic delays and were at increased risk of cognitive, behavioral, and memory problems (de Vries & Jongmans, 2010).

**Moderate NE**

The results of outcome studies for children with moderate NE are mixed (Handel et al., 2007; Wu, 2015). Although these children still score in the average range, they are significantly less intelligent than healthy peers and children with mild NE (Handel et al., 2007). Twenty to thirty five percent of term infants with moderate NE are at risk for neurologic sequelae. Permanent neurologic sequelae can range from mild, such as learning difficulties or attention deficit disorder, to more severe, such as CP, epilepsy, visual or hearing impairment, and severe cognitive and developmental disorders (Wu, 2015).
De Vries & Jongmans reported that a study by Robertson & Perlman of 5.5-to-8-year-olds after moderate NE showed marked delays in reading, spelling, and arithmetic. A study by Lindström et al. of 43 teenagers aged 15 to 19 with moderate NE found that eighty one percent had cognitive deficits with or without other impairments such as CP.

Handel et al. (2007) found increased rates of hyperactivity and autism in children with moderate NE, and recommended behavioral monitoring for all children.

Severe NE
Seventy-five percent of infants with severe NE are at risk of neonatal death, and those who survive have an almost universal risk of sequelae (Wu, 2015).

Handel et al. (2007) noted that outcomes in severe NE are consistently negative and include problems with:
- general cognitive functioning
- educational achievement
- neuropsychological functioning
- behavior
- motor disabilities
- mental retardation
- seizure disorders

Children with severe NE, according to Handel et al., are less intelligent and perform worse on neuropsychological testing and at school compared to healthy children and to children with both mild and moderate NE.

After a review of available studies, Handel et al. recommended:
- preschool assessment of general cognitive and adaptive behavioral functioning
- school age testing of achievement and neuropsychological screenings, in some cases
- standard behavioral screening for all children with NE, regardless of cognitive function.
- detailed neuropsychological assessment, especially for children with moderate NE

Permanent neurologic sequelae — CP, epilepsy, visual impairment, or severe cognitive and developmental disorders — can be severe and disabling. Although there is an increased risk of CP associated with NE, it is not inevitable; and in most cases, the cause is unknown (Wu, 2015).

Life Care Planning Recommendations and Considerations after NE
Building a life care plan for a child with a history of NE can be a major challenge. While the nursing process used in nurse life care planning provides the legs of a plan, collaboration is the backbone of any plan for a child with special needs. Life care plans for moderate to severe NE can be complex.

Depending on the number and severity of neurocognitive sequelae, numerous treating providers could be involved, such as:
- developmental pediatrician
- neurology
- ophthalmology
- otolaryngology
- gastroenterology
- physical medicine and rehabilitation
- neurosurgery
- endocrinology
- pulmonology
- physical, occupational, and speech therapists
- feeding specialist

Collaboration with the child and family is critical for success; no plan of care can succeed if it does not include their goals. If a day-in-the-life video has been or can be made, this is also helpful.

Medical, therapy, school, and billing records, and communication with all current treatment providers are irreplaceable for information on current and future treatment recommendations and the probability of secondary complications to ensure a thorough, comprehensive plan. Review of hospital and procedure records is also important. This is more easily done when there is direct access to treating providers.

If treating providers are not helpful or when contact is not possible, it is still important to have at least one medical expert involved; one experienced in long-term therapies and lifelong needs of the child is ideal. A medical expert focused on liability or life expectancy may not be suitable to provide long-term treatment recommendations. The more knowledgeable the treating physicians or experts are with lifetime medical and therapy options, the better supported the plan and the more protected the child.

Nurse life care planners function within their individual professional scope of practice when developing a plan (Sambucini, 2013). Specialty evaluations may be recommended singly or periodically as needed. For ongoing medical treatment recommendations, however, the plan requires medical foundation by treating physicians and/or medical experts. If guidelines are available, they can be considered.

Early Intervention, IEP, and the IDEA
Depending on age, the child could be receiving early intervention services (EI) up to age 3, special education preschool services before age 5 or special educational school services to age 21. The child may have had cognitive testing, adaptive assessments, or an Individualized Educational Program (IEP) developed. Life care planners would benefit from understanding two U. S. Federal laws: the Individuals with Disabilities Education Act (IDEA) and Office of Civil Rights (OCR) Rehabilitation Act of 1973, Section 504, when developing a pediatric plan (Cosby & Cosby, 2013). Parents, the life care planner, and the case manager who will be implementing life care plan provisions all need to have a good understanding of IEP essentials in order to advocate for the child’s unique needs. A helpful webinar is available at http://www.advocacycenter.com/iep-essentials (Arrington & McCarthy-Proulx)
Ongoing Multidisciplinary Evaluations
Evaluations should initiated early and continue over time so that timely interventions can be provided as deficits are identified. Care should be multidisciplinary and involve specialty evaluations to supplement screening by the treating pediatrician/primary care physician. Even a child without major disability can have impaired motor skills and cognitive deficits. Ongoing physical, occupational, and possibly speech therapy evaluations are recommended.

The initial IEP is developed before the child enters kindergarten and should be updated annually. Educational therapies provided by the school system may or may not suffice, and this should be determined early. Cognitive assessments are conducted by the school system only every three years.

Ongoing evaluations are supported by research studies on behavior problems and academic delays (even with mild NE), possible cognitive and motor deficits (with moderate NE even without major disability), and definite neurocognitive deficits with severe NE.

Neuropsychological Testing
Depending on the individual circumstances, neuropsychological testing may be needed one to three times before age 22. The neuropsychologist should provide the test results and specific recommendations for interventions to improve performance. A neuropsychological evaluation that only identifies deficits without providing possible interventions is not useful.

Academic Support
The child with NE may need extra academic support to keep up with peer grade level work. Academic support services can be built into an IEP for this. This is one area where the case manager or, depending on the life care planner’s preference, a special needs educational consultant can get involved and assist parents evaluate the annual IEP.

Behavior Evaluations
Behavioral assessments are recommended. Evaluating for the likelihood of behavior problems and their severity is important since behavior problems can affect the level of care required. If maladaptive behaviors are significant, an allowance for periodic behavioral therapy may be considered. Home care, residential facility care, and high levels of supervision can be three of the most costly components of a life care plan.

Case Management
Case management services are essential in nurse life care planning (AANLCP Nurse Life Care Planning Scope and Standards of Practice, 2014). These services are important to implement plan recommendations, provide ongoing care coordination, evaluate recommendation effectiveness, and provide needed interventions during care transitions. The case manager also serves as a resource and advocate, and works collaboratively with the child, parents, and treating providers along the care continuum (CMSA, 2008-2014; Giles et al., 2013). The amount of case management services recommended each year depends on the complexity of the child’s needs.

Ongoing review of the child’s evaluations and assessments will require annual case management and/or special needs educational consultant hours, particularly for moderate and severe NE. The case manager or special needs educational consultant may need to help parents work with the IEP team to ensure that the recommended IEP services are appropriate and sufficient. If additional support for the parents is needed, parents can be referred to the National Disability Rights Network and the Center for Parent Information and Resources.

Emergency Information Forms
Every family with a child with special needs would benefit from having an emergency information form (EIF). Children with NE are more likely than not to need emergency services and/or hospitalization at some point, especially those with moderate or severe NE. Children with special needs are more vulnerable to complications if their specific medical information is lacking during an emergency. In 2010, the AAP, the Committee of Pediatric Emergency Medicine, the Council on Clinical Information Technology, the American College of Emergency Physicians, and the Pediatric Emergency Medicine Committee developed this form (Emergency Information Forms, 2010). (Figure 3)

Now that electronic medical records are used, the EIF should be available for every child with special needs. During life care plan development, verify that parents have an up-to-date copy to share with caregivers and team members.

The Medical Home and Bright Futures
The AAP developed a model of delivering primary care called the “pediatric medical home,” defined as “a family-centered partnership within a community-based system that provides uninterrupted care with appropriate payment to support and sustain optimal health outcomes” (AAP Agenda for Children: Medical Home, 2015).

In 2007, the AAP, along with the American College of Physicians (ACP), the American Academy of Family Physicians (AAFP), and the American Osteopathic Association (AOA), jointly endorsed and issued a consensus statement on medical home principles (AAP Agenda for Children: Medical Home, 2015). This model of care is helpful for all children. It is particularly beneficial to children with special needs.

The National Committee for Quality Assurance (NCQA, http://www.ncqa.org/HomePage.aspx) developed a recognition program and national directory of providers of patient-centered medical homes (National Committee for Quality Assurance 2015). The directory is available at the
Figure 3. Emergency Information Form for Children with Special Health Care Needs (ACEP, AAP, 2010) www2.aap.org/advocacy/eif.doc
Our long history of success is based on our development of “real world” programs. Our clinical neuropsychologists integrate evidence-based treatment into individualized treatment plans. These professionals are part of our treatment team and regularly evaluate each patient’s progress and implement program changes as necessary.

**PATE’s therapy types include:**
- Physical Therapy
- Speech/Language Therapy
- Behavioral Therapy
- Animal-assisted Therapy Activities
- Biofeedback
- Occupational Therapy
- Cognitive Rehabilitation
- Vocational Rehabilitation
- Emotional/Psychological Adjustment
- Aquatic Therapy

**PATE’s results-oriented treatment programs include:**
- Community-based Therapy
- Post-acute Residential
- Supported-living Residential
- Post-acute Day Neuro
- Young Adult (ages 16 – 19)

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

For more information on our programs and services for persons with acquired brain injuries, or to learn more about how you can help advocate for better access to care, please visit our website at [www.paterehab.com](http://www.paterehab.com) or call 1.800.992.1149 or 972.241.9334.

Locations in: Dallas, TX • Anna, TX • Fort Worth, TX
“Find a medical home near you” link at http://recognition.ncqa.org/
Bright Futures is a national health promotion and prevention initiative led by the AAP (AAP, 2015). The Bright Futures Tool and Resource Kit has forms and tools for health care providers, patients, and families that are helpful before, during, or after well-child visits (Bright Futures, 2015). Parents of children with NE will undoubtedly have many questions for their child’s primary care physician. The checklist will help parents bring their most pressing questions to appointments.

https://brightfutures.aap.org/families/Pages/Resources-for-Families.aspx


Pediatric Coding for Costs
Attached is an AAP link for Common Procedural Terminology (CPT) coding for evaluations, assessments and treatment sometimes used by pediatric offices.


Aging with NE and cerebral palsy
Studies of neurologic outcomes in NE and HIE have focused on newborns to children of school age. We need more research on adult survivors to learn how the process of aging interacts with individuals after NE. Review of the evidence and outcomes of three major sequelae of perinatal brain injury – CP, epilepsy, and intellectual disability – is beyond the scope of this article. However, since CP is the most common major disabling motor disorder in childhood, consideration of current evidence and a brief look at motor function may be helpful (Haak, 2009).

The 2014 ACOG Executive Summary Task Force Report defines CP as a chronic disability of central nervous system origin characterized by aberrant control of movement and posture, which appears in early life and is not a result of progressive neurologic disease. Although there is a higher risk of CP associated with NE, it is not inevitable. Spastic quadriplegia or dyskinetic CP are associated as possible outcomes with HIE (Executive Summary, 2014; Wu, 2015). Children with CP commonly have such associated conditions as mental retardation, ophthalmologic abnormalities, hearing impairments, speech and language disorders, and disorders of oral-motor function (Ashwal et al., 2004).

The American Association of Nurse Life Care Planners (AANLCP) Core Curriculum has a chapter dedicated to CP that provides an overview of this motor disorder, including characteristics in aging and considerations for life care planning (Trautwein & Bond, 2013). The Gross Motor Function Classification System (GMFCS) is a tool to categorize movement and walking in children and youths with CP (Cerebral Palsy Alliance, 2015). Gross motor function is classified in five different levels. The highest level (Level I), indicates the ability to walk, climb stairs, run, and jump; the lowest level (Level V), indicates impairment in all areas of motor function. See link: at http://tinyurl.com/o62q4rg OR https://www.cerebralpalsy.org.au/what-is-cerebral-palsy/severity-of-cerebral-palsy/gross-motor-function-classification-system/?gclid=CjwKCAijwKFEAjw5SrBDR8ze702_2dlyYSJAAAJK9yurWTv84YxAOCS610NSAjwW5OjRwqKajlTJ37z43sd-S3BoCjajw_wcB

Children reach their motor function potential at a fairly young age. A large Canadian study found that children with CP, on average, reached approximately 90 percent of their motor function by around age 5, and at a younger age if classified in the severest GMFCS levels (Rosenbaum et al., 2002). Although most gains in motor function are realized early on, the authors recommend that therapeutic efforts should continue as the child grows in order to increase independence and participation in activities. Therapy should also address secondary impairments as they arise. Additionally, children may change or improve the quality of their motor control as they continue to develop in childhood.

In 2012, Novak et al. found in a systematic review of children with CP, three in four were in pain
one in two had an intellectual disability
one in three could not walk
one in three had a hip displacement
one in four could not talk
one in four had epilepsy
one in four had a behavior disorder
one in four had bladder control problems

CPT codes of 99339 and 99340 for care plan oversight are of particular interest and may be applicable in some cases for children with moderate and severe NE. When speaking to billing personnel in a pediatric office, it would be helpful for nurse life care planners to know if care plan oversight activities are being provided and charged.

99339 Individual physician supervision of a patient (patient not present) in home, domiciliary, or rest home (e.g., assisted living facility) requiring complex and multidisciplinary care modalities involving regular physician development or revision of care plans; review of subsequent reports of patient status; review of related laboratory and other studies; communication (including telephone calls) for purposes of assessment or care decisions with health care professional(s), family member(s), surrogate decision maker(s) (e.g., legal guardian), or key caregiver(s) involved in patient’s care; integration of new information into medical treatment plan; or adjustment of medical therapy; within a calendar month; 15 to 29 minutes

99340 30 minutes or more (AAP, 2015)
one in five had a sleep disorder
one in five dribbled
one in 10 was blind
one in 15 was tube-fed
one in 25 was deaf (Novak et al., 2012).

**Evidence-based interventions**

In 2013, Novak et al. performed a systematic review searching for evidence for the best available interventions for children with CP. The review identified strong evidence for 15 treatment interventions, e.g., fitness training, goal-directed training/functional training, and home programs. Novak et al. identified weaker evidence for commonly used interventions e.g., orthotics and strength training of the upper and lower limbs, suggesting caution with their use. The review recommended measuring the outcomes to confirm whether or not these interventions are working. The review also identified a few interventions to be avoided, such as craniosacral therapy, hip bracing, hyperbaric oxygen, neurodevelopmental training (NDT), and sensory integration, since they have all been shown to be ineffective in children with CP.

**Adults**

Although CP is defined as non-progressive disorder of movement and posture, individuals can experience a premature loss or accelerated decline in function during their adult years (Scope, 2015; Trautwein & Bond, 2013). Symptoms of decline, in some individuals, can be perceived starting in their twenties, particularly early onset of musculoskeletal complaints (Haak et al., 2009). Some individuals experience decreases in function and mobility, with changes in muscle flexibility, strength, endurance, fatigue, pain, and increased spasticity (Haak et al., 2009). This decline can manifest in a number of ways: physically, in mobility, speech, strength, and dexterity; and psychologically, in ability to concentrate, lack of confidence, or depressed mood (Scope, 2015).

A 2011 review summarized all the articles published on long-term outcomes of CP in adults (Kembhavi et al., 2011). The review identified 58 articles published from 1970 to 2010 involving participants, 80 percent of whom had the diagnosis of CP. Only six studies had longitudinal information, that is, repeated observations over long periods of time for the same participants. The age range within the studies varied widely, from late teens to early 70s. The most common outcomes examined were musculoskeletal impairments focusing primarily on joint contractures, fractures, spinal deformity, and orthopedic surgery. Studies consistently found joint deformities occurring in adults with CP regardless of ambulatory status, diagnosis, or severity of involvement.
More recent studies focused on pain and fatigue. Ten studies reported mobility changes over time. Nine of those 10 studies reported deterioration of ambulatory skills and one study reported that gait problems became less severe. Three articles discussed coping strategies for pain and 10 papers discussed the marked decrease in use of, and access to, health care. Three studies investigated loneliness in adults with CP. Authors of the 2011 review noted that they had difficulty determining if deterioration in locomotor skills occurs because of the pathophysiology in CP, the aging process, or an interaction between the two. The authors made several recommendations, including the need for long-term outcome studies, particularly studies of changes in ambulatory abilities.

**Recommendations for aging with CP**
Based on findings of early decline in ambulatory abilities and symptoms of pain and fatigue with CP, several life care planning recommendations may assist in combating musculoskeletal decline and secondary conditions interacting with the likelihood of premature aging.

- allowances for periodic physical and occupational therapy
- ambulatory supports
- additional physical medicine & rehabilitation visits
- home automation via smartphone
- pain evaluations
- supplemental home care

It would also be advantageous to learn if the evidence-based interventions for children identified in the Novak et al. 2013 review carried over to adults with CP.

**Life Care Plan Examples**
Examples of in-depth life care plans can be found in publications, such as Samples for Success (Powell, 2015), Pediatric Life Care Planning (Riddick-Grisham & Deming, 2011) and Life Care Planning and Case Management (Weed & Berens, 2010). Noteworthy is a method used in a plan for a child with HIE in Samples for Success. Videotaping a neurodevelopmental physical therapy evaluation and sharing it with all physicians and case experts so that they are working from the same data is a valuable method to consider. (Roughan, 2015).

**Conclusion**
The detail necessary to develop a life care plan after NE can be daunting whether the nurse life care planner just received a first pediatric referral or is experienced working with children with special needs. Depending on the severity of NE, the neurologic outcome can result in major disabilities impacting every sphere of life for the child and family over their lifetimes. The challenge remains for the nurse life care planner to include
- ongoing evaluations to ensure that sequelae are identified and treated
- accurate projections for functional level as it changes over a lifetime
- the probability of the development, extent, and effect of secondary conditions

The nursing process, awareness of current treatment protocols and evidence-based interventions, and collaboration are all essential elements.

According to the most recent statistics by the Centers for Disease Control and Prevention, in 2013 infant mortality dropped to 5.96 deaths per 1,000 live births (Kochanek et al., 2014). With continued improvements in maternal-child health care and the discovery of more effective neuro-protective and therapeutic interventions for NE, infant mortality and morbidity will in all likelihood continue to decline.
NEURO-OPTOMETRY, HIDDEN VISUAL PROBLEMS AND LIFE CARE PLANNING

CATHY STERN OD, FCOVD, FCSO, FNORA

KEY WORDS: Neuro-optometry, visual processing, cognition, acquired visual disorders,

Abstract:
Very few health professionals, including those in rehabilitation hospitals, concussion clinics, brain injury centers, settings for children with special needs and those dealing with neurologically compromised patients are adequately aware of visual problems resulting from congenital or acquired conditions. Unfortunately, this creates a gap in rehabilitative services, resulting in incomplete treatment and frustration for the patient, family and treatment team. This article will help the reader better understand neuro-optometry, when a referral to a neuro-optometrist will be helpful, and how to better understand the information report after a neuro-optometry evaluation.

Introduction
Vision is more than 20/20 eyesight. The visual process connects the eye and brain so we not only see clearly but also understand what we are seeing in order to react appropriately to what is happening around us. When vision works well we have good stamina for visual tasks and we process visual information that allows us to appreciate the features of objects and it guides our movement or actions. Vision is therefore not only for seeing but also for perception and action.
Visual problems are common following brain injury and are frequently under-diagnosed or untreated. If a child receives a vision screening or eye exam, it is often normal because a visual processing problem is not a basic eyesight or eye health problem. If a child is nearsighted, farsighted or has an eye health issue, this is typically addressed but the functional vision problems that interfere with daily life are rarely addressed.

Children with physical and communication challenges need optimal visual skill to function successfully. Visual processing problems are more common in children with disabilities. Deficits in sight, visual stamina or visual processing lead to delayed social and cognitive development. Diagnosing and treating developmental or acquired visual challenges that interfere with tasks of daily living is critical to help a child achieve maximum potential.

When considering the lifetime needs for a child with challenges, knowing how the child sees and how the child is processing visual information will significantly impact your recommendations as well as the child’s potential for meeting daily living demands.

What are the Visual Skills Necessary for Optimal Visual Processing?
- Distance and near visual acuity to see clearly and identify objects with little or no effort.
- Oculomotor and binocular vision
  - Visual tracking, the ability to follow a moving target, read across a line of print or locate objects in our visual space
  - Fixation, the ability to keep looking at something until you have enough information to move on to the next thing you want to observe
  - Focus flexibility, how well you can keep things clear at near or how quickly you can look from far to near and back again without blur
  - Eye teaming or binocular vision, coordinating both eyes together as a team
- Depth perception or depth judgment
to judge relative distances of objects - how far or near they are from you
- Peripheral vision to monitor what is happening around you where you are looking
- Contrast sensitivity, ability to see detail when presented against a similar background. Examples include: black print on a deep blue background, mashed potatoes on a white plate, seeing a car coming toward you on a sunny day
- Visualization and visual memory to accurately picture images in your mind and being able to retain and store them for future recall
- Vision perception to understand what is seen by knowing where you are (spatial sense) and knowing what you need to be making important (figure-ground relationships)
- Visual attention to keep focused on a particular object or area without distraction
- Visual field to be aware of everything surrounding where you are fixating or looking

Overlooking hidden visual problems can lengthen or impair rehabilitation therapies if not treated. (see sidebar, Vision Symptom Screening Questionnaire) Symptoms of a visual processing problem may include:
- Blurred or fluctuating vision
- Sensitivity to light
- Double vision
- Headaches with visual tasks
- Reading problems
- Movement of print on the page
- Poor spatial judgment
- Loss of peripheral vision
- Motion sensitivity
- Vertigo or balance concerns
- Poor visual memory
- Limited attention or concentration

Neurological conditions that affect vision
These neurological conditions are frequently accompanied by visual symptoms that involve aspects of the entire visual process, especially vision for perception and action.
- Traumatic brain injury (TBI)
- Concussion / mild TBI (mTBI)
- Cerebral palsy (CP)
- Down syndrome
- Cortical vision impairment (CVI)
- Multiple sclerosis (MS)

<table>
<thead>
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<th>Nursing Diagnoses to Consider</th>
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<tr>
<td>Deficient knowledge (Domain 5, Perception/Cognition; Class 4, Cognition)</td>
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<tr>
<td>Risk for injury (Domain 11, Safety and protection; Class 2, risk for injury)</td>
</tr>
<tr>
<td>Ineffective health management (Domain 11, Safety and protection; Class 2, health management)</td>
</tr>
<tr>
<td>Risk for dry eye (Domain 11, Safety/Protection; Class 2, Physical Injury)</td>
</tr>
<tr>
<td>Risk for falls (Domain 11, Safety/Protection; Class 2, Physical Injury)</td>
</tr>
<tr>
<td>Migraine headaches</td>
</tr>
<tr>
<td>Parkinson’s disease</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
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<tr>
<td>Lyme disease</td>
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</table>

Common vision conditions seen with neurological injury
Traumatic brain injury is often accompanied by post trauma vision syndrome (PTVS). Symptoms of PTVS include: exotropia or high exophoria, convergence insufficiency, accommodative insufficiency, spatial disorientation and unstable peripheral vision. Up to half of all brain injury patients require a prescription for eyeglasses either for the first time or because of a prescription change post-injury. Progressive (no-line) multifocal lenses can make symptoms worse for individuals with brain injury.

Down syndrome and cerebral palsy share in common a high incidence of amblyopia, strabismus, oculomotor dysfunction, spatial misperception, poor eye-hand coordination and significant levels of farsightedness and nearsightedness.

Alzheimer’s and Parkinson’s diseases are affected by visual perceptual changes that may affect depth perception, figure-background or
Sample Vision Symptom Screening Questionnaire

1. Are you having difficulty with seeing or using your eyes for everyday tasks?
2. Do you wear eyeglasses?
3. Are they for distance, near, or both?
4. Are they single lenses, bifocals, multifocals?
5. Do your eyeglasses work as well now as before your trauma or accident?
6. Have you noticed blurred vision? If so is it at near (reading or using your phone), at the computer, or at distance (driving, TV)?
7. Do you ever see double? If so is it all the time or intermittent? Is it more near or far? Does it go away if you close one eye?
8. Do letters jump around on the page while reading?
9. Are you experiencing headaches or eyestrain? Where and when?
10. Do you ever lose your place when reading?
11. Are portions of a page or any objects missing?
12. Do people suddenly appear from one side, that you didn’t see approaching?
13. Do you have difficulty concentrating on tasks?

Functional vision changes may include:
- Visual field loss
- Unilateral spatial inattentiveness (visual neglect)
- Strabismus (eye turn)
- Oculomotor dysfunction
- Convergence insufficiency
- Accommodative (focusing) deficit
- Visual acuity (eyesight) loss
- Visual perceptual disturbance
- Visual motor integration difficulty
- Visual memory loss
- Depth perception deficit
- Decreased blink rate
- Visual midline shift syndrome
- Balance and posture difficulties

Functional vision evaluation is a term often used to describe any assessment that provides information relevant for a child’s daily needs. Especially in a school setting, a teacher of the visually impaired (TVI) conducts an assessment labeled a functional vision evaluation. Occupational therapists (OT) in schools and rehab settings also use the term functional vision evaluation when assessing skills needed for activities of daily living (ADLs). These evaluations frequently include print size necessary for a child to read easily, optical or non-optical aids, environmental accommodations, and sometimes recommendations for additional therapeutic intervention (including referral to a neuro-optometrist).

When this information is important and can help, a neuro-optometrist should always be part of a child’s evaluation team so more specific visual diagnostic and therapeutic intervention can be included in the life care plan. A strong visual processing system is necessary for understanding our world and reacting to our world as 85% of information is processed through the visual system.

When you are reviewing previous...
evaluations, remember that a report labeled as a functional assessment or functional vision evaluation may encompass varied testing and recommendations depending on the practitioner involved. It is important to recommend your client be seen by one or more practitioners that best match to the client’s needs.

Neuro-optometric vision rehabilitation evaluation
A neuro-optometric vision evaluation typically includes a comprehensive medical and family history, current and past medications, visual acuity, refraction or the need for prescription eyeglasses, and eye health testing, just as you would expect during a vision evaluation. In addition, testing of oculomotor (eye tracking), accommodative (focusing) function, binocular eye coordination, depth perception, photosensitivity, balance, motion sensitivity, visual-vestibular function, visual field and further testing of visual information processing (if needed). Sophisticated technology is also available to help doctors better diagnose and treat not only those with minimal-moderate needs but also those with multiple challenges.

Eye disease is addressed and referral is made to specific eye specialists such as a cornea or retina specialist as needed.

Low vision evaluation is added if sight is poor and the child has the ability to utilize optical aids or helpful assistive technology. This may be done by the neuro-optometrist if low vision trained or referral is made to a low vision specialist.

Neuro-optometric treatment recommendations may include:
- Prescription eyewear to improve eyesight
- Prism lenses (temporary or permanent) for double vision
- Vision Rehabilitation – therapeutic activities for visual tracking / eye coordination
- Therapeutic spectacle lenses for focus flexibility (single vision or bifocal)
- Specially tinted lenses for headaches or light sensitivity
- Prism lenses for spatial orientation, balance and posture
- Selective occlusion for strabismus and spatial reorganization
- Visual field expanding devices
- Low vision: optical and non-optical aids for sight loss
- Management or monitoring of eye disease

Today, neuro-optometrists are frequently being recruited to work in rehabilitation settings and with the many veterans affected by brain injury so the rehabilitation team is more complete. In my practice, I consult to a hospital and school for children with physical disabilities. While most of the children carry a diagnosis of cerebral palsy (CP), they also present with multiple diagnoses and challenges. As a neuro-optometrist, I work closely with occupational, speech, and physical therapy along with rehab engineering so a child can achieve maximum school, recreation, and life success.

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has a private practice near Boston limited to the diagnosis of neurological vision problems and treatment with vision rehabilitation. She presents courses in the USA and abroad about acquired brain injury, vision rehabilitation, and working with special needs children. She is a physician mentor for the MIT Health Technology course, teaches the COVD Acquired Brain Injury course and is an instructor for the Neuro Optometric Vision Rehabilitation Curriculum II program. She may be contacted at success@myvisiondoc.com

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Both understanding and treating autism spectrum disorder (ASD) have changed dramatically since an Austrian psychiatrist, Leo Kanner, described “Case One” in 1943 (Kanner, 1943). The clinical symptoms remain consistent:

- Difficulty understanding social symbols such as facial expressions and gestures
- Difficulty understanding and using linguistic symbols such as language
- Preference for predictable and logical systems such as the alphabet, software, Legos, video games, sorting, stacking, engineering
- Rigidity and inflexibility, “sticky attention” (difficulty with transitions), unhappiness, chronic dysregulation (screaming, yelling, crying).

The current DSM-V diagnosis excludes Rett’s Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder-NOS (PDD-NOS), all of which had been possible sub-diagnoses in DSM-IV. The current
criteria (Table 1) focus more specifically on impairments in nonverbal communication, language, social skills, and relationships. (APA, 2015)

DSM-V also broadened the criteria, effectively eliminating Asperger’s syndrome as a distinct and separate diagnosis, and instead, included all signs/symptoms in one category of Autism Spectrum Disorder (ICD-9 299.00). Diagnosticians then categorize the degree of severity, using a scale of greater-lesser need for supports such as prompts, oversight, visual cues, and schedules.

“Case One,” Donald Triplett, was born in 1933 and has had an idyllic life. His family lived in a small Mississippi town, and they enjoyed financial security. His mother’s family owned the local bank, and his father was a Yale graduate and successful attorney. (By report, the father himself exhibited autism-like symptoms, with “nervous breakdowns” and preference for solitary activities; his initial letter to Leo Kanner describing Donald contained thirty-three pages of “obsessive detail.”) Donald had a younger brother, extended family lived nearby, and all were involved in the local church and community gatherings. In his book, “Case One,” John Donvon portrays the town embracing a quirky boy, and then man, as simply one more citizen. Other than one year of unsuccessful institutionalization (after meeting with Dr. Kanner), Donald had a predictable routine and attainable responsibilities within a compassionate social context; he was part of the fabric of the community, graduated from college, and by all accounts, continues to lead a full, rewarding life. (Donvon, 2012; Donvon, 2016)

In contrast, the contemporary long-term outlook for people with ASD presents serious challenges. Consider:

- 92% of high-functioning patients (formerly Asperger’s) are unemployed.
- 60% of teenagers and young adults experience significant mental health issues, particularly depression and anxiety, to an incapacitating degree. Cognitive capacity notwithstanding, many young adults cannot tolerate leaving the house, interacting with unfamiliar adults, or talking on the phone. Lack of practice with independent ADLs and active problem-solving results in avoidance and extreme anxiety. Therefore, therapies, job coaching, and vocational rehabilitation become critical to supporting eventual independent living.
- 62% of disabled adults live with their families.
- Many ASD adults cannot maintain independent living either due to ID (intellectual disability), mental health challenges, or inability to communicate successfully – whether reporting an electric outage, notifying a landlord of a leak, or conveying a message to a neighbor. The most typical reaction to these scenarios is simply to ignore them, because the effort required combined with lack of experience is overwhelming.
- The prevalence rate for autism is now 1:68 children, with boys five times more likely than girls to receive a diagnosis.
- One of the most worrisome issues for families is bullying; while there are no hard data, bullying appears to result in a high suicide rate among ASD teenagers.

While the rise in prevalence is alarming, it is important to understand the link between the broadened criteria above and the Center for Disease Control’s process of identifying children with ASD. The CDC has awarded grants to eleven states whose teams monitor incidence/prevalence rates via chart review in this fashion:

- The team conducts chart reviews from key agencies that would harbor potential ASD-positive children: school districts, disability boards, early intervention programs.
- School documents are tagged not only for Individualized Education Plans (IEPs) positive for autism, but also for charts positive for social deficits, conduct disorders, and behavior disorders.
- The team cross-references charts among agencies to rule out duplicates.
- The resulting number is then extrapolated to represent the entire state. The quantity and location presume preponderance. For example, the SC record review only involves the eastern two-thirds of the state, or a preponderance of the population; the statistical presumption is that the remaining one-third would bear similar results.
- In contrast, the American Journal of Psychiatry reported on a 2014 face-to-face study of all children (approximately 55,000) ages 7-12 years in a South Korean community, and the surprising result was a rate of 1:38, or 2.6% of the population. (Young Shin K, Leventhal B, Yun-Joo K, et al., 2014).

These data suggest that autism is a growing educational, medical, therapeutic, and social concern.

Etiology

The etiology of ASD remains unclear; however, all evidence points to a neurobiological basis rooted in genetics. Annual presentations at IMFAR (International Meeting for Autism Research) highlight the relationship between predisposition/genetic heritability and the effect of the environment, resulting in epigenetics. In the epigenetic model, a baby is born with a susceptibility to ASD, and either the symptoms appear spontaneously or are triggered by an environmental event. In the case of monozygotic twins, concordance of autism is only 80%; if purely genetically-based, both twins would have autism. Conversely, dizygotic twins have 60% concordance, underscoring the role of shared genetics and heritability (Chawarska, Klin, and Volkmar, 2008).

Over time, several issues have confounded rational and scientific understanding of ASD. For example, in 1998 a physician in England named Andrew Wakefield claimed that twelve of his patients developed autism due to vaccinations. However,
an investigation published by “The British Medical Journal” concluded that Wakefield misrepresented or altered the medical histories of all twelve of the patients whose cases formed the basis of the “study,” and that there was “no doubt” that he had done so. The specious and false vaccine issue garnered Wakefield $674,000 from the lawyers “representing” the plaintiffs. Interestingly, despite retraction by “The Lancet” and debunking by the AMA, the story lives on. Many families and lay people still believe the myth.

Other baseless associations include the “evil eye,” owning too much money, air pollution, “refrigerator moms,” finger length, and Lyme disease. “Cures” have come and gone, from hyperbaric oxygen tanks to magnets, megavitamins, bleach enemas, and camel’s milk. Compared to other populations of pediatric disability, ASD families are generally far more susceptible to suggestion, probably due to the nascent level of research pointing to definite genetic traits and absence of a “smoking gun.” What is clear is that children with ASD present with specifically different cortices than other populations (Stoner R, Chow M, Boyle M, et al., 2014; Petropoulos H, Friedman S, Shaw D, et al., 2006). They have:
- 400% more white matter
- 100% more gray matter
- Excess neurons in the prefrontal cortex
- Idiosyncratic neuronal migration to the ventricles
- Failure of apoptosis, i.e., malfunctioning neurons continue to propagate
- Ongoing propagation of faulty neurons therefore results in a cascade effect, generating: Increasingly poor neuronal development
- Increasing social and linguistic deficits
- Misshapen and undergrown cells in the amygdala and hippocampus

Neuroscientists theorize that the increased white and gray matter and excess prefrontal neurons appear to be the brain’s attempts at rewiring itself. We face the daunting conclusion that:
- brain structure is quite different in the ASD population
- the prevalence rate increases annually
- the DSM V criteria have shifted to more functional and relational deficits
- the population of ASD adults will skyrocket over the next few decades

Therapies
The most successful therapies and educational programs for autism focus on predictable, consistent, and intensive teachable moments that offset the cerebral chaos from faulty neuronal development. Patients with ASD thrive on logical systems; visual references are critical. Calendars, schedules, and numbered or alphabetic supports appeal to linear thinking, whereas highly verbal interactions bombard and result in avoidance. Management programs such as SCERTS (Social Communication/Emotional Regulation/Transactional Supports) (Prizant B, Wetherby A, Rubin E, and Laurent A, 2007) incorporate custom supports within an educational setting such as attentional breaks, numbered schedules structured left-to-right or top-to-bottom, and heavy use of pictorial cues.

In addition, occupational therapy is often a linchpin of success, as the vast majority of people with autism have sensory processing disorder (SPD). SPD essentially involves seeking or avoiding information from the five basic senses, as well as proprioception (awareness of the body in space) and vestibular awareness (balance, stability). If managed well, sensory processing improves, and by extension, so do attention, task completion, contentment, cortisol levels, and ability to participate in social activities. While public school therapy can help sustain regulation during the school day, private therapy is more likely to customize the SPD intervention, create an attainable home program, and assiduously track progress over time and as the child ages/matures. Baseline frequency is a minimum of once per week, with three times a week representing a maximum level of support. Ideally, however, the family will receive specific information for carry-over and to maintain regulation throughout each day, offering the child various options to meet his/her needs.

Research
Various universities conduct rigorous research on all aspects of autism, most notably the Yale Child Study Center, the MIND Institute at UC-Davis, UCLA, UC-San Diego, Florida State University, Duke University, and Drexel University. However, the dream of every parent would be to replicate Case One’s life. Donald Triplett remains the exemplar of optimal outcome: having meaningful relationships and independence within a compassionate community.

Residential/Employment
In addition to the university research efforts, effective residential and
business models have surfaced, such as Community Options (in nine states, funded by Medicaid) and WalGreens. WalGreens established a large distribution center in Anderson SC, dedicated a priori to a 30% disabled employee population, many with ASD. Not only did the center generate the highest profit margin among all WalGreens distribution sites, it also generated a wellspring of interest and a corporate training model for other large businesses such as Home Depot interested in combining morals with profits. (Lewis 2014).

Ideally, the sum of all combined efforts – therapy, education, research, housing, employment – will lay a pathway of opportunity, self-reliance, and meaningful relationships for citizens like Donald Triplett.

Implications for Life Care Planning

The impact for life care planning rests more in case management than in litigation, unless ASD is a comorbidity with traumatic brain injury, traumatic birth injury, or other medical event. With the prevalence now so high, it is likely that clients with autism will emerge on case management caseloads.

Diagnoses that have known comorbidity with ASD include prematurity/low birthweight, Down Syndrome, intellectual disability, and multiple disabilities. Advanced maternal age also has a slight influence, representing 2% of the population. While the average age of ASD diagnosis is sadly four and a half years, national and international efforts are pushing for much earlier identification, as signs/symptoms often present at two to four months.

Since communication disorder is a key element of autism, speech-language pathologists are frequently the first to recognize ASD, establish an intensive program, and refer appropriately to occupational therapy, early invention or ChildFind, and psychology or a developmental pediatric group, depending on local availability.

When managing ASD cases, the level of independence in ADLs, depth of self-reliance, and ability to solve problems drive the need for supportive or supervised living. Accurate ADL assessment will guide housing costs, typically more costly than other aspects of a LCP, such as nursing care. Medication costs can be very high, given the high rate of mental illness and related disorders. Residential options vary considerably by community, state, and region; as yet there is no national clearinghouse. With ASD distribution in the population now mirroring the Bell curve, the vast majority presents with average intellect. Therefore, the life care planner can anticipate need for therapies (speech-language and OT), vocational rehabilitation, and job coaching support periodically through the life span to maintain maximum level of independence. Community agencies typically provide vocational rehabilitation via a dedicated autism portal, such Department of Disabilities and Special Needs (DDSN). However, the other services would be an average of $150 to $175 per hour, further cementing the importance of maximizing supports when a child is enrolled in school and/or covered by a parent’s private insurance or Medicaid.

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Is the owner and clinical director of a large private practice for pediatric communication and feeding disorders near Charleston, SC. Her career has focused on autism spectrum disorders (ASD), which she finds enormously rewarding on a daily basis. In addition to clinical treatment, Sally lectures on the sequelae of autism to professional groups, and works with families to develop life care plans. She can be contacted at s.asquith@mycsal.com.

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BY DAVID DILLARD BA, MS

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Dogs have a long history of service to humans as guide dogs for the blind, dogs for the hearing impaired, pet-facilitated therapy dogs, seizure alert dogs, and service dogs for mobility impaired individuals (Olson, 2002). Using dogs to help socialize patients with mental disorders dates back to the 18th century, as documented by the father of animal-assisted therapy, child psychologist Levinson (1969).

The beneficial effects of pet therapy are well-documented in the literature. Using a mood-rating scale, Kaminski, Pellino and Wish (2002) examined the effects of pet therapy and play therapy on 70 hospitalized, chronically-ill children. The pet therapy group was reported significantly happier than the play therapy group. Esteves and Stokes (2008) studied the social effects of a dog’s presence on children with disabilities. They found that three developmentally delayed five to nine-year-old elementary school children exposed to dogs were more focused and responsive resulting from the therapeutic interactions with the dogs.

Therapy dog, service dog, or assistance dog?
Animal Assisted Therapy (AAT) is defined as a goal-directed intervention in which an animal meets specific criteria as an integral part of a treatment process. AAT is directed and delivered by a service professional with specialized expertise, and within the scope of practice of his or her profession. Key features include specific goals and objectives for each individual and measured progress (p.4).
Distinctions between service dogs, therapy dogs, and assistance dogs are based upon the work the dog will perform; this may require energy and endurance, mobility, strength, sociability, curiosity, keen senses, and trainability (Wilson & Turner, 2003; Weiss & Greenburg, 1997).

The Delta Society (2009) is one of the major organizations responsible for certification of therapy animals in the United States. National Service Dogs, Inc. is the largest service dog placement organization for autism and other disabilities. They define service dogs as working for individuals with disabilities other than blindness or deafness. Dogs are trained to perform a wide variety of tasks such as pulling, bracing, retrieving, alerting, and providing assistance in a medical crisis (National Service Dogs, Inc., 2008, p. 6). Therapy dogs are used for giving love and empathetic support in order to educate, lift spirits, and facilitate healing (National Service Dogs, Inc., 2008, p. 6). Assistance dogs is a generic term used to describe guide, hearing, or service dogs trained to do more than one task to mitigate an individual’s disability (National Service Dogs, Inc., 2008, p. 6). The terms service dog and assistance dog are interchangeable, because they are both used for providing assistance to humans. Understanding the differences between the types of canine interventions helps to provide a better picture of which kind of dog might be best used for a given autistic child.

What service dogs can do for children with autism

The child with autism has difficulty connecting with the environment. Disordered sleep can become problematic; wandering is also common in autistic children (Autism Assistance Dog, 2015). The service dog normally sleeps with the child, and most will sleep on the bed and next to the child. This applies deep pressure, calming and beneficial for autistic children who experience sensory deprivation problems. The child sleeps through the night, and the parents benefit from uninterrupted sleep as well (Hautop, 2007).

Agitation, isolation, and inability to form friendships and attachments impede the formation of social relationships for the affected child and family members. Many autistic children have a tendency to bolt into the street without looking. They get out of bed at night and wander around the inside or outside the house. The autism dog is trained to stop the child from running into the street by being attached to the dog via leash and belt system looped around the child’s waist. The parent handling the dog walks the dog using a leash and gives commands to the dog to proceed forward, turn left or right or to stop and stay. If the child attempts to run, the dog braces its footing to slow the child down and stop, giving the parent time to intervene and correct the child’s behavior (Burrows, 2008; Hautop, 2007).

A qualitative study by Waldie (2006) showed that dogs trained to work with children with autism helped them in several ways. These dogs

- Help the child avoid dangerous situations
- Help the child stay calm
- Have a normalizing effect, i.e., others perceive the child with a dog as less “different”
- Facilitate family engagement in outside activities
- Encourage children to speak and interact with others
- Provide a constant source of unconditional friendship
- Help educate the school and community

Because service dogs are trained to stay calm in all places and situations, it helps the autistic child to stay calm by giving a sense of comfort and security. The dog’s contribution to reduction of distress for the child extends to doctor and dental visits, churches, and grocery stores as well as other environments.

Soulon (2010) suggests social development may not merely comprise individual qualities, but may be created through certain forms of social interaction by animals and humans with and without developmental disorders. Archeological evidence documents signs of historical human child affinity with animals over more than 140,000 years. During the past twenty years, studies show animals provide development of the sense of self, imagination, play, empathy, and morality (Ascione 2005). Also, dogs may provide opportunities to enhance an autistic child’s development in ways that humans cannot, because children and dogs often interact in ways unrecognizable to adults.

Challenges of Having a Service Dog

Placing a service dog in a home can’t be expected to be without some challenges. These include parental expectations, community and environmental factors such as public access, and additional time and expense requirement for dog training and maintenance such as food, veterinary care, and licensure.

Most studies focus on positive benefits observed in the context of the therapeutic milieu, but have not looked at whether the effects carry over into other contexts or even if they are retained over time. More research is needed for the scientific and medical communities to seriously consider the effect of AAT interventions. The potentially significant value of dogs as facilitators of the therapeutic process should be a research priority (Kruger, K.A., Trachtenberg, S., & Serpell, J.A., 2004).

Research has not followed families for long periods of time to understand the impact on the family and especially the child when the service dog has to retire, becomes ill, or dies. The Burrows (2008) study provided and in-depth description of the typical life and interaction of families with a trained autism service dog, and provides a good foundation for future research.

Classic Service Dog Network, a non-profit organization in Deland FL, provides service dogs trained for veterans and disabled adults and children (J. Carter, personal communication), August, 2015. J. Carter described how “paws-on” attention enhances the lives of children with autism and benefits the lives of the involved families. A large portion of the initial time spent with families includes education about the
process of acquiring and owning a service dog. The goal is to provide a successful match for the child, the family, and the dog. Service dogs are placed fully trained at adulthood, and many are rescue dogs. Their purpose is as a service animal, not as a pet, however through that service relationship mutual respect and affection will develop. The dogs go everywhere with their child. They assist children with all of their daily activities including attending school. Under the American’s with Disabilities Act (ADA), there are no exceptions to where a service dog is allowed.

The functional domains enhanced by the dogs assist with the challenges faced by children with autism by performing cues and behaviors that focus on safety skills, social skills, communications skills, adaptive skills, and sensory integration processing and needs. The results are powerful. They transform the lives of the autistic child and their entire family unit.

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PATRICIA BROCK PhD, RN, LNCC, CLCP
(“Service Dogs for Autistic Children”) has been a nurse for thirty years. She began her nursing career as an Associate Degree nurse and after two years of med/surg nursing, she worked exclusively in critical care. In 2004, she left the bedside temporarily to obtain her certifications and grow her business, HTI Legal Nurse Consulting and Life Care Planning. She is an active member of the Orlando chapter of the American Association of Legal Nurse Consultants and frequently testifies as a nursing SOC expert. Dr. Brock is a clinical nurse educator for Daytona State College and can be contacted at pbrock@htilegal.com

RESOURCES
US Service Dog Registry www.usdogregistry.org
Hope for Support, listings for service dog organizations by state http://www.hopeforsupport.com/servicedogs.htm
1. What feature of an infant's bone increases the remodeling potential after a fracture?
   a) Bending strength  
   b) High mineral content  
   c) Low elasticity  
   d) Strong periosteum

2. Which is one of the most supported treatments for a brachial plexus injury?
   a) Physical therapy for strengthening and spasticity relief  
   b) Referral to a neurologist with expertise in brachial plexus palsy  
   c) Surgical intervention if functional recovery not obtained within 3-9 months  
   d) Use of splints and braces to stabilize the shoulder area

3. Which federal program requires that services for handicapped children be provided in a child's "natural environment"?
   a) Birth to 5, Watch Me Thrive!  
   b) Children's Health Insurance Program  
   c) Individuals with Disabilities Education Act  
   d) The Rehabilitation Act

Advocacy on Trial: Are the Nurse Life Care Planner's Roles of Advocate and Expert Witness in Conflict?

1. The RN-Expert Witness is expected to give testimony at a high level of professional standards. These standards include:
   a) Advocating for a specific cause or policy  
   b) Arguing for the purpose of the retaining party  
   c) Basing opinions on facts and professional expertise  
   d) Pleading the cause of the client before the court

2. Nursing advocacy implies:
   a) Adversarial bias, objectivity, and commitment to the client's health  
   b) Commitment, subjectivity, and partisanship to the client's health  
   c) Objectivity, non-partisanship, and commitment to the client's health  
   d) Partisanship, commitment, and objectivity to the client's health

3. RNs working in a salaried position within a law firm may:
   a) Give legal advice as deemed appropriate by their employers.  
   b) Practice as nurses per the ANA Scope and Standards of Practice.  
   c) Provide expert opinion testimony in court.  
   d) Use nursing expertise to support legal advocacy.

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Birth Injuries: Knowledge, Knowledge Gaps, and Planning for the Future

1. What feature of an infant's bone increases the remodeling potential after a fracture?
   a) Bending strength
   b) High mineral content
   c) Low elasticity
   d) Strong periosteum

2. Which is one of the most supported treatments for a brachial plexus injury?
   a) Physical therapy for strengthening and spasticity relief
   b) Referral to a neurologist with expertise in brachial plexus palsy
   c) Surgical intervention if functional recovery not obtained within 3-9 months
   d) Use of splints and braces to stabilize the shoulder area

3. Which federal program requires that services for handicapped children be provided in a child's “natural environment”?
   a) Birth to 5, Watch Me Thrive!
   b) Children’s Health Insurance Program
   c) Individuals with Disabilities Education Act
   d) The Rehabilitation Act

Advocacy on Trial: Are the Nurse Life Care Planner’s Roles of Advocate and Expert Witness in Conflict?

1. The RN-Expert Witness is expected to give testimony at a high level of professional standards. These standards include:
   a) Advocating for a specific cause or policy
   b) Arguing for the purpose of the retaining party
   c) Basing opinions on facts and professional expertise
   d) Pleading the cause of the client before the court

2. Nursing advocacy implies:
   a) Adversarial bias, objectivity, and commitment to the client’s health
   b) Commitment, subjectivity, and partisanship to the client’s health
   c) Objectivity, non-partisanship, and commitment to the client’s health
   d) Partisanship, commitment, and objectivity to the client’s health

3. RNs working in a salaried position within a law firm may:
   a) Give legal advice as deemed appropriate by their employers.
   b) Practice as nurses per the ANA Scope and Standards of Practice.
   c) Provide expert opinion testimony in court.
   d) Use nursing expertise to support legal advocacy.

A Message from the AANLCP Education Committee

We are excited to have CEU questions in the JNLCP! This feature will appear in every issue and contain one CEU credit available for 12 months after the date of publication.

At only $10, this is an economical way for you to get recognition for the learning you do as you read the Journal.

We’re looking forward to your feedback and ideas on this, so please take a moment to let us know what you think!

Becky Czarnik MS RN CLNC, LNCP-C
Education Committee Chair, AANLCP
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