

Empowerment

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New Parent Guide for Families of Children with Osteogenesis Imperfecta

Osteogenesis imperfecta (OI), sometimes called “brittle bone disease” is a genetic disorder that affects the integrity of bone development as well as that of other connective tissue in the body. The Latin name is derived from words that translate into “imperfect bone beginning” meaning the problem exists from conception as opposed to disorders like osteoporosis that may begin with healthy bone that deteriorates over time.

There are several types of OI as well as levels of severity. The mildest forms may be barely noticeable to most observers while the most severe forms result in severe bone deformity, reduced stature, easily fractured bones, underdeveloped lungs, poor muscle tone and spinal curvature, dental problems, and hearing loss. All children with OI, however, are prone to fracture more easily than the average child. Ellen Painter Dollar (2001) in her introduction to OI uses

the analogy of a building or bridge to describe the structural problems associated with OI when she depicts the rods and cement that serve as the foundation for stability and flexibility that can withstand normal stresses while remaining stable. If the rods or cement are absent or insufficient in structure or function, the building may not have the stability it needs. Similarly, in the human body, if a defect in collagen (the main protein component of bone) production exists (as in the case of OI), the body skeleton may not have full strength or stability to withstand normal stress and pressure associated with activities like walking, falling, running, jumping, etc.

Currently, there is no cure, but

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physical management of OI includes addressing fractures and encouraging appropriate mobility and independence. Some children undergo surgical procedures to control fractures and improve strength and function by the insertion of rods (rodding) into long bones. Physical and occupational therapy may also be important to maximize function and independence.

Children with OI demonstrate an average range of intellectual function but because of physical issues, low incidence, and the need for staff with expertise in this area, they have not always been able to access an appropriate education in their neighborhood schools. At the Henry Viscardi School (HVS), a program for children with physical disabilities, which is part of the National Center for Disability Services on Long Island, children with OI have been educated for over 30 years as part of the school's student population.

Specialists at the Henry Viscardi School, including physical therapists, occupational therapists, speech and language pathologists, counselors, and other educational staff, have expertise in OI and in working as a team to assure the best possible outcomes for children with this disorder. Those outcomes include education, employment, and independent living. Based on their expertise in this area, a team of experts from the Henry Viscardi School collaborated on a chapter about Educating the Child with OI in the parent guide recently

published by the Osteogenesis Imperfecta Foundation, which is cited below.

Any parent or advocate of a child with a disability knows the importance of accurate information in attempting to assure appropriate educational services. One physical therapist indicated that in many professional preparation programs, OI is one of the disorders that is described briefly in terms of symptoms and then glossed over as an issue that "you may never actually have to deal with." This is exactly why a guide like this with specific information on educational services is so important.

The chapter written by HVS staff summarizes federal mandates covered in the Individuals with Disabilities Education Act (IDEA) that describe the rights and processes involved in determining an appropriate educational program for a child with special needs. Children with OI can fall into the category of orthopedic impairments that qualify a child for special services based on educational need. The chapter details information helpful to parents and teachers about considerations regarding a physical environment that provides the balance of multi-sensory experiences to develop gross motor skills, spatial awareness, and organizational skills as children continue to develop cognitively. Manipulative materials as well as adaptive toys operated by foot switches or remote controls, tape recorders or word processors for written tasks are

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some of the possibilities addressed for insuring active participation by children in the learning process despite possible physical limitations or fatigue.

Low tech and high tech adaptations for classroom learning might also include consideration of pencil grips, adapted scissors, page turners, felt tip pens easels and slant boards as well as adapted mouse, voice activation, and on screen keyboards. The importance of an appropriate physical education program with any necessary adaptations is stressed as well as the ongoing involvement of physical and occupational therapists. The physical environment should be considered to determine architectural barriers, transportation issues, and personal care needs in any educational setting.

Teachers and parents looking for more information on educational adaptations and assistive technology resources for children with OI that facilitate the learning process and maximize their engagement in school based academic, physical, and social activities should read the chapter that was a team effort on the part of contributing Henry Viscardi School staff members. For the complete chapter and book, see:

McCabe, M., & Rosalie, N. (2001). *Educating the Child with Osteogenesis Imperfecta*. In E. P. Dollar (Ed.), *Growing Up with OI: A Guide for Families and Caregivers*. (pp. 161-208). Osteogenesis Imperfecta Foundation.

For additional information on OI, contact Maureen McCabe at the Henry Viscardi School.

Promoting Community Participation through Team-based Health Services

Research has shown that compared to their peers, people with disabilities have a more difficult time attaining a similar degree of social and vocational independence. While they experience the same developmental transitions as their peers without disabilities, young adults with disabilities must deal also with physical, academic, social, and/or medical difficulties. These additional concerns provide health-care and social-care service professionals with "unique opportunities to promote social and occupational integration of disabled and chronically ill youths, helping them to maximize their participation in society" (Bent et al.). By providing healthcare and social services that promote autonomy and self-advocacy, service providers also are teaching young adults with disabilities skills to access and use available resources in their communities.

In reviewing current health services, Bent and colleagues (2002) noticed that often these services were provided in an ad hoc manner by many different organizations with their own

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criteria for determining how services were defined. Consequently, medical concerns are addressed, while many psychosocial issues pertaining to the disability, such as the individual's self-esteem, self-efficacy, proactive attitude, and stress, are overlooked. According to a 1992 report by the United Kingdom National Audit Office, such fragmented services did not meet the transitional needs of young adults with disabilities from childhood services to adult services. To compensate for this shortcoming, specialist teams consisting of a consultant in rehabilitation, a psychologist, therapists, and a social worker should be used to provide a coordinated service that would address both medical and psychosocial aspects of the disability. These observations led Bent and colleagues (2002) to study whether having access to a team-based approach would increase the degree of participation among individuals with physical and chronic disabilities in society, in comparison to those individuals who used ad hoc services, and the cost-effectiveness of using a team-based approach.

Comparing college students without disabilities to young adults with long-term physical disabilities, Bent and colleagues (2002) found that although the college students exhibited higher self-esteem and were less stressed than the young adults with

disabilities, they had lower self-efficacy scores, and were lonelier. In addition, the young people with disabilities rated their health status higher than did the college students. The study also found that pain, fatigue, and stress resulting from the disability influenced the young adult's level of participation in society. More important, not only were young adults with disabilities who were cared for by a specialist rather than an ad hoc team more likely to participate in society, but the cost of implementing the team-based approach was no more than the cost to implement the ad hoc approach.

The study's retrospective design highlighted several barriers that must be addressed when facilitating the transition from pediatric to adult health-care services: (1) the discrepancies between how the disability is reported by service professionals and the way the individual perceived his or her disability, and (2) psychosocial issues tend to change as the individual's resiliency and coping skills change when the young adult moves into adulthood. Therefore, both health care and social-care services must be able to reflect these changes.

Please refer to the full text article for more information:

Bent, N., Tennant, A., Swift, T., Posnett, J., Schuffham, P., & Chamerlain, M. (2002). Team-approach versus ad hoc Health Services for Young People with Disabilities: A retrospective cohort study. *The Lancet*, vol. 360 (9342),

Study Reports on the Self-perceived Training Needs of VR Counselors.

This article discussed the findings of a study that identified some of the training needs of state vocational rehabilitation (VR) counselors. In addition, the article compared the self-perceived training needs of state VR counselors with those of certified rehabilitation counselors (CRCs).

Research Questions of the Study:

1. For which rehabilitation counseling component areas do state VR counselors report the highest need for training?
2. Do perceptions of need for training differ between state-federal VR counselors and CRCs as reported by Szymanski (1993a)?
3. Are there counselor demographic variables that are significantly related to self-reported training need? Specifically, are a counselors' gender, age, ethnicity, years of experience, highest degree earned, CRC status, number of certifications held, disability status, and work location (rural v. urban) significant predictors of his or her need for training?

Instrument and Design

One hundred and sixty-seven VR counselors from three states, Maryland, Virginia, and the District of Columbia completed the Rehabilitation Counseling Knowledge Inventory (RCKI). The RCKI is a two part self-reporting questionnaire composed of 57 rehabilitation counseling knowledge areas. Each of the 57 items is rated in two 5-point Likert-type scales.

The *Importance scale* is used to evaluate each knowledge area in relation to the participant's role as a rehabilitation counselor [0 = not important, 1 = of little importance, 2 = of moderate importance, 3 = highly important, and 4 = very highly important]. The *Preparedness scale* is used to assess the degree to which each participant feels prepared relative to each knowledge area [0 = no preparation, 1 = little preparation, 2 = moderate preparation, 3 = high degree of preparation, and 4 = very high degree of preparation].

The authors followed the methodology established by Szymanski (1993a). *Need for training* was defined as the *difference between* the perceived *importance* and perceived *preparedness* of the items in the instrument. The perceived need for training on each item could range from -4 to +4. The items addressed by the instrument were reduced into 10 components: (1)

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vocational services; (2) case management and services; (3) group and family issues; (4) medical and psychological aspect of disability; (5) foundations of rehabilitation; (6) workers compensation, employer services, and technology; (7) social, cultural, and environmental issues; (8) research; (9) individual counseling and development; and (10) assessment.

Sample

- Average age of participants was 43 years
- Average number of years of experience as a rehabilitation counselor was 10.75
- Race:
 - o 73% Caucasian
 - o 22.2% African American
 - o 3% Other
 - o 1.2% Latino/Hispanic
 - o .6% Asian American/Pacific Islander
- Education:
 - o 46.7% bachelor's degree
 - o 26.3% master's degree in rehabilitation counseling
 - o 15.6% master's degree in a field related to rehabilitation counseling
 - o 9.6% master's degree in a field not related to rehabilitation counseling

- o 1.8% associate degree
- CRC credential - 18%

Results

For which rehabilitation counseling component areas do state VR counselors report the highest need for training? (difference between the perceived importance and perceived preparedness)

1. Vocational services
2. Assessment
3. Workers compensation, employer services, and technology
4. Case management and services
5. Medical and psychological aspects of disabilities
6. Social, cultural and environmental issues
7. Individual counseling and development
8. Foundations of rehabilitation
9. Research
10. Groups and family issues

The mean discrepancy ratings were high or moderately high in 6 out of the 10 components, which indicates that although participants felt an item was important to the performance of their job duties, they did not necessarily feel prepared to complete the task.

These findings suggest there is a large-scale need for training among

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state VR counselors. An interesting finding was that some of the items that were ranked as least important to their jobs, are items highlighted in the educational programs for rehabilitation counselors. This ranking may also reflect on some of the limitations that exist in the rehabilitation counseling practices in state agencies, for example, VR counselors may not be current in terms of cutting-edge technological advancements, which may have a serious impact on rehabilitation outcomes.

Do perceptions of need for training differ between state-federal VR counselors and CRCs as reported by Szymanski (1993a)?

Significant differences in perceived training needs were observed in 4 out of the 10 components. The state VR counselors had significantly greater discrepancy ratings in 3 component areas, which indicated a greater perceived need for training in those areas: assessment, individual counseling and development, and foundations of rehabilitation. Their need for training was lower, as compared to CRCs, in the component area of workers' compensation, employer services, and technology.

Are there counselor demographic variables that are significantly related to self-reported training need?

None of the counselors' demographic variables was a significant pre-

dictor of the total training needed. Highest earned degree was a predictor of need for training in 4 out of 10 of the component areas: group and family issues, foundations of rehabilitation, research, and individual counseling and development. In general, the more education a participant had, the less need for training he/she reported. This finding may support the idea that rehabilitation counselors need a master's degree in order to feel prepared to carry out their job functions.

The authors also included a discussion of the limitations of the study and its findings, as well as recommendations for future research and training.

For full article see:

Froehlich, J. R. & Linkowski C. D. (2000). An Assessment of the Training Needs of State Vocational Rehabilitation Counselors. *Rehabilitation Counseling Bulletin*, 46:1. 42-50.

Other reference:

Szymanski, E. M., Leahy, M. J., Diamond, E. E., & Thoreson, R. W. (1993a). Human resource development: An examination of perceived training needs of certified rehabilitation counselors. *Rehabilitation Counseling Bulletin*, 37, 163-181.

Upcoming Disability Related Conferences

Conference	Dates	Location
Learning Disabilities Association of America International Conference	2/26-3/1	Chicago, IL
CSUN's 18th Annual International Conference	3/17-3/22	Los Angeles, CA
First International Conference on Positive Behavior Support	3/27-3/29	Orlando, FL
Power Up 2003, 10th Annual Conference & Expo on Assistive Technology	4/7-4/8	Columbia, MO
National Business & Disability Council 25th Annual Conference	4/7-4/9	Atlanta, GA
Council for Exceptional Children Conference and Expo	4/9-4/12	Seattle, WA

For more information about these and other upcoming conferences, contact Marguerita Burke at (516) 465-1605 or e-mail mburke@ncds.org.

ABOUT EMPOWERMENT

We are pleased to present this sixth issue of Empowerment, the newsletter that focuses on education, employment, technology, and policy for people with disabilities. Our goal is to empower professionals within the disability field with current information on relevant topics. We accomplish this primarily by summarizing current research articles that are relevant to the disabilities field. If you know of any organizations that might be interested in receiving this newsletter, or if you would like to contribute to future issues, please contact the Research and Evaluation Center. Thank you for your continued feedback and support.

Stephen Morabito
Empowerment Editor

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