



PIVOTAL TOPICS: New content for the Bulletin

We hope you found this year's NAN Conference in New Orleans to be educational, inspiring, and fun. In accepting responsibility for the Bulletin, we are constantly considering how we might provide the best product for the NAN membership. Within the last year, technology has changed the method utilized by officers and committee chairs to update the NAN membership about the state, activities, and direction of the academy. These e-mail communications offer the benefit of rapid and cost effective communication, and allow us to refocus the NAN Bulletin on issues central to the practice and science of clinical neuropsychology. In revamping the content and direction of the NAN Bulletin, we have started a Pivotal Topics format, with the goal of presenting several brief, topical articles loosely organized around a common theme. We hope to use the Bulletin as a tool to stimulate interest, discussion, and collaboration among colleagues on issues in neuropsychology that are important to the field's continued growth in clinical and scientific forums. As you will see, Pivotal Topics will present a variety of article formats, some offering brief research reviews, some providing personal experience, and some giving voice to advocacy efforts or unique perspectives in the field. We welcome content suggestions from members for future issues, as well as comments about this new direction for the Bulletin.

Deborah K. Attix, PhD, ABPP/CN

Tyler J. Story, PhD

Emerging Roles for Neuropsychologists

This fall 2009 issue of the Bulletin presents discussions about new and emerging roles for neuropsychologists. While considering all the new and expanding opportunities in our field is far from feasible, we hope that you agree that the following brief articles offer a sampling of these emerging roles and illustrate the changing landscape of practice and research in neuropsychology. As a result, this may be only the first of several Pivotal Topics issues that will highlight changing roles for neuropsychologists.

TJS & DKA

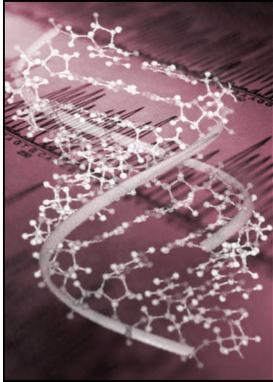
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Neuropsychology at the Cross-Roads of Genome and Syndrome Robert M. Bilder, PhD, ABPP-CN

With the 21st century being referred to as the “post-genomic era”, and the appointment of Francis Collins, well known for his leadership of the Human Genome Project, as new director of the National Institutes of Health, one might wonder: Where does neuropsychology fit into this brave new landscape of biomedicine? Genome-wide association studies (GWAS) and other high-throughput genomic strategies are generating almost daily discoveries, *beginning* to unravel the biological bases of complex disorders. As the data are accumulating, however, it is becoming increasingly clear that genetic discoveries are only the starting point of these investigations (R. M. Bilder, 2008; R.M. Bilder et al., in press). And among the complex disorders, some (such as Type II diabetes) may be a bit less complex than others (such as schizophrenia). It is in this context, where we are aiming to gain traction on the biological ladder that leads from the genome to the syndrome, that neuropsychology is emerging as a crucial transdiscipline.

It has been popular for several decades to speak of *endophenotypes* or intermediate phenotypes based on the assumption that there must be a simpler genetic basis for biological functions that are *closer* to the locus of gene action. There is now some doubt that the genetic architecture of these intermediate phenotypes will be any simpler than for the more complex syndromal phenotypes (Flint & Munafò, 2007), and it is sobering that even molecular expression as a phenotype may share only about 20% variance with genetic variation, while other functional phenotypes at cellular and higher levels tend to share less than 2.5% of variance with genotype. Although the substantial heritability of well-defined behavioral phenotypes probably will be explained by hundreds if not thousands of genetic variants each of which has small effects, there are additional virtues of neuropsychological investigation. Most important perhaps is that neuropsychology occupies a unique position in the hierarchy of biobehavioral knowledge that runs from the genome all the way up to the syndrome. Neuropsychological findings can clearly be linked to syndromal differences, and the research literature is already rich with descriptions of neuropsychological profiles associated with virtually every known disorder of the brain. There is further promise, as the study of brain-behavior relations, that neuropsychological research can bridge the current gap between basic biological and behavioral sciences, thus providing precisely those phenotypic targets that may prove tractable for genetic studies.

How can neuropsychology best bridge these gaps? It is clear already that classically defined neuropsychological functions or “domains” will not be ideal for genetic research. Following Kendler, we might say it is unrealistic to hope we will discover a “gene for memory” or a “gene for language” (Kendler, 2005). Rather, we need to better nail our neuropsychological constructs to their functional anatomic scaffolding at the neural systems and circuitry level, so that these in turn can be better explained by changes in cellular systems and signaling pathways, and that these ultimately will be linked in causal models to the molecular diversity that is programmed by our genes.



To put neuropsychology on the same footing as other disciplines that are rapidly accruing knowledge to leverage the breakthroughs in genomics, we need *ontologies* of neuropsychological functions – formal descriptions of neuropsychological constructs and their relations to measurable phenomena (such as test results)(R. M. Bilder et al., 2009). To aggregate this knowledge rapidly, we also need to work together. The success of Wikipedia may serve as an object lesson in how the “wisdom of crowds” can rapidly generate a useful product. If we can do the same to aggregate empirical data regarding neuropsychological findings we will rapidly have in hand a trove of knowledge ripe for mining (Sabb et al., 2008). Finally, we need to work collaboratively on innovative new methods for representing *formally* the links between brain and behavior, which will in turn demand new causal models focused on translating findings across biological scales (particularly from neural systems to neuropsychological levels), and across species (to foster clearer links between basic and clinical sciences). The Consortium for Neuropsychiatric Phenomics (CNP) at UCLA (www.phenomics.ucla.edu) has embarked on an ambitious program of collaborative transdisciplinary research spanning eight projects and 50 investigators to target some of these goals. This work involves studying more than 2000 human participants, genome-wide association studies, a series of linked basic science investigations, and critical integration of information science, statistics, and psychometrics. The CNP focuses on two themes, to elucidate mechanisms underlying “response inhibition” and “memory” phenotypes. We hope that the results of this work may have some impact on our understanding of the biological bases of behavior and the discipline of neuropsychology.

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Neuropsychology in Diagnosis and Treatment of ALS Tyler J. Story, PhD & Beth K. Rush, PhD, ABPP-CN

Neuropsychologists now contribute to the care and assessment of patients with amyotrophic lateral sclerosis (ALS), or Lou Gehrig's disease. Although our clinical and research involvement is growing quickly, this opportunity remains nascent for the field of neuropsychology. The last decade of research in ALS has shown a convincing link between ALS and frontotemporal dementia (FTD), providing solid grounds for including neuropsychologists early in diagnosis and management of this disease. In the last 5 years, four screening batteries have been introduced by neuropsychologists to assess cognitive and behavioral changes in patients with ALS. The following overview briefly outlines recent evidence linking ALS and FTD, and provides some information regarding current roles for neuropsychologists in ALS clinics.

The Link

ALS is a degenerative disease affecting both upper and lower motor neurons to produce progressive limb, respiratory, and bulbar paralysis. The average age of onset is 55 years old, with mean survival ranging from 3-5 years. For years, cognitive functions were presumed to be well preserved throughout the course of ALS, and frank cognitive impairment and dementia were only recognized in rare cases (Brownell et al., 1970). In the last decade, however, clinical research has provided convincing evidence that progressive cognitive and behavioral impairment accompanies motor function loss in up to 50% of individuals with sporadic ALS (Ringholz et al., 2005) with up to 20% demonstrating a full dementia syndrome (Strong et al., 2009). The profile of cognitive impairment in ALS suggests particular disturbance in frontal and temporal regions, similar to profiles indicating frontal temporal lobar degeneration (FTLD). Clinical phenotypes may be consistent with one of the three Neary subtypes of FTLD (Neary et al., 1998), including non-fluent progressive aphasia, semantic dementia, and FTD.

Basic science research has identified potential biological substrates for the complex clinical phenotype of co-occurring frontal temporal cognitive impairment and ALS. In one notable series of discoveries, histopathological studies revealed similar ubiquitin inclusions distributed in the frontal lobes, temporal lobes, brain stem, and spinal cord for ALS and FTD patients, with involved regions correlating with cognitive, behavioral, and motor symptoms in both groups of patients. These ubiquitin inclusions stain positively for transactive response DNA binding protein 43 (TDP-43), a histopathological marker previously associated with the clinical phenotype of FTD alone (Neumann et al., 2006). More recently, neurogeneticists have suggested that very specific biological markers for the ALS-FTD phenotype may be located on chromosome 9 (Morita et al, 2006; van Es Ma et al., 2009). How such biomarkers modify clinical phenotypes with regard to symptom onset, rate of





disease progression, and individualized responses to treatment remains unknown.

Clinical and Research Application

The suspected link between ALS and FTD has important implications for patient treatment and clinical practice. The presence of cognitive impairment directly impacts patient independence, patient care decisions, family education, and symptom management. For example, Olney and colleagues (2005) found that ALS patients with FTD were significantly less likely to comply with percutaneous endoscopy gastrostomy (PEG) and noninvasive positive pressure ventilation (NPPV), despite medical advice and research showing that these are the two most effective medical interventions available for symptom management in ALS. Further, family-member awareness of cognitive and behavioral symptoms associated with ALS has led to increased requests for information about the symptoms in the context of their illness (Wicks & Frost, 2008).

The physical disability and rate of progression in ALS necessitates flexibility in assessment setting and tools. ALS patients may be anarthric, immobile, or suffering from severe dyspnea, all conditions which can interfere with traditional comprehensive neuropsychological evaluations. These issues prompted the development of clinical screening tools for the early detection of cognitive impairment in ALS patients (see *Screening Tools*). Such screens track symptom severity and progression over time, and are often administered in the context of multi-disciplinary treatment setting. With these tools, the neuropsychologist can provide important education to patients, patient families, and medical providers about clinical course and care issues. In some cases, screenings will prompt referrals for more comprehensive neuropsychological assessments to assist with differential diagnosis and ruling-out other causes of cognitive impairment, such as cerebrovascular disease or Alzheimer's disease. The ALS Association now encourages neurologic clinics treating patients with ALS to develop a multidisciplinary treatment team that includes a neuropsychologist to compliment the diagnosis and treatment provided by the neurologist, speech pathologist, physical therapist, occupational therapist, respiratory therapist, and social worker.

Clinical research opportunities are abundant given the need to further characterize the neuropsychological impairment of these patients and to document the epidemiology of the phenomenon. Involving neuropsychologists is essential for further development and validation of assessment tools for this population, including screens and more comprehensive evaluations tailored to the disabilities of this patient population. Neuropsychologists who are familiar with behavioral and environmental approaches to treating complicated neuropsychiatric manifestations of other dementias may be particularly helpful in providing education to patients, families, and other care providers on the ALS treatment team.

Screening Tools for Cognitive Impairment in ALS Patients

ALS-CBS:

Woolley S. ALS-Cognitive Behavioral Screen (ALS-CBS) Manual. In. November 2008 ed. San Francisco, CA; 2008.

UCSF Screen:

Ahmed F, JM M. Utility of a brief screening protocol to identify cognitive and behavioral abnormalities in ALS patients. In: The ALS Association 2009 Annual Conference; 2009 January 22, 2009; Newport Beach, CA; 2009.



Penn State

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[Morita M](#), [Al-Chalabi A](#), [Andersen PM](#), [Hosler B](#) et al. (2006). A locus on chromosome 9p confers susceptibility to ALS and frontotemporal dementia. *Neurology* 2006; 66: 839-844;

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Wicks P, Frost J. ALS patients request more information about cognitive symptoms. *European Journal of Neurology* 2008;15:497-5.



Advocacy for Neuropsychology **Laura L. S. Howe, PhD, JD & Neil Pliskin, PhD**

As neuropsychologists we inherently know the assessment and treatment services we provide are valued by those we serve, namely our patients, their families, and referral sources. However, we often assume the general public and the insurance industry recognize our value as well, and this is not usually the case. It is therefore critically important for neuropsychology as a specialty to increase the awareness, utilization, and applicability of neuropsychological services both as individual providers as well as on the national level. Opportunities to educate and advocate for neuropsychology present themselves every day, and it is as much our responsibility as individual providers as it is for our elected officers in our major organizations. Activities such as having brochures regarding services readily available, giving talks to increase the awareness of neuropsychology, volunteering with local or national organizations, responding to action alerts, consulting with organizations that represent interests for particular patient diagnoses, sharing knowledge and strategies regarding particular diagnostic populations such as epilepsy with schools to decrease adverse impacts on children, providing accurate and crucial information regarding brain behavior relationships at public hearings, aiding the translation of research findings into clinical practice, and using research findings clinically are among some of the many concrete ways individuals can advocate for the field. Additional ways to become involved are described in an article by Howe, Sweet, and Bauer (in press) and a special upcoming issue of *The Clinical Neuropsychologist* (2010) that is devoted to advocacy efforts within the field of neuropsychology.

In this article, the authors will describe their involvement in advocacy efforts for neuropsychology. One of the authors (L.H.) will present a personal perspective regarding the general experience of advocacy and convey some of the personal benefits of advocacy beyond increasing referrals and monetary gain. Then, the other author (N.P.) will provide an example of his advocacy experience in addressing an important issue pertaining to our specialty - the growing inability to train students to work with older adults.

Laura L. S. Howe, PhD, JD

Advocacy can be conceptualized as taking responsibility for having a part in a movement towards an outcome. When one willingly takes on responsibility, it provides a certain elemental sense of control over a portion of a situation, which can be empowering. You are no longer a passive recipient, but instead, an active participant in the creating, molding, and shaping of an outcome. Within the field of neuropsychology, I have been involved with advocacy efforts ranging from very informal activities such as educating family, friends, and co-workers about what neuropsychology entails, to more formal efforts such as talks and articles to increase the awareness of neuropsychology, a grassroots campaign, founding and organizing a coalition of individuals and organizations who submit amicus briefs in select appellate level cases, and formal and informal consultations with organizations and individuals regarding select topics in neuropsychology. Though at times I have felt unheard, dismissed, misunderstood or simply ignored when advocating on behalf of the field, the



majority of the time I have felt heard and understood, which created a sense of accomplishment and at times led to positive change. Advocating on behalf of neuropsychology has made me feel more connected to the larger goals of the field and increased my understanding of how neuropsychology fits into the broader medical and legal fields. Advocating for the field, even in small ways, can have numerous benefits for the individual, such as an increased sense of connection with the profession, viewing neuropsychology as a career versus a job, increased pride in one's career, increased confidence and ability to be assertive, increased self-awareness, increased sense of self-efficacy, increased communication skills, increased problem solving skills, and an increased sense of optimism that one can make a difference and impact outcomes.

Prior to being a neuropsychologist, I advocated for the homeless and mentally ill in other venues. One driving force for why I advocate is to give a voice to those who cannot or have difficulty speaking for themselves for various reasons, such as opportunity or ability. For many issues, neuropsychologists are uniquely and best suited to advocate on behalf of some patient populations. Our voice can make a difference. It is important to realize, however, that advocacy, no matter how zealous or justified, will not always result in the goal being attained. Without an attempt, however, it is almost certain the goal will not be reached or the change implemented. When being involved from the level of encouraging a colleague to present a lecture to running an organization to create and submit amicus briefs, the overall result was a feeling of knowing that I took control, mobilized, and worked towards something productive in which I believed. Regardless of the outcome, I felt good afterwards since I know I tried.

Neil Pliskin, PhD

My involvement in advocacy began when I started working for NAN's Policy and Planning Committee and then subsequently as Chair of the Practice Advisory Committee and Federal Advocacy Coordinator for APA Division 40. It was this committee work that ultimately provided opportunities to meet and speak to individuals who were in a position to address our profession's issues on a national level.

As our current leaders can attest, we have a number of key professional issues facing psychology and neuropsychology today. The one that I would like to highlight has implications for both clinical practice and education; specifically, the inability of psychology trainees to be compensated for supervised services to older adults. Here is the background: According to the Federal Government, we are not classified as physicians while many other nonphysician specialties are (podiatrists, for example). Because psychologists are not classified as physicians, we do not qualify to receive funds that CMS provides to academic medical centers to train physicians (Graduate Medical Education [GME] funds). Because CMS provides GME funding (which psychology does not qualify for) and considers this their financial contribution, it is against the law to use Medicare Part B money for services provided by psychology trainees. This was reaffirmed in a communication by CMS in 2006 when the new CPT testing codes brought further clarity to the services we provide. Hence the Catch-22 that we find ourselves in as a profession: *we do not qualify for GME but cannot bill Medicare because of GME funding*. This is an issue for training the next generation of neuropsychologists to work with older adults. Without access to GME funds and the lack of flexibility of CMS rules towards services provided by psychology trainees, the outcome will be devastating for the older adults, disabled, and veteran populations that psychologists serve.



Institutions are facing increased financial pressure and simply cannot afford to provide training opportunities for services that cannot be reimbursed. As institutions have faced the reality that Medicare patients cannot be seen by advanced trainees serving as examiners, there has already been a reduction in the number of Medicare slots, resulting in increased wait times for most patient populations, which include individuals who are awaiting evaluation for surgical procedures, as well as those who require medically necessary diagnostic evaluations as supported by direct physician referrals and consultation requests. Moreover, training programs that rely upon their trainees to be self-sustaining (i.e. generate revenue for supervised patient care) no longer have a means by which to pay for their training slots. Internship programs have decreased the number slots and some have closed. Postdoctoral fellowship slots have also had to de-emphasize the involvement of neuropsychology residents in caring for older adults, and some have stopped taking fellows. Psychologists outside of the world of education and academic medical centers may not see this as an issue that directly or even indirectly affects them. Not true. As things stand, for the next generation, there will be a dearth of providers with supervised experience in taking care of older adults.

My advocacy efforts (and it is certainly more than just me) have focused on raising awareness on this GME/training issue and getting others within and outside of psychology to appreciate its relevance. The American Psychological Association is our primary voice in Washington, and obtaining their support has been critical. Getting the attention of our colleagues required support at grassroots level. Through APPIC and other listserves, a request went out for training directors affected by these rules to write and share what impact this is having on their training programs. I compiled these persuasive anecdotes and sent them to key personnel in the Practice and Education directorates at APA. I repeatedly have spoken up in APA policy meetings that I had the good fortune to attend as a member of the Division 40 Practice Advisory Committee. A series of conference calls with members of the APA Practice and Education directorates and NAN took place. It is becoming apparent that one long term solution would be new legislation that redefines psychologists as physicians in order for training programs to qualify for GME funding. This means identifying champions in congress for our cause and working with them to represent our concerns. What can be done at the level of the individual provider to ensure our future as a profession? Give money to our political action organization, the Association for the Advancement of Psychology (aapnet.org) with a note requesting that the money be specifically earmarked for the "GME issue". Ultimately, advocacy is about persistence and having an important issue you believe in and feel passionate about. For me, that includes the growing crisis in training psychologists who work with older adults.

For those wanting to become involved in advocacy issues related to our profession, one great way is to volunteer on a committee of one of our national organizations. Here is how to do it: Send an email to the current president of your organization of choice indicating your interest. They need people willing to volunteer their time and will find a committee for you to work on.

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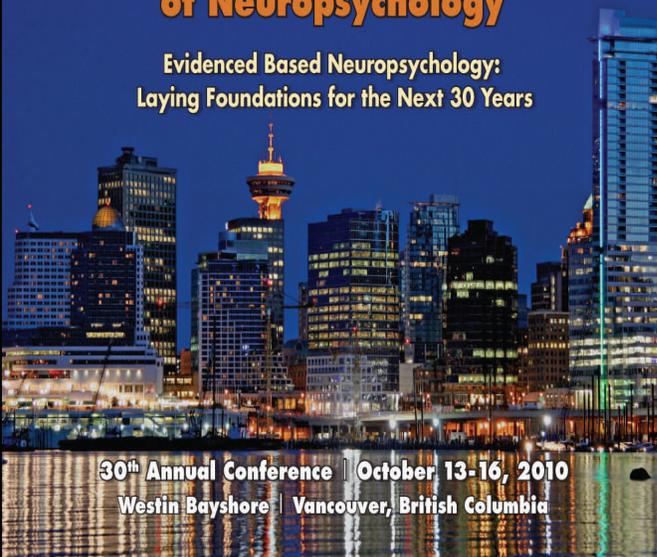
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