



Volume 5, Issue 2, March 2010

## *reSearch*

*A collection of research reviews on rehabilitation topics from NARIC and other information resources.*

### **“Hidden” in Plain Sight: Exploring Invisible Disabilities**

In this edition of *reSearch* we explore invisible disabilities. Just as individuals with disabilities are unique and diverse so are the types of disabilities. Most physical disabilities are usually visibly apparent. However, there are disabilities whose symptoms are less obvious and are considered to be invisible. Examples of these “invisible” disabilities include: mental conditions such as depression, anxiety, or schizophrenia; cognitive impairments related to stroke, brain injury, or Alzheimer’s disease; and chronic pain conditions and autoimmune diseases such as fibromyalgia syndrome, reflex sympathetic dystrophy syndrome, lupus, rheumatoid arthritis, and various others.

Individuals with invisible disabilities face the same issues in function, quality of life and discrimination as individuals with obvious physical disabilities. These issues include stigmatization; interpersonal relationships with friends, family, significant others, and co-workers; employment/job retention; and educational attainment. The primary difference is additional stigmatization they face because their disability is not readily apparent. Since many individuals with invisible disabilities appear able-bodied and/or healthy they receive constant scrutiny about their disability status from family, friends, co-workers, loved-ones, and society in general.

This edition of *reSearch* provides a “snapshot” of research on invisible disabilities. This “snapshot” presents a general overview of invisible disabilities and the everyday issues individuals may encounter. Due to the limited amount of research we did not limit the results to a specific time frame. Combined search terms for this edition of *reSearch* included: invisible and hidden disabilities. Both terms are used interchangeably throughout the literature. A listing of over 100 additional descriptor terms between the NARIC, ERIC, and PubMed databases can be found at the end of this

document. A search of the REHABDATA database resulted in seven documents published between 1982 and 2008. The ERIC and PubMed database searches resulted in five documents between 2002 and 2009 and nine documents between 1993 and 2010, respectively. The complete citations are included in this research brief.

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*Full-text copies of these documents may be available through NARIC’s document delivery service.*

*To order any of the documents listed, please note the NARIC Accession Number (starts with a J, O, or R) and call an information specialist at 800/346-2742.*

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### **NIDRR Funded Projects Related Invisible Disabilities**

In addition to document searches, we searched our NIDRR Program Database to locate grantees/projects related to invisible disabilities. The search resulted in eight NIDRR funded projects — seven currently funded and one which has completed their research activities. Project information and their publications are offered as additional resources for our patrons.

#### **A Center on Postsecondary Education for Students with Intellectual Disabilities**

Project Number: H133A080042

Phone: 617/590-8082

[www.thinkcollege.net](http://www.thinkcollege.net)

#### **Cognitive Remediation, Illness Self-Management, and Supported Employment in Severe Mental Illness**

Project Number: H133G090206

Phone: 603/271-5747

Email: [susan.r.mcgurk@dartmouth.edu](mailto:susan.r.mcgurk@dartmouth.edu)

#### **Early Math Intervention Program for Improved Comprehension and Communication in Problem Solving for Students with Learning Disabilities**

Project Number: H133S090104

Phone: 212/361-3706

Email: [sarah@learnimation.com](mailto:sarah@learnimation.com)

#### **Improved Employment Outcomes for Individuals with Psychiatric Disabilities**

Project Number: H133B090014

Phone: 617/353-3549

Email: [mfarkas@bu.edu](mailto:mfarkas@bu.edu), [erogers@bu.edu](mailto:erogers@bu.edu)

#### **Rehabilitation Engineering Research Center for Cognitive Rehabilitation**

Project Number: H133E090003

Phone: 303/315-1281

Email: [cathy.bodine@ucdenver.edu](mailto:cathy.bodine@ucdenver.edu)

#### **Rehabilitation Research and Training Center for Children's Mental Health**

Project Number: H133B040024

Phone: 813/974-4661

Email: [kutash@fmhi.usf.edu](mailto:kutash@fmhi.usf.edu)

[rtckids.fmhi.usf.edu](http://rtckids.fmhi.usf.edu)

#### **Rehabilitation Research and Training Center on Participation and Community Living of Individuals with Psychiatric Disabilities**

Project Number: H133B080029

Phone: 215/746-6713

Email: [pennrrtc@mail.med.upenn.edu](mailto:pennrrtc@mail.med.upenn.edu)

[www.upennrrtc.org](http://www.upennrrtc.org)

*The following project has completed their research activities:*

#### **Exploratory Study of the Relationship between Stigma at the Workplace and the Vocational Recovery of People with Psychiatric Disabilities**

Project Number: H133G030190

Phone: 617/353-3549

Email: [zlatka@bu.edu](mailto:zlatka@bu.edu)

[www.bu.edu/SARPSYCH](http://www.bu.edu/SARPSYCH)



*Documents from NARIC's REHABDATA search listed are listed below:*

#### **2008**

Bellini, J., & Dalgin, R.S. (2008). **Invisible disability disclosure in an employment interview: Impact on employers' hiring decisions and views of employability.** *Rehabilitation Counseling Bulletin (ARCA)*, 52(1), 6-15.

NARIC Accession Number: J55721

**ABSTRACT:** Study investigated the impact of disclosure of invisible disabilities during the employment interview process. Sixty employers were shown a short interview vignette of a potential candidate and were asked to make a hiring decision and rate the candidate's employability. The vignettes permitted the manipulation of two key variables: type of disability (no disability, invisible physical disability, invisible psychiatric disability) and the extent of disclosure (brief disclosure, detailed disclosure). Results indicated a significant ef-

fect for disability type, with employers rating the candidate with a physical disability significantly higher than the candidate with a psychiatric disability. There were no significant effects for extent of disclosure; for the interaction of disability and extent of disclosure on employability; or for type of disability, extent of disclosure, and the interaction of disability and extent of disclosure on hiring decision. Implications of the study findings for persons with disabilities and rehabilitation counselors are discussed.

## 2005

Stone, S.D. (2005). **Reactions to invisible disability: The experiences of young women survivors of hemorrhagic stroke.** *Disability and Rehabilitation*, 27(6), 293-304.

NARIC Accession Number: J48968

ABSTRACT: Interviews were conducted with 22 young women who were long-term survivors of hemorrhagic stroke to learn about their experiences after the stroke. Participants expressed concerns about the reactions of others in terms of popular ideas about who is affected by stroke and the significance of having invisible disabilities. Their experiences were mediated by the cultural belief that stroke is a disease of old age, and by the belief that disabilities worth taking seriously are readily visible. These beliefs made it difficult for participants to deal with the reactions of others.

## 2003

(2003). *Pioneers in disability rights and community organizing: An interview with Sarah Triano.*

NARIC Accession Number: O15721

Abstract: Taped interview with Sarah Triano, a young woman with an invisible disability, who speaks about the importance and value to her, and to other young people, of knowing and working with others with disabilities and special health care needs.

Martz, E. (2003). **Invisibility of disability and work experience as predictors of employment among community college students with disabilities.** *Journal of Vocational Rehabilitation*, 18(3), 153-161.

NARIC Accession Number: J45659

Abstract: Survey study was conducted to determine whether demographic or psychological variables were the best predictors of employment status among college students with disabilities. The Reactions to Impairment and Disability Inventory and the Internal-External Locus of Control were administered to 200 community college students with disabilities. Psychological variables examined included locus of control, and acknowledgement and adjustment to disability. Demographic variables included perceived visibility of disability, age, education, marital status, age at onset of disability, and work experience. Results indicated that invisibility of disability and work experience were the best predictors of the participants' current work status. Individuals with invisible disabilities were 16 times more likely to be employed than individuals with visible disabilities.

## 1997

Wolff, T.L. (1997). **Becoming visible.** *Careers & the disABLED*, 12(2), 38-41.

NARIC Accession Number: J34628

ABSTRACT: Article about job search and employment concerns of persons with invisible disabilities, focusing on concerns regarding disclosure of the disability, what information to give the employer, and when to give it.

## 1994

Caras, S. (1994). **Disabled: One more label.** *Disability & Society*, 9(1), 89-92.

NARIC Accession Number: J27356

ABSTRACT: Personal account of the author's acceptance of her psychiatric impairment and decision to assume the label "disabled." She describes her initial discomfort with the new identification, how she learned that the Americans with Disabilities Act (ADA) applied to persons with psychiatric disabilities, and how she felt about using the label disabled when her disability was largely invisible. She relates how, despite five years of advocacy work in the mental health arena, she felt excluded from the broader disability knowledge base and the power of a unified cross-disability

movement. She explains some of the protections afforded people with disabilities under the ADA, and suggests that there is much to gain from using the label disabled to take advantage of these protections and become an active member in the cross-disability community.

## 1982

Allen, H.A., Falvo, D., & Maki, D. (1982). **Psychosocial aspects of invisible disabilities.** *Rehabilitation Literature*, 43(1).

NARIC Accession Number: J03098

ABSTRACT: The psychosocial aspects of invisible disabilities and their implications for the rehabilitation professional are explored and discussed. Definitions are offered for the concepts of invisible disabilities and the coping and adjustment mechanisms that may be associated with them.



*Documents from the Education Resource Information Center (ERIC) search at [www.eric.ed.gov](http://www.eric.ed.gov) are listed below:*

## 2009

Berland, J. (2009). **The elephant in the classroom.** *International Journal of Inclusive Education*, 13(7), 699-711.

ERIC #: EJ870782

ABSTRACT: Chronic fatigue syndrome/myalgic encephalomyelitis (CFE/ME) is an invisible disability that forces researchers to delineate new boundaries between illness and impairment, and between medical knowledge and patients' experience. As a neurological impairment, this condition attacks memory and cognition, which paradoxically become the focus of patients' own accounts of their experience and understanding. This paper addresses the pedagogical implications of this invisible disability. Drawing on emergent research on the social ties and social memory of elephants, this paper compares the forgetting in and about

invisible disabilities with the cultures of remembering and caring exemplified by the elephant who "never forgets". Just as the elephant exemplifies the interdependency of social relations and memory, so teachers and administrators can acknowledge different kinds of memory and expectations of memory and social process in pedagogical environments. (Contains 5 notes.)

Matthews, N. (2009). **Teaching the "invisible" disabled students in the classroom: Disclosure, inclusion and the social model of disability.** *Teaching in Higher Education*, 14(3), 229-239.

ERIC #: EJ858138

ABSTRACT: Drawing on the insights of critical disability studies, this article addresses anxieties frequently articulated by academic staff around the implementation of the United Kingdom's Disability Discrimination Act: how to accommodate the needs of students with "hidden" impairments. Following the social model of disability, it argues that universities should avoid the use of medical labels in identifying the learning needs of disabled students, and should make efforts to institute as part of everyday practice a diversity of inclusive teaching strategies. Finally it discusses an induction activity which sought to encourage students to disclose additional learning needs to university staff while opening up a discussion around difference, diversity with the student cohort as a whole.

Trammell, J. (2009). **Red-shirting college Students with disabilities.** *Learning Assistance Review*, 14(2), 21-31.

ERIC #: EJ866923

ABSTRACT: College and university students with disabilities, both visible and invisible, must deal with what sociologist Erving Goffman called information management; they must control and protect their stigmatized identity by considering who to tell what, how much to tell, and when to tell. A growing body of stigma-related educational research, as well as cultural evidence, suggests that postsecondary students with disabilities experience a significant stigma effect; they are in essence forced to wear a red shirt. This literature review article and the research associated with it suggest that disclosure may create as many problems as it solves

and points out the need for students with disabilities to learn better information management strategies. The implications for learning support are myriad and suggest that DSS offices may need to re-educate the entire community, giving practical suggestions.

## 2007

Henning, G. (2007). **What happens if others find out?** *About Campus*, 12(3), 26-29.

ERIC #: EJ791412

**ABSTRACT:** This author relates how, as a college student with an invisible disability, his experience affected his awareness of students with similar challenges and how educators can serve these students better. Henning shares his story in hopes that it will affect others' awareness of these students' challenges. To help students with hidden disabilities, he encourages educators to lay the foundation for relationships, be observant about students' behavior, and be willing to be active members of their students' lives. This will ensure that students with disabilities—visible and invisible—are treated as full members of their campus communities, that their unique needs are met, and that their academic and personal goals are achieved.


## 2002

Clark, C., Gorski, P., Pliner, S., Rector, C., & Singley, D. (2002). **The invisible made visible: Documentaries about living with psychological disabilities.** *MultiCultural Review*, 11(3), 62-65.

ERIC #: EJ656755

**ABSTRACT:** Reviews a decade of films and videos about depression, schizophrenia, and other emotional and psychological conditions as they affect women and men of different cultures. The article begins with a revelation by a recognized leader in multicultural education about his own struggle with depression and about how psychological disabilities are often omitted from the larger discussion of social justice and equity.

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 **Documents from the National Library of Medicine PubMed search at [www.pubmed.com](http://www.pubmed.com) are listed below:**

## 2010

Bosch, A.M., Gentile, J.K., & Ten, H.A.E. (2010). **Psychosocial aspects of PKU: Hidden disabilities — a review.** *Molecular Genetics and Metabolism*, 99 Suppl 1, S64-7.

PMID #: 20123473

**ABSTRACT:** Phenylketonuria (PKU) is an inborn error of metabolism, and its detrimental effects on neurocognitive functioning have been well studied. Early detection and treatment of PKU prevent the severe consequences of this disorder. However, even early- and well-treated patients experience hidden disabilities, including subtle deficits in executive functioning, mild reductions in mental processing speed, social difficulties, and emotional problems that may remain unnoticed for years. Poor executive function (EF) may impact treatment adherence and may lead to psychosocial deficits that are not always visible. These psychosocial aspects include social difficulties and psychosocial problems, such as forming interpersonal relationships, achieving autonomy, attaining educational goals, and having healthy emotional development. Studies report EF deficits in children and adults with early-treated PKU, which contribute significantly to the hidden disabilities in this population. In adults, hidden disabilities affect job performance and social relationships as a result of residual attention deficits, poor EF (e.g., planning, organizing), and reduced processing speed. An indirect relationship also exists between quality of life and EF impairment. In the absence of overt psychiatric symptoms, low level depressive or anxious symptom may be present. The interaction between the neurocognitive deficits and psychiatric symptoms puts this population of patients at significant risk for experiencing hidden disability. PKU is a disorder in which a less than optimal psychosocial outcome arises from the cumulative impact of relatively mild symptoms. The key to reducing risks associated with PKU is metabolic control throughout life. Copyright 2009 Elsevier Inc. All rights reserved.

## 2005

Davis, N.A. (2005). **Invisible disability.** *Ethics, 116*(1), 153-213.

PMID #: 16578955

No abstract available.

## 2004

Cronin, A.F. (2004). **Mothering a child with hidden impairments.** *American Journal of Occupational Therapy, 58*(1), 83-92.

PMID #: 14763639

ABSTRACT: When a mother has a child with a chronic impairment, the occupational demands of mothering extend to address the specialized needs of that child. This research explores how the type of hidden impairment in a child influences family routines and occupations. This qualitative study consisted of interviews with 22 mothers of children with attention deficit hyperactivity disorder (ADHD), a behavioral disorder, and 22 mothers of children with cystic fibrosis, a physical disorder. Open-ended questions were used to explore family demands, resources, time use, routines, concerns, and support. The transcripts of these interviews were analyzed in terms of consistency with existing literature on parenting the child with hidden disability, and for emergent themes. In this analysis the experiences of mothers of children with cystic fibrosis were consistent with research findings on other chronic conditions, with these mothers reporting that family provides them with extensive physical and emotional support. Although mothers of children with cystic fibrosis reported a persistent emotional sorrow, they felt they were able to "normalize" their daily routines. In contrast, mothers of children with ADHD reported little family support, high perception of child-related demands, and less confidence in their success in mothering these children. In describing their daily routines, these mothers often stated that there was no such thing as a "normal" day. They felt constantly "on alert" and did not feel that they had "normal" routines. Based on this study, mothers of children with ADHD felt distress because their child did not easily conform to social standards, and were likely to express exhaustion in their role as "mother." The pattern of responses offered by

these participants differs significantly from that of the participants whose children have cystic fibrosis, and from the usual pattern of coping with chronic childhood disability documented in the literature.

Lipson, J.G. (2004). **Multiple chemical sensitivities: Stigma and social experiences.** *Medical Anthropology Quarterly, 18*(2), 200-13.

PMID #: 15272804

ABSTRACT: Multiple Chemical Sensitivity (MCS), is an intolerance to everyday chemical and biological substances in amounts that do not bother other people, is a medically contested condition. In addition to symptoms and the ongoing difficulties of living with this condition, this hidden and stigmatized disability strongly impacts social relationships and daily life. Based on an ethnographic study, this article introduces the context of MCS in terms of cultural themes, the media, and the economic power of industries that manufacture the products that make people with MCS sick. Participants' experiences with family members and friends, in work and school settings, and with physicians exemplify the difficulties of living with MCS. I dedicate this article to Joan Ablon, my professor and mentor, whose work has always inspired my thinking and research topics.

## 2002

Sturge-Jacobs, M. (2002). **The experience of living with fibromyalgia: Confronting an invisible disability.** *Research and Theory for Nursing Practice, 16*(1), 19-31.

PMID #: 12371466

ABSTRACT: Fibromyalgia (FM) is a complex, chronic, painful musculoskeletal syndrome which is characterized by extreme fatigue, disordered sleep, and other associated physical and cognitive problems. Because its etiology is unknown, and because no specific pathophysiological mechanisms have been found to underlie the syndrome, making a diagnosis is very difficult. FM adversely affects the quality of life, and the societal costs based on medical expenses, lost wages, lost tax revenue and compensation expenditures are very significant. The purpose of this phenomenological study was to describe and enhance the understanding

of the experience of living with FM. The participants included nine women ranging in age from 30 years to 56 years who had been diagnosed with the condition for more than a year. Data were collected by means of unstructured interviews. Thematic analysis, using van Manen's (1990) methodology, identified eight themes: (a) pain-the constant presence, (b) fatigue-the invisible foe, (c) sleep-the impossible dream, (d) thinking of a frog (e) dealing with a flare-up, (f) longing for a normal life, (g) the power of naming-seeking a diagnosis, and (h) living within the boundaries. These themes were integral parts of the whole story, and through their interrelationships, the essence confronting an invisible disability was captured. The findings of this qualitative study have implications for nursing practice, education and research. It has become an increasing challenge for our health care system to adequately cope with the large numbers of persons diagnosed with chronic illnesses. Administrators of these systems can benefit from the information learned during this study.

## 2001

Jurkowski, E.T., & Keigher, S.M. (2001). **Life after a national nightmare: Coping with invisible illness and disability.** *Health & Social Work, 26*(4), 211-5.

PMID #: 11758862

*No abstract available.*

Wolf, L.E. (2001). **College students with ADHD and other hidden disabilities: Outcomes and interventions.** *Annals of the New York Academy of Sciences, 931*, 385-95.

PMID: 11462755

ABSTRACT: Nearly 25 years of special education law have enabled many qualified students with disabilities to graduate from college preparatory high school programs and enter institutes of higher education. The Americans with Disabilities Act enacted by Congress in 1990, the Individuals with Disabilities Education Act of 1975, and Section 504 of the Rehabilitation Act of 1973 all mandate special education services for students with disabilities. A parallel nationwide rise is being reported in the numbers of students with disabilities on college campuses. The greatest increase is seen in

students with so-called hidden disabilities such as learning disabilities, ADHD, and psychiatric disabilities. These students face a number of obstacles once they are admitted to college. Many factors, some intrinsic to the student and others extrinsic to the campus, moderate success in higher education. Overlapping or multiple diagnoses, psychological distress, poor social and interpersonal skills, persisting cognitive deficits (especially in the area of executive functioning), and alcohol abuse are important factors that must be understood as institutions of higher education strive to promote access and provide effective support services on their campuses.

## 1997

Crawford, A. (1997). **Chronic lung disease: an invisible disability.** *Community Nurse, 3*(2), 18-21.

PMID #: 9451112

*No abstract available.*

## 1993

Brooks, P.M., & March, L.M. (1993). **Arthritis: The hidden disability.** *Medical Journal of Australia, 158*(6), 369-71.

PMID #: 8479347

*No abstract available.*

## *Search Terms for Invisible Disabilities*









- 📖 Adjustment
- 📖 Academic Accommodations
- 📖 Activities of Daily Living
- 📖 ADA
- 📖 Adaptation
- 📖 Adjustment
- 📖 Advocacy
- 📖 Antidepressive Agents
- 📖 Arthritis
- 📖 Attention Deficit Disorder with Hyperactivity
- 📖 Attitudes toward Disabilities
- 📖 Barriers
- 📖 Cancer
- 📖 Caregivers/psychology
- 📖 Chronic Disease/Illness
- 📖 Cognition Ability/Disorders
- 📖 College Students
- 📖 Confidentiality
- 📖 Cystic Fibrosis
- 📖 Dehumanization
- 📖 Depression/Control/Prevention/Psychology
- 📖 Disabilities
- 📖 Disability/Classification/Discrimination  
Evaluation/Identification
- 📖 Disclosure
- 📖 Diseases
- 📖 Educational Environment/Practices
- 📖 Employer Attitudes
- 📖 Employment/Interviews
- 📖 Epilepsy
- 📖 Evaluation
- 📖 Fatigue
- 📖 Fibromyalgia/Diagnosis/Physiopathology  
Psychology
- 📖 Head Injuries
- 📖 Heart Disorders
- 📖 Hiring Practices
- 📖 HIV
- 📖 Interpersonal Relationships/Interaction
- 📖 Labeling (of Persons)
- 📖 Lung Diseases
- 📖 Memory
- 📖 Mental Disorders
- 📖 Military Personnel
- 📖 Models
- 📖 Mother-Child Relationship
- 📖 Multiple Chemical Sensitivity
- 📖 Neurological Impairments
- 📖 Outcomes
- 📖 People with Disabilities
- 📖 Posttraumatic Stress Disorder
- 📖 Prejudice
- 📖 Program Descriptions/Implementation
- 📖 Psychiatric Disabilities
- 📖 Psychosocial Factors
- 📖 Qualitative Analysis
- 📖 Quality of Life
- 📖 Rehabilitation Counseling
- 📖 Rehabilitation Programs
- 📖 Self Concept/Disclosure
- 📖 Social Attitudes/Behavior/Bias/Desirability  
Environment/Isolation/Services
- 📖 Special Needs Students
- 📖 Stress/ Etiology/Psychological
- 📖 Stroke
- 📖 Student Personnel Services
- 📖 Teaching Methods
- 📖 Treatment Outcome
- 📖 Universities
- 📖 Vocational Rehabilitation
- 📖 Workers with Disabilities



*About reSearch:*

*reSearch* is an information product from the National Rehabilitation Information Center (NARIC). Each issue is based on real-world queries received by our information specialists from researchers, educators, and rehabilitation professionals around the world.

We search several sources both in-house and online, to fill these requests including:

-  REHABDATA and the NIDRR Program database
-  Education Resources Information Center
-  National Clearinghouse of Rehabilitation Training Materials
-  Campbell and Cochrane Collaborations
-  PubMed and other National Library of Medicine databases
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