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Educational Toolkit for Health Care Providers Working with Adults with Intellectual Disabilities in the Hospital

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Educational Toolkit for Health Care Providers

Working with Adults with Intellectual Disabilities in the Hospital

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<table>
<thead>
<tr>
<th>Table of Contents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract ..........................................................</td>
</tr>
<tr>
<td>Introduction and Background .........................................</td>
</tr>
<tr>
<td>Problem Statement ...................................................</td>
</tr>
<tr>
<td>Review of the Literature ............................................</td>
</tr>
<tr>
<td>Search methods and Results .........................................</td>
</tr>
<tr>
<td>Literature Discussion ................................................</td>
</tr>
<tr>
<td>Use of the Toolkit ...................................................</td>
</tr>
<tr>
<td>Theoretical Framework ...............................................</td>
</tr>
<tr>
<td>Project Design and Methods .........................................</td>
</tr>
<tr>
<td>Educational Resource Packets .......................................</td>
</tr>
<tr>
<td>Population, Settings and Resources ................................</td>
</tr>
<tr>
<td>Organizational analysis of project site ............................</td>
</tr>
<tr>
<td>Evidence of stakeholder support ....................................</td>
</tr>
<tr>
<td>Pilot Project ..........................................................</td>
</tr>
<tr>
<td>Facilitators and barriers ...........................................</td>
</tr>
<tr>
<td>Goals and Objectives ................................................</td>
</tr>
<tr>
<td>Ethics and Human Subjects Protection ...............................</td>
</tr>
<tr>
<td>Results and Interpretation ..........................................</td>
</tr>
<tr>
<td>Conclusion ....................................................................</td>
</tr>
<tr>
<td>References ....................................................................</td>
</tr>
<tr>
<td>Appendices ....................................................................</td>
</tr>
</tbody>
</table>
Abstract

The following is a review of a Doctor of Nursing Practice (DNP) Project that focuses on the improvement of educational opportunities for staff caring for adults with intellectual disabilities and developmental disabilities (ID/DD) in the Hospital. This DNP Project focuses on the important fact that adults with intellectual disabilities experience multiple health disparities. One of the major sources for the continuation of these disparities is the lack of education for hospital staff working with this population. Improvements in care have been noted when education is increased but unfortunately educational opportunities are not widely available.

This DNP project was conducted as a pilot educational program for hospital staff caring for adults with intellectual and developmental disabilities. The pilot program showed evidence of learning for hospital staff. The DNP project included development of a tangible toolkit from the educational offerings that were presented to staff and left for their continued use, thus achieving sustainability of the toolkit as an educational blueprint for the hospital’s health care providers.

This paper summarizes the important actions that were taken to improve health outcomes for adults with ID/DD in the hospital and how to implement them.

Key Words: Toolkit, Intellectual Disability, Developmental Disability, Education
Introduction and Background

The diagnosis of disability unfortunately links those individuals to health disparities in both treatment and access to care. The health of individuals with intellectual and developmental disabilities (ID/DD) is a subcategory of disabilities, which needs emphasis as they experience an even greater number of health disparities (Cooper et al., 2006). These disparities can result from differences in socioeconomic status, ethnicity, access to health care and more (Fischer, 2004; Lezzoni, 2011); and can be related to access to care, preventative health, lack of education, and presence of comorbidities. Adults with intellectual disabilities (ID) have greater health requirements and these health needs are more likely to go unmet than the in general population (Cooper et al., 2006; Havercamp, Scandlin, & Roth, 2005; Krahn et al., 2006; Ruddick, 2005). An important contributing factor to these health disparities is the lack of education for hospital staff. It has been proven repeatedly that health care staff express the need for more education for the care of adults with ID/DD. Providing usable educational materials for health care staff can improve the care being administered as well as health outcomes and the quality of life for individuals with ID/DD.

A needs assessment revealed that there was a lack of resources for health care staff and direct care staff working on a unit that cares for adults with ID/DD. In collaboration with the stakeholders, it was decided that the staff caring for adults with ID/DD could benefit from continued education. A pilot program was conducted utilizing a chart review to elicit potential educational topics and a staff survey was created (Appendix B). After completion of the staff survey, educational resource fliers were created utilizing the three top areas of interest. During the pilot program three user-friendly educational resource fliers were created, peer reviewed and implemented. The pilot program indicated that an improvement in knowledge could be elicited.
through these user-friendly educational resource fliers. These materials as well as a generalized educational program were used to create a toolkit to increase education for health care providers caring for adults with ID/DD in the hospital.

**Problem Statement**

Risk of health disparities among adults with intellectual and developmental disabilities in the hospital is evidenced by increase morbidity and mortality for this population (Cooper et al., 2006; Havercamp, Scandlin, & Roth, 2005; Krahn et al., 2006; Ruddick, 2005). These health disparities are perpetuated by the gross lack of knowledge of health care staff caring for these individuals. Increasing knowledge for direct care staff of adults with intellectual and developmental disabilities will help reduce health disparities and improve outcomes.

**Review of the Literature**

Individuals with intellectual and developmental disabilities are a vulnerable population that experiences multiple health disparities. Health disparities in individuals with intellectual and developmental disabilities can be related to communication difficulties, co-morbidities, social factors, difficulties accessing care and little to no health promotion (Read & Rushton, 2013). In addition, these disparities can be related to three external contributing factors which include the de-institutionalization movement, increase in life expectancy, and lack of educated health care staff. Increasing the education of health care staff providing services to adults with ID/DD can help to target this health disparity by increasing knowledge for health care staff about aging adults with ID/DD who are no longer institutionalized. The use of a toolkit will allow for a simplified educational process as well as create a sustainable solution.
Search Methods and Results

A review of literature was conducted including the following databases: Medline, PsychArticles, and Cumulative Index of Nursing and Allied Health Literature (CINAHL). The subsequent search terms were utilized: education, competency, health care providers, staff, intellectual disability, health disparities, and toolkit. The Medical Subjects Headings (MESH) recommended the use of the term mental retardation, health personnel, curriculum and teaching as well. As the implementation project involved a toolkit the following search term was used intellectual disability educational toolkit, which yielded 139 articles. Of these articles, only one was directly related to the education of health care staff caring for adults with intellectual disabilities. CINAHL yielded two articles when searching with intellectual disability, toolkit, and education neither of which met the inclusion criteria. When removing toolkit from the search, it yielded articles three of which met the inclusion criteria. Inclusion criteria involved English language and articles that were directly related to the education of health care staff and its benefits for individuals with intellectual disabilities.

In order to determine the need for continued education for health care staff caring for adults with ID/DD a search was conducted for health disparities in individuals with intellectual and developmental disabilities, which resulted in nine articles. When the same search phrase was used but the term mental retardation was substituted, 735 articles were found. Limitations to peer reviewed articles in English narrowed the articles down to 576. The Doctor of Nursing Practice (DNP) student reviewed the abstracts and titles of the articles to determine which would be included. Limiting the publications by year would exclude important groundbreaking research, which cannot be ignored. Of these articles, 23 were included due to their relevance to the topic of increasing education to health care staff working with adults with ID/DD. The
specific search was also limited to articles with full text due to the large number of articles produced. The level of evidence ranged from level III or below as randomized control trials are rare among this population (Lennox, Driel & van Dooren, 2015). It is important to note that many clinical practice guidelines do exist for the care of individuals with ID/DD, but their primary focus is on health screening not on health care staff education.

In addition to the searches completed in the aforementioned scholarly databases, a generalized search was conducted on the internet utilizing the key word toolkit. Though many resources for individuals seeking services were produced, there was only one credible source that discussed a toolkit related to the care of adults with ID/DD for primary care providers (PCP) which is included in the literature review.

**Literature Discussion**

Although adults with ID/DD have been experiencing higher life-expectancy, the life-expectancy of adults with ID/DD is still considerably lower than the general population (Cooper et al., 2006; Kuntz, 2005; Lennox, Driel & van Dooren, 2015; Lin et al., 2009; MacArthur et al., 2015; Moran, Rafii, Keller, Singh, & Janicki, 2013; Read & Rushton, 2013; Ruddick, 2005; Scheepers et al., 2005). In addition, individuals with ID were historically taken to state schools, kept in wards of half a hundred individuals and given sparse educational opportunities (D’Antonio, 2004). In recent decades there has been a public health initiative to return these adults to the community internationally as well as increase access to quality health care (Fenton, Hood, Holder, May & Mouradian, 2003; Fisher, 2004; Lennox, Driel & van Dooren, 2015; Schrojenstein & Valk, 2005; Sullivan et al., 2006). Sullivan and colleagues further stated (2006) that it was believed that this transition would improve quality of life for adults with ID, increase socialization, and provide adequate care in the least restrictive setting.
Though the de-institutionalization era was seen as advancement in the rights of individuals with ID, it unfortunately left a gap in the knowledge of general health care staff (Hunt, Rankine & Blackmore, 2006; Ruddick, 2005; Schrojenstein & Valk, 2005; Sullivan et al., 2006). Many staff in hospital settings self-report a need for more education when caring for these individuals (Dagnan, Masson, Cavagin, Roberts et al., 2013; Thwaites & Hatton, 2015; Warfield, Crossman, Delahaye, Weerd & Kuhlthau, 2015). Hunt, Rankine & Blackmore (2006) noted that than 80 percent of uncompensated caregivers and 70 of compensated care givers have not obtained healthcare education related to ID. This lack of education supports the need for increased services such as a toolkit for health care staff (MacArthur et al., 2015).

The aging of adults with ID is an important contributing factor to lack of educated healthcare staff. Within the past two decades, the life expectancy has increased by more than twenty years. That being said, the life expectancy for individuals with ID is still almost two decades lower than the general population (Lennox, Driel & van Dooren, 2015). In addition, many individuals with ID have only ever been examined by a pediatrician (Meijer, Carpenter, & Scholte, 2004). In fact, many individuals with ID continue to utilize a pediatrician as their primary care providers well into adulthood (Meijer, Carpenter, & Scholte, 2004). Rational for continued use of the pediatrician into adulthood was that these primary care providers were the only physicians ever to treat individuals with ID because the individuals never lived long enough prior to recent health care advancements.

Educational topics for health care staff should include how to communicate with adults with ID, competency assessment, disease and behavioral management, and should not be limited to physicians (Schrojenstein & Valk, 2005; Read & Rushton, 2013; Warfield, Crossman, Delahaye, Weerd & Kuhlthau, 2015). Emphasis should also be made on cultural competence
and reduction of stigmatization of adults with ID (Fisher, 2004; Lin et al., 2009). Ensuring that new staff are educated about adults with ID can help prevent the negative health outcomes that occur do to this lack of education (Lin et al., 2009; Moran et al., 2013; Ruddick, 2005). By providing education to health care staff, awareness of the vulnerability of this population will increase which will help promote the necessary ‘equitable’ care needed (Lennox, Driel & van Dooren, 2015; Lin et al., 2009). Evidence supports the initiation of education about adults with ID into both baccalaureate and post-graduation educational programs (MacArthur et al., 2015). Though this is the case, only two developed countries are including the care of individuals with ID in their educational programs the United Kingdom and Australia (Lennox, Driel & van Dooren, 2015). Adding ID to the curriculum of health care staff will assist in the reduction of continued ignorance of future health care staff, but it will not assist with those currently working in this field.

Multiple sources cited the need to change the attitude of health care staff caring for adults with ID (MacArthur et al., 2015; Roberts et al., 2013). In a groundbreaking study on health disparities for individuals with ID, Lennox and Kerr (1997) cited that that attitude of providers and other health care professionals directly effects the care that adults with ID receive. This notion has been supported in many studies released since this initial study (Warfield, Crossman, Delahaye, Weerd & Kuhlthau, 2015). Unfortunately, many health care staff still assume that adults with ID cannot communicate and therefore cannot participate in health care assessment and planning (Ruddick, 2005). Shogren et al. (2006) state that many health care staff think that ill health is the baseline for adults with ID. Due to these and other complications associated with the care of adults with ID, some health care staff even refuse to accept them as patients (Lin et al., 2009). This is very concerning and becomes a public health issue because adults with ID are
one of the most vulnerable populations (Ryan, McEvoy, Guerin, & Dodd, 2010). This lack of educated health care staff has essentially created a physician shortage for this susceptible population (Warfield, Crossman, Delahaye, Weerd & Kuhlthau, 2015). Until recent years, there have been very few public health initiatives for this population. Evidence supports that a focus needs to occur on the development of clinical practice guidelines or other standardized care interventions for the treatment of adults with ID (Lin et al., 2009; Moran et al., 2013).

Use of the Toolkit

Toolkits have been proven to assist with the advancement and development of services in healthcare. Toolkits are defined as, “a set of tools which have been designed for a particular purpose to be used in conjunction with each other” (Read & Rushton, 2013). Implementation of a toolkit to improve the health of individuals with ID in a hospital setting needs to have a focus on improving health services and changing the culture of the health care staff to be effective (Roberts et al., 2013). Lennox, Driel & van Dooren (2015) state that providing tools to health care staff treating individuals with ID can improve health outcomes. Though several toolkits currently exists for the health screening of adults with ID the literature review did not reveal any toolkits that focused on improving the education of staff providing care for adults with ID (Hunt, Rankine & Blackmore, 2006).

Vanderbilt University’s Kennedy Center has developed a successful toolkit Healthcare for Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers. Again, the primary focus of this toolkit is for health promotion of the individual with ID (Vanderbilt Kennedy Center for Research on Human Development, 2015). Multiple tools and checklists are provided for the family or individuals themselves to bring to primary care provider appointments (Vanderbilt Kennedy Center for Research on Human Development, 2015). This
toolkit does include seven ‘health watch tables’ for specific diseases common among individuals with ID. These, however, only provide health-screening suggestions for providers (Vanderbilt Kennedy Center for Research on Human Development, 2015). The toolkit also includes online access to information, printable forms, links to available resources as well as contact information (Vanderbilt Kennedy Center for Research on Human Development, 2015). Keele University also has a similar toolkit, which focuses primarily on the topics mentioned above though its aim was to increase confidence for nurses and other health care staff when providing care by having resources for the individual with ID readily available (Read & Rushton, 2013).

It is important to note that the implementation of most toolkits does involve a component of staff education, but this is generally related to the use of the toolkit (Hunt, Rankine & Blackmore, 2006). The differentiating factor of this toolkit is that its primary emphasis is on staff education. In addition, this toolkit will assist in the educational advancement for direct care staff caring for adults with ID but in no way should be considered a *cookie cutter* method of caring for these individuals. It should be seen as a method of support for providing care to adults with ID in a hospital setting (MacArthur et al., 2015).

 Toolkit implementation does not *recreate the wheel* but allows for utilization of several strategies including: building on existing knowledge, increasing knowledge, and using available evidence (Lennox, Driel & van Dooren, 2015). The implementation of a toolkit for health care staff working with adults with ID will help to ensure that they do not experience limits in access to healthcare once hospitalized (Dagnan et al., 2015; Read & Rushton, 2013; Roberts et al., 2013). Implementation of a toolkit for health care staff, working with adults with ID, will help to provide the needed consistency that is currently lacking for this population (Meijer, Carpenter & Scholte, 2004). Utilization of this tool can help pave the way for continued improvement in this
field of medical care as currently there is no best practice for the care of these individuals when hospitalized (Dagnon et al., 2015; Meijer, Carpenter & Scholte, 2004). In addition, this will be effective because after educational sessions health care providers have reported increased confidence in caring for adults with ID (Dagnon et al., 2015).

The implementation of an educational toolkit for health care staff has the potential to improve staff competency, improve patient outcomes and improve patient quality of life. Increasing education for health care staff has shown to improve health outcomes and quality of life of adults with ID. The utilization of a toolkit to improve the health of adults with ID in a hospital setting is long overdue. Health care providers have been asking for education and an easy to use resources for decades. A toolkit is a cost effective and very beneficial method to making the appropriate sustainable changes for the future health of adults with intellectual disabilities.

**Theoretical Framework**

The Knowledge to Action (KTA) framework was utilized (Appendix C). The framework was designed to increase sustainable changes with knowledge-based interventions (Field, Booth, Llott & Gerrish, 2014). The KTA framework hopes to create an understandable method for the transition of knowledge into action (Field, Booth, Llott & Gerrish, 2014). White and Brown (2012) refer to the KTA framework as a funnel that all the information, or knowledge, is placed in the top, and when it reaches the bottom of the funnel, it is ready for use. The framework has parts including the formation of the knowledge and its dissemination (Field, Booth, Llott & Gerrish, 2014).

The first the problem identified was the lack of knowledge among hospital staff caring for adults with ID. The formation of the knowledge included the creation of the power point
presentation for the toolkit. The power point presentation provided a basic understanding of intellectual and developmental disabilities, the treatment of this population historically, and how this could be changed. In addition, the creation of the educational resource fliers also contributed to the knowledge formation. The dissemination of knowledge involved the power point presentation Care of Adults with Intellectual Disabilities, which was completed in the pilot twice at two different times for continuing educational units. The educational presentation and educational resource fliers were the tools for the KTA framework. The educational program and the educational resource fliers were presented to the target facility as a toolkit. These educational interventions were used as actions to promote change. Barriers to knowledge use were addressed during the pilot program and adaptations to future presentations were made. Users of the toolkit will be able to evaluate the knowledge gained by using the pre and post test methodology. This program is sustainable because toolkits were distributed for others to use as a resource. Qualitative data was used to evaluate the presentation of the toolkit.

**Project Design and Methods**

The DNP Project included a modified systematic review with application of a quality improvement project in the form of a toolkit. The DNP student designed the toolkit with the data collected from a pilot program. As previously stated, the toolkit included a background educational program as well as 12 educational resource fliers (Appendix E). This baseline education was presented to the target facility and involved the creation of a power point presentation. This presentation educated end users about what and intellectual disability is, how it differentiates from disability and developmental disability, the historical treatment and interventions for IDs, and current practices and treatment modalities for IDs. During the pilot, the slides were presented twice at two different times to expose the material to the most staff.
This provided a foundation of education for the toolkit users. This presentation was also included in the toolkit to allow users to review as they wish.

**Educational Resource Packets**

The pilot program provided the topics, from a chart review and staff survey, that were used to create the educational resource fliers. These topics included: Angelman syndrome, autism, cerebral palsy (CP), Down syndrome, fetal alcohol spectrum disorders (FASD), fragile X syndrome, Klinefelter syndrome, phenylketonuria (PKU), Prader Willi syndrome, Rett syndrome, tuberous sclerosis, and Williams syndrome. The educational resource fliers (Appendix E) were created targeting a fifth grade or below reading level for better comprehension of direct care staff. The reading level of the education fliers was tested using the readability statistics in Microsoft Word. The fliers were created with pre and post-tests embedded within them to allow for evaluation of learning from the users of the toolkit. A two-week period was used during the pilot but the length of exposure may vary depending on what is best for the target settings for future implementation. After distribution, the data from the pre and post test was analyzed. This study demonstrated an increase in awareness about the resource flier topic.

These educational materials as well as an implementation process were aggregated to develop the toolkit. The toolkit included an implementation plan (Appendix D), the resources for implementation, which included the power point presentation and the educational resource fliers, an evaluation process, and ideas for program sustainability as well as references.

**Population, Setting and Resources**

The target population of DNP project was the staff caring for adults with intellectual disabilities (ID) and developmental disabilities (DD), age 18 and over, receiving in-patient care
at a local Hospital. The Hospital is one of the five Department of Public Health (DPH) Hospitals in Massachusetts. The mission of the Hospital is “to provide comprehensive treatment, care, and comfort to adults with medical and mental illnesses” (Commonwealth of Massachusetts, 2016). The Hospital has seven Department Public Health (DPH) units, with approximately 220 beds. The average daily census (ADC) is around 200 for the DPH units. Of the seven DPH units there is one unit designated for patients with intellectual and developmental disabilities. The ID/DD unit has a maximum census of 32. The average daily census of this unit is 29. In addition to the designated ID/DD unit, there is an ID/DD overflow unit with a maximum census of 31. The ADC of this unit is also 29. Of these 29 patients, there is an average of five DDS clients present. The overflow unit rarely has times with no ID/DD patients and the current maximum is 10 though there is technically no limit. When necessary adults with ID can also be admitted to any of the other five public health units.

The sample population was the staff caring for adults with ID at the target facility. Inclusion criteria were any staff that had worked with adults with ID/DD in the past 30 days. This education program was piloted for direct care staff, but all hospital staff expressed interest in its use. Due to the interest of the pilot program, it was decided that all staff could benefit from the program. That being said, the licensed staff utilizing the materials may already be aware of some of this information, which could skew the results of the pre and post tests. It is important to note that at the target facility there twelve nurses that work that are Certified Developmental Disability Nurses (CDDN). It was emphasized that this as well as other factors could affect any data Gathered when utilizing the toolkit.

Organizational Analysis of Project Site. The DNP project focused on education of the staff caring for adults with intellectual and developmental disabilities in a hospital setting. Given
that the intervention focused on the staff in this facility for maximum efficiency, the educational
toolkit was presented to the key stakeholder group of nursing leadership. This includes all the
nursing unit managers as well as the staff development department. Toolkits were presented to
the ID/DD unit as well as two other units caring for individuals with ID/DD. The toolkit was
also presented to the Chief Executive Officer as well as the Chief Operating Officer.

The ID/DD unit is staffed differently based on the acuity level at any given time and it
varies per shift. First shift (6:45am-3:15pm) is staffed with a minimum of five licensed staff and
can be a variable mix between registered nurses (RN) and licensed particle nurses (LPN) with a
minimum of two RNs on the unit at all times. There are a minimum of four certified nurse’s
assistants (CNA) for each shift as well. For every patient who is on a higher level of
observation, such as one to one supervision or constant observation, another staff member is
provided. Second shift (2:45-11:15) is staffed the same as first shift minus one licensed staff
member, as there is no designated charge nurse. Third shift again is staffed similarly except
there is usually only three licensed staff. To meet the minimum staff levels on all units a floating
system is utilized based on seniority and union contractual agreements. The DNP student used
the established rapport from the pilot program to make the unit staff aware of the availability of
the toolkit and its use.

Pilot Project. The DNP Student completed a pilot program as the basis of support for
the use of the educational resource fliers. During the pilot, a survey conducted by the DNP
student (Appendix A) revealed that many direct care staff, 40%, felt as though they did not
receive enough learning resources regarding individuals with disabilities (n=12). It was also
noted that 43% (n=13) of staff wished for more educational topics, 13% (n=4) of staff felt as
though it would be beneficial if educational materials were easier to understand, 56% (n=17) of
the staff stated that they wished educational materials were available more frequently.

Surprisingly only six percent of the staff (n=2) referenced lack of time as a barrier to education. Because such favorable learning was noted, nine additional educational resource fliers were created and presented to the identified health care facility.

Evidence of Stakeholder Support. The target hospital opened their ID/DD unit in collaboration with the Massachusetts Department of Developmental Services (DDS). This is a groundbreaking hospital unit that focuses on optimization of health and increased utilization of services for adults with ID/DD. The stakeholders have an interest in maintaining the relationship with the Department of Developmental Services by continuing to provide quality care and produce good patient outcomes. After initiation of this unit, it was noted that increased competency and education would be needed for the health care staff members working on it. Administrative stakeholders support any educational advancement of their employees to help improve patient outcomes and staff satisfaction.

Facilitators and Barriers. The implementation of this educational program was piloted with good success. One noted limitation to this educational program implementation was the inability to assess the reading level of the direct care staff. Due to union contractual agreements the direct care staff did not consent to participating in an assessment of their reading level. It was thought that assessing the reading level of the staff would allow for creation of more user-friendly educational materials. Unfortunately, users did not feel as though they would have ambiguity if reading level was assessed, and felt as though this could jeopardize current and future employment opportunities. It was also thought that participation in the staff survey would decrease if reading level needed to be assessed. Lastly, it was decided that if users thought that their reading level was being assessed they may utilize the product of the toolkit.
That being considered the reading level of the educational resource fliers was targeted at or below a fifth grade-reading level to ensure that all staff including licensed and non-licensed could utilize the education resource fliers effectively. During the pilot, the DNP student was able to take time to go over the education resource fliers with multiple staff members who stated they needed help reading it. This allowed for maximum participation.

The utilization of the pre and post-test data could have been improved from the pilot program. Some users did not complete the pretest or post test of vice versa. To counterbalance this problem many of the educational resource fliers pre and post test questions were similarly. It benefited the end user by letting him or her know what to expect in these test and allowed for self-reflection. A discussion was held, with the staff development department, about changing the pre and post test questions and methods. It was thought that this would help to gather more accurate data, but the original format was well received by the staff development department of the target setting. It was concluded that users of the toolkit will be able to use the pre and post test as a form of self-evaluation, and as a self-learning tool.

Inability to measure improved patient outcomes or quality of life during the pilot and after the toolkit was presented was also a barrier. The implementation of a metric that could measure improved patient outcomes would have been inappropriate for the short timeframe of the pilot program and presentation and likely would not have been accurate due to the cognitive age and comprehension of the adult patients with ID/DD.

The greatest facilitator noted by the DNP student was the readiness and eagerness of the health care staff. After the opening of the specialized ID/DD unit a need for more educational resources was evident, as identified in the gap analysis. Many of the staff requested education and were eager to have it once the toolkit was presented and given to the participating units. In
addition, the feedback from the presentation, which occurred during the pilot program, allowed for modification of the content for inclusion in the toolkit. These modifications included clarification of diagnosis and more details about certain historical examples. In addition, the facility’s staff have committed to the use of the toolkit as a sustainable educational blueprint and staff in-service education.

Goals and Objectives

The goals and objectives of the DNP project were identified as follows. The first goal established after completion of the gap analysis was to improve knowledge of health care staff caring for adults with ID/DD. The corresponding objectives for this goal included: the utilization of pre and post tests to measure an increase in knowledge by the end of the DNP project pilot; and the creation and implementation of a baseline educational program. The baseline educational program was to focus on basic knowledge of adults with ID/DD such as diagnosis, historical treatments, associated stigma as well as current treatment modalities.

The second goal was for the DNP student to create understandable educational materials. This goal’s objectives included: conducting a chart review; creating a staff survey using information from a chart review; dispense the survey to staff caring for adults with ID/DD; and analyze the data from staff survey. The completion of these objectives occurred during the pilot program.

The third goal of the DNP project was to implement usable and understandable educational materials. The identified topics from the staff survey, as listed above, were used to create three educational resource fliers during the pilot program. After the success of the pilot program an additional nine educational resource fliers were created for use. The objective for this goal was the utilization of the created educational resource fliers. The first three educational
resource fliers were used during pilot program which occurred over a six week period. These three fliers as well as the additional nine were included in the toolkit for continued use at the target facility. The DNP student assisted staff in utilization of the fliers when necessary.

The fourth goal of the DNP project was to evaluate the effectiveness of the educational resource fliers. The objective used to measure this goal was the calculation of the data that was collected from the pre and post tests embedded in the educational resource fliers. It was noted that after analysis of this data learning did occur. This data was presented to the target facility for evidence of the potential effectiveness of increasing education about the care of adults with ID/DD with use of the toolkit. This analysis can be completed by the target facility if they wish to continue to show positive learning outcomes with use of the educational resource fliers.

The fifth goal of the DNP project was to increase awareness of the educational toolkit and ensure that the toolkit would be sustainable. The objective for this goal was having the DNP student meet with staff to increase awareness of the toolkit’s existence. A presentation was held with the target facility’s nursing leadership group, which included staff development personnel, to increase their knowledge of the toolkit. Other objectives for this goal included: working with the Quality Improvement Department at the facility to allow the educational resource fliers to be put on the web based policy tracking program PolicyTech. The original goal was for this to occur during this DNP project, but it was decided that the target facility could complete this task after the presentation of the toolkit. Lastly, the DNP student created multiple hard copies of the toolkit. Each unit where the care of adults with ID/DD occurs was given a hard copy of the toolkit. In addition to this the staff development department was also given a toolkit. The toolkit included: a table of contents, toolkit flow chart, the background educational presentation, the pre and post test questions for the background education, all twelve educational resource fliers, and a
reference list subcategorized by diagnosis. The toolkits contained ten copies of the educational resources fliers. One of the copies of each education resource flier was placed in a protective sheet to alert users not to take the last one to ensure that the copies will always be available.

The last goal for the DNP project was to increase satisfaction with learning opportunities at the target facility. It was originally thought that the DNP student would re-survey staff to show that they were more satisfied over time from original distribution of the staff survey and the educational resource fliers. Rather, it was decided that qualitative data gathered from staff members would be utilized to show how the toolkit was received. The staff survey that was created, however, will be given to the target facility to allow the staff development and the leadership team to administer the survey to staff if they want to do this.

These educational resource fliers were designed to increase staff self-awareness with utilization of the pre and post test assessment methods. Allowing for personal comparison via the pre and post test methods will allow for comparison of one’s own progress and can increase learning. Through the use of hospital administration and PolicyTech, a web based policy program, these educational resource fliers could be incorporated into the hospital’s yearly competencies as well as provide continuing educational opportunities for licensed staff.

**Ethics and Human Subjects Protection**

The intervention described above did not involve human subjects research. The target intervention population was for the staff caring for adults with intellectual disabilities, not the individuals themselves. The only ethical consideration that was encountered during this intervention was the inability to assess the reading level of the target audience. As stated above health care staff involved in this intervention, felt as though having their reading level assessed could compromise current or future employment opportunities. This would not be ethical.
Results and Interpretation

The DNP student presented the toolkit to the target facility’s nursing leadership group as well as hospital administration. The DNP student reviewed the process, which lead to the creation and establishment of the toolkit. This process involved six steps: conducting a gap analysis, providing background education, completion of a chart review, completion of a staff survey, completion of a pilot program, and finally creation of the toolkit. The last step included presenting the toolkit to key stakeholders. Prior to the presentation to the key stakeholders, the toolkit was reviewed with the staff development department as well as with some of the clinicians that work on the ID/DD specific unit. The toolkit was well received by the staff development department as well as hospital administration. In addition to that, the DNP student has witnessed employees from the ID/DD unit dispersing educational resource fliers from the toolkit to employees that have floated to the unit or to student nurses to help them better understand the patients with ID/DD on the unit. In addition, within two weeks of implementation, more than 25% of the fliers supplied in the toolkit were dispersed.

After the completion of the presentation, there was a good session of question and answers which showed interest in the project. Personnel from the staff development department requested that the background educational session: Care of Adults with Intellectual Disabilities be recorded to allow other nurses in the department access to the continuing education units. As previously stated, they have immediate plans to disseminate the educational resource fliers on their hospital intranet. Other key stakeholders showed interest in the toolkit by stating that it was a great in-service resource for the current staff within the facility and for its future staff. In
addition, the ID/DD specialist was given a copy of the toolkit and stated that it was an excellent resource that could be translated to the community as well.

Future plans for the educational toolkit *Caring for Adults with Intellectual and Developmental Disabilities* include: ensuring that the toolkit will continue to educate staff in the facility so they can improve the care for patients with ID/DD. In addition, making sure that information about the toolkit and its use will be disseminated locally via the hospital’s intranet. The leadership team and the DNP student plan to present the toolkit as well as the model of care utilized on the ID/DD specific unit at the Developmental Disability Nurses Association Annual Conference and to eventually publish the work.

**Conclusion**

Adults with ID/DD experience health disparities at an alarming rate. This is directly related to the lack of health care education provided to hospital staff caring for these individuals. The implementation of an educational toolkit for health care staff caring for adults with intellectual disabilities has the potential to improve staff competency, improve patient outcomes and improve patient quality of life. Increasing education of health care staff has been shown to improve health outcomes and quality of life of adults with ID/DD. The utilization of a toolkit to improve the health of adults with ID/DD in a hospital setting was long overdue. Health care staff at a national level, have been asking for more education regarding this population in easy to use resources for decades. A toolkit was shown to be a cost effective and beneficial method to ensure appropriate and sustainable increases in education and awareness of health care staff regarding the best healthcare of adults with intellectual disabilities and developmental disabilities.
References


Finlayson, J., Jackson, A., Mantry, D., Morrison, J., Cooper, A. (2015). The provision of aides and adaptations, risk assessments, and incident reporting and recording procedures in


Ryan, K., McEvoy, J., Guerin, s, & Dodd, P. (2010). An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities. *Palliative medicine*, 24(60), 566-572.


Sokol, R. (2012). It’s not all about the testes: medical issues in Klinefelter patients. *Fertility & Sterility*, 98(2), 261-265. Retrieved from [http://ac.els-cdn.com.silk.library.umass.edu/S0015028212005808/1-s2.0-S0015028212005808-main.pdf?_tid=a7900d7c-7b36-11e5-a024-0000aacb35f&acdnat=1445791217_a01e0e5d812f026751a455cf66c09e4e](http://ac.els-cdn.com.silk.library.umass.edu/S0015028212005808/1-s2.0-S0015028212005808-main.pdf?_tid=a7900d7c-7b36-11e5-a024-0000aacb35f&acdnat=1445791217_a01e0e5d812f026751a455cf66c09e4e)


disabilities: Why the ADA is only part of the solution. *Disability and Health Journal, 3*,

253-261
Appendix A

Table 1

Pilot Survey Tool

Please Rank which topics you would like to learn about

- Tuberous Sclerosis
- Angleman Syndrome
- Prader Willi Syndrome
- Trauma Informed Care
- Rett Syndrome
- Klinefelter Syndrome
- Autism
- Cerebral Palsy
- Downs Syndrome
- Fragile X Syndrome
- Williams Syndrome
- Other please specify

Do you feel as though you receive enough learning resources?

- Y
- N
- Comment: __________________

Related to education what could improve?

- More Topics
- Easier to understand
- More frequent
- Time to complete
- Other: _____________________________
## Appendix B

### Table 2

*Pilot Survey Tool Analysis*

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<td>Angleman Syndrome</td>
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<tr>
<td>Prader Willi Syndrome</td>
<td>18</td>
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<td>Trauma Informed Care</td>
<td>12</td>
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<tr>
<td>Rett Syndrome</td>
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<tr>
<td>Klinefelter Syndrome</td>
<td>14</td>
</tr>
<tr>
<td>Autism</td>
<td>12</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>9</td>
</tr>
<tr>
<td>Down Syndrome</td>
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<tr>
<td>Fragile X Syndrome</td>
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<td>Williams Syndrome</td>
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<table>
<thead>
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### Number

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Appendix C

Figure 1. Knowledge to action framework
Appendix D

Step One
Identify a program facilitator: this could be a member of the staff education department of other person

Step Two
Identify target Audience: Health Care Providers (HCP) caring for Adults with Intellectual Disabilities in the Hospital

Step Three
Commence action plan: Present initial Power Point educational program to provide baseline education to HCP

Step Four
Disseminate educational fliers to designated staff in two-week intervals

Step Five
Analyze pre & post test data to evaluate knowledge gain

Step Six
Develop sustainability plan: place resources in central location in physical environment of virtual environment


Figure 2. Toolkit flowchart
Appendix E

Educational Resource Fliers

What is Angelman Syndrome?

What in Angelman Syndrome?
- People are missing a gene on the 15th chromosome that comes from your mother
- Causes developmental Disability all time
- It is genetic
- Happens to 1 in 15,000 people
- Can be inherited, usually it is not

What does AS look like?
- Small head
- Light skin
- Wide smile
- Crossed eyed
- Walks with wide steps and arms out
- Large tongue

Problems (Symptoms)
- Neurological problems
- Seizures
- Trouble with speech
- Trouble with movement
- Get excited easy
- Heart problems
- Drooling
- Sensitive to heat
- Curved spine

Behaviors
- Sleeping troubles
- Laughter outburst
- Happy
- Hand flapping

Treatment
- No cure but do not get worse as they get older
- Start early

Children
- Hard to see when first born
- Often found at 6-12 months old
- Small head
- Trouble learning to talk
- Trouble sitting
- Trouble learning to walk

Angelman Syndrome (AS)

- Speech therapy
- Occupational therapy
- Swim therapy
- Horse therapy
- Help for the family
ANGLMAN SYNDRONE

More about AS...
- 50% of people with Angelman syndrome have autism
- People with Angelman syndrome will probably never live alone
- Is sometimes confused with Cerebral Palsy
- Most people can find out if they have Angelman Syndrome with a blood test
- Discovered by Dr. Henry Angelman in 1965
- Prader-Willi Syndrome is the “brother” to AS because it is caused by the same gene deletion, but comes from your father
- Many people with AS use nonverbal communication

- Also known as UBE3A
- Angelman syndrome happens all over the world
- People with Angelman Syndrome need less sleep than others
- They are less excitable as they get older and sleep can improve
- People with Angelman Syndrome have a normal life span
- Most people do not talk at all
- Many people have trouble understanding others talk
- Seizures usually start before age three

Post-Test yourself...did you learn?
1. People with AS have light skin
   Yes or No
2. People with AS are good with language
   Yes or No
3. Seizures are common in AS
   Yes or No
4. IS there a cure for AS?
   Yes or No

⭐⭐⭐⭐⭐

N B J S D I C K F J P Z D S M
T C E N R W P C M V S P X G
I R S E R H J S T M E G N E
T P O T E Q O K R E N I F N
A W E D Z W M Q L C M K U E
C B E R U C O N F S C J Y T
I D E L E T I O N T R N Q Y I
N P Y O S M C B G F P P C C
U Z L J Y E D G Y H I P B G I
M Q R E D I I S J A T I G L
M K S H G L G Z Q H W K H I P
O M J L U N T M U Q K D I C K
C D Y N G O A L T R C U T M A
V B O Z I D B P U Q E A O L H
H O A P L K U K H E I I X

Word Search

⭐⭐⭐⭐⭐

- Angel
- Seizure
- Genetic
- Speech
- Communication
- Deletion
- No cure
- Water
- Happy
- Light skin
What is Autism?

- Trouble talking
- Some people don't talk at all
- Can have an intellectual disability

Behaviors
- Temper tantrum
- Trouble making friends
- Trouble making eye contact
- Have trouble controlling themselves
- Self-injurious behavior
- Withdrawn
- Anxiety
- Attention problems
- Pica-eat strange things
- Confusion
- Patterns of behavior
- Doing the same thing over and over

Children
- Undiagnosed- until 2-3 years
- Diagnosis is usually before age three
- Used to be diagnosed at age five
- Harder time learning to talk
- Quiet
- Not a lot of eye contact
- Does not like to pretend
- Do not show interest in what is going on around them.
- Babble with parents only

What does Autism look like?
- Sometimes there are no differences
- Some people are great with music
- Some people are great with words

Problems (Symptoms)
- Include family
- Teach parents
- Help with changes and transitions
- Occupational therapy
- Speech therapy
- Medication
- There is no cure for autism

Autism
More about Autism

- Used to be many types such as Asperger syndrome and pervasive developmental disorder but are now all Autism Spectrum disorder
- Autism is not caused by immunizations
- Used to be called children's schizophrenia
- More people are being told that they have autism
- The rate has doubled since 2004
- Two children from the same family can have autism. One can be mild one can be severe
- People with fragile x syndrome are more likely to have autism
- People with tuberous sclerosis are more likely to have autism
- Can happen in any race or ethnicity

Post-Test yourself...did you learn?

1. Autism happens is more in girls
   - Yes or No
2. Autism can be from environmental reasons
   - Yes or No
3. People with Autism always have an Intellectual disability
   - Yes or No
4. Is there a cure for Autism?
   - Yes or No

Word Search
Pre Test yourself...did you learn?
1. CP is caused by a problem in your brain
   Yes or No
2. People with CP always have an intellectual disability
   Yes or No
3. CP causes problems with walking
   Yes or No
4. There are five types of CP?
   Yes or No

What is Cerebral Palsy?

What is CP?
- Neurological problem that happens when you are a baby or child that causes permanent changes
- Caused by changes in the brain
- It does not get worse as you get older
- It can make walking hard
- Does not always cause intellectual disability
- 17 million people have it

What does CP look like?
- Everyone is different
- Walk unbalances
- Drag one foot at times

Problems (Symptoms)
- Muscle problems
- Tight muscles or floppy muscles
- Trouble with movement
- Staw backs
- Trouble sleeping

Behaviors
- Do not have specific behaviors

Treatment
- No cure but do not get worse as they get older
- Start early
- Speech therapy
- Occupational therapy
- Medication for spasms
- Medication for muscles- Botoks
- Surgery for tight muscles
- Braces for legs
- Computer to help people talk
- Special wheel chairs

Types of Cerebral Palsy

- athetoid
- Hemiplegic
- Diplegic
- Quadriplegic
CEREBRAL PALSY

- Can happen from injury when you are young like a car accident or abuse
- Could also happen when you have a brain infection when you are young
- Not all people with CP require help or therapy
- Happens in 1 of every 500 babies born
- Spastic is the most common type of CP
- Ataxic is another type of CP that causes shaky movements
- Dyskinetic is another type of CP when movements happen without your control
- People with CP can have more than one type, this is called mixed

- Levels of CP are measures with gross motor skills
- Half of all people with CP have an intellectual disability
- 30% of people with CP need to use a wheelchair
- People with CP are more likely to get chest colds
- Found in 1862 but was probably around before that
- Seen all over the world than is not more common in poorer countries that richer

Pro-Test yourself... did you learn?
1. CP is caused by a problem in your brain
   Yes or No
2. People with CP always have an intellectual disability
   Yes or No
3. CP causes problems with walking
   Yes or No
4. There are five types of CP?
   Yes or No

Word Search
Pre-test yourself...did you learn?

1. Does Down syndrome happen in boys and girls?
   - Yes or No
2. Are there three types of Down syndrome?
   - Yes or No
3. Do people with Down syndrome live to adulthood?
   - Yes or No
4. Is there a cure for Down Syndrome?
   - Yes or No

---

**What is Down syndrome?**

- Caused by changes in the chromosome 21, people with Down syndrome have an extra copy of it.
- Happens to girls and boys.
- Happens in 1 of every 800 people born (this means that there are around 8000 people born in the United States with Down syndrome every year).
- Down syndrome is not usually inherited.

**What does DS look like?**

- Flat face
- Small hand
- Short neck
- Tongue that does not fit in mouth
- Upper slanting eyes
- Small ears
- Nut shell
- Short fingers

**Problems (Symptoms)**

- Causes an intellectual disability
- Intellectual disability must be big or little
- Anorexia in heart or lung areas
- More likely to have acid reflux
- More likely to have a gluten problem
- Problems with eye sight
- Problems with hearing
- More likely to have memory problems as they get older
- More likely to have heart problems
- More likely to be overweight
- More likely to get sick than others (e.g., pneumonia)

**Behaviors**

- Children can be likely to have temper tantrum
- Trouble with attention
- Obsessive behavior
- Compulsive behavior
- Sleep problems

**Treatment**

- Early intervention for children
- Can be found while the mother is still pregnant
- No cure
- Team approach

**Children**

- Causes weak muscles
- Limp problems happen in half of the children both with DS
- Slower learning
- Can have stomach problems
- Kids are more likely to get leukemia; a type of cancer
- May be hard to understand them when they talk

**Extra chromosomes 21**

---

Down Syndrome (DS)
What is FASD?

What are FASD?
- A term to includes fetal alcohol syndrome and other disabilities
- Is caused when pregnant women drink alcohol
- Would not happen if mothers did not drink
- The number with people with FASD is not known
- More people have FASD in poorer countries

Problems (Symptoms)
- Can have an intellectual disability but not everyone does
- Heart problems
- Trouble hearing
- Trouble seeing
- Kidney problems

Behaviors
- Sexually inappropriate
- More likely to be alcoholic
- Mental health illness
- Anxiety
- Behavior outburst
- More likely to kill themselves
- Impulsive
- Cannot plan well
- Can get into trouble with the law
- Trouble getting jobs as adults

Treatment
- No treatment changes are permanent
- Behavior interventions
- Provide structure
- Start early
- Include family

More about FASD...

Teach parents
- There is no cure for FASD
- Education for mothers not to drink alcohol
- Help with substance abuse for mom and child

Children
- Goes undiagnosed
- Does not develop well—failure to thrive
- Small head
- Trouble learning to talk
- Trouble in school
- Lack of care before the child is born is a risk factor

Fetal Alcohol Spectrum Disorders

What does FASD look like?
- Wide eyes
- Thin upper lip
Fetal Alcohol Spectrum Disorders

- Children to older mothers have more problems.
- South Africa has the most cases of FASD.
- FASD yearly births are more than the new cases of Down syndrome, cerebral palsy, cystic fibrosis, spina bifida, and sudden infant death syndrome put together.
- More people are being told that they have autism.
- People with more money are less likely to have FASD.
- People with drinking problems or drug problems are more likely to have a child with FASD.
- All alcohol causes FASD: beer, wine, and liquor.

- FASD has been around for hundreds of years.
- People who have been exposed to sexual abuse are more likely to have an FASD baby.
- Mothers with poor nutrition are more likely to have an FASD baby.
- Some countries still tell pregnant women they can drink alcohol during pregnancy even though not drinking is the only way to stop FASD.
- Many mothers of kids with FASD die young.

---

**Post-Test yourself...did you learn?**

1. Are FASD preventable?  
   - Yes or No

2. Drinking during pregnancy is safe?  
   - Yes or No

3. FASD is common?  
   - Yes or No

4. Is there a cure for FASD?  
   - Yes or No

---

**Not A Single Drop**

---

**Word Search**

- Fetal
- Alcohol
- Disorder
- Nature
- Pregnancy
- Preventable
- Behavioral
- Kidney
- Heart
What is Klinefelter Syndrome?

What is Klinefelter Syndrome?
- Caused by an extra X chromosome
- Happens to men only
- Causes lower testosterone, the hormone that helps men change during puberty
- It is not inherited, it happens to me
- More common in men
- Happens in 1 of every 1000 men

What does KS look like?
- Not a lot of facial hair
- Small or different penis
- Not a lot of pubic or other body hair

Problems (Symptoms)
- Weak bones
- Potential for intellectual disability
- High calcium
- Sleeping problems
- Higher chance of getting breast cancer
- Higher chance of getting lupus

Children
- Go undiagnosed until puberty
- May have reduced height
- Men with KS can have kids, but the treatment is very expensive and does not always work. It does not happen at all
- Harder time learning to talk
- Quiet
- Sensitive
- Anti-social

Behaviors
- Children can be likely to have temper tantrums
- Not good at sports
- Make bad decisions
- Have trouble controlling themselves

Treatment
- Therapy
- Surgery to reduce breast size
- Work with hormone doctor
- Testosterone replacement therapy started at puberty and continues their whole life

Abnormal (Klinefelter Syndrome), normal
**Klinefelter Syndrome**

**More about Klinefelter Syndrome...**
- Also called XXY
- Does not always cause intellectual disability
- Sometimes there can be more than an extra X chromosome (XXY) the more extra chromosomes the more severe the syndrome
- It is genetic
- Most common genetic reason men cannot have children

**Post-Test yourself...did you learn?**
1. Klinefelter Syndrome happens in girls?
   - Yes or No
2. People Klinefelter Syndrome is from and extra Y chromosome
   - Yes or No
3. Is Klinefelter Syndrome inherited
   - Yes or No
4. Is there a cure for Klinefelter Syndrome?
   - Yes or No

**Male Chromosome**
- Genetic
- XXY
- Tumors
- Heart Problems
- Sensitive
- Hairless
- Hormone
- Impulsive

**Word Search**

E Z G N V E Q U F B Z A Y A F
J M E L D O R P T R A D E X K
G K O P N E K J Z E Q M U A X
V E G S U L U W V V G W J H X
B W N Y O R R I T S E M K Z O
T F Y E Z M S S U A V H K S I
V W B I T L O Z E X I O R V E
J C G D U I F R V Q T O I K
I I T P Z D C I H Y V I M A M E
L I M K Y K U M T C S O T X T
Z I B C C M E L A M N N P O U
P Q D F O D R D Z N E E X K E K
H A I R L E S S H M S O Y T I
V A S C V U Z U C E N N I L X
T L Y N K A N N V G N D H Y P V

Answer: KNNN
What is Phenylketonuria?

**What is PKU?**
- People cannot break down a substance called phenylalanine which is found in a lot of foods.
- When this problem builds up it causes brain damage.
- Once brain damage happens it cannot be reversed.
- It is genetic.
- It is not common.
- Happens to 1 in 10,000 people.
- It is inherited and comes from the mom and dad.

**What does PKU look like?**
- Light skin
- Blue eyes
- Drooping eye
- Small heart

**Problems (Symptoms)**
- Intellectual disability
- Poor memory
- Trouble concentrating
- Bad reaction to time
- Poor bone
- Skin rash
- Seizures
- Shaky hands/tremors

**Behaviors**
- Crabby
- Get angry easily
- Issues in school
- Problems with attention
- Hard time finding a job
- Hard time finishing school
- Depression

**Treatment**
- No cure
- Prevent brain damage by controlling the diet.
- Most children can live normal lives if the diet is followed.

**Phenylalanine (PKU)**
- Phenylalanine is a medication that can increase the amount of the protein that can be eaten.
- Talking with other families can help.

**Children**
- In most of the world babies are screened at birth with a blood test; it is required in all of the 50 United States.
- Newborns do not usually show any signs of having PKU.
- A child born to a PKU mother might have low birth weight & heart problems.

---

**PRE-TEST yourself...did you learn?**
- PKU causes brain damage
- Yes or No
- Is PKU preventable
- Yes or No
- Brain damage can be reversed
- Yes or No
- PKU is caused by diet
- Yes or No
**Prenatal Alcohol Spectrum Disorders**

- Pregnant women with PKU who do not follow the diet can cause damage to the unborn child.
- Foods high in protein need to be avoided.
- One in 90 people carry the gene for PKU.
- This is a preventable cause of an intellectual disability Syndrome with a blood test.
- There is a PKU formula that many people take.
- Foods to avoid are: Milk, Eggs, Cheese, Nuts, Soybeans, Beans, Chicken, Beef, Pork, Fish.

- Aspartame is a substance used in a lot of diet foods will also have to be limited.
- Skim milk may also need to be avoided.
- Keeping a record of foods eaten can help.
- Many people have trouble understanding others talk.
- Other foods with protein will also be limited.
- Letting children deal with their diet early really helps.
- Teachers and other people involved in the child's life will need to know about PKU and how to deal with it.

**Pre-Test yourself...did you learn?**

1. PKU causes brain damage. Yes or No
2. Is PKU preventable. Yes or No
3. Brain damage can be reversed. Yes or No
4. PKU is caused by diet. Yes or No

---

**Word Search**

- A, H, E, F, O, P, N, E, L, S, E, T, Z, Q

**Inhibiting PKU**

[Diagram showing family tree with PKU inheritance]
What is Prader-Willi Syndrome

What is Prader Willi Syndrome (PWS)?
- Genetic disorder related to chromosome 15
- Always comes from your father's gene
- Happens in an child in every 15,000
- Happens in male and females the same amount
- Not inherited

What does PWS look like?
- Almond shaped eyes
- Narrow head
- Thin upper lip
- Turned down mouth
- Small hands

Symptoms
- Never ending hunger starts around age four
- Very overweight
- Difficulty speaking
- Lower level of functioning (intellectual disability)

Behaviors
- Skin picking
- Temper tantrums (usually related to food)
- Can handle a lot of pain
- Good at puzzles
- Love animals
- Love babies
- Talk more

Treatments
- No cure
- Stop over eating
- Lower weight
- Diet control
- Stop access to food
- Physical therapy
- Medication

Debiles
- Babies with PWS have poor muscle tone
- Have trouble feeding
- Are underweight
- Look flabby
PRADER-WILLI SYNDROME

More about Prader-Willi Syndrome...

- Can cause a small or large intellectual disability
- A lot of people with PWS also have Autism
- People with PWS can never be alone to prevent overeating
- Sleep during the day a lot
- Angelman Syndrome is the “sister” to PWS because it is caused by the same gene deletion, but it comes from your mother
- Looking for food will lower when a routine is followed
- They become less excited about activities over time

- Skin picking can cause infection
- Men with PWS get angrier
- People with PWS have trouble making friends
- Problems caused by being overweight are the number one causes of early death for people with PWS

What did you learn?
1. Prader-Willi Syndrome is inherited? Yes or No
2. Prader-Willi Syndrome comes from your father’s gene? Yes or No
3. Prader-Willi Syndrome has no cure? Yes or No
4. Kids with PWS are always overweight? Yes or No

Word Search

- ALMOND EYES
- CHROMOSOME
- DISABILITY
- EYES
- FOOD
- KNEE
- NO HIPS
- OUT, TANTRUM
- PICKING
- SMELL
- TANTRUM
- REST
- crypto
**What is Rett Syndrome?**

- Neurologic disorder
- Caused by an alteration in the X chromosome
- Caused by a change in the MECP2 gene
- Happens mostly to girls
- Affected in 1 out of 10,000 children
- Most cases only happen once in a family

**What does Rett Syndrome look like?**

- Sleeping problems
- Difficulty speaking
- Can affect heart
- Lower level of functioning (intellectual disability)

**Behaviors**

- Hand movements and tapping
- Social withdrawal before age 3
- Easily upset as children
- Unexplained screaming
- Walk on toes with legs spread apart
- Hand motions only happen while awake
- Behavior may improve in stage three

**Babies**

- Normal growth happens from 6 months to 12 months old
  - Speech loss
  - Slow head growth
  - Repetitive hand movements happen
  - Hard time walking or crawling
  - Trouble feeding
  - Poor eye contact

**Symptoms**

- Curved spine
- Grind teeth
- Poor muscle tone

- Cesarean section
- Causes breathing problems
More about Rett Syndrome...

- Often confused with Autism or Cerebral palsy
- People with Rett Syndrome can gain new skills throughout life
- Discovered in 1966 but not recognized until 1983
- Diagnosis can be made on symptoms of genetic test
- There are four stages of Rett Syndrome
  a. Stage 1: 6-18 months old
  b. Stage 2: 1-4 years old
  c. Stage 3: 2-10 years old
  d. Stage 4: 10 years and onwards

- Stage III causes quick loss of skills
- If a boy gets Rett Syndrome, they usually die shortly after birth
- This is a rare disease
- Rett Syndrome happens in everyone all over the globe and happens the same in all racial and ethnic groups

What did you learn?

1. Rett Syndrome affects girls and boys the same amount?
   - Yes or No

2. Rett syndrome has three stages?
   - Yes or No

3. Rett Syndrome has no cure?
   - Yes or No

4. Babies develop normally until 6 months old?
   - Yes or No

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**Word Search**

<table>
<thead>
<tr>
<th>Rett Syndrome</th>
<th>Stages</th>
<th>Girls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurological</td>
<td>Grind tooth</td>
<td></td>
</tr>
<tr>
<td>Poor tone</td>
<td>Disability</td>
<td></td>
</tr>
<tr>
<td>Movements</td>
<td>Therapy</td>
<td></td>
</tr>
</tbody>
</table>
**What is Tuberous Sclerosis**

**What does TS look like?**
- Reddish rash on face
- White spots on arms and legs
- Non-cancerous tumors develop around nose, eyes, and face
- Wart-like tumors around fingernails

**Problems (Symptoms)**
- Seizures
- Skin problems
- Intellectual disability
- Autism-like behaviors
- Sleeping problems

**Behaviors**
- Aggression
- Overactive
- Sudden rage
- Obsessive behavior
- Repetitive behaviors
- Hurts themselves

**Children**
- Abnormal growths in the nervous system
- Tumors in above areas
- Causes seizures

**Treatment**
- No cure
- Regular visits to the doctors
- Procedure to remove tumors
- Medication for seizures
- Speech therapy
- Physical therapy
- Special Education
More about Tuberous Sclerosis...

- TS is a lifelong condition.
- Not very common, 1 per every 6,000 births.
- TS is not catchable.
- Small brain tumors interrupt the wiring of the brain causing seizures.
- Lungs being affected happens mostly in girls.
- No one with Tuberous sclerosis has an intellectual disability.

What did you learn?

1. Is Tuberous sclerosis inherited?
   - Yes or No
2. The tumors caused by TS gene change
   - Yes or No
3. TS always causes severe intellectual disability
   - Yes or No
4. Is there a cure for TS?
   - Yes or No

Word Search

Design
Skin Problems
Disability
Headache
Autism Behaviors
Tuberous sclerosis
Aggression
Inherited
Seizures
Genetic
Sclerosis

KEEP CALM and FOCUSING ON TUBULAR
What is Williams Syndrome

What is Williams Syndrome?
- Caused by a change in normal genes present at birth
- Missing a small piece of chromosome 7
- It is not inherited
- Occurs in 1 in 7,500-10,000 all over the world
- Both males and females get it

What does TS look like?
- Puffiness around the eyes
- White lazy pattern around the inner part of the eye - more common in blue and green-eyed children
- Adults are smaller than average
- Small nose spanned far apart

Problems (Symptoms)
- Heart problems
- Learning disability
- Intellectual disability
- High calcium
- Sleep problems

Children
- Often need emergency heart surgery in the first years of their lives
- Low birth weight
- Have slurred speech
- Have feeding problems related to low muscle tone
- Have abnormal sleep patterns
- May be more colicky

Behaviors
- Social personality
- Friendly
- Anxiety and nervousness
- Picking behavior
- Trouble knowing when a situation is dangerous

Treatments
- No cure
- Speech therapy
- Special education
- Minimize distractions to a minimum
- Social skills training
More about Williams Syndrome...

- People with Williams syndrome are musically talented
- Are very sensitive to noise
- Can have a big vocabulary
- Williams syndrome often have an elfin face
- Heart problems are caused by removal of the elastin & narrowed arteries
- Williams syndrome is not catchy
- Some refer the behavior of people with Williams syndrome the opposite of Autism

What did you learn?
1. Is Williams Syndrome inherited? Yes or No
2. People with Williams syndrome are musically talented Yes or No
3. People with Williams Syndrome can reproduce Yes or No
4. Is there a cure for Williams syndrome? Yes or No

The Superpowers of Williams syndrome

- Super hearing... very sensitive hearing
- Super friendly... people are kind to others
- Super memory... we keep meaningful memories of people and places we will never forget you
- Empathetic and very sensitive to other's feelings... we make a great friend
- Super sense of humor... we love to laugh and have a sense of humor

Word Search

| Williams Syndrome | No cure
| Disability        | Heart
| Anxiety           | Friendly
| Music             | Chromosome
| Calcium           |