

Development of a Learning Resource for Intellectual and Developmental Disabilities

in Long Term Care

by © Lindsay Hunt

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INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

Abstract

Background: The number of residents admitted to long term care (LTC) with a diagnosis of an intellectual and/or developmental disability (IDD) is increasing since this population is aging and have a variety of complex health care needs. Although LTC offers a variety of benefits for this population, there are many issues associated with having a diagnosis of an IDD. As well, many of the resources available are dementia specific and not specific to those with IDDs. **Purpose:** The purpose of this practicum project was to develop a learning resource that would educate staff at St. Luke's Home (SLH) regarding IDDs within LTC. **Methods:** 1) comprehensive literature review; 2) consultations with key health care professionals via semi-structured interviews and email; and 3) development of a resource. **Results:** Issues identified included complex health needs, dementia, challenging behaviors, antipsychotic use, inclusivity, social isolation and loneliness, communication, resident-focused care, the importance of including family/friends, feelings/beliefs of staff, and teamwork. The importance of documentation was also highlighted. Based on the findings from the literature review and consultations, a learning resource was developed. The resource consists of four booklets that encompass the variety of issues associated with caring for residents with IDDs: 1) IDDs in LTC, 2) challenging behaviors, 3) dementia and IDDs, and 4) social isolation and loneliness. A self-evaluation component was included throughout each booklet, such as “test your knowledge” questions, case-studies, and self-reflection activities. **Conclusion:** This learning resource may be used by a variety of health care professionals who work with or are interested in learning more about IDDs in LTC.

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Key Words: nursing homes; long term care; developmental disability; intellectual disability; and aged

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The life expectancy of the elderly has continued to increase due to better management and advancement in treatment of chronic health issues. Those with intellectual and/or developmental disabilities (IDDs) are seeing similar trends and tend to experience similar chronic conditions earlier than the general population (Herron-Foster & Bustos, 2014). By the year 2020, the proportion of people with intellectual disabilities (IDs) over the age of 65 will have doubled (Jethwa & Cassidy, 2010). Therefore, long term care (LTC) for those with IDs is inevitable and is a growing area of concern since this population is aging and has complex health care needs. LTC homes offer an alternative to community-based living and institutionalization, allowing for positive outcomes as this population continues to age. However, since these individuals do have more health concerns, communication difficulties, and challenging behaviors compared to those without intellectual challenges, LTC has to be prepared to meet the needs of this specific population. Education is one-way health care professionals can be better prepared to meet the needs of those with IDs. Hence, this practicum project focused on an assessment of learning needs of staff members working at St. Luke's Home (SLH). A learning resource was developed to increase knowledge of IDs in LTC.

Background

There are two main types of disability. Intellectual disability (ID), formerly known as "mental retardation," is characterized by significant limitations in intellectual functioning and adaptive behaviors (American Association on Intellectual and Developmental Disabilities (aaidd), 2018). Reasoning, learning, problem solving, and everyday social and practical skills may be affected. Developmental disability (DD) is an umbrella term that includes IDs, along with other types of disabilities that incorporate

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either a cognitive and/or physical deficit. IDD's often co-exist and, therefore, the terms are often used interchangeably. However, it is important for health care professionals to be able to distinguish between both terms as they are two distinct types of disability.

A diagnosis of an IDD is a strong predictor of the likelihood of admission into LTC (Bigby, Webber, Bowers & McKenzie-Green, 2008; Ouellette-Kuntz, Martin, & McKenzie, 2016; Patti, Amble, & Flory, 2010). Those with IDD's are living longer and may exhibit an array of chronic health care issues (Herron-Foster & Bustos, 2014; Ouellette-Kuntz et al.). Therefore, advanced care and additional support that can be offered in environment, such as LTC, may be required as individuals may no longer be able to take care of themselves, and/or families are unable to provide care needed due to the complex health care needs of this population as they age. However, health care professionals working with this population often feel that they do not have the resources or education needed to provide quality care as there are many issues associated with having a diagnosis of an IDD. Increasing education in this area will enable staff to provide more effective care and, in effect, lead to positive resident outcomes.

Rationale

As a registered nurse (RN) working in LTC for the past four years, it is evident that the number of residents admitted with an IDD is increasing. I have had the opportunity to work with a number of residents who had a diagnosis of an IDD, many of which are integrated among other elderly residents. I work in a unique leadership role and saw that staff needed guidance in caring for this population as they often express that they are frustrated when dealing with the variety of issues associated with caring for a resident with a diagnosis of an IDD.

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Prior to beginning this practicum project, an informal needs assessment was conducted among staff and the resident care manager (RCM) at SLH. Staff members identified the need for more education in this area as many felt that this was a topic that was often overlooked. Many of the resources available on the units were dementia specific, and not specific to IDD. A need for a tangible resource specific to IDDs in LTC was identified.

Practicum Goal and Objectives

The overall goal of this practicum project was to develop a learning resource that would be used to educate staff at SLH regarding IDDs within LTC. This goal was accomplished through the successful achievement of the following three practicum outcome objectives:

1. Develop a resource, by the end of the practicum project, with support from staff at SLH who are working with residents IDDs in LTC;
2. Analyze issues, learning needs, and potential strategies related to care of residents with IDDs; and
3. Demonstrate advanced nursing practice competencies.

Overview of Practicum Project

There were two main methods used in the development of this practicum project. A literature review and consultations were conducted in order gain a better understanding of IDDs in LTC. These methods also supported the need for education in this area and helped to determine content that would be used in the development of the learning resource. Additional information regarding each methodology will be described below under the appropriate headings.

Through conducting consultations and evidence obtained from the literature review regarding appropriate educational methods, it was decided to develop a learning resource that could be easily distributed to health care professionals who work with residents who have IDD. The learning resource could also be used for those who may be interested in learning more about IDDs. The resource consists of four booklets which will be further discussed below. The booklets can be used by front-line staff, such as licensed practical nurses (LPNs), personal care attendants (PCAs), and RNs. However, information contained within the booklets may also be beneficial for a variety of health care professionals.

Literature Review

A synopsis of the literature review is below. The complete literature review can be found in Appendix I.

Search Methods

The initial search from CINAHL and PubMed resulted in a large number of relevant research articles related to IDDs. Additional articles were retrieved by searching within Google. Broad search terms were used, including "nursing homes," "long term care," "developmental disability," "intellectual disability," and "aged." Article selection was further limited by date (2008-2018) and English language. Using these search terms, several quantitative and qualitative studies were retrieved.

The studies chosen to be included in the literature review consisted of five qualitative studies, nine quantitative studies, and one mixed methods study. The quantitative studies consisted of three cohort studies, two cross-sectional studies, one non-randomized trial (NRT), and one randomized-controlled trial (RCT). The NRT and

RCT, which used strong study designs, were rated high for quality whereas the two cross-sectional studies were considered weak due to their descriptive nature. The cohort studies used moderate designs and were rated as medium quality. Two additional quantitative studies that used uncontrolled before-after designs (UCBA) and one mixed methods study which incorporated both an UCBA and descriptive qualitative design were also included. These studies used weak designs but helped to gain further insight into effective educational methods. Quantitative studies were critically examined using the guidelines/critical appraisal tool kit developed in 2014 by the Public Health Agency of Canada (PHAC). Qualitative studies consisted of two phenomenology studies, two descriptive studies, and one grounded theory study. All were deemed credible and were critically appraised using the CASP (2018) criteria. Further details regarding strength and/or quality of studies can be found in Appendix A of the full report which is found in Appendix I.

Key Findings

There were four main themes found through completing the literature review. Each theme will be described in more detail below.

Prevalence. IDD in LTC are a growing area of concern since the number of those admitted is increasing. As mentioned above, a diagnosis of an IDD was a strong predictor of the likelihood of admission into LTC (Bigby et al., 2008; McKenzie et al., 2016; Patti et al., 2010). In a cohort study conducted by Ouellette-Kuntz et al. (2016), the rate of admission was actually three to nine times higher among individuals with IDDs compared to those without an IDD. Those with an IDD are also usually admitted at an earlier age, are younger, and stay for longer than other residents (Bigby et al.). Therefore,

this population has a greater likelihood of spending their remaining days in LTC (Patti et al.).

Why LTC. Those with IDD are aging and have complex health issues. They have an increased risk for developing other conditions, such as dementia (Jethwa & Cassidy, 2010). Many end up in LTC due to their previous accommodations and supports being no longer able to provide the level of care needed due to their increased care needs (Bigby et al.; Cleary & Doody, 2017; McKenzie et al., 2016; Patti et al., 2010). In a study conducted by Bigby et al. (2008), it was determined that those with IDDs actually have similar levels of dependency as an elderly resident in a LTC home as 60.7% were classified as needing high care despite people thinking they were considerably younger and appeared healthier. Hence, LTC environments are capable of providing the higher level of care required (Patti et al.).

LTC also offers many benefits for this population as they age. Many of these benefits were highlighted in a grounded theory study by Webber, Bowers, and Bigby (2014) which examined experiences of older people with IDs who recently moved from a group home to aged care in Australia. Family members found their loved one's general health had improved once admitted to an aged care facility as previously undiagnosed medical conditions were being diagnosed and treated. Improvements were also noted to residents' overall health related to incontinence, falls, wandering, and behavioral issues which may be due to the fact that LTC offers 24-hour care, holistic care with qualified staff.

Issues. Those with IDDs have many issues, including multiple health conditions, dementia, challenging behaviors, antipsychotic use, family/friends, being inclusive, resident-focused, teamwork, and communication.

Multiple health conditions. The majority of the population is living longer due to better management and advancement in treatment of chronic health issues. Those with DDs, such as Down syndrome, are also living longer but tend to experience similar chronic conditions earlier than the general population (Herron-Foster & Bustos, 2014). Premature onset of age-related conditions and secondary disabilities are often seen which require more complex care associated with limitations in intellectual function and in adaptive behaviors (Bigby et al., 2008; Ouellette-Kuntz et al., 2005). Those with IDD usually have other diagnoses such as depression, attention-deficit disorder, diabetes, dementia and/or autism (American Psychiatric Association, 2013; Patti et al., 2010). These individuals also have comorbid health care needs that may include mental health difficulties, chest infections, epilepsy, dysphagia, pain, constipation, arthritis, immobility, incontinence, and weight loss (Cleary & Doody, 2017). Rates of visual impairment, hearing impairment, and dual sensory impairment are also higher in those with IDDs and may further deteriorate as the person ages (Jethwa & Cassidy, 2010). Overall, these individuals have a greater variety of health care needs compared to those of the same age and sex in the general population (Doody, Markey, & Doody, 2013; Ouellette-Kuntz et al.).

Dementia. It is important to consider dementia in LTC environments since those with IDDs are aging and usually present with some form of memory loss (Jethwa & Cassidy, 2010). The prevalence of dementia in individuals with an IDD is approximately four times higher than that of the general population. Those with both dementia and an IDD have increased care needs as changes occur in both behavior and overall functioning (Cleary & Doody, 2017; Lacono, Bigby, Carling-Jenkins, & Torr, 2014). They may also

become forgetful, lose functional capacity, lose ability to communicate, and have difficulty controlling emotions and/or behaviors (Lacono et al.).

Challenging behaviors. Behavioral and personality changes are symptoms commonly present in those who have IDD (Jethwa & Cassidy, 2010). Challenging behaviors involve a broad range of behaviors which may include disruptive and/or aggressive behaviors (Herron-Foster & Bustos, 2014; Lambrechts, Kuppens, & Maes, 2009). Other behaviors, such as trying to elope, pacing, calling out, agitation, swearing, and repetitive questions may also be present (GPA, 2014). There is usually a reason for a behavioral response which is why challenging behaviors are also referred to as responsive behaviors as the resident's "actions, words, and gestures are a response to express something important about his/her personal, social, or physical environment" (Alzheimer's Society, 2018). Responsive behaviors are influenced by a variety of factors, such as having an unmet psychological or social need (Cleary & Doody, 2017; GPA). For example, aggression may be a common response for an individual who has both an IDD and dementia due to difficulties adjusting to changes in overall health or expressing himself/herself (Cleary & Doody; Jethwa & Cassidy). Usually, behavioral responses are time limited and episodic and, therefore, are not the normal behavior of the resident (GPA).

Antipsychotic use. The use of antipsychotics to treat challenging behaviors has become increasingly common (Kuijper, Evenhuis, Minderaa, & Hoekstra, 2014). Two studies examined the use of antipsychotics to treat challenging behaviors and suggested that there was no evidence that antipsychotic use decreased behaviors in those with IDDs (Kuijper et al.; Tyrer et al., 2008). Researchers also concluded that more than two-fifths

of participants did not have a psychiatric disorder (Tyrer et al.). Antipsychotics, when used inappropriately, are considered chemical restraints when they are used to control behavior rather than to treat an underlying medical condition (GPA, 2014). Individuals who have IDD are actually sensitive to adverse side effects of antipsychotics (Tyrer et al.) and are at an increased risk for falls, delirium, restlessness, increased confusion, tardive dyskinesia, and death (GPA). Therefore, the implementation of non-pharmacological strategies to deal with behaviors is important prior to the consideration of antipsychotics (GPA).

Involving family and friends. Family involvement is crucial, especially with care decisions, as it can improve a resident's overall emotional well-being (Doody et al., 2013). Family can also help provide information to enable staff to develop a consistent and personalized approach to care (Ndengeyingoma & Ruel, 2016). Therefore, supporting contact between the resident and his/her family or friends is essential (Bigby et al., 2008).

Inclusivity. Those with IDD should be integrated among other residents within LTC. However, in a study conducted by Bigby et al. (2008), the most common issue identified by health care providers was the difficulty residents experienced fitting into the type of activity offered. Bigby et al. (2008) also suggested that residents did not participate in activities due to health, cognitive incapacity, and/or emotional and behavioral difficulties. Therefore, the services and activities should be implemented at a slower pace, be age appropriate, and meaningful (Doody et al., 2013). It may also be necessary to tailor certain activities to fit the needs of the disabled resident, thereby incorporating the concept of individualized care.

Social isolation and loneliness. Social isolation and loneliness may also present as an issue for this population (Bigby et al., 2008; Webber et al., 2014). Other residents may be frightened and/or uncomfortable around those with IDD, particularly if they are exhibiting challenging behaviors, and may, therefore, try to avoid these types of residents (Webber et al.). Many residents with IDDs are also in private rooms which may only further increase their risk for social isolation. Providing residents with specific opportunities for social interaction is essential.

Resident-focused care. It is important for all staff members to provide care that is resident-focused and holistic in nature in order to relate to the person with an IDD as a person rather than through the context of their disability (Doody et al., 2013). Being resident-focused will also equip staff to identify asymptomatic signs of ill-health, physiological needs, and desires. Several strategies were suggested by Lacono et al. (2014) that could be used when caring for individuals with IDDs and their associated issues. Examples include engaging residents in a usual routine, using trial and error to determine unmet needs, providing comfort, reassurance, and using a consistent approach to care. As well, using a choice making program whereby residents would be offered choices regarding food and activities could also help with challenging behaviors. A stop and go approach is another strategy that can be used when dealing with residents who have responsive behaviors as it provides them with a sense of relief and may prevent a worsening outcome (GPA, 2014). By using the acronym for stop, staff should stop what they are doing, think about what is happening, observe residents cues and behaviors, and plan when to resume care. These steps allow staff to modify approaches to care. It is important that all strategies be resident-specific as each strategy may not work for

everyone. As well, the implementation of strategies may vary day-to-day due to the unpredictability of those with IDD and associated issues.

Monitor feelings and beliefs. It is important for staff to be cognizant of their own values and beliefs so that this does not interfere with the care provided to those with IDD. Also, it is also important for health professionals to use an unbiased approach to care while also considering the linguistic diversity and cultural differences in the way people communicate, ambulate, and behave (aaiid, 2018). Therefore, being non-judgmental is essential (GPA, 2014). Staff members should reflect on their own thoughts, feelings, behaviors, and responses to feelings, such as anger, in order to develop an interaction style that works for them (GPA).

Teamwork. Studies conducted by Doody et al. (2013) and Lacono et al. (2014) highlighted the importance of teamwork and using an interdisciplinary approach to care that seeks assistance from behavioral specialists and other health professionals. Behavioral assessments and support plans can be useful as they can be developed and implemented to help guide care (Cleary & Doody, 2017). It is also important that a consistent approach be used by all health care professionals, especially when specific strategies are successful in caring for those with IDD (Lacono et al.). Staff members can ensure they are providing consistent care by information sharing, unit meetings, and charting behaviors (Lacono et al.). Documentation is a key component to consistent care that helps ensure all pertinent information is in one place, such as any changes or strategies used while also helping to ensure resident-focused care (GPA, 2014; Ndengeyingoma & Ruel, 2016).

Communication. Effective communication is key (Doody et al., 2013; GPA, 2014). Issues arise with regards to communication for residents with IDD as they may have communication deficits and/or difficulties that make them unable to express themselves appropriately (Ouellette-Kuntz et al., 2005; Ndengeyingoma & Ruel, 2016). Health professionals need to be mindful of residents' communication strategies, while also being cognizant of their own, since this will positively influence their perspective and response (GPA). As well, since the majority of communication is nonverbal, residents can very easily pick up on nonverbal cues even when staff members may not realize they are communicating. Specific strategies to enhance communication are further discussed in the full literature review in Appendix I.

The Need for Education and Suitable Educational Methods

There were several knowledge gaps noted in the literature with regards to the issues identified for IDDs in LTC. One gap in particular was related to dementia care (Cleary & Doody, 2017; Jethwa & Cassidy, 2010). Cleary and Doody (2017) found that participants were generally knowledgeable about the signs and symptoms of dementia and its progression but acknowledged that a deeper level of knowledge was needed. Another knowledge gap was associated with challenging behaviors as participants in the study by Lambrechts et al. (2009) reported that they did not have the skills to effectively care for residents who had IDDs and varying forms of complex behaviors. Hence, addressing such knowledge gaps by increasing education in this area is required in order for health care professionals to meet the needs of residents with IDDs.

Education was positively associated with an increase in knowledge and skill regarding IDDs (Harmon, 2017; Read & Rushton, 2013). Studies by Harmon (2017),

Read and Rushton (2013), and Jones, McQueen, Lowe, Minnes, and Rischke (2015) incorporated workshops, educational seminars, and/or blended teaching methods to demonstrate that knowledge increased with education. For example, Read and Rushton (2013) used a mixed methods design to explore the impact of workshops on the understanding of the health needs of adults with IDD. After completing a workshop, means scores increased significantly from 36.5 to 42.12 ($p < .001$) indicating that participants had learned new knowledge, had become more aware of services available to them, and understood how to better care for individuals with IDDs. Results from the qualitative phase also concluded that participants felt that taking part in the workshop gave them a better understanding of IDDs and that their skills in caring for those with IDDs had improved as they were more aware of the importance of good communication and having patience.

The pros and cons of using different educational methods were also identified by conducting the literature review. Since adults are self-directed learners, use experience as a resource, and are internally motivated to learn, it was decided to develop a learning resource. Independent study methods, such as a learning resource, use limited facilitator involvement and can be done on the learners' time (ASTD, 2013). These methods provide easy access to information as the resource can be placed directly on the unit and be easily copied and/or taken home for review. A booklet or resource manual, such as the learning resource developed, could also be used a reference tool for learners who want specific information when needed. Disadvantages of self-study options are that there is limited interaction and the inability to answer questions (ASTD). However, case studies could be used to serve as an evaluation/reflection of the material learned. Case studies

address objectives and provide learners with a more interactive approach to learning.

However, they can be time consuming and may not produce accurate conclusions.

Additional pros and cons of other appropriate forms of educational methods can be found in complete literature review in Appendix I.

Conclusion from the Literature Review

Those with IDD are aging and often experience complex health care needs. Hence, LTC for most of this population is inevitable and is a growing area of concern since the prevalence of those admitted is increasing. LTC environments should be prepared to meet the needs of this specific population. It is evident through the literature that LTC is appropriate for those with IDDs and can actually offer many benefits for this population. However, as discussed, there are many issues associated with IDDs and LTC. These issues helped to determine information to include in the learning resource. The literature review also identified several key themes and issues which were used to help guide interview questions that were asked during the consultations and also helped to determine content to include within the learning resource.

It is evident throughout the studies reviewed that additional education is needed when caring for those with IDDs in LTC. Increasing education in this area would help health care professionals gain the knowledge and skills required to fulfill both the health and social needs of this population. Hence, a learning resource for the practicum project will enable staff to increase their knowledge base on this topic and, in effect, lead to positive resident outcomes. Since many different educational methods can increase knowledge as described above, preference for the educational method developed was

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requested during the consultations. The learning resource was not decided on until the consultations were complete.

Consultations

A synopsis of the consultations is below. The complete consultation report can be found in Appendix II.

Ethics Approval

The Health Research Ethics Authority (HREA) screening tool, found in Appendix C of the full report which is in Appendix II, was used to determine whether the proposed practicum project had to be approved by the Health Research Ethics Review Board. In completing the HREA screening tool, it was determined that this project did not need to be submitted or approved by the Health Research Ethics Review Board as it was not considered a research project.

Participants

There were two target groups; one group consisted of PCAs and LPNs and the second group comprised of other health professionals, such as the Behavioral Management Specialist (BMS), Clinical Educator, Recreational Therapist (RT), and RNs. Convenience sampling was used.

Data Collection, Management, and Analysis

Data were obtained from a mix of eight PCAs and LPNs using informal semi-structured interviews conducted face-to-face on the unit at SLH. Interviews were conducted in a group setting of approximately four staff members. There were two groups, one per team, in order to allow for input from both teams on each side of the schedule. Data were collected on two separate days, one per team. The interviews were

guided by questions, found in Appendix A of the full report which is found in Appendix II, which allowed for discussion among staff. Data obtained from the interviews were managed using written field notes made during the interviews. The notes were placed in a sealed envelope in a locked locker and taken home at the end of the day. The notes were then transcribed to the computer, using a Word document. The computer was password protected to ensure safety of information. The written notes were destroyed after transcription. The transcribed notes were also shared with the supervisor of the practicum project for the purpose of ensuring rigour of analysis. Once transcribed, data obtained from the interviews were further examined, read and re-read, and analyzed by using content analysis, clustering similar data, and creating themes. Themes were based on data collected from the interviews and provided further insight to address the objectives of the consultations.

Other health care professionals were recruited through email with the practicum project explained and invitation to participate. The email also included questions that were pertinent to their particular profession which helped guide the development of the practicum project. Additional experiences and/or other information felt to be pertinent to the topic were also requested. All participants responded directly by email with answers to questions. Hence, data were collected using the written responses. Data obtained from emails were managed using a specified file folder within the Eastern Health email. Emails were also examined, read and re-read, and analyzed by clustering similar data and creating themes.

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Key Findings: Staff and RNs

The results from the consultations of the staff and RNs are reported using three main themes: knowledge gaps, issues, and educational resource.

Knowledge gaps. Participants felt that they did not have the knowledge required to effectively care for residents with IDD as they had received limited education on this topic. They felt that education they did receive was good but identified several limitations. For example, information was obtained from the BMS but only when staff were having difficulties caring for residents who exhibit particular behaviors. Participants identified that more general knowledge was needed in order to better identify residents' specific needs, triggers, and suitable recreational activities. More information to deal with challenging and disruptive behaviors, such as appropriate communication techniques, were also needed.

Similarly, RNs felt they only had basic knowledge acquired through their nursing school program and limited education was provided during orientation at SLH with the focus being on dementia/Alzheimer's. More targeted education on IDDs for all nursing staff was needed, such as the knowing the different types of IDDs. The RNs felt that the BMS could be consulted to provide staff with information as it is needed, pertaining to specific residents which can be beneficial as it is resident-specific.

Issues. Participants felt that those with IDDs have complex health care needs, particularly when they were exhibiting challenging behaviors. Some participants felt that they were equipped to care for residents' medical and personal care needs, however, lacked the skills and time required to care for those who were exhibiting complex behaviors and had individual needs. Participants also found that more time was needed

when caring for these types of residents as they required more 1:1 care at times and needed more attention. Participants felt that all residents with IDD are different, even if they have the same diagnosis, which can present as a challenge since strategies that work well for one resident may not work for another. The importance of having all staff on the same page was identified as an issue. Challenging behaviors and associated triggers were also identified as issues and are described in more detail in the full consultation report in Appendix II. However, sometimes staff members felt that behaviors occurred for no reason and that the resident was just being difficult. Staff members found caring for those with IDDs to be both challenging and stressful which sometimes resulted in them feeling frustrated.

Similarly, the RNs felt that those with IDDs have complex health care needs that can often be quite challenging to care for. Staff often feel challenged, discouraged, and stressed by some of the behaviors which is evident as staff get reactive in their tone of voice and responses. RNs felt that although nursing staff were good at providing direct care, improvement was needed in re-evaluating resident-specific care and targeted care plans that revolved around resident-specific needs. Often times, individuals with IDDs do not understand the complexity of the environment, have difficulty waiting for staff to assist them with their activities of daily living (ADLs), or like for staff to be able to attend to their care needs more quickly than staff are able.

Integration was an issue identified, with the majority of participants indicating that those with IDDs should not be integrated among other residents in LTC. Participants also felt that other residents were fearful of those with IDDs, particularly when they were exhibiting challenging and aggressive behaviors. The RNs felt differently and thought

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that if the environment was safe to do so, including a system that supports and integrates residents with IDD's was appropriate.

Social isolation and loneliness was another potential issue identified. Participants did not feel that a private room would lead to loneliness but one group acknowledged that it could be a risk. Staff suggested that the need for a private room depended on the particular resident and on the severity/frequency of behaviors. Similarly, RNs felt that the need for a private room was resident-specific as some residents enjoy having their own space while others enjoy company. A private room would also provide a safe space during behavioral episodes.

Participants identified that those with IDD's do not have enough recreational therapy and felt that activities should be provided by the RT. Hence, participants were not aware of their own responsibility in initiating activities on the units. When activities were provided by recreation, participants noted that all residents participated in the same activity and there were no activities specific for residents with IDD's. Simple activities were suggested. RNs similarly felt that there were not enough recreational activities. Activities aimed to distract and redirect residents or activities that give them a sense of purpose/meaning may work well. They also felt that it was important for those with IDD's to participate in general activities with other residents as it may promote socialization and engagement. However, they identified that it can be challenging if individuals have disruptive behaviors that would affect other individuals in the group. Activities may be more beneficial in a group or more 1:1 settings depending on the individual.

Educational Resource. Participants identified topics that were discussed in the context of what additional knowledge was needed would be information to include within

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the resource. They also requested additional general information regarding disabilities that were not necessarily resident-specific. As well, participants wanted more information regarding suitable recreational activities, how to respond to challenging behaviors (specific strategies), how to better identify triggers, and approaches to care. Coping strategies for staff may also be useful. More knowledge regarding social isolation/loneliness, integration, and the association between dementia care and IDD is needed. Participants were open to several formats which are further described in the full consultation report in Appendix II. The ease of accessibility was mentioned. The RNs suggested a breakdown of some of the common IDDs that are being introduced into LTC and self-tests or case studies that staff can avail of as a self-study option. More education behind targeted approaches to nursing care that may help staff understand things from the resident's point of view could also be useful.

Key Findings of RNs: Other Questions

The RNs were asked four additional questions that were not asked of the other staff. Most felt that those with IDDs require different approaches to care and should be resident-specific. RNs also felt it is important to build and target a care plan based on interventions that meet the needs of residents with IDDs. Using stop and go approaches, providing support, and reassurance work well. It is also good to explain every step of the care process to these residents which may involve repeating oneself.

As front line leaders, staff come to RNs all the time, often frustrated or seeking assistance with a particular resident. Staff need to work together and take turns dealing with challenging behaviors. Unfortunately, the available resources are for dementia care

and not specific for IDDS. The BMS and educator are great resources however, the wait times can be long.

Key Findings: Other Consultations

Overall, it was determined that more education is needed on this topic. It was identified that staff have several learning needs when it comes to IDDs. Some of the learning needs identified were related to care planning, resident-centered care, and interdisciplinary care. Participants suggested that staff should develop a resident-centered care plan with the resident, his/her family, and/or significant others as usually family know what is best for the resident. Also, incorporating an interdisciplinary team approach to care is needed.

Participants also felt that staff have the skills to provide the physical care needed for residents with IDDs but may not have skills to adequately provide holistic care. Certain diagnoses, such as Down syndrome, can create many complex physical and mental health needs which can often go untreated. In addition, individuals who have a cognitive impairment, such as those with IDs, are also at a higher risk of developing dementia, and at an earlier age. Individuals who are diagnosed with Autism Spectrum Disorder can also be very complex to manage due to the many sensory integration issues they may experience. Those with IDDs often have difficulty communicating how and why they feel a certain way. Therefore, staff members need good communication techniques and to be aware of residents' complex health needs.

Another learning need identified was related to challenging behaviors. A resident with an IDD can exhibit responsive behaviors similar to any other resident in LTC. Since those with IDDs often have difficulty modulating their behavior, they can often escalate

to the point of physically responsive behaviors. Triggers for these behaviors vary from individual to individual. Strategies for challenging behaviors should incorporate principles of reinforcement rather than punishment. Staff should incorporate strategies that use a least restrictive model of treatment, along with applied behavior analysis. A functional behavioral assessment should also be completed and based upon the function of a behavior, recommendations would be made and tailored to the individual. A discussion of antipsychotic and antianxiety medications may also be useful to help identify whether the medications are beneficial or not in managing challenging behaviors.

The Recreation Department is a good resource to assess and develop diversional and meaningful activities specific to the individual. General activities that may be beneficial to residents with IDD include walking or a general exercise program in order to maintain/increase physical functioning and quiet leisure activities, such as painting, reading, and flipping through books. These activities allow the individual to have some quiet time and participate in activities of interest. Many with IDD also find routine to be important and useful for coping. Therefore, having residents participate in a routine that allows them to complete chores or jobs will help establish a sense of purpose. Depending on an individual's needs, recreational programs are often adjusted in order to make the activity more inclusive.

Conclusion from Consultations

Completing the consultations confirmed important information obtained from the literature review and helped identify additional information to include in the learning resource. Several themes were derived from the data obtained from the consultations, such as the importance of resident-centered care, individualized care, isolation and

loneliness, responsive behaviors, dementia, and documentation which were similar to what was found in the literature review. These topics, drawn from both the literature review and consultations, were included

The key lesson learned through conducting the consultations was the importance of asking the right questions in order to have good discussions/responses among staff and not just yes or no answers. Completing both the literature review and the consultations highlighted the importance of and the difficulty in making learning resources that are both evidence informed but also reader friendly and useful. Using evidence obtained from the literature review and responses from consultations regarding possible educational formats, it was decided to develop four booklets. Again, since adults are self-directed learners, many of the exercises included with the booklets are based on knowledge that participants felt they needed when caring for those with IDD.

Overview of Learning Resource

Findings from the literature review and consultations with key members of the healthcare team supported the development of an educational resource. In identifying issues, knowledge gaps, and learning needs related to IDD in LTC, a learning resource was developed that will help to increase knowledge in this area. The educational resource consists of four booklets, each of which contains learning objectives, key information and self-reflection exercises. There are also true/false questions, case studies and/or other questions to help test the reader's knowledge. Each booklet can be used individually or in sequence depending on the reader's learning needs.

Booklet 1: Intellectual and Developmental Disabilities in Long Term Care. The focus of this booklet is to provide general background information regarding IDD in

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LTC. After completing the booklet, staff will be able to distinguish between IDD, identify the prevalence of IDD in LTC, identify reasons why those with IDD eventually end up in LTC, identify benefits of LTC for those with IDD; and identify strategies health care workers can use to deal with frustration and stress associated with working with residents with IDD.

Definitions of ID and DD are provided and includes the prevalence rates of each. Four reasons are explained for why those with IDD end up in LTC. A table also highlights the many benefits that LTC offers residents with IDD. There is also a ‘tips for staff’ section that offers coping tips for staff members during and after a stressful situation. Case studies, true and false questions, and self-reflection exercises are included throughout. This booklet can be found in Appendix III.

Booklet 2: Challenging Behaviors. The focus of this booklet is to provide staff with information regarding challenging behaviors and IDD in LTC. After completing the booklet, staff will be able to identify common challenging behaviors, identify strategies to prevent challenging behaviors, identify the warning signs of challenging behaviors, identify common potential triggers, identify strategies to prevent triggers, and identify strategies health care workers can use to deal with frustration and stress associated with working with residents with IDD.

A table is used to explain common challenging behaviors and the possible strategies to deal with the behavior. Possible triggers, a description of the trigger, and strategies to prevent triggers are also included in a separate table. This booklet also includes a ‘tips for staff’ section that offers coping tips for staff members during and after a stressful situation. There is also a section on communication and documentation, with

documentation being described using categories of ‘what’, ‘when’, ‘where’, and ‘why’. The roles of different interdisciplinary team members are also highlighted in a summary table that also provides information regarding when it might be beneficial to contact them. Antipsychotic use is also discussed and includes the common types of antipsychotics, their effectiveness, and non-pharmacological alternatives. Case studies, true and false questions, and self-reflection exercises are included throughout. This booklet can be found in Appendix IV.

Booklet 3: Dementia and IDD. The focus of this booklet is to provide staff with information regarding dementia associated with IDD in LTC. After completing the booklet, staff will be able to identify and define the different types of dementia and associated signs/symptoms, identify how to assess for dementia, identify reasons why residents could be experiencing a cognitive decline or a change/deterioration from his/her normal baseline, and identify strategies to help care for those with IDDs and dementia.

A table compares the different types of dementia, cause, and associated signs/symptoms. A separate table is included to help staff assess for dementia by identifying and explaining reasons why a resident may be experiencing a change from their normal baseline. Strategies for caring for those with IDDs and dementia are also included and are divided into two sections, strategies for a resident’s care plan and strategies to use individually or during one-on-one interactions. There are also sections related to documentation and communication. Case studies, true and false questions, and self-reflection exercises are included throughout. This booklet can be found in Appendix V.

Booklet 4: Social isolation and loneliness. The focus of this booklet is to provide staff with information regarding the issue of social isolation and loneliness among those with IDD in LTC. After completing the booklet, staff will be able to compare social isolation and loneliness in those with IDDs, identify reasons why social isolation and loneliness are issues for those with IDDs, identify how recreational activities can help decrease risk for social isolation and loneliness, identify the benefits of recreational activities, and identify suitable types of recreational activities.

The terms social isolation and loneliness are compared using a table. A separate table also describes limitations related to integration, such as health and cognitive incapacity, and why integration can be challenging. The benefits of group/one-on-one activities and the benefits of recreational activities, including emotions, cognitive, and physical benefits, are also described. Information and ways of how services and activities can be tailored to meet resident-specific needs is also included. The booklet also contains suitable recreational activities and whether each should be implemented in group or one-on-one settings. Documentation and communication are also highlighted. Case studies, true and false questions, and self-reflection exercises are included throughout. This booklet can be found in Appendix VI.

Implementation Plan

At the end of this practicum project, the booklets will be presented to management and administration at SLH for revision and approval. Upon approval, the resource will be distributed to all nursing units and could be included within the orientation process of new staff at SLH. Staff working on the units will be provided with a brief overview of

the learning resource during afternoon ‘huddles’ in order to make them aware of the availability of the resource on the units.

Evaluation Plan

Evaluation components in the form of true and false questions, case-studies questions, and self-reflections were provided throughout the learning resource. A quantitative review to formally evaluate learner satisfaction and learning attributed to the learning resource will be conducted by providing any staff members that used the resource with an anonymous survey approximately six months after implementation on the units. The survey will help assess whether staff felt the learning resource provided them with increase knowledge and enhanced their competency in caring for those with IDD. The RCM will also be interviewed to identify whether the learning resource positively impacted staff and resident-care outcomes in those with IDD. A practice audit, pre and post implementation, could also be used to see if care plans have changed and incorporated principles related to the suggestions from the booklets.

Advanced Practice Nursing Competencies

An objective for the practicum project was to demonstrate advanced nursing practice (ANP) competencies. Through completing the literature review and consultations, ANP competencies, as outlined by the Canadian Nurses Association (CNA, 2008), including research and leadership, were demonstrated in the planning and development of this practicum project.

Research

Generating, synthesizing, and using research evidence are central to ANP (CNA, 2008). Information was generated through conducting consultations by using descriptive methods which allowed for additional information to be generated as the experiences from a variety of disciplines were gathered and was used to develop the learning resource. Information was synthesized through conducting an evidence-based literature review. Studies were critiqued using the Public Health Agency of Canada (2014) and the Critical Appraisal Skills Programme (2018) checklists. All qualitative and quantitative research was examined and interpreted in order to use the research evidence to help develop the learning resource. The literature review helped to guide the questions asked during the consultations. The information gathered and critiqued from both the literature review and the consultations was applied to the learning resource by including key information that staff members need to know when caring for those with IDD. An implementation and evaluation plan was also included. The learning resource will contribute to nursing and the health care system as a whole as few resources are available for IDDs within LTC. The majority of current education is dementia specific and is not specific to IDDs. Hence, the resource will act as an informal channel to disseminate knowledge.

Leadership

Advanced practice nurses are leaders where they work and are considered agents of change, consistently seeking effective new ways to practice, and to improve the delivery of care (CNA, 2008). In developing this educational resource, best practices and evidence-based practices for those with IDDs can be implemented within LTC environments and, therefore, improve the delivery of care by enabling staff to be better

prepared and properly informed. The consultations and literature review supported that a knowledge gap exists with regards to IDD in LTC and, therefore, the learning resource will help bridge this gap, by providing staff with better and more informed ways to practice, thereby creating positive health outcomes for this population.

Conclusion

Those with IDD are aging and often experience complex health care needs, such as dementia, secondary disabilities, and challenging behaviors. LTC for most of this population is inevitable and is a growing area of concern since the prevalence of those admitted is increasing. Hence, LTC staff should be prepared to meet the needs of this specific population. Increasing education in this area would help health care professionals gain the knowledge and skills required to fulfill both the health and social needs of this population as they age. A learning resource, such as the booklets developed for the practicum project, will provide one strategy that staff can use to increase their knowledge base on this topic and, in effect, lead to positive resident outcomes.

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Appendix I: Literature Review

Integrated Literature Review: Intellectual and Developmental Disabilities in LTC

Lindsay Hunt, 200827475

Memorial University of Newfoundland and Labrador

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The life expectancy of the elderly has continued to increase due to better management and advancement in treatment of chronic health issues. Those with intellectual and/or developmental disabilities (IDDs) are seeing similar trends and tend to experience similar chronic conditions earlier than the general population (Herron-Foster & Bustos, 2014). By the year 2020, the proportion of people with intellectual disabilities (IDs) over the age of 65 will have doubled (Jethwa & Cassidy, 2010). Therefore, long term care (LTC) for those with IDs is inevitable and is a growing area of concern since this population is aging and has complex health care needs. LTC homes offer an alternative to community-based living and institutionalization, allowing for positive outcomes as this population continues to age. However, since these individuals do have more health concerns, communication difficulties, and challenging behaviors compared to those without intellectual challenges, LTC has to be prepared to meet the needs of this specific population. The purpose of this paper is to summarize literature to gain a better understanding of the topic of IDs within LTC. The literature will also be used to support the need for education in this area and support the content and issues to be addressed within an educational resource. Appropriate strategies that can be useful when caring for this population will also be addressed.

Literature Review

The initial search from CINAHL and PubMed resulted in a large number of relevant research articles related to IDs. Additional articles were retrieved by searching within Google. Broad search terms were used, including "nursing homes," "long term care," "developmental disability," "intellectual disability," and "aged." Article selection was further limited by date (2008) and English language. Using these search terms,

several quantitative and qualitative studies were retrieved. The studies chosen to be included within the literature review consisted of five qualitative studies, nine quantitative studies, and one mixed methods study. The quantitative studies consisted of three cohort studies, two cross-sectional studies, one non-randomized trial (NRT), and one randomized-controlled trial (RCT). The NRT and RCT are strong study designs and were rated high for quality whereas the two cross-sectional studies are weak designs due to their descriptive nature. The cohort studies are moderate designs and were rated as medium quality. Two additional quantitative studies that used uncontrolled before-after designs (UCBA) and one mixed methods study which incorporated both an UCBA and descriptive qualitative design were also included. These studies are weak designs but helped to gain further insight into effective educational methods. Quantitative studies were critically examined using the guidelines/critical appraisal tool kit identified in 2014 by the Public Health Agency of Canada (PHAC). Qualitative studies consisted of two phenomenology studies, two descriptive studies, and one grounded theory study. All were deemed credible and were critically appraised using the CASP (2018) criteria. Further details regarding strength and/or quality of studies can be found within the literature summary tables in Appendix A.

Many of the strategies and/or interventions in caring for those with IDD were from the perspective of participants, including their own attitudes, feelings, and behaviors. As well, many of the articles retrieved were from group home or residential settings. However, results may still be generalizable to LTC environments. Educational qualifications related to staff working with this population also varied and, therefore, may not be representative of qualifications required in LTC settings.

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The Gentle Persuasive Approaches in Dementia Care: Supporting Persons with Responsive Behaviors (GPA, 2014) was a document that provided a guiding framework for this literature review and in the development of the practicum project. Even though the main focus of this framework was dementia care, and not disability itself, it served as an important resource for information while also as a starting point for the literature review. The content will be presented under headings and summarized by providing an overview of studies.

Intellectual and Developmental Disability

Developmental disability (DD) is an umbrella term that includes IDs, along with other types of disabilities that may be apparent during childhood, usually before the age of 22 (American Association on Intellectual and Developmental Disabilities (aaidd), 2018). DDs are often severe and described as a chronic disability that incorporates cognitive and/or physical deficits. Those with cerebral palsy or epilepsy may have physical deficits while those with Down syndrome or fetal alcohol syndrome may have both physical and intellectual limitations. IDs often co-exist and, therefore, health professionals are often working with individuals who have both types of disabilities. Hence, the terms IDs and DDs may be used interchangeably.

According to aaidd (2018), ID, formerly known as “mental retardation,” is characterized by significant limitations in intellectual functioning and adaptive behaviors. Reasoning, learning, problem solving, and everyday social and practical skills may be affected. Awareness that an individual may have an ID usually begins during the developmental period and originates before the age of 18. The American Psychiatric Association (2013) defines ID as any impairment in mental ability that impacts adaptive

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functioning in conceptual, social, and practical areas. The conceptual domain involves skills in language, reasoning, knowledge, and memory. The social domain involves empathy, social judgement, and communication skills, while the practical domain refers to personal care, money management, and organization. These three areas help determine how an individual copes with everyday living, in the development of a treatment plan, and in determining a diagnosis. To determine a diagnosis, the traditional IQ test is used, along with determining an individual's severity of impairments based on overall abilities and deficits in adaptive functioning. A diagnosis of an ID is also included in the *Diagnosis and Statistical Manual of Mental Disorders* (DSM-5).

Prevalence. Approximately 15% of the world's population has some form of disability with the rates increasing due to the population aging and increase in chronic health conditions (World Health Organization (WHO), 2018). According to Braddock (1999), the life expectancy of those with IDD has increased from 18.5 years in the 1930s to 66 years in the 1990s (as cited in Jethwa & Cassidy, 2010). Hence, it is predicted that the proportion of people with IDs over the age of 65 will have doubled by the year 2020 (Jethwa & Cassidy). In 2012, the most recent year for which data are available, 132,020 Canadians 65 and older had some form of learning disability while 19,030 had a DD (Statistics Canada, 2013). Statistics Canada also reported that between the ages of 45 to 64, 51, 690 people had a DD while 260,850 had an ID.

Intellectual and Developmental Disabilities within LTC

In the past, health care was minimal for those with an IDD, resulting in decreased life expectancy for these individuals (Ouellette-Kuntz et al., 2005). The need for specialized care was recognized and many were institutionalized, segregated from the

population, and received minimal care. In the 1980s, a deinstitutionalization movement led to the closure and downsizing of such institutions, and in its place community-based initiatives were implemented in hopes that getting this population integrated back into the community would lead to better outcomes. Some individuals lived on their own, with appropriate supports in place, while others were being cared for by family. Today, those with IDD are living longer and may exhibit an array of chronic health care issues (Herron-Foster & Bustos, 2014; Ouellette-Kuntz et al.). Therefore, advanced care and additional support may be required as individuals may no longer be able to take care of themselves, and/or families are unable to provide care needed due to the complex health care needs of this population as they age.

Prevalence of IDDs in LTC. There were three quantitative studies and one surveillance report that described the prevalence of IDDs. Two cohort studies conducted by Patti, Amble, and Flory (2010) and McKenzie, Ouellette-Kuntz, and Martin (2016) used records and administrative data to determine the likelihood that participants would be admitted into LTC. Another study conducted by Bigby, Webber, Bowers, and McKenzie-Green (2008) used a cross-sectional design to explore pathways of how those with IDDs end up in aged care. All studies were rated as medium and had fairly large sample sizes from a variety of settings, including Canada, Australia, and America. These researchers concluded in one way or another that a diagnosis of an IDD was a strong predictor of the likelihood of admission into LTC (Bigby et al.; McKenzie et al.; Patti et al.). Patti et al. (2010) found that 39% of those with an IDDs resided in a nursing home compared to 9% without a disability. The surveillance report by Ouellette-Kuntz, Martin, and McKenzie (2016) and the study by McKenzie et al. (2016) found that 4.5% to 22.4% respectively of

those with an IDD were newly admitted to LTC compared to 0.9% for the general population. In fact, the rate of admission was actually three to nine times higher among individuals with IDDs compared to those without an IDD (Ouellette-Kuntz et al., 2016).

Findings also indicated that those with an IDD are usually admitted at an earlier age, are younger, and stay for longer than other residents (Bigby et al., 2008). The average age of those with an IDD who moved into aged care was between 59.4 to 63.1 years (Bigby et al.; McKenzie et al., 2016). Those without IDDs were admitted to LTC at age 84.3 which indicates that those with IDDs enter LTC at a younger age (Bigby et al.). The average length of stay was also longer compared to those without an IDD, 5.6 and 2.7 years, respectively (Bigby et al.). Hence, this population has a greater likelihood of spending their remaining days in LTC as 46% of those with a DD had their final placement in a nursing home compared to 20% for those without a disability (Patti et al., 2010).

Appropriateness of LTC. There are many reasons why those with IDDs eventually end up in aged care (Bigby et al., 2008; Cleary & Doody, 2017; Lacono, Bigby, Carling-Jenkins, & Torr, 2014). First, those with IDDs are aging and are at increased risk for developing other conditions, such as dementia (Jethwa & Cassidy, 2010). Second, complex health issues may make them inappropriate for traditional community services and inappropriate for standard mental health services, should they present with psychiatric difficulties, because of their low IQ (Ouellette-Kuntz et al., 2005). Third, previous accommodations and supports are no longer able to provide the level of care needed due to their increased care needs (Bigby et al.; Cleary & Doody; McKenzie et al., 2016; Patti et al., 2010). For example, McKenzie et al. (2016) found

that 36.2% of individuals with IDD had moved to LTC due to caregivers no longer being able to provide care. Fourth, those with IDDs actually have similar levels of dependency as an elderly resident in a LTC home as 60.7% were classified as needing high care despite people thinking they were considerably younger and appeared healthier (Bigby et al.). Hence, LTC environments are capable of providing the higher level of care required (Patti et al.).

Benefits of LTC. LTC offers many benefits and can be a positive experience for those with IDDs. Many of these benefits were highlighted in a grounded theory study by Webber, Bowers, and Bigby (2014) who examined experiences of older people with IDs who recently moved from a group home to aged care in Australia. Family members found their loved one's general health had improved once admitted to an aged care facility as previously undiagnosed medical conditions were being diagnosed and treated. Improvements were also noted to residents' overall health related to incontinence, falls, wandering, and behavioral issues. Since LTC provides 24-hour care, strategies could be implemented around the clock, such as harm minimization strategies which, therefore, reduce incidences of distress. These facilities also provide modified diets to meet individual needs, qualified staff with nursing expertise, and staffing levels to effectively care for this population. LTC environments allow those with IDDs to age in place (Clearly & Doody, 2017) and offers an alternative 'home' for this population, enabling those with IDDs to receive holistic care as they age.

Issues Associated with IDDs

Those with IDDs have many issues, including multiple health conditions, dementia, challenging behaviors, and antipsychotic use. Other issues to consider when

caring for this population are involving family/friends, being inclusive, resident-focused, teamwork, and communication. Since these issues have an impact on a resident with an IDD in LTC, it is important for health care professionals to be cognizant of challenges affecting this population. Exploring these issues will further support the content to be addressed within an educational resource.

Multiple health conditions. The majority of the population is living longer due to better management and advancement in treatment of chronic health issues. Those with DDs, such as Down syndrome, are seeing similar patterns and tend to experience similar chronic conditions earlier than the general population (Herron-Foster & Bustos, 2014). Premature onset of age-related conditions and secondary disabilities are often seen which require more complex care associated with limitations in intellectual function and in adaptive behaviors (Bigby et al., 2008; Ouellette-Kuntz et al., 2005; WHO, 2018). These individuals also have comorbid health care needs that may include mental health difficulties, chest infections, epilepsy, dysphagia, pain, constipation, arthritis, immobility, incontinence, and weight loss (Cleary & Doody, 2017). Rates of visual impairment, hearing impairment, and dual sensory impairment are also higher in those with IDDs and may further deteriorate as the person ages (Jethwa & Cassidy, 2010). These individuals are also more likely to have a physical disability or a communication disorder (Ouellette-Kuntz et al.). In the study by McKenzie et al. (2016), 50% of those admitted to LTC had a mild to moderate cognitive impairment and 35.5% of participants were considered frail which may lead to an array of other health concerns. Hence, these individuals have a greater variety of health care needs compared to those of the same age and sex in the general population (Doody, Markey, & Doody, 2013; Ouellette-Kuntz et al.).

In the study by Patti et al. (2010), 81% of those with IDD had another diagnosis other than dementia. Other possible diagnosis includes depression, attention-deficit disorder, and/or autism (American Psychiatric Association, 2013). Axmon, Ahlström, and Höglund (2017) used a cohort design to compare prevalence rates of diabetes mellitus (DM) in older adults with ID to those in the general population. This study was conducted in Sweden and included a large sample size of 7936 individuals with ID. The researchers concluded that those with IDs were 20% more likely than the general population to have a diagnosis of DM. The relative risk was calculated as 1.20, with a confidence interval of 1.08-1.34. Findings should be interpreted with caution as only 9% of those with an ID had DM compared to 8% in the general population which may indicate that findings may not be clinically important. Those with IDs were also 26% more likely to be prescribed a drug for DM as 13% of those with an ID had a prescription compared to 10% of the general population.

Dementia. According to Jethwa and Cassidy (2010), dementia is defined as “a condition that involves inevitably progressive deficits in numerous cognitive domains, including thought, language, memory, understanding, and judgement” (p.48). Individuals may present with memory loss and have difficulty controlling emotions and/or behaviors. The prevalence of dementia is significant within LTC environments in general since residents are living longer and usually present with some form of memory deficit. However, the prevalence of dementia in individuals with an IDD is approximately four times higher than that of the general population. Those with Down syndrome are at greatest risk and have a 50 to 85% chance of developing dementia (Jethwa & Cassidy; Patti et al., 2010).

It is important to consider dementia care in environments, such as LTC, since those with IDD are aging and are at increased risk for developing this condition (Jethwa & Cassidy, 2010). Also, the care required for individuals having both an IDD and dementia is complex and interconnected. With the progression of the disease, they have increased care needs as there are many changes that occur in both behavior and overall functioning (Cleary & Doody, 2017; Lacono et al., 2014). They may also become forgetful, lose functional capacity, and ability to communicate (Lacono et al.).

Challenging behaviors. Behavioral and personality changes are symptoms commonly present in those who have IDDs (Jethwa & Cassidy, 2010). Challenging behaviors involve a broad range of behaviors which may include disruptive and/or aggressive behaviors (Herron-Foster & Bustos, 2014; Lambrechts, Kuppens, & Maes, 2009). In a cross-sectional study conducted by Lambrechts et al. (2009), a survey design was used to examine associations between staff variables and challenging behavior of those with IDDs. Aggressiveness was considered the most severe type of behavior exhibited by those with an IDD as the mean scores for frequency and severity were 0.72 and 0.78 respectively compared to 0.53 and 0.61 for self-injuries behavior. Frequently occurring challenging behaviors, such as aggressive behaviors, were also associated with negative emotions among staff, including fear, anxiety, depression, and anger. Findings indicated that frequency and severity of aggressive behavior were positively correlated with fear/anxiety among staff as mean scores were 0.47 to 0.59 respectively. Other types of behaviors, such as stereotyped behaviors, were weakly correlated with depression/anger as mean scores were 0.10 and 0.26 respectively. Hence, these results should be interpreted with caution. Similar findings were found in a qualitative

descriptive study by Ndengeyingoma and Ruel (2016) that explored caring for individuals with IDD, intervention strategies used, and their needs to ensure quality care.

Participants identified safety concerns associated with aggressive behavior.

Unfortunately, these participants did not work in a LTC but rather worked in hospital and community settings.

Aggression may be a common response for an individual who has both an IDD and dementia, for example, due to difficulties adjusting to changes in overall health and expressing himself/herself (Cleary & Doody, 2017; Jethwa & Cassidy, 2010). A resident may also exhibit signs of aggression as a means to exert control or to protect himself/herself from something that he/she feels is frightening, frustrating, or threatening (GPA, 2014). Other behaviors, such as trying to elope, pacing, calling out, agitation, swearing, and repetitive questions may also be present (GPA). There is usually a reason for a behavioral response and, therefore, responsive behaviors are influenced by a variety of factors, such as having an unmet psychological or social need (Cleary & Doody; GPA). Behaviors may also be a sign of other health problems, such as pain or discomfort (Webber et al., 2014). Staff actions in response to challenging behaviors have been to escape or avoid (Lambrechts et al.). In these types of situations, it is important to avoid touching the person, remove bystanders, give undivided attention, and offer support from a distance (GPA). Usually, behavioral responses are time limited and episodic and, therefore, are not the normal behavior of the resident (GPA).

Antipsychotic use. The use of antipsychotics to treat challenging behaviors has become increasingly common (Kuijper, Evenhuis, Minderaa, & Hoekstra, 2014).

However, there was no evidence to suggest that antipsychotic use actually decreased

behaviors in those with IDD (Kuijper et al.; Tyrer et al., 2008). Two studies were reviewed that examined the use of antipsychotics to treat challenging behaviors. Both had strong designs and were rated as high quality according to PHAC (2014).

Kuiper et al. (2014) used a NCT design to investigate two discontinuation schedules of antipsychotics at 14 and 28 weeks and concluded that discontinuing antipsychotics prescribed solely for behavior symptoms did not lead to worsening behavior and actually led to overall improvements as 83% who achieved complete discontinuation did not lead to worsening in behavior functioning. These results are significant as 79% of those who did not achieve complete discontinuation still showed no change in behavior. Clear associations were made between behavior and antipsychotic use which may be indicative of the strong study design and quality of the evidence. The majority of participants in this study were less than 65 years of age and, therefore, findings may not be generalizable to the elderly population. However, since the literature suggests that those with IDD are usually younger, results may still be generalized to older adults in LTC.

Tyrer et al. (2008) conducted a RCT that utilized a three-arm, parallel-group pragmatic trial whereby participants were randomly assigned to either haloperidol, risperidone, or placebo groups to compare doses of antipsychotics and the effect of a placebo on aggressive behavior. Findings showed that those taking a placebo had a 95% decrease in aggression compared to 79% and 58% for those taking Risperidone and Haloperidol, respectively. These researchers also concluded that more than two-fifths of participants did not have a psychiatric disorder. Antipsychotics, when used inappropriately, are considered chemical restraints as they are used to control behavior,

such as disruptive behaviors, rather than to treat an underlying medical condition (GPA, 2014). Hence, those with IDD may be prescribed antipsychotics for the wrong reasons which can have negative consequences for these individuals. Individuals who have IDDs are actually sensitive to adverse side effects of antipsychotics (Tyrer et al.) and are at an increased risk for falls, delirium, restlessness, increased confusion, tardive dyskinesia, and death (GPA). Therefore, the implementation of non-pharmacological strategies to deal with behaviors is important prior to the consideration of chemical restraints, such as antipsychotics (GPA).

Involving family and friends. In the study by Bigby et al. (2008), 37% of residents with an ID came to residential aged care directly from the family home. Therefore, it is not surprising that family are actively involved when an individual enters LTC. Family involvement is crucial, especially with care decisions, as it can improve a residents overall emotional well-being (Doody et al., 2013). Family can also help provide information to enable staff to develop a consistent and personalized approach to care (Ndengeyingoma & Ruel, 2016). Therefore, supporting contact between the resident and his/her family or friends is essential (Bigby et al., 2008). Issues may also arise in respect to families exhibiting responsive behaviors particularly in times of stress, as they may feel overwhelmed (Ndengeyingoma & Ruel). It is important for staff to be cognizant, offer reassurance, information, and emotional support to the family as well (GPA, 2014).

Inclusivity. Those with IDDs should be integrated among other residents within LTC. However, Bigby et al. (2008) stated that the most common issue identified by health care providers was the difficulty residents experienced fitting into the type of activity offered. They also suggested that residents did not participate in activities due to

health, cognitive incapacity and/or emotional and behavioral difficulties. Hence, even though it is important for them to participate in similar activities as other elderly residents, such as going to the dining room, the services and activities should be implemented at a slower pace, be age appropriate, and meaningful (Doody et al., 2013). It may also be necessary to tailor certain activities to fit the needs of the disabled resident, thereby incorporating the concept of individualized care. Health care professionals should be encouraging the resident to become involved in the facility, such as adopting a helping role or taking on small jobs (Bigby et al.). These strategies may be useful to consider when caring for this population.

Social isolation and loneliness. Social isolation and loneliness may also present as an issue for this population (Bigby et al., 2008; Webber et al., 2014). Participants in the study conducted by Webber et al. (2014) felt that other residents were frightened and/or uncomfortable around those with IDD and, therefore, tried to avoid these types of residents. Participants also reported that within three months of admission into LTC, 9 of the 10 residents with an IDD were in private rooms which may only further increase their risk for social isolation. Providing residents with specific opportunities for social interaction is essential. It is also worthy to note that those with IDDs are more inclined to form relationships with staff rather than other residents which may present as a challenge (Bigby et al.; Webber et al.).

Resident-focused care. In a study by Doody et al. (2013), a phenomenological approach was used and highlighted the importance of resident-focused care. This study was conducted in Ireland and explored the experiences of nurses caring for the elderly with IDDs. Most of the findings were based on opinions and experiences of either the

participants and/or researchers. Doody et al. (2013) stated that it was important for all staff, such as housekeeping, dietary staff, and management to provide care that is resident-focused and holistic in nature. This will help staff relate to the individual with an IDD as a person rather than through the context of the disability. Being resident-focused will also equip staff to identify asymptomatic signs of ill-health, physiological needs, and desires. Providing resident-focused care may also mean an increased time in caregiving and supporting health needs is required (Cleary & Doody, 2017).

Lacono et al. (2014) conducted a qualitative, descriptive study and suggested several strategies that could be used when caring for individuals with IDD and their associated issues. Examples include engaging residents in a usual routine, using trial and error to determine unmet needs, providing comfort, reassurance, and using a consistent approach to care. As well, using a choice making program whereby residents would be offered choices regarding food and activities could also help with challenging behaviors. These strategies were from the experiences of group home staff who cared for residents who had both IDD and Alzheimer's. A stop and go approach is another strategy that can be used when dealing with residents who have responsive behaviors as it provides them with a sense of relief and may prevent a worsening outcome (GPA, 2014). By using the acronym for stop, staff should stop what they are doing, think about what is happening, observe residents cues and behaviors, and plan when to resume care. These steps allow staff to modify approaches to care. It is important that all strategies be resident-specific as each strategy may not work for everyone. As well, the implementation of strategies may vary day-to-day due to the unpredictability of those with IDD and associated issues.

Monitor feelings and beliefs. It is important for staff to be cognizant of their own values and beliefs so that this does not interfere with the care provided to those with IDD. Also, it is also important for health professionals to use an unbiased approach to care while also considering the linguistic diversity and cultural differences in the way people communicate, ambulate, and behave (Aaiid, 2018). According to the study conducted by Lambrechts et al. (2009), the most frequently occurring behavior in those with an ID was stereotyped behavior with mean scores of 1.00. Therefore, being non-judgmental is essential (GPA, 2014). Staff feelings and beliefs were also associated with reactions to challenging behaviors as discussed earlier (Lambrechts et al., 2009). Staff should reflect on their own thoughts, feelings, behaviors, and responses to feelings, such as anger, in order to develop an interaction style that works for them (GPA).

Participants in a study by Clearly and Doody (2017) found that difficulties existed between both the staff and the resident as they coped with an environment, such as LTC. A phenomenological design was used to explore the experiences of nurses caring for older adults with IDD and dementia and found that caring for individuals with IDDs, dementia, and their associated challenges tend to have difficulty coping and, therefore, may have increase stress. Multidisciplinary teams, informal peer support, personal strategies, and management offer support to those who care for this population. It is also important for health care professionals to talk about their feelings and to feel supported by other staff, such as colleagues and managers, particularly when dealing with complex behaviors (Lambrechts et al., 2009).

Teamwork. Studies conducted by Doody et al. (2013) and Lacono et al. (2014) highlighted the importance of teamwork and using an interdisciplinary approach to care

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that seeks assistance from behavioral specialists and other health professionals.

Behavioral assessments and support plans can be useful as they can be developed and implemented to help guide care (Cleary & Doody, 2017). It is also important that a consistent approach be used by all health care professionals, especially when specific strategies are successful in caring for those with IDD (Lacono et al.). Staff can ensure they are providing consistent care by information sharing, unit meetings, and charting behaviors (Lacono et al.). Participants in the study by Ndengeyingoma and Ruel (2016) indicated that better access to information was needed regarding the needs and routines of patients in order to provide personalized care. Hence, documentation is a key component that helps ensure all pertinent information is in one place, such as any changes or strategies used while also helping to ensure resident-focused care (GPA, 2014; Ndengeyingoma & Ruel).

Communication. Issues arise with regards to communication for residents with IDDs as they may have communication deficits and/or difficulties (Ouellette-Kuntz et al., 2005; Ndengeyingoma & Ruel, 2016). For example, individuals with IDDs may be unable to express themselves appropriately. Health professionals need to be mindful of residents' communication strategies, while also being cognizant of their own, since this will positively influence their perspective and response (GPA, 2014). As well, since the majority of communication is nonverbal, residents can very easily pick up on nonverbal cues even when staff may not realize they are communicating. This may be particularly evident when staff become frustrated in dealing with residents' challenging behaviors.

Strategies to enhance communication include minimizing distractions and noise, using eye contact, speaking slowly, and using simple language (GPA, 2014). It may also

be necessary to visually demonstrate and repeat the message. Informal communication strategies were also suggested by Ndengeyingoma and Ruel (2016) and include using a gentle and comforting approach, being friendly, courteous, and funny, when appropriate. As well, communicating with colleagues can also create more organized care for those with an IDD. Effective communication is key (Doody et al., 2013; GPA).

The Need for Education

It is essential that nurses and other health care professionals gain a better understanding of aging adults with IDDs to ensure positive resident outcomes (Herron-Foster & Bustos, 2014). However, there are a number of issues identified throughout the literature when caring for those with IDDs. It is, therefore, important for health care professionals to be cognizant of these issues and aware of strategies that may help decrease the significance of these issues. Ndengeyingoma and Ruel (2016) stated that dealing with those who have IDDs requires best practices that reflect current research in order to ensure health care professionals are providing the best possible care. However, research and education is lacking in this area and requires further attention (Doody et al., 2013).

Knowledge Gaps

It is evident that several knowledge gaps exist with regards to the issues identified for IDDs in LTC. In the qualitative study by Doody et al. (2013), a lack of understanding and knowledge were identified by health care providers. One gap in particular was related to dementia care (Cleary & Doody, 2017; Jethwa & Cassidy, 2010). Cleary and Doody (2017) found that participants were generally knowledgeable about the signs and symptoms of dementia and its progression but acknowledged that a deeper level of

knowledge was needed. Staff often have difficulty identifying the onset of dementia and, therefore, may attribute an individual's inability to complete tasks to the resident's IDD (Jethwa & Cassidy). With more knowledge in this area, staff will be able to discover dementia in the early stages which will enable practitioners to order medications that may help slow the progression of the disease (Jethwa & Cassidy). Increasing education in this area will also help staff distinguish between behaviors associated with dementia and those related to the disability itself (Jethwa & Cassidy). Additional education, training, and experience is required in order for health care professionals to meet the needs of individuals with IDDs who go on to develop dementia (Cleary & Doody; Jethwa & Cassidy).

Another knowledge gap found within the literature is dealing with challenging behaviors. Participants in the study by Lambrechts et al. (2009) reported that they do not have the skills to effectively care for residents who have IDDs and varying forms of complex behaviors. Additional knowledge in this area will enable staff to gain a better understanding of IDDs, the possible reasons those with IDDs exhibit challenging behaviors, and also help to inform and develop strategies to address them (Lacono et al., 2014). This will allow staff to be cognizant of behaviors and more accepting of challenging behaviors, such as attention-seeking behaviors (Cleary & Doody, 2017). Staff should also be educating colleagues of a resident's typical behavior and be aware that those who do not present with challenging behaviors may still be experiencing dementia.

Studies by Lacono et al. (2014) and Patti et al. (2010) concluded that a LTC facility would be detrimental for residents' well-being and further contribute to this

population's rate of decline if health care professionals do not have knowledge and disability-specific training needed to care for those with IDD. It can also be challenging to meet both the social and health needs required for this population, and hence, additional learning opportunities are needed in order for staff in LTC environments to provide effective care to meet the needs of those with IDDs (Webber et al., 2014).

Strategies to Meet Education Needs

A gentle persuasion workshop is currently being offered to employees at Eastern Health which may help staff care for responsive behaviors of residents with IDDs. However, this workshop is geared toward dementia care and the effectiveness has yet to be determined. In conducting the literature review, three studies used a pre/posttest design to examine the effects of different educational programs/methods. These studies had weak designs since uncontrolled before-after designs were used. However, findings showed that education was positively associated with an increase in knowledge and skill regarding IDDs (Harmon, 2017; Jones, McQueen, Lowe, Minnes, & Rischke, 2015; Read & Rushton, 2013). These studies were not specific to LTC environments, however may still be useful educational methods in this area.

Jones et al. (2015) examined knowledge, skills, and attitudes of students of a variety of disciplines in the field of ID. Participants completed three curriculum components that incorporated blended teaching methods which allowed students to learn through a variety of formats. Findings showed a significant difference in both skill and knowledge after the completion of the education program. Mean knowledge scores increased from 0.51 to 0.64, indicating that knowledge had increased post education. Mean scores in nurses perceived skill level also increased from 0.63 to 0.72, which

according to the researchers, were statistically significant results. Jones et al. (2015) suggested that those with IDD require substantial improvement in health care training and education within current and future professionals. Hence, even though participants were students, educational methods, such as those used within this study, could be beneficial for all health care professionals.

Read and Rushton (2013) explored the impact of workshops on the understanding of the health needs of adults with IDD. This was a mixed methods study that incorporated both pre/post workshop questionnaires as well as qualitative feedback. After completing the workshop, means scores increased significantly from 36.5 to 42.12 ($p < .001$). Participants had learned new knowledge, had become more aware of services available to them, and understood how to better care for individuals with IDD. Results from the qualitative phase concluded that participants felt that taking part in the workshop gave them a better understanding of IDD and that their skills in caring for those with IDD had improved as they were more aware of the importance of good communication and having patience. Overall, participants enjoyed the workshop which may indicate that this was a successful learning method for this topic.

Harmon (2017) conducted an educational seminar, including a lecture, discussion, and a video to evaluate the perceived comfort level, knowledge, and skill of nurses caring for those with IDD. Results indicated that there was positive significant difference in nurses' comfort level providing care to an individual with IDD and in their ability to communicate effectively, $p=0.035$ and $p=0.002$ respectively. However, the researcher only reported the p-values which is considered a limitation. The fact that most of the participants had a master's degree and had not received any education regarding caring

for this population is worrisome and highlights the need that health care professionals require more education on IDD's. Harmon (2017) suggested that lack of education is not related to years of experience, level of education, or years employed in a certain facility. Hence, all staff may benefit from additional education in this area. This study had a small sample size which may have been a result of the type of educational method offered as it was identified by the researcher that a seminar was a barrier since nurses may not have time to attend. Nonetheless, this study highlights the importance and effectiveness of initiating educational programs.

Educational formats. Everyone learns differently, so it is important to consider an individual's learning style in order to provide effective education (American Society for Training & Development (ASTD), 2013). Adults are self-directed learners, use experience as a resource, and are internally motivated to learn. Some prefer to learn using a hands-on approach, while others are more visual or auditory learners. The benefits of using lectures as a learning medium are that they are cost-effective, efficient, and easy to control. However, lectures can lack participation, and can be difficult to assess whether learning has occurred. Scheduling issues may also occur. A lecture via a PowerPoint presentation may be a learning tool that is useful in developing the practicum project as it serves as both an auditory and visual form of learning which may be beneficial for most types of learners. The slide deck could be uploaded to a computer for staff to review outside of a formal education session and, therefore, could be designed as a self-learning resource. However, information placed on slides may be limited and would need to incorporate a script describing the information or uploaded as a mini-lecture.

A more visual learning option, such as a booklet, pamphlet, or learning resource may be beneficial since adults are self-directed learners. These independent study methods use limited facilitator involvement and can be done on the learners' time (ASTD, 2013). These methods would provide easy access to information directly on the unit which could easily be copied and taken home for review. A booklet or resource manual could also be used a reference tool for learners who want specific information when needed. In addition, the booklets could be offered within the orientation package to new employees. Disadvantages of self-study options are that there is limited interaction and the inability to answer questions (ASTD). However, case studies could be used to serve as an evaluation/reflection of the material learned. Case studies address objectives and provide learners with a more interactive approach to learning. However, they can be time consuming and may not produce accurate conclusions.

Online learning is another tool that allows learners to gain knowledge by using technology (ASTD, 2013). Online learning allows for various learning styles to be accommodated, the flexibility of learning anytime and anywhere, and minimal physical space. Disadvantages are technical challenges, inability to ask questions, and suitability for self-directed learners. A blended approach to learning may be useful as it appeals to all types of learners in order to obtain the knowledge and skills needed.

Conclusion

Those with IDD are aging and often experience complex health care needs, such as dementia, secondary disabilities, and challenging behaviors. LTC for most of this population is inevitable and is a growing area of concern since the prevalence of those admitted is increasing. Hence, LTC should be prepared to meet the needs of this specific

population. It is evident through the literature that LTC is appropriate for those with IDD and can actually offer many benefits for this population. However, as discussed, there are many issues associated with IDDs and LTC. For example, Jethwa and Cassidy (2010) and Cleary and Doody (2017) highlighted the difficulties associated with caring for a resident with both an IDD and dementia while Lambrechts et al. (2009) and Ndengeyingoma and Ruel (2016) highlighted associated challenging behaviors. This population also has many health conditions and issues associated with antipsychotic use, inclusivity, social isolation, communication, teamwork, and resident-focused care which make caring for this population complex and challenging.

It is evident throughout the studies reviewed that additional education is needed when caring for those with IDDs, specifically within LTC environments. The recurring theme throughout the literature is that there is a lack of knowledge and understanding in caring for older people with IDDs as Doody et al. (2013) found that most health care providers lacked understanding and knowledge. Hence, increasing education in this area would help health care professionals gain the knowledge and skills required to fulfill both the health and social needs of this population. Since staff have many important roles when providing care to these residents, increasing education will also enable staff to provide more effective care. Hence, developing a learning resource for the practicum project will enable staff to increase their knowledge base on this topic and, in effect, lead to positive resident outcomes.

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Appendix A

Qualitative studies were critically appraised using the checklist from the Critical Appraisal Skills Program (CASP).
Quantitative studies were critically appraised using the tool kit by PHAC (2014).

Abbreviations: Aggressive/destructive behavior frequency, ADB_F; Aggressive/destructive behavior severity, ADB_S; Clinical Global Impression-Improvement scale, CGI-I; Confidence Interval, CI; Continuing Care Reporting System for Long-Term Care, CCRS-LTC; diabetes mellitus, DM; Dipeptidyl peptidase, DPP; Down Syndrome, DS; Generalized linear models, GLM; Group home, GH; Home Care Reporting System, HCRS; Institute for Clinical Evaluative Sciences, ICES; Intellectual disability, ID; Modified overt aggression scale, MOAS; Nursing home, NH; Registered Nurse, RN; Registered Persons Database, RPDB; Residential aged care, RAC; Residential aged care facilities, RACF; Self-injuries behavior severity, SIB_S; Visual Analogue Scale, VAS

Study/Design/Objectives	Sample/Methods	Results	Conclusion
<p>Axmon et al. (2017).</p> <p>Design: Cohort</p> <p>Objective: describe and compare prevalence ratios of DM and hypertension between older adults with ID and their age peers in the general population, and to describe and compare treatment patterns in these two groups.</p>	<p>Setting: Sweden (2012).</p> <p>Sample: 7936 with ID.</p> <ul style="list-style-type: none"> • 55 and older • Alive at the end of 2012. • 44 people with diagnosis of unspecified diabetes mellitus. • Had received support for ID. 	<p>People with ID were 20% more likely to have DM and 26% more likely to have prescription of drugs.</p> <p>9% of those with an ID had DM (8% in the general population).</p> <p>10% of those with an ID had hypertension (19% in the general population).</p>	<p>Strength of design: Moderate</p> <p>Quality: Medium</p> <p>Limitations:</p> <p>May not be representative of all people with DM (Generalizable for severe or complex DM)</p> <p>Inability to adjust for potential confounders, such as risk or protective factors for DM.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	<p>Methods: Swedish national registers used between 2006 and 2012 to define the original cohorts, identify the sub cohorts with diagnosis of DM or hypertension, and collect information on outcomes (drug prescriptions).</p> <p>A same-sized referent cohort from the general population matched by sex and year of birth was established.</p> <p>The two cohorts were compared using GLM.</p> <p>Analyses were only performed when both groups to be compared contained at least five people.</p>	<p>Among those with diabetes, ID was associated with higher occurrence of a prescription of insulin combination drugs and sulfonylureas (13% compared to 10% in the general population).</p> <p>Among those with hypertension, ID was associated with higher occurrence of prescription of diuretics, but lower occurrence of prescription of calcium channel blockers and angiotensin II antagonists (44% compared with 48% in the general population).</p>	Risk or protective factors not considered for DM or hypertension.
<p>Bigby et al. (2008).</p> <p>Design: Cross-Sectional.</p> <p>Objective: To explore the pathways by which older adults with ID come to RACFs, the type of care and</p>	<p>Setting: 114 RACF in Victoria.</p> <p>Sample: 167 people with ID</p> <ul style="list-style-type: none"> Data only available for 158 of the 167. 	<p>Average age of residents with ID who moved to a RACF= 59.4; Average length of stay= 5.6 years.</p> <p>43% lived in a GH or with family prior to RACF.</p>	<p>Strength of design: Weak</p> <p>Quality: Medium.</p> <p>Limitations: Severity of conditions or level of resulting disability not addressed.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
support provided to this group, and the circumstances in which it may be an appropriate option.	<ul style="list-style-type: none"> 82.2% were 55 or older. Females outnumbered males by more than two to one. 60.7% were classified as needing high care. <p>Methods: Reports on the first phase of a 4-year study.</p> <p>A survey was mailed to RAC services listed on the Commonwealth Department of Health and Ageing web site, seeking information about the location and resident capacity of the facility, whether they had any residents with ID, and the main issues arising regarding care.</p> <p>Follow up phone calls were made four weeks later to non-responding facilities.</p>	<p>Residents with ID were younger, have entered at an earlier age, and remained longer than other residents.</p> <p>Dependency profile was similar to others in the general aged care population (60.7% needing high care). Inability to fit into the resident's community, lack of participation in activities, and lack of meaningful relationships identified as primary areas of concern.</p> <p>Those with ID are 'younger old' (60-80 years).</p> <p>Residents did not participate in activities within the RACF due to health, cognitive incapacity and/or emotional and behavioral difficulties.</p> <p>Encouraging the resident to be involved in the facility (i.e., adopting a helping role or taking on small jobs).</p>	<p>Low response rate (35%).</p> <p>The reliability and validity of the survey questionnaire not discussed.</p> <p>Results may reflect an over-sampling of facilities as telephone follow-up revealed that facilities with no residents with IDD were less likely to respond to the survey.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	<p>Additional surveys completed by phone and treated as a structured interview.</p> <p>Data was analyzed using SPSS and thematically by coding open ended survey questions into separate categories.</p>	<p>28% reported having no positive relationships with other residents.</p> <p>50% of residents had weekly contact with an informal network of friends/family.</p>	
<p>Cleary & Doody (2016).</p> <p>Design: Phenomenology</p> <p>Objective: To explore nurses' experiences of caring for older people with ID and dementia.</p>	<p>Setting: Community and residential services in the west of Ireland.</p> <p>Sample: 11 nurses.</p> <ul style="list-style-type: none"> • Male and female. • Nurse managers included. • 9 registered intellectual disability nurses. • 2 registered general nurses. • Experience varied from 10-35 years working with ID. • Experience varied from 3-7 years working with dementia. 	<p>Three themes emerged:</p> <p><u>Knowledge of dementia:</u></p> <ul style="list-style-type: none"> -Staff knowledgeable about the signs and symptoms of dementia and its progression. -Those with dementia may present with aggression. -Necessity of training to support relief staff to develop knowledge and understanding. -When a person with ID and dementia did not present with challenging behaviors, a timely diagnosis was not always made. -A responsive approach would have been used if staff 	<p>Quality: Credible</p> <p>Limitations: Participants were known to the interviewers which may have influenced participants' responses.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	<p>Methods: Data collected using semi structured interviews that were audio-recorded, transcribed, and lasted between 60-90 minutes.</p> <p>Data analyzed using Colaizzi's (1978) framework.</p> <p>Themes were formulated by identifying key statements from each interview and formulating meaning from statements.</p>	<p>had a greater knowledge of dementia at the time. -Concerned of poor recognition among less experienced colleagues.</p> <p><u>Person centered care:</u> -Importance of using a person-centered approach. -Increased time needed in caregiving and supporting health needs. -Addressed under subthemes including health, behavioral support, multidisciplinary team support, provision of activities, impact on peers and staff coping.</p> <p><u>Transitioning within the service:</u> -Moving to a new facility was difficult. -Behaviors following a move reflected the persons distress and often felt ill equipped. -Transferring from the community was needed due to low staffing levels,</p>	

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
		housing being unsuitable, and increased dependency.	
<p>Doody et al. (2013).</p> <p>Design: Phenomenology.</p> <p>Objective: To explore the experiences of registered ID nurses caring for the older person with ID.</p>	<p>Setting: Voluntary service providing community and residential services in Ireland.</p> <p>Sample: 7 participants.</p> <ul style="list-style-type: none"> • Qualified > two years. • Had at least one year experience working with the older person. • Comprised of men (2) and women (5). • Day and night staff. <p>Methods: A qualitative Heideggerian phenomenological approach.</p> <p>Data collected through semi-structured interviews, lasted 60-90 minutes, and were audio-recorded.</p> <p>Interviews transcribed verbatim and analyzed thematically using Burnard's</p>	<p>Three main themes emerged:</p> <p><u>Care delivery:</u></p> <ul style="list-style-type: none"> -Teamwork was essential -RNs play a pivotal role. <p><u>Inclusiveness:</u></p> <ul style="list-style-type: none"> -Service provision and activities need to be implemented at a slower pace, be age appropriate, and meaningful. -Importance of seeing the person rather than the disability. -Promotes integration, relating to activities, and using aged services. <p><u>Client-focused care:</u></p> <ul style="list-style-type: none"> -Best practice is a goal that RNs strive for. -Individuality was a core concept of caring. -Highlights the need to value practice and create evidence from networking of information with others. 	<p>Quality: Credible</p> <p>Limitations: Participants were known to the first author.</p> <p>Not specific to LTC.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	framework, involving 6 steps.		
<p>Harmon (2017).</p> <p>Design: Uncontrolled Before-After.</p> <p>Objective: to improve the perceived comfort, knowledge, and skill level of nurses in caring for those with IDD in the acute care setting.</p>	<p>Setting: Acute care hospital in Massachusetts</p> <p>Sample: 14 people.</p> <ul style="list-style-type: none"> 64.3% had a bachelors or a master's degree. 71.4 % aged 33-52. <p>Methods:</p> <p>A 2-hour educational seminar comprised of a didactic lecture, discussion, and video.</p> <p>Followed by a question and answer period.</p> <p>A pre/post program questionnaire.</p>	<p>Significant differences in nurses' comfort level providing care to those with IDD (p=0.035).</p> <p>Positive significant difference in feeling confident in coordinated and interprofessional team (p=0.002).</p> <p>Increase in self-confidence in understanding patients' needs (p=0.002).</p> <p>Increase in confidence in the ability to communicate effectively (p=.002).</p> <p>Negative significant differences in ability to identify symptoms of common medical issues of those with IDD (p=0.003).</p> <p>Negative significant differences for identifying three nursing strategies when</p>	<p>Strength of design: Weak.</p> <p>Quality: Medium.</p> <p>Limitations:</p> <p>Nurses were unable to attend seminar due to time constraints.</p> <p>Only P-values were reported.</p> <p>Small sample size</p> <p>Conclusion:</p> <p>The negative significant difference may be an indicator that more extensive education is needed.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
		caring for this population (p=.002).	
<p>Jones et al. (2015).</p> <p>Design: Uncontrolled Before-After.</p> <p>Objective: to evaluate the level of change in students' perceived skills, knowledge, and attitudes following course participation evaluated through a learning framework of IPE and collaborative practice.</p>	<p>Setting: Canada</p> <p>Sample: 332 students</p> <ul style="list-style-type: none"> Variety of disciplines Had varying levels of training. Only 247 consented for their results to be included. <p>Methods:</p> <p>Three curriculum components:</p> <p>Foundational knowledge (Independent E-learning, lectures).</p> <p>Client engagement (Experiential learning, groups of 8-10).</p> <p>Case study and team-based approach (allowed for interprofessional learning).</p>	<p>All disciplines had significant differences in perceived skill (Mean score pre-course= 0.64 and post-course= 0.70; p<.01)</p> <p>Nurses had statistically significant differences in perceived skill when grouped alone (Mean score pre-course= 0.63 and post-course=0.72; P=0.01).</p> <p>All disciplines had significant differences in overall knowledge (Mean score pre-course= 0.51 and post-course=0.64; p<.01).</p> <p>Nurses had increased knowledge with mean scores of 0.53 pre-course to 0.63 post-course.</p> <p>No statistically differences in attitudinal changes.</p>	<p>Strength of design: Weak</p> <p>Quality: Medium.</p> <p>Limitations: Not LTC specific.</p> <p>Researches argued that these findings indicate that more education is needed within student curriculums (may not be generalizable to current working professionals).</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	Completed a questionnaire pre/post course. Attitudes assessed using five-point Likert scale.		
<p>Kuijper et al. (2014).</p> <p>Design: a non-randomized control trial.</p> <p>Objective: The primary objective was to investigate the effects of controlled discontinuation of antipsychotics prescribed for challenging behavior. Secondary objectives were to compare the results of two discontinuation time schedules, to compare groups of participants who had and had not achieved complete discontinuation, and to identify patient and medication characteristics that might predict the outcomes.</p>	<p>Setting: 3 care providing organizations in the Netherlands (Vanboeijen Assen, Heerenloo Apeldoorn, and Heerenloo Ermelo).</p> <p>Sample: 98 participants with ID.</p> <ul style="list-style-type: none"> • Aged 15–66 years. • Used for >1 year or more one of the six most frequently prescribed anti-psychotics for challenging behavior. <p>Methods: Two discontinuation schedules of 14 and 28 weeks.</p>	<p>44% achieved complete discontinuation.</p> <p>Controlled discontinuation of antipsychotics did not lead to worsening in behavioral functioning (83% who achieved complete discontinuation had no change in behavior ($p<0.01$); 79% who did not achieve complete discontinuation had no change in behavior ($p\leq 0.55$)).</p> <p>No need to taper off in a specific time frame.</p> <p>Overall health improved regardless of whether patients were actually able to achieve full discontinuation.</p> <p>Mean ABC ratings improved significantly for those who</p>	<p>Strength of design: Strong</p> <p>Quality: High</p> <p>Limitations:</p> <p>Majority <65 and may not be generalizable to the elderly population.</p> <p>Staff-related influences.</p> <p>Reliability and validity of secondary outcome measures (VAS) not discussed.</p> <p>Staff and participants were not blinded regarding discontinuation schedule.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	<p>Anti-psychotics tapered every 2 or 4 weeks (12.5% of the initial dosage). Follow-up 12 weeks after the scheduled complete discontinuation (at 26 or 40 weeks after the first dose reduction).</p> <p>Discontinuation was stopped in case of significant behavioral worsening.</p> <p>Changes in environmental factors (living or work situation, life events and group/staff rearrangements), in medication and in physical health were recorded at 2 or 4 weeks after every dose reduction.</p> <p>Primary outcome measured using the ABC (a 58-item standardized rating scale).</p> <p>Secondary outcome: CGI-I and a VAS.</p>	<p>achieved complete discontinuation ($p < 0.01$) and at follow up for those who did not achieve complete discontinuation ($p = 0.03$).</p> <p>Those who achieved complete discontinuation had decrease of scores of the ABC sub-scale 'irritability' at the time point of complete discontinuation and at follow-up (mean difference = 4.9, CI = 2.3–7.6, $P = 0.001$; mean difference = 3, CI = 0.05–5.9, $P = 0.05$)</p> <p>No significant differences in improvement of ABC ratings between both discontinuation schedules.</p> <p>Higher ratings of extrapyramidal and autonomic symptoms at baseline associated with less improvement of behavioral symptoms after discontinuation ($P < 0.01$).</p>	

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
<p>Lacono et al. (2014).</p> <p>Design: Qualitative descriptive.</p> <p>Objective: To report on the experiences of disability staff in GHs supporting residents with DS and Alzheimer's disease in relation to their understanding of what was happening to these residents, their responses to them, and how they felt about their support role.</p>	<p>Setting: Several small GHs in Victoria, Australia.</p> <p>Sample: 9 adults with DS.</p> <ul style="list-style-type: none"> • Had various stages of Alzheimer's disease. • Aged 42-57. • 4-6 residents in each GH. <p>: 21 Direct care staff</p> <ul style="list-style-type: none"> • Knew those with DS well. • Lacked formal qualifications. <p>Methods:</p> <p>Two semi-structured face-to-face interviews (60-90 min in duration) conducted 6-12 months apart with direct care staff.</p> <p>Participants identified from a larger study cohort of people recruited through invitations sent to next-of-kin and contact people of patients of a specialist university DS clinic, advertisement in</p>	<p>Several themes identified:</p> <p>Struggling to understand change (behaviors and functioning).</p> <p>Taking each day as it comes (difficult to project what would be needed to provide continued support as people deteriorated over time).</p> <p>Commitment (a sense of responsibility and were the best people to provide care).</p> <p>Insight into and understanding of the perceptions and experiences of staff.</p> <p>Moving to an RAC would be detrimental to overall health.</p> <p>Limited understanding of how Alzheimer's disease was impacting the residents in their care.</p> <p>Age diagnosed with Alzheimer's (39-57).</p>	<p>Quality: Credible</p> <p>Limitations:</p> <p>Most direct care staff lacked formal qualifications.</p> <p>The ad hoc responses, distrust of others, and limited knowledge created a microcosm of care that excluded other input/support.</p> <p>GH setting.</p> <p><65 years of age and may not be generalizable to the elderly with IDD.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	<p>disability newsletters and word-of-mouth.</p> <p>Transcripts were analyzed thematically.</p> <p>Qualitative data analysis strategies used (outlined by Creswell (2009)).</p>		
<p>Lambrechts et al. (2009).</p> <p>Design: Cross-sectional survey</p> <p>Objective: To examine associations between several staff variables and challenging behavior of people with severe or profound IDs</p>	<p>Setting: 20 different residential services for people with ID in Flanders.</p> <p>Sample: 51 care staff</p> <ul style="list-style-type: none"> Aged 20-53. 94.1% female. <p>29 residential settings caring for those with severe or profound ID were contacted by telephone.</p> <p>Methods: Each completed 4 questionnaires: Behavior Problems Inventory: Frequency and severity of challenging behaviors. Challenging Behavior Attributions Scale: Staff</p>	<p>Negative emotional reactions were positively associated with challenging behaviors (Fear/anxiety correlated with ADB_F $r=.47$ and ADB_S $r=.59$; SIB_S $r=.33$).</p> <p>Associations between emotional reactions, staff beliefs, and staff reactions were inconsistent. Stereotyped behavior was the most frequent occurring behavior ($r=0.62$).</p> <p>Aggressive behavior was considered the most severe behavior ($r=0.78$).</p> <p>Self- injurious behavior was moderately correlated with</p>	<p>Strength of design: Weak</p> <p>Quality: Medium</p> <p>Limitations: The Reactions to the Challenging Behavior scale was a newly developed questionnaire.</p> <p>Staff answers re. 1 client and may not be representative of feelings, attributions, and reactions concerning challenging behavior in general.</p> <p>Participants were varying backgrounds of education and not necessarily nursing affiliated.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	<p>attributions about challenging behaviors.</p> <p>Emotional Reactions to Challenging Behaviors Scale: Emotional reactions to challenging behaviors.</p> <p>Reactions to Challenging Behavior scale: Staff's reactions to clients' challenging behavior.</p>	<p>aggressive behaviors ($r=0.35$).</p> <p>Aggressive/destructive behavior was weakly to moderately correlated with positive/alternative interventions ($r=0.30/r=0.33$).</p> <p>Reactions to challenging behaviors differed according to the type and frequency of challenging behavior.</p>	
<p>McKenzie et al. (2016).</p> <p>Design: A retrospective cohort modelling study.</p> <p>Objective: to use a frailty index created for persons with IDD to predict admission to LTC among persons receiving home care services in Ontario, Canada.</p>	<p>Setting: Ontario, Canada in 2009/2010.</p> <p>Sample 3,034 individuals with IDD.</p> <ul style="list-style-type: none"> aged 18-99. not living in a RACF. <p>Methods:</p> <p>Three administrative data sets:</p>	<p>66% of those admitted to LTC were more likely to be pre-frail or frail (68%).</p> <p>22% were admitted to LTC.</p> <p>The cumulative incidence of admission was 13.8% (95% CI [12.5, 15.1]) at 6 months and 18.6% (95% CI [17.2, 20.1]) by 2 years.</p>	<p>Strength of design: Moderate</p> <p>Quality: Medium.</p> <p>Limitations:</p> <p>Use of administrative data may have incorrectly identified adults with IDD leading to inaccurate data.</p> <p>Changes in frailty were not considered during study follow-up.</p> <p>Unspecified status of individuals after their first admission to LTC.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	<p>CCRS-LTC: Dates of admission to LTC.</p> <p>HCRS: RAI-HC data.</p> <p>RPDB: Age/date of death.</p> <p>Incidence of admission to LTC calculated for 6 months and 2 years after first home care assessment.</p> <p>Data sets analyzed at the ICES.</p> <p>Time-to-event analysis measured the relationship between frailty and admission to LTC.</p>		
<p>Ndengeyingoma & Ruel (2016).</p> <p>Design: Qualitative descriptive.</p> <p>Objective: To explore nurses' representations of caring for people with an ID, intervention strategies they</p>	<p>Setting: The Outaouais region of Quebec, at the Gatineau centre for health and social services.</p> <p>Sample: 18 RNs</p> <ul style="list-style-type: none"> • 14 females, 4 males. • Experience from 6 months-25 years. 	<p>Four themes emerged:</p> <p><u>Characteristics of ID:</u></p> <ul style="list-style-type: none"> -Vulnerability varies based on nature of the ID -RN's are unable to recognize the inherent nature or specific needs of ID. 	<p>Quality: Credible</p> <p>Limitations: RNs did not work in LTC.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
currently use, and to identify needs to ensure quality care.	<ul style="list-style-type: none"> Worked in hospital and community settings. <p>Methods: Individual semi-structured audio-recorded interviews lasting ~30 minutes, transcribed in French and then translated into English and reviewed for accuracy.</p> <p>Thematic analysis based on Braun and Clarke's (2006) method, involving 6 phases.</p>	<p><u>Challenges of assuring the expected level of quality care:</u></p> <ul style="list-style-type: none"> -informal communication solutions. -communicating with other professionals resulted in more appropriate and organized care. -Insufficient resources lead to the use of insufficient approaches. <p><u>Variance in the current strategies to promote the expected level of quality care:</u></p> <ul style="list-style-type: none"> -Preventing problems. -use appropriate resources (i.e., referrals). -Those with IDD's have difficulty communicating needs. -RNs should be looking for available resources for current/future needs. 	

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
		<u>Perceived needs to ensure the expected level of quality care to patients with ID:</u> -Professional needs that are relational and informational in nature. -Better access to information about the needs and routines of patients to provide personalized care -Different approaches to care. -Importance of including family. -Participants not well equipped to care for ID patients.	
Patti et al. (2010). Design: Cohort. Objective: To explore the incidence of relocation (s) and its relation to end of life care for older people with ID.	Setting: Metropolitan diagnostic and research clinic over a 12-year period. Sample: 140 adults with ID. <ul style="list-style-type: none"> Majority living in GHs in New York. Born prior to 1946. 50+ prior to death. DS group: 61 people (aged 50-71; 36 Men and 25 women). 	Relocations were significantly greater in the DS group (65 times compared with 47 for the non-DS group). 84% in the DS group diagnosed with possible/probable dementia versus only 19 % in the non-DS group. 90% in the non-DS group were in a GH, 10% in a NH.	Strength of study: Moderate Quality: Medium Limitations: The accelerated life course for those with DS was not controlled which may have exaggerated differences in outcomes. Cohort was not population-based (not generalizable).

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	<p>Methods: 5 and 10 year look-back periods used to record moves/relocations.</p> <p>The number of relocations and type of setting obtained from psychosocial records.</p> <p>Look-back period calculated from the year of death for those who had died.</p> <p>Entire look-back period covered a span of 22 years. Dementia status: Determined from a comprehensive diagnostic assessment (Neurological, psychiatric, neurobehavioral).</p>	<p>59% in the DS group were residing in a GH, 39% in a NH.</p> <p>Placement in a nursing home was higher in the DS group (39% compared to 9%)</p> <p>Mortality was earlier in the DS group (61.4 years compared to 73.2).</p> <p>46% died in a NH compared with 16% in a GH.</p>	<p>Disparity in the dementia status between the two groups.</p> <p>The look-back period covered a span of 22 years (survivor bias).</p> <p>Earlier moves/relocations may have been due to changes in policy or availability of services.</p>
<p>Read & Rushton (2013).</p> <p>Design: Mixed methods (Uncontrolled before-after and interpretative descriptive).</p> <p>Objective: to describe the self-evaluation process and outcome of a series of</p>	<p>Setting: UK</p> <p>Sample: 155 people attended 1 of 8 workshops.</p> <ul style="list-style-type: none"> Mainly nurses Qualified and unqualified. 	<p>Pre/post course scores showed statistically significant results as participants gained knowledge after attending the workshop as 79.1% showed an improved score. (Mean pre-test=36.5; Mean post-test=42.12; $P < 0.001$).</p>	<p>Strength of design: Weak</p> <p>Quality: Medium.</p> <p>Limitations: Hospital setting (may not be generalizable).</p>

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

Study/Design/Objectives	Sample/Methods	Results	Conclusion
workshops designed to cultivate understanding of the health needs of adults with ID.	<ul style="list-style-type: none"> 138 females, 17 males. <p>Methods:</p> <p>Workshop developed from a previous toolkit.</p> <p>Pre and post workshop questionnaires- consisted of 16 questions of knowledge, guiding principles of capacity and consent, and holistic care.</p> <p>Qualitative feedback form allowed for constructive feedback and promoted group discussion.</p> <p>Analyzed thematically using Fry's framework.</p>	<p>Participants felt that the workshop increased knowledge, skills, and attitudes.</p> <p>Knowledge (had a better understanding of IDD's, simple changes make a big difference, made them more aware of support/information available).</p> <p>Skills (Communicate in different ways, willing to listen to the patient and give them time, have patience).</p> <p>Attitudes (Humbling experience, patients are people first).</p> <p>Participants positively commented on the overall workshop experience.</p>	
<p>Tyrer et al. (2008).</p> <p>Design: A randomized controlled trial.</p>	<p>Setting: ten centres in England and Wales, and one in Queensland, Australia.</p>	<p>Aggressive challenging behavior in people with ID decreased whether or not active medication is given (MOAS score 3.5 in placebo group; MOAS=2 in</p>	<p>Strength of design: Strong</p> <p>Quality: High</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
Objective: To compare flexible doses of haloperidol (a typical, first-generation antipsychotic drug), risperidone (an atypical, second-generation antipsychotic), and placebo, in the treatment of aggressive	<p>Sample: 86 non-psychotic patients.</p> <ul style="list-style-type: none"> • Had aggressive challenging behaviors. • Predominantly men. • Mild-moderate ID. <p>Methods:</p> <p>A three-arm, parallel-group pragmatic trial.</p> <p>Participants randomly assigned to haloperidol (n=28), risperidone (n=29), or placebo (n=29) groups.</p> <p>Blind assessments of outcome were completed at 4, 12, and 26 weeks after randomization.</p> <p>Participants included if being treated by services for ID and those who had been given antipsychotic drugs in the past but no longer took them.</p>	<p>Risperidone; MOAS=1 in Haloperidol).</p> <p>Aggression decreased with all three treatments by 4 weeks, with the placebo group showing the greatest (95% with placebo, MOAS=9, 79% from baseline for risperidone, MOAS=7, 58% from baseline for haloperidol, MOAS=6.5).</p> <p>No important differences between the treatments were recorded, including adverse effects.</p> <p>Placebo showed no evidence of worse response than those assigned to either of the antipsychotic drugs (ABC scores 51 in placebo; 46 in risperidone; 50 in haloperidol).</p>	<p>Limitations:</p> <p>Study sample was underpowered.</p> <p>May not be generalizable to those with severe IDs.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	<p>MOAS: Aggressive behaviors recorded weekly by telephone interview with the keyworkers over 26 weeks.</p> <p>Multivariate and univariate analyses were used.</p> <p>Clinical assessments of aggression, aberrant behavior, quality of life, adverse drug effects, and carer uplift (positive feelings about the care of the disabled person) and burden, together with total costs, were recorded at 4, 12, and 26 weeks.</p>		
<p>Webber et al. (2014).</p> <p>Design: Grounded theory.</p> <p>Objective: To explore the experiences of older people with ID who moved from a GH to RAC, from the perspective of family members, aged care staff and former group home.</p>	<p>Setting: 9 RACF in Victoria, Australia.</p> <p>Sample: 31 participants associated with 10 older adults with ID.</p> <ul style="list-style-type: none"> • Recently moved from a GH into RACF. • 7 men; 3 women. • Average age was 64. 	<p>All were concerned about social and health outcomes for residents.</p> <p>RAC staff focused on resident's health, safety, and physical comfort. Extensive health assessments completed upon entry to RACF.</p>	<p>Quality: Credible</p> <p>Limitations: Differences in disciplinary training between GH staff and RAC staff resulted in different conclusions/actions. Recently transitioned.</p>

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	<ul style="list-style-type: none"> Many of those with ID had communication difficulties. 9 participants were family members. 10 participants were former GH staff. 12 participants were nursing or management staff from the RACF. <p>Methods: Grounded theory methodologies.</p> <p>Interviews with staff and family members within the first three months of relocation, lasted between 30-60 min, recorded, and transcribed.</p> <p>Follow up interviews 12 months later. Dimensional analysis used to analyze interviews.</p>	<p>GH staff expressed social consequences of living in RACFs.</p> <p>Families were pleased with the care given in aged care.</p> <p>Families were often surprised at how much their relative's general health improved.</p> <p>Previously undiagnosed medical issues had been identified and treated. Families concerned over the disconnection from past relationships (social isolation).</p>	

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Study/Design/Objectives	Sample/Methods	Results	Conclusion
	<p>Data analyzed by an interdisciplinary research team.</p> <p>Axial coding to explore criteria used to assess the experience of living in RAC.</p> <p>Selective coding to explore perceptions about the condition influencing residents' experiences.</p>		

Appendix II: Consultations

Consultation Report: Intellectual and Developmental Disability in Long Term Care

Lindsay Hunt, 200827475

Memorial University of Newfoundland and Labrador

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Since those with intellectual and developmental disability (IDD) are aging similar to the general population, many present with additional chronic health conditions requiring complex care. Those with IDD also have secondary disabilities and complex health care needs due to the nature of their disability (Bigby, Webber, Bowers, & McKenzie-Green, 2008). It is, therefore, inevitable that eventually those with IDDs will be admitted into long term care (LTC). Caring for a resident with IDDs can be particularly challenging given the fact that many are integrated with other residents, though the majority require significantly more care and attention. Bigby et al. (2008) suggested that those with IDDs actually have similar levels of dependency as other elderly residents even though they may appear younger and healthier. Hence, it is very important for LTC to be prepared to care for the increasing number of individuals admitted with IDDs.

After conducting a literature review on IDDs in LTC, it is evident that staff lack both knowledge and skills required to care for this population. The literature suggests that LTC environments have difficulty meeting both the social and health needs for those with IDDs (Webber, Bowers, & Bigby, 2014). Therefore, increased education in this area is one solution for LTC to meet the needs and improve overall care for these residents. This will enable staff to be equipped with the knowledge and skills required to better care for this population. According to Doody, Markey and Doody (2013), this is an area that requires further attention. Hence, developing an educational resource for this practicum project will address the knowledge gap regarding aging adults with IDDs by enabling staff to gain a better understanding of this specific population within LTC. The overall objective of completing the consultations was to gain additional information on this topic

from staff who specifically worked with individuals who have IDD in LTC in order to develop an educational resource at the end of the practicum project. The purpose of the consultations was to identify issues related to caring for those with IDD in LTC, identify specific knowledge gaps and learning needs, identify a preference for the type of resource developed, and identify content to include in the resource.

Methods

Setting and Sample

The setting of the consultations was St. Luke's Home (SLH), with the overall focus being on one particular unit, Trinity Square. The setting was appropriate as there were several residents with IDD who resided on this unit. The setting was also convenient for staff as they were working on Trinity Square during the consultations.

Convenience sampling was used. There were two target groups; one group consisted of PCAs and LPNs and the second group comprised of other health professionals, such as the Behavioral Management Specialist, Clinical Educator, Recreational Therapist, and RNs.

The majority of staff, such as LPNs and PCAs, had been working with residents in LTC for some time and were permanent employees on the unit with experience caring for those with IDD. These staff members work closely with this population and hence were invited to participate due to their first-hand experience. Since the overall goal of the project is to develop an educational resource for staff regarding IDD within LTC, it was important to include staff in the project development. As well, having a better understanding of staff members' learning needs will enable the development of a resource that will contain information staff identified as important for caring for this population.

Staff may also be more inclined to use the resource given the fact that they had a say in the type of resource developed.

Incorporating other health care professionals, such as the Behavioral Management Specialist, Clinical Educator, Recreation Therapist, and RNs, was important as these disciplines had expertise in this area and dealt specifically with those with IDD in one way or another. It also allowed for an interdisciplinary approach and ensured information obtained in developing the resource could be utilized by various disciplines. As well, since the RNs are leaders on the units, it was important to have their input incorporated into the development of the resource as well. Hence, these additional consultations are invaluable to the development of the practicum project.

Data Collection

Data were obtained from a mix of eight PCAs and LPNs using informal semi-structured interviews conducted face-to-face on the unit at SLH. Interviews were conducted in a group setting of approximately four staff members. There were two groups, one per team, in order to allow for input from both teams on each side of the schedule. Data were collected on two separate days, one per team. Additional interviews were not required as sufficient information was obtained. The interviews regarding IDDs and LTC were guided by questions, found in Appendix A, which allowed for discussion among staff. Specific staff experiences in dealing with those with IDDs were encouraged in order to acquire additional pertinent information. The questions and responses gathered from the first interview were examined, in consultation with the supervisor, prior to starting the second interview in order to allow for further brainstorming and the

development of additional questions that were necessary to provide further insight on this topic.

The consultation plan was discussed with the manager of Trinity Square and permission was obtained prior to the start of the consultations. Staff members were approached to participate in the project at work prior to the commencement of their shift with the project being explained using an introduction script as a guide, found in Appendix B. The consultations took place during afternoon “huddles.” Only those present on the unit were asked to participate.

Additional consultations were completed with the other health professionals, including the Behavioral Management Specialist, Clinical Educator, Recreation Therapist, and RNs. These participants were recruited through email, found in Appendix B, with the practicum project explained and invitation to participate. The email also included questions that were pertinent to their particular profession and will help guide the development of the practicum project. Additional experiences and/or other information felt to be pertinent to the topic were also requested. A return date of March 20th, 2018 was included in the email to ensure input was received from disciplines in a timely fashion. Participants were also given the option to discuss in person; however, no one chose this option. All participants responded directly by email with answers to questions. Hence, data were collected using the written responses. An email reminder was sent to one participant, however, the majority of feedback was received from participants prior to the return date.

Data Management and Analysis

Data were obtained from the interviews conducted with staff in a group setting and managed using written field notes made during the interviews. The notes were placed in a sealed envelope and placed in a locked locker. The notes were taken home at the end of the day and transcribed to the computer, using a Word document. The written notes were destroyed after transcription. The computer was password protected to ensure safety of information. The transcribed notes were also shared with the supervisor of the practicum project for the purpose of ensuring rigour of analysis. Once transcribed, data obtained from the interviews were further examined, read and re-read, and analyzed by using content analysis, clustering similar data, and creating themes. Themes were based on data collected from the interviews and provided further insight to address the objectives of the consultations.

Data obtained from emails were managed using a specified file folder within the Eastern Health email. Emails were also examined, read and re-read, and analyzed by clustering similar data and creating themes.

Ethical Considerations

The basic ethical principles of beneficence, autonomy, and justice were maintained. Full disclosure and verbal agreement during the interviews were used as participants had adequate information regarding the practicum project. All participation was voluntary. Returning written responses to emailed questions implied agreement to participate. Those participating in the consultations were notified that information obtained may be used in the development of the educational resource. Confidentiality

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was maintained as specific names of individuals who provided information were not used in the consultation report or in the development of the resource.

There were no risks associated with the consultations. However, potential ethical concerns were related to the interviewer-participant relationship as it could be difficult to remain in the role of 'interviewer' since I was known to participants and worked on the unit. Maintaining focus on the purpose helped prevent the development of close and/or therapeutic relationships among staff. The project did not require review by the Health Research Ethics Review Board as according to the checklist found in Appendix C, the project was related to quality assurance, not research. However, approval was obtained from the manager prior to conducting the interviews/consultations with staff.

Results: Staff and RNs

The results from the consultations are reported by answers to each question asked via the interviews and emails. Questions of similar nature for each group have been combined. The term participants refers to those consulted during the face-to-face interviews while the others that were consulted will be referred to as their specific discipline. The results from the interviews are a general consensus of staff/participants and are not representative of any particular individual.

Do you feel you have the knowledge required to care for residents with IDD's? If no, what additional knowledge is needed?

Participants felt that they did not have the knowledge required to effectively care for residents with IDD's which could be due to the fact that the majority of residents in LTC did not have IDD's. They felt they had some basic knowledge, but not enough, and identified a number of areas where they felt more information was needed. For example,

participants identified that more general knowledge in regards to IDD was needed which could help staff identify a resident's specific needs, triggers, and suitable recreational activities. Participants also identified that information was needed to deal with difficult situations, such as challenging and disruptive behaviors, as many felt they did not know the best way to care for these residents when this occurred. Many participants felt that communication techniques, such as verbal communication strategies, would be useful, especially when behaviors occurred. Hence, they identified knowledge deficits in verbal and nonverbal communication. Some participants acknowledged that residents with IDD have communication difficulties; however, they did not indicate the importance of being aware of a resident's non-verbal communication cues. Participants also suggested that more information was needed surrounding the resident's history, likes/dislikes, and behavioral issues prior to LTC placement. Participants did not identify their own role in obtaining such information at time of admission and gathered knowledge only as they became acquainted with the resident. However, participants did identify that the family can be a good source of information.

Participants also identified needing specific approaches to care that all staff could use, such as approaches that are beneficial when a resident has a communication deficit or exhibiting behaviors. They also felt it was important for everyone to have a similar knowledge base and be "on the same page" when providing care. Some participants identified that they would use the kardex, Meditech, chart, etc., to find information. However, many felt that information and approaches to care were passed along by word of mouth and knowing the residents instead of finding the information in the documentation. Hence, although documentation was not identified as a learning need,

more education in this area is essential to ensure continuity of care and to reiterate the importance of documentation. This is of particular importance for new employees, or employees who float to the unit, as they may not be as familiar with these types of residents and may be unsure where to find the information they need.

Similarly, RNs felt they only had basic knowledge acquired through their nursing school program in a gerontology course. They also identified that they had limited knowledge when caring for certain behaviors associated with IDD. RNs felt that all staff should be required to complete the gentle persuasive approaches (GPA) workshop which was being offered to employees. Also, more targeted education on IDDs for all nursing staff interacting with these residents is needed and additional knowledge regarding the different types of IDDs in LTC.

Have you received education in the past on this topic? If so, what information? From whom? Did you find it beneficial?

Participants had received limited education on this topic. Some information was obtained from the Behavior Management Specialist (BMS) but only when staff were having difficulties caring for the behaviors associated with a particular resident.

Education was usually initiated only when there was a particular issue on the unit, such as increased challenging and/or aggressive behaviors. Staff found the education received was good but identified two limitations. First, the education was only offered to whoever was on the units that day and hence, all staff did not receive the information. Second, information was very resident-specific and helped deal with a particular issue but not considered useful for other residents with IDDs. The majority of staff did complete the GPA workshop but felt that since the focus was on dementia care, it did not fully

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encompass the events associated with IDD's. Although not identified as a learning need, staff may need to learn more about the association between dementia and IDD's.

Similarly, the RNs felt that limited education was provided during orientation at SLH with the focus being on dementia/Alzheimer's. The GPA course was also identified as a good source for information that enabled staff to effectively respond to responsive behaviors. However, the information was geared towards dementia care. The RNs felt that the BMS with Eastern Health could be consulted to provide staff with information as it is needed, pertaining to specific residents which can be beneficial as it is resident-specific.

What do you currently use to guide practice for residents with IDD's? GPA? BMS?

At first, many participants felt they did not use anything to guide practice for these types of residents and they provided care in the same way that they would other residents. After further consideration, some participants indicated that they used common sense and were guided by knowing the residents. Knowing the resident helped them to understand what worked and what did not work, which was usually achieved through trial and error. Participants also felt that it was difficult to have a specific guide to care as they thought residents with IDD's were unpredictable and often difficult to reason with, especially when they were presenting with challenging behaviors. This may be indicative of a learning need. Participants were also guided by staff members who were familiar with the resident and his/her family. Other participants identified the importance of involving both the families and residents as they provide the most valuable source of information regarding history, likes/dislikes, needs, and wants. Participants also felt that practice was guided by the suggestions offered by the BMS. None of the participants identified GPA

as a tool used to guide practice which again may indicate a learning need of the association between dementia and IDD. One group of participants did identify that kardexes were used to guide practice which highlighted the importance of documentation. The fact that no other forms of documentation were mentioned and also that most participants had different guides to practice may indicate a learning need.

RNs identified several different guides of practice, such as using a caring approach, providing resident-centered nursing care, and using best practice guidelines. They also suggested using behavior management techniques, and the dementia observation system (DOS). The DOS was to track patterns in resident behaviors in those with IDDs.

Do you feel those with IDDs have complex health care needs? How so? Do those with IDDs also have chronic health conditions? If so, what are the most common? Is more time spent with these types of residents due to their increased needs?

All participants felt that those with IDDs have complex health care needs, particularly when they were exhibiting challenging behaviors. Most residents on the unit had high medical care needs and also required total assistance for personal care and toileting. Many also had hearing loss, diabetes, seizure disorders, and vision difficulties which required more care and attention, particularly for the LPN who was administering medications. Of the four residents on the unit with IDDs, two were insulin dependent diabetics, two had hearing difficulties, and two had seizure disorders. Participants also identified that residents may also have decreased cognitive ability which may lead to difficulties associated with explaining the plan of care, identifying health needs, and explaining procedures. A resident's cognitive ability may also vary over the course of the

day which may affect how he/she communicates. Some participants felt that they were equipped to care for residents' medical and personal care needs, however, lacked the skills and time required to care for complex behaviors and individual needs. Hence, more education may be required in respect to the importance of resident-specific care.

Participants did not consider dementia to be an issue associated with this population.

This could be due to the fact that there were currently no residents on the unit with dementia which could indicate a potential learning need in this area.

Participants also found that more time was needed when caring for these types of residents as they required more 1:1 care at times and needed more attention that staff just did not have the time to spend. More time is also needed to care for their medical health needs since those with IDD have numerous health issues. For example, more time is needed to administer medications and check glucometers as these residents may be on several different medications. Participants stated that they were also required to stay and monitor a resident if he/she had a seizure which also took additional time. Participants also reported that residents with IDDs refused medications, particularly if a need was unmet or they did not get what they wanted which then required the staff member to offer medication at different intervals. For example, if a resident refused a narcotic that was ordered for pain, the resident would be at an increased risk for developing pain and, in effect, trigger potential behaviors especially if he/she is unable to communicate effectively. Therefore, increased monitoring and intervention was needed. As well, additional time was needed to explain medications or for residents to take medications due to their decreased cognitive ability. Participants acknowledged that difficulty

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understanding could be associated with other health issues, such as hearing loss. The importance of getting to know the resident was also highlighted.

Similarly, the RNs felt that those with IDD have complex health care needs. LTC can be a challenging environment for residents with IDDs and hence, more time was spent with these residents. RNs also felt that although nursing staff were good at providing direct care, improvement was needed in re-evaluating resident-specific care and targeted care plans that revolved around resident-specific needs. Also, sometimes these residents may not fully understand certain health care decisions, need further redirection, and more support with everyday tasks compared to someone without IDDs.

What issues have you identified when caring for those with IDDs? Any aggressive behaviors? Any challenging behaviors? If so, do you find caring for those with IDDs challenging or stressful? Explain.

Participants felt that all residents with IDDs are different, even if they have the same diagnosis, which can present as a challenge since strategies that work well for one resident may not work for another. The importance of having all staff “on the same page” was again identified as an issue. More education on this topic and of the importance of documentation may be necessary to ensure all staff have the information they need. Participants also found that residents have high expectations and, therefore, staff find it difficult to meet their expectations due to the work environment and level of care needed by all residents. Participants also found that these residents had difficulty understanding that there are other people who needed care and attention as well. Since some of these residents had been receiving more 1:1 care prior to LTC, participants felt that they had unrealistic expectations and often had difficulty adjusting to LTC. If the resident’s

expectations were not met, i.e., if participants were unable to provide the attention and care the resident wanted, when they wanted it, challenging and/or disruptive behaviors developed. One staff member provided an example of a resident who placed several cookies in his/her mouth and starting choking. When asked why the resident did this, he/she responded, “no one was paying attention to me.” Some participants felt that due to cognitive deficits, many residents with IDD had the mindset of a child and at times unintentionally treated them similarly by initiating punitive approaches which may not be acceptable. Hence, additional awareness of this issue and knowledge of appropriate approaches will enable staff to better care for this population.

Challenging behaviors were identified as issues and occurred when residents used inappropriate language, yelled, screamed, cried, or made repetitive statements. Participants found that some of these residents were constantly on the call bell and that when they asked for something, the staff did not even get a chance to respond before the residents were asking for something else. Participants identified that behaviors were usually triggered by something, such as having an unmet need, being upset, having to wait for something, seeing something given to someone else that they couldn't have, or being told they could not do something. However, sometimes they felt that behaviors also occurred for no reason and that the resident was just being difficult, which may indicate a learning need since most responsive behaviors have a trigger. Challenging behaviors, such as singing out, occurred when a resident had to wait to go to the bathroom. Participants tried to be cognizant of these behaviors and addressed residents needs as soon as possible to prevent further behaviors from occurring. However, they acknowledged that this was difficult to achieve and felt that when a trigger occurred, they

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did not know the best way to intervene or stop the challenging behavior. All staff being aware of resident-specific triggers could be helpful.

Participants also felt that residents with IDD have good and bad days and identified that behaviors were sporadic and, therefore, difficult to predict. Some participants also felt that environmental factors influenced behaviors and triggered challenging behaviors. Residents could be over-stimulated depending on what was going on around them and behaviors influenced by other residents. For example, a participant stated that one resident got upset when another resident bumped into his/her wheelchair. Participants also recalled numerous times when a resident had become aggressive, not just with staff but with other residents. Participants found it challenging to deal with these situations as sometimes when they intervened, the resident became more upset. Staff were primarily concerned for the safety of other residents and, therefore, attempted to remove the resident from the situation. Participants identified that safety was a concern for this population and that more interventions were needed in dealing with aggressive behaviors. One participant said that he/she would implement the DOS, in consultation with the RN, to monitor behaviors and identify patterns in behaviors.

Overall, participants found caring for those with IDD to be both challenging and stressful which sometimes resulted in them feeling frustrated. Staff coped by removing themselves from the situation and returned once they had calmed down and were ready to do so. Some participants also found it beneficial to vent to other staff which provided a way to discuss issues and/or challenging behaviors of residents. Venting also allowed for staff to learn from another staff member's experience. Given the fact that staff are busy day-to-day, participants found it challenging dealing with residents when they were

exhibiting challenging behaviors as they found that many residents were uncooperative and it was difficult to reassure them. When residents did not get their own way, or had an unmet need, residents often refused to eat, to be cooperative, or take medications, which were particularly challenging when the resident may not fully understand his/her health condition due to the diagnosis or cognitive decline. Participants felt that they were generally unsuccessful when they intervened, explained, and/or attempted to reason with these residents which was also challenging. The need for staff to learn ways to cope with frustration and stress in the workplace may be warranted.

Similarly, RNs also felt that, in certain instances, caring for those with IDD can be quite challenging. Oftentimes, individuals with IDD do not understand the complexity of the environment, have difficulty waiting for staff to assist them with their activities of daily living (ADLs), or like for staff to be able to attend to their care needs more quickly than staff are able. There had been instances when residents had aggressive behaviors, usually presenting verbally towards staff when they were not able to have things immediately completed for them. Staff often feel challenged and discouraged by some of the behaviors. It is evident that staff get reactive in their tone of voice and responses which is likely due to the stress in dealing with the general population of residents, as well as having those with IDD intermeshed.

Are residents with IDD integrated among other residents? If so, do you agree with this? Why?

Surprisingly, the majority of participants did not feel that residents with IDD should be integrated among other residents in LTC. Participants felt that those with IDD were better off around those with similar disabilities as they have more in common.

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Having all residents with IDD on one specific unit could ensure that staff were specialized in this area and better equipped to meet their needs. Participants also felt that other residents were fearful of those with IDD, particularly when they were exhibiting challenging and aggressive behaviors. As well, some noted that other residents often pointed at those with IDD, which triggered responsive behaviors. Participants were not sure how to respond when this occurred. Although not specified as a learning need, participants questioning the integration among other residents suggests the need for more information related to social isolation and the benefits of integration among this specific population.

The RNs felt differently with regards to integration and thought that if the environment was safe to do so, including a system that supports and integrates residents with IDD was appropriate. Every resident in LTC has different complex health needs, even those with and without IDD. Hence, it is important to recognize and treat them the same; however, it may involve further assessment or a different approach to care at times. Safe staffing levels is key.

Do you feel it is necessary to provide a private room to residents with IDD? Why or why not? If yes, would a private room lead to increased isolation/loneliness?

Of the four residents with IDD, three had a private room and the majority of participants felt that this was of benefit to these residents. They acknowledged that the need for a private room depended on the particular resident and on the severity/frequency of behaviors. As well, for various reasons, it can be difficult to pair a resident with IDD with a suitable roommate and, therefore, a private room not only benefited the individual with the IDD but also the other resident. A private room provided more space and

privacy to deal with complex health needs, such as challenging behaviors or medical conditions, including seizures, which may frighten other residents. A private room could also provide an increased quality of life. For example, one resident on the unit does not like a lot of noise and will place his/her hands over their ears when there is too much noise.

Participants did not feel that a private room would lead to loneliness but one group acknowledged that it could be a risk. Social isolation was not an issue for the four residents on the unit as most of these residents did not spend much time in their rooms during the day time. Most could verbally speak for themselves and told staff what they wanted. Hence, the residents currently on the unit with IDD's may be at a decreased risk for isolation. It is possible that social isolation could be an area of concern in the future and, therefore, essential for staff to be aware that isolation and loneliness are potential issues associated with IDD's. Staff should be equipped with knowledge associated with isolation as it may be needed for new residents or if a resident's condition changes.

Similarly, RNs felt that the need for a private room was resident-specific. For some residents with IDD's, it was appropriate as many usually enjoy their own space. Others may prefer the company of another resident in their room. In certain circumstances, a private room would be beneficial, for both the resident with the IDD's and his/her potential roommate, depending on their level of interaction with other residents and their cognitive abilities. A private room would also provide a safe space during behavioral episodes.

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Do you find residents with IDD's have enough recreational therapy? What types of activities? Are they similar/different to other residents?

Participants identified that residents, in general, but particularly those with IDD's, do not have enough recreational therapy. Many identified that activities were provided by the Recreation Therapist but they were not as visible on the units as they felt was needed. Some participants suggested simple activities, such as taking the resident for a walk, giving the resident a doll, playing music, and turning on the TV, which helped occupy the resident and pass time. However, others questioned whether or not behaviors were triggered by boredom which suggests the importance of staff implementing simple recreational activities on the units. Many participants felt there was limited time to implement activities at the unit level and that activities should be implemented through the Recreation Department. It is important for staff to be aware of suitable recreational activities and their responsibility in initiating activities on the units as it is not solely the role of the Recreation Therapist.

Participants identified that they would give one resident in particular small things to do, such as folding facecloths, or passing in the diet sheets to the kitchen, however, acknowledged that these activities were not appropriate for other residents as not all of those with IDD's liked to participate in the same activity. For example, only one of the four with IDD's enjoyed coloring. When activities were provided by recreation, all residents participated in the same activity and there were no activities specific for residents with IDD's. Participants did not feel that there were substitute activities offered to those with deficits, such as hearing or eye issues, or those for those who did not like the activity offered. All residents were integrated when implementing an activity, which

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participants did not agree with, and again may indicate a learning need related to the importance of integration. The need for distractional activities were also highlighted, especially when residents were exhibiting behaviors.

RNs similarly felt that there were not enough recreational activities. More activities would be beneficial, such as music therapy, pet therapy, and other types of approaches to care that “think outside the box”. Activities aimed to distract and redirect residents or activities that give them a sense of purpose/meaning may work well. They also felt that it was important for those with IDD to participate in general activities with other residents as it may promote socialization and engagement. However, they identified that it can be challenging if individuals have disruptive behaviors that would affect other individuals in the group. Activities may be more beneficial in a group or more 1:1 settings depending on the individual.

What would you like to see included within the educational resource?

Participants identified that topics that were discussed in the first question (what additional knowledge is needed) would be information to include within the resource. They also requested additional general information regarding disabilities that were not necessarily resident-specific. As well, participants wanted more information regarding suitable recreational activities, how to respond to challenging behaviors (specific strategies), how to better identify triggers, and approaches to care. Coping strategies for staff may also be useful. It is evident from frontline staff that more knowledge regarding social isolation/loneliness, integration, and the association between dementia care and IDD is needed. Participants also identified the need for communication strategies.

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The RNs suggested a breakdown of some of the common IDD's that are being introduced into LTC and self-tests or case studies that staff can avail of as a self-study option. More education behind targeted approaches to nursing care that may help staff understand things from the resident's point of view could also be useful.

What form would you like to have the resource in e.g., PowerPoint, Pamphlet, etc.)?

Participants were open to several formats. A PowerPoint presentation was something of interest as it could be implemented as an educational session which would provide staff with the opportunity to discuss specific residents and personal experiences. The slide deck could also be placed on a flash drive or desktop at the nursing station and used as a self-study. Since some staff are self-directed learners, other participants suggested a learning module with case studies or a booklet which would allow staff to read the information during breaks, nights, or even to take home. The booklets could also be used when dealing with a particular issue. Having all information in the one education manual that was readily available on the units was also suggested.

The RNs similarly felt that a PowerPoint presentation via an interactive seminar that staff could attend as a lunch and learn would be beneficial. They also suggested a self-study slide deck with an evaluation component, such as self-test or a case study. The ease of accessibility was mentioned.

RNs

The RNs were asked four additional questions that were not asked of the other staff. The questions and answers are presented below.

Do you feel those with IDD require different approaches to care compared to other residents? Explain. Any approaches that have worked well? Does not work?

Yes, more resident-specific care is needed. It is important to build and target a care plan based on interventions that meet the needs of residents with IDD. Using stop and go approaches, providing support, and reassurance work well. It is also good to explain every step of the care process to these residents which may involve repeating oneself more than the staff member would have to with other residents and ensure everything is fully explained for the resident to understand.

Do staff come to you requesting education or problem-solving in caring for this population? If yes, what are the questions or issues they ask about?

As front line leaders, staff come to RNs all the time, often frustrated or seeking assistance with a particular resident. Staff find situations stressful when residents with IDD are acting out or being demanding. Coping strategies for staff would also be useful.

As leaders, do you feel you have the education and resources required to effectively care for this population? Or to lead staff in caring for this population? If no, what do you think is needed?

Yes. There are great resources available through the BMS/Educator. However, sometimes the wait times can be long. There are also many resources and tools for dementia care and behaviors and, therefore, more tools for IDD may be more beneficial and would help to lead staff to the right information. It is all about resident-specific care and targeting the individual needs of residents.

Do you feel that staff are frustrated at times in caring for those with IDD's who exhibit complex health conditions or challenging behaviors? If yes, can you offer any suggestions on how staff should address these frustrations?

Yes. Staff need to work together and take turns dealing with challenging behaviors. It is also important for staff to understand that sometimes, providing everyone else is safe, it may be okay for residents with IDD's to have their moment and recognize that sometimes they cannot fix everything right away.

Results: Other Consultations

The BMS, Recreation Therapist, and Clinical Educator were asked different questions to identify learning needs as well as specific recommendations for strategies that would be helpful when caring for those with IDD's. Responses have been combined and will be presented using common themes.

Staff Have Reached Out Regarding Residents with IDD's

Staff have reached out requesting more information and assistance regarding difficulty providing personal care to residents with responsive behaviors. Staff also sought support in developing positive behavior support strategies, medication compliance, and managing both verbal and physical aggression. The frequency depends on when the need arises and whether a particular resident presents with challenging behaviors. However, consults for residents with IDD's were received less frequently than for those with dementia.

More Education is Needed

Overall, these consultations concluded that more education is definitely needed in this area as the results indicated that a knowledge gap existed among staff caring for

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residents with IDD in LTC. Some education has been provided to staff for residents with Huntington's, Fibromyalgia, and Obsessive Compulsive Disorder but not specifically for IDDs. LPNs and PCAs are usually the staff who require additional information as they are at the bedside most of the time. However, RNs also need to be informed of best practices because they direct the LPN and PCA, develop the plan of care, and consult with available resources.

In particular, those who require more information and education on this topic are newer staff transferring to LTC from acute care and/or new graduates as they often have difficulty transitioning to LTC environments due to residents' high personal care needs and challenging behaviors. Newer employees also tend to have more questions and concerns when dealing with behavioral issues as they do not have as much hands on experience as senior nursing staff.

There are Several Learning Needs

Resident-centered care/interdisciplinary care/care plans. Developing a resident-centered care plan with the resident, his/her family, and/or significant others is essential as usually family know what is best for the resident. Also, incorporating an interdisciplinary team approach to care is needed by utilizing supports, such as Occupational Therapy (OT), Physiotherapy (PT), BMS, Clinical Educator, Resident Assessment Instrument-Minimum Data Set (RAI-MDS) for care planning, Recreational Therapy, and Music Therapy. These disciplines should be consulted in order to help assess and determine an individual's capabilities and interests which aid in the development of an individualized care plan while also ensuring recreational activities/programs are individualized.

Responsive/challenging behaviors. A resident with an IDD can exhibit responsive behaviors similar to any other resident in LTC. Since those with IDDs often have difficulty modulating their behavior, they can often escalate to the point of physically responsive behaviors, such as punching, kicking, and hair pulling. Triggers for these behaviors vary from individual to individual. Behavioral issues and challenging behaviors can also potentially affect the programs and activities offered by the Recreation Department.

Diagnoses. Those with IDDs have more complex health issues. Certain diagnoses, such as Down syndrome, can create many complex physical and mental health needs which can often go untreated. In addition, individuals who have a cognitive impairment, such as those with IDDs, are also at a higher risk of developing dementia, and at an earlier age. As well, individuals who are diagnosed with Autism Spectrum Disorder can be very complex to manage due to the many sensory integration issues they may experience. Staff also seem to be more aware of geriatric issues, and not those that are associated with a diagnosis of an IDD. They often are of the mindset that the individual “knows better” and have a lack of understanding of how a diagnosis of an IDD can impact a behavioral response.

Communication. Those with IDDs have difficulty communicating how and why they feel a certain way. Communicating effectively is key and hence, communication techniques were identified as needed.

Strategies for challenging behaviors. Staff are often looking for suggestions regarding more punitive consequences, such as the removal of privileges. However, strategies that incorporate principles of reinforcement rather than punishment are

recommended. Staff should incorporate strategies that use a least restrictive model of treatment, along with applied behavior analysis (ABA). A functional behavioral assessment should also be completed and based upon the function of a behavior, recommendations would be made and tailored to the individual. A discussion of antipsychotic and antianxiety medications may also be useful to help identify whether the medications are beneficial or not in managing challenging behaviors. It is important for staff to discover what the unmet need is that is triggering the behavior and implement strategies to address them. Theories, such as Maslow's Hierarchy of Needs and Jean Watson's Caring Theory, help build a good framework in addressing unmet needs of residents. Being respectful of the resident is also important.

The BMS would be a key person consulted regarding residents with challenging behaviors. GPA sessions have also been occurring with LTC staff with may be useful for both dementia or any diagnosis with resulting responsive behaviors.

Strategies for distraction/recreational activities. The Recreation Department is a good resource to assess and develop diversional and meaningful activities specific to the individual. General activities that may be beneficial to residents with IDD include walking or a general exercise program in order to maintain/increase physical functioning and quiet leisure activities, such as painting, reading, and flipping through books. These activities allow the individual to have some quiet time and participate in activities of interest. Many with IDD also find routine to be important and useful for coping. Therefore, having residents participate in a routine that allows them to complete chores or jobs will help establish a sense of purpose.

Depending on an individual's needs, recreational programs are often adjusted in order to make them more inclusive. For example, a large group setting would not be appropriate for an individual who does not like much noise. Others may be inappropriate for small or large group activities due to sensory issues or behavioral issues, such as disruptive behaviors. All of this should be considered when looking at appropriate activities and programs in which to engage the individual.

Physical/Personal care. Staff have the skills to provide the physical care needed for residents with IDD's but may not have skills to adequately provide holistic care. It is important for staff to understand that residents with IDD's have a variety of needs to be met, such as emotional, social, psychological, and cultural care. Their needs and the support they require in all aspects of care, including ADLs, depend on the severity of their condition. Hence, information on how to provide holistic care in a humanistic way to a resident with IDD's should be included within the resource.

Possible Educational Formats

Education will need to be delivered in a format that addresses the learning styles of the learner, such as visual, tactile, and auditory, keeping the adult learner in mind. Adults are self-directed learners but depending on the generation, some require face-to-face learning that is instructor-led while others like to learn independently. The resource should also address the domains of learning, including affective, behavioral, and psychomotor.

The resource could be delivered in a couple of formats that would be accessible to the learner when needed. Suggestions included a learning module with a Cole's notes

version in a pamphlet, a PowerPoint presentation for face-to-face dialogue, or a pamphlet. Including a case study to work through could also be helpful.

Conclusion

The consultations helped to identify additional information from staff who specifically work with individuals with IDD in LTC. The consultations also helped to determine specific content to include within the resource as issues in caring for this population, knowledge gaps, and learning needs were identified by participants. Several themes were derived from the data obtained from the consultations, such as the importance of resident-centered care, individualized care, isolation and loneliness, responsive behaviors, dementia, and documentation. These themes will inform the content and development of the educational resource. All disciplines from the consultations agreed that more education was needed on this topic, particularly for frontline staff as many felt that they lacked the knowledge required to care for this population. As well, many of the resources available are dementia care specific and, therefore, developing a resource that will be specific for IDDs is necessary.

Completing the consultations confirmed important information obtained from the literature review. The consultations incorporated an interdisciplinary approach to care since different disciplines, such as LPNs, PCAs, RNs, BMS, Clinical Educator, and Recreation Specialist participated. With input received from the consultations, it is evident that the resource could be applicable to many different disciplines that deal directly with those who have IDDs in the workplace. The consultations also provided a deeper insight into the knowledge required to care for those with IDDs in general. The

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results of the consultations will be used to develop an educational resource that will further educate staff regarding IDD in LTC. The resource will contain basic information that is pertinent for all staff to know when caring for this population and will be particularly useful for new employees that are unfamiliar with IDDs in LTC. The resource will also help ensure that all staff have access to the same information and, therefore, help provide consistency in their approaches to care.

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Appendix A

Questions to LPNs, RNs, and PCAs:

Do you feel you have the knowledge required to care for residents with IDD's? If no, what additional knowledge is needed?

Have you received education in the past on this topic? If so, what information? From whom? Did you find it beneficial?

What do you currently use to guide practice for residents with IDD's?

Do you feel those with IDD's have complex health care needs? How so? Do they have more secondary disabilities? Is more time spent with these types of residents due to their increased needs?

What issues have you identified when caring for those with IDD's? Any aggressive behaviors? Any challenging behaviors? If so, do you find caring for those with IDD's challenging or stressful? Explain.

Are residents with IDD's integrated among other residents? If so, do you agree with this? Why?

Do you feel it is necessary to provide a private room to residents with IDD's? Why or why not? If yes, would a private room lead to increased isolation/loneliness?

Do you find residents with IDD's have enough recreational therapy? What types of activities? Are they similar/different to other residents?

What would you like to see included within the educational resource?

What form would you like to have the resource in (e.g., PowerPoint, Pamphlet, etc.)?

Additional questions specific to RNs:

Do you feel those with IDD's require different approaches to care compared to other residents? Explain. Any approaches that have worked well? Does not work?

Do staff come to you requesting education or problem-solving in caring for this population? If yes, what are the questions or issues they ask about?

As leaders, do you feel you have the education and resources required to effectively care for this population? Or to lead staff in caring for this population? If no, what do you think is needed?

Do you feel that staff are frustrated at times in caring for those with IDD's who exhibit complex health conditions or challenging behaviors? If yes, can you offer any suggestions on how staff should address these frustrations?

Questions for the Behavioral Management Specialist:

Have staff reached out to you regarding difficulty in caring for this population or to problem-solve specific situations? If yes, what about? What types of issues? How often?

Which type of staff? Do newer employees tend to have more difficulty? Explain.

Do you think a knowledge gap exists among staff regarding those with IDD's? If yes, what is the knowledge gap?

Do you feel those with IDD's have complex health care needs? How so? Are staff equipped to meet these needs? If not, what needs to be addressed?

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Do those with IDD's exhibit responsive behaviors? If so, what types of behaviors? Are there any triggers?

Are there any techniques, strategies, approaches you would recommend when providing care to this population? With those exhibiting challenging behaviors? With aggressive behaviors? With dementia?

Are there any recreational activities or distractional techniques that staff can implement? Explain.

Questions for the Clinical Educator:

Do you feel those with IDD's have complex health care needs? How so? Do you think staff are equipped to meet these needs? If not, what needs to be addressed?

Have you provided any recent education regarding IDD's in LTC? If yes, what was included?

Have staff reached out to you requesting additional information or learning opportunities regarding IDD's, dementia care, and/or challenging behaviors? If yes, what specific learning needs did they identify? How often? Which type of staff? Do newer employees tend to have more difficulty? Explain.

Do you think a knowledge gap exists regarding those with IDD's? If yes, what is the gap?

Do you think more education is required?

If not already discussed, are there any other specific issues in caring for this specific population that staff should be aware of?

What would you like to see included within the educational resource?

Are there any forms of learning that are more receptive among staff? Explain.

What form would you like to have the resource in (e.g., PowerPoint, Pamphlet, etc.)?

Questions for Recreation Therapy:

Are there any issues you have identified when dealing with residents with IDD's? Explain.

Any behavioral issues? Challenging behaviors? Complex health care needs?

What distractional, general activities, or approaches are beneficial for residents with IDD's? Are these activities that staff can be implementing on the units? How?

Do you feel that those with IDD's should participate in similar activities as other residents? Why or why not? Benefits? Challenges?

Have you received any additional education regarding residents with IDD's? If yes, what information was included? Did you find this informational beneficial?

Do you feel more knowledge on IDD's is needed within your role? If yes, what are the specific knowledge gaps?

What would you like to see included within the educational resource?

What form would you like to have the resource in (e.g., PowerPoint, Pamphlet, etc.)?

Appendix B

Recruitment E-mail

Dear (Behavioral Management Specialist, Clinical Educator, Therapeutic Recreation, OR RN),

My name is Lindsay Hunt and I am completing my Master of Nursing degree at Memorial University. For my practicum project, I am developing an educational resource for staff working with those who have intellectual and developmental disabilities in long term care. I am writing to ask you if you would kindly answer a few questions regarding this subject as I feel your input would be very valuable to the overall project. You may answer all or just some of the questions below.

Please share any additional information or personal experiences you may have when caring for those with intellectual and developmental disabilities. You can respond by replying to this email before March {insert date here}.

All information shared is completely voluntary and will remain confidential.

If you would prefer to discuss this in person or if you have any questions, please do not hesitate to contact me.

Thank you for your time.

Lindsay Hunt BNRN

St. Luke's Home

{Insert questions here}

Script for interviews

My name is Lindsay Hunt and I am completing my Master of Nursing degree at Memorial University. For my practicum project, I am developing an educational resource for staff working with those who have intellectual and developmental disabilities in long term care. I am asking those working on the unit of Trinity Square to participate in informal group discussions/interviews in order to gain further insight on this topic. Interviews should only take ~20 minutes. Sample questions have been prepared to guide discussions. However, it is encouraged that you share additional insight or personal experiences of caring for those with intellectual and developmental disabilities.

All information shared is completely voluntary and will remain confidential. Information obtained through discussions may be used in the development of the educational resource.

I appreciate your time in advance. Thank you for volunteering!

Appendix C
Health Research Ethics Authority Screening Tool

	Question	Yes	No
1.	Is the project funded by, or being submitted to, a research funding agency for a research grant or award that requires research ethics review		<input type="radio"/>
2.	Are there any local policies which require this project to undergo review by a Research Ethics Board?		<input type="radio"/>
	IF YES to either of the above, the project should be submitted to a Research Ethics Board. IF NO to both questions, continue to complete the checklist.		<input type="radio"/>
3.	Is the primary purpose of the project to contribute to the growing body of knowledge regarding health and/or health systems that are generally accessible through academic literature?	<input type="radio"/>	
4.	Is the project designed to answer a specific research question or to test an explicit hypothesis?		<input type="radio"/>
5.	Does the project involve a comparison of multiple sites, control sites, and/or control groups?		<input type="radio"/>
6.	Is the project design and methodology adequate to support generalizations that go beyond the particular population the sample is being drawn from?		<input type="radio"/>
7.	Does the project impose any additional burdens on participants beyond what would be expected through a typically expected course of care or role expectations?		<input type="radio"/>
LINE A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses)		1	
8.	Are many of the participants in the project also likely to be among those who might potentially benefit from the result of the project as it proceeds?	<input type="radio"/>	
9.	Is the project intended to define a best practice within your organization or practice?	<input type="radio"/>	
10.	Would the project still be done at your site, even if there were no opportunity to publish the results or if the results might not be applicable anywhere else?	<input type="radio"/>	
11.	Does the statement of purpose of the project refer explicitly to the features of a particular program, Organization, or region, rather than using more general terminology such as rural vs. urban populations?		<input type="radio"/>

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12.	Is the current project part of a continuous process of gathering or monitoring data within an organization?		●
LINE B: SUBTOTAL Questions 8 through 12 = (Count the # of Yes responses)		3	
	SUMMARY The sum of line B (3) is greater than line A (1), indicating that the main purpose of the project is for quality/evaluation. Since this project is descriptive in nature, ethics approval is not required.		

Interpretation:

- If the sum of Line A is greater than Line B, the most probable purpose is **research**. The project should be submitted to an REB.
- If the sum of Line B is greater than Line A, the most probable purpose is **quality/evaluation**. Proceed with locally relevant process for ethics review (may not necessarily involve an REB).
- If the sums are equal, seek a second opinion to further explore whether the project should be classified as Research or as Quality and Evaluation.

These guidelines are used at Memorial University of Newfoundland and were adapted from ALBERTA RESEARCH ETHICS COMMUNITY CONSENSUS INITIATIVE (ARECCI). Further information can be found at:
<http://www.hrea.ca/Ethics-Review-Required.aspx>.

Appendix III

Booklet #1

IDDs in LTC

Developed by: Lindsay Hunt
For St. Luke's Home
July 2018

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

This is the first booklet of a series of four booklets. You can use each booklet individually or in sequence depending on your learning needs. Each booklet contains key information and self-reflection exercises. There are also true/false questions, case studies and/or other questions to help you test your knowledge.

The purpose of this booklet is to provide general background information regarding intellectual and developmental disabilities (IDDs) in long term care (LTC). This booklet can be used by personal care attendants (PCAs), registered nurses (RNs), licensed practical nurses (LPNs), and other health care professionals who work with those who have an IDD. The booklets may also be beneficial for those who simply want to learn more on this topic.

Learning Objectives:

Upon completion of this booklet, you will be able to:

1. Distinguish between intellectual and developmental disabilities (IDDs);
2. Identify the prevalence of IDDs in LTC;
3. Identify reasons why those with IDDs eventually end up in LTC;
4. Identify benefits of LTC for those with IDDs; and
5. Identify strategies health care workers can use to deal with frustration and stress associated with working with residents with IDDs.

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

There are two main types of disability, intellectual disability (ID) and developmental disability (DD). Intellectual and developmental disabilities (IDDs) often co-exist and, therefore, health care professionals in long term care (LTC) are often working with residents who have both types of disabilities. The terms IDs and DDs are usually used interchangeably. However, as health care professionals, it is important to be able to distinguish between both terms as the presentation and severity of deficits is dependent upon the diagnosis.

Intellectual Disability

ID, formerly known as “mental retardation,” is characterized by significant limitations in intellectual functioning and adaptive behaviors¹. Awareness that an individual may have an ID usually begins during the developmental period, before the age of 18. Those with an ID usually have an impairment in mental ability that impacts adaptive functioning in conceptual, social, and practical areas^{1,2}. Common deficits in functioning within each of these three areas are listed below. The ability to function in these three areas help determine how an individual copes with everyday living, in the development of a treatment plan, and in determining a diagnosis².

Conceptual	Social	Practical
-language	-empathy	-personal care
-reasoning	-social judgement	-money management
-knowledge	-communication skills	-organization
-memory		

Prevalence

According to the most recent available statistics from 2012:

- 132,020 Canadians 65 and older had some form of ID³
- 260,850 aged 45-64 had an ID³

Developmental Disability

DD is an umbrella term that includes IDs, along with other types of disabilities that may be apparent during childhood, usually before the age of 22¹. DDs are often severe and described as a chronic disability that incorporates cognitive and/or physical deficits. Those with cerebral palsy or epilepsy may have physical deficits while those with Down syndrome or fetal alcohol syndrome may have both physical and intellectual limitations.

Prevalence

According to the most recent available statistics from 2012:

- 19,030 Canadians 65 and older had a DD³
- 51,690 aged 45-64 had a DD³

IDDs in LTC

A diagnosis of an IDD is a strong predictor of the likelihood of admission into LTC^{4,5,6}. In fact, the rate of admission is three to nine times higher among individuals with IDD compared to those without an IDD⁷. Those with IDDs are usually admitted at an earlier age, are younger, and stay for longer than other residents⁴. Therefore, this population has a greater likelihood of spending their remaining days in LTC.

Facts

In studies conducted in Australia and Canada, the average age of those with an IDD who moved into LTC was between 59.4 to 63.1 years^{4,5}. In comparison, the average age of admission of those without IDDs was 84.3 years⁴.

The average length of stay for a resident with an IDD was 5.6 years compared to 2.7 years for other residents⁴.

Why are IDDs Prevalent in LTC?

There are many reasons why those with IDDs eventually end up in LTC^{4,8,9}.

- 1) ***Those with IDDs are aging and have an increased life expectancy.*** The majority of the population is living longer due to better management and advancement in treatment of chronic health issues. Similar patterns are seen in those with IDDs.
- 2) ***Those with IDDs have an increased risk for developing other conditions that require more complex care.*** They have a greater variety of health care needs compared to those of the same age and sex in the general population^{10,11}. Premature onset of age-related conditions and secondary disabilities are often seen which require more complex care associated with limitations in intellectual function and in adaptive behaviors^{4,11,12}. These conditions may only further deteriorate as the person ages¹³. Increased monitoring and interventions may be required. Common secondary issues are listed on the next page.

Common Secondary Issues

- | | |
|---|---|
| - Dementia ¹³ | - Constipation ⁸ |
| - Chest infections ⁸ | - Pain ⁸ |
| - Epilepsy ⁸ | - Dysphagia ⁸ |
| - Arthritis ⁸ | - Immobility ⁸ |
| - Incontinence ⁸ | - Weight loss ⁸ |
| - Visual impairment ¹³ | - Hearing impairment ¹³ |
| - Dual sensory impairment ¹³ | - Communication disorders ¹¹ |
| - Frailty ⁵ | - Mental health difficulties ⁸ |
| - Depression ² | - Attention-deficit disorder ² |
| - Autism ² | - Diabetes mellitus ¹⁴ |

- 3) ***Those with IDD require a higher level of care.*** Previous accommodations and supports are no longer able to provide the level of care needed due to increased care needs related to personal care and activities of daily living (ADLs) as well as secondary issues as described above^{4,5,6,8}. Those with IDD actually have similar levels of dependency as an elderly resident in a LTC home despite people thinking they were considerably younger and appeared healthier⁴.
- 4) ***Those with IDD require more specialized services.*** Services, such as community and mental health services, are inappropriate to meet their needs since many have complex health issues and low IQs¹¹.

Fact: In an American study, 81% of those with IDDs had another diagnosis other than dementia⁶.

Benefits of LTC

Given the fact that those with IDDs are aging and have complex health issues that require a higher level of care, LTC can offer a variety of benefits and can be a positive experience for those with IDDs. Many of the reasons described in the table below are benefits for any resident in LTC. However, due to the level of care and attention required for those with IDDs, these benefits are of particular importance for this population.

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Benefit	Why?
Diagnosis and treatment of medical conditions ¹⁵	Changes in conditions or any issues identified can be assessed. There is a doctor on site once weekly and there is always a doctor on call for any immediate concerns or issues. Those in LTC are still able to attend appointments and follow-ups outside LTC ¹⁵ .
Improved overall health and safety related to incontinence, falls, and wandering ¹⁵ .	<p>Incontinence: Skin problems are common for those with IDD. Toileting schedules can be implemented every two hours to help with bladder training. Appropriate pads are available depending on the level of incontinence which helps prevent skin integrity issues.</p> <p>Falls: Falls are common for those with IDD. They are more frail and may have physical impairments related to their ability to walk that may make them a high falls risk. Harm reduction strategies are implemented (e.g., placing bed in lowest position, keeping one side rail down, initiating a bed alarm/chair alarm, etc.). Assessments are also completed by either the registered nurse (RN) or licensed practical nurse (LPN) when a person falls and increased monitoring is implemented depending on the extent of the injury (e.g., if a resident falls and hits his/her head, a neurological assessment will be completed).</p> <p>Wandering: Some LTC facilities offer locked units for those residents who are exit seeking. ‘Watchmates’ can also be placed on the resident’s arm/leg that will sound via computer system if the resident attempts to wander. Since those with IDD have behavioral issues and/or dementia, wandering may be a concern.</p>
Management of behavioral issues ¹⁵	Behavioral issues are common for those with IDD as they may have cognitive deficits and communication difficulties. Triggers can be identified to help decrease the occurrence and/or severity of behavioral issues. See Booklet #2: Challenging Behaviors.
Modified diets ¹⁵	Modified diets are important for those who may have swallowing difficulties (e.g., those with Down syndrome). The speech language pathologist and/or the dietitian can be consulted to ensure the diet is appropriate for the resident, thereby decreasing the risk of aspiration/choking. The RN on the unit can also change diet textures and fluid consistencies depending on the resident’s condition and the RN’s assessment.

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

Benefit	Why?
24-hour care ¹⁵	Harm reduction strategies can be implemented around the clock to help reduce incidences of distress ¹⁵ (e.g., two-hourly turning schedules can be implemented throughout the night; surveillance completed hourly).
Qualified staff with nursing expertise ¹⁵	A variety of personal care attendants (PCAs), LPNs, and RNs provide care to residents. Each discipline is qualified under his/her appropriate licensure and has a unique scope of practice.
Safe staffing levels ¹⁵	Staffing is provided according to a staff-per-resident ratio that is determined based on the level of care required. Having safe staffing levels is important as it helps to ensure quality, resident-centered care.
An alternative ‘home’ ⁸	Many residents think of LTC as being their home. Items, such as pictures, blankets, and other decorative items, can help make residents’ rooms feel more like home.
Aging in place ⁸	LTC is equipped to care for a variety of health care needs and the level of care that a resident requires. LTC also provides care right up to the end of life as palliative care is offered on site.
Holistic care ⁸	A resident with an IDD has a variety of needs that should be met. Staff members should consider the physical, emotional, social, economic, and spiritual needs of the resident.

Self-Reflection Exercise

Consider a resident that you have recently cared for who had a diagnosis of an IDD. Reflect on some of the reasons why the resident is being cared for in LTC. Does the resident have any secondary issues or concerns?

Test your Knowledge

Please answer the following questions below. Answers can be found in the Appendix at the end of the booklet.

Provide a short answer to each of the following questions.

1. List two reasons why those with IDDs end up in LTC.
2. Describe two benefits for residents with IDDs in LTC.

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

Identify if each statement is true or false.

1. Cognitive impairments mean that language, reasoning, knowledge, and memory may be affected. ____
2. IDD's do not co-exist. Usually a resident will have one or the other. ____
3. Those with IDD's are admitted at an earlier age, are younger, and stay for longer than other residents. ____
4. Residents with IDD's usually require less care than other residents. ____
5. Residents with IDD's experience age related conditions sooner than other elderly residents. ____

Tips for Staff

Caring for older adults with IDD's can be stressful for you since many residents with IDD's present with challenging behaviors and have complex health care needs. You may have feelings of fear, anxiety, depression, and anger¹⁶. Also, in certain situations, safety may be a concern¹⁷. For any resident in LTC, it is important for you to monitor your own feelings and beliefs, be non-judgmental, and consider linguistic and cultural differences. This is particularly important when caring for residents with IDD's since being aware of your own practice can ultimately impact resident outcomes.

Every day, it is important to...

...Monitor feeling and beliefs. It is important to evaluate your own thoughts in relation to ethical responsibilities, such as providing safe, compassionate, and competent care¹⁸.

...Be non-judgmental and unbiased. It is important to recognize and respect the uniqueness of each resident. You should not discriminate on the basis of race, ethnicity, culture, spiritual belief, gender identity, age, etc¹⁸. For a resident with an IDD, it is essential to view the resident as a person rather than through the context of his/her disability. Being non-judgmental facilitates understanding and improves resident outcomes.

...Consider linguistic and cultural differences. It is important to consider linguistic diversity and cultural differences in the way residents communicate, ambulate, and behave¹⁹. You should also use a holistic approach to care that encompasses the physical, emotional, social, economic, and spiritual needs of the resident. Those with IDD's have a variety of complex needs that have to be met.

Coping Tips for Staff

During a stressful situation

Strategy	Description
Remove yourself from the situation and return at a later time	This allows you time to cool down if emotions are high, especially when dealing with challenging and/or stressful situations. Removing yourself from the situation also allows for self-reflection.
Rely on informal peer support	Work together and take turns dealing with challenging and/or stressful situations.
Do not react (e.g., do not raise your voice or use inappropriate non-verbal communication, such as eye-rolling)	Reacting may only further escalate the situation. Residents can also very easily pick up on non-verbal cues.

After a stressful situation

Strategy	Description
Talk to other staff ^{8,17}	Talking to others provides a way to discuss issues and/or behaviors and allows you to learn from each other's experiences.
Use personal strategies ⁸	Use relaxation techniques (e.g., breathe) and exercise (e.g., take a walk on your break or exercise on your days off).
Rely on multidisciplinary teams ^{8,9,10}	Debrief with all members of the health care team to determine if something can be done or could have been done differently. Debriefing in a group can also be helpful to evaluate effective coping strategies of others.
Involve management ⁸	If other strategies have failed, management may be able to offer further suggestions to help cope with a variety of issues in the workplace.

Strategy	Description
Use self-reflection	You should reflect on your own practice and on the quality of your interactions. For example, you should reflect on a specific incident or experience and analyze/critique the situation. You are then able to learn from your experiences and change your practice to improve resident outcomes. This may be particularly important after a challenging event.

Self-Reflection Exercise

Reflect on a time where you felt frustrated or stressed at work. What were you frustrated/stressed about? What did you do to alleviate the frustration/stress? Would other methods of coping have been more suitable? Which ones?

Conclusion

Having a better understanding of IDD in LTC can help health care professionals fulfill both the health and social needs required for this population as they age. Increased knowledge in this area can also help to ensure positive resident outcomes among those with IDD¹². For further information about other aspects of caring for residents with IDD, refer to the other booklets in this series.

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Appendix: Answers to Questions

Answers to short answer questions on page 7

1. Any reason listed on page 4-5.
 - a. Those with IDD are aging and have an increased life expectancy
 - b. They have an increased risk for developing other conditions that require more complex care.
 - c. They require a higher level of care.
 - d. Services, such as community and mental health services, are inappropriate to meet their needs since many have complex health issues and low IQs.
2. Any benefit described on page 6-7.

Answers to true and false questions on page 8

1. T
2. F
3. T
4. F
5. T

Appendix IV

Booklet #2

Challenging Behaviors

Developed by: Lindsay Hunt
For St. Luke's Home
July 2018

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

This is the second booklet of a series of four booklets. You can use each booklet individually or in sequence depending on your learning needs. Each booklet contains key information and self-reflection exercises. There are also true/false questions, case studies and/or other questions to help you test your knowledge.

The purpose of this booklet is to provide information regarding challenging behaviors and intellectual and developmental disabilities (IDDs) in long term care (LTC). This booklet can be used by personal care attendants (PCAs), registered nurses (RNs), licensed practical nurses (LPNs), and other health care professionals who work with those who have an IDD. The booklets may also be beneficial for those who simply want to learn more on this topic.

Learning Objectives:

Upon completion of this booklet, you will be able to:

1. Identify common challenging behaviors;
2. Identify strategies to prevent challenging behaviors;
3. Identify the warning signs of challenging behaviors;
4. Identify common potential triggers;
5. Identify strategies to prevent triggers; and
6. Identify strategies health care workers can use to deal with frustration and stress associated with working with residents with IDDs.

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

It is common for staff in long term care (LTC) environments to care for residents with intellectual and developmental disabilities (IDDs) who exhibit challenging behaviors. Challenging behaviors are also referred to as responsive behaviors as the resident's "actions, words, and gestures are a response to express something important about his/her personal, social, or physical environment"¹. Behavioral and personality changes are also common in those who have a diagnosis of an IDD and hence, many have difficulty controlling their behavior². It is important to note that those with IDD exhibit responsive behaviors similar to any other elderly resident. These types of behaviors are not the 'norm' for the resident and are usually triggered by either someone or something which is discussed further within this booklet³.

Behaviors can be unpredictable and may vary day-to-day. There may be subtle early warning signs that a challenging behavior may occur. Recognizing the warning signs can decrease chance of behavior occurring, thereby avoiding a serious incident or potential safety concern.

Early warning signs⁴:

- Increased pacing
- Changes in vocalizations
- Changes in facial expressions
- Changes in body language.
- Appear unhappy or anxious

Below is a list of common challenging behaviors and possible strategies that staff can use when caring for a resident with an IDD who is exhibiting a challenging behavior.

Strategies should be resident-specific as each strategy may not work for everyone!

All strategies should incorporate least restrictive methods (e.g., avoid punitive approaches such as the removal of privileges).

Common Behaviors	Possible Strategies
Aggression (e.g., punching, kicking, spitting and hair pulling) ^{5,6}	<ul style="list-style-type: none">• Redirect or distract, if appropriate⁴.• Avoid touching the resident as it may only further escalate the situation and safety may be a concern³.• Remove bystanders and/or the resident as safety may be a concern³. The resident may also be overstimulated which could be contributing to the behavior.• Provide comfort and support: Support and comfort may need to be offered from a distance as safety may be a concern³. Offering support and comfort from a distance also allows staff to stay calm by standing back

Common Behaviors	Possible Strategies
	<p>and taking a moment to prepare for the situation at hand.</p> <ul style="list-style-type: none"> • Give the resident time to calm down⁷. • Give undivided attention particularly if residents are a safety risk to themselves and/or others. • Use appropriate communication strategies to de-escalate. • Use non-pharmacological strategies (see p.17). • Use medications (see p.16). • Refer to the gentle persuasion techniques from the gentle persuasive approaches (GPA) manual (e.g., self-protection techniques and gentle redirection techniques).
Being disruptive (e.g., shouting, calling out, and swearing) ^{3,5,6}	<ul style="list-style-type: none"> • Redirect or distract: Use meaningful activities. For suitable recreational activities, see Booklet #4: Social Isolation and Loneliness. • Do not respond⁴. • Ignore the behavior⁴. • Use appropriate communication strategies (see p.13).
Wandering/pacing/Elopement ⁷	<ul style="list-style-type: none"> • Redirect or distract: Use meaningful activities. For suitable recreational activities, see Booklet #4: Social Isolation and Loneliness. • Engage⁴: It is important to interact with the resident regularly which gives plenty of opportunity to get positive attention and may also help prevent boredom. • Adapt the environment to reduce exit-seeking (e.g., hide exit signs, ensure doors are locked, apply watch mates)⁷.
Agitation ^{3,7}	<ul style="list-style-type: none"> • Redirect or distract using meaningful activities: Soothing music and/or pet therapy may be appropriate. For suitable recreational activities, see Booklet #4: Social Isolation and Loneliness.
Being uncooperative (e.g., refusing to eat, take medications, resistant to care)	<ul style="list-style-type: none"> • Try to understand the cause of why the resident may be uncooperative⁷. • Use stop and go approaches to care³: Stop what you are doing, think about what is happening (this may be the point where you are starting to see potential triggers), observe the resident's cues and behaviors, and plan when to resume care. • Use trial and error⁸: Attempt to identify the cause of the resistance, change the routine, and assess its effectiveness.

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

Common Behaviors	Possible Strategies
	<ul style="list-style-type: none"> • Ask what is wrong: Context is important, such as time or day, where, etc. • Give residents an effective way to stop something that they do not like or to remove themselves from a situation/person by using an appropriate method, such as a sign or a word⁴. • Use a choice making program⁸: Giving choices allows residents to feel a sense of control. Staff should offer choices, when appropriate, regarding food and activities. For example, there is usually a second choice for all meals. Teach residents to make choices such as a way to say “yes” and “no”⁴. • Change the way you ask them to do something⁴: The resident may not understand what you mean. • Use simple words- refer to p.13 on communication.
Repetitive questions/repetitive behaviors ⁵	<ul style="list-style-type: none"> • Redirect or distract: Use meaningful activities. For suitable recreational activities, see Booklet #4: Social Isolation and Loneliness. • Provide reassurance⁸. • Teach new skills⁹: Staff should attempt to teach new skills and positive behaviors to replace challenging behaviors. For example, teach residents how to appropriately communicate what they want/need or how to get attention and/or the attention of others by using a specific sign, a word, or a gentle tap. Staff can also teach residents how to get something for themselves by ensuring that they know where things that they may want/need are kept. This may be as simple as the resident knowing to go to the fridge to get a drink. • Make every effort to give the resident what he/she wants as soon as he/she has asked for it appropriately⁴. • Put the answer to the same repetitive question on a piece of paper and ask the resident to read the card instead of vocalizing the question⁷.
Self-harm (suicidal ideation and/or ingestion of objects)	<ul style="list-style-type: none"> • Provide comfort and reassurance⁸. • Engage⁴: It is important to interact with the resident regularly which gives him/her plenty of opportunity to get positive attention. • Give undivided attention, particular if residents are at risk to themselves and/or others³. • Use appropriate communication strategies (p.13).

Dealing with Challenging Behaviors

If any of these behaviors listed above occur, staff should:

1. **Keep a record of behaviors**⁸. Documentation is a key component as it is important for staff to know information regarding residents' behaviors and their patterns in behavior which will help to identify triggers and implement strategies that are resident-specific. Documentation is further discussed in the on p.15.
2. **Examine the context.** It is important to analyze challenging situations and determine whether certain contexts affect potential triggers. For example, a trigger may be more likely to occur during a certain time of the day which may lead to a resident exhibiting a challenging behavior.
3. **Involve family and friends.** Many residents with IDD have family involvement. Family and friends usually know the resident the best and are able to provide information regarding his/her history, behaviors and/or triggers, and likes/dislikes that can help prevent a trigger and challenging behaviors from occurring. Using information provided by family and friends also enables staff to develop a consistent and personalized approach to care⁹. Supporting contact between the resident and his/her family and friends is essential as it can improve overall well-being^{10,11}.
4. **Use an interdisciplinary approach** which is further discussed on p. 14.

Case Study: Part 1

Please answer the following questions related to the case study below. Answers can be found in the Appendix at the end of the booklet.

Marie, a 65-year-old woman with an IDD, has been recently admitted on the unit. The resident requires total care with all activities of daily living (ADLs). A staff member walks by and notices that she looks upset. Marie asks to go to the bathroom but has to wait as staff are occupied with another resident. Marie begins to shout and spit at nursing staff as they approach.

1. What common challenging behavior is Marie exhibiting?
2. Is the resident exhibiting warning signs that a behavior may occur? If so, what behaviors?
3. What strategies should staff members implement?

Test your Knowledge

Please answer the following questions below. Answers can be found in the Appendix at the end of the booklet.

Identify if each statement is true or false.

6. Challenging behaviors are the normal behavior for residents who have a diagnosis of an IDD. ____
7. Changes in facial expressions and increased pacing may be warning signs that a behavior may occur. ____
8. Challenging behaviors are predictable. ____
9. All strategies should be resident-specific. ____
10. Family and friends can provide information regarding a resident's behaviors and/or triggers. ____
11. Documentation is key in dealing with challenging behaviors. ____

Triggers

A challenging behavior is usually triggered by either someone or something. Hence, it is important for staff to identify each resident's potential triggers in order to prevent a challenging behavior from occurring. Triggers can be more easily identified by getting to know the resident, such as his/her normal day-to-day behavior, which can help recognize early warning signs and prevent triggers from occurring⁶. Strategies can then be implemented sooner in hopes of decreasing the chance the behavior will occur.

Staff should always attempt to remove the trigger!

There are many possible triggers for those with IDD's (see table below). As previously stated, strategies should be resident-specific. Being resident-centered equips staff to identify asymptomatic signs of ill-health, physiological needs, and desires, so that appropriate actions can be taken, thereby potentially decreasing triggers associated with challenging behaviors¹¹.

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

Possible Triggers	Description	Strategies to Prevent Triggers
Having an unmet need ^{3,13}	Most behaviors occur because the resident has an unmet need. E.g., the resident may be hungry, thirsty, or need to go to the bathroom.	<ul style="list-style-type: none"> • Ensure the resident has access to whatever he/she needs (e.g., ensure the resident is not left without food/water for too long)⁴. • Make every effort to give the resident what he/she asked for as soon as he/she has asked appropriately⁴.
Having to wait for something	The resident may have to wait to go to the bathroom or have to wait for a snack or drink when hungry.	<ul style="list-style-type: none"> • Make every effort to give the resident what he/she asked for as soon as he/she has asked appropriately⁴. • Use good communication strategies (p.13).
Being told they could not do something	The resident may be told that they cannot go on an outing with recreation due to medication administration time conflict or there may simply not be enough room for him/her to go.	<ul style="list-style-type: none"> • Use good communication strategies (p. 13). • Give in and give the person what they want⁴: This may be necessary if the behavior/ situation escalates and others are at risk).
Seeing something that they cannot have	The resident may not be able to have a sugary snack due to being a diabetic or he/she may not be able to have a certain food texture due to swallowing issues.	<ul style="list-style-type: none"> • Give in and give the person what he/she wants⁴: This may be necessary if the behavior/ situation escalates and others are at risk; however, safety should always be priority (consult with the registered nurse on your unit). • Redirect/distract (e.g., implement activities). • Use good communication strategies (p. 13).
Lack of control ³	Residents with IDD have increased needs and dependency and often lack control over everyday choices and decisions. E.g., a resident may prefer to get up out of bed and dressed	<ul style="list-style-type: none"> • Use a choice making program (p. 5). • Provide comfort and reassurance⁸.

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

Possible Triggers	Description	Strategies to Prevent Triggers
	just in time for breakfast and will be upset if there is any break in routine.	
Feeling frightened, frustrated, or threatened ³	Residents may feel frightened, frustrated, or threatened due to issues associated with communication and self-expression ^{2,13} .	<ul style="list-style-type: none"> • Provide reassurance and comfort⁸. • Use good communication strategies (p.13).
Change	The resident may have difficulty adjusting to changes in overall health ^{2,13} .	<ul style="list-style-type: none"> • Provide reassurance and comfort⁸.
Health problems	The resident may have pain or discomfort ¹⁴ .	<ul style="list-style-type: none"> • Redirect or distract by implementing activities. For suitable recreational activities, see booklet #4: Social isolation and Loneliness. • Use non-pharmacological strategies (p. 17).
A break in routine or feeling rushed ⁹	Those with IDD's enjoy routine and consistency.	<ul style="list-style-type: none"> • Ensure resident-focused care and consistency.
Other residents	Other residents bumping into the resident's wheelchair and/or pointing at him/her.	<ul style="list-style-type: none"> • Remove bystanders and/or the resident.
Tiredness ⁹	Can lead to an increase in agitation.	<ul style="list-style-type: none"> • Ensure residents get a good night's sleep (e.g., ensure low lighting, low noise level). • Medication review. • Prescription for sleep aids may be helpful.
Changes in medication ⁹	Changes in medication may cause a variety of signs and symptoms and/or changes in personality and behaviors.	<ul style="list-style-type: none"> • Ensure regular medication reviews.
Boredom ⁴	Some challenging behaviors result because of the simple fact that residents are bored and are looking for attention.	<ul style="list-style-type: none"> • Offer meaningful recreational activities. For suitable recreational activities, see Booklet #4: Social isolation and Loneliness.

Possible Triggers	Description	Strategies to Prevent Triggers
		<ul style="list-style-type: none"> Regularly engage with residents⁴: It is important to interact with the resident regularly which gives plenty of opportunity to get positive attention and may also help prevent boredom.

Case Study Part 2:

Please answer the following questions related to the case study below. Answers can be found in the Appendix at the end of the booklet.

The next day, Marie asks to go to the bathroom at a similar time (early afternoon). She again starts to shout as staff cannot tend to her immediately when asked. Staff members find that Marie also tends to get bored during the afternoon and appears upset during this time. Staff members notice that her behaviors tend to worsen around the same time every day.

- 1) What are Marie's triggers?
- 2) What is the context of Marie's behaviors?
- 3) What can staff members do to help prevent the triggers from occurring?

Self-Reflection Exercise

How many people on your unit have an IDD? How many experience challenging behaviors? How often? What are their triggers? Are their triggers similar or different?

Tips for Staff

Caring for older adults with IDD can be stressful for you since many residents with IDD present with challenging behaviors and have complex health care needs. You may have feelings of fear, anxiety, depression, and anger¹⁵. Also, in certain situations, safety may be a concern⁹. For any resident in LTC, it is important for you to monitor your own feelings and beliefs, be non-judgmental, and consider linguistic and cultural differences. This is particularly important when caring for residents with IDD since being aware of your own practice can ultimately impact resident outcomes.

Every day, it is important to...

...Monitor feeling and beliefs. It is important to evaluate your own thoughts in relation to ethical responsibilities, such as providing safe, compassionate, and competent care¹⁶.

...Be non-judgmental and unbiased. It is important to recognize and respect the uniqueness of each resident. You should not discriminate on the basis of race, ethnicity, culture, spiritual belief, gender identity, age, etc¹⁶. For a resident with an IDD, it is essential to view the resident as a person rather than through the context of his/her disability¹². Being non-judgmental facilitates understanding and improves resident outcomes.

...Consider linguistic and cultural differences. It is important to consider linguistic diversity and cultural differences in the way residents communicate, ambulate, and behave¹⁵. You should also use a holistic approach to care that encompasses the physical, emotional, social, economic, and spiritual needs of the resident. Those with IDD have a variety of complex needs that have to be met.

Coping Tips for Staff

During a stressful situation

Strategy	Description
Remove yourself from the situation and return at a later time	This allows you time to cool down if emotions are high, especially when dealing with challenging and/or stressful situations. Removing yourself from the situation also allows for self-reflection.
Rely on informal peer support ¹³	Work together and take turns dealing with challenging and/or stressful situations.

Strategy	Description
Do not react (e.g., do not raise your voice or use inappropriate non-verbal communication, such as eye-rolling)	Reacting may only further escalate the situation. Residents can also very easily pick up on non-verbal cues.

After a stressful situation

Strategy	Description
Talk to other staff ^{6,10,13}	Talking to others provides a way to discuss issues and/or behaviors and allows you to learn from each other's experiences.
Use personal strategies ¹³	Use relaxation techniques (e.g., breathe) and exercise (e.g., take a walk on your break or exercise on your days off).
Rely on multidisciplinary teams ^{8,12,13}	Debrief with all members of the health care team to determine if something can be done or could have been done differently. Debriefing in a group can also be helpful to evaluate effective coping strategies of others.
Involve management ¹³	If other strategies have failed, management may be able to offer further suggestions to help cope with a variety of issues in the workplace.
Use self-reflection	You should reflect on your own practice and on the quality of your interactions. For example, you should reflect on a specific incident or experience and analyze/critique the situation. You are then able to learn from your experiences and change your practice to improve resident outcomes. This may be particularly important after a challenging event.

Self-Reflection Exercise

Reflect on a time where you felt frustrated or stressed at work. What were you frustrated/stressed about? What did you do to alleviate the frustration/stress? Would other methods of coping have been more suitable? Which ones?

Communication

Effective communication is key to providing great care^{6,10}. Good communication strategies are needed when caring for residents who are exhibiting challenging behaviors. Communication is comprised of both verbal and nonverbal cues. However, the majority of communication is nonverbal⁶. Residents who have IDD can very easily pick up on nonverbal cues even if you think you may not be communicating.

General strategies to enhance communication:

- Minimize distractions and noise⁶
- Use eye contact⁶
- Speak slowly⁶
- Use simple language⁶
- Visually demonstrate a message by using hand gestures, etc⁶
- Repeat a message⁶
- Use a gentle and comforting approach⁹
- Be friendly⁹
- Be courteous⁹
- Be funny, when appropriate⁹



Since those with IDD often have communication difficulties, these types of residents may be unable to express themselves appropriately. A behavior may be their form of communication⁶. Therefore, it is important to be mindful of residents' communication strategies, while also being cognizant of your own, since this can positively influence the resident's perspective and response.

Interdisciplinary Approach

An interdisciplinary approach incorporates the idea of teamwork and helps to provide better resident care by including a variety of disciplines. Behavioral assessments and support plans can then be developed and implemented to help guide care¹³. For example, these disciplines can also help identify potential behavioral triggers and develop effective strategies that may help decrease the frequency of the behavior or the behavior from occurring altogether. Specific strategies can also be suggested to help staff members deal with the challenging behavior. These disciplines should be consulted on an individual basis.

Discipline	What they can offer
Behavioral Management Specialist (BMS)	<ul style="list-style-type: none"> • Uses applied behavioral analysis and conducts a functional behavioral assessment. • Based upon the function of a behavior, recommendations are made and tailored to the resident. • The BMS can also offer support in developing positive behavior support strategies, medication compliance, and both verbal and physical aggression. • Triggers can be identified and specific strategies suggested that may be useful to either prevent a behavior from occurring or to de-escalate a behavior.
Recreation therapist (RT)	<ul style="list-style-type: none"> • Offers recreational, diversional, and meaningful activities. • Can help prevent triggers from occurring or help develop distraction techniques when behaviors occur. Sometimes behaviors may occur simply due to boredom. • Note: behavioral issues and challenging behaviors can potentially affect the programs and activities offered.
Clinical Educator	<ul style="list-style-type: none"> • Provides information on different topics related to learning needs identified by staff. • Provides assistance when staff have difficulty providing personal care to residents with responsive behaviors. • Suggests evidence-based practices that may help de-escalate a behavior.
Physiotherapist (PT)	<ul style="list-style-type: none"> • Provides exercises and range of motion activities that may help decrease pain and/or discomfort. • May be useful for those who are exhibiting challenging behaviors related to physical discomfort.

Discipline	What they can offer
Occupation Therapist (OT)	<ul style="list-style-type: none"> Provides equipment and pressure relief devices that may help reduce pain and/or discomfort. Communication boards for residents experiencing communication difficulties can also be helpful. Appropriate for those who have behaviors due to physical discomfort. Supplying appropriate equipment, such as wheelchair and walkers, can also help residents remain social and encourage them to attend activities instead of being bed-bound.
Music Therapist	<ul style="list-style-type: none"> Provides activities that encourage singing, rhythm body motion to music and/or to use simple percussion instruments. Music can be used as a distraction technique to prevent behaviors from occurring.
Resident Assessment Instrument-Minimum Data Set (RAI-MDS)	<ul style="list-style-type: none"> Collects data to guide care planning and monitoring of residents. Helps to develop care plans that are resident-centered. Potential behavioral triggers and health issues can be identified.

Documentation

Documentation is important in providing safe, ethical, and effective nursing practice. It includes both paper and electronic-based charting and is part of the daily care staff provide to residents¹⁷.

Where?

- Care plans
- Kardexes
- Complete the Dementia Observation System (DOS), as appropriate, to track patterns in resident behaviors. **Usually the behavioral management specialist will require this to be completed prior to completing an assessment.**



Why?

- All pertinent information needs to be in one place⁶
- Helps staff identify any changes⁶
- Staff need to be able to find information
- Helps to provide consistent care⁷

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

- Helps to provide resident-focused care as information regarding needs and routine are available^{6,9}
- Establishes accountability, promotes quality nursing care, and facilitates communication¹⁷

What?

- The resident's baseline (e.g., what is their norm? ability to perform ADLs? cognition?)
- If there are any potential changes or deterioration in functioning
- Whether the resident has any challenging behaviors

Include:

- 1) Appearance: What the behavior looks like
- 2) Triggers: What triggered the behavior
- 3) Rate: How often it occurs
- 4) Severity: How severe the behavior is
- 5) Duration: How long it lasts
- 6) Action taken when dealing with the challenging behavior and/or sun downing episodes. Include what worked and what did not work

When?

- As soon as possible after an event as this helps to ensure accuracy of details.
- Charting should not be left until the end of the day.

The Role of Antipsychotics

Many residents with IDD are prescribed antipsychotics to treat challenging behaviors¹⁸. However, studies suggest that the use of antipsychotics do not actually lead to a decrease in behaviors^{18,19}. In fact, antipsychotics are considered chemical restraints when prescribed for reasons other than a psychiatric diagnosis as they are used to control behavior⁶.

Types of antipsychotics

- Risperidone (risperdal®)
- Quetiapine (seroquel®)
- Olanzapine (zyprexa®)
- Haloperidol (haldol®)

Other

medications:

- Benzodiazepines, such as lorazepam (ativan®) and diazepam (valium®)



If a pharmacological strategy is required, assess, monitor, document and aim to reduce the use as soon as possible⁶.

Being inappropriately prescribed antipsychotics can have negative consequences for the resident as listed below.

Negative Consequences:

Adverse reactions¹⁹

Falls⁶

Injury⁶

Decreased mobility⁶

Delirium⁶

Increased agitation⁶

Depression⁶

Restlessness

Increased confusion⁶

Tardive dyskinesia⁶

Death⁶

6

Non-pharmacological strategies

Non-pharmacological strategies should be used to deal with behaviors prior to the consideration of antipsychotics³. Examples include:

- Physical exercise²⁰
- Music therapy²⁰
- Pet therapy
- Guided imagery/meditation
- Deep breathing exercises
- Massage/therapeutic touch
- Distraction, such as appropriate reactional activities (**See Booklet #4: Social Isolation and Loneliness**).
- Position changes and localized heat or cold for those with behaviors associated with physical discomfort

Conclusion

Since challenging behaviors are common for residents who have a diagnosis of an IDD, staff members working in LTC environments need to be prepared to meet the needs of this population. Increased knowledge regarding challenging behaviors and IDDs can help ensure positive resident outcomes as health care professionals are better able to fulfill the health and social needs required for this population as they age. For further information about other aspects of caring for residents with IDDs, refer to the other booklets in this series.

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Appendix: Answers to Questions

Answers to case study questions part 1 on p. 6

1. Aggressive (spiting) and disruptive behaviors (shouting).
2. Yes, Marie looks upset.
3. Possible solutions include providing comfort and support, giving the resident time to calm down, and using appropriate communication strategies.

Answers to True and false questions on p. 7

1. F
2. T
3. F
4. T
5. T
6. T

Answers to case study questions part 2 on p.10

1. Marie's triggers are that she has to wait for something and that she has an unmet need (needs to go to the bathroom).
2. Marie tends to exhibit the same challenging behavior at the same time every day (afternoon) and gets upset when staff cannot attend to her immediately. This would be important to document.
3. Since Marie tends to exhibit similar behaviors at the same time every day, care should be resident-focused, meaning that staff could offer to toilet Marie around this time every day in order to prevent the trigger from occurring. Staff should also make every effort to give Marie what she asked for as soon as she has asked appropriately. It may also be beneficial to implement recreational activities during the afternoon as this is the time that Marie generally feels bored and may be looking for attention.

Appendix V

Booklet #3

Dementia and IDD's

Developed by: Lindsay Hunt
For St. Luke's Home
July 2018

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

This is the third booklet of a series of four booklets. You can use each booklet individually or in sequence depending on your learning needs. Each booklet contains key information and self-reflection exercises. There are also true/false questions, case studies and/or other questions to help you test your knowledge.

The purpose of this booklet is to provide information regarding dementia and intellectual and developmental disabilities (IDDs) in long term care (LTC). This booklet can be used by personal care attendants (PCAs), registered nurses (RNs), licensed practical nurses (LPNs), and other health care professionals who work with those who have an IDD. The booklets may also be beneficial for those who simply want to learn more on this topic.

Learning Objectives:

Upon completion of this booklet, you will be able to:

1. Identify and define the different types of dementia and associated signs/symptoms;
2. Identify how to assess for dementia;
3. Identify reasons why residents could be experiencing a cognitive decline or a change/deterioration from their normal baseline; and
4. Identify strategies to help care for those with IDDs and dementia.

Dementia

Dementia is defined as “a condition that involves inevitably progressive deficits in numerous cognitive domains, including thought, language, memory, understanding, and judgement”¹.

Types of Dementia

There are several types of dementia that present with different clinical signs and symptoms. See the table below for a description of some of the common types of dementia and associated signs/symptoms.



Type of dementia	Cause	Signs/Symptoms
Alzheimer's ^{2,3}	Most common type. A progressive disease resulting from brain cells that form neurofibrillary tangles and amyloid plaques.	Memory loss, apathy, depression, impaired communication, poor judgment, confusion, behavior changes and difficulty speaking, swallowing and walking.
Vascular ^{2,3}	Also called multi-infarct. A non-progressive disease caused by cerebrovascular disease and/or a blockage in a blood vessel in the brain, such as a stroke, heart disease, and diabetes. The location, number and size of the brain injury determine severity of damage.	Impaired judgment, inability to make decisions, plan, or organize.
Lewy Body ^{2,3}	A progressive disease caused by an abnormal build-up of protein.	Memory loss, sleep disturbances, hallucinations and delusions, parkinsonian movements such as slowness, gait imbalances, rigidity, and tremors.
Pick's disease ^{2,3}	A progressive nerve cell loss in the brain's frontal and temporal lobes. Usually occurs during middle-late age.	Changes in personality, behavior becomes disinhibited and repetitive, difficulty with language.

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN LTC

Type of dementia	Cause	Signs/Symptoms
Mixed ^{2,3}	A progressive disease where abnormalities are linked to more than one cause of dementia that occur simultaneously in the brain. Most common is Alzheimer's combined with vascular dementia.	Symptoms vary and suggest that more than one type of dementia is present.
Traumatic brain injury ^{2,3}	Non-progressive. Caused by falls, motor vehicle accidents, and self-injurious behaviors.	Inability to remember or learn new information, poor attention and concentration, inability to organize thoughts and plans.
Substance/medication induced ^{2,3}	Non-progressive. Misuse of alcohol can cause severe deficiency of thiamine/ most frequent cause of "reversible" dementia caused by adverse drug reactions.	Problems learning new information, inability to remember recent events, and long-term memory gaps.

Prevalence in LTC

The prevalence of dementia is significant within long term care (LTC) environments in general since residents are living longer and usually present with some form of memory deficit. Those with intellectual and developmental disabilities (IDDs) are also aging and are at an increased risk for developing this condition¹. In fact, the prevalence is approximately four times higher in those who have a diagnosis of an IDD¹.

Fact

Those with Down syndrome are at greatest risk and have a 50 to 85% chance of developing dementia^{1,4}.

Dementia and IDD

Since residents with IDD may already have challenges associated with thinking, reasoning, language, behavior and ability to manage activities of daily living (ADLs), the addition of dementia has a significant impact on quality of life². A diagnosis of both dementia and an IDD may also lead to difficulties associated with a resident's plan of care, identifying health needs, and explaining procedures. For further information about IDDs, see **Booklet #1: Intellectual and Developmental Disabilities in Long Term Care**.

The signs and symptoms associated with different types of dementia were described on pages 2-3. The box below summarizes a list of generalized signs and symptoms for a resident who may be developing dementia. Loss of functional capacity and loss of independence with ADLs are often the initial signs, while aggression is also common. **See Booklet #2: Challenging behaviors** for more information about aggression and other types of challenging behaviors.

Signs and Symptoms

- Forgetfulness⁵
- Memory loss¹
- Changes in behavior^{5,6}
- Difficulty control emotions and/or behavior¹
- Loss of functional capacity^{2,5}
- Loss of independence with ADLs^{2,5}
- Loss of ability to communicate⁵
- Difficulty learning and retaining information²
- Urinary incontinence²
- Onset of seizures or an increase in seizure activity²
- Return of early developmental reflexes²

Test your Knowledge

Please answer the following questions below. Answers can be found in the Appendix at the end of the booklet.

Identify if each statement is true or false.

1. Dementia may result in deficits, including thought, language, memory, understanding, and judgement. ____
2. The prevalence of dementia is higher in those with IDD's. ____
3. Memory loss is often the initial sign of dementia. ____
4. Aggression is common as those with dementia usually have difficulty controlling behavior. ____
5. Lewy body dementia is the most common type of dementia. ____
6. Alzheimer's disease is caused by the formation of amyloid plaques. ____
7. Vascular dementia can be caused by a blockage in a blood vessel in the brain. ____

Assessing for Dementia

Assessment of dementia in residents who already have a diagnosis of an IDD is complex. Usually a change or a deterioration from a resident's normal baseline suggests a diagnosis of dementia^{2,7}. However, there are many reasons why residents could be experiencing a cognitive decline or a change/deterioration from their baseline.

Reason for Changes	Explanation
A normal part of the aging process ²	A decrease in cognitive ability and incontinence, for example, may be normal as one ages.
Have an exacerbation or a new onset of a comorbid health issue (e.g., mental health concerns, respiratory issues, and infections) ²	Due to a health issue, residents may feel lethargic, have a decrease in appetite, and/or feel generally unwell and unable to complete tasks. Infections, such as urinary tract infections, can often cause confusion and changes in mental status.
Sleep disturbances ²	Lack of sleep leads to a variety of health concerns, including forgetfulness and agitation.

Sensory impairments ²	Hearing and vision loss may influence functioning and ability to follow direction.
Medication related issues ^{2,3}	Adverse side effects may mimic signs/symptoms of dementia.

Due to the many reasons presented in the table above, determining what caused a change or a deterioration from a resident's normal baseline can be challenging. For example, the inability to complete tasks may or may not be a sign of dementia¹. There is also no simple test to determine whether or not an individual has dementia. As a result, dementia may progress before the initial diagnosis is made^{1,2}.

For those with mild IDD, dementia appears and progresses similarly to other elderly residents. However, those with more severe or profound IDDs often present with atypical signs and symptoms and are, therefore, not usually diagnosed until later stages of dementia^{2,7}.

If any subtle changes from a resident's normal baseline are noted, the staff member should notify the nurse in charge or the doctor so that a more thorough physical and psychological assessment can be completed. Catching dementia in the early stages is important since practitioners can prescribe medications, such as donepezil (Aricept®) that may help slow/delay the progression of the disease^{1,2}.

Self-Reflection Exercise

Consider a resident you have cared for who has an IDD and dementia. What were his/her key signs and symptoms, and issues that needed to be addressed?

Strategies for Caring for those with IDDs and Dementia

The strategies implemented to care for a resident with both an IDD and dementia should be resident-specific as each strategy may not work for everyone⁸. Using resident-centered approaches enables staff to relate to the individual with an IDD as a person rather than through the context of his/her disability⁹. However, the implementation of strategies may vary day-to-day due to the unpredictability of those with IDDs and their associated issues, such as challenging behaviors and/or dementia⁸. It is also important to consider an individual's current and past interests, preferences, and needs, while also incorporating a holistic approach to care⁷.

Below is a generalized list of strategies that may be useful in caring for a resident with both an IDD and dementia. Some strategies should be included within a resident's care plan whereas others may be used during one-to-one interactions.

Strategies for a resident's care plan

Strategy	Description/Why?
Maintain a structured routine ^{2,7}	<ul style="list-style-type: none"> • A structured routine may help to maintain physical functioning as it increases the likelihood that an ability remains (e.g., tasks, such residents putting on their own shirt in the morning, may be more familiar and easier to complete if they have a routine of getting dressed as soon as they get out of bed in the morning). • Some residents with IDD find structure and routine helpful and therefore, residents may be more inclined to participate in a task if it follows a structured routine as it helps them to feel comfortable and confident as they know what to expect.
Build and maintain skills in the morning ^{2,7}	<ul style="list-style-type: none"> • Residents may have behavior changes (i.e., sun downing) that may occur in the afternoon. Morning may be a better time of day as some residents may become more agitated or exhibit challenging behaviors as the day progresses.
Ensure the environment contains sensory stimuli ⁷	<ul style="list-style-type: none"> • Sensory stimuli can help to reinforce orientation (e.g., holiday decorations, calendars). • Visual or pictorial cues and planners can also be used to help structure their day (e.g., a sign on the bathroom).
Involve family/friends	<ul style="list-style-type: none"> • Family/friends help residents maintain socialization. • Family/friends usually know the resident the best and provide information that enables staff to use a consistent and personalized approach to care¹⁰. • Family/friends play an important role to help identify early signs of dementia, such as changes in behavior, personality, and loss of day-to-day abilities⁷. • Supporting contact between the resident and his/her family and friends is essential as it can improve overall well-being^{9,11}.
Consult the behavioral management specialist (BMS)	<ul style="list-style-type: none"> • The BMS provides staff with information that is resident-specific. • The BMS develops positive behavior support strategies that help with medication compliance concerns, and issues while providing personal care to residents who have dementia and/or behaviors.
Use a consistent approach to care	<ul style="list-style-type: none"> • Using a consistent approach to care involves familiarity and routine as discussed above. • Staff can help ensure consistency by completing documentation (see p. 11).

Strategies to use individually or during one-on-one interactions

Strategy	Description/Why?
Regularly engage residents in low stress activities	<ul style="list-style-type: none"> Engaging residents in activities offers many benefits: <ul style="list-style-type: none"> Helps with boredom. Boredom can be a trigger for challenging behaviors. See Booklet #2: Challenging Behaviors. Distraction activities and recreational activities may help with behavioral issues (e.g., relaxation techniques, such as massage and music, may be useful). However, activities may need be tailored depending on cognitive decline. See Booklet #4: Social Isolation and Loneliness for more information regarding recreational/distraction activities. A person with dementia may be able to sing or hum a favorite tune even after he/she has lost the ability to speak⁷.
Get to know the resident	<ul style="list-style-type: none"> Knowing a resident's likes/dislikes and normal baseline will help identify any changes or functional decline indicative of dementia. Early signs and symptoms of dementia, the progression of the disease, asymptomatic signs of ill-health, physiological needs, and desires can be more easily identified⁹.
Use good communication techniques ⁷	<ul style="list-style-type: none"> Communication is comprised of both verbal and non-verbal communication. See page 12 for communication strategies.
Use prompts and offer reassurance ⁷	<ul style="list-style-type: none"> Residents may get frustrated and/or upset if they are unable to do something. Giving gestures, prompts, and verbal cues by nodding, pointing, or hinting, particularly during tasks that the resident finds more difficult can be useful⁷.
Enable residents to have as much control over their life as possible ⁷	<ul style="list-style-type: none"> Staff members should be offering choices. Implementing a choice making program whereby staff offer choices, when appropriate, regarding food and activities is necessary and allows residents to feel a sense of control⁵. It is important to let residents do as much as they can independently.
Trial and error ⁵	<ul style="list-style-type: none"> Staff members should reflect on what is going on, try a reasonable approach, and assess its effectiveness

Strategy	Description/Why?
Use a stop and go approach	<ul style="list-style-type: none"> Staff members should stop what they are doing, think about what is happening, observe residents cues and behaviors, and plan when to resume care⁸.
Incorporate a 'life story book' or 'memory box' ⁷	<ul style="list-style-type: none"> Incorporating photos and mementos from the past or items that the resident likes or enjoys should be used as it helps the person interact and reminisce. Photos and mementos can also be used to help prevent challenging behaviors from occurring. See Booklet #2: Challenging behaviors.
Use a caring approach	<ul style="list-style-type: none"> A caring approach promotes overall well-being. A caring approach also helps to empathize and form connection with residents.

Case Study

Please answer the following questions related to the case study below. Answers can be found in the Appendix at the end of the booklet.

Bob is 60 years old and was admitted to LTC two years ago. He was previously cared for at home by his family but they were no longer able to do so due to his increase in care needs. Bob has a diagnosis of Down syndrome, diabetes, hypertension, and depression. He requires one person to assist him with all activities of daily living (ADLs) but can usually get dressed with limited assistance and little prompting. However, lately staff have noticed that Bob forgets how to button his shirt and is unable to find the bathroom at times.

1. Is it possible that Bob is developing dementia? Why or why not?
2. What are the possible reasons why Bob may be unable to complete his care independently?
3. What strategies could be implemented that would help Bob?
4. What should staff do when a change from a resident's usual baseline is noted such as in Bob's case?

Documentation

Documentation is important in providing safe, ethical, and effective nursing practice. It includes both paper and electronic-based charting and is part of the daily care staff provide to residents¹².

Where?

- Care plans
- Kardexes
- Complete the Dementia Observation System (DOS), as appropriate, to track patterns in resident behaviors. **Usually the behavioral management specialist will require this to be completed prior to completing an assessment.**

Why?

- All pertinent information needs to be in one place⁸
- Helps staff identify any changes that may help diagnose dementia in early stages
- Staff need to be able to find information (e.g., changes in behavior)⁸
- Helps to provide consistent care⁵
- Helps to provide resident-focused care as information regarding needs and routine are available^{8,10}.
- Establishes accountability, promotes quality nursing care, and facilitates communication¹².



What?

- The resident's baseline (e.g., what is their norm? ability to perform ADLs? cognition?)
- If there are any potential changes or deterioration in functioning
- Whether the resident has any challenging behaviors¹³
Include:
 - 1) Appearance: What the behavior looks like
 - 2) Triggers: What triggered the behavior
 - 3) Rate: How often it occurs
 - 4) Severity: How severe the behavior is
 - 5) Duration: How long it lasts
 - 6) Action taken when dealing with the challenging behavior and/or sun downing episodes. Include what worked and what did not work.

When?

- As soon as possible after an event as this helps to ensure accuracy of details.
- Charting should not be left until the end of the day.

Communication

Effective communication is key to providing great care^{8,9}. Communication is comprised of both verbal and nonverbal cues. However, the majority of communication is nonverbal⁸. Residents who have IDD can very easily pick up on nonverbal cues even if staff members are not aware they are communicating signals. It is important for staff members to be mindful of residents' communication strategies, while also being cognizant of their own, since this can positively influence the resident's perspective and response.

It is also important to note that those with IDD and dementia may have communication difficulties and may be unable to express themselves appropriately. They may have difficulty expressing how and why they feel a certain way. An individual's cognitive ability may also vary over the course of the day which may affect how he/she communicates.



Strategies to enhance communication:

- Minimize distractions and noise⁸
- Use eye contact⁸
- Speak slowly, softly, and clearly⁸
- Use simple language⁸
- Visually demonstrate a message by using gestures⁸
- Repeat a message⁸
- Explain care steps using simple sentences with only one-to-two steps when giving instructions, especially before starting a task or activity.
- Use a gentle and comforting approach¹⁰
- Be friendly¹⁰
- Be courteous¹⁰
- Be funny, when appropriate¹⁰
- Use consistent words and phrases for familiarity
- Frequently use soothing and reassuring words

Conclusion

Having a better understanding of IDD in LTC can help health care professionals fulfill both the health and social needs required for this population as they age. Increased knowledge regarding dementia and IDD can also help to ensure positive resident outcomes among those with IDD. For further information about other aspects of caring for residents with IDD, refer to the other booklets in this series.

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Appendix: Answers to Questions

Answers to True/False questions on page 6

1. T
2. T
3. F
4. T
5. F
6. T
7. T

Answers to case study questions on page 10

1. Yes, it is possible. Bob seems to be experiencing a change in his normal functioning which is often an initial sign of dementia.
2. Bob being unable to button his shirt or find the bathroom may or may not be a sign a dementia. There are other things to rule out, such as a change in medication, infection, normal process of aging, sleep disturbances, and sensory issues.
3. Strategies that could be used would be to use a caring approach, involve family and friends, use prompts and offer reassurance, and ensure the environment contains sensory stimuli.
4. Staff members should notify the RN in charge or doctor and document any changes from the resident's baseline.

Appendix VI

Booklet #4

Social Isolation and Loneliness

Developed by: Lindsay Hunt
For St. Luke's Home
July 2018

This is the fourth booklet of a series of four booklets. You can use each booklet individually or in sequence depending on your learning needs. Each booklet contains key information and self-reflection exercises. There are also true/false questions, case studies and/or other questions to help you test your knowledge.

The purpose of this booklet is to provide information regarding social isolation and loneliness for those with intellectual and developmental disabilities (IDDs) in long term care (LTC). Suitable recreational activities are also discussed. This booklet can be used by personal care attendants (PCAs), registered nurses (RNs), licensed practical nurses (LPNs), and other health care professionals who work with those who have an IDD. The booklets may also be beneficial for those who simply want to learn more on this topic.

Learning Objectives:

Upon completion of this booklet, you will be able to:

1. Compare social isolation and loneliness in those with IDDs;
2. Identify reasons why social isolation and loneliness are issues for those with IDDs;
3. Identify how recreational activities can help decrease risk for social isolation and loneliness;
4. Identify the benefits of recreational activities; and
5. Identify suitable types of recreational activities.

It is important to be able to distinguish between the terms social isolation and loneliness as they are two separate issues that may affect residents with intellectual and developmental disabilities (IDDs).

Social Isolation¹	Loneliness¹
Objective	Subjective
Lack of social contact or support	A feeling of being either alone or isolated
Potentially leads to increased loneliness	Multifaceted; may not be resolved by simply eliminating social isolation

Residents can be socially isolated without feeling lonely or feel lonely even when they are among others.

Those with IDD are particularly vulnerable to social isolation and loneliness for a variety of reasons^{2,3}.

1. Other residents try to avoid those with IDD as they may be frightened and/or uncomfortable around them, especially if they are exhibiting challenging behaviors³.
2. Other residents may not accept those with IDD because they look different and appear younger².
3. Those with IDD may have private rooms due to the many associated benefits, such as having more space and a private space to care for challenging behaviors or other complex health care needs. A private room may also be appropriate for roommate compatibility issues. However, a private room may only further increase the risk for social isolation and loneliness. Determining whether or not a resident with an IDD requires a private room should be resident specific.
4. Residents with IDD may have limited family/friend involvement. Family involvement has many benefits for those with IDD as they usually know the resident best and can offer valuable information which can be used to develop a care plan that is individualized. In fact, contact between the resident and his/her family and friends is essential as it can improve overall well-being^{2,4}. If a resident does not have much family/friend involvement and/or does not participate in recreational activities, the risk for social isolation and loneliness increases.

5. Those with IDD may have issues related to inclusivity. There are several limitations that make the integration of these types of residents a challenge.

Limitation	Why?
Health ²	Residents with IDDs may have impaired mobility, multiple comorbidities, sensory impairments, and/or pain that affects whether or not they want to socialize and be around other residents.
Cognitive incapacity ²	An IDD or a diagnosis of dementia affects cognitive capacity, such as ability to concentrate. The resident may also have other mental health issues that affect their cognition.
Emotional and behavioral difficulties ²	Residents with IDDs often exhibit challenging behaviors. When behavioral issues occur, these residents may need to be removed from others and be alone due to safety issues. Other residents may also not want to be around a resident who is disruptive or uncooperative. Behavioral issues and challenging behaviors can potentially affect the programs and activities offered. See Booklet #2: Challenging Behaviors.
Difficulty fitting into the type of activity offered ²	Those with IDDs may have different interests than other residents, are younger, or have difficult behaviors or care needs. Cognitive ability also affects the type of activity offered. Regardless of the severity of the IDD, many recreation activities can be adapted to enable their participation. For example, those who are in wheelchairs can still participate in a modified seated version of bowling ⁵ .

Despite challenges, it is essential for those with IDDs to be integrated among other residents within LTC.

Staff should continuously assess for risks associated with social isolation and loneliness and provide residents with specific opportunities for social interaction.

Fact

Those with IDD are more inclined to form relationships with staff rather than other residents^{2,3}.

Test your Knowledge

Please answer the following questions below. Answers can be found in the Appendix at the end of the booklet.

Identify if each statement is true or false.

1. Residents may be socially isolated without feeling lonely. ____
2. When a resident is among others, he/she never feels lonely. ____
3. Having a private room may lead to increase loneliness and isolation. ____
4. A resident's health status does not affect whether he/she wants to socialize and be around other residents. ____
5. It is difficult for recreational activities to be tailored to meet the needs of residents with IDD. ____
6. Family/friends help decrease risk for social isolation and loneliness of residents with IDD. ____

Self-Reflection Exercise Part 1

Think of a resident who may be at risk for social isolation and/or loneliness. Why is he/she at risk?

Recreation

Activities can help decrease social isolation and loneliness as they may help prevent frustration, boredom, and challenging behaviors⁵. Activities can occur in a variety of settings, ranging from the residents' room, the lounge, a specialized activity room, or a location outside of the facility.

The recreation department plays a large role in offering recreational activities on a daily basis to all residents. They are a good resource to help assess and develop diversional and meaningful activities specific to the resident. The recreational therapist (RT) can be consulted for both informal and formal activities described below and can offer activities in both one-on-one and group settings.

Group settings

Organized activities in group settings allow residents with IDD to get to know one another and potentially form relationships outside of the recreation activity. Group activities also promote contact with other residents which can help maintain or enhance social skills⁵.

One-on-one settings

One-on-one activities allow the resident to participate in meaningful activities that are specific to the resident and his/her interests. One-on-one may be more suitable for residents who do not like a lot of noise, have behavioral issues, get distracted easily, or do not cope well in a group setting.

Initiating recreational or diversion activities is everyone's role! Simple activities can be easily implemented by ALL staff. There are different types of activities available on the units for staff to use anytime!

Residents with IDDs should participate in similar activities as other elderly residents. However, the services and activities offered may need to be tailored to meet their individual needs.

Services and activities should be:

- 1) **Implemented at a slower pace⁴**: This may be necessary due to cognitive deficits, cognitive decline due to age and/or dementia, and overall health issues.
- 2) **Age appropriate⁴**: Residents will not want to participate in the activity if it is not appropriate for them. Do not assume that those with IDDs enjoy child-like activities. For example, not all residents with IDDs will enjoy coloring.

3) **Meaningful**⁵

- Consider the resident's skills and abilities.
- Be aware of physical limitations.
- Focus on enjoyment, not achievement: Incorporate favorite activities.
- Encourage involvement in daily life activities; This helps promote routine and establish a sense of purpose. Relate to past work life.
- Consider time of day: It may not be effective to offer certain activities when a resident is exhibiting behavioral issues. Behavioral issues may also occur during a certain time of day. Consider offering activities during this time in order to decrease the chances that the behavior will occur.

4) **Individualized**²: Those with IDD's may need more individualized attention. All care should be resident-centered, including the activities and programs offered, which allows programs to be adjusted and tailored to fit the resident's needs, thereby making the programs more inclusive. For example, a large group setting would be inappropriate for those who do not like much noise. Small or large group activities may also be inappropriate for some residents due to sensory issues or behavioral issues, such as disruptive behaviors. Hence, activities may be more beneficial in a group or more one-to-one settings depending on the individual. Residents with IDD's also have a variety of needs, such as emotional, social, psychological, and culture that should be considered. Being resident-centered also requires staff to incorporate a holistic approach when looking at appropriate activities and programs in which to engage the resident.

Examples of Recreational Activities and Benefits

Recreational activities can offer many benefits for those with IDD's including emotional, cognitive, and physical benefits. Below is a list of recreational activities that can be used with residents either individually or in a group setting. Many of the group activities may be more easily implemented by the recreation department (formal activities) whereas informal activities may be easily implemented by nursing staff on the units.

Note: A resident's participation in a recreational activity does not mean that he/she is not at risk for being lonely or that he/she is not lonely. For example, quiet leisure activities and walking programs may be completed individually and therefore, still lead to social isolation and loneliness.

Emotional benefits

Engaging in meaningful activity can generate positive feelings that may help reduce stress. Successful engagement in activities fosters a sense of competence for residents while also enhancing self-esteem. For example, adopting a helping role or taking on small jobs may help establish a sense of purpose². Activities may also allow the resident to have some 'quiet time' and participate in activities of interest⁶.

Informal Activities	Setting (Individual/Group)
Dolls	Individual
Quiet leisure activities (e.g., painting, coloring, flipping through books)	Individual
Adopt a helping role/taking on small jobs (e.g., folding face clothes, passing in diet sheets)	Individual
Watching TV	Individual or group
Music (e.g., turn on radio, sing/dance)	Individual or group
Baking	Group

Formal activities	Setting (Individual/Group)
Gardening	Individual or group
Music therapy (e.g., performances, bands)	Group
Pet therapy	Group

Cognitive Benefits

Recreational activities that involve creativity, strategic thinking, or learning new information or skills can provide mental stimulation and help improve self-expression, sensory awareness, attention span, memory and decision making abilities⁶.

Informal activities	Setting (Individual/Group)
Crossword puzzles	Individual
Reading	Individual
Playing cards	Individual or group
Bingo	Group
Board games	Group

Physical Benefits

Recreational activities that incorporate a physical component can help with the maintenance or enhancement of a resident's physical endurance, energy level, range of motion, eye-hand coordination, fine and gross motor skills, flexibility and strength depending on the type of activity. An increase in physical activity level may help to improve appetite, sleep, and mood while also decreasing agitation, anxiety or challenging behaviors⁶.

Informal activities	Setting (Individual/Group)
Walking	Individual

Formal activities	Setting (Individual/Group)
General exercise program	Individual or group
Outings (bus rides, shopping)	Group
Floor bowling	Group

Case Study

Please answer the following questions related to the case study below. Answers can be found in the Appendix at the end of the booklet.

Tom tends to keep to himself on the unit. He is very quiet and does not usually socialize with the other residents. He laughs and interacts occasionally with staff on the unit and tends to stay around the nursing desk. Tom dislikes noise and gets distracted easily. He tends to start getting restless and bored in the late afternoon but for the most part is very pleasant with staff. The recreation therapist usually visits in the morning to complete recreational activities. He enjoys coloring, painting, and other such quiet leisure activities.

1. Is Tom at risk for social isolation? Is he at risk for loneliness?
2. Should Tom participate in group settings or one-to-one settings? Why or why not?
3. When should a staff member initiate activities for Tom?
4. What type of activities should be offered?
5. What are the benefits of implementing recreational activities for Tom?

Self-Reflection Exercise Part 2

Think of the resident from the previous exercise. Is there anything being done to help decrease risk for social isolation and loneliness? Explain. What types of recreational activities would be suitable?

Documentation

Documentation is important in providing safe, ethical, and effective nursing practice. It includes both paper and electronic-based charting and is part of the daily care staff provide to residents⁷.

Where?

- Care plans
- Kardexes
- Complete the Dementia Observation System (DOS), as appropriate, to track patterns in resident behaviors. **Usually the behavioral management specialist will require this to be completed prior to completing an assessment.**

Why?

- All pertinent information needs to be in one place⁸
- Helps staff identify any changes
- Staff need to be able to find information⁸
- Helps to provide consistent care⁹
- Helps to provide resident-focused care^{8,10}
- Establishes accountability, promotes quality nursing care, and facilitates communication⁷



What?

- The resident's baseline (e.g., what is their norm? cognition?)
- If there are any potential changes or deterioration in functioning
- Whether the resident is at risk for social isolation and/or loneliness
- Whether the resident has any challenging behaviors¹¹
 - Include:
 - 1) Appearance: What the behavior looks like
 - 2) Triggers: What triggered the behavior
 - 3) Rate: How often it occurs
 - 4) Severity: How severe the behavior is
 - 5) Duration: How long it lasts
 - 6) Action taken when dealing with the challenging behavior and/or sun downing episodes. Include what worked and what did not work.
- Activities that resident enjoys/prefers
- Whether resident is better in group or one-on-one settings

When?

- As soon as possible after an event as this helps to ensure accuracy of details.
- Charting should not be left until the end of the day.

Conclusion

Having a better understanding of social isolation and loneliness among those with IDD in LTC can help health care professionals fulfill both the health and social needs required for this population as they age. Recreational activities, such as those described in this booklet, play an important role in decreasing risk of social isolation and loneliness while also providing a way to distract, redirect, and engage residents who may be exhibiting challenging behaviors. For further information about other aspects of caring for residents with IDDs, refer to the other booklets in this series.

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Appendix: Answers to Questions

Answers to true/false questions on page 5

1. T
2. F
3. T
4. F
5. F
6. T

Answers to case study questions on page 9

1. Tom is at risk for both social isolation and loneliness as he tends to keep to himself and does not socialize with other residents. However, Tom seems to interact more with nursing staff than other residents.
2. Tom may benefit more from one-on-one settings since he dislikes noise and gets distracted easily. He also likes to keep to himself and may not feel comfortable in a group setting.
3. Activities should be offered early/late afternoon, before Tom usually starts to get bored and restless.
4. Tom seems to like quiet leisure activities that offer emotional benefits. Other appropriate activities include music therapy and pet therapy.
5. Participating in quiet leisure activities can generate positive feelings that may help reduce stress. Tom may also feel he is engaging in meaningful activity as he is participating in an activity of interest.