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# Caring for the adult with intellectual disabilities in the acute care setting

Donna Harmon

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## CARING FOR THE ADULT WITH INTELLECTUAL DISABILITY

Caring for the Adult with Intellectual Disability in the Acute Care Setting

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## CARING FOR THE ADULT WITH INTELLECTUAL DISABILITY

## Abstract

The U.S. Surveillance of Health of People with Intellectual Disabilities, A White Paper (2009), reported people with intellectual disability (PWID) are more likely to have complex conditions, limited access, missed cancer screenings, poorly managed chronic conditions, undetected poor vision, and mental health issues. Research has shown there continues to be a gap in the educational preparation of healthcare providers in the care of people with intellectually disabilities, which contributes to substandard quality of care and increased morbidity and mortality. Best practices for this population include education of the healthcare provider. A quality improvement project aimed at improving the knowledge and practices of acute care nurses caring for adults with intellectual disabilities was conducted at an academic medical center. The purpose of a two-hour educational program provided to nurses was to articulate the best practices in caring for this patient population. Following the education, 94.4% of the attendees were inspired to learn more about the subject and 88.9% reported they would apply the new knowledge to their practice. Increased knowledge and skill set of nurses caring for the intellectually disabled adult in the acute care setting improves the quality of care and has the potential to decrease morbidity and mortality. This program further supports the need for expanding nursing curriculums to include the care of this population across the lifespan.

**Keywords:** Intellectual disabilities, education, acute care, nurses,

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### **Introduction and Background**

There are marked health care disparities between people with intellectual disability (PWID) and the general population. PWID have increased health care needs, poorer quality of care, and increased morbidity and mortality (Vander Ploeg Booth, 2011). Themes that have been identified in the research to explain the disparities include provider lack of understanding or knowledge in the care of people with disabilities, delay in diagnosis, and diagnostic overshadowing or attributing all symptoms of an illness to the disability instead of looking for the true etiology (Bultas, 2012; Lewis & Stenfert-Kroese, 2010). Diagnostic overshadowing is the result of clinician bias toward people with disabilities that affects their clinical judgment (Kanne, 2013). Studies have shown that nurses who have little or no education or training in caring for PWID have negative attitudes about providing care for PWID which impacts the quality of care (Lewis & Stenfert-Kroese, 2010). From the parents' perspective education of providers is needed to improve the understanding and effect of hospitalization on the family as a whole (Bultas, 2012; Minnes & Steiner, 2009). Syndrome-specific education also was identified as needed to improve the care of people with intellectual disabilities in the acute care setting. Multiple studies have shown education increases the comfort level and perceived knowledge of providers in caring for this population (Jones, McQueen, Lowe, Minnes, & Rischke, 2015; McGonigle et al., 2014; Read & Rushton, 2013). A case report provided supporting evidence that an integrated team approach and shared knowledge can improve the care for persons with intellectual disabilities in acute care setting (Hsieh, Oh, Chellappa, Szeftel, & Jones, 2014).

Mencap is the leading charitable organization in the United Kingdom that advocates for persons with intellectual disabilities. Founded in 1946 by the mother of a child with

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developmental disabilities, it has grown into an internationally known organization that's promotes equal rights, health care and opportunities for people with intellectual disabilities and their caregivers (Mencap's history, n.d.). The 2008 Mencap report of six people who died due to substandard quality of care was the catalyst for new policies to improve the care of this population, however there continue to be reports of avoidable deaths. A follow up report in 2012 identified 74 people with intellectual disabilities between 2008 and 2012 that died due to poor care (Death by Indifference, 2012). One specific example of poor care given was of David, a 49-year-old man accompanied by his mother who was brought to the hospital by ambulance (Death by Indifference, 2012). The hospital staff continued to treat David for asthma despite his mother's repeated attempts to communicate to the hospital staff that David had a heart condition. David died of a heart attack. The 2012 report describes the causes of the 74 deaths - 26 died because of a delay in diagnosis and treatment and 11 died due to a failure to recognize the patient was in pain. Five individuals were given the designation of "Do not resuscitate" without the consent of the patient or the responsible person. The family members reported to Mencap issues of the hospital staff being hostile, denying basic patient care, poor communication and the presence of staff who had a lack of knowledge and skill working with PWID.

The purpose of this project was to develop a quality improvement project to implement the evidence-based practices found in the literature for improving the care of the adult with intellectual disability in the acute care setting. An Interprofessional Educational Seminar was conducted at an academic medical center. The objectives of the program were to:

- (a) Identify two signs and symptoms of common medical complications associated with this population
- (b) Discuss the unique needs of the patient and family during the hospitalization

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(c) Explain the nursing challenges of caring for adults with intellectual disabilities in the acute care setting

(d) List 3 strategies to care for the adult with intellectual disabilities in the acute care setting

### **Problem Statement**

The risk of increased morbidity and mortality among adults with intellectual disability in the acute care setting is related to evidence of diagnostic overshadowing, poor quality of care, and delay of care that results from a lack of provider training, confidence, and experience in caring for this population. This quality improvement project provided education in caring for the person with intellectual disability in the acute care setting to nursing staff at a major tertiary hospital in Western Massachusetts.

### **Review of the Literature**

#### **Method**

An extensive review of the literature was conducted to describe the hospital experience of persons with intellectual disabilities and what evidence-based interventions have been recommended. The search included the years from 2010 through 2016 and was completed using the electronic bibliographic databases, Current Index to Nursing and Allied Health Literature (CINAHL), PubMed/Medline, Nursing@Ovid, Google scholar and UMA Worldcat. Search terms used included a variety of combinations of Autism, Down syndrome, developmental disability, intellectual disabilities, mental retardation, acute care, emergency care, hospital, hospital staff, healthcare provider, nurse, experience of care, education, knowledge, disparities, patient experience, and quality of care.

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The initial search revealed from two to over 2000 articles depending on the key word combination and the database. The results of the search was refined by including the following limits: research article, full text downloadable, English, and peer-reviewed articles. If the main topic did not speak to one of the specific purposes of this review - experience of the PWID, experience of the healthcare provider or interventions to improve the care of the intellectually disabled person in the acute care setting the articles were excluded. Studies that were based on the JACOX model were a level VI or had strength and consistency level of D were excluded. The titles and abstracts were then manually reviewed to exclude any studies that were related to sexuality, hospice, end of life issues, community based care, primary care or genetics which reduced the number of articles to twelve. Studies that were included focused on the lived experience of patients and families, health care disparities, and studies that evaluated possible interventions to improve the quality of care in the acute care setting through closing the gap in healthcare provider knowledge.

### **Existence of the Problem**

An exhaustive literature review revealed several recurrent themes, including poor access to care (Wang, Choe, Meara, & Koempel, 2004) and lack of provider knowledge regarding the syndrome (Lewis & Stenfert-Kroese, 2010; Read & Rushton, 2013). Additional themes include diagnostic overshadowing, a tendency to overlook symptoms or attribute them to the intellectual disability instead of looking for an alternative etiology, and poor quality of care (Minnes & Steiner, 2009). Healthcare providers were found to have a lack of comfort providing care due to lack of training or experience with this population. Communication issues such as providers not knowing how to communicate with the person or how the person communicates with others were also found to be a contributing factor (Friese & Ailey, 2015; Jones et al., 2015; McGonigle et al.,

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2014; Read & Rushton, 2013; Temple & Mordoch, 2012). Recurrent financial concerns include increased hospitalizations that may have led to higher mortality rates and increased cost of care (Helsop et al., 2014; Lokhandwala, Khanna, & West-Strum, 2011; Zhu et al., 2013.)

Intellectual disability is a significant limitation in both intellectual function and adaptive behaviors. These behaviors can include many everyday social and practical skills and the onset is before the person reaches 18 years old (Read & Rushton, 2013). Compared to the general population PWID have increased healthcare needs, more comorbidities many of which are undiagnosed and increased rates of mortality (Lewis & Stenfert-Kroese, 2010; Lokhandwala, Khanna, & West-Strum, 2011).

### **Economics**

Studies that were retrospective reviews of charts and databases revealed the extent of the disparities in the care of PWID. From an economic point of view, Lokhandwala, Khanna and West-Strum (2011) did a cross sectional descriptive analysis of the 2007 Health Care Utilization Project Nationwide Inpatient Sample (HCUP-NIS) database looking at the hospital cost of people with Autism. There were 25,919 hospital admissions of people with autism in the United States in 2007; the total cost of care was approximately 638 million dollars. The hospital length of stay was 1.5 times longer compared to a person of the general population (GP) with the same diagnosis. Records showed patients who had private insurance were hospitalized more often than those with public insurance; public insurance is known to have a lower reimbursement rate. A study by Wang et al. (2004) demonstrated people with government insurance have unequal access to care. A study that surveyed 100 physicians found that only 27 would see a patient that had government insurance and if the patient required surgery eight of the 27 would refer the patient to another physician.

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A retrospective review was completed by Skorpen, Nicolaisen, and Langballe (2016) of the Norwegian Labour and Welfare Service and the Norwegian Patient Register from the years 2008-2011. There were 7,573 PWID out of a GP of 1,764,072 hospitalizations. Skorpen et al (2016) found the rate of hospitalizations to be similar in the PWID cohort and the GP cohort which was contrary to the study by Zhu et al. (2013) who found persons with Down's Syndrome were hospitalized more than twice that of the GP and had length of stays more than three times that of the GP. Skorpen and colleagues (2016) found that PWID were hospitalized more at a younger age than older age, compared to the GP where there are more hospitalizations as the people age. The difference in the study results may be explained by a report from the habilitation service that stated most younger PWID are treated within the habilitation service as outpatients, yet this study included only inpatients.

### **Increased Mortality**

The relevance of these studies is supported by the study by Helsop, Blair, Fleming, Hoghton, Marriot, and Russ (2014) and the systematic review by Iacono, Bigby, Unsworth, Douglas, and Fitzpatrick (2014), both of which report PWID have a higher rate of avoidable deaths. The increased number of hospitalizations have been linked with increased mortality. Helsop et al. (2014) did a "Confidential Inquiry" into 247 cases of PWID who died. Thirty seven percent were classified as avoidable deaths, and 22% occurred before the patient reached the age of 50. Iacono et al. (2014) found similar statistics. Their review included their early work (Iacono & Davis, 2003), which reported on 119 adults with intellectual disabilities who were hospitalized. The study found numerous medication errors including missed medications with only 12% receiving the correct medications and 22% receiving their medications late. Patients were also described as receiving poor care with 18% not being well hydrated, 39% not being

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brought to the bathroom when they needed it, and 11% not being assisted out of bed when they needed to get out of bed. Iacono and colleagues (2014) reviewed 16 articles and identified seven predominate themes: 1) PWID are afraid of hospitals; 2) lack of care such as the treatment of pain and diagnostic overshadowing; 3) caregivers stay with the PWID because of fear the PWID will not get their needs met due to the staffs reliance on the family; 4) hospital staff with negative attitudes towards PWID; 5) staff that lack the knowledge and skills to care for PWID; 6) failure to adjust to the needs of PWID such as communication issues and assistance with activities of daily living; and, 7) some hospitals have successfully instituted adjustments to systems, procedures and policies that focus on the needs of PWID in the acute care setting. Education and training of nursing staff and providers is one adjustment that was found to be effective.

### **Education and Training**

Healthcare providers are not experienced with or prepared to meet the challenges that come with caring for patients with PWID (Lewis & Stenfert-Kroese, 2010; Read & Rushton, 2013). Healthcare providers receive little if any formal education about intellectual disabilities, and the characteristics of these patients can create challenges in the acute care or emergency departments (Read & Rushton, 2013). A small pilot study followed by a larger study enrolled a total of 262 nurses who completed questionnaires which explored the attitudes of nursing staff in the United Kingdom towards caring for people with any type of disability (Lewis & Stenfert-Kroese, 2010). The results indicated nurse' attitudes were more negative in caring for a patient with intellectual disabilities compared to caring for a person with physical disabilities. The nurses were less likely to attend to the patient with intellectual disabilities and less likely to explain treatments or perform invasive treatments. These patients were also more likely to be

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placed in a side room away from the rest of the patients. Nurses reported insufficient skills and training in caring for the PWID as the contributing factor.

Bekkema, de Veer, Albers, Hertogh, Onwuteaka-Philisen and Francke (2014) also found nurses who worked with PWID felt they were insufficiently trained. The study revealed little has changed regarding education of nurses as compared to earlier findings. Temple and Murdoch (2012) conducted a cross sectional survey of nursing students in their second and fourth year and found 82% of the second-year students and 63% of the fourth-year students did not receive any education on how to interact with PWID.

A needs assessment conducted by the Pennsylvania Department of Public Welfare in 2011 also supported the prevalence of a lack of knowledge (McGonigle et al., 2014). The survey found families reported the person with Autism Syndrome Disorder (ASD) was often heavily medicated or put in physical restraints due to the emergency room staff not having knowledge of the communication and behavioral challenges this population may have (McGonigle et al., 2014). The study consisted of a pre-and post-intervention survey of 110 emergency service personnel and emergency nurses. The educational intervention consisted of three training sessions, one 3-hour session, one 1.5-hour session, and a 1-hour session. Pre-intervention surveys found mean scored responses of overall subjective level of comfort assessing and treating these patients was low at 2.98 and the post intervention mean was 3.81 which demonstrates a statistically significant improvement ( $p = 0.001$ ) in comfort level.

### **Impact of Provider Education**

Studies have shown providing education to healthcare providers improves the level of perceived confidence levels, knowledge, and skills in caring for the patient with intellectual disability (Friese & Ailey, 2015; Jones, McQueen, Lowe, Minnes, & Rischke, 2015; Read &

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Rushton, 2013). Read and Rushton (2013) conducted a study with the objective of improving the competence level of nurses. The study included the development of a toolkit for healthcare providers as well as eight workshops. Of 155 participants, 83% completed both the pre-and post-questionnaires. Participants had increased knowledge, learned more effective communication skills, and had a change of attitude towards this population after attending the workshops. The Quality Improvement Project conducted by Friese and Ailey (2015) supported the findings of this study.

The Friese and Ailey (2015) Quality Improvement/study was implemented to improve the nursing staff communication skills, understanding of the needs of and the care of people with intellectual disabilities. The quality improvement project included the development of standardized care plans and an online education modules. Three hundred nurses participated in the modules. Seventy-five nurses completed the pre-training survey questionnaires and 90 nurses completed the post survey questionnaires. Chi-square analysis of the surveys revealed significant improvement in the nurse's confidence in caring for and communicating with patients, and providing referrals for family members of patients with intellectual disabilities. These findings were like that of Jones, McQueen, Lowe, Minnes, and Rischke (2015).

Jones and colleagues (2015) developed a course curriculum using the National Inter-Professional Competency Framework (NICF) with the aim of evaluating the change in the knowledge, clinical skills, and attitudes of healthcare workers across the interdisciplinary disciplines in caring for PWID. The participants were 247 students all from various curriculums including medicine, nursing, psychology, physiotherapy, and occupational therapy. The students participated in sessions of e learning, didactic lectures, experiential learning, and team based case study learning. The students completed a pre-education online questionnaire as well as a post-

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education online questionnaire. The results were then analyzed using paired-sample t-tests, all disciplines overall had a significant difference in pre-course and post-course scores in perceived skill ( $p \leq .01$ ), however nursing was the only discipline that when grouped alone had statistically significant difference in pre-and post-course scores ( $p = .01$ ). All disciplines demonstrated a significant difference ( $p \leq .01$ ) in pre-and post-scores in overall knowledge. There were no significant differences in the pre-and post-score for attitudinal changes although all students' attitudinal scores ranged from neutral to positive at the start of the study (Jones et al., 2015).

The studies in this review demonstrate a gap and need for education of providers on the care of people with intellectual disabilities. When education is provided there is improvement in attitudes, perceived knowledge, comfort level, and skills in caring for PWID (Friese & Ailey, 2015; Jones et al., 2015; Read & Rushton, 2013). Based on this review, implications for future research are to determine what impact these changes have on the patients and their caregiver's perception of care in the acute care setting. Additional studies should include a review to assess for change in the financial burden, morbidity, and mortality levels.

### **Theoretical Framework**

The theoretical framework that guided Quality Improvement (QI) project to address the issue was the Synergy Model for Patient Care developed by the American Association of Critical Care Nursing (Kaplow & Reed, 2008). The Synergy theory is well suited for this QI project as the objective of the model is for the nurse and patient to develop a synergistic relationship. The Synergy model is based on assumptions that guide the nurse to assess each patient as an individual, each at their own developmental stage, and to view the patient as a multi-dimensional being. These dimensions include the physical, psychological, social, and spiritual aspects. These dimensions of the Synergy model require the nurse to understand the possible trajectory of

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the illness. Through the knowledge of the most common medical complications this population may encounter the nurse will have a knowledge base of the possible trajectory of the patient's illness and therefore the needs of the patient and family/caregivers.

The nurse includes the family unit, because it is the patient, family, and the community that come together and contribute to the nurse-patient relationship. The nurse assesses the patient on levels of characteristics, which include, resiliency, vulnerability, stability, and complexity. The family is included when the nurse is assessing the (a) availability of resources which may be financial, or support systems, (b) the ability to participate in care, (c) the ability to participate in decision making and (d) the predictability or trajectory of illness (Kaplow & Reed, 2008).

The goal of the model is for the nurse to have the competency required to evaluate the patient/family unit and to assist them to reach the highest level of wellness that is appropriate for that patient. The areas of competency assessed of the nurse include (a) the ability to use critical thinking skills to make clinical decisions, (b) the ability to advocate for the patient and family, to be able to assist with coming to a resolution of ethical issues, (c) to be able to identify the patient or family current or future needs, (d) to promote interdisciplinary collaboration to achieve the best outcomes for the patient and family, (e) the ability to negotiate through the health care system and has knowledge of available resources, (f) to achieve cultural awareness, (g) the ability to assess the education needs of the patient or family and provide the teaching in a manner the patient or family will understand. All the characteristics for the patient, family, and nurse are assessed and assigned various levels. When the nurse and the patient are at levels of characteristics that match then they have reached synergy, and optimal wellness can occur (See Appendix A).

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The synergy model acknowledges that each patient is unique, which is exemplified in this population in that each person has a different degree of intellectual disability, further necessitating a nurse to assess each person individually, and evaluate specifically what level of functioning the patient is at, what is their resiliency level meaning what is their ability to cope, do they have any coping mechanisms, what is their endurance level? Each patient will have a different reaction to stress and the nurse needs to assess how vulnerable the patient is. Resource availability is a significant issue for this population that needs to be assessed. These are a few examples of how this model can work well in informing the care and addressing the issue of improved quality of care for the intellectually disabled person. Parley (2001) conducted a study that demonstrated positive outcomes when a person-centered model of care was applied by nursing; Parley's (2001) study supports the use of a model that is very person-centered such as Synergy with PWID. Implementing a Quality Improvement project with the underpinnings of the Synergy model is congruent with the mission of the proposed site, which is to improve the health of the people within the community with quality and compassion and a focus on the patient experience.

### **Project Design and Methods**

#### **Design**

The Quality Improvement Project used a quantitative evaluative design to evaluate the perceived comfort level, knowledge, and skill of nurses in the care of people with intellectual disabilities in the acute care setting. The project consisted of a two-hour educational seminar that included didactic lecture, discussion, and video followed by a question and answer period. One barrier to the success of the program was nursing having the availability to attend, therefore the time was limited to two-hours to overcome that barrier. A Likert-scale pre-and post-

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education program questionnaire was used to assess the effectiveness of the program. The questionnaire included demographic information as well as the nurses' level of comfort, knowledge, and skill in caring for the PWID prior to and after the educational session (See Appendix B).

The QI project was guided by the RE-AIM Model (Glasgow, Vogt, & Boles, 1999). This model places the focus on the elements and the ability to improve the implementation of the evidence-based interventions as well as to make it sustainable (White & Dudley-Brown, 2012). The RE-AIM model has five steps - Reach, Effectiveness, Adoption, Implementation, and Maintenance which were used to evaluate the intended outcome of the program.

**Setting and Resources.** This QI project was conducted at a 716-bed academic medical center. The main campus includes a children's hospital, a woman and infants' unit and is a designated Level 1-trauma center. The program was advertised to all the adult registered nurses through an email sent to the unit managers who then disseminated it to their nursing staff via intranet (in -hospital) email. Flyers were also posted on the various adult medical units. Excluded units were the children's hospital, outpatient, day-stay, and the women and infant's units.

Resources used in this project include multiple staff members and colleagues who had agreed to help facilitate implementation of the data collection, information technology, completing the application for continuing education credits, attainment of a conference room, speakers and application to the internal review board. The Manager of Quality Outcomes, and Education assisted in the data collection from the facility database. The telemetry staff educator assisted in application for continuing education credits. The facility Media Specialist provided the video recording of the seminar and posted to the organization's YouTube © channel. The human research protection program specialist assisted with the application for approval to the

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Facilities' internal review board. The Director of the Heart and Vascular department served as the DNP student's mentor and consultant.

**Description of population.** The target population for this project was nurses from adult care patient areas. Inclusion criteria for the educational seminar were staff nurses working in an area of the hospital that is an inpatient unit or emergency room and serves patients that are greater than 18 years old.

**Organizational analysis of project site.** The facility is a 716-bed academic tertiary Magnet-certified medical center in Western Massachusetts. The nursing leadership includes the Chief Nursing Officer, directors, unit managers, and assistant managers while the charge nurse, and staff nurses provide most of the direct care. Champion nurses serve on each unit who lead specific team initiatives to improve patient care. In keeping with the Magnet Model of Care ("ANCC Magnet," 2016), nurses are recognized for individual accomplishments, promotion of excellence in nursing and quality patient care initiatives ("Magnet," 2015). The Magnet Model of Care made this facility an excellent location for this program because the culture of the hospital encouraged nurses to be active participants in initiatives that improve patient care.

**Facilitators and barriers.** Barriers anticipated in the implementation of this quality improvement project included recruitment of nurses to participate. Continuing education credit was offered to encourage participation and two continuing education credits were awarded from the American Nurses Credentialing Center (ANCC) upon completion of the program. Another anticipated barrier was attendance and nurses finding the time to engage in the program. To facilitate the nurses having easy access to the educational program the education seminar session was limited to two hours and recorded for later viewing. One unanticipated barrier that was

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encountered was that the Director of the Professional Development Department took an early retirement and the position was not filled at the time of this program completion. Therefore, the program was unable to be uploaded to the facility's online education system, nor was it able to be submitted for including in the annual mandatory nursing competencies. However, it was uploaded to the facilities' private YouTube © channel for continued viewing by nursing staff.

### **Goals, Objectives and Expected Outcomes**

The overall goal of this project was to improve the perceived comfort, knowledge and skill level of nurses in caring for the intellectually disabled adult in the acute care setting with the terminal goal of improving the quality of care for the PWID. The objectives of the program were determined using the Synergy model as a guide. Providing a baseline education of intellectual disabilities was essential for the nurse to begin to use critical thinking skills in making clinical decisions. A neurodevelopmental physician provided education regarding the most common etiologies of intellectual disabilities as well as common medical issues associated with this population. This part of the program provided the nurses with the knowledge of signs and symptoms to be aware of and encouraged the nurses to use interdisciplinary collaboration to achieve the best outcomes through communication with physicians, social workers, and rehabilitation specialists such as speech, occupational and physical therapy.

The parent of a young woman with intellectual disabilities and multiple hospitalizations shared her lived experiences which allowed the nurse's the opportunity to become familiar with the patient and families current and future needs from the perspective of the family. This portion of the program spurred discussion regarding cultural awareness and assessing the need for and the best methods for educating the patient, family or caregiver. This knowledge could then be applied to the nurse's future patients and their families.

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An overview of care planning for this patient provided best practices for the nurse to draw from when caring for the adult patient with an intellectual disability. The care planning segment reviewed assessing the patient's ability to cope with the hospital environment, identify the level of understanding the patient had regarding the care being given and to assess any additional needs of the patient or family.

At the completion of the educational seminar, the data showed significant differences in the ability of the registered nurse to:

- a) Identify two of the possible signs and symptoms of common medical complications associated with people with intellectual disabilities. A neurodevelopmental primary care physician presented a PowerPoint presentation and overall review.
- b) Discuss the patient and family needs during hospitalization. A parent of a person with intellectual disability discussed their perspective of past hospital experiences.
- c) Explain the nursing challenges of caring for people with intellectual disabilities in the acute care setting. Two registered nurses who have cared for a person with intellectual disabilities discussed their experience caring for a person with intellectual disabilities. They discussed the challenges they faced and how they overcame them.
- d) List three strategies for caring for the person with intellectual disabilities in the acute care setting. The DNP student reviewed care planning for caring of the person with intellectual disability in the acute care setting using a PowerPoint presentation.

The Synergy theoretical model components were used to develop the program content and the expected program outcomes (Table 1.)

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Table 1. *Synergy Theoretical Model Components Linked to Program Development*

Synergy Theoretical Model Components	Program Content	Program Outcomes
Critical thinking; Assess the physical aspects; Ability to assess the trajectory of illness	Overview of medical complications/issues common to this population	Identify two possible s/s of medical complication/ Critical thinking skills to make clinical decisions
Evaluate the patient and/or family's ability to participate in care and decision making	Discuss the patient family needs from the family's perspective	Ability to advocate for the patients and family/ caregiver
Assess the patient and or/ families coping abilities. Evaluate the patient /family's resources, or support systems.	Family perspective of needs/ experiences in the acute care setting	Identify current or future needs, coping strategies/ Achieve Cultural awareness

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Knowledge of available resources, medical, spiritual, financial, support services

Nurse's experience in managing the challenges of caring for a PWID.

Discuss the nursing challenges of caring for PWID and hospital resources available. / Interdisciplinary collaboration to achieve best outcomes

Ability to assess each patient's needs as an individual and provide appropriate patient education

Care Planning for the PWID in the acute care setting

List three strategies for caring for the care of the PWID

### Implementation Plan

**Methodology.** Best practices for caring for this population include education of the health care providers in the care of the intellectually disabled ("Benchmark of Best Practice," 2010; "Improving general hospital care," 2014; "Service Framework," 2012; "Working together 2," 2014). Currently in the facility where this QI project was implemented there are no educational programs focused on care of the intellectually disabled patient. This QI project was guided by the RE-AIM Model because this model places the focus on the elements and the ability to improve the implementation of the evidence-based interventions and to make the project sustainable (Glasgow et al., 1999). The RE-AIM model has five steps Reach, Effectiveness, Adoption, Implementation, and Maintenance.

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**REACH.** Reach refers to the target population; the target population in this QI project is the registered nurses. The register nurses were reached through an email invitation as well as announcements posted in the various staff rooms on the individual units.

**Effectiveness.** Effectiveness refers to determining if the intervention achieved the intended goal, in this case increasing the nurses perceived competency level in the ability to critically assess the needs of the patient and or family and the ability of the patient and/or family to cope with the stresses of the hospitalization and the perceived competency level to determine the needs of the family and collaborate with various disciplines to meet those needs when caring for PWID. Determining if the goal was achieved was measured through a Likert scale questionnaire that was completed just prior to the start of the educational program (See Appendix B). An educational program was provided for the participating nurses that included the following content, medical issues for people with intellectual disabilities; nursing care challenges; and parents' perspective and care planning. A post education survey evaluated the effectiveness of the educational program in improving the comfort level, knowledge and skill level of the nursing staff in the care of the person with PWID. The surveys were then analyzed using SPSS V24. The expected outcome was a statistically significant difference in the nurses perceived comfort level, knowledge and skill in caring for the intellectually disabled.

**Adoption.** Adoption is the process of anticipating potential barriers to implementation and acceptance of the project and planning steps to overcome those barriers. The barriers anticipated in the implementation of this QI project included recruitment of nurses to participate. Continuing education credit was obtained to encourage participation. The nurse's ability to find the time to attend was another anticipated barrier; to facilitate the nurse's attendance the program was limited to two hours, and to achieve having easy access to the educational program the face-

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to-face educational session was recorded. The Media department assisted with recording and uploading the recording to the facilities private YouTube © channel system.

**Implementation** Implementation of the educational intervention must be consistent so that all participants receive the same information. The face-to-face sessions were recorded with the goal of ensuring all participants received the same information.

**Maintenance.** Maintenance refers to the sustainability of the program. The program will be maintained on the facility YouTube © channel and it is feasible for the program to be updated as appropriate. An application for the program to be part of the annual competency requirements was unable to be submitted to the director of professional development because the position was vacated and has not yet been filled. As part of the annual competency there is the potential to create a culture change within the organization and to make these competencies the norm rather than the exception. A barrier to having this program added to the annual required competencies was demonstrating a need. That barrier was overcome through a database search which determined approximately how many PWID had been cared for at this facility over a three-month period. Although a need has been demonstrated the program will not be submitted for annual competency but has been made available on the YouTube © channel.

**Data Collection.** To assess the scope of the patient population served by this facility there was an ICD-9/ICD-10 data collection that was completed using the Midas database to ensure no patient identifier information is obtained. This data was used to determine the approximate number of patients with the ICD-9/ICD-10 codes, 299.00/F84, 758.0, Q90/Q90.9, 759.83/Q99.2, 319/F79, 317/F70, 318/F71, 318.2/F73, and 318.1/F72. No patient identifiable information was obtained therefore no consent was required. ICD-9 data from revealed from January 2015 to March 2015, they served 62 adults diagnosed with Autistic Disorder, 3 with

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Fragile X syndrome, 58 with intellectual disability, nonspecific and 5 with severe intellectual disability, a total of 128 persons (D.A. personal communication, February 2016). This number may be higher as this data only captures people who carried the ICD-9 codes in the electronic medical record; it does not capture the person who's care provider did not enter the specific IDC-9 code. It would be reasonable to extrapolate from that data there are at a minimum of 512 people annually, not including the families and caregivers that are affected by this problem.

### **Ethics and Human Subjects Protection**

An application to the Institutional Review Board (IRB) of the UMass Office of Research and Engagement and to the facility was submitted and was approved as exempt by both the facility and University of Massachusetts IRBs.

### **Results**

**Outcomes.** Demographic information was obtained for the purpose of identifying if age, level of education or years employed at this facility had an impact on the nurse's level of comfort or knowledge in caring for this population. Most of the nurses were between the ages of 33 and 52, had a master's level of education and had worked for the facility 11- 15 years. Demographic data is presented in Table 2.

**Table 2.**

*Summary of Demographic Data of Participants*

	Frequency	Percent
<b>Age</b>		
63-71	1	7.1
55-62	3	21.4
33-52	10	71.4

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<b>Education Level</b>		
Diploma	1	7.1
Associate	4	28.6
Bachelor	4	28.6
Masters	5	35.7
<b>Years Employed at Facility</b>		
Less than one	1	7.1
1-5	3	21.4
6-10	3	21.4
11-15	4	28.6
Greater than 15	3	21.4
<b>Nursing years' Experience</b>		
1-5	1	7.1
6-10	2	14.3
11-15	3	21.4
Greater than 15	8	57.1

**Data Analysis**

The number of participants in the education program was 17. A pre-and post-program questionnaire was developed to determine if the program was effective in improving the competencies of the nurse to use critical thinking skills to make clinical decisions, advocate for the patient who was not coping well, identify the patient or family current or future needs, promote interdisciplinary collaboration, have knowledge of available resources, and the ability to assess the education needs of the patient or family.

Three questionnaires were eliminated from the data collection because two were not registered nurses and one was incomplete. The total questionnaires used for data collection was

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N = 14. The data from a pre-and post-education program questionnaire was analyzed using SPSS 24. The assumptions for a paired t-test (N = 30) were not met (N=14) therefore a Wilcoxon statistic was computed. The analysis showed there was a significant difference in a positive direction ( $p = .035$ ), in the nurses' comfort level providing care to an adult with intellectual disabilities who was not coping well with the hospitalization. There was a positive significant difference ( $p = .002$ ) in feeling confident in coordinated and interprofessional team. There was a positive significant difference ( $p = .011$ ) in nurses' level of comfort in providing resources to caregivers experiencing caregiver role strain. Self- confidence in understanding the patient needs had a positive significant difference ( $p = .002$ ). Confidence in the ability to communicate effectively showed a positive significant difference ( $p = .002$ ). The ability to list three nursing strategies in caring for this population had a negative significant difference (sig .002). The analysis also revealed negative significant difference in ability to identify symptoms of common medical issues in this population ( $p = .003$ ) indicating a need for more education. There was a negative significant difference in the nurses understanding of nursing challenges ( $p = .046$ ), indicating more extensive and specific education is needed in this area.

### **Discussion**

The demographic data demonstrates the lack of education is not related to years of experience, level of education or years employed in this facility. The data suggests this subject has not been part of the nursing curriculum for many years and continues to be absent from most, if not all, nursing curriculums. Most the attendees were master prepared and still had not received education regarding the care of this population. This project supports the need for nursing schools to add courses in caring for the intellectually disabled person to the nursing

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curriculums to ensure that nurses at the undergraduate and graduate level have the competencies to care for this population (Gardner, 2012). Most of the nurses, are in fact middle age (33-52) with likely many more years to work prior to retirement.

Two of the questionnaires that were eliminated from the data analysis were from people in disciplines other than nursing, their participation speaks to the need for interprofessional education, which has been shown to be a need and beneficial in improving care (Harper & Wadsworth, 1992; Hsieh, Oh, Chellappa, Szeftel, & Jones, 2014; Jones, McQueen, Lowe, Minnes, & Rischke, 2015).

The Synergy Model of Care calls for the nurse to be able to use the skill of critically thinking to make care decisions, however to have this competency the nurse must have a basic level of knowledge which leads to a level of comfort in making those decisions and providing care. This program revealed the level of comfort the nurses had prior to the program was significantly improved after the educational program, demonstrating there was a lack of comfort prior to the program and supported the need for the education. This data support the studies (Bultas, 2012; Minnes & Steiner, 2009) that found parent's perception was there was a lack of knowledge. These results are like other studies that found education and training reinforced best practice (Read & Rushton, 2013) and can significantly improve the level of confidence in providing care for patient with ID (Friese & Ailey, 2015).

The areas that resulted in negative significant differences may be attributed to the limitation of a small size of the attendance. It could also be an indicator that more extensive education is needed. This is an area for further investigation and possibly an area for a future improvement project within the facility.

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To fully implement a program that would improve all the areas of Synergy Model of Care competencies was beyond the time limit of this project, therefore many activities this author initially wanted to include had to be eliminated. One tool the author determined was essential for the nurse to assist the patient in coping with the hospital environment was an activity cart. The activity cart was one of the nursing interventions introduced in the care planning section of the program. The care planning lecture provided knowledge of the best practices for caring for this population. The activity cart contained items that would be appropriate for various developmental levels of the patient, for example some items the cart contained were noise reducing ear phones, a lap top computer, a DVD player and DVDs for different age groups, magazines, colored pencils and other various items.

The number of people with intellectual disabilities climbs higher and higher every year. Nursing schools need to add content caring for this population to the nursing school curriculum to ensure nurses can provide safe, quality care for the adult with intellectual disabilities in the acute care setting. This project further supports the research by Ailey and Hart (2010), Friese and Ailey (2015), and Hsieh and colleagues (2014) among others that nurses and providers want to be educated in the care of the intellectually disabled and through education the quality of care can be improved. The nurses want to provide improved health care and to improve the experience of the intellectually disabled adult in the acute care setting. This project provided education to a small number of nurses. The nurses demonstrated a significant difference in their level of comfort caring for this population after the educational program. Many nurses from the facility and those who participated have requested this be presented on an annual basis. They have demonstrated an interest in continuing to be active in promoting improved quality of care for this population.

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**Barriers.** A barrier to implementing the portion of the project to continue the program online and to continue to be able to offer continuing education credits could not be implemented due to an unexpected labor reduction in which the person in charge of the online education took an early retirement. The hope is in the future when that position is filled it will be able to be implemented.

One of the recommended interventions was to provide activities to distract the patient and assist them in being calm in the hospital environment. Obtaining the funding for an Activity Cart became a barrier. To overcome that barrier, the DNP student funded the cart personally. The cart contains items such as a DVD player, Laptop computer, noise reducing headsets, coloring pencils, sensory toys, and other items. These items are available for loan to any nurse caring for an adult with intellectual disability. To disseminate the awareness of the cart the facility media person took a photo of the cart and nurses, and wrote an article about the program. This article along with the photo displayed on the home page of the facility intranet (in hospital) in the month of April. As the nurses have heard about the cart some nurses have volunteered to continue to add to the items in the cart.

### **Limitations**

Limitations of this QI project is the small size of participants. Further QI projects should include creating an educational tool to determine the educational needs and an annual mandatory educational program to ensure competency. Utilization of an assessment tool to determine nurses' competency or lack of competence would be helpful to determine the educational needs of each institution (While & Clark, 2014).

### **Conclusion**

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The health care disparities between people with intellectual disability and the general population persists despite multiple studies and papers discussing the populations increased morbidity and mortality. Despite the studies that have clearly indicated nurses and providers are lacking education there continues to be a gap in the formal education of providers.

Approximately 60% of nurses in a New Jersey study had no education during their formal education or since licensure in the care of PWID (Walsh, Hammerman, Josephson, & Krupka, 2000). Therefore until the formal education addresses the gap education needs to be provided to currently practicing nurses to decrease the health care disparities and reduce the rate of morbidity and mortality. The results of this program showed nurses with a knowledge base of how to care for the adult with intellectual disability in the acute care setting perceive themselves to be more comfortable caring for these patients, can identify possible medical complications, and overcome many of the challenges in caring for this population.

**Dissemination.** This Quality Improvement project is being disseminated to the hospital community through the hospital intranet. An article announced the availability of an activity cart for use with adult patients with intellectual disabilities as well as the YouTube © recording of the program. This will help to promote sustainability of the program. The Sigma Theta Tau International 44<sup>th</sup> Biennial Convention has accepted the abstract for an oral presentation. This will allow for dissemination to international scholars, academia, and professionals and hopefully the start of new programs at other institutions. The author would especially like to see educators add courses relating to caring for this population in their curriculum. The author will participate in a podium presentation to the faculty and students rather than a poster at Scholarship Day at the university to reach not only scholars but up and coming students who are the future scholars. It is the authors hope that presenting on Scholarship Day will spark an interest for continued work in

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this area. Lastly, the author is working with an established scholar to fine tune the work and submit for publication to an appropriate journal that promotes research, innovative education for nurses and improved care for this population.

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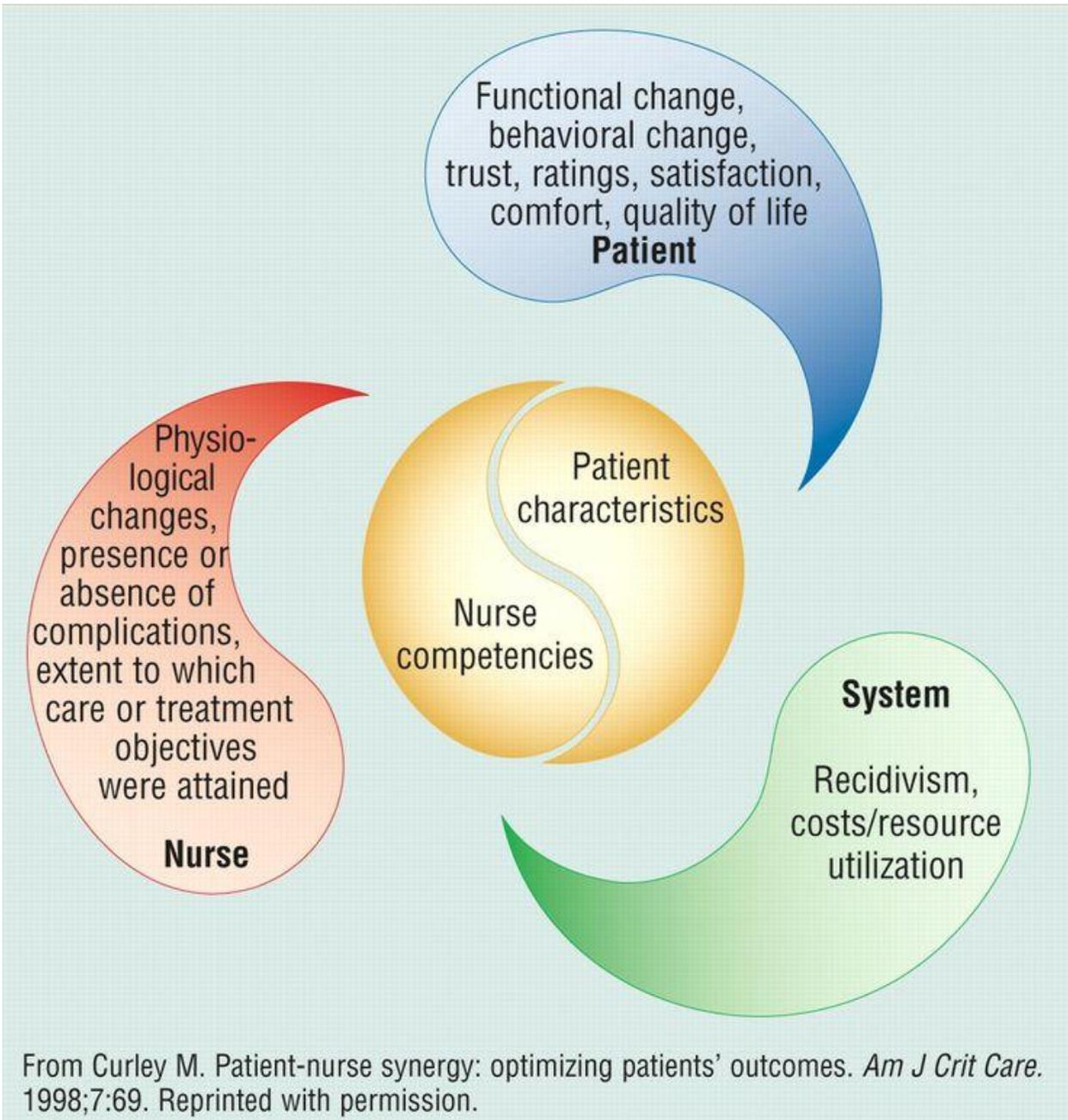
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Appendix A



From Curley M. Patient-nurse synergy: optimizing patients' outcomes. *Am J Crit Care*. 1998;7:69. Reprinted with permission.

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## Appendix B

**Providing Care to Adults with Intellectual Disabilities**

Welcome

**The purpose of this survey is to gather information to explore nurse's perceptions of comfort and knowledge in providing care for adult patients with intellectual disabilities in the acute care setting. The survey should take about 2 minutes to complete and your responses are anonymous. Thank you for your participation!**

**Providing Care to Adults with Intellectual Disabilities**

1. I work on the following unit:

2. The year of my birth is within

- 1937- 1945
- 1946 - 1954
- 1955 - 1964
- 1965 - 1984
- 1985 - 2000

3. I received my RN license within:

- Less than 1 year
- 1- 5 years
- 6 - 10 years
- 11- 15 years
- greater than 15 years

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4. The highest level of nursing degree I have received is

- Diploma
- Associate degree
- Bachelor degree
- Masters
- Doctorate

5. I have worked at Baystate Medical Center for:

- Less than one year
- 1- 5 years
- 6- 10 years
- 11 - 15 years
- greater than 15 years

6. I have personal experience in providing care for an adult person with intellectual disabilities.

Yes	No			
<input type="radio"/>				

7. As a nurse, I have provided care to an adult patient with intellectual disabilities.

Yes	No			
<input type="radio"/>				

8. How comfortable are you in providing care for adult patients with intellectual disabilities who are not coping well with hospitalization?

Never Comfortable	Rarely Comfortable	Sometimes Comfortable	Usually Comfortable	Always Comfortable
<input type="radio"/>				

9. I can identify at least two symptoms of at least one of the most common medical complications that are associated with this population

Yes	No			
<input type="radio"/>				

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10. I feel confident that I have an understanding of the needs of the adult patient with an intellectual disability?

Never Confident	Rarely Confident	Sometimes Confident	Usually Confident	Always Confident
<input type="radio"/>				

11. I am confident in my ability to co-ordinate care with an inter professional team in the acute care setting for adult patients who have intellectual disabilities.

Never Confident	Rarely Confident	Sometimes Confident	Usually Confident	Always Confident
<input type="radio"/>				

12. I am confident in my ability to communicate effectively in the acute care setting with adult patients who have intellectual disabilities.

Never Comfortable	Rarely Comfortable	Sometimes Comfortable	Usually Comfortable	Always Comfortable
<input type="radio"/>				

13. I am comfortable referring family member (of an adult patient with intellectual disability) who is experiencing caregiver strain to appropriate resources.

Never Comfortable	Rarely Comfortable	Sometimes Comfortable	Usually Comfortable	Always Comfortable
<input type="radio"/>				

14. I understand the nursing challenges in caring for the adult with an intellectual disability

Yes	No			
<input type="radio"/>				

15. I can list three nursing strategies for caring for the adult with an intellectual disability.

Yes	No			
<input type="radio"/>				