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Implementation of an evidence-based seizure algorithm in intellectual disability nursing: A pilot study

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Abstract

Based on the results of the *Surrogate Decision-Making Self Efficacy Scale* (Lopez, 2009), this study sought to determine if nurses working in the field of intellectual disability experience increased confidence when they implemented the “American Association of Neuroscience Nurses Seizure Algorithm” during telephone triage. The results of the study indicated using the AANN Seizure Algorithm increased self-confidence for many of the nurses in guiding care decisions during telephone triage. The treatment effect was statistically significant $-3.169, p, .01$ for a small sample of study participants. This increase in confidence is clinically essential for two reasons. Many individuals with intellectual disability and epilepsy reside within community based settings. Intellectual disability nurses provide seizure guidance to this population living in community based settings via telephone triage. Nurses improved confidence is clinically essential and has implications for practice. Evidenced-based training tools provide a valuable mechanism by guiding nurses via best practices. Nurses may need to be formally trained for seizure management due to high epilepsy rates in this population.

Key Words

Algorithm, confidence, intellectual disability, nurses, seizures

Introduction

According to the World Health Organization about 15% of the world's population lives with some form of disability (World Health Organization, 2011). The prevalence of epilepsy in children with intellectual disability living in community based settings has been projected to be between 14% and 44%. Although no definitive study has defined the exact prevalence of epilepsy in IDD persons by country, it is estimated that one-fifth of individuals with IDD may present with epilepsy symptoms (Welch Office 1995 in Bowley & Kerr, 2000).

In the United States it is estimated that there are 15% or one in six children diagnosed with an intellectual disability (Boyle et al., 2011), and 4.3 million individuals with intellectual disability living in community-based settings (United States Department of Health and Human Services, 2006); and over 634,000 who receive state and federal funding (State of the States in Developmental Disabilities Report, 2015). Research findings surrounding children diagnosed with intellectual disability suggests that the trend for diagnosing will continue to increase over the next decade with a noted increase of 17% during the years from 2006-2008. Studies also demonstrate that the comorbid condition of seizure activity is also on the rise with an increase of 9.1% identified during the same time period for individuals diagnosed with an intellectual disability (Boyle et al., 2011).

Seizure management in the intellectual disability population is a health problem that is impacted by many factors specific to this population. In a prevalence systematic review, Oeseburg et al. (2011) found approximately 30% of people with intellectual disability also have the diagnosis of epilepsy. This percentage increases concurrently with the severity of the

disability (mild, moderate, severe, profound) and co-existing complications such as other neurological conditions, cardiovascular disease, sensory, and musculoskeletal. Individuals with refractory seizures are also at an increased risk for injury and death, including ‘sudden death’ due to the underlying causes of the epilepsy (Vallenga et al., 2006). Seizures in this population are oftentimes atypical in presentation making it difficult to accurately make a diagnosis. Persons with intellectual disability can also have multiple types of seizure activity making seizure identification and treatment choices more difficult for practitioners, nurses, and direct care providers (Keller, 2012). Individuals with intellectual disability often have complex and fragile health concerns that can increase the complexity of health care decision-making including seizure management.

Due to a shift in state and national policy over the last decade, persons with intellectual disability have transitioned out of institutions and into community-based settings (United States Department of Health and Human Services, 2006). While this is a desired change in environment that affords individuals the opportunity to be involved in their community it also produces an increased risk to individuals with intellectual disability. Comparatively, over the last decade, other countries including Canada, England, Wales, and Australia have also embraced deinstitutionalization in favor of community based living (Braddock, Emerson, Felce, & Stancliffe, 2001). Therefore, the possible increased health risk for individuals with intellectual disability diagnosed with epilepsy may also exist in other countries as well.

Children and adults with disability especially those with intellectual disability, cerebral palsy, and autism are at an increased risk for medically refractory epilepsy, and prolonged or

repetitive seizures. Delaying therapy or decisions regarding seizure care until individuals are in the emergency department can result in increased morbidity (Ramsay, Shields, & Shinnar, 2007). These special circumstances increase the risk for these individuals when care is provided by non-licensed care givers known as direct support professionals (DSPs). DSPs often have little or no healthcare background. Nurses working in the field of intellectual disability provide guidance and support to the DSPs often through telephone triage.

In the United States, problems exist even though practicing nurses encounter people with intellectual disability in their practice research studies reveal that most have not received education related to this population (Walsh et al., 2000) and many times little experience with how intellectual disability interfaces with epilepsy. Adding to this barrier is the fact that nurses working within the field of intellectual disability are charged with providing telephone triage to DSPs before, during, and after seizure activity is experienced by a person with intellectual disability living in a community-based setting.

Nurses practicing in the field of intellectual disability in the United States can be registered nurses (RN) or licensed practical nurses (LPN). RNs at minimum possess an associate degree in nursing but may hold a Bachelor's, Master's, or Doctoral degree. LPNs most often hold a one year technical degree (Cherry, 2014). ID nurses provide routine care based on the needs of the individual they are serving, the type of community based setting, and in accordance with State and Federal Regulations. Settings are generally divided into Supported Group Living, commonly known as "Group Homes" or Home and Community Based Settings known commonly as "Waiver Homes".

Group Homes are federal programs administered by individual states. For example, in The State of Indiana, “Rule 460 IAC, Article 9”, provides the guidelines for nurses. The rule requires nurses to complete a face to face assessment on each individual at minimum one time per month; and in accordance with their needs. Nurses working in Group Home Settings will complete an assessment and develop a plan of care to be followed.

Waiver Homes are also federal programs administered by each State and can be varied depending on the State in which care is delivered. In the State of Indiana, Waiver nurses must complete an online assessment that determines the minimal number of face to face assessments and care activities that must be completed by the nurse. These requirements are outlined in The State of Indiana “Rule 460 IAC 6” and is overseen by the Bureau of Developmental Disabilities Services. Nurses participating in this study provided nursing care to individuals residing within both types of community based settings and followed the guidelines set forth in the above mentioned rules. The role of the ID nurse in community based settings also appears similar in other countries. In the article by Sheerin (2011) the role of the ID nurse in the United Kingdom and Ireland includes: assessment, health surveillance, health promotion, and coordination of services.

When compared to the living arrangements in other countries the research by Braddock et al. (2001) state that adults with intellectual disability live within a variety of home settings; including the countries of Canada, England, Wales, and Australia, and are most often determined by the authorities responsible for providing care to this population. This description appears similar to how living arrangements are determined within the United States.

Telephone triage is a critical component of intellectual disability nursing. Intellectual disability nurses generally are assigned a caseload of individuals who live in community-based settings. These homes are most often geographically spread out making it difficult for the intellectual disability nurse to be onsite when seizure activity occurs for one of the individuals on their caseload. In general, the intellectual disability nurse receives a phone call from a non-licensed DSP describing the seizure activity and requesting advice. As previously stated, many times these nurses have little experience with intellectual disability and epilepsy in this population, and even less experience with telephone triage. Additionally, nurses may be unprepared to use evidence-based practice nursing tools to support the care of persons with intellectual disability (Hahn, 2014).

Research studies support the use of telephone triage for guiding nursing practice reporting that telephone triage models demonstrated medical appropriateness of care and that patients followed through on nursing advice (Marklund et al., 2007). Study results verified that nurses support the use of decision-making tools and would use them when they are provided (Cole, Pointu, Wellsted, 2010). In the coordination of primary and community-based care, evidence demonstrated that the role of the primary care provider may be augmented by the use of guidelines used by epilepsy nurses in the community. This augmentation may have the potential to improve care for individuals with disabilities (Rajpura & Sethi, 2004).

This study is timely for both intellectual disability nurses and individuals with intellectual disability with the comorbid condition of epilepsy. Across the country large institutions are closing down and more persons with intellectual disability are living in community-based settings, and are

being supported by intellectual disability nurses using telephone triage to guide care. In addition, people with intellectual disability are living longer than ever before (Lakin & Stancliffe, 2007). These two changes necessitate a need for more intellectual disability nurses practicing with evidence-based tools and making better care decisions for persons with intellectual disability and epilepsy.

The purpose of the study was to measure nursing confidence during intellectual disability seizure telephone triage management. Empowerment of nurses is critical to appropriate clinical decision-making. Importantly, this study implemented the “American Association of Neuroscience Nurses Seizure Assessment Algorithm” (AANN, 2011) and evaluated its impact on the confidence level of intellectual disability nurses before and after using the AANN Seizure Algorithm by self-scoring the *Surrogate Decision-Making Self-Efficacy Scale* (Lopez, 2009).

Method

Study Aim and Objective

This was a three month long implementation pilot study of an evidence-based seizure algorithm for nurses working in the field of intellectual disability. Participant nurses provided nursing care to individuals with intellectual disability and epilepsy living in community-based settings via telephone triage. The aim of the implementation pilot study was to test the confidence level of nurses prior to implementing the evidence- based algorithm and three months post implementation of the seizure algorithm. Statistical tests appropriate to the study design were carried out pre and post intervention.

The research proposal was submitted to the Internal Review Board (IRB) at Indiana University to determine that it was ethically sound prior to implementation. After reviewing the information with the IRB the board determined that the study would be an Exempt Research Study based on the four key facts: 1. The study did not make use of students 2. The research did not involve children in survey procedures, interview procedures, or observation of public behavior 3. No information would be recorded in a way that human subjects could be identified 4. No disclosure of subjects' responses outside the research would place the subjects at risk for criminal or civil liability or be damaging to the subjects' financial standing, employability, insurability, or reputation (IRB, 2013). Participants were volunteer nurses and no information related to individuals with ID and epilepsy was used within this study.

The One-Group Pre-Test –Post-Test Design was chosen for this study due to its appropriateness for collecting pre and post intervention data and measuring change within a group (Polit & Beck, 2004). Additionally, this design permits associations between the intervention and outcome to be examined. The study measured nursing confidence using the Surrogate Decision-Making Self Efficacy Scale (SDM-SES) prior to and 3 months following the use of the AANN Seizure Assessment Algorithm. Following the conclusion of the three month study the following questions regarding professional education and experience were asked via email correspondence: 1. How long have you been a nurse working with the ID population? 2. Have you received formal training in seizure management in the past (excluding nursing school?).

Instrumentation

The SDM-SES is an evidence-based Likert Scale consisting of five questions with ranked orders from Strongly Agree (4), Agree (3), Disagree (2), to Strongly Disagree (1). The SDM-SES was originally constructed to test the confidence level of caregivers acting as surrogate decision makers for individuals with dementia. The Surrogate Decision Making Self Efficacy Scale is composed of five questions that were drawn using a grounded theory approach to determine how surrogate decisions were made for treatment of acutely ill nursing home residents. The face validity was determined by requesting three experts to review the five questions for clarity, comprehension, and relevance (Lopez, 2009). Face validity for the instrument was acknowledged appropriate when presented to IDD nurses and was determined to be sensitive for the items measured.

The SDM-SES was adapted by this researcher with permission by its author (Lopez) for use with the intellectual disability population and served to measure the potential quantitative change in nursing confidence before and after implementation of the AANN seizure algorithm. The SDM-SES scale language was revised to replace the term “individual with memory impairment” to “the individual with intellectual/developmental disability experiencing seizure activity”. In addition this study tested the confidence level of nurses during telephone triage so that language was also included. The adapted scale was sent to Dr. Palan Lopez for review and approval. No changes were made to the actual scoring of the scale to ensure its validity and reliability.

The construct validity of the SDM-SES was previously conducted with confirmatory factor analysis (CFA). The results of the CFA in previous studies using the SDM-SES indicated that the single factor model explained 99% of the variance and all items loaded highly (greater than 0.60) to the theoretical construct. Therefore the psychometric properties of the instrument are sound (Guarino, 2014) in assessing nursing confidence. The AANN Seizure Assessment Algorithm is part of a comprehensive seizure management plan authored and endorsed by the AANN. The Algorithm is included in the educational packet entitled “Care of the Patient with Seizures” that was developed by a panel of experts “The Seizure Guide Task Force”. The purpose of the educational document is to provide clinical practice guidelines for nurses and other health care professionals; in order to provide safe and effective care to patients with seizures (AANN).

Participants

The subjects for this study included members listed on the email database of the Indiana Developmental Disability Nurses Association. These nurses implemented the AANN Seizure Assessment Algorithm during telephone triage to help guide seizure care for individuals with intellectual disability that were also diagnosed with epilepsy and who resided within community based settings in the State of Indiana between the dates of May 1, 2014 and August 1, 2014.

Procedure

The sample was one hundred seventy-two nurse volunteers who were solicited via an email from a survey listed on the Indiana Developmental Disabilities Nurses Association email database in May of 2014. This database sample was used to solicit the population of nurses in the

State of Indiana who practice in the field of intellectual disability. A total of 15 volunteers indicated their interest in study participation.

Data variable identification, collection process, and data analysis

Nursing confidence was the dependent variable of this this research project. The data was collected using the pre and post scores of the Self-Efficacy Surrogate Decision Making Self-Efficacy Scale (SDM-SES) prior to and three months following the implementation of the evidenced-based intervention (independent variable): “The American Association of Neuroscience Nurses Seizure Assessment Algorithm”. The SDM-SES was sent out via email to the fifteen nurses of the Indiana Developmental Disabilities Nurses Association who agreed to participate in the study. Upon return of the SDM-SES via email the results were entered onto a spread sheet and de-identified using numbered codes.

Following the completion and submission of the initial SDM-SES the volunteer participants received training via email that included a power-point presentation and information training sheets on how to implement the independent variable intervention the “American Association of Neuroscience Nurses Seizure Assessment Algorithm”. The start date for implementing the algorithm (May 1, 2014) was established as well as a discontinue date of August 1, 2014. At the conclusion of the study the pre and post test scores were entered into two separate data columns in the Statistical Package for the Social Sciences (SPSS, Version 21, 2014); matching the first score participant in column one and the second score in the second column. The Paired Samples T Test was used for analysis. The treatment effect was statistically significant $-3.169, p, .01$ for the small sample of participants.

Results

Following the discontinuation date in August 1, 2014 the 15 voluntary participants received the post intervention SDM-SES test. The volunteers returned the SDM-SES via email. The results were added to the initial spreadsheet, de-identified, and correlated with previous pre-testing data results, entered onto the spreadsheet, and prepared for analysis. The statistical process used to conduct the Repeated Measures T Test using SPSS.

Of the one hundred seventy-two nurses recruited via email request, fifteen volunteered to participate within the study. During the study, one participant did not return the initial SDM-SES pre-test, one volunteer left their position, and two participants did not submit the post-SDM-SES test resulting in 11 nurses who completed the entire study.

The results of the study indicated using the AANN Seizure Algorithm increased self-confidence for many of the nurses in guiding care decisions during telephone triage. Of the 11 nurses who completed the study; 8 were registered nurses and 3 were licensed practical nurses. The mean pre-confidence score was 15.6364 and the mean post-confidence score was 17.6364 with a mean difference of 2.00 ($M = -2.00$, $SD = 2.09$). A further breakdown between registered nurse response and licensed practical nurse response was also calculated. The mean increase in registered nurse scores was 2.8 with two having the same (highest available) score both pre and post testing. The mean increase of licensed practical nurses was 3.3 points, indicating a possible greater need for seizure education and use of evidence based tools for licensed practical nurses in the field of intellectual disability nursing. The treatment effect was statistically significant (paired t test (10) = -3.162, $p < 0.01$), $t = -3.162$, ($df = 10$) = -3.169, $p = .01$, Cohen's $d = 0.95$, $r^2 = 0.49$. Pre and Post Intervention Responses are detailed in table 1.

Table 1. Pre intervention responses and post intervention responses

Surrogate Decision Making Self-Efficacy Scale

	Strongly Agree (4)	Agree (3)	Disagree (2)	Strongly Disagree (1)
1. I am confident that I know when I need to make decisions during telephone triage for the individual with intellectual/developmental disability experiencing seizure activity	Pre- 6 Post-9	Pre- 5 Post-2	Pre- 1 Post-0	Pre- 0 Post-0
2. I am confident that I can obtain the information I need to make informed decisions during telephone triage for the individual with intellectual/developmental disability experiencing seizure activity	Pre- 3 Post-5	Pre- 7 Post-6	Pre- 2 Post-0	Pre- 0 Post-0
3. I am certain that I can weigh the risks and benefits of various treatment options during telephone triage for the individual with intellectual/developmental disability experiencing seizure activity	Pre- 6 Post-6	Pre- 4 Post-5	Pre- 2 Post-0	Pre- 0 Post-0
4. I am capable of making the best treatment decisions during telephone triage for the individual with intellectual/developmental disability experiencing seizure activity	Pre- 6 Post-6	Pre- 5 Post-5	Pre- 1 Post-0	Pre- 0 Post-0
5. I am confident that I know what treatment options that the individual with intellectual/developmental disability experiencing seizure activity would choose during telephone triage if he/she was able to express his/her preference	Pre- 2 Post-4	Pre- 4 Post-6	Pre- 6 Post-1	Pre- 0 Post-0

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It is also important to note that 10 out of 11 participants answered professional education and experience questions via email at the conclusion of the study. The results of these questions suggest that there is a need for evidence-based practice tools in seizure management for nurses working with the intellectual disability population as well as post nursing education in epilepsy.

Table 2. Post study participant responses related to professional education and experience

How many times did you use the AANN Seizure Algorithm during the 3 month study?	Results indicated that the AANN Seizure Algorithm had been used 116 times during the 3 month study period, indicating a significant need for evidence-based tools to guide care.
How long have you been a nurse working with intellectual disability population?	The mean length of time the nurses had practiced within the field of intellectual disability was 9 years, demonstrating that most nurses were comfortable providing care to this population.
Have you received formal training in seizure management in the past (excluding nursing school)	Lastly, only one nurse responded that they had received seizure training outside of nursing school indicating a possible need for education in the field of epilepsy and intellectual disability nursing practice.

Discussion

Individuals with intellectual disability have a higher incidence of epilepsy than the general population (Ramsay et al, 2007). The housing trend in the United States (United States Department of Health and Human Services, 2006) and other countries including Canada, England, Wales, and Australia, over the past decade, has been to transition individuals with intellectual disability out of state institutions and place them in community based settings (Braddock, Emerson, Felce, & Stancliffe, 2001). Care for this population in community-based settings is most often provided by direct support professionals with little or no healthcare background (U.S. Department of Health and Human Services).

These direct support professionals oftentimes rely on nursing personnel to help guide care including seizure management. Intellectual disability nurses frequently carry large caseloads of individuals that are geographically spread out. These conditions make it difficult for intellectual disability nurses to be present when seizure activity occurs for an individual under their care.

Intellectual disability nurses therefore, often provide guidance via telephone triage. Nurses working in the intellectual disability field may be reluctant to use evidence-based practice interventions to guide their recommendations (Hahn, 2001). In addition many intellectual disability nurses have little or no formal training in seizure management or in working with this specialized population (Walsh et al, 2000). These two facts may impact the confidence level of intellectual disability nurses when guiding care during telephone triage.

This pilot study provided the nursing participants with an evidence-based intervention for guiding seizure care during telephone triage. The final results indicate that using evidence-based protocols may increase the confidence level of intellectual disability nurses when guiding seizure care during telephone triage. It also implies that nurses provide seizure guidance via telephone triage to direct support professionals at a significant level. Due to this high level of epilepsy support required for this population, there may be a significant need for seizure training management for intellectual disability nurses who provide telephone triage to direct support professionals.

Decision-making in nursing is complex and includes weighing decisions that need to satisfy many interests such as the family, institution and physicians (Lopez, 2009). Competence and self-confident have been identified as the most important variables that influence nurse decision-making (Hagbaghery, Salsali, Ahmadi, 2004). This pilot study demonstrated that decision-making confidence was significantly improved for the nursing participants. This finding, although specific to this study, holds important clinical meaning.

The pilot study also supports the theory that intellectual disability nurses may use evidence-based protocols in other areas of nursing practice when these protocols are made available to them. Lastly, the possible use of the AANN seizure algorithm may be a valid training tool to help determine certification requirements in the field of intellectual disability through the national Developmental Disabilities Nurses Association (DDNA).

It is important to acknowledge that the study did not include testing of the adapted version on the SDM-SES confidence instrument. This study is also limited by the small number of participants as well as the short time span of the post-test period. The study should be replicated to improve generalizability.

Conclusion

Based on the results of the *Surrogate Decision-Making Self Efficacy Scale* (Lopez, 2009), this study sought to determine if nurses working in the field of intellectual disability implemented the “American Association of Neuroscience Nurses Seizure Algorithm” during telephone triage calls for individuals with intellectual disability who are experiencing seizure activity; would their confidence to manage seizures successfully increase?

The results of the study indicated using the AANN Seizure Algorithm increased self-confidence for many of the nurses in guiding care decisions during telephone triage. The treatment effect was statistically significant $-3.169, p, .01$. This increase in confidence is clinically essential for seizure management. Many individuals with intellectual disability and epilepsy reside within community based settings and intellectual disability nurses provide seizure guidance to this population living in community based settings via telephone triage. Implications exist for clinical practice as intellectual disability disparities are real. Services for this population need attention and nurses need training and tools to guide practice. Access to appropriate healthcare provided by clinicians proficient in this population is lacking. This creates a gap in appropriate seizure management for this population. An evidenced-based tool to assist intellectual disability nurses to make seizure management decisions during telephone triage may offer access to appropriate care that is not currently available.

References

- American Association of Neuroscience Nurses (2009) Care of the patient with seizures: Second Edition, AANN Practice Guideline Series. www.aann.org.
- Boyle C, Boulet S, Schieve L, Cohen R, Blumberg, S, Allsopp M, Visser, S, Kogan, M (2008) Trends in the prevalence of developmental disabilities in us children, 1997-2008. (2011) <http://pediatrics.aappublications.org/content/early/2011/05/19/peds.2010-2989.abstract>.
- Bowley, C., Kerr, M. (2000). Epilepsy and intellectual disability. *Journal of Intellectual Disability Research. Vol 44, part 5*,
- Braddock D, Emerson E, Felce D, and Stancliffe R (2001) Living circumstances of children and adults with mental retardation or developmental disabilities in the united states, Canada, England and wales, and Australia. *Mental Retardation and Developmental Disabilities Research Reviews* 7: 115-121.
- Cherry B and Jacob S. (2014) *Contemporary Nursing: issues, trends, & management*. St. Louis: Mosby
- Cole C, Pointu A, Wellsted D and Angus-Leppan H (2010) A pilot study of the epilepsy risk awareness checklist (ERAC) in people with epilepsy and learning disabilities. *Seizure-European Journal of Epilepsy. Vol 19, Issue: 9, pp. 592-596*.
- Guarino A J (2014) Center for Interprofessional Studies and Innovation, MGH Institute of Health Professions, Boston, Massachusetts.
- Hahn J (2014) Evidence-based nursing practice with persons with intellectual and developmental disabilities. *International Journal of Nursing in Intellectual and Developmental Disabilities. Vol. 5, 1*.

- Hagbaghery MA, Mahvash S and Ahmadi F (2004) The factors facilitating and inhibiting effective clinical decision-making in nursing: a qualitative study. *BMC Nursing* 3:2.
DOI: 10.1186/1472-6955-3-2 <http://www.biomedcentral.com/1472-6955/3/2>
- Indiana Administrative Code (2011) Article 9. *Community Residential Facilities for Persons With Developmental Disability*
- Indiana Administrative Code (2014) Article 6. *Wellness Coordination, Indiana CIH Waiver*
- Indiana University Institutional Review Board. (2013) *Exempt research checklist, IRB Form v*
- Keller S (2012) *Exceptional parent magazine*. www.eparent.com.
- Lakin K and Stancliffe R (2007) Residential supports for persons with intellectual and developmental disability. *Mental retardation and developmental disabilities research*. Vol. 13:151-159.
- Lopez R (2009) *Surrogate-Self-Efficacy Scale*. School of Nursing, MGH Institute of Health Professions, 36 First Avenue, Charlestown Navy Yard, Boston, MA 02129-4557
- Lopez R (2009) Decision-making for acutely ill nursing home residents: nurses in the middle. *Journal of Advanced Nursing* 65(5), 1001–1009. doi: 10.1111/j.1365-2648.2008.04958.x
- Marklund B, Strom M, Mansson J and Borgquist L (2007) Computer-supported telephone nurse triage: an evaluation of medical quality and costs. *Journal of Nursing Management*. (15):180-187.
- Oeseburg B, Dijkstra GJ and Groothoff GJ et al. (2011) Prevalence of chronic health conditions in children with intellectual disability: a systematic literature review. *Intellectual and Developmental Disabilities* 49(2):59-85. doi: <http://dx.doi.org/10.1352/1934-9556-49.2.59>
- Polit, D., Beck, C. (2004). *Nursing research: principles and methods*. Lippincott. Williams, & Wilkins: Philadelphia, PA

- Rajpura A and Sethi S, (2004) Evidence-based standards of care for adults with epilepsy-a literature review. *Seizure-European Journal of Epilepsy*. 13(1): 45-54.
- Ramsay R, Shields W and Shinnar S (2007) Special issues in the management of young children older adults and the developmentally disabled. *J Child Neurology* 22(5):53-60.
- Sheerin, F. (2011). Intellectual disability nursing: responding to health inequity. *British Journal of Learning Disabilities*, 40, 266-271
- State of the States Report on Intellectual Disabilities (2015). University of Colorado Division of Psychiatry. <http://www.stateofthestates.org/>
[http://www.stateofthestates.org/images/documents/2015_02_18Alliance%20and%20Legislators%20Denver%20Art%20Museum\[Compatibility%20Mode\].pdf](http://www.stateofthestates.org/images/documents/2015_02_18Alliance%20and%20Legislators%20Denver%20Art%20Museum[Compatibility%20Mode].pdf)
- United States Department of Health and Human Services. (2006). *The supply of direct support professionals serving individuals with intellectual and developmental disabilities and other disabilities: report to congress*.
- Retrieved at: aspe.hhs.gov/daltcp/reports/2006/DSPsupply.pdf.
- Vallenga D, Grypdonck M, Tan F, Landemeijer B and Boon P (2006) Decision-making about risk in people with intellectual disability. *Journal of Advanced Nursing* 54(5), 602-611.
- Walsh K, Hammerman S, Krupka P, (2000) Caring for people with developmental disabilities: survey of nurses about their education and experience. *Mental retardation* 38(1):33-41.
- World Health Organization (2011). *World report on disability*.
<http://www.who.int/disabilities/en/>

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